**Chapter 12**

**The Metanarrative of Cancer:**

**Cancer and the death of an adult son**

**Nicola Martin**

**Preliminary Discussion**

Metanarratives of cancer seem to be laced with battle language which suggests that if the affected person puts up a good enough fight they will be able to defeat the disease. My personal narrative disrupts this unscientific and oppressive notion.Cancer killed John, my athletic vegan twenty-five-year-old son on 12-12-12 after he had endured a year of gruelling treatment. Metanarratives around grief and bereavement seem to be built on the idea that grief is time limited and time will heal. Faliure to follow a particular trajectory towards accommodation of the loss can result in the acquisition of a diagnosis of ‘Complicated Grief’ (White 2013). As a bereaved mother I dispute this idea. There is nothing complicated about my grief apart perhaps from my resulting indifference to my own cancer diagnosis in 2016. Complicated Grief is categorised clinically as lasting to a debilitating degree for two or more years (White, 2013). Undoubtedly my grief will last for the rest of my life. I simply have a broken heart. It is not difficult to imagine. Cancer is a monster which lurks in the collective imagination and every parent’s worst fear is the death of their child. I rather resent the role of Cinderella’s thirteenth fairy that my frightening life experiences have forced upon me. She is the one who appeared uninvited and cursed Cinderella at her christening. Fairy tales can be very grim. Winston Churchill would certainly not be my role model but his expression ‘keep buggering on’ resonates more with me than the thirteenth fairy’s approach of spreading gloom over everything. He was a bereaved father.

Metanarratives of cancer are laced with terror as well as battle language. On a personal level my own brush with cancer did not terrify me. Cancer is a broad church. Mine was stage one and curable. I am in remission. John’s was stage four, fatal and absolutely terrifying. I wish we could have swapped places. Although I am expected to balance my experience with his in this personal narrative, doing so feels impossible because we did not get an equal dose. Noticing two spots of post-menopausal bleeding, going to the GP on the insistence of my partner, diagnosis, surgery (three times over one year) and recovery does not compare with being handed a death sentence. Cancer Lite. I was certainly messed up physically by the operations and have been left with residual physical impairments. John had multiple rounds of debilitating chemotherapy which was ultimately pointless. Metanarratives around having a positive attitude and therefore somehow being able to defeat cancer offend me deeply. I got cancer, received effective treatment and carried on. My son never really had this option.

When I returned to work eight weeks after my second operation, I was a mess. My hands were numb, I walked with a stick and could not stand up straight. Unable to push open the heavy doors, I kept getting stuck behind them and had to rely on passers-by to rescue me. Some sort of phased return to work was arranged by occupational health but I just plodded on until I had to have further surgery. Following another eight-week absence, I returned to my job, overdid it and ended up back in hospital with dangerously high blood pressure. Pain and fatigue were considerable for about two years after my final surgery.

Psychologically I was preoccupied with the idea that I should not be alive when my son was dead. Without a doubt the worst thing was telling people about my diagnosis. John had died less than four years earlier and I had been reassuring my children that there was no reason to assume that cancer would pay another random visit to our house. Having swallowed my feelings since my son was diagnosed in order to function, I had developed an overwhelming desire not to be a nuisance. While he was ill, I was terrified of not being able to cope and I had got used to wearing a mask of capability which looked as if it was about to slip. I also nurtured the idea that John’s death was my fault. My worries were not about myself but about causing yet more pain to others.

There is little else to say about my cancer. Perhaps people look at me and think ‘cancer survivor’. I don’t know. What I do know is that I really do find the battling metanarrative of cancer unacceptable . It is not a case of my fighting and winning and my son giving up and losing. He said, ‘People will think I didn’t try hard enough.’ He did. It was never a fair fight. Ticking time bomb is another of those military metaphors of which I disapprove, but I must admit to feeling that one day cancer will explode and kill me. Realistically the odds are in my favour and old age should get me first. Although in legal terms a cancer diagnosis equates to disability, despite my resulting physical limitations it is grief which impacts on my identity and day to day life to a disabling extent. Metanarratives of disability only really encompass grief when the tipping point is reached and ‘Complicated Grief’ or similar labels can be applied. The medicalised labelling of psychological pain is problematic on many levels. Unfortunately labels often act as gateways to services and legal protections through equalities legislation. Accessing mental health support without going through some sort of diagnostic process is tricky especially when services are under pressure. In my fortunate situation compassion and empathy from friends and family did not dry up after a prescribed period of mourning. Metanarratives of grief are punctuated with suitable time lines over which the bereaved person should not stray. My friends and family disagree and so do I.

**Methodological Discussion: Autoethnography**

Methodology feels like a grand word in this context. I am telling my story from my perspective with reference, as appropriate, to theory and scholarship. Autoethnography fits this approach. My positionality is clear. There is no such thing as objective truth and this narrative is mine alone. The analytical frame I adopt involves theorising grief, loss and cancer in relation to disability, then considering my experiences through intersectional personal and professional lenses, before wrapping things up with some sort of conclusion which I hope is not too trite. Life goes on might be an appropriate cliché if this story was just about me, but the problem is that John’s life did not go on. From this point in the telling, my cancer is a minor character and grief is the main story, because that is just how it is.

**Analytical Discussion 1: Applying Grief, Loss and Bereavement Theory**

Metanarratives around grief, including Complicated Grief, are not all about bereavement but are always associated with loss. The experience of loss could relate to something like children growing up and leaving home, or missing out on a bonus at work. Life events such as these can be felt acutely even if they seem insignificant from the outside. Insecure early attachments and childhood trauma can result in ambiguous feelings of loss in adulthood. (Bowlby, 1969, 1982; Freud and Strachey, 1964). Jung refers to ‘individuation’ as the achievement of ‘a true integrated self’ (Kotzé, 2014, p.16) and contends that the process can be disrupted by childhood trauma. Being built on a firm footing of love and safety from early in life, and having strong social support, makes it easier apparently to deal with life’s challenges. My childhood was not traumatic and I was built on solid foundations of attachment. I got to the age of fifty-three before a monster called. Despite my best efforts I cannot say the same for my children who were in their early twenties when their lives were knocked sideways by John’s cancer diagnosis. He was sick for a year, during which time I was in such a deep pit of denial that I was almost impossible to reach. In this respect I feel I failed as a mother and this feeling is hard to shake. Metanarratives around good enough parenting are built on notions of creating security through firm, loving attachments and keeping the precious child safe.

Throughout John’s treatment I expected someone to materialise who was tasked with looking after his mental health and I hoped there would be some consideration of the mental health of the rest of the family too. This did not happen, despite the rhetoric of organisations like Macmillan who proudly display the slogan ‘no one should fight cancer alone’ <https://www.macmillan.org.uk>. It should have. Since we lost John, the rest of us have had various encounters with bereavement counselling, some more successful than others. At least some sort of mental health support was on the agenda. We needed it sooner.

Denial was originally identified in 1970 by Kübler-Ross as a stage of grieving. She conducted research with terminally ill patients and their families and identified a more or less stable pattern of five stages of grief: denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 1970). Guilt, isolation and hope were also part of the mix and Kübler-Ross concluded that progress through the stages was not necessarily linear or time limited. Her work was not just about bereavement, she was also interested in the perspectives of dying people. I am still preoccupied with John’s suffering during the year he was sick. Days before the end he said, ‘I thought it would be all right mum.’ You and me both, son.

Various stage theorists followed suit after Kübler-Ross and described variations on her original theme. Parkes and Prigerson (2010) used terms like numbness, pining, disorganisation and reorganisation. In an attempt to gain some sort of control we were actually more organised than ever before in our household while John was sick. We did not let things fall apart organisation-wise afterwards either. There were even days when the dishwasher and the washing basket were both empty. The surface of our pond was calm but just underneath we were frantically paddling to keep afloat.

Reorganisation in the Parkes and Prigerson (2010) model involves accommodating ‘Continuing Bonds’ with the person who has died. That is the easy part for us and is made easier because we still have Max. Although they are identical twins, my sons are really different but Max’s beautiful face is a reminder of his brother. I am not able to look at photographs of John but I don’t need to as he is always in my imagination. Not all grief theorists are as positive as Parkes and Prigerson about Continuing Bonds. Some view the idea as symptomatic of ‘Complicated Grief’, particularly if the feeling that the loved one is somehow not really dead seeps into the mix (Field et al, 2005; Klass et al, 2014; Scott, 1997; Stroebe et al, 2010). I know my son is dead but that does not mean that I have reached Kübler-Ross’s (1970) magical state of ‘Acceptance’. It is totally unacceptable to me that a twenty-five-year-old should lose his life and I am troubled about having survived cancer when he did not. Worden (2018) discusses addressing the tasks of grief in stages which include working through the pain, adjusting to the new situation and emotionally relocating the deceased in the past. Recently I was at a conference and I commented that working at Sheffield Hallam University was the best time of my life. An innocent delegate offered the opinion that it was such a shame to hear me talk like that because it was as if I had shut the door on the idea of better things ahead. He did not know my situation and I didn’t say anything. In reality that is exactly what I have done. When I had three living children my life was better. I am leading a diminished life. Metanarratives around bereavement imply that the journey of grief comes to an end at some point which is often referred to as acceptance. Kübler-Ross (1970), however talked about ‘Chronic Sorrow’ and acknowledgement of this idea is important. That’s where I live. Amazingly it is possible to function with a broken heart.

Nobody has diagnosed me with ‘Complicated Grief’, but the internet reliably informs me that I tick all the boxes. I disagree with the internet because my grief seems simple to me. White (2013) would certainly describe it as complicated. Features include a tendency ‘to push the pain away’ (p.17), avoid going out and making contact with people, stopping exercising, and developing poor eating and sleeping habits.’ All these things persisted for me for about three years and I am still a chronic insomniac. My one visit to John’s grave was on Christmas Eve 2012 on the day of his funeral. It was pouring with rain. I have no plans to return because I don’t trust myself to be in that space and not lie down beside him in the dirt. The idea of him being there in all weathers troubles me. By now my lovely son must be a skeleton. I am horrified by this idea. White calls it ‘Avoidance’. I call it a coping mechanism. Grief is worse in the middle of the night. In my dreams John is usually alive but often has cancer. Sometimes he is dead but still here and nobody is quite sure. I want to dream about him, and I constantly imagine conversations we might have together. This all seems perfectly reasonable to me but I imagine the *Diagnostic and statistical manual of mental disorders* (*DSM-5)* (American Psychiatric Association [APA], 2013) would disagree. Even if Continuing Bonds are indicative of Complicated Grief, John is not someone I can relocate in the past and I have no wish to do so. My love for my son occurs in the present tense. To me this seems remarkably uncomplicated. Of course, my bond with him continues. I am his mum. Metanarratives of parenting are underpinned by the idea of permanent unconditional love. Dissonant notes are sounded when the child has died. This situation subverts the whole order of things and makes others feel uncomfortable and afraid. I do not want to evoke this reaction.

Post-traumatic stress disorder (PTSD) and Complicated Grief, according to White (2013), often walk hand in hand. He describes the symptoms of PTSD as lasting more than six months and involving ‘intrusive repeated images and mental pictures related to the death and/or its consequences’ (White, 2013, p.16). While this is still part of my experience, I no longer run a full-colour moving picture of John’s death in my internal peripheral vision, but I do always have his image in my mind.

On 13-09-18, Oxford University’s Dr Anke Ehlers delivered a lecture at The Royal Society in London entitled ‘Haunted by Memories’. Ehlers used terms like ‘intrusive memories’, ‘triggers’ and ‘flashbacks’ to explain PTSD. All these ideas are familiar to me, but what I found most interesting was the idea of ‘Derealisation’, which she discussed in relation to a self-portrait by Frida Kahlo. The artist painted it after the near-fatal bus crash which left her disabled. Kahlo described the sensation of looking in on her body from the outside. My memories of the hospice and of John’s funeral are like this.

In his memoir *Reasons to Stay Alive*, Matt Haig (2015) described derealisation as feeling ‘detached from oneself’ (p.187). ‘I derealised. The string that holds on to that feeling of selfhood, the feeling of being me, was cut, and it floated away like a helium balloon’ (p.187). I know that state.

I used to say that I no longer felt like a real person. The word ‘dehumanising’ crept into my vocabulary to express my anger that nobody medically qualified realised that I was in a florid sense of denial throughout John’s treatment. I felt that if someone medical had spoken to me about my son’s terminal prognosis, I would perhaps have been more use to him and the rest of my family. Perhaps they did in euphemistic terms, using words like: ‘We are going to have to have some difficult conversations.’ None of that penetrated my shell. Grief theory is complicated and convoluted because these angry emotions also come with a side order of inevitable guilt.

Ehlers also talked about the feeling of wanting to die. No one is supposed to admit to that one, but I wanted to die when John died. In fact I wanted us all to die because I could not imagine our family without him there. Owning up to this would probably have landed me in hot water in relation to mental health services, but I had the sense to keep it to myself. As far as I know, PTSD is not recorded in my medical records, but seven years after the death of my son I still feel as if I am walking beside myself. My engagement with the world is split between keeping on buggering on, and managing the constant acute awareness of John’s permanent absence. Generally I function in this state. Sometimes I just run out of steam. The idea that this terrible thing must be happening to another family rather than mine preoccupied me while John was ill, and I still cannot reconcile my sense of self with the identity of bereaved mother.

Haig (2015) provides a list of symptoms of clinical depression to which I can relate, and reminds us that anxiety and guilt are often depression’s bedfellows (p.87). Depressive indicators include fatigue, low self-esteem, slowing of movement and speech, appetite disturbance, irritability, introversion and anhedonia (which is ‘the inability to experience pleasure in anything’). While I have never been told that I have this diagnosis I do recall a trip to my GP to discuss my insomnia, at the insistence of my partner. She asked me why I wasn’t sleeping, and within two minutes of telling her I found myself back in the waiting room with a prescription for anti-depressants, which made me feel somewhat invisible and also not really worthy of her attention.

Haig’s description of his guilt about being depressed reveals a degree of complexity which I did not experience and a metanarrative laden with value judgements.

If you feel the same amount of depression as someone would naturally feel in a prisoner of war camp, and are instead in a nice semidetached house in the free world, then you think ‘Crap, this is everything I ever wanted, why aren’t I happy?

(Haig, 2015, p164)

Compounding depression and anxiety by overlaying a big dollop of guilt only makes matters worse, but it would be a mistake to think that these reactions can be consciously controlled. My guilt is extremely tangible, because I firmly believe that if I had got John to the doctor about his migraines, they would have carried out blood tests and found and fixed his cancer. This is of course nonsense, but Complicated Grief and PTSD do not traditionally walk hand in hand with rational thinking.

Anxiety symptoms include restlessness, a sense of dread, feeling constantly on edge, difficulty concentrating, irritability, impatience and distractibility (Haig, 2015, p58). Physical signs include dizziness, drowsiness, pins and needles, palpitations, dry mouth, sweating, shortness of breath, stomach-ache, nausea, diarrhoea, headache, excessive thirst, frequent urinating, period problems, and insomnia (Haig, 2015, p.156). Stress makes matters worse, and low self-esteem is common in people experiencing grief and PTSD. Although I can relate to all of this, I have somehow managed to choke my anxiety into submission, or more accurately suppression. It may come back and strangle me later. In order to function, I have to keep troublesome ideas tightly controlled and have developed an uncanny capacity to do so. *DSM-5* (APA, 2013) will undoubtedly have a label for this. John is an identical twin. He shares all his DNA with Max. I have chosen not to think about the possibility of the monster calling on our family again. Freud might classify this response as ‘reaction formation’ (Freud and Strachey, 1964; Granek, 2010). It feels like one of my more useful defence mechanisms.

Scholarship informed by the lived experiences of bereaved mothers is in short supply and dads hardly get a look in at all. In 1997 Dr Judith Bernstein conducted a study with around fifty others similarly bereaved. She called the resulting book *When the bough breaks: forever after the death of a son or daughter*. The word ‘forever’ is pivotal and prolific in metanarratives of child loss by bereaved parents. None of Bernstein’s participants had any expectation of getting over their loss. They were doing their best to muddle through.

In 2016 Sara Ryan published an autoethnographic account of her experience of the sudden and preventable death of her son, Connor. The manner of Connor’s death meant that the family then had to endure a protracted inquest. John’s death was unavoidable, and Connor’s was not. We experienced kindness from family and friends following our loss and were generally ignored by the medical establishment. Sara and her family endured a lengthy ordeal at the hands of the legal profession. We both talk about PTSD, which Ehlers associates with sudden death. I experienced John’s death as sudden because I had not accepted its inevitability. Connor’s sudden death was different. It is not helpful to apply what Sara Ryan calls ‘that grief theory bollocks’ (which was largely conducted with populations other than bereaved parents) to every loss of every child. Although there are numerous studies which gaze in a medicalised way at the symptoms people in my situation display, there is very little insider perspective scholarship which takes a more nuanced view.

Disability adopts a peculiar place in the metanarrative about the loss of a child. In 2017 the story of terminally sick baby Charlie Guard was all over the news. Charlie’s parents were unable to accept medical opinion that their baby was profoundly disabled and dying. Charlie was their beautiful boy and of course they were doing everything in their power to persuade the doctors to save him. Empathy for the young couple appeared to me to be in short supply. Having taught children with multiple and profound impairments and life-limiting conditions, I understand that love is unconditional and permanent. Researchers need to talk directly to bereaved families before applying labels like ‘Complicated Grief’. They need to include parents of disabled children in these conversations and set aside any ableist assumptions.

Labelling the particular flavour of psychological reaction is only going to be useful to bereaved families if doing so results in some sort of useful intervention. Access to help without having to negotiate a medicalised gateway would be simpler. People able to pay can bypass referral and diagnostic obstacles, which hardly seems fair. Others who cannot afford to ‘go private’ may be able to access up to six sessions of Cognitive Behavioural Therapy (CBT) on the National Health Service in the UK. CBT is designed to challenge the client to think more positively about life events (Pearce, 2019). It would have been useless to me. There is nothing positive about the death of a young man of twenty-five. Grief theorists agree that there is no quick fix, but long-term psychological therapy is only really available to people who can pay. I have not come across any research about psychological interventions with parents hospitalised after the death of their child.

Research into how bereaved families find help is lacking. The chances of being able to source mental health assistance while in thrall to PTSD, Complicated Grief, depression, anxiety, derealisation, profound loss and other flavours of unimaginable psychological pain are vanishingly slim. Resources could be signposted much more clearly. Peer support is available from charities such as The Compassionate Friends (TCF). Service providers, such as the GP, do not have access to any sort of directory which would name organisations such as TCF.

Research ethics are a bit of a minefield. I have contributed to research from my perspective as a bereaved mother. The location of the interview was, disconcertingly, in a psychiatric hospital. It was just a bookable university room but hardly a natural space. The preamble and follow up were rigorous, but I left feeling upset and patronised by the suggestion that I should go and have a nice cup of tea and a piece of cake afterwards. Questions like: ‘Do you know where your son is now?’ floored me. Of course I know, but I could have done without the image of John in a cemetery. I just hope the findings translate into something of practical use.

**Analytical Discussion 2: Being at Work**

The previous section makes it quite clear that the loss of my son had a major impact on my mental health and the longer-lasting effects still persist, albeit in diminished proportions. In relation to being at work, it is both clear to me that work is work not therapy, and that having a job I love is an absolute lifesaver for me. Nevertheless, navigating the image I project in the workplace has become rather a complex balancing act between being honest and not freaking people out.

Roulstone and Williams (2014) observed that being open about disability at work carries a certain degree of ontological risk. Words like ‘cancer’ and ‘bereaved mother’ tend to conjure up uncomfortable images in people’s imaginations (Dias et al, 2017; Tiedtke et al, 2017). Although honesty feels more important than attempting to curate myself in a favourable light in the hope of some future gain, I am aware that speaking openly about my grief might well lead people to draw their own conclusions about the state of my mental health. My protracted grieving and ticking time-bomb cancer situation could well influence the way my colleagues see me and would probably make prospective employers think twice. If I were to apply for another job I would not mention these inconvenient truths, despite being a fierce champion of the contention of the UK *Equality Act 2010* that disability is irrelevant to recruitment and reasonable adjustments are an entitlement for disabled employees. I recently heard from a prospective doctoral student who was troubled because cancer had been mentioned in their reference. This is not ok.

Undoubtedly, losing my son has influenced my subsequent career decisions alongside every other facet of my life. John died on 12-12-12 and I went back to work on 03-01-13. At the time I was Head of Disability and Wellbeing Services at the London School of Economics (LSE). Although I was able to act the part, I questioned my own integrity because the students’ concerns seemed trivial to me in comparison to what happened to my son. Despite being nurtured and supported at LSE, I moved on. Academia UK popped up in the corner of my screen with an advert and I found myself sleepwalking into a new job in September 2013, without thinking it through. Amazingly it was possible to go through the motions of an interview and when asked if I was a firm candidate my honest reply was, ‘I don’t know, my son died five months ago’. Somehow, in September 2013 I found myself as Principal Lecturer in Inclusive Education at London South Bank University (LSBU).

Currently I am a Professor of Imposter Syndrome at LSBU. I feel like a bit of a fraud. Professor of Imposter Syndrome is not my real title but work is awkward because I know that I am the thirteenth fairy. Most of my teaching is in the Division of Education. Inevitably child development is on the syllabus and I do talk about bringing up my children because it comes naturally to me to do so. In my head I am still a mum of three perfect adult children, Max, John and Anna, twenty-three months apart including identical twins.

Professionalism stops me from using work as therapy and I am very careful not to burden my students with my grief. If I am asked a direct question like ‘How old are your twins?’ I say: ‘They were born in 1986.’ It is problematic, I feel inauthentic and I wonder whether my colleagues, who all know, are quietly cringeing. My sense of self is impacted by my bereavement. I feel doubly stigmatised as that woman who lost her son to cancer, then got cancer herself. Mothers are supposed to keep their children safe. I failed. The fact that I recovered is almost embarrassing.

In many ways I overcompensate at work. I feel like a pit pony. Every day I turn up and get on with it. Having dyspraxia presents its own challenges too and I am often embarrassed and apologetic about all the things I am not very good at. Getting to grips with technology is not my forte and my short-term memory is very short term indeed, which does not make it any easier. Getting promoted to Professor shocked me. Before John died I was moving in that direction but afterwards I felt like a different person. Stuff on my CV which predated 2011 had become irrelevant to me.

Psychologically I knew I just had to keep going at work and at home. I knew I must not stop but I didn’t really anticipate getting anywhere. Side by side in my head I experienced feelings of caring and not caring. During a conversation with my boss about whether something I had published was worthy of inclusion in the Research Excellence Framework submission, I remember thinking ‘try to look as if you care’. Ambition had left the building and it was hard to see why any of it mattered. Only very recently I felt a twinge of annoyance with myself for not applying for a job which I had felt a twinge of enthusiasm for and was probably right up my street. Progress maybe, of a sort.

As a researcher I am wedded to the notion of ‘nothing about us without us’ (Charlton, 1998). Emancipatory principles (Watson, 2019) underpin everything I do as part of the Critical Autism and Disability Studies Research Group at LSBU. Our group is inclusive, and insider perspective is central to all our projects. We avoid the trap of milking insiders for their knowledge without even offering fair renumeration, and usefulness is always a primary concern. My experience, in relation to the study I described in the previous section, felt like being subjected to the medicalised gaze, rather than being an equal partner in an interaction with shared objectives towards making the world a better place for bereaved families. I am very committed to making sure that I do not make anyone feel like this.

Organisations such as TCF are sometimes approached by researchers and have to balance on a tightrope between the idea of not subjecting vulnerable people to possible harm, and contributing to something with the potential ultimately to be beneficial. When John first died, I was very vulnerable and would have talked to anyone about my experience of loss. Ethical protocols are there to protect vulnerable people. At work I am the ethics Rottweiler.

Currently I am training part time to become a counsellor. It is quite possible that I will never practise but I thought it might be interesting. I am acutely aware that my circumstances are relevant. Counsellors need to work ethically and to demonstrate congruence and unconditional positive regard. Comparing other people’s experiences with my own and awarding myself the gold medal in the grief Olympics would not be helpful but I might not be able to stop myself. Ethically the therapist must make an informed judgement about their own competence and should signpost on if necessary. I imagine myself enacting counsellor behaviours such as active listening while thinking ‘Too trivial’ or ‘Come on, Grandma was a hundred and three’. This is not unconditional positive regard. My experience of the death of my son is always going to be an influence. I would need to be absolutely honest with myself about how this may impact on my ability as a counsellor.

My interest in my colleagues and students is genuine. I feel like it is not my turn to climb the ladder of success but that I should be right there behind anyone who is hard working and ambitious. Encouraging other people actually gives me a sense of purpose. I would almost venture to suggest that I even feel like I might be a tiny bit good at it. Thank goodness for work. It gives me something to do which has a real purpose. At the end of every day I ask myself what I have done which has helped another person. If the answer is ‘Nothing really’, I will do something like fire off a random encouraging email. Maybe other people think this is part of my strangeness. Although I get good feedback about my contribution, derealisation still stalks me. My sense of self left in late 2011 and has not returned fully. For this reason I could not possibly say what other people think of me because I just can’t work it out.

**Analytical Discussion 3: Keeping on Buggering On**

The most important thing in my life is my family, and the fact that I have two surviving children gives me a reason to keep buggering on. Work and personal life are not totally separate entities in my book. Work is good for me because it gives me a sense of purpose and is a major distraction. When I’m writing, or even marking, I am mindfully absorbed in something other than my loss. I get the same feeling when I’m with friends and extended family and I am able to be supportive and engaged with their lives. My creeping lack of unconditional positive regard occasionally raises its ugly head and my inside voice says things like ‘For goodness sake – it’s only Australia – she’ll be back’ or ‘So what? He can do his A levels again if necessary.’ At least it’s only my inside voice now, which is some sort of progress.

When John died I did not want to go anywhere or do anything ever again, but I had to because of my other son and my daughter. In relation to keeping on buggering on, I was going to work, seeing people, moving house and apparently functioning as a sadder version of my usual self. In reality my only concern was to keep going for my two other children and I was completely numb with grief. Carol Shields has the right words for this state of being:

It happens that I am going through a period of great unhappiness and loss right now. All my life I’ve heard people speak of finding themselves in acute pain, bankrupt in spirit and body, but I’ve never understood what that meant. To lose. To have lost. I believed these visitations of darkness lasted only a few minutes or hours and that these saddened people, in between bouts, were occupied, as we all were, with the useful monotony of happiness. But happiness is not what I thought. Happiness is a lucky pane of glass you carry in your head. It takes all your cunning just to hang onto it, and once it is smashed you have to move into a different sort of life.

(Shields, 2002, p1)

The fact is I regarded my happiness as completely unattainable, irrelevant and undeserved. As well as my identity in the eyes of others shifting towards the tragic, in my own view I felt like an undeserving failure because I could not keep my son alive with my love. Seven years on and I am able to experience joy in muted colours. I no longer consider that what happened made a mockery of everything we ever did before as a family and everything we will ever do in the future. Socrates is associated with the expression ‘an examined life is not worth living’. I have examined my life and I am living it with dignity, compassion and love. Maybe my grief is still disabling and I am a worthy candidate for some of those labels from *DSM-5* (APA, 2013), specifically Complicated Grief. Maybe I am lucky enough to be surrounded with love and support and this takes the edge off.

It is possible to frame bereavement reactions in social model terms to an extent, in that good social support makes the whole vile experience more bearable and lack of social support makes it worse. Additional intersecting factors such as poor housing, unemployment, sickness, isolation and money worries also contribute to making life feel like a bucket of shit. My life does not feel like a bucket of shit. One majorly shitty thing happened and some shit has stuck to my blanket, but it is still a nice blanket woven with love. My having cancer was not optimal but I got off lightly there. I know other parents who have lost a child and have not been as lucky as I have in relation to social support, and have all sorts of other worries which I do not have about money, health, housing and so on. Bereaved parents frequently talk about other people letting them down. Unwillingness to mention the name of the dead child, not marking anniversaries, crossing the road to avoid awkward encounters with surviving family members are all common experiences. None of these things apply in my case. It makes a huge difference. The fact that John’s medical team did everything they could for him also helps. Unlike Connor Sparrowhawk, John’s was not a death by indifference. My partner Mike says, ‘At least we don’t have to hate anybody’.

Often I imagine how John’s life might have been. He would have graduated from Oxford four years ago. Maybe he would be working in a bookshop and married to a lovely man who shared his sense of humour. His sister, Anna is in America and I think he would have been a frequent visitor. Max and John would still look the same but different. John was always the less flamboyant dresser although he might have changed in that respect. My three children were best friends. They inspire me. I am counting my blessings and know with absolute certainly that if I was given the choice of having John for twenty-five years or not, I would always choose to have that time with him.

**Concluding Discussion**

I got over my cancer and filed it away. Some may regard this as unhealthy or a symptom of poor mental health. The Complicated Grief metanarrative undoubtedly floats around me but I reject its pathologising connotations.

My work as a lecturer is a lifeline but I am troubled by feelings of inauthenticity as I can’t exactly hit a bunch of students with the C bomb and expect them to come away unscathed, so I hide behind my professional cloak of invisibility in this regard. I do my best to be a decent person and a good enough employee. Encouraging other people motivates me more than other aspects of my work. Luckily I do find my job distracting and interesting.

If I ever practice as a counsellor, I will wrestle my own self obsession to the ground and work with the understanding that grief and loss come in all shapes and sizes. I will flex my empathy and positive regard muscles and keep them highly toned and be mindful of neither projecting my heartbreak on to others or minimising their losses by comparison with my own.

The majority of this narrative interrogates grief theory from the perspective of bereavement, and I acknowledge my own positionality as a bereaved mum. I only really know about my own grief. It is necessary to understand grief in detailed and subtle ways, rather than piling everyone into the Complicated Grief sack together and rolling us towards a mountain of pills.

Being surrounded by love is the best thing. Some people just know how to help because they are naturally kind and empathic. My family has not experienced people looking the other way. We are very lucky because we are secure and surrounded by kindness and always have been. Not everyone comes from a stable childhood and operates in a secure home with enough money and an army of people ready to help.

The intersection between prolonged profound grief and disability is complex. Applying a *DSM-5* (APA, 2013) label such as Complicated Grief to my situation does not strike me as a particularly productive thing to do. Having had cancer, I am notionally offered some protection by the *Equality Act 2010* as a disabled person. Politically I think this is a good thing. Emotionally, for reasons I have tried to explain, I don’t really associate cancer with myself because I closed the lid on that box some time ago.

**References**

American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders: DSM-5.* Arlington, VA: American Psychiatric Association.

Bernstein, J. (1997) *When the Bough Breaks: forever after the death of a son or daughter.* Kansas City, MO: Andrews McMeel Publishing.

Bowlby, J. (1969) *Attachment and Loss: Volume I: Attachment*. London: The Hogarth Press and the Institute of Psychoanalysis.

Bowlby, J. (1982) Attachment and loss: retrospect and prospect. *American journal of Orthopsychiatry*, 52(4), p.664.

Charlton, J. (1998) *Nothing about us without us: disability oppression and  
empowerment*. Berkeley, CA: University of California Press;

Dias, N., Docherty, S. and Brandon D. (2017) Parental bereavement: Looking beyond grief. *Death studies,* 41(5), pp.318-327. DOI: [10.1080/07481187.2017.1279239](https://doi.org/10.1080/07481187.2017.1279239)

*Equality Act 2010*. London: The Stationery Office

Field, N.P., Gao, B. and Paderna, L. (2005) Continuing bonds in bereavement: An attachment theory-based perspective. *Death studies*, 29(4), pp.277-299.

Freud, S. and Strachey, J.E. (1964). *The standard edition of the complete psychological works of Sigmund Freud*. London: The Hogarth Press.

Granek, L. (2010). Grief as pathology: The evolution of grief theory in psychology from Freud to the present. *History of Psychology*, 13(1), p.46.

Haig, M. (2015) *Reasons to Stay Alive*. Edinburgh: Canongate Books.

Klass, D., Silverman, P.R. and Nickman, S. (2014). *Continuing bonds: New understandings of grief*. Abingdon: Routledge.

Kotzé, Z. (2014). Jung, individuation, and moral relativity in Qohelet 7: 16–17. *Journal of religion and health*, 53(2), pp.511-519.

Kübler-Ross, E. (1970) *On Death and Dying*. Oxford: Routledge.

Parkes, C.M. and Prigerson, H.G. (2010). *Bereavement: Studies of grief in adult life.* 4th Edition. Hove: Routledge.

Pearce, C. (2019). *The Public and Private Management of Grief*. Cham, Switzerland: Palgrave Macmillan.

Roulstone, A. and Williams, J. (2014). Being disabled, being a manager: ‘glass partitions’ and conditional identities in the contemporary workplace. *Disability & Society*, 29(1), pp.16-29.

Ryan, S. (2017) *Justice for Laughing Boy: Connor Sparrowhawk - A Death by Indifference*. London: Jessica Kingsley Publishers.

Scott, S.M. (1997). The grieving soul in the transformation process. *New directions for adult and continuing education*, 1997 (74), pp.41-50.

Shields, C. (2002) *Unless.* London:Fourth Estate*.*

Stroebe, M., Schut, H. and Boerner, K. (2010) Continuing bonds in adaptation to bereavement: Toward theoretical integration. *Clinical psychology review*, 30(2), pp.259-268. DOI: [10.1016/j.cpr.2009.11.007](https://doi.org/10.1016/j.cpr.2009.11.007)

Tiedtke, C.M., de Casterlé, B.D., Frings-Dresen, M.H.W., De Boer, A.G.E.M., Greidanus, M.A., Tamminga, S.J. and De Rijk, A.E. (2017). Employers’ experience of employees with cancer: trajectories of complex communication. *Journal of Cancer Survivorship*, 11(5), pp.562-577. DOI: <https://doi.org/10.1007/s11764-017-0626-z>

Watson, N. (2019). Agency, structure and emancipatory research: Researching disablement and impairment. In: Watson, N. and Vehmas, S. (Eds.) *Routledge Handbook of Disability Studies*. 2nd edition. Abingdon: Routledge.

White, C. (2013) *Living with Complicated Grief*. London: Sheldon Press.

Worden, J.W. (2018) *Grief counselling and grief therapy: A handbook for the mental health practitioner.* 5th Edition. New York, NY: Springer Publishing Company.

**Useful website**

The Compassionate Friends (2015) <https://www.tcf.org.uk/> [Accessed 26-07-19]