THE EXPERIENCE OF BEING NEWLY DIAGNOSED WITH PARKINSON'S DISEASE: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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Chapter 1

Introduction to Portfolio

1.1 Overview

This portfolio consists of five pieces of work, which demonstrate the importance of reflexive practice in Counselling Psychology as well as the significance of the development of strong therapeutic relationships both within client practice and psychological research. Section B comprises of an original piece of research into the qualitative experiences of newly diagnosed Parkinson's Disease patients, using interpretative phenomenological analysis to reveal complex psychological issues which can occur within this patient population. Section C is a case study which demonstrates how the therapeutic alliance can be utilised within a cognitive-behavioural therapy (CBT) framework when working with a complex client case presentation. Similarly, Section D aims to show how important self-reflexive practice is within psychodynamic casework and a process report is presented from a client's assessment session. Section E is a critical literature review of the CBT models of treatment for chronic fatigue syndrome (CFS). This piece of work challenges the current treatment models of CFS, highlighting the complex interplay between physiological and psychological components of medical conditions such as this. Finally, Section F is a reflexive commentary upon my doctoral journey, and aims to give the reader a trajectory into the material presented within this portfolio from both a personal and professional reflective viewpoint.

1.2 The Research Component

Section B of this thesis is an original piece of research into patients' experiences of being newly diagnosed with Parkinson's disease, using an interpretative phenomenological analysis (IPA) approach. This is the first study of its kind to explore the psychological impact Parkinson's disease can have upon patients within the first three months of being given their diagnosis. Newly diagnosed Parkinson's disease patients were interviewed and an in-depth analysis of the data revealed three main superordinate themes to describe patients' experiences. These were:

1) "Impact upon the Individual"

2) "Impact upon the Social Self" and

3) "Self-Preservation".

These three superordinate themes encompass seven major themes:

1) "Emotional Reactions to Diagnosis

2) "Self as Compromised by PD"

3) "Social Anxiety"

4) "Identity and Social Role"

5) "Support vs. Autonomy"

6) "Emotional Self-Preservation" and

7) "Practical Self-Preservation"

Based upon the results of this research study, a model is proposed to explain the impact that a diagnosis of Parkinson's disease has upon the patient as an individual, the effect it has upon social interaction, and the emotional and practical coping measures used by patients during this early stage of the disease. The results of this study are discussed in relation to the existing research literature with respect to long term health conditions, and recommendations are made for future psychological research within the area of Parkinson's disease, with the aim of providing evidence-based practice with this particular client group. Suggestions are given with regards to possible specialised Counselling Psychology interventions which could benefit patients at this early phase of the illness. Currently, there is a lack of specialist psychological counselling available to patients with Parkinson's disease in the UK. This research study supports recent suggestions in the research literature that psychological therapy should to be made more accessible to Parkinson's patients.

1.3 The Case Study

Section C is a case study which demonstrates an evidence-based Cognitive-Behavioural Therapy (CBT) approach to working with a suicidal client with a history of childhood sexual abuse and a longstanding binge eating disorder. The case analysis focuses upon the unfolding process of therapy and explores the psychological interventions used to promote therapeutic change, in terms of the client becoming increasingly more aware of how her past abuse linked with her current eating disorder and suicidal feelings. The significance of the therapeutic alliance between the client and therapist is explored in terms of how this helped the client to make important changes over the course of the therapy within the framework of CBT. This case study shows how a CBT approach to a complex problem such as this can be effective, and two models are proposed during the course of therapy to explain the onset and maintenance of this client's difficulties. The analysis has allowed for a degree of professional and personal self-reflection with regards to my practice as a Counselling Psychologist, especially in terms of working with clients presenting with complex psychological issues in the future.

1.4 The Process Report

In Section D, a process report is presented which explores a psychodynamic approach to my work with a female client with a history of drug and alcohol addiction who presented for therapy following the break-up of a personal relationship. The in-depth analysis of an excerpt from the initial assessment session with this client focuses upon the therapeutic relationship which developed, specifically in terms of the transference and countertransference that occurred. Psychodynamic theory regarding attachment issues and addiction issues, as well as the use of the therapeutic relationship itself, allowed for an interesting analysis of this client's first therapy session, which provided a foundation for future sessions of therapy. Together, both the case study and process report demonstrate the significance and importance of building a strong therapeutic relationship, in terms of providing a vehicle for understanding the complexities of these two clients' issues brought to therapy and in helping to promote the therapeutic change which occurred during the course of the sessions. The process report has allowed for a deeper examination and exploration of the process of therapy than within the case study. However, both the case study and process report have provided a valuable opportunity for self-reflection with regards to my professional development as a Counselling Psychologist in terms of working with complex client issues.

1.5 The Critical Literature Review

Section E is a critical literature review, which focuses upon the CBT approach to treating Chronic Fatigue Syndrome (CFS). This draws together elements of the previous three sections of this thesis, in terms of focusing upon evidence-based psychological therapy in the treatment of long-term conditions. Similar to the area of psychological research into Parkinson's disease, there is a lack of available detailed research literature to provide a good foundation for evidence-based psychological models in the treatment of CFS. There is considerably more controversy surrounding the psychological basis to and maintenance of CFS than in Parkinson's disease and this is explored within the critical literature review with regards to how this issue influences the CBT models that have been proposed for its treatment. Exploration of current CBT models of treatment are made in the context of other psychological models that have been proposed, together with alternative psychological research that exists to explain patient presentations of CFS. In order to critically review the current CBT models of CFS, particular reference is made to other aspects of this condition, including psychiatric co-morbidity in CFS, the psychosocial and developmental issues which exist and in terms of the more severe presentations of the condition, which currently are not explained by traditional CBT models. On the basis of this critical literature review, the CBT model of treatment for CFS is shown to be inadequate in addressing the complexities of this particular patient population. Recommendations are made which could potentially improve current psychological treatments for this condition and suggestions are put forward as to the necessary research which is required to further our understanding of CFS and provide more effective evidence-based psychological interventions for this condition.

1.6 The Reflexive Commentary

The final part of the thesis, Section F, is a reflexive commentary upon my experience of the doctoral journey, and encompasses each section of the thesis. This chapter was added following the completion of my viva examination and aims to give the reader an insight into the material presented within this portfolio, in terms of my own personal and professional reflections. This self-analysis section expounds upon my reasons for carrying out this particular study and highlights the central theme across the entire portfolio; that being the significance and importance of developing strong therapeutic relationships within the profession of Counselling Psychology.

SECTION B: RESEARCH

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Chapter 2

Abstract

This study explores the lived experiences of newly diagnosed Parkinson's Disease (PD) patients using an interpretative phenomenological analysis (IPA) approach. Nine patients who had been given a diagnosis of PD within the past three months were interviewed and three superordinate themes explained their lived experiences. These were: "Impact upon the Individual", "Impact upon the Social Self" and "Self-Preservation". These themes described the impact that PD had upon the patient both emotionally and physically, their social interactions with others and the strategies that were used to cope since being diagnosed with the illness. These three themes incorporated seven subthemes, which were: "Emotional Reactions to Diagnosis", "Self as Compromised by PD", "Social Anxiety", "Identity and Social Role", "Support vs. Autonomy", "Emotional Self-Preservation" and "Practical Self-Preservation". The patients interviewed in this study spoke of the significant changes that had occurred since developing PD, which compromised their psychological, physiological and functional well-being. This included issues of an altered body image and changes in identity. As a result, social anxiety was described as a common problem and patients described the struggle that occurred between the requirement for reliance upon others whilst still retaining a level of functional independence. Patients described taking practical and emotional measures to cope with the variety of psychological and physical difficulties of the condition in order to minimise the detrimental effects these had upon their lives. The significance and importance of building strong therapeutic relationships in Counselling Psychology were considered. Recommendations are made for future psychological research within the area of PD, and suggestions are made for specific psychological interventions which may benefit patients with the disease at the early post-diagnosis phase of the illness. Ideally this would take a bio-psychosocial perspective.

Keywords:
Parkinson's Disease; long-term illness; Interpretative Phenomenological Analysis (IPA); diagnosis and adjustment; bio-psychosocial therapeutic interventions; counselling psychology.

2.1 Overview

A long-term health condition can be defined as any illness that is incurable and has a perpetuating and disruptive effect upon a person's health. The illness may be physically disabling and can often cause some level of disfigurement to the patient. The condition will require ongoing medical investigations, observations and treatment and may in some cases lead to a shortened lifespan (Blount, 1998). As a result of a long-term condition, a person's life may become affected in a variety of ways. This may include changes in a person's emotional well-being, their level of social functioning, spirituality and financial situation. In effect, a long-term condition can impose a significant level of threat to many vital aspects of a person's life (Hymovich & Hagopian, 1992).

One such long-term condition is Parkinson's Disease (PD), which is a common, progressive and incurable neurodegenerative disorder of the central nervous system. PD affects approximately 100 to 180 per 100,000 of the population, and between 6 to 11 per 6000 of the general population in the UK (Dodel, Eggert, Singer, Eichhorn, Pogarell & Oertel, 1998). This equates to about 120,000 people, affecting 1.6% of the over-65 age group in the UK (McCall, 1995). The age of onset is typically between 50 and 70 years, with a rising prevalence with age and there are no sex differences (de Rijk, Rocca, Anderson, Melcon, Breteler & Maraganore, 1997). Approximately one in ten people are diagnosed before the age of 50, with some patients developing the illness in their third decade of life (McCall, 1995).

The major symptoms of PD include physical slowness and poverty of movement, muscle rigidity, tremor and shaking of the limbs, postural instability and fatigue. The cause of PD is unknown but some research has suggested a possible genetic link. The disease stems from the loss of the dopamine-producing neurones in the basal ganglia, which leads to the progressive loss of this neurotransmitter, causing physical and cognitive symptoms of the disease. There is no set pattern to the onset or symptomatic progression of PD, however the Hoehn & Yahr (1967) scale is often used as a general marker of disease severity in patients. This scale classifies five 'stages' of disease progression, from Stage 1 defined as "Little or no functional impairment" through to Stage 5, where the patient may be confined to a wheelchair or bed [Appendix 1]. As the disease progresses the patient may experience problems related to muscle tone and control, such as the lack of facial expression, manual dexterity, verbal and non-verbal communication, gait and trunk movement, and bladder and bowel function. The disease also affects feeding including problems swallowing and salivating, can cause sleep disturbance and sexual dysfunction, as well as mental state changes such as cognitive impairment (Pentland, 1999).

Treatment comes mainly in the form of pharmacological intervention to stimulate the production of existing dopamine within the brain. Medication is most effective within the early stages of the disease and is a method to slow down the symptoms of PD. However, the disease is incurable and the effectiveness of such medication is time-limited and may produce adverse side-effects, such as sleep disruption, nightmares and hallucinations. A survey by Lloyd & Smith (1998) indicates that medical care typically centres around the patient's general practitioner (GP), neurologist, physiotherapist, speech therapist, occupational therapist and community specialist nurse. It is clear from this study that currently little psychological intervention is formally being provided within PD clinics in the UK. However, many sufferers are members of the Parkinson's Disease Society (PDS), a national charity which holds regular support groups and provides information for sufferers and their families. PD patients' well-being is often assessed by healthcare professionals in terms of a restricted measure of physical symptoms, rather than based upon any measure of psychosocial difficulty (Abudi, Bar-Tal, Ziv and Fish, 1997), suggesting that patients' psychological needs may currently be overlooked within medical settings.

Current Department of Health (DoH) guidelines in the UK call for improved services to people suffering with long term conditions, including a focus upon their social care (DoH, 2005). However, within these guidelines and those proposed by the National Institute for Clinical Excellence (NICE, June, 2006), there are no specific references to or recommendations for PD patients' psychological needs. Although a substantial body of research exists regarding the psychological impact of long-term health conditions, there is a paucity of research specifically focussing upon PD. Within the research conducted in PD, none has specifically addressed the psychological issues raised when a person is newly diagnosed with this disease. This may reflect the lack of specific advice and guidance that is currently available to health professionals within the UK, in terms of the provision of specialist psychological services for PD patients.

The following section is a literature review of psychological research relevant to this project. The review focuses upon psychological co-morbidity within the PD patient population, coping behaviours in illness, the psychosocial impact of illness, the psychological adjustment to long-term conditions and the psychological adjustment to a diagnosis of PD. Due to the lack of PD-specific psychological research, these issues are explored within the wider context of other long-term health conditions, such as heart disease, diabetes, cancer and rheumatoid arthritis. A rationale for the current study is then proposed, in light of the gaps inherent within the extant literature, explaining the significance and importance to the field of Counselling Psychology and within the field of general medicine to studying the lived-experiences of newly diagnosed PD patients.

2.2 Psychiatric Co-morbidity in Parkinson's Disease

A review of the existing literature investigating the psychosocial adaptation to long term illness strongly suggests that the onset of a chronic condition results in an array of different emotional responses. These range from patients displaying negative affect, such as depression, anxiety and anger, to accepting their illness and making an adjustment to their lives, despite the physical, cognitive, emotional or social limitations of living with a long-term condition (Livneh & Antonak, 1997; Smart, 2001; Wright, 1983).

A review of the current literature on the prevalence of depression within the PD population reveals that between 4% and 90% are clinically depressed (Cummings, 1992; Dakof & Mendelsohn, 1986; Gotham, Brown & Marsden, 1986; Huber, Friedenberg, Paulson, Shuttleworth & Christy, 1990), with an average prevalence rate of approximately 45% across all studies (Livneh & Antonak, 1994). The variance in these findings may be due to several factors, including the use of different definitions and diagnostic criteria for assessing depression and the use of different assessment tools or methods applied in these studies.

In a questionnaire study conducted by Abudi et al., (1997), PD patients reported problems with social interaction, communication, stress and strain, shame, frustration, depression and anxiety. Of all these difficulties, depression is the most common psychiatric co-morbid factor in the PD patient population (Bunting & Fitzsimmons, 1991). Levels of depression correlate with patients' abilities to perform activities of daily living (Cummings, 1992; Ehmann, Beninger, Gawel & Ripopelle, 1990a; Gotham, Brown & Marsden, 1986) and also relates to the severity of the disease (Kremer & Starkstein, 2000). Disability among older people is one of the strongest predictors of depressed mood (Prince, Harwood, Thomas & Mann, 1998) and physical illness can lead to higher rates of depression, emotional distress and suicidal behaviour when compared to rates within the general population (Whitlock, 1986).

As well as depression, patients often present with anxiety, and these two factors are positively correlated, with one study reporting 38% of PD patients presenting with both anxiety and depression (Henderson, Kurlan, Kersun & Como, 1992). Although anxiety and depression may have some neurobiological aetiology in PD (Richard, Schiffer & Kurlan, 1996), it is also likely that the numerous negative consequences of living with such a long-term illness contribute to this. The experiences of patients living with PD and other long-term conditions will now be explored further, and this is broken down into four sections:

1) Coping strategies in long-term illness
2) Psychosocial impact of illness
3) Psychological adjustment to illness
4) Psychological adjustment to a diagnosis of PD.

2.3 Coping Strategies in Long-Term Illness

Pinder (1990) interviewed PD patients to ascertain the different styles of coping employed by them in the face of this disease. Patients were categorised into three main groups: "Seekers", who spoke of their active search for information about their illness and need to find out what might happen to them; "Weavers", who selectively interpreted information about their illness to fit with their level of psychological adjustment; and "Avoiders", who deliberately chose not to seek out any information about PD due to their fears about the illness. Similarities have been found across other long-term conditions. This process of "denial", as displayed by the "Avoiders", is a common coping strategy within other conditions, such as multiple sclerosis (MS), where it correlates with lower levels of depression (Robinson, 1988; Sullivan, Mikail & Weinshenker, 1997) and cancer (Hyman, Baker, Ephraim, Moadel & Philip, 1994), suggesting that a certain level of avoidance might be useful to minimise the threat of the illness to the patient. It is theorised that at the early stages of an illness, denial can provide the patient with the time necessary to assimilate some of the threatening information about their condition and disability so that they can then consider alternatives for coping (Shontz, 1975).

By working around the limitations of one's illness, patients may instil a better sense of control, thereby reducing levels of uncertainty in their lives, which has also been demonstrated in patients with PD and leukaemia (Comarroff & Maguire, 1981; Pinder, 1990). Coping strategies, such as consciously valuing positive life events, maintaining meaningful occupation and roles, altering one's philosophies of life and taking part in disability activism are all positive strategies utilised by MS patients, and this may contribute to a better sense of quality of life in these patients (Reynolds & Prior, 2003). Benefit-finding coping strategies have been associated with less distress and a reduction in symptoms amongst patients with lupus and cancer (Katz, Flasher, Cacciapaglia & Nelson, 2001). Developing such a sense of control is an important aspect of dealing with a long-term illness and this was demonstrated in Pinder's (1990) study, where PD patients spoke of developing a combative stance towards their condition. However, they found it a struggle to gain a reasonable balance between learning to accept the illness's "fate" and taking decisive action against it. Patients described "fighting" against PD, and this has also been demonstrated by PD patients in other qualitative interview studies (Bramley & Eatough, 2005; Habermann, 1996; Krakow, Haltenhof & Bühler, 1999). PD patients may relieve some of their distress by comparing themselves to patients who are more hindered by the condition than themselves, and by choosing to live life in the present and not think about the future (Pinder, 1990). In this way, Charmaz (1991) suggests that patients attempt to develop a concept of the illness as something separate from themselves, as a means of coping with the difficulties of living with a long-term condition.

Patients therefore demonstrate varied behavioural changes and conceptual alterations in order to cope with a long-term incurable condition. The patient however is not in isolation, and must make these alterations within their social world. The psychosocial impact of living with a long-term illness is now explored.

2.4 Psychosocial Impact of Long-Term Illness

Radley (1997) suggests that it is only when we are "unable to play our part in the world of the fit and healthy" (p. 61) that the social impact of ill health becomes quite apparent, where "normality" equates with being well, and not ill or incapacitated. In this sense, the patient strives for normality in daily life without their being remarked upon by others (Radley & Billig, 1996). People will tend to seek medical help only when they feel they can no longer cope with their symptoms (Zola, 1973), suggesting that there is a natural inclination for people to carry on as normal, and attempt to manage in the face of the limitations imposed by illness.

Posen, Moore, Tassa, Ginzburg, Drory & Giladi (2000) in their study of female PD patients found that it was common for people to hide their symptoms from others for as long as this was possible. Clearly, stigma is a factor within PD, and this is reported in studies with patients suffering from other chronic conditions too, such as cancer (e.g. Mathieson & Stam, 1995). Interview research with PD patients reveals that main concerns centre on feeling stigmatised by physical symptoms of the disease, the development of an altered body image and an ambivalence about asking for help from others (Caap-Ahlgren & Dehlin, 2001; Pinder, 1990; Posen et al., 2000). In a study conducted by Chesson, Cockhead & Romney-Alexander (1999), 30 families were investigated in terms of their quality of life when living with PD, showing that PD patients felt too dependent upon their partner or other family member as their carer. They described experiencing a struggle to find an appropriate balance between being cared for whilst also having a sense of independence. PD sufferers reported feeling "a loss of freedom" as a result of this dependency upon their carer and the physical restrictions of their disease. Other significant findings suggested that PD patients often felt a loss of confidence and increased embarrassment in social settings due to their visibly recognisable symptoms, such as shaking, and one participant explained how he felt his social status had markedly changed as a result of the disease. Indeed, Charmaz (1991) suggests that chronically ill people "do not wish to be seen as patients first and person's second" by others

(p. 286). In terms of family life, patients may find it hard to interact properly with their relatives as compared to how they used to before they became ill. This is demonstrated in patients suffering from chronic obstructive pulmonary disease (COPD), where being able to play with one's grandchildren had been shown to be significantly compromised by the illness (Seamark, Blake & Seamark, 2004).

Patients generally report finding social support of great benefit when living with a long-term health condition such as PD. There are quality of life benefits for older people when there is a good level of social support available. (Sherbourne, Meredith, Rogers & Ware, 1992). At the time of diagnosis social support is highly valued by patients, as reported by women who have suffered from breast cancer (de Morgan & White, 2000). The value of social support is supported by research that shows that married cancer patients have a better survival rate than unmarried patients (Goodwin, Hunt, Key & Samet, 1987) and there are positive correlations between social support and immune system functioning (Kriegsman, Pennix & van Eijk, 1995). However, it may be that it is perceived support rather than actual support that is a better predictor of adaptation to illness (McLeod, Kessler & Landis, 1992). This is an important factor, and may explain why some cardiac patients can experience levels of social support in negative terms, when this is perceived as intrusive (Garrity, 1973), mirroring PD patients' negative experiences of care and support (Chesson et al., 1999).

The process of adaptation to PD is a complex one, and there is a lack of research into the course of psychological adjustment to this disease. There are however, a variety of theories and models which have been proposed to explain some of the factors involved in adjusting to other chronic illnesses, that might be relevant to patients suffering from PD.

2.5 Psychological Adjustment to Long-Term Illness

Although much research has focused upon elucidating the negative psychological consequences of developing a long-term illness or disability, as outlined above, recent studies have highlighted some more positive experiences linked to the psychosocial adaptation process (Dunn, 1994, 1996; Folkman, 1997; Folkman & Moskowitz, 2000). Examples of these are the acknowledgement, acceptance and psychosocial reorganisation that takes place in the face of chronic ill health (Johnson & Morse, 1990; Katz & Florian, 1986). 'Acceptance' is part of a dynamic adjustment process that involves making changes to a person's values and as a consequence, alters a person's social interaction with others (Wright, 1983). It has been described as a process of agreeing to one's status without struggling, envy, sorrow or anger (Kübler-Ross, 1969). Patients who accept their illness and level of disability present with higher levels of self-esteem and lower feelings of hostility (Li & Moore, 1998; Linkowski & Dunn, 1974), suggesting that acceptance might be beneficial to those suffering from PD.

Successful adjustment may require regulating one's self-identity in the light of ill health (Brownlee, Leventhal & Leventhal, 2000). This may explain the findings of a study into women's experiences of living with MS, cancer and diabetes (Kralik, Brown & Koch, 2000). The women in this study spoke about the disparity between their pre-illness self and their current identity as a chronically ill person. Participants spoke about the loneliness experienced as a result of becoming ill and feeling vulnerable about their situation. In the face of chronic illness, patients will often question their identity in terms of their past, present and future (Charmaz, 1991). Additionally, an immersion into the medical world as a result of becoming unwell can be a strange and frightening situation for many patients (Lapham & Ehrhart, 1986). And in the case of being diagnosed with a potentially life-threatening disease, such as HIV, patients may even become suicidal (Stevens & Tighe Doerr, 1997). Identity issues may therefore be a significant factor in terms of patients' adjustment to developing PD.

In a narrative analysis of cancer patients' experiences, Little, Jordens, Paul, Montgomery & Philipson (1998) report that after diagnosis patients described having felt disorientated, with a sense of loss, lack of control and uncertainty. Following this, patients described a phase of "suspended liminality", in which meaning is constructed and reconstructed regarding their changing selves and their altered bodies. This is a similar process to that described by Ohman, Soderberg & Lundman (2003) in their study of patients with varied long-term health conditions. Participants spoke of their bodies as having become a hindrance to them, of being alone in their illness and struggling for normalcy as a consequence of becoming unwell. Part of the adjustment process for these patients seems to be one of a reformulation of the 'self' in light of living with a chronic condition.

The process of psychological adjustment to any long-term condition is a complex one and many different theories have been suggested to explain how a patient incorporates illness into their life. The Response-Shift model (Sprangers & Schwartz, 1999) suggests that an individual's standards and values change as a result of facing a situation, such as ill health. A person's priorities change given their new circumstances. For instance, a person may focus more attention upon family matters rather than their career when living with a long-term illness (Thompson & Janigian, 1988). A person may search for new meanings in their life, integrating their illness into their "life scheme" by changing pre-existing beliefs or the meaning of the illness situation, so that it becomes congruent with helpful pre-existing beliefs (Park & Folkman, 1997). This may not be sufficient however for a person to succeed in restoring a necessary equilibrium, which may occur when a person is thrown into crisis by the onset of long-term ill health (Thompson & Janigian, 1988). Part of the experience of adjusting to a long-term illness involves the process of loss and grief (Zemzars, 1984), often with a sense of loss of control, which may lead to feelings of powerlessness over one's own body (Miller, 1983). This clearly might be a relevant issue for sufferers of PD, given the high prevalence rates of depression and anxiety in this patient population.

An adjustment model has been recently proposed by Sharpe & Curran (2006), which builds upon previous theories of chronic illness to explain patients' psychosocial adjustment to long-term health conditions. They suggest that common to all existing adjustment models is the issue of patients incorporating a representation of their illness into pre-existing belief structures about themselves, the world and others. They suggest that patients face the prospect of having to incorporate these representations into an adaptive view of themselves and the world, in order to restore a sense of equilibrium. Views of the patient's world and priorities within it are re-evaluated, as their pre-existing beliefs, values and schemas are challenged by the onset of a chronic illness.

Adjustment models to long-term illness may help to explain some of the processes involved in incorporating disease into patients' lives. However, they are largely based upon studies looking retrospectively at patients' experiences of accepting an illness into their lives. In order to understand PD patients' experiences of living with their disease, it is important to take into consideration their reaction to being given their diagnosis, in order to encapsulate their whole experience of adjustment to this disease.

2.6 *Adjustment to a Diagnosis of Parkinson's Disease*

Only two studies have investigated the lived-experiences of PD patients in relation to their diagnosis, from a phenomenological perspective (Bramley & Eatough, 2005; Habermann, 1996). Both studies involved interviewing PD patients about the day to day demands of living with the disease. In both studies there are only limited amounts of data that focus specifically upon their experiences of being given a diagnosis. Habermann (1996) reports that once diagnosed, participants identified a need to know more about PD, reflecting similar results to Pinder's (1990) study. Patients reported that information was difficult to process at the time of their diagnosis and they recollected feeling shocked and confused at the time. One participant in this study recalled that the information given to him by his doctor was brief and that this left him feeling that an inadequate amount of time had been spent discussing how the disease would affect him or what could be done to help him. This could reflect the lack of clinical guidance available to medical practitioners regarding patients' psychological needs in PD and other chronic illnesses.

Regarding adjustment to PD, the results from Habermann's (1996) study suggest that PD patients' experiences involve: acknowledging symptoms and seeking help, balancing emotional responses, dealing with a changing body, gaining formal and practical knowledge about PD and dealing with unpredictability. Many patients described feeling "entrapped" within uncooperative bodies as a result of developing PD. Similarly, Bramley & Eatough (2005) in their case study of a single female PD patient reported the patient's feelings of being imprisoned by her own "defective" body as a result of having PD. This patient reported that her sense of identity had changed as her disease restricted the 'self' she knew prior to becoming unwell. This is reflected in Sacks' (1991) work with PD patients, suggesting that, "their very sense of self is grotesquely changed by illness" (p. 232) and mirrors the identity issues reported by patients in the study by Kralik et al., (2000). Adjustment in this sense might suggest that changes in self-identity occur in PD as a result of a re-evaluation of pre-existing beliefs and that the illness challenges patients' self-concepts, as explained by the model proposed by Sharpe & Curran (2006).

Both the studies by Habermann (1996) and Bramley & Eatough (2005) provide rich phenomenological data about the lived-experiences of PD patients, and this can be framed within some of the adjustment to illness models outlined above. However, in order for psychological practitioners to fully understand patients' adjustment to PD, research is required to focus upon all aspects of the disease experience. Currently there is a gap in the literature regarding patients' experiences of the earliest stages of their illness, i.e. patients' adjustment to their diagnosis of PD. Any research that has addressed this issue in the area of PD has done so retrospectively, often with a gap of many years between the onset of illness and participation within the study. Across the PD research reviewed above, the average length of time between being given a diagnosis and taking part in a research study is nine years. This suggests that patients' experiences of being given a diagnosis of PD have not adequately been explored in sufficient detail, leaving a dearth of information about the process of adaptation itself.

2.7 Rationale for the Current Study

The earliest phase of receiving a diagnosis of chronic illness is one in which a considerable amount of psychological distress and adjustment is experienced, according to the nursing literature. At the time of diagnosis, nurses are encouraged to facilitate communication with the patient in order to enhance their prognosis, and reduce their levels of stress and adjustment difficulties at that time (MacMahon & Thomas, 1998). Furthermore, it is common for PD patients to experience the actual communication of their diagnosis as having been carried out poorly by their doctor (Jones, D'Eath, Harnsford, Hutchinson, Hyde, Thurlow & Spanton, 1999). In mental health services currently available for PD patients, there is a clear lack of psychological support available to this client group, with a survey demonstrating only one dedicated psychologist within one multidisciplinary team being identified as working solely with PD patients in the UK (Mukherjee, Madan, Dewan, Matthews, Parchimowicz & Morrison, 2002). In a more recent review of psychological services in clinical health psychology Wainwright & Bender (2005) identified similar gaps in services for PD patients, and suggest that issues regarding diagnosis and adjustment to the disease should be important areas for possible future psychological research and clinical intervention.

Cognitive-behavioural therapy programmes have been shown to be an effective intervention for long-term health conditions including rheumatoid arthritis (Astin, 2004), HIV and AIDS (Antoni, Cruess, Cruess, Kumar, Lutgendorf, Ironson, Dettmer, Williams, Klimas, Fletcher & Schneiderman, 2000), MS (Mohr, Likosky, Bertagnolli, Goodkin, Van Der Wende, Dwyer & Dick, 2000), and cancer (Edelman, Bell & Kidman, 1999). It can therefore be assumed that given further research within the field of PD, individual and group psychological interventions might be as beneficial to PD patients as they are to patients with other chronic illnesses. Research which focuses specifically upon the early stages of a PD patient's illness would provide data to inform evidence-based psychological practice to assist in patients' adjustment to this disease.

The current study aims to explore the experiences of PD patients who have been recently diagnosed with the disease, with interviews taking place early within this timeframe, in order to capture rich phenomenological data. The current study aims to elicit qualitative data regarding the lived experiences of newly diagnosed PD patients in order to inform psychological practitioners of the possible issues surrounding adjustment to PD at this relatively early point in the patients' illness. Such data could be utilised to assist in the provision of evidence-based psychological therapy to this client group. Increased psychological research within the area of PD such as the current study follows the suggestion made by Wainwright & Bender (2005), that further psychological support and services should be made available to PD patients within the UK, based upon further research in this field.

It is clear from the existing literature, that most research within the area of psychological adjustment to illness has been carried out using quantitative methodology. Stone, Greenberg, Kennedy-Moor & Newman (1991) suggest that this type of research methodology may not be so appropriate for elucidating data regarding patients' experiences, as the tools used may not be sensitive enough to identify particular issues that may be relevant to patients. This is especially so when exploring a new area of psychological experience. Therefore, an interpretative phenomenological analysis (IPA) (Smith, Jarman & Osborn, 1999) approach has been taken, following the phenomenological studies into patients' lived-experiences of PD conducted by Habermann (1996) and more recently by Bramley & Eatough (2005).

IPA is a qualitative phenomenological approach which is concerned with exploring and understanding participants' personal perceptions and lived experience, rather than to produce an objective statement of the event itself (Smith et al.,1999). The IPA process is a dynamic one in which the researcher's aim is to get an "insider's perspective" (Conrad, 1987) about the topic under investigation. The process involves a level of interpretation in that the researcher must make sense of the participant's personal world. IPA is a data-driven approach, rather than a theory-driven one. As such, IPA as a research methodology and analysis tool has the potential to uncover constructs that have not previously been developed by other researchers or theorists (Shaw, 2001).

IPA takes an idiographic mode of inquiry as opposed to the nomothetic approach which predominates in psychological research (Smith, Harré & Van Langenhove, 1995) and aims to draw conclusions about a defined group of participants, rather than generalise to wider populations. Therefore, sampling is purposive in order to obtain a closely defined homogenous group of participants for whom the research question will be significant. A smaller number of participants are required in IPA studies than in other types of qualitative research, with many studies using 5 to 8 participants. Recently, more single-case IPA studies have been published, allowing for more in-depth analytical interpretation of a participant's lived experience (e.g. Bramley & Eatough, 2005). This methodology has been suggested as being particularly useful in the field of health psychology (Shaw, 2001; Smith, 1996). It is also a method specifically suited to Counselling Psychologists, as it requires the researcher to be inquisitive, reflexive, and empathic within a real-time interactive data collection process in order to clarify and explore particular topics brought up by the interviewee (Smith, 2005, personal communication).

Finally, from a personal perspective, the researcher was interested in the particular topic of patients' experiences of PD due to her own personal experience of the disease within her own family. This equipped the researcher with prior personal knowledge and experience of being around people with PD, having been part of local PDS patient support groups and having had contact with patients and professionals in the field alike.

Chapter 3

Methods

3.1 Design

IPA methodology requires that an homogenous participant sample is used. This ensures that a detailed analysis can be carried out in order to explain the lived experiences of participants from a particular group, rather than to make general claims about the wider patient population (Smith & Osborn, 2003). Participants were purposively sampled from one NHS acute hospitals Trust (Barking, Havering & Redbridge NHS Trust). They were taken from the patient population attending Neurology clinics across two hospitals. Patients were deemed suitable for inclusion within the study if they had been diagnosed with idiopathic PD by a Consultant Neurologist within the past three months.

For data collection, a semi-structured interview schedule was used [Appendix 2]. This method was chosen as it allows the researcher to access the respondents' inner social and psychological world, in line with previous phenomenological approaches to data collection in past studies within PD (e.g. Bramley & Eatough, 2005; Habermann, 1996). The semi-structured nature of the interview, with open-ended and exploratory questions, allowed the participant to talk freely about their experiences of being newly diagnosed with PD, so that they had the maximum opportunity to tell their own story (Smith & Osborn, 2003). The flexibility of the interview schedule gave the researcher some guidance as to possible areas of interest or relevance to the participant, and was based upon general concepts and theories gleaned from the extant literature.

Interviews focused upon eight general areas relating to participants' possible experience since being diagnosed with PD.

These were:

1. The experience of hearing their diagnosis
2. The emotional impact of being diagnosed
3. Changes in self-identity
4. The experience of physiological changes to the body
5. The personal meaning of being diagnosed with PD
6. The social impact of having PD
7. How patients viewed their future since diagnosis
8. Life changes since being diagnosed with PD.

The full interview schedule can be found in Appendix 2.

The interview schedule was continually revised in the light of themes or topics that emerged during each meeting with a new participant. As such, the interview schedule was used only as a guideline to preserve the participant-led, ideographic nature of data collection in IPA (Smith, 1996).

Following data analysis the results were fed back to the participants to ascertain a good level of data validity. The data was also triangulated with feedback from two focus groups who differed in age and timeframe since diagnosis in order to couch the project data into the context of the wider PD population. These focus groups were a local PDS group for older patients who had been diagnosed with PD for longer than three months, and a group of young onset PD patients under the age of 40 years.

3.2 Methodology

The Consultant Neurologists working within the Trust were contacted to discuss their wish to be included in the study as a referring doctor. All five doctors contacted agreed to take part in the study, and a folder containing details of the project was provided to them. This contained information about the rationale for the study, details regarding the recruitment process and copies of the referral forms and ethical consent forms [Appendix 3].

Eligibility criteria for inclusion into the study was as follows:

1. The patient had received a diagnosis of idiopathic PD from a Consultant Neurologist within the previous three months, prior to being referred into the study.
2. The patient had been assessed by the consultant neurologist to be under Stage 4 of the Hoehn & Yahr scale (1967) [Appendix 1], to ensure that the patient was not physically or mentally unable to take part in the study.
3. The patient was able to communicate effectively without the need for an interpreter.
4. The patient had not been given a diagnosis of any other chronic illness within the previous six months.
5. The patient was not a young onset PD patient.

Once a suitable patient had been identified by the referrer, the participant was provided with an information sheet about the study [Appendix 4]. If they expressed an interest in taking part in the research, the patient was referred to the study using a referral form [Appendix 5]. Within one week, the patient was contacted by the researcher by letter [Appendix 6] and followed up by a telephone call to confirm whether or not they wished to participate in the study, and to answer any questions that they may have had. If the patient agreed to take part, a suitable time and place to conduct the interview was arranged. Participants were given the opportunity of being interviewed within their home environment or a hospital setting. All participants agreeing to take part requested that they be interviewed at home.

Prior to commencement of the interview, participants were given another opportunity to ask questions about the study, before signing a consent form [Appendix 7]. An audio tape recorder was used to capture the interview for later verbatim transcription and analysis. All participants chose to be interviewed alone, apart from one person whose husband joined the discussion for the last five minutes of the interview.

Interviewees were given the opportunity to talk freely about their experiences of being newly diagnosed with PD, using the interview schedule as a general guide. The researcher reflected upon issues raised by the participant in order to clarify their significance and meaning to the patient. Interview length was determined by the point at which the participant stated that there was no more they wished to raise within the conversation, and that they had talked about all issues significant to them regarding their experiences of being newly diagnosed with PD. The average length of each interview was 50 minutes, with the longest lasting 1¾ hours and the shortest only 30 minutes.

At the end of the interview, participants were thanked for their time, and information about the Parkinson's Disease Society (PDS) and local counselling services was provided to them, with the option that they could contact these resources should they feel the need to do so in the future for emotional support or education.

Interviews were transcribed verbatim and analysed according to the specific methodology outlined by Smith & Osborn (2003). Each interview was analysed in order to ascertain significant emergent themes from the data, and was then used as a guideline towards conducting the next scheduled interview with the next participant with regards to possible new areas of significance to patients. Once no new emergent themes were identified in the analysis process, the recruitment of new participants into the project was halted. This resulted in nine patients being interviewed in total.

Heron's Co-operative Inquiry (1996) was utilised as a means of increasing data validity by involving the participants themselves in the analysis. This was achieved by providing the participants with a list of the master themes following data analysis and asking them to confirm or challenge these results by giving written feedback to the researcher [Appendix 8].

Additionally, the results were discussed within two distinct focus groups for triangulation and comparison purposes in order to reduce the occurrence of bias and confirm the dependability of the research (Robson, 1993). The first comparison group consisted of members of a local PDS meeting for patients within the Redbridge area who were over the age of 60 and had been diagnosed for longer than three months. The second comparison group were younger members of the PDS, aged below 40 years and diagnosed for longer than three months, who attended an educational event at Westminster University, entitled "An Information Event for People of Working Age with Parkinson's". This took place within the forum of an optional seminar group led by the researcher. The results of these discussions were not recorded or transcribed. Instead, written notes were made by the researcher based on the verbal feedback from the focus group members. The results of this part of the data collection process were to gauge a measure of how generalisable these results might be with regard to related patient populations. The results were utilised for comparison and discussion purposes to view the data within the wider context of the mainstream Parkinson's Disease patient population.

3.3 Participant details

Ten participants were referred for inclusion to the study. Of these, nine agreed to participate in the interviews after receiving more information about the study, and following this there were no further withdrawals from the study. Of the nine participants interviewed, seven of these were women and two were men. Their age ranged between 58 and 76, with an average age of 66 years old. Six participants were retired from work fully, two described themselves as semi-retired and one person was still working full-time as a GP. Two participants were widowers, one was divorced and six were married. All participants described their ethnicity as white and British. The average length of time between being diagnosed with PD and taking part in the research interview was 2.7 months.

Two focus groups were interviewed following data analysis for triangulation and data comparison purposes. The patients interviewed within the first focus group, who were members of a local PDS support group, shared similar demographics as those interviewed individually. However, they had all received their diagnoses much earlier in time than the nine main participants, with an average of 3.5 years between being given their diagnosis and taking part in the research project.

With regards to the second focus group, those patients who participated in the optional educational seminar at the PDS event in London were of a younger age range, with the youngest participant being in their 30's and the oldest in their late 40's. These participants had also been living with their diagnoses of PD for a longer time period than the nine individually interviewed patients, on average having had their diagnoses for 3 years.

3.4 Ethical considerations

Prior to conducting the study, ethical consent was gained from the London Metropolitan University Ethics Committee and the Local Research Ethics Committee for Redbridge & Waltham Forest Health Authority. The Research & Development departments for North East London Mental Health NHS Trust and also Barking, Havering & Redbridge Acute Hospitals NHS Trust also required consent from their ethics committees, which was duly granted [Appendix 9].

Patients were given the opportunity to be interviewed within a hospital setting or their own home and with or without a companion of their choice. Participants' doctors were not made aware of which of their patients had agreed to take part in the study, and participants were assured that their decision of whether or not to take part would not affect their current and usual medical care.

Details of support services for PD patients were provided to patients at the end of each research interview. This included details of the PDS, which is a national charity developed for PD patients to provide support, education and advice. Participants were also given details of local counselling services they could access should they feel this was necessary.

Participants were given the opportunity to ask questions about the study prior to their giving consent to taking part. Participants were asked to sign a consent form confirming that they agreed to participate and that they were aware of details regarding the research process. Participants had the right to withdraw from the study at any time without giving their reasons for doing so. Participants were aware that their identity would be protected throughout the publication of the study to preserve their anonymity.

Chapter 4

Analysis

4.1 Overview

Interviews were transcribed verbatim and analysed using the specific methodology suggested by Smith & Osborn (2003), which involves the researcher immersing themselves within the data transcripts and identifying emergent themes. The themes were then checked within the raw data to clarify their validity across all interviews. Each transcript was read and re-read several times to make sure the emergent themes were a true reflection of the participant's experiences described within the interviews. This form of analysis is iterative and involves close interaction between the researcher and the text. The process of analysis is interpretative, in that the researcher is constantly interpreting the meaning of the data from the text whilst continually checking these interpretations with the raw data for validity purposes (Smith & Osborn, 2003).

Initial lists of themes were then clustered according to more overarching themes and then checked back within the raw interview data to ensure an optimum level of validity. The superordinate themes which were clustered from the emergent theme list, once validated from within the raw data, represented the issues most significant and descriptive of the participants' experiences described within the research interviews. The interview transcripts can be found in Appendix 10, including an example of a transcript displaying emergent themes, which were identified as part of the analysis process.

Three superordinate themes were identified, which encompassed seven major themes. These were:

Superordinate Theme	**Major Theme**
	1. Emotional Reactions to Diagnosis
1. Impact Upon the Individual	2. The Self as Compromised by PD
	3. Social Anxiety
2. Impact upon the Social Self	4. Identity and Social Role
	5. Support vs. Autonomy
3. Self-Preservation Strategies	6. Practical Self-Preservation
	7. Emotional Self-Preservation

Figure 4.1 Superordinate themes and Major themes identified

A model has been proposed to explain the interaction between the different themes (*Fig. 4.2*) and will be discussed in further detail below.

Feedback from the nine participants following completion of the study revealed that these themes were a true representation of their current experiences, with no patients contesting these.

Feedback from the focus group conducted at the local PDS meeting revealed that these themes were also relevant to these patients, with an emphasis upon the "Practical Self-Preservation" theme as the most significant experience for them since being diagnosed with PD.

The young onset PD patients who attended the PDS educational seminar stated that although these seven themes were relevant to them, their fears about the future were the most pressing issue for them. Within the theme of "Identity and Social Role", the younger participants at this event spoke about the importance of "dignity" for them, and of not wanting to be treated any differently to other young people.

The three superordinate and seven master themes will now be explored in more detail, with examples of each theme being illustrated by excerpts from the participant interview transcripts. The excerpts are numbered according to where they occurred during the participant interview. The full interview transcripts can be found in Appendix 10.

4.2 Impact upon the Individual

Participants described their experiences of being newly diagnosed as impacting upon them as an individual from an emotional perspective as well as from a physical and functional point of view. Their experiences were explained by two major themes: "Emotional Reactions to Diagnosis" and "Self as Compromised by PD". These will now be explored in further detail.

4.2.1 Emotional reactions to diagnosis. The nine participants recalled various emotional responses upon hearing that they had a diagnosis of PD. They explained how this impacted upon them with respect to the time of hearing their diagnosis in the consulting room through to discussing the emotional consequences of living with this condition.

Jess recalled feeling rather confused upon hearing from her consultant that she had PD, explaining that she did not know anything about the disease at that time, nor how it might affect her in the future. During the interview it became apparent that this was still indeed the case, and she spoke about the many unanswered questions she had about the condition she now faced:

Interviewer 1: How do you feel about ... when you think back to when you were given your diagnosis of having Parkinson's? What went through your mind?"

Jess1: Well, not a lot really. I just got my mum's... well they thought she had it but she didn't, Alzheimer's. Whether it leads to that, I don't know. I've never really thought about it a lot. I just hope that I don't get a lot worse."

Jess demonstrated some confusion with respect to the similarities between her mother's Alzheimer's disease and her own diagnosis of PD, and seemed worried about the possible link between the two. She expressed some fears about her future deterioration in health, which was described again a few minutes into the interview:

Interviewer 5: Did you have any emotions in the room? Or did you think about it afterwards?

Jess 5: Not really no. I mean it did go through my mind how bad it would get. I don't know really how much worse you can get. I don't really know much about it.

Later in the same interview, Jess became upset and tearful:

Interviewer 37: Do you feel different about yourself since being told you have got Parkinson's?

Jess 37: [PAUSE 5 SECONDS] Bit sad sometimes... [*nervous laughter*]. I don't know I...

Interviewer 38: So sometimes it makes you feel a little bit sad?

[PAUSE 10 SECONDS]

Interviewer 39: Is the sadness because... at the moment you are not quite sure of how it is going to affect you?

Jess 39: Yes.

Interviewer 40: Hmmm....

[PAUSE 10 SECONDS]

Interviewer 41: There's lots of questions which you want to know and have answered...and understand...

Jess: 41 [*Starts to cry*]

[PAUSE 5 SECONDS]

Interviewer 42: I can see and I can feel this is quite... painful for you.

Jess 42: Hmmm.... [*Continues to cry*]. I've never thought about it before.

Jess's response during this part of the interview clearly demonstrated her distress and grief regarding her newly diagnosed status. Response 42 suggested that Jess had not, up until this point, connected with some of her feelings or cognitions about what it meant for her to be diagnosed with PD. This could be suggestive of some psychological processes such as denial, which had been protecting her from acknowledging some uncomfortable or difficult emotions regarding being diagnosed with such an incurable condition. Only upon questioning in the research interview had Jess given conscious attention to such thoughts or feelings.

A few minutes later, Jess suggested that she was "not much help" to me in the interview:

Jess 45: Yes. I don't know what to say.

Interviewer 46: Hmmm… [PAUSE 10 SECONDS] OK.

Jess 46: I'm not much help to you, am I?

Expressing such helplessness with regards to her input to the research study may have been an indication of Jess's own feelings of helplessness in terms of her current situation of being diagnosed with an incurable illness. Not knowing "what to say" in the interview suggested a sense of feeling rather lost and stuck in her own situation.

Later in her interview Jess expressed the wish to have no contact with other PD patients, and this might have reflected again her sense of denial or self-protection. This issue is explored in more depth within the master theme of "Emotional Self-Protection". In summary, Jess clearly expressed some difficulties in adjusting to her new condition based upon the exploration of her feelings during the interview. In conjunction with this, the feelings evoked within the researcher during the interview were those of a deep sense of loss and sadness, and at times desperation. These responses within the researcher may have reflected some of the emotional states experienced by Jess, with regards to possible transference reactions.

Jess was not alone in expressing some distress upon hearing that she had PD. Cynthia also spoke of feeling "numb" at her consultation when informed of her diagnosis, and Nora and Maureen both recounted how they broke down in tears in the consulting room. All three participants wept during the research interviews when recalling their experiences of receiving their diagnosis:

Nora 3: Oh yes. And when he told me. Like when he said and we sat down after he'd given me these tests and examined me and then when he said "Mrs T I think you've got Parkinson's", of course my daughter starts crying. I was upset [*Participant starts crying*] and I thought oh it's only a short while after losing Dave [*Participant's husband*].

Maureen10: Well… I get upset on occasions… [PAUSE 5 SECS] [CRIES] Sorry.

Interviewer 11: That's ok.

Maureen 11: [CRIES – 10 SECONDS] I got upset when I saw the doctor about it. When I went to tell her I was a bit depressed. She said she's sending me for some counselling.

Clearly, taking on board a diagnosis of PD can be a distressing experience for some patients. It can be a shocking event, rendering patients with a variety of difficult, negative emotions. Speaking of the loss of her husband in relation to hearing her diagnosis, Nora might have been reflecting a sense of loss too in terms of her physical health. Both these losses were clearly distressing to her, to the extent that she began to cry within the interview upon recalling the event.

The theme of loss was common across all participants within the study, in terms of speaking about the frustrations of living with the illness and the restrictions that it imposed upon their physical and functional abilities. For instance, Edith spoke about how PD had affected one of her hobbies:

Edith 54 : … And I can't knit properly. I have to keep holding it down there and sort or winding it round. I used to knit so fast. And I think, "Now that's frustrating me" and I put it back and wait a little while.

As well as a sense of loss and frustration, participants spoke about the stigma of having PD, which Cynthia explored in relation to other illnesses people could be diagnosed with:

Cynthia 14: ... Especially something like that. I mean he *[Participant's ex-husband]* had a heart bypass and then everybody seems to think that that is somehow different to like Alzheimer's or Parkinson's. I always get a feeling as if people think you might be a little bit different.

Interviewer 15: Yeah. So people might have a different opinion of you, knowing that you have got Parkinson's? As opposed to if you had broken your leg, or … a heart condition.

Cynthia15: … Yeah, that's right….

Interviewer 16: … Do you think people would have more sympathy for people with a heart condition? Is that what it feels like?

Cynthia 16: No, I don't think it's that really. It's just it seems, well it's the wrong word really, but glamorous, but glamorous to have a heart operation or have your leg in plaster, but this they sort of look at you…

Here, Cynthia speaks about her illness in terms of the negative reactions it has elicited from others in her life, expressing her sense of stigma about having PD. Later in the interview she explained that it had been hard to tell people that she had PD, for fear of them thinking negatively about her regarding her health status. This sense of stigma relates to the social impact of having PD, which is explored a little later, within the master themes of "Identity and Social Role" and "Social Anxiety".

In contrast to some of the negative emotions associated with hearing about their diagnosis, some patients spoke about it as somewhat something of a relief to know what is wrong with them. For instance, Harriet spoke about the benefits of finally having a label to explain her physical symptoms which she had been suffering from for some time prior to receiving her diagnosis:

Harriet 3: Relieved really… to know what was wrong. I was beginning to think I was putting it on… you don't know *what's* wrong. So I was relieved to know what's wrong.

Part of this sense of relief was in part due to some participants' understandings that PD is not a fatal illness, but one that can be managed with medication, as expressed by both Walter and Bertha:

Walter9: Yes. Can't be cured I know, but at least they can treat it.

Bertha8: Yes. So when they confirmed the diagnosis I was relieved in a way because I knew I hadn't got a life-threatening illness.

Interviewer 8: It actually came as a relief?

Bertha 9: Mmm… It did.

However, a little later in the interview Bertha expressed mixed emotions regarding how she felt about her diagnosis:

Bertha19: Apart from the fact that I get a bit down sometimes… but I don't … it's just a general feeling of being a bit low. I don't sit down and think, "Oh, why me?" because I think I could have been diagnosed with some terrible life threatening cancer or something like that. So, no I know I can live with this but I'm just … I get a bit low at times because I feel… I can't do things that I want at times … I can't do things that I *want* to do.

The reality of having PD has meant that Bertha has a level of disability which was not present before becoming unwell, which made her feel depressed at times. However, she seemed to console herself with the fact that PD is not a fatal illness, and that things could in fact have been worse if she had been diagnosed with a more sinister illness.

Having a condition such as PD meant that some patients expressed a sense of needing to accept the fact that they will have to live with the illness for the rest of their lives. This was aptly demonstrated by Maureen:

Maureen7: … so I knew it wasn't something that gave you a death sentence. It's just a progressive disease that I would have to learn to live with.

Peter, a GP with PD, in his interview described having PD as an illness of "inconvenience and irritation" with regards to the impact upon his daily life, but understood this in the context that illness could also be seen as a regular part of life, requiring, as Maureen suggested, a level of acceptance:

Peter 40: Almost as though it is a natural part of ageing. You see it to a certain extent that everybody gets old, bits drop off. You know...

Nevertheless, having a diagnosis of PD could evoke strong negative emotions in patients, especially when thinking about the future. Edith spoke about the possible deterioration of both her physical and mental capacities over time as a result of having PD. Like Jess, Edith was unclear about how this illness might affect her in the future, and she expressed her frustrations that even medical professionals could not predict what the future might hold for her:

Edith 53: But it is a funny illness. Will most illnesses you are told the prognosis but they don't know it. They don't know what you're going to finish up like. That's worries me a little bit – the mental side and having things done for me. I can see there's going to be a time when I'm going to have to be bathed. I know that's going to happen. I can see that now.

Edith's main fears were that she would lose her independence, so that others would be forced to care for her, and this view was shared amongst most of the other participants also.

In summary, participants described a range of emotional reactions with regards to how they experienced hearing their diagnosis. Patients expressed a sense of deep sadness, loss, helplessness, confusion and shock. For some, the experience of talking about their diagnosis was upsetting and four out of the nine participants cried at some point during their interview. Indeed, for some it was the first time they had spoken or even thought in depth about it. However, for most patients, having a clear diagnosis also came somewhat as a relief, in terms of finally knowing what was wrong with them and to explain their myriad symptoms which they had been living with for some time.

Participants in general viewed their illness as something that could be managed with medication, but expressed some strong fears about what might happen to them in the future in terms of the inevitable deterioration in their health and increased levels of personal care which they might require.

The focus group of young onset PD patients fed back that this theme was particularly important for them also. Members of this group confirmed that their fears for the future were particularly significant to them, given their stage in life, with many people stating that having a young family posed particular concerns for them in view of their certain deterioration in health. In terms of their emotional reactions to their diagnosis, members recalled having many questions for their doctors regarding how serious their illness was, whether or not it was an hereditary disease that they could possibly pass on to their children, and in some cases the expression of a fear that their "life was over".

All participants spoke about their frustrations with regards to living with the symptoms of PD and this is explored within the next master theme, "Self as Compromised by PD", where patients described the impact that the disease had upon their bodies and their ability to function physically.

4.2.2 Self as compromised by Parkinson's disease. As a consequence of having PD all participants described how their lives had changed in terms of how their body functioned, how they appeared physically to others, and how they conceptualised the disease. This theme encapsulates participants' experiences of being physically and functionally compromised by PD.

When Edith was diagnosed by her doctor, she recalled that he had been able to tell just from her facial appearance that she had PD. This was something that had played on her mind ever since and troubled her at the time of her interview:

Edith 2: […] And when I went down that night and he told me, I thought well how did he see that just in my face? When I got home I just stood in front of the mirror, looking for what this was that he'd seen. I still haven't found it *now*.

Interviewer 3: So it was difficult to see what he *saw* and knew so *accurately*?

Edith 3: Yeah! Straight off. He said, "You've got Parkinson's".

Bertha also described how her facial expressions had changed as a result of developing PD, and how this had had a detrimental effect upon her social interaction with others:

Bertha 54 […] Sometimes someone would say I've got a vacant expression on my face and I'd think, "Oh God, people think I don't care". I did but I couldn't do anything about it"

Both Bertha and Edith described how their faces had altered as a result of having PD, and that their facial expressions were no longer congruent with how they felt inside or wished to appear to others, resulting in a level of frustration and annoyance. For Edith, her facial appearance had been compromised by the disease in such a way that she was still unaware of how her doctor had been so sure that she had PD. In some ways, it seems as if Edith had been betrayed by her own physical appearance.

Participants also explored how other aspects of their physical appearance had altered as a result of developing PD. Jess spoke about how the disease had affected her general outward appearance, in terms of her posture. She was now bent forward more than she used to be, and this outward marker of her disease distressed her in terms of how she felt about her body since being diagnosed:

Interviewer 30: […] Do you feel any different about your body since having a diagnosis of Parkinson's… since being told this is what you have got? Has it changed how you *view* your body?

Jess 30: Well… I feel sort of hunched up sometimes…

Similarly to Jess describing herself as "hunched up", Nora spoke about how she was "shrinking", and that her clothes no longer fitted her as they used to as a consequence of her illness:

Nora 42: […] I got trousers at Christmas time and they're supposed to be three quarter, well I suppose they're just above the ankle now. When I tried them on the other day, I mean they're round my ankles. The ones that did fit me are now on the floor. I mean I showed Terry and he couldn't believe it. And I'm tripping up.

A little later in the same interview, Nora spoke about how her grandsons now call her "Little Nanny" as a nickname due to the marked alteration in her appearance:

Nora 42: When I walk in the door… I mean the two of them they're massive and they call me "Little Nanny". I'm shrinking by the way. I'm shrinking!"

Nora contrasts herself in terms of her stature with her tall grandsons to emphasise the point that she is physically getting smaller. This remark was made directly after speaking about how "useless" she felt around her family now that she could not do so much due to her illness. The subtext in this instance might have suggested that Nora was feeling somewhat of a "lesser" person, both physically and practically speaking as a direct result of her illness. Her body and her ability to function were being markedly compromised by PD.

Other participants related how they felt with regards to their physical appearance and their unintentional display of outward symptoms of PD. Cynthia related how she tended to cover up her symptoms of shaking in public due to embarrassment about her illness:

Cynthia 21: [...] I mean if it starts shaking while I'm out, I cover it up with *[Demonstrates how she grabs her shaking arm with her other hand to steady it]*. You can't do it with a paper, because the paper rattles! *[Laughs]*. You can't hide it! *[Laughs]*.

Shortly afterwards, Cynthia stated her worries about attending her daughter's wedding next year due to her PD symptoms being noticeable to others:

Cynthia 23: Yeah. My youngest gets married in May but I don't want to be a shaking lady at the wedding!

By labelling herself "a shaking lady", Cynthia was stating explicitly how pertinent this issue was for her. This is similar to Nora's adopted nickname of "Little Nanny". As a result of developing PD, patients have described their experiences of physically changing in appearance and, as a consequence, identity. This was especially with regards to how they perceived themselves and were seen by others. The social aspects of this are explained by the superordinate theme of "Impact Upon the Social Self", which will be described later in the Analysis section.

Coupled with describing the changes that had occurred to their bodies as a result of developing PD, participants spoke about how out of control they felt with regards to the functioning of their own bodies. This was a significant issue for many participants, so much so that some patients reported this phenomenon as if their body had a distinct mind of its own. This is demonstrated in an excerpt from Cynthia's interview where she talks about her left arm:

Cynthia 76: No, just that this part wants to do what he wants to do and not what I want to do! *[Laughs]* [...]

And a little later within the same interview:

Cynthia 78: And after a couple of minutes of taking over, the other hand is shaking, so it's got a little mind whatever it is!

In these two excerpts, Cynthia described parts of her body as having an almost separate identity from her, using the reference "he" when referring to her own arm. This separation of wills within her own body was also reflected in Maureen's interview:

Maureen 65: I mean I don't really know all about it. I mean sometimes I feel my forehead going up and then back down again.

Interviewer 66: It does things by itself…

Maureen 66: Yes. And my leg actually went like that [*Shows me her leg moving upwards*] and I'm thinking I didn't do that, it did it itself.

Interviewer 67: So it's like you've been…

Maureen 67: Taken over. And this morning in bed, the whole of this side just shot up out of bed without me doing it.

In these excerpts Maureen described her body as having been "taken over" by some other force. And this phenomenon was common across other participants, as explained by Edith and Cynthia:

Edith 65: It's like you've been invaded in some way, you know?

Edith 77: It is like a *thing*. That's just want it feels like. Yeah. A *thing*.

Cynthia 79: Yeah, a thing that's taking over and you think, "Behave! Stop it!" you know? It's something that's in there. It's the white cells dying off, or is it the red?

This concept of one's body being taken over by some malevolent force, reflected participants' descriptions of the struggle they experienced within their own bodies, often resulting in feelings of frustration and annoyance with themselves, as described by Edith, Nora and Bertha:

Edith 54 […] sometimes you go to do something and you can't do it. You know what you want to do but you're not doing what you want to do. Your brain's doing something different and I think, "Oh! It's driving me mad". And I sit down and think, "I'm going to *do it!* and I do know how to do it and I'm *going* to do it".

Nora 18 I get annoyed with myself. I get annoyed. You know? Oh! And… I can't explain you know? I get annoyed with myself and I start calling myself names and talking to myself

Bertha72 [...] It's an inconvenience more than anything. You don't feel ill. You've got no pain. But it's a *frustration.* Because you think, "Why *can't* I do this?". I mean I was opening a new pack of tea bags. You know they're all sealed with cellophane? Well you've got to stick a knife under it and I can't... That's when I get annoyed with myself. Because once upon a time you'd do that without thinking about it. But sometimes it's the little fiddly things that *do get irritating.*

Maureen, when talking about how panicky she often got as a result of this struggle with her own body, described her situation as being akin to being at war:

Maureen 48: But you know it makes me get into such a panic about it like World War One!

Maureen's statement could suggest a metaphorical experience of being in battle with a strong and opposing force, reflecting the reports of most other participants regarding how PD had physically and functionally compromised their bodies. Sometimes the frustration of such a struggle with one's own body was too much, and one participant described how after going to a restaurant with her family, this extremely negative experience put her off from going out to eat again:

Edith 37 [...] We went out for a meal and that made me say, "Right, I'm not going out anymore". I could *not cut this meat.* And I said, "This meat ain't half tough" and he said, "Oh is it?". "It's really tough and I can't cut it". So he said, "Well you can have my knife, maybe it's sharper?". And it still wouldn't cut it. So I said to him, "Why can't I cut that meat? I suppose it's something else I can't do now". I was getting really mad at myself...

When speaking about how PD affected patients' abilities to function normally, participants reported a sense of restriction within their own bodies, and as a consequence many had lost interest in formerly pleasurable activities and past-times:

Bertha 19: [...] I can't do things that I want at times... I can't do things that I *want* to do.

Interviewer 20: So it limits you?

Bertha 20: It does limit me. I mean I can't walk as far as I used to. I used to like walking, but I can't walk as far

> Peter 1 I'd lost interest in the garden because I couldn't do it. Daily activities had started to become difficult and you think, "What is going on here?" because this isn't just a tremor. And I really didn't want to walk the dog. I'd always enjoyed it but because it was an effort…

> Edith 18 Yes. I can't get in and out of the bath. And I *love* having a bath and now I don't like having a bath.

By compromising the body's ability to function normally, the disease was described as affecting patients' quality of life so that hobbies and enjoyable activities were transformed into chores requiring much more effort compared to when they were well. These restrictions formed an integral part of how patients conceptualised their condition, as explained by Edith:

> Edith 76 […] I'm not ill. It's not an illness. My husband says, "No, it is an illness", and I say, "It's not an illness that makes me feel ill, it's an illness that stops me doing things".

Edith's description of how she viewed PD was very similar across all participants, in that they described their illness as something that limited their ability to function, rather than experiencing it as any other more usual type of illness they had had before.

In summary, as a response to the onset of PD, participants described their physical selves as having become compromised to the effect that their physical appearance was no longer congruent with the inner representation of both their physical and emotional states. Patients described how in many ways their self-identity had altered as a result of how the PD had compromised their appearance to both themselves and others. This was most apparent within social contexts, where participants described a certain amount of dismay or embarrassment with regards to their altered appearance to those around them, including their display of uncontrollable physical symptoms.

The deterioration in functional ability was described as having a clearly detrimental effect upon patients' quality of life and sense of general well-being. Formerly enjoyable past-times or activities were no longer perceived as pleasurable, as they had been prior to the onset of PD.

The disease was described by participants as manifesting itself within the patient's body as some type of external entity. As a consequence, participants described the struggle they had with their own bodies, where it was felt that their bodies had been almost hijacked by the disease.

Lastly, participants spoke about how they conceptualised their condition as quite unlike any other illness they had experienced before. PD was described as an illness of functional deterioration resulting in a struggle with one's own body. In a sense, this describes the essence of the theme of the self becoming compromised by PD.

Both focus groups stated that this theme held relevance to their experience of having PD. This was seen as a theme which described their day to day struggle with the symptoms of their illness.

4.3 Impact upon the Social Self

The themes of "Emotional Reactions to Diagnosis" and "Self as Compromised by PD" have explained the impact upon the individual patient at this early post-diagnosis stage of the illness. However, patients' experiences of PD were also described in terms of the social impact it had upon them. The superordinate theme of "Impact upon the Social Self" incorporates the three major themes of "Social Anxiety", "Identity and Social Role", and "Support vs. Autonomy". An exploration of these themes now follows.

4.3.1 Social anxiety. Participants described how their levels of general anxiety had increased since becoming unwell. Many symptoms of PD were described as being noticeable and obvious to others and this resulted in patients feeling more self-conscious in public, having less self-confidence and at times feeling embarrassed or ashamed of their physical presentation. Social interactions were reported as being strained at times and in general patients complained of getting more stressed or anxious than they used to prior to becoming ill.

Being seen as physically unwell, with outward symptoms of shaking or walking difficulties, rendered some participants socially anxious, especially in public places. Nora reported how she has had to overcome such anxiety when leaving her house to go across to the local supermarket directly opposite her home:

Nora 33: [...] Well there have been days where I haven't got the confidence to go across to the car park [of the supermarket]. And I force myself.

Nora's PD had made her increasingly self-conscious in public with regard to her uncontrollable display of symptoms, which she felt others would clearly notice:

Nora 35: [...] I feel like when I pass... well you might be walking past a couple talking and I know like they've passed me and I can feel that they've turned round and looked.

Similarly, Bertha explained how her symptoms of PD could be potentially easily misconstrued by people who did not know that she had the disease, leading to her feeling self-conscious in public and making her lose confidence in herself:

Interviewer 64: What is it about those times that makes you feel more anxious?

Bertha 65 [*Pause 5* seconds] I think the fact that I [*Pause 3 seconds*] .... I feel.... People will look at me and ... people look at me and think well what's wrong with her? Or, it's not just that... I think because I ... I just haven't got the confidence that I used to have and people will think well what's, what's.... I mean I do walk differently. I walk differently now and sometimes I walk shuffley but then I think well don't be silly it doesn't *matter* what people think. You've got to do this for yourself. You've got to *overcome this.*

Both Bertha and Nora seemed to be explaining the same difficulty. Being seen as different to others made them feel uncomfortable in public, leading to increased levels of self-consciousness and social anxiety. Similarly, Edith described how she found it difficult to deal with her lack of agility when out shopping, resulting in her feeling embarrassed when out and about:

Edith 22: [...] When you go shopping ... I don't go on my own. I can't get the money out my purse quick enough. And my friend said to me last night, "So there's a *queue,* let them *wait*! You're at the *front* of the queue". And I said, "Yeah, well it's rotten Pat. They're all queuing up and it's getting longer".

Interviewer 23: So it makes you panicky.

Edith 23: And then you get panicky and then you get embarrassed.

Interviewer 24: And does the panic then make it worse?

Edith 24: Yeah. Cos then I'll start *really* shaking.

Participants not only spoke about the social anxiety they experienced in public, but also amongst people they knew, such as family, friends and colleagues. Cynthia explained how she did not want her work colleagues to be aware that there was anything wrong with her, and therefore had chosen not to inform them that she had PD:

Cynthia 60: [...] I've just told one lady and the headmaster. Nobody else knows at the school. I thought, "Well they might look at me differently", although they are a lovely group of ladies. They'd be keeping an eye on me and I don't want that just yet.

Participants reported in their interviews that at times, the anxiety could be overwhelming at social occasions involving friends and family, leading to one participant describing how she felt almost "detached" from the social situation:

Bertha 53:	[...] I would be with people but I was on the outside. You felt slightly detached from people. You weren't really... there. [...] I was with people but I wasn't...On the outside looking in.
Bertha 71:	[...] But mentally, I feel... Sometimes I still... get this slight feeling of detachment. It's nowhere near as bad as it *was*. But I do sometimes still get this feeling of detachment from everybody.

Amongst family and friends Bertha described being "on the outside looking in", relating to her experience of feeling detached from social occasions, almost like an outside observer. This may reflect the heightened levels of anxiety that some patients experience even within familiar surroundings and amongst people who know them.

In summary, the theme of "Social Anxiety" describes a variety of issues that are significant to newly diagnosed patients with PD within their social contexts. Participants described anxieties relating to being perceived as "different" to others or noticeably unwell, so that their level of anxiety tended to increase within social settings. Patients described anxieties occurring in public around strangers, as well as within their social circles of friends, family and work colleagues. This anxiety led to feelings of lowered self-confidence, higher states of self-consciousness and at times the experience of feeling socially detached from people.

The young onset PD focus group members stated that social anxiety was a concern for them also. Participants stated that in certain situations, such as at work, they were aware of becoming more self-conscious, especially with regards to their symptoms being apparent to others at times. For these younger patients, the need to fit in and to not be seen as "different" to other people was described as a significant issue for them also.

From this study it seems quite clear that social anxiety is a significant issue for patients newly diagnosed with PD. As a result of the impact of PD, participants also described other changes within their social systems, and this is explained within the next theme, of "Identity and Social Role".

4.3.2 Identity and social role. Participants described how since developing PD their roles within social systems, such as within their families, had altered. Issues regarding how they perceived their self-identity in the light of the illness were highlighted as important factors within social contexts.

When asked about how their illness had changed things within their families or social networks, all participants stated that in the main they had received a great deal of support, both emotionally and practically from their friends and family members. In some cases participants spoke of how this had brought them emotionally closer to their close family, as described by Harriet and Walter:

Harriet 68: [...] He says he appreciates me more. Not that he didn't before.

Walter 49: [...] They have all acted positively to it. Not that I see my son a lot, but my daughter has. They've all been very good to us actually... very supportive to us.

Part of this support was described in terms of the encouragement that family members or friends often provided to the patient. For example, Bertha spoke about how her sons were helpful in persuading her to do practical tasks that she was not confident in carrying out due to her symptoms of shaking:

Bertha 80 [...] We are lucky we have got support around us because I've got two strapping sons and they won't let me give in. I mean we had them all round on Sunday and we had a barbeque. And my eldest son said... I said something about a cup of tea and he said, "Well go on then". So I said, "I thought you were going to make it for me Nick". He said, "There's nothing wrong with you. Go on. You can make it". You know and they... it is said in a joking way but I know they are right. It is good for me to keep doing things.

Similarly, Edith explained how even though putting on make-up was more of an effort now that she had PD, her friend would tell her off if she had not at least attempted to do this, which she reported as being helpful in terms of motivating her to maintain a sense of everyday normality:

Edith 60 [...] Even things like putting make-up on properly. Then I think, "Oh, so what. I'm not bothered at my age". But as soon as I go out this afternoon. Well as soon as my friend knocks for me. If I haven't got make-up on she says to me "Put your face on" and I know she's going to say it so I do it. And when she comes along she'll say "Good. You've done your make-up".

Encouragement to persist with practical tasks despite the restrictions that PD imposes upon patients was deemed useful by the participants. If that encouragement was not there, patients spoke of how it might lead to them becoming complacent and depressed.

As a result of the patient becoming unwell, participants described how their friends and families adapted different roles within their lives, to support them. Walter explained how his wife would most probably take on more of a caring role towards him over time as his health deteriorates further. In his interview he had described himself as always having been a very active person but since being told he had PD, he had decided to give up driving after 40 years due to safety reasons, and had "slowed down" the pace of his lifestyle. Having PD for him determined some significant changes within the roles of this partnership, which although necessary, left him feeling "humble" with regard to his wife's changing role within their marriage:

Walter 14: [...] It's changed the way I've had to act. I've had to give up driving... and also my wife. You know. It's a shock for *her*. I mean it's not a shock... we knew it was coming, but it is a shock. That fact it's put on her.

Interviewer 15: Right. So it's affected *her* differently than how it's affected you?

Walter 15: Well... I don't really know how it's affected her but I know how it affected me. I feel that she is going to have to do a lot more to look after me as time goes by...

Interviewer 16: ... Mmm... so from that perspective... it's made you feel, not *guilty*... I don't know... How does that make you feel?

Walter 16: Ahmmm… Very humble I suppose.

Other participants explained how these social system changes affected them in a rather negative fashion, leaving them feeling somewhat "useless" at times or a "burden" to those around them of whom they cared about, as described by Bertha and Nora:

Bertha 51 […] I did feel that I was a burden to people, I must admit. Because when I was first diagnosed… the first summer… we normally do go away with the same group together. We've always done a lot of walking and I got quite upset because I couldn't walk as far and I said, "I don't think I'd better come on holiday with you anymore", and they said, "Don't be ridiculous. It doesn't matter to us".

Nora 41 Yes, yes. Because you know, like I should be going over my daughter's and I feel… useless… I mean I should be going over to the kitchen and helping but I'll only get in their way.

The negative impact of having PD upon the patient's role within their family social system is succinctly demonstrated by two participants, Bertha and Cynthia, who spoke about their distress at being grandparents within the context of developing PD:

Bertha 41: […] The only thing is… only silly thing… I do feel … cos when … just before my first grandson was born… he was out in November, just before I was diagnosed. And I feel I missed his babyhood because I couldn't hold him. I was frightened to hold him. Because I thought I might drop him and that's the only thing… regret that I've got. I don't feel that I … I missed out on him being a baby, because by the time I was diagnosed it was the April and it had been four or five months and I just felt I missed out on him being a baby. But that's the only… The big regret. It's a minor thing only, but it made me upset because whenever they said to me, "Do you want to hold him?" I would if I was sitting still and he wouldn't wriggle. But as soon as he got bigger, I was frightened to pick him up. But then I was diagnosed and put on the right tablets so the problem sort of cleared itself. He's a bit of a handful at the moment… terrible two's! Yeah. But they are expecting another one in January so perhaps I'll be more involved with that baby, you know?

Interviewer 41: So in a way you'll be able to make up for the other baby?

Bertha 42: Yes, that's right. They didn't ask us to babysit or anything. My son said, "You can just about be able to cope with yourself, you can't cope with a baby as well". So it felt I missed out on the early part of his life. So that's … the only regret that I've got really.

Clearly, Bertha recounted her role as a grandmother as having been an extremely distressing experience for her during the first months of her first grandchild's life, as a direct result of having developed PD. The lack of confidence she experienced as a result of her symptoms had led her to feel that she had "missed out" on his babyhood. She described this almost as if she had not been part of his upbringing, in terms of her expected role as a grandmother.

When asked about the place that Parkinson's had in her life, Cynthia responded by talking about the impact it might have upon her future role as a grandparent, reflecting similar experiences to Bertha's:

> Cynthia 49: [...] If uhm... [*Cries*] If my daughter has a baby, I won't be part of it.
>
> Cynthia 52: [...] That I won't be able to... because you see all the nannies and granddads you know, and they look after their children for their families. I mean it's early at this stage but you don't know how long it will be but you think to yourself I wouldn't trust myself to look after them.

A little later in the same interview, Cynthia links this deterioration in her health and consequential possible inadequacy to look after her children's babies with feelings of being a burden to them:

> Cynthia 70: But you think... I don't know what age it would be, but I want to spend... I know it's silly, to see my girls have babies. But at the same time I don't want to be a burden to them, you know? I want to be with them, but I don't want to be a burden to them.

In this excerpt, Cynthia made links between how she viewed herself as a future burden to her daughters and the similarities in such a dependency that would occur when they have children of their own. The sense of being a burden or not fulfilling one's expected role as a grandparent was a common thread between the examples provided by both Bertha and Cynthia.

Harriet in her interview spoke about how her children viewed her differently now that she had PD and how despite the physical and functional deterioration that had occurred as a result of the illness, she still maintained the same core identity as she did prior to becoming unwell, which she had to make explicit to her children:

Harriet 39:	As I said to the children, "I'm still the same person. I might be changing, but I'm still the same person.
Harriet 42:	[...] I'm not *invincible.* I think that's what it is. You always think your parents are going to be there forever, don't you?

In summary, as a result of becoming unwell with PD, participants described some significant changes that had already occurred within their social systems and the negative impact this tended to have upon their self-identity and social role. Participants welcomed the support and encouragement they received from their family and friends. However, due to the impact the illness had upon their levels of functioning, participants described feeling "useless" at times around others and "humble" or a "burden" with regards to potentially having to be dependent upon others in the future, such as their partner or children.

PD was described as having a rather significant impact upon participants in terms of their expected roles and identities within their families, most notably that of becoming a grandparent. The alterations imposed upon patients' social roles within the family was described as having been affected in a rather negative fashion, with participants relating their sadness at these changes, such as within their marital or parental relationship.

The feedback from the young onset comparison focus group confirmed that this theme was of particular significance to them also. Members stated that since being diagnosed they had major concerns with regards to how their role within their family life and work life would change. Participants spoke about their fears of a role-reversal occurring, with their children possibly caring for them in the future. Members also stated that they had concerns that they might be forced into taking early retirement and ending their careers. The young onset group also fed back the importance for them of not being seen or treated any differently from other people, especially within the work environment. The importance of preserving and maintaining a strong sense of identity within their various relationships was deemed as an important factor for this group.

The impact of PD upon patients' social systems has highlighted some specific issues regarding the need for both support and independence, and this is now explored within the following major theme of "Support vs. Autonomy".

4.3.3 Support vs. autonomy. Despite a deep appreciation of the support systems around them, provided by family, friends, colleagues and health professionals, participants reported how they struggled to gain a reasonable and acceptable level of independence within these social contexts. Participants expressed a certain amount of ambivalence towards the support and help they received from others. At times the well-intentioned supportive behaviour of people around them led to feelings of frustration and despair within the patient.

Participants spoke highly of the emotional and practical support they received from their family, and from the NHS staff who had been working with them. Indeed, feeling understood by their health practitioner was a key factor in helping patients feel positively supported, as described by both Bertha and Nora:

Bertha 30: […] I know now that because as Katy [PD Specialist Nurse] said, if you are worried about anything, phone up. If there's something happens which is new to you and you are not sure, if it's the

Parkinson's or not, ring us and we can talk it through. And being able to talk it through with somebody that understands exactly how you are feeling is marvellous.

Nora 4: […] I mean I have to go and see the nurse about every 2 months. She phones me regularly, about once a week. She does. Often we have a phone call and we sit and talk. When she's in the clinic and like she's between patients and she'll phone up and she'll say "Mrs T, it's Sue". I've got to know her now. I mean it's only been since August.

However, participants described how there would come a point in the future where being looked after by others could be an overwhelmingly negative experience, as demonstrated by Edith:

Edith 59 Yeah. I've always said that it wouldn't worry me going into a care home and being cared for. Be alright wouldn't it? I'd just sit back and let them get on with it. But I don't feel the same way now. For somebody doing this and somebody doing that.

For some participants, this was already the case, where friends who were trying to help them, were perceived as doing this rather intrusively. In this case, over-caring had become somewhat over-bearing, as recounted by Edith and Maureen:

Edith 34: […] We've just come back from a week in Dorset. It was lovely but I had to watch him [*Patient's husband*] all the time because it was, "Do you want a cup of tea? I'll make you a cup of tea". He's doing *too much*.

Maureen 58: […] I go to bowls now, only down the road, but I'm loath to picking up any of the balls now. Last week when I went I stopped for moment and I said, "Oh, I should be fine in a minute". And the lady instructor told the others that I was not allowed to pick up the balls and she asked a gentleman there to go around with me.

Interviewer 59: So you had your own personal butler there picking up all the balls!

Maureen 59: [*Laughs*] Yeah. He said, "I hope I've looked after you well enough" and I said, "Well you've been given instructions I think!"

The research interviews highlighted that it was important for participants to feel as independent as they could within the confines of their illness. Nora described how she made the decision to become more self-reliant despite regular offers of help from her family:

Interviewer 21: Hmmm. Right. So is that important for you then? So the things you can do right now you make sure you do them?

Nora 21: Oh yes. Yes I do. My girls used to come over and take it in turns. They used to do the shopping. And I said to myself, "I could do that". I could go over there to Sainsbury's. It's only across the road.

However, later in the same interview Nora recalled the despair at her lack of independence she often felt when she became reliant upon her neighbour or daughter to help her dress or eat:

Nora 52: [...] I mean, things like that, silly little things. I mean it can take you well I'd say five or ten minutes to do a zip up! I mean that's just to get it in place and pull it up. And to do laces up. I'm finding that whenever I put on my booties he'd always come over and do the laces up for me, you know. And I was thinking, when I was watching him bending down doing them, I was thinking "Oh".

Nora 58: That's another thing. I can't cut my meat up. Terry does it for me. He knows I can't do it. I mean I said to Jennifer [Participant's daughter] when she was here... she said, "Oh don't worry, we'll chop your dinner all up for you". But I said, "Yeah, but the children will all be round the table" and she said, "Well if you want to sit in the front room on your own Mum you can!"

In both examples, Nora described a process of being made to feel almost like a small child who needed help doing basic self-care tasks such as cutting up her food or tying her shoe-laces. She described how her interaction with her daughter had altered, almost as if there had been a role reversal, where mother is looked after by daughter, as her own daughter would look after her young children.

In summary, the theme of Support vs. Autonomy describes how newly diagnosed patients experience a certain amount of ambivalence with regards to their support needs within this early stage of their illness. At times, the support received from others is welcomed, but at other times it is resented. Participants described a fine line between wishing to be autonomous but also being willing to receive an acceptable level of practical or emotional support from those around them. This ambivalence was accompanied by various negative emotional states such as frustration, embarrassment and sometimes despair.

The young onset PD patient focus group fed back that this theme was of particular significance to them also. Patients spoke about the importance of maintaining a sense of "dignity" within their working, family and social lives. In order to achieve this, participants stated that they felt the need to preserve their independence as far as possible within the various roles they held in their lives. The struggle between needing support and yet remaining as autonomous as they could, was described as a significant factor in the need to preserve their dignity. Additionally, the young onset patients stated that they had experienced a general lack of emotional or practical support from the medical professionals who were treating them. Some participants spoke of the need for access to counselling services, especially around the time of diagnosis when they stated how difficult a time this had been for them in general.

4.4 Self-Preservation

The themes of "Impact upon the Individual" and "Impact upon the Social Self" have described the wide ranging impact that PD has upon the patients' internal and social worlds at the early post-diagnosis stage of PD. As a result of such significant changes to patients' lives, participants spoke about the practical and emotional strategies they used to cope on a day to day basis and also in terms of how they perceived their future as a person suffering with PD. This is described by the superordinate theme of "Self-Preservation", which is divided into two major themes entitled, "Practical Self-Preservation" and "Emotional Self-Preservation". These will now be explored in more detail within the following section.

4.4.1 Practical self-preservation. All participants spoke about how they had made practical changes to their lifestyles since being given their diagnosis of PD, as a means of coping. This included adapting the home environment, taking more safety precautions, deciding whether or not to take medication, enlisting practical support from friends and family and making a determined effort to keep up with hobbies and activities of daily living. One major theme, which consistently emerged across all interviews, was the changes in attitude participants had made with regards to how they viewed their lives, both within the present time and in the future. Participants spoke about the wish to do as much as they practically could now, whilst they still had the ability to do so, rather than to plan for the future as they had prior to becoming unwell. These issues are illustrated below.

With regards to patients' needs for increased security and safety since being told they had PD, Walter described how he had decided to give up driving, having been a driver for more than 40 years. He stated that he was prepared to use buses now to travel around with his wife, and presented a rather solution-focused attitude towards his lifestyle upon hearing his diagnosis and possible prognosis:

Walter 19: [...] And with 46 years of never having an accident, I didn't want one at this stage. I thought, "That's it".

Interviewer 20: No... no... You took the sensible action.

Walter 20: Yes. You get around on the buses alright, so.

Interviewer 21: Alright.

Walter 21: Haven't been used to them for 46 years. But there you go!

Later in his interview Walter reported having joined the Parkinson's Disease Society and had started to attend a local patient support group, where he explained he would like to learn from other patients how to cope with this illness:

Walter 31: I found that very useful, yes. Meeting people with the same disease, you know. [...] Haven't really learnt from their experiences at the moment because we've not really had the chance to talk to them.

Other participants also spoke about how their need for more information about PD, both for themselves and to educate others, in order to increase their perceived levels of personal safety. Harriet described how she had contacted the Parkinson's Disease Society to request an information card to show to members of the public should they wonder why she was displaying symptoms such as instability or shaking:

Harriet 27: That's right. I sent out for things. And I've also got the card that I carry with me. They do a card – "I've got Parkinson's". I've got to be careful. If I'm not going to get better, it's best to be safe. So people can know what's wrong.

Later, in response to a question asking her about how she viewed her future, Harriet spoke about how she had decided to adapt her entire house so that she could manage better from a practical point of view, mirroring Walter's solution-focused approach:

Harriet 47: Ahm... I know that I've had to adapt everything. We are trying to do things to make it easier for me... We have a thing for opening tins on the wall... to make things easier for me. Looking towards the future, we are thinking of putting another rail on the stairs. So we've just got to adapt the house and adapt what we do to it.

As well as making practical changes to their home environment, participants spoke about how they had to adapt their levels of functioning around the restrictions that PD had imposed upon them, by taking things at a slower pace, in order to do things such as household chores and retain a level of functional control:

Bertha 47 I've adapted to things like that. And if I'm doing ironing, I find that difficult to stand for any length of time. I seem to get a little bit wobbly. So I do a few bits and sit down for 5 minutes and do another bit. So... I can cope with things. It takes me longer but I get there.

Both Bertha and Harriet communicated a sense of confrontation with the problem in hand in order to protect themselves physically. Other participants explained how safety issues had now become much more apparent for them since they had deteriorated further physically. An example is provided by Nora:

> Nora 9: But when I was saying I'd had all these gadgets fitted, I said I don't really need them. But she [*Occupational Therapist*] said I'll find in time that I would need them. Now I do, because when I'm on the toilet it's got arms and I can sit and it's more comfortable.

All participants spoke of how medication had considerably improved their level of functioning and ability to do things. Peter recounted how within a relatively short time period of initially taking his PD medication, his symptoms reduced markedly. This made him reflect on how important it was in life to be able to do small, every day tasks; something he had not acknowledged fully prior to becoming unwell:

> Peter 15: Within two hours. It was really as dramatic as that. It makes life so much easier. It is the basic parts of living that… nobody ever tells you these things. You don't read about them. You just find them out yourself.

Taking medication was seen to be one of the most important practical ways to cope with the symptoms of PD, as reflected by Harriet:

> Harriet 24: Well, if it's going to help… you… you use them. If it helps… it can't be bad can it?

However, the decision of whether or not to take medication was a contentious one. For instance, Cynthia did not have a clear understanding of what the medication regime would be like and how it would affect her in the long term and for this reason had decided not to start taking drugs at this point in time:

Cynthia 22: […] I mean I don't know… at the moment I've decided not to go on medication. […] I said to the doctor, "I don't mind doing a tablet if I'm going out tomorrow and sort of take it then", and he said, "Well, no, it doesn't work that way". […] I want to try to keep off medication, but now I think to myself, will I deteriorate quicker if I don't?

All participants related in their interviews the need to preserve a sense of normality in their every day lives in terms of carrying out activities and tasks. This included the decision to try not to give up hobbies entirely, but to adapt them around the restrictions of their illness, in order to remain as active as they could. For instance, Jess stated that she and her husband had decided to make a concerted effort to maintain an active daily routine:

Jess 82: Yeah… oh yeah… I do something every day.

Interviewer 82: Has that been a conscious decision?

Jess 83: Well we used to go out a lot but, so if it's only to go out to Romford and walk round the shops… cos you can sit down in Romford can't you? And walk round the shops… We… make the effort to try and get out.

Patients also spoke of doing as much as they still could from a practical point of view, rather than putting things off for another time or planning ahead for the future. An example of this was the decision to go on holidays or spend savings now, rather than saving money for the distant future or leaving their savings as an inheritance. Bertha sums up such a shift in attitude which had occurred since becoming unwell and being aware of her probable prognosis. This was common across most of the patients who participated in the study:

Bertha 49: Only as I say, that you feel you live for today. You see so many people saying "We've got to save for this. We can't do this. We can't afford to do this. We can't afford to do that", and I feel, "Do it!". And that's the most important thing about how I feel about it at the moment. No-one knows what the future holds.

Bertha stated that she did not want to give up hobbies such as dancing and going to quizzes, even though the disease had affected some aspects of her ability to participate:

Bertha 55: Yes. I mean we used to go to a lot of dances. I can't dance like I used to because my co-ordination has been affected slightly. But I still like to go because you are still talking to people and joining in. And we like quizzes. We do a lot of quizzes. And I must say I'm not giving that up because, touch wood, my brain hasn't been affected. I've got a very good memory and we do like doing the quizzes.

She stated later in her interview how important it was for her to persevere with whichever task was in hand, however difficult this might be in order to remain self-efficacious and in control:

Bertha 75: Push yourself, yeah. That's right. I mustn't give in to it. I've got to make myself do as much as I can.

For every participant, the determination to remain as autonomous and active as possible was a significant issue for them in light of how the PD had a compromising effect upon their ability to function normally. Edith aptly demonstrated this phenomenon by explaining that she did not want to have "special" adaptations to help her as long as she could still manage to do things by herself, however difficult this seemed to be for her:

Edith 65: It's like you've been invaded in some way, you know? And you are not going to let it beat you. You are not going to let it win. But it's trying all the time to win.

Interviewer 66: But you are always fighting it and determined not to let it get the better of you?

Edith 66: Yeah. Sometimes, when I'm drinking the cup will start to shake or my hand will slide round the handle. Well, so now I've learned to hold it with both hands. They do do special cups, but I've said I don't want a special cup. I'll hold it with both hands. When I can't hold a proper cup with both hands, then I'll have a special cup. But I'm not having it while I can use it.

Edith's determination to remain as autonomous as she could within the confines of her illness linked to her internal struggle with her own body as a result of the PD. It is clear from this study that patients make decisions regarding the practical changes that are required in order to increase patients' quality of life and functional abilities to carry out activities of daily living. For some patients the decision to give up certain activities was a question of security and personal safety. For others, there seemed to be a determination to hold on to a sense of normality within one's daily life, with hobbies and activities either adapted or not altered at all to preserve a sense of control, independence or quality of life. All patients spoke in a solution-focused manner with regard to the practical changes in lifestyle they had made since being diagnosed with PD.

In discussing this theme with the comparison focus group of older PDS patients, they stated that the issues of practical self-preservation were significant for them at this stage of their illness also. The focus group confirmed the importance of taking practical measures to improve their quality of life, with an emphasis on adapting one's environment in order to minimise the impact of the PD symptoms and also of planning as many enjoyable things to do within the near future such as going on short holidays away or spending quality time with their family.

The members of the younger onset PD focus group spoke about the importance of being given clear options with regards to the decision of whether or not to take medication. They stated that this was a concern for them due to the time-limited effectiveness of drug therapy in PD. The younger onset members confirmed the importance of making the most of their lives now, whilst their symptoms were on the whole still manageable.

As well as practical measures of self-preservation, participants also described and demonstrated within the interview setting itself the emotional coping strategies that they utilised in order to maintain an acceptable level of independence or quality of life. This is described within the following theme of "Emotional Self-Preservation".

4.4.2 Emotional self-preservation. Participants spoke about a variety of emotional means of coping which they had implemented since being diagnosed with PD. Participants expressed ways in which they conceptualised their experience of becoming unwell and how they employed emotional coping strategies as a means of preserving their sense of self. Sometimes these were demonstrated explicitly during the interviews by participants recalling efforts made to preserve their sense of self or well-being. At other times, participants seemed to be unaware of the psychological processes they were utilising to deal with their current situation of being newly diagnosed with an incurable degenerative disease, such as unconscious processes of denial or the determination to explicitly block out negative emotions and thoughts. These are illustrated below.

Most participants spoke about the level of acceptance they had developed since being given their diagnosis. Some people reported how the development of an illness was seen as a normal part of life, so that incorporating PD into their lives was an overall acceptable experience. However, the notion that their illness was incurable was described by some patients as a difficult factor to assimilate. Nonetheless, patients explained how despite its incurable nature, the illness must be accepted as something that they must learn to manage in their lives. This is illustrated by Walter and Peter:

In response to a question about the future with PD, Walter responded thus:

Walter 12: Ahmm… it's made me realise that it won't *kill me* but it may disable me I suppose in time, but ah… I suppose it's part of life isn't it?

Peter explained how he did not take too much time out to worry about what was happening to him in terms of his deterioration in health, but instead took a similar attitude to Walter:

Peter 29: Yes. You say what's the purpose? To a certain extent "Que sera".

Similarly, Edith stated that although the diagnosis, prognosis and lived experience of PD was a largely negative experience for her, she had come to the conclusion that a certain level of resignation and acceptance was indeed necessary in order to live with such an illness:

> Edith 27: No. No, you know. People say, "Oh, you are funny. Doesn't it worry you what you've got?" and I just say, "It worries me, but you know, if you've got it, you've *got it*. You know? If it's not curable, it's not curable".

In many instances, on the surface, participants did not express a sense of true despair within the interview setting. On the contrary, most patients spoke about their experience of developing the illness as a matter of fact. A certain amount of denial or "blocking out" of difficult feelings or thoughts associated with their diagnosis seemed to be the most common phenomena demonstrated by the participants interviewed in this study. By utilising such psychological processes, patients could be demonstrating an aspect of self-protection from the potentially overwhelming emotional experience of being diagnosed with a degenerative incurable illness.

For example, a certain level of avoidance was expressed by many of the participants in their research interviews. Some patients explained how they had not attended any support groups for patients with PD and had chosen not to read up too much about the disease at this early stage, as demonstrated by Bertha:

> Bertha 33: No. I haven't joined the… I have joined the [Parkinson's Disease] Society but I haven't been to the meetings because I am a bit of a coward in that respect because I don't want to see people worse. I am quite happy going along as I am at the moment, but I don't want to know what is going to happen in the future.

Peter, being within the medical profession, explained that he had access to numerous medical journals and detailed information about PD. However, he had tried to avoid seeking out much information about PD for fear of making himself feel worse or worrying unnecessarily:

Peter 38: Yes. A phase of "I'll just have a quick flick through this", and then saying to myself do I *need* to? I know this, I know that and the other. There's nothing I can do about it, but just accept it.

Peter described how he felt it was more important for him at this point just to accept his current position as having developed PD. By seeking out detailed information about PD, Peter recognised that he might be looking for answers to questions that cannot in fact be answered, and like Bertha was protecting himself emotionally from his fears about the future.

One other coping mechanism described by participants was that of comparing oneself to others who were less fortunate, or more debilitated with illnesses other than PD. By doing this, participants described using a process of focusing upon the positive aspects of their particular condition, rather than the negative implications of suffering with it, often taking the attitude of "things could always be worse". Bertha demonstrated this process in the following two excerpts:

Bertha 19: [...] I don't sit down and think, "Oh why me?" because I think I could have been diagnosed with some terrible life-threatening cancer or something like that.

In the second excerpt, Bertha went on to describe her rather overwhelming experience of meeting patients with other conditions to herself in the Disablement clinic that she attended for her outpatient appointments:

Bertha 39: Yes. That's right. And another thing. When I went to the [PD] clinic, because it's in the Disablement clinic, seeing all these people in wheelchairs, having artificial limbs fitted, I thought "What am I complaining about?". It made me feel quite humble really and I felt a fraud... I said to Katy [the PD nurse] "I feel a bit of a fraud, because I can do most things". When I see people with one limb or lost both legs and had to have them amputated and are having to have new *legs* fitted, and he [a patient] was saying, "Oh I told them I wanted new ones, not like those *old* ones", and they were so *cheerful*. All these people. I felt like, well what am I *doing* here? I feel as if I shouldn't *be* here.

Another example of emotional self-preservation that was described by participants was the theme of not taking things for granted now since being diagnosed with PD. Harriet, a religious Christian woman, described this in the following two excerpts, the second of which illustrated how she viewed her illness within a religious context:

Harriet 56: [...] I suppose I am more thankful perhaps. I'm not taking things for granted and that.

Harriet 62: [...] I know that when I die, I'll be perfect again. That's something to look forward to.

Interviewer 62: Hmmm... So no matter what happens here on Earth, when you die then things will be back to perfection?

Harriet 63: Yes. That's right.

Participants also spoke about how useful humour can be as a way of coping emotionally with their situation. For example, Maureen joked about how she hoped her symptoms of not being able to control her leg movements would not compromise her visit to the chiropodist!

Maureen 78: [...] I mean I have to make an appointment with the dentist. I've been putting that off. I also need to see the chiropodist and hopefully not kick him in the jaw! [*Laughs*].

Despite these seemingly positive attitudes and reactions towards their diagnoses, participants also demonstrated a significant level of suppression of difficult feelings within the interviews. In this way, participants seemed to be protecting themselves from the painful emotions associated with suffering from an incurable long-term illness. Patients spoke about putting a "brave face" on things so as to protect themselves, their families and friends who cared about them. This is demonstrated by Peter, who reported making a concerted effort not to show any signs of emotional distress to the medical staff who were treating him:

Interviewer 51: Hmmm... So looking at it from a very practical view. In terms of how you've been treated by neurologists, by your GP, by your physio and by anybody else, do you feel that they've taken in view your psychological side of PD?

Peter 51: No. But maybe they would do if I gave them clues. If you don't give the opportunity it won't come back to you unless it is in your face.

Similarly, Cynthia described how her family attempt to protect one another in this way, by hiding their true distress from each other:

Cynthia 88: […] I mean they've never shown me their worried side. I'm sure they must do to their husbands but I mean they never show a weak side to me.

In this excerpt, Cynthia described the concept of displaying emotion to others as having a "weak side" to one's character. Indeed, throughout the interview itself, Cynthia often cut herself off mid-sentence when talking about a particularly sensitive issue. The following example was in the context of questioning her about how she viewed her future:

Cynthia 40 It doesn't… it doesn't worry me to that extent that way, but I suppose when the time comes to… [PAUSE 3 SECONDS] I'll ask you a question now.

In this instance, Cynthia cut her sentence off midway regarding how she viewed the possible time in the future when she might be cared for by others. A little later in the same interview, she made a rather off-hand comment regarding how she viewed "life", and the same process occurred when she asked me a question about my own father whom she was aware also had a diagnosis of PD:

Cynthia 72: That's right. I mean, that's it. Life is hard anyway. Not an easy old place to live in is it, this world of ours? But hmmm…. What's your dad's age?

In these examples, Cynthia may have been demonstrating an unconscious process of cutting off from difficult emotions. This may be an indication that patients utilise such methods to protect themselves from the emotional impact of being newly diagnosed with PD. Indeed, for some participants the research interview was the first time in which they had spoken in depth about their experiences of being newly diagnosed with PD. This was the case for Jess who became tearful at the point at which she spoke about her sadness at being diagnosed. She disclosed at this point that she had never spoken before about her feelings regarding this and indeed this was the first time she had also cried about it:

Jess 41 [Starts to cry]

[PAUSE 5 SECONDS]

Interviewer 42: I can see and I can feel this is quite... painful for you.

Jess 42: Hmmm.... [continues to cry]. I've never thought about it before.

Interviewer 43: Hmmm... Like you said... it's one of those things you haven't really given much thought about.

Jess 43: Hmmm.... No.... [PAUSE 10 SECONDS]. It's the first time I've really thought about it.

Similarly, Maureen cried during her interview, simply stating:

Maureen 29: Talking about it has made me cry.

She followed this a little later in her interview with a reflection about her emotional state:

Maureen 31: Talking about it is probably the best thing I can do really. I'd rather talk about it without crying.

This statement might suggest that Maureen felt rather uncomfortable about showing her emotions to other people, including the researcher, in a similar fashion to both Peter and Jess.

In summary, participants described a number of ways in which they protected themselves emotionally from the effects of being newly diagnosed with PD. Participants employed various means of emotional self-preservation, from perceiving their illness from a more positive point of view and focusing upon the "here and now", to the avoidance of difficult emotions and cognitions by a process of closing off from themselves and others emotionally, and blocking out negative thoughts and feelings with respect to their diagnosis.

Participants spoke about the efforts they had made to carry on with life, ensuring that they protected themselves from as much emotional distress as possible. In some instances this was carried out on a conscious level, such as by blocking out negative thoughts about the future, and at other times this seemed to be an unconscious process, an example of which was the denial of feelings to oneself regarding the negative consequences of being diagnosed with PD. This study has indicated that participants use emotional self-preservation as an adjunct to practical means at this early stage in their illness as a way of coping with the sometimes overwhelming negative impact that PD had upon their lives.

4.5 Proposed Model

On the basis of these results, a model has been proposed to explain the lived experiences of newly diagnosed PD patients (*Fig. 4.2*). This draws together the three superordinate themes and seven major themes, and shows their interaction.

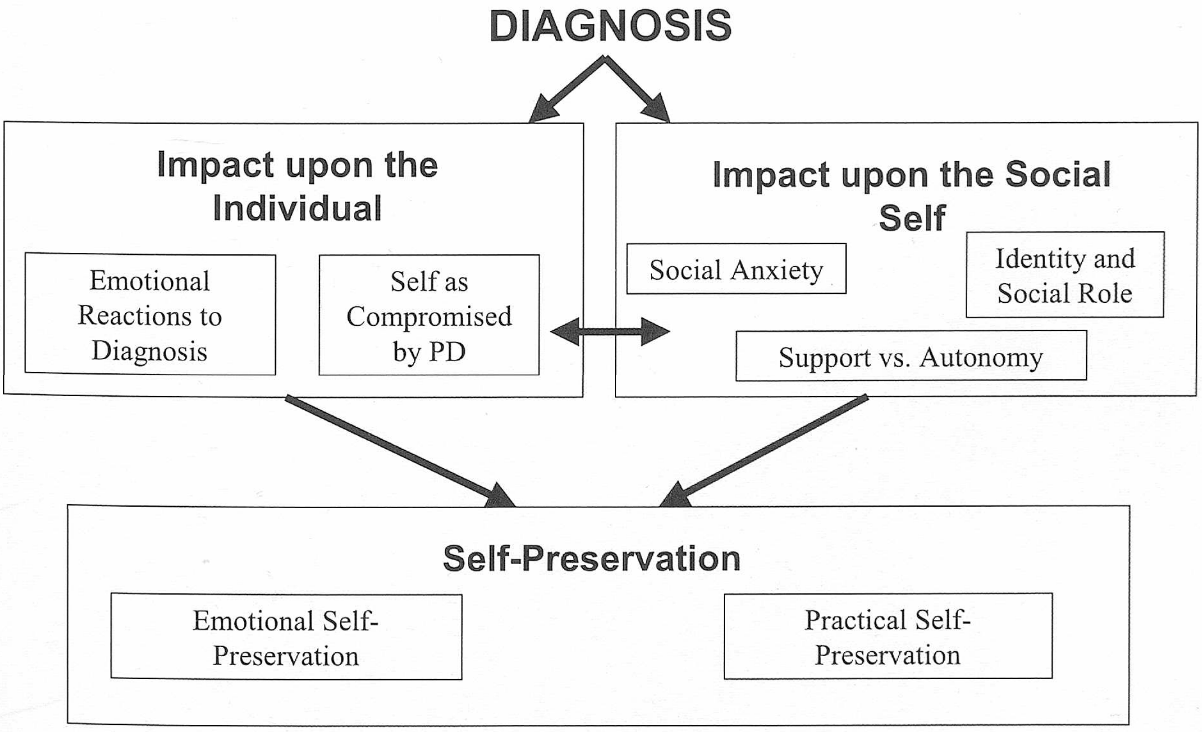

Figure. 4.2 The psychological impact of being newly diagnosed with PD - the interaction between the impact upon the individual, the patient's social context and the coping strategies that are utilised.

This model is now explored in more detail, in relation to the existing research literature. Reference is also made to the feedback gained from the two focus groups in terms of placing the data into the wider context of the PD patient population. Recommendations are proposed for future research to build upon the results from the current study, and suggestions are made with regards to evidence-based psychological therapy, which might benefit PD patients at this early stage following the communication of their diagnosis.

Chapter 5

Discussion

The interview data from the nine participants revealed that their experiences of being newly diagnosed with PD were explained by three overarching themes: "Impact upon the Individual", "Impact upon the Social Self" and "Self-Preservation". Participants explored the impact of being given a diagnosis of PD within the past three months in terms of how this affected themselves as individuals, their social interactions with others and their coping strategies to minimise both the practical and emotional restrictions the disease had upon their lives.

The first theme, "Impact upon the Individual" incorporates two themes: "Emotional Reactions to Diagnosis", which describes patients' feelings since learning about their diagnosis, and "Self as Compromised by PD", which explains participants' experiences of how the disease has affected them on a physical, functional and psychological level. The second superordinate theme of "Impact upon the Social Self" encompasses three themes: "Social Anxiety", "Identity and Social Role" and "Support vs. Autonomy". This overarching theme describes newly diagnosed patients' experiences of how the disease has impacted upon their ability to socially interact with others in light of the illness. Participants described the changes that had occurred within the three months following their diagnosis in terms of their anxiety in social settings, the effect upon their perceived identity, both by themselves and by those around them, their social role and the difficulties the illness imposed upon them in terms of finding a balance between being independent whilst also receiving practical support from others.

As a result of the psychological, functional and physiological impact upon patients, both upon an individual level and social level, participants explored their responses to being newly diagnosed with PD, in terms of coping strategies used to minimise both emotional and physical distress.

This is explained by the superordinate theme of "Self-Preservation", which is split into two themes: "Emotional Self-Preservation" and "Practical Self-Preservation". Patients described the importance of taking measures to preserve a sense of normality and control within their lives since being diagnosed with PD. The strategies they took to protect themselves emotionally and physically were carried out both on a conscious as well as an unconscious level.

5.1 Impact upon the Individual

The first superordinate theme, "Impact upon the Individual" describes the emotional, physiological and functional impact that having a new diagnosis of PD has upon the individual patient. This theme is split into two smaller themes, "Emotional Reactions to Diagnosis" and "Self as Compromised by PD" and these will be explored now.

5.1.1 Emotional reactions to diagnosis. There are several similarities between the issues raised by the participants within this study and those elicited from previous research. For instance, the PD patients interviewed by Habermann (1996) described similar issues to the patients within the current study, described within the theme of "Emotional Reaction to Diagnosis", such as sadness, shock and confusion upon hearing their diagnosis, confirming these as significant emotional responses experienced by newly diagnosed PD patients. Additionally, patients within the current study spoke of their grief at the various losses they had experienced as a result of developing PD, which supports the adjustment to illness model proposed by Zemzars (1984). The current study has allowed for a detailed exploration of such losses, such as in terms of patients' health, ability to function on a day to day basis, as well as to continue with hobbies and other previously enjoyable activities. Losses were described in terms of patients' functioning within social settings, such as within their families, social groups and the work environment. The current study has demonstrated therefore that loss is a major factor for patients at the early post-diagnosis phase of their illness.

Within the current study, patients had the opportunity to describe in detail their emotional experiences since being diagnosed, and expressed significant fears about the future in terms of their deterioration in health and the possible consequences of this. Although fear has been described in previous literature, this study has allowed patients to explore these experiences in more depth, due to the IPA methodology used. Fear was common to all participants within the current study, and although this was not described as disabling to patients at this point, it was deemed as an important issue to raise within the interviews. The manner in which patients dealt with these fears was to acknowledge them, but to focus their minds away from them, lest they became too overwhelming for patients to deal with at this stage in their illness.

The current study also elicited descriptions of some positive emotional reactions with regards to patients being informed of their diagnosis, such as relief, which has not been specifically highlighted within any previous study. Although adjustment to illness models explain shifts in beliefs to incorporate a long-term illness into one's life (e.g. Sharpe & Curran, 2006) they do not fit with the findings of the current study, in terms of the relief that patients experienced in relation to hearing their diagnosis. The findings from the current study would suggest that the process of adjustment to a diagnosis of PD might occur earlier than predicted by the model proposed by Sharpe & Curran (2006).

5.1.2 Self as compromised by Parkinson's disease. The study has elicited rich phenomenological data with regards to the possible reasons to explain the prevalence of clinical depression in PD which has not been explicitly demonstrated in other studies at this early stage of the illness history. Patients spoke in their interviews about how their quality of life had deteriorated markedly since developing their illness, and this had impacted negatively upon their ability to enjoy hobbies, day to day activities and other tasks. The interviews allowed patients the freedom to express the reasons for this deterioration in quality of life, and it was clear that this related mainly to the functional restrictions the disease imposed upon them. This was described by the major theme of "Self as Compromised by PD", and supports previous findings from phenomenological research into PD conducted by Habermann (1996) and Bramley & Eatough (2005), where patients had described feeling "entrapped" within their own bodies and restricted by the disease. This lack of bodily control expressed by patients within the current study also relates to the concept of powerlessness described by patients with other chronic illnesses (e.g. Miller, 1983). Of particular significance, there were distinct similarities between the experiences of PD patients described by Habermann (1996) and Bramley & Eatough (2005) and those of the participants within the current study, with regards to the concept of being in battle with one's own body. The current study therefore confirms that this is a significant issue for newly diagnosed PD patients, as well as those who have been living with the illness for some years. This study, by nature of the IPA methodology utilised, has allowed patients to explore this concept in richer detail than in most previous research studies. Patients described, for instance, feeling that their bodies were not truly representing their inner emotional states. For instance, participants spoke of how their facial appearance was often incongruent with their true inner thoughts or feelings, and that this posed difficulties with respect to effective communication in social situations. Additionally, the issue of stigma was highlighted as a significant issue for newly diagnosed patients, which related to the noticeable symptoms of the disease when the person was within a social setting. This is explored in further detail below. In view of the significance of this theme across all participants within the current study, it can be assumed that this may be an issue worthy of psychotherapeutic intervention for newly diagnosed patients. Psychological therapy might focus upon helping patients to manage their feelings with respect to coping with a body which has been physically compromised by PD, in order to increase their levels of self-efficacy and self-confidence, and to reduce feelings of powerlessness and frustration.

5.2 Impact upon the Social Self

The second superordinate theme, "Impact upon the Social Self", described three major themes: "Social Anxiety", "Identity and Social Role" and "Support vs. Autonomy". Previous literature has highlighted that chronic illness affects patients' social interactions with others and can cause changes in self-identity and role within various social contexts. However, the current study has demonstrated how important an issue this is for newly diagnosed PD patients and has allowed for a richness of phenomenological data that has not been demonstrated in most other previous studies.

5.2.1 Social anxiety. Anxiety has been shown to be a common co morbid factor in PD (Henderson et al., 1992) and the current research has suggested some possible underlying psychological reasons for this. The participants described that social anxiety was a problem for them since being diagnosed with PD, and that this was due to the stigma they often felt with regards to their symptoms being noticeable to others, within their workplace, social life or family circles. This supports the findings of Posen et al. (2000), where patients described attempts to hide their PD symptoms from others. The current study however has allowed for a more in depth analysis into this concept, with patients describing how not only their symptoms, but their general outward appearance, such as their posture or facial expression, was impacting upon their levels of self-confidence and social functioning. This study has captured individual patients' experiences of social anxiety, so that it has incorporated descriptions of social detachment in relation to patients' social interactions with others. To date, no other study has allowed for such a detailed exploration of patients' social anxiety and this research has highlighted this as a significant theme for newly diagnosed PD patients. In view of these results, newly diagnosed patients might benefit from specific psychological interventions to help them overcome some of their social anxieties in relation to the development of PD and the difficulties this raises for them in terms of their interactions with others. Psychological therapy could focus upon increasing patients' levels of self-confidence and reducing the impact of their anxiety within social settings, relating to how their physical appearance and functioning has changed as a result of developing PD.

5.2.2 Identity and social role. The theme of "Identity and Social Role" explains a variety of changes that had occurred for patients as a result of developing PD and supports the findings from various previous studies in chronic illness. Charmaz's (1991) statement that people with long-term illnesses do not wish to be seen as "patients first and persons second", is wholly supported by the current study's findings. Patients indeed spoke of the changes having a diagnosis of PD had upon them in terms of their identity, with a clear demonstration within the interviews that they struggled to convey a sense of stability in terms of their identity, supporting previous research carried out with other PD patients (e.g. Bramley & Eatough, 2005; Kralik et al., 2000; Sacks, 1991). However, within the current study patients demonstrated this concept of identity in relation to their physical appearance, which had altered as a result of developing the disease, which had not been raised as an important factor with respect to identity issues in previous research. Clearly, from this study it has been shown that a patient's appearance impacts upon their sense of identity, especially in relation to their interaction with others, such as within their families. For example, Nora's grandsons' nickname for her of "Little Nanny" or Cynthia's description of herself as being a "Shaking Lady" at her daughter's wedding, demonstrated in some detail the relationship between the physiological impact of the disease and how this affected patients' identities within their social contexts. This would suggest that newly diagnosed PD patients might benefit from psychological interventions which allow for a focus upon identity issues, in order to help people adjust to the changes which occur as a result of the illness. This might also be an interesting area to explore within future research.

In line with the results Seamark et al. (2004) regarding COPD patients' social interactions with their families, the patients interviewed within the current study also described the negative impact their PD had upon their ability to socially interact in a normal fashion with their relatives. The IPA methodology allowed for patients to express their experiences in depth in terms of the significant emotional impact that this particular issue had upon them. For instance, patients spoke at great length about the distress they experienced in relation to being a grandparent with PD. Having a diagnosis of PD was described as having a detrimental effect upon patients' ability to function within their expected and desired roles within their family. Patients described numerous alterations within their relationships with family, friends and colleagues as a result of being diagnosed with PD, especially with regards to the marital, parental and grandparental roles they held. The impact of this issue was significant, with patients displaying considerable levels of despair and sadness within the interview sessions themselves. In terms therefore of patients' needs at this stage of their illness, psychological interventions might focus upon the social impact that a diagnosis of PD has upon the family unit and perhaps involve other members of the patient's family within therapy sessions.

5.2.3 Support vs. autonomy. The theme of "Support vs. Autonomy" described similar issues to other studies within the field of PD and other long term health conditions. The importance of positive perceived social support (McLeod et al., 1992; deMorgan & White, 2000; Sherbourne et al., 1992) and the requirement for continued practical and emotional support was quite apparent as an important issue for patients interviewed within the current study, as well as for participants within the two focus groups, in particular the younger onset PD patient group. The current study highlighted that even within three months of being diagnosed with PD, patients experienced a struggle regarding the need to attain an acceptable level of independence and functional autonomy, whilst still acknowledging a requirement for emotional and practical support from others. This mirrors findings from other studies (e.g. Caap-Ahlgren & Dehlin, 2001; Chesson et al, 1999; Pinder, 1990; Posen et al, 2000). The feedback from the young-onset PD patient focus group highlighted this issue as especially relevant to them due to the possibility of a role-reversal in terms of future care being provided by the patients' own children. This would warrant further qualitative investigation in future research studies to understand this issue better for young-onset PD patients. The role-reversal issue was significant for the older participants interviewed within the current study, with some patients expressing their distress at being looked after like a child, with regards to their impaired abilities to feed or clothe themselves properly. Clearly, this issue is a significant one for all PD patients, and has been shown within this particular study to be apparent for newly diagnosed PD patients. There could therefore be a role for Counselling Psychologists to address these issues within psychological therapy to help patients find ways in which they can receive help from others, whilst at the same time maintaining an acceptable level of autonomy.

The social impact of being newly diagnosed with PD has been shown within this study to be of major significance to patients. Psychological interventions might be beneficial with respect to addressing these issues with patients at this early stage of their illness. Assisting patients in finding an acceptable balance between being supported by others and remaining autonomous and self-efficacious might be helpful within a psychotherapeutic context. This might warrant involvement with other family members, in order to address the social system impact that being newly diagnosed can have upon patients and their families, such as changes in social roles or other aspects of social interaction. The focus groups highlighted social factors which might warrant further investigation, particularly with respect to the young-onset PD patient population.

5.3 Self-Preservation

In terms of how patients described or demonstrated their coping strategies, participants spoke of both emotional and practical methods of dealing with their illness, as a consequence of the impact PD had upon themselves as individuals and within their social systems. This was illustrated by the superordinate theme of "Self-Preservation", which was split into the two major themes of "Emotional Self-Preservation" and "Practical Self-Preservation".

5.3.1 Emotional self-preservation. Benefit-finding coping (Katz et al, 2001) was demonstrated by the participants, with patients stating that they chose to consciously focus upon the positives in terms of their current situation in order to cope with the emotional impact of their PD. This has also been demonstrated in other PD research studies (e.g. Pinder, 1990) where patients have been shown to focus upon the present more than the rather contrasting bleak outlook they have of the future in terms of living with PD. However, the current study has shown that newly diagnosed PD patients utilise a certain amount of unconscious psychological processing to cope with their condition, such as denial or the "blocking out" of distressing negative thoughts and feelings regarding their future deterioration in time. Denial has been proposed as a useful process when faced with chronic illness (Shontz, 1975) as this might allow the patient to avoid becoming depressed and being unable to cope with their situation adequately. This was clearly demonstrated by the patients who took part in the current study, confirming that this may also be the case for newly diagnosed PD patients. However, one unique outcome from this study is that for most patients this was the first time they had spoken about their thoughts or feelings about being newly diagnosed with PD. As a consequence, some patients displayed and experienced emotions that they had hitherto not acknowledged prior to taking part in the study. This suggests that at this early stage post-diagnosis, patients might not be consciously aware of particular aspects regarding how they feel about having PD. It might only be the case that when the matter is discussed openly with patients that these deeper emotions and associated schemas are accessed. Psychologists and other health practitioners working with newly diagnosed PD patients therefore would benefit from being aware and sensitive to these unconscious psychological processes which may occur within this client group at this particular timeframe post-diagnosis.

Other unique outcomes from the current study which are encompassed within the theme of "Emotional Self-Preservation" are that patients cope at this early stage in their illness with the use of humour and sometimes within the context of their religious beliefs. Both these concepts have not been described in previous literature specifically relating to PD. However, these were both described as beneficial coping strategies by the participants who took part in the current study. This may suggest that certain patients might incorporate their experiences of being newly diagnosed into a religious framework of understanding in order to make sense of this new experience. This would support the adjustment to illness model suggested by Park & Folkman (1997), where it is suggested that patients integrate their illness into their "life scheme" by changing the meaning of their illness, so that it becomes congruent with helpful pre-existing beliefs, such as those of a religious nature. Future research focusing upon psychological coping measures in PD would be beneficial in terms of helping to provide evidence-based psychological interventions for this patient group. Outcomes of this study suggest that issues such as denial and acceptance could be important issues to explore further in future qualitative studies with PD patients.

5.3.2 Practical self-preservation. The theme of "Practical Self-Preservation" illustrated the most unique outcomes with respect to the existing literature within the field of chronic illness and PD. Although previous studies have demonstrated that there is a strong drive towards preserving a sense of "normality" in patients' lives following the onset of chronic illness (e.g. Radley & Billig, 1996; Ohman et al, 2003; Sharpe et al, 2006), the participants within the current study spoke of this and other practical coping strategies in great detail, highlighting this as a potentially highly significant issue for PD patients at the early post-diagnosis stage. Some patients sought out information about PD in order to equip them with some knowledge about their condition. However, at this early stage, other participants relayed that this was not the case for them, and that they would rather not seek out too much information at this point.

Interestingly, this mirrors exactly the behaviours of PD patients described by Pinder (1990), suggesting that even at this early stage post-diagnosis, PD patients may still demonstrate some ambivalence with regard to how much information is required to be known at this stage of the illness. The reasons for the individual differences in information-seeking behaviour are unknown at this time. Future research might therefore focus upon eliciting the underlying reasons for these discrepancies, possibly exploring certain personality factors or issues relating to patients' prior life experiences which might help to explain this issue.

Other practical measures taken by participants within the current study which had not been described in such detail by previous studies, were the issues of: taking precautionary safety measures since being diagnosed (e.g. giving up driving or carrying an "I've got Parkinson's Disease" card issued by the PDS); adapting one's home environment to fit around the restrictions of the disease; deciding whether or not to take medication; and lastly, taking measures to increase one's quality of life such as taking holidays or spending life savings rather than putting this off to some point in the future, and persevering with hobbies by adapting these in ways to fit around the illness.

These issues were confirmed as vitally important to members of both focus groups also, suggesting that previous research has not been carried out in such a way as to highlight these as important issues for PD patients. Nevertheless, these practical coping measures have been shown to be significant factors for newly diagnosed PD patients, and this may relate to the concept of increasing one's sense of control over a situation, in the face of feeling rather powerless in situations of chronic illness (Comarroff & Maguire, 1981; Pinder, 1990). These may also be significant in terms of practically helping to increase patients' quality of life and maintain an acceptable level of normality within their lives in the face of living with an incurable, long term illness. Psychological interventions might therefore be useful at this point to help patients gain a better sense of control over their illness, by encouraging them to take practical measures such as those outlined above, in order to increase their quality of life at this point within their illness timeframe.

5.4 Conclusions

The results from the current study suggest that there is a wealth of information concerning the lived experiences of newly diagnosed PD patients which up until now has not been elicited as significant by previous research studies. The proposed model (*Fig. 4.2*) suggests that patients undergo significant changes in light of receiving a diagnosis of PD, in terms of their emotional, physiological and functional well-being, both intrapsychicly as well as within their social systems. As a result of these changes, both practical and emotional measures are taken to cope with the variety of different psychological difficulties that occur as a result of being diagnosed with PD, in order to attempt to minimise the detrimental effects these can have upon them. This information is currently missing from the adjustment to illness models proposed by Park & Folkman (1997), Sprangers & Schwartz (1999) and Sharpe & Curran (2006), suggesting that early experiences of illness are not fully explained by these models. However, the adjustment model proposed by Ohman et al. (2003) comes closer to explaining some of the current study's results, in that patients are theorised as undergoing a "reformulation of the self" in the light of living with a chronic illness. The results of the current study may highlight some of the psychological experiences of patients, which could underlie the early stages of such a self-reformulation process that takes place in the light of being diagnosed with a long term illness such as PD.

The current study has raised several issues which may be significant for newly diagnosed PD patients, as compared to patients who have been living with their illness for some years, as demonstrated by the issues raised within this study compared to previous research, and with regards to the feedback from the focus groups.

The benefit of conducting qualitative IPA research has been that new information regarding the significant psychological issues for this particular client group have been raised, due to the idiographic, participant-led nature of this methodological framework. On reflection, as a Counselling Psychologist, this research method worked well in terms of the ability to access somewhat sensitive data from participants and also with regards to handling the sometimes intense emotional interview environment in a sensitive and supportive manner. However, during some interviews there was some pressure to obtain a reasonable working balance between being a Counselling Psychologist and Research Psychologist, in order for the interview not to develop into a psychological counselling session, but instead to provide an acceptable amount of emotional support within the confines of a research interview.

From a personal perspective, having a father with PD assisted rather than hindered the research process. Some participants who were aware of this fact related to me after the interview that it had made them feel at ease with respect to talking about their experiences of being newly diagnosed with this disease. However, I feel my skills as a Counselling Psychologist were the main factor in providing a safe environment for participants to talk openly about their experiences. Most participants related to me after the interview that they had found it helpful to talk about their experiences of being newly diagnosed with a psychologist. This would support the opportunity for psychological interventions to be made available to patients within this early stage of their illness, supporting the suggestions made by Wainwright & Bender (2005) that further psychological service provision should be accessible to patients with PD. Newly diagnosed patients may clearly benefit from access to psychological counselling at this early stage in their illness, to focus upon the issues and concerns raised by the participants in this study, in terms of the impact this has upon them individually and within their social systems.

Additionally, the focus groups highlighted some differences between younger onset PD patients and older patient groups, suggesting that their psychological support needs might require specific investigation, perhaps utilising IPA methodology as recommended by Shaw (2001) for health psychology research, to explore these issues in more detail. Lastly, it is clear that the current NICE (June, 2006) guidelines available to health care practitioners within the UK do not address many psychological factors which are likely to be significant for patients with PD. Until more research is published with respect to PD patients' psychological needs, service provision will not cater specifically to patients' psychological requirements. The current study has made an initial exploration into PD patients' psychological experiences and difficulties three months following diagnosis. Future psychological research would ensure that patients are more likely to have access to evidence-based psychological therapy at each stage of their illness.

Abudi, S., Bar-Tal, Y., Ziv, L. & Fish (1997). Parkinson's disease symptoms: patients' perceptions. *Journal of Advanced Nursing.* Vol 25 (1), pp 54-59.

Antoni, M., Cruess, S., Cruess, D., Kumar, M., Lutgendorf, S., Ironson, G., Dettmer, E., Williams, J., Klimas, N., Fletcher, M. & Schneiderman, 2000)

Astin, J. A. (2004). Mind-body therapies for the management of pain. *Clinical Journal of Pain.* Vol. 20. No. 1, 27-32.

Blount, A. Ed. (1998). Integrated Primary Care: The Future of Medical and Mental Health Collaboration. New York: W.W. Norton & Co.

Bramley, N. & Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology and Health.* Vol. 20. No. 2, 223-235.

Brownlee, S., Leventhal, H. & Leventhal, E. (2000). Regulation, self-regulation, and construction of the self in the maintenance of physical health. In M. Boekaerts, & P. Pintrich (Eds.), *Handbook of self-regulation* (pp. 369-416). London: Academic Press Inc.

Bunting, L. K. & Fitzsimmons, B. (1991). Depression in Parkinson's disease. *Journal of Neuroscience Nursing.* Vol. 23, No. 3, 158-164.

Caap-Ahlgren, M. & Dehlin, O. (2001). Insomnia and depressive symptoms in patients with Parkinson's disease: Relationship to health-related quality of life. An interview of patients living at home. *Archives of Gerontology and Geriatrics.* Vol. 32, 23-33.

Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time.* New Jersey: Rutgers University Press.

Chesson, R., Cockhead, D. & Romney-Alexander, D. (1999) Quality of life with Parkinson's disease: Families' perspectives. In R. Percival & P. Hobson (Eds.) *Parkinson's Disease: Studies in Psychological and Social Care.* London: BPS Books.

Comarroff, J. & Maguire, P. (1981). Ambiguity and the search for meaning: Childhood leukaemia in the modern clinical context. *Social Science and Medicine.* Vol. 15, 115-123.

Conrad, P. (1987) The experience of illness: Recent and new directions. *Research in the Sociology of Health Care.* Vol. 6, 1-31.

Cummings, J. L. (1992). Depression and Parkinson's Disease: a review. *American Journal of Psychiatry.* Vol. 149, 443-454.

Dakof. G. A. & Mendelsohn, G. A. (1986). Parkinson's Disease: The psychological aspects of a chronic disease. *Psychological Bulletin.* Vol. 99, 375-387.

Department of Health guidelines (2005). Supporting people with long term conditions: An NHS and social care model to support local innovation and integration.

De Rijk, M. C., Rocca, W. A., Anderson, D. W., Melcon, M.O., Breteler, M. M. & Maraganore, D. M. (1997). A population perspective on diagnostic criteria for Parkinson's disease. *Neurology*, Vol. 48, No. 5, 1277-1281.

Dodel, R. C., Eggert, K. M., Singer, M. S., Eichorn, T. E., Pogarell, O. & Oertel, W. H. (1998). Costs of drug treatment in Parkinson's disease. *Movement Disorders,* Vol. 13, No. 2, 249-254.

Dunn, D. S. (1994). Positive meaning and illusions following disability: Reality negotiations, normative interpretation, and value change. *Journal of Social Behaviour and Personality.* Vol 9, 123-138.

Dunn, D. S. (1996). Well-being following amputation: Salutary effects of positive meaning, optimism and control. *Rehabilitation Psychology.* Vol 41, 238-302.

Edelman, S., Bell, D. & Kidman, A. (1999). Group CBT versus supportive therapy with patients who have primary breast cancer. *Journal of Cognitive Psychotherapy.* Vol. 13. No. 3, 189-202.

Ehmann, T. S., Beninger, R. J., Gawel, M. J. & Riopelle, R. J. (1990a). Coping, social support, and depressive symptoms in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology.* Vol. 3, 85-90.

Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine.* Vol. 45, 1207-1221.

Folkman, S. & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist.* Vol. 55, 647-654.

Garrity, T. F. (1973). Vocational adjustment after first myocardial infarction: comparative assessment of several variables suggested in the literature. *Social Science and Medicine.* Vol. 7, 705-717.

Goodwin, J. S., Hunt, W. C., Key, C. R. & Samet, J. M. (1987). The effect of marital status on stage, treatment and survival of cancer patients. *Journal of the American Medical Association.* Vol. 258. 3125-3130.

Gotham, A. M., Brown, R. G. & Marsden, C. D. (1986) Depression in Parkinson's disease: A quantitative and qualitative analysis. *Journal of Neurology, Neurosurgery and Psychiatry.* Vol. 49, 381-389.

Habermann, B. (1996) Day-to-day demands of Parkinson's disease. *Western Journal of Nursing Research.* Vol. 18 (4) 397-413.

Henderson, R., Kurlan, R., Kersun, J. M. & Como, I. (1992) Preliminary examination of the comorbidity of anxiety and depression in Parkinson's disease. *Journal of Neuropsychiatry and Clinical Neurosciences.* Vol. 4 (3) 257-264.

Heron, J. (1996) Co-operative Inquiry: Research into the human condition. London: Sage.

Hoehn, M. M. & Yahr, M. D. (1967) Parkinsonism: onset, progression and mortality. *Neurology,* Vol. 17, 427-442.

Huber, S. J., Friedenberg, D. L., Paulson, G. W., Shuttleworth, E.C. & Christy, J. A. (1990). A pattern of depressive symptoms varies with progression of Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry.* Vol. 53, 275-278.

Hyman, R. B., Baker, S., Ephraim, R., Moadel, A. & Philip, J. (1994). Health belief model: Variables as predictors of screening mammography utilization. *Journal of Behavioural Medicine.* Vol. 17, 391-407.

Hymovich, D. P. & Hagopian, G. A. (1992). Chronic illness in children and adults: A psychosocial approach. Philadelphia: W.B. Saunders.

Johnson, J. L. & Morse, J. M. (1990). Regaining control: The process of adjustment after myocardial infarction. *Heart and Lung.* Vol. 19, 126-135.

Jones, R., D'eath, C., Harnsford, J., Hutchinson, H., Hyde, L., Thurlow, L. & Spanton, L. (1999) The needs of people with Parkinson's disease and their families: the Parkinson's Disease Study, Devon and Cornwall, 1989-92. In R. Percival & P. Hobson (Eds.) *Parkinson's Disease: Studies in Psychological and Social Care.* BPS: UK.

Katz, S., Flasher, I., Cacciapaglia, H. & Nelson, S. (2001). The psychological impact of cancer and lupus: A cross validation study that extends the generality of benefit finding in patients with chronic disease. *Journal of Behavioral Medicine.* Vol. 24. No. 6, 561-571.

Katz, S. & Florian, V. (1986). A comprehensive theoretical model of psychological reaction to loss. *International Journal of Psychiatry in Medicine.* Vol. 16, 325-345.

Krakow, K., Haltenhof, H. & Bühler, K. (1999). Coping with Parkinson's disease and refractory epilepsy: A comparative study. *Journal of Nervous and Mental Diseases.* Vol. 187. No. 8, 503-508.

Kremer, J. & Starkstein, S. E. (2000) Affective disorders in Parkinson's disease. *International Journal of Psychiatry.* Vol. 12 (4), 290-297.

Kriegsman, D. M., Pennix, B. W. & van Eijk, J. T. (1995). A criterion0based literature survey of the relationship between family support and incidence and course of chronic disease in the elderly. *Family Systems Medicine.* Vol. 13, 39-68.

Kübler-Ross, E. (1969). *On Death and Dying.* New York: Macmillan.

Lapham, E. V. & Ehrhart, L. S. (1986). Young adulthood: Establishing intimacy. In E. V. Lapham & K. M. Shevlin (Eds.), The impact of chronic illness of psychosocial stages of human development (pp. 91-104). Washington, DC: National Centre for Education in Maternal and Child Health.

Li, L. & Moore, D. (1998). Acceptance of disability and its correlates. *Journal of Social Psychology.* Vol. 138. No. 1, 13-25.

Linkowski, D. C. & Dunn, M. A. (1974). Self-concept and acceptance of disability. *Rehabilitation Counseling Bulletin.* Vol. 18, 28-32.

Little, M., Jordens, C. F., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: a major category of the experience of cancer illness. *Social Science and Medicine.* Vol. 47. No. 10, 1485-1494.

Livneh, H. & Antonak, R. F. (1994). Review of research on psychosocial adaptation to neuromuscular disorders: I. Cerebral palsy, muscular dystrophy and Parkinson's disease. *Psychosocial Perspectives on Disability*. Vol. 9, No. 5, 201-230.

Livneh, H. & Antonak, R. F. (1997) *Psychosocial adaptation to illness and disability*. Gaithersburg, MD: Aspen Publishers.

Lloyd, M. & Smith, M. (1998) *Assessment and Service Provision Under the New Community Care Arrangements for People with Parkinson's Disease and their Carers*. Archived Research Reports, No. 13. University of Manchester.

McCall, B. (1995) Coping with Parkinson's disease: the patient's and carer's experience. *British Journal of Therapy and Rehabilitation*, Vol. 2, 549-554

McLeod, J. D., Kessler, R. C. & Landis, K. R. (1992). Speed of recovery from major depressive episodes in a community sample of married men and women. *Journal of Abnormal Psychology*. Vol. 101. No. 2, 277-286.

MacMahon, D. G. & Thomas, S. (1998) Practical approach to quality of life in Parkinson's disease: the nurse's role. *Journal of Neurology*. Vol. 245 (Suppl 1): S19-S22.

Mathieson, C. M. & Stam, H. J. (1995). Re-negotiating identity: Cancer narratives. *Sociology of Health and Illness*. Vol. 17. No. 3, 283-306.

Miller, J. E. (1983). Coping with chronic illness: Overcoming powerlessness. Philadelphia: EA. Davis

Mohr, D., Likosky, W., Bertagnolli, A., Goodkin, D., Van Der Wende, J., Dwyer, P. & Dick, L. (2000). Telephone administered cognitive-behavioral therapy for the treatment of depressive symptoms in multiple sclerosis. *Journal of Consulting & Clinical Psychology*. Vol. 68. No. 2, 356-361.

deMorgan, S. & White, K. (2000) Experience of diagnosis, information and support needs of women diagnosed with ductal carcinoma in situ (DCIS). *Woolloomooloo (New South Wales) Information Source – National Breast Cancer Centre*. http://www.nbcc.org.au/pages/info/resource/nbccpubs/dcx.exec.htm.

Mukherjee (Chair), Madan, Dewan, Matthews, Parchimowicz & Morrison (July, 2002) *Availability of the multidisciplinary team during Parkinson's disease clinics: a national survey*. Paper presented at the 8th National Conference – Multidisciplinary care in Parkinson's disease and Parkinsonism: from science to practice. London, UK.

National Institute for Health and Clinical Excellence (NICE) (June, 2006) CG35 Parkinson's Disease: Diagnosis and management in primary and secondary care. UK.

Park, C. & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology*. Vol. 1. No. 2, 115-144.

Pentland, B. (1999) The Nature and Course of Parkinson's Disease. In R. Percival & P. Hobson (Ed)(1999) *Parkinson's Disease: Studies in Psychological and Social Care*. BPS: UK.

Pinder, R. (1990). *The Management of Chronic Illness: Patient and Doctor Perspectives on Parkinson's Disease.* Basingstoke: Macmillan.

Posen, J., Moore, O., Tassa, D., Ginzburg, K., Drory, M. & Giladi, N. (2000). Young women with Parkinson's disease: A group work experience. *Social Work in Health Care.* Vol. 32, 77-91.

Prince. M. J., Harwood, R. H., Thomas, A. & Mann, A. H. (1998). A prospective population based cohort study of the effects of disablement and social milieu on the onset and maintenance of late life depression. *Psychological Medicine*, Vol. 28, 337-350.

Radley, A. (1997) What role does the body play in illness? In L. Yardley (Ed.) Material Discourses of Health and Illness. London: Routledge.

Radley, A. & Billig, M. (1996). Accounts of health and illness: dilemmas and representations. *Sociology of Health and Illness.* Vol. 18, 220-240.

Reynolds, F. & Prior, S. (2003). "Sticking jewels in your life": exploring women's strategies for negotiating an acceptable quality of life with multiple sclerosis. *Qualitative Health Research.* Vol. 13. No. 9, 1225-1251.

Richard, I. H., Schiffer, R. B. & Kurlan, R. (1996) Anxiety and Parkinson's disease. *Journal of Neuropsychiatry and Clinical Neurosciences.* Vol. 8. 334-341.

Robinson, I. (1988). *Multiple Sclerosis.* London: Routledge.

Robson, C. (1993) *Real World Research: A resource for social scientists and practitioner-researchers.* Oxford: Blackwell Publishers.

Sacks, O. (1991). *Awakenings.* London: Pan Books.

Seamark, D. A., Blake, S. D. & Seamark, C. J. (2004). Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers. An interpretative phenomenological analysis. *Palliative Medicine.* Vol. 18. 619-625.

Sharpe, L. & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science and Medicine.* Vol. 62. No. 5, 1153-1166.

Shaw, R. L. (2001). Why use interpretative phenomenological analysis in health psychology? *Health Psychology Update.* Vol. 10. No. 4, 48-52.

Sherbourne, C. D., Meredith, L.S., Rogers, W. & Ware, J. E. (1992). Social support and stressful life events: age differences in their effects on health-related quality of life among the chronically ill. *Quality of Life Research. Vol. 1, 235-246.*

Shontz, F.C. (1975). *The Psychological Aspects of Physical Illness and Disability.* New York: Macmillan.

Smart, J. (2001). *Disability, society and the individual.* Gaithersburg, MD: Aspen Publishers.

Smith, J. A., Harré, R., & Van Langenhove, L. (1995). Idiography and the case study. In J. A. Smith, R. Harré and L. Van Langenhove (eds.) *Rethinking Psychology.* London: Sage.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health.* Vol. 11. No. 2., 261-271.

Smith, J. A., Jarman, M. & Osborn, M. (1999). Doing interpretative phenomenological analysis. In: M. Murry & K. Chamberlain (Eds.) *Qualitative Health Psychology: Theories and Methods.* (pp. 219-240). London: Sage.

Smith, J. A. & Osborn, M. (2003). Interpretative phenomenological analysis. In: J. A. Smith (Ed) *Qualitative Psychology: A Practical Guide to Research Methods.* (pp. 51-80). London: Sage.

Sprangers, M. & Schwartz, C. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine.* Vol. 48. No. 11, 1507-1515.

Stevens, P. E. & Tighe Doerr, B. (1997). Trauma of discovery: Women's narratives of being informed they are HIV-infected. *AIDS Care.* Vol. 9. No. 5, 523-538.

Stone, A. A., Greenberg, M. A., Kennedy-Moor, E. & Newman, M. G. (1991). Self-report, situation-specific coping questionnaires: What are they measuring. *Journal of Personality and Social Psychology.* Vol. 61, 648-658.

Thompson, S. & Janigian, A. (1988). Life schemes: A framework for understanding the search for meaning. *Journal of Social and Clinical Psychology.* Vol. 7, 260-280.

Whitlock, F. A. (1986). Suicide and physical illness. In A. Roy (ed.). *Suicide,* pp 151-170. Baltimore: Williams & Wilkins.

Wright, B. A. (1983). *Physical disability: A psychosocial approach.* 2nd ed. New York: Harper & Row.

Zemzars, I. S. (1984). Adjustment to health loss: Implications for psychosocial treatment. In S. E. Milligan (Ed.). Community health care for chronic physical illness: Issues and models (pp. 44-48). Cleveland: Case Western Reserve University.

Zola, I. K. (1973). Pathways to the doctor: from person to patient. *Social Science and Medicine.* Vol. 7, 677-689.

SECTION C: CASE STUDY

Binge Eating Disorder and Childhood Sexual Abuse: Working within a Cognitive-Behavioural Therapy Framework

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requirements for the degree of Practitioner Doctorate in
Counselling Psychology

(D Couns Psych)

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Chapter 6

Introduction

6.1 Rationale

I have chosen to present this case study due to the complexity of this client's presentation in therapy, involving the effects of childhood sexual abuse, suicidal ideation and a longstanding binge eating disorder. The Cognitive-Behavioural therapy (CBT) context allowed for an exploration of underlying core beliefs and schemata which triggered and maintained her problems. Through guided exploration both my client and I were able to understand these beliefs and work to alter them in order to effect change, which was measured by an amelioration of suicidal ideation, an improvement in her subjective mood and a reduction in the frequency of the binge eating episodes. Through therapy, my client was able to effect positive change in these three main areas, and this case study aims to explore the mechanisms of change within the therapy sessions.

6.2 The Therapeutic Framework

A CBT framework was employed for three main reasons. Firstly, there is good evidence to suggest that this approach is effective for clients presenting with eating disorders, including binge eating (e.g. Telch, Agras, Rossiter, Wilfley & Kenardy, 1990). Secondly, it has been proven to be an effective method to treat and prevent relapse of depression and suicidal ideation (e.g. Rush et al 1977; Kovacs et al. 1981; Hollon, DeRubeis, & Seligman 1993). Lastly, my client demonstrated a good understanding of the main underlying principles of CBT, and a keenness to work within this type of therapeutic model from the outset of therapy.

6.2.1 Cognitive behavioural therapy. CBT assumes that one's thoughts are related to one's emotions, physiological state and behaviours (Persons, 1989). This model proposes that one's core beliefs about oneself and one's environment are critically important in producing and maintaining one's behaviours, emotions, physiological responses and overt thought patterns. Therapy aims to intervene at each of these identified levels to promote corresponding change. Success is measured by behavioural, cognitive, physiological and emotional alterations in terms of symptom reduction. In this case, therapy aimed to reduce my client's suicidal ideation, low mood and binge eating behaviour.

6.2.2 Binge eating and sexual abuse. Binge eating disorder frequently exists with other mental health problems, such as anxiety disorders, substance abuse and depression (APA Work Group on Eating Disorders, 2000). It is characterised by recurrent episodes of binge eating excessive amounts of food within a discrete period of time, with a perceived lack of control during the episode (Spitzer et al., 1992). The food is eaten much more rapidly than normal, when not hungry and feeling low in mood, and the sufferer feels distressed at the binge eating behaviour itself. It is not associated with compensatory behaviours such as purging, the use of laxatives or the use of excessive exercise (Marcus, Wing & Hopkins, 1988), which distinguishes it from other eating disorders such as anorexia nervosa or bulimia nervosa. Research has shown that the likelihood of binging increases when a person is either hungry or experiencing negative feelings (Apple & Agras, 1997) and is positively correlated with lowered self-esteem (Johnson et al, 1987).

Binge eating disorder is frequently associated with a history of sexual abuse (Streigel-Moore et al., 2002) and several other forms of impulsive self-destructive behaviour (Wonderlich et al, 2001). It has been suggested that sexually abused children will develop patterns of low self-esteem which could involve body dissatisfaction (e.g. Briere, 1992; Wonderlich et al., 2000).

Issues of control are significant in female binge eaters who have experienced childhood sexual abuse as opposed to those who report no such history (Waller, 1998). This study proposes that clinical work with eating disordered women with a history of sexual abuse may benefit from a focus on cognitions regarding personal control in clients' lives.

Chapter 7

Initial Assessment

7.1 Referral Details

"Sarah", a 32 year old Scottish office worker, was referred to a 24 hour crisis team for adults with severe and enduring mental health problems, by her GP following the disclosure of suicidal ideation and a two week history of depression and "flashbacks" of childhood sexual abuse since attending a workshop on building self-confidence. Sarah attended for an initial assessment within the multidisciplinary team within a week of referral, with a view to offering short-term crisis intervention to reduce her levels of suicidal ideation and to offer some therapeutic input with regards to her binge eating problems.

7.2 Therapist's Initial Impressions

On initial assessment Sarah presented as a pleasant, casually dressed, rather obese lady. She was tearful throughout the session, but managed to engage well, with appropriate eye contact and body language, and seemed willing to talk openly about her situation. She related that she was keen to attend the mental health services for some support.

7.3 Client's Understanding of the Current Problem and Referral

Sarah stated that she had felt suicidal following a workshop she had attended which had brought back memories of sexual abuse perpetrated by one of her brothers, from the ages of 12 to 16 years. She described a history of binge eating since this time in her life, but since attending the workshop she had begun to binge more regularly and had felt extremely low in mood. She stated that another of her brothers was due to visit her from Scotland in the near future, and that she felt compelled to disclose the sexual abuse to him, which she said was making her feel anxious and distressed.

With regards to her binge eating, Sarah reported having had a problem with eating since age 12, following the abuse, and that she had attended "Overeaters Anonymous" in the past to try and deal with this, with little effect. Over the past 18 months Sarah stated that her binge eating had become more of a problem for her, and as a result she had put on over 7 stones in weight. She linked this to the difficulties she had been experiencing in her life over the past two years, including a short-lived marriage to a man whom she described as "manipulative" and "emotionally unstable". At the time of therapy Sarah was currently engaged in divorce proceedings and was living alone.

Sarah said she had had no contact with mental health services in the past but had seen three private counsellors over the past two years, which had been reasonably helpful. Her GP had recently prescribed antidepressants which she had been taking for one month.

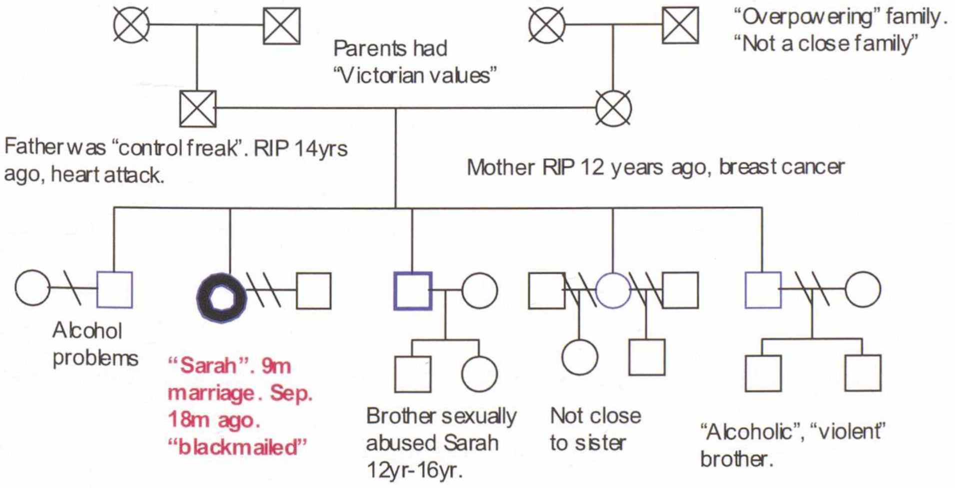


Figure 7.1 Sarah's Genogram

As part of the initial assessment, a genogram (*Fig. 7.1*) was formulated to capture information about Sarah's family structure, family history and details about the relationships she had with her relatives. Sarah found this exercise helpful in terms of making connections between the problems that she was experiencing now in her life and events that had taken place, particularly within her childhood. She stated that she was able to see patterns of behaviour and personality traits across different members of her family and related this to some of the difficult experiences she was currently having herself.

Sarah said that she grew up on a farm within a large family which she described as "not close". She said her parents instilled rather Victorian values upon the children concerning the non-expression of emotion and strong negative views regarding sex. Sex was viewed as "dirty" and the children were expected to dress modestly at all times. She said that she was not close to either of her parents, and that they did not generally display any form of positive attention towards their children. Sarah says that her parents argued frequently and that she thought her mother had been very unhappy in the marriage.

Sarah described her schooling as having been a difficult time for her. She said that she was not a popular child and only had one close friend whom she described as later "betraying" her. Between the ages of 12 and 16 one of her brothers began to sexually abuse her. She did not disclose the abuse to anyone at the time, but instead managed her distress by binge eating in secret. She denied any other form of self-harm or suicidal ideation at that time.

Sarah left home at the age of 20 to live and work in England, describing this as "running away from my family". Shortly after this both her father and mother passed away. Sarah said that her family remained in contact with one another, but that she was not particularly close to any of her siblings. At age 28 she met her husband whom she stated she was "blackmailed" into marrying due to his threats of suicide one Christmas time. Sarah described this marriage as a "sham". They lived with his parents throughout their marriage, and Sarah stated that the emotional strain of supporting him both emotionally and financially, had been a great source of stress for her.

7.4 Therapist's Assessment of the Problem

On assessment, Sarah's recent thoughts of suicide, low mood and increase in binge eating habits seemed to be related to the precipitating factors of attending a self-help workshop which had triggered memories of her past sexual abuse, possibly bringing to light historically negative schemata and core beliefs about herself. Anxieties and worries about disclosing the abuse to her older brother seemed to have exacerbated her difficulties. Modulating variables seemed to be Sarah's subjective mood and her perception of events, so that when she was under a great deal of stress she was more likely to binge. Her cognitions seemed to centre around an issue of "control". Sarah stated, "I have no control over my emotions", and this seemed to be a major factor in Sarah's binge eating too, when she stated that she felt "totally out of control" during these periods.

It was hypothesised at this point that Sarah's negative core beliefs centred around a perceived negative sense of self, and that these were related to the sexual abuse she had endured during her childhood, coupled with the influence of her parents' strict and punitive attitude towards sex and the body. Sarah had coped with her distress in the past by binge eating, and this had become a long-term dysfunctional behaviour linked to issues of control. Up until this point Sarah had not received any mental health support with regards to her suicidal feelings or her binge eating, and having attended a self-esteem workshop, it was hypothesised that deep rooted schemata regarding her negative sense of self were triggered with regards to the effects of the sexual abuse. Sarah did not seem to have many useful coping methods to deal with her emotions, and had resorted to old patterns of binge eating and was experiencing thoughts of ending her life.

7.5 Therapeutic Formulation and Plan

Hypotheses at this point were that Sarah's childhood experiences of growing up in a strict and "Victorian" family where sex was frowned upon, and where she had been the victim of sexual abuse at the hands of her brother, had had a major impact upon the development of her binge eating disorder, her negative sense of self-worth, and later depressive episodes. Sarah had been using binge eating to cope with anxiety and low mood throughout her life, and had experienced suicidal ideation as a result of the workshop she attended which triggered traumatic memories and negative schemata in relation to the sexual abuse.

Sarah was offered a course of short term Counselling Psychology intervention to work upon primarily decreasing the risk of suicide, dealing with the effects of childhood sexual abuse and helping her to understand her binge eating better. Due to the confines of the service, a course of only 12 sessions of psychological therapy was available to Sarah. Following these, Sarah would be referred on to a more specialist eating disorders unit for longer-term therapy. Sarah was agreeable to this plan.

7.6 Therapy Contract

A contract was agreed for us to meet on a weekly basis for up to twelve sessions. Sarah understood that she would be registered on the CPA system (Care Plan Approach) within the NHS mental health setting, and issues of confidentiality were explained at the outset. Sarah signed a consent form to allow information from our sessions to be used for assessment purposes [Appendix 11].

Chapter 8

Development of Therapy

8.1 Therapeutic Interventions Utilised

Throughout therapy Rogerian core principles were utilised including empathy, non-judgement and unconditional positive regard, underpinning the therapeutic framework of CBT employed in our sessions (Rogers, 1961).

Cognitive interventions included the identification of negative automatic thoughts, core beliefs and underlying schemata. They were identified and linked with triggering situations and experiences. Over the course of therapy these were questioned and challenged, with the aim of introducing Sarah to alternative, more functional, patterns of thinking about her situation.

Behavioural interventions included the exploration of her binge eating behaviours in terms of its antecedents, mediating factors and the nature of her binge eating patterns.

Cognitive-behavioural interventions focused upon diary keeping to link her binge eating patterns with their accompanying cognitions and emotions, to increase Sarah's understanding of the multifaceted nature of her problems.

Educational material was used within the sessions, including handouts regarding binge eating, as well as an introduction to CBT principles and therapy. At the end of our sessions a referral was made to a specialist eating disorders unit for longer-term work relating to her binge eating disorder.

8.2 Key Content Issues for Sessions 1 to 9

Session 1

Sarah explained that since taking the antidepressants she no longer felt actively suicidal, although did feel low in mood and in need of emotional support. She described her primary problem as the "eating disorder" and stated that this had never been formally recognised by the medical professionals she had been in contact with thus far. I educated her with regard to the DSM-IV criteria for eating disorders other than bulimia nervosa and anorexia nervosa, which includes "binge eating disorder". Sarah clearly fitted into this category and we explored this further during the first session of therapy.

Sarah described her binge eating as "addictive", " like a fix" and "a buzz", as well as in more negative terms, such as "I punish myself" and "It is self-abuse". She said she felt a distinct lack of control during these periods, which she told me might have been a reaction to the overly controlled family environment she grew up in and the sexual abuse by her brother. Sarah was able to link binge eating episodes to emotional states of high anxiety or depression, so that if she had had a bad day at work, she might go home and binge eat that evening.

In terms of Sarah's self-perception, she said, "I can't accept feeling good about myself", highlighting an issue of low self-esteem as a possible significant issue for her, and possibly underlying and maintaining her depression and binge eating behaviours.

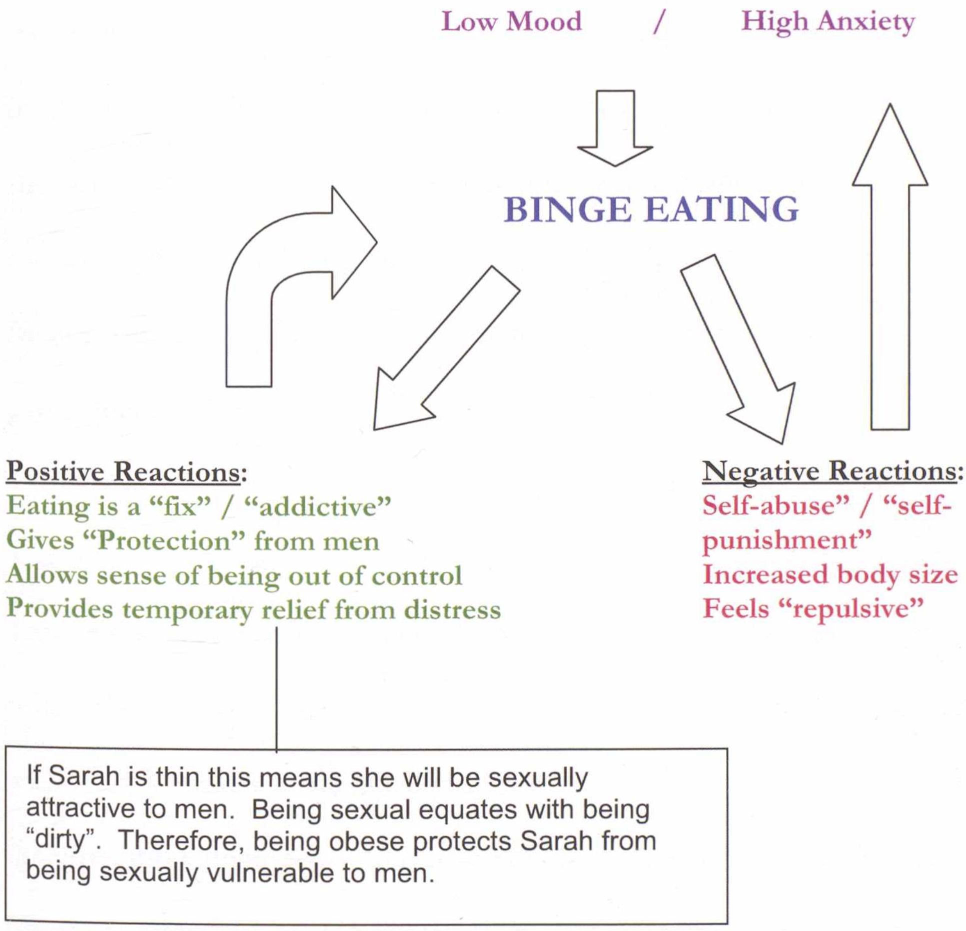
During the course of the first session the main principles underlying CBT were explained to Sarah, and an analogy of a car engine was used as synonymous to the multi-modal system of how one area of life may affect another. This was proposed in relation to how one's cognitions, behaviours, physiology and emotion may interact together to maintain a problem such as binge eating or low mood states. Sarah was given some introductory literature to read about CBT, and she was asked to keep a diary to record her binge episodes and how these linked to her emotional states during the day.

Session 2

Sarah appeared objectively brighter in mood and described having felt a little better compared to how she had been the previous week. She reported that she had not filled in the binge eating diary, but stated that she had felt "more aware of what is going on". When questioned, Sarah said that she had noticed how her mood during the day related somewhat to her binge eating patterns during the evening, in terms of high anxiety or low mood states.

Sarah said that over the past week she had seen improvements in terms of a reduction in the number of binge eating episodes, from approximately eleven the previous week to eight this week. She related this to the fact that she had now been seen within the mental health services and felt "motivated to change".

This second session focused upon Sarah's use of binge eating as a coping mechanism, and how it was acting as a vicious cycle in which binging and low mood increased further binge eating and low mood (*Fig. 8.1*). In our assessment of her binge eating, it seemed that this had some 'benefits' as well as marked disadvantages for her. Sarah showed a complex pattern whereby binge eating fulfilled a physiological "need" in the form of an addictive fix. As a result of putting on a lot of weight in a short amount of time this 'allowed her' to be unattractive sexually to men, who historically have been a threat towards her, both physically and emotionally. Although binge eating allowed Sarah to feel "out of control", which she got a "buzz" from, it also gave her an element of control itself. Sarah explained that she *took control* by deciding to binge eat, which counteracted her experiences of feeling *controlled by others,* such as by her brother or her ex-husband. However, the downside to this behaviour was that being obese also made her feel low about herself in terms of her self-image and indeed she described herself as "repulsive". This in itself reinforced her compulsion to binge as a form of self-abuse or punishment, relating to the abuse and punishment she experienced during her childhood. It was hypothesised at this point that Sarah's negative core beliefs about herself being deserving of punishment and abuse were triggered during binge eating episodes.



If Sarah is thin this means she will be sexually attractive to men. Being sexual equates with being "dirty". Therefore, being obese protects Sarah from being sexually vulnerable to men.

Figure 8.1 Sarah's vicious cycle of binge eating

Being thin or exposing one's body in an immodest fashion had very negative sexual connotations, instilled by her parents' "Victorian values" regarding sex and the body. A belief identified in the session was, "If I am sexually attractive, I am a tart". Having been sexually abused, Sarah's negative schemata about herself were that she was entirely responsible for the abuse, as she had presented herself as being sexually attractive, and was thus a "tart" and deserving of punishment. Binge eating assisted her in terms of carrying out a form of self-punishment and contributing to a sense of self-protection around the time of the abuse. This had continued to be a maladaptive coping strategy in adulthood, which linked to these long-standing negative schemata and core beliefs that she held about herself and her body image.

Sarah expressed how this session had given her a clearer picture as to the relationship between thoughts she held about herself and her binge eating pattern, and described it as "very productive". At the end of the session she stated, "I don't need all this rubbish inside me anymore", which I felt could have symbolically represented some of the negative core beliefs she had about herself, and even possibly the food she ate during a binge episode. This indicated Sarah's beliefs regarding the possibility for change now that she was actively engaged in psychological therapy.

Session 3

This session explored in more depth the relationship between binge eating and Sarah's core beliefs about herself. Again, we highlighted a possible "Catch-22" situation in terms of Sarah's wish to look attractive and like herself physically, whilst the binge eating made her larger and therefore more unattractive to others in her opinion. Being thinner as a result of stopping the binging would make her like herself more, but as a consequence could also be considered as making her more sexually vulnerable to men.

Sarah described her current situation as, "I am in a mess. I'm not OK". When questioned about what she would like to achieve via our sessions, she stated that she wanted, "To feel good about myself". She stated in passing, "When I feel OK, I feel physically half my weight". This allowed for a deeper discussion at this point as to the possible misinterpretation that losing weight equated with feeling more positive about herself, and emphasised the importance of self-appraisal as possibly the key factor in her recovery, rather than simply losing weight.

We explored her difficulties related to not being able to accept praise from others, which she felt might have some relevance to her parents' view of her as "undeserving", "not believed" and that "nothing was ever good enough for them". Clearly, her parents' views of her had had a major impact upon Sarah's own negative beliefs about herself. At the end of the session Sarah concluded that in order to change her binge eating she needed to "Change how I feel about myself", thus making a link between her negative core beliefs, schemata, sense of self and behavioural changes.

Session 4

Sarah arrived at the session and related to me that her week, although stressful, had been on the whole positive in terms of a reduction in binge eating episodes; binging only three times during the week and reporting that she had an increased awareness of the triggers to a binge episode. These included "feeling stressed" and letting her "emotions bubble under the surface". She said, "I need to face them and talk about them, rather than binge". When asked how she managed to reduce her binge eating, Sarah replied that she had on the whole felt better within herself. She said she felt "valued" within our sessions and stated, "Finally, my eating disorder has been acknowledged". We looked at this in terms of its significance, and Sarah felt that during most of her childhood her family had seen her as a "liar". By externalising her problem via our sessions and being validated and believed during psychological therapy, Sarah reflected "I don't have a screw loose after all". She may have felt more empowered to change her situation via therapy. The therapeutic relationship and Rogerian core conditions utilised therein had allowed Sarah to challenge her underlying schema that she was a "liar" and therefore should not be trusted or believed.

Sarah also felt that she had been allowing herself to care for herself, for the first time. Her future goals in this area were "For me being allowed to have the confidence not to beat myself up". She was able to list positive characteristics about herself during the session, which included being a loyal friend and an honest person. Clearly, Sarah was indicating more confidence in challenging negative schemata about herself as a liar or a bad person. Sarah said at the close of the session that she would like to "Stand up and be counted" now. Homework included Sarah making more time for herself in terms of self-care as opposed to punishing herself via binge eating. Sarah named this "Me Time".

Session 5

Sarah related that she had been eating "normally" over the past week and had not binged at all. Our session explored in detail Sarah's childhood sexual abuse and how it had made her feel guilty and responsible. Sarah also related another significant event during adolescence regarding a lesbian attraction she had developed to a girl at school. She said that this had left her feeling "filthy and abnormal", and she went to great lengths to keep this a secret from her family. We explored how her parents' values had impacted upon her beliefs about herself as dirty, ashamed and responsible for the abuse and regards to her sexuality. Sarah was able to challenge some of these core beliefs and question these maladaptive schemata. I asked her to think about where these "belonged" – to *her now*, or to her parents? Sarah answered that these beliefs in truth belonged to her parents and herself as a child, rather than to her now as an adult. Sarah was educated as to CBT theories relating to the development of schemata and core beliefs, and the scope for possible change in this respect. Sarah stated she was "… worthy of my own opinion". Therapy at this point was empowering Sarah to challenge long held beliefs regarding her self-worth and personal value systems.

Session 6

Sarah related that she had felt "up and down" during the week and had binged at least three times. She had been assessed by a dietician on the advice of her GP and had requested a psychiatric assessment in support of a legal issue regarding non-payment of mortgage arrears. She reported having had a disagreement with the psychiatrist and had felt generally quite stressed. She also felt worried about her older brother's visit in a month's time. During the session Sarah was able to link her low mood and stress levels to the increase in binge eating. She said she felt "mentally challenged" during the week and that she had a "fear of failure" and had therefore not enrolled on a floristry course that she had planned on doing that week. Again she had used binging to cope and described this as "pushing the self-destruct button". We explored this further and discussed how a "self-care" button might have had a more of a functionally beneficial effect, building upon our earlier sessions regarding reinforcement of positive self-regard. Sarah said that she was beginning to understand more about the patterns of her behaviour and its relationship to her thoughts and feelings during the week.

Session 7

Sarah began the session by reporting that she had felt better over the past week, although still "up and down", and had binged just once. She had finally enrolled on the floristry course, which she felt pleased about and was looking forward to starting next week. We explored again the underlying beliefs to her binge eating (*Fig. 8.2*). We looked at things Sarah might do or think about which might have a positive influence upon her self-value and self-appraisal. She felt that by keeping busy and making good autonomous decisions, as opposed to defaulting to others' views, would be helpful to her. This built upon issues regarding Sarah taking positive control in her life, rather than feeling controlled by others as she had in the past. Sarah felt she needed to "keep focused" in order to get well. I asked her to explore ways of doing this during the week. Meanwhile, I would refer her to the eating disorders clinic, which Sarah was keen to attend for longer-term intervention.

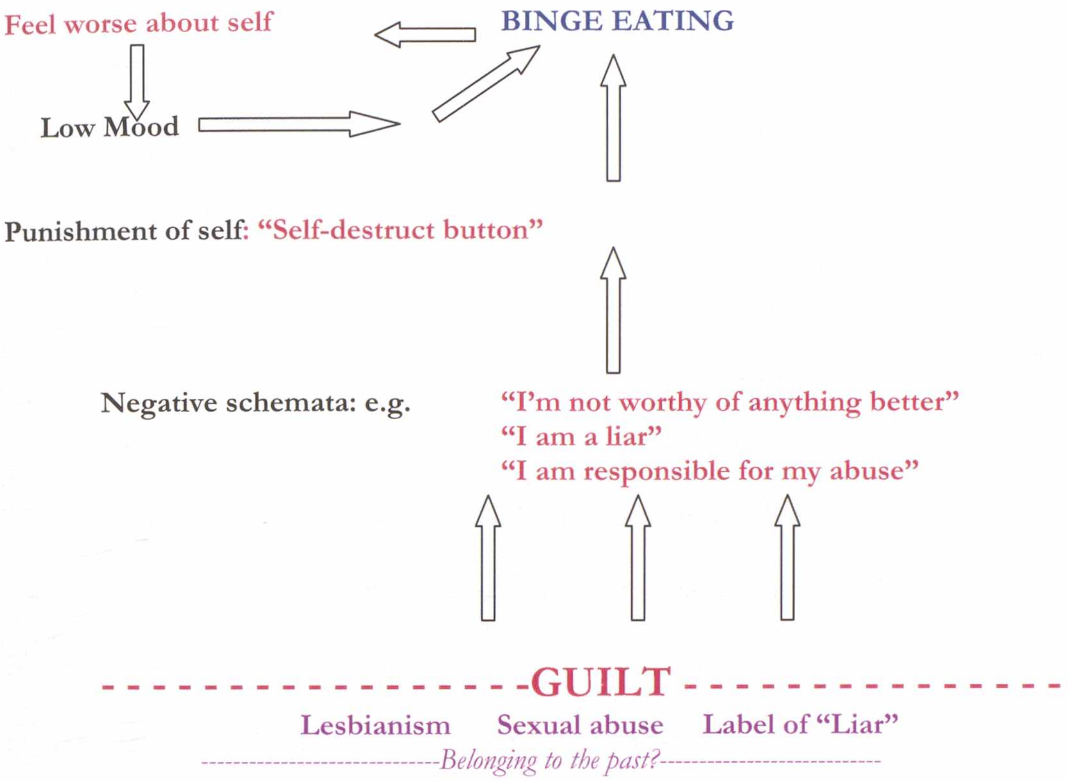


Figure 8.2 The role of guilt and negative schemata to Sarah's binge eating

Sessions 8 and 9

Sarah felt that it had reached a point where she felt a lot less disabled by her binge eating, and her mood had improved significantly. She and I felt that we would bring the sessions to a close at this point, and that her care would progress satisfactorily in due course with her upcoming assessment at the eating disorders unit. We left a two week break between the 7th and 8th session and a month's break between the 8th and 9th session, and during this time Sarah reporting having not binged at all. She told me, "Emotionally I don't feel I need food anymore. I'm satisfied in other ways and no longer have that emptiness inside me". We explored how food may have "filled an emotional gap", as well as her increased levels of self-care and self-understanding developed via therapy. This related back to her poignant comment at the end of Session 2 regarding the "rubbish" inside her.

Sarah reported having met now with her older brother and that she had discussed at length with him the childhood sexual abuse, which she felt relived to have disclosed. She described this as having been a great weight off her mind. She explained how she felt more aware of her emotions and how they related to her binge eating. Sarah felt that she had "made a fresh start and a new beginning" in terms of her floristry career, the disclosure to her brother and attending for psychological therapy.

Our last session focused on the termination of therapy, reflecting back upon our therapy sessions and the insight she had gained from this. Sarah was anxious that the eating disorders clinic would not accept her for treatment now that she had significantly managed to reduce her binge eating! She was encouraged to tell her assessor the true picture so that they could make a good assessment for longer-term work issues. Sarah explained that her self-confidence had markedly increased, and that therapy had encouraged her to challenge some of her negative views she had held about herself for so long.

The session ended on a positive note and Sarah was discharged from our service with advice that she could contact our service at any time for further crisis support, should she feel this to be necessary.

Chapter 9

Discussion and Evaluation

9.1 Therapeutic Process and Changes over Time

Over the 16-week period in which Sarah had been seen for psychological therapy she was able to significantly reduce her binge eating, improve her mood and no longer had thoughts of ending her life. She used the sessions to explore the underlying issues relating to her negative self-perceptions and the development and perpetuation of her binge eating. During therapy we were able to identify triggers to binge eating episodes, and how they related to core beliefs and schemata formed in childhood and maintained throughout adulthood. Her negative self-perception altered during the course of therapy via exploration and open discussion regarding the validity of her core negative appraisals and beliefs about herself and her experiences. She was able to challenge these and reinvent some aspects of how she viewed and valued herself, such as challenging her feelings of responsibility for the abuse, her dysfunctional patterns of self-punishment and being unworthy of care. This was further reinforced via the positive life changes she made which demonstrated an increased level of self-care, self-confidence and gave her the opportunity to take control of her life in a functional way. For instance, she made a positive decision to enrol on a floristry course and was able to disclose the sexual abuse to her brother, which reinforced her self-confidence.

Sarah was able to identify and link cognitions, behaviours, emotions and even physiological responses to one another and this formed the foundation for the possibility of positive change. She described this as "increased self-awareness" and felt encouraged that she had been able to take control in a positive way, rather than her previous maladaptive manner, which primarily involved binge eating with a consequential *loss* of control during the episode. The work carried out during our sessions confirmed the suggestion by Waller (1998) that therapy should focus upon issues of personal control in female clients presenting with binge eating and a history of sexual abuse.

By exploring the underlying schemata and beliefs Sarah held about herself, she was able to free herself up to the possibility of changing longstanding patterns and maladaptive coping strategies. By challenging her underlying cognitions she was able to effect change at other levels, namely the behavioural and emotional aspects of her presenting problem. Therapy within this context built some form of foundation for longer-term eating disorder focused work in the future. The therapeutic alliance allowed for open exploration about difficult emotions and engendered a new type of trusting relationship where my client felt valued, understood, believed and empowered. It may have been a positive template for Sarah to model herself upon in terms of caring for herself rather than perpetuating the "self-abuse". Her negative schemata such as "I am a liar", "I am worthy of punishment" were challenged during the course of therapy, with Sarah tentatively discovering alternative and more functional replacements. This was achieved via the development of a strong therapeutic alliance, based upon Rogerian core conditions, which allowed Sarah to feel validated and deserving of support and positive things to be in her life. Indeed, Sarah reported in Session 4 feeling "valued" and "validated", which may have been a significant factor in terms of her being able to develop a more positive self-perception and associated behavioural changes during the course of therapy.

The therapy sessions allowed Sarah the space to talk openly and freely about her difficulties, which contrasts starkly to her childhood experiences of keeping secrets, feeling ashamed and not being able to share her feelings with others. Through a process of mirroring, Sarah may have begun to demonstrate a level of self-care, relating to a more positive sense of self-worth, developed from our strong therapeutic relationship.

This case study supports the previous research literature, in that my client had developed low levels of self-esteem (Johnson et al, 1987) in response to her history of childhood sexual abuse (Streigel-Moore et al., 2002) and that this had affected her negatively in terms of her body image (Wonderlich et al., 2000) and her vulnerability to depression and suicidal ideation in times of stress (APA Work Group on Eating Disorders, 2000). Her binge eating showed clear signs of compulsive self-destructive behaviour (Wonderlich et al, 2001) and this clearly increased as a response to difficulties which she felt she had no control over (Waller, 1998). The work carried out within the sessions confirms the suggestion that working upon issues of control and self-abuse can be beneficial to clients presenting with binge eating and a history of sexual abuse.

9.2 Difficulties Encountered

Having never worked with an eating disordered client before, presenting as suicidal and with a history of sexual abuse, I was rather apprehensive about the particular techniques that would need to be employed in order to effect change in therapy. I overcame this by working collaboratively with my client and focusing upon the issues she felt were most important during each session. The short-term nature of my work within the crisis team did not allow for deeper exploration of her underlying schemata and more detailed examination of issues regarding her binge eating and childhood sexual abuse. Longer term work would have been able to focus upon each of these issues individually and a structured case formulation approach (Beck, 1995) would have been of most benefit in this case, given the complexity of her difficulties. Each session built upon the last, however I feel in hindsight the sessions could have been more structured and focused, with a specific agenda set at the beginning of each session. Formal functional analysis within the sessions may have been beneficial, especially with regards to covering particular issues in depth. However, the use of a genogram (*Fig. 7.1*) and two diagrams (*Fig. 8.1 and Fig.8.2*) to examine and explain Sarah's binge eating were of great benefit to both myself as a practitioner and also my client, in terms of understanding the complex nature of her problems.

In terms of homework exercises, it may have been more useful to have stressed to Sarah the importance of keeping records and diaries etc. In this way she would have been able to link more clearly her cognitions to her behavioural, emotional and physiological states. She was able to do this to some extent without the record keeping, however it would have provided a permanent record of analysis for comparison over the nine sessions.

9.3 Evaluation of my Work

In summary, I feel my work with Sarah was beneficial in terms of achieving the goals set at the beginning of therapy. She was no longer suicidal, had significantly reduced the number of binge eating episodes and had dealt with a great deal of underlying issues triggering and maintaining her problems by the end of therapy. This work has given me a greater understanding of how childhood sexual abuse can affect clients' perceptions of self-worth and can lead to a binge eating disorder. In future work with similar clients I would look at working in a more structured fashion, taking on a case formulation approach incorporating functional analysis, and utilising written CBT homework as useful tools in therapy. The therapeutic relationship from the outset provided a safe and trusting environment for my client to explore her problems and helped her to change aspects of herself in terms of her maladaptive cognitions, emotional patterns and behaviours, which was in hindsight extremely important for change to occur.

This case analysis has allowed me to reflect upon how our therapeutic relationship had been essential in terms of effecting therapeutic change in my client. This reinforced to me the importance of building a trusting therapeutic alliance when working within a CBT framework, as a foundation and vehicle for therapeutic change.

Apple, R. F. & Agras, W. S. *Overcoming eating disorders. A cognitive-behavioral treatment for bulimia and binge-eating disorder.* San Antonio: Harcourt Brace & Company, 1997.

American Psychiatric Association Work Group on Eating Disorders. Practice guidelines for the treatment of patients with eating disorders (revision). *American Journal of Psychiatry,* 2000. Vol. 157 (1 Suppl) pp 1-39.

Beck, J. S. (1995) *Cognitive therapy: basics and beyond.* NY: Guilford Press.

Briere, J. N. (1992). *Child abuse trauma: theory and treatment of the lasting effects.* Newbury Park, C. A.: Sage.

Johnson, C., Connors, M.E. & Tobin, D. L. (1987). Symptom management of bulimia. *Journal of Consulting & Clinical Psychology,* Vol. 55, pp 668-676.

Luadzers, D. (1998). Treatment outcome in eating disorders and sexual abuse history. *Dissertation Abstracts International.* Vol. 59 (5-A) pp 1776.

Marcus, M. D., Wing, R. R., & Hopkins, J. (1988). Obese binge-eaters: Affect, cognitions and response to behavioral weight control. *Journal of Consulting and Clinical Psychology,* Vol. 56, pp 433-439.

Persons, J. B. (1989) *Cognitive therapy in practice: a case formulation approach.* NY: Norton.

Rogers, C. R. (1961). *On becoming a person.* Boston: Houghton Mifflin.

Spitzer, R. L., Devlin, M., Walsh, B. T., Hasin, D., Wing, R. R., Marcus, M. D., Stunkard, A., Wadden, T., Yanovski, S., Agras, S., Mitchell, J., & Nonas, C. (1992). Binge eating disorder: A multisite field trial of the diagnostic criteria. *International Journal of Eating Disorders.* Vol. 11, pp 191-203.

Streigel-Moore, R. H., Dohm, F., Pike, K. M., Wilfrey, D. E., & Fairburn, C. G. (2002). Abuse, bullying and discrimination as risk factors for binge eating disorder. *American Journal of Psychiatry.* Vol. 159 pp 1902-1907.

Telch, C.F., Agras, W. S., Rossiter, E. M., Wilfley, D. & Kenardy, J. (1990). Group cognitive-behavioral treatment for the non-purging bulimic: An initial evaluation. *Journal of Consulting and Clinical Psychology.* Vol. 58, pp 629-635.

Waller, G. (1998). Perceived control in eating disorders: relationship with reported sexual abuse. *International Journal of Eating Disorders.* Vol. 23, pp 213-216.

Wonderlich S. A., Crosby R. D., Mitchell J. E., Thompson K. M., Redlin J., Demuth G., Smyth J., Haseltine B. (2001). Eating disturbance and sexual trauma in childhood and adulthood. *International Journal of Eating Disorders.* Vol. 30, pp 401-412.

Wonderlich, S. A., Crosby, R. D., Mitchell, J. E., Roberts, J. A., Haseltine, B., DeMuth, G. R. N., & Thompson, K. M. (2000). Relationship of childhood sexual abuse and eating disturbance in children. *Child and Adolescent Psychiatry.* Vol. 39, pp 1277-1283.

SECTION D: PROCESS REPORT

Addicted to Love? Psychodynamic Therapy in the Context of Addiction

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Process Report submitted in partial fulfilment of the
requirements for the degree of Practitioner Doctorate in
Counselling Psychology

(D Couns Psych)

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Chapter 10

Introduction

10.1 Rationale

I have chosen to present this process report to demonstrate the psychodynamic principles which underlie the relationship forming behaviour of a 24 year old female client who had a previous history of drug and alcohol abuse and who was seeking therapy following the break-up of a relationship. This report illustrates the emerging similarities between my client's former drug using behaviour and the ways in which she forms relationships with others.

10.2 Principles of Psychodynamic Therapy

Exploration of the psychodynamic principles underlying my client's issues brought to therapy and the process of therapy in this process report centre upon the following main topics: Intrapsychic Issues and the Development of "Self"; Interpersonal Relationships and Communication; and The Therapeutic Relationship and the Process of Change.

These are now explored below in relation to the psychotherapeutic work carried out with my client.

10.2.1 Intrapsychic issues and the development of "self". Freud (1923) theorised that all human behaviour is motivated through specific basic 'drives', which are sexual or aggressive in nature and are not within our conscious control. Instead, our unconscious mind is governed by the Id, Ego and Super-ego. The Id is responsible for impulses such as anger, sexual gratification and other strong emotional reactions and these drives are in a constantly agitated state for expression (Badcock, 1988). The Ego maintains a balance between the Id's need for expression and the demands of the outer world, such as society's expectations and pressures for conforming to specific behaviours or social norms. The

Id's drives are often unconsciously 'repressed' and sometimes more consciously 'suppressed' and these mechanisms are explained below. The Super-ego is governed by rules and regulations for behaviour of the 'self', which have been influenced by ideals moulded and modelled by significant others, such as one's parents or other authority figures. These aspects of the self are particularly important for socialisation (Freud, 1973a).

One's perception of oneself and one's ideal way of being, or 'Ego-ideal', is influenced by one's social group ideals or ideal personal characteristics and ways of behaving (Freud, 1985b). Related to this concept is that of presenting a 'False self' over one's 'shadow self', which are aspects of the self often not consciously expressed, and masked by one's 'persona', which is expressed to others as a socially acceptable presentation of one's 'self'. Joffe & Sandler (1965) explore the concept of one's 'ideal self' and 'actual self', whereby a discrepancy between the two can cause psychic pain in the form of anxiety or depression, and is thought sometimes to cause bodily symptoms (Merskey & Spear, 1967).

The therapeutic process of 'Individuation' (Jung, 1964) is the coming to terms with aspects of one's self which we wish to change and this process is one of self-exploration via therapy and at times dream analysis. One way to achieve this in therapy is to become aware of one's 'shadow self' which are unconscious negative aspects of the self which are only realised through projection or other defence mechanisms. Defence mechanisms exist to protect these aspects of the self, for if they were consciously experienced rather than being controlled by such processes, unbearable anxiety or psychic pain may ensue. Anna Freud (1936) theorised a number of defence mechanisms which could be employed, such as 'regression', 'repression', 'projection', 'splitting' and 'introjection'.

Concerning addiction to drugs and alcohol, Sander (1926) described how this could be a way of satisfying archaic oral drives as a way to feel a sense of security and increase one's sense of self-esteem. This is reminiscent of an infant's sense of gratification from feeding from its mother's breast. In a sense, a drug addict will be feeding themselves to fulfil a pre-genital drive of oral gratification, and particularly so through drinking alcohol, which is literally taken orally. Sander (1933) explains how the addict will gain a sense of well-being in this way, as a child gains from seeking the warmth and sustenance from its mother. In terms of the effect upon intrapsychic issues, Fenichel (1945) explains how becoming intoxicated through alcohol can have the effect of dampening the control of the Super-ego, and thus wish-fulfilments can be acted upon via the loss of inhibitions the alcoholic experiences.

10.2.2 Interpersonal relationships and communication. Attachment theory, developed by Bowlby (1969, 1973, 1980) suggests that humans have an instinctual need to form close bonds with others. The reciprocity of early relationships is a precondition of normal human development (Hofer, 1995) and the attachment behaviours of the infant, such as proximity-seeking, are reciprocated by adult attachment behaviours, such as holding, soothing or touching. The infant's subjective experience of security or insecurity depends upon these attachment behaviours within their social environment. The experience of security is the goal of this attachment system and is the primary regulator of emotional experience for the child (Sroufe, 1996). Bowlby (1973) theorised that one's past experiences with a caregiver are aggregated into a representation system, termed an 'internal working model'. Bowlby proposed that internal working models are relatively stable across the lifespan (Collins & Read, 1994). The child's own sense of self as fully autonomous emerges from secure parent-child relationships (Lieberman & Pawl, 1990).

The work of Object Relations theorists, such as Winnicott (1965), Guntrip (1961) and Fairbairn (1952) illustrate that the primary motivational drive in human beings is that of seeking out relationships with others. In psychotherapy, the therapist provides a 'secure base' for one's client to develop a temporary attachment (Bowlby, 1977). Certain developmental phases have been proposed (e.g. Erikson, 1965), which explain the impact of a child's development of self through their interactions with significant others, from childhood, adolescence and into adulthood. In the first year of life, for instance, a basic trust in others is formed (Erikson, 1965), provided that 'good-enough' mothering occurs (Winnicott, 1965), whereby one's physical needs are instantly gratified. The 'Individuation process' (Mahler, Pine & Bergman, 1975) begins to occur once the child begins to encounter separation periods from its mother or other significant other and this is the first step towards independence. The different stages in development introduce the growing child to new concepts of self in relation to others around them (Hampson & Hampson, 1961).

When relating socially to others, people often employ specific 'strategies' of communication and behaviour in their interactions which can be sometimes be maladaptive in nature (Cashdan, 1973). These strategies can be explored during the therapeutic context by looking at the communication patterns displayed within the therapeutic relationship which might reflect those being used by the client outside of the therapy room. In this way they are seen as an integral way in which to understand the client's experiences of themselves in relation to others. Cashdan (1981) states that 'dependency' strategies are the most prevalent type, whereby the use of 'helplessness' is a means of forming and maintaining relationships. Interactional psychotherapy deals with such maladaptive strategies in stages, whereby each strategy is identified, explored and finally replaced with more adaptive strategies of communication and interaction with others. Three levels are proposed by Chashdan (1981) in this respect. These relate to the exploration of early communication patterns, the client's current relationships and the therapeutic relationship, which aims to correct or adapt the maladaptive past and current interpersonal relationships.

10.2.3 The therapeutic relationship and the process of change. The purpose of therapy is to promote self-awareness and mutual understanding in the client and therapist and to cathartically allow one's client to feel (Craib, 2001). It is not a prescriptive cure, but instead a mutual search for understanding of the client's inner world, which in itself can promote psychotherapeutic change. Psychotherapy involves the exploration of unconscious processes brought to light in the therapy room by the therapist through working with the transference and countertransference, and aims to bring to the client's awareness the significant dysfunctional relationship patterns regarding how they interact with others outside of the therapy room.

Transference refers to the unconscious transfer of experience from one interpersonal context to another. Past relationships are 'relived' in current situations, and has been described as such: "The patterns of our later interpersonal relationships are formed in our early lives, repeated in our later lives, and can be understood through the medium of their repetition" (Fromm-Reichmann, 1950, p.4), particularly so within the client-therapist relationship. The expression of transference by one's client affects the therapist on an emotional level, and this experience is termed 'countertransference'. The therapist's countertransference feelings are a direct and specific response to the client and may indicate something significant about the client's current thoughts, feelings or experiences.

Transference and countertransference patterns are seen as mutually formed experiences jointly created by both the client and the therapist, rather than as exclusive expressions of either participant's intrapsychic world. That is, the client's transference influences and is revealed in the therapist's countertransference. Conversely, the therapist's countertransference partly shapes and is revealed in the client's transference. Transference and countertransference are viewed as expressions of one's self and one's situation in terms of unconscious motivations and experiences of both the client and the therapist (Fiscalini, 1994). Exploration of both transference and countertransference issues is therefore a useful and necessary tool in psychodynamic therapy in terms of promoting a mutual understanding of the client's current interpersonal difficulties.

Chapter 11

Therapy Session

11.1 Client Details

"Sandra" was a 24 year old client referred by her GP to an in-house NHS Counselling Psychology service, which provided brief psychotherapy for up to a maximum of 8 sessions. The referral letter stated that Sandra had been feeling depressed and tearful since the break-up of a long-term relationship approximately one month ago. She had just begun a course of anti-depressants and had requested that she receive some psychological counselling. She was seen for an assessment within two weeks of receiving the referral.

11.2 Therapeutic Contract

We agreed to meet weekly for up to the maximum number of 8 sessions allowed with the Counselling Psychology service, in order to allow Sandra to feel that enough work had been done for her to feel significantly less depressed and able to "move on". We agreed to review her progress after each session. Issues of confidentiality within the service were explained to Sandra and she gave written consent for audio-taping of the sessions and for information to be used for assessment purposes [Appendix 12].

11.3 Therapist's Initial Impressions

Sandra attended her first appointment and appeared agitated in terms of her body language. Throughout the session she displayed behaviours such as wringing her hands and her tone and style of speech indicated that she was quite anxious about coming for therapy. However, she engaged well, maintained good eye contact and was forthcoming in talking about her difficulties. Sandra was well dressed and groomed, attended the session on time and gave the impression that she was eager to talk about her current difficulties.

11.4 Client's Background Information

Sandra worked as a publishing assistant for a busy commercial firm and described this job as being quite stressful. She had been signed off work for three weeks by her GP in relation to her current emotional distress. Sandra lived by herself but explained that she had a good level of support from her friends and, most recently, her sister. She told me that she was a current attendant at Alcoholics Anonymous (AA) meetings as well as Cocaine Anonymous (CA) and Narcotics Anonymous (NA), and that she found these groups very helpful in terms of coming off drugs and alcohol, and with regards to the ongoing support and insight they had provided regarding her problems over the past year.

Sandra had finished studying for a degree at university one year ago and since that time had been working at the publishing firm. She gave a history of using various illicit drugs, including crack cocaine, speed, marijuana as well as abusing alcohol whilst at university. Once she finished her studies she lived with friends whom she described as 'users' and a drug dealer in a shared house. Having moved accommodation two years ago, she became "clean", having started attending AA, CA, and NA group therapy programmes. At the time of therapy, Sandra was on to Step 4 of a 12-Step detoxification programme provided by AA. This related to "letting go" of difficult emotions that could prompt a relapse, by asking the client to burn old photos and letters relating to the past. Since beginning these groups Sandra told me that she had not gone back to using drugs or alcohol.

11.5 Lead into Transcribed Section

The following section of therapy occurred ten minutes into the first session. Sandra had just spoken about two recent relationships break-ups. The first was with "Daniel" who was also an alcoholic, whom she split up with shortly before starting a new relationship with "Sean", a recovering alcoholic. Prior to the transcribed section, Sandra related that she felt she had an "addictive personality", whereby she easily gets "obsessed, especially with men". Sandra explains her reasons for splitting up with Sean and the circumstances surrounding the ending of their relationship.

Chapter 11

Transcript of Session Section

Client 1: I thought… if I wasn't with him in this way that *he* obviously wanted then perhaps we wouldn't be… yeah… perhaps we wouldn't even have a friendship or something. It was like I didn't want to lose him so I was kind of doing this and convincing myself that this was good. And you know it was… it was great. He was a fantastic looking guy and he was really, really nice and he was really nice to me.

Sandra relates to me that she seemed to find no fault in this new partner, and might have been convincing herself that he was perfect, and yet realises that she made a great sacrifice to be with him, due to her fear of losing him.

Therapist 1: But you kind of defaulted to his… his terms?

My intervention focuses on this sacrificial element to their relationship, feeling at this point it could be a key factor in how my client begins and maintains relationships, i.e. at the expense of herself.

Client 2: Yes. Well he wasn't… he told me at the beginning he wasn't looking for a full-on relationship. He wasn't looking for a girlfriend. And as sort of time went on he would say to me, you know, that his feelings were really *growing* and he was *scared* in a way and I was as well. It was sort of *overwhelming*. But when it came down to it, really, you know, everything else was more important. Everyone got more time and energy than I did.

Sandra appears to be communicating that her feelings towards Sean were different to the strength of his towards her, especially at the start of their relationship. Although their feelings grew for each other, this scared them both and it seems it disrupted their relationship somewhat. Sandra sees in hindsight that from the beginning of their relationship to its end, she was lower down on her partner's list of priorities than she had wished.

Therapist 2: So it sounds like… almost a black and white thing where one side of the story is that this is the perfect man where it's a wonderful kind of fantastic relationship, where you are almost living in a kind of fantasy relationship. But there is the other side, where it's kind of well actually I'm not the number one on his list. Things aren't right for me. Things aren't 100%. It sounds like you are kind of looking back on things in hindsight and thinking about the *beginning* of the relationship…

I summarise the information Sandra has related earlier in the session concerning how she had seen Sean as her "dream man", in relation to her ex-boyfriend, Daniel. At this point, I am hinting to Sandra that she is seeing this new partner as some sort of drug which can take away her pain, and which she takes without contemplating about the negative side-effects. Using this drug metaphor, the "coming-down" from this "drug" is the realisation that Sean is not in fact perfect, and can actually harm her. Her instant gratification, fuelled by the drive of her Id, was pushing her to seek out a man, as she might a fix of a drug.

Client 3: I know at the beginning I went against my gut feelings. I needed a distraction. I needed something to lose myself in, you know, and drinking and taking drugs are not an option because I don't know where that could take me. I've heard such awful stories. I know people who have gone out and have got hold of something and have *died*. And I don't want that to be me.

Sandra picks up on the significance of the start of her relationship as something to "lose" herself in, which mirrors the drug metaphor I had used in my previous interjection. Her "gut-feeling" was ignored and this was because she wished to distract herself from all bad feelings. Sandra is clearly talking about her ex-partner in the same way she would about drugs. She was "using" a relationship to distract herself from painful inner feelings, as she would abuse a drug. However, she does not at this point explicitly recognise the similarity in terms of her "using" relationships and using drugs.

Therapist 3: Hmm…

I use a short empathic encourager to let Sandra know that I am listening to her and to encourage her to continue talking about this important issue.

Client 4: And I did kind of lose the will to live about three weeks ago and I think that's why Dr. R. put me on anti-depressants. You know, I was just broken… you know, and I think how I *felt*, you know, how upset I was when things ended with Sean, was … I just realised that I was a bit surprised that … I didn't feel this way when things ended with Daniel. You know, I was running around *laughing* when things ended with Daniel.

Although Sandra changes the subject, the previous intervention helped to create a safe therapeutic environment for Sandra to disclose her suicidal ideation. Living without drugs or a partner had led Sandra to feel suicidal and "broken". Her need for instant gratification was no longer being satisfied. Sandra additionally communicates to me that her reaction to leaving Daniel was very different from that of leaving Sean, and I wished to explore this further.

Therapist 4: Things were really different?

I am intrigued and by intervening in this reflective manner, I encourage Sandra to expand upon this subject.

Client 5: Yeah. And I kind of see now that of course I wasn't going to feel sad about Daniel because I was going straight into a new relationship with Sean and it was all "He's so amazing"…

Sandra begins to gain some insight into why her reaction might have been so different. Having Sean to move on to after splitting up from Daniel "distracted" her from the pain (See Client 3 response). She saw Sean as the "perfect drug" that she could "lose" herself in.

Therapist 5: Right. So things at the end of the relationship had been a bit clouded over and pushed to the wayside because of this new fantastic relationship?

My intervention here reflects my thoughts concerning how she used Sean to distract her from the pain she felt inside.

Client 6: Yeah [*Uttered solemnly*]

Sandra, although she appears to agree with my reflection, does not expand upon this, although my next intervention was delivered quite soon and may have halted any further exploration by Sandra at this point.

Therapist 6: So you were saying that you were feeling suicidal three weeks ago… What strengths have you drawn on to … to keep yourself going for these past few weeks? What stopped you? What's kept you going?

My intervention focuses upon Sandra's coping skills and strengths, which although could be seen as therapeutic, may also be a reflection of my client's transference. I am impelled to make my client feel better, in a similar fashion to how Sandra seeks out an instant "fix" to distract her from her own painful feelings. My countertransference at this point may reflect how Sandra seeks out people in other relationships to take her pain away, in taking on a passive and dependant role. .

Client 7: I don't… I don't think I actually wanted to die. I think I just wanted to be somewhere else. To get away from myself.

Again, my client indicates to me that the suicidal ideation itself was a wish for distraction from painful feelings or situations. She is indicating here that she wishes to distance herself from parts of her self which are acutely distressing, by escaping somehow from her pain.

Therapist 7: To escape?

A simple reflection, which indicates that I am understanding what she is saying to me, and is meant to allow Sandra to continue to explore this sensitive and important issue.

Client 8: Yeah…
[PAUSE OF 10 SECONDS – CLIENT BEGINS TO WEEP]

Sandra is clearly distressed and breaks down in tears. This could be due to the realisation that although she is in recovery from drink and drugs, she is still suffering from addiction behaviour in terms of needing to *escape from uncomfortable parts of herself through engaging in dysfunctional relationships or feeling suicidal. This issue seems to be a rather significant issue, judging by Sandra's emotional reaction of breaking down in tears, and required further exploration in the session.*

Therapist 8: Is there anything you feel you have done to help yourself escape?

Again, I act upon my client's transference in order to rescue her, by attempting to focus upon the positive aspects to her escape plan. In hindsight, I feel this intervention may have been confusing for my client. I seem to be reinforcing that one should escape from one's problems. Maybe a better intervention at this point might have been to explore the notion of 'escapism' and how this relates to both drink, drugs and relationships, based upon her recent responses.

Client 9: I've gone on anti-depressants. Yeah… that's an escape isn't it?

Sandra views taking any form of tablets as an escape. Taking drugs is being used to distract her from her pain once again.

Therapist 9: Hmm…

At this point I feel stuck! I seem not to be able to handle my earlier intervention of viewing escapism as a useful concept, as her method has been to take a drug! Thus, she has not broken one historical pattern.

Client 10: Dr. R. explained to me that… I would need… I would be off work for quite a long time. She thought I would be off work for quite a long time if I didn't use them, because she said you can get back to yourself… sort of function again… if you do them… I know they are not a relapse. I know I am still clean. I am using mind-altering substances… I guess anti-depressants *have* to be but they are being used… they are medically prescribed… I'm not using them…

This is confusing for my client. She explains to me how she is not "using" these prescribed drugs as she would the illicit drugs. She reinforces this concept to me and seems to be trying to convince herself of this too.

Therapist 10: That's right. There's a big difference between taking prescribed drugs and also it sounds like something very *positive.* This is something that is helping you in a positive way.

At this point I indicate to my client that indeed this is correct and that she has taken a positive choice in terms of helping herself, rather than ending her own life or attempting to "escape" by using illicit drugs.

Client 11: Yeah. And I talk to my sponsor a lot… my AA sponsor… I just done quite a big thing with her. I am on a 12-Step programme and I've just been writing my Step 4. It probably started before the time Daniel and I split up.

The process at this point is one of Sandra proving to me that she indeed has taken positive steps recently. In some ways, her "using" of her sponsor is quite different to how she engages in other types of relationship. Sandra has responded to my reflection about her taking positive action by telling me about her progression in AA.

Therapist 11: Ah huh…

A minimal encourager helps Sandra to continue to expand upon this important subject.

Client 12: That was all about my past and things that I was ashamed of or resentments I had against people. Putting it all down on paper…

With the benefit of hindsight, I can see that Sandra is indicating to me that opening up about difficult emotions has been beneficial to her, rather than defaulting to her usual dysfunctional pattern of distracting herself from these painful issues. I am interested in hearing more about her past, hypothesising at this point that other significant earlier relationships or some type of abuse had had a significant impact upon her development of self and ways of forming relationships with others later in life.

Therapist 12: Ah hmm…

A minimal encourager is used to indicate to Sandra that I am listening and wish for her to expand upon this issue further. .

Client 13: I could see that *I* was as much a part of it as anyone else and you know it was just nice… about my stepfather… and I just read it to my sponsor and it was kind of a really freeing thing and I was no longer walking around with the shame and the guilt and remorse of all those things.

Sandra is signalling to me that sharing difficult emotions with another person can indeed be helpful. She may be indicating at this point an unconscious wish to be able to do the same thing with me in our sessions. By my allowing her to continue talking about her past, Sandra has brought up a significant issue hinting at some type of abuse that she may have experienced at the hands of her step-father. This is an indication that our therapeutic alliance was strong enough for Sandra to trust me with talking about difficult and painful issues.

Therapist 13: A great burden has been lifted.

I paraphrase to allow Sandra to hear that I have understood her and share this important revelation that she made to her sponsor. My mind is racing at this point with questions as to what exactly happened in the past concerning her step-father, with an hypothesis that some type of abuse had occurred. However, I do not wish to pursue this further at this point, feeling that it may be too soon in our therapeutic relationship to delve too deep into distressing issues and emotions. However, this may also reflect my unconscious desire to avoid painful issues as a way of protecting Sandra. My avoidance of painful feelings might be reflective of Sandra's transference to seek out a "perfect" therapist in order to distract her, as other relationships have provided in the past.

Client 14: But at the same time that happened, just before I finished with Sean… my sponsor told me that once you've done Step 4 and 5 you won't accept second best again. You will know that you deserve the best. And I don't know what it is about it… but there was just something… something that just stuck in my mind that made me realise that … you know, this is an empty relationship… a memory. I don't…

Sandra indicates to me that her AA sponsor had influenced her feelings towards Sean, as well as carrying out the steps in the programme. At this point, my initial reaction was to feel in some ways that I had to live up to my client's high expectations in terms of being as influential and helpful as her sponsor had been.

Therapist 14: So you could have gone on and on but you decided to take a real… a real *change* in life. All the stuff you had learned about yourself through the 12-Step programme you had decided that you deserve the best or better.

I feel impelled to give Sandra some positive feedback about her positive actions with regards to making positive changes since discovering these suppressed emotions (i.e. Client responses 12 and 13).

Client 15: But this is kind of where I get stuck. Because you know… yes I left him… yes I am absolutely gutted that the relationship is finished. That it wasn't what I thought it was going to be. You know… and there's sort of a bit of me that is kind of positive about it and saying that, you know, that if you were meant to be together then you will be together and maybe this wasn't the right time. I kind of felt that now wasn't the right time but I just feel so vulnerable and so unsure of myself and trying… Oh, I don't know… And just feeling so negative about myself and kind of where my life's going and what am I about.

Sandra is making it clear to me that it may be too soon for positive praise in our sessions which I had provided in my last intervention. At this point she wishes me to understand that she is confused, vulnerable and feeling quite on the contrary, i.e. very negative about herself and her situation at the current time. Her realisation that the relationship she entered into with Sean had not fulfilled her fantasy of what it could have been like, was an indication to me of her need to seek out an escapism within relationships.

Therapist 15: Hmm…

I allow her the space to continue to talk about her confusion and negative feelings. I feel at this point that Sandra is asking for some space to reflect upon her feelings. Although she has indeed made positive progress, it is clear that Sandra is still in a relatively confused and negative state of mind and needs time to explore these issues more fully in therapy; this being only our first therapy session.

Client 16: I suppose in early years I was used to being around lots of people, drinking and taking drugs. But I kind of see that I always used my boyfriend's friends. I always went out in a group, but it was never a group of *my* friends.

By allowing her the opportunity to talk more openly, Sandra has begun to make in-roads in terms of gaining some possible insight into how and why she has entered into dysfunctional relationships in the past. She beings to talk about how she "uses" her boyfriends' friends, relating this to the culture of using drugs and alcohol. However, an important factor here is that these so-called friends were not in fact her own. Her relationship with them instead was very much the same as the one she had with drink and drugs themselves, that is, in some respect, superficial .

Therapist 16: It was always boyfriends' friends…

I focus upon this fact that her "friends" were not in fact her own, to encourage her to explore this point a little further, as I felt this was an important factor to consider.

Client 17: Yeah, or you know… occasionally I would work in a place where people were quite up for it and I would kind of hang out with them, but again they weren't really friends. They were people I worked with. I mean a couple of them – one girl and another girl – one girl in particular, Justine. We've stayed really good friends but… So I suppose maybe I was looking for a social life with Sean I certainly wasn't getting that. And then I was like, well maybe if I'd done this differently, or done that differently then…

Sandra expands upon this type of superficial relationship formation pattern, in that her social life has always revolved around people she was not true friends with, be this at work or with ex-partners.

Therapist 17: Hmm…

I allow her to continue as I do not wish at this point to make an interpretation, but to encourage her to stay on this issue which I felt was a significant one.

Client 18: Maybe I just need to get a social life of my own? I don't know…

My hypotheses here are that Sandra is using false friendships and intimate partnerships as a form of distraction, in the same way she was using drugs. However, the flip side to this is that her social life was not enjoyable because of this. Sandra, at this point, does not see the relationship between her use of drugs, drink, partnerships and friendships.

Therapist 18: It sounds all very confusing. It sounds like this juncture in your life, where you have made major changes, has been positive, but you have been left with all these questions about what you are about and the kind of things you enjoy and the types of friends you enjoy going out with… the types of things that make your life enjoyable.

My summary at this point of the session indicates to Sandra that I understand that despite all the positive changes she has made, there are negative aspects of her self which need to be addressed in future therapy sessions, which she is currently in some confusion about. By reiterating the major issues covered in our session thus far, I am inviting Sandra to talk about whichever issue is most important for her, taking a client-led approach in this assessment session, in order to strengthen our therapeutic alliance.

Client 19: Yeah… and I kind of… I didn't really understand what a healthy loving relationship was. I was seeing Daniel for three years on and off and we were so bad for each other. We completely abused each other. And I started … in the end when I was realising that this wasn't a great thing for me, and it wasn't working for me.

At last my client is beginning to see the "abusive" relationship she has engaged in within personal relationships and in terms of her drug-taking. Sandra sees at this point that it was not a good type of relationship for her personally to be involved in. She seems to be gaining some insight into this issue within our first session, with regards to recognising certain dysfunctional patterns in the way in which she tends to form different types of relationships with others, in a rather abusive fashion. This would be an issue for further exploration in future sessions, with respect to the link between this and her previous using behaviours with respect to her abuse of alcohol and drugs.

Chapter 13

Discussion

Through the former use of alcohol and drug taking, it is hypothesised that Sandra had been experiencing instant gratification and the subsequent loss of inhibition through the dampening effect upon the Super-ego (Fenichel, 1945). This provided her with a sense of well-being, which she found so difficult to gain through any other means. Having detoxified, she had become instead addicted to falling for "dream / fantasy" men, whom she centred her whole life around, and gained a sense of false well-being, security and warmth (Sander, 1926, 1933). She was always looking for the perfect man in the same way she used to rely on the "perfect drug" in order to protect her from difficult or painful feelings.

Sandra's Id impulse for instant gratification through previous drug and drink abuse was indicated during this session to still be a major factor (Badcock, 1988). By giving up the drink and drugs, she could no longer dampen the effects of the Superego or act upon unconscious wishes via such loss of inhibitions she used to experience (Fenichel, 1945). Concerning Sandra's former addiction to drugs and alcohol, following the work of Sander (1926), describing how this could be a way of satisfying archaic oral drives in order to feel a sense of security and increase one's sense of self-esteem, it is interesting to note that Sandra's need during this session was to gain a sense of security from the therapeutic relationship itself. This dependency and possible passivity within the therapeutic relationship would be an important issue to focus upon during subsequent therapy sessions in order to confirm this.

Through countertransference reactions, I found myself wanted to protect my client from some of her unbearable and painful feelings at times; to cocoon her and provide a holding environment, reminiscent of the pre-genital stage of instant gratification and proving a secure attachment. This follows Bowlby's (1977) theory concerning the role of the therapist in providing a 'secure base' for the client to develop a temporary attachment. Having broken off her last relationship, Sandra was experiencing a sense of loss of this somewhat false security and gratification, which had led to her feeling suicidal and needing to "escape". The therapeutic formulation and plan at this stage in therapy was to help Sandra to gain some insight and understanding into how she "uses" men and friends in much the same way as she used to use drugs and alcohol, in terms of looking for a means of escapism or sense of security. I felt this issue could be addressed in future sessions in terms of how she might begin to seek out gratification in more adaptive and functional ways other than through intimate dysfunctional relationships or by abusing illicit drugs or alcohol.

Through the escapism of using drink and drugs and associating with false friends, Sandra may have been presenting a "false-self" over her true "inner self" (Laing, 1960), which she may have found too painful to acknowledge or show to others. This may possibly have linked to earlier childhood abuse, which she had hinted at during the session, in terms of the development of an insecure or negative sense of self. Her "ideal self" or fantasy self differed markedly from her "actual self" (Joffe & Sandler, 1965) and this discrepancy had led to her experiencing psychic pain in the form of depression and more recently, suicidal ideation when she could no longer bear the pain of her actual self, having broken off her relationship with Sean. At that time she may have been experiencing a false ideal self (Merskey & Spear, 1967) due to her drug taking behaviour. These concepts would benefit from further exploration within future sessions to increase my client's awareness and understanding of herself.

Her strategy of communicating with others (Cashdan, 1981) was explored during the current therapy session and experienced within the therapeutic relationship itself in terms of my countertransference reactions. My countertransference was relatively strong during this initial session, and it manifested itself in terms of my desire to "save" Sandra at times, to help her distance herself from difficult and painful emotions, and potentially to fulfil the role of being the "perfect" therapist, in much the same way as she has tended to seek out the perfect drug or partner to help her cope with distressing feelings. Plans for future sessions was therefore to help my client to understand some of her maladaptive communication strategies, via the therapeutic relationship during our sessions, and to allow for more functional communication patterns to develop within and outside of the therapy room (Cashdan, 1981).

As Craib (2001) describes as an essential part of psychotherapy, my client was able to use the session usefully, by cathartically allowing herself to *feel* and express herself during this initial session. This was a result of our growing therapeutic alliance, which was fostering a sense of trust between Sandra and myself, so that she felt safe enough to express some difficult feelings and talk about distressing issues. This section of the first session may have illustrated the beginnings of a therapeutic process of individuation (Jung, 1964), as Sandra was starting to explore aspects of her self which she had the desire to change. Through a process of exploring the defence mechanisms she uses and the transference and countertransference reactions during this and future sessions, my therapeutic plan at this point was to help Sandra to achieve some kind of individuation through a process of self-discovery.

References

Badcock, C. (1988) *Essential Freud.* Oxford: Basil Blackwell.

Bowlby, J. (1969) *Attachment and Loss. Vol. 1: Attachment.* London: Hogarth Press and the Institute of Psychoanalysis.

Bowlby, J. (1973) *Attachment and Loss. Vol. 2: Separation.* London: Hogarth Press and the Institute of Psychoanalysis.

Bowlby, J. (1977) The making and breaking of affectional bonds. II. Some principles of psychotherapy. *British Journal of Psychiatry.* Vol. 130: 421-431.

Bowlby, J. (1980) *Attachment and Loss. Vol. 3: Loss, Sadness and Depression.* London: Hogarth Press and the Institute of Psychoanalysis.

Brown, D. & Pedder, J. (1991) *Introduction to Psychotherapy: An outline of Psychodynamic Principles and Practice.* 2nd Ed. NY: Routledge.

Chashdan, S. (1973) Interactional Psychotherapy: Stages and strategies in behavioural change. NY: Grune & Stratton.

Cashdan, S. (1981) Interactional Psychotherapy: Using the Relationship. In J. Anchin & D. Kiestev (Eds) *Handbook of Interpersonal Psychotherapy.* NY: Pergaunon.

Colllins, N. R. & Read, S. J. (1994). Representations of attachment: The structure and function of working models. In K. Bartholomew & D. Perlman (Eds) *Advances in Personal Relationships. Vol. 5: Attachment Process in Adulthood.* (pp 53-90). London: Jessica Kingsley Publishers.

Craib, I. (2001) *Psychoanalysis: a Critical Introduction.* UK: Blackwell.

Erikson, E. H. (1965) *Childhood and Society.* Harmondsworth: Penguin Books.

Fairbairn, W. R. D. (1952) *Psychoanalytic Studies of the Personality.* London: Routledge.

Fenichel, O. (1945) *The Psychoanalytic Theory of Neurosis.* NY: W. W. Norton & Co.

Fiscalini, J. (1994) The interpersonally unique and the uniquely interpersonal. *Contemporary Psychoanalysis.* Vol. 30: 114-134.

Freud, A. (1936) *The Ego and Mechanisms of Defence.* London: Hogarth Press.

Freud, S. (1923) *The Ego and the Id. Standard Edition of the Complete Psychological Works of Sigmund Freud. Vol 19.* London: Hogarth Press and the Institute of Psychoanalysis

Freud, S. (1973a) Anxiety and Instinctual Life. In *The Pelican Freud Library Vol. 2. New Introductory Lectures in Psychoanalysis.* Harmondsworth: Pelican.

Freud, S. (1985b) Group Psychology and the Analysis of the Ego. In *The Pelican Freud Library Vol. 12. Civilisation, Society and Religion..* Harmondsworth: Pelican.

Fromm-Reichmann, F. (1950) *Principles of Intensive Psychotherapy.* Chicago: University of Chicago Press.

Guntrip, H. (1961) *Personality Structure and Human Interaction.* London: Hogarth Press.

Hampson, J. L. & Hampson, J. G. (1961) The ontogenesis of sexual behaviour in man. In W. C. Young (Ed) *Sex and Internal Secretions.* London: Bailliere Tindall.

Hofer, M. A. (1995) Hidden regulators: Implications for a new understanding of attachment, separation and loss. In S. Goldberg, R. Muir, & J. Kerr (Eds) *Attachment Theory: Social, Developmental and Clinical Perspectives.* (pp 203-230). Hillsdale, NJ: The Analytic Press Inc.

Joffe, W. G. & Sandler, J. (1965) Notes on pain, depression and individuation. *The Psychoanalytic Study of the Child.* Vol. 20: 394-424.

Jung, C. G (Ed) (1964) *Man and his Symbols.* London: Aldus Books.

Laing, R. D. (1960) *The Divided Self.* London: Tavistock Publications.

Lieberman, A. F. & Pawl, J. H. (1990) Disorders of attachment and secure base behavior in the second year of life: Conceptual issues and clinical intervention. In M. T. Greenberg, D. Cicchetti & E. M. Cummings (Eds). *Attachment in the Preschool Years* (pp 375-398) Chicago: University of Chicago Press.

Maher, M. S., Pine, F. & Bergman, A. (1975) *The Psychological Birth of the Human Infant.* London: Hutchinson.

Merskey, H. & Spear, F. G. (1967) The concept of pain. *Journal of Psychosomatic Research.* Vol. 11: 59-67

Sander, R. (1933) The psychoanalysis of pharmacothymia. *Psychoanalytic Quarterly.* Vol. 2.

Sedgwick, D. (2001) *An introduction to Jungian Psychotherapy: The Therapeutic Relationship.* UK: Brunner-Routledge.

Sroufe, L. A. (1996) *Emotional Development: The Organization of Emotional Life in the Early Years.* NY: Cambridge University Press.

Winnicott, D. W. (1965) *The Maturational Processes and the Facilitating Environment: Studies in the Theory of Emotional Development.* London: Hogarth.

SECTION E: CRITICAL LITERATURE REVIEW

The Use of Cognitive-Behavioural Therapy to Treat Chronic Fatigue Syndrome: A Critical Literature Review

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Critical Literature Review submitted in partial fulfilment of
the requirements for the degree of Practitioner Doctorate
in Counselling Psychology

(D Couns Psych)

London Metropolitan University

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Chapter 14

Introduction

Chronic Fatigue Syndrome (CFS), also known as myalgic encephalomyelitis (ME) is used to describe the condition characterised by significant levels of fatigue lasting over six months in duration, accompanied by a significant level of physical and mental disability. The symptoms of the syndrome are not explained by any underlying physical disease, but may include a sore throat, tender lymph nodes, muscle pain, multi-joint pain, unrefreshing sleep, and post-exertional malaise lasting for more than 24 hours (Holmes, Kaplan, Gantz, Komaroff, Schonberger, Strauss et al., 1988; Sharpe, Archard, Banatvala, Borysiewicz, Clare, David et al., 1991). The nature and aetiology of CFS remains controversial (Wessely, 1991) due to the fact that there is a general lack of an agreed pathology, spanning both medical and psychiatric explanations for the symptoms and treatment of the condition (Afari & Buchwald, 2003; Sharpe, 2005). Treatment for CFS currently centres around physical therapies, such as graded exercise and pacing of activity, as well as drug therapy, typically in terms of antidepressant medication, and psychological therapy in the form of cognitive-behavioural therapy (CBT), which is the recommended treatment for CFS in the UK (CFS/ME Working Group Report, 2002). However, currently there is little systematic evidence for the effectiveness of these treatments, and none have been generally accepted as a 'cure' for the condition (Wilson, Hickie, Lloyd, Hadzi-Pavlovic, Boughton, Dwyer & Wakefield, 1994a).

This literature review will explore the models of CBT which have been proposed for the treatment of CFS, critically evaluating the advantages and shortcomings of this particular approach. Suggestions are made to improve upon the current CBT models of CFS, in conjunction with other therapies, and recommendations are made to address the gaps in the current research literature. The review will focus upon the CBT approach to CFS is divided into six sections:

1. The Clinical Presentation of CFS
2. CBT models of CFS
3. Psychological and Psychiatric Co-morbidity in CFS
4. Severe Presentations of CFS
5. Psychosocial and Developmental Issues in CFS
6. Conclusions

This critical literature review recommends that a pure CBT approach to patient care is inadequate in terms of explaining and addressing CFS patients' often complex psychological needs.

14.1 The Clinical Presentation of CFS

CFS occurs in adults and to a lesser extent in children and adolescents (Jordan, Landis, Downey, Osterman, Thurm & Jason, 1998), with predominance within females between the ages of 30 and 40 years (Jason, Richman, Rademaker, Jordan, Plioplys, Taylor, McCready, Huang & Plioplys, 1999; Steele, Dobbins, Fukuda, Reyes, Randall, Koppelman & Reeves, 1998). Patients describe the onset of the illness as having been abrupt, and as having had excellent pre-illness fitness and energy levels (MacDonald, Osterholm, LeDell, White, Schenck, Chao, Persing, Johnson, Barker & Peterson, 1996). The symptoms of CFS are described as being close to those of the 'flu (Salit, 1997) with the additional complaints of intolerance or sensitivity to light, noise, alcohol and other drugs, as well as dizziness, night sweats and nausea (Komaroff, Fagioli, Geiger, Doolittle, Lee, Kornish, Gleit & Guerriero, 1996).

There is some weak evidence to suggest that there may be a genetic influence upon the development of the condition (Buchwald, Herrell, Ashton, Belcourt, Schmaling & Goldberg, 2001). However, more research is required to rule out the effects of possible environmental issues which may interplay with predisposing hereditary factors. Research has found some correlation between immune system functioning and the perceived impairment associated with CFS (Cruess, Klimas, Antoni, Helder, Maher, Keller & Fletcher, 2000). However, there are no immunological diagnostic tests currently available to confirm CFS and improvement in patients' symptoms does not correlate with any detectable immune system alteration (Peakman, Deale, Field, Mahalingam & Wessely, 1997; Strober, 1994). Despite the fact that many patients report the onset of their CFS as having developed after a virus, such as glandular fever, there is no clinical evidence to support that CFS is caused by an infection (Hotopf & Wessely, 1994).

Patients report that even minor attempts at physical activity can lead to a significant worsening of their fatigue and other CFS symptoms and therefore excessive rest is often used to cope with the condition (Vercoulen, Swanink, Galama, Fennis, Jongen, Hommes, van der Meer & Bleijenberg, 1998). As a consequence of developing CFS, patients experience significant decreases in social contacts (Sharpe et al., 1991) and many people leave work or school for a period of time in order to try to recover (Bombardier & Buchwald, 1996). CFS patients are less physically active than comparison control groups and tend to take longer rest periods after activity peaks. This reduced level of activity is thought to contribute to the ongoing symptoms of CFS via a process of muscular deconditioning (Van der Werf, Prins, Vercoulen, van der Meer & Bleijenberg, 2000), which can serve to perpetuate the symptoms of muscle pain and weakness.

With regards to the CFS patient population, those with the condition are frequently reluctant to consider the role for psychological factors in the onset and perpetuation of their illness, as this brings into question the element of personal responsibility in terms of the onset and perpetuation of CFS (Ware, 1992). Instead, many CFS sufferers believe that their illness is due to an underlying disease mechanism, despite the current lack of medical evidence supporting this. Indeed, patients who attribute failure and incapacity to physical disease, rather than psychological factors, are able to maintain a more positive self-view (Powell, Dolan & Wessely, 1990), which may contribute to the adherence of such a belief system. However, viewing CFS as being due to an underlying medical reason is also associated with greater disability (Sharpe & Bass, 1992) and predicts a worse outcome in treatment programmes (Wilson et al., 1994a). This may suggest that patients' perceptions of their illness may affect their physical experiences of CFS and have a profound influence upon its maintenance. Psychological interventions therefore are required to address patients' own perceptions of their illness in order to effect any true change.

14.2 CBT Models of CFS

In an attempt to overcome the debate between the medical and psychological explanations for CFS, treatment has centred around identifying and altering the factors which perpetuate the symptoms of the condition. This has led to the development of treatment programmes aiming to alter the physical and psychological factors contributing to CFS via the use of CBT (Wessely, David, Butler & Chalder, 1989). CBT aims to expose the client's overt cognitions, emotions and behaviours and how these interplay, as well as the underlying dysfunctional cognitions or core beliefs which maintain the client's difficulties (Persons, 1989), which is represented diagrammatically below (*Fig. 14.1*).

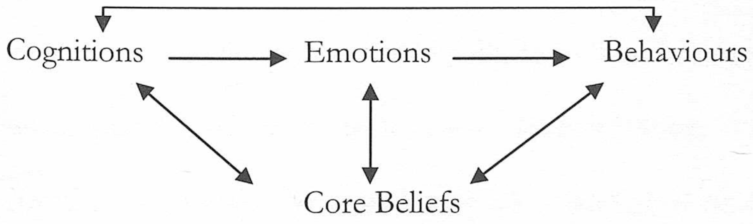

Fig. 14.1 Persons' (1989) model of client difficulties

It is theorised that early negative experiences, such as dysfunctional relationships with others, can lead to the formation of early maladaptive schemas (Young, 1990). These schemas act as templates for the processing of experiences, so that in times of stress or in response to a significant event, these underlying negative schemas are activated, which instils and maintains cognitive, emotional and behavioural dysfunction. Common dysfunctional thought processes identified by Burns (1980) include all-or-nothing thinking, over-generalisation, personalisation, automatic discounting and jumping to conclusions, which can maintain patients' symptoms, and these are described in further detail below. Cognitive therapy (Beck et al., 1979) aims to help clients become aware of their maladaptive interpretations of events which may be contributing to their current levels of distress and dysfunction, in order to ameliorate their effects and reduce the client's depression or anxiety.

The CBT model proposed by Wessely et al. (1989) suggests that the patient's beliefs in having a physical disease, their consequential inactivity and underlying depressive disorder all interact to perpetuate the condition (*Fig. 14.2*). The model suggests that the attribution of symptoms to physical disease leads patients to become inactive, which exacerbates the depressive elements of the condition and contributes to muscle wasting which then perpetuates the symptoms of CFS, depicted below as a vicious cycle. This paper is helpful in explaining the maintenance of patients' illnesses due to the interaction between their non-activity and negative thinking styles. A firm belief in one's condition as being due to a medical cause is likely to promote feelings of helplessness and reliance upon a medical "cure" for CFS, which currently does not exist. However, this CBT model has some shortcomings, in that it does not adequately explain the large variety of clinical features of CFS, as well as the onset of the condition. The unacceptability of the model to many CFS patients has also led to a high treatment refusal rate (Butler et al., 1994). In order for a CBT model of treatment to be effective therefore, it must appeal to patients as an acceptable and valid form of treatment, and take into consideration the complexity of CFS with respect to the attributions regarding its onset, maintenance and the possibility for recovery. The Wessely model therefore seems a little too simplistic to encompass all factors relating to the syndrome and its treatment.

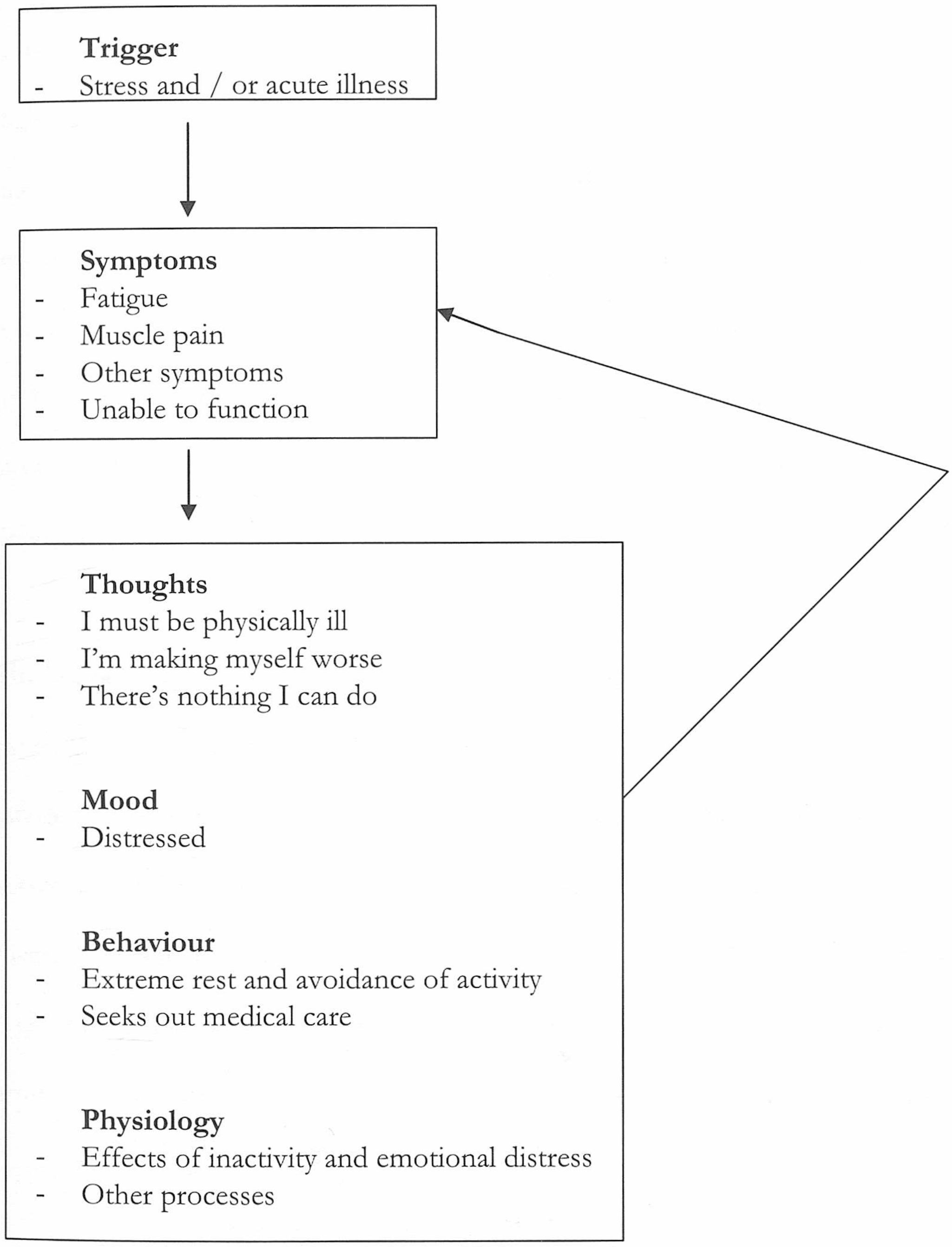

Fig. 14.2 Cognitive Behavioural model of CFS (Wessely et al. 1989)

Building upon this early model proposed by Wessely et al. (1989), Surawy, Hackmann, Hawton & Sharpe (1995) have suggested an alternative, more complex, CBT approach to CFS, based upon observations concerning the typical characteristics of patients who present with chronic fatigue. This model explains how certain life stressors can precipitate the onset of CFS and suggest how cognitive, behavioural, physiological and social factors may interact to perpetuate the illness (*Fig. 14.3*). This model assumes that patients are predisposed psychologically to develop CFS in response to a life stressor, such as following a virus. Dysfunctional underlying assumptions and schemas typically held by patients are that personal achievement and having high standards underlies their self-worth and the respect of others. The failure to meet such high expectations is associated with feelings of rejection and perceived as a sign of personal weakness. This would include the ability to achieve under pressure or in circumstances of incapacity, such as when suffering from an illness. The model proposes that patients therefore try harder to meet their targets despite increasing levels of exhaustion when faced with a life stressor. When this strategy fails, the person enters a state of chronic fatigue, frustration and demoralisation.

This model suggests that patients, when ill, will continue to strive to meet targets and expectations, which serve only to perpetuate the symptoms of CFS. The repeated experience of failure to function at a pre-illness level and a fear of exacerbating the condition through activity serves to reinforce patients' views that they are suffering from an incurable disease and causes further emotional distress. The model proposes that the condition is perpetuated in a vicious cycle, alternating between bursts of activity and ineffectual rest, and maintained by the attribution of symptoms to an underlying medical disease and fear of failure to perform.

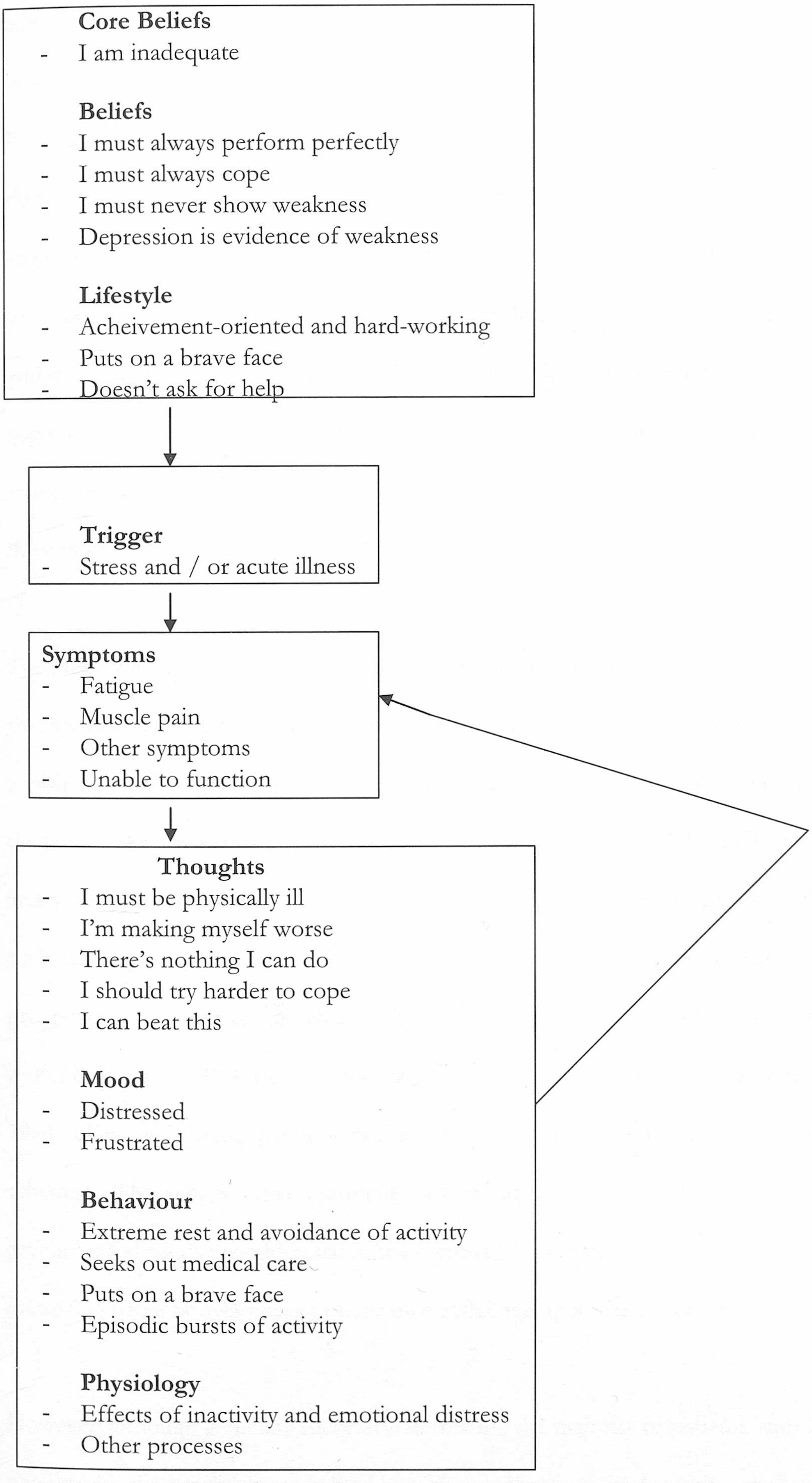

Fig. 14.3 Cognitive Behavioural model of CFS (Surawy et al., 1995)

Surawy et al. (1995) propose that the therapist and client must develop a good therapeutic relationship in order to be able to engage the patient in a successful CBT treatment programme. Patients are encouraged to become more aware of the interactions between their behaviour, their dysfunctional cognitions and core beliefs concerning their illness, their mood and physical symptoms. Patients are advised to use 'activity scheduling' to reduce the number of oscillations between activity and rest, and to strive for attainable goals, rather than unrealistic and over-ambitious aims. Thought diaries are used to help patients understand the influence of their cognitions upon their activity levels and experience of symptoms. Behavioural experiments seek to increase activity levels and provide evidence on which patients can question their beliefs about the nature of their illness.

The Suwary et al. (1995) model takes into account some of the underlying dysfunctional schemas that are held by CFS patients which makes them more susceptible to developing CFS and explains how their condition is maintained by these fuelling dysfunctional negative beliefs about the illness. This is a clear improvement upon the earlier CBT models of CFS which had not taken into account some of the underlying personality characteristics of susceptible patients, such as a fear of failure and perfectionism. There is evidence to suggest that such CBT programmes of treatment are indeed effective for some people with CFS (Bonner, Ron, Chalder, Butler & Wessely, 1994; Butler, Chalder, Ron & Wessely, 1991; Wessely, Hotopf & Sharpe, 1998), by way of altering patients' dysfunctional assumptions and challenging their negative schemas. This suggests that treatment for CFS can be successful when patients' emotional and psychological needs are addressed in the context of the symptoms of the illness, thereby increasing patients' awareness of their own influence upon the condition.

However, although generally successful in treating the majority of patients with CFS, not all people with the condition are helped by CBT interventions, and this review seeks to uncover some of the reasons for this. A more recent study conducted by Prins, Bazelmans, van der

Werf, van der Meer & Bleijenberg (2002) examined the specific predictors of treatment outcome for patients with CFS undergoing CBT. They found that patients who were described as "passively active" prior to undergoing treatment failed to improve during CBT treatment. This mirrors the results of a similar investigation conducted by Prins, Bleijenberg, Bazelmans, Elving, de Boo, Severens, van der Wilt, Spinhoven & van der Meer (2001) which showed that CBT was only effective as a treatment for those patients who were moderately active at the time of engaging in the programme. These studies suggest that in order for CBT programmes to be useful in treating patients with CFS, they must address the underlying cognitive schemas relating specifically to a fear of activity during illness. It can be assumed that patients who hold strong beliefs about activity being harmful to them in the context of their CFS, will fare worse in terms of treatment outcome. If this is not addressed within a psychological model of treatment, then a proportion of patients will fail to make improvements in their condition.

CFS patients tend to make somatic attributions for common everyday symptoms, such as headaches or tiredness and are less likely to make psychological attributions for symptoms (Dendy, Cooper & Sharpe, 2001; Watson, Kapur, Arguelles, Goldberg, Schmidt, Armitage & Buchwald, 2003). CBT models are not currently addressing this issue, given the results of studies such as Sharpe & Bass (1992) and Wilson et al. (1994a). In fact, the preference for attributing common symptoms to physical factors, rather than to psychological or environmental issues was found to be the most important risk factor for developing CFS following a viral illness (Cope, David, Pelosi & Mann, 1994). Spence & Moss-Morris (2006) in a prospective study of CFS, found that patients were more likely to develop the condition post-virally if they were more distressed by the effects of the virus and believed they had little control over the illness. Similarly, Candy, Chalder, Cleare, Peakman, Skowera, Wessely, Weinman, Zuckerman & Hotopf (2003) found that the belief that symptoms would last a long time and that the illness had serious consequences were predictive of the development of ongoing CFS. In terms of coping with CFS, patients who demonstrate highly exaggerated expectations about their illness, in terms of the likely consequences of pushing themselves beyond their current physical state, were more disabled and fatigued than patients who did not catastrophise (Petrie, Moss-Morris & Weinman, 1995). For those patients who are able to address their dysfunctional belief systems regarding exercise tolerance and activity levels, there is a good outcome when undergoing a CBT treatment programme (Deale et al., 1997). However, for those who hold extreme fixed beliefs about their ability to perform tasks and activities, the outcome is much poorer. CBT treatment programmes therefore must take into consideration some of the underlying psychological factors, such as dysfunctional attributional styles, which have contributed to the onset and maintenance of patients' CFS symptoms. If these are not adequately addressed by CBT treatment programmes then patients will fail to make improvements in their physical health. CBT models of treatment currently do not address these significant issues.

A neglected area within the existing research literature and in the CBT models proposed for treating CFS is that of understanding how patients cope with their emotions. One study has highlighted the fact that CFS patients tend to demonstrate a defensive highly anxious style of dealing with emotions when compared to healthy controls or other chronically ill patients (Cresswell & Chalder, 2001). The way in which a defensive coping style might contribute to the symptoms of CFS must be explored further in future research in order for it to be incorporated into the CBT models of treatment for CFS. Currently, this is lacking in proposed models of CBT for CFS. The results of Cresswell & Chalder (2001) suggest that the unique anxious style of coping emotionally when confronted by illness in the CFS patient population would be best explored and challenged within a CBT treatment model.

Cresswell & Chalder (2001) suggest that more qualitative research in CFS would be useful to understand patients' experiences of their condition, in order that CBT models could then incorporate such data. This would inform current models of therapy and treatment. However, only a handful of studies exist which have taken such a qualitative approach to explore patients' experiences of CFS (Asbring, 2001; Clarke & James, 2003; Whitehead, in press). One interesting current study (Whitehead, in press) shows that patients undergo a transformation in self-identity throughout the temporal course of the illness, and this process is termed, "identity reconstruction". During the 'acute phase' of the illness, patients described feeling totally disabled by the constraints of the condition and many adopted the "traditional sick role". Over time patients reconstructed their identity in relation to the changes the condition had made to their lives, e.g. having to give up work and coping with a debilitated body. The outcome of this study confirms the concept of "loss of self" that can often occur as a result of developing a chronic illness (Charmaz, 1983; Fontana & Smith,1989). Similarly, Asbring (2001) describes the struggle women with CFS experience when striving for their "former identities" after becoming unwell, but that "these attempts often failed and disappointment then followed" (p. 317). Identity transformation was affected by the changes to patients' lifestyles following the development of CFS, particularly in terms of their social life and occupation. These studies suggest that CBT models of therapy might be more beneficial to patients if they included issues of identity and its transformation in relation to CFS and the lifestyle alterations which can occur as a result of the condition. More qualitative and exploratory research is clearly required in order to corroborate the findings of the above studies, and provide further evidence to enhance treatment programmes. Currently, the proposed CBT models do not take into consideration such phenomenological data regarding identity transformation even though this issue might be quite significant for many patients, especially those who have been living with the condition for some time and those who have progressed from childhood through to adolescence or adulthood with the condition.

Butler, Chalder & Wessely (1991) investigated the effectiveness of CBT in a sample of 50 patients fulfilling the diagnostic criteria for CFS. Of those patients who did not improve at all, or who fared worse after treatment, most had been suffering with a concurrent affective disorder alongside CFS. These patients also tended to attribute their illness to physical causes. This suggests that the CBT model used had not addressed this important factor adequately during treatment. More importantly, this study has highlighted the requirement to adapt CBT programmes so that they encompass the impact of co-morbid factors, such as depression, anxiety or other forms of affective disorder. If these issues are not taken into consideration, then CBT treatment for CFS can be ineffectual for some patients who are not "pure" CFS patients with no other psychological co-morbidity. Whether the co-morbid factors should be addressed prior to treatment of CFS or vice versa, or whether the two conditions could be treated in tandem is unknown at this point due to lack of research within this area.

The CBT model proposed by Surawy et al. (1995) has been tested using a randomised control trial (Sharpe, Hawton, Simkin, Surawy, Hackmann, Klimes, Peto, Warrell & Seagroatt, 1996). It was demonstrated that CBT is more effective as a treatment for CFS than medical treatment alone. However, the participant sample did not include patients who also had a diagnosis of depression, thus ensuring an homogenous sample of "pure" CFS patients. This may have contributed to a higher success rate with CBT treatment than demonstrated by Butler et al. (1991). The difficulty however with this is that co-morbidity rates of CFS with affective disorders are reasonably high within the CFS patient population. The criteria for inclusion into CBT studies therefore may be unrepresentative of the normal CFS population requiring treatment. The effect of psychological and psychiatric co-morbidity will therefore now be explored in order to address this issue in relation to CBT models of treatment.

14.3 Psychological and Psychiatric Co-morbidity in CFS

Hickie, Lloyd, Wakefield & Parker (1990) investigated the psychiatric status of CFS patients and found that nearly half of the sample reported having had a major depressive episode during the course of their illness and that 12.5% had reported having suffered from major depression prior to the onset of CFS. Additionally, CFS patients were found to suffer from high rates of anxiety, demonstrated by nearly a third of all the participants involved in the study. A study carried out to screen for the prevalence rates of psychiatric disorders in CFS revealed that 35% of the patients investigated had a current psychiatric disorder and that there was an 82% lifetime prevalence rate of psychiatric disorder (Buchwald, Pearlman, Kith, Katon & Schmaling, 1997). Post-traumatic Stress Disorder (PTSD) has also been found to occur in higher rates within the CFS patient population as compared to the general population (Taylor & Jason, 2002). A review by Afari & Buchwald (2003) suggests that 50% to 75% of all CFS patients have a current or lifetime history of major depression (Katon, Buchwald, Simon, Russo & Mease, 1991; Wessely, Chalder, Hirsch, Wallace & Wright 1996; Wessely & Powell, 1989; Manu, Matthews & Lane, 1989; Wood, Bentall, Gopfert & Edwards, 1991). Generalised anxiety disorder is more prevalent within the CFS patients as compared to the general population and other medical control groups (Fischler, Cluydts, DeGucht, Kaufman & DeMeirleir, 1997; Wessely et al., 1996). The results of the above review and of Hickie et al. (1990) suggest that CBT models of CFS must include and address the impact and possible interaction of co-morbid affective disorders upon the maintenance of this condition, which is not currently addressed within the classic CBT models of treatment. Given that co-morbidity within the patient population is so high in some cases, it would suggest that these factors would need to be incorporated within either CBT models of treatment or addressed within other types of therapeutic intervention.

Additionally, the current exclusion criteria for CFS as defined by the Centers for Disease Control and Prevention (CDC) (Holmes et al., 1988; Fukuda, Straus & Hickie and the International Chronic Fatigue Case Definition Study Group, 1994) include the co-morbid psychological disorders of psychosis, substance-related disorders, bipolar depression, anorexia nervosa and bulimia nervosa. There is no exclusion however with regards to patients presenting with CFS who have other psychiatric disorders, such as generalised anxiety disorder, obsessive-compulsive disorder or personality disorder. As a result, patients who may present with psychiatric co-morbidity alongside a diagnosis of CFS may not be receiving adequate treatment with respect to their CFS symptoms, as the current CBT models of treatment are clearly inadequate to address such issues. This may explain some of the treatment failure rates for this client population in the studies discussed above.

In order to address some of the more complex psychological issues in CFS, psychodynamic approaches to treating CFS patients have been proposed by both Taerk & Gnam (1998) and Curkx, van Houdenhove & Neerinckx (1994). Taking a psychoanalytic approach to therapy, Taerk & Gnam (1998) describe the therapy of two CFS patients in terms of object relations, particularly within the transference. A reduction in symptoms occurred as a result of the development and understanding of this relationship. Curkx et al. (1994), in their treatment of a CFS patient with a history of childhood abuse and personality disorder, described how psychodynamic oriented therapy was essential in terms of addressing this client's complex difficulties within the context of a multidisciplinary inpatient environment. Curkx et al. (1994) suggest that taking a purely CBT approach to treating a patient such as this would not have been as successful as combining different approaches, both psychological and physical; in this case, providing psychodynamic oriented psychotherapy with physical rehabilitation alongside cognitive behavioural group therapy. However, this paper is a case study of only one CFS patient and generalisations from this can only be extremely tentative.

In summary, it is clear that co-morbidity with other psychological and psychiatric disorders is not currently addressed in the CBT models of treatment for CFS. Other forms of psychological therapy might benefit such patients, such as psychodynamic psychotherapy, alongside the traditional CBT treatment programmes. More research however must be carried out to expand upon this theory.

An additional problem is that most CBT studies have been conducted with CFS outpatients and do not include the more severe presentations of CFS, despite the fact that a proportion of patients are so severely affected that they are bed-bound and may require hospitalisation (Deale, Chalder, Marks & Wessely, 1997; Sharpe et al. 1996; Vercoulen et al., 1996; Wilson, Hickie, Lloyd & Wakefield, 1994). This issue will now be addressed.

14.4 Severe Presentations of CFS

To date, only four studies exist which have investigated the treatment of severely affected adult CFS patients within an inpatient setting (Chalder, Butler & Wessely, 1996; Cox, 2002; Cox & Findley, 2000; Essame, Phelan, Aggett & White, 1998). All four studies found that there were some improvements in terms of patients' functional abilities and fatigue levels post-treatment. Cox & Findley (2000) investigated the multidisciplinary approach to treating the most severely affected patients based upon a CBT framework, including occupational therapy "lifestyle management" (Christiansen & Baum, 1997a; Creek, 1997; Wilson et al, 1994), which involves grading and pacing of activity. Patients were divided into four categories according to their level of disability (Cox, 1998; Cox & Findley, 1998), from Grade 1 where patients were able to self-care and manage light tasks, through to Grade 4, describing those patients who were so severely affected that they were unable to mobilise or carry out any daily task for themselves and who were in bed for the majority of the time. These patients were often those who were intolerant to any noise and were generally extremely sensitive to light. The patients who were most severely affected stayed in hospital for up to 26 weeks of intensive treatment, with an average treatment period of just 7 weeks and showed some improvement in terms of their symptoms over this time period, although not a full recovery.

The patients within this study had been diagnosed with CFS for approximately 6 years, which is significantly longer than patients who have been included in all the other studies outlined above. Patients with a shorter duration of symptoms have been shown to be more likely to improve than those presenting with a longer duration (Vercoulen et al., 1996), suggesting that the more severe a patient's presentation, the more time-consuming a treatment programme might have to be in order to address the complexity of their CFS which may have developed over time.

Indeed, Essame et al. (1998) have suggested, following their pilot study of a multidisciplinary inpatient rehabilitation programme for severely incapacitated patients, that, "an 8 week admission to help a 6 year illness with severe disability can only be an introduction to change" (p. 57).

Despite the relatively short period of treatment available to the more severely affected patients, Cox & Findley (2000) suggest that an inpatient programme can still be helpful. Cox (2002) in a follow-up study suggests that patients who had received inpatient input perceived themselves as being more in control of their symptoms, felt they were managing their condition better and were less fatigued than prior to treatment. This suggests that inpatient programmes for the most severely affected CFS patients can be of some use in increasing patients' control over their condition. However, the multidisciplinary team which treated the patients in these studies did not include a psychologist, and the CBT techniques employed by the team were carried out by occupational therapists with only limited skills in psychological therapy, with an emphasis on graded activity and pacing as well as medical interventions as the mainstay treatment. In order to assess the impact of CBT for the most severely affected CFS patient population, therefore, future investigations would need to incorporate a dedicated psychological CBT approach as an adjunct to the work carried out by occupational therapists and other professionals within the multidisciplinary team, sharing a specialised CBT framework. The length of treatment programme would also need to be increased from 7 weeks to a more substantial period of time in order to adequately address these patients' complex needs. Future research with the most severely affected CFS patients would require changes to the design and research methodology, with patients being randomised to treatment groups, rather than using convenience sampling, as utilised by the above studies. A difficulty with interpreting the results of the Cox & Findley (2000) study is the fact that patient stays within the hospital for treatment were largely dependent upon the availability of funding from patients' Primary Care Trusts, rather than necessarily as a result of their clinical improvement in some cases. This would need to be controlled for within future research studies examining this inpatient population in order to provide a more substantial evidence base for CBT practice with this subset of severely disabled patients.

CFS patients who require hospital admissions for treatment are likely to have more complex needs to those who can cope with outpatient therapy (National Task Force on CFS/ME, 1998). CBT models of treatment therefore need to encompass the complex needs of the more severely affected bed-bound CFS patients, which they currently fail to do, and this may explain the poorer outcomes within the inpatient research studies. Current CBT models do not explain how patients move from mild to moderate to severe disability and additionally do not provide a clear basis for treatment interventions with the more severely affected, often bed-bound, patients. Additionally, in order for CBT models to address the complex nature of CFS patients, they must also incorporate into them some of the more recent psychological research that has been carried out in this area, such as the psychosocial and developmental issues which can occur in CFS, particularly within the more severely affected patient population. This is now explored in more detail.

14.5 Psychosocial and Developmental Issues in CFS

The psychosocial impact of CFS has been poorly investigated, with only a handful of research studies focusing upon the interaction between the patient and their social system. One study which has looked at relatives' perceptions of CFS, showed that they tended to attribute the patients' symptoms to physical causes (Butler, Chalder & Wessely, 2001), which reflects the results of patients' own attributional styles discussed above. Mirroring the outcome of Butler et al. (2001), in their study of partners' beliefs and attributional styles in CFS, Garralda & Rangel (2001) demonstrated that families of children with CFS also have an enhanced tendency to believe in the presence of an underlying disease causation, despite the lack of medical evidence to suggest this. This persists even after the child's recovery, which suggests there may be enduring dysfunctional health beliefs within the families of children with CFS. Additionally, a study which looked at childhood onset of CFS revealed that parental mental distress and emotional over-involvement with the child is more marked in this illness as compared to other paediatric disorders (Rangel, Garralda, Jeffs & Rose, 2005). It has been suggested that parental over-involvement in the child's health may contribute by reinforcing the illness, and thus help to perpetuate the symptoms of CFS in childhood (Brace, Scott Smith, McCauley & Sherry, 2000; Rangel et al., 2005). It is clear that current models of CBT fail to address the significance of the patient's social system in terms of its onset and perpetuation of the condition, which is a serious downfall in this approach to CFS.

Additionally, patients' own perceptions of symptoms correlates to how they interact socially with others, with patients who see themselves as more physically incapacitated by their CFS withdrawing from their usual social contexts (Heijmans, 1998; Moss-Morris, Petrie & Weinman, 1996). The complex social impact of CFS is not currently addressed within CBT models, and this may be due to the lack of evidence-based research within this particular area. However, it may be beneficial to include in CBT models the impact of certain social interactions, in terms of how this can affect the patient's CFS. Particularly in the case of childhood CFS, family interventions have been recommended and a recent study conducted by Chalder, Tong & Deary (2002) has demonstrated that family-based CBT interventions can indeed improve levels of fatigue in children with CFS. However, this study took a psychoeducational approach in terms of helping parents to understand the nature of CFS and the usefulness of a CBT programme, rather than addressing some of the psychosocial issues raised by Rangel et al. (2005) or Brace et al. (2000) in terms of specific family dynamics which may be contributing factors to the child's CFS.

Lacking from the current models of CBT for CFS are the potentially significant developmental factors which can arise when a child or adolescent has CFS. These may include a disruption to the normal individuation process and separation from parents, particularly when parental anxiety and dependency upon them by their child is high (e.g. Garralder & Chalder, 2005). For instance, the child may be isolated from their peers due to a decrease in participation within social activities due to the impact of their illness. This is particularly so in the case of a child who has to be taken out of school because of the level of their disability. When the child is removed from their normal social environment and activities for some time, it may impede their abilities to manage the developmental stressors of childhood and adolescence. As a result, they may not be able to adequately manage normal social relationships as well as their peers and their school work may deteriorate, leading to emotional difficulties, such as feelings of failure, loss of confidence or a general feeling of being "left behind" (Garralder & Chalder, 2005).

A simple CBT model of CFS is clearly not adequate in terms of addressing such complex psychosocial issues as those described above, regarding the impact of the family dynamic upon the patient, the social isolation which may occur, and the developmental milestones which may be impeded by the condition. It may be that more family-focused work, which takes a systemic approach to treatment, might be more appropriate for some of the most severely affected patients, especially when they have been almost entirely dependent upon their parents for many years for their personal care and emotional needs.

14.6 Conclusions

This critical review of the literature has highlighted both the advantages and pitfalls of using a CBT approach in treating CFS. The current CBT models of treatment do not encompass all of the psychological factors which are relevant to patients with CFS, such as patients' dysfunctional attributional styles with regard to their perception of the onset and maintenance of their illness, and typically unhelpful emotional coping styles demonstrated by patients. In order for therapy to be effective, it must appeal to patients as an acceptable and valid form of treatment. The therapist should take into consideration patients' views about psychological approaches to the treatment of CFS, especially with regard to those patients who use somatic attributions for their condition, as this can lead to patients dropping out of therapy or the treatment failing to be effective (Butler, Chalder & Wessely, 1991). Those patients who are more passively active at the outset of therapy fare worse in CBT therapy, and this may be due to their dysfunctional cognitions regarding activity in CFS. CBT models of treatment must therefore focus upon addressing those underlying cognitions regarding the consequences of being active whilst suffering from this condition. The controversy which surrounds CFS regarding whether it is indeed a true medical disease or more psychosomatic in nature, may have a large impact upon patients' abilities to engage well in therapy. Indeed, currently in the UK there is a large proportion of patients who campaign within "anti-psychiatric" patient organisations that CFS should be viewed as a purely medical disease which requires solely a medical treatment programme, discounting any requirement for psychological or psychiatric input (e.g. ME Action UK). It is clear to see that patients holding such views would not be open to psychological treatment programmes such as CBT, and this could explain some of the treatment failure rates found within the literature noted above. It would be wise therefore for psychological practitioners to explore these issues with patients prior to treatment so that the interplay between the mind and body can be explored and acknowledged as significant within this particular condition, as it often is with other long-term health conditions (Charmaz, 1983).

In those cases of patients presenting with a history of childhood trauma or complex personality issues, on the basis of this critical review, it is recommended that a pure CBT model may not be successful as a standalone treatment. Instead, other psychological approaches, such as psychodynamic therapy, combined with more traditional methods of treatment may be required (Cuykx et al., 1994). Given that there is a high percentage of psychiatric co-morbidity within the CFS population, unless this is specifically addressed in conjunction with the symptoms of CFS, then simple CBT for CFS treatment will be not be beneficial to patients. More research is required to explore the specific interaction between psychiatric disorders and CFS symptoms, and treatment programmes could then be adapted to encompass these relatively common complexities within the patient population, rather than allowing CBT to be unsuccessful for a large proportion of CFS sufferers.

One area in which a pure CBT model fares the least well when applied alone, is when severely or very severely affected CFS patients are treated. In these cases, it has been suggested that inpatient multidisciplinary approaches are most beneficial. In these instances, other psychological approaches might be helpful in terms of addressing the complex nature of the patient's presentation alongside traditional CBT models. This would serve to address some of the psychosocial and developmental issues which assert a significant impact upon some patients, particularly those who have been severely affected throughout their childhood, adolescence and early adulthood. CBT approaches combined with systemic family therapy might be more appropriate for these patients, so that important psychosocial, family dynamic and developmental issues can be addressed in relation to the patient's CFS. Future research within this area would provide an evidence base for treatment for this subset of severely affected patients, especially with respect to the factors underlying the transition from being a well individual through to a person who is wholly incapacitated.

In summary, although the CBT approach to CFS has been shown to be an effective treatment for many patients, the current models proposed would benefit from some adjustment in order to address some of the wider psychological issues common to CFS patients. Therapists would be wise to explore patients' views regarding their diagnosis in terms of their beliefs about how they developed CFS and their possible biases towards a medical underlying cause over any psychological factors. CBT may be most beneficial in conjunction with other therapies to address some of the more complex psychiatric, psychological, psychosocial and developmental issues which can occur in some patients, particularly those who are severely or very severely affected.

Afari, N. & Buchwald, D. (2003). Chronic fatigue syndrome: A review. *American Journal of Psychiatry*. Vol. 160, pp. 221-236.

Asbring, P. (2001). Chronic illness – a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*. Vol. 34, pp. 312-319.

Beck, A. T., Rush, A. J., Shaw, B. F.& Emery, G. (1979) *Cognitive Therapy of Depression*. New York: Wiley.

Bombardier, C. H. & Buchwald, D. (1996). Chronic fatigue syndrome and fibromyalgia: disability and health-care use. *Medical Care*. Vol. 34, pp. 364-370.

Bonner, D., Ron, M., Chalder, T., Butler, S., & Wessely, S. (1994). *Chronic fatigue syndrome: a follow-up study*. Vol. 57, pp. 617-621.

Brace, M. J., Scott Smith, M., McCauley, E. & Sherry, D. D. (2000). Family reinforcement of illness behavior: A comparison of adolescents with chronic fatigue syndrome, juvenile arthritis and health controls. *Developmental and Behavioural Pediatrics*. Vol. 21, pp. 332-339.

Buchwald, D., Herrell, R., Ashton, S., Belcourt, M., Schmaling, K. & Goldberg, J. (2001). A twin study of chronic fatigue. *Psychosomatic Medicine*. Vol. 63, pp. 936-943.

Buchwald, D., Pearlman, T., Kith, P., Katon, W. & Schmaling, K. (1997). Screening for psychiatric disorders in chronic fatigue and chronic fatigue syndrome. *Journal of Psychosomatic Research*. Vol. 42, pp. 87-94.

Burns, D. (1980) *Feeling Good: the New Mood Therapy*. New York: New American Library.

Butler, S., Chalder, T., Ron, M., & Wessely, S. (1991). Cognitive behaviour therapy in chronic fatigue syndrome. *Journal of Neurology, Neurosurgery and Psychiatry*. Vol. 54, pp. 153-158.

Butler, S., Chalder, T., Ron, M., & Wessely, S. (2001). Causal attributions for somatic sensations in patients with chronic fatigue syndrome and their partners. *Psychological Medicine*. Vol. 31, pp. 97-105.

Candy, B., Chalder, T., Cleare, A. J., Peakman, A., Skowera, A., Wessely, S., Weinman, J., Zuckerman M. & Hotopf, M. (2003). Predictors of fatigue following the onset of infectious mononucleosis. *Psychological Medicine*. Vol. 33, pp. 847-855.

CFS/ME Working Group Report (2002). A report of the CFS/ME working group: report to the Chief Medical Officer of an independent working group. London: Department of Health.

Chalder, T., Butler, S. & Wessely, S. (1996). Inpatient treatment of chronic fatigue syndrome. *Behavioural and Cognitive Psychotherapy*. Vol. 24, pp. 351-365.

Chalder, T., Tong, J. & Deary, V. (2002) Family cognitive behaviour therapy for chronic fatigue syndrome: an uncontrolled study. *Archives of Disease in Childhood*. Vol. 86, pp. 95-97.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness.* Vol. 5, pp. 168-195.

Christiansen, C. & Baum, C. (1997a). Understanding occupation: definitions and concepts. In *Occupational Therapy: Enabling function and well being.* C. Christiansen & C. Baum (Eds). 2nd Edition. NJ: Slack International.

Clarke, J. N. & James, S. (2003). The radicalized self: the impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science and Medicine.* Vol. 57, pp. 1387-1395.

Cope, H., David, A., Pelosi, A. & Mann, A. (1994). Predictors of chronic "postviral" fatigue. *Lancet.* Vol. 344, pp. 864-868.

Cox, D. L. (1998). Management of CFS: development and evaluation of a service. *British Journal of Therapy and Rehabilitation.* Vol. 5, pp. 205-209.

Cox, D. L. & Findley, L. J. (1998). The management of chronic fatigue syndrome in an inpatient setting: presentation of an approach and perceived outcome. *The British Journal of Occupational Therapy.* Vol. 61, pp. 405-409.

Cox, D. L. & Findley, L. J. (2000). Severe and very severe patients with chronic fatigue syndrome: perceived outcome following an inpatient programme. *Journal of Chronic Fatigue Syndrome.* Vol. 7, pp. 33-47.

Creek, J. (1997). *Occupational Therapy and Mental Health.* Edinburgh:
Churchill Livingstine.

Cresswell, C. & Chalder, T. (2001). Defensive coping styles in chronic fatigue syndrome. *Journal Psychosomatic Research.* Vol. 51, pp. 607-610.

Cruess, S. E., Klimas, N., Antoni, M. H., Helder, L., Maher, K., Keller, R. & Fletcher, M. A. (2000). Immunologic status correlates with severity of physical symptoms and perceived illness burden in chronic fatigue syndrome patients. *Journal of Chronic Fatigue Syndrome.* Vol. 7, pp. 39-52.

Cuykx, V., Van Houdenhove, B. & Neerinckx, E. (1994). *General Hospital Psychiatry.* Vol. 20, pp. 382-384.

Deale, A., Chalder, T., Marks, I. & Wessely, S. (1997) Cognitive behaviour therapy for chronic fatigue syndrome: a randomised control trial. *American Journal of Psychiatry.* Vol. 154, pp. 408-414.

Dendy, C., Cooper, M. & Sharpe, M. (2001) Interpretation of symptoms in chronic fatigue syndrome. *Behaviour Research and Therapy.* Vol. 39, pp. 1369-1380.

Essame, C. S., Phelan, S., Aggett, P. & White, P. D. (1998). Pilot study of a multidisciplinary inpatient rehabilitation of severely incapacitated patients with chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome.* Vol. 4, pp. 51-60.

Fischler, B., Cluydts, R., DeGucht, V., Kaufman, L. & DeMeirleir, K. (1997). Generalised anxiety disorder in chronic fatigue syndrome. *Acta Psychiatrica Scandanavica.* Vol. 95, pp. 405-413.

Fontana, A. & Smith, R. W. (1989). Alzheimer's disease victims: the unbecoming of self and the normalisation of competence. *Sociological Perspectives.* Vol. 32, pp.35-46.

Fukuda, K., Straus, S. E. & Hickie, I. and the International Chronic Fatigue Case Definition Study Group (1994) A comprehensive approach to its definition and study. *Annals of International Medicine.* Vol. 21, pp. 953-959.

Garralderm, M. E. & Chalder, T (2005). Practitioner review: chronic fatigue syndrome in childhood. *Journal of Child Psychology and Psychiatry.* Vol. 46, pp. 1143-1151.

Garralda, M. E. & Rangel, L. A. (2001). Health attitudes in chronic fatigue syndrome of childhood. *American Journal of Psychiatry.* Vol. 158. pp. 1611.

Heijmans, M. J. W. M. (1998). Coping and adaptive outcome in chronic fatigue syndrome: importance of illness cognitions. *Journal of Psychosomatic Research.* Vol. 45, pp. 39-51.

Hickie, I., Lloyd, A., Wakefield, D. & Parker, G. (1990). The psychiatric status of patients with the chronic fatigue syndrome. *British Journal of Psychiatry.* Vol. 156, pp. 534-540.

Holmes, G. P., Kaplan, J. E., Gantz, N. M., Komaroff, A. L., Schonberger, L. B., Strauss, S. E., et al. (1988). Chronic fatigue syndrome: A working case definition. *Annals of International Medicine.* Vol. 108, pp. 387-389.

Hotopf, M. H. & Wessely, S. (1994). Viruses, neurosis and fatigue. *Journal of Psychosomatic Research.* Vol. 38, pp. 499-514.

Jason, L. A., Richman, J. A., Rademaker, A. W., Jordan, K. M., Plioplys, A. V., Taylor, R. R., McCready, W., Huang, C. F., & Plioplys, S. (1999). A community-based study of chronic fatigue syndrome. *Archives of International Medicine.* Vol. 159, pp. 2129-2137.

Jordan, K. M., Landis, D. A., Downey, M. C., Osterman, S. L, Thurm, A. E., & Jason, L. A. (1998). Chronic fatigue syndrome in children and adolescents: a review. *Journal of Adolescent Health.* Vol. 22, pp. 4-18.

Katon, W. J., Buchwald, D., Simon, G., Russo, J. E. & Mease, P. J. (1991). Psychiatric illness in patients with chronic fatigue and those with rheumatoid arthritis. *Journal of General International Medicine.* Vol. 6, pp. 277-285.

Komaroff, A. L, Fagioli, L. R., Geiger, A. M., Doolittle, T. H, Lee, J., Kornish, R. J., Gleit, M. A. & Guerriero, R. T. (1996). An examination of the working case definition of chronic fatigue syndrome. *American Journal of Medicine.* Vol. 100, pp. 56-64.

MacDonald, K. L., Osterholm, M. T., LeDell, K. H., White, K. E., Schenck, C. H., Chao, C. C., Persing, D. H., Johnson, R. C., Barker, J. M. & Peterson, P. K. (1996). A case-control strudy to assess possible triggers and cofactors in chronic fatigue syndrome. *American Journal of Medicine.* Vol. 100, pp. 548-554.

Manu, P., Matthews, D. A. & Lane, T. J. (1989). Depression among patients with a chief complaint of chronic fatigue. *Journal of Affective Disorders.* Vol. 17, pp. 165-172.

Moss-Morris, R., Petrie, K. J. & Weinman, J. (1996). Functioning in chronic fatigue syndrome: do illness perceptions play a regulatory role? *British Journal of Health Psychology.* Vol. 1, pp.15-25.

National Task Force on CFS/ME (1998). NHS services for people with chronic fatigue syndrome / myalgic encephalomyelitis. Bristol.

Peakman, M., Deale, A., Field, R., Mahalingam, M. & Wessely, S (1997). Clinical improvement in chronic fatigue syndrome is not associated with lymphocyte subsets of function or activation. *Clinical Immunology and Immunopathology.* Vol. 82, pp. 83-91.

Persons, J. B. (1989) *Cognitive Therapy in Practice: a Case Formulation Approach.* New York: Norton.

Petrie, K., Moss-Morris, R. & Weinman, J. (1995). The impact of catastrophic beliefs on functioning in chronic fatigue syndrome. *Journal of Psychosomatic Research.* Vol. 39, pp. 31-37.

Powell, R., Dolan, R., & Wessely, S. (1990). Attributions and self-esteem in depression and chronic fatigue syndromes. *Journal of Psychosomatic Research.* Vol. 34, pp. 665-673.

Prins, J. B., Bazelmans, E., van der Werf, S., van der Meer, J. W. M. & Bleijenberg, G. (2002). Cognitive behaviour therapy for chronic fatigue syndrome: predictors of treatment outcome. *International Congress Series.* Vol. 1241, pp. 131-135.

Prins, J. B., Bleijenberg, G., Bazelmans, E., Elving, de Boo, T. M., Severens, J. L., van der Wilt, G. J., Spinhoven, P. & van der Meer, J. W. N. (2001). Cognitive behaviour therapy for chronic fatigue syndrome: a multicentre randomised controlled trial. *The Lancet.* Vol. 357, pp. 841-847.

Rangel, L. A., Garralda, M. E, Jeffs, J. & Rose, G. (2005). Family health and characteristics in chronic fatigue syndrome, juvenile arthritis and emotional disorders of childhood. *Journal of the American Academy of Child and Adolescent Psychiatry.* Vol. 44, pp. 150-158.

Salit, I. E. (1997). Precipitating factors for the chronic fatigue syndrome. *Journal of Psychiatry Research.* Vol. 31, pp. 59-65.

Sharpe. M. C. (2005). Psychiatric diagnosis and chronic fatigue syndrome: Controversies and conflicts. *Journal of Mental Health.* Vol. 14. pp. 269-276.

Sharpe, M. C., Archard, L. C., Banatvala, J. E., Borysiewicz, L. K., Clare, A. W., David, A. S. et al. (1991). A report – chronic fatigue syndrome: Guidelines for research. *Journal of the Royal Society of Medicine.* Vol. 84, pp. 118-121.

Sharpe, M. C. & Bass, C. (1992). Pathophysiological mechanisms in somatization. *International Reviews in Psychiatry.* Vol. 4, pp. 81-97.

Sharpe, M., Hawton, K., Simkin, S., Surawy, C., Hackmann, A., Klimes, I., Peto, T., Warrell, D. & Seagroatt, V. (1996). Cognitive behaviour therapy for the chronic fatigue syndrome: a randomised controlled trial.

Spence, M. & Moss-Morris, R. (2006) To "lump" or to "split" the functional somatic syndromes: can infectious and emotional risk factors differentiate between the onset of chronic fatigue syndrome and irritable bowel syndrome? *Psychosomatic Medicine.* Vol. 68, pp. 463-469.

Steele, L., Dobbins, J. G., Fukuda, K., Reyes, K., Randall, B., Koppelman, M. & Reeves, W. C. (1998). The epidemiology of chronic fatigue in San Francisco. *American Journal of Medicine.* Vol. 105, pp. 835-905.

Strober, W. (1994). Immunological functioning in chronic fatigue syndrome. In *Chronic Fatigue Syndrome.* S. E. Strauss (Ed). NY: Marcel Dekker. pp 207-237.

Surawy, C., Hackmann, A., Hawton, K. & Sharpe, M. (1995). Chronic fatigue syndrome: a cognitive approach. *Behavioural Research Therapy.* Vol. 33, pp. 535-544.

Taerk, G. & Gnam, W. (1998) A psychodynamic view of the chronic fatigue syndrome. The role of object relations in etiology and treatment. *General Hospital Psychiatry.* Vol. 16, pp. 319-325.

Taylor, R. R. & Jason, L. A. (2002) Chronic fatigue, abuse-related traumatization, and psychiatric disorders in a community-based sample. *Social Science in Medicine.* Vol. 55, pp. 247-256.

Van der Werf, S., Prins, J. B., Vercoulen, J. H. M. M., van der Meer, J. W. M. & Bleijenberg, G. (2000). Identifying physical activity patterns in chronic fatigue syndrome using actigraphic assessment. *Journal of Psychosomatic Research.* Vol. 49, pp. 373-379.

Vercoulen, J. H., Swanink, C. M., Galama, J. M, Fennis, J. F., Jongen, P. J., Hommes, O. R., van der Meer, J. W. & Bleijenberg, G. (1998). The persistence of fatigue in chronic fatigue syndrome and multiple sclerosis: development of a model. *Journal of Psychosomatic Research.* Vol. 45, pp. 507-517.

Ware, N. C. (1992). Suffering and the social construction of illness: the deligitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly.* Vol. 6, pp. 347-361.

Watson, N. F., Kapur, V., Arguelles, L. M., Goldberg, J., Schmidt, D. F., Armitage, R. & Buchwald, D. (2003). Comparison of subjective and objective measures of insomnia in monozygotic twins discordant for chronic fatigue syndrome. *Sleep.* Vol. 26, pp. 324-328.

Wessely, S. (1991). Chronic fatigue syndrome. *Journal of Neurology, Neurosurgery and Psychiatry.* Vol. 54, pp. 669-671.

Wessely, S., Chalder, T., Hirsch, S., Wallace, P. & Wright, D. (1996). Psychological symptoms, somatic symptoms and psychiatric disorder in chronic fatigue and chronic fatigue syndrome: a prospective study in the primary care setting. *American Journal of Psychiatry.* Vol. 153, pp. 1050-1059.

Wessely, S., David, A. S., Butler, S. & Chalder, T. (1989). Management of chronic (post-viral) fatigue syndrome. *Journal of the Royal College of General Practitioners.* Vol. 39, pp. 26-29.

Wessely, S., Hotopf, M., & Sharpe, M. (1998). *Chronic Fatigue and its Syndromes.* Oxford: Oxford University Press.

Wessely, S. & Powell, R. (1989). Fatigue syndromes: a comparison of chronic "postviral" fatigue with neuromuscular and affective disorders. *Journal of Neurology, Neurosurgery & Psychiatry.* Vol. 52, pp. 940-948.

Whitehead, L. (in press). Toward a trajectory of identity reconstruction in chronic fatigue syndrome / myalgic encephalomyelitis: A longitudinal qualitative study. *International Journal of Nursing Studies.*

Wilson, A., Hickie, I., Lloyd, A., Hadzi-Pavlovic, D., Boughton, C., Dwyer, J. & Wakefield, D. (1994a). Longitudinal study of outcome of chronic fatigue syndrome. *British Medical Journal.* Vol. 308, pp. 756-759.

Wood, G. C., Bentall, R. P., Gopfert, M. & Edwards, R. H. T. (1991). A comparative assessment of patients with chronic fatigue syndrome and muscle disease. *Psychological Medicine.* Vol. 21, pp. 618-628.

Young, J. (1990) *Cognitive Therapy for Personality Disorders: a Schema Focussed Approach.* Sarrasota, FL: Professional Resource Exchange.

SECTION F:

A Reflexive Commentary on my Doctoral Journey

Alice E. Green

Submitted in partial fulfilment of the requirements for the
degree of Practitioner Doctorate in Counselling Psychology

(D Couns Psych)

London Metropolitan University

July 2007

Chapter 15

A Reflexive Commentary on my Doctoral Journey

15.1 Introduction

The profession of Counselling Psychology demands one to be a scientist practitioner who is reflexive in their approach to carrying out therapy and in undertaking research. This final section of the thesis therefore aims to explore my personal reflections as both a therapist and researcher throughout my doctoral journey. The reflexive commentary will focus mainly upon my experiences of conducting the research component but will also cover the other sections of my portfolio, with regards to my experiences of devising, carrying out, writing up and presenting my doctoral thesis.

This Section is divided into 5 parts. These are:

15.2 Section B: Research
15.3 Section C: Case Study
15.4 Section D: Process Report
15.5 Section E: Critical Literature Review
15.6 Concluding Remarks

14.2 Section B: Research - The Experience of Being Newly Diagnosed with Parkinson's Disease: An Interpretative Phenomenological Analysis"

The main body of my doctoral thesis is devoted to the research study within the field of Parkinson's Disease (PD), and this section focuses upon my experience of carrying out this piece of work, spanning its history from conception through to its completion and dissemination of the results. I reflect also upon the consequences this has had upon me as a Counselling Psychologist.

When I initially began my professional training in Counselling Psychology, I had the notion that at some point within my career and studies I would undertake a practitioner doctorate in counselling psychology. The idea that I could contribute to the scientific literature encouraged me to make this a reality, and at the end of my Chartership training I applied to undertake the doctorate programme. My work up until that point had been within the NHS, working as a Counselling Psychologist in both Primary Care and Tertiary Care within the field of Mental Health. My career path altered considerably as a result of carrying out my research, taking a turn from pure mental health into the domain of Health Psychology.

The decision to carry out research into PD resulted from a personal connection to this illness. My father was diagnosed with the condition approximately 7 years ago and as a daughter to someone with PD, I understood some of the psychological consequences this could have upon the family. Being involved myself within the PD community, and having conversed with other families affected by the illness, I knew that it would be a worthwhile endeavour to carry out psychological research within this area. A preliminary research literature review revealed a relatively sparse amount of academic research within the area of psychology and PD. This, combined with a lack of specific practicing guidelines for those working with PD patients within a psychological context was the impetus for choosing the research topic. During the entire process of carrying out my research, I have reflected upon my personal reasons for choosing this subject area. At this point, at the end of my doctoral journey, I can conclude that from a personal perspective I have had a need to confront some of my own issues with regards to my father having PD, with regards to my own fears, concerns and the need for a deeper understanding of the condition from a psychological perspective. In retrospect, I feel this has indeed allowed me to do this. But more than this, it has been a vehicle for professional growth. By carrying out the research and disseminating my findings to the wider scientific, academic and patient communities it has given me the opportunity to influence patient care, and promote further research and discussion within the area of psychological care in PD.

This practitioner doctorate has had the effect of putting me in a unique position as a scientist practitioner. At various times during the doctoral journey I have taken on various guises, reflective of the different roles that were involved in the research process. Firstly, being a member of the PD family community, my personal insights to the disease from an emotional perspective allowed me to develop a strong level of enthusiasm and tenacity in carrying out the doctorate. Additionally, rather like a Venn diagram, this position overlapped somewhat with the other roles I had to varying degrees; these being both an academic researcher and a Counselling Psychologist, with the latter two positions sharing the most similarities with one another. As a result, the research has required me to be reflexive at all points of the study so as not to allow one role to mask another in a way which would result in possible negative bias or neglect. For instance, when interviewing the participants, I was aware that my personal experience of PD might influence the outcomes of the interviews due to the questions that I asked or the interpretative analysis that followed. Being aware of this and being reflexive at each stage of the research process allowed me to control for these factors, as best I could, and perhaps understand the study better as a result.

Interpretative phenomenological analysis (IPA) was chosen as the most appropriate research and analysis tool for this study. Indeed, an integral part of the process of IPA requires the researcher to be self-reflexive in terms of eliciting emergent themes and significant data. My chosen area of research required a methodology and analysis tool which took into consideration the exploratory nature of my study, due to its novelty within the extant research literature. The research design demanded a "bottom-up" and qualitative approach in order to elicit rich and meaningful "new" data. Therefore, the study was best suited to a phenomenological approach and IPA was deemed the most fitting tool to use because of its dynamic and interpretative quality, which other qualitative tools might have failed to fulfil as well, such as content analysis or grounded theory. The exploratory nature of my study would not have been justified by use of a predetermined quantitative approach due to the lack of prior knowledge within this area of psychology. An explorative open-ended questionnaire study would also not have been as useful as a form of data collection or analysis, again due to the predetermined nature of the possible research questions, which would have elicited only a subsection of the data gained from using IPA. The dynamic and interpretative stance that IPA took seemed most relevant for this particular study and took into consideration the relationship between myself as the researcher, my relationship with the participants and the data elicited during the interview process as well as during the detailed analysis phase. This would not have been the case had I used a different "bottom-up" approach, such as grounded theory for instance.

The use of IPA was extremely useful in terms of fitting the research methodology around the participants in order to elicit the most important data, due to its dynamic nature and interpretative stance. However, the interviews themselves raised several issues for me as a research psychologist. One of the main difficulties I experienced whilst carrying out this research was in terms of preserving certain boundaries at the different stages of the study. As stated earlier, the research topic had some personal significance to me and therefore I felt it was important to maintain a high level of open-mindedness with regards to the emergent data in terms of data collection and analysis. It was important for me to be self-reflexive at all times during these periods also, so as not to compromise or bias the data. However, it was also helpful to make it known to the participants that my father was living with the condition. This, I found in many cases helped to create a more relaxed environment during the interview sessions and some participants related to me that they felt more at ease discussing their own situation with me for this reason, rather than if I had had no personal experience of what it is like to live with PD. With regards to the choice of interview questions, I reviewed the existing literature with respect to areas of possible relevance for the participants involved in my study. My personal experience of PD in terms of living with the illness within my family and my contact with other people with the condition impacted also upon the selection of initial questions. However, as the interviews progressed from one participant to another, the questions I asked changed according to the data that emerged during the interview process, as recommended when using IPA.

I was aware that my own contact with PD, in terms of knowledge, experience or emotional reactions, could in some cases confound the data in terms of its elicitation during the interview stage or my interpretation at the analysis phase. It was for this reason that during the interviews I remained inwardly self-reflexive, constantly checking my own emotional or cognitive reactions, in order to allow the participant to talk as freely as possible. As a result, the interview questions evolved over time, to take into consideration emergent themes that I had not pre-empted or expected. On reflection, at times this was extremely difficult. For instance, during the first interview the participant became very upset to the extent that at one point she became silent and cried, clearly expressing a deep emotional reaction in response to some of my questions. As a Counselling Psychologist, I felt a great empathy with her; as a daughter of a person with PD, I too felt deep sorrow and angst at that point. Being aware of these nuances with regards to my own emotional reactions allowed me to handle the situation in hand professionally and ethically. Additionally, in many cases the boundaries between my role as a Counselling Psychologist and that of a research psychologist were challenged during the interviews. Many of the interviews were emotionally charged and my therapy skills were indeed necessary at times in order to contain strong emotions within the interview setting. Having a career background within mental health and crisis intervention helped me as a researcher, as my skills were honed to providing a safe environment in which participants could explore their emotions openly. I used supervision to talk through these boundary issues and my own emotional reactions to the interviews, due to its significance and possible impact upon the conduction of further interviews and then the later data analysis.

I have explored the possible difficulties that being personally involved in one's research topic can have upon data collection and analysis. However, there were many benefits to this also. As well as the participants feeling possibly more at ease with me during the interviews as a result of my personal connection with PD, my own understanding of each interviewee may have been richer than if I had had no prior experience of PD myself. For instance, when participants spoke about the diagnostics and treatment of the condition or their struggles to cope practically with the consequences of the illness, I was able to relate to this myself. This may have helped me in terms of promoting the natural flow of the interview and asking relevant follow-up questions. Another benefit of being personally involved in the research topic was the fact that it fuelled my enthusiasm for keeping on track with my doctorate in terms of meeting certain deadlines, and with regards to the development of a personal sense of satisfaction that my research interviews were in many cases helping participants explore their psychological reactions to the situation they found themselves in, which was fed back to me in many cases as being beneficial.

My personal involvement in the study also gave me the impetus to disseminate my results and highlight for discussion other parts of the research process to various different audiences during the course of the study. This included at the outset, presenting my research proposal to a Trust-wide NHS research and development open day, and discussing the project with a local group for PD patients and their carers. Once I had my preliminary results I presented these to the 7th National Annual IPA conference and was able to carry out a workshop and focus group at the Parkinson's Disease Society open day at the University of London. Nearer the end stage of my analysis and write up I presented a poster at an NHS research and development conference, for which I won a prize. These events in themselves provided me with deadlines to work towards and satisfaction at their completion, and further fuelled my enthusiasm towards completing my thesis on time. In terms of my professional development, these events have helped me mature as a research psychologist and increased my levels of confidence with regards to public speaking.

Having personal involvement in the study has also provided me with the drive to communicate my results to the wider academic community in order to help effect change within hospitals and clinics for practitioners who work with PD patients. To this end, I plan to publish aspects of my study within scientific journals, with the aim to communicate my results not only to fellow Counselling Psychologists, but also to other medical staff who are involved in the care of PD patients, such as within the field of neurology, with the hope that future research will build upon the current study. Having begun my doctoral research, I decided to take a different direction in terms of my career, and moved from a mental health team to a position working as a psychologist within a neurology department. In this way I hope to help influence the availability of psychological interventions for PD patients, at least within the NHS Trust I am employed by. To this end, I have published a summary of my findings within an acute hospitals Trust-wide research and development magazine, and hope to disseminate my results to a wider audience in the future.

15.3 Section C: Case Study - Binge Eating Disorder and Childhood Sexual Abuse: Working within a Cognitive-Behavioural Therapy Framework

"Sarah" had been one of the most clinically interesting client cases I had worked up until that time during the course of my training. As a result, the case provided me with a valuable learning tool upon which I could develop as a practitioner with future complex clients. At the time I was working within a 24 hours a day, 365 days per year mental health service which catered for clients with severe or enduring mental health problems in crisis. My client work within that service provided me with experience of working with people suffering from a host of different mental health issues and approximately 60% of the clients referred to me for psychological counselling presented with suicidal ideation. Clinical supervision was crucial within this role, and I presented this case for peer supervision as well as discussing it with my manager in one-to-one meetings.

Sarah had presented as a lady with a binge eating disorder, with a history of childhood sexual abuse and relationship issues which had resulted in her having a rather poor self-image in adulthood and a susceptibility for suicidal ideation. She was assessed by myself and a community psychiatric nurse colleague from within the crisis team. It was agreed that she would be suitable for psychological counselling and at its cessation to be referred on to a more specialist service to deal specifically with her eating disorder. In the past, Sarah had received cognitive behavioural therapy (CBT) and reported that she had found this helpful. It was agreed that we would embark upon a course of CBT to focus upon her suicidal feelings as well as her eating disorder. Evidence-based practice suggested that CBT could be useful for both these problems and therefore I proceeded to work within such a framework with Sarah's consent. The CBT model was outlined to Sarah at the initial therapy session to gauge her suitability for this type of therapy. My interactions with her within the first session seemed to suggest that CBT would be most appropriate for her, rather than a more exploratory psychodynamic therapy or systemic therapy.

The therapeutic relationship that was cultivated during the course of therapy, I felt, was absolutely fundamental in terms of the improvements Sarah was able to make over the weeks she attended for therapy. Although at times I felt the complexity of her issues overwhelming, especially at the start of therapy, I worked in a self-reflexive way in order to diminish the likelihood of my own issues as a practitioner inhibiting the progress of therapeutic change in my client. Supervision was invaluable for this reason and gave rise to my viewing this case as an opportunity for personal and professional growth. The therapeutic alliance remained strong throughout the course of therapy, from the initial session through to after we had finished therapy. An example of this was when Sarah contacted me for advice and support on two occasions after the cessation of therapy. Although therapy had officially ended, the therapeutic alliance and bond remained so that Sarah had felt comfortable enough to re-engage for some telephone support some 6 months post-therapy, as a "top up" from within the crisis team.

The team offered brief crisis therapy to clients and Sarah was offered a course of 12 sessions, which was the maximum amount of therapy allowed within the boundaries of the service. Although at the outset of therapy I felt this to be too short a time to help Sarah to a significant level, I was proven somewhat to the contrary when she began to make good progress over a relatively short amount of time. This may have been due to the strong therapeutic alliance we had developed over the course of therapy. Additionally, over time my work within the crisis team proved to me that this was often the case, so that short-term therapy could indeed make positive and significant changes to clients presenting with mental health crises. This may have been due to the multidisciplinary make up of the team which provided a 24 hour "life-line" or "safety-net" to clients. That is, the nature of the supportive relationship open to clients referred to the service was an integral and fundamental part of their scope for recovery.

As a result of this case study I felt my practice as a Counselling Psychologist improved in terms of how I might work with a similar complex case in the future, especially when involving issues of childhood sexual abuse or binge eating. The significance of developing a trusting therapeutic bond with a client has been proven to me in this case to be an essential and fundamental part of therapy.

15.4 Section D: Process Report - "Addicted to Love? Psychodynamic Therapy in the Context of Addiction"

As with the case study, my work with "Sandra" provided me with an opportunity to develop my skills as a practitioner and reflect upon the processes of therapeutic change, especially with regards to the importance of the therapeutic alliance. The psychodynamic framework allowed for an in-depth analysis of the transference and countertransference that occurred during our therapy sessions. Again, clinical supervision was vital in terms of allowing me the reflective space to enhance the progression of therapy with Sandra, and to increase my awareness of the important dynamics within that therapeutic relationship.

Writing the process report and the reflexiveness required to do so within its preparation and during the viva process, has proved to be a valuable tool for me in terms of improving my clinical practice and my professional development. By focusing upon the nuances of the therapy and the dynamics within this initial session, my awareness developed regarding how the therapy progressed over time on a microlevel, rather than on a macrolevel as demonstrated by the case study. This process report served as a useful adjunct to the formal clinical supervision I received at the time. During the viva itself I explored further significant factors which may have impacted upon the process of therapy during this particular session. This included aspects of my countertransference which may have fed into the dynamic of therapy and contributed to Sandra's apparent neediness within this session. The "allure" of working with a rather needy client, as a practitioner with possible unconscious desires to be "needed", perhaps contributed to this particular dynamic within the therapy. This had potentially strong consequences with regards to the progression of therapy, given Sandra's somewhat "addictive" personality. It was clear during the process of analysis of this first session that Sandra was looking to find the perfect solution from myself as her therapist, as another "perfect drug" substitute. In this case, the viva itself was a forum for further discussion to promote my skills and knowledge for future client work, as an adjunct to my clinical supervision and the analysis itself contained with the process report.

15.5 Section E: Critical Literature Review - "The Use of Cognitive-Behavioural Therapy to treat Chronic Fatigue Syndrome: A Critical Literature Review"

The decision to write my extended essay on the topic of Chronic Fatigue Syndrome (CFS) was based upon my experience of working within a dedicated CFS team as the sole psychologist within that service. My role involves working with both inpatients and outpatients presenting with a diagnosis of CFS within a national service. NICE guidelines call for evidence-based practice with CFS patients, suggesting that CBT is the treatment of choice. My role within the multidisciplinary team allowed me the experience of working within such a CBT framework, with varied outcomes depending upon the nature of client presentation and degree of disability. I was therefore interested in critically reviewing the existing literature to examine the basis for such guidelines and to explore possible alternatives within an evidence-based framework.

The impetus for embarking upon this critical literature review was in terms of my experience of working with certain CFS patients who either did not respond well to CBT or where CBT was deemed wholly inappropriate to their needs. For instance, many of the inpatients within the CFS unit presented with co-morbid psychological factors such as eating disorders, personality disorders or complex family issues. Additional factors regarding patient recovery within my own experience centred around therapy being conducted around the bedside space on an open hospital ward, and the involvement of family members in treatment sessions or post-discharge. This particular service is the only one in the UK to treat extremely severe cases of CFS, and so I had the opportunity to work with a minority subgroup of patients with the condition. Despite an extensive review of the research, relatively very few studies have focused upon the more severely disabled patient group, which may have reflected the lack of specific guidance from NICE in terms of the therapeutic interventions appropriate to this client group. Instead, CBT is suggested as the treatment of choice for all CFS patients.

Additionally, having worked for some time within the field of CFS as a psychologist, I have had the unfortunate experience of being publicly criticised and targeted by an "anti-psychiatry" patient activist group. This has given me first-hand experience of the controversy surrounding the psychological factors involved in the development and maintenance of CFS and the impact some extreme patient groups can have upon other people with the condition. By conducting the critical literature review and presenting my findings to a national CFS conference and a working group, this has helped me critique the appropriateness of CBT for all CFS patients. Again, there is a common thread between this section of my thesis and the other chapters, in that it highlights the importance of the therapeutic relationship between client and practitioner, in terms of providing adequate treatment, especially with regards to the treatment of complex psychological issues or relationship dynamics. Writing this chapter gave me the opportunity to critique the present psychological literature with respect to the treatment of CFS. As a result, this has had a beneficial effect upon my professional development as a practitioner and has prompted me to enter into further interesting discussions and debates with my CFS colleagues regarding the most effective treatment for this condition within a multidisciplinary service.

15.6 Concluding Remarks

The process of carrying out my doctoral research was very difficult at times, especially whilst working full-time and being pregnant with my first child during the time of writing it up. However, I found it was useful to impose upon myself deadlines to meet, such as presenting at conferences or publishing my results. These kept the process moving forwards, especially in terms of meeting the writing up deadline before going into labour! The viva was carried out shortly following the birth of my daughter and the final section of my thesis was written when my baby was six months old. As a result, in hindsight, this doctorate has accompanied me throughout a rather tumultuous and eventful period in my life which has included getting married, moving house, changing jobs, starting up a private practice, which involved working six days a week, and having my first child. This in itself is a reflection of my character and work ethic, and may have been a major factor that pointed me towards applying for a place upon the doctorate programme initially and helped me cope with the demands of completing such a piece of academic endeavour.

The entire process of writing my doctoral portfolio and presenting it at my viva examination has been an invaluable learning experience. The viva gave me the opportunity to discuss my client work and academic research with distinguished practitioners and allowed for this portfolio to be viewed as a whole piece of work, drawing together common themes across my work as a scientist-practitioner. In many ways this has been a rather validating experience and has served to help me acknowledge my own skills as a Counselling Psychologist and to explore the impact and contributions I have made with regards to my work. I have no doubt that having now completed my doctorate, my career will again take a different course due to my professional development and it may even affect other aspects of my life too, I am sure, in a very positive way.

APPENDIX 1

Hoehn & Yahr (1967) Scale

Stage Zero:

No signs of disease.

Stage One:

PD symptoms on one side of the body only.

Stage Two:

PD symptoms on both sides of the body. No impairment of balance.

Stage Three:

Balance impairment. Mild to moderate disease. Physically independent.

Stage Four:

Severe disability, still able to walk or stand unassisted.

Stage Five:

Wheelchair bound or bedridden unless assisted.

APPENDIX 2
Interview Schedule

Being Newly Diagnosed with Parkinson's Disease: An Interpretative Phenomenological Analysis

Communication of Diagnosis

1. Could you start off by telling me a little bit about the time of your diagnosis?
2. How did you feel at the time when you heard that you had Parkinson's Disease?
3. What was going through your mind at that time?

Emotions

4. How have you been feeling since being told you have Parkinson's?
5. Have your feelings altered over time?

Identity

6. Do you view yourself differently since being given your diagnosis?
7. Has the way you view who you are changed? How?

Body

8. Do you view your body any differently now?
9. Do you feel physically different in any way?

Meaning of having PD

10. What does having Parkinson's mean for you?
11. What place does Parkinson's have in your life?

Perception by Others / Social Impact

12. Have you noticed any changes in the way people are towards you? (Friends / Family / Colleagues etc.)
13. In what way do people see you differently now?

Future

14. How do you see the future now?
15. Is it different to how you had imagined things to be before?

Life Experiences

16. How have things changed in your life since being diagnosed?
17. Do you view your life differently now? If so, how?
18. What do you think has been changed the most for you since receiving your diagnosis?

APPENDIX 3
Recruitment Letter to Referrers

North East London NHS
Mental Health NHS Trust

Alice Green, Counselling Psychologist
24/7 Mental Health Service
c/o Community Care Advice Centre
Aldborough Road North
Newbury Park
Ilford, Essex IG2 7RS

Tel: 07957 149 806 (mob)
Tel: 020 8491 1960 (work)
Fax: 020 8708 7375

18th February 2004

Dear Dr……….

Re: Research Study within NELMHT:

The Psychological Experience of being newly diagnosed with Parkinson's Disease: An Exploratory Study

I am writing to ask for your participation in the above research, which I am carrying out as part of my doctorate in Counselling Psychology at London Metropolitan University.

I am interviewing patients who have been given a new diagnosis of idiopathic Parkinson's Disease, within the past three months. The aim of the study is to identify the common psychological experiences Parkinson's Disease patients present with shortly after being given their diagnosis. The results will aim to help professionals understand better the impact a new diagnosis has upon patients, and will hopefully lead to the provision of more substantial psychological input within neurology clinics. There is currently very little formal psychological input for Parkinson's Disease patients in the UK.

Inclusion Criteria:

- Patient has been given a diagnosis of idiopathic Parkinson's Disease within the past 3 months.
- Patient is medically fit to partake in an interview about their experiences.
- Patient is not above Stage 4 of Hoehn & Yahr (1967) scale.
- Patient is able to communicate effectively, and without need for an interpreter.
- Patient has not been given a diagnosis within the past 6 months of an additional chronic illness.
- Referrals may come from Neurologists and Specialist Nurses in the field.

Each interested patient will be given the opportunity to discuss the study with me and if willing to participate, will take part in an individual interview with me about their experiences, which should not take more than one hour.

For your convenience and information, I have enclosed a green file which contains:

1. Patient Information Sheet	(to be given to patient at diagnosis)
2. Patient Contact Sheet	(to be filled out and sent to me at diagnosis)
3. Research Protocol	summarised version (for your information only)
4. Consent Form	(for your information only)

Once you have made a new diagnosis of idiopathic Parkinson's Disease, please would you provide a *Patient Information Sheet* to your patient, and with their consent send me a completed *Patient Contact Sheet.* Once I receive this information I can then contact each participant and discuss the research with them in more detail before inviting them to an interview which will be audio-taped for later transcription purposes. I am hoping to conduct the interviews within rooms at Oldchurch Hospital, Harold Wood Hospital or the C.C.A.C. for your patients' convenience.

Please note there is no pressure for any person to participate in this research, and those that do take part will have full assurance that confidentiality issues are adhered to at all times. This research has been given Regional Ethics Committee approval and has been registered with the Research & Development department within NELMHT.

I would be grateful if you would you kindly let members of your team know about this project. If you have any questions please do not hesitate to contact me.

Thanking you in advance for your participation in this study.

Yours Sincerely,

Alice Green B.Sc. (Hons) M.Sc. PGDip.
Counselling Psychologist
North East London Mental Health Trust

APPENDIX 4
Participant Information Sheet

North East London
Mental Health NHS Trust

Parkinson's Disease Investigation
Information Sheet

Dear Volunteer,

You are being invited to participate in a study investigating the experience of receiving a diagnosis of Parkinson's Disease. This study is being undertaken to help healthcare professionals understand how best to work with people who have been given a recent diagnosis of Parkinson's Disease. This will ultimately help to improve patient care.

To participate in this study you would be required to attend only one meeting lasting approximately 1 hour, which will take place in a confidential setting, most people preferring their own home. The meeting will be conducted by myself, Alice Green, a Counselling Psychologist within the Trust, as part of my doctoral research. I shall ask you a number of questions about your experience of receiving your diagnosis of Parkinson's Disease and what this means to you. If you find any of the questions particularly difficult you do not have to answer them and there will be no pressure placed upon you. The interview will allow you to talk about your experiences of having received a diagnosis of Parkinson's Disease.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a form recording your consent. If you decide to take part you are still free to withdraw at any time and without giving a reason. Your decision will not affect in any way the standard of care you receive.

All information collected about you during the course of the research will be kept strictly confidential. Your name and other identifying information will be kept separate from your medical notes held by your GP or consultant. People involved in your health care will not have access to the research information at any time and will not know whether or not you have taken part in this study. The interview audio tapes will be destroyed on completion of the study.

This study has been considered by the Local National Health Service Research Ethics Committee who has raised no objections to the study on ethical grounds. However, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal NHS complaints procedure will be available to you.

Thank you so much for your time. It is very much appreciated.

Kindest Regards,

Alice Green M.Sc. PGDip
Chartered Psychologist
North East London Mental Health Trust
E-mail: Alice.Green@nelmht.nhs.uk

APPENDIX 5

Participant Contact Sheet

North East London NHS
Mental Health NHS Trust
Alice Green, Chartered Psychologist
Home Treatment Team
Rosemary Suite
Goodmayes Hospital
Barley Lane,Goodmayes
Essex IG3 8XJ

Alice.Green@nelmht.nhs.uk

Participant Contact Sheet

Please would you kindly fill this sheet out for each patient you are referring to the project, and post it to me at the above address, as soon as they are interested in taking part.

Name of Referrer	
Name of Participant	
Date of Birth	
Address	
Contact Tel No.	
Date of Diagnosis	

Thank You!
Alice Green
Chartered Psychologist

APPENDIX 6

Recruitment Letter to Participants

North East London
Mental Health NHS Trust

Alice Green, Counselling Psychologist
24/7 Mental Health Service
c/o Community Care Advice Centre
Aldborough Road North
Newbury Park
Ilford, Essex IG2 7RS

Tel 020 8491 1960
Fax 020 8708 7375

5th March 2004

Dear...............

Recently Dr....... at Oldchurch Hospital let me know that you would be interested in taking part in my doctorate research project, "*The psychological experience of being newly diagnosed with Parkinson's Disease: an exploratory study*".

I am writing to thank you for your interest, and to let you know that I will be in contact with you within the next two weeks to arrange a suitable time for us to meet.

The interview will last for approximately one hour and I will be asking you some questions about your personal experiences of receiving your diagnosis.

The aim of this research is to improve the service provided by healthcare practitioners in the field of Parkinson's, and to highlight important psychological factors which come into play once a diagnosis has been given.

Although this may be a difficult time for you, your own personal experiences will be of great importance in influencing healthcare services in the UK. I hope to publish the research on its completion, and will provide you with a copy of my findings if you wish.

Of course, there is no pressure whatsoever for you to participate. You may contact me at any time to let me know that you no longer wish to be involved, and this will not affect your care provided by your doctor in any way.

If you wish to contact me, please do not hesitate to do so.

Kindest Regards,

Alice Green BSc (Hons) MSc PGDip
Counselling Psychologist
24/7 Mental Health Service
North East London Mental Health Trust

APPENDIX 7
Participant Consent Form for Research Study

North East London **NHS**
Mental Health NHS Trust

Parkinson's Disease Investigation
Consent Form

"The psychological experience of being newly diagnosed with Parkinson's Disease: An exploratory study"

Have you read the Information Sheet?	YES/ NO
Were you given an opportunity to ask questions and discuss this study?	YES/NO
Are you satisfied with the answers to your questions?	YES/NO
Do you consider you have received enough information about the study to make your decision?	YES/NO
Do you give your consent to the interview being tape-recorded?	YES/NO
Do you understand that audio-tapes of your interview will be destroyed once the project has been completed?	YES/NO
Do you understand that you are free to decline entry into the study, and to leave the study at any time without having to give a reason for your decision, without this affecting the standard of your medical care?	YES/NO

Signature ______________________ Date ______________________

Name (in capital letters) ______________________

Alice Green B.Sc. (Hons) M.Sc. PGDip
Counselling Psychologist
North East London Mental Health Trust
E-mail: Alice.Green@nelmht.nhs.uk

APPENDIX 8
Letter to Participants Requesting Feedback

North East London NHS
Mental Health NHS Trust

Alice E. Green MSc PGDip C.Psychol.
Highly Specialist Psychologist
Chronic Fatigue Syndrome Team
Dept. of Neurology
Oldchurch Hospital
Romford
Essex

alice.green@bhrhospitals.nhs.uk

9th August 2005

Dear ....

Thank you so much for taking part in my research last year. You will remember that I interviewed you along with other newly diagnosed patients with Parkinson's disease. I have now analysed all the interviews and as promised I am enclosing a summary of my results. Please would you kindly provide me with some feedback as to whether these themes adequately explain your experiences of being diagnosed with Parkinson's disease?

I am at the stage now of disseminating the results to healthcare professionals, including nurses, doctors, specialist neurologists and other patients, at various conferences and meetings. This means that your experiences, which you kindly spoke about with me, will help others who have been given a diagnosis of Parkinson's. When I publish this research it will help to support funding for possible psychological services within NHS clinics.

Once again, thank you ever so much for helping me by taking part in this important study. You have helped so many other people by participating in my study.

Please do not hesitate to contact me at any time. Any feedback would be much appreciated.

Sincerely yours,

Alice Green (née Sherman)

APPENDIX 9
Ethics Committee Approval Letter

REDBRIDGE & WALTHAM FOREST LOCAL RESEARCH ETHICS COMMITTEE

Becketts House
2-14 Ilford Hill
Ilford IG1 2QX

Telephone: 020 8926 5025
Fax: 020 8926 5922
e-mail: janet.carter@rwfha.nhs.uk

Ms. A. Sherman
Counselling Psychologist
24/7 Mental Health Service
c/o Community Care Advice Centre
Aldborough Road North
Newbury Park
Ilford IG2 7RS

16th January 2004

Dear Alice,

Re: LREC (R&WF) 2003/195
The psychological experience of being newly diagnosed with Parkinson's disease: An exploratory study

Thank you for your letter of the 19th December 2003 responding to the issues raised by the Redbridge & Waltham Forest Local Research Ethics Committee.

I am pleased to advise you that Committee noted your letter on the 8th January 2004 and approved the commencement of this study.

The Committee looks forward to receiving a final report of your research findings in due course.

With kind regards,

Mrs. Janett Carter
Administrator to LREC

An advisory committee to North East London Strategic Health Authority

APPENDIX 10

Participant Interview Transcripts

(Including example of one transcript, 'Interview 5', demonstrating part of the process of data analysis)

Interview 1 – "Jess"

Interviewer 1	OK, Well I'm just going to ask you some questions about your experience of being diagnosed recently. I want to find out if this has affected you in any way. How do you feel about … when you think back to when you were given your diagnosis of having Parkinson's? What went through your mind?
Jess 1	Well, not a lot really. I just got my mum's… well they thought she had it but she didn't. Alzheimer's. Whether it leads to that, I don't know. I've never really thought about it a lot. I just hope that I don't get a lot worse. I've got extra tablets and I've been better since. I haven't been on them long. I've had to wait 6 months before I saw the specialist. My GP wasn't sure. I had to wait 6 months. I've only been on them 4 or 5 months.
Interviewer 2	Hmmm… So at the time were you kind of expecting that you had it?
Jess 2	Yeah… yeah I think so. I don't know what to say.
Interviewer 3	Yeah. Hmmm…
Jess 3	I haven't thought much about it really.
Interviewer 4	So you expected to hear the diagnosis. What it was.
Jess 4	Yeah.
Interviewer 5	Did you have any emotions in the room? Or did you think about it afterwards?
Jess 5	Not really no. I mean it did go through my mind how bad it would get. I don't know really how much worse you can get. I don't really know much about it.
Interviewer 6	Hmmm… So you were feeling a bit apprehensive. Are there lots of questions you would like the answers to?
Jess 6	I'm in the habit of keeping my eye out for whether I get worse. I've not really asked anything yet. The Parkinson nurse … I've only seen her once. She said I can ask her anything I want. I don't see her until the end of the month. I might think of more things to ask then as its early days.
Interviewer 7	Hmm… So it felt like it didn't come too much as a shock…
Jess 7	…No…
Interviewer 8	…You didn't think too much about it. You didn't give it too much thought…
Jess 8	No, not really.
Interviewer 9	… And you are left with a lot of questions about how bad is it… is it going to get worse…
Jess 9	…Yes…
Interviewer 10	… will the tablets work?
Jess 10	Hmmm… Yes… I haven't asked them yet. When I go out I get a bit more self-conscious about whether or not I'm alright because I can't cut up things alright all the things I can't cut up. *(Nervous laughter)*
Interviewer 11	Yeah… So when you go out things are … magnified for you?
Jess 11	Yes. I'm alright yet. I don't feel I want to stop going out anyway.
Interviewer 12	No. I mean how would you describe this… phase? Is it manageable?

Jess 12	It is at the moment, yes. I've just slowed down on a lot of things. I can't explain it really. I'm not very good at explaining things any way (*nervous laughter*).
Interviewer 13	Hmmm… So it's made you slow down a little bit?
Jess 13	I can't really describe it…. It's just slower.
Interviewer 14	Hmmm…
Jess 14	It's hard to explain really. You go to make the bed and you think oh its taken me a long time to do that. If I put my tights on it will take me ages to get them on. All those little things…
Interviewer 15	Hmmm…. That you took for granted.
Jess 15	Yeah. You go to get ready and … before it was…. Hmmm…
Interviewer 16	Have you thought much about what meaning it has for you, having a diagnosis of Parkinson's?
Jess 16	[Pause] Well I don't understand it really. I don't know a lot about it…
Interviewer 17	So it's a bit like the great unknown at the moment?
Jess 17	Yes. I haven't got round to asking what I'll end up like or … whether I can end up normal again… I don't know.
Interviewer 18	Hmmm… Yeah…. There are a lot of question marks now for you?
Jess 18	Yeah… I've got things to ask.
Interviewer 19	Hmmm.. Yeah. When you said when you go out you said you notice that you are a bit more aware of things you didn't do before when you were more able… cutting up food…
Jess 19	Hmmm…
Interviewer 20	Does it worry you about what other people… Do you think others view you differently?
Jess 20	[Pause] At a meal there's only family and friends. Those times when I am slower, people tend to be more helpful – do you want things packed? Or can I hold your bag? I don't actually stop doing things, but I think people…
Interviewer 21	But other people….
Jess 21	…might notice me, yeah.
Interviewer 22	How do you feel about that?
Jess 22	Well.. I don't think… I don't think it's a bad thing to be helped.
Interviewer 23	So it's not a bad thing?
Jess 23	When I get up on a bus, and it swings if it is moving… that's when I sort of don't feel safe, if I'm on my own on the bus. It's really the little things.
Interviewer 24	It's just those little things that weren't there before?
Jess 24	That's right.
Interviewer 25	And you have to live with them…
Jess 25	… Hmmm… Yeah and think hard… If the bus jolts or stops hard and you think you are going to fall… Those little things.

Interviewer 26 Yeah. You have to be more careful about how to go about... ?

Jess 26 Yes. Be careful just to make sure.

Interviewer 27 Hmmm... Have your family been... How do you feel your family have reacted?

Jess 27 No different to normal. They make sure I go to the doctors when I should do ...

Interviewer 28 Checking up on you? [*Laughs*]

Jess 28 [*Laughs*]. I think they looked it up on the Internet. One thing or another. [*Laughs again*]

Interviewer 29 Yeah... So they're interested in it?

Jess 29 Yeah...

Interviewer 30 Hmmm.... [PAUSE] Do you feel any different about your body since having a diagnosis of Parkinson's... since being told this is what you have got? Has it changed how you *view* your body?

Jess 30 Well... I feel sort of hunched up sometimes...

Interviewer 31 Hmmm...

Jess 31 I think they told me about that anyway... About it ...

Interviewer 32 Being aware of your posture?

Jess 32 Hmmm.... Aware of my posture. They've said try and walk like a model walks ... think of that and they go up two inches.

Interviewer 33 Hmmm....

Jess 33 But at the moment I feel sort of a bit hunched...

Interviewer 34 Hunched over?

Jess 34 Yes. That is part of it I think.

Interviewer 35 Hmmm... Do you think it's a ... strange thing to take on board, affecting your body, or is it something that...

Jess 35 I don't know really.... Hard to explain.

Interviewer 36 Hmmm... And like you said, you haven't really given it much thought. So some of my questions might sound really strange..

Jess 36 [*Laughs*]. Hmmm....

[PAUSE 10 SECONDS]

Interviewer 37 Do you feel different about yourself since being told you have got Parkinson's?

Jess 37 [PAUSE 5 SECONDS] Bit sad sometimes... [*nervous laughter*]. I don't know I...

Interviewer 38 So sometimes it makes you feel a little bit sad?

[PAUSE 10 SECONDS]

Interviewer 39 Is the sadness because... at the moment you are not quite sure of how it is going to affect you?

Jess 39 Yes.

Interviewer 40 Hmmm….

[PAUSE 10 SECONDS]

Interviewer 41 There's lots of questions which you want to know and have answered…and understand…

Jess 41 [*Starts to cry*]

[PAUSE 5 SECONDS]

Interviewer 42 I can see and I can feel this is quite… painful for you.

Jess 42 Hmmm…. [*continues to cry*]. I've never thought about it before.

Interviewer 43 Hmmm… Like you said… it's one of those things you haven't really given much thought about.

Jess 43 Hmmm…. No…. [PAUSE 10 SECONDS] . It's the first time I've really thought about it.

Interviewer 44 Hmmm… [PAUSE 5 SECONDS]. It sounds like the way you've been dealing with it is to… find out more… to adjust to what's happening… take things a bit slower… take each day as it comes.. and I'm sure you are thankful for all your family for being so supportive…

Jess 44 Hmmm…

Interviewer 45 And it is one of those things… which isn't easy to think about. And like when you are experiencing here… when you *do* think about it, it can be quite … quite difficult to even know where to *begin* to think about it.

Jess 45 Yes. I don't know what to say.

Interviewer 46 Hmmm… [PAUSE 10 SECONDS] OK.

Jess 46 I'm not much help to you, am I?

Interviewer 47 You are a *lot* of help! It's very helpful for me and I think its going to be very helpful hearing other people talk.

[PARTICIPANT'S HUSBAND COMES INTO ROOM AND SITS DOWN. JESS WEEPS.]

Jess 47 It's the thinking about it, I think.

Interviewer 48 [*To Husband*] As Jess was saying, she hasn't really thought too much about it. Sometimes when we look at it as what it is, it can have a bigger impact on us.

Jess 's Husband1 She's definitely getting better to what she was.

Interviewer 49 Hmmm… You have your family on your side. [Jess *smiles*].

[PAUSE 10 SECONDS].

Interviewer 50 I can feel your pain actually, and maybe a lot of fear about it.

Jess 51 Yes.

Interviewer 52 If the medical profession can begin to understand how *you're* feeling they can begin to be more understanding when you have appointments… when advice it given to you then it can be … given to you in a better way and this is really why I am doing this research.

Jess 52 Talking about it has… brought it all out…

Interviewer 53 Hmmm…

Jess's Husband2: It might be a good thing. Get it over and done with and you can start [*inaudible*]. I'm in charge [*Smiles at Jess*].

Jess 53 Hmmm.. [*Smiles*]

Interviewer 54 There you are… he's in charge!

Jess 54 [*Laughs*]. He's very good.

Jess's Husband3: I do my best!

Interviewer 55 I think sometimes… I mean I work in this profession and … when we hold on to so much inside and we don't really want to look at those feelings because they are… *painful…* and that's why some of my questions have really made you … look at that. Sometimes it *does hurt*, but it can be useful to talk… and I suppose… *acknowledge* those feelings…. Is it shocking to you to find yourself crying today?

Jess 55 A little bit. [PAUSE 5 SECONDS]. It's the first time I've cried about it. I've never felt like it before.

Interviewer 56 No…

Jess's Husband4: And it'll be a long time before you think like that again. No more!

Jess 56 [*Smiles*].

Interviewer 57 Sometimes it's very good to cry… to get it all out…

Jess's Husband5: That's why I give her a good hiding!

Jess 57 [*Laughs*]

Interviewer 58 [*Smiles*]. But I can hear and I can see it has probably affecting you more than … more than you thought from an emotional level…

Jess 58 But that's quite normal. I think probably everyone in your situation and I think everyone that I'm interviewing… because actually *you* are my first person to be interviewed. But I know from my experience of talking to other people who *have* Parkinson's… you know that there are times when it just *hits* them.. They need to cry and they need to think about … think about having it really. But in every day life.. we cope and we put on a brave face and we deal with daily life really, but I think … you know… don't feel *embarrassed* about crying … I think it's quite normal and quite natural. I think if you *didn't* cry I'd be a bit worried!

Jess 58 [*Smiles and laughs*].

[PAUSE 10 SECONDS].

Jess 59 I don't think I've helped you really.

Interviewer 59 No. You are a *lot of help* actually. Because hearing what you've had to say and even from just to see and feel what you are feeling, is important.

Jess 60 Really?

Interviewer 60 I think if people *understand* just a little bit about how you are feeling and about how other people are feeling then they can provide a bit more understanding and a bit more support. Because it is a *tough time.*

Jess 61 Hmmm…

Interviewer 61 This is a difficult phase, and you'll probably go through lots of different phases and lots of different adjustments to having Parkinosn's, and maybe some of those will be very positive. At the moment it feels a little bit… rocky.

Jess 62 Hmmm…

Interviewer 62 How do you feel now that you've had a bit of a cry?

Jess 63 I'm OK now.

Interviewer 63 Hmmm….

Jess 64 I don't know what to say.

Interviewer 64 Sometimes it's difficult to… to say *anything* actually and up until this time, until *today*, you have cried and you'd not really given it much thought which is why you hadn't cried until today and that's why it probably feels a little bit painful…

Jess 65 Hmmm….

Interviewer 65 Do you feel that when you met with your neurologist and he told you that you had Parkinson's… do you think he handled it well? Did you have any …

Jess's Husband6: Well you see, the doctor thought it might be Parkinson's and that's why he recommended to see the professor.

Jess 66 Well he was quite nice. He explained it and everything.

Jess's Husband7: He said the tablets would make an improvement, didn't he and they have made a definite improvement. And you've had the physio …

Jess 67: I had to see them because I couldn't move. I turn a lot in bed and it's a job to turn over. I sprained a muscle in my groin and of course over the past 5 or 6 weeks I've had trouble getting out of bed. But luckily enough last couple of days it's clearing up. By the end of the day I could hardly get up the stairs. That's made me feel a little bit … down. The last couple of days I've been able to move. I think it's gone.

Interviewer 67 Hmmm… but I can imagine. Its can be unpredictable – how its going to affect you… what it's going to do…

Jess 68 Yeah. I haven't got round to asking if it will get worse or whether I'll be stabilised. I haven't thought to ask yet.

[*INAUDIBLE…*]

Jess 69 I won't worry anyway…

Jess's Husband8 She keeps turning in bed now.

Jess 70: I'm twisting and turning… before I got to sleep, all night.

Interviewer 70: Well.. you are a twister and a turner!

Jess 71 [*Smiles*]. It's a woman's prerogative…

[*INAUDIBLE…*]

Jess 72: [*Laughs*]

Interviewer 72: *Every* man complains about that!

Jess 73: [*Laughs*] I move one way and the other.

Interviewer 73: It sounds to me that since you've been living with Parkinson's, you've been focusing on the positives. Is that… is that true, or?

Jess 74 Hmmm… positive points… yes

Jess's Husband9 Are you more positive?

Interviewer 74 Focusing on the positive to cope?

Jess's Husband10 You figure it out. I mean, before, when you first started taking tablets there was a hell of a lot of things you couldn't do… even peeling potatoes.. you couldn't do that. You can now. You cut a sandwich in half!

Jess 75 [*Laughs*] Yeah! I have improved yes.

Interviewer 75 Yeah… it sounds like you've had to relearn certain things, or do things in different ways?

Jess 76 Yeah.

Jess's Husband11 As the doctor said.. You don't look your age!

Jess 77 [*Laughs*]

Interviewer 77 I know you said at the moment that the future is a little unpredictable for you. Has that changed… how you view the future for you?

[PAUSE 5 SECONDS]

Jess 78 I worry about how I might move about.

Interviewer 78 Your independence… Hmmm….

[PAUSE 5 SECONDS]

Jess's Husband12 You still go out on your own, don't you?

Jess 79 Hmmm…

Interviewer 80 So you are at the moment a very independent lady…

Jess's Husband13 *Very* independent!

Jess 80 [*Laughs*]

Interviewer 81 Yeah. Certain things you've had to adjust to. And even though you have anxieties about what's going to happen in the future, there are lots of question marks. At the moment you just *deal* with things.

Jess 82 Yeah… Oh Yeah… I do something every day.

Interviewer 82 Has that been a conscious decision?

Jess 83 Well we used to go out a lot but so if its only to go out to Romford and walk round the shops … cos you can sit down in Romford can't you, and walk round the shops… We … make the effort to try to get out.

Interviewer 83 Hmmm…. So its made you really think about doing things whilst you can?

Jess 84 Whilst we can… yes.

Interviewer 84 Have you had an contact with any other people who have got Parkinson's?

Jess 85	No.. I think we probably need to … I think there is a club… at
Interviewer 85	The PDS… at the actual hospital?
Jess 's Husband	No, in Chadwell Heath
Jess 86	The Parkinson's…
Interviewer 86	Disease Society.
Jess 87	Yeah.. Somewhere… They've put my name down for that. You can meet other people and you can have physio there and all sorts of things.
Interviewer 87	Well I've gone along to lots of those meetings
Jess 88	Oh
Interviewer 88	It's quite nice actually because you meet a whole load of other people who have also got Parkinson's…
Jess 89	Hmmm…
Interviewer 89	They also have guest speakers in. it's like a social group really. There's information and education. People discuss what medication works… tips… that kind of thing.
Jess 90	Hmmm… Oh yeah….
Interviewer 90	Hmmm…. It sounds like its quite errr… it's all so like the great unknown. You don't quite know what to expect…. When you go to a group meeting….
Jess 91	Hmmm…. I'll wait and see about that.
Jess 's Husband	[*Inaudible*]
Jess 92	[*Laughs*]
Interviewer 92	No… that's right… Hmmm…. Hmmm… Are there any questions that you feel I haven't asked… anything you feel is important?
Jess 93	[PAUSE 10 SECONDS] No.
Interviewer 93	Well… It's been really helpful to listen to what you've said. I know it's been difficult … I suppose it's difficult to prepare for something like this…
Jess 94	Hmmm….
Interviewer 94	… you didn't know what kind of questions… what kind of emotions would come up.
Jess 95	Ah huh…
Interviewer 95	It's been really helpful for me to get an understanding of you and how … how it's impacted upon your life… in many different ways.
Jess 96	Hmmm…
Interviewer 96	… You've told me about *physically*, emotionally, affecting your family, affecting your view of your life, your future.
Jess 97	Hmmm…

Jess's Husband	Don't you think it's down to the person themselves? I mean someone might say, "I've got it, that's it, I'm finished!".
Interviewer 97	Hmmm... That's right.. yeah...
Jess's Husband	But I won't let her do that! [*Smiles*]
Jess 98	[*Laughs*]
Jess's Husband	We go out.. we come back... I go out to the pub for dinner ... things like that.
Interviewer 98	Hmmm...
Jess's Husband	[*inaudible*] I mean it's the same as when you retire.
Interviewer 99	Hmmm....
Jess's Husband	I mean I've been retired for 18 years. I could have said, "Right, that's it, I'm going to sit back and watch television".
Interviewer 100	That's right. Your state of mind can definitely have an impact.
Jess's Husband	[*Inaudible*]
Interviewer 101	And that's exactly what you've been doing. You find the things you *can* do and you are doing that.

Interview 2 – "Walter"

Interviewer 1	OK. So, how long was it ago that you had your diagnosis given to you?
Walter 1	It was in April that I had the diagnosis but I knew it beforehand…
Interviewer 2	Oh right…
Walter 2	… my father had the disease so…
Interviewer 3	Oh, OK.
Walter 3	I was very prepared for it then
Interviewer 4	Did you … did you think that that's what you had then?
Walter 4	Yes. I did. I told the doctor what I had.
Interviewer 5	I see. You diagnosed yourself.
Walter 5	Yeah.
Interviewer 6	And so… did it not come as a shock to you?
Walter 6	It didn't come as a shock… no.
Interviewer 7	What kind of things went through your mind when the doctor said I think you have Parkinson's?
Walter 7	Well first of all he said "I think you have"… but not til we had the tests that I really found out. I was rather pleased actually that I did have it, rather than one of the other Parkinsonisms. At least they can *treat* it… so ahmm…
Interviewer 8	Mmm… That's right. So you were quite pleased?
Walter 8	Quite pleased really yes.
Interviewer 9	Mmm… Because it can be treated…
Walter 9	Yes. Can't be cured I know, but at least they can treat it.
Interviewer 10	They can, that's right. So did they prescribe you some tablets?
Walter 10	Yes. I'm on Sinamet Plus.
Interviewer 11	So it's come as… not as a shock but actually as something quite positive for you. Because you were kind of expecting it…
Walter 11	Yes. Yes I was.
Interviewer 12	Do you have any preconceived idea then, of how the course will run for you in terms of your health? Having seen your father with Parkinson's, how has this influenced you in any way, if at all?
Walter 12	Ahmm.. It's made me realise that it won't *kill me* but it may disable me I suppose in time but ah… I suppose it's part of life isn't it?
Interviewer 13	Ah hmm… So it's something that you feel is unfortunate but it's part of life.
Walter 13	Part of life.. .that's it.
Interviewer 14	Has it changed the way you feel about life then?

Walter 14 Not really, no. It's changed the way I've had to act. I've had to give up driving… and also my wife. You know. It's a shock for *her*. I'm mean it's not a shock – we knew it was coming but, it's a shock. The fact it's put on her.

Interviewer 15 Right. So it's affected *her* differently that how it's affected you?

Walter 15 Well… I don't really know how it's affected her but I know how it affected me. I feel that she is going to have to do a lot more to look after me as time goes by…

Interviewer 16 … Mmm… so from that perspective… it's made you feel not "guilty"… I don't know… How does that make you feel?

Walter 16 Ahmm… Very humble I suppose.

Interviewer 17 Mmm… Has it changed the way you view your body in any way?

Walter 17 Not really… I can't walk as far… I want to do things in a rush, when I should be slowing down.

Interviewer 18 It's difficult to adjust to the restrictions…

Walter 18 Restrictions… yes.

Interviewer 19 And like you said… you've had to give up *driving*. Is that because the DVLA have …

Walter 19 No no. I gave it up anyway. And with 46 years of never having an accident, I didn't want one at this stage. I thought "That's it".

Interviewer 20 No… no… You took the sensible action.

Walter 20 Yes. You get round on the buses alright.. so.

Interviewer 21 Alright.

Walter 21 Haven't been used to them for 46 years. But there you go!

Interviewer 22 Mmm… So it's forced changes upon how you live you life.

Walter 22 To a certain extent, yes.

Interviewer 23 And how are you coping with that?

Walter 23 Took it really well I think. I think we are coping very well. We are adapting to it.

Interviewer 24 Hmm…

Walter 24 Getting round by buses. Taxis. That sort of thing.

Interviewer 25 Hmm… You are making the necessary changes to get on with life?

Walter 25 That's it. Carry on with life.

Interviewer 26 Has your perspective towards the future changed because of this? In what ways has it made you think differently?

Walter 26 Not really no. I have got a future I hope. And that's it. Whenever it may be and I'll take each day as it comes.

Interviewer 27 Taking each day as it comes.

Walter 27 That's it.

Interviewer 28 Have you noticed it has made you feel any differently about your self in any way? Have you had times when you've felt hazy or has it had an emotional…

Walter 28 Not really. I don't think it has had too much of an emotional effect. As I said, I was expecting it, and I was pleased it was Parkinson's and it can be treated. That was it.

Interviewer 29 Right. So you'd obviously been prepared for it.

Walter 29 Yes I was prepared for it.

Interviewer 30 Has it made you want to look into information about Parkinson's?

Walter 30 Well I belong to the Parkinson's Disease…. I've joined the … err….

Interviewer 31 Society

Walter 31 Society, yes. And I belong to the local and national.

Interviewer 32 Ah right. So have you gone to any of those meetings?

Walter 32 I went to two of the local meetings, yes.

Interviewer 33 And how was that? Did you find that useful?

Walter 33 I found that very useful, yes. Meeting people with the same disease, you know.

Interviewer 34 Hmmm…

Walter 34 Haven't really learnt from their experiences at the moment because we've not really had the chance to talk to them.

Interviewer 35 Because it's at that early … stage?

Walter 35 Stage. Yes.

Interviewer 36 But what you want to learn is from other people?

Walter 36 That's it.

Interviewer 37 And… How … Do you think it has changed the way your wife sees you?

Walter 37 I don't think it's changed her way she perceives me… but I think it's changed … Well in later life it could change.

Interviewer 38 Hmm…So looking towards the future, might be different.

Walter 38 … I think in later life it could change and be different, yes.

Interviewer 39 yes. You were saying that it would change things for her as she might be more of a *carer*, would you say?… or changing things in terms of how you both deal with things daily ?

Walter 39 I think it changes ways she cares for me. She'd have to give more care but other than that I don't think so.

Interviewer 40 It sounds like what you are doing is living life day by day… taking things day by day… coping…

Walter 40 That's it.

Interviewer 41 And as you say you were pleased you were given your diagnosis. Was there a long while where you didn't have this diagnosis and you were…

Walter 41	Well it took 18 months in all. From when I first went to my doctor to when I had to see the consultant.
Interviewer 42	So that's quite a long time.
Walter 42	A long time….
Interviewer 43	I can see how it has come as some kind of relief.
Walter 43	Yes. It has.
Interviewer 44	Do you think it might have affected you differently if your father hadn't had Parkinson's?
Walter 44	Yes. It may well have done.
Interviewer 45	Did your dad cope well with his Parkinson's?
Walter 45	Reasonably well. Might you he was 83 when he died so … He got it later in life and he was in a home for most of the time. The last couple of years of his life he spent in a home. Mum tried to look after him but she couldn't after a while, so he had to go into a home.
Interviewer 46	Does that make you fear that the same thing might happen with you? Or are things different now to how they were say 10 to 15 years ago?
Walter 46	Well he only died about 4 years ago… but… yes I think … Hope that won't happen to me eventually… but that's to come.
Interviewer 47	So… don't worry about the future right now.. you are more focused on the present.
Walter 47	Yes, That's it.
Interviewer 48	I know your wife is obviously being quite supportive…
Walter 48	Oh yes, yes.
Interviewer 49	… have the rest of your family acted in the same way?
Walter 49	Ah, yeah. They have all acted positively to it. Not that I see my son a lot but my daughter has. They've all been very good to us actually… very supportive to us.
Interviewer 50	That's good. There's lots of support around you. Have you noticed any changes… since you've had the symptoms. Have things changed in terms of how other people perceive you? … I don't know what symptoms you have but with say tremor sometimes people can feel embarrassed..
Walter 50	… Well I don't think anyone feels embarrassed but I don't think I've got that far yet, but … no.
Interviewer 51	Nothings changed in terms of that then?
Walter 51	No. Not really.
Interviewer 52	Is there anything you want to say to me that I've probably missed out?
Walter 52	Not really, no. I think you have covered most of it really.
Interviewer 53	Ok. Well it's interesting to chat with you and find out what it means to you and the impact that it has because for each person it is unique.
Walter 53	Yes that's true.
Interviewer 54	Your experiences are unique to you, based on things like how you have seen your dad and the family support that you have.

Walter 54 Yes.

Interviewer 55 But it's really useful to speak with you. By speak to yourself and other people perhaps we could picture together people's experiences of having Parkinson's, especially at this early stage. Possibly people react in different ways, but if we can help doctors understand and nurses understand what newly diagnosed patients are feeling or thinking then hopefully services can be improved. I appreciate the time talking to you. Thank you very much.

Interview 3 – "Harriet"

Interviewer 1 So, when was it that you were told that you had Parkinson's?

Harriet 1 In February. I think it was around the 23rd of February this year…

Interviewer 2 So quite recently…

Harriet 2 … quite recently. It was after 4 years of going backwards and forwards for tests. They didn't know what was wrong. So then, Dr de Silva thought it was Parkinson's.

Interviewer 3 Can you recall how you felt or what you were thinking at that time?

Harriet 3 Relieved really… to know what was wrong. I was beginning to think I was putting it on… you don't know *what's* wrong. So I was relieved to know what's wrong.

Interviewer 4 Yeah…because for all those years you have been having symptoms.

Harriet 4 Yes. That's right.

Interviewer 5 Were there any other thoughts you had at that time, or since that time?

Harriet 5 Ahm… not really. Just learning how to cope with it you know… what to do and how to make the best of it. To laugh and to cry. You just have a laugh about it at times. How I move in bed… [*Laughs*]

Interviewer 6 Yeah… So you make a joke of it.

Harriet 6 Yeah, that's right. My son… my youngest son found it hardest. He's eighteen. So I said I'd be a daddy… so that helped.

Interviewer 7 Hmmm…. So… has it been like a double-edged sword then… Like half of you felt a little uneasy about it and half of you felt …

Harriet 7 Not so uneasy about it… just learning to *live* with it really. Other people are worse off than me. So it's just one of those things.

Interviewer 8 So your feeling now is to cope with *having* it?

Harriet 8 Yes, and I'm feeling OK. We are going to Canada in the summer so we were told to do long journeys in the next couple of years, so we plan to go to China next year. It's not going to stop us.

Interviewer 9 Has it changed the way you feel about life?

Harriet 9 Ahmm… Not really. I know everyone at church has been praying and I felt that I had the answer to know what it was. My husband said that at least he has still got me.

Interviewer 10 So it's made you look at things from a different perspective?

Harriet 10 Yes, that's right. Yeah.

Interviewer 11 Looking at what you've got rather than what might have been.

Harriet 11 Yes, what might have been.

Interviewer 12 And so you have decided to do lots of things now.

Harriet 12 Well we had started to do it anyway over the last 2 or 3 years cos we only have one boy at home and so we thought we would spend our money now rather than for the children.

Interviewer 13	Yeah. Spending on yourself and living life to the full.
Harriet 13	Yes. That's right.
Interviewer 14	What meaning does Parkinson's have for you at the moment?
Harriet 14	Ahm.... It .... Ahmm..... Things are going to get more difficult eventually. My gran had it so I saw her each year deteriorate... without any drugs.
Interviewer 15	Right... So it might be different?
Harriet 15	Yes, that's right. But I suppose you ... have to cope with it don't you?
Interviewer 16	Hmmm... So for you Parkinson's has a place in your life, in that it's an obstacle that you have to cope with and deal with ...
Harriet 16	I get frustrated at not being able to do things.. not being able to talk properly. I still sing in a choir, but I can't take part in the way I would like to. I still go along but I get frustrated more than anything else.
Interviewer 17	Yeah. Cos you've got lots of abilities like singing and talking which may have been taken for granted.
Harriet 17	I've always had a stammer but its actually got worse, so I understand people with stammers but I can't always control it as I used to before.
Interviewer 18	So it means to you that it affects your life in ways that can be very frustrating.
Harriet 18	Yes. That's right.
Interviewer 19	You used to enjoy singing in the choir and it is stopping you from doing it as much as you would like.
Harriet 19	That's right.
Interviewer 20	So you feel the important thing for you is to ...
Harriet 20	Carry on and still do as much as I can. I still go to ..... I don't want to give that up unless I have to. I think if you give things up you go down. I still help my mother-in-law... she's 92.
Interviewer 21	You feel that if you give up then things will get worse?
Harriet 21	That's what I think anyway. I still walk. I don't drive at the moment now. I find I can't use my arms, so it would be a danger. So I thought the safest thing to do is to be off the road.
Interviewer 22	But you still walk...
Harriet 22	Yeah. I did have a bad turn last week. My doctor told me to put the drugs up one milligram. And it was obviously too much. I felt like I was drunk! I rang the helpline nurse and she said to cut it down. I'm still a bit wobbly, but I'm not as bad as it was. It was quite funny... well it *wasn't* funny it was worrying really but ah....
Interviewer 23	You felt like you weren't in control?
Harriet 23	That's right, yeah.
Interviewer 24	How do you feel about taking the drugs?
Harriet 24	Well if it's going to help... you.... you use them. If it helps... it can't be bad can it?
Interviewer 25	No. So you've seen your grandma and she went through Parkinson's. Do you feel this has affected how you have taken it on board?

Harriet 25 Ahmm… no I don't think so. I think I just had a name for what was wrong with me I think.

Interviewer 26 And that's why it's been a relief?

Harriet 26 It's been a relief, yes.

Interviewer 27 It sounds like now that you know, it's been a relief, but with it you've decided to find out more information about it.

Harriet 27 That's right. I sent out for things. And I've also got the card that I can carry with me. They do a card – "I've got Parkinson's". I've got to be careful. If I'm not going to get better, it's best to be safe. So people can know what's wrong.

Interviewer 28 So you've taken a very sensible approach to it.

Harriet 28 I hope it's sensible! [*Laughs*].

Interviewer 29 You are preventing anything from becoming *worse.*

Harriet 29 Yes, that's right. I think if I'm frustrated, other people tend to not understand and try to do things to help you, but I'd rather do things *myself.*

Interviewer 30 And that can be a bit irritating?

Harriet 30 Yes. I know they are only being kind but it doesn't help *you*, does it?

Interviewer 31 No, sometimes it can make you feel a bit … lack of independence.

Harriet 31 Attitude…

Interviewer 32 Do you think people are reacting to you differently now?

Harriet 32 Ahm… not most of my friends. They accept me still. They are for me but they try to stand back and let me do things.

Interviewer 33 Hmmm… They understand that…

Harriet 33 How you feel…

Interviewer 34 They haven't changed there, and they respect your independence…. Doing things for yourself.

Harriet 34 Yeah. That's right.

Interviewer 35 What about people in other places, like in the shops or in public?

Harriet 35 I … say … "I'm sorry, I'm a bit slow". They say "That's alright". Most of them are alright….

Interviewer 36 So it sounds likek you are dealing with it in a positive way?

Harriet 36 I think I am and my husband is and my children are. They still come over.

Interviewer 37 So, was your husband relieved aswell?

Harriet 37 Yes he was. I think you get annoyed that they couldn't have found it sooner.

Interviewer 38 That not knowing can be….

Harriet 38 Wearing.

Interviewer 39 Wearing…. Has it made you feel different in terms of your identity?

Harriet 39	No. As it said to the children, "I'm still the same person. I might be changing, but I'm still the same person".
Interviewer 40	You still maintain a strong sense of your own identity and the way you view yourself.
Harriet 40	Yes. One of my sons didn't want to go away. I found out and said, "Steven, don't stop doing that… so I mean.. it's not as if you are going to die tomorrow, but you've just got to carry on. I mean a friend of ours he lost his wife to cancer so I mean its not as bad as that is it?
Interviewer 41	Hmmm…. It's made you put things into perspective in terms of … things could be much worse…
Harriet 41	They could be…
Interviewer 42	And Steven took it as maybe more of a shock, and it has affected him in a different way to you, in terms of how you feel.
Harriet 42	Maybe… in that I'm not *invincible*. I think that's what it is. You always think your parents are going to be there forever, don't you?
Interviewer 43	So you can understand why he could be … worried and unsure how he could help, or what its all about. Did you have any inkling that it could be Parkinson's?
Harriet 43	I didn't know if it could be a stroke, as my dad had strokes. He was affected all over one side, so I didn't know if it could have been that. But I suppose … we didn't really think it was, but deep down you wonder.
Interviewer 44	Hmmm…. Hmmm… so it was obviously a difficult phase for you, not knowing what it was.
Harriet 44	That's right. They tested for MS as well as that has similar symptoms I suppose?
Interviewer 45	… yes.
Harriet 45	And I thought more of strokes because of my dad I think.
Interviewer 46	Yes. Well at the end of the day you can only go on what you've seen yourself.
Harriet 46	That's right. I'm not a surgeon or medical person, so it's easy to look back in hindsight and say I should have known. You don't know.
Interviewer 47	So the way you view the future… has that given you a different slant on things?
Harriet 47	Ahm….. I know that I've had to adapt everything. We are trying to do things to make it easier for me… we have a thing for opening tins on the wall… to make things easier for me. Looking towards the future, we are thinking of putting another rail on the stairs. So we've just got to adapt the house and adapt what we do to fit.
Interviewer 48	You are adapting the house to fit with Parkinson's.
Harriet 48	That's right. I have a pen and things like that.
Interviewer 49	It's the little things.
Harriet 49	So I'm still … as self-reliant as I can be.
Interviewer 50	Hmmm… I can hear that is important for you.
Harriet 50	And also I'm going to get a trolley for shopping so that it will help. The tablets have helped my walking but the trolley may make things better. So I am thinking of doing thigns like that. I have got a folding stick which I can take out in emergencies, you know. Just so that I can be independent.

Interviewer 51	Yeah. It sounds like a very good idea. As you were saying before, being self-reliant and independent. These are important things for you. so even though it is not a *wonderful* thing to have Parkinson's…
Harriet 51	... No…
Interviewer 52	… you are dealing with it by adapting your environment…
Harriet 52	...To suit.
Interviewer 53	To make the most of what you've got. Have you always lived your life like that? To the full?
Harriet 53	I think so. We had five children so we had to adapt holidays … going camping. So you just have to suit whatever you've got, haven't you?
Interviewer 54	Hmmm…
Harriet 54	We've never gone on the best holidays. But the children certainly enjoyed holidays we had camping, so your life changes as circumstances change.
Interviewer 55	You go with the flow and you adapt to whatever is happening.
Harriet 55	That's right.
Interviewer 56	Do you think you've changed since February when you got your diagnosis? Have your feelings changed over these past few months or have things stayed stable?
Harriet 56	I don't think they have changed really…. I suppose I am more thankful perhaps. I'm not taking things for granted and that. Ahm…. But I don't things have changed that much.
Interviewer 57	Hmm… so things have been pretty stable but they have changed the way you view things.
Harriet 57	Sometimes you wish you could do things that you can't do. I think that is only normal.
Interviewer 58	But in general you kind of swallow that [*Both Laugh*] and think, "OK, what *can* I do?".
Harriet 58	That's right.
Interviewer 59	And not taking things for granted and being thankful for things that you do have.
Harriet 59	That's right.
Interviewer 60	Do you think your religion has helped?
Harriet 60	Yes, I do.
Interviewer 61	You go to church regularly?
Harriet 61	Yes, I do. We can pray and I feel like it helps. I know my friends will pray for me as well and I think that helps.
Interviewer 62	So that can make you feel more secure, and looked after.
Harriet 62	Yes, that's right. I know that when I die, I'll be perfect again. That's something to look forward to.
Interviewer 63	Hmmm… So no matter what happens here on Earth, when you die then things will be back to perfection.
Harriet 63	Yes, that's right.
Interviewer 64	Are there any other things that I haven't asked you which you feel are important?

Harriet 64	Hmmm… The backing of my husband is good and that I can rely on him and on my children.
Interviewer 65	Your family are very important to you, I know. Maybe more so now than a few years back. This can help.
Harriet 65	Yes. It gives you strength so you can cope.
Interviewer 66	And your husband is really there, backing you, and giving you strength.
Harriet 66	Yes, yes he is.
Interviewer 67	Do you feel you have changed in your relationship since your diagnosis?
Harriet 67	Hmm… My husband says he loves me even more.
Interviewer 68	Ah! So, it must have affected *him* in a way.
Harriet 68	Yes, I think it definitely did. He says he appreciates me more. Not that he didn't before…
Interviewer 69	Yeah… It's made him think from a different perspective as well.
Harriet 69	Yes. That's right.
Interviewer 70	And I am sure that it probably changed for you as well, because he is there for you.
Harriet 70	He said "Don't put the rollerskates on the stairs", and I said "I need you alive now!".
Interviewer 71	Really?
Harriet 71	[*Laughs*]. We tend to joke now and I think it helps.
Interviewer 72	Yes, because as you said before, it is easy to get depressed about illness. It being very frustrating about the things you *can't* do. And one way you can cope is to think about the things you *can* do and the things you will be able to *adapt* to and make light of it.
Harriet 72	That's right.
Interviewer 73	And maybe joining the Parkinson's Disease Society is another way to adapt and …
Harriet 74	Know what to do…. New things come out all the time.
Interviewer 75	Yes, because there's always research that is going on.
Harriet 75	That's right.
Interviewer 76	Hmmm… Well it's been really interesting to talk to you.
Harriet 76	Has it helped?
Interviewer 77	Absolutely! I mean *your* experiences are important because then I will be interviewing other people and even though everyone's experiences are unique, there might be some…
Harriet 77	Some similarities
Interviewer 78	That's right. Similarities across most people and then what I am hoping is that when I write up the research and give it to all the neurologists and nurses then other neurologists and PD nurses across the UK will have an insight into people's experiences like yourself. Those early experiences in those first few months.

Interview 4 – "Bertha"

Bertha 1	I've never actually seen a specialist. Kirsten said she would refer me. She would make me an appointment to see him and also told me about the other services that are available. I thought she was talking about the health centre. Last week I had an occupational therapist, a dietician and a physiotherapist all come home to see me.
Interviewer 1	Wow!
Bertha 2	I think its absolutely marvellous. Its incredible. Our doctor is very good, but she's not a specialist. She said to me do I want to see Kirsten and I said yes. It was so nice to sit and talk to somebody that understood how you *felt*. You know because our doctor's a very nice lady and she's very sympathetic but as she said, she may only see a dozen people with Parkinson's, but Kirsten deals with it all the time.
Interviewer 2	So for these two years… was it your GP who originally said you had Parkinson's?
Bertha 3	She confirmed it but I virtually diagnosed my own problems. Because what happened… I had problems for a couple of years with an enlarged thyroid. That's a family thing – my mother and my sister both had it, and they tried suppressing the thyroid with drugs. I had drugs to stop it working and then Thyroxine to counterbalance it and that went on for two or three years. Then they said they would do … they would suppress the thyroid with radioactive iodine and I was going back for check ups. I was feeling terrible and I went I had to have regular blood tests. I had a blood test and the doctor said all your thyroid levels have been steady now for six months.
Interviewer 3	Right…
Bertha 4	So I said, well if my thyroid levels are steady, why do I still feel as ill as I do? And he said well I'll do another set of questions. And my husband had said to the doctor, we have got a feeling that we know what the problem is. Because at the time there had been a lot of publicity with Michael J. Fox, who is a very young actor who had serialised his life story in the paper. I had read it and with these symptoms that I'd had I felt were the same as what he was talking about.
Interviewer 4	Yes. You could recognise what you felt.
Bertha 5	So when I said to the doctor, "I think I have Parkinson's", he said, "Well that was my next set of questions and set of tests". And he confirmed it. But I suppose they would have got to it but I just had a feeling because there were so many things, like walking into things and dropping things and shaking and just feeling generally unwell. But I thought I'm not a stupid woman. I'd read all these things about Parkinson's and I thought that is what it is.
Interviewer 5	So you basically had diagnosed yourself?
Bertha 6	Mmm… Yes. I am not saying they wouldn't have diagnosed it. It was just the fact that at that time the book was out. We got the book and read it and I thought I'm sure that's what … that I've got the same problem.
Interviewer 6	Mmm… Thinking back, when your doctor did say, "Yes, I think it is Parkinson's"…
Bertha 7	It was a relief to know what the problem was. Because I knew from my mother and my sister. They both had their thyroids surgically removed because they had more worse problems than I had. But I thought once their thyroid levels were steady, they felt fine. I thought well if my thyroid levels are steady, why am I feeling as bad as I do? So in a way I was relieved because I was beginning to think that it was MS or something even more serious, you know?
Interviewer 7	Hmm… a lot worse.
Bertha 8	Yes. So when they confirmed the diagnosis I was relieved in a way because I knew I hadn't got a life-threatening illness.
Interviewer 8	It actually came as a relief?

Bertha 9 Mmm… It did.

Interviewer 9 And presumably once you got your diagnosis it could start to get treated?

Bertha 10 Yes, within a very short time having been put on Sinemet I felt so much better that we knew that it had been the right diagnosis.

Interviewer 10 And so just recently your GP said that you should be seen by the PD clinic?

Bertha 11 Yes. Because what happened was I was talking to her and I said to her… she increased my tablets to three and she said she would increase them to four because I said I feel I haven't got outward tremors but I feel shaking inside. So she increased the tablets to four and I was saying to her about having never seen a neurologist. So she said there was no hard and fast test that would show it up but we are convinced that's what's wrong because you are so much better on the tablets. She said there is a Parkinson's clinic in Harold Wood, would you like to see them? So that was in April that I went to see Kirsten and …

Interviewer 11 … And then they confirmed the diagnosis.

Bertha 12 Yes. That's right.

Interviewer 12 And how did that feel? Were you expecting that?

Bertha 13 Oh yes, because I know how much better I feel for taking the tablets, because if I forget to take one or am late in taking one I start to feel a little bit shaky so I know they have explained that the body cannot store the chemical and they are not short acting but they don't last indefinitely. You've got to take them at the right time. When I take a tablet I set the kitchen timer for the next one and that's become a regular habit now. And so I set the alarm clock to take the first tablet in the morning so I have a biscuit and a drink of water before I've even got out of bed.

Interviewer 13 So you've got into a routine.

Bertha 14 Yes, yes. But these were all things that Kirsten had told me to do. And it was so nice to talk to somebody that understood how you were feeling.

Interviewer 14 So before then you hadn't felt that there were people how had understood how you were feeling?

Bertha 15 Oh, well I say that my doctor has been very good but she's not a specialist in the subject. So … and I do get… I must admit that I do get days when I'm feeling very low. I had an arthroscopy done on my knee because of a cartilage problem. But they've told me I've still got arthritis which I can't do anything about. What with one thing and another I've been feeling a bit down recently. I expected the arthroscopy to be a miracle. I really thought I was going to be running around once they'd done that, but it hasn't worked like that. So the doctors have put me on a mild antidepressant. She said again that depression is part and parcel of Parkinson's.

Interviewer 15 That's right. I think nearly half of people, 40% of people with Parkinson's have depression.

Bertha 16 But my husband's very good. He's always been caring, but in the last couple of years … we're both retired… he's done a lot indoors which he didn't do before because he was working. But he helps and he's also good in that he makes me get out.

Interviewer 16 So he's a good motivator.

Bertha 17 That's right. I think it would be very easy if you were on your own just to give up. Cos I'm quite happy to read, do crosswords and do knitting, but if I'm with him we go out somewhere. I think he's very good in that respect.

Interviewer 17 So he's changed. And adapted because of the Parkinson's.

Bertha 18 Yes… Yes…

Interviewer 18 Do you feel *you've* changed since having Parkinson's?

Bertha 19 Apart from the fact that I get a bit down sometimes... but I don't ... it's just a general feeling of being a bit low. I don't sit down and think, "Oh, why me?" because I think I could have been diagnosed with some terrible life threatening cancer or something like that. So, no I know I can live with this but I'm just ... I get a bit low at times because I feel... I can't do things that I want at times ... I can't do things that I *want* to do.

Interviewer 19 So it limits you?

Bertha 20 It does limit me. I mean I can't walk as far as I used to. I used to like walking, but I can't walk as far. We do the housework between us which I feel is fair as we are both retired now. I can Hoover and do things but if he says "I'll do the Hoovering", I'll let him do it. But I still do the cooking.

Interviewer 20 It's important for you to carry on...doing the tasks that you would normally do.

Bertha 21 I don't want to give in. But ahhmmm... it's just sometimes you do feel a bit down in the dumps and you think oh you know. I suppose it's part and parcel of getting old, and being retired is a different stage in life. But ah... I have a good family... we see a lot of the family... so ... we have very good friends who live in the road. We nearly all moved in virtually the same time and our children grew up together, so they are friends as well as neighbours.

Interviewer 21 And your friends have been supportive?

Bertha 22 Oh yes.

Interviewer 22 Did they react any differently to you when you told them that you had Parkinson's? What have people's reactions been?

Bertha 23 Mainly, although they were perhaps ... not surprised ... the same as I felt... it was a relief to know what it was. Because, as one of them said, and it's very touching, she said after a couple of minutes, "We've got the old Bertha back again".

Interviewer 23 They could see a change?

Bertha 24 Yes. Because my friend who lives three or four doors up said, "Oh we had been worried about you, wondering what was wrong. But she said it's nice to know that alright, we know you have got something wrong with you, but it's *treatable*. Because they knew somebody whose husband used to work for years and she said that you could live with it for years. And so it was really a relief to everybody to know what the problem was.

Interviewer 24 Because once you had identified the problem then it could be treated and it seems like you have taken the perspective of well life could be worse, at least it is not anything like MS or...

Bertha 25 Yes, that's right. What's that other one? Motor Neurone Disease. When you begin... your mind works overtime. And you begin to think, "well what *is* wrong with me?". Because I used to work and I was going to work only because Ken had retired and he could take me because it was in Harold Hill and it was difficult on the bus, so. He used to take me and bring me back again. I was working three days a week. I was *trying* to cope with that but the only way I could cope with it was taking tranquillisers. The doctor gave me Valium because she said she still though the thyroid was out of sync. But when I told them what the problem was they made me redundant. They worked it so that they could make me redundant because I was 64 so you'd be retiring next year anyway. So they made me redundant and were very generous to me. But ahm... it was an effort sometimes if I had to walk down the road, to put one foot in front of the other. Everything was too much of an effort and I got very depressed but within a month or so of taking the tablets I felt 90% better. I felt like the old me again, you know?

Interviewer 25 I was just about to say that. Like your friends were saying. We've got the old Bertha back.

Bertha 26 That's right. Yes. Yes.

Interviewer 26 What meaning do you feel Parkinson's has in your life? What meaning does it have to you?

Bertha 27 … Well its an inconvenience more than anything. Just the fact that I can't do everything the same as I used to. I know I've slowed down and I find that if I do get worried or worked up about anything I start getting this panicky feeling. But it hasn't made a tremendous difference to our lives because I feel life would have probably slowed down a bit anyway…

Interviewer 27 Coming up to retirement…

Bertha 28 Mmm…

Interviewer 28 But it's more of an inconvenience?

Bertha 29 Yes. Oh yes. And with all the help that's been offered, I just can't believe that all these people come home *to me!* They said about this care centre and Sarah said she has got my name on the list and I thought I'd probably wait for months and then I got a phone call to say that somebody was coming, and then somebody else and then somebody else, you know and I thought I can't believe all the treatment that is available.

Interviewer 29 So actually having the diagnosis and seeing the right specialist has actually made you feel a lot ….

Bertha 30 Better about it. Because I know now that because as Katy said, if you are worried about anything, phone up. If there's something happens which is new to you and you are not sure, if it's the Parkinson's or not, ring us and we can talk it through. And being able to talk it through with somebody that understands exactly how you are feeling is marvellous. The doctors have been good but if you phone the doctor you might wait a week for an appointment, and then as I say she is very good, but as I said she doesn't see that many people with Parkinson's, so she doesn't understand all the symptoms.

Interviewer 30 Whereas at the PD clinic they are so used to it as they see people every day. They are there for you.

Bertha 31 That's right. Because it was like even I know I was walking badly and when the occupational therapist came I said to her I feel as if I walk flat-footed. She said well you do because this is the first thing that can be affected and instead of walking heel-toe you are walking … you are a bit off balance. You are walking differently. And even little things like that being explained …

Interviewer 31 So in a way it has made things more normal for you

Bertha 32 That's right. You don't feel that you are on your own.

Interviewer 32 Have you met any other people with Parkinson's? Have you joined any groups?

Bertha 33 No. I haven't joined the… I have joined the Society but I haven't been to the meetings because I am a bit of a coward in that respect because I don't want to see people worse. I am quite happy going along as I am at the moment but I don't want to know what is going to happen in the future.

Interviewer 33 Is that where your main worry is?

Bertha 34 Yes. Because I have seen… Because I go to WI and there's a lady there who has Parkinson's and she has had it for a long time and something… I saw her… I don't *know* her but I saw her. And she's like this the whole time and thought oh God I might get like that one day. So this is why I don't go. Because then I got home and I was really tearful about that. So I would rather cope day to day. Well I know… I've read books... I know what can happen in the future but I just want to cope day to day.

Interviewer 34 That's the way that you cope.

Bertha 35 Yes. Yeah. Not think about the future.

Interviewer 35 Has it made you feel any different about your body? I know that you've had thyroid problems and you've dealt with that… How do you feel you have adapted to your body… changing? Do you see your body differently?

Bertha 36 … I get annoyed. Particularly in the night, I've got to get up to go to the toilet and I've got to stand and get my balance and sometimes when I'm doing things. I find it difficult now to… sometimes to undo a jar… or if a thing's all sealed up with polythene I don't feel that I've quite got the co-ordination that I had before. Although I *do* it, it takes me *longer* and I do get annoyed with myself. But I can't say that it's made *that* much difference. The dietician's been .. you know … to discuss losing weight, which I've known for a long time I need to. Again, I think she was very nice. It's just the fact that you feel somebody *cares.*

Interviewer 36 Someone who's understanding and that you're not alone.

Bertha 37 That's right. Yeah.

Interviewer 37 Did it feel that you were coping alone, or felt isolated with the Parkinson's at the beginning?

Bertha 38 Ahmm… at the beginning I did, I did feel like that but friends have been very very good. If I was on my own … if I needed anything there are half a dozen people.. if I'm desperate for help I know there's someone there. And … no everybody's been very good about it.

Interviewer 38 The support from everyone has made you feel that you don't have to cope alone.

Bertha 39 Yes. That's right. And another thing. When I went to the clinic, because it's in the Disablement clinic, seeing all these people in wheelchairs, having artificial limbs fitted, I thought what am I complaining about? It made me feel quite humble really and I felt a fraud… I said to Katy, "I feel a bit of a fraud, because I can do most things". When I see people with one limb or lost both legs and had to have them amputated and are having to have new *legs* fitted and he was saying, "Oh I told them I wanted new ones, not like those old ones", and they were so *cheerful.* All these people. I felt like, well what am I *doing* here. I feel as if I shouldn't *be* here.

Interviewer 39 It made you feel really humble?

Bertha 40 It *did.* Yes.

Interviewer 40 It gave you a new perspective on things.

Bertha 41 It did because I thought there's always someone a lot worse. So we cope. With my husband's help and the family, we cope very well. The only thing is… one silly thing… I do feel … cos when … just before my first grandson was born… he was out in November, just before I was diagnosed. And I feel I missed his babyhood because I couldn't hold him. I was frightened to hold him. Because I thought I might drop him and that's the only thing … regret that I've got. I don't feel that I … I missed out on him being a baby, because by the time I was diagnosed it was the April and it had been four or five months and I just felt I missed out on him being a baby, but that's the only … The big regret. It's a minor thing only but it made me upset because whenever they said to me "Do you want to hold him?", I would if I was sitting still and he wouldn't wriggle, but as soon as he got bigger I was frightened to pick him up. But then I was diagnosed and put on the right tablets so the problem sort of cleared itself. He's a bit of a handful at the moment – terrible twos! Yeah. But they are expecting another one in January so perhaps I'll be more involved with that baby, you know.

Interviewer 41 So in a way you'll be able to make up for the other baby.

Bertha 42 Yes, that's right. They didn't ask us to babysit or anything. My son said, "You can just about be able to cope with yourself, you can't cope with a baby as well". So I felt I missed out on the early part of his life. So that's… the only regret that I've got really.

Interviewer 42 But generally it's got better. Even though you do have the fears of the future you are coping with things every day. Has it made you change the way you live your life in the things you do now that you didn't do or the things you don't do know that you did?

Bertha 43 Ahmm… We're not worrying too much about … the future as say when we retired. We think we'll make the most of the time that we've got. Because no-body knows what you've got anyway. But where we were holding money back to think well we'd have that when you know…. We think well now sod it let's spend it! [*Laughs*]. Let's do things. We don't go abroad for holidays because my husband can't cope with the sun. I've got this terrible fear about flying anyway, but we do have quite a few breaks in this country and where we were saying we've got to keep money behind us for emergencies, we think well let's spend it and spend it while we can enjoy doing it.

Interviewer 43 So it's had a positive effect, in a way.

Bertha 44 In a way, yes. I mean I get annoyed with myself because I can't garden anymore. Not so much the Parkinson's, but because of my knees I can't bend from the knees as well. I used to love pottering about in the garden. It's a mature garden. We filled it with shrubs and I used to enjoy pottering around in the garden. If I do weeding I've got to bend from the waist and it gives me backache and sometimes I feel a bit light-headed when I get up again. It's the silly little … probably inconsequential things but they *do* affect your life.

Interviewer 44 Yes. The little things. But it's when there's a lot of them.

Bertha 45 Yes. Yes. Like when I cook the dinner sometimes. I mean I do still manage to cook every day. But there are some days when I think I wish I hadn't got to cook today. But I'd be quite happy just to sit and then I think no you've got to make yourself do it.

Interviewer 45 The easy option is not to do it and for someone else to do it.

Bertha 46 Yes. Well my husband can't cook, he's hopeless. So we do … I mean he'll always say "Do you want me to do anything?", but … like if I'm preparing vegetables I'll sit down in the kitchen rather than stand up where I used to do them so…

Interviewer 46 You've adapted to …

Bertha 47 I've adapted to things like that. And if I'm doing ironing I find that difficult to stand for any length of time. I seem to get a little bit wobbly. So I do a few bits and sit down for 5 minutes and do another bit. So… I can cope with things. It takes me longer but I get there.

Interviewer 47 Yeah. Yeah.

Bertha 48 It's not the end of the world.

Interviewer 48 Do you feel you have come along way? Have things changed over time since you've been told you have Parkinson's? … Your perspective on things or the way you feel within yourself?

Bertha 49 [*Pause 5 seconds*]. Only as I say that you feel you live for today. You see so many people saying we've got to save for this, we can do this, we can't afford to do this we can't afford to do that. And I feel … "Do it". And that's the most important thing about how I feel about it at the moment. No-one knows what the future holds. I mean I saw it with my husband's parents who used to say "We got to save for our old age. We've got to save for our old age". And then she had a stroke and died at 66 and he had lung cancer and died the following year and I think with all the savings for their old age and they never did anything. So…

Interviewer 49 So it's made you feel that it's all very well saving but then you have to *use* those savings. Because you don't know what's round the corner.

Bertha 50 Yes that's right. I mean Parkinson's not a killer but something else might be. So I think you see this so often so you have to enjoy your life. We have a good social life and we were away this weekend. It was a friend's 60th birthday so there are sixteen of us all going to a hotel for 14 days to celebrate.

Interviewer 50 So you've not allowed it to impact upon your social life.

Bertha 51 No. I did first of all … I did feel that I was a burden to people. I must admit because when I was first diagnosed – the first summer – we normally go away with the same group together.

We‘ve always done a lot of walking and I got quite upset because I couldn’t walk as far and I said “I don’t think I’d better come on holiday with you anymore” and they said “Don’t be ridiculous. It doesn’t matter to us. We’ll adapt the holidays to do what you want to do”. And I said “I’m quite happy to walk so far and then I can sit and watch the world go by if you want to walk further”. And everybody has been so understanding about it. The first year we did turn down invitations because I didn’t want to … didn’t want to mix. I didn’t want people to see me until I’d got myself on the right footing as it were. People have said, “No don’t be silly, it doesn’t affect the way we see you in the slightest. You’ve still got to come on holiday with us and we’ll adapt the holiday to suit you”.

Interviewer 51 Was that difficult for you to hear?

Bertha 52 It was difficult in the beginning because I felt I was holding people back. Because my husband used to say… I’d say to him “Look, you go off and have a happy walk. I’m quite happy” - if we were home or wherever we were on holiday. I’d say well “If you want to go off on a long walk, I’m happy to sit here with a book “ or we’d walk so far and I’d find somewhere to sit. But he wouldn’t. He would stay with me and that would make me feel guilty. But now he’s accepted the fact that I’ve got limitations and he will go off … and I’m quite happy.

Interviewer 52 So you’ve all adapted to it. At the beginning you were worried about how they would see you.

Bertha 53 Yes. Yes. And as well at the beginning I used to get feelings that are quite common in Parkinson’s. I would be with people but I was on the outside. You felt slightly detached from people. You weren’t really… there. I mean I didn’t realise in the beginning but again this was part and parcel of the Parkinson’s, when the doctor explained it to me that it was normal. I’ve heard that some people feel as if they freeze when it gets worse but as soon as the drugs get into the system… I was with people but I wasn’t. on the outside looking in.

Interviewer 53 You feel as if you couldn’t engage in conversation.

Bertha 54 Yes. It was difficult. It was an awful feeling. People used to talk to me but one of them said I had a vacant…. I’d be talking to them but it would be an effort to make myself do it. Sometimes someone would say I’ve got a vacant expression on my face and I’d think, “Oh God, people think I don’t care”. I did but I couldn’t do anything about it.

Interviewer 54 Yes. Because it is part of the Parkinson’s. They call it the mask-face.

Bertha 55 Yes. I mean we used to go to a lot of dances. I can’t dance like I used to because my co-ordination has been affected slightly. But I still like to go because you are still talking to people and joining in. And we like quizzes. We do a lot of quizzes. And I must say I’m not giving that up because, touch wood, my brain hasn’t been affected. I’ve got a very good memory and we do like doing the quizzes.

Interviewer 55 So from a physical perspective, it’s stopping you, restricting you, slowing you down on the things you would have normally done and not thought too much about.

Bertha 56 That’s right. Yes.

Interviewer 56 And that can be frustrating and that has made you feel at time anxious and detached in social situations.

Bertha 57 Yes. It did at first but now I don’t feel like that.

Interviewer 57 Now, you’ve learned to adapt to it and others have learned to adapt to it tool

Bertha 58 Oh yes. And the friends that we socialise with mostly are very, very good. I mean I feel most times when we go to a dance, if I sit for any length of time I have a job to stand up and get my balance, but there’s always someone there who says, “Do you want a hand, are you alright?”. Once I’ve got my balance I’m fine, but it’s just that initial standing up. I used to feel quite worried because I used to think people would think I’m drunk. But then I’d think, no, my friends know my situation and if anybody else don’t know then I don’t care. I don’t know who they are and that's their problem. But that's how I used to feel at the beginning that people would think I'd drunk because I was walking badly.

Interviewer 58 Because of the embarrassment, like if you were to go to the shops and..

Bertha 59 That's right. I mean I'm alright going to the local shops because that's just round the corner but if we do a big shop, what we do is my husband takes me in the car, he'll drop me off at the supermarket and he'll either go and sit in the car or he'll wander round the other shops. But, I shop on my own because I feel I've got to do things as much by myself.

Interviewer 59 I was going to ask you that in my next question about independence. Has it affected the way you feel about ....

Bertha 60 I don't feel as confident on my own as I used to but I say, we've got this arrangement with the shopping. When I'm in a supermarket I'm ok if I've got a trolley as something to hold on to but what does get me is when I get to the till and I've got to stand at the till and wait. I get quite agitated at times. What we do now is I've got my mobile and I'll ring my husband to say, "Right, I'm coming up to the till". He'll come into the shop then and help me pack. Because... I'm slow when you are packing the things in the bag, and when you've got someone behind you who's impatient and is tutting ...

Interviewer 60 Yes... and whey you are trying to get the money out of your purse, or signing your name...

Bertha 61 Yes. I'm not too bad on that. I mean my writing is terrible at the beginning because like as I say it is just getting smaller and smaller. But I'm alright on that but it's just putting things away in the bags. So I normally say, "Is there anyone available that can help me pack?". I don't say why, I just say "Is anyone available?". But I know I am slower. My coordination has been affected and you just can't seem to get the things in the bags properly at times and undo the carrier bags. And it's little things like that which I do find frustrating. But I do as much as a can because I feel I don't want to give up doing *everything* myself.

Interviewer 61 You want to do the things you would normally do.

Bertha 62 That's right. It's just little bits and pieces that you need. Like today, he's out playing golf and this morning I had a couple of things needing to be taken to the dry cleaners and I thought I can cope with that, just going down the road and coming back. I don't feel ... because it's familiar territory, and if I did get into difficulties there are people I know. I could knock on someone's door.

Interviewer 62 Yeah. There's always someone around.

Bertha 63 Yeah. But I'm not very good now in strange situations. It definitely has affected my confidence in that respect. If I go somewhere new on my own... but having said that I have been going to yoga classes, but I know everybody there, I need to restart that... but in the past year I did do evening classes. I was doing keep-fit and yoga but I wanted something to keep my brain more active so I was going to the local school and doing evening classes and I didn't know anybody there but I went. I enjoyed it once I got there.

Interviewer 63 So you overcame a fear?

Bertha 64 Yes. But I was as nervous as a kitten when I first went. But I thought I've *got* to do things. So I felt because it was the first time I went there I didn't know where the room is and my husband came along just to make sure that other people were there and then he'd left and then he comes to pick me up again. Because I can't walk that far and I don't drive. But, ah... yes, once I'd done the first week I was alright. But I am not as confident as I say in unfamiliar territory or weird situations.

Interviewer 64 What is it about those times that makes you feel more anxious?

Bertha 65 [*Pause 5* seconds] I think the fact that I [*Pause 3 seconds*] .... I feel.... People will look at me and ... people look at me and think well what's wrong with her? Or, it's not just that... I think because I ... I just haven't got the confidence that I used to have and people will think well what's, what's.... I mean I do walk differently. I walk differently now and sometimes I walk shuffely but then I think well don't be silly it doesn't *matter* what people think. You've got to do this for yourself. You've got to *overcome this.*

Interviewer 65 Hmm... so you had that initial thought about "what will people think about me?". I mean, will they think I'm drunk?

Bertha 66 That's right. But ah... I mean once I started the classes... I mean I've always been interested in history. They covered about all the Mediterranean countries. I found it very, very interesting, but the only thing was was that they had trips to the British Museum. I mean I went on one, but I just couldn't cope with the all the stairs, up and down the stairs there.

Interviewer 66 So things can be physically more demanding...

Bertha 67 That's right. Because they do classes about discovering London and I'd always promised myself that when I'd retired I'd do those, but you do one week in the classroom and then one week on a field trip. And I thought no, you've got go backwards and forwards and you've got to go on the Underground. I'm a bit nervous about travelling now. I can cope going to Upminster because the buses are those little Hopper buses. I'm alright just going to Upminster again because it's familiar territory, but when we went to the British Museum one of the women that I'd been chatting to there, she lived in ... I met her at the local station and we travelled up together. But on my own, I wouldn't have done it. Because I worry about getting on and off the trains and the escalators.

Interviewer 67 You want to make sure that you are going to be OK.

Bertha 68 Yes. Yes. Somebody there to give you little bit of self-confidence.. a bit of Dutch courage. But that's... that's the biggest thing is the way... it has affected my confidence. But having said that, once I'm *there*, I'm fine. I can chat to anybody...

Interviewer 68 It's just that initial.. worry.

Bertha 69 Just that initial worry. Yeah.

Interviewer 69 Is there anything I haven't asked you that you feel is important? In terms of your experience or the way you feel?

Bertha 70 I don't think so. No. I'd say on a day to day basis I think we are coping very well. I mean so much help is available. They said ... I mean I said I felt quite guilty about all these people coming to see me. I said I felt like a fraud. But they said well you've been assessed, you are on the system now and if you have any problems you can ring somebody and you've got a *name.* A face to a name. It's not just like ringing somebody up. If you can put a face to them you can relate to them. I thought that was absolutely fantastic, all that. But ah... No it's just the confidence thing. Doing things on my own. I mean my mother used to live in Leyton and I used to go over there once a week on the train. But then a couple of years ago when all this started I had a panic attack on the train and I just couldn't go on the Underground again. So then I thought it would take me over. But I felt duty-bound to go over and *see* her. But ahmm.... I just couldn't go over once I'd had that panic attack. I couldn't travel on the Underground again on my own.

Interviewer 70 And now being able to cope it *physically*...

Bertha 71 With the journey and all that. Yeah. But she's moved in my sister now so we don't have that problem. That's one less thing to worry about. But ah.... No. I feel physically I'd say I feel 90% better than I *did.* But mentally, I feel... Sometimes I still... get this slight feeling of detachment. It's nowhere near as bad as it *was.* But I do sometimes still get this feeling of detachment from everybody. But as I say, my brain ... I mean we do go on these pub quizzes and they say, "We've got to have you on the team". I love quizzes. We always liked anything like that. My memory is not affected.

Interviewer 71 It's just the worry and anxiety about being *physically* able to do things and the restrictions Parkinson's imposes upon the body.

Bertha 72 Yeah. It is. I mean you are right. It's an inconvenience more than anything. You don't feel ill. You've got no pain. But it is a *frustration.* Because you think, "Why *can't* I do this?". I mean I was opening a new pack of tea-bags. You know they're all sealed with cellophane? Well you've got to stick a knife under it and I can't ... that's when I get annoyed with myself. Because once upon a time you'd do that without thinking about it. But sometimes it's the little fiddly things that *do get irritating.*

Interviewer 72 Yes. It's interesting that you say that it's not like an illness where you feel ill. You do you actually feel?

Bertha 73 Well. It is an illness, but I'm not in pain. And I know that if I don't take my tablets regularly, I start to feel shaky. So I know that the tablet, if I didn't take *those* I would feel bad again. But ah.... No it's .... I think of it as Parkinson's Disease and not as Parkinson's as an illness. An inconvenience really more. It's a ... funny thing. I mean I've heard of people who've had it for more than 25 years. Alright I mean they might finish up in a wheelchair and that's why I don't want to think too much into the future because I might get like that. Alright I'm 66 now, and I've had it for 2 years. Alright I might need more tablets as it progresses and I might get less mobile. This is why we'll do the things we want to do *now.* I try not to think too much about what could happen in the future. But ah... I mean I've got a good example in my mother. I mean she's 86. She had both knees replaced and both hips done twice with arthritis and she still gets out and about. Alright not as much as she used to but she still says "I've got to make the effort" and she tries to and I think well I've got a good example. Because I am .. basically... I take the easy way out. I'm not *lazy*. Yeah. I will take the easy way out. I mean sometimes I say to my husband, "Do we have to go out? Because I'm quite happy staying in and reading a book" and he says, "Come on. We're going out". So we do actually get out every day. But I know I've *got to do that.* I know it's for my own good. But if I was left to my own devices I would take the easy way out. I could easily become some type of couch potato you know!

Interviewer 73 So you might have to struggle against it?

Bertha 74 Sometimes I do. I mean it's an effort to make myself get ready. One day last week I had to go down the road and get something and I kept putting it off saying "I'll go in a minute. I'll go in a minute". Well, by the time we'd got changed and got ready it was about 4 o'clock but I could easy take the easy way out.

Interviewer 74 So you've got to mentally ... take the other route.

Bertha 75 Push yourself, yeah. That's right. I mustn't give in to it. I've got to make myself do as much as I can.

Interviewer 75 Right. So I think you've answered all my questions. It's been really interesting to chat with you and to hear what your experiences are and how you cope with it and your feelings about having Parkinson's disease.

Bertha 76 Have you interviewed many people?

Interviewer 76 I've interviewed now 4 other people.

Bertha 77 And do you think they've had the same sort of reaction?

Interviewer 77 There are a few similarities. Like you've said, some people say they won't let it get the better of them. That's quite common. Also feeling that it is an inconvenience and that it slows you down. If you want once I've done the research and analysis I will write to you with a summary of my findings.

Bertha 78 Oh yes that will be interesting.

Interviewer 78 And hopefully once I've done the research I'm hoping this will influence services for people with Parkinson's, such as having a psychologist or counsellor in the team.

Bertha 79 I think having a counsellor in the team would be a good team because I think often the mental aspect is as important as the physical one. There are drugs that can help with the physical side but… you know you need to sit and talk to somebody about the mental side of it.

Interviewer 79 Well, like you said, it is important for you now that you realise there are people out there, you are not alone and people can understand what you are going through. And you have gone through a lot of changes yourself in terms of how you have adapted to living with Parkinson's.

Bertha 80 Yeah. Because you know, I think it would be a good thing because I'm lucky I have got a very good husband, I've got a good family but if it was a person on their own they could because very …. Very depressed. We are lucky we have got support around us because I've got two strapping sons and they won't let me give in. I mean we had them all round on Sunday and we had a barbeque. And my eldest son said… I said something about a cup of tea and he said, "Well go on then". So I said, "I thought you were going to make it for me Nick." He said "There's nothing wrong with you. Go on. You can make it". You know and they … it is said in a joking sort of way but I know they are right. It is good for me to keep doing things. Where if…

Interviewer 80 Rather than giving it to it.

Bertha 81 That's right. I made it but I called them when I'd made it. I'm not confident enough to carry a tray as there's steps to the garden. But I made it and poured it all out. Yeah. I said about the cup of tea and he said "No you go and do it. There's nothing wrong. You can do it". They're right… you know? But they don't treat me as if there's something wrong.

Interviewer 81 Sounds like you have a good family.

Bertha 82 Yeah. We have yeah. They are very good. I mean both their partners are very good. They've got a little one now. He's a little demon! But he keeps me on my toes. It's a nice thing because I feel now I can cope with him now he's talking and charging around. He takes me by the hand and says "Come on Nan, *you do it.*". And I think make myself do things for his sake as well. But we take him out, go to the park, you know. He says "Come on Nanny". I mean I can't *run around* but…

Interviewer 82 You have to do the things that you still can do.

Bertha 83 That's right. I wouldn't say I would do it on my own. I mean I need my husband there as well. Because if he were to suddenly dart off I wouldn't be able to catch up with him. I can't run. But with the two of us there we do cope with him. He's pretty good. And it does keep you on your toes.

Interviewer 83 I'm sure, especially at that age!

~~"Josephine"~~

"Edith"

Interview 5 – 27th May 2004 JS △ 2004

AS So when was it that you were given your diagnosis?

Very quick initial diagnosis

① JS I went to the doctors in January and he was not at all interested in the fact that I'd just come in for a repeat prescription. He said "Could you just do me a favour, and walk across the room?". And I walked across the room. And he said "When I call your name I want you to come back ", and I did and came back to his desk and he said, "You've got *Parkinson's*". He said "I'm 99.9% sure you've got Parkinson's". He said it was something to do with the muscles in my face. When I told Professor Findley, he said "I wouldn't know because I wouldn't know what you looked like before, but the GP knows you" and he said "He's a very good doctor to notice that."

Disbelief, shock, unpreparedness for this diagnosis

Shock at diagnosis! Unprepared.

Disbelief.

AS So what went through your mind when he said that to you?

② JS Well I was dumbstruck! Because I hadn't gone down there for that. I had my leg kept shaking. My right leg was shaking and I'd told my doctor this a long, long time ago. But it had never really got any worse. And then I'd been a few times for repeat prescriptions. Not for *that*. And when I went down that night and he told me I thought well how did he see that just in my *face*? I when I got home I just stood in front of the mirror, looking for what this was that he'd seen. I still haven't found it *now*.

AS So it was difficult to see what he *saw* and knew so *accurately*?

Had seen mother suffering with PD + Alzheimers

Little knowledge about PD

Mother had PD + Alzheimers

③ JS Yeah! Straight off. He said "You've got Parkinson's". My *mum* had Parkinson's but I don't know if he connected the two at the time. I said to him my mum had Parkinson's, and he was her GP as well. And it was only what six years ago that she died. And I told Professor Findley – thinking about it – it was wrong, that *she* had had it about six months to a year, but that was only when the shaking started. But until then I mean she had Alzhiemer's and lots of other things besides. So until then we'd been putting it all down to the...

AS The Alzhiemer's....

Dramatic effects of meds for PD

Difficult to diagnose with certainty for a long time

Effects of drugs had dramatic effect upon mother.

Hadn't ever recognised her illness as PD.

④ JS ... yeah and her age and Parkinson's had never entered our thoughts. Until she had to go into a nursing home and straight away I said to the matron, she's shaking, like. And she said "It's Parkinson's". But she had no tests or anything for it. They put her on tablets and she stopped shaking. Within *two* days she'd stopped shaking. And she was really ... sort of at peace then. Because every time she'd have a cup of tea it would spill and it was getting more. That's when we noticed it. I mean I don't know, she might have had it for years.

AS She may have done. Like you were saying, looking back... the sense of smell, the writing and other things.

Others do notice effects of PD in her

Loss of prior skills which not taken pride in.

Loss of prized abilities.

Others now do notice the effects of PD

⑤ JS Yeah. You just don't. I mean my granddaughter, the oldest one, said "Oh gran! Don't you write small?" and I said "Yeah", and I thought "Yeah I do write smaller, and squiggly". It's horrible because people used to say to me, "Write me a list of so and so. Your writing's nice".

AS So people had always admired your writing.

PD as a strange illness in its disjointed effects on the body.

PD as a strange type of illness

⑥ JS But they wouldn't want to know now. It's right scruffy!. And it's a weird sort of illness. I can't get out of the car properly. I mean you wouldn't connect that with your handwriting going squiggly, would you?

AS So it affects the whole of your body, but in different ways.

Perculiar disease.

⑦ JS It's perculiar.

AS With your mum having had Parkinsons, do you think that's had an impact about how you feel about having it?

Faith in meds as treatment

Faith in meds.

Insensitivity/ ignorance of some people in their comment/ reactions

Other people's knowledge + reactions can be shocking/ insensitive.

⑧ JS Probably. Because I know you can't cure it. But because I saw my mum shaking and because on the medication *immediately* she stopped shaking. Well I'm on different medication to her because of my age. But I think it did make a difference to me. My hairdresser for instance, said to me, "You alright?". She could feel couldn't she? Because she was feeling my head and could touch it. And her mum had Parkinson's. And I said to her, "Trust you! I've just been diagnosed with Parkinson's". So matter of fact she said "Oh don't let it worry you – you'll be out of your head anyway before you die. You just go doolally and you don't know nothing about it". And I thought "Crikey. I ain't half glad I know the difference". Cos she could have really. Cos she didn't know … I'd have thought "Cor, crikey. I don't want *that*".

Helped to have prior experience + knowledge about PD.

Helped to have a prior knowledge about PD.

AS So having known all about it it's helped.

⑨ JS It's helped. Yeah definitely.

AS But it was a shock because you hadn't expected to hear that you had Parkinson's, because you'd gone about something else.

⑩ JS I've been forgetful but then that might be nothing to do with my age as I've always been forgetful. I run upstairs for something and I think "What did I come up here for?". I mean that could just be me anyway.

AS Sure that's right, or if you've got a lot on your mind you might forget things.

⑪ JS That's right.

Changed the way she lives her life

AS So, has it changed the way that you view your life?

⑫ JS Yes, yes it has.

Do things now, whilst she can

AS In what way?

PD won't stop her from doing things she likes to do.

PD is just an illness to her which ultimately could stop her doing things in the future – so she's making the most of her time to do things now

⑬ JS I feel now that … I should do what I want to do. Might as well do it now as I might not be able to do it later. That's not the *Parkinson's*. I could have something else and it would stop me from doing whatever it is I want to do.

AS So it could've been anything?

"Live for today + not for tomorrow"

⑭ JS It could have been anything. Because it's Parkinsons. Really Parkinson's is nothing. I mean it could have been something a lot worse.

AS Yes.

Decision to deal with the fact she has this illness

(15) JS And I just think, "Well you've *got it*. You've got to get *on with it*.

Decision made to deal with it now she has the illness

AS Mmmm.... To make the most out of the things you can do *now*.

(16) JS Yeah. And then later on if I can't do something well I won't *like it*, but I'll have to get on with it. But hopefully if they get the prescription like. I mean I've only been on it for 13 days today. It's not long. Not really in my system yet is it? I'm still shaking a bit. The other thing I don't like is it makes your feet swell. I know it's funny but when you ... they're coming up now. Now give it another sort of two hours, they'd be right up like balloons. That is the Parkinson's. I don't like that. If you want to wear nice shoes, you can't. If you want to wear a nice skirt you can't. Well you can, but ...

Must accept the illness.

PD's effects on the body restricts pleasure in wearing nice clothes etc.

Symptoms restrict her from wearing nice clothes.

AS But your body is changing ...

Body has changed so quickly - deterioration.

(17) JS Well I suppose it's gonna change anyway as you get older. But it seems to have done it all in one go. It seems to have changed.

Dramatic bodily changes

AS And like you were saying, it's kind of accepting your body in different ways.

Altered her pleasure in small things - no longer enjoys some things.

(18) JS Yes. I can't get in and out of the bath. And I *love* having a bath and now I don't like having a bath.

Altered her sense of wellbeing re things she used to enjoy, which she can't now.

AS It's changed...

(19) JS It's changing things like that. It's little things that I can't do but I'll insist that I can do it. I *make* myself do it. Another thing is that my brother-in-law is in a wheelchair. He has been for years... because of an accident. He'll want to get a newspaper and someone who's there will pick the paper up for him. And he'll look up. And he's said before to me, "People will do things for you. Don't let them". He said, "If it comes to it, be rude and say ' I *don't* need your help'". Because it's so easy to fall into the trap of somebody waiting on you hand and foot.

Makes herself do things.

Determination not to give up.

Will for independance/ self reliance

Dislike of others helping her.

AS And always needing someone.

(20) JS Yeah. He said there will be some things that you can't do. Like I can't do shoelaces up. I can't bend down far enough. I can do the laces up but I can't get down there to do it. Silly things...

Frustration at disabilities re everyday tasks.

Physical restrictions.

AS So there's lots of little things, and obviously some big things like having to get out the bath. That has restricted you *doing* things, but it seems like you are determined not to let things get the better of you.

Social embarrasment

(21) JS No.

Feels self-conscious

AS You want to be independent and do things for yourself.

Embarrassing in social situations eg shopping. Feels self-conscious.

(22) JS If you can. When you go shopping ... I don't go on my own. I can't get the money out my purse quick enough. And my friend said to me last night, "So there's a *queue*, let them *wait*! You're at the *front* of the queue". And I said , "Yeah well it's rotten Pat. They're all queing up and it's getting longer".

Panicky + embarrassed in social situations at times

AS So it makes you panicky.

(23) JS And then you get panicky and then you get embarrassed.

Panicky + embarrassed in social situations that require dexterity / co-ordination.

Viscious circle

Anxiety breeds worsening of symptoms

Panic/anxiety makes symptoms worse.

AS And does the panic then make it worse?

(24) JS Yeah. Cos then I'll start *really* shaking.

AS So your friends perspective was "Don't you worry! They can wait!". But … at the time it can feel a bit anxiety provoking…

Determination not to be beaten by this illness

Fight this battle with PD. Must not give in.

(25) JS But I won't let it beat me. I won't.

AS No. But it sounds like you've got this fighting spirit in you.

Easier to give up, but refuses to

(26) JS It would be so easy to sit down and say "Oh, I've got Parkinson's" and whatever. But maybe I've been under a hospital since I was 10 as I've had a kidney removed. And I've got loads of things wrong with me over the years. It might be that I've got used to going up hospitals, seeing doctors.

AS So it's not so much of a hassle to go and see a doctor.

ACCEPTANCE

Acceptance of the illness

(27) JS No. No. you know. People say "Oh, you are funny. Doesn't it worry you what you've got?" and I just say, "It worries me but you know, if you've *got it*, you've *got it*. You know, if it's not curable, it's not curable".

Acceptance of having to deal with the illness now she's got it.

AS Hmm… and you've just got to accept it?

(28) JS Yeah. But it might be because I've been under doctors for a long time.

AS It could be. Because you are used to coping with medical problems.

Prepared about what PD is through mum's illness.

(29) JS And my mum – my mum was ill. So… I've sort of *seen* it.

AS Yeah. You know what to expect. It's not the *great* unknown.

Others' insensitive/scary stories.

Be careful telling people as they can say insensitive + shocking comments.

(30) JS Yeah. And Prof. Findlay… Be careful what you tell because they come up with some real horror stories.

AS Like what happened at the hairdresser's…

(31) JS They'll say you'll go out your mind and … *some* people will but then some people will anyway.

AS Because of old age

DO THINGS NOW!

Will not put things off til a rainy day, will do things now

Determined to do things sooner rather than at a later date.

(32) JS Yes. It has made me sort of take a chance. Where as before I might have thought oh no, now I'll do it.

AS You're more likely to do something… even though you think "oh maybe I won't", you *do*.

Attitude shift towards making the most of each day. Live for today + not tomorrow.

Live for today as life is so unpredictable

(33) JS Yeah. You do. I mean I might not be here tomorrow. And my husband has always said, "Do it! Whatever it is, do it! You could walk out of here tomorrow and get knocked over by a bus". I think, "Well you're cheerful aren't you?" [*Laughs*]. But he don't worry.

AS But you've taken on *his* attitude because of what's happened.

Others too doing much for her – Loss of self reliance.

Importance of role normal – grandchildren

㉞ JS Yeah. We've just come back from a week in Dorset. It was lovely but I had to watch him all the time because it was "Do you want a cup of tea? I'll make you a cup of tea". He's doing *too much.*

Husband is tending to fuss around her since Δ

AS Have you found that then? That your husband's taking on the carer role?

㉟ JS Yeah. And the grandchildren do it, they're doing it. Even the little'en is doing it and then the second eldest one – she's the only one that's picked up on the shaking or said anything about it. She keeps getting hold of me and holding me like that [*Show's me*] and she says to me, "Stop Nanny, stop". And she has noticed it but the others I don't even think have noticed it. As long as I can keep playing with them I'm alright.

Family do notice her shaking.

Being a g'ma is v. important – won't let illness get in the way.

AS So it's made you think about the future and about the present and what you can do now. But also it seems to have affected those around you. as you were saying, people will tell you horror stories, and as your brother was saying that people will try and want to do things for you ...

㊱ JS ... Yeah.. all the time...

AS ... how does that make you feel when people are kind of trying to panda to your needs?

Social embarrassment and frustration at diminishing abilities re everyday skills.

Angry at self

Avoidance of social engagements!!

㊲ JS Sometimes it's alright. Sometimes I don't mind. But another time, I want to do it. We went out for a meal and that made me say, "Right, I'm not going out anymore". I couldn't cut the meat. I could *not cut this meat.* And I said "This meat ain't half tough" and he said "Oh is it?". "It's really tough and I can't cut it". So he said "Well you have my knife, maybe it's sharper". And it still wouldn't cut it. So I said to him, "Why can't I cut that meat? I suppose it's something else I can't do now". I was getting really mad at myself and he said "Just calm down. I'll cut the meat". He cut the meat but as much I wanted him to cut the meat, I didn't want him to cut it. *I wanted to cut it.* There was something stopping me. What it is I don't know. I couldn't cut it – it was impossible. I would have just said oh just forget it. So I said I'm not going into a restaurant no more.

Frustrating experience in public eg cutting food.

Angry at self for inability to cut food up.

Upsetting that husband had to help.

Put her off going out again for food.

AS Because you were so angry and not...

㊳ JS ... being able to do it.

Had previously taken things for granted.

AS Because that's something that you've done all your life and have taken it for granted...

Previously taken abilities for granted.

㊴ JS ... That's right. I think that's it. You take too much for granted. But like I say you never know what's round the corner. So do it, whatever it is that you want to do, do it. While you can.

Do things whilst you can!

Do things you like now – while you can!

AS ... That seems to be the main shift.

㊵ JS The week before last I had a phone call to say that one of my friends had been killed. She was in America and she went to turn right. She was driving. But she had an American licence so she was used to driving there. So she was going to turn right but someone's come straight across the road and hit into her. And her head's gone straight into her husband's and smashed his jaw and bruised his brain and she was killed. And I didn't half shake then. That really sort of... And I said to

Must not take life for granted.

Steve, she saved up for a long, long time for that holiday. She really wanted that holiday. Luckily she got it. I said but… she not long ago had cancer. She got over that you know? I think you've got to be determined. You can't let it get to you. if you do, well there's no point is there?

Don't take life for granted. Be determined to fight illness + live life.

Determination & carrying on as normal + fight illness.

AS Hmmm… So like you were saying you could have just sat back and said "Oh poor me. I've got Parkinson's and there's nothing I can do" but you've taken a different route. You've said yes I've got Parkinson's but there's plenty of things I can do. And maybe some things I can't do.

PD is a nuisance esp. when in social situations.

㊶ JS Yeah, it's just a nuisance. More than anything. You know? I know for a fact tomorrow when I go to that funeral, and it will be a lot worse than what it is like today. And I have told two of my friends who are going to be there. Pat said, "Don't worry, I won't let anyone come and pester you". And I said "I don't know what it's going to be like Pat, and I'm going to be in a right state". And she said "Well that's alright. We'll go to the pub when we come out". I can't go to the pub – I can't drink on those tablets! [*Laughs*]. But for me, I can't let it get me. I won't give in to it, I won't.

PD is a nuisance. Symptoms get worse in public when anxious.

Won't let PD get the better of her – won't give in to it.

Won't give in to PD.

AS Hmmm…. It's almost like Parkinson's is a *thing*.

㊷ JS It is. It's like invaded your life.

AS Like a space invader!

PD as an invader of the body'

PD as an invader of the body.

㊸ JS That's right! And I think no I won't let it win, I won't let it beat me.

Won't let it beat her

Fighting a battle against PD.

AS So it's like a battle in a way.

㊹ JS Yeah, it is in a way.

AS And you are winning it!

Fighting a battle against PD

㊺ JS I hope so!

AS Are there any questions that I haven't asked – anything that you feel is important?

Helps having had illness as a child – faith in medical profession + acceptance of them.

㊻ JS I don't think so. Because everybody else is different. As much as I can look at it that way, somebody else won't be able to, you know? But I think it is because I've had a lot to do with doctors. I'm sure it's that.

It helps that she's had contact with doctors re illness in the past.

AS You're used to…

㊼ JS … I'm used to them. I'm not scared of them. No, I'm sure it's that.

AS And that's why you are coping so well. Whereas other people who haven't had experience of hospitals or haven't seen other relatives or friends with Parkinson's – they would be dealing with it a different way.

㊽ JS Well my friend – this Pat – her step-father had it and it was about 10 or 12 years ago at the time and he was bad but then they didn't have the drugs that we've now got. And all the time… I mean that's a new drug that's he's trying me on now. I've not been on it long enough to test it.

Faith in medical profession + meds + research to help c̄ symptoms.

AS But there's hope will all these new drugs and treatments coming out and lots of research.

(49) JS Yeah. I mean I remember my great gran used to shake and we was told she had bad nerves. Well she might have had Parkinson's and they'd never heard of it *then*. But she used to shake all the time.

AS So it's to your advantage then that in this day and age we have treatments now that we didn't have then.

(50) JS That's right.

AS Well thank you so much for sharing with me your experiences and …

(51) JS That's alright.

AS … and the way you are dealing with it and coping with it and see it. I mean it's obvsiously going to really help.

(52) JS I think it will.

Uncertainty of prognosis is worrying.

AS I hope ultimately that it will improve services if not just in our borough but hopefully UK wide.

Worried re prognosis which is unknown.

with

(53) JS But it is a funny illness. Will most illnesses you are told the prognosis but they don't know it. They don't know what you're going to finish up like. That's worries me a little bit – the mental side and having things done for me. I can see there's going to be a time when I'm going to have to be bathed. I know that's goin to happen. I can see that now. I won't like it but it could be a lot worse. You know? I mean, poor old Joan, she's had it hasn't she? I think no I'm not going to give in.

Scared of being ~~+~~ cared ~~for~~ in future.

Must not give in!

Scared of being cared for in the future. Loss of dignity?

Won't give in!

AS Things could be a lot worse.

(54) JS Yeah. But it is a funny illness. There's funny things that you can't do. I can't turn over in bed – that's another one. And I think why can't I turn over in bed? And another thing – sometimes you go to do something and you can't do it. You know what you want to do but you're not doing what you want to do. Your brain's doing something different and I think "Oh! It's driving me mad". And I sit down and think "I'm going to *do it*!" and I do know how to do it and I'm *going* to do it. One thing I can't do – I used to be a very good knitter. Anything, it doesn't matter what the pattern was, there's loads of aaron stuff I made and I can't do it. I can't even… I tried the other week and I had to put it in the cupboard. I thought I'm going to make this cardigan. I'm going to do it but I can't cope with the pattern so it's going to have to be a simple pattern. And I can't knit properly. I have to keep holding it down there and sort or winding it round. I used to knit so fast. And I think, "Now that's frustrating me" and I put it back and wait a little while.

Oddness of PD!

Frustrating battle every day to fight against it.

Upset at loss of hobbies / skills because of it.

Strange illness! Odd symptoms. V. frustrating. Determined to do tasks.

Frustrated at loss of prior complex abilities eg knitting.

AS It's frustrating.

Slows body down.

Frustration.

Slowed down.

(55) JS It's more frustrating than anything else. Everything you do is slower. But why, I don't know. And all the different things that happen makes you think well perhaps that's the Parkinson's? I don't know.

Qus all disabilities to the effects of PD.

AS It's difficult to know what's the Parkinson's and what is normal…

Not clear what is due to PD + what is not.

Difficult to know.

(56) JS What ~~is~~/would be like anyway? Yeah. I mean I've got a bad back. Now that's scan's just come through for this back scan. Well I know that it's going to find out what's wrong with my back and he'll treat it and it's going to be better. Well I hope so anyway! But with the Parkinson's I've had all the scans but I'm having scan after scan and medication and all that and I know it's not going to get any better but it might halt …

Dismay at lack of cure. But faith in meds

Upsetting that there is no cure for PD despite ++ tests + ↑meds.

AS There isn't a cure but..

(57) JS … That's right, but it might be able to help it.

AS Slow it down.

(58) JS Slow it down, yeah.

AS But I can hear. If you worry and worry – you couldn't worry about the future and think about the things that you won't be able to do and you might end up being cared for.

Fears re being cared for in the future.

(59) JS Yeah. I've always said that it wouldn't worry me going into a care home and being cared for. Be alright wouldn't it? I'd just sit back and let them get on with it. But I don't feel the same way now. For somebody doing this and somebody doing that.

fearful now of the possibility of future care-home.

AS That's right. But even things like brushing your hair…

Easy to give in to PD. Must though make the effort!

(60) JS Yeah – silly things. Even things like putting make-up on properly. Then I think, "Oh, so what. I'm not bothered at my age". But as soon as I go out this afternoon. Well as soon as my friend knocks for me. If I haven't got make-up on she says to me "Put your face on" and I know she's going to say it so I do it. And when she comes along she'll say "Good. You've done your make-up".

Difficult to motivate self in the face of difficult everyday tasks.

AS So she's a great help.

(61) JS She's a help. An inspiration. But people will try and do things for me. I mean I have to stop myself with Derek. I really have to stop myself. If he says to me "Will you pass us that book?", that's alright because he's said it. But if I see him struggling to get to something I think it's so easy to get it to him.

Understands dilemma of self-reliance + help from others.

Difficulties with others offering help at times.

AS So you can see from the other side.

(62) JS I can see both sides of it.

AS You feel like you want to help.

Can understand why others wish to help but

(63) JS Say they drop something and it's on the floor and you think well they've got to bend down and get that. And he can't because he's in his chair. He's got a big stick thing that he uses and picks things up. But that takes time. I could just go over there and pick it up for him and give it to him.

AS You can see when the table's have turned.

(64) JS Yeah. Because it's frustrating him. Because now I know what Derek feels like.

AS So it sounds like Parkinson's is a frustrating illness. It's like a struggle, you are forever in a battle.

Constant battle with PD. Won't let it win!

(65) JS It's like you've been invaded in someway you know? And you are not going to let it beat you, you are not going to let it win. But it's trying all the time to win.

Constant battle with invading illness!

AS But you are always fighting it and determined not to let it get the better of you.

Determination to be self-reliant!

(66) JS Yeah. Sometimes when I'm drinking the cup will start to shake or my hand will slide round the handle. Well so now I've learned to hold it with both hands. They do do special cups but I've said I don't want a special cup. I'll hold it with two hands. When I can't hold a proper cup with both hands, then I'll have a special cup. But I'm not having it while I can use it.

Determined to be self-reliant. Will adapt to symptoms.

AS Because you don't want it to change your life and for you to become the sick patient.

(67) JS That's right.

AS You still want to be yourself.

PD makes her feel older

(68) JS Still want to be me. That's right.

PD makes her feel older.

AS How has it changed the way you view "Me"?

(69) JS It's made me feel older. I don't know why it has. But it's made me feel older. But in myself... [CHANGE TAPE SIDES]

Realises she used to take things for granted before.

AS So the difference is that it's made you feel older.

Life now centres around her illness.

Must not now take things for granted

(70) JS I Suppose it's showed me a reality. I was taking things for granted before. I mean I went to the doctors and they diagnosed angina and then they diagnosed osteoarthritis and then a couple of weeks ago they diagnosed rheumatoid arthritis and said "Oh crikey! Have you got anything else I can have?" [*Laughs*]. And he says you are being a bit greedy at the moment, keep of having these different things! I said it's not only that, I have to keep going up to the hospital to the specialist and I'm forgetting where I've got to go! My son came to meet me a few weeks back and he couldn't find me and he phoned my daughter and said do you know what time mum's appointment was and she told him and he said "I've been walking up and down the corridor and I can't find her anywhere". And she says "Dave where are you?" and he says "I'm at Oldchurch" and she says "Mum's at Harold Wood". He gone to Oldchurch and I was at Harold Wood with Dr. Shah. And he came in and sat there. He's terrified of hospitals. He's just been diagnosed with diabetes. And it's really shook him. It really has shook him. But you forget what you're saying. My speech sometimes... I know what I want to say but I can't say it. I'm actually waiting for an appointment to see an uhmmm....

Illness makes her realise what life is all about

Life now centres around illness, hospitals and treatment.

Speech is affected.

AS Speech therapist?

(71) JS Speech therapist, yeah.

AS So it sounds like a frustrating illness...

(72) JS It's frustrating more than anything.

AS ... It restricts the things that you've taken for granted like writing, or getting out the car or getting out the bath or even putting your make-up on or eating. It's so wide...

(73) JS It's all different things. You can't just use your hands properly because you can with a lot of things.

AS It's just certain things like cutting or knitting.

(74) JS Yeah.

AS But the way you are dealing with it is like "Well, it could be a lot worse". And so you are not taking things for granted now and you are doing things that you may not have done before, because you *can*.

(75) JS Because you can do them, yeah.

PD not a classic illness as such.

Defiantly independent.

AS Because you want to do them now.

(76) JS The other night we went out and we couldn't park the car near to the theatre - it was so far away. And there was four of us. My husband, my son and my daughter-in-law. She said "I'll stand here with you and you two can go and get the car". So I said, "No, I'm going to walk to the car" and she said "No you're not, you'll muck your back up". So I said "It won't muck my back up. I'm going to walk to the car". Now all three of them are against it and in the end I said "Now leave me alone! * I'm not ill. It's not an illness." My husband says, "No, it is an illness" and said "It's not an illness that makes me feel ill, it's an illness that stops me doing things. You are not going to stop me from walking to the car".

Rather, something that stops her from doing things initially.

PD is not an "illness" that is classically making one feel unwell. Rather its an invader of her body which stops her from doing things.

AS So it's not an illness that makes you feel bad or ill in the traditional sense but it's like a restricting thing...

PD is a THING.

(77) JS It is like a *thing*. That's just what it feels like. Yeah, a thing.

PD is a 'thing'.

AS But it's obviously making you feel a bit frustrated and angry especially with other people's perception of it – how they are expecting you to feel or do.

(78) JS Yes. Or this could happen or that could happen. I say well nobody knows what's going to happen. I could get run over by a bus. I used to say oh don't say that, it's horrible. Now I just say it. But I've noticed over the last few days, I've not been very good with my balance. Now I think to myself "Oh crickey, I hope I'm not going to be falling about". I still think its those tablets because I've only had them 2 weeks.

Never take life for granted. Live each day as your last.

AS So you're thinking it could be something to do with that.

(79) JS Could be, couldn't it?

AS It's not a predictable thing. But you are coping.

Keep doing things every day whilst you can.

(80) JS But they say you'll never like wake up and find you can't see or find you can't hear or find you can't do something that you could do yesterday. Gradually you'll find you can't do things. You don't just wake up and something's happened. So as long as you can keep doing that ...

Keep doing things whilst you can.

AS And it seems as though it is important for you to be educated about Parkinson's and know about it?

(81) JS Apparently there is one book that they recommend. She said not to get loads of books because they can frighten you as well. Kirsten said there's one you can buy in the chemist just about Parkinson's and it tells you just enough. But she says that if you are going to be nosey, you are going to find out things you don't want to know. It is tempting to find out what is it that I'm going to find out what I don't want to know? And it's like yeah I know what it could be but I'm not going to find out.

Wants to educate self re PD - but not to read too much for fear of being scared!

Does not want to read too much about PD in case it scares her.

AS So it's like a basic user's manual for people with Parkinson's.

(82) JS Yeah, that's right.

AS And have you met anyone else with Parkinson's, like at the Parkinson's Disease Society?

FAITH IN TREATMENT

(83) JS No, no. I did think of joining the society but I still probably will. But I did meet one man at Harold Wood Hospital. I just happened to pick on him. I said "Can you tell me where Kirsten's office was" and he said "Parkinson's person?" and said "yes" and he said "Who's got Parkinson's then?" and I said "I have" and he said "So have I". He said "would you know that I've got Parkinson's?" and I said "No". He was working at Harold Wood Hospital on the reception desk. And you woulnd't have known. He said "I tell you something. Don't miss your tablets". He said "Last week I went to visit my mum" and he said "And it wasn't until I was nearly there that I remembered I hadn't taken my tablets" so he said "I've got no tablets for the whole day. It was too far to go back to get them" so he had to go without tablets the whole day. But he said "The time I got back, my wife had to come and pick me up and I was shaking from head to foot". He said "it was only because I missed my tablets". So I said to him "Well it shows you how good the tablets are" because without those tablets he'd be like that all the time. He said he'd had it 6 years.

PD is not immediately noticeable in people who are on meds

Comfort that meds are so useful in treating PD, + that on 1st impressions one cannot tell who has PD or not!

AS And you would never had known.

(84) JS You'd never have known.

Controllability of illness with meds

AS So it was useful to meet him and get some tips.

MEDS

Hope + faith in PD meds

(85) JS Yeah. But I still think about my mother. I mean the way she stopped shaking. It makes me feel that they can control it, not curable but it's controllable. Better than nothing isn't it?

AS Absolutely.

PD AS AN INVADER / BATTLE!

(86) JS And as I say, my friend over the road says "I can't understand you. if the doctor told me that, I'd give up.". I said "Oh! You mustn't give up! If you give up then it's won, hasn't it?" . and she says "You talk about it like it's something growing" and I said "Well whatever it is it's not going to get much bigger, I tell you. I won't give in to it. I won't. I don't want to".

Defiant against battle with illness.

Absolutely defiant against PD. Won't let it win!

AS Like you said, it's like a thing. Like an invader. Like a virus.

(85) JS It is. Yeah. You are not going to beat me. It probably will in the end, but if it does, it does. I'll give it a good run for its money! [*Laughs*].

Interview 6 – "Peter"

Interviewer 1 OK. So tell me how it all happened.

Peter 1 Right. My father, my brother and my aunt – my father's sister- all had a tremor and I presumed that I had inherited this tremor for about 5 or 7 years. Towards the later part of my father's life it was obvious that he had a Parkinsonism tremor, the way he rose up and everything else. And then what really prompted me to say I've *got* to do something about this, was the fact that my writing had deteriorated. I couldn't actually physically do my job properly. In fact I still have a stenographer and she transcribes and puts things into the notes for me. And so that was that. One thing that I was finding was that I was getting difficulty with tardive dyskinesia. I'd lost interest in the garden because I couldn't do it. Daily activities had started to become difficult and you think "What is going on here?" because this isn't just a tremor. And I really didn't want to walk the dog. I'd always enjoyed it but because it was an effort and …

Interviewer 2 It was becoming a problem…

Peter 2 … Yes. So this eventually I sort of seized this before Christmas and went in to see my GP. And I thought if I'm going to do this I will do this properly, because doctors are notorious for doing this properly. And I was very certain that we'd go through all the rigmoral of symptoms and diagnosis and there was no doubt in my mind that I had Parkinson's.

Interviewer 3 So you were fairly sure that's what you had.

Peter 3 Yes, I was fairly sure. It came as no great bolt from above.

Interviewer 4 OK. So when you were sitting in that room and the neurologist said "Yes, I think you have got Parkinson's" it didn't come as a shock?

Peter 4 Not in the slightest. Because of course the other thing was that I'd done a six month first job as a .. in neurology.. and while he was sitting there examining things, well this is the same tests you did 40 years ago while testing for Parkinson's. The ironic thing is that I was involved with Les in the first use of L-Dopa. So I can remember patients coming down the hill to the hospital as cripples and then striding back up. So the whole thing's come totally…

Interviewer 5 Full circle…

Peter 5 Full circle.

Interviewer 6 So although you knew more or less this is what you had and for a long while you had kind of … yeah … been in a bit of denial…

Peter 6 Yes…

Interviewer 7 ... is that because you were fearful of the actual diagnosis?

Peter 7 Not really. No. I already had one patient. I have a list of 2000 or thereabouts. And it's never an illness that threw me. As I say, it was one of inconvenience and irritation. People say it's depressive. I don't think I was actually clinically depressed. I may have looked depressed but may that's just because of the Parkinson's face and my face has altered from that. It came at the same time as I'd had a prolapsed disc as well. I had a CAT scan to show this, so I had on the one hand this tardive dyskinesia and then I had this back pain.

Interviewer 8 Gosh. So you were going through a bit of a time.

Peter 8 Yes. I was going through a bit of pain in my back.

Interviewer 9 So you've obviously noticed changes like your writing, walking the dog, even your face

Peter 9 And driving the car. I felt that the car was steering to the right the whole time. I have a … I shall write it up in the BMJ but I have a wonderful story about my watch which was given to me as a 21st birthday present. It is an automatic self-winder which moves around on your wrist. Normally what happens is that you take it in every five or six years because it stops. And it would not go. It would not go. I took it back about four or five times and they said there's nothing the matter with it. And as soon as I started taking the L-Dopa the watch started! So obviously, whatever my actions were as such, of which I was totally unaware, of the fact that there wasn't enough activity.

Interviewer 10 Yeah. So that was interesting …

Peter 10 Interesting…

Interviewer 11 Sign that you wouldn't have ever…

Peter 11 Picked up.

Interviewer 12 Yeah. Has it made you feel differently about your body?

Peter 12 I mean I've had six half days off work …

Interviewer 13 Does it make you feel any different about… I know you've said your face has changed… Do you notice differences in the way people relate to you?

Peter 13 Strangely enough nobody in the health centre have even mentioned it. The staff have said how much better I look but they haven't quantified "better" without saying what "better" is.

Interviewer 14 Right… And how does that make you feel about that?

Peter 14 It's flattering when they take the time to say it.

Interviewer 15 And have you felt different since you've been taking the medication?

Peter 15 Within two hours. It was really as dramatic as that. It makes life so much easier. It is the basic parts of living that … Nobody ever tells you these things. You don't read about them. You just find them out yourself.

Interviewer 16 … find them out yourself. Hmmm…

Peter 16 One or two dreams where I've had a horrendous nightmare. But that's the future I suspect on medication. I've lost an amount of weight, which is good! Sleep is a little disturbed whereas before I used to go to sleep and wake up never more than one time. Now I can't even last the whole of the 10 O'Clock News but that's a feature of old age as well.

Interviewer 17 Yes. Fatigue. What meaning or what place does Parkinson's have in your life?

Peter 17 Nothing really. It's just a matter of taking medication three times a day. And if I don't and occasionally I'll miss two or three doses I am aware of it. Otherwise I just have to remember it.

Interviewer 18 So it doesn't have any particular significance…

Peter 18 It doesn't have an all-encompassing … I mean Les said to me "Let's have a chat and see how we can manage the next couple of decades".

Interviewer 19 Hmmm…

Peter 19 It's a positive approach to it which is how I feel it should be for the rest of my life.

Interviewer 20 Yes. Has it put things into perspective for you? Has it changed anything…

Peter 20 Not really. It would be nice to say that it has, but not really.

Interviewer 21 It sounds like you have just accepted it as part of …

Peter 21 Part of living.

Interviewer 22 … part of living. Hmmm.. How have your family reacted since they've known.

Peter 22 They … They say how much better I am. Matthew who's the middle one doing a PhD in Seattle and he was concerned that I was ill. I wasn't ill it was just that my back was bad. But also feels that I am much brighter. Whereas before she [wife] would say we'd have a conversation for quarter of an hour and then I'd retreat back in my shell. Now it's to and fro-ing in conversations.

Interviewer 23 Hmmm… So the way your family have taken it is that although they've been a bit concerned they are happy to see improvements.

Peter 23 Yes. That's right. So I have not pushed it too far but pointed out the complications and the fact that over time medication may not be too successful but they are well into stem cell research. Let's be positive.

Interviewer 24 Yes. That seems to be the main feeling from you that it is not a complete disaster but that it's more…

Peter 24 You could get diabetes which is a lot worse for yourself … or has the potential for being worse.

Interviewer 25 Do you think it has helped, having been a GP and having seen a lot of different…

Peter 25 Oh yes. You learn a lot of coping mechanisms. You cope with unhappiness in other people which transfers itself into you and I think to survive as a GP you have to have those mechanisms.

Interviewer 26 Hmmm… And so you feel that you cope with those mechanisms? To say things could be a lot worse, I could be suffering from something worse.

Peter 26 Yes. It doesn't alter my life as far as I'm concerned.

Interviewer 27 How do you see the future panning out?

Peter 27 Ermm….

Interviewer 28 Do you have any fears for the future?

Peter 28 If one thinks too long and thinks as maybe a geriatric … yes if you dwell on that … it can be very gloomy. So if you are positive and say well …. There are 80 or 90 year old that shake a bit.

Interviewer 29 Hmm… So if you sat down and thought about it and maybe if you weren't working and didn't have stuff to occupy your mind, it could go into a depression or gloominess but you stop yourself from doing that?

Peter 29 Yes. You say "What is the purpose?" To a certain extent "Que sera".

Interviewer 30 Hmmm… I'm running out of questions!

Peter 30 It's not what you expected to hear?

Interviewer 31 Well. Umm… everyone is different. Everyone has their own experiences. It sounds like the way you deal with it is to look on the positive side of things. To carry on as normal even though it can be a frustrating experience.

Peter 31 Yes. I think intellectually I'm not altered. Which is what everybody else says, which is a plus. I think it would be difficult because I spend so much time writing - if I couldn't do that. But my writing has come back with the medication so I *can* write. Whereas before I had difficulty using a computer.

Interviewer 32 So it sounds like at the time of diagnosis it has been a positive experience because it has meant that you have had access to medication…

Peter 32 Absolutely.

Interviewer 33 It has unlocked you from…

Peter 33 Yes. That's right. And I think whilst one's tried to play absolutely straight and say I'm in the business and be seen preferentially, I purposely didn't do that.

Interviewer 34 That was important for you to go down the main route.

Peter 34 Yes. That's right.

Interviewer 35 In terms of the way you view PD, you were saying that your son was worried because he felt like it was an illness but I got from you that you don't feel it is such an illness?

Peter 35 I think he saw a deterioration – because he was in Seattle we didn't see him a lot – he saw a deterioration in my ability to walk and in the physical things, and that was true. But of course I had this prolapsed disc. So there were two things coinciding. But he's doing his PhD research and he is well aware that he sees the pros and cons of treating and not treating the illness.

Interviewer 36 Do you think it helps then coming from a medical background and coming from a medical family, as they can understand?

Peter 36 Yeah. They get an honest answer. I mean if they ask an awkward question and I don't know the answer I am quite happy to go off and find out what the answer is. But I suspect possibly that when patients come and speak to you on that kind of score, you realise there is a huge agenda that they've got and you only deal with a little bit of this. And it is this business of going into a consultation and remembering only four things of what the GP said so if you deal with three and reinforce them and send them off and do another three the next time.

Interviewer 37 Hmmm… So it helps being from the medical profession. You can have access to the BMJ journals and ponder over them and…

Peter 37 That's right. I try not to get too obsessed. You know.

Interviewer 38 Have you found that? A phase of …

Peter 38 Yes. A phase of "I'll just have a quite flick through this" and then saying to myself "Do I *need* to? I know this, I know that and the other. There's nothing I can do about it, but just accept it".

Interviewer 39 Hmmm. That's what is sounds like you are doing. Accepting it.

Peter 39 Yes. That's right.

Interviewer 40 Have you found that it has been frustrating that there are still things that it stops you from doing? Do you see it as an *it?* How do you feel?

Peter 40 Almost as though it is a natural part of ageing. You see it to a certain extent that everybody gets old, bits drop off. You know…

Interviewer 41 Yeah. So you can see it in the context of what happens to our bodies. You know, bits of our brains start not working properly.

Peter 41 Yes. Like 'Why have I gone upstairs? I'll go down and start again!' [*Laughs*]

Interviewer 42 Yes!

Peter 42 [*Inaudible*]

Interviewer 43 Hmmm. Mmmm… Have you found you have had to adapt your life around PD? Or not at all?

Peter 43	Not really. I mean... either because of the nature of the job or ... It's nothing very exciting.
Interviewer 44	Hmmm... so it's just like an add-on.
Peter 44	Yes.
Interviewer 45	And at times you said you can kind of feel a bit down. Sorry! I know I'm sounding really negative here!
Peter 45	No
Interviewer 46	I don't mean to but I know that it's quite common for people to feel a bit low at times.
Peter 46	Yes. I don't honestly feel I've had any true depressive symptoms [*inaudible*].
Interviewer 47	Hmmm... And in terms of going out and doing general things. Have you had to change how you do things?
Peter 47	[*Inaudible*]. That was because when everything started it was just a *pest.* The car was turning to the right and this was presumably an imbalance of dyskinesia where it affects one side more than the other. I don't think anybody would have picked that up. I mean it's a fairly sophisticated thing to be able to pick up.
Interviewer 48	Hmmm... And maybe only someone experienced like yourself could pick that up.
Peter 48	That's it.
Interviewer 49	It seems to me that PD kind of affects the body in all sorts of different ways.
Peter 49	Oh yes. I mean when I started after I'd been given a scan I somehow got trapped with my shoulder which I could not move at all and yet with medication it resolved it. It was a very positive experience. I was handicapped with the pain but actually with therapy its fine...
Interviewer 50	Yeah.
Peter 50	...I don't have a problem with it. So I think this is why I say the same thing to people with an anxiety state. You say "You'll come through it and you can look back. You can take positive steps and say well next time I feel this way you *know* that it is because of this, this and this."
Interviewer 51	Hmmm... So looking at it from a very practical view. In terms of how you've been treated by neurologists, by your GP, by your physio and by anybody else, do you feel that they've taken in view your psychological side of PD?
Peter 51	No. But maybe they would do if I gave them clues. If you don't give the opportunity it won't come back to you unless it is in your face.
Interviewer 52	So if it wasn't kind of intuitively picked up...
Peter 52	That's right. Again, I haven't got much angst about it because in my own mind, in my own heart of hearts, I knew what the diagnosis was.
Interviewer 53	Sure. And in a way you are part of the medical profession.
Peter 53	Part of it.. yes.
Interviewer 54	Do you feel that it would be useful if neurologists, speech therapists, physios would be more ... or take a more psychological or emotional point of view?
Peter 54	I find it difficult to answer because I'm me and I don't know what other people would do... Well yes I do know what other people would do to a certain extent. You may find that it does them more harm than good. I mean I saw a patient last week who had a cancer on the bone. She said

it's good news because it's just a tumour. I said well here you are. I mean she was happier to think of it as this word rather than actually a condition. And maybe you need to be like that. You can get too close to people and disturb them too much.

Interviewer 55 So there can be some things just bubbling under the surface and sometimes its not appropriate to look at those things.

Peter 55 But again that's how you see yourself as far as your health is concerned.

Interviewer 56 Hmmm… I know that you were saying that your way of coping is to look at things from a very practical point of view. To view it in terms of well this is more part of normal ageing and our bodies do have bits that go wrong at times. And you stop yourself from dwelling on the negative. I'm not quite sure where I'm going here… but those times when you do feel low, how … what kind of things are you thinking about? What kind of things do go through your mind?

Peter 56 Fear of the future. It's the future of 20 years. I mean if it was the future of 20 days, you'd be counting down and that would be depressing. Suppose you got a chest infection that didn't quite get better, you'd be looking towards [*inaudible*].

Interviewer 57 Hmmm… Sure. Is there anything else that I haven't covered or talked about?

Peter 57 No. No. Interviewer 58 OK. Well thank you very much.

Interview 7 – "Maureen"

Interviewer 1 Ok, so how long ago was it that you were diagnosed?

Maureen 1 I'm not actually sure. I think it was a couple of months ago. It's not that long, I really don't know.

Interviewer 2 Uh hmmm…

Maureen 2 The memory doesn't really hold a lot of information these days.

Interviewer 3 Sure. And was is that neurologist that spoke to you and explained to you about Parkinson's?

Maureen 3 Well, he didn't really explain about it but he told me that's what I've got. I had gone to see my GP about some tablets that didn't agree with me and then I went to see the other one so basically I was diagnosed … twice.

Interviewer 4 Twice. Hmmm… And thinking back to that time, when you went to those appointments, and they told you that this is what you've got, what kind of feelings did it stir up in you? Can you recall?

Maureen 4 Not really, because I'd been to … I've got a damaged muscle in my leg so I've been in physiotherapy and my husband had noticed something in my right arm, so I asked the physiotherapist was there a reason, and she said the only reason she knew was that it could be Parkinson's, so I had an inkling that…

Interviewer 5 Yeah… you had an idea…

Maureen 5 … there was something wrong and she said that and so I assumed there was a possibility that that's what I had.

Interviewer 6 Yeah. So everyone had ideas that that was probably what it was.

Maureen 6 Yes.

Interviewer 7 And when you got that confirmed, what feelings or thoughts did you have at that time?

Maureen 7 Well I have trained as a nurse. I know a little bit about diseases and I also worked before I retired in a sheltered housing unit and three of the people there had Parkinson's, so I knew it wasn't something that gave you a death sentence. It's just a progressive disease that I would have to learn to live with.

Interviewer 8 Yes. So it was a case that you knew it…was one of those progressive diseases

Maureen 8 I knew it. Yes.

Interviewer 9 So you felt you had to … grin and bear it.

Maureen 9 Yes. Get on with it!

Interviewer 10 Did you have any feelings… any negative feelings about that?

Maureen 10 Well… I get upset on occasions… [PAUSE 5 SECS] [CRIES] Sorry.

Interviewer 11 That's ok.

Maureen 11 [CRIES – 10 SECONDS] I got upset when I saw the doctor about it. When I went to tell her, I was a bit depressed. She said she's sending me for some counselling. They wrote to me with a date but I was going away on holiday so I couldn't make it til I got back, but I've heard nothing more from them anyway. I feel alright about it now. Apart from when I talk about it perhaps.

Interviewer 12 Sure. And I understand that it can be difficult to talk about it. And if you don't want to talk about it, it's fine as well. But I suppose it's useful for me to hear how it's really affecting *you.*

Maureen 12 I mean on the whole I'm alright.

Interviewer 13 On the whole you cope, on a day to day basis. And at times when you think about it or talk about it…

Maureen 13 Uhmm….

Interviewer 14 … it upsets you.

Maureen 14 Yes. I don't know why.

Interviewer 15 Is it the fear?

Maureen 15 No, not really. I get very frustrated when I can't do things. I get tired more easily and that can get really frustrated because I can't… I used to do a lot of sewing and knitting and I can't do that anymore.

Interviewer 16 Hmmm… So it's stopped you from doing things that you loved, and that's frustrating for you. And upsetting for you.

Maureen 16 It is when I think I should be doing something and I'm not because I can't do it. I mean I did actually sew a button on something the other day but that was difficult as I had to thread a needle and I couldn't do it. I mean, I used to do a lot of embroidery but… I try and do rug making now as that's not so ah….

Interviewer 17 Yes. That's not so intricate.

Maureen 17 But I haven't done much of that for a while. And I get so tired.

Interviewer 18 Would you say that's the most upsetting thing about Parkinson's – that it stops you from doing things you enjoyed in the past? Or?

Maureen 18 I wouldn't go to that point, but I just find it so frustrating that you can't do things. I mean I've had to have a cleaner in, whereas I used to do cleaning regularly, although you wouldn't think it by looking around.

Interviewer 19 So you've had to make changes to you lifestyle.

Maureen 19 I don't go out very much on my own in case I don't feel well when I'm out. I only go locally. I go out locally shopping but I'll take somebody with me. But everyone goes out walking and after a while I'm fed up with walking. So I've given that up. I do go out locally. I usually take the dog out for a walk and I line dance. Well I try to.

Interviewer 20 It's made you want to continue to do the things that you *can* do but it's really frustrating and upsetting that it's stopping you from doing the things you have been doing… forever. Things like going out shopping…

Maureen 20 I still go out shopping but I haven't got 100% control over my bladder anymore.

Interviewer 21 Right…

Maureen 21 So you have to be careful where you're out. The other day I had nowhere to go. [CRIES]

Interviewer 22 Of course… of course.

Maureen 22 So we usually go where there's somewhere where I can get to the toilet.

Interviewer 23 Yes.

Maureen 23 Because I can't run…

Interviewer 24 No. No. It sounds like Parkinson's for you is something that has taken control over various parts of your body, and it's a case of working with it and rather not against it.

Maureen 24 …Yes. I mean I just need to find out how I can get to the toilet. It's hard being incontinent, but there are pads and …

Interviewer 25 Yes, there are things you can do.

Maureen 25 I mean I don't know whether or not I can trust them. I mean I wear panty liners but I'm not sure how much they can hold if I make a mistake.

Interviewer 26 Of course… There are incontinence specialists that you can be referred to see.

Maureen 26 Well I don't know why you see I had a letter yesterday from somebody and it was telling me all about Tenalady and I wondered if it was a coincidence.

Interviewer 27 It could be an advertising thing where they send it to all the people over a certain age.

Maureen 27 Yes, it could be. I mean I haven't read it properly. But yes, I know there are things I can do about it.

Interviewer 28 It sounds like at the moment you are a bit of an explorer. You have to explore the territory you can go into and make it safe for yourself. It sounds like life has really changed for you, quite dramatically.

Maureen 28 [*CRIES*] Yes, I suppose so.

Interviewer 29 And I can see that is very worrying for you. Upsetting for you.

Maureen 29 Talking about it has made me cry.

Interviewer 30 Hmmm… I suppose sometimes when we talk about things we have to think about the things we've not wanted to think about.

Maureen 30 Quite possibly.

Interviewer 31 But sometimes talking about it can also help as well.

Maureen 31 Talking about it is probably the best thing I can do really. I'd rather talk about it without crying.

Interviewer 32 Hmmm… I'm used to people crying. I've heard lots of different stories, and lots of similar things to yourself and I think most people whom I've spoken to have cried and have become quite upset when they're talking about their feelings and how their life has changed. It's quite normal.

Maureen 32 I mean I've tried to get on with things and do what things that I can do.

Interviewer 33 Yep. Yep. You've taken that step and made that decision.

Maureen 33 I'm going to do what I can do while I can do it. I'm not giving in to it that easy.

Interviewer 34 No. … Is it like a … a battle?

Maureen 34 It's a challenge I think.

Interviewer 35 A challenge. Yes. You've got a fighting spirit in you!

Maureen 35 Somewhere along the line, yes! But it doesn't help that I also have a leg problem. There's weakening of the muscle around the buttock so that frustrates me even more, that I can't walk properly, it's not solely that I've got Parkinson's. I've had physiotherapy on it. I have to do things for it myself. I go to the physiotherapist who just gives me another exercise to do. So they don't do much while I'm at the physiotherapy.

Interviewer 36 It's more like self-help.

Maureen 36 Yes. I just have the instruction and then I go home and do it. I mean if I go for four weeks, I mean I couldn't be doing it quite right.

Interviewer 37 You wouldn't know.

Maureen 37 I wouldn't know and maybe I'm not doing it exactly as he told me to do. I've got to have some x-rays and go back to the orthopaedic doctor and it's a lot of waiting.

Interviewer 38 It's that not knowing that can be difficult.

Maureen 38 I mean they came together unfortunately, these two things.

Interviewer 39 Yes. Yes. .... What would you say the place is that Parkinson's has in your life? What place does it have in your life?

Maureen 39 It's something I've got and I just have to get on with it I suppose... I try not to let it get me down and I try to carry on.

Interviewer 40 So it's something that is always there...

Maureen 40 It's there. I suppose there's no way you can forget it's there because you can't forget it. Every time I walk down the road I feel I can't walk properly.

Interviewer 41 It's always there. Does it effect every part of your life?

Maureen 41 Not to a great extent, but obviously it does. There are things I can't do anymore but I try not to let it stop me from doing things I want to do. I mean before I got over tired and I just lay down on the couch.

Interviewer 42 Hmmm...

Maureen 42 I had a bit of lunch and then you arrived more or less. But I try to cope. I'm going to my daughter's in a week. She's got three boys. It will take an hour to get there. My other daughter we're going to has got two boys. So it can be a lot to cope with.

Interviewer 43 Hmmm... Do things tend to make you more anxious? Or more stressed?

Maureen 43 More stressed I think. I can't cope with too much at once.

Interviewer 44 Right.

Maureen 44 I mean sometimes I walk around like a headless chicken! I'll put things down and forget where I've put it and can't find it and it stresses me out. My husband will say "don't worry, I'll find it, you lay down". [*CRIES*]

Interviewer 45 Hmmm... yes. It's frustrating that you've put things down, you don't know where you've put it and you're husband has to say, "I'll find it, you lay down", and that can upset you. It is frustrating then that you have to rely on your husband?

Maureen 45 No, not really, I'm just annoyed at myself, for not being able to cope with it.

Interviewer 46 Right. Hmm...

Maureen 46 I mean he's very good about it.

Interviewer 47 Yes, he's quite supportive. And you're lucky to have people like that around you.

Maureen 47 Yes.

Interviewer 48 But it just makes you more annoyed at yourself.

Maureen 48 But you know it makes me get into such a panic about it like World War One!

Interviewer 49 Yes, and that can escalate

Maureen 49 Yes, I don't know why I get like that.

Interviewer 50 In fact, you saying World War One makes me think you are in a war zone.

Maureen 50 [*LAUGHS*] Yes!

Interviewer 51 You are dealing with these bombshells and try to avoid the devastation, by being strong and struggling through it and making it through.

Maureen 51 I try to be strong.

Interviewer 52 Yes. Yes. Because if you allow it to get you down it can make you feel worse and worse.

Maureen 52 Hmmm…

Interviewer 53 Do you feel differently about your body now that you know you have got Parkinson's?

Maureen 53 No, I don't think so, I mean the only thing that gets me is the weakness of the bladder. That's the only thing that's bugging me.

Interviewer 54 Hmmm…

Maureen 54 I mean when I'm at home here I can sit for a long time without wanting to go because I know I can if I want to.

Interviewer 55 Yes.

Maureen 55 But when I go out I'm alright for half an hour and then I'm desperate to know where the toilets are.

Interviewer 56 Right. Because you need to know ….

Maureen 56 I need to know where it is because I know I shall want to go, but sitting at home here it doesn't bother me at all. I sleep most nights now without having to get up. I mean I don't drink water before I go to bed, or coffee and I don't buy fizzy drinks. I can make you a cup of tea if you'd like?

Interviewer 57 Oh, I'm fine. Thank you. … So mainly, the most frustrating thing about Parkinson's is the way it's affecting your body? The restrictions that it has on you… it makes you more worried and anxious about having to know certain things like having to know where the nearest toilet is so when you are at home you feel more safe, apart from the time when you don't know where you've put your keys.

Maureen 57 Yes. I now normally chuck my keys on the table as I come in the door.

Interviewer 58 Have you noticed any family or friends treating you any differently? Has your relationship with them altered in any way?

Maureen 58 Not my family, I haven't noticed, but I go to bowls now, only down the road, but I'm loath to picking up any of the balls now. Last week when I went I stopped for moment and I said "Oh, I should be fine in a minute". And the lady instructor told the others that I was not allowed to pick up the balls and she asked a gentleman there to go around with me.

Interviewer 59 So you had your own personal butler there picking up all the balls!

Maureen 59 [*LAUGHS*] Yeah. He said, "I hope I've looked after you well enough" and I said, "well you've been given instructions I think!"

Interviewer 60 He was under orders!

Maureen 60 Yes! I mean It's nice to know that they do help out but I feel a bit silly about not being able to do it. I take the tablets three times a day and after a couple of hours I feel I'm nearly ready to take another one. I can't explain how I feel. My head feels muggy and woolly and want to lay down and have a sleep and then I'm ok for another three hours.

Interviewer 61 Yes. Yes. Has it made you feel any differently about your life in general, or the world?

Maureen 61 I've not really thought about it. I mean I can't say there's really anything I can't cope with apart from the need to go to the loo so frequently when I'm out.

Interviewer 62 And it's the coping with it that 's quite difficult for you.

Maureen 62 I suppose it affects your life in that when I'm out in the high street I find myself thinking about what shops to go into and whether or not they've got toilets in them.

Interviewer 63 But I can see from that perspective it's making you think about things that maybe you would have never thought about a few years ago. So, looking back, before you were affected by Parkinson's, are things very different now?

Maureen 63 Yes. Yes they are.

Interviewer 64 Because I suppose it's come out of nowhere, and no-one knows why it's happened. It's something that you feel like you have to live with. You've also had experience of knowing people in the past who have had Parkinson's. Do you see this as a disadvantage?

Maureen 64 Uhmmm… I don't think so, no. Because it makes me know what the problems are and I hope I just don't get them all.

Interviewer 65 Hmmm…

Maureen 65 I mean I don't really know all about it. I mean sometimes I feel my forehead going up and then back down again.

Interviewer 66 It does things by itself…

Maureen 66 Yes, and my leg actually went like that [*SHOWS INTERVIEWER HER LEG MOVING*] and I'm thinking I didn't do that, it did it itself.

Interviewer 67 So it's like you've been…

Maureen 67 Taken over. And this morning in bed, the whole of this side just shot up out of bed without me doing it.

Interviewer 68 What did you think about that?

Maureen 68 Uhm… it's not doing me any damage, so I hope it isn't.

Interviewer 69 So it just feels a bit strange…

Maureen 69 Yes. I suppose it depends on the situation and what I'm doing. I mean I can laugh at it, like when I was sitting on the sofa the other day. And I think I did probably kick him in bed the other night! And I suppose I'm just waiting for what other things are going to materialise, you know.

Interviewer 70 Uh huh…

Maureen 70 I do have trouble speaking sometimes too.

Interviewer 71 Yes, it can affect your speech. From what I know of it, it can affect all different things… Do you know anyone else who you are in contact with or do you go to any Parkinson's Disease groups?

Maureen 71 No, I don't. I don't really want to see people there like me.

Interviewer 72 Yeah…

Maureen 72 But there again, if I go then I can say that I've *been* to it.

Interviewer 73 Absolutely…I mean I've gone to them myself as my father has Parkinson's, and it can feel strange at first, because you are going into an unknown situation.

Maureen 73 Yes.

Interviewer 74 So is there anything else that you feel I haven't asked you, that you feel is important to tell me about your experience?

Maureen 74 Well I'm still learning about it so I don't really know what to say. I mean there's things that I can't do, but maybe that's just because I'm getting on a bit!

Interviewer 75 But at the moment you feel you want to know more about Parkinson's Disease, and get to know what it's all about.

Maureen 75 I suppose I will eventually, but at the moment it's enough to cope with what I've got.

Interviewer 76 Yes, of course. Taking things step by step.

Maureen 76 Yes. I suppose I will eventually.

Interviewer 77 Hmmm…. Hmmm… It does sound like a … a bit of a journey. It sounds like you are at the beginning of a journey. You're getting to grips with how things are right now and how to cope with things. You're not at the top of the mountain right now but are taking things step by step.

Maureen 77 I'm trying to, yes.

Interviewer 78 Taking things as they come.

Maureen 78 Probably, yes. I mean I have to make an appointment with the dentist. I've been putting that off. I also need to see the chiropodist, and hopefully not kick him in the jaw! [*LAUGHS*]

Interviewer 79 [*LAUGHS*] Yes! I would warn him!

Maureen 79 While he's doing my feet! But I must book the appointment.

Interviewer 80 Is it hard telling people you have Parkinson's?

Maureen 80 No, not really. I mean to a certain extent it's hard because a lot of people don't know about it.

Interviewer 81 People don't know what Parkinson's is?

Maureen 81 Well, even if they did they might think "Well what's she telling me for?". But it's nice to know the people who I do see more often … that they do know I've got Parkinson's, but …

Interviewer 82 Do you think people react to you differently knowing now that you have got Parkinson's?

Maureen 82 Well a friend at bowls keep asking me if I'm alright.

Interviewer 83 Right…

Maureen 83 And when I'm there she's always asking if I want to sit down. I don't always want to sit down.

Interviewer 84	No. You don't want to be treated differently to anyone else, but it's nice that people …
Maureen 84	Yes, but she was carefully going after every ball before I could get anywhere near it to pick it up off the floor! Because it is quite… tiring, all the bending down.
Interviewer 85	Yes, it must be.
Maureen 85	Yes, I mean there's only four of us playing. So two of you bowl first then the other two and you've got to pick the balls up, and then you walk down and need to go up and down again.
Interviewer 86	Yes, it's quite active really.
Maureen 86	Yes. It's worse when there's only four of you playing because it makes it a lot more hard work.
Interviewer 87	You have to adapt your life around Parkinson's so that you are doing things that you enjoy.
Maureen 87	I don't what I can do.
Interviewer 88	Yes, you do what you can do. But you just have to take things a little bit easier.
Maureen 88	I have to go at it a bit slower than I used to.
Interviewer 89	Yes, it's really a process of adaptation really. So is there anything else?
Maureen 89	No, I think we've covered everything.
Interviewer 90	OK, well thank you so much for letting me speak with you today.
Maureen 90	Well, I hope it's useful to you.
Interviewer 91	Oh, absolutely

Interview 8 – "Cynthia"

Interviewer 1 OK. So when was it that all of this happened? Was it just recently that you were diagnosed?

Cynthia 1 It was this year that I went and had … I had an ordinary scan at Oldchurch and then I had one at Great Portland Street. I've got my letter out just in case… I went there… a DAT scan. I had a DAT scan. It was ages until they got it back, but we got it in the end. I went to see Mr De Silva.. Dr. De Silva and I went to my physiotherapist and it seemed to have started in my left big toe. It was always stuck up. I didn't know what it was. They did some tests and um … she said "You ought to see a specialist". It had been a good year or 18 months. So I said well I'll pay privately for that, just to get your mind settled and that.

Interviewer 2 Sure.

Cynthia 2 And they said it was all sort of early stages. Then I went to see him. The shaking started and I seemed to have cupped that hand [*shows me her left hand*] a bit. When I'm not doing anything.. If I'm doing anything as I'm right handed, I look over and thought to myself, "Why am I doing that?"…

Interviewer 3 … yeah you do everything with your right hand… And the same thing like with your toe doing it's own thing?

Cynthia 3 Yeah. You can't stop that because the next minute… it gets quite sore, the joint, because you are pulling … it's pulling itself up.

Interviewer 4 Yes.

Cynthia 4 They never said it wasn't and never said it is, but I had an operation on my feet 3 or 4 years ago and that was doing it then but then over the last year I had a shoulder operation and I had some physio, but she said to me "Why are you cupping your hand, when I'm doing physio on your right?". And it wasn't until I got home that I was deciding whether or not it was Parkinson's… so that was the reason then. Now, … so basically it's down my left side and then that sort of shakes and shakes.

Interviewer 5 Yes…

Cynthia 5 And sometimes when I'm out, I don't think it's because you are doing things, but you don't notice until you sit down, when you are resting. That's when it all seems to start.

Interviewer 6 So you were diagnosed just recently then for sure, by Dr. De Silva?

Cynthia 6 Yes, yes.

Interviewer 7 And uhm… when he told you that that's what he thought you had, what kind of thoughts went through your head? What kind of emotions?

Cynthia 7 That's when I felt numb. You know, I took it, because I'm one of these people – I don't show very much, but you know, I felt numb because I felt a little bit before it was all diagnosed because I didn't know whether or not it could have been a slight stroke?

Interviewer 8 Yes…

Cynthia 8 Because, again, I don't know much about it but I wondered if that was it, and I thought "Could it be Parkinson's?", you know? Because I read that Michael Jackson…

Interviewer 9 Michael J. Fox?

Cynthia 9 Yes, his book. Both the girls have been with me to my appointments at Dr. De Silva. And I don't know sometimes… I mean I want them there because they listen. You take it in and it's gone out the other ear, you know? But I wondered if I don't say… well I think Dr. De Silva said in here "I don't think she's telling me all her umm… daily things that might traumatise her a bit", you know. All he says is "You're making light of it a little bit". It's not that, it's just it's my way of coping.

Interviewer 10 Yeah, your way of coping is not to say really, exactly what is happening…

Cynthia 10 No, because you think, "No, it can't be that", you know.

Interviewer 11 You try to protect yourself?

Cynthia 11 Yeah. Yeah, in a way.

Interviewer 12 So you felt initially, quite numb. Was it quite shocking to hear your diagnosis?

Cynthia 12 Yes, and no. You know. I knew it was going to be something but as I say it … I mean I'm not *worrying*. I don't feel like I'm worrying but you'll see me, I'll start going a bit more [*Shows Interviewer her shaking left hand*].

Interviewer 13 Yeah.

Cynthia 13 But uhm… Yeah, it is a shock and I know this is going to sound silly but because I've got an ex-husband, I didn't want him to know, because I felt as if I was going silly, you know? It was all part of … I mean I didn't tell the girls this, but I thought I don't want him to know.

Interviewer 14 Yeah. You didn't want him to know that there was something wrong with you?

Cynthia 14 Yeah. That' s right. Especially something like that. I mean he had a heart bypass and then everybody seems to think that that is somehow different to like Alzheimer's or Parkinson's. I always get a feeling as if people think you might be a little bit different.

Interviewer 15 Yeah. So people might have a different opinion of you, knowing that you have got Parkinson's? As opposed to if you had broken your leg, or … a heart condition.

Cynthia 15 … Yeah, that's right….

Interviewer 16 … Do you think people would have more sympathy for people with a heart condition? Is that what it feels like?

Cynthia 16 No, I don't think it's that really. It's just it seems, well it's the wrong word really, but glamorous, but glamorous to have a heart operation or have your leg in plaster, but this they sort of look at you… I mean I've told quite a few of my closest friends because I felt again that, if they're like you're talking to me, I would think about the answer before I said it so that they wouldn't think "Well, what's wrong with *her*?" So I felt I had to for people who really care for me.

Interviewer 17 To actually tell them…

Cynthia 17 Hmmm….

Interviewer 18 Do you think there is some kind of stigma or some kind of uneasiness about having it.

Cynthia 18 Yes. You do really.

Interviewer 19 Do you think it is because of the shaking, or the outward symptoms? What is it that makes you feel uncomfortable?

Cynthia 19 Well this does [*Points to shaking arm*]. It's not a pain, it's just frustrating. There's something they call a lazy leg or an uncomfortable leg or something like that?

Interviewer 20 Restless legs?

Cynthia 20 Yes, that's right! It's something like that which is there all the time. You get it all down the one side. And you look at yourself in the mornings some times and I think "Are my eyelids getting puffier?" Because I think I was asked this: "Facially, had you changed?", and I said, "Well you'd better ask the girls" I mean you don't look at yourself. I mean the lids feel a bit heavy, you know.

Interviewer 21 So your outward appearance to others is changing….

Cynthia 21 I think so, I don't know about… I mean if it starts shaking while I'm out, I cover it up with [*Shows Interviewer how she grabs her shaking arm with her other hand*]. You can't do it with a paper, because the paper rattles! [*Laughs*]. You can't hide it! [*Laughs*]

Interviewer 22 Yes, and tea cups and things, rattling.

Cynthia 22 That's right! I mean I don't know … at the moment I've decided not to go on medication. I thought to myself…. I mean there was a programme on television. He was a newsagent.. .somebody who works with papers and things… and he had this brain implant, you know they screw it into the brain, and he had got Parkinson's. And uhm…. And he was talking about these tablets. He said "If I'm going out tomorrow for lunch I'll take it". To cut a long story short, anyway, I said to the doctor "I don't mind doing a tablet if I'm going out tomorrow and sort of take it then". And he said, "Well, no, it doesn't work that way" . He said there's a starter, he called it a starter pack. But he sent a letter to my GP and if I need it before I go and see him in 6 months, he wants her to put me on this particular course. But I don't' know… now I think to myself is it best that I'm … I want to try to keep off medication but now I think to myself, will I deteriorate quicker if I don't? But he didn't say anything to me that it would happen. He said it was a good idea because your body doesn't get used to the drug, so… I will go and see him in 6 months but if I need to see him before…

Interviewer 23 Then you can…

Cynthia 23 Yeah. My youngest gets married in May but I don't want to be a shaking lady at the wedding! [*Laughs*].

Interviewer 24 No. I mean I know … from my only experience with my dad, that medication is quite fabulous in some cases.

Cynthia 24 That's right. This is what I think to myself. I would have thought that Dr. De Silva would have said "No, I recommend that you go on it", but he didn't.

Interviewer 25 It's up to everyone, each individual.

Cynthia 25 Yeah. So I'm leaving it for the time being.

Interviewer 26 Sure. So you have some reservations about taking medication.

Cynthia 26 Yeah. I don't like to if I can help it, you know. But if he said, "No actually I think you ought to" I mean there would be no question. I would go on to the medication.

Interviewer 27 Has it been difficult then, to take on board that you've developed this disease?

Cynthia 27 In some respects. Yes. Some days… I don't get depressed very quickly you know, it takes a lot to get me down. I make myself do something, you know, saying "You silly old fool!", you know…

Interviewer 28 To take your mind off it…

Cynthia 28 Yeah. To take my mind off it. I haven't really. I mean I had a fall in October, but I don't know.. I've got a feeling it's to do with this, but I don't remember tripping. I got a black eye. But I told the doctor and he said "Do you think it could have been that?" but I said I don't remember tripping and I don't even remember… I was walking side-ways and I was acknowledging a gentleman, and the next minute I was down. I don't remember. But that's the thing. I feel I can't co-ordinate properly. It annoys me so much!

Interviewer 29 Hmmm… the things that you've done…

Cynthia 29	Yeah. Before, you take things for granted and uhm…. Things like pulling a trouser leg inside out or taking down the washing.
Interviewer 30	Yeah…
Cynthia 30	I say to myself, "What are you *doing? Concentrate*!" But that happens sometimes, and it makes you think is it Parkinson's or is it something I'm just being soppy, you know? [*Laughs*].
Interviewer 31	Yeah, I can hear, a lot of the time you tell yourself, "Stop being so silly! Pull yourself together"…
Cynthia 31	Yeah, "Get on with it!"…
Interviewer 32	"What's wrong with me", but now you're questioning actually is it the Parkinson's itself that is to blame? It's not really you as a person. That you're being lazy or…
Cynthia 32	Hmmm….Oh yeah. I did say that to him I said some days I do feel lazy. I said I'm tired. He said no that's part and parcel of the complaint, it can be. I don't feel so bad now as I thought I was just being lazy. [*Laughs*].
Interviewer 33	Yes. So at this point it's like a discovering journey that you're on and you are discovering what's Parkinson's, what's not Parkinson's, what does Parkinson's actually mean? What it is.
Cynthia 33	Hmmm… That's right.
Interviewer 34	There must be a lot of question marks.
Cynthia 34	Yes. You know. When they show you these X-rays and all these little white dots. The first time I had it, the normal scan at the hospital, he said that the little white dots were quite normal for my age and elderly people start getting these little white dots, you know. But then there was a bigger patch on that scan so they said it was all as thought, which confirmed it. And that's it really. I do get nervous. Say I'm going to meet my daughter up town. I mean I'm never a good traveller anyway, but on the trains and that and I hate for the train to stop if I was on the Underground. It would make me nervous, you know, sort of more nervous. My mum used to say years ago, she's been dead 19 years now, but she said "I always thought my daughter was a very confident…" But you see again, my own mother didn't know that inside there were butterflies.
Interviewer 35	So you are the kind of person to put on a brave face on things…
Cynthia 35	Yes, yes! [*Laughs*].
Interviewer 36	But often inside it is not like that.
Cynthia 36	Yes, it's turmoil. I mean everybody else would have taken a train journey, but as I said I'd never travel far.
Interviewer 37	But it's made it worse for you.
Cynthia 37	Hmm…. That's right. I'd rather go a long way around that sort of get off at this one, get the fast train and you know. I'll sit on my train and I'm happier that way.
Interviewer 38	What is it that makes you more anxious? What are the things that are worrying you when you are travelling?
Cynthia 38	I don't like… I get a bit claustrophobic if the trains stop in the Underground but luckily enough they are not too much on the District line so it's not too bad. Other than that, it's just my lack of confidence in myself. I can't really put a name to why I do that.
Interviewer 39	But you don't feel quite as confident as you used to.
Cynthia 39	No.
Interviewer 40	Are you concerned about how others might see you?

Cynthia 40 It doesn't… it doesn't worry me to that extent that way, but I suppose when the time comes to … I'll ask you a question now.

Interviewer 41 OK.

Cynthia 41 I get less movement in joints. Is that how it progresses is it?

Interviewer 42 I think for everyone it is different. But I know that in Parkinson's, a lot of people complain of being less agile. You can't do the fiddly things like writing and sewing or anything that …

Cynthia 42 I've done some sewing this time, but after a while I'm holding that hand. I mean I have difficulty putting my mascara on.

Interviewer 43 It goes all over the place?

Cynthia 43 Yes! [*Laughs*]. I think my goodness me. It doesn't matter if you hold it tight or anything. It's just those little things like putting a bit of make-up on, you know. I'm alright with lipstick, but holding the mirror and putting on a little bit of mascara…

Interviewer 44 Co-ordination…

Cynthia 44 Yes, that's right.

Interviewer 45 So, is that frustrating then?

Cynthia 45 Well as I don't wear much make up at the moment, it's not. But no, as you say… I wouldn't say it's too bad. I mean, household chores … but as you say … I have to hold on tighter to things so that they don't slip through my fingers. It hasn't happened yet but whereas before I'm terrible as you can imagine I'd take my time on cleaning the house, so…

Interviewer 46 You have to take more time over doing things now.

Cynthia 46 Yeah, I mean my gardening, I've got a lot of pots that uhm… my back aches, but I suppose that could be your age as well. It's deciding whether it's the Parkinson's or its just your normal deterioration.

Interviewer 47 Yeah. It's difficult to know which is which.

Cynthia 47 I mean, like driving, you know at certain times you have to have clutch control and then that leg starts shaking and that takes my confidence right away and then I'm holding the steering wheel that will. I mean it hasn't affected where you're going in the car, but it's there.

Interviewer 48 Yeah. So it's more that it's affecting your confidence in yourself.

Cynthia 48 That's right. Apart from that…

Interviewer 49 If Parkinson's has a place in your life, what place would it have in your life? What meaning does it have to you? I know it's a strange question!

Cynthia 49 No! no, no. Angry – in as much alright I'm 66, I'm not ancient, but I'm not young, but if uhm…. [Cries]. If my daughter has a baby, I won't be a part of it.

Interviewer 50 That's worrying for you.

Cynthia 50 Yes, heartbreaking.

Interviewer 51 Heartbreaking.

Cynthia 51 I've always wanted to have a grandchild.

Interviewer 52 Hmmm…. But it worries you that you…

Cynthia 52 That I won't be able to … because you see all the nannies and granddads you know, and they look after their children for their families, I mean it's early at this stage, but you don't know how long it will be but you think to yourself I wouldn't trust myself to look after them.

Interviewer 53 I can see how heart rendering that could be. Because you'd want to care for them…

Cynthia 53 … Care for them, but you know I would feel now, I mean I'm not bad at all, but I thought I wouldn't be able to let them feel happy if they left me with the baby.

Interviewer 54 Because of that confidence thing.

Cynthia 54 Hmmm…. So yeah.

Interviewer 55 I understand. Especially at the moment where things aren't very good for you in terms of your agility and just the mundane things.

Cynthia 55 That's right. I mean I do a midday lady job at a special needs school. I mean I told my supervisor because I thought well when it was confirmed I thought well I've got to because you don't know if the council have policies to think well no she can't, so she said I should speak to the headmaster and apparently she said "as long as she's happy", that's me. I mean at the moment there's the children – I mean they will still pick up on it.

Interviewer 56 Children – they don't have tact either.

Cynthia 56 No! oh no. But even that hour. It's only hour and ten minutes, but we've got 20 of them between 2 ladies and they run around like Willow-the-wisps. You think what some of the young parents have to put up with a lot of these. I mean we haven't got badly disturbed children, most of them is either of that, what is that when they are very hyper?

Interviewer 57 ADHD.

Cynthia 57 Yeah. But so, I mean they are quite happy with me to stay there until it is too much for me or I mean once the children start or I feel that … I mean when they ask about shoelaces and I do them up sometimes. But yesterday it was so cold out there, my fingers had gone dead and apart from Parkinson's… [*Laughs*].

Interviewer 58 Yeah, it makes it doubly as difficult.

Cynthia 58 Yeah, but they seem to make my happy, it breaks my day up and …

Interviewer 59 Well it must be nice to know that you are still helping … you *are* helping children.

Cynthia 59 Yeah.

Interviewer 60 Ok, they are a bit older.

Cynthia 60 Well 4 and a half to 10. The school goes up to 16. We've got 100 children there. It's a lovely school. Some of the ladies I work with.., I've just told one lady and the headmaster. Nobody else knows at the school. I thought "Well they might look at me differently", although they are a lovely group of ladies. They'd be keeping an eye on me and I don't want that just yet.

Interviewer 61 Yeah, so it's a bit concerning thinking about what other people might think about you or assume about you…

Cynthia 61 That's right.

Interviewer 62 … just because you might have a slight shake.

Cynthia 62 That's it. That's when you want to sort of … in case they start noticing it. I've got one friend. She's a real Johnny Blunt. She goes "What's the matter with you? Silly old fool!" [*Laughs*]. But she knows. It's best to tell her than to sort of …

Interviewer 63 And how have you felt when you've told people?

Cynthia 63 You look at their reaction. They sort of. They go, like an intake of breath, and they go … there's a couple of different reactions. A couple of them, Irene, gave me a big cuddle and said "Oh I'm so sorry. I'm so sorry" and I go "Oh well! These things happen" you know, and I cover up because they feel…

Interviewer 64 That's right, you're comforting them.

Cynthia 64 But uhm… they've all taken it like "Oh Jane!", you know. And at the time they don't really say much more because they don't really know what to say.

Interviewer 65 Yes. I suppose like yourself, they don't really know what Parkinson's is…

Cynthia 65 No that's right…

Interviewer 66 … at the beginning and so they don't quite know how to react.

Cynthia 66 That's right. They don't know whether to … I don't know really. I have a feeling that they either want to cuddle you up or you know absolutely…

Interviewer 67 Bewilderment.

Cynthia 67 Yeah. I think it is.

Interviewer 68 And I suppose for you yourself, you probably went through the same type of dichotomy as well, not knowing whether or not to comfort yourself, like "Oh don't worry".

Cynthia 68 Yeah, that's right. I mean the girls … none of them have broken down because I think we all are covering up for each other. You know, giving that strength to each other.

Interviewer 69 Yeah. You are all very supportive to one another.

Cynthia 69 I mean the girls say, "Well when the time comes, you won't be on your own!". I think to myself, I don't know what life's … I mean it doesn't actually kill you does it? [*Laughs*].

Interviewer 70 No! Definitely not!

Cynthia 70 But you think, I don't know what age it would be but I want to spend, I know it's silly, to see my girls have babies. But at the same time I don't want to be a burden to them. You know. I want to be with them, but I don't' want to be a burden to them.

Interviewer 71 Sure. And it's when you think about the future that it gets…

Cynthia 71 When you think about the future and what might happen.

Interviewer 72 You have a lot of fears about the future because you don't know what will happen.

Cynthia 72 That's right. I mean, that's it. Life is hard anyway. Not an easy old place to live in is it, this world of ours? But hmmm…. What's your dad's age?

Interviewer 73 My dad is 66 as well.

Cynthia 73 Oh! It must be right time! [*Laughs*].

Interviewer 74 Must be! [*Laughs*]. But absolutely, I think it's quite normal for people in your situation to start thinking about the future. And it's normal to have fears about the future, especially at your stage when you are not quite sure what it's all about.

Cynthia 74 No, that's right.

Interviewer 75 How it's going to affect you.... what Parkinson's *does*.

Cynthia 75 That's it. I mean I had a little bit of ... like I said I had this fall, but now I'm trying to swing that leg a bit. I'm afraid that if I look at the pavement, I mean one time I looked up and strode along but now it's like: Was that a trip or was it a fall? Or was I pushed? [*Laughs*]

Interviewer 76 Yeah. So now you are a bit more conscious, or aware of what your body's doing and why it might be doing that, and how to prevent any stumblings or falls. Do you view your body differently now? Does it seem different to you?

Cynthia 76 No, just that this part wants to do what he wants to do and not what I want to do! [*Laughs*]. But no, not really. I mean as I say just that comment about my eyes, but I'm not a vain person, you know. But hmmm...

Interviewer 77 It's just a bit weird, that half of your body is doing what it feels like doing and the other half is behaving itself.

Cynthia 77 That's right. I mean I know it's silly, but you try and stop it and you can't.

Interviewer 78 No. And so that must be a strange feeling or experience that your body's doing something and you are not consciously doing it.

Cynthia 78 That's right. And after a couple of minutes of taking over, the other hand is shaking, so it's got a little mind whatever it is! [*Laughs*].

Interviewer 79 So it's almost like a *thing*.

Cynthia 79 Yeah, a thing that's taking over and you think, "Behave! Stop it!", you know. It's something that's in there. It's the white cells dying off, or is it the red? [*Laughs*]

Interviewer 80 Well it's the lack of dopamine ...

Cynthia 80 Oh that's right and it's getting ... less....

Interviewer 81 And there's less of the cells that produce dopamine and the less of the cells that there are, the less dopamine you have in your brain to tell your muscles what to do.

Cynthia 81 And that's what we need.

Interviewer 82 And we haven't got as much control as we used to.

Cynthia 82 Hmmm...

Interviewer 83 And I think what the medication does is it stimulates the ones that are still left there and so they make more dopamine and then ..,

Cynthia 83 And that's why I'm thinking am I doing wrong my not going on medication. I suppose I've left it with Dr. De Silva. I mean I'm sure he would have put me on the right path as he thought, if I needed them.

Interviewer 84 Yes. I think a lot of people decide whether or not they want to go on medication now, or later.

Cynthia 84 Yes.

Interviewer 85 But obviously this is a big decision. Because ...

Cynthia 85 Apparently if I'd started on these two packs apparently I would have to finish the whole course because it's not a thing you can take three this week and think "Oh I feel better", and leave it. He said no, you have to finish the course.

Interviewer 86 Yes, yes.

Cynthia 86 I don't know if I keep on with him, but I said to him I'd rather stay without tablets but can I come and see you again? He says, yes, he said I promise… and that's when he was telling us about your … what you are doing. But he says "No, I promise you you can come and see me in 6 months", or ask my doctor for a prescription of those if I need it before.

Interviewer 87 OK, so you've always got that option.

Cynthia 87 Yeah.

TAPE IS TURNED OVER … SMALL DISCUSSION NON-RELATED TO INTERVIEW ….

Interviewer 88 OK, I'm going to look down my list, because I wonder if I've missed anything important to ask you … I suppose the only thing that I haven't really asked about much is your relationship with your daughters, which is obviously a really strong one. Do you think they are … that their relationship with you has changed at all?

Cynthia 88 No. They are very protective of me. But they've always done that since their dad left, so, you know – mum is on her own, you know, we've got to look after mum. No, they are … I don't know … I mean they've never shown me their worried side. I'm sure they must do to their husbands, but I mean they never show a weak side to me. They are always sort of there for me and … No I can't sort of … I suppose it has altered in as much as they without me knowing really, but they care for me… not care for me *more*, but sort of uhm…

Interviewer 89 More concerned for you?

Cynthia 89 Yeah. Yeah. But they've never shown me. They say "Oh we're all strong, we'll get through all this together", you know.

Interviewer 90 It sounds like your family motto is to be strong and copers.

Cynthia 90 [*Laughs*]. That's right. I mean one of the girl's cards… I mean Vicky, she writes like a book in the card. She picks a lovely card and then put "Whatever is been through, we will get through this all together". You know, so.. that's lovely.

Interviewer 91 That's lovely. That's very touching hearing that. You've obviously got a very supportive family.

Cynthia 91 I mean, I've got a sister. She lives up in Scotland, but I mean I had to tell her. The girls said "You should mum". She's fine. But I mean, it's a long way to travel for her. She's my baby sister. She's 63. [*Laughs*].

Interviewer 92 Ahh… [*Laughs*].

Cynthia 92 They're my two great nephews [*Points to pictures of her family*]. But because they live up there you don't see them. That's my eldest daughter, that's Shelly.

Interviewer 93 What a glamorous family you have!

Cynthia 93 [*Laughs*]. They're getting married in March.

Interviewer 94 So that's lovely. That's something to look forward to.

Cynthia 94 Hmmm… Yes. It should be a nice wedding. They want all the men to wear black ties and the women to wear cocktail dresses so that everybody can dress up.

SMALL DISCUSSION ABOUT FAMILY, UNRELATED TO INTERVIEW ISSUES

Interviewer 95 OK, So is there anything that I might not have asked you?

Cynthia 95 I don't think so, we've covered the way I feel. No I don't think so really.

Interviewer 96 OK, well thank you very much!

Cynthia 96 Oh it's a pleasure.

Interview 9 – "Nora"

Interviewer 1 So shall we start with when you first got told you had Parkinson's Disease? What was your experience of that meeting you had?

Nora 1 Well when I saw the neurologist and I went in to see him, my daughter came up there with me. And of course we went up there thinking I'd had a slight stroke on this side and well the doctor arranged for us to go and see him and he done a few tests. You know, when you walk across the room. They can tell the way you walk can't they?

Interviewer 2 Yes, that's right.

Nora 2 There's a certain way you walk. Like my shoulder hangs down. Well he said… Now I'm beginning to get… I bend over. I used to be upright, so upright, but I've tried to bring my back up but it hurts and so my daughter said to me "Well don't try and do it. We don't notice you walk like that". Cos now I'm walking really bad.

Interviewer 3 So you notice the difference and the neurologist saw that you were walking differently and that your shoulder was hanging down.

Nora 3 Oh yes. And when he told me. Like when he said and we sat down after he'd given me these tests and examined me and then when he said "Mrs Tucker I think you've got Parkinson's", of course my daughter starts crying. I was upset [*Starts crying*] and I thought oh it's only a short while after losing Dave [*Participant's husband*]. And I thought well I said to him would it be the stress I had with my husband. He said he didn't know. He said maybe it helped but he said it's not usually …

Interviewer 4 They don't know the cause.

Nora 4 No, no. I mean I have to go and see the nurse about every 2 months. She phones me regularly, about once a week. She does. Often we have a phone call and we sit and talk. When she's in the clinic and like she's between patients and she'll phone up and she'll say "Mrs T, it's Sue". I've got to know her now. I mean it's only been since August.

Interviewer 5 Not long really.

Nora 5 No. But she's been a big help. She really has. She's advised me about different things like the Attendance Allowance which I didn't realise I was entitled to that. And she said "You put in for it Mrs. T." She said "get your daughter to help you fill the forms in". But I was turned down first of all. And then I had appeal against it. And there's someone Sue knows who deals with Parkinson's and she works helping people to get Attendance Allowance. Last week I got a letter to say I've got it.

Interviewer 6 Oh that's good.

Nora 6 And they've backdated it to August. So I've phoned the bank up yesterday and I've got £740 paid into the bank.

Interviewer 7 That will help around this time of year.

Nora 7 Oh. It would.

Interviewer 8 So going back to what you were saying, it was a shock was it initially? For you and for your daughter to hear.

Nora 8 Yes. It was.

Interviewer 9 And what kind of things went through your mind at that point?

Nora 9 Well I wanted to know does it increase like with the increase would increase gradually? But the nurse has explained to me like I feel more at home with her. I've only met him once, the neurologist, and the nurse has been saying some people are different from others. It develops a lot quicker for some people. But when I was saying I'd had all these gadgets fitted I said I don't really need them. But she said I've find in time I would need them. Now I do, because when I'm on the toilet it's got arms and I can sit and it's more comfortable.

Interviewer 10 More comfortable.

Nora 10 Before I used to hold on the wall at the side of the toilet and I'd hold on that.

Interviewer 11 Yeah.

Nora 11 Now when I do the bathroom I move it out the way.

Interviewer 12 So things are a lot more convenient for you and it was important to have someone like Sue to explain some of the questions that you had

Nora 12 Oh yes, yes, definitely. She's a very nice girl she is. I was surprised because she's so young and she dresses like you, very modern – boots and jeans. Is that hand made?

Interviewer 13 No, unfortunately not. No.

[SHORT DISCUSSION ABOUT MY CLOTHES]

Interviewer 14 OK. So going back to what we were saying. At the beginning it was a bit of a shock. Were you shocked because you didn't know what it was? Or did you know about Parkinson's before?

Nora 14 Well years ago. This is going back about 30 years, well even 40 years I'd say. I remember we used to go and see my brother-in-law because he lost his wife, my sister, and he lived in a country like this cottage and he lived right out in the wild. And he developed Parkinson's and when we used to go and see him, we used to stay over the weekend, like me and a couple of my sisters. And he was saying to us when we were all sitting in his lounge, "I get so worked up. He said and I find I'm shaking. When I've got people coming".

Interviewer 15 Right.

Nora 15 Well I've got that know. When I think back to what he used to talk about.

Interviewer 16 You can relate to that?

Nora 16 Yes, because I find if I'm trying to get ready to go out and I've got to be somewhere on time, you drop things. I mean it just seems to take you over, you can't help it, you know?

Interviewer 17 Yeah. So the more anxious or nervous you are, it comes on.

Nora 17 Yes. It does.

Interviewer 18 And that's frustrating?

Nora 18 I get annoyed with myself. I get annoyed. You know, oh! And … I can't explain you know. I get annoyed with myself and I start calling myself names and talking to myself.

Interviewer 19 Uh huh. Kind of telling yourself off?

Nora 19 Yes. And also when I walk down the stairs, I mean when I'm like that, I'm liable to fall.

Interviewer 20 So it makes you even more panicky.

Nora 20 Yes. When I do a little bit of housework, I'm all relaxed. I mean ok this hand shakes most of the time, but I sit on the floor and do the back of the TV, pull the bits out. I mean there will be a time when I can't do it, but at the moment I *can* do it.

Interviewer 21 Hmmm. Right. So is that important for you then? So the things you can do right now you make sure you do them?

Nora 21 Oh yes. Yes I do. My girls used to come over and take it in turns. They used to do the shopping. And I said to myself, "I could do that". I could go over there to Sainsbury's. It's only across the road. Just put it all in the trolley…

Interviewer 22 And just wheel it back.

Nora 22 Wheel it back and I always leaves it on the step, the trolley, and my neighbour Steve always runs it back.

Interviewer 23 So being independent is important for you?

Nora 23 Oh yes.

Interviewer 24 Have you always been an independent person?

Nora 24 Oh I have. I mean I get annoyed now when there's certain things I can't do, like when I've done the pictures on the wall and I can't reach up to do them and I mean I used to do my cabinet out once or twice a year I'd say, but I haven't done it for about a year and a half because of Dave and … He made that, Dave. And the bookcase on the landing.

[TALKS ABOUT HER HUSBAND'S CRAFTWORK IN THE PAST]

Interviewer 25 So there's things that you used to do, which you don't do now?

Nora 25 No, I can't. I mean I could ask Ted and he do that in a couple of hours even. But I wouldn't ask him to do it. I mean often they come down here. He cooks for the younger one and he phones me up and says "I hope you're not cooking something for yourself". And I say "I was going to" and he says "Mrs T, you are going to have meals on wheels tonight".

[TALKS ABOUT HER NEXT DOOR NEIGHBOURS].

Interviewer 26 So you've got lots of people around you who are very supportive.

Nora 26 Oh yes.

Interviewer 27 And since you've had the diagnosis, has that increased? Like you said your daughter came along to help you?

Nora 27 My condition you mean?

Interviewer 28 No, I mean have they been more supportive of you?

Nora 28 Oh yes. I mean when Dave was very ill they bought a DVD for him, the boys, and they came here and brought him DVDs to watch in TV.

[TALKS ABOUT HER FRIENDLY NEIGHBOURS]

Interviewer 29 Has it been difficult for you to accept that they've been so helpful?

Nora 29 Well I'd be lost without them.

[TALKS ABOUT HER FRIENDLY NEIGHBOURS]

Nora 30 I mean there are days when I've got to … what can I say … get the courage to walk over the road. Because I'm walking a bit funny now and I'm thinking to myself, in my mind, people know you've got this – why be ashamed of it?

Interviewer 31 Yeah. But it sometimes make you feel ashamed or uncomfortable?

Nora 31 I feel … you when you walk past people as you're going along and you're wondering whether they are looking at you – the way you are walking, the way you are bent over and I just think to myself. I mean I thought to myself yesterday, get on the bus and go shopping.

Interviewer 32 Hmmm…

Nora 32 And I stayed there until I had got my neighbours' presents. And then I came back. And when he felt the weight of that jar he said "You never carried all of this back? No wonder your back keeps going".

Interviewer 33 But I can hear what you saying, that it does something to your confidence. Your confidence goes down.

Nora 33 You could be. Well there have been days where I haven't got the confidence to go across to the car park. And I force myself.

Interviewer 34 You have to be hard with yourself.

Nora 34 Because I've often said to my neighbours… when they knock on my door, he says "Do you need any shopping" and I used to say he could get me a few bits. And then I go to myself one day, "I'm not going to say that again. I'm going to go over to the shops myself". You do lose your confidence. You do.

Interviewer 35 Because it worries you that people may look at you in a different way or…

Nora 35 Oh yes. You know. I feel like when I pass.. well you might be walking past a couple talking. And I know like after they've passed me I can feel that they've turned round and looked but I mean I'd admit years ago I can remember there used to be a lady who worked in a shop in the newsagents over the road to us, the lady behind the counter. I used to stand there watching and I used to say to myself "It must be terrible to be like that". Whether she had Parkinson's, I don't know.

Interviewer 36 But you remember looking at her and thinking, gosh it must be awful for her.

Nora 36 Because she used to shake more at some times than others. She never picked anything up. She was inclined to drop things which I do. I notice that and I tell myself like… where I've not got a lot of use in my right arm… my right arm is dead as you say, but you knock things with it you know, your right arm, because you're not as conscious of it anymore.

Interviewer 37 You haven't got as much control as before?

Nora 37 No, no. Whereas my left hand I can do everything with it.

Interviewer 38 The right one, it does what it wants?

Nora 38 Yes. Yes. It does.

Interviewer 39 How does that affect you? How does that make you feel?

Nora 39 Well I try… I mean you know they say the brain sends messages to it, but I tell myself… I mean I can't pick things up as good with this hand and I keep trying and trying and like I bend down and in the end I do get it. I might get it up and then I drop it again. That's when I get annoyed with myself.

Interviewer 40 It's a struggle isn't it?

Nora 40 Well it is.

Interviewer 41 But you are adamant to do it anyway… it's important for you.

Nora 41 Yes, yes. Because you know like I should be going over my daughter's and I feel … useless… I mean I should be going over to the kitchen and helping but I'll only get in their way. That's what annoys me. Like, my grandson's, well I've got one of 21, another's that nearly 20, the next one's

18 in March, the one after that is 17, and I've got two of 15. Sometimes, that's when you feel your grandchildren might look at you in a different way.

Interviewer 42 Uh huh…

Nora 42 When I walk in the door… I mean the two of them they're massive and they call me "Little Nanny". I'm shrinking by the way! I'm shrinking! I got trousers at Christmas time and they're supposed to be three quarter, well I suppose they're just above the ankle now. When I tried them on the other day, I mean they're round my ankles. The ones that did fit me are now on the floor. I mean I showed Terry and he couldn't believe it. And I'm tripping up.

Interviewer 43 Maybe it's not that you're shrinking, but maybe it's your stature that's changing?

Nora 43 Mind you, even the trolleys in the Sainsbury's, the handles. I mean Steve says as you get older you all shrink. I said I bet I'm not five foot now. I was five foot two.

Interviewer 44 I want to go back to a couple of questions we talked about a while ago, but has it made you feel differently about your body?

Nora 44 I suppose it must do. I don't know how to put it really… I can't do a lot of things. There are certain things I can't do.

Interviewer 45 So in some ways you do view your body differently because of the way it's not letting you do certain things.

Nora 45 Uhm… I do. I mean I try to hold my back up. Posture, you know? I can't get rid of that bend in my back. I mean I try so hard. I mean sometimes when I'm walking down the path like, I'm holding myself all stiff.

Interviewer 46 Uh huh…

Nora 46 They all know what I've got. I mean the girls in the Sainsbury's they all know me. They're good to me, you know? They get things that I can't reach.

Interviewer 47 Yes. So the people who know about your Parkinson's are very helpful and understanding.

Nora 47 Oh yes.

Interviewer 48 But when you are out in public, just walking down the road, it worries you sometimes about what strangers might think.

Nora 48 When I'm not in this area. If I keep to this area I know people around here know. When I went out in Ilford yesterday … well I ought not to have bothered really. I wanted to get the boys some presents.

Interviewer 49 So you were quite determined.

Nora 49 Yes. I was pleased that I could do something nice. I bought something nice for them. I mean I know that they liked it and he was saying "I know exactly where we are going to put this".

Interviewer 50 So it was important for you to give them a gift.

Nora 50 Oh, it was.

Interviewer 51 They mean a lot to you.

Nora 51 They do. Honestly, they do. I tell you something, I'm finding it hard now to zips up and all my shoes – I've got little booties, and they've got laces on them. And the girls keep saying "Why don't you get the slip on ones?" but they've all got heels. I'll have to try after Christmas.

Interviewer 52 So that's another thing, another effect that it's having on your life that you've had to change the clothes that you wear.

Nora 52 Oh yes. And doing zips up. I get so annoyed. I really get annoyed. I can't get the bottom bit. And then I stand up and I say to myself "Right, I've got to do it". It takes me… where as before I used to put it on and zip it up. I mean, things like that, silly little things. I mean it can take you well I'd say five or ten minutes to do a zip up! I mean that's just to get it in place and pull it up. And to do laces up. I'm finding that whenever I put on my booties he'd always come over and do the laces up for me, you know. And I was thinking, when I was watching him bending down doing them, I was thinking "Oh".

Interviewer 53 Uh huh…

Nora 53 Now my friend who's a nurse.. she advised me to call my GP. She said phone the Parkinson's nurse up and see what she says. She might want you to go to the hospital. But she wanted me to see my GP. It's hard, I'd have to get a cab there and a cab back. That's where the attendance allowance comes in handy.

Interviewer 54 Yes.

Nora 54 Yeah, it's a good help, like to the hospital. And I explained what I had I mean I felt like I was pregnant! But I wanted to go to give me peace of mind. I mean when I was there… I never used to say a lot, but … I couldn't eat so much. That's another thing I can't do.

Interviewer 55 Hmmm…

Nora 55 I can't eat so much now.

Interviewer 56 It's changed your appetite.

Nora 56 It has changed.

Interviewer 57 I suppose it could be a number of things. It could be something like side effects of the tablets

Nora 57 Yes, yes.

Interviewer 58 I know before that you were saying that you get embarrassed in front of people

Nora 58 That's another thing. I can't cut my meat up. Terry does it for me. He knows I can't do it. I mean I said to J when she was here… she said oh don't worry, we'll chop your dinner all up for you. But I said "Yeah, but the children will all be round the table" and she said "Well if you want to sit in the front room on your own Mum you can!"

Interviewer 59 Oh no!

Nora 59 Yeah! No, but I do have trouble. I mean last year I don't remember doing nothing.

Interviewer 60 Has having Parkinson's made you look at life differently? Has it given you a different perspective on things?

Nora 60 Well I suppose I do say, like when I'm talking to my daughters, they've said "Do you think you'll be going away this year?" and like I'd say "oh no, I don't think I'd be able to do that". And then I think to myself, after I'd said it, you think to yourself well why not? I think to myself … I mean I've been over to Australia about five times and I've got a lot of family over there.

Interviewer 61 So somehow having this diagnosis has made you feel well I can't be doing that in the future.

Nora 61 Yeah I know.

Interviewer 62 Have you thought much about the future?

Nora 62 Well today I suppose. I mean at the moment no. I have a nephew that's taking me to court, so that is on my mind as well.

Interviewer 63 It sounds like that's an added stress that you don't really need right now.

Nora 63 Yes. It is.

Interviewer 64 I mean you have gone through such a lot over the past year or so.

Nora 64 Yes, and I wonder if it's all the stress that's brought this on.

Interviewer 65 Well I know with Parkinson's it can make you more stressed as well. It can make you more worried and anxious anyway. So it certainly doesn't help having all these things that are worrying you. You're trying to live with the Parkinson's itself, which is difficult in itself.

Nora 65 It is. And that's why I wish… I mean I shouldn't say this… but I wish I was able to … walk into that court and they'll see this frail old lady.

Interviewer 66 You feel that you want to be strong to walk into that court and full bodied as you say and be strong for your family.

Nora 66 Yes, that's right. I don't know what is going to come of this. I don't know.

[Long conversation about current family feuds]

Interviewer 67 Well thank you ever so much for speaking with me about your experiences.

Nora 67 That's alright. It's been good to talk to you.

APPENDIX 11

Client Consent Form for Case Study / Process Report

24/7 Mental Health Service
c/o Community Care Advice Service
Aldborough Road North
Newbury Park
Ilford
Essex
IG2 7RS

Tel 020 8491 1960
Fax 020 8708 7375

Assessment Procedures Consent Form

I hereby give my permission to Alice Sherman, Counselling Psychologist in training at London Metropolitan University, to use information gained from within our Counselling Psychology sessions at the 24/7 Mental Health Service, for supervision and assessment procedures at London Metropolitan University.

I understand that should this information be used in assessment procedures, all identifying details will be altered so that my identity will remain anonymous.

I understand that I can withdraw this consent at any time in writing.

Client's Signature……………………………………………………………

Client's Name (Printed)…………………………………………………..

Date:…………………………………………………………………………..

Counselling Psychologist's Signature………………………………….

Counselling Psychologist's Name:……………………………………..

Date: ………………………………………………………………………..

Hampstead Group Practice

Counselling Psychology Service

Consent to Audio Tape and Assessment Procedures

I hereby give my permission to Alice Sherman, Counselling Psychologist Trainee, to audio tape my counselling sessions. I shall be informed of the taping at the beginning of each session taped and I can withdraw this consent at that time.

I understand the tape might be used as part of supervision and assessment procedures and will be confidential within the Counselling Psychology Service and London Guildhall University. It will be erased once it has been used for this purpose.

I understand that should it be used for assessment purposes, my anonymity will be preserved. I can withdraw my consent to this at any time in writing.

Client's Signature……………………………………………………………..

Client's Name (printed)…………………………………………………….

Date:

Counsellor's Signature……………………………………………………….

Counsellor's Name (printed)

Date: