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Title page

Perspectives on the experience of sudden, unexpected child death: The Very Worst Thing?
For Amy and Dan

Who have taught me everything I know about how to live, laugh and love.

And for all those who allowed me the privilege of listening and working with their stories- thank you.

Remembering:
Joseph Michael Toby Turner

(Joe)

13 August 2003 - 14 March 2005

‘Perhaps they are not stars, but rather openings in Heaven where the love of our lost ones pours through and shines down upon us to let us know they are happy.’
On the surface, this is a book about death. Beginning with the death of Joe, a very young boy, and my search as his mother, to make meaning out of this experience – meaning which involved encountering the stories of many other deaths. Under the surface however and most importantly, this is a book about life – Joe’s short life which in its way held so much meaning and purpose; my life which continued after his death and the lives of Joe’s surviving brother and sister. Additionally, it is a book about the lives of parents who participated in the original research which led to this book; those of their children, surviving friends and families and all those who have been involved with or touched by the stories contained within this book. Ultimately this is a book about survival and building meaning from whatever endures after the death of a child. Much of the process which led to this book represented a search to locate painful and often untellable events, rendering the book ‘a place for experience’ (Hoggett, 2000). At the heart of this experience are the processes which commonly follow the sudden, unexpected death of a child, yet which are so little known or discussed.

That the book has been made possible at all is a small wonder, for as Hoggett observes, ‘Academics, literary agents, editors and publishers form part of a broader ‘expert system’, which manages access to the publicly written word’ (2000, p. 116) and thus they are key players in deciding which experiences are rendered available to thought. However, the field of death and dying has recently gained in popularity, resulting in several bestselling publications (Kalanithi, 2016; Rentzenbrink, 2016) and thereby paving the way.

The book itself is based on a doctoral research study, undertaken over seven long years and culminating in a subsequent PhD thesis. The catalyst for this was the sudden, unexpected death of my son, Joe, in March 2007 and the events that followed. As a former social worker, I was particularly interested, at the time, in understanding the professional responses to Joe’s death. Through conducting the research, I have become absorbed by cultural responses to grief and how these construct individual experiences – both personal and professional. The book’s intention is to understand - it is not about blame, nor is it about reprisal. Its primary aim is to make meaning from the events which followed the sudden, unexpected death of my son and thereafter to act as a means of support for others who may be involved with similar events in the future. Finally, the book is my perspective on this unique experience. I do not know how I would react, where I ever to face this event again, nor am I making any judgements on how other people should or should not react.
Ultimately the book is offered in the spirit of trying to make some meaning from what may appear, on the surface at least, simply as meaningless.

**Introduction**

The sudden, unexpected death of a child is now an unusual event in the Western world. Improved housing, sanitation and medicine, together with more effective child protection procedures, have contributed to a gradual decline in such deaths, although specific data on different causes is still very difficult to quantify (Shoesmith, 2016). However, Ferguson (2011, p.27) reports a total of 1,226 child deaths in 1914 which had fallen to 600 in 2004 (RCPath & RCPCH, 2004, p. 3). The latest statistics from the Office of National Statistics endorse this, showing that infant deaths decreased from 252 in 2014 (a rate of 0.36 deaths per 1,000 live births) to 212 in 2016 (0.30 deaths per 1,000 live births) which is equivalent to a 17% decrease in the rate.

However, despite this irrefutable reduction in child deaths, the contemporary news media is rife with stories ranging widely from cyber-bullying to historical abuse and the refugee crisis, all of which pose potential threats to the continuing welfare of children. Such news stories have the capacity to evoke public anxiety on a large scale, as Moeller (2002) suggests:

> Children are perceived to be one of the sure fire ways to attract eye-balls (p.37).

Although they may actually be safer than in previous history (Madge, M & Barker, 2007, p. 57) contemporary anxiety for the safety of children, fuelled by the media, may often seem correspondingly greater (Warner, 2015).

The discussion which follows in this book is underpinned by a series of events which occurred over a decade ago, in 2003, causing the news media to filter potential harm to children through a slightly different lens. The release on Appeal of Sally Clark, Angela Cannings and Trupti Patel, three mothers who had all been wrongfully convicted for causing fatal harm to their children, precipitated a Working Party and subsequent recommendations for the investigation of all sudden, unexpected child deaths. (RCPath & RCPCH, 2004, p. 1) – all aimed at improving investigation and concomitantly avoiding similar
miscarriages of justice in the future. The findings of this Working Party were published in 2004 as the report ‘Sudden, Unexpected Death in Infancy’ a multi-agency protocol for care and investigation’, which rapidly became known as the Kennedy Report, after its Chair, Baroness Helen Kennedy. The process which resulted in the Kennedy Report, together with its recommendations, are fundamental to this book, as it defined much of the process and procedure which surrounds sudden, unexpected child death and therefore helped to circumscribe the experience of parents and other family members with whom this book is predominantly concerned.

‘Rapid Response.’

The Kennedy Report and the Working Party which underpinned its publication in 2004, sought to prevent a repeat of the miscarriages of justice which had precipitated it. However, in the context of significant public concerns about child maltreatment, the Report also committed to ‘protecting the interests and safety of children’ (2004, p. 1). This was a delicate balancing act which attempted to walk the line between every parent’s ‘right’ to have their child’s death ‘properly investigated’ and the requirement to protect infants and children who may be ‘at risk’ ( p. v). The Report, together with the Children Act (HM Government, 2004) and new government advice on safeguarding children all contributed to new national standards for responding to and learning from sudden, unexpected childhood death (Garstang and Sidebotham, 2008).

Key to the Report’s recommendations was the formalisation of the professional ‘Rapid Response’ or Joint Agency Approach (JAA) (Garstang, Debelle, Aukett, 2013) which occurs immediately after a sudden unexpected child death and includes direct investigation by the police. Dubbed the ‘golden hour’, the police investigation formed part of the Kennedy Report’s commitment to properly investigate child deaths by gathering ‘crucial evidence before it can be lost or contaminated’ (RCPath & RCPCH, 2004, p. 13). Within the guidance, Police are required to treat sudden, unexpected child deaths as a ‘potential crime’ (ACPO Guidance 2005) and although the Kennedy Report notes that ‘very few of these deaths will be cause for suspicion’, (p. 13) it also acknowledges that there will be some deaths that are. Thus the Report recognizes the ‘almighty challenge’ for the police and other professionals in attempting to meet the requirement that ‘the family should be at the centre of procedures
and every process should be sensitive to the family’s needs’ (p. 3) whilst also meeting the legal requirements for evidence gathering and investigation. This challenge is also apparent in the literature within this field which splits into work concerned with safeguarding and that concerned with the medical investigation of sudden, unexpected child death – a potential conundrum which will be explored further in Chapter Two.

Under the Kennedy Report’s new protocol, it was recommended that the initial police investigation should be followed by examination in A & E and a later home visit, within 24 hours if possible. This home visit would be carried out ideally, by a ‘trained and experienced health professional’ usually a paediatrician, whom, the Kennedy Report suggested, should ‘have the confidence of the family and authority with the police’ (RCPath & RCPCH, 2004, p. 2).

Once ‘full information about the family and the death is available’ the Report also advocated for a multi professional meeting to discuss the family and the death and ‘provide a ...report for the coroner’ (RCPath & RCPCH, 2004, p. 3). This would usually be the first of several meetings aimed at considering ‘how procedures at the time of the death and afterwards were managed’ (FSID, 2011, p. 6).

In addition to defining these standards for investigation the Kennedy Report also placed great emphasis on the need to support families, stating that ‘parents suffering a terrible tragedy need sensitive support to help deal with their loss’ (RCPath & RCPCH, 2004, p. 1). Arguing for a ‘compassionate’ approach to investigation, the Report identified a strong need for ‘appropriate training’ which would both enhance ‘good communication between professionals and between professionals and parents.’ Furthermore the Report advocated that ‘professionals should be sensitised to emotions being experienced by parents’ and whilst some of this may come ‘instinctively,’ training was also identified as vital in achieving emotional understanding. This commitment to sensitising professionals to the ‘emotions being experienced by parents’ is a key aspect of the research which underpins this book and will be discussed throughout.

‘Turning a blind eye?’

In a paper on the events which surrounded the death of Victoria Climbie, Rustin suggests that the professionals involved with Victoria ‘seem to have been convinced that they could
escape having to think about Victoria and her aunt’ (2005, p. 12). Despite stemming from a very different set of circumstances, the Kennedy Report is characterised by related omissions, which may be interpreted similarly as attempts to escape uncomfortable thoughts – a theme which will recur throughout this book. Perhaps the most noteworthy of these omissions, given the pervasive commitment to effecting better understanding between practitioners and parents, is the complete lack of parental representation on the Working Party. Parents’ views are confined to an Appendix and limited to answering specific questions generated from a postal survey, administered by the Foundation for the Study of Infant Deaths (FSID), now known as The Lullaby Trust. In the series of multi-professional meetings which follow a sudden, unexpected child death, parents are also omitted, thereby limiting the opportunities to improve mutual understanding between professionals and parents (FSID, 2011, p.6).

The Kennedy Report acknowledges these shortcomings, stating that ‘given the nature and sensitivity of the subject, ‘some contentious issues remain.’ Rustin’s work, provides a lens for viewing these ‘contentious issues’ which suggests that ‘turning a blind eye’, or ‘failing to see what is before one’s eyes’ is created by an avoidance of the ‘psychic disturbance’ that admitting it to consciousness may cause (2005, p. 12). In other words, it is possible that parents were excluded from the Working Party for the Kennedy Report because the narratives and emotional content they might have generated were too challenging or threatening for the Inquiry to contain. Awareness of this possibility for ‘turning a blind eye’ is profoundly important for the study of sudden and unexpected child death, for as Ahmed (2004, p.196) states, significant child deaths can create a shared emotional response where the death is framed collectively:

The child represents the face of innocence; through the child, the threat of difference is transformed into the promise or hope of likeness. That child could be mine; his pain is universalised through the imagined loss of any child as a loss that could be my loss.

Following Ahmed’s argument, if a child dies suddenly and unexpectedly in a society where such deaths are rare, the collective ripple this causes may be too disturbing to think about - as if one child can die then any child could die - or as Ahmed states, ‘that could be my loss.’ The emotional disturbance created by this thought in a society where such deaths are now
rare may be, as Rustin suggests, too distressing to admit to consciousness, thereby leading to omission and ‘turning a blind eye.’ Rustin’s work also helps to set the tone for the theoretical foundation of this book which is discussed in further detail below.

**Context and approach of this book**

This book is drawn from an original research study which initially aimed at addressing some of the limitations of the Kennedy Report by including the testimony of parents who had experienced professional intervention following sudden, unexpected child death. There is almost no research on this, leading Garstang (2017) a medical researcher in this field, to make the claim that her research is ‘unique’ (p.9). In a contemporary study of the Joint Agency Approach and particularly the Joint Home Visit, Garstang, et al (2017) demonstrate that 13 years after the publication of the Kennedy Report, the conflation of investigation and support remains conflictual for professionals, whilst causing unnecessary distress for parents. This book and the research on which it is based aim at addressing both the gap identified by Garstang, as well as the distress caused to professionals and parents alike. Ultimately the book and the original research aim at improving the experience of sudden, unexpected child death by acting on the recommendations of the Kennedy Report and helping to ‘sensitise’ professionals to the ‘emotions experienced by parents’ (RCPATH & RCPath & RCPCH, 2004). However, whilst the Kennedy Report and its ongoing repercussions set the immediate context for this book, the key motive behind the research that underpins it was personal - grounded in my experience as a former social worker, but more crucially by the sudden, unexpected death of my son, Joe, in March 2005. Joe’s death, combined with my previous professional work, led me to research sudden, unexpected child death with the aim of understanding and contextualising my own experience, whilst concomitantly exploring the taboo nature of child death and ultimately attempting to improve investigation for both parents and practitioners.

My position within the research on which the book is based then closely mirrors that of Ellingson’s description of ‘multiple viewpoints’ (1998, p. 500) - as a researcher, a parent who has experienced the sudden, unexpected death of my child and a qualified social worker. This multiple positioning necessitated an approach to the work which permitted me to
explore the surface and depth of my own complex positionality, together with the emotional disturbance that sudden, unexpected child deaths can evoke in a Western cultural context of death denial (Rugg, 2006).

My approach throughout this book is therefore fundamentally psychosocial, drawing from Hollway's interpretation of this as holding ‘together an understanding of the workings of the psyche and the social without reducing one to the other’ (2009). Although definitions of the psychosocial have been and remain contested (Frosh and Baraister, 2008; Hollway, 2008) my understanding and approach within this book is that any individual’s capacity for responding to trauma or distress is shaped by their upbringing and distinctive personality traits, in combination with concurrent cultural influences in the external world. This approach then combines the subjective, inner, ‘psyche’ with the outer, ‘social’ to comprehend responses to sudden, unexpected child death as a complex interplay between the two. Fundamental to the psychosocial approach that I have adopted in this book is the concept of ‘surface and depth’ (Cooper and Lousada, 2005, p.145) which provides a means of exploring the superficial rapid response investigation and the Kennedy Report itself, juxtaposed with the cultural complexities which underpin them. This approach has also enabled me to locate my compound positioning and experience, together with that of the parents who participated in the initial research, as parts of a much wider exploration of the context and meaning of sudden, unexpected child death within a western cultural setting, which generally sequestrates death and dying. Jalland (2010) describes this cultural ‘silence’ around death as emanating from the mass killings of the First World War, which still influence the inviolable nature of the topic. Lakhani (2014) writing in the Guardian, further endorses this, suggesting that death avoidance is almost endemic in Britain, whilst research especially commissioned for Dying Matters Awareness Week (2014) found that 83% of the British public believe it is too difficult to discuss death.

Adopting a psychosocial approach has allowed me to explore these historical and cultural factors whilst simultaneously accounting for the inner, subjective experience of child death and thereby reaching a more profound understanding of the omissions from the Kennedy Report, which themselves exist within a generalised culture of death avoidance (Rugg, 2006).
Characteristics of the Research Study

The original research interviews, on which the book is based, utilised a psychosocial methodology which draws from the Biographic Narrative Interpretive Method (BNIM) (Wengraf, 2011) a qualitative, interpretive method, described in detail within Chapter 3. The term ‘child’ used throughout this book corresponds to the definition given in ‘Working Together to Safeguard Children’ (HM Government, 2006, p. 132) which describes this as a young person between 0 and 18 years. Similarly, I have adopted the ‘Working Together’ definition of sudden and unexpected death as one that was ‘not anticipated as a significant possibility 24 hours before’ (2006, p.132). Whilst the recommendations of the Kennedy Report are applicable chiefly to babies and very young children, there is much that also applies to the death of an older child, with the case for extending this until 18 years made within the Report itself (RCPath & RCPCH, 2004, p. 14).

The book is based on eight qualitative, research interviews with parents who had experienced the sudden, unexpected death of a child, with an accompanying professional investigation but no resulting criminal proceedings. The lengths of time between the death itself and the research interview vary and this is discussed in greater depth in Chapter Three.

Structure of this Book

Chapter One describes my experience of the birth and subsequent death of my son Joe in 2005, thereby establishing the personal context which motivated the original research.

Chapter Two introduces the concept of ‘emotional politics’ (Warner, 2015) and builds on this to discuss media reporting and public inquiries as background to the investigation of sudden, unexpected child deaths. Significant literature in the fields of death and dying and safeguarding are also explored and discussed. Chapter Three focuses on the methodological processes and decisions behind the narratives which form the heart of the book. Debates within psychosocial studies are mapped and explored, alongside a discussion of key concepts and the significance of these for the research narratives. The Biographic Narrative Interpretive method (BNIM) is discussed and critiqued, placing particular emphasis on the
use of data analysis panels for interpreting painful material. In Chapter Four, the experiences of five of the research participants are collated to form a collective story. Chapters Five, Six and Seven extend the threads drawn in Chapter Four containing the unabridged, in-depth narrative accounts of three research participants. The final Chapter, draws together key insights from the research process and its aftermath, with particular reference to media dissemination and subsequent online feedback. Drawing from psychosocial theory, this feedback is investigated alongside a discussion of different forms of splitting following a child death. The Chapter ends by discussing potential reasons for this splitting and suggests ways of reconciling these polarities in a way which improves the experience of sudden, unexpected child death for all those involved.

As I have discussed throughout this Introduction, the topic of sudden, unexpected child death is one which can cause significant emotional disturbance in an era where medical science and technology promise protracted lifespans and even the prospect of cryogenic freezing after death (Bowcott and Hill, 2016). During my time as a researcher, I was constantly mindful that this topic can engender social awkwardness and emotional upheaval, causing me concomitant anxiety and bringing me frequently to the brink of an apology. However, despite this, I remain in close agreement with Cooper (2009) in his assertion that we should maintain the courage to engage with difficult and painful aspects of life, no matter how unwelcome. Moving forward therefore, I invite the forbearance of all who read this book, in the fervent hope that your efforts will be rewarded.
Chapter 1

‘A Place for Experience’

Introduction

As I was preparing to write this book, I attended a talk by Lisa Graves, Curator of World Cultures at Bristol Museum and Art Gallery, who was responsible for a major Exhibition, ‘Death; The Human Experience’ (2016). As part of her address, Lisa told the story of a call she received, one afternoon, from staff in the gallery asking her to come downstairs and speak to a member of the public. It was late in the day and Lisa knew that the Exhibition had been thought contentious in some quarters, so she went downstairs anticipating a potentially difficult encounter. She was met by a man holding two small painted figures, who explained to Lisa that both his sons had died. He had begun a project where he placed these toys around the world, in public spaces and encouraged others to do the same. He asked Lisa to add the painted, toy figures to the Exhibition. Lisa agreed. What struck me as I listened to her story was its resonance with the title of her ground-breaking exhibition - for death is ultimately a ‘human experience’ and in agreeing to house these two small figures within this prestigious display Lisa was sanctioning this humanity and allowing the man to pursue the search for meaning which had followed his son’s deaths.

This story captures many of the themes which will recur throughout this book. It begins with a loss or as Lott (1996) describes it a ‘disappearance,’ which left in its wake an absence that somehow demanded to be filled. The subject of Lisa’s story was responding to this absence by physically locating meaningful objects in the spaces that were left behind.

In his story of the death of his first child, Ryan (1989, p. 132) describes a similar need to occupy the space by forging something creative from the death, to ‘personalise’ his grief. Despite never having done anything like it before, he finds a piece of granite and carves a headstone, an act which, when completed, helps him to ‘reach closure ‘and to ‘rest more easily ‘with the loss.

As I described in the Introduction, many of the processes surrounding production of the Kennedy Report are also characterized by absence – for example the lack of parental representation on the Working Party. Parental narratives are also absent from the Kennedy Report itself and much of the leading work undertaken since then repeats this omission. For
example, in their paper on establishing an interagency training course in the management of unexpected childhood death, Garstang and Sidebotham (2008) detail one of the main Course objectives as improving the skills of practitioners in communicating effectively with bereaved families. However, they do not describe how parents were involved in the training or how they designed the Course to meet this objective, thereby creating another absence similar to that produced by the lack of direct parental involvement in the Kennedy Report. This also mirrors my personal experience after Joe died, when I sought stories of experience similar to my own and found only more absence.

Much of this book and the research study which led to it then are concerned with bringing meaning and understanding to loss and absence. At the centre of both the research and the book are another set of absences – the children who died and their parent’s experience of this. The personal loss which brought me to this research and ultimately to authoring this book, is also where I have chosen to continue this first Chapter.

‘Joe’s Story.’

Joseph Michael Toby Turner (Joe) was born in August 2003, during the hottest summer ever recorded at that time. He was the oldest, by a minute, of twin boys delivered by emergency caesarean section at 32 weeks. It had been a difficult pregnancy and despite the trauma of the birth there was also an immediate relief in losing the debilitating edema that I had suffered throughout. However, the delivery of the twin boys, Joe and Dan precipitated more upset. Dan weighed only 2 pounds 13, yet Joe at a heavier 3 pounds 11 faced a series of crises and stayed in intensive care for several weeks. For days after his birth he was attached to so much machinery, it made it impossible for me to see his face. He just appeared as a tiny scrap of flesh divided from the world by the glass of his incubator, struggling to maintain his tenuous hold on life.

Dan’s tiny form seemed to strengthen daily and he sped through the hierarchy of the Baby Unit, from intensive to fairly low support Special Care, Joe however, failed to thrive and he was diagnosed variously with deafness, necrotizing enterocolitis and other infections, for which he was given powerful doses of antibiotic. In a scene that seemed drawn directly from hospital drama, he suffered a collapsed lung and I was unceremoniously thrust out of the
room whilst medical personnel fought for his life. Joe recovered but it was days before a brain scan confirmed that he had not in fact suffered the brain damage that doctors had feared.

Gradually, Joe was allowed to spend time outside of his incubator. As I could not yet drive I had to rely on friends to help me make the twelve mile return journey required twice daily to establish breast feeding. At night I expressed milk for the boys and the days were busy with hospital visits and caring for my daughter, Amy, then aged 4, who had just started primary school.

On 22nd September 2003, my birthday, Joe and Dan were discharged from hospital and I began the long task of adjustment to having two babies, as well as a new schoolgirl in the home. Gradually a routine established itself and the boys grew from tiny scraps to more robust toddlers. Joe, always the larger of the two, was a chubby boy who by his first birthday could walk and say quite a few words. By nature he was a stoic child with a sense of humour and infectious chuckle. He made few demands and I viewed him as a real treasure, a kind of miracle child who had triumphed over the odds. As Speedy (2008) suggests, we tell all sorts of stories to give reference to our lives and this formed one of mine.

Physically Joe was very inclined to colds and chest infections. Disturbed by this I made several trips to the GP where they told me Joe was simply a ‘Happy Wheezer’ and not to be concerned.

By March 2005, Joe and Dan were 19 months old and my daughter Amy, now 6 had settled well at school. I had reinvented myself as a contemporary middle –class mother of three, with as Rose (1989, p. 199) suggests ‘everything… so organized, programmed, sequenced and monitored as to ‘achieve maximum success’ in ensuring my three children’s safe passage from harm.

One Sunday night in March 2005 Joe seemed a bit snuffy. I took his temperature which was normal, checked for signs of a rash and reassured put him to bed as usual. He drank a good bottle of bedtime milk. Colds were very common and because I had been told Joe was a ‘Happy Wheezer’, I was not unduly concerned.

In the morning, Amy came into bed with me before I went downstairs to get the boys their milk; she went in to say good morning to them. When I walked into the room a few moments later, she was sitting in Dan’s cot reading to him. Joe was lying face down in his own cot. “Joe’s still asleep Mummy “she said. I took one look at him. He was cold, stone
coloured, like marble. I knew immediately that he had been dead for hours. The moment is frozen in my mind like a still from a film. It is one of those moments that perhaps most parents rehearse in their heads, hoping it will never happen and wondering what they will do if it does? What I did was to get Amy and Dan out of the room. Joe was dead. There was nothing I could do for him. My instinct, in that second was for my two living children. “Yes,” I said, “Joe’s still asleep. Let’s not disturb him” And I settled them downstairs.

Mechanically, in a kind of haze, I woke the children’s father with the stark words “Joe’s dead”. He immediately started to cry and then reached for the phone to call an ambulance, whilst in my haze I remained utterly calm and detached. I remember being almost curious at his tears and not wanting him to call an ambulance, which I now think may have been a form of denial (Hindmarch, 1993, p.16). Frozen in that time, there were still the five of us but the second the ambulance arrived I knew Joe’s death would become a reality and that our story would change forever. I would no longer be the mother of twins; we would no longer be a family of five and Joe would no longer be the miracle boy who triumphed over everything. Instead the ambulance would confirm that he was dead and would wake me from my attempts to keep the world and reality at bay.

The ambulance arrived in seconds. The paramedics crashed through the house, into Joe’s room and seconds later crashed out again, ashen faced saying there was nothing they could do. It all seemed slightly farcical to me, in my detached state because Joe had obviously been dead for hours. A paramedic took Amy into her room, whilst downstairs my husband wept on the sofa. The paramedic, told him to ‘pull himself together’, that he should be “putting his arm around his wife”.

Our marriage, since ended, was already tenuous and thus I did not want to sit and be comforted but rather to prioritise taking care of Amy. She didn’t yet know Joe was dead and I didn’t want her to know that he had died in the night at home, and further that she had been sitting in the room with her dead brother thinking he was asleep. It was still only about quarter past 8 in the morning and I wanted to take her to school and then tell her later that Joe had died in hospital, thus protecting her from everything that was taking place in her home.

I announced my intention to the paramedic, thinking that he would affirm my courage and clear headedness. Instead he looked aghast, telling me firmly that I was to stay at home and mourn Joe and further that we should all spend the day grieving Joe as a family. He added,
almost as an aside, that we weren’t allowed to leave the house. I reacted badly to this, insisting on my right to take Amy to school and he advised me again not to try and leave. The argument became heated and voices were raised, with the paramedic attempting to control a situation that was simply uncontrollable. I threw a coat over my pyjamas and left the house with Amy. My ex-husband stayed at home with Dan as a sort of hostage to ensure I did not simply ‘do a runner.’

At the school, I broke down for the first time, telling the Headteacher, in a confused stream of words that Joe was dead and Amy still did not know. The Headteacher stayed calm and capable though visibly shocked. We will look after Amy she said. You look after yourself.

When I returned home after taking Amy to school, it was clear that a ‘Rapid Response’ investigation had begun, for a marked Police car was outside my house, whilst a uniformed police officer seemed to fill the small hallway. As I walked into the front room I found it crammed with professionals who all seemed to know me, like some ghoulish form of cocktail party.

Following procedure, police officers interviewed me and my ex-husband separately, whilst in the boys’ room cameras flashed. The interviewing police officer asked what the children had for tea the night before. It had been tuna and pasta which led him to speculate that Joe had choked on a fish bone. During the questioning, other investigating officers made sorties from Joe’s room carrying his last nappy, his cot sheet and the ‘grow bags’ which both boys had slept in. These had been a gift I was very pleased with. Now the policeman brought the grow bag in with a concerned look enquiring “Whether these were the only bedding Joe had been given.”

By the end of the police interview I was convinced that Joe had died by choking on a fish bone, or of hypothermia or simply of my negligent mothering. Part of me anticipated the moment of my arrest and the removal of my two surviving children. Like Davies (2010, p. 7) I felt ‘undermined, disbelieved and threatened’, propelled by random tragedy into a world of police investigation and forensic evidence where I was a suspect in my own home, only minutes after finding my son dead in his cot.

Shortly after the interview as I was still confined to one room in the house, a female police officer told me that there “may be social workers on the way.” I remember replying that “I was a social worker” in the hope that this information may help to ameliorate my earlier
belligerent display with the paramedic. In fact this knowledge seemed to confound the
depolicewoman, who, faced with me there in my pyjamas, retorted “Really, I thought you were
the mother.” This has remained a powerful memory and one to which I will return
throughout this book.

However despite the police officer’s suggestion that social workers may be on the way they
never arrived and I was grateful to be spared more potentially distressing and humiliating
interventions. What did surprise me however was that hardly anyone came. The G.P called
briefly that night to check on Dan. After the tidal wave of professionals who filled our home
that morning had dispersed, we were left in the weeks that followed to cope with our two
surviving children; the shock of Joe’s death and the surrounding events, as well as the
countless tasks that follow a death, with almost no support.

When a child dies, their body becomes the property of the Coroner (Sidebotham & Fleming,
2007, pp. 129 & 147) and is still referred to in the early investigation as the ‘crime scene.’
When Joe died, the Coroner’s officer, one of the many officials who occupied my home that
morning, told us that his body would be taken to London where a paediatric pathologist
would carry out the post mortem. Joe was taken away in a body bag according to her
instructions and it was over three weeks before we had any news of him.

One afternoon during this time, the Coroner phoned and barked at me that I had not
registered the death. Impatiently she explained that I was holding up the process at her end
and therefore requested that I go and complete this task immediately. I felt foolish and
compromised as I had not realized I would have to do this. Dutifully, I set off with Dan in the
buggy, to the Registrar’s Office. The same registrar, who registered Joe’s birth only a year
and a half before, now registered his death in perfect penmanship without uttering a word,
leaving in this hushed space where birth and death crossed each other so intimately no hint
of humanity.

When the post mortem results arrived they showed that Joe had died from a very sudden
form of meningitis, brought on from having a lowered immunity due to the circumstances of
his birth, together with some chronic and undiagnosed chest problems attributable to the
collapsed lung. It seemed then that Joe was not such a ‘Happy Wheezer’ after all. But
despite this I still blamed myself.

Before the Coroner would release the body for a funeral we were told we would have to pay
a £100 charge to bring Joe back from London. We disputed this because the Coroner had
taken over legal jurisdiction of Joe’s body at the point of death. The Coroner told us that the charge was the fault of the undertaker whose job it was to transport the body. However, the undertaker told us it was the responsibility of the Coroner. Both told us to complain to the other but as we simply wanted to hold a funeral for our son, we paid the fee.

Years later, at a conference I asked the Coroner responsible for my District whether such a charge was ever levied on parents. She seemed appalled to be asked and told me in no uncertain terms that it did not. During the coffee break, several professionals working with bereaved families told me of various incidences where their clients had been made to pay similar charges. None of them had the confidence to say it to the Coroner and had all waited until the coffee break when they could tell me privately. I was left wondering about this silence and the possible effects of this.

A while after Joe’s death our health visitor, who had been on leave at the time, phoned me in tears. She told me how terrible it was and that it shouldn’t have happened, leaving me somehow with the impression that it had happened to her. Responding to her offer of practical help, however, I asked her to contact the Council about a memorial bench we had decided to place in a local park. Six weeks later she telephoned to say actually she was very busy and asked me if I would be able to do this. One of her colleagues later stopped me when I was in the park with my daughter and told me how difficult it had been for my health visitor to cope with Joe’s death. She was, her colleague told me, having a terrible time.

That remains one of my lasting impressions of Joe’s death. That most of the professionals involved were having a terrible time. No one seemed genuinely able to cope. The horror of the situation, the fear of being held culpable and the sheer randomness of the death seemed to immobilize people’s basic humanity at this most human of times.

Hindmarch (1993, p. 100) suggests that ‘whatever their role, any visitor to the home of a bereaved family is likely to feel apprehensive’ or even ‘terrified’.’ This was certainly my experience following Joe’s death and its effect left me struggling with shock whilst trying to maintain routine and ‘normality’ for Amy and Dan. However, whilst I was surprised and disappointed by the derisory quality of the interventions we received, as a former social worker myself, I could also empathise with the professionals involved. Ferguson (2011, p. 168) writes lucidly of an experience familiar to many social workers upon discovering a family are not at home, when ‘suddenly the world seems like a better place again, all because you don’t have to struggle through yet another tortuous session.’ This was certainly
recognizable to me from my own practice and I found myself dwelling on this and wondering if I had appeared as indifferent to people, as many of the professionals now seemed to me. There were professionals who remain in my memory as points of light. The Headteacher at Amy’s school was one. Once she learned of Joe’s death, Amy refused to have any evidence of him out on display. She wanted all his photos and possessions to be placed and contained within a box. On her return to school, Amy insisted on taking this box with her and the Headteacher took both box and Amy with her into class, using it to tell the other children what had happened to Joe. She showed them the contents, amongst other things Joe’s toothbrush, his shoes and his favourite toys. That day they kept the box in the school library and Amy was allowed to visit as often as she wanted and to keep it there if she liked. At the end of that day, however, Amy said it was all right to take it home. I felt that it had done what it needed to do. She had brought her dead brother to school and made him and the events of his death real. And she had done all this with the support and humanity of her Headteacher.

**Being a ‘Bereaved Parent.’**

In the immediate seconds after finding Joe dead my instincts had been for Amy and Dan, my two surviving children. My drive to both protect and navigate them through this time did not diminish as the weeks passed. The funeral came and went and so did the professionals involved with the death. My health visitor telephoned several times with the numbers of counsellors or family therapists she advised I should contact although I did not choose to follow these up. I was still shocked and focused on keeping things ‘normal’ for Amy and Dan and I did not want counselling, but rather practical support. I felt then as Hindmarch, (1993, p. 99) suggests that referrals to counselling are ‘often made by … professionals who feel out of their depth and lacking the competency required’. I consequently experienced the health visitor’s attempts at support as cursory.

The one helping professional I did speak to was a psychologist who offered his advice via a short ‘phone conversation about Amy’s refusal to have any evidence of Joe in the house and her request to put all his things in a box. The psychologist was practical and helpful, advising me that Amy’s behavior was ‘normal’ and as long as I was ‘all right’ then Amy would be too. (2004, p. 61) suggest that ‘the effect of a sudden, unexpected family death means that are
bereaved and are living amidst the grief of their parents. I was determined my two children
would not live 'amidst my grief' and thus the psychologist’s telephone edict that I should ‘be
all right’ became the magnetic north I followed in trying to protect them from the aftermath
of Joe’s death.

The difficulty I experienced was in finding useful advice on how to ‘be all right’ following a
sudden, unexpected child death. In the small, largely prosperous town in which I live the
twins, in their double buggy, had been a focus of attention and Joe’s death consequently
caused shockwaves. People often struggled with what to say and would do the clichéd thing
of crossing the road to avoid me. Other people simply did not mention the awkward social
fact that one of my children had completely disappeared and others still seemed to feel I
was not grieving as I should. One man, the partner of a friend, illustrated this with his query,
‘I mean haven’t you even broken down yet?’ Several more people questioned whether the
death ‘had hit me’ and I lost count of those who told me “I would never get over it.” At
playgroup with Dan someone told me I would “always be known in the town as the woman
whose twin boy had died” whilst out on a brief shopping trip with the children, another
woman I barely knew simply stood in the street in front of us and sobbed uncontrollably.

At first this behaviour was tiring and sometimes upsetting and I explained it to myself by
how difficult it must feel for people to know what to say to me. Additionally, my own guilt
was enormous and I therefore found myself avoiding the well-meaning ministrations of
those who repeatedly told me ‘not to feel guilty’ thus unwittingly increasing the feeling

Another social phenomenon which occurred around this time was people told me, often in
whispers, their own stories of pain and loss, most of them kept secret for years. I suddenly
learned of miscarriages; still births; generations of lost babies and struggling marriages.
Shisler (2006) too, identified this tendency after her own son’s death, suggesting that the
experience opened her eyes to this ‘invisible land’ (p. 201). This ‘invisibility’ is also explored
by J. K. Rowling (2003) in one of the ‘Harry Potter’ novels through her description of the
‘thestrals’ - mysterious winged creatures that can only be seen by people who’ve seen
death, but who are also largely avoided because they are a bit ‘different.’

In the aftermath of Joe’s death it was as if I was suddenly able to see the ‘thestrals’ and I
remember being startled by them and curious that Joe’s death had rendered me witness in
this way. Since carrying out this research, however, I see these experiences as part of what
Frank (1995, p. 39) describes as the ‘great permission’ provided by confrontations with death and thus view the telling of these stories as attempts at making meaning, thereby creating healing and cohesion. These are themes which I will return to repeatedly throughout this book.

In my own quest to follow the psychologist’s advice to be ‘all right,’ following Joe’s death I faced an uncomfortable social message which suggested I should instead be ‘breaking down’ or letting the experience ‘hit me’. I began to search for connection in other people’s accounts of experience. This search was at first totally undiscriminating and I read anything that contained a child death of any nature. Later I discovered books more relevant to my experience, but I was disappointed to find that these were usually written by professionals for other professionals. This genre also commonly interspersed chapters on ‘Supporting Families’ with others on ‘Fatal Child Maltreatment’ (Sidebotham & Fleming, 2007) and I became accustomed to keeping literary company with people who had harmed or murdered their children, with the boundaries often seeming to blur in front of my eyes.

Whilst my own narrative of Joe’s death included an element of accepting it as a random tragedy, I remained enduringly disturbed by the experience - particularly by the ‘Rapid Response’ investigation and I found both my memories and my dreams invaded by images of policeman; intrusive flash photography; seizure; accusation and humiliation.

Davies (2010, p. 201) in a personal account of a child protection investigation discusses the ‘secondary victimization’ suffered by parents and poses the question ‘We suffered twice. Was this inevitable?’ My own training and experience as a social worker told me that people sometimes harmed their children and yet the response we had experienced after Joe’s death seemed to me altogether inadequate; disjointed and lacking in humanity. I began to question whether the ‘tricky business’ of ‘weighing up who is at risk and those who pose a risk’ (Davies, 2010, p. 203) was indeed so complex it too often resulted in heavy-handed and inept interventions, which at best served a lowest common denominator and at worst caused as much harm as they attempted to prevent. Garstang et al’s study (2017) demonstrates that twelve years after Joe died the ‘tricky business’ of trying to support parents whilst simultaneously investigating them may continue to exacerbate the very harm it is trying to prevent.

Part of this potential harm centered around surviving siblings, who simply do not appear either in the Kennedy Report or in the literature on Rapid Response. Even one of the most
comprehensive and creditable books I discovered in my early forays into the literature, mentions investigation on only 4 of its 200 pages, with the longest reference saying simply that “the requirements for many sudden deaths to be investigated by the police can cause families further distress” (Dent & Stewart, 2004, p. 35). The work does not expand further on what specifically causes this distress; what its long term consequences may be and how this distress could be ameliorated and I could find no other work that did.

The other common depiction within the literature was of the death as ‘unacceptable’ (Judd, 1989, cited in Bridgeman, 2009, p. 255) and the ‘bereaved parent’ as almost a thing apart, a special kind of species rather than simply a fully rounded human being who had experienced an unexpected and arbitrary tragedy. The ‘bereaved parent’ was generally spoken of in ‘hushed tones’ as ‘crushed’ (Chalmers, 2007, p. 3) or as a person that never ‘feels o.k really ever’ (Dent & Stewart, 2004, p. 174). This portrayal is echoed in training material like the DVD ‘Why Jason Died’ (2008) produced by the Department for Education as a key training resource for a range of professional audiences, where the ‘bereaved mother’ is played by an actress, with all other parts played by professionals themselves. The mother is thin, frail and rarely speaks. She is supported through a variety of scenes in which she passes ghostlike, shedding the occasional tear and trembling slightly, but shows no emotional range other than passive despair. This is a very familiar depiction of the ‘bereaved’ as some amorphous, incapacitated group, climaxing in Garstang’s description of research participants as ‘death mothers’ (Garstang, 2017).

Whilst some of the literature did acknowledge the ‘intensity and range of feelings’ which ‘bereaved parents’ may experience, this defaulted to describing these as ‘a roller coaster of shock, disbelief, anger, guilt, blame, sadness, weariness and hopelessness’ (Dent & Stewart, 2004, p. 174). The last word ‘hopelessness’ is particularly significant as, alongside ‘unnatural’ much of the literature within the field endorses the observation that ‘the sudden death of a child is the most shocking and devastating event anyone must face’ (Simons, 2004, cited in Dent & Stewart, 2004, p. x).

Doka, (1989, p. 132) suggests that it is a common experience following bereavement, to search, as I did, for ‘books in which people shared their experiences and told what helped.’ However what I had sought for did not seem accessible. Rather than ‘books…that helped’, I found a great many which reinforced my uncomfortable feeling that I had not behaved as a ‘proper’ bereaved parent should. I did not view Joe’s death as ‘unnatural’ nor as ‘the most
shocking and devastating event anyone must face.’ Furthermore I had been belligerent to the paramedic and subsequently had not properly broken down in front of people. It seemed to me then that not only had I allowed Joe to die, but also that I didn’t even seem to be able to mourn him as it seemed I should. I had failed as Speedy (2008, p. 148) suggests ‘to shape up to normalizing judgments about bereavement processes.’ What would have helped me at this time were ‘narratives of survival’ (Ellis, 1993, p. 711). Clinging fast to the psychologists advice to ‘be all right’ for Amy and Dan, yet threatened by the swirling waters of ‘hopelessness’ and the ‘most shocking and devastating’ event that can ever happen to anyone, I simply wanted someone to tell me that ‘there are survivors’ (Ellis, 1993). At this time, as Nicholson suggests ‘it would have helped me to know that someone else out there had gone through this experience and survived to see the light again’ (2005, p. 8).

‘What survives the storm’

In an insightful piece on the individuality of bereavement experiences Chalmers (2007, p. 4) suggests that ‘parents ability to survive emotionally will be impacted by what has gone before in their lives, by their own childhood experience of parenting and by what they have invested in their relationship with this child.’ Thus rather than homogenizing sudden unexpected child death into dramatic and generic descriptions she offers an approach which personalizes the experience and frames it as a life event. Frank carries this idea forward in his description of death and fatal illness occurring ‘in a life that already has a story’ (Frank, 1995, p. 54), which can then begin the ‘repair … by taking stock of what survives the storm.’ Whilst what Frank describes as ‘the old map’ may now ‘be less than useful…it has hardly been carbonized ‘and traces will remain which point towards new directions and ways of navigating out of a place of ‘hopelessness.’ This was certainly my experience in the immediate days, months and years which followed Joe’s death when I was able to draw from previous life experience, together with the time I had spent with Joe and the continuing lives of Amy and Dan, who kept me very firmly ‘on the map.’ Additionally the circumstances of becoming pregnant and having children at all formed part of the ‘taking stock’ and the previous life experience described by both Frank and Chalmers. I had never taken it for granted that I would have children and when I did
become pregnant, it was reasonably late in life. This carried an increased element of risk, which manifested in the prematurity of all my children and the twin pregnancy itself, which medical staff advised was age related. I had therefore always felt very grateful for the lives of my children which were actually ‘unnatural’ – the living products of incubators; breathing apparatus and the power of modern technology, without which they would almost certainly not have survived.

Thus the births and continuing lives of my children, particularly the circumstances of Joe’s early weeks had left me with an unshakable sense of the fragility and also the preciousness of life. Although I am not a religious person the lines ‘The Lord giveth and the Lord taketh away’ from the Bible (Job 1: 21) seemed best to sum up my enduring narrative about Joe’s death. He had so nearly died in the womb, had so nearly died several times in hospital, that despite my feelings of devastation, guilt fear and failure, there was also a ‘felt sense’ (Gendlin, 1996, p. 19) flickering below all these feelings. This whispered to me that his short life, so precariously given, had actually been a miracle in itself and that we had been fortunate to share the 19 months he had lived.

‘What survived the storm’ of his death was my continuing role as a parent. Yet in the literature I accessed, as well as the Kennedy Report, there is little or no consideration given to the fact that many ‘bereaved parents’ may still be parents, and that this, as in my case, may still be what defines them. The attention given to siblings also often focuses around the death as an event which may affect these children as adults, influencing their capacity to manage changes like ‘going to a new school, leaving home, and getting married’ (Dent & Stewart, 2004, p. 177). I could find little that echoed the phone advice I had been given with regard to Amy, that if I was ‘all right’ then she probably would be too. I continued to navigate by this, as most of the available literature seemed to reinforce the widespread social message that none of us ‘would ever get over it.’ This is discussed in greater depth within Chapter 8.

Hindmarch (1993, p. 99) suggests that following a sudden child death ‘there is usually a need for practical support…parents in extreme shock may find themselves unable to care adequately for their other children.’ Following Joe’s death I was surprised by the lack of support we were given in caring for Amy and Dan, although I never felt I could not ‘care adequately’ for them. Where I did completely fail in confidence, however was over any
matters that affected their physical health. When I put Joe to bed the night he died he was just a tiny bit sniffly and so, particularly in the immediate aftermath, I was terrified of something similar occurring whenever Amy or Dan became ill. With Joe’s death I crossed a threshold into a world where death is a reality and where, particularly at first, there seemed little middle ground between a child being ill and a child being dead. The type of ‘practical’ advice identified by Hindmarch (1993) would have been invaluable to me in ameliorating these anxieties.

‘Seeking a ‘place for Experience’

In his work on ‘emotional life’ and contemporary welfare, Hoggett (2000, p. 84) writes passionately of the need for ‘a place for experience’ within contemporary social science, which resonates with my early forays into the literature. Looking back on these, I now see myself seeking such a place – somewhere to locate my own experience where it could find shelter in those of others. The research which underpins this book as well as the book itself have both become receptacles for this – akin to Ryan’s carving of the headstone (1989) and the locating of two small toy figures described earlier. However, as I have described I was dismayed at how little literature on this experience was available, even within the Kennedy Report which places such importance on it. Garstang, Fleming and Sidebotham are the principal researchers in this area, but as I have previously discussed, their work refers to mothers who have experienced the death of a child as ‘death mothers’ (Garstang, 2017) and often does not include parents at all (Garstang and Sidebotham, 2008) thereby limiting the capacity to excavate parent’s diverse emotional experiences.

Davies (2010, p. 209) calls for ‘more research to study the impact on the families’ following investigation ‘particularly when the outcome is no action.’ The research which underpins this book, developed from my experience following Joe’s death addresses Davies’ call, whilst this book and the thesis which preceded it have become my places for experience, as Hoggett (2000, p.41) describes. Additionally, and perhaps most importantly for me, the processes of researching and writing have provided me with the capacity to ‘contain’ my experience by ‘being able to think about it.’ Hoggett (2000, p. 41), drawing from Bion suggests that this capacity for containing experience through thought is one of the ‘essential
tasks of life’ and this in turn complements the work of many modern grief theorists who locate ‘meaning reconstruction in response to loss’ as ‘the central process in grieving’ (Neimeyer, 1999, p. 11). These are concepts which will recur throughout this book, as different meaning making processes are unfolded and analysed.

Conclusion

In this Chapter, I have introduced many of the themes which will recur throughout this book. Crucial amongst these is the concept of meaning making (Frank, 1995; Ryan, 2000) which is illustrated by the story of the two, small two figures and further by Ryan’s carving of the headstone (1989). My own authorship of this book and the research which underpins it, also creates meaning from Joe’s death whilst crafting a place for both Joe and my experience of his death. Within this search for meaning the Chapter also identifies loss and absence, as two key factors in experiencing bereavement, as well as in the dearth of research around sudden, unexpected child death itself. The discussions of how to ‘be’ a ‘bereaved parent’ and to ‘survive’ child death, within a contemporary cultural setting that commonly strips it of subjectivity and depicts it as ‘the most shocking and devastating event anyone must face’ (Simons, 2004, cited in Dent & Stewart, 2004, p. x) are other strands which will repeatedly recur within this book, culminating in Chapter 8 with a discussion of the emotional reactions provoked by early media dissemination of the research and the potential meanings of these. In the next chapter I situate both the Kennedy Report and other responses to child death in a wider context, using Warner’s concept of ‘emotional politics,’ which helps to illuminate the broader setting in which sudden, unexpected child deaths are situated.
Chapter 2

Death in an era of inquiry

Introduction

As I have previously discussed, research on sudden, unexpected child death is largely characterised by absence. There is a corresponding absence of empirical research in this area, leading Garstang (2017) to claim that her study is ‘unique’ and an accompanying absence of parental voice and consultation, as evidenced by the Kennedy Report and Garstang and Sidebotham’s work on training professionals (2008). A third absence is represented in the literature on child death which tends to occupy two distinct, yet separate areas. Firstly, there is a considerable literature on bereavement and loss, much of which includes the death of children from ‘natural’ causes (Dent and Stewart, 2004) and secondly there is a similarly sizable literature on safeguarding, chiefly concerned with the deliberate harm that can be inflicted on children. The rapid response and Joint Agency Approach to sudden, unexpected child death from natural causes, falls into an uneasy space somewhere between these two areas, due to the nature of the initial investigation which is Police led and can therefore lead parents to feel criminalised.

In this Chapter, I aim to create links between these disparate literatures by locating sudden, unexpected child deaths within a culture that is both death avoidant (Rugg, 2006) whilst at the same time exhibiting a prurient fascination with high profile celebrity deaths, together with child and other homicides (Warner, 2015; Shoesmith, 2016). As part of this discussion, I have included an analysis of child death inquiries, as a means of locating the Kennedy Report and of illustrating how responses to child deaths have developed both historically and culturally.

Additionally, much of the literature that I have used as foundation for this Chapter is not specifically concerned with death, children or safeguarding, but rather with exploring the absences I have already identified in the Kennedy Report, between emotional experience and social policy. Hoggett (2000), Cooper and Lousada (2005) and Clarke and Hoggett (2009) all take a psychosocial approach to excavating the breakdown of the connection between the two, and I have found each of them invaluable in providing a bedrock for this Chapter.
'Emotional Politics'

Since the death of Maria Colwell in 1973, the deaths of certain children have become ‘moral panics’ (Parton, 1985) provoking significant media outrage and concomitant public fury, often against professionals identified as having failed the child and by their negligence having caused the death. In often exhaustive coverage the Press shadows these professionals at work, home and in their social lives, thereby establishing them as folk devils (Cohen, 1972) and creating the conditions for threats both to them and to members of their family (Shoesmith, 2016). Warner (2015) dubs the intricate relationship between the Press, political regimes and public feeling ‘emotional politics’ and argues for deeper understanding of this in order that the effects on public policy and practice can be ameliorated. Warner’s concept is highly relevant to the study of sudden, unexpected child death which sits within the wider culture of emotionality and fear she describes. The consequences of this ‘emotional politics’ for professional practice are demonstrated clearly by the response to the death of Peter Connelly, whose death and pseudonym ‘Baby P’ are now internationally renowned (Shoesmith, 2016). Peter, aged only 17 months was found dead at home in August 2007, although the ‘emotional politics’ provoked by his death did not occur until nearly 15 months later in 2008. At this time Peter’s mother Tracy, her boyfriend Steven Barker and his brother, Jason Owen were convicted of ‘causing or allowing’ Peter’s death under the Domestic Violence, Crime and Victims Act (Shoesmith, 2016, p.13). The growing media frenzy which followed the death of Peter Connelly is now well known and documented (Jones, 2014; Shoesmith, 2016; Warner, 2015) and the ‘Baby P effect’ (Shoesmith, 2016) has also had far reaching consequences for both policy and professional practice involving children. For example, in the first ten days following media reporting of Peter’s death, the number of care applications rose by 26 per cent (Shoesmith, 2016). By the end of 2009, the year after the media turmoil in relation to Peter’s death, the number of children referred to social services departments jumped from 547,000 to 607,000 (Gaber, 2011), reaching 65,500 by March 2011 (Shoesmith, 2016, p.19).

The rise in demand for children’s social care placed intolerable pressures on already stretched local authorities which suddenly needed to create new posts or divert resources
from other services (Gaber, 2011). Additionally the long term effects on the wellbeing of staff were dramatic. The locum paediatrician Sabah Al-Zayyat, who was accused of failing to identify Peter’s injuries was suspended and has long term mental health difficulties as a result of her involvement. Sharon Shoesmith, the Director of Haringey Children’s Services was dismissed from her job on national television and subject, like the social workers involved, to a prolonged period of hate mail and death threats, as well as a media campaign led predominantly by The Sun (Shoesmith, 2016). The effect on practitioner recruitment has also been marked as illustrated by the social worker vacancy rate in Haringey, in the year following the Baby P revelations, which stood at one in three. (Gaber, 2011).

Arguably the most significant of the consequences generated by the ‘emotional politics’ which Warner (2015) describes is the effect on the practice of those involved with children which can make them fearful and reactive as a defence against mis-interpretation by the public and the media (Gaber, 2011).

Whilst the high profile deaths described are the results of deliberate harm to the child, they are also consequential in relation to the investigation and identification of sudden, unexpected child death from natural causes, as demonstrated powerfully by the case of Jayden Wray.

Jayden Wray was four months old when he died in July 2009 (two years after Peter Connelly) as a result of rickets that had been caused by a genetic condition passed unknowingly from his mother within her breast milk. His parents had initially taken him to the GP early one morning with concerns about his tongue, which was stuck to the roof of his mouth, causing a consequent inability to feed. The GP referred Jayden to University College Hospital’s walk in clinic, for precautionary reasons only. As it was not considered an emergency, Jayden’s parents made their way to the hospital by public transport. At the walk in clinic Jayden started to fit, although the paediatrician failed to respond to this. When the fitting continued, the baby was transferred to A & E and referred for intubation. At this point, there followed a series of fatal errors, with an initial 90-minute delay before intubation occurred. When this finally happened, the tube was inserted incorrectly, causing Jayden’s lung to collapse, although this was not initially identified. There was then a four-hour delay, during which Jayden’s condition seriously deteriorated. During routine tests, Jayden was found to have multiple fractures and, although the radiologist queried whether these may have been caused by severe rickets, this was dismissed by the consultant paediatrician. The discovery
of the multiple fractures instead led to concerns that Jayden was a victim of non-accidental injury. He was later transferred, now as an emergency to Great Ormond Street Hospital, where the consultant paediatrician pronounced his condition as ‘incompatible with life.’ This paediatrician later acknowledged that the system for transfer of the notes between hospitals was ‘chaotic’. At Great Ormond Street, further tests began to confirm the suspicion of non-accidental injury, with the consultant paediatrician specifically rejecting another suggestion of rickets.

Jayden’s parents were therefore arrested by his bedside, on suspicion of causing grievous bodily harm, on 23 July 2009. They never saw Jayden again. Although released on police bail, conditions prohibited their return to the hospital where Jayden was baptised and later died on 25th July 2009. No parent or family member was allowed to be present.

Following Jayden’s death, the Coroner instructed Dr Scheimberg, a paediatric pathologist, to perform the post-mortem, although this was against the express wishes of the Metropolitan Police. She observed radiological signs of rickets on the Great Ormond Street Hospital x-rays and these were confirmed on her physical examination of Jayden’s ribs and skull. On the basis of this, the pathologist initiated requests for Vitamin D testing of both Jayden and his mother. She later faced police criticisms in the criminal trial for this. The tests showed that Chana (Jayden’s mother) had severe vitamin D deficiency, which she had passed to Jayden whilst still in the womb, leading to congenital rickets. This condition became more serious after Jayden’s birth as Chana’s vitamin D deficiency remained undetected and therefore continued to be passed to Jayden through her breast milk. Despite this, the forensic pathologist, Dr Cary, instructed by the Metropolitan Police, determined the cause of death as non-accidental injury, leading to a charge of murder. When the couple’s daughter Jayda was born on 17 October 2010, neither the father nor any other family members were allowed to attend, and the baby was removed at birth. Chana was not allowed to see her own baby (Delahunty et al., 2012)

The parents were eventually acquitted of murder by the Old Bailey in December 2011, two years after Jayden’s death. The trial judge, Justice Theis, said in her judgment that Jayden had received ‘suboptimal care’ from both University College and Great Ormond Street hospitals. Baby Jayda was finally returned to her parents by the family Courts in April 2012 (Delahunty et al, 2012).
This case and the missed opportunities, which led a non-urgent visit to the Doctor to result in a death and subsequent imprisonment can be viewed firmly through the lens of ‘emotional politics’ (Warner, 2015). Crucial to understanding this is identifying why only certain child deaths become the subject of significant media campaigns such as that which followed the death of Peter Connelly. Whilst Peter’s death led to repercussions on a national scale (Warner, 2015) Jayden’s death barely garnered any publicity. Both Warner (2015) and Shoesmith (2016) argue that the contemporary political climate is a key part of this and that during or in the aftermath of crisis the population will seek guidance from politicians as to how they should feel. The death of Diana, Princess of Wales, provides an example of this, with the public outpouring of grief both mediated and engineered by Tony Blair, the then Prime Minister in his designation of her as the ‘people’s princess’ (Warner, 2015). The unprecedented reaction to this created a seemingly endless public willingness to ‘wait for hours to sign books’ and ‘to sleep out overnight in order to glimpse the passing of a coffin.’ (Clark, 1998, p. 393). This is mirrored in the public response to Peter Connelly’s death which Warner argues crystallises the ‘idea of the empathetic, heroic politician who is personally identified with child protection’ (2015, p.23). This same ‘heroic’ figure embodies two key elements which are central to the public reporting of Jayden Wray’s death compared to that of Peter Connelly, as well as to the study of sudden, unexpected child death. The first of these is the relationship between politicians and the media, which Shoesmith (2016) argues was particularly salient to the outcry which followed Peter Connelly’s death. Faced with both media and public outrage and a concomitant threat to electoral success, Ed Balls the Secretary of State for Children attempted to take on the mantle of ‘empathetic, heroic politician ‘by publicly sacking Sharon Shoesmith on national television, thereby identifying himself as the protector of children (Warner, 2015). A decisive element for this role is making the public assurance that deaths like Peter’s will be the last of their kind, eradicated by successful political processes in perpetuity. Shoesmith however refused to make such an assurance stating instead ‘You can’t stop people who are determined to kill their children ‘ (Warner, 2015, p.40) and thereby undermining public trust in political process and particularly in the public inquiries which invariably follow such events.

In Jayden Wray’s case the political climate was not the same as that which followed the death of Peter Connelly, nor was the death itself as symbolic. Whereas Peter’s mother Tracy, easily fitted into the role of the monstrous ‘chav mum’ who prioritised her boyfriend over
her child (Warner, 2015, p.95) Jayden’s parents did not slot so easily into this stereotype. However, perhaps more significantly, in relation to the key focus of this book, Jayden’s death was caused by a series of omissions rather than by violence or neglect. In a society which readily identifies naturally occurring child deaths with accountability and blame (Stanley and Manthorpe, 2004) the death of a child in such circumstances may represent ‘dangerous knowledge’ (Cooper and Lousada, 2005) which threatens the contemporary myth that children do not die (Chalmers, 2007). Shoesmith (2016, p.40) contends that ‘familial child homicide...breaks the most fundamental taboo of all.’ However, I would argue that the media populism which surrounds such deaths has actually dispelled this taboo and made them accessible to public thought, but only when certain tacit conditions are met. Warner (2005, p.9) suggests that these tacit conditions include, ‘who or what, in moral terms, the dead child’s parents are.’ Returning to the morning of Joe’s death, the policewoman who was shocked that I was both his mother and a social worker demonstrates this. As in the case of Tracy Connelly, child deaths are accessible to thought particularly if the parents are seen as lacking in moral worth (Warner, 2015) but crucially there must be someone to blame. In contrast to Shoesmith (2016) therefore I argue that the most fundamental taboo of all is actually children dying of natural causes, where there is no accountability and no one to blame. If children can die in this random way, there is no denying that it can happen to any one of us, or as Ahmed (2004, p.196) states so powerfully, ‘the loss of any child... could be my loss,’ thereby creating truly ‘dangerous knowledge’ (Cooper and Lousada, 2005).

Cooper (2014, p.3) stretches both fundamental taboos and dangerous knowledge even further in his proposition that adult society contains ‘deep ambivalence about children, about parenting and about the propensity in all of us to feel like doing violence towards our own children’ (2014, p.3). This suggestion shatters the contemporary cultural conviction that good parenting and particularly good motherhood are both intensive and selfless in responding to children’s every need. Herland and Helgeland (2014, p.1) found that the way women view themselves as parents cannot be separated from these culturally normative discourses of motherhood and therefore any failure to match an impossible standard of exhaustive selflessness can easily be constructed as failure. Women like Tracy Connelly, as Warner suggests (2015) match the stereotype of the ‘bad mother’ in a group populated by ‘the welfare mother, the teen mother and the career mother’ (Herland and Helgeland,
2014). Sally Clark, a Lawyer, belonged to this last category, a fact used against her by the prosecution at her trial for murdering her child (Batt, 2004.) Arguably then, Sally Clark also belonged to another category of ‘bad mothers,’ as although she was eventually released from prison on Appeal she was never acquitted and her children still died, thereby representing perhaps the most catastrophic failure of modern motherhood in a society dominated by entitlement and notions of ‘the good life’ (Clack, 2013). Viewing this through a psychosocial lens, Cooper’s ‘dangerous’ suggestion that there is a ‘ubiquity of hatred within the ordinary, everyday job of parenting’ (2014,p.3) can be split off from the majority and projected onto the categories of ‘failed’ mothers who become the familiar repositories for blame and unconscious terrors. (Herland and Helgeland, 2014).

The potentially catastrophic consequences of this readiness to attribute blame can be seen within the cases of Sally Clark, Angela Cannings and Trupti Patel, which led to the Kennedy Report. (2004). However, thirteen years since publication of the Report and despite its recommendations, the culture of fear and culpability that surrounds sudden and unexpected child death continues to contribute to miscarriages of justice, like that of Jayden Wray. Garstang et al’s recent research (2017) also demonstrates the continuing conflict and accompanying distress caused by the rapid response, joint agency death investigation, which in turn compromises the Kennedy report’s aim of ‘maintaining high standards in the interests of justice for parents whilst also safeguarding the young’ (RCPath & RCPCH, 2004, p. 15).

‘The Age of the Inquiry’: ‘failure’, ‘blame’ and ‘defensive practice’

As I have discussed, the ‘emotional politics’ (Warner, 2015) which surrounds the deaths of children like Peter Connelly, is often accompanied by ‘heroic’ politicians promising that this death will be the last of its kind and will never be allowed to happen again. Attendant to this promise is an ‘age of inquiry’ (Stanley and Manthorpe, 2004) in which public bodies undertake to pinpoint errors of judgement; identify who is to blame and change processes so that there is never a recurrence (Stanley and Manthorpe, 2004). After the death of Peter Connelly, as I have stated, it was Sharon Shoesmith’s insistence that this was not possible which partly fuelled the public and media hostility towards her (Warner, 2015).
Following the release on Appeal of Sally Clark, Angela Cannings and Trupti Patel, the Inquiry facilitated by the Royal College of Pathologists and the Royal College of Paediatrics and Child Health (2004) led to the Report ‘Sudden Unexpected Death in Infancy’ (2004), which remains the most substantive contribution to information on sudden and unexpected death in childhood. With its focus on avoiding similar miscarriages of justice in the future, the [Kennedy] Report, like numerous other inquiries before and after, attempted to create the conditions for future prevention. However, as the case of Jayden Wray demonstrates, the Kennedy Report was unsuccessful in its mission. However, within the context of further exploring the ‘emotional politics’ (Warner, 2015) which surrounds child death, it is worthwhile considering the inquiry as part of a genre (Cooper & Lousada, 2005, p. 151).

Reder, Duncan and Gray (1993) systematically analysed all known reports of child deaths from non-accidental abuse or neglect from the first, that of Graham Bagnall in 1973, through to that of Doreen Aston in 1989. Their rationale centred on the notion that, far from improving practice, the ‘accusatory styles’ of inquiries ‘grounded in the adversarial framework of the legal system’ (1993, p. 3) too readily apportioned blame, and thereby increased professional defensiveness, creating a vicious circle, which dehumanised both staff and service users in favour of bureaucratic process.

Reder, Duncan and Gray (1993) hoped that their own systematic analysis of each death and subsequent review might delve deeper, thereby helping to identify some of the ‘psychological processes which had influenced events’ (p. 3), so that lessons could be learned without scapegoating. Like the Kennedy Report, they produced a number of recommendations, which included a call for improved training and research, but which hinged on the necessity of understanding the ‘complex, fluctuating, emotive and stressful’ nature of child protection work which may then be exacerbated by criticism and blaming, leading to many workers practising from a ‘defensive posture’ (Reder, Duncan & Gray, 1993, p. 122).

Munro (2004) also charts the growth of the public inquiry into child abuse and neglect, from Graham Bagnall’s death in 1973 to the inquiry into the death of Victoria Climbié in 2003. Her account provides valuable insights into how the miscarriages of justice of Clark, Cannings and Patel occurred within the culture produced by these inquiries. Munro, for example, suggests that the inquiry into the death of Jasmine Beckford (1985) caused a shift in the emphasis of child protection work from a ‘rule of optimism’, where professionals attempted
to work with families and were slow to intervene, to a more intrusive stance which primarily protected children and placed the ‘rights of parents’ in second place’ (2004, p. 77). As Munro notes, there was a highly noteworthy shift in emphasis from the very first inquiry into the death of Graham Bagnall, which saw parents and children as equally in need of ‘assessment and help’ (2004, p. 78). Following the Beckford Report in 1985, the numbers of children placed on child protection registers rose from 11,844 in 1978 to reach 45,300 by 1991 (Munro, 2004, p. 78).

In 1987, two newly appointed paediatricians in Cleveland diagnosed sexual abuse in 121 children from 57 families, all within a five-month period (Munro, 2004, p. 78). The public reaction to this, fuelled by often hysterical media coverage, constituted a backlash against professionals who were seen as ‘becoming too powerful and unnecessarily breaking up families’. The Cleveland report of 1988 echoed this public outcry, criticising the professionals involved and recommending much greater co-operation between professionals and families. However, despite the Children Act (1989), which pre-empted the recommendations of the Kennedy Report in advocating a ‘better balance’ between ‘the need to protect children and the need to enable parents, later studies showed that this balance had been difficult to achieve. Munro (2004, p.78) quotes a Department of Health summary of research published in 1995, which highlighted the fact that social work interventions were still ‘too often characterised as investigations’.

In 1991, the first of a series of ‘Working Together’ documents (Department of Health, 1991) acted as an attempt to stem what had now become a flood of inquiries by placing responsibility for the new ‘Part 8 inquiries’ (later to be known as serious case reviews) at a local rather than a national level. Despite this, Munro argues that ‘the threat of a public inquiry has remained a major influence on professional action, encouraging a defensive style of work’ (Munro, 2004, p. 74), and accordingly making a culture of ‘balance very difficult in practice.’ Paradoxically, this defensiveness has arisen at a time when for most social workers and related professionals ‘actual direct experience of death is very limited’ (Ferguson, 2011, p. 34), thus making the death of a child perhaps truly the ‘most shocking and devastating event’ professionals may face (Simons, 2004, cited in Dent & Stewart, 2004, p. x).

Reder and Duncan (2004) chart the history of fatal child abuse inquiries ‘from Colwell to Climbie’, and suggest that these have at least four purposes: learning, disciplining, catharsis and reassurance (p. 107). All four purposes can be identified within the Kennedy Report,
which, despite its central concern with investigating miscarriages of justice rather than the fatal abuse or neglect of children, is permeated by child abuse and death, declaring ‘child protection is a responsibility all of us must bear because of the special vulnerability of the youngest amongst us, who have no voice’ (RCPATH & RCPCH, 2004, p. 15). The exclusion of parents from the Working Party for the Report, however, also leaves parents with ‘no voice’, and thus the ‘learning’ focus of the Report is diminished.

Reder and Duncan (2004) suggest that generally such ‘learning’ has been one of the most successful outcomes of public inquiries in terms of heightening public awareness of child abuse and neglect. Ironically, however it is this very success that may have led to the wrongful convictions of Sally Clark, Angela Cannings and Trupti Patel. The ‘bureaucratic rather than the human focus’ adopted by inquiries leads, as in the Kennedy Report’ to protocol and to procedure rather than to a close listening to the voices of those involved.

This exclusion of humanity can lead to a closed and defensive style of work (Munro, 2004), focused only on apportioning ‘failure’ or ‘blame’, and in this climate it becomes understandable that professionals cannot allow for the fact that babies die from natural causes. The convictions of Sally Clark, Angela Cannings and Trupti Patel can be viewed as the direct result of the ‘conveyor belt practice,’ spawned by inquiries that cannot risk looking at other possibilities, within a general culture of blame (Stanley & Manthorpe, 2004, p. 10).

Following the death of Peter Connelly in 2007, changes were made to professional practices on a previously unparalleled level, spurred on by the public outcry described earlier. These changes were particularly significant for the social work profession which was most heavily criticized following Peter’s death. A new College of Social Work was created (and subsequently disbanded in 2015) and The Munro Review of Child Protection was initiated in 2010 by the Secretary of State for Education. The Munro Report is acutely critical of blame culture and calls for a renewed emphasis on relationship building between professionals and families, instead of the narrow focus on ‘forms and procedures’, which Munro holds to account for increasingly defended practice:

A one-size-fits-all approach is not the right way for child protection services to operate. Top down government targets and too many forms and procedures are preventing professionals from being able to give children the help they need and assess whether that help has made a difference (Munro, 2011).
Assessing ‘what help has made a difference’ with respect to sudden and unexpected child death is extremely difficult when, as I described in Chapter 1, parents are excluded from all meetings that follow, including the case review, thus stemming the potential flow of feedback.

Excluding parents in this way can be viewed psychosocially as a form of ‘splitting’. Drawing on the work of Klein and the tradition of psychoanalysis which succeeded her, Cooper and Lousada (2005, p. 30) describe how splitting can occur at an early developmental stage as a response to pain and other frustrations. These potentially dangerous and uncontainable feelings are projected into another, thus stemming the immediate threat to the self and creating a ‘split.’ This can occur as a psychological event or within external processes involving individuals and organisations. This is a concept that I will revisit in Chapter 3 and throughout this book.

Hoggett (2000, p. 39) also draws on Klein and her successors to locate another of her key concepts within the welfare field. Projective identification occurs at a very early stage of child development and ‘is the first form of communication available to us’, a means by which we express experiences ‘that we cannot adequately give words to’. Hoggett suggests that this constantly occurs too within social groups and organisations when ‘the more the individual or group feels itself to be endangered…the more violent will be the processes of projective identification into the other’ (2000, p. 40).

Viewed through this lens, the exclusion of parents from the public opportunity to give any form of feedback following sudden and unexpected child death could be seen as ‘splitting’ their experience, which may be too painful or threatening to hear. Correspondingly, the reason that is often offered for this - that the meetings would be ‘too upsetting’ for parents - can be seen as a form of ‘projective identification’ in which parents are seen as a threat to the organisation, which is struggling to contain the experience. This can also be related to Bion’s theory of containment (1962) in which the parent or therapist figure contains unwelcome and overpowering projections from the child or client and then restores them in a manageable form, thereby enabling them to do the same. However, in the case of the Kennedy Report, the Working Party appears to lack this capacity for containing the distress of the experience, thereby leaving parents with unprocessed feelings which may be exacerbated by lack of inclusion and an outlet for their narratives.
The same issues can be detected within the inquiry system where ‘the controlling fantasies of ... audit’ serve the function of precluding ‘true engagement with suffering, deprivation and loss’ (Cooper & Lousada, 2005, p. 81). However, Reder and Duncan (2004, p.107) provide a different lens, suggesting that public inquiries into child abuse and neglect do offer a form of containment as public ‘catharsis’ - a means of purging the horror of the events and remembering the child who has died. Furthering this argument, echoing Bion (1962) they suggest that inquiries may therefore perform a ritual function in which the ‘unthinkable’ can be thought about and contained, with the accompanying promise that such events can be prevented from ever happening again.

Within this ritual function, as Stanley and Manthorpe (2004, p. 2) argue, each report ‘tells a story’ of its own, providing a ‘narrative account replete with human drama and action...heroes, villains and victims’ in which form plays a significant part. This can be clearly identified in the Kennedy Report, which demonstrates a highly charged emotional tone throughout, declaiming, for example:

> When we no longer feel rage at injustice, we will have lost our humanity and our claims at living in a civilised society’ (RCPPath and RCPCH, 2004, p. 15).

The purpose of the Report in sensitising professionals to the ‘emotions experienced by parents’ also demonstrates an overtly emotional intent, which is then lost in another form of splitting by the complete exclusion of any emotional accounts. In a profound analysis of the Climbie report, Cooper and Lousada identify a similar ‘breakdown of linkage between ... emotional and evidential sources’, which they locate within a wider discussion of the problem of achieving ‘emotionally intelligent’ policy within a culture that has ‘great difficulty in maintaining contact with painful emotional realities’ (2005, p. 147).

Munro (2004, p. 85) also discusses the Climbie report, which she describes as ‘in a class of its own, describing a level of practice that was frighteningly bad’. Detailing much of this bad practice, from social workers through to housing workers, police and healthcare workers, Munro builds a picture of ‘a set of professionals trying to avoid taking responsibility for Victoria’s welfare by minimising their interpretation of their own role as much as possible and relying on someone else to do the necessary work’. The report into Victoria’s death was thus able to detail twelve separate incidents during a nine month period, where professionals failed to carry through the thorough investigation needed (Munro, 2004). Munro echoes Cooper and Lousada in suggesting that the ‘bureaucratic solutions’ produced
by child death inquiries, like that of Victoria Climbié, have a very limited value in prevention, and argues for ‘the importance of understanding the psychological dimension of practice’ (2004, p. 88).

In the 1950s, Menzies Lyth conducted a now definitive study of organisational defences within a London hospital, which demonstrates that the professional avoidance highlighted within the Climbié and other inquiry reports is by no means new (1960). Her work describes a culture of scapegoating, where both staff and patients were de-personalised, emotionally detached from each other and lacking in effective care and support. Amongst staff, this produced both poor morale and a high resignation rate, particularly within the cohort of student nurses deemed to be the most emotionally intelligent, thus echoing the picture of social work painted by Munro (2011).

In their discussion of ‘From Menzies Lyth to Munro’, Lees, Meyer and Rafferty offer a critique of the ‘managerialism’ that has developed as ‘an attempt to defend against the uncertainties of cases, fears of making the wrong decision and…public criticism’ (2013, p. 542). Comparing many of the findings of the Munro Review of Child Protection with those of Menzies Lyth decades earlier, Lees et al. uncover many parallels. Notable amongst these are the ways in which rules and procedures may be adopted as a means of creating a boundary between professionals, and the often distressing life experiences of service users. Menzies Lyth suggested that such attempts to protect against ‘primary anxiety’ created further ‘secondary anxieties’, which echo the contemporary experience of child protection workers and are also highly relevant to those involved with sudden and unexpected child deaths. According to Menzies Lyth, ‘secondary anxieties’ were experienced as the impending ‘threat of crisis and operational breakdown’, whereby workers felt overwhelmed by their tasks, leading to emotional detachment and a consequent inability to deploy professional judgement (Lees, Meyer & Rafferty, 2013, p.543).

Lees et al. suggest that both primary and secondary anxieties are at play in contemporary social work, which they also link to the culture of public inquiry. Whilst supportive of Munro’s recommendation that professionals should be helped to overcome defensive use of boundaries, they also stress the need for appropriate containment and support in helping professionals to achieve this.

Hoggett’s work on linking emotional life with welfare and social policy offers some similarly valuable ‘linkage’ between the ‘contemporary rationalism’ of the inquiry genre and the
concurrent ‘devaluing of emotion’ (2000, p.12). Hoggett focuses on ‘the power of what is unthought and unthinkable in our lives’ (2000, p.12), which helps explain why professionals avoided the necessary investigation into Victoria Climbié’s injuries. Cooper and Lousada, (2005, p. 146) draw from Rustin’s concept of ‘turning a blind eye’, and I have followed their example in trying to explain this. Similar to the Kennedy Report, the Working Party seems to have forgotten to include parents or to elicit narratives that would help with the underlying task of improving emotional understanding between professionals and parents. Rustin suggests that those involved with Victoria ‘seem to have been convinced that they could escape having to think about Victoria and her aunt’ (2005, p. 12). This in turn begs the question of why they convinced themselves of this, and by way of answer, Rustin suggests that ‘failing to see what is before one’s eyes’ is caused by an avoidance of the ‘psychic disturbance’ that admitting it to consciousness may cause (2005, p. 12). In other words, we avoid what is too threatening or frightening for us to think about, unless we are well supported to do so.

This is profoundly important for the study of sudden and unexpected child death, which, within a ‘culture of inspection and control,’ has become one of the most overpoweringly ‘unthinkable’ events. This helps to explain some of the apparently avoidant, negligent or cold-blooded behaviour of the professionals described within inquiry reports and within this book. The general ‘disappearance of child death in child protection practice’ (Ferguson, 2011, p. 26), created by improved health and conditions together with safeguarding practices, has created a culture in which random child death is now ‘unnatural’, and yet at the same time, the media interest in inquiries and the ‘blame’ attributed by these has led to a paradoxical fear that child death is lurking around every corner. In these circumstances, any form of knowledge that reflects a real child death, can rapidly become ‘unthinkable’, leading to the suppression of personal narratives as a way of helping to explain and link events that are otherwise inaccessible to thought (Cooper & Lousada, 2005).

‘Systematic investigation’ and a ‘sensitive, caring approach’: professional perspectives.

Aside from the ‘Kennedy Report’, and despite the paucity of literature on sudden and unexpected child death, there are nevertheless leading professional contributors to the field. Notable amongst these are Joanna Garstang a medical Doctor, whose PhD thesis
focussed on sudden, unexpected child death, together with Peter Fleming and Peter Sidebotham. Both the latter are Consultant paediatricians, with the former serving as a member of the Kennedy Report Working Party and the latter as a trustee of FSID, whose Director also sat on the Working Party. Garstang, Fleming and Sidebotham’s work forms the major contribution to UK research in this area and Sidebotham and Fleming’s book, ‘Unexpected Death in Childhood’ (2007) was a response to the Kennedy Report itself. The book aims at both exploring and reviewing the guidelines that arose as a result of the Kennedy Report, whilst advising professionals on the ‘skills needed to respond to unexpected childhood deaths in a systematic yet sensitive manner’ (p.98). The book is intended as a ‘Handbook for Practitioners’ and yet, once again, despite the recommendation in the Kennedy Report that professionals be ‘sensitised to emotions being experienced by parents’ (RCPPath and RCPCH, 2004, p. 12), there are no direct parental accounts contained within it.

Additionally, the book contains Chapters both on ‘A Family’s Journey’ and ‘Fatal Child Maltreatment’ within the first seventy-five pages, leading to a rather uncomfortable tension at times, particularly for any innocent parents who may turn to it for information. Within this apparent tension, the authors try to avoid overt ‘splitting’ by stating that their work is:

> Underpinned by two important principles: a thorough systematic investigation of the circumstances of death based on the best available evidence and a sensitive, caring approach to supporting the family (Sidebotham and Fleming, 2007, p. 98)

Whilst they clearly state that ‘that the two are not mutually exclusive’ (Sidebotham & Fleming, 2007, p. 98), this is somewhat undermined by the detail given to the circumstances of investigation, as opposed to the lack of direct parental testimony, and the brevity given to the potential effects of the Rapid Response on parents. The Chapter ‘A Family’s Journey’, written by a professional with great sensitivity and insight, says of the ‘Rapid Response’, that ‘the system which swings into action when a sudden death occurs can leave parents feeling powerless, with everything out of their control’ (Chalmers cited in Sidebotham & Fleming, 2007, p. 6). This goes only a small way to further the detailed understanding between parents and professionals advocated by the Kennedy Report.
Sidebotham and Fleming also neglect an opportunity to explore this further in an article evaluating the response to sudden and unexpected death in one English region (Sidebotham et al., 2010). Here these two authors combine with others to conclude that ‘with appropriate protocols and support, the joint agency approach to the investigation of unexpected infant deaths can be successfully implemented’ (p. 291). However, ‘successful implementation’ seems to have little connection with parents, whose experiences are described thus:

Although we have not been able to formally evaluate the parents’ experiences throughout the 4 years of the study we were not aware of any complaints in respect of the joint agency approach (Sidebotham et al., 2010, p. 294).

A four-year study, which focuses entirely on the joint agency response to sudden and unexpected child death and declares this ‘successful’ without including parents, seems to illustrate my earlier discussion of avoidance, both at a personal and organisational level.

Garstang and Sidebotham (2008) similarly describe the implementation of a training course for professionals involved with the multi-agency response to sudden, unexpected childhood death. This three day training was designed for senior figures in the police, paediatrics and other relevant professional groups and evaluated through post course questionnaires (Garstang and Sidebotham, 2008). Amongst the key objectives for the training were ‘to improve their skills in communicating effectively with grieving families’ and ‘to recognise the training and welfare needs of professionals’ (Garstang and Sidebotham, 2008, p.357). The findings indicate that the three day training courses were successful - with participants rating the course ‘very highly’ (Garstang and Sidebotham, 2008, p.358). However, these findings are based on the professional’s own evaluation forms following the training, rather than their subsequent experience in the field or perhaps most importantly of all, their subsequent interactions with and feedback from parents. Whilst one of the key objectives was to communicate effectively with grieving families, the families experience of this remains untold.

Cooper and Lousada (2005, p. 158) develop this concept of ‘untold stories’ in their discussion of the Laming Report into the death of Victoria Climbie, which also seems relevant to the above studies. Whilst Cooper and Lousada concentrate their analysis on professional avoidance of the ‘suffering of the child’, it seems possible that Garstang,
Sidebotham, Fleming and their colleagues may be avoiding the ‘suffering’ of the parents, whose emotional narratives may have interfered with the ‘successful implementation’ of their studies.

Similar absences of parental testimony occur in ‘Sudden Death in Childhood: Support for the Bereaved Family’ (Dent, A & Stewart, A, 2004), another noteworthy book within the field. This aims at providing a ‘sensitive and thought provoking practical study of how health professionals can help a family cope with the unexpected death of a child (p.ix).’ Unlike the work of Garstang, Sidebotham and Fleming, it does not attempt to encompass ‘fatal child maltreatment’ or the more legal and professional aftermath of child deaths, but rather aims at guiding health professionals through the various stages and aspects of sudden and unexpected child death.

The book is significant for its attempt to include many often marginalised aspects of grief and those who share the mourning process, but in over 220 pages it makes four single sentence references to police investigation and the ‘Rapid Response.’ Such limited analysis within a work of this scope once again does not go far towards building a comprehensive picture of the lived experience of investigation and professional intervention following sudden and unexpected child death. The absence appears to be based on a tacit understanding that the ‘catharsis’ of the Kennedy Report was sufficient to lay the cases of Clark, Cannings and Patel to rest, and that there is therefore no further need to focus on the ‘unthinkable’.

This pattern is reflected in most works within the broader field of child loss, where parents’ experiences are largely depicted by professionals, and investigation is either omitted altogether or summed up in a sentence. Raphael’s highly influential work, ‘Anatomy of Bereavement’ is indicative of this, stating simply that ‘the legal requirements are a further terrifying factor, for some kind of investigation is usually required’ (Raphael, 1984, p. 256). Rando, in her book ‘Parental Loss of a Child’ lists the ‘legal system’s involvement’ as the fifth ‘unique feature’ of a sudden and unexpected child death’ (1986, p. 165). In one paragraph, she briefly states:

There is all too often an insinuation that the death was caused by some act of commission or omission on the part of the family and this places an undue additional burden of guilt and pain on them (1986, p. 166).
Ironically, it is the detailed description of the police response to sudden and unexpected child death that points to how intrusive this may feel for parents, and consequently to what support may be helpful. Fox (2007, p. 141) provides a flow chart of decision making for police in possible homicides, which demonstrates clearly how the police investigation is focused. Despite employing the generic formula of providing ‘support to the family’ (Fox, 2007, p. 146), he describes how ‘the body itself is always designated as a [crime] scene’, and that the police often refer to the immediate period after death as ‘the golden hour.’ This is based on the principle that ‘...effective early action can result in securing significant material that would otherwise be lost to the investigation’ (Fox, 2007, p. 150). Consequently, Fox describes how the ‘scene’ (normally the child’s room or family home) is either guarded by a police officer or ‘locked and sealed until a proper investigation can be carried out with crime-scene investigators’ (Fox, 2007, p. 148). However, he does not contextualise this or discuss the potential impact or consequences for other children living within the area of the ‘crime-scene.’

Fox also quotes from the ACPO guidelines (2002), which state that ‘healthy children are not meant to die’, a phrase that puts an uncomfortable tension on the notions of balance and fairness emphasised by the Kennedy Report. As the stories in this book show, apparently healthy children do die and it is consequently vital that investigating officers during the ‘golden hour’ are firmly aware of this possibility.

Fox also adds his voice to the Kennedy Report’s call for training as a means of increasing empathy and understanding between parents and professionals, stating:

Good training will help senior investigators become confident about what they can and cannot allow and this should lead to less over-reaction and inflexibility (2007, p. 146).

‘Good training’, however, mainly appears to take place without parental involvement. As Garstang and Sidebotham (2008) describe, the major training course for professionals within the UK, established following the Kennedy Report, is run by Warwick Medical School, and uses actors to play parents rather than inviting parents themselves to participate. Whilst there may be an argument for maintaining training that does not involve parents directly, when this occurs routinely, as a rule rather than as an exception, it does seem to mitigate against the major objective of ‘communicating effectively with grieving families (Garstang, 2008, p. 357).
The DVD ‘Why Jason Died’ (Department for Education, 2008) also uses professionals to play themselves, with only family members played by actors. Again, there are persuasive arguments for this in mitigating the potential distress of interacting with real life stories. However, the consequences of increasing emotional understanding are demonstrated when Peter Fleming addresses the camera directly. He states authoritatively that, whilst professionals often worry that they will do or say something that will make the situation worse; he is able to reassure them that they cannot possibly make it any worse, a statement which contrasts strikingly with accounts given in the literature and within this book.

The Warwick Medical School training for professionals involved with sudden and unexpected child death is convened by Peter Sidebotham, Fleming’s colleague, and is endorsed by both the FSID and the British Association for the Study and Prevention of Child Abuse and Neglect (Garstang and Sidebotham, 2008). Thus, as with Fleming and Sidebotham’s work ‘Unexpected Death in Childhood’ (2007), there is an inescapable association between child death and child harm. Perhaps as a result of this link, in all the work and training material discussed thus far, the ‘systematic investigation’ is covered in intricate detail, yet the ‘sensitive, caring approach’ required to balance this, remains another liminal space, with mostly generic, rather than detailed description. Significantly too, as I have now repeatedly discussed, the accounts of what constitutes a ‘sensitive, caring approach’ are almost always made by professionals on behalf of parents rather than by parents themselves. The Fleming example in the DVD discussed above, demonstrates clearly the pitfalls of this in increasing understanding.

The most frequently occurring advice to professionals intervening with families immediately after death, is to allow them to ‘spend time with their dead child’ (Sidebotham & Fleming, 2007, p. 279), and to offer mementoes, including handprints and locks of hair (Dent & Stewart, 2004, p. 142; Sidebotham & Fleming, 2007, p. 279). However, without a profound understanding of the emotions parents may be experiencing, these offers can seem mechanical, or even worse, they may be a gross intrusion into the parent child relationship at a traumatic and significant juncture. Parents who have begun the day freely able to care for their children, end it with their child the property of the Coroner, often not even knowing where their child’s body is, and invited by professionals to visit their child or gather mementoes. This is another conflict of practice with the professional literature, which
advises that ‘parents need time to assimilate information’ and should be offered this ‘over the following few days’ (Dent & Stewart, 2004, p. 139-40).

Unusually within the literature on sudden and unexpected child death, Rando makes some of the avoidance and denial around the topic explicit, referring to it as a ‘morass’ (1986, p. 163). She describes researching for her book and being advised by a national consultant for SIDS (Sudden Infant Death Syndrome) to ‘stay away from it’, which resonates with so much of the literature in the field. The emphasis within this literature is nearly always on preventing deaths, rather than offering intelligent and user led support when a death does occur. A significant exception to this can be found in the work of Dyregrov, (2006) whose focus on parental perspectives of loss, whilst not specific to sudden and unexpected child death, is nevertheless highly relevant.

In a study of professional assistance after traumatic death, Dyregrov suggests that professionals often disempower bereaved populations, telling them ‘how they should understand, regulate, and experience their bodies’ and ‘increasingly amassing power and influence by controlling more and more of the life world of human beings’ (2006, p. 182). Dyregrov suggests that, as an antidote to this, people should be empowered to have ‘more control over their lives, to have greater voice in institutions, services and situations which affect them’ (2006, p. 182). This will be discussed in much greater complexity within Chapter 8.

A similar study (Dyregrov, 2004) showed that parents bereaved by the sudden and unexpected death of a child frequently report feeling disempowered. They may also have contact with a multitude of health professionals, in what can be strained relationships following a death of this nature. This study also found that it is common for parents to withdraw following the death of a child, and thus the ‘sensitive, caring approach’ as cited by Sidebotham and Fleming may be of real value here. However, Dyregrov’s findings demonstrate a similar breakdown in linkage to the ones I have described, leading her to comment:

In view of prevailing laws and the comprehensive health concept, the lack of professional help to traumatic bereaved groups in our society is rather surprising. (2004, p. 187).

When linked to my earlier discussion of the defensive practice that has grown up partly as a result of the ‘age of inquiry’, Dyregrov’s observation is perhaps not so ‘surprising’ and
indeed recalls Munro’s description of those involved with Victoria Climbié, who tried ‘to avoid taking responsibility for Victoria’s welfare by minimising their interpretation of their own role as much as possible and relying on someone else to do the necessary work’ (2004, p. 85). Raphael also found that following the death of a child more than 50% of doctors found themselves ‘unable to handle parents’, whilst ‘reports from other workers are similar’ (1984, p. 261). The climate of fear, which can surround the death of a child, may have caused professionals distancing themselves, as they did with Victoria Climbié, leading to Dyregrov’s observation about the lack of ‘professional help to traumatic bereaved groups’. In these circumstances, Sidebotham and Fleming’s confident assertion, that ‘systematic investigation’ and a ‘sensitive, caring approach’ are ‘not mutually exclusive’ (Sidebotham & Fleming, 2007, p. x), indicates a need for much more complex understanding.

‘Like a surrealist play’: parental perspectives

As I have discussed, the literature on sudden and unexpected child death contains few direct parental accounts of the experience of professional intervention following the event. Garstang, whose Doctoral thesis focussed on the experience of multi-agency investigation following child death, is amongst the major UK contributors in this field. However, as a Medic, working closely with Peter Sidebotham, Garstang’s professional epistemology is clearly evident in her work. In her paper, ‘Rigour and Rapport’ (2017) Garstang provides a clear example of this when she refers to mothers who have experienced the death of a child as ‘death mothers’ (2017, p.9). For a paper aimed at exploring the distress parents may experience following the joint agency investigation, labelling the mothers ‘death mothers,’ demonstrates a deficit in understanding the power of language which parents discuss in Chapters 4 – 7 of this book. Garstang (2017) does consider ‘issues with uniformed non-specialist police traumatizing parents’ which is also described within this book. However her conclusion that ‘some parents require more emotional support and professionals should assist in accessing this’ (2017, p.2) negates the emotional complexity of the experience for professionals and parents alike and thereby fails to respond to the Kennedy Reports call that professionals be ‘sensitised to the emotions being experienced by parents’ (RCPATH & RCPCH, 2004, p. 12).
Two much older and briefer articles, by Stead (1997) and Harman (1981) engage the ‘emotions experienced by parents’ in much more complexity and thereby demonstrate successfully how professional interventions both helped and hindered – rather than exploring these at a more surface level. Despite the age of the articles, they resonate profoundly with both my own experience and with those offered in Chapters 4-7 of this book, demonstrating how consistent many parental reactions remain, regardless of changes to procedure.

Harman’s article ‘Death of my baby’ (1981) describes an experience uncomfortably close to the more recent accounts of Andy, Cathy and Laurie, presented in Chapters 4, 5 and 7 of this book, and raises the question of how, despite the work of Garstang, Sidebotham and Fleming and the recommendations of the Kennedy Report, so much has remained unchanged. Harman divides her article, following an initial preamble, into two sections, ‘what helps’ and ‘what hinders’. Within the former, she places ‘sleeping pills’ and ‘keeping busy’ together with the birth of a subsequent child. There is little direct ‘help’ linked to professional intervention, although she does mention being prescribed medication to stop lactation, echoing Julia’s story (Chapter 6). Harman also mentions support organisations, although she states clearly that she did not ‘personally make use of this facility.’ In her ‘what hinders’ section, Harman describes her sense of public humiliation in the hospital following her son’s death, where she was left waiting for two hours to be stared at by ‘bemused strangers’ (p. 35). This description again has uncomfortable resonances with many of the narratives in this book, together with her description of being ‘utterly horrified’ by the intervention of the police, for which she was totally unprepared.

Harman describes the experience of professional involvement, particularly that of the registrar, as ‘like a surrealist play’ (p. 36), a portrayal that vividly resonates with my own experience of Joe’s death and with many of the other accounts within this book. Similarly, Harman provides a rich emotional account, both of her own guilt and of the stigma of ‘maternal negligence’, coupled with the ‘taboo’, which accompanies the death of a baby, and which has altered little since her experience (Cooper, 2014).

Stead’s article (1997) describes the sudden and unexpected death of her son Dominic, and echoes Harman’s example of the ‘surrealist play’ with a similar description of the ‘disorganization’ that can follow traumatic death, often accompanied by ‘erratic and illogical behaviour’ (p. 25). This is particularly significant when placed in the context of the police
‘golden hour’, as discussed earlier. However, Stead’s account is perhaps most helpful in the
details that helped her at the point of her son’s death, for example the way his clothes were
taken care of:

The one thing that struck me as being one of the most caring acts of all,
was the fact that someone had folded all Dominic’s clothes up neatly
and had placed his little play boots in the bottom of the trolley. They
hadn’t been dumped into a hospital property bag as they so often are.
It was something so small that meant so much (p. 26).

This ‘caring act’ contrasts sharply with Ellen’s account of trying to get her daughter’s clothes
back (see Chapter 4), whilst Stead’s description of photographs, which were taken by the
nurse arriving at her house a month later, is also reflected negatively in a similar account
given by Cathy (see Chapter 5).

As a nurse herself, Stead determines to show the same ‘empathy, understanding and
compassion’ in her own continuing practice that she was shown herself, and, in contrast to
Fleming’s assertion in the training DVD discussed earlier, she draws on a 1995 RCN Report to
demonstrate that ‘the quality of the initial care provided has a major impact on the
relative’s bereavement’ (p. 27).

Aside from Garstang’s work and these few personal accounts, most of the available parental
perspectives derive from the safeguarding field. However, these are useful in casting light on
the experience of professional intervention following sudden and unexpected child death,
which itself is underpinned by a safeguarding rationale. I have therefore included some of
these within this Chapter.

In their account of parents’ experiences of safeguarding investigations, Cleaver and Freeman
(1995, p. 64) introduce the notion of victims and suspects, which is highly relevant to
parents’ experience of sudden and unexpected child death. They also pose the related
question ‘What does it feel like to be suspected of abuse?’ Whilst arguably a suspicion of
abuse or neglect is not as grave as being suspected of murder, the parents in Cleaver and
Freeman’s study report very similar reactions to those in presented in Chapters 4-7 of this
book. Notably, parents felt ‘frightened, ashamed, guilty or powerless’ (Cleaver and Freeman,
1995, p. 70), whilst the ‘enduring psychological reaction to investigation was guilt and self-
blame’ (p. 71). The notion of ‘justice’ also appeared in parent’s responses, as it does within
the Kennedy Report, with most parents reporting ‘feeling guilty until proven innocent’ (Cleaver and Freeman, 1995, p. 82), which is an oft-repeated theme within Chapters 4 – 7. Cleaver and Freeman’s research is concerned with child abuse rather than child death, yet it also highlights the potential difficulties of the police ‘golden hour’ earlier described, during which parental interviews form part of evidence gathering:

The impact of an investigation is very considerable. Parents feel angry, resentful and violated...it is difficult in these early stages to distinguish the anxiety and anguish of the innocent from the fear and remorse of the guilty (1995, p. 89). The difficulty in distinguishing the ‘innocent’ from the ‘guilty’ endorses the case for making direct parental testimony a part of the professional training that is promoted so widely. By listening to parents themselves, professionals could be helped to understand the very real emotions highlighted by Cleaver and Freeman, and this in turn may improve investigations and help reduce the miscarriages of justice, which prompted the Kennedy Report.

Cleaver and Freeman’s research into investigation is also useful in identifying some of the potential family consequences of investigation:

There is much to suggest that an investigation can irretrievably damage family dynamics...the quality of relationship between parents and children, as well as between siblings is all too frequently damaged (1995, p. 117).

The impact of Rapid Response on children features both within ‘Joe’s story’ (Chapter 1) and particularly within ‘Laurie’s story’, which forms Chapter 7, as well as manifesting within Chapter 4. Yet, this remains another powerful absence within the specific literature on sudden and unexpected child death. Where the possible effects of investigation and Rapid Response are discussed at all, it is almost always as part of the literature on child abuse rather than on sudden and unexpected child death.

A more recent piece of relevant research in the safeguarding area focuses on parents’ experiences of situations where concerns of non-accidental injury were raised. This was carried out as part of a series commissioned by the Department for Children, Schools and Families and the Department of Health, in order to ‘improve the evidence base on recognition and effective intervention in child abuse’ (Komulainen & Haines, 2009). This study aims at describing how participants remembered and reflected on their experiences as well as increasing professional awareness as to what is perceived as helpful from the parents’ perspective (Komulainen & Haines, 2009).
Although the research focuses on reports of non-accidental injury rather than sudden and unexpected child death, the study participants also reported many factors similar to those identified by my interview participants and by the parents in Cleaver and Freeman’s work. Significantly, parents felt they were not listened to and that staff treated them with suspicion. They also requested clear communication (preferably in writing) that ‘their case was closed’. Some parents, even years later, expressed uncertainty over whether they were still being ‘monitored’, and this was conflated with a general feeling that the investigation left them ‘distressed’, with a long lasting effect on the whole family as well as disappointment with ‘the system’ (Komulainen & Haines, 2009). The study authors conclude that further work should be carried out to establish a constructive dialogue between parents and child protection teams, regardless of whether concerns of non-accidental injury are substantiated (Komulainen & Haines, 2009).

A similar study by Peter Dale looking at ‘Parents perceptions of child protection services’ endorses this need for ‘further work’ by recommending additional ‘research focused on family perceptions of services’ (2004, p. 137). Dale found ‘the views of many parents can extend beyond the biases of their particular personal experiences and consequently offer sophisticated and insightful contributions that are of much value’ (2004, p. 138). This finding highlights powerfully the worth of listening to parents' stories rather than constructing their experiences for them, as so often occurs within the literature and training material within this field. Far from remaining in a ‘victim role’, many parents are able to achieve significant insights, as Dale suggests, and these could successfully be utilised by professionals.

Ghaffar, Manby and Race (2012) explored the experience of forty-two families subject to child protection plans within the north of England, and found that parents welcomed the ‘opportunity to talk about, and reflect on, their experience...hoping that their experience could improve practice for others’ (p. 901), which is another theme raised by parents within this book. Similarly, they found that ‘the investment in working with parents and responding to the needs of the whole family can produce positive results’ (p. 902), a lesson that is directly translatable to professional intervention following sudden and unexpected child death.

Brandon (2008) carried out a significant piece of longitudinal research which followed the progress of 105 young people, within the UK, who had recently been identified as having experienced significant harm or neglect and explored the available support for them and
their parents. The study found that in many cases the level of skill needed by professionals was inadequate to the demands of the case and further that to achieve the kinds of sensitive, complex support required by families, training and supervision was required across multi-disciplinary teams in ways that helped provide consistency and sensitivity. Whilst it is concerned with safeguarding, Brandon’s study (2008) also has much to contribute to the training of professionals involved in the response to sudden, unexpected deaths.

Within the safeguarding field there are also two notable personal and reflective accounts which elaborate on issues salient to the professional response following child death. Pamela Davies’ account (2010) is an intimate description of being investigated for the potential abuse of her son. As an academic, working within the social sciences at a UK university, Davies has both the language and the resources to describe this experience and garner an audience; opportunities that are not available to most parents in these circumstances. Davies describes the investigation that followed an unexplained swelling on the head of her five year old child Frederick, caused, she speculates, by his rolling off a sofa. Although she is careful to note that ‘proper professional procedures were followed’ by a worker who was ‘fair, open, respectful and reliable’ (2010, p. 1), she nevertheless found the experience ‘devastating’. Her conclusions once again echo those of other research into child protection investigations, noting ‘poor communication’ (2010, p. 8) and suggesting that ‘practitioners might be more consciously reflexive about balancing power with compassion.’

Davies describes the emotional impact on herself and her family of a system which seemed ‘indifferent to her ‘pain’ and which wielded the ‘crushing force’ inherent in accusing a parent of harming their child. The theme of ‘justice’ so forcibly urged by the Kennedy Report also appears in Davies’ description of feeling ‘guilty until proven innocent’, which is another consistent thread within this study. Davies uses her own experience to suggest that the ‘system’ is potentially responsible for ‘victimizing’ parents, and she evokes the concept of ‘secondary victimization’ to support this. ‘Such ‘secondary victimization’ could also apply to the parents themselves, and more significantly to their other children. Like Dale, Komulainen and Haines, Davies calls for further research to explore the harm that investigations of this nature can cause in the service of protecting the vulnerable.
This notion of ‘professional abuse’ is picked up in Richardson’s article on the personal impact on her and her daughter of a child protection investigation (2003, p. 123). Richardson is also an academic, and has the voice to write about her experiences. Her article charts the ‘information sharing’ process following an allegation of indecent assault against her husband, although these later proved unfounded. Her account, like Davies’, shares much in common with my own and with those presented in Chapters 4-7.

Richardson reports both feeling ‘on trial, without representation’ (2003, p. 127), and wanting to be considered ‘innocent until proven guilty’ (p. 128). To support this, she evokes the Human Rights Act (2000), which affords everyone this basic human right, and thus, as Richardson suggests, should have ‘considerable implications for child protection practice’ (2003, p. 128).

Most significant in Richardson’s article is her focus on wanting to protect her nine year old daughter from the effects of the investigation, a topic which, as I have noted, is entirely absent from most of the literature on sudden and unexpected child death.

In a passage, which echoes my own experience with my daughter on the morning of Joe’s death, Richardson describes:

    Insufficient consideration was given to the difficulties of informing me of the allegations while my daughter was in the house...In my opinion the initial investigation demonstrated a lack of planning and co-ordination, and the failure of the professional to allow me to protect my daughter from this traumatic situation constituted professional abuse’ (2003, p. 125).

The desire to protect children from professional intrusion forms a major part of ‘Laurie’s Story’ (Chapter 7), whilst the hope of accessing professional support to help them to cope with their children during and after investigation is described lucidly in Chapters 4 – 7, as well as within Richardson’s account:

    I desperately needed encouragement, constructive help and support and felt the role of the professional should have been to support me to plan and develop effective strategies to provide my daughter with appropriate information to protect her from the impact of the investigation. It was after all a potentially damaging and abusive situation but many aspects of this were outside my control and all I could do was attempt to limit the damage’ (2003, p. 126).
Richardson also identifies another apparent inconsistency within safeguarding practices, which manifests within the response to sudden and unexpected child death and which I have described in Chapter 1. Once the initial investigation was over, but before any conclusive results could be proven, we were left as a family with almost no professional support to care for two young children, whilst under suspicion for murdering their brother. ‘Cathy’s Story’ (Chapter 5) makes this point forcibly, as does Richardson, following the allegations made against her husband:

As a nine-year old child she was potentially exposed to the very real threat of danger and yet nobody offered us any protection or expressed any concern for her welfare’ (2003, p.126).

This is a theme that is picked up by Dale (2004) in his research into parents’ perceptions of child protection services where one parent states:

I could have murdered them and they would have been none the wiser because nobody was ever here. There was nobody to talk to, no back-up (2004, p. 147)

The description of the ‘black hole’ given by parents in Dale’s study conjures the ‘morass’ of sudden and unexpected child death evoked by Rando (1986, p. 163). It is highly significant too, that the majority of parental perspectives are drawn from safeguarding investigations, where the death of a child can perhaps be made ‘thinkable’ by the apportioning of blame and the promise of prevention within the culture created by the ‘age of inquiry’ discussed earlier.

In exploring some of the relevant literature relating to sudden and unexpected child death and then seeking to bridge the significant gaps with parental accounts drawn from the safeguarding field, I have attempted to show how the professional rhetoric of the Kennedy Report and its associated ‘experts’ does not consistently match those of parents themselves.

The parental narratives which form Chapters 4 -7 of this book offer a further bridge between the two. However, attempting to account for the widespread absence of similar stories within this field requires excavating the contemporary landscape of death and dying and associated taboos (Rugg, 2006). In his book, ‘Levels of Life’, which reflects on the death of his wife, Julian Barnes (2014) identifies one of these taboos as the language which surrounds death, stating:
One euphemistic verb I especially loathed was ‘pass.’ ‘I’m sorry to hear your wife has passed’ (as in ‘passed water?’ ‘passed blood?’)....

“Someone I had met only twice wrote to tell me that a few months previously he had ‘lost his wife to cancer’ (another phrase that jarred: compare ‘We lost our dog to gypsies’... You do not have to force the word ‘die’ on others, even when you use it yourself. There is a midpoint. At a social event...an acquaintance came up and said, simply, ‘There’s someone missing.’ That felt correct in both senses.’

In Chapters 4 – 7 the parents who participated in the research study which underpins this book, endorse Barnes’ view of language, as a means of avoiding challenging and problematic issues. Cathy, for example, discusses the language of the inquiry which followed her son’s admission to hospital, whilst Laurie, in Chapter 7, relates a story of trying to discuss the death of her son with his older brother. Both stories indicate the problematic nature of locating a language suitable for capturing the dangerous and sometimes unthinkable knowledge that a child can die both suddenly and unexpectedly in this era of sophisticated technology and scientific breakthrough.

‘Knowing the right moment’

I have suggested throughout this book that child death represents a form of ‘dangerous knowledge’ (Cooper and Lousada, 2005) in prosperous Western countries where such deaths are now rare. Ferguson (2011, p.27) charts the history of this, showing how improvements to diet, sanitation, housing and medical advances within the early years of the twentieth century all contributed to a fall in NSPCC child death cases, from 1,226 in 1914 to 277 in 1936. Even in the late 1940s, Ferguson describes how ‘child protection workers could still expect to have, on average, one child death on their caseload every year’, whereas prior to this, in the early days of practice, ‘the deaths of children in child protection cases were commonplace’ (p.27).

‘Dangerous knowledge’ then exists within the common expectation of today’s parents ‘that their children will survive them’ (Chalmers 2007, p. 3) rendering it a contemporary phenomenon, prefaced by a period when ‘most death including that of children was a domestic event and a normal part of communal life’ (Yates, 2000, p. 221).
Gawande (2015) chronicles this shift within a theory of medical development which sees this as concomitant with a country’s economic development. When a country is experiencing poverty, most deaths occur in the home, whereas as incomes rise so does the populations expectations of medical care. Giddens’ classic work on the sequestration of death endorses this theory, suggesting that the ‘professionalisation of medicine’ (1991, p. 161) arising from greater prosperity, has moved death from the home and into hospitals where it has become gradually concealed from the general view. Giddens argues that death has become a largely mediated experience, facilitated either by experts or through ‘fictional realism’ devices such as soap opera and popular writing (p. 169). The media fascination with ‘high profile deaths’ like that of Diana, Princess of Wales, provides an example of Giddens’ argument, mediating her shocking death in a car crash into a ‘fairy-tale’ ending where a nation in mourning was depicted as ‘willing to wait for hours to sign books’ and ‘to sleep out overnight in order to glimpse the passing of a coffin.’ (Clark, 1998, p. 393). Giddens argues that this ‘mediated experience’ further sequesters the reality of death, encouraging people to ‘live outside the self’, conducting fantasy intimacies rather than facing the often uncomfortable realities of their own experience (Giddens, 1991, p. 560).

Cooper (2014) argues that high profile child deaths such as that of Peter Connelly, discussed earlier, play a similar role in helping people to manage their own uncomfortable feelings about parenting, by displacing these into the ‘real abusers’ who are ‘over there’ in the pages of the nearest tabloid newspaper (p.4). The ‘eruptions of public and media concern’ (Cooper, 2014, p.4) occur as a way of the public facilitating the private (Cooper, 2014, p.12). Central to Cooper’s argument then, is the notion that people displace intolerable feelings into public eruptions of emotion or fantasy intimacies, all of which help to control what is otherwise uncontrollable. Quoting Bauman, Cooper argues that ‘death is…the ultimate humiliation of reason’ (2014, p.13) and thereby an insult to the supremacy of medical science which has turned death and dying into medically mediated events (Gawande, 2015). Giddens’ work on the sequestration of death echoes this suggesting that death is ‘nothing other than the incipient loss of control: death is unintelligible because it is the point zero at which control collapses’ (1991, p. 203).

Kellehear (2009, p.62) contends that within prosperous countries the emerging debates about ‘managed dying’ (p. 62) represent new ways of retaining control over the unacceptable realities of death. In the Netherlands, for example, assisted suicide has existed
for decades and grown exponentially, with other Western countries, including the UK, hoping to follow the Dutch lead (Gawande, 2015). The elderly, ill and infirm within Western culture are therefore increasingly confronted with choosing the right moment to die. Kellehear (2009, p.62) argues that there is a powerful moral code within this choice which distinguishes ‘shameful’ deaths from ‘successful’ deaths by selecting the right moment’ to die and thereby maintaining power and control. Kellehear argues, that elderly people who linger past their ‘time’ are ‘shameful’ and suffer from consequent stigma, having failed to live up to the ‘tiresome cosmopolitan tendency to focus on health, along with wealth, youth and beauty’, which he suggests ‘continues to threaten the social reciprocity at the core of the dying experience’ (p. 65). Kellehear’s argument about dying at the ‘right’ moment and the morality which he attributes to this, extends to the sudden, unexpected deaths of children, which Chalmers (2007, p. 3) describes as deaths ‘out of time’, leading to their depiction as ‘unnatural’ (Wheeler 2001, p. 530).

The rapid advance of digital technology has added another dimension to Kellehear’s arguments about choosing the right moment to die, offering increasing opportunities for digital immortalization. Walter et al (2012) suggest that the internet has fundamentally altered Gidden’s theories of sequestration by moving death into the public domain, where it is widely accessible. Sites such as MyDeathSpace.com initially offered the opportunity to upload someone’s MySpace profile after they had died without seeking consent from immediate family and friends (Walter et al, 2012). More contemporary social networking sites have been forced to intervene in these difficult moral arenas with Facebook establishing a bespoke memorializing feature (Kasket, 2012).

As digital technology advances further, businesses are emerging which offer to analyse social media postings and then continue with these after death, under the strapline ‘When your heart stops beating, you’ll keep tweeting’ (Merz, T, 2013) whilst the Swiss Lifenaut project has already utilised data from social media profiles to create an accurate robotic clone, thereby potentially defying the right moment to die in perpetuity (Mayer, N. N.D).

Mitchell et al (2012) consider memorialization sites, another popular phenomena made possible by the internet and advances in digital technology, which include online memorials to Peter Connelly and other children whose deaths have attracted high profile media attention. Virtual memorials are usually created by grieving family and friends using a template and are now very popular as a form of memorializing children so that a digital
immortality is assured. Whilst this practice can be seen as ensuring some kind of ‘continuing bond’ with the deceased child (Klass, 1996) Mitchell et al conclude that they may act detrimentally by extending mourning indefinitely, particularly where the deaths are ‘deeply problematic’ (Mitchell et al, 2012, p.413) such as those of children.

To return to Kellehear’s discussion of the right moment to die, what renders child deaths so ‘deeply problematic’ (Mitchell et al, 2012, p.413) is their symbolic capacity to capture a ‘point zero’ (Giddens, 1991) which is the very antithesis of control - thereby acting as a shocking reminder of how deeply uncontrollable and random life can actually be. To borrow from Giddens, the Rapid Response ‘mediates’ the potential trauma by providing a bridge between the random death and a bureaucratic attempt to control the circumstances. Hoggett explores this further in his discussion of the professional ‘psychological investment’ at play in ‘maintaining a reality which, while it may be unfair ‘...is at least orderly and predictable’ (2000, p. 57). He argues that ‘such forms of routinisation provide workers with a way of not thinking or feeling too much’, a claim further supported by Cooper and Lousada, who quote a social worker who, during a project into European child protection practices, asked ‘How would we manage without the child protection procedures?’ (2005, p. 181), a question that highlights the way in which routine can provide a means of ‘containing anxiety and other negative emotions aroused by working with ...the dying’ (Hoggett, 2000, p. 57).

In providing this function, the ‘Rapid Response’ can also be compared to historical forms of ritual practice that mediated death, via ‘ritual actions which contain[ed] death by making it open, public but subject to religious and social control’ (Mellor & Shillling, 1993, p. 414). Leader (2008), in his work on contemporary experiences of loss and depression, also cites ritual practices that can be seen to have an echo in ‘Rapid Response.’ Describing primitive cultural rituals in which ‘guilt is assumed from the start’, Leader explains that, ‘when a loved one dies, the mourner is treated as guilty without any trial. The community behaves as if that person is guilty, so pre-empting their own unconscious guilt’ (p. 122). In this way, Leader suggests that the ‘mourner is recognized as guilty’, whilst the ‘grief is inscribed into the social structure’ (2008, p. 123).

Mellor and Shilling conclude that ‘death is so alarming in contemporary societies’ because the grief is not, as Leader describes it, inscribed by ritual into the social structure, but rather because modernity has deprived most people of this ‘overarchingly existentially meaningful
ritual structure’ (Mellor & Shilling, 1993, p. 427). Thus, the ‘banding together’ that characterised ritual mourning in past societies has been replaced in ‘high modernity’ by ‘people standing alone in the face of death’ (Mellor and Shilling, 1993, p. 427). This ‘banding together’ together recalls the ‘systematic investigation’ discussed earlier (Sidebotham and Fleming, 2008) and the Kennedy Report’s emphasis on ‘creating rules and procedures’ (RCPATH & (RCPath and RCPCH, 2004), 2004, p. 15). Whilst these undoubtedly have a role, the lack of balance evokes a sense of ‘banding together’ in response to the collective threat posed by sudden, unexpected child deaths which are ‘out of time’ (Chalmers, 2008). Crucially here too, as in Leader’s description, this ‘banding together’ occurs in a context where the ‘mourner is recognized as guilty’, thus inscribing the grief into a social structure where child harm is more culturally intelligible than the unexpected tragedy of child death (Cooper, 2014).

‘A good death’

In 2015, the UK House of Lords rejected a major Bill which sought to give chronically ill and infirm people the ‘right to die’ (Gallagher and Roxby, 2015) was hotly contested and the emotional temperature which surrounded it remains elevated. Much of the context to this debate is shaped by the popular concept of a ‘good death’, which Gawande (2015, p.244) identifies as profoundly philosophical:

We are running up against the difficulty of maintaining a coherent philosophical distinction between the right to stop external or artificial processes that prolong their lives and giving them the right to stop the natural, internal processes that do so.

The notion of a ‘good death’ then is intimately linked to choice and control – including the ‘right moment’ (Kellehear, 2009). Debates about ‘good death’ also link closely to the notion of fighting disease, which in turn arose from the pioneering work of the hospice movement. Beginning as a reformist faction, with the goal of mitigating the increased institutionalisation of death and offering an alternative model of care (Corner & Dunlop, 1997), the hospice movement has been responsible for a contemporary national campaign to increase overt discussion of death, ‘Dying Matters’ run by the National Council for Palliative Care, as well as
for much of the current debate about assisted dying, end of life care, living wills and a ‘good death’ (Kellehear, 2009; Corner & Dunlop, 1997). Despite the undoubtedly positive contributions of the hospice movement, in relation to sudden and unexpected child death, the consequences of its widespread influence are complex. The ‘good death’ concept as Kellehear describes, has taken on additional ‘moral’ attributes, concerned with dying at a ‘good’ time, together with other ‘redemptive social practices’ (2009, p. 61) and a ‘romantic obsession with heroic storylines of people dying of cancer...fighting for the right to die with ‘dignity and choice’ (p. 65).

Additionally, as Corner and Dunlop describe, the ‘good death’ concept itself has been assimilated into the very institutionalization it originally hoped to oppose. They quote a study within a hospice nursing unit, which found that ‘certain features of the ‘good death’ ideal had become routinised, so that such deaths were ‘required’ by staff in the interest of what might be considered socially acceptable’, and where ‘nurses were at risk, over time, of developing a rigidity in their views over what constituted a good death, so that those patients who did not conform to this ideal...were seen to have problems’ (1997, p. 289).

Gawande (2015) constructs the ‘good death’ debate through the lens of failure. Where many involved in this arena see the success of ‘right to die legislation as a ‘success’ (Gallagher and Roxby, 2015) Gawande (2015, p.245) suggests the contrary:

Our ultimate goal, after all, is not a good death but a good life to the very end. The Dutch have been slower than others to develop palliative care programs that might provide for it. One reason, perhaps, is that their system of assisted death may have reinforced beliefs that reducing suffering and improving lives through other means is not feasible when one becomes debilitated.’

Although it does not appear immediately relevant, Gawande’s discussion helps to emphasise key factors in attitudes to sudden, unexpected child death – perhaps most significantly that children who die in this way are popularly viewed not to have had a ‘good life’ or indeed any life at all, whilst their deaths similarly cannot be viewed as ‘good’ because of the brevity of their lives. In addition, the very success of the hospice and associated palliative care movement has led to a broad association in the public consciousness between death and cancer, when in fact approximately only a quarter of deaths occur in this way (Corner and
Dunlop, 1997). There is evidence that the model of care used for cancer patients cannot be transferred easily to other groups, and the dominance of palliative care with cancer patients has led to accusations of exclusivity and exclusion (Corner & Dunlop, 1997).

‘Organising disturbing experiences.’

The ‘exclusivity’ that the dominance of palliative care has elicited can also be recognised within the prevailing influence of the Kubler-Ross ‘stage model’ (1969), which was developed in relation to patients dying of cancer. This charts five stages following a death, beginning with ‘Denial and Isolation’, moving through ‘Anger’, ‘Bargaining’ and ‘Depression’, before culminating with ‘Acceptance. The Kubler-Ross stage theory was further amended by Worden (1991) into a series of ‘tasks’, beginning with orientation to the reality of the loss and moving to the achievement of a new relationship through withdrawing from the old one.

Stage theories have gained widespread popular acceptance and are taught as fundamental within many professional training courses. Seale suggests that their enduring popularity lies both in their ‘classificatory system’ for ‘organising ‘disturbing experiences’ and in their link to modernity, in which the ‘tasks’, properly followed, make death and mourning almost a ‘progression or an achievement’ (1998, p. 106–7), and therefore ‘good’. Thus stage models lend professionals a sense of purpose as well as a job to do in the face of threats to basic security’ (Seale, 1998, p. 107). In this way, they echo many of the procedural outcomes of the inquiries and much of the literature already discussed.

Despite their enduring popularity, stage theories have also been widely critiqued for potentially pathologising those who fail to fit into accepted models and for developing the ‘good death’ model as a paradigm that also separates the ‘normal from the pathological’ (Seale, 1998, p. 107). With respect to ‘Rapid Response’ and the ‘golden hour’, this can create particular difficulties when any departure from ‘normal’ forms of grief behaviour displayed by parents, may be viewed as evidence of their potential guilt. As an example of this, Angela Cannings was criticised for immediately removing her baby’s cot (Cannings, 2006, p. 8), whilst Sally Clark’s attempts to keep from breaking down led to accusations that she was ‘callous’ and ‘detached’ (Batt, 2005, p. 154).
Contemporary grief theorists, amongst them Klass (1996), Neimeyer (2000) and Stroebe and Schut (1994), have moved away from these limiting stage-based paradigms towards models that try to embrace the infinite nature of bereavement and loss. Klass (1996) shows that ‘acceptance’ is never fully achieved, but rather becomes part of the ‘continuing bond’ between the bereaved and the deceased. Other leading figures in the contemporary landscape of death studies (Neimeyer, 2000; Bonanno & Kaltmann, 1999; Stroebe & Schut 2001) emphasise ‘meaning-making’ as the ‘central process in grieving’ (Neimeyer, 1998, p. 110), which they agree is essential for any kind of ‘adjustment or healing’, although they offer no prescriptive format for achieving this.

The technological developments discussed earlier in this Chapter which offer a form of life after death also further complicate the potential of meaning making, where a loved one can be cloned or continue to post to social media in perpetuity (Walter et al, 2012). In this rapidly shifting climate, the ‘normalising judgements’ about grief and bereavement which Speedy (2008, p.148) identifies are likely to become ever more complex.

**Conclusion**

In this Chapter, I have offered a number of different strands drawn from significant work within the fields of death, dying and safeguarding. I have explored ‘emotional politics’ and organisational defences, as well as the ways in which cultural norms around death and bereavement are being shifted by rapid technological change. I have argued that the intentions of the Kennedy Report to avoid further miscarriages of justice via ‘simple practical training’ and sensitising professionals to ‘the emotions being experienced by parents’ (RCPath & RCPCH, 2004, p. 12), may have been hampered by a lack of opportunity to learn directly from parents themselves, thereby potentially influencing the welfare of surviving siblings. The Chapter has also highlighted a more general ‘sequestration’ of death, together with a decline in meaningful public ritual. Many of the themes introduced here recur in the next Chapter, where I chart the development of a methodology capable both of evoking the experience and complexity of loss.
Chapter 3

Discovering the Depths

Introduction

In the previous Chapter I explored significant literature in the field of death, dying and safeguarding as context for the narratives which form the heart of this book. In this Chapter, I also set the scene for these narratives by exploring the surface and depth of the methods, philosophies and processes which led to their formation. Debates in the psychosocial are considered alongside the methodological detail of the panel process which illuminated my understanding of cultural responses to sudden, unexpected child death. Awareness of this panel process will also help readers to understand the particularities of the panels described in Chapters 5 - 7. Finally, whilst I have used this Chapter to record the methodological process, the decisions I made and the reasons for these, I also consider the limitations of attempting to describe this dynamic progression within the confines of the written word.

'Researching beneath the surface'

In Chapter 2 I explored Warner’s concept of the ‘emotional politics’ (2015) which she argues surrounds the death of children. Whilst a superficial picture may construct the public outrage evoked by these deaths as purely driven by emotion, Warner argues for a much more complex picture which includes contemporary attitudes towards children; the political
state of the nation; the media and other factors. In undertaking the research on which this book is based, I required an approach capable of accommodating the multiplicity of factors involved with emotional politics and, as described in the Introduction, I have found the psychosocial method of ‘researching beneath the surface’ (Clarke & Hoggett, 2009) invaluable in excavating the emotional and unconscious processes which may accompany sudden, unexpected child death.

I view the psychosocial, as linking the uniquely subjective and personal, or inner process to wider cultural, societal, or outer processes. Central to my understanding of the psychosocial is a belief in the power of unconscious actions, first mooted by Freud, as an explanation for apparently irrational and erratic behaviour (O’Brien, 2016). According to Freudian theory, conscious actions, are merely the tip of the iceberg and therefore if behaviour is to be understood more fully, the unconscious has to be accessed via dreams, word association and other techniques. Freud’s theory of personality included three parts – the id; the ego and the superego. The id is present at birth, Freud suggested, and represents the immature impulse concerned solely with instant gratification and the pleasure principle (O’Brien, 2016). The ego, according to Freudian theory is established at a conscious level and dominated by the reality principle which acts as a soft policeman for the id, ensuring that its pleasure seeking impulses are kept in check (O’Brien, 2016). Lastly, the superego, acts in a managerial capacity, largely developing from the child’s relationship with figures of authority, most notably parents and encompassing their moral code. The ego mediates between the primitive needs of the id and the moral compass of the superego, thereby creating the conditions for conflict and subsequent anxiety if external or internal stimuli present a threat to stability and wellbeing (O’Brien, 2016). Freud argued that in these circumstances, the ego uses coping mechanisms to intervene, with the most common of these being repression, denial, projection and displacement (O’Brien, 2016) all of which are fundamental to the study of sudden, unexpected child death. Freud suggested that repression is the capacity to exclude painful mental memories and other content from conscious awareness, thereby reducing its capacity to evoke emotional pain, whereas in denial the person may be aware of the issue but simply refusing to acknowledge its existence. Projection, according to Freudian theory, is yet another form of primitive defence in which a hostile or painful impulse is turned away from the individual and projected outward, whilst displacement is the relocation of angry or otherwise unacceptable emotion.
from one person or situation to another (O’Brien, 2016).

Fundamental to the analysis of sudden, unexpected child death within this book is the belief that these defence mechanisms and forms of unconscious communication operate not only at a personal level but simultaneously at group and institutional levels (Clark and Hoggett, 2009). This is highly relevant to the concept of ‘emotional politics’ (Warner, 2015) where at a collective as well as a personal level, unconscious processes may be seen to contribute to political decision-making. Shoesmith (2016) illustrates this powerfully in her analysis of stakeholders involved in the aftermath of Peter Connelly’s death, highlighting that Gordon Brown (then Prime Minister) and David Cameron (Leader of the Opposition) had both personally experienced the deaths of children, whilst Rebekah Brooks who led The Sun newspaper campaign, was not able to have children (Shoesmith, 2016). Drawing from Freud and taking a psychosocial perspective, such personal experiences of child death and loss may have caused these key figures to defend against their own pain and anxiety by projecting this outwards into the ‘heroic’ politician figure (Warner, 2015) or in Brooks’ case by leading a major campaign which called for retribution.

Freud’s theories, whilst still highly influential today were later developed by Melanie Klein and the object relations school, notably Winnicott (1964) and Bion (1962), whose theories are also very germane to the study of sudden, unexpected child death. Object relations is concerned chiefly with early developmental relationships, most notably with the child and their primary caregiver, usually the mother. Klein believed that this primary object or person provided the relational satisfaction to meet the most fundamental of human needs. Further, the experience of relating to the primary object (or caregiver) is introjected into the individual’s inner world, thereby blending with the unconscious. Object relational theories then, are useful as a way of explaining how internal objects, such as early caregivers, can influence ongoing reactions to figures and events in the external world. As a theoretical approach, object relations and particularly Klein’s work on defence mechanisms are highly relevant to this study of sudden, unexpected child death and are therefore considered further below, as a foundation for understanding the panel analysis and public reactions which follow in subsequent chapters.
Klein and the ‘space that connects’

As I discussed in Chapter 2, Cooper and Lousada suggest that the culture of audit and inquiry which follows significant child deaths has created a societal structure for containing and ordering ‘evidence of unwelcome and disturbing aspects of social life’ (2005, p. 59). In common with the bureaucratic procedures discussed in Menzies Lyth’s now classic study, the age of inquiry has also paradoxically perhaps created a climate of blame and fear, where a child dying from natural causes is an affront to the popular Western mythology of childhood and has therefore become almost ‘unthinkable’ (Hoggett, 2000, p. 20). However, this accounts only for what Clarke and Hoggett (2009) would describe as the ‘surface’ of the discussion and not for the deeper causes.

Hoggett (2000) locates these causes through the work of Klein and others in the ‘object relations’ tradition, and particularly within the concept of the ‘paranoid-schizoid’ position (2000, p. 68). This is the term Klein used to describe a primitive or early stage of development, where terror of the unknown is kept at bay via the defence of ‘splitting’ described earlier. Within this split, objects and events become either universally good or universally bad. Crucially however, this position is underpinned by terror and the creation of mechanisms to avoid feeling this (Hoggett, 2000; Cooper & Lousada, 2005). Bion, a member of the object relations school, who developed Klein’s work, argued that key amongst these mechanisms is the construction of ‘otherness’ (1962). Where anxiety is potentially overwhelming, Bion argued, it is projected into the ‘other’ who becomes the container for all the nameless terrors that the individual or the group repress or deny within themselves (Bion, 1962; Hoggett, 2000). This resonates with Warner’s theory of ‘emotional politics’, in which the baying of the media mob can be seen as othering the professionals involved with Peter Connelly at the time of his death. Hoggett argues similarly, that, at both group and individual levels, these split off terrors render ‘actual failure’, such as sudden and unexpected child death, to be ‘experienced as catastrophic’ (2000, p. 67), leading perhaps to their popular depiction in cataclysmic terms and offering no model for survival (see Chapter 1). Death is particularly significant here, for Klein argued that one of the most basic of human terrors is the fear of annihilation present in both the idea and the ultimate reality of death, which is then also split off into others who become containers for these bad experiences (Hoggett, 2000, p. 145). This may offer an explanation for why parents are not
included within any of the meetings that follow sudden and unexpected child death – they are split off and kept ‘unthinkable.’

At a group level, structures like audit and inquiry offer what Hoggett describes as a ‘protection racket’, offering ‘good’ citizens security from their nameless terrors, as long as they do not suffer misfortune that ‘others’ them or ‘the police come knocking at the door’ (2000, p. 68).

Within this book and the research which underpins it, I have attempted to take on the challenge of offering a different form of ‘protection’ by offering a ‘space that connects’ (Hoggett, 2000, p.125). Central to this connection is the capacity to feel as well as to think, as the Kennedy Report itself guides in its directive that ‘professionals should…be sensitised to emotions being experienced by parents’ (2004, p. 12). In approaching this task I am therefore facing the same challenge as the authors of inquiry reports discussed in the previous Chapter, who were also required to provide ‘linkage’ between …emotional and evidential sources’ (Cooper & Lousada, 2005, p. 147). To heal the ‘othering’ and splitting described here, the often painful work of linking thought with emotion, and thinkability with unthinkable, has to be accomplished in the service of creating a more holistic understanding of sudden and unexpected child death. As Cooper describes the terror of sudden, unexpected child death can only be mitigated through ‘fearless engagement with it and recognition of its nature’ (Cooper, 2009, p. 441).

**Debates in the Psychosocial**

Much of the discussion in this book is underpinned by both the miscarriages of justice which led to the Kennedy report and the procedures which followed in the aftermath. Despite the psychosocial approach which I have adopted throughout, I am mindful that the miscarriages of justice which initiated the Kennedy Report occurred through the contested evidence of ‘experts’ and I am consequently aware of the debates which also exist between authorities in the field of psychosocial studies and how these may risk diverting from the research itself. These debates have influenced my own position which is one of utilizing psychosocial approaches to explain experience rather than becoming mired in discussion about the precise application of these.

Key amongst the debates which have helped to influence my approach are the papers of
Frosh and Baraitser (2008); Hollway (2008) and Baraitser (2008). In the first of these Frosh and Baraitser debate the use of psychoanalytic concepts within the field of psychosocial studies, arguing that the collapsing of one into another is not always helpful and may indeed be rather dangerous in any claims made for finding the ‘deep truths of human nature’ (2008, p. 346). The paper contrasts Kleinian approaches to psychosocial studies with a more ‘deconstructive approach’ represented by Lacan. As a part of this discussion the paper critiques the work of Wendy Hollway, leading to fierce debate in the field and Hollway’s own swift response in an article entitled ‘Doing intellectual disagreement differently?’ (2008). In this article, Hollway describes feeling ‘wounded’ by the ‘accusations’ of Frosh and Baraitser. This evoked a further paper by Baraitser entitled ‘On Giving and Taking Offence’ (2008).

In trying to locate myself inside these vivid debates, I have been guided by Hollway’s responses in the debate between herself and Frosh and Baraitser, where she writes:

> Psychosocial interpretations are useful at helping us to understand experiences. They illustrate the limitations of a single approach...they don’t fix and they add depth (2008, p. 3).

Returning to Klein’s theory of splitting, I have tried in this book to embrace a multiple interplay of perspectives, while privileging none’ (Cooper & Lousada, 2005). Crucial to this perspective too is my own identity and experience as a parent who has experienced sudden, unexpected child death and who is researching others with similar experiences. A psychosocial approach has helped me to link my multiple positions by keeping me constantly aware of the dangers of blame, denial and splitting, as well as remaining forever suspicious of the source of my own knowledge (Frosh & Baraitser, 2008) as I have tried to simultaneously peer both inwardly and outwardly.

‘A space not fully one or the other’

Throughout this book and the research which underpins it I have tussled with my own postitionality as a researcher occupying ‘a space not fully one or the other, but with elements of each and the perspective of an outsider’ (Ellingson, 1998, p. 501). Before beginning the research on which this book is based, I had opted for removing my own experience altogether, as despite the ‘narrative turn’ (Atkinson, 1997) in the social sciences,
integrating the personal within academic writing and research continues to run the risk of work becoming ‘underrated, dismissed and trivialized’ (Vickers, 2002, p. 611). In a discussion which echoes Klein’s theory of ‘splitting’ as a means of protecting against anxiety, Lerum (2001, p. 467) suggests that academics may protect themselves by assuming ‘academic armour’ which excludes the personal and shores up their status in the academic world. However, as Vickers (2002, p. 612) argues stripping off this academic armour may simultaneously leave academics undefended and ‘writing on the edge and without a safety net.’ My own decision to include the personal within my doctoral thesis and now this book, has resulted in some difficult and painful consequences and occasions during which I have withdrawn into the position of defended researcher (Hoggett and Clarke, 2009, p. 12), protected by my ‘academic armour.’ However, in addition to the psychosocial concepts which have allowed me undertake deep exploration of personal experience within a social context, I have been inspired by academic writers who have led the field themselves and thereby helped others (Bochner, 1997; Ellis, 1993; Richardson, 1995; Speedy, 2008). Amongst these, Laurel Richardson (1997) has been particularly influential to my work. Although not avowedly psychosocial, Richardson situates the narratives and experiences of people’s lives ‘within the context of larger social and historical forces’ (1997, p. 19). She is also a passionate advocate of accounts that tie together the ‘knower and the known’ (p. 18), thus championing reflexivity within her work, both for herself and for others. In one paragraph, which illustrates my own passage from ‘expert’ to a more open and ambiguous position, Richardson argues that:

Separating the researcher’s story from the people’s story implies that the researcher’s voice is the authoritative one, a voice that stands above the rest...by objectifying ourselves out of existence, we void our own experiences. We separate our humanity from our work. We create the conditions of our own alienation (1997, p. 18).

Richardson’s account recalls Cooper and Lousada’s description of the Climbié and other inquiry reports where the enormity of the task finally leads to a ‘terse lifeless, abstract series of recommendations’ (2005, p. 155), thus voiding the experience.

The ‘enormity and complexity’ involved in my own task led initially to a similar position, one where I was crossing the research road in order to avoid myself, as people had actually
crossed the road following Joe’s death, thus creating ‘the conditions of my own alienation’. This alienation was not just personal, but professional as well. As a former social worker, I was able to understand why sometimes ‘professionals respond in the way they do’ (Parton, 1997, p. 232), and particularly how very real organisational constraints combine with personal anxiety to create a ‘defended community’ of practice (Hoggett, 2000, p. 92). Remembering the police woman on the morning of Joe’s death who, in that situation, could not reconcile my being both Joe’s mother and a social worker, I hoped to use my personal and professional experience to create a dialogue between the two rather than splitting them as the police woman had done (see Chapter 1).

Finlay (2003, p. 106) describes the reflexive journey as moving ‘through the looking glass’ to accomplish being ‘both subject and object’ within the research. Having attempted this, I now view my position as one which has shifted radically from ‘defended researcher’ to ‘reflexive researcher’, and as one who, according to Hoggett and Clarke, endeavours to be ‘engaged in sustained self-reflection on our methods and practice, on our emotional involvement in the research and on the affective relationship between ourselves and the researched’ (2009, p. 2–3).

However, as the debates that took place in 2008 between Baraitser, Frosh and Hollway demonstrate, there are continuing disagreements and risks, even within the general agreement on reflexivity as central to a psychosocial approach. Frosh and Baraitser, for example, focus on the difficulty of ‘what account can in fact be given of the investment of the researcher in the knowledge making process’ (2008, p. 359), and argue that what the researcher declares about the process can only ever be partial. Hoggett (2009, p.109) offers similar advice, suggesting that ‘much of the vitality, tragedy and mystery of everyday life unfolds in a way that few, if any of the participants are fully conscious of’ - a passage that resonates vibrantly with my experience of writing this book. Despite my attempts to remain as reflexive as possible, I am lingeringly aware of the spaces in-between what I have said and what I have missed, a place which Gendlin describes as a ‘felt sense’, an ‘awareness of the border zone’ between the conscious and the unconscious’ (1996, p. 16).

In my efforts to remain reflexive, therefore, there will always be spaces that I cannot reach. However, I have tried as far as possible to allow for these, and to look both further and deeper rather than using reflexivity simply as ‘an excuse – a cover story – which allowed me
to look at my reflection’ (Finlay, 2003, p. 112).

Another cost of working reflexively is, where the research is difficult for others to hear, the danger of losing an ‘expert’ role may result in the work being dismissed as a self-indulgent form of ‘victim art or confessional’ (Bochner cited in Giorgio, 2009, p. 149). This form of ready dismissal can be seen as another cultural form of ‘splitting’ in order to defend against exposure to painful experience, the risk for the researcher lying in being correspondingly dismissed as a ‘victim’ by their very sharing of experience.

In navigating this complex terrain of reflexivity I have attempted to repudiate all fixed positions leaving me with one of the ‘essential attributes…of the psychosocial researcher’ - a space of ‘being in uncertainties, mysteries, doubts, without any irritable reaching after fact and reason’ (Keats cited in Clarke & Hoggett, 2009, p. 16).

**Writing as a ‘method of inquiry’**

Hoggett (2000, p. 85) criticizes contemporary academic writing for largely adopting a style which is ‘impersonal, distanced and ultimately boring,’ thereby unwittingly evoking Cooper and Lousada’s description of the Climbié Report where the ‘enormity and complexity of what had been exposed’, translated during the ‘writing up’ into a ‘terse, lifeless, abstract series of recommendations’ (2005, p. 155).

In writing this book, I have faced the challenge of trying to accommodate my own complex positionality within a language which navigates the emotional politics described in Chapter 2 and the ‘terse, lifeless ‘ and ultimately ‘boring’ documents described by Hoggett (2000) and Cooper and Lousada (2005). I have also sought for a means and language which complements the psychosocial stance of this book and thereby accommodates both surface and depth.

Richardson (1997, p. 66-67) suggests that this may be an impossible task as how we think about lived experience and ‘how we experience lived experience are at odds...leaving us only ever therefore able to write ‘accounts’” (1997, p. 66–67, original emphasis). However, to counteract yawning her way through academic research for years (2005), Richardson does propose an alternative in her concept of ‘writing as a ‘method of inquiry’ (2005, p.959), which has underpinned my own writing process in this book. ‘Writing as a method of
inquiry’ argues that writing should be a means of discovery, rather than a way of describing what has already been determined, whilst also freeing writers from ‘trying to write a single text in which everything is said to everyone’ and allowing them to be more experimental in their work (Richardson, 1997, p.67).

Advancing this theory further, Speedy (2008, p. 138) suggests that writing is not just a conversation between author and method but stretches beyond that to author and reader, providing a bridge between the two and thereby engaging them ‘in conversation.’ Speedy’s notion resonates with the psychosocial stance of this book, delving into absences in order to provide both linkage and a ‘space for experience’ via the narrative methodology described in the following sections.

Telling stories

As I described in Chapter 2, many contemporary grief theorists (Neimeyer, 1998; Bonanno & Kaltmann 1999; Stroebe & Schut 2001) emphasise ‘meaning-making’ as the ‘central process in grieving’ (Neimeyer, 1998, p. 110), and whilst they agree that this is essential for any kind of adjustment or healing, they offer no direct formula for achieving this. Frank (1995), however, advocates for story telling as a major way of achieving meaning and this is echoed powerfully in myriad works on the topic of bereavement and child loss. Wimpenny et al., 2006, p. 113, in a thorough review of bereavement, found that ‘the importance of individuals being able to tell their story is mentioned frequently,’ whilst Dyregrov’s study of bereaved parents’ participation in research found that for the 75% who scored the experience as positive, the major positive was ‘telling the story’ (Dyregrov, 2004, p. 300). Riches and Dawson similarly describe giving the respondents the ‘opportunity to tell the story from beginning to end’ as ‘amongst the most important findings in the project’ (1996, p. 363). This was a major influence on the design of the research study underpinning this book, which also allowed participants to ‘tell their story from beginning to end.’

As this book and the research on which it is based both excavate a subject where stories are largely ‘untold’ or even ‘unthinkable’ (Cooper & Lousada, 2005), ‘giving voice to people to tell their stories in their own words’ can be seen as both ‘cathartic and therapeutic’ (Grafanaki, 1996 p. 336), contrasting powerfully with what Cottle, describes as ‘the myth of vulnerability’ (2002, p. 536). This refers to the widespread notion that ‘people of certain
groups or those having had certain experiences are so ‘damaged’ that they cannot speak for
themselves’, and seems perhaps to underlie much of the popular depiction of bereaved
Cottle argues for the power of narratives in providing a meeting point between self and
other where the teller has the potential to transform the listener in their mutual sharing of
the story, a purpose that meets so many of the profound aims of the research on which this
book is based.
However, despite the affirmations of ‘story-telling’ within the literature, there are also many
fierce objectors engaged in debate, which echoes that of Frosh, Baraitser and Hollway in the
psychosocial field. Amongst these, Atkinson is at the forefront, questioning both the
usefulness of narrative alongside his concern over the ‘multiplication of narrative methods’
(2005, p. 334). Similarly, there is also ‘considerable disagreement about the precise
definition’ of narrative (Riessman, 1993, p. 17). Several key writers, including Riessman,
try to solve this by offering templates for narrative studies, whilst others
(Polkinghorne, 1988; Lieblich et al., 1998) divide narrative research more broadly into
studies that use narratives simply as alternatives to more traditional forms of quantitative
analysis (charts, numbers, graphs etc.), and those that use stories to bring meaning to
events and experiences.
Amongst most of the significant writers on narrative (Riessman, 1993; Clandinin & Connelly,
2000; Sarbin, 1986), there seems to be a general consensus that endorses Polkinghorne’s
definition of narrative as ‘the primary form by which human experience is made meaningful’
(1998, p. 1). This initially attracted me to using the narrative form within the research on
which this book is based, as this ‘meaning-making’ function seemed to fit with the similar
‘meaning-making’ imperative postulated within contemporary theories of grief (Neimeyer,
2000).
However, writers within the psychosocial field, notably Hollway and Jefferson (2000) and
Wengraf (2011), have criticized the tendency for research to take narratives at face value,
suggesting that meaning needs to be found in the encounter. They argue, therefore, that the
stories themselves are not sufficient for understanding these meanings without a similar
reflexive process on the part of the researcher, together with placing both in a historical and
cultural context (Hollway & Jefferson, 2000, p. 32). Whilst Hollway & Jefferson use narrative
within their method, they make a distinction between ‘traditional narrative analysis’,
‘preoccupation with coherence’ in the form of structure, and their own focus on ‘free association narrative interviewing’, which uses psychoanalytic concepts to explore ‘contradictions, elisions’ and ‘avoidances’ (p. 37).

Hollway and Jefferson’s ‘free association narrative interviewing technique’ has its origins in the German ‘biographical-interpretative method’, which also inspired Wengraf’s ‘Biographic Narrative Interpretive Method’ or BNIM) (2011), extensively discussed in the following section. The two approaches, both avowedly psychosocial, share a common commitment to avoiding closed questions; eliciting story rather than simply a pre-determined answer to a query; avoiding the use of ‘why’ questions which can lead to explanation rather than story; and to keeping the same sequence of events and form that the research participant has used, thus honouring the often unconscious meaning in this order (Hollway & Jefferson, 2002). By use of these techniques, Hollway and Jefferson argue that their method of ‘free association narrative interviewing resonates with psychoanalysis in eliciting narratives that ’are not structured according to conscious logic’, thereby offering pathways ‘defined by emotional motivations rather than rational intentions’ (2002, p. 37).

**The Biographic Narrative Interpretive method**

The proven meaning making capacity of narrative rendered it very attractive to me and as a novice researcher at this time, the Biographic, Narrative Interpretive Method, or BNIM was especially enticing due to the prescriptive set of processes which helped to contain my underlying anxiety. The BNIM focus on both context and teller also fitted with my psychosocial stance, where the requirements of the ‘outer’ world could impact so greatly on the ‘inner’ world of parents at such a traumatic time. Within BNIM this is described as ‘facilitating understanding both of the ‘inner’ and ‘outer’ worlds of historically-evolving-persons-in-historically-evolving situations’, and particularly the interactivity of such inner and outer world dynamics’ (Wengraf, 2004, p. 30). Additionally, BNIM’s location within the recent ‘innovations to psychosocial methodology’, as described by Clarke and Hoggett (2009, p. 8), made it a potentially exciting means of achieving the connections between my aims and my methods.

Unlike other biographic narrative methods however, BNIM also offers a very structured set of approaches to both interview and analysis, advocating the use of data analysis panels to
encourage greater researcher objectivity. Part of this structured approach lies in BNIM’s distinction between verifiable life events, which it deems ‘the lived through past/living of the lived life’ (Wengraf, 2001, p. 234) and the ‘structuring principles of the story as told/the telling of the told story’, which represents the way the teller chooses to tell his or her story within the interview. For BNIM purposes, ‘the living of the lived life’ can concern any episode described in an interview, which for this study were the events surrounding sudden and unexpected child death.

Within the BNIM process interviews begin with a ‘SQUIN’ (Single Question aimed at Inducing Narrative). For the eight interviews I conducted I formulated my own ‘SQUIN’ using an advisory template (Wengraf, 2001, p. 111) that aims at eliciting open narrative, rather than utilising structured or semi-structured questions. I used my SQUIN at the start of all my research interviews, staying as close as possible to these words on every occasion:

Please tell me the story of.....’s death...all the events and experiences that have been important to you personally. Begin wherever you like. I’ll just listen, I won’t interrupt. I will just take some notes for afterwards.

The open invitation provided by the SQUIN was invaluable in allowing parents to frame their own stories and to tell these freely ‘from beginning to end’ (Riches & Dawson, 1996, p. 363). Despite my initial concern about the limited scope for my own interventions, in practice this seemed to enable parents to enter a narrative space where they were almost unconscious of my presence. If, on occasion, I did interrupt or make my presence known, this invariably distracted them and altered the course of their narrative flow.

Following the interview stage, BNIM includes a number of processes, comprising the production of two ‘tracks’ from the verbatim transcripts of the interview which are then used to create a ‘working document’ containing ‘transcript chunks’ condensed from the interviews. This document is later presented for microanalysis at a data interpretation panel (Wengraf, 2010).

Data Analysis panels

Panels are used within BNIM to ‘kick start’ the interpretive procedure, with members ideally
being ‘non-specialists’ capable of bringing diverse viewpoints to the process. Within the BNIM guidance, panels are discussed as a routine part of the process, used primarily to challenge ‘researcher autism’ (Wengraf, 2011, p. 104), rather than becoming an inherent part of the data itself.

Routinely, panels are presented with ‘chunks’ of the transcript, which help to form a ‘special sort of contents page’ or ‘working document’ (Wengraf, 2010). This was a task I initially struggled with, as it seemed to me that what I chose to both include and exclude within the ‘transcript chunks’ would have a significant effect on enacting the reality that the panel then observed. Finding it almost impossible to resolve this issue, I eventually chose to depart from the advice given and presented large ‘chunks’ of the transcript to the ‘kick start’ panels I convened.

Wengraf advises that the panel process is ‘for all concerned – as a personal and professional learning experience [is] both insightful and often funny’ (Wengraf, 2011, p. 104). When setting up my own panels, I was advised by this as well as by the advice to try, as far as possible, to create diversity within the panel structure. Every panel consisted of three members, drawn from friends, colleagues and others who were recruited through professional contacts. Each panel had one member who was, or had been a social worker, as I found this useful in representing the views of the child protection practitioner in the panel process.

Prior to each panel, I sent out an ‘Information Sheet’, which detailed the potential sensitivity of the material and encouraged people to think about this before deciding to commit. Alongside this, the Information Sheet also suggested areas for the panel members to focus on, drawn from BNIM guidance. The suggestions were ‘what might the interviewee have been feeling and thinking (experiencing) at the time of a particular event’ and ‘what does the way the interviewee is now talking at this point in the logic of sequence suggest about their later perspectives and current perspectives on that same event as originally experienced?’ (Wengraf, 2010, p. 413).

Additionally, the BNIM guide advises panel members to consider that the interviews commence with a SQUIN, which sets no conditions other than a simple opening question, thus leaving both form and content open to the interviewee. This, therefore, poses the further question of ‘how did the interviewee experience the interviewer and his interventions and non-interventions?’ (Wengraf, 2010, p. 413), which panel members are
also asked to consider.

In my Information Sheet I also detailed the concept of ‘future blindness’, which aims to mirror the experience of the interviewee as the actual events unfold. Everyone agreeing to participate in a panel for my research knew that the transcripts concern child death. Due to the nature of the material, I believe this was ethically responsible. However, no other detailed knowledge was disclosed to panel members prior to the panels themselves.

Before convening a panel for the first time, I was sceptical about the usefulness of the process. Although I did find them valuable in practice, this was not necessarily for the intended reasons but rather for the window they opened onto the complex feelings that sudden and unexpected death can engender at both conscious and unconscious levels. I will offer a fuller discussion of this in Chapters 5-7 and in the discussion of ethics that follows.

**Ethics**

Selecting which interviews to bring to the panels also caused me ethical and moral difficulties as BNIM guidance simply suggests that researchers identify ‘gold star’ interviews, raising again questions of selection akin to the ‘chunks.’ Whilst it was not practical for me to convene panels on all the interviews due to the level of work involved, I was aware in choosing some as ‘gold star’ versions that I was demonstrating the ‘asymmetries of power and divisions of interest’ (Giddens, 1999 cited in Shaw & Gould, 2001, p. 19) that I was trying to uncover. This represented an ethical concern as each of the interviews had been offered in the same way, with the same understanding. Thus, by highlighting some rather than others, I felt as if I were reneging on my ‘moral stance of caring for the Other’ (Bauman, 1993) cited in Kellner, 2002, p. 30). I ultimately solved this practically by running panels for five of my eight interviews based on their value in offering a breadth of experience and meeting my research purpose. On a personal level, however, I still struggle with this notion of selection.

One of my first ethical decisions was where and how to seek participants. Raphael’s discussion of professional reactions to child death was valuable here, persuading me not to seek participants through the NHS or other statutory bodies, where:

> Doctors ...often wish to avoid any discussion of the dead baby and display general discomfort and ignorance about such deaths’ (1984, p. 261).
This resonated with my own experience at the time of Joe’s death, and it is a perspective further supported by Dyregrov’s study of parent’s participation in research where she notes that ‘it is well documented that research proposals in this field are more likely to be rejected by Institutional Review Boards’ (2004, p. 5). I therefore decided to concentrate on seeking participants via specialist charities operating in the area of child death and bereavement and it was a requirement of the research that I gain institutional ethical approval for this.

Van Den Hoonoord (2002) compares this process of gaining ethical approval to ‘walking the tightrope’, and although I had initially viewed it essentially as a ‘procedural or practical issue’ (Dunne, Pryor & Yates, 2010, p. 1), there were times when, in practice, it did feel like trying to cross a high-wire. My original submission for ethical clearance, submitted at the beginning of my third year, was rejected on the grounds that the Committee was not yet satisfied of the ethical case made. Whilst some of the comments reflected my status as a ‘novice researcher’ (Gray, 2004, p. 16), there were others that were particularly significant to my work, which left me with an enduring sense of unease. Amongst these were the repeated descriptions of my research as ‘ethically sensitive’ and the participants as ‘vulnerable’, both of which troubled me as they seemed to uncritically endorse the ‘myth of vulnerability’ (Cottle, 2002, p. 536), and thus to construct both the research and the participants in a particular way before I had even embarked on fieldwork.

Whilst assumptions like this are commonly made and ‘research on vulnerable populations’ habitually considered ‘unethical because it may rip open old wounds’ (Dyregrov, 2004, p. 8), a growing body of evidence has shown that ‘instead of causing distress, research may be educational, enriching, therapeutic or empowering for vulnerable populations’ (Dyregrov, 2004, p. 6). I was consequently troubled by the tone of the ethical decisions. Whilst I completely acknowledged the need for safeguards, I pondered whether those categories of people labelled as ‘vulnerable’ may in practice be those who make others feel vulnerable, for as Henderson et al. argue, ‘vulnerability is by definition, relational’ leaving ‘one … always vulnerable to someone’s or something’s influence’ (2010, p. 50).

Henderson et al. further suggest that in research contexts, ‘applying vulnerability to only one party’ may contribute to conceptual confusion’ as the latent vulnerability of ethics committee members can be masked by their authority (2010, p.50). The potential consequences of this undisclosed vulnerability for what is researched, then lies in less overtly ‘sensitive’ studies being privileged over that which may make professionals feel
uncomfortable, but which nevertheless is hugely valuable in researching traditionally uncharted areas. Van Den Hooanard therefore suggests that ethics could be made more ‘ethical’ by including ‘the perspectives of the populations being studied’ (2002, p. 183).

However, despite the focus of the ethical review procedure on some aspects of my research, it was the panels, which were not highlighted at all, which proved to be the most ethically challenging in practice. I had also understood the panels initially at a fairly superficial level, advised by the BNIM Guide’s description of them as both ‘insightful and often funny’ (Wengraf, 2011, p. 104), which contributed to my under-estimation of the potential effects of the ‘chunks’ on the panel members. Whilst I had advised them both in person and within the ‘Information Sheet’ that the nature of the material was sometimes highly emotive and challenging, for three panels in particular, these ethical concerns were demonstrated by the acute emotional responses produced, with members describing feelings of being chronically ‘polluted’ by the process of ‘picking over’ people’s words, together with a general sense of unease. The feelings reported by panel members recall the nameless terror which Klein posited was inside all of us, leading ‘threats to the social fabric’, such as that represented by sudden and unexpected child death, to bring about the ‘experience of catastrophic anxiety’ (Hoggett, 2000, p. 67), or in the experience of panel members, a feeling of chronic pollution. Andy’s interview, described further in Chapter 4, which focuses on the death of his young son, particularly resulted in significant distress for one panel member, who was reminded painfully of experiences in her own past. She was clear that this was not the narrative she had expected to hear and was hugely discomfited by the version of society that Andy’s narrative portrayed. Describing this as a ‘living nightmare’, she reported feeling the need to try and find some good in this, something, in her words, to hang onto. Similarly, the panels for both Julia’s and Cathy’s interviews (see Chapters 5 and 6) provoked emotional reactions ranging from distress to anger. In retrospect, I found it hard to believe that neither I, nor the ethics procedure, considered this possibility, focusing instead on the parent participants.

These ethical conundrums led to a discussion with Tom Wengraf the author of the BNIM guidance, who placed a caveat into later editions which suggests that panels are ‘not always funny...sometimes, the panel may be unexpectedly distressing’ and advises ‘counselling back-up for the interviewees...but also for those who sit on panels’ (Wengraf, 2011). The length of time since the death was also a criterion that exercised me greatly in designing
the study. Initially, I was anxious about including experiences where the death was very recent, or conversely where the death had occurred years prior to participation. Some of the literature I read during these early design stages was useful in helping me reach a decision about this. For example, Riches and Dawson’s study of marital breakdown following child death comments on:

‘The powerful and sustained attention which parents gave to their child’s life, death and continuing importance regardless of the time which had elapsed. It was as strong in parents whose children died over 12 years ago, as in parents with more recent losses’ (1996, p. 359).

Drawing from these previous studies and my own experience of Joe’s death, I decided that neither historical accuracy nor even contemporary relevance were the key lessons in what could be learned’ from parents’ experiences. I was chiefly interested in the way that parents remembered the story, the sequence and those parts that took on the greatest significance and accordingly aimed to be open to experiences that reflected different time periods and different memories.

Despite my continuing concerns about the design complexities and some of the ethical aspects of my work, I was granted approval following my second ethical review application. This enabled me to begin the search for participants. In line with my ethical consent, I wrote to over twenty organizations with an interest in the field, finally gaining permission to place an advert on the website of two national charities, with a third agreeing to recruit on my behalf.

Anyone who expressed an interest in participation was sent an Information Sheet and eventually eight people agreed to participate in the research interviews which form the heart of this book.

‘Real humans’

Richardson makes a distinction between research design and what then occurs when we ‘bring real humans into our stories (1995, p.115). The ‘real humans’ who became inextricably involved with my own story were Cathy, Andy, Hafsa, Laurie, Chrissie, Julia and Terri and their narratives form the following four Chapters of this book.

Cathy and Andy are married and contacted me initially via an advert which they had seen on
Ellen, Hafsa and Laurie were all approached by a charity with whom they were involved and which contacted them on my behalf. I met Chrissie at a different charity Open Day and later followed up the contact via email. Julia and Terri both came forward via mutual acquaintances and I contacted them both via email and telephone prior to their agreement to participate.

Given my initial struggles to locate my positionality within the research, several of the interview participants told me that they had only responded to my request because it stated that I had experienced the death of a child, thus endorsing both my decision and Dyregrov’s finding that ‘parents claimed it had been especially important that the researcher clearly understood our situation’ (2004, p. 20). Most of the parents in my study seemed content with knowing that I was a ‘researcher’ who clearly ‘understood’, and they did not pursue information regarding my own experience. However, two parents, Cathy and Laurie, were specifically interested in me as ‘one of us’ (Ellingson, 1998, p. 499), and this interest required careful consideration ethically (see Chapters 5 and 7).

All interviews were conducted in the person’s home or, if this was not possible, a secure and uninterrupted space, mostly chosen by them, and each interview was audio recorded. Despite the emphasis of the ethics committee on their ‘vulnerability’ as participants, the interviews were all ‘quite trouble-free’ (Van Den Hoonaard, 2002, p. 12). Some of the participants were tearful, although this was not so much a reflection of great pain, but rather indicated Klass’s concept of the ‘continuing bonds’ (1996) and their hope that ‘their research participation might help other people in their situation’ (Dyregrov, 2004, p. 5).

After the interview, once home, I thanked each participant by email and their feedback about the experience was generally warm and thoughtful.

Once the transcripts had been completed, all participants received a copy, apart from Ellen, who had previously asked not to be sent one. Her choice casts some further light on the ethical review process, where so much is decided in advance, for whilst she was happy to give the interview, Ellen experienced the transcripts as something ‘other’ and did not wish to be presented with her words set in stone.

Several participants did not wish to be anonymised as they specifically wanted their story to be heard and to make a difference, which proved a genuine ‘lived dilemma’ for me within the field. We did, however, easily agree on their being anonymised within the work, according to my previous ethical undertaking, and they understood that their story would
help to ‘make a difference’ regardless of the name used. The ‘consent forms’ which had formed a condition of my ethical approval also felt ‘obtrusive and established an atmosphere of formality and mistrust’ (Van den Hoonaaard, 2002, p. 10). Although this was quickly dispelled during the interview, I was left reflecting on Richardson’s notion of trying to decide so much in advance on behalf of the ‘real humans’ who will eventually form the participants in our carefully planned research.

**Conclusion**

In this Chapter I have described both the surface and depth of the methodological processes at the heart of this book – including the practical processes and the manner in which I have tried to write. Particular significance has been given to the Biographic Narrative Interpretive Method, emphasising the potential difficulty of utilizing data analysis panels to interpret emotionally painful material. In summarizing this Chapter whilst it attempts to clearly chart the decisions I have made, I am also aware that in the end this can only ever be an ‘account’ and it thereby ironically shares much in common with Cooper and Lousada’s description of the Inquiry Report into the death of Victoria Climbié:

> The events recounted constitute a story...with many missing dimensions, connections, lost threads and silences...factually coherent, but also radically incomplete (2005, p. 152).

In the following Chapters, I hope to fill some of these ‘silences’ both with the narratives threads and complete accounts of sudden and unexpected child death, which form the heart of this book.
Chapter 4

Collective Stories

Introduction

In the previous chapter, I described my difficulties with selecting both ‘transcript chunks’ and ‘gold star interviews’ according to the BNIM process (Wengraf, 2011). However, as Riessman and Speedy (2007, p. 435) describe, this ‘data reduction’ is an inevitable ‘task which confronts all qualitative investigators’ eventually and is therefore unavoidable. My own struggles were linked to the intense gratitude and loyalty engendered by the eight participants in my original research - as these people had trusted me with stories of pain, loss and courage. I was also aware that one of the only times they may previously have shared these details within an interview setting may have been with the police, and this increased my consciousness of how to speak for people who had already been portrayed as either victims or suspects.

Viewing their stories as material suitable for the ‘codification of procedures’ (Richardson, 1997, p. 20), did not seem to me sufficiently respectful of these very real people, neither did it adequately account for warnings such as those given by Riessman and Speedy (2007) against over-use of ‘reductionist techniques’ in research studies where too often:

Lengthy accounts ...were abstracted from their contexts of production, stripped of language and transformed into brief summaries (2007, p. 434).

Writing of her own desire to co-research ‘unheard of stories’, Speedy (2008) refers to ‘the possibilities that lurk beneath the surfaces of the ‘statues’ that have been made of them’ (2008, p. 57). I feared that in fracturing the text into ‘sound bites’, I would similarly make ‘statues’ of the words, thereby setting them in stone, devoid both of context and of
meaning. This was a process that already seemed to have taken place within so much of the literature in this field, where parents' views were ossified out of existence in favour of professional perspectives. I did not want my research to further re-produce this.

In ‘Fields of Play’ (1997), Richardson describes the concept of the ‘collective story’ which succeeds by ‘emotionally binding people together who have had the same experiences, whether in touch with each other or not’ (1997, p.33). Richardson’s description recalls my unsuccessful attempts, detailed in Chapter 1, to find accounts of experiences similar to my own following Joe’s death. At this time, unwittingly, it was the ‘collective story’ that I had hoped would call to me, reassuring me that ‘I am not alone’ (Richardson, 1997, p. 33).

Richardson also describes struggles with data reduction similar to my own and in particular being ‘frozen by indecision’ when faced with how to represent the people within her research, in a way that stayed close to their words and experiences. To counter this stasis, she imagines the research as a ‘tapestry composed of threads of many different hues’, posing the question so resonant with my own dilemmas:

> How do we speak the tapestry...because wherever text is being produced, there is the question of what social, power, and ...relationships of production are being produced. How does our writing, including this writing, reproduce a system of domination and how does it challenge that system?’ (1997, p. 57).

Richardson’s dual metaphors helped me to tackle the inevitability of ‘data reduction’ (Riessman & Speedy, 2007, p. 435) by imagining the five narratives which form the basis of this Chapter as threads within the collective tapestry which Richardson portrays. The remaining three narratives are retained as the complete accounts which constitute chapters 5 -7. My hope is that all eight narratives remain in dialogue with each other as well as with my own experience (see Chapter 1), thus ‘emotionally binding people together’, as Richardson suggests.

The narratives in this Chapter belong to Terri, Hafsa, Andy, Chrissie and Ellen. The latter four came forward in response to charity links, whilst Terri was reached via a personal source. Andy, in his late twenties, is the husband of Cathy, and her narrative describing the death of their very young son forms Chapter 5. He was the only male willing to participate in the study. Hafsa is in her early thirties and her Muslim religion and lone parent status are very significant within her story. Hafsa’s daughter died at only a few weeks old, eighteen months prior to the interview. Hafsa has an older daughter and another young baby, having become
pregnant very quickly again following the death. Ellen is in her early thirties and has three surviving children. Her daughter, a second child, died at 71 days, 11 years prior to the interview. Chrissie is in her thirties and her son died, at a few weeks old, less than a year prior to the interview. Chrissie has a stepson by marriage but no other children of her own. Lastly, Terri is in her fifties and describes the death of her son, aged six, twenty one years prior to the interview. He left a surviving sister and Terri had two subsequent children following the death.

The five narratives demonstrate striking similarities, both in the way they are told and in the emotions expressed, although in studying them, I was ever open to the ‘element of surprise’, which Hoggett and Clark (2009) cite as fundamentally psychosocial. Variations did assert themselves in the diverse ways that meaning was constructed from events, and also in the importance that individual narrators placed on different experiences, particularly in the aftermath of the death. All five accounts share a strikingly collective ‘beginning-middle-end sequence’ (Sarbin, 1986, p. 248), and it is with this and with the notion of time which underlies such structuring that I want to begin my discussion of the threads.

‘It’s all been in pods of time’: threads of temporality

Time enacts itself in complex ways within and outside the narratives. They are all narratives of remembering, which were spoken at a fixed point in time within an interview situation. In telling their stories, the participants are ‘choosing what to remember’, and in so doing, they are ‘giving meaning to the past from the point of view of the present and future’ (Richardson, 1997, p. 30). In the act of recording and writing about the interviews, I too am ‘remembering the remembering’, an undertaking which recalls a set of Russian dolls, one contained within the other.

Giddens (1991, p. 48) suggests that ordering activity within the structures provided, both by daily time and the concepts of past, present and future, creates a general sense of ontological security in which ‘the world is as it is because it is as it should be.’ Hoggett echoes this view, suggesting that routine activities, such as work, reinforce ontological security by offering ‘orderly and predictable’ routines, which prevent people from ‘thinking or feeling too much’ (2000, p. 57). Disruptions to this sense of security, such as that presented by sudden and unexpected child death, can therefore be seen to provoke the
‘experience of catastrophic anxiety’ (Hoggett, 2000, p. 67), which I discussed in the previous chapter.

This ‘catastrophic anxiety’ stems in part from an unconscious fear of annihilation posed by the threat of death and loss, which serve as a reminder that ‘non-being is part of one’s own being’ (Giddens, 1991, p. 49). Arguing that ‘the unconscious cannot conceive of its own death’, Giddens suggests that primary anxiety therefore develops in relation to the loss of others, notably care-givers, from whose possible absence ‘fears of death and sickness emerge with regard to the self’ (1991, p.49). Defences against this anxiety lead to the ‘splitting’ described by Klein, which in contemporary attitudes to death manifest in Kellehear’s distinction between ‘shameful’ deaths and ‘good deaths’ (see Chapter 2). Kellehear suggests that the moral distinction between the two is provided by ‘knowing the right time to die’ (2009, p. 62), which renders the sudden and unexpected death of a child truly a ‘death out of time’ (Chalmers, 2007, p. 3), and contributes to the incomplete picture of the experience contained both within literature and within training material.

Amongst the multiplicity of practical and emotional tasks faced by parents then, is a symbolic one of repairing the ‘thread of continuity’ (Hindmarch, 1993, p. 24), which has been so harshly broken by their child’s death. Richardson suggests that narrative accounts can help in this repair, by retrieving the past and reliving it in the present so that a future is made possible (1997, p. 30). This is demonstrated within this research by the parents expressed desire to ‘make a difference’; thereby giving continued purpose to their child’s life, together with a ‘place for experience’ (Hoggett, 2000, p. 84).

More pragmatically within the narratives themselves, time is utilised as an underlying structure via common use of a ‘beginning-middle-end-structure’ (Sarbin, 1986, p. 248), which helps to order the scenes of chaos and trauma, and thus to make them ‘hearable’ (Burr, 2003, p. 191). ‘Beginnings’ frequently feature the death itself and often the hospital, whilst ‘middles’ show the parents returning home, disoriented yet trying to accomplish necessary tasks. ‘Ends’ commonly illustrate a coming to terms or reparative, meaning-making capacity within the narrative telling.

Ellen also demonstrates a clear ‘beginning-middle-end structure’ in her description of the course of events over time:

It’s all been in pods of time if that makes sense...there was the initial event and
then a few months later we got all her things back and tried to put life back to some kind of normality. We got on an even keel and then decided to have another baby...

Each of the five narrators begins their story by locating themselves at a point in time. Ellen and Andy begin with the day or time of death, in Andy’s case ‘it was a Saturday morning.’ Chrissie also begins with the specific date of death, whilst Terri locates this in both the past and the present:

Well it’s a long while back; he’s just had his 27th birthday, amazing isn’t it because he was 6 when he died so it’s 21 years now.

Hafsa begins her narrative by locating the death of her baby in the recent past but also seamlessly within the present and the future:

It’s only been a short time...well it was last March that I lost her...she died last March and a couple of months later I got pregnant again and in my mind it was like a kind of continuation, which sounds awful in a way but I was just beginning to unleash this love and something else had stopped dead.

The endemic use of time as a means of beginning the stories demonstrates how powerfully it organises life, as Berger and Luckmann suggest:

...In cases where I may be ‘disoriented’ for one reason or another I feel an almost instinctive urge to ‘reorient’ myself within the temporal structure of everyday life. I look at my watch and try to recall what day it is. By these acts alone I re-enter the reality of everyday life (Berger & Luckmann, 1966, p. 42).

With an experience as shattering as sudden and unexpected child death, ‘reality’ is transformed and the consequent disruption to ‘everyday life’ is also depicted within the stories, as Ellen observes:

It’s funny how such a normal day...well we had been out shopping ...to buy a few bits of pieces with gift vouchers in the afternoon and to go from having such a normal afternoon to by 7 o’clock our whole lives had just been decimated.

Andy, in his description of the hospital that forms part of the ‘beginning’ of most people’s narratives, utilises time graphically to illustrate his sense of powerlessness, with repeated phrases such as ‘it felt like a lifetime’, together with his evocative description of the doctors prolonged attempts to keep his child alive:

It was just dragging it out. It was quarter past 7 in the morning we found him
and it wasn’t until half past ten that night they switched off the machine...longest day of my life.

Similarly, Ellen invokes time to illustrate her sense of dispossession:

Within the space of about three quarters of an hour, everything had just been torn apart and I remember sitting there and thinking ‘well what do I do now?’

Andy also references ‘unnatural time’ when he describes the medical staff getting ‘a heartbeat back by giving him drugs’, together with his own sense that this was simply ‘dragging it out’, a phrase he uses often. Andy’s sense of impotence in the face of this attempt to raise his child from the dead is vividly portrayed by his joke:

What’s the difference between God and a surgeon? God doesn’t walk around thinking he’s a surgeon.

Many of the other parents use the idea of waiting, as a platform to illustrate difficulties with professionals on both the day and in the aftermath of the death. Chrissie describes waiting in the hospital for an ‘Inspector from Project Indigo’, the Metropolitan Police’s Special Investigation Team, for whom they ‘waited and waited and waited. It must have been at least five or six hours from us arriving at the hospital.’ Andy, Hafsa and Ellen all give lengthy accounts of waiting for contact from the coroner, together with delays with both the post mortem and with other procedures, as Hafsa describes it:

I finally got the post-mortem report but only because I’d said look I’m taking this to the Chief Executive because it’s ridiculous that it’s taken this long...and suddenly as if by magic the report was ready within three days.

As the narratives reach their ‘ends’, time is used increasingly as a tool for remembering and building meaning, as well as for expressing regret. Hafsa reflects the latter in looking back on her baby’s life:

The time I had with her, well if anyone had told me you’ve got 70 days with her, make the most of it...but you don’t. You do all your normal things like ‘Oh my god I’ve got to do this and remember to do that.’

Ellen, who has had longer since the death than Hafsa, also uses time in her meaning-making:

It would be easy just to say she was never here...to shut it off and just pretend it never happened...but for your own good you can’t just back away and we were lucky enough to have her for 71 days, 71 happy days and if people don’t get to have that time, maybe if their babies are stillborn or
they’ve been stuck in an incubator for all the life they’ve had. The whole of her life was a happy time; it was something to properly celebrate.

Within these ‘end’ sections, descriptions of time shift gear from the past to locating the parents more firmly in the present, with a sense also of looking towards a future, in which participation in the interview itself may form a part. The talk here is of becoming involved in support organisations and other charitable events, as Ellen and Hafsa both describe:

...And about 6 years after she died I got in touch with the Trust then because I wanted to offer some support because I had so much it was unbelievable (Ellen)

And I got to do a walk in memory and that helped and I thought if I’m doing something useful; fundraising whatever to stop me dwelling on it and help other people at the same time as raising awareness (Hafsa)

Ellen effectively expresses her wish to keep her child’s memory alive in a culture that is unwilling to allow this:

I’ve got a friend and she’s in remission from cancer but she can talk about that because she’s getting better, but when you mention the death of a child, it’s like ‘gasp...we don’t want to hear about that, just shut that away’ but I think it’s important to keep the whole awareness thing going...

All five narratives explored here blend together ‘autobiographical time, mythical time and narrative time’ (Speedy, 2008, p. 7), and demonstrate powerfully how these can be used narratively to ‘tell one’s story...and deeply give meaning to the past in order to give meaning to the present life of the person’ (Richardson, 1997, p. 30).

’I was a bit annoyed’: threads of emotion

One of my primary aims in completing the research which underpins this book was to help meet the Kennedy Report’s recommendation that ‘professionals ...be sensitised to emotions being experienced by parents’ (RCPATH & RCPCH, 2004, p. 12). Emotion, therefore, is a highly significant thread to twist within these narratives.

Guilt is named as an emotion within all five accounts. Terri, for example, describes her circumstances at the time of her son’s death when she was a young single parent, and
states, ‘this is where the guilt already starts coming up.’ Hafsa, a single parent with two young children, was staying with her sister at the time of the death. Her sister offered to look after the baby, giving Hafsa a rare opportunity to go shopping alone. Shortly after she returns, Hafsa finds the baby dead in her cot. She expresses her feeling of guilt poignantly:

My conscience is pricking me and I’m thinking ‘why did you not go up and check on her, you’re meant to do it every ten minutes or is it every 20 minutes, but I wasn’t there and I just wanted to get away from my kids for a bit, you know, I am on my own and if you get an offer to help you take it with both hands.

Hafsa returns to this towards the end of her interview querying whether

She just died in her sleep or did she wake up and call for me and I wasn’t there or I just didn’t hear her ‘cos the telly was on...when you’re at home, you have your monitor on but I was at my sisters and I wasn’t near the room and I wouldn’t have heard her...you know you just go over and over it trying to think why was I not there for her in those last few minutes, I was there for my mum, why couldn’t I be there for my baby?

Burr suggests that such feelings link to common cultural assumptions about culpability:

In our culture, we see ourselves as to some degree responsible for catching a cold; we may have gone out without our coat...this moral dimension has implications for the extent to which we can claim sympathy (2003, p. 37).

In cases of sudden and unexpected child death, where a ‘suspicion of child abuse profoundly affects people’ (Cleaver & Freeman, 1995, p. 83), the feelings of guilt expressed by the narrators are often linked to fear focused on the police response. As Chrissie states:

The fear about being blamed for his death overrode a lot of the initial grief. Instead of thinking ‘how will I live without my son?’, I was thinking, 'do I need a solicitor?'

Such fear as expressed by Chrissie is often articulated through references to the ‘emotional politics’ (Warner, 2015) and media reporting discussed in Chapter 2. Dent and Stewart (2004, p. 57) refer to the influence of the media in cases of sudden and unexpected child death, and Hafsa reinforces this, describing ‘CSI’ and ‘all the things you see on the telly’, 
whilst Andy states ‘I was aware of the Baby P case.’ Chrissie expresses her fear vividly: There is a thing in your head which prompts fear when the police want to talk to you and if you’ve ever watched crime drama on the TV you have a perception that they can somehow ’read’ you like Derren Brown...

These feelings of fear and guilt, expressed so lucidly through popular media depictions of authority, cast shadows on the ‘Kennedy Report’s’ oft-quoted it ‘is every family’s right to have their death properly investigated’ (2004, p. 1). As Chrissie reflects, the police prompt ‘fear’ in many people and thus it is vital that investigating professionals are aware of this as a common emotion ‘experienced by parents’ (RCPath & RCPCH, 2004, p.12).
Alongside the guilt, parents’ often implicitly express anger towards professionals. Dent (2000) found that parents anger in cases of sudden and unexpected child death was most often directed at others, whilst guilt caused many parents to search ‘for what they did to cause the death’ (Dent & Stewart, 2004, p. 57). Both these emotions are reflected in Garstang’s study (2017) and the five narratives discussed here.

Ellen, who tries to emphasise positives within her narrative, expresses anger tacitly in a long story of trying to get her dead daughter’s clothes back from the police. She describes enquiring about the clothes and being constantly told ‘we have to hang onto them.’ Four months after her daughter’s death, Ellen enquires once more and is told ‘they weren’t sure where they were’, which puts her into a ‘panic.’ Finally, Ellen contacts the coroner, who has the clothes in his office and she is told to collect them from the police station, which Ellen describes as follows:

I don’t quite know what I was expecting but I was handed back two big brown cardboard envelopes and they were sealed with a tag...and I just felt that this was really impersonal I mean they could have handed them back to me without the bag...it felt like they were, well they were evidence I suppose.

Ellen also describes her anger with the policeman, during the investigation interview: I felt like he was wasting time...and I wanted him to go and find me an answer from all these questions.

Andy is particularly angry with professionals, whom he also identifies as ‘blaming everybody else.’ He apportions much of his own anger to a lack of ‘common courtesy’:

I used to run a garage and we specialised in MOT’s...and I think we used to
keep people more informed about their cars than they did...it’s just common
courtesy...that’s all it needed really...that would have been such a big help.

Andy’s most forceful statement, however, is towards the end of the interview when he
declares:

The day itself and how we were treated was worse than actually losing him.

Although anger appears in the narratives, it is frequently hidden behind other emotions.
Chrissie, for example, describes being ‘very unhappy’ at being taken home in the back of a
police car, when what she seems to be reporting is anger. Ellen also often touches on anger,
but then tones this down, as can be seen here in her description of the police interview:

He was asking me all these questions but he kept staring at the baby in this
Moses basket and...I was a bit annoyed and I thought actually I shouldn’t be
annoyed, you’ve probably never seen a dead body before, let alone a dead
baby.

Dent and Stewart account for the frequent suppression of anger, suggesting that it is ‘not
necessarily seen as a socially acceptable part of grief’ (2004, p. 172), whilst Batt suggests
that ‘the urge to co-operate with authority is compelling; it is irresistible to most ordinary
people’ (2005, p. 71), which may also account for the reluctance to express anger. A fuller
exploration of this is given in relation to ‘Cathy’s story’, which forms Chapter 5.
Feelings of shock and disbelief also feature alongside guilt, often in relation to professionals,
as Terri illustrates:

I do remember when the police showed up thinking they can’t possibly
think I’ve done something...do they seriously think I mean do they honestly
think that I could’ve killed him?

Many of the narrators report being ‘in shock’, particularly during the ‘beginnings’ of the
narratives. This is confirmed by Dent and Stewart (2004, p. 138), who suggest that for many
parents ‘shock and disbelief may prevent the reality of the situation from being absorbed.’
Hafsa evidences this in her description that it all seemed a ‘nightmare, or a dream, or a
trance’, and describes rocking her baby for hours in the hospital, all the time thinking, ‘It’s
time to feed her; if I feed her she’ll be fine.’ Chrissie sums up the feelings of many parents
when she says ‘I felt like I was dead as well.’

The feelings of dispossession described here point to the intense complexity of achieving the
‘thorough systematic investigation of the circumstances of death ...and a sensitive, caring approach to supporting the family’, which Sidebotham and Fleming (2007, p. x) suggest are not ‘mutually exclusive’. Hafsa’s powerful disassociation and Chrissie’s sense of being ‘dead as well’, both suggest that if the two aims are going to be successfully linked, then professionals will require a profound, rather than a superficial, understanding of the ‘emotions experienced by parents.’

As with guilt, feelings of shock and disbelief link to concepts of media and technology. Hafsa vibrantly describes finding her baby dead in a passage that also links to time with technology and the contemporary drive to renew:

I mean in the age that we live in everything’s rechargeable isn’t it? So my first thought was ‘that’s ok’, I can fix it. Where’s my charger. Your camera, your phone and everything. You can just re-charge it or get another one- or new batteries...

For Hafsa, the feelings of shock also manifest as ‘flashbacks, which you just sort of re-play,’ whilst for Chrissie the shock is physical and she cannot return to her house where the baby died.

Also reported in the narratives is ‘felt sense’, similar to that which I experienced when Joe died. Gendlin describes ‘felt sense’ as an ‘awareness of the border zone’ between the conscious and the unconscious’ (2007, p. 16), which echoes Winnicott’s notion of ‘transitional’ or ‘potential space’ (cited in Hoggett & Clarke, 2009, p. 16), in which a different form of knowing emerges.

All five narrators briefly reference this sense of ‘knowing’ in relation to their child’s death, as illustrated here by Hafsa:

I knew what had happened straightaway. I thought that’s it...she’s gone.

In his account of terminal illness, Frank (1995, p. 141) also speaks of spaces where ‘embodied knowledge is in excess of speech’, thus reflecting this space of knowing yet not knowing. Whilst such accounts can be reduced to mechanisms for retrospective meaning making, they form a strikingly common thread, which links with my own experience of Joe’s death (see Chapter 1).

These accounts of ‘felt sense’ or ‘knowing’ are significant, as they may affect the ways in which parents respond at the point of police interview. Sidebotham and Fleming (2007, p. 99) suggest that in most cases of sudden and unexpected child death, the parent or carer
will immediately seize the child ‘to establish any responsiveness.’ However, this is not what I did when Joe died, and the narratives shown here, together with the accounts of ‘felt sense’, show that there may be nothing that is done ‘typically’ as Sidebotham and Fleming suggest, a factor which is crucial within the investigation that follows.

‘She really did put herself on the line’: threads of professional intervention

One vivid thread in all the narratives is the succession of professionals that intervene with the parents during the beginnings, middles and ends of their reported experience, and frequently beyond. These professionals densely inhabit the narratives and are often accompanied by value judgments, which clearly demonstrate the findings of the Royal College of Nursing (1995), as discussed in Chapter 2, that ‘the quality of care to relatives at the point of death can have a major impact on the subsequent bereavement process.’

The police are inextricably woven into every narrative to a greater or larger extent, and appear very near the beginning of each. For Terri, the police do not feature as a key part of the experience, as she reports:

I don’t really remember, I just remember the health visitor…I don’t think the police stayed terribly long.

However, for other parents the police intervention and their response to it forms a significant part of their narrative and is mostly associated with stigma. This resonates with Garstang’s study (2017) but forms a sharp contrast with the Appendix to the Kennedy Report which suggests that a number of parents were ‘reassured by the police investigation because when they have come through it they feel they have been formally exonerated of any suspicion of wrongdoing, so that no stigma can remain’ (2004, p. 55). For most parents in the study which underpins this book, far from removing stigma, the police investigation directly contributes to it, and when they speak of the police it is often as a symbol of authority and fear.

The dichotomy between the ‘reassurance’ cited in the Kennedy Report and the different reports from parents in this research can be located within Hoggett’s theme of ‘allusion’, which forms the link between ‘a violence that is embarrassed or ashamed to speak about itself and the everyday life which proceeds in the shadow of this force’ (2000, p. 105). Furthermore, he suggests that when this ‘violence’ is ‘alluded’ to rather than made explicit,
‘it vanishes’ ((2000, p. 105).

Hoggett’s analysis has uncomfortable resonances with the Kennedy Report’s ‘alluding’ to parental experiences by placing these separately in an Appendix, where the powerful stigma often associated with police investigation may be ‘vanished’ by the emphasis on lack of stigma.

The parents in these five narratives and those which form Chapters 5–7 tell very different stories, which point to Hoggett’s discussion of the violence that is always present at the borders of ‘everyday life’:

So we phoned emergency services and probably naively we imagined it would just be an ambulance that would turn up and help but it was actually a police car (Ellen).

Two uniformed officers arrived...a great big guy with full uniform on (belt etc) and not sure if he was armed, I didn’t really look to check (Chrissie).

Well we had armed police, because I saw a Taser and I said ‘Is that a Taser gun? And she said ‘no it’s a real gun’ (Andy).

The police shut the bedroom door and we weren’t allowed back in...And I remember thinking ‘Crime Scene.’ (Andy).

Hafsa vividly depicts her fear of the police, which is endorsed by Chrissie:

I’m thinking ‘bugger, I’m in trouble now, that’s it I’m going to get handcuffed and you know what have I done wrong because I hadn’t checked her enough and I’m going to get done for that you know (Hafsa).

I don’t have any contact with the police, on either side of the fence, including any friends/relatives in the force, we simply don’t know any police officers .....you have a perception they will decide on the truth and fit a case against you around it... (Chrissie).

These anxieties of having ‘done wrong’ are aggravated by the very real language and behaviour used in the Rapid Response:

And then we had two plain clothes turn up, ‘The Child Abuse Team’ their business cards said, or words to that effect, rather than child protection...so you were sort of guilty until very much proven otherwise (Andy).

I didn’t like being in the back of a police car...when we got to our house;
several neighbours were outside keeping an eye. There was a uniformed officer outside and a squad car (Chrissie).

These accounts of the police cast further doubts about the efficacy of interviewing parents so soon after the death of their child, when, as Klass reports, the ‘initial response to... death is disassociation’ (1997, p. 151). This is powerfully evidenced by Chrissie:

I was lying on a gurney...I didn’t want to be awake and was considering asking for sedation...and he sat by me and asked me the basics, my name and baby’s name and how old...

Andy describes how the police took him away for interview, in the hospital, whilst his son was still being kept alive via life support:

The two coppers interviewed us separately, they took us off whilst they were still trying to resuscitate him...which was a bit much.

Ellen gives a bizarre description of being interviewed in hospital with her dead baby lying in a Moses basket beside her:

My husband was taken away to a separate room in the hospital by a police sergeant and the policeman had a sort of list of questions to run through like what her feeding habits had been, where she slept and basically how her day had been before we realised she wasn’t breathing...

The memories of the police evidenced by the parents in this study paint a very different picture to the one depicted in the Kennedy Report, where parents were commonly ‘reassured by the police investigation’. This once again highlights the complexity of achieving ‘a thorough, systematic investigation of the circumstances of the death which also integrates ‘a sensitive, caring approach to supporting the family’ (Sidebotham & Fleming, 2007, p. x).

Hafsa’s account offers yet another prism with which to view this notion of ‘thorough, systematic investigation’, as, far from experiencing investigation, she is left waiting for it:

I was thinking, you know...of all the things you see on the telly...don’t they need to tape off the room and take away bedding and evidence. Well they didn’t do anything. But we left everything as it was just in case they needed to.
This sense of the inconclusivity of police investigations is particularly present at the ends of narratives, as Ellen and Andy both describe:

And as I say they never...we were just kind of left, well we never had any sort of conclusion from the police (Ellen).
So then the police weren’t involved after that but they never sort of rang or got in touch, to say or to tell us anything...we just didn’t hear from them again (Andy).

Ellen and Chrissie also report having to attend the police station months after the death to collect the clothes that their babies had been wearing when they died. Their accounts are a sharp contrast with Stead’s description (1997), referred to in Chapter 2, of someone folding her son’s clothes and shoes and not ‘dumping’ them into a property bag.

Despite powerful memories and strong feelings towards the police, many of the narrators of these five stories also made a considerable effort to understand the police perspective and to show compassion, thereby avoiding the ‘splitting’ described by Klein, and helping towards achieving the ‘depressive position’ (Klein, 1935) (see Chapter 1).

Chrissie, who explains so powerfully her own fear of the police, also describes the officer first on the scene who was ‘mostly soft spoken and looked terrified’. Andy, who is most candid with his anger, similarly states that ‘the actual uniformed officers were pretty good. One of them had a baby the same age so I think he was finding it pretty hard’. Hafsa adds to this, stating ‘you do feel like you’re in trouble but they have to do it haven’t they? It’s part of their procedure.’

It is Ellen who ‘humanises’ the police the most in a powerful anecdote about encountering the police officer who interviewed her several years later whilst waiting for a routine health visitor appointment. Ellen is initially traumatised when she sees him with his own baby:

He had this baby in his arms, this little thing, wrapped up in a pink shawl and I could just see him taking my baby away...I started crying and the health visitor asked what was wrong and I said that was him, that was the policeman...and she says ‘oh right, ok, what can I do’ and I said ‘well nothing its nobody’s fault’...it was just a flashback to that night although it was about six years since I’d seen him...but obviously having his own children sort of prompted something inside him and he got in touch with the support
organisation I volunteer for and he ran the half marathon and asked if he could mention my baby’s name in his ‘just giving page’ because that was his inspiration for doing the run.

For Ellen, this story helps her to understand the professionals that are involved and the personal effect it has on them. By so doing, she avoids the splitting of ‘us and them’, consistent with Klein’s ‘paranoid-schizoid’ position, moving instead towards an understanding of sudden and unexpected child death as an event that has affected everyone involved, and thus locating the ‘bad’ inside the experience rather than within the participants (Hollway & Jefferson, 2000).

Aside from the police, medical staff also feature as dominant professionals within the narratives, often with similar attempts to unite ‘good’ and ‘bad.’ Andy, for example, describes the doctor in the first hospital he has contact with, as ‘quite good and kind of honest,’ whilst others receive less favourable comments.

For most people following the deaths, paramedics are often the first point of contact and they therefore commonly appear at the beginning of the narratives. Andy describes the paramedic talking him through trying to resuscitate his baby:

I was talking to the guy on the phone and he was telling me what to do to try and resuscitate him...so I was trying and blood was coming out of his mouth and I kept clearing his mouth but nothing was happening...I’ve never done anything like that before so I didn’t really know but the guy on the phone was very good.

Hafsa also vividly describes her sense of panic with the emergency services:

So I was saying to the 999 people no you’re not listening, you need to send someone now, and then the paramedics came and they tried to give her mouth to mouth resuscitation as well but I said no I’ll do it but I just couldn’t and I felt her forehead and it was starting to get cold.

In the middle of nearly all the narratives there is a description of waiting in a hospital. It is generally medical personnel who take the narrative baton from the police within the marathons these parents metaphorically run on the day of their child’s death. Hospitals are associated with a sense of disassociation and alienating protocols. Hafsa gives a powerful illustration of this as she describes transporting her dead daughter within the hospital:
They put her in this basket and we had to carry her through the hospital and I couldn’t understand it but I thought, maybe that’s why she’s in a basket, so other people won’t know she’s dead while we’re walking past them.

For Andy, whose baby son is kept alive on life support within the hospital, the process is described as mostly painful and alienating, similar to his descriptions of the police:

The doctor said he’d come and get us once they had got him settled and we waited. It must’ve been an hour, an hour and a half or so, it felt like that...Then it turned out they’d forgotten to come and get us.

Andy also describes a ‘language barrier’, and, whilst acknowledging that a lot of ‘foreign doctors have better English than I have’ he states regretfully, ‘but this one wasn’t particularly good.’ He is quick to follow this, however, with ‘the nurses they were good’, demonstrating his investment in fairness and understanding.

Procedural blunders were a recurrent theme in the narrative. Andy’s son is transported between two hospitals, which led to professional delays and errors. He describes this as follows:

They were blaming everything on the fact we were moved between hospitals and so no-one liaised between the different counties...they were all saying ‘well it happened in P hospital’, but in this day and age how difficult is it for someone at one hospital just to ring or email the other one? I don’t know...we just felt on our own with it really.

Despite his criticisms and obvious anger, Andy continuously demonstrates his attempt to unite ‘good’ and ‘bad’ in the ‘balancing’ comments, which often follow his reproaches. For example, his comment that the ‘nurses...were good’ and his description of the ‘human’ nurse who ‘lost a baby to cot death herself about twenty years before.’

The Kennedy Report states that ‘Coroners play a vital role in cases of sudden unexpected infant death’ (RCPath & RCPCH, 2004, p. 9), and in these narratives, they are the only professional group who receive collective censure. For most parents, the death will be their first experience of contact with a coroner. All the narrators report distressing and alienating experiences with coroners, suggesting a need for improvement. Andy describes the coroner as remote and unaccountable in that ‘he just blamed everyone else’, whilst Ellen reports having to give permission for a post mortem but being told ‘it would happen anyway,
whether we signed it or not’. Everyone describes the waiting and procedural delay caused by coroners, echoing Hafsa’s account of waiting:

20 weeks for the post mortem…I had to chase them up…and even then I can’t remember half the legal terms, but it was like going into Court.

There are professionals however, who are described in the narratives as being of great support, with health visitors depicted most positively. Terri, Andy and Ellen all describe health visitors as helping them cope. Terri encapsulates this as follows:

Thank god for that health visitor, who I don’t even know if I had met before, this lovely woman... She was the only thing that was keeping me even vaguely together.

Ellen, whose narrative is filled with particular anecdotes about professionals, tells the tale of a nurse that powerfully illustrates the difference that they can make to the parent experience, even years after the death. In her story, Ellen, who has just given birth, requests a hospital apnoea monitor but is told she has no reason for one. The new baby is healthy, and Ellen’s only reason for wanting a monitor is her enduring fears from the death of her daughter years before. Procedurally, this is not a sufficient reason to issue a monitor. However, emotionally for Ellen, the monitor is vital for her to feel confident enough to take her new baby home, as she describes:

And of course I just immediately burst into tears...So this nurse basically smuggled me out of the hospital with the apnoea monitor...she really did put herself on the line to do that for us. I think she had some idea of what it actually did mean to have that but I just thought it was so insensitive of that doctor to say ‘no you can’t have it’.

Other professionals are alluded to within the narratives, but none take centre stage as strongly as the police or the medical personnel. Funeral directors, mentioned by both Terri and Hafsa, are seen as helpful. Terri mentions that the Co-op ‘do free funerals’, thus
alleviating an important practical and financial strain. Ellen, Terri, Andy and Hafsa all mention referrals for counseling, which Terri finds invaluable and Ellen conversely describes as being a ‘fat lot of good to me.’ Hafsa also mentions the ‘hospital bereavement team’, although she is disparaging about this service:

They had a very sympathetic voice but they didn’t really know what I was saying. It was all ‘ooh…ah…how are you doing? Well I was ‘no as a matter of fact, tell me what’s happening, cut the crap, you know she’s gone now, I’ll deal with that, I need to know…why you are not following the procedures, you know?

Many of the parents spoke about voluntary support organisations, who, in Ellen’s words, are ‘just brilliant’, although initial contact with these is often made at the parents instigation rather than through any formal referral system. Ellen describes ‘picking up the ‘phone’ to her local support organisation after the birth of her youngest child, when ‘everybody just assumed that I would be fine.’ She telephones the support agency to say ‘I’d quite like some support thank you very much’ and they send out a befriender. Later, Ellen undertakes ‘befriending training’ herself, whilst Hafsa and Chrissie also become support agency volunteers following the deaths of their children. These voluntary agencies feature strongly as source of both formal and informal support within the narratives (RCPath & RCPCH, 2004, p. 1).

Despite the Kennedy Report’s call for improved communication between ‘professionals and between professionals and parents’ (RCPath & RCPCH, 2004, p. 12), descriptions of professional interventions within these narratives demonstrate that ‘provision of care’ is still largely influenced by ‘the interest and commitment of individual health professionals’ (Dent & Stewart, 2004, p. 111), whilst the instances of police involvement demonstrate a wide chasm between professional rhetoric and the actual experiences of some parents.

‘The point where I was most unlike myself’: threads of parental identity and agency

Hindmarch describes how ‘the loss of one’s child…is often fundamental to one’s sense of self’ (1993, p. 30). This is fully illustrated in the narratives, where personal identity and
agency are implicated in sudden and unexplained loss of a child. Chalmers states that ‘the system which swings into action when a sudden death occurs can leave parents feeling powerless, with everything out of their control’ (2008, p.6). This can be immediately made concrete by the arrival of the police.

Hoggett (2000, p.99) locates privacy as the socially containing border between ‘violence’ and ‘everyday life’, a place where private identities can be protected, rendering the ‘Rapid Response’ investigation a direct violation. In these narratives, this is poignantly symbolised by those parents who describe wearing their pyjamas or slippers both as the police enter the house and even later in the hospital. Their private identity, represented by intimate domestic apparel is thus breached and brought under the public gaze, alongside their identities as parents and even their ‘ownership’ of the child who now becomes the ‘property of the coroner.’

Chrissie illustrates vividly both her personal loss of power and her sense of identity:

When you are at that level of trauma, you don’t trust your own actions, you don’t trust anything...it seemed to me that I was going to be scrutinised at the point where I was most unlike myself and most afraid.

Hafsa also describes strongly her attempts to restore her own sense of self and judgement, whilst professionals intervene around her:

You’re just thinking ‘hang on, I just need to figure out what’s going on’...but you’re not even thinking really...it’s all a bit of a nightmare.

Echoing Chalmers’ description of the ‘system’ swinging into action, Bridgeman describes the time following death as one when ‘formal processes of investigation prevail to exclude the parents in their attempts to care for and protect their child’ (2009, p. 269). Despite ‘good practice’ guidelines, which advise that ‘parents need time to assimilate information’ and that this should be offered ‘over the following few days’ (Dent & Stewart, 2004, pp.139–40), the reality of Rapid Response makes this impossible. Instead parents are offered contact with their child, who is no longer their property and which is mediated through professionals. Thus, ‘good practice’ recommendations in the literature are usually accompanied by a list of ways in which parents can be enabled to ‘spend time with their
dead child’, including the offering of handprints and locks of hair (Sidebotham & Fleming, 2007, p. 279).

However, as the earlier discussion of time demonstrated, sudden and unexpected child death occurs on an ‘ordinary day’, when only moments before the parents were totally responsible for their own child’s care. The immediate move from this to contact mediated through professionals can therefore be difficult to process, as Hafsa movingly demonstrates in her description of leaving her dead daughter:

So we had to leave her there and I just thought ‘Is she just going to be in that room, on her own?’...because it was a tiny little room, with dim lighting and a nice little Moses basket and I thought, ‘is this where I’m supposed to leave her? I mean is that it? I’m just expected to go home and go to sleep tonight and be normal?...There could be all sorts of creepy people about and I’m thinking I actually didn’t have a clue what was going on and what was going to happen next.

As Hafsa’s description poignantly shows ‘Death does not extinguish the relationship between parent and child: the child remains the child of the parent, and they continue to feel a sense of responsibility towards their child’ (Bridgeman, 2009, p. 265). Trying to sustain this relationship and responsibility towards the dead child in the face of the ‘systematic investigation’ provoked by professional intervention can leave parents struggling for respect, agency and a coherent sense of self, as evidenced by Andy in a very affecting passage within his narrative:

We were in a cubicle on a big ward rather than in a private room…I mean it had curtains, but a lot of the time you’re looking over at other kids and parents…and they kept telling us to get out of the way while they did this and that...so they just switched everything off and we had a chance to say our goodbyes, but it would have been nice to go to a private room...they sort of pulled the curtains round but he sort of died in my arms gasping for breath...everyone else could hear, everyone else was around.

For Ellen, Andy and Chrissie also, whilst they are at the hospital the police are at their houses, as Ellen describes:

The police had been to the house, whilst we were still at the hospital and they took away some bottles, her clothing that she was in and some bedding.
For Andy, the sense of violation implied by this unendorsed entry into his home is expressed via his description of the family pet:

The plain clothes officers had come to look around the house and do whatever...I think they were here most of the day because they shut the dog in the garden, poor thing and he was barking...I think one of the neighbours took him out for a walk.

In their seminal work on ‘The Social Construction of Reality’, Berger and Luckmann state that ‘identity is...a key element of subjective reality and like all subjective reality stands in a dialectical relationship with society. Identity is formed by social processes’ (1966, p. 194). Hoggett supports this, drawing both from Honneth and Winnicott to suggest that ‘being’ is a ‘fundamentally social’ state in which our ‘well-being is equivalent to being well with others’ (2000, p. 6).

Furthering this, Hoggett argues for Honneth’s model of three different forms of identity, all linked to recognition. The first of these, ‘individual identity’, emerges primarily from consistent loving care and secure attachments in childhood, whilst the other two are particularly significant for parents following sudden and unexpected child death. ‘The struggle for self-respect’, which Hoggett links to recognition by the state, expressed in the form of ‘rights’, is withdrawn from parents immediately after the death when free access is denied, both to their child and to their home.

Lastly, the ‘recognition of one’s traits and abilities by the ‘communities of value’ to which one belongs’, which Hoggett (p. 7) argues is essential in achieving ‘the struggle for self-esteem’, is also threatened following sudden and unexpected child death. As I have argued elsewhere, contemporary debates around dying have created value judgements, which focus on the concepts of a ‘good death’, together with the correct timing of this, in which the random deaths of children are rendered almost ‘unthinkable’. Therefore, parents who experience this find that membership of their ‘communities of value’ may be severely restricted, stripping them of their familiar social identity. Instead, they are faced with a denial of their ‘rights’ and are viewed simultaneously as both ‘victims’ and ‘suspects’, creating a new and uncomfortable social identity, which they then have to overcome.

In this context, agency has to be reasserted and identified anew. In my research, this is demonstrated within the five narratives discussed here, usually towards the ‘ends’. Paradoxically, for Hafsa the funeral arrangements restored some choice and self-confidence,
despite her recognition of the irony in this:

I had to go to the funeral director and pick a coffin...and the name plaque and you know it’s like picking wallpaper and I’m thinking, I’ll have that colour, I like the brass...I was being really kind of matter of fact about it because I was thinking, I’m going to do this myself and I’m going to do it right and I don’t want somebody else making those choices.

Other parents assert their agency through written complaints. Andy writes to the Case Review via the health visitor, but is doubtful of the outcome:

They didn’t want to hear our criticisms...but they’ve written to us to say they’re trying to put things into practice. Whether they will or not I don’t know.

For others, participating in the research interview itself may have formed part of their rebuilding of agency and identity via ‘telling their story from beginning to end’ (Riches & Dawson, 1996, p. 363), and thereby helping towards the ‘making a difference’, which so many parents stressed. Becoming befrienders and support volunteers themselves as previously discussed is another important way in which parents restored their sense of belonging to a ‘community of value’, thereby re-building identity following the initial loss.

‘And my daughter came running in’: threads of siblings and subsequent children.

As I have discussed in Chapter 2, bereaved brothers and sisters have been called the ‘forgotten mourners’ within the literature in this field (Hindmarch, 1995, p. 37). There is therefore a dearth of research literature, especially around the potential effects of Rapid Response (Dent & Stewart, 2004). Amongst the narratives in this chapter and within my own experience, siblings and subsequent children feature significantly throughout, highlighting their importance and adding to the knowledge in this area.

At the beginnings of the narratives, when the death and the immediate police response are described, other children are often identified as present, as Terri illustrates:

I screamed and I was trying to give him mouth to mouth and you know I was just hysterical obviously and my daughter came running in and I just told her to go away because everything was such a mess.

Andy also describes his other children, who were ‘all a bit unsettled and didn’t really know
what was going on, so I was trying to sort them out’, whilst Chrissie describes her three year old stepson and his father finding her asleep on the sofa with the baby, who is not breathing. All these narratives subsequently describe the act of finding care for these children, whilst simultaneously confronting death and the subsequent response. Terri recalls taking her daughter next door, ‘because she had a little friend next door’, whilst Andy and his partner ‘rang the godmother, who only lives up the road, to see if she’d come. Chrissie’s stepson is driven back to his mother’s house, whilst his father and Chrissie are taken to the hospital.

However, these arrangements are impromptu and thus reflect the lack of any provision for siblings within the protocols for investigating sudden and unexpected child death. This also reflects the common focus on parents as ‘bereaved parents’, rather than, as in many cases including my own, as people with other children to care for. This continuing caring role and the difficulties caused by the death, feature prominently within the narratives discussed here. Many of the parents explain their fear of another death occurring, as Hafsa describes in relation to her new baby:

I’m still paranoid and you know I end up checking the baby’s cot all the time, thinking ‘oh my goodness she’s not breathing’ or ‘oh my god, she feels a bit cold’...or I can’t hear her and if she’s a bit snuffly, I watch her like a hawk and I do try not to because she doesn’t know what’s happened. I mean what kind of a weird world have I brought my daughter into?

Like Ellen, Hafsa borrows a monitor for the new baby, which provides her with some reassurance. Chrissie endorses this anxiety, stating ‘it took weeks before I stopped checking everyone in the house as they slept to make sure they hadn’t died in the night’, whilst Ellen also illustrates the fear connected to other children:

I don’t think I slept for probably a good year and a half...I would wake, give a prod and it would be ‘oh you’re fine’ and then back to sleep for a bit.

Ellen also describes her strategies for controlling the overwhelming anxiety that engulfed her after the birth of her youngest child, several years after the death:

When I had him I’d got it into my head that everything had to be done in a set order and if I didn’t do it in that order he would die and if I broke the pattern he would die and I did drive myself a bit nuts.
Despite their fears for their surviving children, many of the parents describe also how they gave them a reason for living, as Hafsa illustrates:

> In my mind, that night I ended up thinking what’s the point of anything, she’s gone, so I may as well be gone as well...and as I turned on my side I saw R there with me and I thought actually there is a point, I’ve got to get on with it, I’ve got to be there for her.

Terri echoes this, stating, ‘I just remember thinking that I have to be there for her,’ whilst Ellen recalls ‘having to pull our socks up and get on with it for her which was probably a good thing’. Whilst all these extracts demonstrate the positive effect that surviving children may have on parent’s well-being, they also point to the potential difficulties for parents who have no other children once the death has occurred. This is therefore a strong thread for professionals to be aware of in their expressed desire to provide ‘sensitive support to help deal with their loss’ (RCPath & RCPCH, 2004, p. 1).

Towards the ends of the narratives, many parents describe trying to explain the death and helping their surviving child or children cope with the effects. This is mostly a task they accomplish alone, with no reference to professional input. Given findings that it is not the death itself so much as ‘changes and readjustments to the family system’ (Dent & Stewart, 2004, p. 85) that may most profoundly affect children after a sibling death, there are opportunities here for professionals to provide the ‘sensitive support’ so often referred to in ways that could be genuinely beneficial. Ellen explains her struggles with trying to explain death to her 15 month old daughter, following the death of her sibling:

> Obviously you can’t explain death to a 15 month old...the whole concept of death and things meant she would just ask where her sister was and it was just like, well, we said she had gone to heaven but she couldn’t understand how she wasn’t coming back from this place.

Hafsa too discusses how she is attempting to help her young daughter to understand the sudden and unexpected death of her baby sister:

> Whenever R wants to talk about her then I say, ‘of course, you’re free to talk about her’ and I say ‘what do you think she’s doing now? Do you think she’s got teeth yet?’...I think I’ll just be led by her questions as she gets older, whenever she wants to know and if I think she’s ready to know.
Terri also describes her immediate worries for her surviving daughter:

I was really beside myself and of course I was really worried about my daughter, because they were really close and you know, what do you say, what do you do?

These difficult decisions are also reflected in the funeral process, where professional support, apart from that of funeral directors, seems entirely lacking. Terri describes the funeral as ‘just awful’, although she says she knew her surviving daughter ‘needed to go’, whilst Hafsa conversely describes her feelings of guilt at not allowing her daughter to attend:

I didn’t really want R to go and I think looking back maybe that was unfair of me, but she had seen so much because she was only two at the time.

Towards the ‘ends’ of the narratives, all five parents describe how their surviving children have helped to orient them towards the future. Hafsa also demonstrates the complexity of this, alongside the enduring effects of the death:

I don’t think I would ever take her to the cemetery. Can you imagine trying to explain, ‘well I do love her, but I buried her and then I leave her and come home’. I think that’s too much, that’s disturbing even if you’re 16.

Terri also reflects on not ever having spoken to her daughter, who is now an adult, about the death:

I’ve never. Well you know I’ve never spoken to her, I can’t remember ever speaking to her about what she remembers about that day. I think she said at some point that she remembers a lot of screaming, you know it’s not good memories...

Within Ellen’s family, the dead child is both narratively and visibly integrated as a part of the family history:

Her pictures will always be on the wall, the boys know who she is, her sister is always going to know who she is...it’s just about being as positive about it for them as possible.

Ellen’s description has strong echoes with Julia’s story, which forms Chapter 6, and both demonstrate the importance of surviving children, both at the point of death but also within the continuing narrative of their families. These strong threads render the absence of surviving siblings within the ‘Rapid Response’ and in the processes that follow, as a lost
opportunity for providing support and increasing understanding.

Sidebotham et al. in their evaluation of the Rapid Response state that processes should be evaluated with respect to ‘assessing outcome in terms of...understanding of child death and support for families’ (2010, p. 295), thus signposting the need for more comprehensive consideration of other children and endorsing the call for further research in this area (Dent & Stewart, 2004, p. 87).

‘Is there ever going to be a light at the end of the tunnel?’: threads of chaos and meaning-making.

In Chapter 2, I discussed the emotional politics which surround high profile child deaths (Warner, 2015) and their popular depictions as ‘abhorrent’ (Raphael, 1984, p. 235), ‘unnatural’ (Wheeler 2001, p. 53), or as ‘one of the most disturbing, shocking, unacceptable events that can occur’ (Bridgeman, 2009, p. 255). I argue that such depictions may encourage a practice of cultural ‘paranoid-schizoid’ positioning in relation to the experience, which splits it from reality and the possibility of restitution.

However, as the earlier threads demonstrated, parents are often keen to show the ‘good’ things that emerge from the initial chaos, together with their own ways of managing this and beginning to create meaning. Many of these are located within religious belief or spirituality. Andy, for example, describes trying to get a chaplain at short notice to baptise his son, which, although not being especially religious, felt to him and his wife like a way of managing a process that was largely out of their control. Hafsa, who is a practicing Muslim, describes most powerfully the support her faith gave her:

You think ‘am I ever going to get over it? Am I never having children again?’

You know all these things, ‘How will I get on? How will I do it?’ But you just do and I think at a time like that your faith kind of pulls you through...because at a time like that I just thought God gave me the baby, God has taken the baby back.

For Hafsa too, washing the body, a religious ritual, helped her to manage the immediate chaos and to reclaim a sense of agency and responsibility towards her dead child:

How you wash them, it’s like a little vertical table, but there’s like a shower there and we used normal soap and everything and it was really just like giving my baby a bath, but she was asleep.
For other parents, it is those people or professionals around them who help them manage the chaos. Terri’s health visitor was an ‘absolute star’, whilst Chrissie describes the arrival of her father who removed the sofa on which her baby son died. Hafsa also turned to her brother-in-law and family for support, whilst Terri felt the lack of this:

Maybe if I’d had loads of relatives that would’ve come and stepped in ... I don’t know siblings or something. Someone that could’ve come and helped do the organisation...because I had no idea what to do. I mean it’s not something you plan for is it? And you have to face all this stuff, that you never thought you were ever going to be facing, ever.

‘Facing all this stuff’ moves all the narratives towards some form of the meaning-making, which contemporary grief theorists emphasise as vital in moving on from death (Neimeyer, 1998, p. 110). For Hafsa, this process was emotionally demarcated by the funeral:

I couldn’t really relax until she was buried really and once she was buried then you could sort of start getting on.

Establishing a cause of death is also an important boundary for parents. Terri describes this as ‘helpful’, whilst Andy feels cleared of suspicion by being ‘found innocent’ via the post mortem. Hafsa reads through the post mortem with her boss, who is a doctor, and whilst she is initially distressed by the conclusion, she reflects on this:

It came back with ‘cause unknown.’ And I thought ‘Great, I’ll never know, but then I thought, ‘Maybe that’s a good thing because she wasn’t suffering, there was nothing wrong with her and at least she was o.k.

The meaning-making is also demonstrated by looking towards the future and trying to change things for others, either by complaining or by joining support organisations, as Ellen describes:

I’ve supported a lot of families...some of them just come and go, it’s only maybe one ‘phone call’ or whatever, it’s just what everyone needs because sometimes you’re just really having a bad day and you think, ‘Is this normal? Is there ever going to be light at the end of the tunnel?

Will I ever smile again?

For Ellen too, the sense of renewal and meaning is drawn from professionals remembering the death, like the policeman who runs marathons and other professionals for whom her
baby’s death had ‘made a huge difference.’

Ellen also describes always telling people that she has four children, which resonates with Julia’s story (see Chapter 6) as another way of ensuring a ‘continuing bond’ (Klass, 1996):

At work I’ve got pictures up and people ask ‘I thought you had 4? And I say ‘Well I have had 4 and then they’re like ‘Oh I’m really sorry and I’m like, ‘well you don’t have to be sorry, I didn’t have to tell you!’

For Terri, there is a profound spiritual dimension to her meaning-making and she draws on dreams and symbols to explicate this. Amongst these is the tale of a fox killing the family pet rabbit, shortly after the death of her son:

And I’m grappling with this death in my garden...and I managed to hide the rabbit from my daughter and to tell her that it had run away or something. I just couldn’t cope with telling her about her rabbit dying. But to me it was just like ok I get the point, these things happen. Nature is as cruel as it is kind...we have to face the fact that death is part of life, just as life is part of, well life and death are connected.

Hafsa also describes simply yet richly how ‘life and death are connected’, demonstrating the ways this experience has changed her own approach to life:

It changes the way you get on with things...life’s too short so I started using things I had put away for my daughter, you know ‘no I’m going to save that for a good day’ and instead I said ‘you’re going to wear it, because today’s a good day, every day’s a good day from now on.

Whilst so much of the literature and training material in this field depicts sudden and unexpected child death as apocalyptic, these accounts, shared by so many of the parents in this study, demonstrate instead a powerful drive towards reparation and meaning-making, as Ellen summarises:

I think if you can have a good experience of this situation... then I think we had the best experience we could possibly have.

Similarly, whilst the professional literature often places sudden and unexpected child death at the pinnacle of cataclysmic experience as ‘the most shocking and devastating event anyone must face’ (Simons, 2004, cited in Dent & Stewart, 2004, p. x), the parental narratives here demonstrate a different perspective. Hafsa, for example,
muses:

I thought at least she’s not missing because my heart goes out to parents whose kids have gone missing; my god there’s no finish line. I think I’d actually go loopy if that happened to me…I knew where she was and she’s in a good place and in my heart I believe the angels are taking care of her.

Hoggett’s notion of ‘communities of value’ (2000, p. 7) is also useful for understanding the meaning-making that follows the death, via the unsolicited sharing of previously untold stories of child loss, which are shared with the parents. This echoes my own experience following Joe’s death (see Chapter 1) in which, like the ‘thestrals’ described by Rowling (see Chapter 1) the experience seemed to provide access to new ways of both seeing and hearing. Andy summarises this, stating ‘after it happened, the amount of people you find out it’s happened to as well’, whilst Hafsa similarly describes:

And then people would come out with ‘well I lost a child and he’d be 17 or she’d be 30 now’ and then there was this one woman who hadn’t actually spoken about it at all but she lost a child to cot death as well and all her other kids were grown up.

This sharing of previously untold stories helps all those parents bereaved by child death, no matter how long ago, to form a new ‘community of value’ in which the death may form a ‘great permission’ (Frank, 1995, p. 39) to finally release this experience. Richardson’s concept of the ‘collective story’, within which this chapter is embedded, can also be seen as a way of calling ‘I am not alone’ (1997, p. 33), which Hafsa portrays simply yet profoundly:

It helped them to talk about it and it helped me to hear their stories and to think that I’m not on my own.

It is Hafsa too, who sums up the need to move on and accept the death, when at the end of her interview she says simply:

I think everyone’s different and I think that’s the end of my story apart from just getting on with life...

**Conclusion**

I began this Chapter by describing my struggles to do justice to the stories that had been told to me, whilst facing inevitable choices about what I could realistically include within this
book. My solution sprang from Richardson’s notions of weaving a tapestry composed of ‘threads of many different hues’ (1997, p. 33), in order to form a ‘collective story’ (p. 33). Inspired by her ideas, I have conceptualised the five parental narratives within this chapter as threads weaving together with both my own experience and that of parents in the three chapters that now follow. The threads discussed in this chapter can still be distinguished very visibly within the following three accounts and should be kept in mind whilst reading them. In Chapter 8, I will weave them all together in my final discussion of the stories themselves and my experience of researching them. Additionally I will revisit the concepts of ‘collective story’ and the ‘great permission,’ which Frank connects to talking about death, and problematize these within the context of the ‘emotional politics’ engendered by media dissemination.

Chapter 5

Cathy

“There was no framework for society.”

Introduction

This Chapter and the two that follow build on the themes offered in Chapter 4 by offering three complete narratives and a subsequent analysis. Whilst they are all complete accounts of the interviews, I have removed the pauses and breaks, which in the original transcripts did not seem to enhance the text but rather distracted from it. Richardson describes such interruptions to the text as ‘like answering the doorbell in the middle of a lively conversation’ (1997, p. 167). I have therefore chosen to follow her example and have removed these. By so doing, I hope to capture the spirit of the accounts, which were all
offered in a fairly seamless and sometimes urgent manner. Following each of the three accounts, I will discuss the interpretation of the BNIM data analysis panels, together with my understandings of these.

Whilst I view these Chapters as forming part of the ‘collective’ as described in Chapter 4, by offering these three in their entirety, I hope to provide greater direct access, thereby helping to reduce the inescapable space between author and reader and to avoid ‘making statues’ of the material (Speedy, 2008, p.57). However, as I discussed in Chapter 3, the nature of the researcher role is that they alone have had personal contact with participants, and this informs all their later judgements and interpretations, no matter how rigorously they may try to avoid this (Clarke & Hoggett, 2009). My other main aim therefore, within this Chapter and the subsequent two, is to focus more closely on my personal understanding of their stories, formed both from our meetings and from working with the transcripts, combined with my own personal experience. Subsequently, I will explicate how these personal understandings were radically and sometimes shockingly challenged during the BNIM panel interpretation processes, in a manner which eventually led me to a much richer understanding of all those involved in the research, as well as the early dissemination, discussed in Chapter 8.

**Context**

Cathy is a young, white woman in her mid to late twenties. She is married and lives with her partner, Andy, who is the father of all four of her children, including twin boys. I also interviewed Andy separately from Cathy, and his narrative forms part of the analysis discussed in the preceding Chapter.

Cathy responded by email to a request for participants, which I had placed on a national charity website. The request described the research study and made brief reference to my own experience of sudden and unexpected child death.

Cathy initially requested the ‘Information Sheet for Participants’. Following this, again via email, she stated that she was willing to take part. We had an exchange of emails during which Cathy made some basic enquiries about my own experience, including Joe’s name and age. She referred to her own child and Joe collectively as ‘angels’, which initially discomforted me, although this altered during our meeting. Apart from this, Cathy’s
questions were straightforward and clearly part of her process in assessing whether she was safe with me as a researcher. This impression was supported by a telephone conversation I had with Cathy prior to meeting her. She told me that her experience of sudden and unexpected child death had left her very suspicious of professionals, and that she had only agreed to talk to me because she knew that I had ‘been through it’, thereby validating my decision to include my experience in the recruitment of participants.

Cathy’s interview concerns the death of her youngest child, Dylan, at eight weeks. Dylan was premature and had experienced breathing difficulties, which had necessitated a stay in the hospital’s special care baby unit after his birth. His death had taken place approximately ten months prior to the interview.

Cathy was keen to participate in the interview, which took place in her home. She arranged childcare so that we would not be disturbed. She presented as helpful, articulate and at times feisty, telling her story in an almost uninterrupted flow of dense speech and barely pausing for breath. The urgency with which she spoke gave me the impression that she had thought a great deal about what she wanted to say, and saw the interview as an opportunity to create some meaning from both Dylan’s death and from the experience that had followed.

Following the interview, I had limited contact with Andy and Cathy. Andy had been ill when I had visited, which Cathy had put down to nerves and ‘man flu’, but she later emailed me to say that he had been taken to hospital the following day with appendicitis.

Once the transcripts were complete, I sent them via email. However, they did not comment on these and I have had no further contact. The transcript was later converted into ‘future-blind chunks’ for presentation to the BNIM interpretation panel. This process was carried out as described in Chapter 3.

The panel for Cathy’s story consisted of three people, all white British females in their early fifties. Within this Chapter, they are identified by pseudonyms to assist confidentiality. Charlotte is a marketing company executive; Susan is a craftsperson and teacher; and Maggie, a Senior Social Work manager. Charlotte and Susan are friends of mine, whilst Maggie answered a generic advert aimed at recruiting interested participants. Charlotte and Susan both have children and Susan is also a grandmother. Maggie did not disclose this information, and so her parental status is unknown. The
Cathy’s story

Dylan had been ill when he was born but he had got better and come home and so we just expected him to be o.k.
The night before he died we went to bed about half past six or thereabouts. It’s hard to remember times accurately which I found difficult later when the police were asking all these questions about time, because normal life doesn’t work like that. In the morning I was feeding Dylan and we both fell asleep again, but then my husband, Andy came into wake me up because the other kids were shouting for me and I knew then that Dylan was dead. I think you just know these things. Andy thought I was joking when I said that Dylan was dead and then I don’t remember quite what happened. I remember Andy being on the phone and coming into me and I was saying “I’ve killed him”, because he was in bed with me. I was saying that it was all my fault all along, even when the police came because he was in bed with me and I was bed sharing.
Then the house swarmed with people, people with guns and so many other people. I have no idea who any of them were because I don’t remember them introducing themselves. They may have done but I don’t remember. I just felt that they were trying to separate me, from Andy and from Dylan.
They took Dylan off into an ambulance, and it was so different from when my other son was ill. He was premature as well, when he was born and he had some problems and we had to call an ambulance, but he was still alive thankfully so they treated me like his Mum. They were helpful and made sure I came in the ambulance and offered to sort out his brothers. They treated us like we were the parents of a sick child, but this time, with Dylan from the moment that the police came, it felt like Dylan was their child and we were...murderers. Perhaps that’s too strong a word to use but I just felt right from that moment that we weren’t innocent until proven guilty, we were guilty and we might be found out otherwise.
As a concept that shook me because I’ve never been in trouble with the police and it meant that so many parts of my life and the cornerstones of society that I believed in,
including the idea of justice, I no longer accept or believe in. When I read stories like mine
I’m now much more shaken because I felt when Dylan died that they thought we had
shaken him or that we’d done something. Obviously with sudden death there is a bit of
blood but I felt it was as if the blood was evidence of my shaking him.

At that point I also felt it was my fault and I told them this because Dylan was in bed with
me. I did think that then, although I don’t really think it now, because I chose to bed share
with all my children. I still think ultimately it is the best option and if I had another child I
would still bed share. I did a lot of research before deciding to do it too. I research all my
decisions because I’m a very controlled person and then all of a sudden, something like
this happens and you are left with no control over your children or anything.

Dylan went in the ambulance and we went in a separate ambulance and no one would tell
us anything or at least that was my overwhelming feeling. I was quite hysterical but
nevertheless in all other walks of life you get informed and, people talk to you, whereas
people here were sort of herding and patronizing me until we got to the hospital.

Once we reached the hospital there was a big difference, because the hospital treated me
like a mother and the police thought I was a murderer. It was very stark and very
noticeable because the police said we need to interview you, you need to come away. My
son was dying; they were working on him, they’d got a heartbeat back and my son’s was
dying and I believed he was actually dead and yet all they wanted to do was separate me
from him and from my husband to find out what had happened.

The way I see it is there is a line between police officers that are human and police
officers who maybe are hardened by what they’re seeing day in and day out. I realize that
they do see lots of children that are battered and that those battered children deserve a
policeman to stand up for them and bring them some justice and I accept that. However, I
don’t accept the way in which every family is seen to be the worst case scenario. When I
was actually interviewed, I was interviewed by a policeman called Jack and he was human
and he really listened and so talking to him I didn’t feel like I was being interrogated. He
told me he had to interview me and that he didn’t want to and that was honest. He also
mentioned briefly that he had a young son himself and that just made it more human. It
helped me realize that it was a job that he had to do and of course they have to do their
job it’s just the manner.

One of the biggest factors that I would like to see changed is national so I doubt it will
ever happen but it happened when I had just finished talking to the human policeman. He was helpful and understanding and just doing his job and I was happy with that but I then encountered some plain clothed detectives who gave me a card saying ‘Child Abuse Team.’ I had just left a policeman who basically wanted to know the story, because at the end of the day, Dylan had come to harm, even if we hadn’t harmed him. So straightaway I go to someone giving me a card that says ‘Child Abuse Team.’ It made me think “Shit…Do they now think I’m guilty?” There was a part of me that felt guilty anyway, as I had failed as a parent because my child was dying so I couldn’t fail any more than that. So to then have this feeling that they actually thought that, gave me this fear of being like that solicitor that went to prison and she didn’t do it…Sally Clark it was I think and so I knew that it happens and that all of a sudden it’s happening to me, although I knew I wasn’t guilty.

Before all this happened I knew that people in this country were innocent until proven guilty. Now I know it doesn’t work like that and I was guilty until proven innocent so therefore anything else that I held true and believed no longer existed. There was no framework for society at all. I felt I had been very naïve because suddenly the world I’d been brought up in had changed.

In the hospital I wasn’t dressed in much more than pyjamas and I had police staring and standing around me and everyone else in A & E was looking at me. Some of the police were even armed. Part of me just thought that I didn’t give a damn what they thought but there was another part of me that thought I was part of a circus and that everything was playing out like a hospital drama and there was no understanding that this was my life and that that this was our world. It was our child, our son, not just another case or not just another thing for someone else to gawp at. I wanted a bit more privacy and maybe a bit more respect and dignity for my son as well.

It felt like from the beginning that we were sidelined and we weren’t his parents because, we had very little choice or say in anything. There was one doctor who listened to me and he got Dylan’s heart beating.

I was pleased because Dylan was baptized and that meant a lot to me but really I wish he’d just died straightaway because I didn’t want a dead child alive. I didn’t want him to die, but you can’t die and then live and I knew that he was dead, straightaway and I accepted that he was dead. In some ways I found all the rest of it a bit perverse, that they
were trying to get a dead body going but then they’re doctors and that’s their job. I know they did their best and it was hard for them.

After that we were transferred between hospitals and the two hospitals treated us very differently. Perhaps doctors see the good in parents and the police see the bad in parents but I was very surprised by how different the hospitals were. In P hospital, we were parents and I felt like Dylan’s mother and then we were transferred by the police, which didn’t help, to S hospital. All of a sudden in S hospital was just another mother and Dylan was just another baby and possibly we were parents who might have harmed him. Obviously the police contacted the hospital first and they did seem to treat us differently.

We were just left in a room there at first. They took Dylan and I kept thinking that he’d only been alive for eight weeks and he was sort of living because his heart was going. So we were left in this room and no one came, although we were told someone would come and get us but no- one did. I would have gone and asked but I felt like they were looking at me as if I’d murdered him. And I felt I should just be doing as I was told because everything seemed to have snowballed, so if I was told to sit and wait then I would just sit and wait. I also thought Dylan may be dying and I didn’t want to stop them getting him settled. I was thinking that perhaps it was just taking them longer to get him settled but those two hours seemed so long. Normally I would have got up and demanded to see someone but I didn’t feel strong enough to do anything. Those were an extra two hours we could’ve been with Dylan and we were just left sitting in a room.

Once the doctor finally had to make the decision about his life support she made it like she had done it hundreds of times before. She probably had, but she just didn’t have the courtesy to see that I hadn’t done it hundreds of times before. If she’d come to me and said ‘I’m going to do tests A, B and C and test C especially is very hard for you to see so maybe you’d like to leave the room while I do this,’ then maybe I would’ve been more accepting. As it was she did not explain anything and it felt like she did this morning, noon and night so why should I be concerned about what was happening? They did these tests by switching Dylan’s life support off and back on again. To see him gasping like that and to not know what was happening was awful.

I am someone who likes to have facts, like the MMR, I researched the MMR before it happened and I knew which treatment I wanted because I believe in being proactive and having facts. I don’t go into things blindly but this time I just sort of sat whilst everything
was taken away from me. I wish that the doctor had been able to talk to me first and that doctors were taught to deal with bereaved parents. You lose all control and you are not who you are so I was really passive and to see Dylan and to not know if this was the moment he was going to die, was really hard.

When he did actually die it was really bad. They pulled the curtains round and I was thinking that perhaps I watch too much telly because there you’re taken off into a room and left in a bit of privacy. When Dylan died there was a baby next to us on a ventilator who we knew was better than Dylan because his arms and legs were moving. Dylan was just a body and then they turn him off and you know that you’re watching your son die. And there’s a separate self that’s watching you watching your son die and therefore that part of me was aware that there were nurses going about their business in the curtain next to me, walking past and then the other part of me is just watching him die and I thought this is his dignity. He is dying in a curtained hospital cubicle.

They took some photos just before Dylan died and I hope they’re etched on my mind as they deleted them because they don’t understand the whole data protection act. This makes me cross because I do, but they told us they would forward us these pictures. In them Dylan looked like a character from a children’s TV programme, the one who wears the little blue hat and a little blue suit. The clearest picture I have of him is when he was in the funeral home but they look a bit weird there. I would have liked to have the photos of him in the hospital because although he’s dead he’s alive dead; he’s not stuffed dead, like in the funeral parlour.

It was just another huge lack of respect that they deleted those photos. He was my son and they deleted him, a dead boy, a dead baby and those pictures can never be taken back. If I’d known he was going to die I’d have taken a camera with me but you don’t plan for these things. There is something callous that I still can’t quite forgive and it’s probably my biggest bugbear about the whole situation, that someone can just delete a dead baby without contemplating what they might be doing. Even worse is the idea that it might be data protection because that just makes me cross in so many walks of life.

I can see that the doctors in S hospital are doing a hard job and they’re fighting for the living and it must be pretty clear cut who’s going to die, so a part of me can accept that they have got to focus on the living, I know that money is tight.

Then there was the huge problem of our treatment in-between Dylan actually dying and
being cleared of what felt like accusations of murdering him. After he died there was this huge vacuum and we didn’t know where to go next. When Dylan was transferred between hospitals there was this big feeling that he might come back well and he might be O.K. but he didn’t and he died. So then what? You already know that they think you might be responsible for harming him and then when he died you’re obviously the next level up. But when he died there was, nothing but this vacuum.

On the Saturday, we spent the day in hospitals and I was interviewed on and off all day. Then the Sunday comes and there was just nothing, no one comes, no one rings, no one does anything. I kept wondering what I was meant to do and whether I was charged and a suspect. I came home on that Saturday night to Dylan’s home and his stuff and his bed and his blood on the floor and I knew the police had been there to take photographs because they think I may have murdered him, I just did not know where to go with it and we didn’t have anyone that we felt we could contact so we contacted the hospital. They were friendly but they just told us we had to speak to the coroner. So we rang the coroner but he told us he couldn’t talk to us because the police would not let him. After that we rang the police, specifically the person that had given us a card that said ‘Child Abuse Team’. By this time it was about 6 o’clock on the Sunday and I told them I could not wait any longer without knowing what was happening and they told me a home visit appointment had been made for 5 o’clock on Monday.

I remember thinking that I had three living children and that I’d been here with them while they had been organising and talking about Dylan and what’s going to happen to me and planning it all but none of them had even given me a call or told me that a meeting was arranged for 5 o’clock on the Monday. It was like we weren’t in the loop and that there were all these machines that were going on behind us.

If they’d made a ‘phone call on the Sunday, if they’d informed us it would have made such a difference. These things didn’t have to cost very much money because I know everything is limited resources and we can’t expect what we might want. But a ‘phone call just to check that you hadn’t hung yourself or just a call to check that you were there or whether you needed some sedatives. And also just to check that my other children were all right because there was part of me that thought ‘hang on a minute; you think I’ve killed my son, but you don’t actually care where my other children are.’ It all seemed a bit weird because if I had killed my son then someone needs to be looking after us or at least
asking. We were just there waiting so it would not have been that hard just to ring me up and talk to us about things. If they had done this the whole situation would’ve been easier.

When the meeting happened the police came with the doctor and you suddenly realize that they’re asking you questions about your past and I wasn’t sure if it was an interview or if they were trying to find things out. It was weird. It was a meeting but I didn’t know what kind of a meeting it was because there was a woman there who I knew was a Child Abuse team Officer and I felt unsure of the situation and of what they were trying to work out.

The police officer was called Deirdre Bailey and she made me feel all along like I’d hurt Dylan. Then again after that meeting on the Monday there was nothing and we never heard from her again. She never called to say ‘Oh by the way, yes, you were right, you didn’t hurt him.’ I felt it was rude and I was cross. I wanted and want to say ‘How dare you come into my house and accuse me of hurting my son and when you realize I’m telling the truth, you can’t even have the decency to ring me up and say actually “What happened is every parents’ worst nightmare and there’s nothing that you could’ve done.” Obviously she would have waited for the post mortem because by then they knew I hadn’t battered him.

I wanted to know what time Dylan was going to have the post mortem. I wanted to know what time it was going to start and I wanted to know what time it would finish. And that Tuesday was as bad in many ways as the day he died because I woke up knowing that morning he was going to be cut open and all I could think of and see was him being cut open. We were trying to get hold of the coroner to find out when it was going to happen so we ‘phoned and he said, "Yeah, yeah it should be tomorrow." This was on the Monday and then he rang up the next morning and told us it should be sometime that day. Andy and I said, ‘Look we need to know when it finishes, we need to know,’ but we didn’t hear anything and I was pulling my hair out because I just wanted to know that he was back together. I don’t have any religious beliefs about any of this but I just didn’t want my son on the scales in bits.

If you have an operation the doctors tell you when you’re going to come in. My father-in-law had a big back operation and they told him when he was going to go in and as soon as
he came out they rang us and said ‘He’s out, he’s well. He’s in recovery.’ With Dylan it was like we didn’t deserve it or was it because at that point they still thought we had battered him. Maybe until the post-mortem has been done then they still thought that.

It all felt inhumane, that was my biggest feeling. I’d lost my son and I needed some help getting through the formalities, some human decency, a bit of understanding, that it’s not another coroner case, it’s not another body. Dylan is my son and he has a name and he is loved and that funnily enough, as a mother, I’m not a big fan of him being chopped up and weighed. They told me that apparently I’m the only mother who has ever said she wanted to know exactly when the post-mortem ended but I don’t believe that. It’s probably just that I voiced it clearer because I got cross.

I felt there are ways of telling people things, like ringing time zones because when someone dies you are aware of every second and you cope by the minute, by the second, probably. You’re aware of every moment and although I knew they were doing their best, once they had said they were going to phone at 4 then I needed them to phone perhaps at 1 minute to, or at least at 4. Whereas quarter to 5 is three quarters of an hour that I’ve noticed every millisecond waiting for that ‘phone. You can’t agree times with the recently bereaved unless you’re going to meet them and if you say you’re going to ring in two weeks, and then you ring in two weeks and one day then that extra day is more than a day, it feels like a lifetime but there was no understanding of this.

I go on internet forums where other people have mentioned waiting for the coroner and for the police but I don’t think the authorities realize that we are waiting and that we are aware of what they said. It’s not that we can’t accept that things take longer, what I can’t accept is that they can’t be bothered to ring me to tell me that it’s going to take longer. A ‘phone call in the morning to say ‘I know you’re expecting it today, but it’s going to be tomorrow’ would’ve been fine. I still would’ve been a little bit cross but I was prepared for that and at least I wouldn’t have gone through the whole day waiting, waiting and you get to 5 to 5 and you just sort of think ‘Are they going to be going home?’ and you think they’re a coroner, so maybe not and you think ‘Do I ring, do I hassle?’ and you feel so separate from it all. You don’t want to hassle but you want to know and that’s what I want changed and I want people to realize that.

It’s about realizing its people. I did a report for my hospital Child Death Team, although initially no one even told me when the Death Review was. It was my health visitor who
realized that the Death Review was going to be on this date and she informed me but the officials, who I’d kept on at, asking them to keep me in the loop, didn’t realize that it would be important for me to know when the Death Review was. It’s hard for me to see how they could think that because they’re talking about my son and my life. How could they not think it was important?

I don’t know what they think grief is. I don’t know if they think that once you’re in the ground that’s it, because we did bury Dylan. When the post-mortem report came I was very glad that he had died of something because after the police make you feel guilty, there was a very big part of me that didn’t want him just to have died of nothing. To have him die of an illness, made it easier although they still said it was a sort of cot death because they can’t explain why it killed him so quickly. It was better than nothing because otherwise I think it would’ve been harder to deal with perhaps.

Dylan had a ‘Sensomat monitor’, so if he’d died when he’d been on that it would have alarmed. My previous son slept on his tummy and although I don’t believe in things like that really the Health Visitor said if he was sleeping on his tummy, I should have a monitor. So I still wonder if Dylan had been in his Moses basket, would he have died but probably he would’ve died anyway because he was just poorly.

My very biggest wish is for them to realize that we’re parents and I’m a mother and to treat us as if he’s our baby, our child and that I’m his mother. That’s what I came away with I guess, that Dylan wasn’t just a case, that he was a baby, a person and that he matters to a whole world. He’s not just a job that they’ve done a hundred, thousand times and I just sometimes think they need to realize that. I asked Deirdre Bailey the police officer, 'Look can you not treat us, can you not realize what’s happened to us, can you not see,' and she said, ‘Oh even if someone has smothered their baby, a lot of them still genuinely regret it and feel grief, so even those people should be treated with compassion.’ If that is the case then we can’t be treated like someone that has just picked someone else off the street and deliberately murdered them, because that’s what I felt like. Like just a criminal. Even if people have hurt their children, then they deserve to be treated as mothers that have snapped or whatever, but not as pre-meditated murderers because that’s different. It felt like the police were speaking in code aware of what they said in case it all got on the T.V.
I think it has all left me rather against any sort of professional because all along it felt like they increased your grief by not doing things as they are done in the real world. If you buy things off eBay; you get emails and phone calls all the time about where it’s coming and what’s happening.

We get surveys about stuff from the Council all the time too which I’m always doing because I enjoy them, but when Dylan died there was no one to hold accountable, there was no one to go to and say this is what’s happened and this is how I am feeling. The coroner and the police were above everything and there was nowhere else to go.

I know this person whose son was killed by a serving police officer who got away with everything when the case went to court. So who does a very grieving, slightly hysterical at times, mother go to because you want to feel that someone is watching out for you but no one’s watching and you don’t feel you have got anyone to complain to.

I did a report for the Child Death Panel so that I could feel there was something positive going on but even doing something like that depends what kind of background you’ve come from. You have to be quite confident about compiling reports that are going to be seen by professionals. I did that whilst I was at university so it doesn’t daunt me, but I know other people that said they’d got loads to say but wouldn’t know where to begin. I tried to do it as unemotionally as possible and I tried to be just clear. On forums I told people I was going to do this report and they warned me to be careful and that they may just say that I was talking rubbish. I think that fear is one of the many reasons that people don’t complain about things like this.

‘An aggressive story’: Cathy’s interpretive panel.

In this discussion, I will focus primarily on the interpretations of the BNIM panel, setting these within a psychosocial context, to demonstrate how these differed radically from my own. However, in order to set the scene, I will initially explain my own responses to Cathy and my interpretations of her story, as well as connecting these to the narrative threads previously discussed in Chapter 4.

Throughout the methodological processes described in Chapter 3, I re-visited Cathy’s narrative repeatedly. Each time I remained struck by the force of her telling, which had also
impacted on me at the time of our meeting. As Hollway and Jefferson observe, ‘first impressions contain much that eludes our conscious mind’ (2000, p. 46), and I had experienced Cathy as being helpful and open. Whilst she was also obviously angry, I could see both the pain of her narrative as well as her determination to tell it.

This determination rendered the interview itself as part of her attempt to ‘change things,’ as she describes. Both the attempt to make meaning implicit in this, together with other sections of Cathy’s narrative, pick up threads present in the other stories and in my own experience of Joe’s death. This is particularly significant in view of the ‘unconscious dynamics’ (Hollway & Jefferson, 2000) that I now see were present. Like me on the morning of Joe’s death (see Chapter 1), Cathy was angry and yet struggling, as I myself was, to ‘change things’ and to help others. From working with her transcripts and the various interpretations over time, I now see that I identified with Cathy by transferring some of my own feelings onto her, whilst she in turn returned this by identifying with me as ‘someone who had been through it’ (Hollway & Jefferson, 2000).

These complex and initially unconscious identifications left me very protective of Cathy, who in so many ways reminded me of myself. I understood her story as primarily a ‘cry for witness’ (Frank, 1995, p. 137) and I wanted to assist her with finding a voice that would succeed in ‘changing things,’ as she described. Hoggett argues that ‘finding your voice’ is for silenced and marginalised groups a task that is linked to audience and therefore not just a matter of being heard, but also of helping this audience ‘learn to hear in new ways’ (2000, p. 115). I thought of Cathy’s story with its powerful and sometimes hard to hear descriptions, such as those of Dylan’s death ‘and there’s a separate self that’s watching you watching your son die’, as perfectly fitted for this purpose. It was this and my own unconscious relationship to her that I brought with me to the BNIM panel.

With the benefit of hindsight, I can see now that I expected the panel to share my own perceptions of Cathy and, as I explained in Chapter 3, I was not sufficiently prepared for the powerful feelings that would emerge in the panels, nor for the ‘not uncommon… differences of opinion’, which ‘occur amongst research teams particularly where data interpretation is involved’ (Morgenroth, 2010, p. 268). I therefore want to focus on these ‘differences of opinion’ and particularly on the ‘thread’ of anger, which became so pre-eminent for the BNIM interpretation panel. The challenge of understanding how their analysis differed so brutally from my own has deepened and extended my awareness, both of the stories
themselves and of the factors which may influence professionals involved with sudden and unexpected child death. This is further explored in Chapter 8 in the context of the emotional politics evoked by media dissemination of my own story.

The panel began the process by speculating on how Cathy would ‘manage the interview’, whether she had rehearsed it and if she would be able to ‘talk without crying’, showing from an early stage clear expectations as to how a bereaved mother might behave. As the process progressed, the panel members became discomforted by the narrative itself, but most significantly by Cathy’s style of ‘telling’. Whilst I both identified with her experience and felt protective towards her, the panel rapidly became critical of her reporting style, which they termed as ‘like a police drama’ and only describing ‘outrage’. They were particularly uncomfortable with what they characterised as Cathy’s ‘angry’ tone. I had been aware of this, and had identified with it from personal experience on the day of Joe’s death. Anger is also an emotion shared by many of the participants discussed in Chapter 4, and I therefore viewed Cathy’s anger as a driving force and something that had helped to carry her through the obvious alienation she so forcefully describes. The radically different opinions of Cathy, which the panel was already beginning to form, proved a challenge to my own. At points in the narrative where I had felt outrage like that experienced by Cathy herself, for example at the arrival of ‘people with guns’, the panel simply dismissed this as ‘there must have been a reason for the guns’. Instead, they focused on Cathy’s ‘mess’ of feeling and her intertwining of her own grief with the police response, of which they were sharply critical.

From their initial assessment of Cathy, the panel rapidly began to form the hypothesis that she may actually have killed Dylan, possibly by ‘shaking’ him, a fear she herself expresses, whilst Maggie repeatedly postulated that the family may already be ‘known’ to the police and social services, thus providing a rationale for the guns. In the middle of the narrative, as Cathy describes the scene in the first hospital with Dylan on life support, it seemed to me as facilitator that the panel reached a crisis in their choice of how to interpret this story. They described ‘not knowing how to make sense of the events’ and asked ‘Do we question the family?’ or ‘Do we question the police?’ Whilst they feel ‘cross’ that the police take Cathy away for questioning although Dylan is still alive, an event which initially provoked my own feelings of outrage, the panel rapidly question whether this actually happened, suggesting that Cathy has misremembered it. From this ‘crisis point’, the panel’s judgment of Cathy concretises and she is made a ‘statue’ (Speedy, 2008, p. 57). Returning to their initial
consideration of how Cathy would ‘get through the interview without crying’, the panel now
concurs that ‘this is not the story they expected to hear’, that it is an ‘aggressive story’, and
that therefore the telling of it is a ‘surprise’. Maggie in particular becomes increasingly
angry with Cathy, stating that she is ‘really struggling with ‘this belligerent woman’ who
makes her very ‘angry’. The two other panel members, whilst more sympathetic than
Maggie, agree that Cathy has a ‘strange way of articulating her needs’.
Maggie remains visibly enraged by Cathy throughout the remainder of the process,
demonstrating this by remarking both that Cathy ‘does not behave as a grieving mother
should’ and that ‘she has choice in the way that [she] reports her grief’. For Maggie, Cathy
has made the wrong choice.
Although the panel recognises that Cathy is ‘trying to show she is ok’, they do not view this,
as I had in my interpretive reading, as a means of holding back the tears and trying to
achieve some meaning by ‘making things better’, as she herself suggests. Instead, they are
sharply critical of her ‘lack of emotion’ and remain ‘angry and troubled’ by this narrative,
which they reiterate was not what they had been ‘expecting to hear’.
The panel members ultimately summarise their thoughts, concluding that this was a
‘rehearsed interview’ and describing Cathy as ‘never off the stage’. They dislike what they
view as her ‘control’ and her lack of emotion’, and describe her as ‘not altruistic’.

‘The story I expected to hear’: exploring meaning in Cathy’s panel

This panel for Cathy’s story was the first that I had convened and I was therefore still
influenced by the BNIM Guide’s description of panels as ‘both insightful and often funny’
(Wengraf, 2011, p. 104). Whilst eventually the panel did generate insights, it was a while
before I was able to gain from these, as initially I was shocked by the panel’s judgments
about Cathy, which produced my own complicated emotions.
During the process and immediately afterwards, I could see that the panel members, and
particularly Maggie, were enacting ‘feelings of shock surprise and confusion’ (Hollway &
Froggett, 2011, p. 2). However, as facilitator, interviewer and a parent with an experience
similar to Cathy’s, I found that my own ‘shock, surprise and confusion’ at the panels
characterisation of her, initially mirrored their own. I did not recognise Cathy as they
depicted her, nor what I then viewed as their failure to identify vital parts of Cathy’s
narrative. Following the panel process, as I worked with the material, I found myself initially experiencing feelings of guilt at involving people, two of whom were friends, in a process that had upset them. One of them, Susan, later reported feeling ‘chronically polluted’ by the process of ‘picking over’ Cathy’s words, which increased my own sense of guilt. However, this guilt was later replaced by my own feelings of anger towards the panel members, whose understanding of Cathy differed so radically from my own.

I felt that the panel had displaced the emotional force of Cathy’s account, letting themselves be sidetracked by her lack of tears, which they distinguished as her drive to present as ‘unemotional as possible.’ In my understanding, far from seeming ‘belligerent’ or ‘lacking in emotion’, Cathy demonstrates vividly her own vulnerability and lack of agency.

In her exploration of conflict within data interpretation panels, Morgenroth (2010, p. 277) suggests that the ‘emotional and bodily reactions experienced by data interpretation panels can be said to provide valuable insights into the research data’ and the ‘data’s latent meaning’. Gradually, through the process of supervision and writing, I began to see much further into the ‘latent meaning’, both of the panel’s responses and of my own, and these insights were to prove fundamental to my entire research project.

Returning to the concept of ‘splitting’, which I have discussed in previous Chapters, Cathy’s story represents an eruption of disturbing material, from a ‘comparatively sequestered domain’ into the ‘public arena’ (Cooper & Lousada, 2005, p. 10). Thus, as the panel say themselves, it is not the ‘story they expected to hear’ and they felt ‘polluted’ by it. Cathy becomes a ‘bad object’ – she is not ‘behaving as a grieving mother should’ – and she is making the panel face difficult and almost unbearable emotions. By investing the ‘bad’ in her, they contain the experience and make it bearable once more.

Hollway and Froggett (2011, p. 5) provide further helpful explication of this form of ‘splitting’ in their work on ‘scenic understanding’. Drawing on the work of Lorenzor, a German psychoanalyst and social theorist, they suggest that when accounts or experiences are understood as ‘surprises’, as in the panel’s statement that this is not ‘the story they expected to hear’, a ‘disjunction’ in world view occurs, which can produce a profound personal sense of ‘irritation and ‘lack of fit’.

For the panel, this ‘lack of fit’ produces a split, evidenced not just by their ‘irritation’, but also by their overt anger at certain points within the process. Maggie in particular is almost furious with Cathy and condemns the ‘choices’ she has made, which for Maggie are not as
they ‘should’ be. Her notion of how a ‘grieving mother’ should behave recalls both the popular depiction of bereaved parents as ‘hopeless’ together with the portrayal of the mother in the DVD ‘Why Jason Died’ (see Chapter 2). The actress who plays the role is thin, vulnerable and barely speaks, she certainly never raises her voice, thus setting a model for how ‘grieving mothers’ ‘should behave’, which renders Cathy’s powerful account almost aberrant. Additionally, Cathy’s own battle with meaninglessness, evidenced by statements such as ‘there was no framework for society’, provides an ever present menace, bringing the account disturbingly close at times to the chaos narratives described by Frank (1995). The ‘lack of fit’ produced by Cathy’s vision of a world where there is ‘no framework’ for society recalls the Kennedy Report’s warnings of ‘losing our humanity and our claims at living in a civilized society’ (2004, p. 15), which therefore understandably causes the panel to project this onto Cathy herself, thus preserving their own ‘capacity for containment’ (Cooper & Lousada, 2005, p. 11).

However, as I analysed the material further, I recognised that my ‘irritation’ with the panel members echoed their anger with Cathy, and that consequently I was mirroring their own ‘splitting.’ As I have discussed, I identified with Cathy, whose anger resonated with my own on the morning of Joe’s death. I also recognised much of the detail in her narrative, both from my own experience and from other stories I had heard. Consequently, I read Cathy’s lack of an overt display of grief as an attempt to be taken seriously and not dismissed as a hysterical mother, whilst also defending herself against the threat of chaos, which is ever present in her narrative. Her anger too did not surprise me as it seemed to be consistent with the situation she found herself in and with her powerful drive to produce meaning from Dylan’s death. Thus, where I had ‘a fit’ for the situation, the panel had none. However, initially I blamed them, just as they had blamed Cathy, being unable to tolerate their inability to understand her, which in turn presented as an inability to understand the part of myself that I had invested in Cathy.

Gradually, I also realised that the process itself may act as ‘a provocation’, leading to a potential ‘disjuncture’ (Hollway & Froggett, 2011, p. 5), which may thus have caused strong reactions. The panel members were offered the transcript chunks’ in a ‘future blind’ way (see Chapter 2), and therefore as facilitator I was the only person present who knew what was coming next, which vested in me an uncomfortable power imbalance, together with a sense of tantalising the panel members as I revealed the transcript chunks. Although this
was an unintentional byproduct of the process, there are possible connections between the panel’s outrage as they tried to restore their sense of the world, and Cathy’s own outrage on the day of Dylan’s death. As the professionals ‘swarm’ around her house, undermining her own agency, Cathy turns to them for containment but finds they are mostly unable to offer this. Like the panel members, the professionals are depicted as struggling with an event they ‘did not expect’, which is unfolding in a ‘future blind’ way and where they too do not know ‘who to question.’ Where Maggie becomes outraged, the professionals defend themselves behind guns and the ritualised procedures described in Chapter 2, including interviewing Cathy before Dylan had even died. Cottle (2002, p. 541) describes this powerfully in his discussion of the potential impact of traumatic reports and events:

To reject the gaze or words of another and thereby engage in the act of disaffirmation is an endeavor on my part to preserve the nature of the perception and knowledge I have of the world and myself. It is an attempt to solidify my identity.

For professionals, arriving at the scene of a sudden and unexpected child death, expected to balance care and support with thorough yet sensitive investigation, a mother who responds, like Cathy, outside of their own unconscious expectations may provoke them to feelings of hostility or anger in the same way that the panel was provoked by Cathy, and I was in turn was provoked by the panel. The ‘rage at injustice’ (RCPath & RCPCH, 2004, p. 15) referred to within the Kennedy Report may rapidly turn to rage against the parents or simply at ‘the lack of fit’, which the experience itself evokes.

Conclusion

In this Chapter, I have presented Cathy’s story in its entirety as an attempt to allow the reader to make their own ‘pathways through the material’ (Morgan, 2000 cited in Speedy, 2008, p. 185). The panel process was fully described, in order to provide context for a further discussion of the ‘lack of fit’ between my own view of Cathy and that which the panel formed. In the final section, I explored the panel’s standpoint that this was not the ‘story they expected to hear’, locating this within the concepts of ‘splitting’ and ‘defence mechanisms’ discussed in previous Chapters. Hollway’s concept of achieving ‘objectivity through ‘subjectivity’ (2009) was then illustrated via my struggles to understand the panel’s
reactions, which initially made me feel guilty and subsequently angry, before reaching an understanding. Finally, I compared the reactions of panel members, who are struggling to control what they are hearing and the professionals involved in sudden and unexpected child deaths, who may also be defending themselves. These similarities will be further investigated in the next two Chapters, which, in contrast to Cathy’s ‘angry’ narrative, offer different forms of meaning-making and corresponding difficulties within the panel process.
Chapter 6

Julia

‘We were so blessed.’

Introduction

In this Chapter I focus on Julia, whose story I also offer in its entirety, following the same format that I used in Chapter 5. I chose Julia’s story as one of the three complete narratives, partly because it picks up many of the threads already discussed. However, it does so in a way that is not immediately apparent, and which therefore caused me to dismiss it initially. As the panel in the previous Chapter found with Cathy’s narrative, Julia’s was not ‘the story I expected to hear’ and it was only through the processes of transcription and interpretation that I began to recognize its latent power, particularly in terms of my own unconscious processes. Whilst it is a radically different account from Cathy’s, recounted in a similarly different style, the panel also responded to Julia’s story with ‘irritation’ (Hollway & Froggett, 2010, p. 5), and their reactions, alongside my own, cast further light on the concept of what is ‘thinkable’ when responding to sudden and unexpected child death.

Context

Julia is a professional woman in her early fifties. She lives with her husband, Steve, and they have three sons who are now in early adulthood.

Julia contacted me via a mutual friend who had mentioned my research study to her. Our initial contact was by email, followed by a telephone conversation and the relevant processes agreed within my ethical consent.

Julia’s story concerns the death of her first child ‘Sophie’, who died during her first weeks of life, more than 20 years prior to the interview. Julia was keen to be helpful and to participate in the study, although she expressed anxiety that the great length of time since the death may render her story less then valuable. Whilst she was very willing to participate...
in the interviews, Julia was not interested in seeing the transcripts. Her major concern was that the story would be ‘useful’ in some manner.

The interview took place in her home and lasted for well over an hour. As with all the interviews, the narrative was prompted by the initial SQUIN (see Chapter 3). Unsurprisingly perhaps, given the length of time since the death, Julia had clearly told the story before and it is notable for its ‘scenic’ sense (Hollway & Froggett, 2011, p. 1), derived from the location of the death, which features powerfully within the narrative.

During the interview, there were occasional interruptions from a son still living at home, as well as a lengthy tea break in the middle during which Julia chatted openly. She presented as a highly gregarious and hospitable person at the hub of her family.

After the interview, I had some brief email contact with Julia once the transcripts were complete, and also after my appearance on a BBC radio programme. Julia admires the presenter and was keen to hear about my experience. We therefore exchanged emails. Following this, we have had no further contact.

The transcript was later sectioned into ‘future-blind chunks’ for presentation to the BNIM interpretive panel. The panel for Julia’s story consisted of three people, all white British and friends of mine. Their names have been changed, as in the previous Chapter, to ensure confidentiality. Marcus is in his fifties and is now a specialist social worker, having previously worked in child protection, Belinda is an academic in her forties and Esther is a graphic designer and craftswoman, also in her forties. All three are parents.

**Julia’s story**

Sophie was born in spring 1984 and she was beautiful. She was our first child and so it was a lovely special moment. There had been no problems and she had come home as normal.

When she was 6 to 8 weeks old we went on holiday, up to a remote island where we’ve always gone on holiday since I was a child. We were so excited because we wanted to introduce her to friends and we went via my husband Steve’s parents and his grandmother who was very, very old and in a home. She was very excited to see her great grandchild as my husband hasn’t got any siblings, so this was all very exciting. We took Sophie to see my sister and my nephew and nieces as well and they were all pleased because it was the first next cousin. It was all lovely.
We got to the island after a good journey and because I’d been going to this place since I was very young, we knew everybody so it was like going home. Everyone was very excited that this new little baby had come and up and I hadn’t seen it before, but they crossed her hand with a coin.

We were with friends of ours who’d got a little girl called Helena who was 9 months older than Sophie. I had been at school with Gill, the Mum and we’d been bridesmaids together. So they were very good friends and we were having a lovely time.

Half way through the week, I think it was either a Monday or a Tuesday, after we’d had a nice day I fed Sophie and put her to bed as normal. We had Sophie’s crib and this and that because we didn’t want anything to be different from home as she was just getting used to that routine. I think every parent with their first child takes everything because you don’t want to disturb the routine and you still have room in the car. So it wasn’t as if she was sleeping in anything different.

I put her to bed about 8 o’clock and Helena had gone to bed too so Gill and Rick and Steve and I were enjoying the evening. About 11 I went up to feed Sophie like I always did and I thought, ‘Oh my god, she’s stiff.’ I can just remember saying to Steve that he must come and that ‘I think Sophie’s dead, I can’t pick her up.” Steve picked her up and said she was dead and should he try and resuscitate her. I can remember we didn’t know what to do and so we were going, “Yes, no, yes,” because we didn’t know how long she’d been dead for and he did try to resuscitate her because there were no phones there, it was completely isolated.

The house is so amazing, I just love the place. On the hill there’s some people that I’ve known forever, Alison and Peter, the local fisherman, who are just lovely. So Gill said, “I’ll go and get Alison to call the doctor,” and she rushed up the hill and Alison called the doctor.

We were just so blessed, I can’t tell you how blessed we were because a doctor came and confirmed what we already knew that Sophie was dead and that she was probably a victim of cot death. The doctor stayed with us and she was just lovely. She was an island doctor – youngish - who said she had young children of her own. She told us that because of the circumstances she would have to call the police. And this is another reason that we were so blessed because the police on the island are the local farmer and the local fireman and the ambulance man.

In those days the special policeman was Reggie, who I’d known forever and seen him in lots
of different outfits, in his kilt and other things. So about half an hour or perhaps an hour later Reggie turned up in his police uniform which was like the dressing up box of a child. He was the most wonderful gorgeous man and I knew he’d had some tragic experiences in his life, because on island life they all have. So Reggie came in and I can remember, he just threw his arms around me and said, “We’re all here together.” That was all he said but he gave me the biggest hug and I said, “Reggie my boobs are killing me” because of the milk. Everyone was laughing and Steve was still holding Sophie and she was wrapped in this beautiful hand-made blanket that an old lady had knitted. It was a patchwork one that I had wanted and couldn’t make myself. Sophie looked so beautiful and serene, just perfect really.

We just had to go through and give a statement to Reggie but it just felt like telling somebody with real empathy what had happened. The doctor was wonderful and told us she would take Sophie back to her house because the surgery was just like a house. Then she explained that Sophie would have to go for a post-mortem, which would be on the mainland and asked if we were ok with that. We just felt that she had to do what she had to do but she told us we could visit Sophie the next day before she was taken off the island.

She had such a wonderful balance of empathy for this sudden death and also such empathy with me and my physical needs of being a new first time Mum who was breast feeding. She also had such empathy for our friends who had their own small baby, just 9 months old and for the anxiety that they might be feeling. The doctor and Reggie the policeman took all of us in and nurtured the whole group and of course me and Steve as well. They were phenomenal, absolutely phenomenal and they gave us that time and peace, so we were very blessed.

The doctor had brought some vitamin B and told me I had to take several that day to help with the recovery of my breast feeding. I was so uncomfortable and she had thought of that and so we were really blessed.

Steve managed to phone my Mum and Dad and also my sister and they were all devastated. A long while after Sophie died we discovered that my husband had siblings on either side of him, who had been stillborn because of the Rhesus factor, but his parents had never shared this with him and he always thought he was an only one. He had always been wary of having children although he did want them but from the moment Sophie was born she was such a Daddy’s girl and the bond was huge between them from that first moment.
On the night she died we went to bed in my very favourite place and although we were in shock because we’d been so cherished in that horrendous 2 or 3 hours I can remember saying to Steve, “Gosh, we’re just so lucky. We’ve had what some people never have. We’ve had the most beautiful daughter whose never done anything wrong, we’ve never had to tell her off, we’ve just been able to love her really and explore the joy of parenthood with her. She was a real blessing.” I remember Steve saying that he hoped we would have more children but if we couldn’t we would always have the lovely daughter that some people never have and can’t have. I can also remember him saying that if we did have any others we would never forget that Sophie’s our eldest and any other children would always know. He is such a quiet and reserved man but he wanted to ensure that people always knew about Sophie and that we would always tell people about her and that they mustn’t be embarrassed. He saw it as our mission.

The next day, two extraordinary things happened. The first was that there was a ferry strike which meant that they couldn’t get Sophie off the island and also that my Dad who had been up all night, couldn’t get on the Island. So suddenly that day a helicopter arrived on a nearby patch of grass and all of a sudden I have my Mum, Dad and sister. It was such a parental thing to do. My Dad just said, “I’m your father, I needed to be here for you, I needed to be here,” and I have always remembered it. I never found out how much it had cost him. I was very close to my father and although I have two brothers and a sister, my Dad was special, everyone says so and we were very close. What he did that day was incredible, because I would never have asked him to come. We were all right but we were even better once he had come.

The other good thing about Sophie not being able to leave the island was that she had to wait for the lifeboat to be off duty and to come and pick her up... This all meant we could go to the doctor’s house, which was lovely and there was Sophie in her crib, wrapped up in her blanket, looking absolutely rested and serene. My Mum and Dad and my sister and Steve and I all held her and then, and then the doctor told us that we were lucky because the lifeboat was coming straight into the groyne by her house and so we didn’t have to go in the ambulance across the island to get the ferry. So again it was the quality of local life which was the blessing and this is why we felt so blessed. When the lifeboat came we all took Sophie on board and the lifeboat men were crofters, so I felt so lucky to be able to hand her over to people who didn’t do this day in and day out and who took it so seriously.
It was a really emotive, memorable moment to be witnessing. The lifeboat men told me that they would look after her until they handed her over to the ambulance people, who were going to drive the ambulance on the long journey on the mainland.

After that we weren’t allowed to leave the island until the results of the post-mortem, which was fine. Sophie’s death had to be registered on the island, which was also a blessing because it gave us time to do things to remember her by in a place which was so unique and special. Our dear friends Gill and Rick stayed as well because they loved the place too and were in no rush to leave. My Mum and Dad and my sister also stayed and the island people were wonderful. One of them, a fisherman, told us that he didn’t know what to say but he asked Steve to go lobster fishing with him because he knew Steve loved this.

Once we had registered Sophie’s death we had to come home and although it wasn’t planned Sophie was brought back on the same flight as my Mum and Dad. When I got back home my Mum told me that the plane had circled the place where I grew up for several minutes before they were given permission to land and things like that were just incredible.

As soon as we got back here it was like entering another world really. In some ways we were still lucky because it was just about at the end of having a family GP. It’s all different now because I don’t even know who my GP is. Our old family GP was good and he came round and told me that he didn’t know what to say but that he was really sorry. He knew me well enough to know that I would see him if I needed to but apart from that he really didn’t know what to say, which I remember thinking was open and honest.

After that we had some odd people who came round. I don’t know where they came from but they were most odd and they said they were bereavement befrienders. They told me that this should not have happened to me and asked me what Steve and I worked at. I told them we were both teachers and they said as we were both professionals, it really shouldn’t have happened to us. I also remember them asking if we smoked and we didn’t, so they said it should DEFINITELY not have happened to us. When they learned we were home owners they emphasised that cot death should simply not happen to professional, non-smokers, who own their own home and for the first time I was really angry.

I told them not to tell me that it shouldn’t have happened because it had happened and we had been really blessed to have had the most beautiful, stunning daughter that anyone in the whole world could have. It had happened and it was proof that it could happen, so I
asked them to let us enjoy what we had. Then they asked me if I would like to make a regular appointment to talk about the bereavement process, to which I said, “No thank you.”

We were absolutely fine by that time and oddly it was only a few weeks later that I became pregnant again. Steve and I had agreed that if we had another baby, we would be happy but not to get fixated on it. When I became pregnant again, I did not see my own GP but a random doctor who told me it was extraordinary because I’d had a birth, a death and now I was pregnant again. I remember thanking him for confirming the pregnancy although I wasn’t sure he had handled it in the best way. After that I made sure I saw my own GP.

We were really well supported by the vicar that we’d known for ages who was just phenomenal. We went to church the day we got back and he said, “Gosh, how wonderful to have lived a life of love, she’s given love and received love.”

He told me and Steve this story about a man of 85 he had just buried. He was a good man, he said, but he had known things other than love, that had made his life perhaps rich, but also sad. Sophie had never known sadness or suffering and we thought how nice it was to look at it that way. Then we had to think about the funeral and there were certain things we wanted and that Steve said we would do. The funeral service was very important but it didn’t really feel like a funeral but more a service of thanksgiving. I was young then and I hadn’t been to many funerals other than grandparents. I just wanted people to share in the celebration of Sophie’s life and that’s what we did. We made it a service of celebration. The vicar helped make it that too and that was really important to all our friends. I couldn’t believe how many people came but there were so many friends and colleagues from work and I thought that was great because they’re getting a sense of how important it is to do that. Steve was adamant that he was carrying Sophie into church because he had carried her around during her 8 weeks of life and he did not want her carried by an undertaker. I will always remember him walking just as he had held this little thing in life, even in a coffin.

The little things were really important to Steve. As Sophie was a baby they assumed we would want a white coffin but we didn’t. Steve said no because we wanted to make our mark on it and I think we did. Things like that were really special. I think we were able to do all of this because of the nurture that we’d had.

I had taken maternity leave with Sophie which in those days was unusual. My plan had always been to go back to work and I know a lot of people really disapproved. The Head was
clear with me that it was my right to return as soon or as late as you wanted and I was really
touched by that because she was trying to show me there was no pressure. So I knew
whatever I decided would be respected and I can remember starting back much earlier than
expected. I will always remember one of the young people saying to me, “We’re so sad
about Sophie, so sad but then we’re so glad because it means that you’ve come back to us
sooner.” I still remember her name, Claire Richardson she was called and she was such a
naughty girl, so it was so touching.
I remember thinking at the time that out of the mouths of children comes the quality
conversation because she could acknowledge it. It was so important that she could
acknowledge it and say it to me and I knew she could only do that because I had such a very
positive relationship with her.
Sophie’s life has touched us like nothing else really. Her three brothers are all very clear that
they’ve got an older sister and they’re very proud of that older sister who they never knew.
A number of times at school, when you have to write about your family or whatever the
teachers would ask us if they boys are all right because they didn’t realise they had lost a
sister. We would always say that the boys would not have mentioned it if they weren’t all
right about it and people knowing about it. The boys have always talked about Sophie and
they still do. They say, “She’s the best sister in the world, she’s the sister around us but she
doesn’t need make up or clothes and she doesn’t fill up the bathroom with stuff.” So we
laugh about it and sometimes we talk about family dynamics. The boys realise that if Sophie
had survived we would all be different people and we have long conversations about this.
Sophie’s eldest brother my next one, Tom was born on her birthday, a year, exactly a year
after her.
So that was always strange. When he was born no one offered me any support or anything
like checking I was all right to take home a baby home after I had experienced a cot death.
We had no support at all and nobody would acknowledge it. Of course we acknowledged it
and because of the way we were and the beliefs we had we were always very clear that we
would treat this baby in exactly the same way that we were going to bring Sophie up.
So if it cried we would let it cry and it wasn’t going to sleep next to us as Sophie wasn’t going
to sleep next to us. We had to support each other hugely in making sure of this but we
didn’t need a parent’s book to tell us how to bring up your children in the first eight weeks
because Sophie had written it for us. I know that sounds arrogant, but that’s how we
handled it. Other than that nobody ever asked or offered us anything other than my befriending friends who couldn’t befriend us!

No one ever openly talked about the chances of it happening again but then it happened to my cousin. Her baby was six years younger than Sophie, the same birth weight and the same gender. It was just extraordinary and even then there was nobody who took an interest even when we had subsequent children. My youngest was only three months after my cousin’s daughter died and people knew this but nobody was interested. Of course we didn’t want them to be interested, but we were just surprised that nobody talked to us about the likelihood of it happening again and what the chances were. When it happened with my cousin’s child I had this fear of there being a second time around and something happening to my youngest two. It was hard to shake the fear...

One of my boys was born in the winter with a heart problem, the sort of thing babies can have I can remember wanting to stamp my foot and say what was all the fuss about but on the other hand to say we had experienced a cot death and could they just help us. I hated the fuss but I can be stubborn and I remember wondering if I was being stubborn or being strong or simply going into denial. I wondered whether I should be noticing and watching everything but I can remember my Dad talking to me about it. My Dad sometimes took the boys to the Doctors when they were young so it was my Dad and my Mum who were often making that decision.

Shortly after my youngest boy was born, cot death became quite high profile. It certainly wasn’t so when Sophie died so around that time people would ask me if I was ok and I was fine because these things happen.

Sophie has had such an impact on my life because you know statistics are pointless and that awful befriender woman who told us that statistically it should never have happened to us was meaningless because what happens happens.

I think it’s why I can’t get excited about children’s statistical achievement in school now. Whether they 5A stars, 50% or 40% because in the end it’s about people and individuals. I do wonder sometimes about Sophie sleeping on her front but then Ben slept on his front too. I can’t remember when we were supposed to put them on their backs. Who knows?

All I do know is that I wish that everybody could experience the kind of love and real support, caring and quality of time that we had on the island when Sophie died. It was
quality time not based on results or outcomes or somebody only being allowed to be with us for ten minutes. I have a friend who was a district nurse and she gave it up because she was told not to spend too much time with vulnerable people. She really listened to people so she was told she shouldn’t have a cup of tea with a person she was injecting with insulin for example. She knew she provided the only human contact that person may have had and that human contact is as important as the medical intervention for quality of life. Steve and I had that quality of support because in the situation we found ourselves in, we had people who knew very genuinely how to be empathetic.

We were with people who knew. We still go there, to the island and we still look at the lifeboat. They have all the outings on a board and it goes right back to the lifeboat that took Sophie off the island. It says on this date a body was brought from the island to the mainland and things like that are so important. They are acknowledgement that it was real work and they did it in such an empathetic way.

That’s my story really.

‘A beautiful story’: Julia’s interpretive panel

Although I had liked Julia and enjoyed our meeting, I found myself initially becoming very vexed by her story, which on further reflection I understood as indicative of the ‘lack of fit’ (Hollway & Froggett, 2011, p. 5), which was discussed in the previous Chapter. Whilst Cathy’s story did not ‘surprise’ me, Julia’s insistence on ‘being blessed’ did, leading to my initial dismissal of the story as unsuitable for presentation to an interpretive panel. Gradually, and somewhat uncomfortably, however, I began to see that I was mirroring the very processes that I was also critiquing in others. I had ‘split’ Julia’s story from the ‘collective’, and my irritation came from defending myself from her ‘otherness’ (Cooper & Lousada, 2005, p. 86). Whilst I had wanted stories that said ‘you are not alone’, Julia told a different story, one in which she was ‘blessed’ and contained, and thus I initially did as Cooper and Lousada describe and stripped her of her citizenship and right to be included as worthwhile (2005, p. 86).

In this, I also recognised ‘counter-transferences’ (Morgenroth, 2010, p. 267) similar to those within the panel response to Cathy’s story, and this growing and uncomfortable realisation
helped me realise that, far from excluding Julia’s story from panel interpretation, I needed the assistance that a panel could provide. As Ogden (2009 cited in Hollway & Froggett, 2011, p.281) suggests, it ‘requires two minds to think a person’s most disturbing thoughts’, and thus, far from being unsuitable for panel interpretation, I understood that it was actually vital for me to introduce another set of voices.

In common with all the other narratives, Julia’s commences by locating itself temporally – ‘Sophie was born in the Spring of 1984’. However, the threads of emotion and professional involvement contained within Julia’s narrative are markedly different from the others, particularly at first examination. Julia’s narrative is also unique amongst all the accounts for its sense of the ‘scenic’ (Redman, Bereswill & Morgenroth, 2010) with which it is saturated. There is a forceful drive towards the thread of managing chaos and finding meaning, as explored in Chapter 4, which is demonstrated by the repeated use of the word ‘blessed’. Whilst in Cathy’s story this thread is half-hidden by her powerful and often disturbing description, in Julia’s it is predominant, and this is perhaps partly explicable by the ‘distance’ both of time and of ‘the telling’ (Frank, 1995, p. 8), a factor that emerged during the discussion of this thread in Chapter 4. Julia shares with Terri a sense of the symbolic within Sophie’s death, and whereas for Terri this is expressed through the tale of a fox killing the family pet rabbit, for Julia it is expressed through the almost mythical nature of the island, where ‘real work’ happens.

Siblings are another common thread within Julia’s story. Although Sophie is her first child and only daughter, she is very careful to locate her relationship to the subsequent boys both within the contexts of their lives and within the interview: ‘Her 3 brothers are all very clear that they’ve got an older sister and they’re very proud of that older sister’. This has strong parallels with Ellen’s description in Chapter 4, where two brothers, also born subsequent to their sister’s death, will ‘always know who she is’. For Ellen and Julia alike, maintaining this ‘thread of continuity’ (Hindmarch, 1993, p. 4) seems to form an essential part of their meaning-making.

Julia and Ellen’s stories are also linked in their understanding of the professionals that are involved. Whilst Cathy invests much of her outrage towards professionals, both Julia and Ellen describe demonstrations of humanity. In Ellen’s story this manifests as the policeman who runs marathons in memory of her child, whilst in Julia’s the policeman, Reggie shows her great warmth. And consequently whilst Julia feels ‘blessed’, Ellen believes she has had
‘the best experience’ possible.

Through multiple readings and interpretations of Julia’s story, I began to see that, despite its extraordinary aura, derived from Julia’s love and investment in ‘the island’ and my own initial reaction to this, the story has far more threads in common with the others than I had originally perceived. I approached the panel process intrigued to discover what threads would dominate and what ‘counter-transferences’ (Morgenroth, 2010, p. 267) of their own the panel might bring to this story, together with how they would interpret these in the wider context of sudden and unexpected child death.

The panel began by immediately commenting on the ‘filmic’ quality of the transcript, which they concur is described almost as a ‘pilgrimage’ to a ‘place of great importance’. They are clearly bemused by this, and there are early echoes that, like Cathy’s panel, it is ‘not the story they expected to hear’. At this early stage, the panel shows a degree of consensus in their understanding of Julia and all identify class as being an important aspect of her identity. They view her as locating herself early on as a middle class parent who ‘gets things right’.

In common with both Cathy’s panel and the collective threads, in Chapter 4, the concept of blame begins to manifests itself, although not, as with Cathy, as a suspicion of her harming the baby. In this panel, blame is raised by Marcus, who asks, ‘Was it a good idea to take such a young baby to somewhere so isolated, where there are no phones?’ In a parallel with Maggie within Cathy’s panel, Marcus’ sense of irritation with Julia becomes rapidly discernible early in the panel process, although he is able to temper this with humour. Marcus feels that Julia’s self-narrative has been ‘tripped up’ by the death of Sophie and that the story she tells is designed to reinstate it.

There is a long discussion within the panel of Julia’s repeated use of the term ‘blessed’, and they question, ‘Why was she so blessed when her baby has just died?’ Seeking to answer this hypothetical question, the panel members then formulate the twin hypotheses that the ‘blessed’ may simply be a denial of the death or may actually feel real to Julia because people were nice and there was so little officialdom. The panel agree that there is deep connection shown within the relationships in this story, and that the ‘blessed’ is also invested deeply in the mythical nature of the location. The panel dub the island ‘Balamory’ after a children’s television programme, which they agree is fitting for such a ‘fairy tale’ aimed, in their view, at not being ‘judged harshly’ and at ‘being understood’.
In contrast to other panels, this one (despite Marcus’ growing irritation) demonstrates great humour in response to this story. This was the only panel where members frequently laughed and the narrative is disdained at times. One example of this is a period where the panel starts speculating on who will make the film of this story and which actors will play the various characters. Despite this, at no point does the panel suggest that ‘this is not the story they expected to hear’, nor query whether it actually happened, as Cathy’s panel did in response to a more distressing narrative. This suggests that, although Julia’s perhaps seems the most implausible of all the narratives, it is not as emotionally demanding as Cathy’s and thus there was less need to defend against it.

However, the panel suggests that Julia herself has defended against a terrible tragedy from which she can’t escape by ‘wrapping herself’ in ‘Balamory’, which becomes the grounding for her attempts to avoid the reality of Sophie’s death. Julia thereby protects both herself and others from being deluged with unbearable feelings by her scenic reconstruction of a magical island where people are ‘blessed.’

The panel also observed the absence of technology in Julia’s story, which both dates it and provides a stark contrast to Cathy’s narrative. Here the attempts to resuscitate Dylan, to make a ‘dead baby alive’ as she describes it, together with the ‘deleting of a dead baby’ in the photographs, all add to the unbearable quality of the account. By comparison, Julia describes Sophie being wrapped in a shawl on an island where ‘tragedy happens’. The modern world does not intrude except in ways that are gentle and helpful, such as the doctor providing her with a way of stopping her milk production. The panel comments on this vivid description of Julia as a person with her needs being met, a feature that is entirely absent from Cathy’s story.

Interestingly, although Julia does not mention Sally Clark or Angela Cannings as other narratives have, the panel raises these cases as part of the ‘absence of the architecture of modern life’ within her narrative. There is a long discussion in the panel about how these cases, together with the high profile child deaths, discussed in Chapter 2, inform our cultural understanding of sudden and unexpected child death. They note that, perhaps due to the time of the death, this aspect is totally absent from Julia’s narrative.

Marcus’ irritation with Julia, which increased throughout the panel process, became gradually heightened as the transcript chunks progress, leading him to comment that, ‘If I met her at a support group, I would have to leave, because I would be getting angry’.
Belinda responds by saying she feels sorry for Julia, whom she feels is ‘not feeling the pain of her loss’. This has parallels with the panel for Cathy’s narrative, where Maggie’s anger was paramount, but equally where all panel members felt they knew what Cathy ‘should’ be feeling in some way.

In parallel with the ‘crisis’ I identified in Cathy’s panel, in Julia’s story the arrival of the helicopter is an influential moment. Esther, who had previously been quite jovial, began to cry and eventually explains this in terms of wanting ‘the man in the helicopter for herself’. Consistent with the mythical quality of the island, it seemed as if ‘the man in the helicopter’ provides the figure of the ‘hero’ (Frank, 1995, p. 119), who is able to accompany Julia on her ‘journey of suffering’ and to help her ‘bring back the boon’ (Frank, 1995, p. 119). Not everyone on the panel responded to ‘the man in the helicopter’ in the same way as Esther did, however, with Marcus once again expressing scorn and describing the scene as both ‘tragi-comic’ and ‘ridiculous’. Despite this, no-one queried, as in Cathy’s panel, whether this actually happened.

The helicopter landing also provides the demarcation between what has happened on the island and the imminent introduction of the outside world. From this point, and as Julia describes leaving the island, the panel members are very divided. Marcus feels that the ‘lovelies’ and the ‘blesseds’ are now being ‘laid on with a trowel’, whereas Belinda and Esther feel that there is ‘closure’ here and that Julia is telling a ‘beautiful story’ in which she is ‘held.’

The panel members all note a difference between the manner in which Julia reports the island and what they describe as the ‘real world’, which is ‘harsh.’ Julia’s description of her response to the ‘odd’ befriencers – ‘I was really angry’ – is the first time that her emotions have mirrored the thread of anger so strongly present in Cathy’s story and in many of the other narratives. Marcus feels that this is because they have ‘burst Julia’s bubble’, and paraphrases this as ‘I went to a magical place and real life intervened.’

In parallels with the panel’s experience for Cathy’s story, this one closes with a generic feeling of ‘irritation’ towards Julia, whose narrative is finally interpreted by them as one ‘lacking in humility’ where she never explicitly ‘deals with her guilt’. Thus, despite responding to the atmosphere of the story, which Belinda formerly described as beautiful, this panel echoes Cathy’s in expressing what Julia ‘should’ be feeling in these circumstances. There is little allowance within the panel for different emotions or for meaning-making,
which forms a strong thread in Chapter 4 and which ultimately drives Julia’s story.

‘Why is she so blessed when her baby has just died?’: exploring meaning within Julia’s Panel

Whereas in Cathy’s panel the radically different understanding of Cathy made me feel an outsider, I initially felt closer to Julia’s panel as I had experienced similar ‘irritation’ in my original response to Julia’s story. At first, therefore, the panel process was more collusive than that experienced with Cathy’s. However, as it continued I began to feel increasingly protective of Julia and thereby to experience a sense of ‘irritation’ and ‘lack of fit’ with the panel themselves (Hollway & Froggett, 2010, p. 5).

Analysing my own reaction was aided by Morgenroth’s work on ‘provocation’ within data interpretation panels (2010, p.168). She discusses ‘excluded elements of the scene’, which nevertheless are implicitly present within the data and thus cause the ‘provocation’ caused by the ‘lack of fit’ between these. The panel identifies one of the main ‘excluded elements’ in Julia’s story as ‘the big issue of mortality’ (Frank, 1995, p. 84), which they feel Julia evades, leading them to question ‘why is she so blessed when her baby has just died?’ Despite the differences between the accounts, Julia, similar to Cathy, is therefore identified by the panel as not ‘behaving as a grieving mother should’ in turning her account into a ‘beautiful story.’ The panel mirrors Cathy’s too in their implicit judgment that Julia has shown ‘the wrong choice’ in how she reports her grief, which they view as a means of never explicitly dealing ‘with her guilt.’

Thus Julia and Cathy’s stories, which in many ways are the antithesis of each other – one spreading ‘restitution’ (Frank, 1995, p. 83) whilst the other teeters on the edge of chaos – find union within the panels, who both blame the women for not behaving as they expect them to and for challenging them by not ‘telling the story [they] expected to hear’.

My own corresponding provocation led to me to replace my initial irascibility with Julia and to transfer this to the panel. In so doing, the ‘excluded elements’, which had previously been invisible to me within Julia’s narrative, started to reveal themselves. Rather than evading the ‘big issue of mortality’ as the panel felt she was doing, I began to view Julia’s narrative as an attempt to counter the common depiction of sudden and unexpected child death as ‘the most shocking and devastating event anyone must face’ (Dent & Stewart, 2004, p. x). Thus, like Cathy whose drive ‘to change things’ steers her away from ‘chaos’, Julia’s account, so
finely honed over twenty years, leads her from the darkness of Sophie’s death to the light of a new day. This answers the panel’s question ‘why she is so blessed when her baby has died’ for, echoing Ellen in Chapter 4, Julia strives to believe that she has had a ‘good experience’, one that leaves her, like Hafsa, in ‘a good place.’

As the panel suggests, this is not a ‘true’ version of the story, but its truth in ‘factual’ terms is not what is important in coming to understand the meaning of Julia’s narrative. As Hollway and Jefferson discuss within their own application of Kleinian principles, remembering is in ‘continual tension between a truthful acknowledgement of the (emotional) reality of a past event and defensive distortions of that reality in the service of psychological self-protection’ (2000, p. 151). Thus, whilst Julia has certainly defended herself as the panel suggest, her account represents a reworking of events in the light of later meanings (Hollway & Jefferson, 2000), including the birth of her sons and their assimilation of Sophie into the family history.

Whilst this challenges the panel who project their own shock and distress into Julia, finding her lacking, the account she gives is actually an ‘example of maintaining depressive positioning functioning rather than resorting to paranoid-schizoid splitting’, which the panel does. (Hollway & Jefferson, 2000, p. 151). My own initial irritation stemmed from a similar splitting, as the containment Julia describes was so unlike my own experience, I found it harder to hear than Cathy’s angry narrative, thus causing me to initially reject it.

For Julia, this containment is crucial to her remembering and to her integration of the experience, thereby allowing her to move towards a depressive position. As she herself says to the befriender, ‘It had happened and it was proof that it could happen so I asked them to let us enjoy what we had.’

**Conclusion**

This Chapter focused on Julia’s complete account of her baby Sophie’s death, which occurred over twenty years ago. Like Cathy’s story in Chapter 5, I have presented the entire narrative, together with comments from the panel and my later understanding of these.

Most notable in this Chapter has been my own shift in position from dismissing Julia’s account as a superficially ‘beautiful story’ with little relevance to my research, to a deeper understanding of its importance within the wider context of sudden and unexpected child death. The role of the panel in helping me to achieve this transformation in attitude,
demonstrates further their potential to act as far more than a simple ‘kick start’ procedure. It was by observing and intertwining the panel’s response to Julia with my own that I was able to empathise with her and to recognise the reasons for my own initial dismissal of her story, which was too hard for me to hear. Julia’s account of Sophie’s death, contains profound lessons for professionals responding to sudden and unexpected child death, whose actions may exert significant influence on parents’ meaning-making processes over time.

Chapter 7

Laurie

‘We have just been doing things right.’

Introduction

My aim in presenting the entire stories within these three Chapters has been to follow
Richardson’s metaphor of the ‘tapestry’ by weaving them together with the threads in Chapter 4 and my own experience of Joe’s death described in Chapter 1. These full versions weave in and out of the threads and strands discussed in Chapter 4 in a way that I hope encourages deeper understanding both of what is in the text and what falls between - what Clandinin refers to as ‘the borderlines and cracks between stories’ (2008, q. in Bell, 2012, p.49). Laurie’s story and the panel interpretations which follow are in many ways defined by these ‘liminal spaces’ (Speedy, 2008, p.28). Whilst Cathy’s story confronts the audience directly and Julia’s tries to soothe them, thus both provoking strong reactions from their panels, Laurie’s story and her way of telling, seem to suppress such strong emotions and ultimately leads to a sense of disengagement within the panel.

**Context**

Laurie is a married woman in her mid-thirties. She lives with her husband Mike and their young son Josh. Laurie contacted me by email in response to one of the requests for participants that I had placed on the website of a support charity with which Laurie is closely involved. I sent Laurie the Information Sheet and she then agreed to be interviewed. We followed this with two telephone conversations. Laurie’s partner Mike had recently had a serious medical procedure at the time of the interview and, as I had a cold, Laurie arranged to meet me at a friend’s house due to the possible risk of infection. She had also arranged for her son Josh to be looked after elsewhere so that the interview would be uninterrupted.

Her narrative concerns the death of her two year old son George 19 months prior to the interview. It was prompted by the SQUIN and was the longest of all the interviews in this study, lasting well over two hours. Laurie was often emotional throughout and she showed me photographs of her two sons. Laurie presented as gregarious and sociable with a strong driving force to ‘make meaning’ from her son’s death. It was clear that she saw the interview as part of this process. Laurie remains very active within her local support charity and has featured in several media pieces on the work she has done since the death of her son. She undertakes regular fund raising work and has her own online presence.

Following the interview, Laurie has kept in regular contact, describing the experience as
'very powerful’. She has seen the transcript of her interview and offered comments on this, notably corrections to minor details. The transcript was divided for the panel into numbered ‘future-blind chunks’, following the same process that had been used for the other panel sessions. The panel consisted of three people, all white British and previously known to me as colleagues and friends. This was probably the least diverse of all the panels as each member had formerly been employed as a child protection social worker, a fact that may be significant. All names have been changed, as before, to ensure confidentiality. Stan is in his early sixties and is now retired from a long career within child protection, Jess is also in her early sixties and still works part time as a social worker and Betty is a former social worker in her mid-forties who now works as a person centred counsellor. All three are parents.

‘Laurie’s Story’

George had always been a healthy boy, throughout his life. He had celebrated his second birthday on 5th May 2009. Ten days later on Sunday 15th May, he died. He was 2 years, 11 days old.

He'd been in the park with his Dad, Mike, and his brother Josh that day. On the way home in the car George had dozed off so Mike, had come home, taken off his waterproofs and wellies and just put him to bed for a nap, as he would have any other day. Mike and I just thought he was having a longer nap than usual.

When Mike went to check him, because we were busy doing some jobs in the house, he realised that something was really wrong and that George wasn't breathing, so the utmost panic arrived at that point in time. Mike brought him downstairs and we phoned the emergency services.

His brother Josh woke up as well. He'd also been napping and was quite terrified at the panic that was going on. Mike tried to resuscitate George whilst we were waiting for the emergency services to arrive. Being in quite a rural location that took something like 15 to 20 minutes, but it obviously felt like a very, very long time.

Whilst George had been napping, we'd both been in the room at times and not thought anything was amiss, I put the covers over his legs, but I hadn't actually touched his face or anything like that.
Once the ambulance did arrive, they drove him to hospital and I went with them. All the way to the hospital, which is about 25, 20 minutes in an ambulance from here, they continued with my help to try and resuscitate George. At the hospital we were taken over to the A & E department where there was a flurry of people waiting on him and they tried their utmost to revive him. I think I knew in my heart in the ambulance that there wasn't really much they could do. Knowing what little I know about medical stuff – they couldn't find a vessel and there was no output on the monitors so you sort of know. Then we were then led away into a room and I think the medical team agreed that they would stop trying and there was nothing further that they could do. The paediatrician came into the room and told us that George had died.

A lot of what happened that day is quite hazy. I do remember we were asked about a few things like organ donation which is very close to our hearts but we couldn’t donate an organ because they didn’t really know why George had died. It was explained to us that when a child dies unexpectedly there is a legal requirement for a post mortem and that’s something that is instructed by the Coroner, not something we could give our permission for. We totally understood this.

After a while we were then taken to the relative’s room to let us spend some time with George which was very special. At that point the nurse was there and then a Minister came in just for a short while and then we were left with him for a short while ourselves. I think I probably would have stayed longer, but my husband was really keen to get back for our other son Josh. At that time he was 4 and a half.

As I had left in the ambulance with George, Mike had followed in the car and at the same time my friend Sue had come to the house with her seven year old daughter. They had seen the ambulance and thought there was something wrong with my husband and they had met the paramedic leaving the house with George, so they had also taken charge of Josh at that point. Whilst Mike and I were away the Police had arrived at our house and at that point in time my friend Sue, her daughter and Josh were still in the house and were just preparing to go up to Sue’s house. Sue has worked as an ITU nurse for a number of years and had a lot of experience in dealing with families who lose children, luckily or by fate who knows. Sue was keen to take Josh off to her house and provide him with just warmth and love. She didn't know how much he understood about what had happened but she knew it wasn't her place
to tell him anything else other than to provide him with a safe place until we returned. When the Police arrived at the door, they entered and they informed Sue that she, her daughter and my son should not leave the house. I think what happened after that is that Sue had finally persuaded them that that was not the right thing to do in the circumstances. I don't know exactly how that conversation went.

Sue's house is in the same village as ours and she understood that the most important place for Josh to be was around his peers, his friends and comfort and not with them, but Josh obviously remembers the Police man arriving at the house.

Back in the hospital Mike was insisting that we leave quickly in order to come back up the road and tell Josh what had happened because in his words there was nothing else they could do for George, but it was very important that we handled Josh the way we chose to, the way we thought was right and fair. Mike had phoned and told the two or three families that were at Sue’s house and it's a small village so word travelled incredibly fast.

As we got back to our village, we pulled in past the house and up to this point we had had no input from the Police at all. We were aware that the Police Force was going to be involved, but we hadn't been made aware then of the actual Police involvement. When we arrived in the road I said to Mike, well, “there's a Police car parked in our street, I wonder why that's there.” Then I realised all the windows were open which seemed really strange. As we drew closer to the house we could see the Policemen standing on our front door step and so we pulled in and went up to the door and the Policeman said “you can't come in, this is a crime scene” and Mike said “well, no this is our house, what do you mean we can't come in?”. And the Policeman said “No well until my... I've just been told to come here” He was just following instructions, which I understood but Mike could've quite happily punched him into next week as the way in which the Policeman handled the situation wasn’t particularly sensitive.

Later on we were told by the T Police that we were in their area whilst the hospital is in the S Police area, so they had radio-ed across to S and been told that someone from the S Police would meet us at the hospital and explain what we should expect next. It was because there was a mistake and that meeting never took place, that we were left with having just left our dead son at the hospital to come home, to be told our house was a crime scene, immediately thinking “Are we under suspicion of something?” which was hideous. However, I immediately said to Mike “do you know what, in the scheme of things, this really
doesn't matter.”

As I have said ours is a small village and the ripple effect must have been working as my friend Kay's mum Josie had obviously just heard what had happened because she came walking down the street and found us there and she took us up to her house. I think Josie had got past the Policeman to get jackets for us, because we were in shock and we had left the house in our slippers and all sorts. Josie told us that we were in no fit state to go and speak to Josh and she tried to give us tea and coffee and stuff, but at the time obviously our main concern was Josh. We wanted to handle it well, to say the right things. So we spent a short time at Josie’s house and then it was really important that we go and talk to Josh. Before we did this I wanted to work out first when we could get back into our house because if it wasn’t going to be that night then I wanted to be able to set Josh's expectations as well as our own, So Josie took us back then to our own house and at that time the forensic guy was there and he was the one that obviously had to take photographs, take away bedding, check the scene and make decisions about whether there was anything suspicious or not.

I can totally understand why they would have to do that and I respected why they would have to do that, because at the end of the day, the Police have to be in some tragic situations and I suppose they have to suspect bad things until they can prove otherwise. However the way we were dealt with just didn't seem fitting with the situation. When we went back to the house, we spoke with the forensics guy who was obviously a little bit more trained at dealing with situations like this or certainly appeared to be unless it was good luck. He told me they would hope that we would be back that night so that was enough for me to go and talk to Josh.

At that point my parents arrived, my brother arrived, a few neighbours arrived, and then Mike and I went off on our own to speak to Josh. Earlier when Mike had been trying to revive George, Josh had been saying, “Mummy, mummy what's he doing” and I said “Your brother's not breathing, your Dad's trying to make George breathe again” and so the first thing that Josh said to me when I saw him was “Did the doctor's manage to make George breathe?” and I said “No sadly, really sadly they didn't.” I told him that George had died, that his heart had stopped and I used all the language associated with adults because it was instinctive and in hindsight it looks like we'd done all the right things because he
understands that when someone’s heart stops beating and they stop breathing they die.

Of course Josh was distraught. Because of Mike’s renal failure, we’ve had a lot of dealings with hospitals and so he was a very well adjusted, 41/2 year old. I’ve done home dialysis with Mike for years and so Josh is very familiar with hospital equipment and all the rest of it. George’s death was like shattering Josh’s illusions that doctors are wonderful in one fell swoop, but we had to tell him the truth. I think it was important that we told him it as it was and we didn’t allude to the fact that George had ‘gone to sleep’ which I think in a lot of people’s situations, can be quite damaging for children. So we explained what had happened and it was one of the most devastating things I’ve ever had to do. Then we took Josh back down the road to our house. By that time the Police had gone and it was just my mum and my dad and the friends that had brought my mum and dad over to our house, because they live 50 miles away. The main objective for us was to get Josh settled and get him to bed but at the same time Mike was badly due dialysis as he was about to have it when George died and so my brother took him down to hospital to get emergency dialysis.

So Mike had to go away and spend 5 hours attached to a dialysis machine with far too much time to think but the hospital staff treated him with the utmost respect and understood the situation, they were amazing.

Before he left the Police returned because they needed a statement from both Mike and I, so there’s Mike needing dialysis and before he could leave the Police were in our house and we had to give statements. I can’t remember then exactly what they wanted but it was more or less about any illnesses that George had suffered and everything that had happened that day, I guess it was evidence for the Police pass on to the Coroner and the pathology people, to be able to make whatever judgements they make. I guess decisions on the rightness of the situation or the wrongness of the situation.

After Mike had gone for dialysis we were told by the Police that because the T Police people hadn’t met us in S, I would then have to go back that night to the hospital to formally identify George. So my husband’s already gone to the hospital, to a different hospital for dialysis and I have to go and do this. I told the Police that there was no way I was doing that until my other son had settled. George had died about half past 3, or at least that’s when the ambulance had arrived and it was around 10 o’clock before Josh settled.

Once he had gone to sleep I got a lift down to S Hospital, where I had to go to the mortuary and formally identify George. My mum and my dad came with me and, bizarrely it was one
of the most spiritual experiences I've ever, ever had. It just felt like he was moving to somewhere better and that was weird and contradictory all at the same time because what could be better than being with his mum? I am very glad I did it because it just gave me a sense of hope and belief that he was ok and he felt very much at peace.

The Police who met us at the hospital were lovely and very sensitive. They also very understood and apologised for their colleagues in the other police area. I think one of the policewomen was playing the role of a Family Liaison Officer and the other was doing whatever role he did. I think he was part of the forensics team.

George had to have a post mortem and I do understand this and the logic behind why they have to move children who die, but it made me quite angry the night it happened. George had been taken by A&E from here to S Hospital, he was then in the mortuary at S Royal, but because he was under the care of T Police he had to be moved from S Hospital to Police Headquarters which is around an hour's drive away. All that moving about really upset me on the day. It just seemed ridiculous somehow. And then the next day they had to take him from D down to Y Hospital in G which is the only place that does children's post mortems and the driving about at the time made we think why on earth are they having to that. It seemed so disrespectful and unnecessary. In hindsight I understand that's just the way it had to be, but it didn't seem very logical on the day he died. It just seemed unnecessary stuff.

After all that moving around I think the post mortem was late on the Monday or the Tuesday morning although I can't actually remember for certain. After that they released his body and gave an initial cause of death of unascertained pending further investigation, which is quite common because they were assuming at that time that he died of cot death. At that point it was explained to me that it would take some time to get the full post mortem results but now we had a provisional cause of death and we could now go ahead and plan a funeral. That was another logical step along a crazy week.

It's so hard to remember all that happened that week but I do remember that the Police had been to the house before they let us back in and had examined the scene. I think they were happy that there wasn't anything untoward, but when they came back in the evening, after I had identified George's body, they said to us that they really needed to take away the bedding.

George had shared a bedroom with Josh, so I had mentioned to my mum, when we got back down to the house, before Josh came home, that there was blood on his sheets. I told
her that I didn’t want Josh freaked out any more than necessary and asked her to just run
the sheets through the washing machine. And of course clearly you want to protect your
other son from seeing things that he doesn’t need to see; you know it’s a hard enough
situation for him. So the Police ended up taking away the bedding, soaking wet out of the
washing machine. For what purpose god knows, but they obviously needed to tick a box on
a form that said bedding collected.
And that’s kind of the way I rationalised that because it seemed ridiculous, but it was clearly
necessary and they maybe should have done it when they were there the first time around.
There are so many strands of things that went on and the Police were obviously back and
forward the week in between the Sunday the day he died, all the way through the rest of
that week. The Police Liaison Officer, Ruth was fantastic. She did keep in touch with me and
let me know by phone as soon as the post mortem was complete. She really kept me in the
loop as far as what was happening, because there were a lot of things that happened that
were very negative as far as the Police were concerned, but Ruth in particular sticks out as
someone who was very positive and made the experience a lot less bad.
The evening I had been at the hospital with Ruth identifying George, one of the other Police
Officers had popped a Cot Death or Sudden Infant Death leaflet through my door at home
but at no point had anyone said to me that this potentially could be a cot death. I remember
asking the Police Officer that evening whether in these cases hard as it is to generalise, do
parents ever get to know what happened? “ Whilst George was in A&E they obviously didn’t
know what had gone wrong. They tested him for meningitis and all sorts of things that may
cause this, blood sugars, all sorts of common things and uncommon things to see what could
have been wrong. However at no point did anyone say we suspect cot death, because I
assumed at that point in time that only babies die of cot death. So I came home from
hospital to find this leaflet and I immediately ’phoned Rosie back and said “what are you
suggesting here?” I told her that this was the first time cot death had been mentioned to me
and I asked if the assumption was then that this was a cot death. Rosie told me that no
answer could be given until all of the tests have been done associated with the post
mortem, but it that it was possible and even likely because George had died in his cot
while he was sleeping. That left me really confused but it all settled to one side because I
didn’t contact the Cot Death Trust until after the funeral was past. However, it shocked an
awful lot of people because we had just assumed that babies die of cot death and also my
husband’s brother had died of cot death.

So in my head I was making awful connections about the genetics and all kind of things and whether Josh was at any risk. Anyway, we went ahead and organised George’s funeral and we decided that the right thing to do was cremate him. I didn’t really think too much about what most families do but in hindsight, it looks like most people bury their children, in order that they have a grave. Obviously since George died I have spoken to many bereaved parents and there seems an incredible lack of information on how to explain cremation to a 4 year old, which hadn’t really occurred to me until we were making the decision. There was no one really to advise us so I sent numerous friends on a mission of child bereavement books and other things. I hadn’t really gone online since George had died and so the books and information my friends found provided me a whole of information. I was lucky that Josh couldn’t read actually, because I read these books and then I had to say to Josh this is a coffin and that sort of thing because words like coffin are not part of a four year olds vocabulary. So every day I was basically just stressing to Josh what was about to happen next.

The morning after George had died, I got up and took Josh to nursery because I thought it was really important he had his peer group and wasn’t around a bunch of sad adults because I thought he is going to see enough sadness. Mike told me that I shouldn’t be forcing him to go to nursery, but I wasn’t forcing him. I told Mike that I would sit with him for the morning and if he wanted to come home I would let him. One of my friends had already told the nursery what had happened and they had drafted in extra staff to help them cope, not just with the parents and the children, but also the staff, because although George had only just started at that nursery the week before, he was well known to the staff. Its’ a very small community and George used to come with me to collect his brother. All of the parents there were very shocked to see me that day, but I stuck with it and I’m really glad because it was the right thing to do. I’m just relieved that I had the strength to do it because it was the right thing for Josh, without a shadow of a doubt.

And that’s how it was really for the first six months really. I was so driven by helping Josh to deal with the situation that my reaction to the fact that George had died was very much put on hold.

Josh was 4 ½ and about to start school that in August which is quite a critical part in a child’s education, so it was really important to me that he and I didn't drift apart and that we
maintained a relationship. I wanted him to know how much I loved him and I think also the fact that my husband lost his brother was on my mind. My husband was the oldest of the two boys when his brother died he was much younger than Josh was, but he has grown up feeling second best. I know times were different in the 70's when his brother died and there weren't the resources or the support that there are now, however it was utmost in my mind that Josh should not grow up with any sort of resentments or worries that he couldn't talk to me about things. I became almost obsessed to the point of reading just about every grief book in the library.

And once back online I went on numerous websites just looking for information. One charity was fantastically helpful and although they couldn't help practically because I wasn't in their area they spoke with me for over an hour on two different days by phone, about how to explain cremation to a four year old. It was information that I just just couldn't find anywhere else. For example the day before the funeral I took Josh for a drive down to the crematorium and I told him that is was where we would be coming tomorrow and that there would be a lot people who cared for us, and cared for him and cared for George. And I also told him that George would be there because it was important to me that Josh understood what was going on.. I never doubted taking Josh to the funeral because the last memory he had of George was of his Mike trying to resuscitate him, panic in the house, all the people trying to resuscitate him and the ambulance arriving, so it was important. The undertaker was really supportive because I asked his advice on whether I would scare Josh for life and he just told me to follow my instincts. As it happened instincts was the only thing I was flying by that week because everybody else was pretty much useless.

Then Mike’s parents came to stay and I don’t have a great relationship with them although neither does he. They stayed with us the week between George dying and the funeral and it was hideous. I do have a great relationship with my parents however although I've realised now that my mum is not the emotional rock I thought she was, but my dad is.

As I was kind of left to deal with most of the funeral arrangements it became very clear to me just how important funerals are. I'd never arranged a funeral before nor seen let alone touched anyone that had died. My grandparents had died when I was still a pretty young child and so I wasn't at any of their funerals and nobody in my close circle had died.

Once George's body had been released by the hospital, the undertaker took him back to the small village not far from here where I grew up. The undertaker was so amazing and the job
they do is just worth its weight in gold. One of his colleagues was a guy who was in the year below me at school and it just weird but comforting. We had made the decision that Josh would come and see George if he wanted to and I didn’t want him to feel this was thrust upon him, but I did want him to have the choice for when I got questioned in later years, like when he’s a teenager.

I would want to be able to say to him with my hand on my heart, “Well you had the choice.” So both Mike and I sat down and explained to Josh. At that time we were just basically going day to day, so that anything that happened the next day we were trying to prepare him for. So we told him that tomorrow we were going to visit George and if he wanted to he could come. And I actually think there is nothing that would have stopped Josh from visiting his brother.

When you are a mum there are other mums that you're friendly with who are like mums to your own children and I had two friends like this who I’d asked to come with me to see George. It was a lot to ask because it’s a good 50 minute drive from here. I’d also asked my closest friend Judy whether her son Ned who is Josh’s best friend, would want to come too. From a very selfish perspective, I was thinking that Josh would have a shared experience with one of his peers and someone else will have the memories that he has in years to come. So Judy asked him and although perhaps other parents would have baulked at that idea, Ned had already seen people that had died. His family's half African, so they had been out there a lot and children do die out there sadly. It was maybe just fate or by coincidence or not, but it certainly felt like the right thing to ask Ned and he was more than happy to do it. Josh looked out a few toys and a few other people had written out a few things they wanted us to put in his coffin. We tried to explain to Josh what he'd see when he got there, so in the car on the way, he then suddenly asked if the head would be there as well. We asked him what he meant and he told us that we were always talking about ‘George’s body’ and so he was wondering if the head would be there as well.

So we told Josh that when people die other people often talk about visiting their body but this means the whole body as in their arms, legs, feet, head the lot. Through Josh’s 4 year old eyes I could totally see where he was coming from and then the conversation became even more surreal, when we went into the undertakers. Initially just Mike, Josh and I went in to have family time first and then said Ned and Judy and the others joined us. When we got in there Josh was not at all fazed by seeing George. We explained to him that his body would
be cold and that he wouldn't breathe. Josh was very much aware of the discolouration of his lips. We stood with the undertaker behind us and Josh suddenly said “You know if I die I'm gonna have a bigger coffin that that”… and if you die Dad you'd need a bigger coffin and Mummy you'd need an even bigger coffin too” I could see Josh heading for the undertaker too and he turned round quickly, tears streaming down his face and left because it was just such a weird but surreally grounding thing for a child to say given the seriousness of the situation. Children’s grief astounds me and at some point in the future I’m definitely going to follow up on it.

I do believe Josh is a very well-adjusted boy for whatever reasons and you know, part of it I think is parenting but part of it is also just how he is. He wasn’t at all fazed and he and his friend Ned were both standing over George's coffin having a good chat. It was weirdly lovely and beautiful all at the same time. Then obviously my friends had been in to see George too. It was a very moving day and then Josh suddenly asked when he could go to the park...and you know that you're back in the zone...!

So Josh and Ned went off to the park with my other two friends and Mike and I had some time ourselves with George. That was on a Thursday and then I went back up to see him myself on the Sunday which was Mother's Day and the funeral was the Monday. March will always be a difficult month.

There is such a lack of information on cremation. There are lots of books that skirt around death or use animals but nowhere tells you how to explain what happens in a cremation. The charity I contacted told me that Josh would ask me questions, in his own time and that I should answer them as honestly as I could and at a level which he could understand. I asked them about explaining cremation without giving Josh a constant fear of fire because children at that age are obsessed by fire engines and fire stations and think they're fantastic.

We are religious, we don’t go to Church but we do have a faith and we had explained to Josh already that George had gone to heaven. We talked about all kinds of things in the first few days, but a lot of months went by before Josh actually asked me what had happened to George’s body. I had been advised by the charity to use the analogy of a glove to describe the body/spirit thing. It was along the lines of if you were to put your head inside a glove you can move the glove around but if your hands not inside the glove, then the glove can't move and it serves no purpose. So if you were to put your hand inside the glove and put both of them in the fire they would get hurt, but if only the glove was on the fire, then there
is no pain and there is no hurt. Josh had it sussed before I even got to the end of the story. The work that charity does is immense and what I learned from them was that it was important to be honest with the children, because if you don't answer the questions that they ask, they'll keep asking the questions until they get the answers.

When we left the crematorium we went straight to a hotel and I had banned black although I wear it a lot. I wanted people to remember George with joy and happiness and the sparkly little thing that he was. It was tragic and sad enough, so I didn't want people feeling morbid all day. I encouraged people to bring their children because Josh needed his peers and the children needed to understand at whatever level. I said to all the parents that every family does it differently and they didn’t have to bring their children but if they felt it was the right thing for their family then the children would be welcome and that in time they will help all of us. We had put together a big picture board of pictures because when kids are two there’s a lot of people who haven’t seen them for a year and a lot happens at that age. We put the picture board out and left lots of crayons and pens and paper so that kids could draw pictures or whatever they chose to do which was beautiful. Someone's husband had described it to them as if people had looked in they might have thought this was a wedding or a christening, certainly not a funeral. The majority of people who came have described the funeral to me as beautiful and oddly lovely and that was all I could have wanted because it did make me realise just how important funerals were and it's important that it was very George which it absolutely was.

After the funeral we had to think about scattering the ashes and I talked with the same charity about it. I had assumed perhaps naively that we would put all the ashes in one place but they suggested to me that this did not necessarily have to be the case. Initially this felt like too much to organise as Mike and I could not agree on one place. However, the charity suggested letting Josh choose somewhere that's special to him and told me I may be surprised by what he comes up with.

When Josh wanted to talk or ask questions it was normally Mike rather than me and he usually left it until just before bedtime when they were having a last cuddle. I had previously explained to him that at a cremation there’s a machine called a furnace and the job of the machine is to make bodies into dust and we had left it at that for a long time. The one evening just before bed, Josh asked his Dad “What happened to George's dust?” We then explained that at some point we would pick special places although Mike and I hadn't
actually discussed it as a couple, we’d just kind of loosely talked about it. When Mike and Josh got talking about it that it made it more accessible and more real and so Mike told Josh that we would pick special places and we'll scatter George's ashes in those special places that mean a lot to us. Even before Mike asked if he would like to choose somewhere, Josh said that he knew a really good place. He remembered a boat trip we had taken on a previous summer holiday and how much George had loved it there.

The phrase 'out of the mouths of babes' seems so appropriate to me because children have led me through my grief. Not just Josh but all his little friends. I've seen numerous parents squirming at the voices of their children saying things like “George's dead” and replying, “Yes I know and it's really sad and everything” From the ages of 2 – 10, the little ones are just looking for confirmation that that's actually the case, whilst the slightly older ones are beginning to connect with it a little bit more, but their children's grief can teach adults a heck of a lot of stuff because adults pussy foot around it all shockingly. They think that there's things they can do that will upset you, whereas the acts of omission are probably more upsetting than anything that could actually come out of people's mouths. So the scattering of the ashes was very important and we still have some and we haven’t chosen the last place yet. We've picked three places individually and three very different places. From speaking to other people I understand that some people keep their ashes in the cupboard for years which is absolutely fine if that's what's right for them, but it’s not for us. We have just been doing things right for our individual family.

I think I've finished now.

‘A useful story’: Laurie’s interpretive panel.

Laurie was the only participant who kept in touch with me following the interview and this continuing contact with her alters my interpretation of her story, placing this into a different context from all the other parents with whom my contact was limited. Laurie’s updates regarding events in her life and how she was using the experience of George’s death constantly shifted my relationship with the transcript of her interview during the analysis stages. However, my early impressions were largely reinforced rather than radically altered by this continuing relationship, and the very fact of Laurie maintaining contact at all is significant in this. Where Cathy’s narrative borders on ‘chaos’ and Julia’s on ‘restitution’
(Frank, 1995) Laurie’s account seems to speak to Frank’s question:

How does one rise to the occasion?...by telling not just any story, but a good story.
This good story is the measure of...success (1995, p. 62).

This success is very important to Laurie in her drive to make meaning from George’s death. She does not want to be dismissed as aggressive or worse, derided. She wants to tell a ‘good’ story and like Cathy wants to ‘change things’, although she is not driven by anger but rather by ‘doing things right’ as she herself states. Managing chaos and making-meaning, a thread described in Chapter 4 and further drawn in both Julia’s and Cathy’s stories is at the forefront of Laurie’s account, which is dominated by descriptions of pro-active endeavour in her quest to do things ‘right’.

The thread of siblings, which emerges in Chapter 4, is perhaps at its strongest in Laurie’s story, where she makes the powerful statement ‘children have led me through my grief’. Laurie is strongly protective of her son Josh, and much of her quest to get things ‘right’ is motivated by her fears for him. Her descriptions of her efforts to protect Josh resonate with both my own account in Chapter 1 and with Hafsa’s statement that ‘there is a point, I’ve got to get on with it, I’ve got to be there for her’, as she describes her continuing relationship with her surviving child.

Professionals also form a strong thread in Laurie’s narrative, which at times shares parallels with Cathy’s in her description of bungled bureaucracy and seemingly arbitrary acts of authoritarian control. However, although Laurie uses the description ‘everybody else was pretty much useless’ to describe events, she does not fall into blaming the professionals as Cathy does, but rather mirrors both Julia and many of the parents in Chapter 4 in attempting to understand the professionals involved. This attempt at understanding is significant, as Laurie’s is predominantly a ‘rational’ account. She rarely descends into rage or retribution but rather steadily ploughs through the events in her narrative, omitting few details and ensuring that this is useful story. I admired Laurie’s stoicism, courage and her sense of humour. My expectations for the panel were that they would feel the same.

The panel responded to the early transcript ‘chunks’ by commenting on Laurie’s ‘matter of fact’ reporting style, together with the absence of anger and heightened emotion. Rather than questioning Laurie herself, or the veracity of her account as other panels had, most notably in Cathy’s case, this panel immediately felt that Laurie is a ‘victim’ and that everything is about the locus of control that belongs to ‘professionals’. However, they
comment that actually ‘everything is out of control’ and that no one is able to contain this situation. They are very concerned by this, particularly as they have all at one time been child protection professionals themselves. The panel feel that Laurie is the one fighting to take control, and comment that her warmth and love show through the narrative, as she is faced with separation from Josh in order to be with George.

The panel continues to find love and warmth, together with a strong theme of friendship, as the narrative progresses. The panel contrast this ‘friendship, love and warmth’ against the austere power of the authorities and they become especially angry with the police. This too is in stark contrast to the panel for Cathy’s story where she herself was identified as the problem.

Early in the process and before Laurie explicitly states this herself, the panel recognise Laurie as motivated by ‘trying to get it right’, particularly in relation to Josh. They describe ‘her meaning-making as very strong’ and suggest this is how she manages to keep so calm. Betty questions whether Laurie is ‘angry’, commenting ‘I would be really cross’. This provides another contrast with the panel for Cathy, where her anger caused Maggie in particular so much agitation. The panel speculate as to what Laurie is ‘really feeling’ under the ‘reasonable and understated’ veneer of her narrative and wonder whether, as well as feeling cross, she is also frightened and attempting to deal with this by staying calm. They raise, as all the panels have, the themes of guilt and blame, noting that these seem absent from Laurie’s narrative. The panel suggests that the emphasis on ‘getting it right’ is Laurie’s way of preventing herself from feeling guilty. Related to this, the panel also speculates as to the impact of the professional intervention on Laurie’s determination to ‘get it right’ in contrast to the authorities who are getting it, in the panel’s view, so badly wrong. The panel collectively view the professional intervention as ‘a mess’, with the emphasis on procedure paradoxically causing a complete lack of control. Once again, as in Cathy’s panel, the group asks ‘can this actually be true?’ – a question that was never asked by Julia’s panel.

This panel, perhaps because of their previous and current professional roles, becomes most focused of all the panels on matters of procedure, and there is a long discussion relating to this. Stan asks ‘why is no one communicating properly’ with reference to the way in which the professionals are interacting with Laurie and Mike. However, the other members counter ‘well how do you get an investigation right?’ thus identifying one of the key dilemmas at the heart of sudden and unexpected child death. This panel’s unease with
protocols and dismay at the professional ‘mess’ increase as the transcript chunks progress. When the narrative reaches the description of the police taking the bedding from the washing machine, Stan becomes exasperated saying ‘If there was a case against these parents it would break down’ and that it makes ‘a nonsense’ out of any procedure. In contrast with other panels, once again Laurie is vindicated, and it is the authorities that hold the chaos whilst Laurie herself tries to control it. Compared to Cathy, who saw ‘no framework for society’ following Dylan’s death, Laurie presents to the panel as ‘trying to manage the impossible’, with an overriding drive to maintain the ‘framework’ in the way she tells the story. Laurie cannot afford for everything to collapse as she has too much invested in ‘getting it right’ for Josh, so she ‘manages everyone’ in order that her relationship with the world is maintained sufficiently for her to do this. She is not prepared, like Cathy, to allow the collapse of the ‘framework for society.’ The panel concur that this experience is ‘horrific’, not just because George has died but also because of the process that follows. As the process continues, the panel are increasingly impressed and ‘moved’ by Laurie as a person, finding her ‘resilient’, ‘pragmatic’, and with a strong gift for meaning-making. They see profound thought in Laurie’s actions and are continuously impressed by the warmth, love and support of the friends she describes. Jess comments ‘this is a woman who has a huge network’, which also forms a direct contrast with the manner in which Cathy portrays herself. They identify correctly that Laurie will ‘use the story’, which she has done in her media and charity work, and that telling a story which is ‘useful’ is a strong part of her meaning-making process. Betty feels that Laurie also meets this through Josh, and that ‘getting it right’ with him and seeing the results of this help to reinforce her own identity. Jess comments on the possible pressure this may put on Josh. As the panel draws to a close, they re-affirm their original sense of Laurie as someone who needs to ‘get it right,’ commenting that she never descends into anger or uses the kind of powerful language she could have chosen. These are viewed as admirable traits by the panel in contrast with Cathy who is judged as ‘belligerent’ and whose own attempts to ‘control’ are viewed negatively.

This panel’s frustration and anxiety focus not around the narrator as in Julia and Cathy’s stories, but around the authorities that they see as having failed Laurie. In another reference to technology, Stan reflects that ‘you would hope there would be some support. I mean if you lose your mobile phone you get a counsellor...you lose your kid you get nothing’. Whilst
he agreed that the voluntary agencies are very supportive to Laurie, he sees them as not being proactive and so it is left to Laurie to seek support. The panel members agree that this is very disappointing and they are all saddened by it.

‘Everything is out of control’: exploring meaning within Laurie’s panel

Laurie’s panel was the penultimate one I convened and in many ways the easiest, lacking ‘explosive’ content, which Morgenroth (2010, p. 268) refers to in her own work with panels and which had manifested on previous occasions. At face value, Laurie’s narrative and particularly her way of telling the story seemed to ensure an adequate ‘fit’ and thus minimised any ‘provocation.’ In contrast to both Cathy and Julia, Laurie is seen to be ‘behaving as a grieving mother should’, and the panel therefore locate ‘the blame’ and the ‘provocation’, not with the story teller, but with the authorities whose interventions are described as ‘a mess’.

However, during the panel itself and whilst revisiting their account, I was troubled by their apparent lack of engagement with Laurie’s narrative. Whilst the panel members, like Laurie herself, behaved well and tried to get things ‘right’, there was an absence of the embodied expression and emotion that had characterized both Cathy and Julia’s panels. Although Stan became angry at times, this was always appropriately contained and nobody become tearful, as in Julia’s panel. This made the panel process much easier, but given the content of the narrative ‘chunks’ and the panel’s own description of these as ‘horrific,’ it seemed incongruent. Returning to Morgenroth’s previously helpful suggestion that the reactions of data interpretation panels are often ‘responses to something present in the data and not simply reactions generated by the biographies of individual panel members’ (2010, p. 278), I located the ‘lack of fit’ not within the story itself, but rather in the panel’s reaction to it.

Cathy’s narrative suggests that the ‘chaos’ she presents becomes enacted by the panel members who blame Cathy for bringing this so uncomfortably close to them, whilst in Julia’s story the panel, faced with the proximity of the death are unable to achieve the depressive position that Julia has reached during the intervening years. However, in Laurie’s panel, whilst the members acknowledge that ‘everything is out of control’, they seem unable to fully engage with this, let alone contain or find meaning in it, a process Bion identified as crucial for the avoidance of ‘nameless dread’ (cited in Cooper & Lousada, 2005, p. 30). Thus,
they end the panel process filled with generic sadness and disappointment. Their inability to fully engage with the ‘horror’ they identify may also be located within their own roles as helping professionals, causing a similar emotional detachment to that identified by Menzies-Lyth (see Chapter 2).

The sense of ‘lack of fit’ also recalls Doka’s work on ‘disenfranchised grief’, as discussed in Chapter 2, in which he suggests that permission to express the emotions surrounding a death is only awarded to those with ‘recognizable kin ties’ (1989), leaving others in the wider network ‘disenfranchised.’

My experience of this emotional detachment and corresponding ‘lack of fit’ within Laurie’s panel altered my previous relationship with both Cathy and Julia’s panels. Where I had been critical of their anger and sharp judgments, I began to view these as congruent with Cooper’s argument for engaging with the ‘smell of the real’ (2009, p. 432). The danger here, as Cooper warns, is of hating or despising people intensely, and some of the ridicule of Julia’s panel and the anger of Cathy’s demonstrate this vividly. Despite this, both panels attempt to engage with the ‘destructive and negative’ elements in the stories, even if they are ultimately unsuccessful in containing these (Cooper, 2011, p. 441), whereas in Laurie’s panel, emotional engagement with the death and with the unfolding events is kept largely at bay.

This highlights potentially important lessons in answering the Kennedy Report’s call for professionals to ‘be sensitised to emotions being experienced by parents’ (RCPath & RCPCH 2004, p. 12), as perhaps, without experiencing the ‘explosive reactions’ evidenced by Cathy and Julia’s panel, it may be too easy for professionals to become emotionally detached, hiding behind professional roles and thus avoiding engagement with the reality of sudden and unexpected child death.

**Conclusion**

In this Chapter, I have focused on Laurie whose interview was the longest of the eight that I conducted, reflecting her purpose of leaving no stone unturned in her efforts to construct meaning from George’s death. The panel seems to understand Laurie’s efforts to get things right and they label her story ‘useful’, commenting correctly that she will use it to help effect change. However, whilst they empathise with Laurie and do not criticise her as the panels
for Julia and Cathy had done, they nevertheless demonstrate an emotional detachment, which in turn reflects Laurie’s own style of telling.

My own process of trying to understand the responses to Laurie’s story altered my initial perceptions of the panels in the previous two Chapters, which I had viewed as harsh and condemnatory. Returning to the nurses discussed in Menzies Lyth’s influential study of professional defence mechanisms, I recognised similarities between them and Laurie’s panel, whose attempts to manage a story where ‘everything is out of control’ caused a similar level of detachment. The panels for Julia and Laurie’s story conversely attempt the ‘fearless engagement’ that Cooper recommends (2009, p. 441), but this is largely unsuccessful and they fall prey to the danger of losing parts of themselves in their splitting and their projections onto Cathy and Julia (Cooper, 2009, p. 432). In the final Chapter I will pick up stitches from the threads I have woven through these complete narratives and the themes in Chapter 4, comparing these to responses from early media dissemination of the research.

Chapter 8

‘Arriving where I started.’

Introduction

In his poem ‘Little Gidding’, Eliot declares that ‘the end of all our exploring will be to arrive where we started and know the place for the first time’ (2001, p.42). This final Chapter resonates with Eliot’s statement – attempting to close the circle by revisiting the themes which have occurred throughout this book and linking these to my original purpose. Key amongst these is the difficulty of speaking outside what Frank (1995) dubs the contemporary language of survival, which is highly complex and linked inextricably with maternal identity and notions of both good and bad. As I described in Chapter 1, this manifested, after Joe’s death, in my troubling feeling that I had not behaved as a ‘proper’ bereaved parent should, as I did not view Joe’s death as ‘unnatural, nor had I broken down
in front of people, as they seemed to expect. These troubling emotions later contributed to the research study which underpins this book, which in turn uncovered further ‘normalizing judgments,’ evidenced by the descriptions of Cathy, Julia and Laurie. In this final Chapter, I will continue to explore these unconscious verdicts on how grieving mothers should and should not behave, through examples drawn from the research process, as well as my personal experience of Joe’s death, and later contact with the mainstream media (Moorhead, 2014). Using examples from this media contact, I will consider the potential splits created by narratives of the right way to grieve and will advocate for a middle ground which mirrors Klein’s ‘depressive position’ (1935). Finally, I will excavate the ‘excluded middle,’ created by conflicting and contested narratives, by highlighting key themes from the research and dissemination processes.

**Navigating ‘a place for Experience’**

Throughout this book I have revisited the metaphor of finding ‘a place for experience’ (Hoggett, 2000, p.84) prompted by the aftermath of Joe’s death, when people hurriedly crossed the road to avoid me, or conversely broke down in front of me. I grasped slowly then that no bespoke shape existed to contain this experience and therefore, like Ryan carving the headstone (2000), or the man with the two small toy figures, described in Chapter 1, I would have to shape my own. This book and the research thesis which preceded it represent my own form of memorial, my ‘place for experience’ (Hoggett, 2000, p.84) - for Joe and the children whose brief lives form the basis of Chapters 4 – 7. What I did not realise, when I set out to create this, however, was how challenging it would be to give voice to an experience that speaks outside the common language of survival (Frank, 1995) and is therefore largely unheard or untellable. The case of Jayden Wray, which I described in Chapter 2 demonstrates this vividly, highlighting the difficulty of holding in mind that children do still die from natural and preventable causes, within an age driven by inquiry (Stanley and Manthorpe, 2004). In this culture, naturally occurring child deaths may represent the ‘dangerous knowledge’ (Cooper and Lousada, 2005) discussed in Chapter 2, which counters the contemporary beatification of children, alongside the myth that they do not die randomly of natural causes and certainly not without someone to blame (Shoesmith, 2016). The accompanying fear of blame and litigation amongst practitioners links to the vulnerability I discussed in Chapter 2 and particularly the concept that those who are
described as ‘vulnerable’ may actually be those whose stories make others feel vulnerable. This was evident in the process of ethical review, where participants were universally constructed as ‘vulnerable’ whilst panel members and the practitioners themselves were not even considered. As the reality of the panels demonstrated however, it was the members who often felt discomfited by the narratives as evidenced in Susan’s description of ‘feeling chronically polluted’ following Cathy’s analysis panel. Similarly, many of the parents in the narratives which form Chapters 5-7 describe the vulnerability of professionals, who were obviously distressed by the circumstances, as Ellen’s description of the Policeman who has never ‘seen a dead baby before’ demonstrates (see Chapter 4). The vulnerability experienced by those confronted with the sudden, unexpected death of a child, within a wider culture of blame and denial (Shoesmith, 2016) may create a boundary beyond which people are simply unable to travel (Cooper & Lousada, 2005) and I have experienced this both within and beyond the research process, demonstrating to me that navigating around my particular ‘place for experience’ (Hoggett, 2000, p.84) may always be uncomfortable and contested terrain.

**Can a Parent get over the death of a child?**

The most profoundly contested terrain I encountered, following dissemination of the original work which led to this book, concerned the prevailing cultural permissions for grieving after a child death. These permissions revisit the panel’s designation of Cathy as ‘not behaving as a grieving mother should’ and penetrate to the core of the ‘normalising judgements’ about bereavement processes (Speedy, 2008, ) which have featured throughout this book. Additionally, this deeply contested terrain resonates with the ‘emotional politics’ discussed in Chapter 2, particularly in connection with the role of mothers and moral worth (Warner, 2015).

Throughout the research process, I encountered many occasions when people were unable to manage the emotions provoked by my study, claiming that it needed a preliminary ‘Warning’ or leaving my research presentations in tears. Consequently, I became adept at anticipating anxiety or changing the subject to protect others from uncomfortable discussions. However, my most testing and yet enlightening encounter with the ‘provocation’ (Morgenroth, 2010, p. 268) created by my research occurred in the aftermath
of a mainstream media article (Moorhead, 2014) and the ensuing contributions to the ‘Comments’ page. In discussing this encounter, I hope to show how it resonates with many of the key findings within this book, as well as demonstrating the difficulty of uncovering the ‘dangerous knowledge’ required to build a suitable location for my experience (Cooper and Lousada, 2005).

In the summer of 2014, nine years after Joe’s death and after the completion of the research work which led to this book, I was interviewed for The Guardian newspaper, as a publicity item linked to a Conference presentation. Although I was initially anxious about appearing in a popular newspaper, the professional necessity to make ‘impact’ from research work, combined with my original aims of giving voice to others through my experience, led me to agree. The journalist who arrived to interview me two days later was skillful and personable, drawing from me the ways in which I had explored and made meaning from Joe’s death in the intervening nine years. The ensuing article was published later in the week, as the front page of the Saturday Guardian Family section with an alarmingly large photograph, erroneously dubbing me, ‘Denise Taylor,’ together with the provocative headline ‘Can a parent get over the death of a child?’ (Moorhead, 2014). Initially it was both overwhelming and enlivening to be storied in print, although neither the article nor the headline were what I would have produced myself. Returning to Speedy’s concept of making statues of people (2008), both the incorrect surname in the hard copy editions and the larger than life photograph also contributed to me feeling mildly ossified, whereas the words which were attributed to me and which I had certainly spoken, seemed stripped from their context and no longer belonged to me - a salutary lesson to a researcher who had storied the participants within my own research.

Only minutes after the article appeared online the first comment was removed by moderators because of its abusive content. This became a common occurrence as the Comments section grew alarmingly, over the next few days, eventually reaching over two hundred, often disparaging and outraged posts. These Comments reflected many of the themes which have occurred throughout this book and the research which underpins it – in particular the responses of the data analysis panels. As I have described in previous Chapters, facilitating these panels provoked unexpected emotional responses in me, which I was compelled to explore further. However, following publication of the Guardian article
it was my own mediated narrative that formed the subject of other people’s scrutiny, with their reactions echoing the themes which have emerged throughout this book.

In an account of her own research becoming similarly ensnared in a media noose, Sikes suggests that ‘moral research practice involves showing one’s own positionality’ (2008, p.250). Her consequent belief is that the chief concern of qualitative research within the social sciences is to introduce private concerns into the public domain in order to bring about positive change. Whilst hindsight has helped me to agree with this view, in the immediate aftermath of the Guardian article, I was profoundly distressed and perhaps as Davies (2010) suggests, even re-traumatized by the anguish I appeared to have created. Echoing C. S. Lewis, I wondered if it would be better for me to be ‘isolated in a special settlement’ (cited in Ellis, 1993) where my responses to Joe’s death and its aftermath were not so profoundly out of step with others. As time passed, and the Comments continued however, I found my emotions turning from guilt to irritability and then indignation, which I later recognised as mirroring the panel’s attempts to defend against difficult emotions during the analysis sessions. In order to understand why the article had created so much anguish I needed to view the Comments through the same lens I had used to filter the panel interpretations and thereby to examine both the ‘provocation’ (Hollway & Froggett, 2011, p. 5), and the ‘lack of fit’ discussed in earlier Chapters (Morgenroth, 2010, p.268).

A clue to both lay in the idea which repeatedly appeared in the Comments, that I had not sufficiently cared about Joe - an idea which is reflected in populist reports of grieving, which suggest:

The depth of her sadness was simply a measure of the love she had for her daughter.

(O’Malley, 2015)

As I discussed in Chapter 2, popular depictions of successful motherhood and indeed femininity require women to be fully immersed in their children’s needs to the extent that these take precedence over the mother’s needs at all times (Krane and Davies, 1997). Love is therefore measured by a mother’s successful capacity to lose herself and her own identity within that of her child (Krane and Davies, 1997). Where child death is popularly reported as the ‘the most shocking and devastating event anyone must face’ (Dent & Stewart, 2004, p. x) or indeed as ‘unnatural’ (Wheeler 2001, p. 53) then a mother who has ‘succeeded’ in conflating her own identity with that of her child is rendered incapable of accepting the
unacceptable. I described in Chapter 1 that I did not ever view Joe’s death as either unacceptable or ‘unnatural,’ as it was tragically linked to his prematurity and time in intensive care, both of which actually rendered his short life, rather than his death ‘unnatural.’ What I experienced as ‘unnatural’ were the events which followed and which are discussed at length throughout this book. However notions of failure and blame are reflected widely within the narratives as Cathy summarizes:

There was a part of me that felt guilty anyway, as I had failed as a parent because my child was dying so I couldn’t fail any more than that.

The Comments which followed publication of the Guardian article also reflected both the idealization of motherhood and the panels various judgements of how grieving mothers should behave. As the Guardian does not license these Comments for reproduction, they can only be discussed in thematic terms, mirroring the threads in Chapter 4. A powerful theme in several posts was temporality – or in particular, not allowing a moment to pass without thinking of the deceased child, as well as being perennially heartbroken. The concept of carrying out career tasks that the deceased child would have pursued was also introduced as a sign of merit, whilst my display of what one contributor considered a personal matter within a public newspaper was berated.

This dialogue relating to my ‘moral worth’ (Warner, 2015) and that of other mothers, resonates with the discussion in Chapter 2 and was furthered by the by the error in hard copies of the newspaper which erroneously dubbed me ‘Denise Taylor.’ The apparent disjuncture between ‘Taylor’ and my actual surname, which was corrected in the online editions and on social media, caused contributors to speculate that I was a single parent without a male partner as if this carried significance for the article and my narrative of Joe’s death.

Throughout the Comments are other reverberations with themes which have recurred throughout this book. Many of the posts are not solely ‘Comments’ but rather stories of child and other deaths which resonate with the discussion of ‘thestrals’ in Chapter 1 (Rowling, 2003, p. 760). Many contributors posted long and emotionally touching narratives,
indicating an inability or a lack of desire to move forward as this would imply forgetting about their child. In this context the term child did not only relate to those under 18 but was used to relate stories of the death of a child at any age – even in advanced adulthood.

Considering these contributions from a psychosocial perspective, Bion’s work on containment (1962) suggested that primitive and uncontrollable feelings can be provoked by events like sudden, unexpected child death, which may be too disturbing for thought. In Bion’s model, the overpowering emotion produced by this needs to be projected into a ‘container’, usually a containing figure, who then returns this in a more controllable form.

The online Comments which followed the Guardian article (Moorhead, 2014) can be viewed through this lens, with the ‘Denise Turner’ or ‘Denise Taylor’ in the article acting as a repository or ‘container’ for people’s primitive emotion and their stories. This explanation is furthered by the direct email and other correspondence which I received in the aftermath of the article and which has continued to the present, nearly three years later. During this period over forty people have emailed me directly to share their experiences of child death as well as to comment positively on the article’s contribution to their lives. Most of these emails arrived in the immediate aftermath of the article, but I still receive them occasionally, with the latest reaching me only last week. In contrast to the Comments, the direct emails are universally positive, but can still be seen as requiring a ‘container’ for difficult and in some cases, unprocessed feelings:

‘We lost our oldest child in an accident last year. I came across an Article (Guardian, 2014) and a lot of your views fit with mine. I decided on my way to the morgue that I was going to keep going, that while I had every excuse in the world to curl up in my bed and never get out of it, I was going to keep going, for me, my partner and my other two children. And that’s what I’ve done. My children are getting on well ...and we steer clear of people who can’t handle how we are dealing with things. We miss our son, miss him so much. But I can’t bring him back by turning away from life and the world...I just wanted you to know that your article gave me great comfort and belief that I’m on the right track.

I am reaching out to you after searching the internet on the subject of child death and how parents who have experienced this conduct themselves. The subject came up
when a relative asked me why I never speak about my child. I tried to explain my feelings but after that I really started to question myself. Decades ago I had what I thought was a normal pregnancy. I gave birth and we were overjoyed. The following day my nightmare began ...she died in my arms and I wept for months. Despite giving birth to other healthy children I still struggle to talk about her to this day... I am reaching out to you because of an article I read about your experience. It made me feel that I am not the only one that feels this way. It is not that I don’t love her with all my heart...or miss her...or cry still to this day. I thought there was something wrong with me to not satisfy other people’s judgements of how I should be behaving. I am relieved to have read this article and to know I’m not alone.’

I just wanted to say thank you for your article about losing a child. My beautiful baby is unlikely to live until he is even two. I really needed to know that people can survive child loss, can continue to be happy. Even though I’m utterly heartbroken I’m convinced we will take positive things from the experience.’

I just wanted to say thank you for the piece in The Guardian. It was good to read an article by another parent who has experienced child death but has not reacted in the way that society seems to expect. I lost my child a few years ago and was determined to be ok and carry on moving forwards. People seem to think I’m a bit strange or unusual and after a while you can wonder yourself at times; so thank you for sharing your story, and helping me with mine.’

All these examples demonstrate many of the themes which have recurred throughout this book, as well as highlighting Bion’s theory of containment (1962). The writers of all these emails, each of them female, require a container because what they are expressing is profoundly challenging in a society that judges the ‘moral worth’ (Warner, 2015) of bereaved mothers by the nature and extent of their grieving following a child death. To suggest , as they do that they are going to ‘keep going’ or even take ‘positive things’ from the experience is breaking a taboo in a society where they are not meant to ‘feels o.k really ever’ (Dent & Stewart, 2004, p. 174) and where even one of the principle writers on the
topic dubs them ‘death mothers’ (Garstang, 2017, p.9). The ‘container’ (Bion, 1962) provided by finding a witness to their story allows these women permission to feel their own emotions around the death of their child and to deal with this in their own way, rather in the manner which is culturally prescribed (Krane and Davies, 1997).

‘Getting over it.’

The online Comments which followed the Guardian article, unlike the letters and emails, which I received directly, were frequently preoccupied with the headline – ‘Can a Parent Get Over the Death of a Child?’ This had been assigned to the article by the newspaper, along with my inaccurate surname, and whilst I had not posed this question myself, the headline was derived from my account of people who had told me directly after Joe’s death, that I would ‘never get over it.’ At the time, in the immediate aftermath of Joe’s death, this had terrified me as, vulnerable as I was at the time, I felt that I would be consigned to feel the pain in perpetuity (see Chapter 1). My purpose in the interview which informed the article had been to reassure others that this would not necessarily be the case. However, I had not foreseen the storm that this would cause, with many of the contributors furious with me for suggesting this and countering that it is never possible to get over the death of a child.

The Cambridge Dictionary defines to ‘get over’ as ‘to feel better after something has made you unhappy’ and as I have discussed, my original intention, informed by my own experience, had been to reassure people of exactly that – that they could ‘feel better.’ I was totally unprepared therefore, for the storm of outrage that the headline provoked and initially extremely distressed by it. However, I now view this storm as indicative of themes which have recurred throughout this book and which can be interpreted through a psychosocial lens. Key to the outrage that was produced by the idea of ‘getting over it’ is Klein’s concept of ‘splitting’ which, as I discussed in Chapter 2, can occur as a defence against pain and other frustrations. Potentially dangerous and uncontainable feelings are split from the source and projected into another, thus stemming the immediate threat to the self. This process can be traced within the Comments, where the ‘Denise Taylor’ of the article became split both from the group and the prevailing notion of ‘good’ motherhood – becoming a ‘bad object’ who had not loved her child enough (Krane and Davies, 1997)
had not had a man on the scene. This recalls the panel who judged Cathy as ‘not behaving as a grieving mother should’ and reacted with anger to a narrative which ‘was not the story’ they ‘expected to hear’ (see Chapter 5).

Similar splitting appears throughout the Comments in the form of hierarchies of grief which are highly significant for understanding the field of sudden, unexpected child death. Sally Clark, as discussed in Chapter 1 was berated in the media for being a professional lawyer and therefore somehow ‘cold’ – a misconception which assisted her wrongful conviction (Batt, 2005). This stereotype is countered within the replies to the Guardian article (Moorhead, 2014) by mothers who compete for who suffers the most and assign themselves membership of a club of tragedy. A significant thread of the Comments involves an often uncomfortable struggle for sovereignty amongst contributors who have experienced the death of a child at different ages, or conversely are childless. Some contributors suggest that experiencing the death of an older child is much worse than the death of a baby or infant, whilst others suggest that being childless is the very worst thing.

These ideas speak to Kellehear’s distinction between ‘good’ and ‘shameful’ deaths discussed in Chapter 2, whereby there is a hierarchy of what is acceptable and conversely unacceptable, as well as ‘splitting’ different experiences and somehow ‘ranking’ these.

Similar splitting is distinguishable in the responses I received from various educators and professionals working in the field, after publication of the article (Moorhead, 2014). One academic writing to me, explained how distressed the article had made people with whom she was in professional contact and she apportioned much of the blame for this to the ‘getting over it’ of the headline. Within her email to me, she stated that ‘It's a difficult topic with a fragile group,’ thus dislocating me from this group as if I had not experienced sudden, unexpected child death myself. This mirrored the police woman on the morning of Joe’s death who had also been unable to believe that I could be both a social worker and the mother of a child who had died (see Chapter 1). In referring to ‘this fragile group’ the corresponding academic also seemed to re-assert Cottle’s ‘myth of vulnerability’ as a universal norm, whilst splitting me from this group despite the article’s emphasis on the death of my own son. By appearing in this article it seemed that, like Cathy, discussed earlier I was ‘not behaving as a grieving mother should’ and thus membership of the ‘tragic club’
was denied me. This resonates with the ‘othering’ of the ‘bereaved parent’ that I discussed in Chapter 1, rendering them as almost a separate species rather than simply ordinary people affected by random tragedy, as well as prescribing strict grieving rules which they must follow in order to be seen as having loved their child enough (O’Malley, 2015; Krane and Davies, 1997). The notion of ‘getting over it’ is tightly bound to these grieving rules as many contributors to the Guardian Comments indicate. ‘Getting over it’ can be seen to break a universal rule of motherhood in which women have to behave according to idealized notions of motherhood, thereby creating a split between ‘bad’ and ‘good’ mothers (Herland and Helgeland, 2014) who do or do not ‘get over it.’

‘Excluded middles.’

Splitting of this nature also creates what Cooper & Lousada (2005, p. 140) dub the ‘excluded middle’ – a place of ‘binary logical choice, of reasoned determination of truth and falsity according to the evidence available.’ These experiences are reflected in the literature on sudden, unexpected child death, discussed in Chapter 2, where mostly professionals speak on behalf of ‘bereaved parents’, thus defining the experience for and about them. The ‘excluded middle’ is also evident in the absence of parental accounts within the literature (see Chapter 2), together with the omission of parents from the Working Party that formed the Kennedy Report and from all the meetings that follow the death of a child, culminating in the Case Review (See Chapter 2). The Child Death Overview Panels, which meet several times a year to discuss child deaths within their area and to ‘report on the lessons learnt’ (FSID, 2011, p. 6), also have no parental representation. Therefore, in the reports produced for local Safeguarding Children’s Boards, there is no direct communication with parents. Despite the Kennedy Report’s emphasis on ‘good communication between professionals and parents’ (RCPath & RCPCH, 2004, p. 12), there is a clear hierarchy in the systems that surround sudden and unexpected child death, which seem to understand ‘good communication’ as largely a one way process in which parents are kept informed by professionals rather than playing a more pro-active role. As Cathy summarises in Chapter 5:

  We get surveys about stuff from the Council all the time too which I’m always doing because I enjoy them, but when Dylan died there was no one to hold accountable,
there was no one to go to and say this is what’s happened and this is how I am feeling. The Coroner and the police were above everything and there was nowhere else to go.

However, when parents are invited to speak, as I was for the Guardian article (Moorhead, 2014) my original complacent notion that I could somehow assist others by telling my own story and thereby transform this ‘excluded middle’ was sharply rebuffed. As many of the narratives contained within this book have striking similarities to my experience, with parents like Laurie taking control of an uncontrollable situation, I had too easily assumed that my narrative of Joe’s death was a universal one. In doing so I had unwittingly created the form of binary which Cooper and Lousada allude to in their discussion of the ‘excluded middle.’ My initial reaction, as I have documented, was to follow Lewis and isolate myself (cited in Ellis, 1993). However, as time has passed I have understood the contributions to the Guardian Article as an intense rationale for further understanding the experience of grief, particularly where this relates to child death. Returning to the motivation of the Kennedy Report which sought to ‘sensitise’ professionals to the ‘emotions experienced by parents’ (RCPath & RCPCH, 2004) this understanding of the complexity of grief is absolutely paramount. One reply to the Guardian article (Moorhead, 2014) strikingly suggested that the article had helped to mitigate thirty years of self-hatred, grief and blame. This powerfully highlights the dangers of splitting and the ‘excluded middle’ having fallen into the gulf created for thirty years in which they had pathologies themselves. Returning to Bion (1962), the Guardian article, which they read decades after the death of their son, provided some sort of container for this experience and they were able to express their distress and record this within the online replies.

Throughout my experience of writing this book and conducting the research which underlies it, I have become increasingly aware of further ‘excluded middles’ created by splits, including those I have unwittingly generated myself. Just as I was ‘excluded’ from the ‘fragile group’ of bereaved parents by the academic who responded to the Guardian article and from the ‘tragic club’ by the parent contributors, practitioners involved with child deaths may be excluded from ‘a socially recognized right, role or capacity to grieve’ by virtue of their professional role (Doka, 1989, p. 3). As I discussed in Chapter 2, this may lead professionals in these circumstances to become ‘disenfranchised’ from their feelings about
the death, thus intensifying ‘feelings of anger, guilt or powerlessness’ (Doka, 1989, p. 7). These unprocessed and disenfranchised feelings may help to explicate some of the more apparently ‘inhuman’ behaviour evidenced by the guns and marked cars described in both Andy’s (Chapter 4) and Cathy’s stories (Chapter 5), together with the ‘uniformed officers’ and the ‘great big guy with full uniform’ described by Chrissie, in Chapter 4. It is therefore possible to view Rapid Response simultaneously as both a form of ‘splitting’ (Klein, 1935) and as a container for professional anxiety (Bion, 1962). The containing rigidity of procedure helps to dispel the anxiety and powerlessness that practitioners may feel whilst concomitantly ‘splitting’ them from the horror of the situation and thereby creating the conditions for the lack of humanity reported by parents in Chapters 4 – 7. As the social worker quoted in Chapter Two suggests, it is interesting to pause for a moment with this in mind and to reflect on how professionals would manage a sudden and unexpected child death without these procedures (Cooper & Lousada, 2005, p. 181).

These professional anxieties are not widely reported in the literature and the training material in the field of sudden, unexpected child death. In the DVD ‘Why Jason Died’ (Department of Education, 2008), for example, the professionals are all played by themselves and are shown as confident, speaking authoritatively directly to camera as they move seamlessly through a series of protocols, and support the terrified mother. Peter Fleming, a Professor of Infant Health and international expert in the field of sudden and unexpected child death states authoritatively in a key moment within the film that, whilst professionals often worry that they will do or say something that will make the situation worse, he is able to reassure them that they cannot possibly make it any worse. Fleming’s statement in such significant training material, which is widely distributed to social work teams and Local Safeguarding Children’s Boards across the UK, contrasts strikingly with Andy’s powerful statement (see Chapter 4):

The day itself and how we were treated was worse than actually losing him

As my experience of Joe’s death and many of the other stories within this book also demonstrate, professionals can make it a great deal worse, although as Chrissie, Andy and the other contributors show, this is often due to their own terror at finding this shocking
death at the centre of their working lives. Chrissie comments that the police officer involved with her baby’s death ‘looked terrified’, whilst Andy too describes the police officer as ‘finding it pretty hard’. Ellen particularly demonstrates the impact that child death can have on professionals in her story of the police officer who runs for charity in memory of her baby. (See Chapter 4). Portraying practitioners as invulnerable as they are depicted in ‘Why Jason Died’ fails to account for the ‘psychic damage’ (Cooper & Lousada 2005, p. 95) the death of a child may invoke, thereby consigning this to another ‘excluded middle’, as well as furthering the ‘myth of vulnerability’ where parents can be viewed as universally vulnerable and practitioners as unassailable.

The most surprising example of the ‘excluded middle’ that I have identified within this research lies in the lack of consideration given to surviving siblings within the professional response. In ‘Why Jason Died’, Jason’s siblings are described as staying with relatives and are therefore never seen and only fleetingly mentioned. This mirrors the literature within the field where siblings are never accounted for in both the Rapid Response and in the aftermath of a sudden and unexpected child death. However, my own experience (Chapter 1), and that of many of the parents described within Chapters 4–7, prioritises the welfare of surviving children both as an immediate and as a longer term concern. Terri, Cathy, Andy and Laurie all speak vividly of their surviving children, with Laurie’s account perhaps forming the most powerful (Chapter 7). In the Comments to the Guardian article too, the contributors highlighted the significance of other children within the home and particularly their effect on the quality and longevity of a parent’s grief.

The omission of siblings from the literature on sudden and unexpected death supports the proposition made throughout this book that over engagement with procedure and the related focus on high risk events, is in danger of creating the very situation it is setting out to avoid – the risk of harm to children. Whilst audit replaces relationship and professionals are not supported adequately, there is the ‘impulse to turn a blind eye...creating structures that purport to see but in practice turn away’ (Cooper and Lousada, 2005, p. 113). Siblings therefore fall into the ‘excluded middle’, out of view, in a place where they cannot interfere with ‘systematic investigation’ (Sidebotham & Fleming, 2007, p. 98).

In the next section I will explore some possible solutions to excavating the ‘excluded middle’ and to answer the question posed by Cooper and Lousada (2005, p. 113):
How do we manage the social task of both addressing toxicity and damage in a contained or safe enough manner without thereby sequestering it, or pushing it so far out of mind that we come to turn a blind eye to its reality?

‘It’s Good this Grief’

In addition to the emails and online contributions provoked by the Guardian article (Moorhead, 2014) I also received several letters which were sent directly to my work address. I have explained how I moved from initial distress at many of the online Comments, to understanding them as part of the complexity of the grief which follows sudden, child and other deaths. One of the most moving and meaningful responses to the article, for me personally, was a small book and accompanying letter I received in the post.

The book ‘A Letter to Henry’ (Wingate, 2010) was written by the father of a young man, Henry, who died in a car crash, aged 24. It is a very direct book which confronts taboos and, like Cathy’s narrative, in Chapter 5, is both angry and profoundly moving. In common with Raymond’s carving of the headstone (1989) and the two small toy figures’ discussed in earlier Chapters, the book is also a ‘place for experience’ (Hoggett, 2000, p.84). Within the book, the author offers a potential solution to bridging the ‘excluded middle,’ together with a further contribution to the debate about ‘getting over it’ discussed previously:

I realise it breaks a taboo to say this, but that doesn’t make it any less true: it’s good, this grief. I wouldn’t have sought it under any circumstances; it’s unthinkable to welcome it. But now that I have had it thrust upon me, I must make something of it (Wingate, 2010, p.13-14)

Viewed through the Kleinian lens which has been referenced throughout this book, Wingate’s description demonstrates achieving the ‘depressive position’ which bridges the excluded middle (Hollway & Jefferson, 2000, p. 20). Klein offers an example of this in her case study of Mrs A whose initial reaction to her son’s death was of ‘feeling numb and
closed up’, but who gradually moves to a realisation that ‘she could, and would, go on living and this meant that she could accept the event of the death free of the entanglements of her own fears and fantasies’ (cited in Small, 2009, p. 154).

Returning to the fierce debates provoked by the Guardian article, the ‘depressive position’ mediates between the forms of paranoid-schizoid splitting’ (Hollway & Jefferson, 2000, p. 151) which can be seen in the hierarchies of loss and grief constructed by contributors. A debate raged about the comparative levels of grief for children at different ages and indeed whether it was possible to grieve for unborn children.

Frank draws from the ‘depressive position’ in his concept of ‘bringing home ‘the boon’’, which he suggests is the task of all those who have suffered. The ‘boon’ in Frank’s model is the ‘insight that must be passed onto others,’ which in the case of fatal illness and death, is an acceptance of ‘mortality as common’ with a consequent absence of fear’ (1995, p. 121). What is needed for this to occur, however, is an adequate container for holding this fear – as in the case of Mrs A who used therapy to achieve this (cited in Small, 2009, p. 154). However in a culture where death is largely taboo (Rugg, 2006) this containment may rely on sequestered activities like therapy and consequently be difficult to source. The contributor to the Guardian Comments who described spending ‘over 30 years thinking there was something wrong with me’ evidences this powerfully as does Wingate in his description of breaking a ‘taboo’ to describe his grief as ‘good.’ (Wingate, 2010).

To act on Frank’s words and help towards a cultural depressive position where death can be viewed as ‘common’ calls for some way of honouring and connecting with the often ‘unthinkable’ experience of death. When Joe died, my initial reaction was to stop. It was clear that he had been dead for hours, and initially I did not even want to call an ambulance. Whilst this could be explained by denial, I have always maintained it as something other: as the ‘felt sense’ of a connection between life and death (Gendlin, 1996, p. 63). In this moment, the ‘still point’ as Eliot dubs it in Four Quartets (2001) there was paradoxically perhaps, a lack of fear and acceptance of death, just as Frank describes. In his poignant description of watching his father die, Lott (2013b) also highlights this acceptance of death as both ‘profoundly average yet utterly exceptional’, eliciting this still point as he describes his father’s last hours:
It took two more days before the end came. That time passed differently from how I had expected. Sad, but also tender and positive and beautiful. Death is so intimate – more intimate than first love. I could hold his hand, gaze into his eyes, stare unhindered at his tender face, stroke his frosty hair.

Lott’s description recalls the discussion in Chapter Two where both Kellehear (2009) and Gawande (2015) identify the growing cultural trend to split deaths into ‘good’ and bad.’ Child death is undoubtedly in the latter category and when this death is also sudden, there is no opportunity for acceptance, tenderness or the saying of goodbyes which Lott describes. As many of the narratives within this book demonstrate, from the second the ambulance arrives, the house ‘swarms’ with people, there is suspicion, investigation, flash photography and sequestration of the body by the Coroner. Far from the holding of hands and stroking of hair as described by Lott, the best parents may be offered is a lock of hair or brief contact with a child who is now the ‘property of the Coroner’ – a child who was alive only a few hours beforehand.

I suggested previously that much of this frantic activity may act as a form of ritual response to the enormity of death with which we struggle culturally (see Chapter 2), viewing it as the ‘antithesis’ to life, and therefore as a ‘failure’. (Dent & Stewart, 2004, p. 185). Many of the narratives contained within this book show, in common with Wingate (2010) a humbling acceptance of the death, which matches Frank’s call to ‘bring home the boon.’ Terri’s description of the death in her garden (see Chapter 4), together with Ellen’s description of the nurse who smuggles the apnoea monitor out of the hospital, thereby putting ‘herself on the line’, helps to restore humanity and tenderness to her situation and to bridge the gulf left by death. The Headteacher who, after Joe’s death, was able to talk to the children and to cope with ‘Joe’s box’, shows a comparable humanity and an ability to deal directly with the death itself and its immediate consequences (Chapter 1). Similarly, funeral directors, who literally bridge the gulf within their role, are the only professionals consistently described positively by parents (Chapter 4), thus demonstrating the healing capacity of ‘fearless engagement’ with the experience and the magnitude of death itself (Cooper, 2009, p. 441).
In his discussion of ‘bringing home the boon’ Frank (1995) suggests that ‘fearless engagement’ is achieved by ‘transforming fate into experience’ via the telling of stories. As I discussed in Chapter two, the growth of the internet and different forms of social media are generating new ways of achieving this story telling, dissolving taboos and creating a more direct engagement with the mundanity of death (Walter, 2012). The ‘online forums’ run by many charities are an example of this. However, whilst helpful, all forms of social networking tend to follow the model of parents talking only to parents and not to professionals, who in turn talk to each other. Additionally, internet forums can also extend mourning indefinitely (Mitchell, Stephenson, Cadell and MacDonald, 2012) as well as creating unhelpful splits when the wrong kind of story is being told (Warner, 2015). The Comments to the Guardian article (Moorhead, 2014) evidence both the powerful individual drive to narrate one’s story, thereby holding the promise that ‘all those who suffer can also be healers’ (Frank, 1995, p.xii) whilst simultaneously creating splits and unhelpful divisions between ‘good’ and ‘bad’ grief. This is also apparent in Chapter 5 when the interpretive panel expresses their dismay that Cathy is not ‘telling the story they expected to hear.’ However, I suggest that these are precisely the stories we need to hear if, as a society, we are to truly understand the ‘emotions experienced by parents’ (RCPath & RCPCH, 2004) and to allow their voices to speak outside the prevailing ‘language of survival’ (Frank, 1995). These are the voices that can lend comfort to someone who has spent 30 years feeling like a ‘bad mother’ as the contributor the Guardian Comments so movingly confessed. These are the voices which can heal the splits, reclaim the excluded middles and help us as a society to achieve the ‘depressive position’, moving forward slowly when we feel emotionally crippled by the sudden unexpected death of a child:

I seem to have made it back to the shore and found safe havens on solid earth... In spite of the continuing aftershocks, I find myself able to stand up and walk steadily and while I don’t know what comes next, I don’t feel afraid (Wingate, 2010)
**Knowing the place for the first time**

In the Four Quartets, Eliot alludes to the cyclical nature of human endeavour, suggesting that ‘the end of all our exploring will be to arrive where we started and to know the place for the first time’ (2001, p. 43). This description flawlessly defines my experience of writing this book and completing the research that underpins it. Both have both been intensely personal journeys which have helped me to arrive where I started, with a profoundly intensified understanding. My position as an insider researcher has led me to navigate many obstacles and face disagreeable and discordant surprises both in the research process and its aftermath, which have forced me repeatedly to confront my own perceptions and preconceptions. Perhaps chief amongst these, as I set out on the research path, was the notion that I could help to create a narrative for parents and thereby heal the split between their lived experience and the influential professional accounts written on their behalf.

Motivated by my own experience, as I described in Chapter 1, I wanted to help others understand that ‘someone else out there had gone through this experience and survived to see the light again’ (Nicholson, 2005, p. 8) as well as excavating the ‘emotions experienced by parents’ (RCPath and RCPCH, 2004). I also wanted a place for my own experience, which, like Raymond’s carving of the headstone and the small toy figures, discussed in Chapter 1, made some meaning of both Joe’s death and of the events that followed. In the early part of the research process, this sense of mission provided me with self-awarded ownership of the ‘great permission’ around child death, as having experienced this myself, I felt able to help others (Frank, 1995, p. 39) and to describe their feelings. However, the research process and its aftermath, most particularly the data analysis panels and reactions to the Guardian article (Moorhead, 2014) have taught me to heed Nicholson’s accompanying advice about the repercussions of death – ‘There will be a fight...you can’t stop it happening’ (2005, p.7). The inevitably of this ‘fight’ has taught me much about my original intentions to help by excavating the ‘emotions experienced by parents’ (RCPath and RCPCH, 2004), as well as the psychosocial model which has informed this book.

As I discussed in Chapter 3, this psychosocial foundation allows for ‘a space of ‘being in uncertainties, mysteries, doubts, without any irritable reaching after fact and reason’ (Keats cited in Clarke & Hoggett, 2009, p. 16) with many of the associated methods built around observing and reflection (Hollway, 2009; Trevithick, 2005). My original intention to
construct a ‘collective story’ (Richardson, 1997, p.33) of child death capable of speaking back to the Kennedy Report (see Chapter 1) and other professional accounts which omit parental narratives (Garstang and Sidebotham, 2008) called for such a space of ‘uncertainty’ where the concretised ‘expert’ narrative could be confronted and countered. However, in my conviction that I could help others navigate the experience of sudden, unexpected child death, I had replaced one form of concretization for another and failed to understand that the unique nature of grief renders constructing one ‘collective story’ completely impracticable. The reactions of the interpretive panels (see Chapter 5 –7) and the disparate responses to the Guardian article indicated clearly that there was no coalesced ‘collective story’ to be told and yet in the absence of this, I identified the splitting and defences I have discussed throughout this book. At times, these fissures together with the complexity of achieving my original mission, have recalled Rando’s experience of being advised to ‘stay away’ from researching child death altogether(1986, p.163).

Taking a psychosocial viewpoint on this, Hoggett (2000, p.15) suggests that we are compelled to ‘stay away’ from ‘dangerous’ topics like child death because they activate the ‘mad, bad, dangerous, and profane and dirty parts of our own subjectivity’ which we may prefer to deny or project into others. As a solution to this, Hoggett advocates for viewing difference ‘as a source of …wonderment’ in which the ‘depressive position’ (Klein, 1935) replaces ‘splitting’ as the dominant form.

Many of the accounts contained within this book offer similar solutions to splitting and defence. Julia’s story, for example, highlights her acceptance of Sophie’s death and the meaning making wrought by the passage of time, whilst Wingate’s declaration that his grief is ‘good’ proposes a similar form of the depressive position. Whilst the experience of writing and researching for this book have shown me unambiguously that grief is an entirely unique event (Ryan, 1989, p. 132) there is a form of collective story in many of the narratives which chart the experience of reaching the bottom and finding it is ‘solid’ (Frank, 1995, p. 126).

Recalling Cottle’s ‘myth of vulnerability’ (2002, p. 536) whereby certain groups are considered too sensitive or damaged to speak for themselves, these stories show that far from being universally vulnerable, many parents have a great deal to offer professionals in coping with their own fear and unease around child death. Doka (1989) suggests that practitioners are at great risk of disenfranchisement after an event like child death, as the
combination of their role and the socially prescribed grieving norms leave them outside the immediate kinship group and thereby unacknowledged – a factor I had not considered at the beginning of my research. Additionally, whilst parents remain excluded from meetings and consultations, professionals do not have access to their stories and are thus unable to listen, even when they are willing to do so.

Cooper suggests that ‘the power of the destructive and the negative is reduced or attenuated through fearless engagement with it’, and in this way listening to parents’ stories can assist professionals with facing their own anxieties and moving towards a position of ‘greater freedom, creativity and even happiness’ (2009, p. 441). This is a place of connection, where a different form of collective story can be formed. Ellen’s account of the policeman who ‘asked if he could use my baby’s name in his ‘Just Giving’ page’ because that was ‘his inspiration for doing the run’, powerfully demonstrates this (Chapter 4). The human connection made here, and the policeman’s ability to turn his own anxieties into a creative act, demonstrates how together they made the ‘unthinkable’ thinkable.

In the circumstances of sudden, unexpected child death, however, the potential of ‘fearless engagement’ is lost as those professionals immediately involved may never see the family again. In addition, many professionals are cast in the role of supporting bereaved parents before they have processed their own feelings, leading to the potential errors and appearance of indifference described throughout this book. Furthermore, when professionals do attempt to engage in an emotionally honest way they may be scapegoated by punitive management practices. Shulman (1991) examined the impact of traumatic events like child death on social workers and found that avoidance strategies prevailed. Instead of lending support to vulnerable practitioners, managers also widely apportioned blame, whilst attempting to avoid this themselves. Lees, Mayer and Rafferty (2013) endorse this in their study of organisations highlighting that where procedure may purport to be ‘promoting community interest’, it too often acts as a mechanism for ‘institutional self-preservation’ (Edwards, 2004, p. 50) and a means of controlling the terror of blame and failure, which has arisen under the culture of managerialism (Lees, Meyer & Rafferty, 2013). Munro’s review of child protection, as discussed in Chapter 2, is clear that these ‘managerialist policies’ are defensive, creating as many problems as they attempt to solve, and therefore, like Hoggett (2000) she advocates for ‘new’ ways of working.’
This call to action is vital in addressing the issues identified by the parents in Chapters 4–7 of this book. Psychosocial methods, as I have suggested, are often reliant on ‘observation’ and ‘reflection’ (Hollway, 2009; Trevithick, 2005) but it is paramount that these do not become used as excuses to avoid action. In uniting both the ‘psycho’ and the ‘social’ the ‘fearless engagement’ necessary to achieve social change may be rendered possible.

The gradual decline in mortality rates documented in Chapter One offers an opportunity for this action allowing parents and professionals a fresh opportunity to respond to sudden and unexpected child deaths in uniquely individual ways, as well as fostering greater social understanding of grief and bereavement, with the ‘sensitivity’ so often referenced in the Kennedy Report.

As the narratives in Chapters 4–7 shows, action also needs initiating over the experiences of any surviving children who are involved in sudden and unexpected child death. As I have documented, siblings are absent both from literature on ‘Rapid Response’ and in the training DVD ‘Why Jason Died’ (Dept. for Education, 2008), and yet were so powerfully present in Joe’s story (Chapter 1). In the narratives which form Chapters 4–7 there is also a catalogue of blunders with respect to surviving siblings, largely created by the defensive and often highly ritualised processes which accompany Rapid Response (Lees, Meyer & Rafferty, 2013).

Action also needs taking over the role of language which, as Hollway and Jefferson suggest, often expresses unconscious beliefs and ‘never represents the world neutrally’ (2000, p. 14). Whilst both the Kennedy Report and the professional literature repeatedly use the language of ‘balance’, combining ‘robust investigation’ with a ‘sensitive approach’ (Sidebotham et al., 2009, p. 294), the designation used when police attend a sudden and unexpected child death is commonly that of ‘Child Abuse Team’. As Cathy, Hafsa and Chrissie so vividly describe in Chapters 4 and 5, this can be terrifying for parents who already feel guilty and under suspicion. If balance was really the desired outcome, the language could easily be altered to help demonstrate this and to achieve greater symmetry, thereby reducing anxiety and fear for families.

Another issue that arises from the police response and language used is that of closure. Despite the recommendations in the Kennedy Report that all child deaths are followed by a
joint home visit, many parents do not understand this and may view it, as Cathy does, as a further act of suspicion or blame (Chapter 5). What many parents in this research have specifically requested is some form of written document from the police, which informed them that the case was ‘closed’ (Chapter 4). This lack of formal exoneration has been one of parents’ most enduring concerns and this could easily be ameliorated if it were made a formal part of procedure (Garstang, 2017).

These different forms of active change engage the potential schism between the psycho and the social, moving from ‘observation’ to transformation, a process which has mirrored my own passage through the research. Confronting my emotions has been intrinsic to the psychosocial underpinning of the research process and has taught me much about myself, as well as those who have both physically and metaphorically crossed the road to avoid me. At times, attempting to combine understanding my own motivations with my efforts at objectivity has been tortuous. I do not claim, therefore, to have succeeded fully in integrating my own emotional experience, should this ever be possible. However, I do believe that this book challenges accepted ways of knowing about sudden and unexpected child death, within an academic format that commonly drains research of its emotional meaning and dismisses the personal as invalid (Hoggett, 2000). As bell hooks declares:

> I see how many of the people who are writing about domination and oppression are distanced from the pain, the woundedness, the ugliness. That it’s so much of the time just a subject – a ‘discourse’...I say remember the pain because I believe true resistance begins with people confronting pain, whether it’s theirs or somebody else’s, and wanting to do something to change it (cited in Hoggett, 2000, p. 122).

To capture stories of sudden, unexpected child death as I have done throughout this book means confronting pain and at times provoking it, as the interpretive panels and aftermath of the Guardian article demonstrate (Moorhead, 2014). Understanding the ‘emotions experienced by parents’ as well as those experienced by professionals and wider society calls for taking the time to step away from the populist ‘emotional politics’ (Warner, 2015) incited by child deaths and to view them instead as individual forms of tragedy mourned in individual ways. My oversight in the early days of the research was to divide the ‘emotions experienced by parents’ from the emotions experienced by professionals in yet another
form of splitting. The ‘collective story’ I had sought to tell is in reality multiple stories but with one common theme – humanity. All the parents in this book speak of the need for this humanity and my own experience adds to this collective. Whilst Joe’s death was totally cataclysmic, I had always remained prepared for it by the circumstances of his birth. What made his death truly traumatic then were the events that followed, which lacked humanity and which I simply could not comprehend.

Whilst I may not have succeeded in telling one collective story, thereby uniting parent’s experiences of sudden, unexpected child death I hope that I have created a place for my own experience which simultaneously offers a meaningful and compassionate resting place for those disenfranchised by the experience of sudden, unexpected child death. As Frosh so strikingly affirms:

> For destructiveness to be meaningful and loss appreciated, there has to be something there that can be identified with, something that can love as well as lose, hope as well as be betrayed. In this something, this self, there is enduringly the spark of resistance, a potential to respond in a humanly worthwhile way to the mess that is all around (1991, p. 19).

**Conclusion**

In this final Chapter I have attempted to close the circle and arrive where I started at the beginning of this process, by discussing the uncomfortable and contested terrain which surrounds sudden, unexpected child death, in an era when children are expected to outlive their parents. As I have discovered throughout this research process, when children do die in an unexpected and untimely manner, the homogenisation which may befall the grieving processes of those who remain, can create unhelpful splits or ritualised responses which in turn may defend against unfathomable pain. Within this Chapter I have explored this via the responses to a Guardian newspaper feature and compared these to themes which arose in the narratives which form the heart of this book. Additionally, I have discussed the experience of allowing my own narrative to be mediated by a third party just as I have expedited those of the research participants. I have discovered the extreme discomfort of having my words picked over and frequently concomitantly misunderstood by strangers - a salutary lesson to me as a researcher. Most importantly, however, the experience described
within this Chapter, has highlighted the naivety of my original intention to create a universal narrative that would support people through the grief of sudden, unexpected child death. Despite this, as I reach the end of my exploring (Eliot, 2001, p.43) I hope that the narratives and discussion in this book will provide a means of grasping a topic that too often remains culturally unreachable and that they will be of some use to all those involved with the experience of sudden, unexpected child death.

Afterword

Joe died in 2005, aged nineteen months. By the time he died he had already lived through so many struggles - he had a distinctive personality and character and could both walk and talk. When he died my ‘miracle boy’ was no more.

In 2007, two years after his death, I began the research which underpins this book, finally completing this in 2013. Both Joe’s death itself and the completion of the thesis which
describes it felt like full stops, punctuating my life at junctures where I imagined somehow that time would simply halt, protecting me from having to engage further in the often painful process of existence. However, as Eliot (2001, p.43) describes ‘to make an end is to make a beginning’ and life does not allow us to pause for long, before the next event unfolds and sweeps us forward in its wake.

Reflecting on this and the panel response to Cathy’s story (Chapter 5) as I look back over the twelve years since Joe’s death I ponder, once more, if I have behaved ‘as a grieving mother should?’ and further if I have ‘got over it?’ As I consider this, the UK threat level has been raised to critical, following the bombing of a Concert hall, resulting in multiple child deaths and many grieving parents (Guardian, 2017). Perhaps in some mysterious way this provides an answer to my questions. There is no one way for a ‘grieving mother’, or indeed any mourner, to behave following a child death. All those whose children died in this tragedy, the tragedies that have come before and those that will inevitably come after, will have to learn how to grieve in their own ways. There is no template. Every death is unique, just as every child is unique. The narratives and other accounts within this book, including my own, demonstrate this vividly, with some choosing to gain support from each other as members of a tragic club and others, like Oliver Wingate embracing the ‘immeasurable’ and extraordinary’ gifts that remain (Wingate, 2010,p.38). These responses too, are only moments in time and will change shape as life events continue to unfold. They indicate, however, the complexity of sensitising professionals to the ‘emotions experienced by parents’ as the Kennedy Report initially set out to accomplish.

As for ‘getting over it’, in the strict definition of the term, then yes, I feel better. The extraordinary pain that stalked the immediate aftermath of Joe’s death has abated. In its wake it has left the lingering and disquieting knowledge that my two surviving children can be taken from me at any moment, as the line between life and death is extraordinarily fragile. As I listen to the parents whose children died in the most recent bout of UK terrorism, the fear which followed Joe’s death returns and I find myself keeping my children very close. Perhaps that is the single most difficult legacy of Joe’s death.

For the booklet that accompanied Joe’s funeral, I quoted from the words of Kahlil Gibran (1996) and I find comfort in these even now:
Your children are not your children.

They are the sons and daughters of Life’s longing for itself.

They come through you but not from you.

And though they are with you they belong not to you

We cannot hold onto our children, nor can we protect them, or even ourselves from everyday pain or tragedy. We can only be open to each day and grieve in the way that is most meaningful for each of us. What we can do for each other is build a form of ‘collective story’ which accepts the individuality of grief and does not pathologise people for behaving or not behaving as we think they should. This includes the professionals who respond to sudden, unexpected child deaths, as much as it applies to parents. My belief, endorsed by the experience of conducting the research and writing this book is that the entire experience is a collective one and that splitting the emotions of professionals, parents and even siblings is unhelpful. The ‘humanity’ which parents in the research so frequently cited, is for all those of us involved with the difficult business of being human - particularly when tragedy strikes.
References

Preface

Introduction


Chapter 1


**Chapter 2**


Cleaver, H. and Freeman, P. (1996) *Parental perspectives in cases of suspected child abuse*, University of Bristol, Dartington Social Research Unit.


Dyregrov, K. (2004a) 'Bereaved parents’ experience of research participation', Social Science and Medicine, vol. 58, no. 2, pp. 391-400.


Komulainan, S. and Haines, L. (2009) Understanding parent’s information needs and experiences where professional concerns regarding non-accidental injury were not substantiated, London, Department for Children and Families research brief.


Walter, T ; Hourizi, R; Moncur, W and Pitsillides, S (2012) Does the Internet Change how we die and mourn? Overview and Analysis Omega 64(4) pp.275 -302


Chapter 3


**Chapter 4.**


Cleaver, H. and Freeman, P. (1996) *Parental perspectives in cases of suspected child abuse*, University of Bristol, Dartington Social Research Unit.


Chapter 5


Chapter 6


Chapter 7


Chapter 8


Krane and Davies (1997)


Sikes, P. (2008) 'At the Eye of the Storm: An Academic(s) Experience of Moral Panic’ *Qualitative Inquiry* 14, 2, pp. 235 -253


**Afterword**

Dodd, V; Pidd, H; Rawlinson, K; Siddique, H and MacAskill, E (2017) 22 Killed; 59 Injured in suicide attack at Manchester *The Guardian* Available at: https://www.theguardian.com/uk-news/2017/may/22/manchester-arena-police-explosion-ariana-grande-concert-england

