

listen carefully to what everybody said, to test our impressions of what different people said against other accounts, and to come to the best and most fair conclusion. It was not my role to discount what anybody said without reason, and it was not the role of the chair to order me, or my colleagues to do so. It's hard to convey how difficult I find it to make interventions like this, and because it is so hard I often (as in this case) suspect that I say too much and go too far, but I had no doubt that something needed to be said, and that I would speak out even if nobody else would. Though the chair of the committee had no option but to concede the point I made, things proceeded frostily after that.

I was not altogether surprised, given my estimation of the review chair as His Master's Voice, that when she drafted the first version of our report, there was no mention at all of what I viewed as a crucial part of what we had found. Every single person we spoke to who worked in the department and the faculty concerned spoke about staff unhappiness. They had different explanations for the unhappiness, but all agreed that there was a stupefying malaise in the organisation, which many described as toxic, and which most ascribed to authoritarian management practices coming from the top. When we interviewed the completely terrifying representative of senior management at the institution, however, this person informed our committee that every other person we had interviewed was "mistaken". The truth was that the staff were all well cared for and happy – they just complained a lot. This view, of course, chimed perfectly with our chair's injunction to dismiss the comments of a colleague as those of a "complainer". The word "doubleplusungoodthinkful" swam into my mind – there was something chillingly Orwellian in the assertion of authority to know the truth on the part of the power elite, and in their relegating the concerns of the many to thoughtcrimes. I did not for a minute expect our review chair to agree with my assessment of the situation, but I did think it was fair to insist on two things. First, I thought it was important for the committee to note this glaring discrepancy between the views of the senior manager and those of every single other person we interviewed. I did not insist that we take any sides on this gaping difference of opinion, but I insisted that the difference be mentioned. The second thing I wanted was that the committee comment not on the content of the difference of opinion, but on the impact such a serious difference in perspective can have for the functioning of any organisation, with a recommendation that this issue be further investigated as it could affect staff morale and quality of work.

Predictably, these recommendations were not welcomed by the review chair, and there ensued a long slew of round robin emails with the chair and me arguing about whether to include mention of the discrepancy in views. The chair said that commenting on differences in views between staff and management was beyond the terms of reference of the committee. I countered that if we ignored a major issue affecting staff morale, we could not make informed assessments and recommendations about academic quality and productivity in the department. And so we went round and round, copying each response to all the other committee members. Eventually I suggested that those people on the committee who agreed with me could offer a minority report in addition to the main report, and alongside the minority report the chair could provide a document outlying why she thought the minority report was effectively *ultra vires*. I was not giving up. I drummed up support for my approach from other committee members, but there is no question that I was the ringleader of the insurrection. Then transpired one of those moments that are really not thought about enough in this postmodern, interconnected world. This is a variation on the terror of the mistaken "Reply All" when one is saying rude things about some of the All (it is not for nothing that Reply All is a popular meme travelling, I am sure, at this very minute, somewhere on the internet). My rebellious behaviour (and my clear refusal to back down over it) was causing some consternation in the institution I was corresponding with, and, by accident, I was copied into an email string which clearly was not meant for my eyes. In this email string, there was a discussion about what to do about my irksome intervention. I cannot express strongly enough the extent of my pride when I read a comment about what to do about me. This read, "We cannot be seen to be giving in to the one who is shouting loud." All my life, I had waited to be seen as "the one who is shouting loud". I had my moment, but I had more. I have long held the deeply scientific and evidence-based view that there is a link (could it be fibre-optic?) between the unconscious and the World Wide Web. Given this undisputed fact, I had no doubt that this person who was so angry with me for shouting loud, at some deep level wanted me to know about all the trouble I was causing, and why that person was not standing for it. Goody. I think I won what was an essentially Pyrrhic victory after all this mess, as I got my way, but I very much doubt whether very many people ever saw the report, but that's not important here. What is important is that though I had been absolutely correctly identified as very quiet and on the sidelines, I am now probably known much more for shouting loud – getting in there, boots and all.

The truth is (and I honestly don't think many people know this – and especially many who get on the wrong side of my self-righteous indignation) that I commonly find shouting loud really difficult to do. I worry for hours about having upset and hurt people, and I anticipate terrible retributions which generally speaking do not come. But I grit my teeth and (usually) do it. I realise as I say this that, unfortunately, the book I should have written instead of the one you're reading has already been written – it's called *Feel the fear and do it anyway: How to turn your fear and indecision into confidence and action*¹⁵. Like the author of this Eight Million Copies Sold! work, I believe that though on the surface it may be a million miles between the quiet one on the edge, never saying a word, to being the one who is always Shouting Loud, it's actually not that far. And you know who knew this in 1939? None other than Lee Alexander – Bobbe's hero. Lee did not want to be seen as a "softie", and his heart "thump-thump-thumped in maddening crescendo". But, as she puts it so simply, "he had courage". Well, so did Bobbe, and, being my mother's son, so, I hope, do I. To be honest, I don't think life has thrown as much at me as it did Bobbe – I often say that I think I have had a better life than my parents had, because I have had better parents than they did. But I did learn from Bobbe, very young, that mixed in with all the brokenness and the difficulties (and she really suffered with her "nerves") is a kind of strength and determination to make life better. And because I knew this, because I saw her courage and tried it on for myself, I broke her heart, and more than once.

My cover story for leaving home at seventeen was water-tight. My ghastly grandmother was very much around, living with us, bullying everyone, and interfering in my life, going through my desk drawers, and shouting, shouting, shouting. Combine this with the charms of the Buchenwald Chicken, and you have the best reason to argue that it's time to get as far away as possible. I don't remember much about broaching the subject of my going away to university rather than staying in Johannesburg as was the custom, but I do know that my wish to do this was devastating for Bobbe. When we had moved to South Africa, Jenny had gone off to boarding school for the rest of her school life, and from the next year I was gone too, only to live at home again over three years later, when my parents had moved to Johannesburg. Now, just after Bobbe had her children back, here I was, planning to

¹⁵ Jeffers, S. (1987). *Feel the fear and do it anyway: How to turn your fear and indecision into confidence and action*. New York: Vermillion.

go away again. Even more upsetting, I had gone to boarding school not from my first year of high school, as had been the custom for English-speaking children in Lichtenburg, as there was no English-medium high school in the town. Instead, I had gone a year earlier (I had suggested this, and my parents had sadly but readily agreed), because of the very bad fit between me and Lichtenburg Primary School. So in the big reckoning of things, which Bobbe made, and made publicly, not only was I suggesting that she lose me, but she had already had an unfair burden of having lost me before. For the rest of her life, she would tell people that I “more or less” left home at the age of ten, and, apart from a brief respite, never returned home, and this was more or less – more more than less – true. From my point of view, in all this painful conflict, my father was magnificent. He supported my wish to go to Cape Town, and helped make sure that it happened. We all stuck to the cover story that I was getting away from Arsenic and Old Lace, but I suspect that my father, at some level, knew that another reason, and possibly even a more fundamental one, was that I felt I had to get away from my mother. The problem was not that I did not get on with Bobbe. Quite the contrary. I knew a mama’s boy when I saw one, and I saw one in the mirror. It is completely true that I needed to get away from Granny and Leah, away from the cliques of King David in which I never felt at home, but, most of all, I had to force myself to grow up away from the mother I loved so desperately. I had to make my own life, and I felt in my bones that if I stayed in Johannesburg I would never grow up. I knew that this would hurt Bobbe deeply, and it did, but the only way I could think of getting away was with this difficult, traumatic, and, for me, wonderfully exciting, breach. Years before, I had been sent to big school without the cushion of a nursery experience I still believe I really needed. Here I was, launching myself off into the unknown of a university and a town I had never seen, as far away as it was possible to get and still stay in the same country, but at the time I had no sense of how, in breaking with my mother at this age, I was at the same time reproducing a decision she had made about my education all those years ago, in pre-petrol rationing Rhodesia.

I was far too young for university. I had just turned seventeen, and I was a young and in many ways very naïve seventeen-year-old, not that I would have described myself as naïve in those days. My parents did not have a great deal of money, and I was desperate to get good bursaries so as to lessen any burden on them. While still in my last year of school, I applied for a generous and prestigious bursary to study law. The bursary was given by a huge corporation based in downtown

Johannesburg, and as a shortlisted candidate I went to the imposing offices of the company for an interview. Despite the fact that my father worked in an office block not far from this one, and discussed office politics every evening at home, I didn't have a clue. I had not researched the organisation at all, and I had not made the obvious link that if they want to train young lawyers they probably wanted these lawyers, or some of them, to work for the company. When asked about what kind of law I was interested in, I didn't have a clue. I mumbled something about going into my own law practice. I was a child. But I was a child who hurled myself out of the nest, ripped off the bandaid joining me to my mother and my family, throwing myself out into the world. Luckily for me, it was, I think, the best decision of my life. I struggled in my first year at university, passing all courses but none of them well (much to the delight of an envious cousin, who cheerily informed me that it was a known fact that people who did very well in high school academically all struggled at university), but I adjusted slowly and really came into my own, or what I thought was my own. I was off into the world, and to be honest I did not think that much about what a loss this was for my mother. I had given up being her little man, and she would have to get over it.

To make matters worse, I suspect, I travelled not only from Johannesburg to Cape Town when I went to university, but also from one social class to another. I don't know quite how it happened, but I fell in with a group of people at university all of whom were interested in classical music. I had wanted a piano and to study music as a child, but my parents said we could not afford this, and petrol rationing did make things tricky. Now my friends were people who had studied classical music all their lives and played instruments proficiently. Many of them lived in draughty old houses with shabby furniture and smelly overindulged dogs – the epitome of old money. When I read Curtis Sittenfeld's novelisation of the life of Laura Bush, wife of George H W Bush¹⁶, I identified with the main character's introduction to the fictionalised Bush family, who were clearly old money but seemed to take a patrician delight in the lack of comfort of their summer home. I learned from my new friends that really rich people act poor and that hopeless arrivistes, like my family, were the only people who would sink to the comfort of fitted carpeting. Friends in this group would in time flit off to Oxford and Cambridge in time-honoured upper class or colonial service Church of England tradition. I did not choose my friends on the basis of class or

¹⁶ Sittenfeld, L. (2009). *American wife*. New York: Random House.

religion, and I had my share of Jewish and Afrikaans friends (there were almost no people at UCT in those days who were not White), but I was dazzled by this new world, which seemed to accept me more than King David had done. Not that all of this was without its edges. One day, with two of my friends, I was making a joke in a broad Yiddish accent and one of them interrupted me, saying, “Just stop that, Leslie. Stop it. Stop it.” I honestly don’t think that this cruel intervention was anti-semitic or had anything to do with social class, new money or old. The friend in question was depressed and irritable, and not known in general for tact. But, I am ashamed to say, the comment really cut me – why else would I remember it today? It said to me that though I was clever and interesting enough to be part of the group, I would never really belong and be accepted – I had escaped the there of King David, but I would never fully be here. Story, in some ways, of my life, and story of Bobbe’s life too.

After the war, Bobbe took the outrageous step of going overseas for a few years. Off she went on her own, a single woman, to live and work in bombed-out London. This was many years before gap years and ramblings around the world to find oneself. She went off to a foreign country where she knew nobody, unimaginably far from Johannesburg and the shtetl of just a generation earlier. Brave, foolhardy, risky, probably hurtful to her mother, but it all sounds remarkably familiar. Like son, like mother. Bobbe had a number of clerical jobs in England, the longest being with the Jewish Board of Deputies, which she really enjoyed. Her boss was a senior figure in the organisation, a scion of Anglo Jewry, and he was kind to Bobbe, inviting her for weekends to his country house with his family. He was also, Bobbe told me, inclined to “*tapn*”¹⁷ her, as she put it. She didn’t like this “tap-tap-tapping” as she described it, but she had to put up with it. She worked for a time, she told me, with Greville Janner, who was a few years younger than she was, and who went on to become a Labour MP and a peer, and who had a long association with the Jewish Board of Deputies. In the 1990s Janner was accused of child sex abuse, something he denied. Janner died a few years after Bobbe and before the allegations had been fully investigated. The allegations took up a life of their own and became intertwined with anti-Semitic invective. Janner’s daughter, Rabbi Laura Janner-Klausner, continues to argue for her father’s innocence. I have no idea at all whether Janner was innocent or not, and like Rabbi Janner-Klausner, I believe both that victims must be heard, and that there are cases where people are indeed falsely accused. When I

¹⁷ “*tapn*” is Yiddish for groping or feeling.

came across Janner's genial face while researching for this book, I thought of the genial face of Bobbe's boss, who was so kind to her but was also "tap-tap-tapping". She had to put up with it, and there was no question at the time of her making any complaint about this.

London after the war was cold, wet, and dirty, with legendary pea-souper fogs, which Bobbe used to speak about often. She was often cold and did not always have enough money to put in the gas heater. Bathing was allowed once, and occasionally twice, per week at the grubby boarding house where she stayed. But she loved it. She described being taken on dates by a South African artist and photographer. He took her to look at bombed-out buildings and pointed out the beautiful colours and patterns in the rubble. "The man was mad," Bobbe would say, "these were ruins of houses where real people used to stay." But she was thrilled by a different way of seeing the world.

She loved sitting drinking tea and eating something at the Lyons Corner Houses, with their waitresses known as "Nippies", then really at their heyday, serving good quality food and drink at low prices. When we would eat Lyons Maid ice creams, including the two-in-wonderful Mivvi, in Rhodesia, Bobbe would sometimes talk about the link to the Corner Houses, owned by the same J. Lyons and Co. Recently I read and enjoyed a popular history of the company entitled *Legacy*¹⁸, and the descriptions helped me visualise a young, pale, Elsie Cohen, sitting drinking tea, alone in a bustling café on a grey London day. I had one of those moments of wanting to phone her to tell her that I had found this book and its related website so that she could read the book, enjoy it, and reminisce. It made me think of other books we had enjoyed together and especially Jung Chang's *Wild Swans*¹⁹, which, like *Legacy*, was a nonfiction family saga spanning generations. Bobbe would have loved reading about the Gluckstein family and their journey from poverty and oppression in Germany through a long route to being so influential in shaping the outlines of the postwar London that she revelled in.

London was certainly not all excitement and minor setbacks. A young woman travelling on her own at that time (and probably today) was seen as vulnerable and fair game. There were unwanted advances to fight off, as I have mentioned, and a

¹⁸ Harding, T. (2019). *Legacy: One family, a cup of tea and the company that took on the world*. London: William Heinemann.

¹⁹ Chang, J. (1991). *Wild swans: Three daughters of China*. London: Harper Collins.

reputation to try to maintain. There was the cold, the wet, the fog. Bobbe had run away, but she still had herself to maintain and keep together. But she could (and did) do it. And when I think of this act of bravery, this breaking of convention, I can't help remembering that a generation later, irony of ironies, I also ran away, as far and fast as I could. The running has been a lot of fun, and I have such a good life. But here's the thing: just like Bobbe, I ran and I ran and I ran. The pace at which I work and live my life is testament to how I am still running. But of course, the further you run away from home, the further you run from yourself. I'm working on trying to find my way back. Paradox of paradoxes, though many have helped me with this, Bobbe is one of them.

Chapter 8: Coming home

My father died suddenly in 1983, and Bobbe was a widow at the age of 58. He lived longer by far than Bobbe's brother Hymie, her brother-in-law Alec, who died in their 40s, and my cousin Stanley who died in his early 30s. So the family's anxiety about Bobbe's being a very young widow had been misplaced to an extent, but 58 is still young. My father lived to see both his grandsons but died before I had children.

The fact that my parents had such a happy marriage, despite many difficulties along the way, is something I treasure and am grateful for. Partly because I was so close to Bobbe, I was much further away from my father when he died, and this is something I still regret, but there is so much I have from him which is not to regret. Bobbe was devastated by her loss, as was my grandmother – it is no easy task to bury your only son. Almost immediately, though, Bobbe had a battle on her hands, as Granny and the Buchenwald Chicken decided that as my father was now dead, the best plan was that they move permanently into my mother's flat with her. It was a large flat and they could each have their own room, and the plan was that they would all settle into a kind of toxic but comfortable intergenerational mourning, tended to by Anna Mothupi, Bobbe's long-suffering domestic worker, and one of the few people who knew how to handle the vicious old women.

How did Bobbe handle the demand for creating an intergenerational commune, akin to a Johannesburg suburban equivalent of a Lorca play? I worried that she might just succumb to the pressure, as she had done to varying degrees (to her cost and ours) throughout her long marriage. She proved herself made of sterner stuff, but went to some rather extreme lengths to get done what needed to be done. She was absolutely clear that she would not have Granny and the Chicken come and live with her. She would visit them, take them out on weekends, and tend to their needs, but she was not going to have them live with her. Bobbe's sister, Hannah, herself a widow now, and to whom Bobbe felt close, came to stay, but there were still two free bedrooms in the flat. Saying no to the old ladies felt impossible, so there was only one thing to do: move to a smaller flat. Not long after my father died, I went to Johannesburg for a few days to visit Bobbe, and she took me along to see another flat she was interested in. In my view, everything was wrong with this flat, including the fact that a huge shopping centre was about to be built just a few feet away from it. The estate agent was, like Bobbe, a Johannesburg widow, but a good bit older than Bobbe, and a distant relative. Using all the rhetoric of concern for the welfare of

a distant relative in need, the estate agent put on a virtuoso performance of how urgent it was that Bobbe sign immediately to secure this highly desirable property. This story is like so many others about estate agents, and there was indeed something of a cliché about the whole situation, but what shocked me, and made me realise how deeply Bobbe had been affected by her bereavement, was how completely docile she was in this woman's hands. Had I not been there, I have no doubt (and Bobbe herself had no doubt), she would have signed there and then. Needless to say, I was not the estate agent's favourite for shouting loud just as she was moving in for the kill. But who gets killed? The ones who are weakened and separated from the pack. Bobbe was alone. She had her children and grandchildren, Anna Mothupi, and her sisters and other relatives, but so alone in her grief. She was in the process of manoeuvring her way out of being invaded by the toxic old ladies, but before my eyes she almost succumbed to the pushing and shoving of an unscrupulous older woman. Old habits, alas, run deep.

In the event, Bobbe solved the problem by moving into a smaller flat in the same block where she lived, and now there were only two bedrooms – one for her, one for Hannah, and none for you know who. She continued caring for those old women and dealing with their attacks, and arranged for them to move into a comfortable aged home. The Chicken developed Alzheimer's and in a radical reversal of character, all the sweetness and kindness that she had been repressing for years now emerged as her brain's frontal lobe withered away – she became compliant and sweet, and a favourite of the care staff at the home. Granny, for her part, softened too, and even began thanking Bobbe for what she did. Jenny and her family were in the process of emigrating to Australia, and Bobbe wanted to move to Cape Town to be closer to me and my family once they were gone, but she dutifully delayed her move until Granny died. Bobbe cared for this woman to the end, fulfilling to the letter the injunction her own mother had given her all those years ago. She did leave Auntie Lea behind, but by that stage, she felt that Lea's capacity to recognise her was completely diminished. Nevertheless, she felt a bit guilty about putting her own needs above those of a woman who had tormented her for over thirty years.

I wish I could say that I felt ambivalent about Bobbe's move to Cape Town in 1994, but that would not be true. I was dreading it. I had run away and run away, and until her dying day, Bobbe never forgave me for having married out of the faith, and for having two children who, technically, were not Jewish, because in Judaism, religious

status is inherited from the mother. My father was amazingly supportive about my decision to marry “out”, and given Bobbe’s own marginal status in the Jewish community, I did not anticipate quite how hurt she would be and quite how badly she would behave. She railed at me, shouting, “The blood of Eli is in your veins.” I had no idea who Eli was and what his blood was doing in my veins, and for some inexplicable reason I was reminded of the title of a film I had never seen, “Who is Harry Kellerman and why is he saying those terrible things about me?” Luckily, I managed to restrain myself from informing Bobbe of this facetious connection, but it does speak to my adolescent reaction to her upset.

Bobbe behaved badly about my decision to marry out, both before and after the event, but she tried her best to be reasonable and forgiving. In some ways this made things much worse, and I found myself at times wishing that she had done what many lesser people in her position had done – to cut me off, refuse to speak to me, even sit *shiva* for me as though I was dead. Instead, mixed in with all the kindness was the drip-drip-drip of disappointment and disavowal, with what felt to me awful and cruel things popping up almost by themselves into what otherwise felt like ordinary conversations. On the wedding day itself Bobbe was magnificent, as were her sisters, who came all the way to Cape Town for the wedding, were kind, and behaved themselves. It really helped that by the time I got married (and, later, divorced), our extended family was inured to scandals, marryings out and the like – it helped to be the youngest cousin. I was unable to top the marrying out of one of my cousins, who not only married out, but had the distinction of having a Catholic nun for a mother-in-law. Her mother-in-law had taken orders after being widowed, and by comparison my marriage to a non-observant Anglican was small potatoes.

If Bobbe never forgave me, there is much, I realise, that I am still deeply angry with her for. Though this changed later, and dramatically so, she really struggled to accept my children, and I found it hard to feel that they were being rejected through no fault of their own. In the Jewish tradition, Alison was named for my late father, and I remain pleased and proud about this decision to this day, but it did not seem to mollify Bobbe, not that that was ever the primary aim with naming. When Alison was about three months old, Sally and I went on a trip first to Johannesburg and then on to Zimbabwe to introduce the new grandchild to our mothers and siblings. There is no question that Sally and I were anxious and probably over-attentive parents to our precious new child, and when the three-month old burst into very loud tears after

being handled roughly and spoken to very loudly by a visitor who was never known for her softness, subtlety and tact, we did rush in to comfort our fragile child. “Poor thing,” proclaimed Bobbe to all the assembled tea guests, all of them Jewish women of a certain age, “she doesn’t like Jewish people.” I cannot begin to count the ways in which this stung me. It seemed hopeless to point out, though I did, that Alison’s godmother, and still one of my dearest friends, was not only Jewish but very serious about her Judaism, as she remains to this day, or that we had many friends who were Jewish. This would get us straight into the “Some of my best friends are Jews” rabbit-hole, and there’s really no decent way out of that one. Bobbe was right, of course, that I struggled with my Jewishness, as did she, but she had pushed me somewhere rather awful and I felt deeply misread. It is not for nothing that I have, in my atheist way, celebrated every Passover and New Year (eating a lot but observing the occasion nevertheless) since I left home at seventeen.

The approbation waxed and waned, but it was always there, and it seemed to me that the story was more about betrayal than about religion itself. One Thursday evening, Bobbe phoned me, and said, rather aggressively, “What do you say?” “I don’t know what you mean?”, I replied. “What do you say? What do you say?” I knew I was expected to say something, and that I was being tested (and failing) but for the life of me I didn’t know what the thing was that I had to say. Eventually, after multiple, and increasingly exasperated “What do you say?”s, Bobbe shouted, “You say, ‘Good shabbos’.” Now, we had never been a family ritually to say “Good shabbos” as a Sabbath greeting to one another every Friday evening over the phone (though there are plenty of families that do that). There was another technical problem, as I took some relish in pointing out. It was Thursday evening. Nobody says “Good shabbos” when it is not shabbos. I tell this, of course, partly as a funny story against Bobbe, but there is also a part of me, with the benefit, and the cost, of distance, time, and her death, which feels desperately sad for her. I had done it – I had run away, cut her off, married out, broken her heart. Try though she might to forgive and to accept, and she did try, I was lost, lost lost to her.

And Bobbe certainly did not have the copyright on bad behaviour. For much of my life, though I was an adult, I behaved towards her with the casual cruelty of an adolescent. Anybody who knows my younger daughter, Rebecca, knows that from a very young age and until this day, she has been very sceptical of received wisdoms, and especially wise to the shenanigans of manufactured piety. We sent our

daughters to a state school, but there was a strong, and, in my view, stickily coercive and saccharin, ethos of Christianity in this notionally non-sectarian institution. Alison was once advised to be the little light of Jesus in her father's dark home, which did not sit well with this heathen father, but that's another story. Many of the proponents of Christianity at the school – teachers, other pupils, and parents – went in for what I saw as a kind of commercialised, new-agey born-againism, very different from what I saw as the demanding and substantial Christianity practised by religious friends I greatly admired (and still do). Accepting Jesus as your personal saviour, in this context, felt to me like a kind of religious Get Out of Jail Free card (many of the most pious girls were also bullies in their spare time), and a guaranteed entrée into what I nastily called The Christian Girls' Dance club. At every school event, the Christian girls, the most pious ones, would club together and do a dance to the latest pop song, complete with suggestive hip movements, but tastefully done. Don't put your daughter on the stage, Mrs Worthington.

But I digress. Well – not really – I guess what I have been trying to say is that I did not and do not accept this Uriah Heap-style coercion dressed up as piety, not that there may not have been some genuine religious conviction in some of the girls thus practising piety. And in terms of scepticism of all of this, fair or unfair, Rebecca was with me – she was having none of it. So when I casually said to Bobbe that Rebecca had accepted Jesus as her personal saviour, in my conscious mind I was making a very funny joke about my respect for Rebecca's astonishing ability to see through cant and humbuggery, from a very young age. To my horror, of course, Bobbe took my comment literally, saying that she had always known that Rebecca had been very keen on Christianity and why shouldn't she be after all? Bobbe was deeply hurt, her worst fears realised, and of course I can now see the aggression towards her in my ill-judged joke. I still think the idea of Rebecca accepting Jesus as her personal saviour, at that age and under social pressure she would never buckle under, is nothing short of hilarious. My cruelty towards my mother, however, was far from funny. Worst of all, though I tried my best to explain the joke and to make things better, I think that for a time it put extra strain on the relationship between Bobbe and her non-Jewish grandchild. I hurt them both.

My marriage broke up not long after Bobbe moved to Cape Town and for a long time I was broken. I was terrified of telling Bobbe about the failure of a marriage she had not approved of in the first place, and I waited for "I told you so", but it never came. I

was worried that, in a macabre and ironic re-enactment of what Granny and the Chicken had planned after my father died, she might try to move in on me, to take me back as her little man. I knew for sure that I would never have another adult relationship, and I feared slipping back into everything I had run away from – mama's boy.

In the event, Bobbe was wonderful. She was supportive but did not intrude, listened to me but never bad-mouthed Sally (I could not have borne this). Best of all, I started to see a change in how she was with the children, who had a lot to bear at this difficult time inflicted on them by their parents. Bobbe rose to the occasion, and though things were often difficult (no miracle here), she started, it seemed to me, really to see Alison and Rebecca for the remarkable people they were – far more than as evidence of my betrayal, but living, breathing beings in their own right. Strangely enough, it was in this time that I began to allow myself to see fully what I had been subliminally aware of for some time. There had been major changes in Bobbe over the past ten years.

For a long time after my father died, it felt to me that Bobbe would never recover. Slowly, though, she began to change. I arrived in Johannesburg to discover that she had dyed her hair, something she had never done in her life, and she looked much younger now that her hair was not grey. Her clothing changed, and I never saw the green and black slacks suit again, indestructible though it was. She told me and others that she was in the market for a new husband, that she didn't want to remain alone for the rest of her life. This shocked some people as inappropriate and disloyal to my late father, but I saw it differently. My parents had had a marriage beset with difficulties and constantly in danger of being overshadowed by the bile of the older generation. But it was not for nothing that, to my embarrassment, I used what has become a Shakespearean cliché to describe their marriage as one of "true minds". Whatever else (and there was a lot of else), my parents respected each other, each with a real interest in the mind and feelings of the other. The fact that after thirty-two years of marriage, my widowed mother could step out into the world and say she wanted more from life was a tribute to her marriage and not a disavowal of it. She did not have to prove anything, to remain stuck in a show of mourning to know in her heart just how much she had had, and how much she had lost. Her good marriage allowed her, encouraged her, to move on. For a while, she went out with a widowed relative of a relative – a man both she and my father had known and liked for many

years. Jenny and I hoped that this might lead to something more, but it ended. There were one or two other hopeful-looking possibilities, but nothing developed very far.

More fundamental than Bobbe's wish to find a husband, though, was how different she became in the world. The change in physical appearance was dramatic. Here was a woman who had convinced herself and others (including me) that she was ugly, and now she was a stylish dresser always beautifully turned out. I had always known that she had astonishingly bright blue eyes ("Royal blue, like Elizabeth Taylor," people would say). Now these eyes seemed more prominent and noticeable. Her adventures with hair-dye were short-lived, but the well-coiffed grey hair seemed to set off her eyes very well indeed. Of course Bobbe, being Bobbe, did keep up old habits. She was living in an aged home in Sea Point, determined never to do what her mother-in-law had done – she would never want to live with us and interfere with our lives. Sea Point, apart from being the natural habitat of elderly Jewish women, is also the playground of the young and glamorous, and has no shortage of shops offering to beautify you, including hair salons. Trust Bobbe to find a really excellent hairdresser, great at cutting hair, but clearly with a serious drug habit and a salon which was dirty and depressing. On one occasion, she insisted that I go to this man to have a hair and beard trim. It was not a good day at the office for him and he cut my neck, not too badly, but enough to draw blood and to hurt. When I told Bobbe that I would not be returning for further butchery, her response was, "Shame, if we don't go to him, who will go to him? The poor man is trying to make a living." For some reason, this reminded me of an exchange between the hero's parents in the film *Annie Hall*:

THE FATHER: You fired the cleaning woman?

THE MOTHER: She was stealing.

THE FATHER: But she's colored.

THE MOTHER: SO?

THE FATHER: So the colored have enough trouble.

- THE MOTHER: She was going through my pocketbook!
- THE FATHER: They're persecuted enough!
- THE MOTHER: Who's persecuting? She stole!
- THE FATHER: All right – so we can afford it.
- THE MOTHER: How can we afford it? On your pay? What if she steals more?
- THE FATHER: She's a colored woman, from Harlem! She has no money! She's got a right to steal from us! After all, who is she gonna steal from if not us?

In a word: if this hairdresser didn't have my throat to cut, whose throat, after all, would he have to cut? Bobbe stayed loyal to this man until it was absolutely clear that the injectables had won, but in keeping with the changes happening in her and in our relationship, we laughed and laughed about the situation, and told anyone willing to hear about Bobbe's support for this man and his drug habit. Enabling addiction has never been more hilarious.

Another side to this, though, was that after the grief following my father's death, and that of her mother-in-law, Bobbe's courage, as she had put in her story, though there was no question that it was always there, came much more clearly to the fore. If she wanted to have her hair done by a drug addict, so be it. She relished, in fact, in shocking some of her straight-laced friends with stories of what she termed "the drug abdict", explaining her using one of Granny's many malapropisms. She had always held very strong, and sometimes surprising, opinions – for as long as I can remember, for example, she was vocally in favour of women's rights to abortion on demand, being pro-choice before pro-choice became a thing in the 1970s in South Africa. But now she shouted loud, and a lot. She told anyone who would listen what she thought, why she thought it. My particular favourite related to her decision, after she decided she did not want to drive any more, to use mini-bus taxis at times. In Cape Town, it is very rare indeed to see White people in these crammed and fast-

moving vehicles, vehicles which definitely do have higher accident rates than others, given their common state of disrepair and legendary dangerous drivers. So it was not surprising that other women at Sea Point Place would ask her how she could possibly use these taxis. Bobbe proudly recounted her response: "Why not? Are you scared the black skin will rub off on you?" Trust Bobbe to get to what was probably the heart of the matter: the racism and classism of her contemporaries. She revelled in her stories of how kind everyone was to her, and I am sure they were – it was important to her to treat people respectfully. When I became worried that she was giving money to street addicts with which they would probably buy drugs, she had two responses. The first was that if she chose to give someone a gift, as her own mother had said, the minute the gift leaves your hand, it is no longer your property, but that of the person who had received the gift. In one fell swoop she had firmly addressed my multi-layered paternalism towards the drug users of Sea Point – what they did with their money, Bobbe was saying, was none of my business. The second solution to my worry about her giving money to addicts, and rather to give them food or other things they needed, deviated somewhat from how I had envisioned things. From then on, Bobbe made sure that she always had an assortment of delicious sweets in her handbag, and she delighted in telling anyone who would listen that she became known as "the lollipop lady" to all the addicts, and would be hailed as such: "Hey, Lollipop Lady, you got a sweet for me?" Given that many of the addicts were shooting what was colloquially known as "hard candy", I doubt that the joke of calling Bobbe the Lollipop Lady (as opposed to the Candy Man, I suppose) was lost on them.

I think with such pride of this small, elderly, well-turned-out Jewish lady with a handbag riding the Sea Point minibus taxis, and more. But of course there is more to it, and Bobbe was not "cured" of her troubles. Her car was not the most reliable, but the main reason she gave it up was that she remained terrified of driving and hated it. She sternly instructed her granddaughters never to drive on highways as they are too dangerous (an almost impossible injunction to obey in Cape Town), and she had got herself into a number of dodgy situations in Cape Town's impossibly narrow streets, while trying to take her own advice. We were lucky we never had to face the situation many of my friends have faced, of trying to convince an elderly parent, who has become a hazard on the roads, to give up on driving and all that it means. Similarly, I was initially shocked at Bobbe's decision about where she would live when she came to Cape Town as a healthy and competent 69-year-old (not much

older than I am now). She secured a very small sea-facing room in an old aged home. She was absolutely determined not to repeat what Granny had done to her in moving in on her in various ways (though when I divorced I worried, without foundation, that she would do just this). Having worked in an office in an aged home earlier in life, she said that the time to go there is when you are well. This gives you a chance to make relationships with people (other residents and staff), and when you become frail, as is inevitable, it will be easier for people to care for you as they know you. Though she was not much of a joiner – she eschewed most social things at the home apart from playing bridge ferociously several times a week – she worked at her relationships with people whose help she might need later. In this she was not cynical or insincere – she made friendships with people she really liked, but she was also strategic, and why not? And the fact is that much of this was designed as a long-term gift to me and my family. She was all too aware that I was her only child in South Africa, and she did not want to become a burden.

Things got better and better with Bobbe – both in terms of how she felt about herself, her adjustment to living in Cape Town, and her relationship with all of us – including her grandchildren. She had her bridge and her friends, and she was healthy and active, walking the roughly 5km round trip to the Waterfront a few times a week. Her confidence in her bridge playing improved, and she became sought after not only as a player but as somebody who was a good and patient teacher. Much to my surprise, not that long after my first marriage broke up, I met and fell in love with Louise, who lived in Johannesburg. When it became time for me to introduce Louise to Bobbe, Bobbe was thrilled, though she did pull me aside and say, “She’s very nice, dear, but isn’t she a bit young for you?” Louise is 18 months younger than me, so we could laugh about this. Bobbe adored Louise and the feeling was mutual, and after Louise came to live with us in 1997, things got better.

Bobbe turned 80 in 2005. Jenny and Ian came all the way from Australia, and we had a magical time, including a few days away in the country with friends for the birthday celebration. Bobbe had the capacity to enjoy absolutely everything. She never tired of eating ice cream and was always up for trying out new varieties. She enthusiastically enjoyed the theatre and the movies, and it was a pleasure to take her there. There was a showing of *Capturing the Friedmans* at the brutally uncomfortable Labia Cinema, and from the early moments of this brilliant and upsetting documentary, I felt worried that this film about child sexual abuse

allegations might upset her. She loved it, and talked about it afterwards. I was (and am) so proud of this bright, witty woman, afraid of nothing, and so much part of the world, arguing about politics and loving every minute of the argument. She was a brave woman who had found her stride, taking on the world.

It wasn't all so simple, of course, and the wounds were still there. Before she had moved to Cape Town, I was promoted to senior lecturer, and I told her the good news while driving her in my car up Adderley Street. She looked at me sideways on, with my long hair and scruffy beard (I have been an academic cliché my whole life), and she said, "You know, Leslie, if you look so messy, people won't take you seriously, and you won't get far in life." When I was promoted to full professor the year after she moved to Cape Town, I took her to a restaurant to tell her the news. "Look," she said, "You can even get chips with your pita here." I won't pretend that these things did not hurt me – would I ever be good enough? – but the real sadness I feel is for her. Here she was, this brilliant woman (brighter than most academics I know) who somehow had participated in never finishing high school, and felt she had never been taken seriously as a woman of substantial and serious opinions. And I had had it so easy. Which I had – I had gone to the university of my choice, studied what I felt like, fell into a job quite quickly, and was promoted fast. In no small part, to add insult to injury, because of her. She was no *Goodwill Book* matron sacrificing herself for the next generation, but in some ways this is exactly what happened. I was visibly successful, and it hurt. Thinking about my mother's envy toward me, my own envy toward my children, or the envy any parent may feel towards their child is not an easy thing to do, but there it was. This did not stop Bobbe for one second when it came to beaming genuinely proudly and delightedly at my inaugural lecture, complete with the pomp of academic robes – a world she would have felt so at home in if she had had, or given herself, a chance. And at the core of it, I came to think, was her having to reckon with the consequences of the sacrifice she had made all those years ago. We don't know, and won't ever know, whether she fell or was pushed, but the loss was real.

All of this makes her enthusiasm for life, her pleasure in everything, all the more remarkable. She had lost and was losing, but she was also fully aware of her privilege, and in some ways her joy was also an enactment of responsibility – she would not take all she had for granted. This was the Bobbe that many of my friends knew, this woman who would tell anybody and everybody that she loved being old.

She was sad to have lost my father, and she always acknowledged it, but when you are old, she said, you can do just as you please, nobody can tell you what to do, and you can get away with everything. She did sometimes take things much too far with her new-found confidence. Though she was much more accepting of me than she had been, and the fact that Louise is half-Jewish and identifies culturally as Jewish (though technically she isn't) really helped Bobbe get away from the idea that I was what is nastily termed a "self-hating Jew". But Bobbe did love a good argument and would attack an argument with the same pleasure she attacked a chocolate ice cream cone, and issues Middle-Eastern and Muslim were a great place to start. I honestly don't think that she was Islamophobic (and I have many relatives who are), and she really liked some of my Muslim friends, but discussing the injustices or otherwise of the occupation of Palestine was always a guaranteed way to get me going, and I fell for it every time. After 9/11 and the Iraq war, the issue of women wearing the hijab became a hot topic, with a huge amount of scaremongering about people – especially dangerous men – covering themselves to avoid being recognised as they committed violent acts. Bobbe firmly declared, looking me straight in the face, and just waiting, waiting for me to explode, that she didn't think the "kebab" was a good form of dress. You could never know who or what was under there and besides – and here she looked at me even more intently – didn't I think that forcing women to cover themselves like this was a form of oppression and interfered with their liberty? I could have strangled her. Sometimes I rose to the bait, and sometimes I did not, but she had great fun seeing me squirm. Those twinkling Elizabeth Taylor eyes, and the recognition that we were really fighting, but this was such fun.

She did, I am embarrassed to recount, take her fights to the streets as well. One day, she was sitting on a bench at the Waterfront while we were completing her shopping. A woman who was completely covered from head to foot, with dark lace covering even her eyes, came to sit down next to Bobbe. "Do you like wearing that thing?", Bobbe asked in the tone of a schoolmarm. "I get frightened when I can't see people's faces – don't you think you should at least show your face." The woman was silent. Bobbe tried again, and again got no reply. She turned to me and said, gesturing to the woman sitting absolutely motionless next to her, "Poor thing. I suppose she doesn't understand." I did my best to get Bobbe out of there, and fast. Once we had all calmed down, Bobbe was well able to laugh at what she had done. I didn't think this exonerated her in any way, but this did show that though she was a

woman of very strong opinions, she could also think about and reflect on what she may have done wrong.

It was often sheer fun to be with Bobbe for these years, and her capacity for gratitude and enjoyment made everything so much easier. It could have felt burdensome to see her every week and take her out – and it was – but mixed in with the exercise of responsibility was so much real joy. I've thought long and hard about the irony that Bobbe only really came into her own after the man she loved so much died, and I am well aware that many people would welcome a story about this which would be compelling but, as far as I can judge it, untrue. This is the story of the dutiful woman, oppressed by her husband and his mother and aunt, but really only finding herself once they were dead and buried, and good riddance to them. This story fits neatly with so many others, but I honestly think that it would amount to an "honest trifle", to use the phrase from *Macbeth*. Of course it was true that Bobbe was now free from the burden of having to look after my father, Granny, and the Chicken, and I think her relief at having served her time in thrall to the old women was unambivalent. My father had not been an easy man and had taken setbacks later in his life hard – he could be cantankerous and angry. I don't think she missed that. But she also mourned and mourned what they had had together and she never had again – and, to me, this is what made the joy stronger. She knew, this clever, sensitive, insightful woman, what loss was. She had faced it and was still facing it. And it was precisely that constant connection with loss that made the many good and bright things better and brighter.

Chapter 9: Avoiding surgery

Getting old is difficult, my mother used to say, but the alternative is worse. Of course, she had to deal with both the getting old part and the alternative. She was so well at 80 that it's hard to think that she didn't live for another twenty years. Babe lived until she was 103, outliving Bobbe by a number of years though she was ten years older than Bobbe. But life happens, and so does death.

She started developing stomach pains. We began the rounds of consulting health professionals. Bobbe had always had a stated predilection for Jewish doctors, and in fact had expressed to me her upset that the family doctor I had chosen to go to was not Jewish. But when it came to it, she started going to a White Afrikaans rugby-playing doctor, an outlier in her area. This man was gruff and distant, and though I have no doubt about his competence, he was a far cry from sweet, understanding Dr Levy of Salisbury days. I had gone to him once at Bobbe's recommendation when my own doctor was ill, and very shortly after my first marriage had broken up. I was feeling weak and vulnerable. I had a palmar wart which was growing fast and was quite painful, and I wanted advice about what to do about it. Without discussing options and without preparing me for the brief but intense pain I was about to undergo, the doctor applied liquid nitrogen to the wart. I flinched. "Bite the bullet," he said. He did not tell me what would happen next, and through the ensuing weeks I dealt with a sore palm with a blackened spot, and eventually, finally, with the wart being loose enough, I was able to pull it off at its root. I did not understand why Bobbe was going to this doctor when there were other choices, but I was reminded of the issue of the hairdresser with the bad haircut. What was there still lingering about her not allowing herself to get proper care?

The doctor did various investigations, but it became clear that he had Bobbe down for a neurotic old lady (which she was), and as a result, did not take her complaints seriously (which was unprofessional but not uncommon). After much goading on my part, Bobbe came round to getting a second opinion, and off we went to consult with the doctor recommended by Bobbe's friends. The waiting room was large, peopled by old women and men, most of them clearly Jewish, and there was a lot of loud conversation. The reception staff were also chatty, and the whole place had the atmosphere of a market. The subject matter of the talk was often somewhat depressing: "Well, my dear, my lungs are just finished."; "The next thing I knew I was lying there on the street – on the street!"; "It's in the family so what can I do?"

Despite the subject matter, the atmosphere seemed to me to be quite jolly – everyone seemed to be part of a shared community of suffering, but doctor would help as best he could. Bobbe insisted that I accompany her in to her consultation with the doctor, who spoke to her as though she was about five years old and not too bright with it, a patronising man who seemed so self-satisfied that I wanted to punch him. Still, he was better than the rugby player. Suspecting diverticulitis, he referred Bobbe to a consultation with a dietician he worked with.

It was the height of Sea Point summer when we went to the dietician, and it was clear from the waiting room that most of the practice focussed on helping people lose weight. The door opened and there was a young woman, very tanned, in the shortest possible mini-dress with a low-cut halter-neck and a full, tanned back showing. Bobbe shot me a look, and I could hear my father’s voice in my head, saying, “Look at the dress she’s almost wearing.” In the event, it became clear that this young woman was competent and professional, and she gave Bobbe good advice about eating a high-fibre diet and good dietary hygiene, advice I knew there and then Bobbe would not take. Bobbe had been told by somebody that you treat diverticulitis with low fibre food, white bread, and none of the fruit and vegetables that Bobbe loved. In short, nursery food of the kind given to Victorian children was to become the order of the day.

The stomach pains got worse and worse, and Bobbe began to tell everyone who would listen, and those who wouldn’t, that she was hanging on and avoiding surgery for her deteriorating health. I had been present at every medical consultation she had been at, and there had never been any discussion of surgery – there was no surgery to avoid. When I pointed this out to her, she was adamant, and I had many jokes at her expense about this, much to my shame as I write this.

Things got worse and she was losing weight. There was a crisis around inflammation of the intestines, and there was a worry that she would have a rupture in the intestines. She was admitted to hospital for a few days where she was fully examined, X-rayed, prodded and poked, and sampled for blood, within an inch of her life. The hospital stay was not designed to be therapeutic in itself, but Bobbe felt much better for having been taken seriously. I was hoping that we had reached a turning point.

We had not. Bobbe continued having pains, and we went back to her GP and a few others, taking our portfolio of X-rays and pathology reports with us, but with no explanation for her feelings of pain and general malaise, accompanied by some weight loss. The doctor who had referred her to hospital helpfully informed me that my mother was a “neurotic old woman”. Well, that came as a revelation. When I suggested to him that it was quite possible that a person could be simultaneously “a neurotic old woman”, as he empathically put it, and have a painful health condition which could benefit from treatment, he was not impressed.

We went on like this for about eighteen months. I lurched between being sympathetic with Bobbe and berating her for “avoiding surgery”, between support and overt aggression. I don't know why it took me, a psychologist, so long to come to this decision (though I have my suspicions), but eventually I suggested to Bobbe that we consult a psychiatrist who also had a strong interest in medical conditions. It was completely obvious that Bobbe was anxious about her health, and had struggled with anxiety her whole life, but perhaps she was masking a serious depression given that there seemed to be no obvious medical reason for her ongoing pain and weight loss. Wonderful Bobbe, unlike so many of her generation and others, had no qualms at all about going to a psychiatrist.

It was one of those beautiful late-summer days in Cape Town when I took Bobbe to see Michele Rogers, a psychiatrist whom I knew slightly, and who was known to be a good diagnostician, as at home with “physical” conditions as with brain disorders and emotional difficulties. We entered her office, which was furnished like a slightly old-fashioned comfortable sitting room, putting our large sheaf of X-rays and medical reports on the floor beside us. Michele is warm and attractive, and she unobtrusively asked us why we were there. I offered to leave so Bobbe could speak privately but she was having none of it. She asked me to start. I told Michele about the history of vague complaints that a number of doctors had said had no cause, about a history of anxiety (in Bobbe and in our family), and about my worry that Bobbe might be depressed. Michele turned her open face to Bobbe and started to take a history. The more Bobbe talked, the more happy and animated she became. Michele was a skilled listener and seemed genuinely interested, and here was my notionally depressed mother becoming more and more animated, witty, funny, and utterly charming. There could be nothing that looked less like the behaviour of a person with depression, and I felt a bit embarrassed at my completely obvious misdiagnosis

– no seriously depressed person could fake the engaged animation that Bobbe was showing. She just needed the right listener. And for months, if not forever, that right listener had not been me. Eventually, Michele looked through all the bits of paper we had brought along, one by one, and then she turned to the X-rays. She didn't have a light box (she was a psychiatrist) but just to get an idea, she held up the X-rays one by one. They had been taken eighteen months previously in the hospital, and we had been toting them around to various health personnel ever since. She turned to us, and said with quiet, but direct clarity, for which I will always be grateful, that there was evidence of a lesion on the lung, and that we would have to have a repeat X-ray now to confirm her suspicions. We knew that she was pretty sure Bobbe had lung cancer, which was later confirmed. She showed us the lung X-ray (which I had never looked at myself) and there, absolutely clearly, was a well-defined spot on the lung. And it had been there for over a year. The X-rays had been available to every clinician in the hospital and every person Bobbe had consulted since. It had taken a psychiatrist to diagnose my mother with lung cancer.

It's hard to catalogue the range of feelings I had in that moment. I felt embarrassed about my worry about depression, about my not having diagnosed lung cancer myself, even though I have no training at all qualifying me to do so. I felt enormous relief, as the pieces of a puzzle going on for years suddenly fit seamlessly into place. I felt (still feel) rage at the arrogant health care professionals who had judged my mother and her neuroses without doing the basics of looking at the medical evidence (Why bother, after all? This was just another neurotic old biddy in a long line of neurotic old biddies). I felt terrible, crippling regret, because, Michele thought though she could not be sure, it was likely that the cancer that could have been dealt with by surgery eighteen months ago had metastasised and spread. Michele estimated that Bobbe was probably in Stage 4 cancer by now – way beyond any chance of operability and cure. Michele referred us to her brother Sean, a pulmonologist, for full diagnosis and follow-up. In everything she did for us that day, Michele was a good doctor and a good person.

Bobbe and I left the clinic into the warm summer day, and I took her for lunch at a nearby café/pub. We sat outside, and I can still see the shadows of the oak trees dappling Bobbe's face. "What do you expect?" Bobbe said, "I'm old. I've had a good life and this isn't the end of the world." I couldn't stop myself, true to form, from blaming her for having cancer because she had smoked for so many years and I had

warned her of this very outcome. But mostly I was comforted by her – she was so well in herself, as though the weight of what she, and she alone, had known all along was there, had been taken off her, and she could face the truth. She said there and then, before she had the diagnosis confirmed, that she did not want treatment – she didn't want to suffer to prolong her life, and she would take what was coming to her. Well, here we were. The woman who had spent her life jumping at shadows, beset by worries about things that nobody – even she herself – believed to be real, was now facing down the reality facing her with composure, and, yes, relief. She could do this.

There followed a quick round of consulting doctors before we settled into a pattern. Sean, whom Bobbe found delightful, had a gung-ho, hail-fellow-well-met persona which belied a soft and caring interior. He confirmed Stage 4 cancer, and referred Bobbe for ongoing care to an oncologist. To my relief, there were no heroics here. The oncologist respected Bobbe's wish to have palliative care only – no chemotherapy, no radiotherapy. She worked closely with St Luke's Hospice, she told us, and would contact them when the time came. In the meantime, she suggested, we should get on with life.

There was a part of me that wanted to round up every person who had disavowed Bobbe. I toyed for five minutes with finding a lawyer so we could begin to sue for malpractice all those practitioners who had not bothered to do the basics of their job. But Bobbe did not want this, and neither did I. It was time to get on with the next phase of our lives.

Chapter 10: Closing in

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

Susan Sontag, *Illness as metaphor*²⁰

I have lived my whole life as a healthy person. I had my tonsils and adenoids out when I was five, and I had an operation to repair an inguinal hernia. That's it. Especially because of my work in disability, I know this could change tomorrow. It may already have begun to change – there may already be something lurking inside of me which will later manifest as illness or debility. Over thirty years ago, in my work as a psychologist, I was fortunate to be consulted by an exceptionally articulate and intelligent middle-aged man. Amongst other concerns he had, he worried that he had early onset dementia. Something, he felt, was not quite right. To me, there was absolutely nothing to support his fear – I had seldom met someone so articulate, and whose thinking seemed to be so well-organised and controlled. But in order to respect his experience, and to get a more expert view, I decided to refer him for a second opinion. Neuropsychology was not very developed as a field in Cape Town in those days, and I referred my patient for an assessment to a neurologist, writing in my referral letter that I could find no evidence of dementia, but wanted to be absolutely sure. Not unexpectedly, I got a rather exasperated response from the neurologist, who also found not a shred of evidence of dementia, and who seemed irritated that I had wasted his time. I worked with this man for a number of years, and never once in those years did I revise my view that he did not have dementia, but we did discuss in some detail his fear of dementia and of what it might have been about in terms of how he felt about himself and his future.

Many years later, and long after we had stopped seeing each other, I read a newspaper article about a freak accident that had befallen this patient's brother, to whom he was very close. It is always tricky as a psychologist to make contact with a former patient, especially after many years, but on balance it felt like the humane

²⁰ Sontag, S. (1978). *Illness as metaphor*. *New York Review of Books*, January 16, 1978, <https://www.nybooks.com/articles/1978/01/26/illness-as-metaphor/>; Sontag, S. (1978). *Illness as metaphor*. New York: Farrar, Straus and Giroux.

thing to do and I sent a brief letter of condolence. A few weeks later I got a letter from my former patient's wife, who was also a health professional. She thanked me for my concern, and informed me that my patient could not himself reply as he had dementia, now quite advanced. She had been going through his things, my patient's wife wrote, and she had seen a copy of my correspondence with the neurologist all those years ago. She commented that perhaps I had known something about the dementia all along.

I had not known this, and it is of course completely possible that my patient had an irrational fear of dementia when he was well, but then did indeed develop dementia later. But to my mind, though the rational part of me says this may just be magical thinking, something fell seamlessly into place. This man, with his exceptional insight, intelligence, and self-knowledge had known all along, I thought, that there was indeed something going wrong. Early dementia is indeed more difficult to diagnose in highly intelligent and articulate people than in others, as the intellect and all it has built over the years can mask and compensate for the decline – this was brilliantly portrayed in John Bayley's now-controversial memoir of his wife, the novelist Iris Murdoch²¹. Though I was very sad to hear about my former patient's dementia, part of me felt vindicated for taking him seriously. But I had also worked with him on the assumption that he was not dementing, and I wonder now to what extent I disavowed something which was not only real to him but was also empirically true, but not yet measurable and noticeable to others. I don't think I behaved badly or unethically in this case, but it has forced me to think about what I might have been doing completely unintentionally (and with, in fact, the best of intentions). Along with everyone else, I may have been saying that I knew better than he did. He thought he was in the kingdom of the sick, and he may well have been right, but we would not countenance this – we revoked his passport and insisted he was really in the kingdom of the well, rendering him, to all intents and purposes, stateless and in limbo.

For Bobbe, receiving the cancer diagnosis was many things, including a relief and a vindication. She had for years known, or felt, that she was ill when others thought she was well, known that she was dying as she struggled with the panic attacks for which at that time neither she nor anyone else had a name. She had decided to live after my father died and had taken on life with gusto, but had been avoiding surgery

²¹ Bayley, J. (1998). *Iris: A memoir of Iris Murdoch*. London: Gerald Duckworth and Co.

for years. Though the concept of “avoiding surgery” had given us some cruel laughs at Bobbe’s expense, there was a part of Bobbe that always knew in which kingdom she had rightful citizenship, and that was the kingdom of the sick. She was frightened to a degree, she would rather not have cancer but, as she said, “what do you expect?” She was sick, but she was home. All the nameless flutterings and giddiness of the past, all the feelings of stumbling at the edge of the kingdom of the well, technically in that country but not feeling completely of it, could now be replaced by a calmer foothold of a different place.

The problem was, though, that this migration required of all of us around her to move with her. And I didn’t want to. Bobbe was wonderfully calm and philosophical about being so ill – a model of mature acceptance. But with her illness came a time of neediness and clinginess which pulled me back to somewhere I would rather not revisit. One day, we were taking her to the shops, and I wanted to dash in somewhere for a few minutes while Bobbe sat safely in the car with Louise, whom she adored. Bobbe did not want me to leave her to do a simple errand. As much as both Louise and Bobbe, I was surprised and frightened at the rage I felt and expressed towards Bobbe in that moment. “Just let me go,” I thundered. “You will be fine.”

Just let me go. You will be fine. There must be a thousand ways of saying these two sentences, and the best of them must be in a calming but reassuring tone, “friendly but firm”, as Dr Spock would have it. But Bobbe was not my child and I was not her father – but what was I? The way I said those words calmed nobody, and spoke not to reassurance, but to my desire to abandon Bobbe, to get out of the small banged-up Toyota outside the Silwood Kwikspar and to run as fast as I could, not looking back, do not collect \$200 as you pass Go. I had been doing so well looking after Bobbe, was doing so well, but here was something I wasn’t in control of, as elemental as the rage every parent must feel (and I had felt it) when an infant will not stop crying. I often say that the strange thing about child abuse in some ways is not that there is so much of it but that there is so little. Show me a parent who has not felt rage towards their howling and inconsolable infant and you will be showing me a liar, but somehow most of us overcome the urge to hit out at that tiny roiling vessel of rage. And this is how, unbidden, unheralded and shamefully I felt towards Bobbe – I wanted her to shut up, let me go. And I didn’t really care whether she would be “fine” or not. I wanted out. Out of the car, out of her grip, out of a story of caring for her

on native soil, his cherished land,
to her as devout,
as to child and spouse,
and in her honour sees echoed his honour stand.

I like a man who reveres his mother
in tongue from devout lips mastered,
detesting the bastard breed
to his soul indeed,
who, spurning her, themselves do banter.²²

Let me count the ways in which I found, and find, this poem offensive. I don't like the nationalism, I don't like the gender politics, I don't like the racism. I can give you a thousand or more academically-argued reasons why I don't like this poem. But when I had to learn it as a ten-year-old, it spoke directly to me and my sense of shame. The first few words – “Ek hou van 'n man wat sy man kan staan” – say it all. “I like a man who can stand his ground against another man”, is how I understood it. This was a poem telling me all the ways a (White, Afrikaans) man should be – and mother's boy that I was, I felt my failure in all of the ways. I felt that I was the last person to stand my ground, I was fearful and weak, and would avoid conflict, despite some evidence to the contrary, even at that young age. I had an autograph book when I was a teenager (we all did), and an Israeli adult I knew wrote in it in Hebrew “Chazek v'amtez” (this is my transliteration) which is roughly equivalent to “Be strong and powerful”²³. I hated this as much as I hated the Celliers poem, as it also seemed to require from me a manly toughness that I didn't have. I could not be the person who stood up like a man – I was a boy tied to his mother.

As I bolted out of the car that day outside the Kwikspar, with the words “Just let me go – you will be fine”, I felt I was being a different kind of man – the kind of man who is cruel, ignores the feelings of vulnerable people, is inured to the needs of old sick women. Celliers's poem, as it continues, though, has a lesson for me: “Ek hou van 'n

²² I thank Eduan Naudé for this translation, and Ilse Feinauer for approaching Eduan on my behalf.

²³ A Hebrew-speaking friend tells me that the term is metaphorical for something like “Go forth and prosper”. I think it is equivalent to “May you go from strength to strength”.

man wat sy moeder eer/In die taal uit haar vrome mond geleer". "I like a man who honours his mother/In the language learned from her pious mouth." I find this exhortation to mother love mawkish, and it makes my flesh creep. Every part of me rails against the cliché of the pious mother as custodian of culture and language, and it doesn't help that the word "vrome" (pious) is so close to the Yiddish word "frum", meaning pious. We were not frum people, and had never been. But a good man, the poet tells me, looks after his weak old mother, with all her softness and frailty.

The problem, of course, was that I was not nine years old, but a grown man of nearly sixty. With all my conscious heart I wanted to help my old, sick mother as best I could (and on balance, I believe I did), but I felt almost undone by the strength with which I was resisting doing the right thing. It was, of course, the rage of a nine-year-old boy who had been done an injustice – the injustice of having to care for his mother as a father would a child, or as a good man would care for his wife. I was not a good man at the age of nine – I was not a man at all. I should have been furious and in a rage at the age of nine, but what nine-year-old can allow himself this fury? What could this fury do to his weak and fragile mother? I had learned about what in the trade we call parentified children in my training as a clinical psychologist, and had certainly seen families with such children (it's not that uncommon in clinical practice), but somehow I had not made the links to myself as I felt them so viscerally now, and in such an out of control way. In *Able Bodied* I spoke of how all children feel that things that go wrong with their own parents are their fault – to learn that you are not the centre of the universe and the source of all good and bad is a developmental achievement. I also mentioned that, in my case, I think this issue was complicated because my father, being disabled and having chronic pain, clearly had been damaged in some way, and, as any child would, I believed not only that I could cause this damage (look at the evidence!) but also that I could do it again. So how could I possibly allow myself to be angry with my mother's demands when I was just a child, and still dependent on her. I am not a great fan of the "pressure cooker" model of human emotions – the view, much peddled by mental health professionals and advocates, that if you do not express your feelings, they will build inside you until you eventually explode. The metaphor feels just too mechanistic to me, and sometimes an excuse for people to behave cruelly ("I was just expressing my feelings/I was just being honest"). But here I was, having just the kind of explosion of feelings which the pressure cooker metaphor predicts, and it scared me. I also, at this time, remembered something that I used to do to my mother when I was little, and only at

times when she was feeling strong – never when she was in her most nervous state. I can see myself now, lying on the parquet flooring in the passage of our Salisbury house, completely still and my eyes open and staring. Bobbe would find me like this, and I would not move until she was genuinely distressed, convinced that I was dead or had fainted. I managed to do this a few times before she got wise to me. What can I say? Funny joke. I had it in me to punish her, though I had no words for it then.

My whole life, then, up till my rage outside the Kwikspar (and since), had not been lived as clearly in the kingdom of the well as it might have appeared to have been. I did have that easy way of taking my physical health for granted, as is common with children. As I experience very minor but real symptoms of ageing, like arthritis and hearing loss, I smile ruefully at the “youth is wasted on the young” adage, because I took so much for granted, as was appropriate then. But I also felt weak, unable, small, and of a different species from the bulked-up men at the gym Bobbe took me to. Other boys could speak of wanting to grow big and strong, like their dads or other men, but this did not seem like an option to me. And now, with my career established and my children grown, and in a good relationship with a good woman, it was time to man up and look after my dying mother. Part of me, and probably the larger part of me, knew that I could and would do it. But another part felt undone by what was being asked of me. Years before, I had read Michael Ignatieff’s *Scar tissue*²⁴, a remarkable fictional account of a man who falls apart as he cares for his mother with dementia, the trajectory of whose life mirrors the insistent decline of the increasingly chaotic brain of his mother. It’s hardly surprising that this novel, whatever else its considerable merits were, would appeal to me, with its theme of sacrifice to caring for the older generation. And here I was at the precipice – the edge of the end, the void that caring for Bobbe might mean for me.

One of the things that Ignatieff describes so well, is how incomprehensible the book’s protagonist’s life, consumed with care for his mother, becomes to others around him. As his mother becomes more mysterious and difficult to read, so does his life to others. Imperceptibly, he has crossed over a threshold, if not to the kingdom of the sick, as he himself is not ill, but to a fundamentally different in-between world, a world very real to him, but not possible to see from the world of the healthy. When we talk of youth being wasted on the young, where exactly is the “waste” we speak of? I

²⁴ Ignatieff, M. (1993). *Scar tissue*. London: Chatto and Windus.

think that it lies in the unconsciousness that many young people have that their health and physical strength, their vitality and acuity, are all in fact qualities which they are lucky to have and will not stay the same throughout. The waste we speak of has nothing to do with waste, but with the taking for granted of what is, and should be taken for granted, by young, healthy people. There is plenty of time to learn about frailty, about our bodies not effortlessly doing what we want them to do. But the gift that is the effortless is not experienced by many young people as a gift – it is simply the way the world is. And given what we as a society do with illness, ageing and disability – we do many things, but here I’m talking about our hiding them away – the world of caring for those affected by illness, disability and ageing is also hidden away. I did not know it at the time, but some of my Kwikspar rage was not just at my mother (though she bore the brunt of it) but also at all the other people who went about their own lives and could not see or imagine what my family and I had been going through. I had felt this sense of disconnect with others and the world in general, more powerful than a general sense of being out of step with others, once before in my life. This was around the time of my divorce, which came as a shock to me. Not only did I have to grieve for the end of my marriage, it also felt as though everything I had ever known about the world and my place in it was wrong. When I saw others going through their ordinary predictable lives, there was part of me that could not understand how they could just carry on. Bobbe had liked the old Skeeter Davis song called *The end of the world*, with the lyrics:

Why does the sun go on shining?
Why does the sea rush to shore?
Don't they know it's the end of the world?
'Cause you don't love me any more

Why do the birds go on singing?
Why do the stars glow above?
Don't they know it's the end of the world?
It ended when I lost your love

I wake up in the morning and I wonder
Why everything's the same as it was
I can't understand

No, I can't understand
How life goes on the way it does

Why does my heart go on beating?
Why do these eyes of mine cry?
Don't they know it's the end of the world?
It ended when you said goodbye

Why does my heart go on beating?
Why do these eyes of mine cry?
Don't they know it's the end of the world?
It ended when you said goodbye

I had always found these lyrics silly and sentimental (and I can see why I did!), but there was indeed part of me that wanted to know how life could go on around me, with me teetering at the edge of the happy, grown-up world I had created, when everything, it felt, could fall apart.

I am absolutely clear that these strong feelings that I had, came from me and from the pull of my own particular past on my particular present. I also got to learn, though, about the otherworldliness that was caused, not by me, but by taken for granted social arrangements about what it means to be a successful, functional adult in the world. Well, not everybody's world, perhaps, but the dominant world I lived and worked in. Part of the problem of care, I came to see, was not the care itself, but the wholesale failure of imagination about what care is. There is probably no parent caring for young children who has not at some time had the experience of what the weight of this care is being misunderstood – or, more accurately, not seen at all – by others. Women (and it's usually women) know what it means when co-workers (of both genders) become exasperated when the child is sick again, or the childminder is late again, when the reality of care disrupts the rhythms of work. Childless friends (and even some who have older children) complain of feeling abandoned by those who have recently become parents and whose lives are wholly absorbed in the complexities of caring, trying to get enough sleep, and trying to keep a life and household going. These acts of disavowal of care, of its invisibilization, and of reading the real burden of care into a character flaw of the person doing their best to care, are well known. We have feminist scholarship to thank for showing us how this

issue with my friend. What's going on here? I think that between the project leader and my friend, there was something in all of this about Leslie's allowing the needs of his sick mother to overtake the more important needs of the role he must play as a professional man in the world, doing his work as part of an international project which has its own demands and deadlines. As for me, though, a big part of the reason for my writing the book I am writing now is that I want to talk about the problems we have in our invisibilization of, disavowal of, the realities of care. But you know what? I may be writing this book, but I have not had the courage to deal with this issue directly with the people concerned, because, try as I may to tell myself otherwise, there is an important part of me that agrees with them. What kind of a man, what kind of successful professional, backs out of an important meeting to look after his mother? Only a weak mother's boy would do this – only somebody who is an impostor and not a real man at all. I hate writing that and part of me really wants to erase it, because it feels much too totalising. But it is there, a part of me, inside me. So much has been written about the internalisation of oppression by people in oppressed groups – the ways, for example, that women come to believe that they are weak, that disabled people believe they are disgusting, that Black people believe that they are unintelligent. But part of all of our problem with all of this is that powerful people like me do this too – we keep the cop in our own head alive. And you know what? As we do this dance of keeping us looking independent and strong, a dance we are often not aware of doing, we make life worse for ourselves and, indeed, get others lower down the pecking order to do the caring on our behalf. If I sound angry about this, it is because I am. I cannot bear the honey-coated nonsense of Celliers's man honouring his pious mother. Honour is easy, and makes you look bigger. Trying your best to do the work of care is much more difficult. I'm by no means clear that I've succeeded at it, but at least I have given it a try.

and to link the room to the outside. Five minutes later I would return to find that Bobbe had told the carer to close everything up, including the security gate, which made the room feel to me like a prison. I wasn't, of course, sure exactly whose prison it was, and for whose needs I was so insistent that we needed fresh air and a bracing environment.

I was in no doubt that Bobbe needed to be with us, and it felt much easier having her in our home than anywhere else – no more dramatic call-outs. But especially in those early days, I would lose myself and become very irritable with her. Just as in the Kwikspar incident, I would suddenly find myself shouting. I was often cruelly sarcastic. I don't know where the words came from but I also know that they came from me. Bobbe would then say that it was clearly time for her to leave us and to return to Sea Point – she didn't want to be in the way, this was what she had been afraid of, nobody should have this burden. This would enrage me further as Sea Point did not seem to me to be an option, for reasons we had repeatedly discussed. I raged against her suggesting she would leave, when this felt impossible. I remembered a row we had had when I visited her from university. I was trying to say to her, as rationally as I could, that I wished she had protected Jenny and me more from the poisonous old ladies who had blighted her life and ours. I was trying very hard to be rational and grown-up, and with my newly-found psychological skills (skills which I rapidly and repeatedly came to realise are of no value whatsoever when you are trying to argue with your family). I was trying to share (perish the word) with her that I understood that she herself had been in a difficult position, but I wish she had done things differently. All those years ago, and I still flinch at the memory of her response, which was, "Well, I suppose I have just been a bad mother." When I try to think rationally about it, I guess this was an honest response, spoken with a kind of resignation. But I was damned if I was going to be caught either agreeing with her – "Yes, you have been a bad mother" – or disagreeing with her and reassuring her – "No you haven't, you're wonderful, it's just this one small thing etc etc". My parents' joint failure to protect their children from the nasty old women is no small thing, and however difficult it was for them, they should have done better. But they were also wonderful parents in other ways. I did not want to be trapped by Bobbe's response and I fought (unsuccessfully) to get out of the trap. And here I was, in her little prison room with the security gate and curtains closed, feeling trapped again. I could throw her out and abandon her to falling and the ignominy of the impossibly bleak sick-bay, or I must be a good boy. I wanted her to see me as more complicated than either of

those things – I wanted to be as good a son as I could be, warts and all. But spare me from being all good or all warts. It's so easy to chalk up what Bobbe was doing as "manipulation". But as I tell my students, when they describe patients as "manipulative", life must be pretty hard for you if the only way you feel you can get things is by manipulating other people, by being devious, and then never knowing if what you get was freely given. I think it's more accurate to say that at that stage Bobbe and I were both trapped – she was my jailer as I was hers. A big part of each of us wanted out, just as we were searching for a way to be properly in. So this felt like a replay of everything, everything that had ever happened between us, but it was also something new, and terrifying for both of us. Bobbe could not stop being ill – the only way out of this for her was death. So I held more power, I suppose, but at the time it didn't feel like that – her illness was what the anthropologist James Scott²⁵, in another context, calls a "weapon of the weak", and I felt she was using it.

As I write this, though, I worry about giving too one-sided a picture. I want to be clear about how hard this all was for all of us, but that's not the whole story. Earlier, I mentioned Ignatieff's brilliant novel, *Scar tissue*, which deals so unflinchingly with scars and with the hurts that cause them. Bobbe and I had spent a lifetime of scarring, and being scarred, each by the other, in the dance of mother and son bumping up against each other because we were much too close. But there was (is) a lot more to both of us than the scars. When my first daughter was a very tiny baby, a friend summed up early parenthood in a way which I quote to every new parent I know: "It's better and worse than you can possibly imagine". There is no way to be prepared for the assault that new parenthood is, for the sheer physical schlep of it all. But there are also no words for the wonder of life with a new baby, a life at the edge. I am glad the ordeal of it all is over, and with hindsight I don't know how we did it, but it was also one of the best things I have done in my life. I would sign up for it again, despite how hard it was, and in fact, Louise and I did sign up for this kind of experience again, which is something I'll get to later in this book.

We settled into a sort of routine, much of which was full of pleasure and fun, but with an admixture of really awful bits in between. It was important to me to get Bobbe out of the house as much as possible, and this involved endless cups of tea at the garden centre nearby (they got to know us well and were always kind), and various

²⁵ Scott, J. C. (1987). *Weapons of the weak: Everyday forms of peasant resistance*. New Haven: Yale University Press.

treats. Though Bobbe could walk, she was weakening, and I got to know about which places had wheelchairs available. Trips to see the flowers at Kirstenbosch were hard on my back as I pushed the wheelchair, but always pleasurable. The waterfront was also a good place to trundle around.

We would try to keep Bobbe as involved as possible in managing her own life. I had power of attorney and dealt with her business affairs, such as they were, but if she wanted something from the shops we would try to get her, where possible, to go with us to buy just what she wanted. One day in Pick n Pay she complained of feeling weak and nauseous. I got her to the front of the shop and she sat down. Her whole body seemed to convulse, and she vomited on the floor. I will never forget the look of revulsion and rage of the first shop assistant who saw what had happened. “What have you done?” she said, looking at Bobbe. Wasn't it obvious? But the message was clear – Bobbe had been a Naughty Girl. I was embarrassed, seriously concerned about Bobbe and what this might mean for her ever-deteriorating condition, and also absolutely furious. The mess was mopped away more quickly than were the feelings, and after this it became more difficult to persuade Bobbe to get out of the house, much as we felt she needed it.

One day I got a frantic phone call to come home as there had been a crisis. Bobbe's false teeth were missing. She looked at me with that tiny, sunken face, like a little goblin adrift in the world. We tried to think where the teeth could be and I crawled around under the bed to no avail. Eventually, and hugely embarrassed, the carer of the day told me that Bobbe had vomited (yet again) and that, as usual, the carer had managed to catch the vomit in a bucket and had flushed the vomit down the toilet. Could the teeth have fallen out and been in the vomit. We all inspected the now pristine toilet as if our looking at the clear contents would suddenly magic the teeth into appearing. No luck. I phoned the emergency plumber. “You're not going to believe this...,” my communication with him began. Two young men in denim overalls and with a variety of tools arrived at the house. After what felt like a very long time, one of them, working in the drain outside, held in his gloved hand a set of dentures, none the worse for wear except for a layer of vomit and shit. This was a first for him too. I feel such a pang of longing and tenderness when I think about how we laughed and laughed over those teeth, which once I had carefully cleaned and disinfected them were as good as new and continued to provide sterling service.

did not want her to be dying forever. My life was so upside-down, so consumed by what the illness meant, that I wanted an end date, a date by which this would all be over. And with those murderous thoughts, I felt guilty. The only way the suffering could be over – Bobbe’s and ours – would be if and when she died. I never doubted that I wanted to care for her and that we were there for as long as it would take, but it would be a lie to say that I did not wish, often, for it to be over. Like teenagers sneaking off to the movies, Louise and I would sometimes meet surreptitiously after work for a quiet cup of coffee before returning home to the demands, the vomit and the shit (both of which, understandably, preoccupied Bobbe), and, worst of all, to the presence of the carers, on whom we were completely dependent, but who also felt like intruders in our home. Looking at this from a distance, now, I can see nothing at all wrong with our taking these cups of coffee, and I have no doubt we needed them, but the trysts felt like acts of abandonment, and even murderous in themselves. We wanted this to be over, and for me, though I hate to think about this, that meant I wanted Bobbe dead.

This said, and my talk of murder is true (I did feel that way), there was also something astonishing about how Bobbe was dying. Until the last six weeks of her life, and through the wasting of her body, Bobbe was 100% alive. She was herself, alert, out there. As her world became smaller and smaller, her mind continued to soar. She couldn’t concentrate enough to read books anymore, and barely looked at the newspaper, and I would get very upset at this – reading had been so much part of her that in not reading she was telling me that I was losing her. But she listened to the radio constantly (that bloody 567 Cape Talk, which I hated), and watched television, and still loved to argue about politics and what was going on in the world. We didn’t always agree and would have arguments about things, but she loved the fight – her blue eyes in that shrunken face blazing with life. Once, a carer, who meant well, stood behind Bobbe as I shouted at her about how wrong she was to differ with me on a political issue, and rubbed her eyes, indicating, as far as I could read the gesture, that in my wrath I would make my mother cry. Quite apart from my feelings about being put in my place by this woman, something I’ll get to later, I knew she was wrong. If Bobbe could no longer eat what I cooked for her, she could sustain herself, in part, by the fact that I still thought of her as a worthwhile sparring partner, a powerful adversary. Our arguments were only in part about the content of what we were talking about – they were also acts of love. We were two people, mother and son, and for now, as we argued, we knew that we were both alive. I

usual, exceptionally productive, I have never quite got over the humiliation of this whole farrago. This goes beyond the usual recurrent flashes of anguish I often feel years later about silly things I have done, or ways in which I have embarrassed myself. I have no evidence for this apart from my own feelings, but I think that a key reason I got into trouble in this project was not that I was not producing. I have performed worse before and since then in other projects. The key problem was that, responsibly, I thought, I told other people that I thought that my caring for Bobbe as she died could impede my work functioning. I irritated other people by making this admission that caring for Bobbe was a central and defining part of my life. Both men and women, but men in particular, I felt, were irritated that my short-term misfortune, which could be tolerated, had become long-term carelessness, which was unforgiveable. Didn't I have a wife who would look after things, I could hear them saying. Couldn't I organise my life properly and put this issue of my dying mother in its rightful (and private) place? In experiencing the disavowal and, at times, the retaliation from others, I was not, of course, in much of a different situation from millions of women who get into trouble at work because of their need to care for their children (and, not infrequently, the father of their children).

But I think I got an extra knock from some of my colleagues precisely because I was a man. What I was doing in caring for my mother and allowing the whole process to affect me, was unmanly. I deserved the knocks I was getting because, as the poem says, "Ek hou van 'n man wat 'n man kan staan". My soppy girlishness – the ongoing preoccupation, anxiety and grief – was reprehensible and it must stop. Men get over things, men get on with things. I feel an enormous amount of pride that I refused to give in to this, and I can even see my continued caring for my mother, and my continued talking about it, telling others that it mattered and affected my life, as an example of shouting loud. But with all of this, of course, was my tacit agreement with everything that was said and not said. What kind of man was I, after all? The soppy fellow who looks after his mother, who can't manage his wife to do this for him – somewhere inside I felt that that was me. It's important for me to point out that throughout Bobbe's illness, Louise was there doing everything she could and, it often felt, even more – she could not have been better. The problem was not that I could not manage my wife (who has never needed managing from me, in any case), but that I chose not to offload my feelings on to her, for her to look after. My father dealt, in part, with the burden of emotion he felt about his own impossible mother by offloading her on to my mother (and on to us). I did not and would not do that.

The film *Jerry Maguire* has made the sentence “You had me at hello” famous, and there are now many versions of this, travelling as memes and Gifs on the internet, with two of my favourites being “You had me at turd sandwich” and the culturally appropriate “You had me at shalom”. Well, if you had me at hello, Deborah Moggach lost me at Rejoice. Part of me feels that, if I were more charitable, I would, like Phil Baker, writing in *The Sunday Times*, be able to see that the book is a “masterpiece”, by an author “at the height of her powers”²⁷. But I am not about to offer charity to a book, the third paragraph of which, to me, smacks of racism, classism, and a middle-class Englishness content to reduce working-class women, one of whom is a Black African, to comic bit parts, like Oompa Loompas providing an hilarious background to the magic that is Willie Wonka. To be fair, the paragraph that I quote here is written in the voice of one of the characters, and is not an authorial comment. I am not accusing Moggach of racism and classism. It is true that the book is a kind of moral fable through which snobby middle-class people come to see the value, contribution, decency and fundamental honesty of their working-class counterparts. But the carefully-named Rejoice (there are indeed Zimbabweans with this name and names like this, but the choice of this name does not seem to me to be by chance) and (Saint) Teresa are relegated to the flotsam of plot devices. Rejoice is mentioned once again in the book, again with reference to her constipating cultural food choice (the words “some sort of maize-meal” really give the game away), and as I quickly made the way through the book I did not see Teresa and her cigarettes again, but I may have missed them. The Zimbabwe reference is the one that really gets me, as there is nobody in Southern Africa who has not been affected by the tragic reality of the Zimbabwean meltdown, with Zimbabweans themselves, of course, bearing the brunt. The Zimbabwean diaspora is not a matter of choice, and women like Rejoice are keeping people in Zimbabwe from starving. Moggach, accurately, I think, describes *The carer* as “a comedy about class, and death, and family secrets”²⁸. But there may be, I suspect, a mote in Moggach’s own eye while she so entertainingly demonstrates the motes in the eyes of others.

²⁷ Baker, P. (2019). Fiction at a glance: The carer by Deborah Moggach; Everything you ever wanted by Luiza Sauma; When we were rich by Tim Lott. <https://www.thetimes.co.uk/magazine/culture/fiction-at-a-glance-the-carer-by-deborah-moggach-everything-you-ever-wanted-by-luiza-sauma-when-we-were-rich-by-tim-lott-rqzlh3zsb>.

²⁸ Moggach, D. (2019). Winter 2019 (website posting). <https://www.deborahmoggach.com/deborah-moggach-news/2019/11/18/winter-2019/>.

Why am I so worked up about a piece of light fiction by the author of *The Best Exotic Marigold Hotel* (I'm holding myself back, I promise you, from commenting about that title as well)? Let's get some obvious contenders out of the way. I would love to be a bestselling novelist. I would love to reach a wide audience with a discussion about the dilemmas people face when employing carers. In a word, I'm jealous and mean-spirited. I can agree with all of this, but I also believe that the complexity of intimacy and exploitation, the layers of dependency, the gentleness and the violence, that are intertwined with the employment of paid carers, really have not been thought about enough. In researching for this book I have read many books about death, and death as a topic is very in these days. Even a writer as brilliant and insightful as Atul Gawande slides past the question of paid care in his deservedly highly praised *Being mortal*²⁹. For me, one of the most brilliant and useful recent books about ageing and death, and about a lot of other things, is Nicci Gerrard's *What dementia teaches us about love*³⁰. In this book, Gerrard does mention paid carers but doesn't really deal with the issue in any depth. I'm not saying that there aren't any accessible books about paid carers, because there are³¹, but I think it's true to say that paid carers often play bit parts in other stories – they are often portrayed briefly as “wonderful” as the story moves on to focus on the more interesting, wealthier, characters. The book you are reading now – my book – is of course reproducing this tradition, as my book focuses on my mother and on me, but I hope I can do the issue of paid carers, and of paid care, some justice here.

I grew up with domestic workers, and, as I've mentioned earlier, accepted it as natural that a grown woman would wake me in the morning with my tea, and would finish her day washing up my dinner plates. Like most middle-class people in Africa (and the vast majority of these people are not White), I depend on the labour of domestic workers. Susan Filtane looked after my children when they were small and still works part-time for Louise and me today, over thirty years later. I hope I am less exploitative than most, and Susan is certainly much better paid. I don't know, and given the power relationship, will never know, how Susan feels about our relationship – she is paid, has a pension scheme and benefits. She is in my home a few times a

²⁹ Gawande, A. (2014). *Being mortal: Illness, medicine, and what matters in the end*. New York: Profile Books.

³⁰ Gerrard, N. (2019). *What dementia teaches us about love*. London: Allen Lane.

³¹ Interestingly enough, some of the most interesting accessible (non-academic) discussions of care are by South African or ex-South African writers. I think here particularly of Marlene van Niekerk's (2004) *Agaat* (Cape Town: Tafelberg); Ena Jansen's (2019) *Like family* (Johannesburg: Wits University Press); and, to my mind, the vastly underrated *Slow man* (2006) by J M Coetzee (New York: Penguin).

week, and has played a key role in the upbringing of my children and the care of my mother and my father-in-law after her. I have always paid a multiple of the recommended wage, but I feel in my bones like an exploiter, and money is not the only issue here. I also know that if we had chosen not to employ Susan after we no longer needed childcare, her chances of finding employment, especially at a living wage, would have been slim. There are a million ways of justifying anything. I was at a conference on care ethics a few years ago and there was excited discussion about the potential of robots to do domestic work. Joan Tronto, one of the people I admire most in the field, and a friend, provided an alternative to this brave new world of automated helpers: "Let him pick up his own damn socks." Care work is so inflected with gender, class, race, and the intimacy of both genuine affection and concern and genuine exploitation that we don't like to think about it or talk about it.

From the first day of our employing carers in our home, I made some decisions which suited me but which deeply affected our relationships with them. I was in such a vulnerable psychological state, that I did not want to be the formal employer of carers. I wanted somebody else to be the boss, and somebody else to have the worry of making sure that we would get full coverage of people to see that Bobbe did not fall, regardless of the circumstances of a particular carer on a particular day, the weather, taxi strikes, and so on. I did not want any of these things to be my problem. So we enlisted the help of an agency recommended highly by the oncologist. I was shocked at how much all of this would cost, but this felt to me preferable to having to deal with carers as direct employees. We had to pay for it, but everything would be at one remove. Business was business, or so I hoped and thought. It was quite a few months into this arrangement when I found out what I had known in my heart for a very long time. These women, who came into our home with the huge responsibility of looking after a dying woman, making sure that she did not fall, keeping her clean, preventing bedsores, spending hours sitting around bored stiff but on hand in case something went wrong, these women who had a job which to me would be worse than my worst nightmare, were earning almost nothing. We were paying a huge amount, but each of them was earning, for 48 hours per week, a fraction of what Susan got for 16 hours a week – they were at the bare edge of what is considered a living wage in South Africa. I could cluck at how exploited they were (and I did), but I was paying – and paying a lot – for the privilege of not having to deal directly with this exploitation. If I had taken the money we were paying monthly to the agency and paid it directly to carers, the income we paid to each of the carers would

self-interest in the way we treated the carers. We believed that if we treated them well, they would be kind to Bobbe. The carers told us that they fought among themselves to come and work in our house because we were nice people, because the food was good and because that whenever Bobbe was well enough we took them on outings with us to nice places.

One of the carers, Flora³², in particular, became very friendly towards us. After some time, though, Flora began to seem resentful and angry. We were not sure why. One issue was that she began dropping large hints about her need for money. We "lent" her some money which we did not expect would be repaid. One day when Louise's father was due to come and stay with us for a few weeks, we were unable to find his radio. We thought that we might have put it in Bobbe's room and we started searching for it there, looking through her cupboard. We did not usually go through Bobbe's things. Flora did not say anything, but clearly became very angry indeed. We stopped looking for the radio (which in fact was in the cupboard, as we discovered after Bobbe had died) and asked her what was wrong. Flora said that she did not like being accused of stealing, and would not listen to our protests that we did not think she had stolen the radio (which we did not). Very ostentatiously, she began writing notes in Bobbe's file. When she had left in the morning and another carer had taken over, I read the file for the first time. We had been told about the file when the caring agency had started working with us, and had been given access to it, but it had never occurred to me to look at it. I was shocked to read lengthy notes by Flora about how nasty and disrespectful we were to her, going back weeks. Other carers agreed in the notes that we were rude and difficult and that I was particularly rude. On one occasion, apparently, I had failed to greet one of the carers when I came home and she was angry about this. I am sure it is true that on one day I did indeed not greet her, but nowhere in any of the notes was recorded the long conversations we had with carers, the food, the outings, the ("illegal") "loans" we gave them not expecting to be repaid, the printing out of pages from the internet for

³² In the stories of Flora and Sarie, and others, which follow, I have changed details and amalgamated some stories. I am not in touch with the people who collectively make up the characters I mention, and I am convinced that nobody can be identified here. I have used the stories of Flora and Sarie, in slightly different form, in two journal articles, and some of the text is reproduced directly. The articles are: Swartz, L. (2012). Race, gender, and the impossibilities of care. *Medical Humanities*, 38, 34-37. doi:10.1136/medhum-2011-010073; and Swartz, L. (2015). Care and the luxury of trauma: A South African story. *Palliative and Supportive Care*, 13, 399-404. doi:10.1017/S147895151400042X

homework exercises for their children, and so on. I was surprised by how very hurt I was by this, and also by the fact that these notes were read every week by the care agency but nothing had been said to me about my allegedly abusive behaviour. In the event, the discovery of the notes was a positive turning point, from our point of view. We asked that Flora be transferred to another patient, and we had some painful but I believe very helpful discussions with the other carers, who all stayed on and to our knowledge did not complain about us again.

I felt humiliated and wronged by how I had been portrayed, and by the fact that I had been given no opportunity to get feedback and to change. The agency's response to my query as to why they had not informed us and taken us to task about our allegedly rude and exploitative behaviour was that we had allowed the carers to get too close to us. We must stop giving them food and we must stop including them in discussions in the way we did. We chose not to take this advice. When I try to make sense of this very painful incident in the long story of Bobbe's illness, a number of things come to mind. There are echoes here of generations of stories about domestic workers who are accused of stealing. I can hear other echoes of the way people talk casually about domestic workers in South Africa – don't pay them too much or they will get ideas, don't let them get too close. The agency's solution to the difficulties we had, it seemed to me (and I was enraged by this), was to put us back into the comfortable ascribed roles of White oppressors of Black women. I refused to do what the agency said, but of course we were employing through the agency women who were appallingly paid with dreadful working conditions. Who were we fooling? It's really not surprising in some ways that our being "kind", although initially clearly attractive to the carers, seemed to come to some of them to feel worse than our not being kind. We behaved as though we were their equals and friends when in reality we were not offering friendship. Indeed, when Flora upset us, we made sure we never had to see her again.

Another person who made a huge impact on me was Sarie. When she came to work with us, Sarie was living with her husband and her two youngest children in a council house in the greater Cape Town area. Her elder two children, aged 18 and 17, were living with relatives in Wellington, about 50 km away. Some time into Sarie's stay with us, her neighbour's house burned down and two of her neighbour's children came to live with her temporarily. This was Sarie's third job as a care worker – she had been employed previously by two other agencies but she was much happier working for

her current employer who, she said, treated the care workers more fairly than the previous employers had done. Unlike some of the care workers we met, she expressed a keen interest in care work and she told us that, had she not had to leave school at 17 when she was pregnant, she would have liked to have got her matric and become a registered nurse. Her husband worked on a casual basis as a security guard; her very low salary was the only marginally steady income coming into the house. She was employed on the basis that she was paid only for the days that she worked. If the agency did not have clients for her to care for, she did not earn. Two weeks prior to her coming to work for us, the young woman for whom she had been working as a care worker for six months had died as a result of a brain tumour; Sarie had not worked in the intervening two weeks.

We immediately took to Sarie and she to us. She especially liked the fact that while Bobbe was well enough we would take her out whenever we could – usually for tea and as much cake as we could get Bobbe to eat. The first time Sarie came with us to a shopping centre (one which caters mainly for the middle class), she commented, “Jesus must have sent me to you – you are taking me to such a wonderful place.” Born and bred in Cape Town, Sarie had never been to this shopping centre or to any shopping centre like it. Her first visit to the Waterfront was also with us; she enjoyed pushing Bobbe in her wheelchair near the water’s edge. When she wanted to go to the toilet, I pointed out the public toilet. “No, Mr Leslie (I could not convince her to call me Leslie),” she said, “that is not for people like me.” After much remonstration on my part, she agreed to use the public toilet.

One day when Bobbe was not well enough to stop for tea, I took her and Sarie for a short drive near our house. I drove up to Rhodes Memorial above the University of Cape Town (UCT) and explained to her how the wealthy colonialist, Cecil John Rhodes, had given a large estate to the South African nation. I pointed out UCT and Groote Schuur Hospital and explained how the National Botanical Garden, Kirstenbosch (where we had also taken Sarie for the first time in her life) was also part of a gift to the nation from Rhodes. A few days later, Sarie said to me, “You know, Mr Leslie, Mr Leslie is a very generous man.” I laughed and asked her why. “Well,” she said, “Mr Leslie gave all that land to the nation.” In my telling of the story of Rhodes’s gift to the nation, Sarie had thought that I had been the benefactor. To this woman, a fellow citizen of Cape Town, whose home is 20 minutes’ drive from my own, I was unimaginably wealthy. Feeling the considerable financial strain of caring

for through the agency. She walked out on her abusive husband in the only way she knew how – by walking out on her own two children and the neighbour's two children, leaving them in the care of her abusive and substance-abusing husband, and by walking out on us. We never heard from Sarie again. After Bobbe died, through other care workers at the agency, we invited Sarie to a memorial tea for Bobbe which we held at our home. She did not come to this, and we don't know if she ever received the gift we sent her via the other care workers to thank her for the kindness she had shown Bobbe over a period of months.

There are so many other stories about the carers, and I am not convinced that they are mine to tell. After Bobbe died, I worked with a graduate student to capture and tell some of the carers' stories³³, and I am glad I did this, but I am not sure this really helped anyone. I have what feels like a thousand stories to tell. Some are telling, and funny, like my own reaction to the carer who was clearly actively psychotic and experiencing delusions. In my professional work and teaching, I make it clear that the stigma and discrimination many people with mental illnesses face is unacceptable, and that even when people are actively psychotic, they may be able to function quite well, and that they should be supported in this. Now that Josephine, who had been called by the Lord (and not in a low-key way that could be explained away by evangelical religion – we had a lot of those and this was different), was in my home, and caring for the tiny, broken bird that was my mother, I could feel every prejudice I thought I did not have against people with serious mental illness well up inside me. I immediately worried that Josephine was dangerous, not to be trusted, you name it. Luckily for us both, I managed to contain myself, and Josephine managed to do both her and the Lord's work rather well. But there is no question that I had been caught out.

The carer I liked least was an older woman I will call Hetta. Hetta was exceptionally competent and experienced, unlike some of the terrified young women who turned up on our doorstep to work. She had home nursing qualifications, and her understanding of human anatomy and physiology seemed to me far superior to the sometimes alarming understandings held by some of the carers. She was not going to suggest, for example, that regular vomiting would help Bobbe purge herself of the cancer, and that the vomiting should be encouraged rather than avoided. But Hetta,

³³ Wilson, A., & Swartz, L. (2013). Paid carers talk about emotionally charged experiences in caring for dying people: A South African study. *Journal of Palliative Care*, 29(4), 246-252.

some twenty years younger than Bobbe, would address Bobbe as follows, “Now little mommy. Is little mommy going to put on Mommy’s shoesies for Auntie Hetta? Mommy must eat up nice and good so Mommy can get better. Mommy’s little beddie needs a good good cleaning so Hetta will put Mommy in the little chair so long.” An added problem was that Hetta would not shut up – there was a constant jingle of “Mommy – little – shoesies – beddie – poo-poo – wee”, which just went on and on and on. The mixture of Bobbe being called “Mommy” and treated like a rather stupid baby, and all in a sing-song nursery voice, nearly drove me bats. Part of the fun of Hetta, though, was that though Bobbe never complained to her face, the eye-rolling and knowing exasperation Bobbe showed on her tiny face, blue eyes flashing, the minute Hetta’s backie was turned, were a tonic to us. I loved to be a co-conspirator with Bobbe, who could not be further from the second childhood Hetta (“Shame, you know, sir, they just go back to their second childhood”) ascribed to her. Of course, Bobbe’s first childhood was probably nothing like this second one she was claimed to have returned to, but I wasn’t going to argue this with Hetta. This worked for Hetta, if not for us (and certainly not for Bobbe), and I understood from the care agency that Hetta’s services were much valued by others. Give me the crazy light of the Lord any day.

Most of the stories the carers told us, or that we came to learn in bits, though, were not funny at all. They were stories of poverty and abuse, of families torn apart, children and parents lost to one another. We knew (and this was true) that when Bobbe died, this difficult chapter of our lives would be over, whatever its long-term effects for us. We would resume what for us was normal (read: privileged and predictable) life. For the carers, when Bobbe died, if they were lucky they would move straight on to care for another dying person. If they were unlucky, they would wait, unpaid and unemployed, for the next call, or they would look for other jobs. I lost count of the number of them who asked if they could come to work for us as domestic workers – anything, anything. Not that long after Bobbe died, I was asked to give a keynote address at a conference focussing on trauma. At that conference, I told, in slightly different form, the story of our relationship with Sarie. I used this story to point out how the concept of “trauma”, so much part of the currency of contemporary psychology and contemporary society more broadly, still depends on the view of a functioning, predictable world. The concept of posttraumatic stress disorder, which entered the lexicon as recently as 1980, depends on life going on as “normal”, something terrible happening, then people having to react to it, and to live

grace the conference with a senior academic name). I was flattered, I guess, and in this case, flattery gets you everywhere and nowhere.

In so many ways, having the carers in our house and our multiple mistakes in dealing with them, were the most difficult part of that last year with Bobbe. We couldn't manage without them, and I remain grateful to all the women who looked after Bobbe so kindly and respectfully, especially at the end, when things were really difficult. But what a mess it all was. Part of my problem in thinking about this, is that I am not sure if, or how, I would do things differently if I had to have the time over. I was beside myself, distracted, vulnerable, angry. Unlike so many people all over the world, I didn't have to deal directly with my dying mother's body – I didn't have to clean her up, apply creams to her, see her naked. I don't think she would have minded this all that much, to be honest, but I had the carers to protect me from something I would have minded a lot. Of course I was exploiting them – I live with this knowledge – but if I am honest, I can't see myself being able to play the role of traditional master to their traditional servant role. This was the solution suggested by an experienced and reputable agency, smacking as it did of comments from other middle-class people that you should not pay domestic workers too much as they will get "spoilt" and "get ideas". Maybe the agency was right – let the police be the police – and if we had been clearer we would have had fewer problems. But we also had many good experiences with most of the carers – and I am good at hanging on to my privilege, as I did and do, but less good at the police stuff. That's me, softie that I am.

Bobbe's story about Lee Alexander was a story, in part, of jewellery theft, and for some reason I am reminded as I write this about what a friend and colleague once said to me about a very famous academic. This academic has built a considerable international reputation by writing beautifully about the lives of oppressed and excluded people. My friend said about this academic, "She wears other people's pain like jewellery." Regardless of how fair this comment was about the particular academic concerned, there is no doubt at all that many academic careers are built on well-written stories of other people's miseries. These people as portrayed in the stories, furthermore, elicit an emotional reaction from readers, and I do think there is sometimes a conflation between an academic's describing misery and abjection well, and the academic's being seen as a good academic. Even worse, we often assume that simply collecting information about people in difficult situations must be good for them and make their lives better. As I write this, my friend and colleague Jason

emotion, especially in animals, but with the rare insight of youth, Jenny and I had an excellent, and valid operational method. We would clear all furniture off the threadbare red-coloured lounge carpet, one of us would plonk Winky as close as possible to the centre of the carpet, and then Jenny and I would sit at opposite ends of the carpet, calling Winky to come to us. In terms of our research protocol, whichever of us Winky came to as we thus called, was the person who was more loved. As any scientist will understand, there were numerous confounding factors to consider including:

1. Who of us plonked Winky down in the middle of the carpet;
2. The orientation of Winky relative to the two potential love objects when so plonked;
3. The tenderness of the plonking;
4. How loudly each of us called Winky;
5. How imploringly each of us called Winky;
6. Wind conditions;
7. Barometric pressure.

And so on (believe me, this is not an exhaustive list). This required multiple experimental trials under a range of carefully-adjudicated conditions. After all that work, and after all these years, I honestly don't know what the experimental outcome was (but I know deep in my treacherous heart exactly where Winky's affections truly lay, and science be damned). If you think, though, that this intense wrangle in the 1960s for love from an animal weighing five kilograms has no bearing on issues of care for my dying mother, you don't know me. The fight for love, the fight all siblings have, and the fight Jenny and I had in spades, had a lot of influence on how two late middle-aged people dealt (on balance, very well, I think) with our mother's illness and death.

If this seems trivial and a stretch, just you wait. The year I turned thirteen, along with millions of Jewish boys before and after me, this involved my having my barmitzvah, which in turn involved having to buy a new suit. As the older sister, Jenny would also be on show, and she would need a new dress. Bobbe drove us all the way from White's, where we were living at the time, to Welkom, the nearest town of any size. I remember nothing of buying my suit, blue shirt and polka-dot tie, but what I do remember, over fifty years on, is how long it took to find a dress for Jenny. It's completely understandable that as a teenaged girl she felt self-conscious and wanted

knowing something about Bobbe's needs that I didn't, my hackles would be up. After Bobbe died (surprise, surprise), I started to do some research with colleagues about adult siblings, emigration and care for ageing parents³⁶. I learned, to my relief, that these sibling issues are far from unique, and I was comforted by that, and my story is my story. About six weeks before Bobbe died, Jenny and Ian came to see us on what was to be the last visit. Bobbe was deteriorating, hardly leaving her bed, thinner than I thought a person could be, with cancerous growths causing lumps and bumps to the skin. The sheer schlep of managing all of this was really getting to me, and I think I had two conflicting wishes in my head regarding Jenny's visit (alongside a whole lot of others). The first was that I really needed a break and for Jenny to take over for a bit, and the other was that I wanted Jenny to see what I was going through and to let me get on with it and not to interfere. I had been through the late nights, the vomit, the scariness of it all, and, through no fault of her own, Jenny had not.

On the second day Jenny and Ian were here on this visit, Jenny told me that I couldn't see it, but Bobbe was actually much better than the last time they had been here. I have no doubt that this was well meant and kind, but I felt blind rage. First, from where I stood, it was glaringly obvious that Bobbe was close to death and much much worse. Could Jenny not see this? And therein, of course, was the second source of my rage: Jenny had said to me that there was something I could not see about our mother, something she could see. She was the big sister, the authority, the one who knew things I didn't. All a grown up and macabre replay of testing for Winky's love. I was proud that I managed to contain my anger (though Jenny would probably have preferred me to express it), and I just changed the subject. It would soon become clear if Bobbe was better, I thought, not without guilt as I was almost willing Bobbe's decline as a way of proving my sibling point.

By the time Jenny and Ian (and their lovely son Dean) got here, we were hardly taking Bobbe out at all as she was so ill. Against my advice, they took her out a few times, and I thought this exhausted her. After Bobbe came back really tired after one

³⁶ See, for example: Marchetti-Mercer, M., Swartz, L., Jithoo, V., Wolfe, M., Briguglia, A., & Mabandla, M. (in press). South African international migration and its impact on older family members. *Family Process*; Swartz, L., & Marchetti-Mercer, M. (2019). Migration, technology and care: What happens to the body? *Disability and Society*, 34, 407-420. <https://doi.org/10.1080/09687599.2018.1519409>; Swartz, L., & Marchetti-Mercer, M. (2018). Disabling Africa: the power of depiction and the benefits of discomfort. *Disability and Society*, 33, 482-486. <https://doi.org/10.1080/02684527.2017.1400240>

of these outings, I was sitting quietly with her for a few minutes when Jenny came into her room. Jenny called me aside. "I think you're exhausting her, Les – I know it's hard, but you must give her time to rest." Imprinted on my mind is my marching to another room in the house, where I was changing the sheets. The sheets were a particularly strong shade of light green, and Louise and I had just bought them, and loved them. I see the sheets billowing over the bed as if handled by some sort of demon or dervish. I tried to keep quiet, but when Jenny, who could read banner headlines when she saw them, wanted to know what was wrong, out it all spilled in a messy rush, "You come here and you tell me she's better, when she's really much worse. She's dying, she's dying, Jenny! Then you take her out and exhaust her when I warned you not to do this, bring her back in pieces, and then have the gall to tell me, who has had a year of this, who has been here every day, taken her to every appointment, dealt with everything, you tell me of all people to get out of the way..." And so on (I regret), and so on. And then, of course the floods of tears and the apologies, with Jenny being really good about hearing everything and really really trying her best to listen. We were trapped in the cul-de-sac of our mother's death, our shared grief, our divisive rivalry, every good thing and every bad thing that had happened in our family brought to bear on that moment. I thank goodness that Jenny has such a capacity to listen, that she is so kind and cares so much. It's enabled us to go on as loving sister and brother. But my rage was my rage.

Part of the problem with all of this, though, was that the reality was that we were not doing at all badly as a family, but this brought with it its own pressures. I loved it that our GP Alan, and all the doctors at Colinton, commented on how well we were doing, keeping Bobbe at home and caring for her in an extended family in which our children, my cousin Pamie, and our friends played no small part. I loved it that people praised us as an extended family for spending the little money Bobbe had left in her savings not on wills and memorials, but on contributing to some of the considerable costs Jenny and Ian incurred flying out to see her four times in that last year. The approval and good wishes, in sharp contrast to some of the hostility I experienced with work colleagues, really helped keep me going. But they added to the pressure to get everything right, and I didn't know if I could.

Yvonne had spent many years working with families going through the process of someone dying, and it meant a great deal to me that she valued the care and attention we were giving to Bobbe. She strongly supported our choice for Jenny and

Ian to visit so often. When Louise and I were close to the end of our tether, some months before Bobbe died, we spoke to Yvonne, asking her if she knew anyone who could look after Bobbe for a few days so we could have some respite. Her first reaction was that we had the carers, but she did not argue when we said we didn't feel that we could leave them alone with Bobbe with nobody else here. She promised to think a bit and to see if she could find someone else, but in the event our friend Sharon Kleintjes stepped in and we did go away for a night. But while we had been talking with Yvonne, she had mentioned her admiration for our family, how close we were, how well we got on, and so on. I really don't want to deny Yvonne's perceptions, and I knew, as she had said at the start, that she would not lie to us. And, as I have mentioned before, Louise says that there is a generosity in receiving, and it's important to accept compliments with grace. But part of me felt really uncomfortable, not only because I was so overwhelmed and feeling that I was doing nothing at all right, but also because I worried that the happy families exterior we were managing to show to everyone was not really true, and that eventually the disappointing cracks would show. The last thing I needed was for people I was so dependent on to find out all that was wrong with me and then to remove their care. It never happened, and there was something a bit mad in my anxiety about this, but I had earned the right to be a bit mad, I guess.

There was something else going on at the time, though, and this has stayed with me. It has to do with the economy of care. I am hugely admiring of Yvonne and of St Luke's Hospice and all they did for us. I was amazed that though we had resources, they would not charge for their services, preferring instead to allow us to make contributions as we would see fit. St Luke's is an organisation which is doing work which others often don't like to think about – the work of death. They often get very little in return. I have come to see that part of what they wanted from us was not a big thing, not a bad thing to ask or to want – they want us to be the family (or one of them) that gave someone what they would call a Good Death. They wanted us to be in concert with them, to give them a rare chance to see their work and their philosophy reflected back to them through a good experience for Bobbe, and for us. And, you know what, for all the tensions, the difficulties in the family that felt so impossible at the time, the exploitation of others in the service of what we needed, my vacillations between good care and raging at my dying mother, despite all of those, and perhaps because of them, I think we did do quite well. But the idea of our being a poster family for how to help someone to die scared me then, and it scares

me now. I can't do it, and I don't want to. But in all the roiling emotions from everyone, I think this is what Yvonne and the other St Luke's people wanted or needed from us, their small and really harmless payback for all they did. In some ways, I prefer this idea of there being an implicit payback to the idea of the work of Yvonne and others being "thankless" – to me, people who want no thanks are not quite human. They may be better than human, but not quite human nevertheless.

For most of the (almost) year that she spent with us, Bobbe was dying very well indeed. She was so alive, and though the cancer spread all over the place, it didn't go to, or seemed not to affect, her brain. I kick against the patronising belief that old, sick, people who are not demented and have "all their marbles" are "wonderful", somehow better morally than those who succumb to the often cruel ravages of brain disease. Bobbe was lucky, and so were we – she had lived her whole life by her wits and her keen intellect, and as she died this did not change. When a kind friend commented, "There are no flies on your mother!" I suppose I should have been flattered and taken this in good part. I was irritated. We were lucky, that's true, and while Bobbe could indeed be praised for being realistic and cheerful about her own death, the fact that she could still think and behave like the adult she was, with an intact brain, was a matter of luck.

If most of the year was, on balance, good, though, the last six weeks were awful. I'm well aware that compared to what many families go through, Bobbe's experiences and ours were small potatoes. In addition, things that would really upset others didn't bother Bobbe at all – I was bemused and not a little angry at her enthusiastic embrace of incontinence pads and nappies, for example. I found it almost unbearable to think of her not being continent; Bobbe, who had waited her whole life to be cared for in some ways, had no problem being dressed and undressed by others, wiped clean by gentle hands, powdered, disinfected and perfumed. I would hear her through the door chattering away to the carers as they ministered to her, no doubt making their embarrassing and distasteful work easier. But within a week of Jenny and Ian arriving that last time, the deterioration which had been there all along seemed to me to get faster and more dramatic. More lumps and bumps on that yellow old body, even more weight loss (though she was already so thin that it had seemed to me impossible that she could lose another gram and continue to live), and much, much more pain. Worse than all of this for us, and probably partly as a result of the morphine and other drugs, she was not always fully conscious or fully aware of

herself, in the way we had almost come to take for granted. One day, when Louise and I were sitting with her, she opened her eyes and looked at me with a terrified expression, and said, “Leslie, I’m dying here.” These were the last words she said to me, and they were filled with such fear, such bewilderment, such desperation, and so different from how she had been throughout her illness. She was pleading with me, and I could not, or would not help her. I can rationalise everything, I can say that she didn’t really know what she was saying, I could say a million things, but that naked fear was as real as I have ever seen, and I wish she hadn’t said those words.

A big part of the problem was that she just wouldn’t die. She had outlived the oncologist’s reluctant prognostications by a good number of months, and her heart was strong. I kept thinking about Babe, who had not been a smoker like Bobbe, and who was doing well and living a very long life. With all the anguish of these last weeks, my mind kept returning, rebelliously, to the issue of Bobbe’s smoking. I had never blamed Bobbe for starting smoking at the age of seventeen, but from a young age I had really hated her smoking and had argued with her about it, largely because the smoking made my eyes itch and my nose run. Bobbe hadn’t smoked for some years – a very clever gynaecologist had told her she had to give up smoking before having a hysterectomy and though she always threatened to smoke again, Bobbe never had. But round and round in my head went the thought that if only Bobbe had not smoked, she would not now be on her death bed. Her heart was so strong that perhaps without the smoking she would have lived forever, or at least outlived me so I wouldn’t have to go through this. I was so angry, but of course it does not take a psychoanalytic training to see that my anger was about the loss, and the horrible, senseless, pain on the way to death, and blaming Bobbe for smoking was much easier than blaming her for leaving me, as she was doing. To complicate matters, there is no question that I wanted her dead there and then – I wanted the pain to be over – but part of me didn’t know if I could survive this. What was to become of me?

I should have helped her to die. It would have been the easiest thing in the world to put a pillow over that tiny face, to hold it down, and to let her go. What was the point of all of this suffering, when it was clear where it would end? I would never have taken the decision to help Bobbe die without consulting Jenny and the rest of the family, and I was also terrified of being convicted of murder. I just didn’t have the guts to take this on, though, and this is something I still regret. I am greatly admiring of Sean Davison, who helped his mother and others to die, and for the work done by

Chapter 14: Death admin

The expression “life admin” seems to be everywhere these days, and is even the title of a recent book by a savvy academic who understands the market³⁸. I’ve never been very good at life admin, and, embarrassingly have to tell all my students that I have two response times to email: immediate, or never, as I forget everything all the time unless I deal with it. Well, if life admin is a lot, death admin, though not as long-lasting, is even more work.

When my father died in 1983, he was buried in Johannesburg, where he lived, and as is the custom, a place next to his was reserved for Bobbe. I am not one for visiting graves, and for believing that it is at the grave that one can find or speak to the dead person, but to Bobbe it was very important to be buried next to her late husband. Long before she died I started liaising with Rabbis in Cape Town and in Johannesburg – if she was to be buried in Johannesburg, we had to arrange for the body to get there, and we would have to have a Rabbi from Johannesburg perform the burial, as was Bobbe’s wish. The Chevra Kadisha (Jewish Burial Society) were used to moving bodies around and they said that we could contact them. They did not work on the Sabbath but if Bobbe were to die on a Saturday, we could leave a message for them, and they would pick up the body after the Sabbath. As luck would have it, Bobbe did die on the Sabbath, and because we had had a difficult time with no visit from a medical doctor to confirm Louise’s mother’s death eighteen months earlier, we knew to get the doctor in, though it was after hours. Alan Wood’s partner from Colinton came, and he was businesslike and kind. We could send the carers on their way, off to the next privileged family going through death, but with the promise of a tea for them in a few weeks’ time to thank them.

I phoned the Chevra to leave a message. Instead of getting the answering machine I got a very cross response from someone who berated me for calling on the Sabbath when I should have known better. No point in yes-butting. In the event, the men from the Chevra came when they could with their trolley. I didn’t watch them putting Bobbe on the trolley, but the sound of the wheels bumping over the concrete slabs in the garden didn’t please me. She was gone. Her room was still full of medicines and ointments, pictures of my father and the grandchildren, bits and pieces of her. But the bed was stripped and bare, and it was time to pack her away. I don’t know why I

³⁸ Emens, E. (2019). *The art of life admin. How to do less, do it better, and live more*. New York: Penguin.

took a photograph of the dressing table full of things – I did this some time before she died, but I am so glad I did. In some ways this photograph speaks more to me of Bobbe's illness and death than do photographs of Bobbe herself.

We all flew to Johannesburg and stayed in the same bed and breakfast where Bobbe had stayed when she visited. Jenny and Ian had been extending and extending their tickets, as they had not planned to stay so long, and Jenny had to get back to work in Australia. I am so grateful that they just managed to stay for the funeral before having to fly off home. We all needed to be there. The funeral was low-key and quite pleasant. In the middle of the proceedings, a cell-phone rang and the owner struggled to turn it off. We laughed. As it happened (and in confirmation of all my theories about the link between technology and the unconscious), the owner of the phone was someone who considered themselves very pious, disapproved of the Reform Shul, which was far too liberal theologically, and had been quite nasty to Bobbe in the past. Bobbe, being Bobbe, had forgiven what I had thought was very bad behaviour and was on good terms with this person. But all of us chuckled at how Bobbe would have laughed that of all the cell phones in the world not to have been properly switched off, it would be this one, in a House of God at the cemetery. The unconscious had spoken.

It was ages since I'd been in any religious service, apart from the Catholic funeral of Louise's mother the previous year, and I was pleased to see that the Reform Shul had moved a lot on issues of gender, allowing women to act as pallbearers, for example, so we all had a role in the proceedings. Jenny didn't want to speak, so only I spoke very briefly at the funeral, mainly thanking people, I think, but I have no recollection of what I said. It had been a good funeral, we were able to say good goodbyes to Jenny and Ian, and we returned home to life. There were issues of death certificates, closing of banking accounts, winding up Bobbe's affairs. By the time Bobbe died there was very little money left in her estate – we'd all agreed to spend what she had on life, on bringing the family together, and I never regretted this.

I like to tell everyone that Jenny and I fought over the will, and this is true. Bobbe's instructions were very simple – apart from a few very small bequests, everything was to go to Jenny and me, fifty-fifty. Then the fights started, but not in the way you'd think. "You take the money," Jenny said, "you did all the work." "No, you take the money, you had to be so far away." "No, you take it." "No, you take it." And so on. I

can't quite remember what we did in the end, and maybe things would have been different if there'd been more money to fight over, but, frankly, I don't think so. Bobbe had rolled her eyes at Rabbi Greg's suggestions that she write an ethical will, but she'd clearly bequeathed something to us that was much more important than money. I remain so grateful to have my sister, and to have her love, even if I know in my heart, and on the basis of the best evidence available to me, that Winky loved me more than he loved her. I think we both knew that for people who are not living on the breadline, there are much more important things to worry about than how much money you can cheat from your sibling. Bobbe's life was full of compromise and lots of mistakes, as are all lives, but she'd done good by us. She's done good.

In many ways, I was completely unprepared for going through the long process of Bobbe's dying, but in other ways, this was something to which my whole life was leading. I think those eleven and a half months of having Bobbe with us, dying but mainly living, were in many ways the very worst time of my life, but also a time I feel deeply grateful for. As I write this, I am in that magic time of life where by many standards I am considered old (something I have no problem with – what's wrong with being old?, I hear Bobbe say), but physically well and with very few care responsibilities. I have been known to irritate my children when I say, "I'm in the best time of my life – I am healthy, the parents are dead and the children are grown up." But it's true, and there may even be some research to back this idea up³⁹. It's not that long since Bobbe died, and I honestly don't know how I managed it. But of course, it's just as true to say that I didn't manage it – these things come at us, and, mostly, we survive them. Not through any special moral qualities but through the fact of survival. One foot in front of the other, and one day after the other. And in my case, I had so much help. In so many ways, I wish Bobbe's life had been different – I wish she'd had a career as a writer, I even wish she'd won the Nobel Prize. I wish she hadn't entangled me in her life so much – it wasn't fair. But I am so grateful for her, and I miss her. For the first few months after her death, especially, though I was so relieved the ordeal was over and we had the house to ourselves, I would get moments, completely unbidden and seemingly random, of convulsive grief. I had dreams of being abandoned, of being left at school with no school shoes, of

³⁹ Ryan, R. M., & Deci, E. L. (2001). On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. *Annual Review of Psychology, 52*(1), 141-166.; Cheng, T. C., Powdthavee, N., & Oswald, A. J. (2017). Longitudinal evidence for a midlife nadir in human well-being: Results from four data sets. *The Economic Journal, 127*(599), 126-142.

middle-class successful people construct our world on the illusion that we are independent, when in fact we depend every day on others for our lives and well-being. Think of life without garbage-collectors. We need them in order to get on with our lives. More than this, though, I think there is something we see as shameful when we give care its rightful place in our lives – when we give it legitimacy. This goes, I think, both for our need to be cared for, and our need to care for others. We all love heroism and big dramatic gestures, we all idolise parents of disabled children, calling them “selfless” and “wonderful”, but why do we have to make them so otherworldly?

I trained as a clinical psychologist in the early 1980s – somewhat to my shock, I realise that I have been a psychologist for almost forty years – well over half my life. At the time I studied psychology as an undergraduate, the field of developmental psychology as it was taught to me dealt only with child development – we stopped thinking about development at adolescence. Erik Erikson, who won a Pulitzer Prize for his study of Ghandi’s nonviolence, had in 1959 written his *Identity and the life-cycle*, examining human development across the lifespan, but it took some time, in South Africa at least, for us to consider developmental psychology as the study of all of life. I was also taught, as a budding clinical psychologist, that there was not much point in trying to do in-depth psychotherapy with people in what has now come to be known as the “second half of life”. This was because, the story went, the personality has already been formed by early adulthood, and older people are likely to be more rigid and resistant to change than are others. The irony of my having been taught this by a psychologist who was himself about seventy years old at the time, and very much still exploring life, was not lost on me. This neglect of most of life by my discipline as I was taught it angered me at the time, but since Bobbe died, I’m even more angry. I am furious that the experience I had of trying my best to look after my dying mother, struggling, doing some things well but failing in other ways, was something my discipline hardly looks at. As I have given talks on these issues and spoken with dozens and dozens of people, the number of people who have said to me, “I thought I was the only one who had to deal with this”, has been staggering. I don’t want to deny that there is something in the nature of caring for a sick or dying person which may in itself be isolating – life does just shrink when you are so focussed on bodily needs, on whether someone has eaten, vomited, pooed. But there is something else at work here, and this is the lack of a social space to speak about such things, to have this experience of care helped a bit by the knowledge that

I am not the only one going through it. I have looked at a lot of lifespan developmental psychology textbooks recently, and generally they say very little, if anything at all, about the very common reality of the demands (and opportunities and pleasures) of care of people other than children, as part of development. Even feminist books looking at women's development often don't take care across the lifespan seriously.

I can give you a million academic explanations of why I think this is so, but I think they all boil down to ideas about people being individuals pursuing their individual life-goals. It's not for nothing that a life-goal for Jung, the founder of analytic psychology, is called "individuation", or that Carl Rogers, who played an important part in popularising psychology and counselling in the USA, spoke about "self-actualisation". It's also important that in contemporary South Africa, following the example of Nelson Mandela and Desmond Tutu, there is a push-back against this individualism through *Ubuntu* philosophy, with personhood being defined as something that happens in relationship – "a person is a person through other people". In general, though, and certainly through the discipline of psychology which I am part of, we just don't make public the reality of care issues for many, if not most, people. This is part of why, after Bobbe died, I decided to write this book – mine is one story, and I am telling it for all the selfish reasons anyone would want to tell their own story, but also because I honestly believe that ordinary stories like mine need to be told. I'm pleased that there are now more and more books being written about dying, and some of these do talk about care, but there needs to be more.

St Luke's, and Yvonne in particular, had been an enormous help to us, and Louise and I wanted to do something, apart from giving money, to try to begin to repay their care. As these things happen, we bumped into an old friend while walking our dogs in the park, and she was now working at St Luke's. She asked us if we could do some work with the Spiritual Care team of volunteers. Louise was not free during the week because of work commitments, but I could make the time. I was lucky enough to spend quite a bit of time with a caring, insightful, and generous group of people, from a range of religious and non-religious (including atheist) backgrounds, who allowed me to hear about their work, their joys and frustrations. One thing that became clear is that they worried, like so many people doing caring work, that their work was not visible, and was difficult to explain to others. This concern about invisibility was so familiar to me – about death and care, as I have mentioned, but

support to families and communities in dire need, worried that their work could not be seen, could not be properly explained, and would not be seen as being of value in a world in which measurable outcomes are so highly valued. They spoke about how, from their point of view, the fundraising efforts of St Luke's (which they clearly agreed were essential for their work to continue) were more highly valued than what they actually did for dying people and their families. I think part of why I worked so happily with the spiritual carers is that I had been through the experience of leaving the kingdom of the well and living in that strange, nameless, and peculiarly invisible world of care. And this was exactly where they did their work. I wanted (and still want) our society, and my discipline of psychology, to become more open about the kind of experience that so many people go through.

A year to the day after Bobbe died – on 15 January 2012 – I sat down to write this book. I knew I wanted to make visible to others what had become visible to me. Well, here's a piece of advice one would not expect someone of my background to need. Don't try to write a book about the loss of your mother at the very time you are in such grief for her, when it is just a year since she died, you are busy with the unveiling of her tombstone, and your father-in-law, like your mother before him, is living in your house very close to death. Big mistake, and an obvious one. I'm not altogether surprised by my trying to do this, though. I always say that the only people who have to present themselves as big and powerful are those who feel small and powerless inside. We often forget that narcissism and all the self-aggrandisement that goes with it, is not about self-love, but about the worry that if I don't puff myself up to be big and wonderful, nobody will notice me. The sheer omnipotence on my part of thinking I could knock off a book about Bobbe quickly and so soon after her death now tells me everything about how powerless I felt during her dying, and afterward, how without words to tell what had happened to me. Just like the St Luke's spiritual carers and many others, I was reproducing the very problem I wanted to address. I had no choice but to put the book project aside and to allow it to percolate as a continual but barely-perceptible hum under everything else I was doing in my personal and professional life, like the sound of an air conditioner you can tune out sometimes, but is always there⁴². The book was always there, and in

⁴² When Louise read this part of my manuscript, she reminded me that for some psychoanalysts, especially in the Kleinian tradition, the concept of "phantasy" (as opposed to "fantasy") has been likened to a background hum (see, for example, Robert Young's online essay on Klein: http://www.psychanalysis-and-therapy.com/human_nature/papers/pap127h.html). The concept of phantasy, simply put, is that we see and

fact Alison and Rebecca quite frequently asked when it would eventually be written, but it was also not there. This did wonders for my career, as it happens. Most people, in my experience, have helpful ways of avoiding writing. These may involve cleaning the kitchen, tidying the desk, eating muffins for energy and inspiration, deciding I just have to read these 45 articles before I can possibly write mine, and so on and so on. Like all writers and academics, I constantly live with the curse of procrastination, and in fact I am astonished that in all the talk at the moment about a mental health crisis among academics, there is so little discussion of how procrastination eats you out from the inside and affects your mental health.

As ever, though, I don't think what was going on with my avoiding committing to writing this book was pure procrastination. Leaving aside the fact that I always have to be special – no garden-variety procrastination for me – I had to let my process of not writing this book teach me something, something I thought I already knew. Since Bobbe died, I have been exceptionally productive academically, writing huge amounts, getting articles and other (edited and co-written) books out at a cracking pace. All of which had value, and lots of joy and pleasure, in itself. But instead of cleaning the kitchen instead of writing, reading to avoid writing, doing mountains of meticulous administration which somebody else could do (and complaining about it) to avoid writing, I had another avoidance at work. I was writing to avoid writing – I wrote and wrote things which were quite easy for me to write, so I didn't have to face the problem of my not writing this book. It got to the point where I was publishing more in one year than many colleagues publish in an entire academic career (I kid you not). If I went any faster, I would, like the tigers in the Rudyard Kipling story I read as a child, chase around and around, until I turned into a pool of butter⁴³. I couldn't stop, and I was enjoying moving so much that why would I even think of stopping? But the hum kept humming, and the slight but barely perceptible discomfort of the grit in the shoe, or in the oyster, was there all the time. I could not dodge this one forever.

For all my wanting to understand absolutely everything (I think I'm like Bobbe in this), some things are mysterious, and I honestly don't know how I came to break the

experience the world through the organizing lens of our past experiences. Everything I was seeing was to some degree or another structured by my experience of Bobbe's death.

⁴³ The Kipling story is, of course, *The Story of Little Black Sambo*, which is, of course, rightly called racist these days, and I am no Kipling fan, but the image of rushing and rushing until the very structure of you disappears – until you fall apart – is something which speaks clearly to me.

wonderful, wonderful mother, whom I miss so much to this very day – was tantamount to being engulfed in her own needs, to losing myself. I realised that even my decision never to tell my parents about my difficulties at boarding school was partly to protect them, but mainly to stop me from being washed away in a torrent of anxiety and concern – all offered in love, but to me a dangerous torrent nevertheless.

I loved doing my first PhD, which I completed as a young father, and I knew that I would never be crazy enough to do another one. As far as the certainty of that prediction goes, all I can say in my defence is that at that time I also knew for sure that I would never be bald, as I had so much hair. It's not possible to be more bald than I am at this stage of my life. No harm in getting things wrong. But there were two rather odd things about my first PhD – well, not about the PhD itself, which I remain proud of, but about the process. The first was that in the early stages I really didn't want to hear anything from my supervisor, Don Foster – I wanted to do everything on my own, without his help. Don read me well, backed off, and gave very helpful feedback at later stages. But yet again, as a young PhD candidate, I had run away from home and the help I could have got earlier on, which would have made life much easier. The second thing I did with that first PhD was even closer to home. At the time, I was married to Sally, my first wife, and we had two very young children. Sally was very supportive and helpful of my work. But throughout the process, I never told Bobbe, who was in Johannesburg, that I was doing a PhD. You might think it would come up, and it would in any usual family. But I felt at the time that I would not be able to bear her anxiety, and her constant questions about my progress. Now, it is the job of any concerned parent, and certainly of any Jewish Mother, to worry over her child's progress and to ask how things are going on. Most children of parents and of Jewish Mothers learn to deal with this concern, and even to welcome it, in many cases. There are, after all, worse things than having people care about you. But in some ways, not for me. The first Bobbe heard of my doing a PhD was when I received my results. She didn't know about the struggles I had had at boarding school, and she didn't know about the struggles which were an inevitable part of doing a PhD.

A PhD, like a barmitzvah, like dying, is a rite of passage. I had not fully allowed myself to go through the passage the first time – I didn't allow my supervisor fully to be my guide, and I didn't allow my surviving parent to experience the worry that parents of children doing PhDs are privileged to experience (and I know this privilege

from the inside as both my daughters have PhDs and, boy, did I worry! And proudly worry...). In my mind, I had made my barmitzvah partly not about myself but about the memory of Jenny looking for the right dress. How unfair of me. Since Bobbe's death, I had become an advocate for giving issues of care their due place in the world. But it took what felt like forever eventually to realise that if I really wanted to deal with what I had learned from looking after Bobbe as she died, I needed to do something about allowing myself to be cared for. In that day in Shaun's office, I came to see that at last I was doing something care ethicists talk about – for care to be completed, it has to be received. As Louise says, there's a generosity in receiving. For a long time I had been mean to Bobbe and others on this count.

I am not claiming a Damascene moment of dramatic change here, and I resist with every fibre of my being the thought of all difficult experiences, like Bobbe's death, being Things That Have Been Sent To Teach Us About Life. Spare me the humbug. It is also far from true that I am not, or have not been, capable of accepting care from others – I depend on, and have done for years, the support of many others, not least of them being Louise and my children. I'm still not fabulous at allowing too much opportunity for supervision – I am not a completely new person. But as I sit here ten years almost to the day after Bobbe moved in with us to live and die in our home, I know that something, however small, has changed in me. I wish Bobbe were alive to see it, but, of course, if she were alive, it wouldn't have happened. Sad but also wonderful, when you think about it.

Chapter 15 How I lost my mother

How do you lose your mother? How do you lose anyone? It's not the same as losing spectacles or keys. I lose these constantly, and my family have learned to say, "Don't panic. They are where you put them. Have you actually looked for them?" Well, I have actually looked for Bobbe, and I suppose that I can say that she is, if not a hundred percent right, a hundred percent here. And a hundred percent not here. I don't believe in life after death, I don't believe she's looking down on me smiling indulgently (or even furiously, or exasperatedly). But like everyone who has lost someone, and we all have or will unless we are very very unlucky to be lost before everyone else, I have to deal with, and live with, memory.

When I lose my glasses or my keys, my family says, "Think where you were when you last had them, and work from there." Good, helpful advice. But where was I when I last had Bobbe? I can think of the day she died, but of course the longing and the loss start long before that. I joke with friends who have young children: "Ruin them emotionally when they're young," I say, "Or they will leave you." And in fact I do believe that one of the greatest ironies of parenting is that our crowning success comes when our children can go off into the world and make their own lives, becoming adults. I went off into the world and did well, and for Bobbe this was in many ways a great betrayal. And to be fair, though I never would have admitted this to her, I was actively betraying her. I wanted out, I wanted my life, and I made sure that, like Shakespeare's Macduff, I was "untimely ripped" from my mother, leaving us both scarred. In some ways, though, I had lost her long before that, when she needed me to be something other than her child, and psychoanalysis would, of course, say that every birth is a traumatic separation of infant from mother. You lost me at Day 1, and I lost you.

Life, as they say, goes on. Louise's father David was still living in Johannesburg, and as far as we could see, he was really struggling. He had had a bruising and exhausting battle to do his best by his beloved wife, Rose, who had died of dementia under very difficult circumstances in April 2009. He had faced some family difficulties in addition to this, and we were concerned that he was depressed. Louise was caring for him by phoning him (literally) four times per day, but we thought it would be better, if he wanted this, if he would come and live with us. He decided to visit us over the December holidays the same year Bobbe died, and we hoped he would decide to stay. We met him at the airport, and he looked thin and gaunt. He had a

troublesome cough, and he had seen his GP in Johannesburg a few times. He had told him that he had a postnatal drip, and, according to David, the doctor had told him that he must not fuss over his health. Having met this doctor before, I had no doubt that David was accurate about what had been said to him. To us, though, he looked very ill indeed, and we did not like the sound of his having been coughing for months. Louise took him to see Dr Dani Cahill, who at that time was still working at our trusted Colinton Surgery. In the very first consultation, within a matter of minutes, Dr Cahill suspected that David had lung cancer. This was confirmed on further examination, and it was now Stage 4. If this sounds familiar, that's because it is. They say that lightning never strikes twice, but both Bobbe and David had been fobbed off by doctors, told effectively that they were imagining things, and both were seriously ill. Both eventually got excellent health care from wonderful doctors, but by then, both were in Stage 4 cancer. If this is how the health of two elderly people with privilege can be handled – with disavowal, inattention and rank incompetence, I can only imagine how other people are treated. As had been the case with Bobbe, there was a part of me that wanted to sue the doctors concerned, and perhaps we should have, but our focus was much more on the immediate issue of the best possible care going forward.

We dug in for the long haul. It was less than a year since Bobbe had died, and we had not foreseen that we would once again have the decision about having a sick parent living with us. There was no question, though, that we would do this, and though Louise had been very close to Bobbe, and would have taken her in even if I had not been there, I did feel that this was a chance for me to pay her back a bit. We were concerned that when we went back to work, David would be lonely, so we got two small dogs to keep him company. When they arrived, the first thing they did was to go to sleep under his bed, so they seemed to understand their role very well. In the event, David's health deteriorated dramatically and very quickly. The unveiling of Bobbe's tombstone was coming up, a year after her death, and we were due to go to Johannesburg for this. It became clear that David was now very ill, so Louise stayed with him. Thank goodness she did. A week later, and in fact exactly a year and a week after Bobbe died, David died in our home, in the same bed where Bobbe had died before him.

Not long after Bobbe had died, Rebecca had been awarded a large scholarship to do her PhD in London. Shortly before she left, she and I, very unusually, had an

enormous row, most of the details of which I honestly can't remember (repression is a wonderful thing), but which affected me deeply for months, and even years. It's really not that unusual for people who are about to be parted to have an argument just before the time of parting, and we can speculate that having the fight may be a way of making the parting easier. One thing I do remember very clearly from our argument, was Rebecca's telling me that she felt that while I was very proud of her achievements (which I was), she felt that I kept myself at a distance from her and was not that interested in her as a person. I found this feedback devastating, but I have had similar comments from Alison, and I've really had to think about this.

I am very clear that I adore and admire my children with a ferocity and love which I had not thought possible, so the problem was not that I didn't care enough. There was something else I was doing. And then it dawned on me. I don't know if this is how my children see it, but this version makes some sense to me. I had spent much of my life adoring, but feeling swallowed up by Bobbe, and I was determined not to do the same to my children as was done to me. It wasn't fair. I added to this determination in the wake of my divorce. I believed then and believe now that other things being equal, parental divorce is not a kind thing to do to a child. I felt (feel) that I let them down – whatever the rights and wrongs were with my divorce (and these things are always more complicated than they seem), I was one of the adults putting children through this. It wasn't fair. To complicate matters further, I felt so broken after the divorce and before I met Louise that all I wanted to do was to grab my children to myself for comfort, and never let them go. I felt this powerfully, and for a very long time. But as the child of a woman who needed too much from me, who unwittingly but nevertheless unfairly made me into her little man at a very young age, I was determined not to do the same to my own children. I let them go, tried my best not to demand, and tried to convince them in every way possible that I was fine and happy, out there in the world doing fun things. I didn't want them to look after me. Though I treasure the good relationships I have with my children, and the good very substantially outweighs the bad, I have to live with the feeling I have that each of them, in her own way, has felt at times that my attention was not on her, that, not to sugar-coat this, I have in some way abandoned her.

I am so lucky that I have come to know this in the context of what are mainly very close relationships with my children (I adore them and I believe that they adore me), but by not wanting to demand too much, I've given them reason to feel abandoned in

some way. You can dress this up any way you like, but my feeling is that I've wounded them, even if in a small way. And where does my wounding come from? I don't know the full answer to this, but I am certain that at least part of the story is that I didn't want to inflict the same wounds on my children as my mother had inflicted on me. She couldn't bear to let me go, she couldn't see me as fully separate from her, so off I go to the other extreme and communicate to my own children that I am only too keen to let them go, to be separate and different from me. In the big picture of how we all get on and love one another, this is really not a huge issue, but it's real for me. I don't know properly how to ask my children for things, and it is a slow process of learning from them that I may ask, and that my needs will not engulf them as I felt engulfed. I am lucky and grateful that they are my teachers and helpers in this regard, as is Louise in no small measure. I have to learn fully the generosity of receiving.

I don't fully understand how, and when, I lost my mother. I am lucky and grateful that I don't have to write a book called "How I lost my children." Unwittingly, and with the very best of intentions, I was working on that book for some time. It's inconceivable to me as I sit here that that book will ever need to be written, and I am grateful for that, but in trying not to engulf my children with closeness, I ran the risk of their feeling me to be far, far away. Like everyone else, I try my best, but it is partly a matter of profound luck, and a matter of the generosity and kindness of others, that the best I tried did not have catastrophic consequences. I don't like thinking about this, but it does help me be more understanding of Bobbe. Some of her engulfing, smothering warmth to me, after all, may have been occasioned by her own experience of being the outsider, unwanted, the wrong person in her family. If I allow myself the luxury of thinking that I meant well with my children but over-compensated for my own wounds, I must allow the same for Bobbe, who may also have been compensating. Closeness and distance, closeness and distance. So hard to find a good path through that.

In the Jewish religion, the unveiling of the tombstone is supposed to mark the end of the mourning period, the return to life as usual. It didn't feel that way. Louise was dealing with the terminal illness of her father (who in fact died in that week), and so were we all. Rebecca had gone off to London to start her PhD, and in the three weeks that she was away, her step-grandfather had deteriorated very badly in health and was now terminally ill, and her beloved uncle from Zimbabwe (her mother's

to Dinky when I was a teenager and we were both still in Johannesburg. There was no question in my mind that Bobbe would have wanted me to give Dinky the honour of being the second unveiler.

Once I had made this decision, I saw what I read as the stony face of a distant relative but family patriarch. This man was much older than me, and he had had quite a rocky relationship with Bobbe. He was also, I knew, a stickler for protocol and doing things by the book. Not only had I made what to Orthodox Jews was indeed the scandalous decision to allow women to be involved in unveiling (this was for men only), but I had snubbed the person who should have by rights and tradition been first in line for the honour – the patriarch. If I had to make the decision over again, I don't think I would change it – for Bobbe it was important to welcome somebody, like Dinky, who had had approbation from the family back into the fold, to mend broken bridges. I tried to be pleasant to the patriarch, and I tried on quite a few occasions to get in touch with him after Bobbe died, because I think that is what she would have wanted. But he has never got back to me. I don't know if he is now officially on non-speaking terms with me (how would I?), but I do know that he has a history of not speaking to people who have slighted him or family members. I guess I'll never know. I don't especially want or need to see him again, but it was important for me to try to do what I think Bobbe would have wanted me to do. So I tried. Maybe not hard enough, but I did try.

In some ways, this is such a trivial issue – I had not seen the man for years before Bobbe's death and I don't think I would enjoy seeing him again. My worrying, till today, all these years later, that I may have offended him comes not from guilt about him, but from something which is important to me. So often, and at unexpected times, our family are in a situation in which we ask, "What would Bobbe do?" Not infrequently, we imagine Bobbe telling someone that she is "a hundred percent right", or nodding vigorously in agreement and then surreptitiously rolling her blue eyes at us. It's tender to think of her and remember her like this. I find myself talking in a cadence that is hers, hearing her voice through me, wagging my finger in a particular way, wanting to show Bobbe that I too, now have arthritic fingers just like hers, and there's nothing as good as an arthritic finger-wag. The concept of haunting (very fashionable in current psychoanalytic circles) is often seen as something scary and chilling. Much though I was afraid of being engulfed by Bobbe for much of my life, though, not quite knowing where she ended and I began, I find being haunted by her

in this way – finding myself speaking with her voice, wagging her finger, seeing with her eyes, comforting and warming. In many ways the “What would Bobbe do?” question, is the very opposite of the currently fashionable question so beloved by evangelicals, “What would Jesus do?” I can just hear Bobbe – I can really hear her – saying, “Well, it’s clear as day. What would Jesus do? He’d vote for Trump.” And those eyes would roll. She died long before Trump became president, but I have no doubt in my mind that she would be appalled, and would find the business of rebutting anyone who supports Trump such, such fun. Shouting loud, fighting the fight.

So when we ask, “What would Bobbe do?” what are we asking? I don’t think we are asking for a moral legacy for the saintly department, and Bobbe shared my irritation with the instant beatification of anyone immediately upon their death. But Bobbe, who struggled through a lot of her life and did many things she shouldn’t have, like all of us, also, and especially in later years, had such vitality, such ability at last to enjoy things, that a “What would Bobbe do?” question is not about what the right thing to do is, but about the sheer joy of the struggle, the delight of being out there in the world, having opinions, arguing, changing your mind sometimes but working even harder to change the minds of others.

All legacies are mixed, the good with the bad, the things you wish had not happened, the losses, the scars which won’t go away, along, if you’re lucky like me, with the wonder of having known an exceptional person. And the struggle, the struggle – that’s the essence of life. When I read “What would you have done?”, A Problem Story by ELSIE COHEN, 59 Abel Road, Johannesburg, I didn’t at first realize that the first name of the hero was so similar to mine – identical to the second syllable of my name, in fact. Maybe part of me started a long time ago, maybe part of me, like Bobbe now, will have some meaning into the future. In the meantime, since we are talking here about endings, allow me here to paraphrase the end of Elsie Cohen’s Problem Story:

Leslie did the right thing....

What he did I leave to you, dear reader, to decide.

Section 2: Reflections on *How I lost my mother*

Section 2: Reflections on *How I lost my mother*

The artist usually sets out - or used to - to point a moral and adorn a tale. The tail, however, points the other way, as a rule. Two blankly opposing morals, the artist's and the tale's. Never trust the artist. Trust the tale. The proper function of a critic is to save the tale from the artist who created it.

(D H Lawrence, 1923; reprinted 2014, p. 14)

What are the qualities of a good (a plausible, even a compelling) story? When I tell other people the story of my life – and more importantly when I tell myself the story of my life – should I try to make it into a well-formed artefact, passing swiftly over the times when nothing happened, heightening the drama of times when lots was happening, giving the narrative a shape, creating anticipation and suspense; or on the contrary should I be neutral, objective, striving to tell a kind of truth that would meet the criteria of the courtroom: the truth, the whole truth and nothing but the truth?

What relationship do I have with my life history? Am I its conscious author, or should I think of myself as simply a voice uttering with as little interference as possible a stream of words welling up from my interior? Above all, given the wealth of material I hold in memory, the material

of a lifetime, what should or must I leave out, bearing in mind Freud's warning that what I omit without thinking (i.e. without conscious thought) may be the key to the deepest truth about me? Yet how is it logically possible for me to know what I am unthinkingly leaving out?

(J M Coetzee, 2015, pp. 1-2) in (Coetzee & Kurtz, 2015).

Chapter 1: Getting to writing

During the last year of my mother's life, and as we cared for her in our home, I knew that I wanted to write a book about the experience. *Able Bodied*, which was in part a memoir about my father, who died in 1983, was published in the middle of 2010, by which time many medical personnel had expected my mother to have died. I had asked my publisher to speed up publication of the book as much as they could, because I wanted my mother to be alive to see it. In the event, and luckily, there she was at the launch of *Able Bodied*, impossibly small and thin in her wheelchair, but so delighted with the book, and with the fact that I had chosen to honour the memory of her late husband in this way. *Able Bodied* was many things to me, and though I had not planned this at all, it felt to me in part like a gift to my mother. Before I discuss issues in the process of writing *How I lost my mother*, I shall briefly discuss some of the concerns I was addressing in *Able Bodied*, because there are both similarities and differences between the two books.

Writing *Able Bodied*

My primary motivation for writing *Able Bodied* was personal and had to do with my trying to understand my family and myself. But it was also, for me anyway, a profoundly political book. As part of my commitment to disability studies and to my role as an activist scholar, I wanted to bring disability issues to the attention of the reading public, to help people to see issues which I believed were commonly invisibilized in mainstream society. In pursuing this aim, I was working within a genre which is a recognised part of disability studies. Disability studies in general, and feminist disability studies in particular, emphasise the legitimacy of insider voices and the importance of popular accounts as a form of activism in the service of disability inclusion and participation (Egner, 2019; Garland-Thomson, 2005; Goodley & Tregaskis, 2006; Kittay, 2009; Simpican, 2017; Whitburn & Goodley, 2019). Issues of epistemic access and epistemic justice (Fricker, 2007; Kidd & Carel, 2017; Kittay, 2009; Scully, 2018) have been extensively discussed in relation to disability exclusion, and writing accessible texts has been viewed as a way to counter this exclusion. As founding editor-in-chief of *African Journal of Disability*, and as someone committed to developing disability studies scholarship on our continent, in an article on methods in disability research aimed at an African audience, I explored, amongst other issues, both the promise but also the pitfalls of this insider, narrative approach (L. Swartz, 2014).

The memoir theorist G Thomas Couser (Couser, 2011) has famously discussed the move from what he terms the Somebody memoir to the Some Body memoir (Couser, 2009). This is the move from memoir written by famous public figures at the end of well-known careers, to memoir written by people who write about their own experience of illness and disability. The motivations for writing these illness and disability memoirs are multiple, complex, and not always completely admirable. For example, I believe that there may be an element of prurience in how first-person narratives are collected and consumed (Bantjes & Swartz, 2017), and there is an interesting genre in which the celebrity memoir overlaps with the disability and illness memoir (Richards, 2015). Indeed, I often joke that the glossy magazine *Hello!* always has at least one story per issue in which a famous personality shares their heartbreak and shows the reader their luxurious new home. The 'heartbreak' is not uncommonly related to illness or disability (A. W. Fisher, 2011). The story of disability or illness may well be recorded in an implicitly prescriptive way, with a view to instructing the reader to be interpellated into a highly individualised and marketed discourse of self-love and self-care in the interests of health (Eriksson & Machin, 2020; Franssen, 2019; Genz, 2015; Rottenberg, 2014).

It is also true, as Arthur Frank and others since have shown, that narratives about disability and illness commonly fall into a small series of narrative types, namely, the restitution narrative, the chaos narrative, and the quest narrative (Frank, 2000, 2013; Naldemirci, Britten, Lloyd, & Wolf, 2020). Questions have been raised both about the extent to which many illness and disability narratives simply reproduce dominant tropes, and especially those of overcoming and resilience (Brokerhof, Ybema, & Bal, 2020; Wendland, 2019), and about the degree to which the author of any first-person illness or disability narrative can claim to be the same "I" as the "I" being written about. Richards refers to this issue as "writing the othered self" (Chang, 2016; Richards, 2008, 2019). These considerations all concerned me with the writing of *Able Bodied*, but did not on balance shake my conviction that the political work of making disability more visible to a wider (including non-academic) audience was important to me. Throughout my academic career, I have been interested in the politics of invisibility (Hassan et al., 2018; Lourens & Swartz, 2016; L. Swartz et al., 2018; L. Swartz & Kilian, 2014), and in how overlooked or denied topics can be brought to the attention of the public.

I had a second, less obvious, political motivation for writing *Able Bodied*. I am a white, able-bodied, South African man, and a health professional to boot. On my very first engagement with people working in disabled people's organizations, I was told, without any evidence offered, that because of my positioning, I supported "the medical model". It is not relevant to my argument here to provide an analysis of how problematic the idea of "the medical model" as a single entity is (Shakespeare, 2013; L. Swartz & Bantjes, 2016). It is enough to say that in the political and moral economy of the time, and to some extent still, adherence to "the medical model" was bad and oppressive, whereas support for "the social model" was good and emancipatory. If disability studies as an academic discipline is about nothing else, it is about the politics of voice (L. Swartz, 2018; L. Swartz & Marchetti-Mercer, 2018), and I take very seriously the need in the discipline to hear the voices of disabled people themselves, as well as those of other marginalised and excluded groups. But I also object to and resist some of the ways in which assumptions are made about me and the way I work on the basis of aspects of my identity.

Part of what crystallised for me the wish to write *Able Bodied*, and in a sense to write back from a position of power, was an incident which occurred not long after the publication of *Disability and social change: A South African agenda* (Watermeyer, Swartz, Lorenzo, Schneider, & Priestley, 2006). There are aspects of the incident which amuse me, but the issues are serious as well. When I was seconded from Stellenbosch University to work at the Human Sciences Research Council for three years in the early 2000s, I established the disability studies research thrust there, and as part of the work I decided that South Africa needed to have its first compendium volume laying out the state of affairs regarding disability rights and inclusion in our country. I secured funding for the project, roughed out a preliminary chapter list, and consulted with partners, both in academia and in the disability sector, to ensure that the book would be a joint product from a number of academics and disability organizations. I also insisted that the first editor of the book should be a disabled person, though I could have with justification taken that role myself. I wanted the book to come from a collective, and I wanted it to embody the principle of disability leadership in disability-related research, something I continue to believe in.

The book was launched to some fanfare, with considerable disability participation, and even with a special event at the Constitutional Court, all designed to emphasise disability inclusion and leadership. Shortly after the book was published, I convened

a meeting of a group of disability academics and a representative of a national disabled people's organization (DPO) to discuss the possibility of a new project looking at issues of violence against disabled women, which is an enormous problem globally (van der Heijden, Abrahams, & Harries, 2019). As was commonly the case, I was the only man in the newly-forming research group. The representative of the DPO at the table, a disabled woman of colour, turned to me and informed me, angrily, that I did not understand disability research processes and the importance of full participation by disabled people in research. She further insisted that if I wanted to learn about such processes, I should read a recently-published book, a book which had got the processes right. The book was *Disability and social change: A South African agenda*. I did not in this meeting or subsequently point out to her the fact that I had conceived the book and had a major role in getting the book published. Part of me was pleased at the degree of ownership the disability sector seemed to have taken of the book, in line with my own political commitments. Two of the other three participants in the meeting had also been contributors to the book, and knew of my role. Neither of them said anything either, and I did feel some resentment that they chose not to defend me. Part of why I wrote *Able Bodied* was to speak back to the kinds of assumptions which were made about me, and my identity, on the basis of the obvious markers of race, gender, and academic status.

From *Able Bodied* to *How I lost my mother*

Writing *Able Bodied*, was, for me, something akin to undergoing psychotherapy. As a clinical psychologist, I have some training in psychotherapy, have worked as a psychotherapist, and I have myself been in psychotherapy as a patient. There is an established research tradition exploring the role of expressive writing or reflexive journaling as part of or an adjunct to psychotherapy, or as having psychotherapeutic effects in itself (Crumb, 2019; Dahne et al., 2019; Faccio, Turco, & Iudici, 2019; Maslej, Srikanth, Froentjes, & Andrews, 2020; Rijkeboer, Daemen, Flipse, Bouwman, & Hagedaars, 2020; Schnitker & Richardson, 2019). The recent book on this topic, entitled *Om tot verhaal te kom – Verwerk trauma en verlies deur skryftherapie*, by Lizette Rabe, professor of journalism at Stellenbosch University (Rabe, 2019), is not only well-written, appealing and accessible, but also a helpful intervention in the local context, where very few South Africans have access to professional mental health services (Docrat, Besada, Cleary, Daviaud, & Lund, 2019; Petersen et al., 2016). I knew, as well, from my own academic writing, how exhilarating the process of writing

can be, and how it can help me organize my thoughts, and, indeed, to find out what my thoughts are. But I was not fully prepared for the emotional impact of writing *Able Bodied*. While writing that book I would often burst into tears mid-sentence. The tears felt helpful, and, ten years after the book's publication, I still feel grateful for how the writing helped me to shift my internal relationship with my father. It felt like, and feels like, a gift.

It would be dishonest of me not to admit that my primary motivation in writing *How I lost my mother* was personal rather than academic. I wanted the chance to use writing to work out (as far as this is possible) my complicated feelings about caring for my mother, her illness, and her death. Having her living and dying in our house for that last year was, for me, both one of the most difficult times of my life, as well as something I am very glad I experienced. As I went through what felt to me the motions of a successful working life, I felt profoundly isolated from my colleagues, and from their everyday struggles and achievements. I entered into a world of medications, wheelchairs, adult diapers, eggbox mattress covers and the like. My privacy felt violated by the presence of people on whose help I depended, and whom I felt I exploited. I experienced kindness and humiliating conflict; I felt proud of how I managed and was embarrassed at all the times I failed. I raged at my mother and I felt more love for her than I knew I had. Writing would be a way for me to try to put some order to all this emotion.

When I planned and wrote *Able Bodied* I had a plan that every chapter would bring to the attention of the audience something I thought important to understand about the politics of disability inclusion. There is no question that my primary motivation for writing *Able Bodied* was personal. This was true on two levels. First, I wanted to understand more about my feelings about my father, but secondly, and less obviously, *Able Bodied* represented for me an opportunity for me to do my own writing again. I had spent (and continue to spend) much of my academic career writing with other people, editing and developing their work. I love doing this, and in some ways I feel that the most important contribution I have made to disability studies in southern Africa is not in all the research I have done, but in the process of helping inexperienced authors to get their ideas and their work out in a form which the public can easily read. I don't regret this at all, but by the time I wrote *Able Bodied*, I felt I needed that book to help me find myself again. This involved rediscovering my own voice as a writer. It is not by chance that *Able Bodied* was the

first single-author book I had produced since my first book (L. Swartz, 1998), though I had been central to working with others on a number of other books since then. I felt that I was, like many people in my position, an accomplished ghost writer, but also someone who did not know who I was as a writer any more. Having enjoyed writing *Able Bodied* as much as I did, and having learned through the process, I wanted to have another chance at writing. A number of people suggested that I should turn my hand to fiction. It felt to me that a book about my mother was in the way of my making any decision about writing fiction, and I was also not sure that I could write fiction. My mother's death, and her joy at seeing *Able Bodied* published when she was so ill, emphasized to me the inevitability, it felt like, that I would write a book about my mother.

It was of course an act of stupidity to sit down on the anniversary of my mother's death, and with my father-in-law close to death in my house (he would die a week later), to write a book about her and her death. The idea that I could do this so soon amounted to an assertion of what psychoanalysts would call omnipotence on my part. There is a long tradition going back to Freud suggesting that omnipotently hanging on to the person who has been lost – keeping the dead alive, symbolically – may complicate and interfere with mourning (Freud, 1957; Hansell, 2000; Schneider, 1987; Steiner, 2005). I had no sense of this applying to me at the time, and I attributed my difficulties with starting writing to technical challenges in how to put the book together. In general, much to the chagrin of some of my colleagues, I write quickly, easily, and even joyously, but I could not write this book, and in fact it is only after completing a full draft of the book that I can see more clearly than I did before the defensive role that the book offered to me. Even before my mother died, as I have mentioned, I knew I would write a book about her. I can now see that this was a way of not allowing her to die – if I kept her alive by writing about her I would not have to face my grief, which was enormous, and felt unbearable. I do not wish to pathologize myself here – I am in substantial agreement with Nancy McWilliams, former president of the Division of Psychoanalysis of the American Psychological Association, that the term “defence” is something of a misnomer – we all need defences to get through life (McWilliams, 2011).

So, there is no question in my mind that part of my struggle, and the biggest part, with writing *How I lost my mother*, was emotional. I could not write my way out of mourning and had to take my time. But there were also technical challenges. In

writing *Able Bodied* I faced all the usual challenges memoirists face (Faulkner, 2017; Moore-Gilbert, 2014; Morris, 2019; Mulvihill & Swaminathan, 2017), including questions of memory, time, voice and register. But part of what made the writing easier was that for each chapter in *Able Bodied*, I had a specific point that I knew I wanted to make about disability studies and about how people in society think about disability. I had a scaffold of the familiar – although I cannot claim to be an expert on everything to do with disability, I am confident that I know the field quite well, and I knew what basic point I wanted to make in each chapter. With *How I lost my mother*, by contrast, I was much less clear on how what I wanted to say mapped on to a series of chapters. There were two major reasons for this. First, though through my work on disability I had become more and more interested in the field known as ethics of care, and I am part of the Care Ethics Research Consortium (<https://care857567951.wordpress.com/>), I consider myself much more as a novice in care ethics as a field than I do in disability studies. Second, from what may be termed an academic perspective, I really wanted to write about three basic points, which boiled down to the following:

1. There is a link between how old people are cared for by younger people, and specifically by their adult children, and how these old people acted as caregivers to their children in the past.
2. Caring for older adults is common, and in fact a feature of changing global demographics, but it is individualised and invisibilized.
3. Care of elderly and frail people globally is commonly undertaken by poorly-paid women of colour, and in the dynamics of this care is an interface between intimacy and exploitation.

I had seen each of these points acknowledged in various ways in my reading, but I had not seen the three issues brought into sharp focus, nor had I seen anyone try to address these three issues simultaneously through one text. I also did not know, before I started, whether or how I would craft a story which interwove these three elements.

With the benefit of hindsight, I can see that these three points, though important to what I have eventually produced, fail to capture what the memoir came to be for me, and, indeed, what it truly was all along. I am all too aware of D. H. Lawrence's 1923 profoundly psychoanalytic aphorism quoted at the beginning of this section of the dissertation: "Never trust the artist. Trust the tale." (Lawrence, 2014), and in some

senses, in this tradition of thinking, I am the worst person, as “the artist”, to make an assessment of what the memoir “truly was”, as I put it. I can return to an assessment of the work rebutting an earlier view of my own about it, and, to me, displaying more insight. I can then revise my revision, and so on in an endless recursion, but none of this can solve the fundamental problem of my own subjectivity and its limits in assessing the true purpose of my writing. In a post-Freudian world in which the idea that anyone has privileged access to their own motivations (Agassi, 1969) has been troubled and debated strongly by philosophers from a variety of perspectives (Gertler, 2017), it would be disingenuous of me to claim that I can be sure that my current view of what I have been doing in the writing is correct. With this caveat in mind, though, I am in agreement with G Thomas Couser (p. 12), who writes of people who produce memoirs about their parents, “Most are attempting to complete unfinished business of one sort or another” (Couser, 2011). This certainly rings true for me, and the “unfinished business” part of the work certainly trumps, in my experience of the process, the three content points I mention above. I am (once again in a post-Freudian world) not so naïve as to believe that “business” is ever “finished”. But the book is a reckoning with my understanding and experience of my internal world and the central role that my mother plays in it. It is also, for me, an act of love towards my mother, an attempt at a posthumous gift to her. The question then arises, as Couser (2012) puts it, what the “work of memoir” may be in this particular case. This is an issue I address in the following chapter.

Not writing

I am well aware of how lucky I am to enjoy writing, and to write quickly and easily. Many academics do not enjoy writing (Kamler & Thomson, 2004; Thomson & Kamler, 2016) and it is not by chance that one of the items on a recently validated questionnaire on writing (Cerrato-Lara, Castelló, García-Velázquez, & Lonka, 2017) reads “I hate writing.” The issue of procrastination among students and academics is well known (Al-Majed, Al-Kathiri, Al-Ajmi, & Al-Hamlan, 2017; N. C. Hall, Lee, & Rahimi, 2019; Malouff & Schutte, 2019; Rozental & Carlbring, 2014; Steel, 2007; Stupnisky, Hall, & Pekrun, 2019), and in fact I often wonder why this very common problem is not more prominent in current debates about mental health of students and academics (Bantjes et al., 2019, 2020; Cuijpers et al., 2019; Karellou, 2019). Though I write more than most, I am no stranger to procrastination or to what has

been termed “binge-writing” (Boice, 1997; Murray, 2014; Silvia, 2007), the much-maligned practice of writing a large amount in a short period of time, often in a panic, perilously close to a deadline, and commonly after a long and painful period of procrastination. In general, though, I manage to write a lot, and get words on to paper.

With this book, though, it was different. I had multiple false starts, and many computer files of abandoned written fragments. When attending a skills development course in Rational-Emotive Behaviour Therapy, I volunteered myself and my writing problem as a live example for the facilitator and fellow-trainees to try to work with. The facilitator, whose work as a psychologist I greatly admire, was gently insistent that my problem was one of procrastination, pure and simple, and something his therapeutic approach could work with (Pychyl & Flett, 2012). Though I was willing to try anything to get the book written, and I listened carefully to what was being said to me, I balked at the idea that my problem was procrastination. The proof of the pudding, in any event, was in the (not) eating – after the workshop I diligently applied everything I had learned in the workshop, and produced more fragments and false starts. I have to allow for the possibility that my narcissistic need to be special could have been part of what was driving my resistance to the diagnosis of procrastination for my writing problem. No garden-variety, generic diagnosis for me! But I am much more drawn to the idea that my struggle with writing was a struggle with grief. I think I needed time, and much more of it than I had thought necessary, to process the enormous emotional impact of caring for my mother, and of her death, on me, before I could write about it. I managed to write two articles about the carers (these are drawn on heavily in Chapter 12 of the book manuscript), but I think I could write these because I saw them centrally as political pieces and interventions into debates (or lack of debates) about the exploitation of care workers. The articles were not about the particularity of my very passionate relationship with my mother, something I viewed as core to the whole project. And the project was going very slowly indeed. More accurately put, it was not going anywhere at all.

The issue of what has been termed “slow scholarship” has attracted a great deal of attention in the academy of late. The 2012 manifesto on this issue by Hartman and Darab (Hartman & Darab, 2012) has been cited well over 100 times according to Google Scholar; the 2015 similarly strident article by Mountz and colleagues (Mountz et al., 2015) has received over 400 citations in five years. The concept of slow

scholarship has been taken up eagerly in South Africa, notably by Bozalek and colleagues (Bozalek, 2017; Bozalek & Boughey, 2012; Collett, van den Berg, Verster, & Bozalek, 2018; Leibowitz & Bozalek, 2018), as a response to the strongly neoliberal influence on South African universities, with an emphasis on the rapid production of many, countable “outputs”. I myself have been part of a research team exploring perverse incentives and their relationship to research production in South Africa (Breet, Botha, Horn, & Swartz, 2018). We were interested, amongst other things, in how the pressure to increase outputs might impact research quality and time to reflect, and to incentivise what has been termed “salami slicing”, which is the breaking down of reporting of complex data into multiple, trivial, research papers.

Though I am convinced particularly of the feminist ethics of care arguments underlying the promotion of slow scholarship, I must confess that I am mistrustful of some of the ways in which the concept of slow scholarship is used. When I was at UCT, I had a colleague, for example, who rather contemptuously informed me that though other academics were happy to dash off piles of low quality work, his own work was “deep” and “careful”, as he put it. This colleague was not a productive researcher, and published nothing at all for many years. I understand that people have trouble writing, as did this colleague, and I run workshops to help people with this difficulty. I do however become irritated when people’s (real) difficulties are miraculously parlayed into evidence of noble resistance against the demands of an oppressive academy. Part of what makes Bozalek’s insistence on slow scholarship convincing to me, is that she is a consistently productive academic researcher. Her arguments for the virtues of slowness, clearly, are not self-serving justifications for a lack of productivity.

And yet, here I found myself as a writer – remarkably productive in many respects, but also unable to write the one book I really wanted to write. Some of this, I think, had to do with the fact that *Able Bodied* did not sell at all well – I often refer to that book as a critical success and a commercial disaster, which is true. It is difficult to start to write something similar knowing the disappointment of lack of readership, and I also knew that the disastrous commercial fate of *Able Bodied* could weigh heavily on decisions from publishers about getting the next book published. In fact, my publisher for *Able Bodied*, with whom I had worked very happily, and who clearly liked the book very much, made it clear that I should not consider sending further manuscripts for consideration. In terms of commercial considerations, once bitten

was quite clearly twice shy in this case, and appropriately so. I could (and did) say to myself repeatedly that because of what had happened with *Able Bodied*, this book was not worth writing as nobody would read it. But again, this argument feels more like a post-hoc excuse for my not writing rather than as a reason not to write. I could not hide behind commercial considerations (real though these are) – I had to face the not writing.

Part of the problem with the not writing was that I could easily disguise the not writing by writing all sorts of other things, which I did, but I knew I wanted to do this, and my family (my daughters in particular) would repeatedly ask me where the book was. The late Stephen Watson, who ran the creative writing programme at University of Cape Town for a long time, had once said to me that in his view one of the main functions of creative writing degrees was to keep writers writing, and that conversation from years ago proved very helpful. I had no need of another degree, but I am absolutely clear that had I not undertaken a degree, the book would not have been done. I am greatly admiring of Louis Menand's *New Yorker* piece, highly sceptical of creative writing courses (Menand, 2009), and I cannot resist reproducing its first, withering, paragraph here:

Creative-writing programs are designed on the theory that students who have never published a poem can teach other students who have never published a poem how to write a publishable poem. The fruit of the theory is the writing workshop, a combination of ritual scarring and twelve-on-one group therapy where aspiring writers offer their views of the efforts of other aspiring writers. People who take creative-writing workshops get course credit and can, ultimately, receive an academic degree in the subject; but a workshop is not a course in the normal sense—a scene of instruction in which some body of knowledge is transmitted by means of a curricular script. The workshop is a process, an unscripted performance space, a regime for forcing people to do two things that are fundamentally contrary to human nature: actually write stuff (as opposed to planning to write stuff very, very soon), and then sit there while strangers tear it apart. There is one person in the room, the instructor, who has (usually) published a poem. But workshop protocol requires the instructor to shepherd the discussion, not to lead it, and in any case the instructor is either a product of the same process—a person with an academic degree in creative writing—or a successful writer who has had no training as a teacher

of anything, and who is probably grimly or jovially skeptical of the premise on which the whole enterprise is based: that creative writing is something that can be taught.

Having participated in more bruising group therapy training sessions than I care to remember, I was very anxious about embarking on a university training in creative writing. Nevertheless, I started to explore options and, through a circuitous (and very lucky) route I ended up registered for a PhD in creative writing. This enabled me to get moving with the work, and, importantly, to get supervisory help from two academics I trust and admire. This got me writing, and also got me thinking, in a much more focussed way, about the craft of writing memoir and what I was trying to do with the book. For this I am very grateful.

Concluding thoughts: the benefits of discomfort

Through much of my academic career I have been interested in the issue of discomfort as a spur for thinking and research (L. Swartz, 2007; L. Swartz & Marchetti-Mercer, 2018). In the field of psychology, and in many other disciplines which claim to have some scientific status, the concept of “research-mindedness” is much discussed and praised (Ain, Sabir, & Willison, 2019; Sims, 1981; Willison, Sabir, & Thomas, 2017), and one of the aspects of research-mindedness is the ability to see things which do not fit into preconceived paradigms and then to try to find out why things do not fit or how they should fit. Zembylas and his colleagues (Zembylas, 2015; Zembylas & Boler, 2002; Zembylas & McGlynn, 2012), in work largely concerned with education in divided societies, discuss the values of what they term a “pedagogy of discomfort” – a way of teaching and learning which acknowledges that learning often occurs as a result of the emotional experience of discomfort. In foregrounding emotions in the way they do, Zembylas and colleagues deepen our understanding of “research-mindedness” to give due place to the affective alongside the purely cognitive. My decision to write this book and to do this PhD has led to my having to confront both the notionally cognitive and the notionally emotional aspects of discomfort as a spur for new ways of thinking. In the next chapter I briefly discuss how these issues emerged through the process of writing the book.

Chapter 2: The work of my memoir

In this concluding chapter I focus on two things. First, I discuss issues in the process of crafting the memoir, choices I made as a writer, and the consequences of these choices. Second, I engage with the question of the “work” of this memoir – what it tries to do. By way of introduction I give some background to my general approach to academic work and research in general.

Bricolage as a way of engaging from the margins

As will be clear from the memoir which forms part of this dissertation, and was equally clear from *Able Bodied*, I have always experienced myself as marginal in a range of ways, positioned at the edge of or between things, not quite fitting. Quite apart from the fact that my father was disabled, I think that part of my continuing interest in disability studies stem from my interest in what the disability studies literary theorist Rosemarie Garland-Thomson calls “misfitting” (Garland-Thomson, 2011) – the experience of many disabled people, but not only disabled people, of living their lives in a world not designed for them. In fact, in her review of *Able Bodied*, Garland-Thomson characterises the book as, essentially, a *bildungsroman* of a life led at the edges – a story in which the hero comes to embrace the very social exclusion with which he has struggled his whole life (Garland-Thomson, 2012). I have struggled, and continue to struggle with my masculinity, the sense of my own body, my Jewishness, my whiteness, my professional role as a psychologist, my place in the academy, to name but a few. I do not wish to claim marginality as a source of social capital in the context of an economy of hurt, damage and vulnerability especially prominent in contemporary university politics in South Africa and elsewhere (Bashonga & Khuzwayo, 2017; Graefer, 2019; Ndlovu, 2017; S. Swartz, 2018; Wahl-Jorgensen, 2018a, 2018b). There is no question that in terms of the trappings of power and esteem in the academy (and, to a degree, in society more broadly), I have done well – I am a senior academic at a prestigious university, for example. As I mentioned, half-jokingly, in my inaugural lecture at University of Cape Town in 1996, if you hang about on the margins for long enough, the mainstream will move to find you. My career is a history of involvement in fields which were once thought to be of little prestige (such as community psychology and disability studies) but which have later come to be taken more seriously.

More significant for this discussion, perhaps, than marginality in terms of power or identity, but linked to it, is my interest in a wide range of methods and approaches to understanding the world. As an undergraduate, I completed a combined degree in arts and sciences, with major and submajor subjects of psychology, English, mathematics, and mathematical statistics. In my current work as an academic clinical psychologist, I draw more, probably, on my undergraduate studies in English, mathematics and mathematical statistics than I do on my undergraduate study of psychology itself. I have often found myself in an in-between space in heated methodological and interdisciplinary debates. For example, when I was training as a clinical psychologist, I was confronted by a fellow student who accused me of refusing to take a stand against psychiatry – at that time many psychologists viewed psychiatry as reductionistic and biologicistic, reducing social problems to symptoms of individual psychopathology (Ingelby, 1980; Littlewood, 1991). While I was sympathetic to this view (and I remain so, especially in the current heyday of brain science), I was also fascinated by organic psychiatry and the real question of brain pathology. I responded to my classmate that I had indeed taken a stand, but it was not the same stand she had taken. As a psychologist, I was outside the world of psychiatry and brain science, but I was also not a proponent of being anti-psychiatry as a confirmed ideological position, as many of my colleagues were. Similarly, though most of the research I do and write about is qualitative in nature, I enjoy quantitative methods and do not share the view of some qualitative researchers that only qualitative research can provide data which are “deep” and “rich” (Lim et al., 2017). In summary, I have often found myself, both personally and professionally, at the margins, in between, not feeling fully part of broader movements.

The Oxford English Dictionary defines bricolage as follows:

1. The process or technique of creating a new artwork, concept, etc., by appropriating a diverse miscellany of existing materials or sources.
2. An object or concept created or constructed by appropriating a diverse miscellany of existing materials or sources, particularly (in *Art*) of found objects. Also in weakened sense: a miscellaneous collection of accumulated objects or detritus.

This method of working – of putting together things which are not commonly seen together, and of making something new out of diverse ideas and things – seems to me to describe my way of working rather well. I often say that I am relieved to be an

old academic, as there is great emphasis currently in the academy on developing narrow areas of specialization. When I first came to Stellenbosch University, I was asked what my “niche area” of research was and I was unable to answer. A colleague has described my *curriculum vitae* as akin to somebody having put a sprinkler system on to a rugby field – bits and pieces of things sprouting everywhere, with no fixed pattern. I was, furthermore, amused to learn of some very clever experimental psychological research which suggested that messiness may spark creativity (Vohs, Redden, & Rahinel, 2013). I am a messy person, both literally (my desk is a jumble of things) and figuratively (I draw on many different sources and intellectual traditions). I think this does have to do with my sense of marginality, which I have discussed above, but also with the fact that I find all sorts of things fascinating but am easily bored by detail. Though I like statistics and am in favour of careful amassing of data, I often say that I am grateful to others who enjoy large-scale research with huge amounts of data. This kind of research, though I have successfully completed big projects, makes me anxious as there is so much to think about at once. In addition, I am embarrassed to admit, I inevitably get bored with projects which in their nature have their outlines predetermined before data are collected. I am much more drawn, and always have been, to the interesting story and the anecdote, and even in publications in quite conventional scientific journals, I commonly use anecdotes to illustrate larger points. I was relieved, on reading for this degree, that my reading and research practices – which often feel chaotic, but are usually tremendously enjoyable for me – fit in to a recognised pattern of research, that of bricolage (Bosanquet, 2019; Hurst & Greenhalgh, 2019; Kincheloe, 2005). I was also, I have to say, chastened by J M Coetzee’s comment, after his assertion that “most of my critical essays have followed after raids into territory strange to me, often into foreign linguistic territory”, that there is a danger that such excursions may become what Coetzee terms “mere academic tourism” (Coetzee, 1992, p. 243). Coetzee, of course, has a depth of reading in the fields into which he ventures, and this protects him from being a mere tourist. But I believe he has a point. Given the links between bricolage as a research tradition and postmodernism, with its emphasis on surfaces and on movement and instability (Quayson, 2005), what I read as an implied allegation about “bricolage”, at worst, being a form of “academic tourism” may well be justified. Some supporters of bricolage may reject the dismissive qualifier “mere”; more relevant to this discussion is the fact that part of why I see myself as a bricoleur is precisely because of my tourist status between

disciplines and identities, being of no fixed abode either personally or intellectually. In this, I agree with Coetzee, there may be a degree of sloppiness or lack of the rigour of a writer and reader more firmly rooted and less playful.

I was interested, in reading about bricolage as a method, to learn that there is now a great interest in what is termed “collective bricolage” (Cartel, Boxenbaum, & Aggeri, 2019; Loughlin et al., 2019), a process by which groups of academics or co-workers engage with new projects. Much of my work is with diverse teams from a range of disciplines and backgrounds. It is not unusual for me to be working, on the same day, with a team of epidemiologists, then with people in disability studies, and then with a group of people interested in philosophy of education. Much of this has to do with my marginality and my rather fluid professional identity, but I am in agreement with other scholars that many of the best ideas come from serendipity, and from what conversation unexpectedly throws up, especially at the margins between disciplines and approaches (Green, 2018; Klevan, Karlsson, & Grant, 2020; Klevan, Karlsson, Turner, Short, & Grant, 2018).

In his essay on the poet and songwriter, Leonard Cohen, David Remnick notes how in the famous song *Hallelujah*, and by implication in the rest of his work, Cohen mixes the sacred and the profane (Remnick, 2016). Cohen’s lines from his song *Anthem* have by now become clichés, but, as quoted by Remnick and many others, they bear quoting here:

Ring the bells that still can ring
Forget your perfect offering
There is a crack a crack in everything
That's how the light gets in.

In these words, some of which I use in the memoir, it seems to me, Cohen is asserting not just the reality of brokenness but also the value of brokenness as part of the act of creation. I am suspicious of romantic notions of creativity, and I believe, with many others, that writing is a craft, which takes discipline and practice. But the idea that the most interesting and light-filled things are created from shards and bits and pieces which may not fit properly together, appeals to me.

My reading, listening, and looking practices: Researching across media

When my supervisor suggested that it would be a good idea to have some discussion of my reading practices in my dissertation, my initial reaction, internally, was that I don't have any habit or way of working that could be dignified with the name "reading practice". Some of my incredulity about being asked to write about my reading practices, and, indeed, my resistance to beginning to write about these "practices" stems, I think, from the broader issue I discussed in the previous chapter of the question of whether any writer is in full conscious command of her or his work, a question addressed succinctly and pointedly by J M Coetzee in the paragraphs cited at the beginning of this section of the dissertation. But I do not think this is the whole story, and I think the whole story has something to do with bricolage.

Since I was a young child, I have been a voracious reader. I have gone through periods in my life when I have banned myself from reading "for pleasure" so that I could focus on reading "for work", but these have always been temporary, and difficult, for me. Currently, I read less than I used to – I play a lot of Scrabble online, and have something of what is now called a "behavioural addiction" to the smartphone and the internet (Alter, 2017), but I am a reader. In *Able Bodied*, I mentioned that my parents – and my mother in particular – believed very strongly that there was no such thing as "good reading" versus "bad reading". She believed that the love of reading was what should be cultivated. Many of our friends were not allowed to read comics, or had restricted access to them. We were allowed to read as many comics as we wanted to, and when we wanted to. My mother had read all of Dickens by the time she left school at fifteen, and she was sad that her encouragements of us to do the same did not bear fruit⁴⁴, but she stood by her principle of allowing us to read what we wanted to read. I have never had a reading "programme" as such.

In thinking about this chapter, I realised that I have two stock jokes that I make about my reading practices. The first is that mine must be one of the few houses which have piles of magazines, among which are *The New Yorker* (which I love reading as much for the quality of the writing as anything else) and *YOU* magazine. *YOU* magazine, as I try to explain to my British friends, is a glossy which makes *Hello!* look like Shakespeare. The writing is often terrible, and it presents an array of celebrity

⁴⁴ I was delighted, in my last year of English studies at university, to take an elective course on Dickens and George Eliot, and I did get to experience the thrill of reading one long Dickens novel after another.

gossip, cooking, and sensationalist news. There is in every issue at least one article which falls into the freak show tradition, a tradition of great interest to writers in the field of disability studies (Garland-Thomson, 1996; Hunt, Swartz, Braathen, Carew, et al., 2019). So I can pretend to have an academic interest in *YOU* magazine, but what actually drives me to read *YOU*, like many readers, I suspect, is prurience rather than principle. In short, though I enjoy reading what is termed “literature” more than reading other things, I also enjoy reading what some (and I myself) would call “rubbish”.

The second story I tell about myself is that, unlike many of my friends, I do not read detective fiction. This is because I tend to read quickly, and much more for tone and feeling in the work than for plot. It is not an exaggeration for me to say that a problem I have with reading whodunits is that I often don't know who has been killed and who is still alive. I often forget important plot details of books long after I finish reading them, and I commonly enthusiastically recommend books to others but I cannot tell them what the books are about. One of my favourite writers of fiction for a long time was Anita Brookner, and part of what I enjoyed about her novels was that in terms of plot there was often, to this reader, not much to differentiate between the novels. But I never tired of the careful descriptions of the utter desolation of genteel loneliness.

As with some other bricoleurs, I have less of a plan for my reading, less of a formal “reading practice”, than I believe that others have. I follow my fancies and happily change direction if something comes along that happens to catch my eye unexpectedly. I very much enjoy reading memoirs, and one of the pleasures of preparing for this dissertation is that I have had an excuse to read many memoirs and to label this “work”. I also enjoy work which problematizes the easy divide between “fact” and “fiction” in the worlds of fiction, memoir and autofiction, and I find the work of Philip Roth troubling the divide between the “true” and the “made up” especially interesting. As it happens, I read Michiel Heyns's *The children's day* (Heyns, 2002), which is a novel, at more or less the same time I read JM Coetzee's *Boyhood* (Coetzee, 1997), which is in some editions presented as a memoir, but is recognised as problematizing the boundaries, as Roth does, with Boehmer referring to the book as “memoir fiction” (Boehmer, 2016). I found it much easier to view *The children's day*, which presents itself unproblematically as fiction, than I found *Boyhood*, as a “true account” of white South African youth.

Hugely influential for me as a reader have been the many memoirs of disability and mental disorder (commonly referred to as psychosocial disability in the disability studies field), often written by women with illnesses or disabilities. Lucy Grealy's *Autobiography of a face* (Grealy, 1994) is, for me, one of the finest accounts of adolescence that I have read, quite apart from (or interwoven with) the fact that it is also quite distinctive – the story of being an adolescent with facial cancer. Mary Felstiner's *Out of joint* (Felstiner, 2005) deals with rheumatoid arthritis as a disability and feminist issue. But it also tells an important story about the demands of an academic life and the cultural pressures of this life (which is beautifully satirised in another form in Koos Kombuis's hilarious but searching novel about Stellenbosch University, *Raka: Die roman* (Kombuis, 2006). Harriet McBryde Johnson's *Too late to die young: Nearly true tales from a life* (Johnson, 2006), problematizes, even in its title, the divide between “truth” and “fiction” while providing a rollicking account of a life (including a professional life) outside the borders of what many consider to be “normal”. More conventionally academic as a text is Havi Carel's *Illness: Cry of the flesh* (Carel, 2019). Carel, a philosopher, uses her own experience as a person with a chronic health condition, to introduce readers to questions about the experience of illness, and also to provide readers with what to me is the most accessible introduction to phenomenology that I have read. If phenomenology, in part, is about bodily experience, then I cannot think of a better way of introducing phenomenology than through taking seriously the bodily experience of illness and difference.

As I write here, I am tempted to name many other examples of books and articles which I have enjoyed and which have influenced me, but I think the key point about my reading practices has been made. I am attracted to writing on and from the margins, and I am interested in the interface between this marginality and mainstream life. When I trained as an undergraduate in psychology, I was told of the virtues of neutral, unbiased “objectivity” in the human sciences, which is something I have never believed in as an absolute, so these stories from the edge, rooted in bodily experience and in emotion, are important to me. It is also true, though, that I read part of what I read because I want to write something which goes against a powerful grain in this kind of writing, and in writing about this writing. In an article on Grealy's *Autobiography of a face*, for example, Mintz begins as follows:

The disabled woman who writes the story of her body transgresses a particularly charged ideological boundary. Her rootedness in textual flesh, her stubborn insistence on telling the tale of a broken body, defy the disembodied consciousness, the triumphant will and mind that are the legacy of Cartesian dualism as well as the originary point of much life writing by men.

(Mintz, 2001, p. 172)

I do not want to be unfair about Mintz's interesting article, and it is not my intention here to analyse that article as a whole, but I do want to say something about these two opening sentences. In some ways, the sentences are unexceptionable – they speak to writing by disabled women as transgressive and important, and I agree with this. As a scholar who is not a philosopher or historian of science, I really do not know enough about Cartesian dualism to know whether it is completely accurate to argue that “the triumphant will and mind are the legacy of Cartesian dualism”, and I also, notwithstanding my agreement with Couser's description of the “somebody memoir” (Couser, 2009), am not clear of the extent to which “the triumphant will and mind” constitute “the originary point of much life writing by men.” Mintz is careful to use the qualifier “much” to indicate that she speaks here not of all life writing by men but of some. I think it is fair to assume, though, that discursively Mintz is creating a binary between the embodied, transgressive and vulnerable (Couser, 2004) disabled female memoirist and the triumphant, disembodied, powerful, conventional nondisabled male memoirist. Like all binaries, this one reveals some truths but obscures complexity. I am a person who embodies all the obvious trappings of power of one side of the binary – I am white, male, nondisabled, academically successful. I have been lucky to be successful academically (though some of that success undoubtedly comes from privilege that many others, including my mother, do not or did not enjoy), but I have also chosen this as a path and worked to be successful. But I did not choose, nor do I have control over, other aspects of my identity on one side of the binary Mintz and others set up. I read memoirs like *Autobiography of a face* partly for the pleasure and even, at times, the prurience with which I believe all readers read, to some extent. But I also read these texts because they speak to me affectively – they make me feel in certain ways, and they provide me with access to my own emotional life. Much as I resent the idea that disabled women writers are all heart and no head, I resent the idea that I am all head and no heart. It is not fair to blame Mintz for setting up her essay in the way that she does, as she fits into a long tradition of writing which is content with this kind of binary

shorthand, going back at least fifty years (Ortner, 1972). One of my favourite authors, Chimamanda Ngozi Adichie, famously spoke of “the danger of a single story” in a much-watched and much-quoted TED talk (https://www.ted.com/talks/chimamanda_ngozi_adichie_the_danger_of_a_single_story?language=en) (Adichie, 2009; Mkhwanazi, 2016; Woodiwiss, 2015). Like Ngozi Adichie, all I read as a child were books written in the North. And like many other children in what was then Rhodesia, this little Jewish boy wrote stories about the vicar coming to tea on a sunny day after days of sleet and rain, all in the style of Enid Blyton. I read a range of different things and I read across margins and divides mainly because this is what pleases me, but also because I want to be read across margins.

Through my interest in memoir, and especially memoir about illness, I have, to my surprise, become interested in a genre of writing and creativity which crosses boundaries. As Couser notes, what have come to be called “graphic novels” are often memoirs using the written word, cartoons, and sometimes other materials such as photographs (Couser, 2011). Art Spiegelman’s *Maus* is not only a remarkable record of the holocaust but also a searching exploration of the relationship between father and son, as well, in part, a discussion of the challenges of writing in general (Bosmajian, 1998; Schuldiner, 2002; Spiegelman, 1992). Though Alison Bechdel is probably best known for her graphic novel about her father, *Fun home* (Bechdel, 2007), I was far more affected by her book about her relationship with her mother. In this memoir, Bechdel skilfully weaves in text from the psychoanalyst D W Winnicott into an exploration of a difficult mother-daughter relationship. The book, with an intertextual reference to a Dr Seuss beginner book, is entitled *Are you my mother?*, (Bechdel, 2013), and poses questions about relationships which I explore, to some extent, in my memoir. Bechdel also collaborated with the prolific writer on psychoanalysis, Brett Kahr, first on a book entitled *Tea with Winnicott* (Kahr, 2018b), and then on *Coffee with Freud* (Kahr, 2018a). Kahr, as it happens, is a friend of a friend of mine, who is a psychoanalyst in London, but it was through reading graphic novels that I got to read the boundary-breaking writing Kahr is doing in making psychoanalytic ideas broadly accessible (Kahr, 2019). Given my interest in writing accessibly for a wider audience than academics, this connection has been important to me.

Not long after my mother died, Roz Chast, who is my favourite New Yorker cartoonist, published the astonishing *Can't we talk about something more pleasant?* (Chast, 2014). This book combines cartoons, text, photographs and other art work, and has won awards and critical acclaim in the academic literature (Kam, 2018; Phelan, 2016). When I read the book for the first time, it felt to me that Chast, through her use of multiple media, had said better than I ever could, some of what I was hoping to say in my memoir. On the back cover of the edition I have is the following blurb written by Alison Bechdel:

If you've ever wondered about the origins of Roz Chast's quavery, quietly desperate anti-macassar-bestrewn universe, look no further. This grim, sidesplitting memoir about the slow decline of her meek father and overpowering mother explains it all. Bedsores, dementia, broken hips – no details are spared, and never has the abyss of dread and grief been plumbed to such incandescently hilarious effect. The lines between laughter and hysteria, despair and rage, love and guilt, are quavery indeed, and no one draws them more honestly, more...unscrupulously, than Roz Chast.

I agree fully with Bechdel's assessment, and given my interest in what Bechdel calls "quavery lines" of all kinds – across emotions, disciplines, genres, identities – I am enormously admiring of Chast. If I had had Chast's skills at drawing, I might well have wanted my dissertation to be the second one I know about in graphic memoir form, the first being Sousanis's dense and challenging Columbia University PhD, subsequently published as a book (Sousanis, 2015). I do not believe that I have adequate vocabulary from the visual arts to articulate fully why I believe that use of cartoons and the visual can add an affective dimension to the written word, but this is something I have believed for a long time, and certainly experienced in work colleagues I have done where we have used photographs (A. Hall, 2015; Hunt, Swartz, Braathen, Carew, et al., 2019; Hunt, Swartz, Braathen, Jordan, & Rohleder, 2019; McDougall, Swartz, & Van der Merwe, 2006). Crossing boundaries, I think, may highlight emotion and help with expressing emotion.

In this regard, another margin I have traversed in recent years is that from printed text to listening to audiobooks and podcasts. I listen all the time – when driving my car, when walking my dog, when cleaning my kitchen. Because I am usually doing something else while listening, I find that I lose plot even more than when I read on the page. For this reason, most of what I listen to is nonfiction, where I am less

worried about losing plot. This way of “reading” has been helpful for me in terms of background research for the memoir. For example, I found the podcast “A Good End” (https://www.myjewishlearning.com/landing/_agoodend/), which deals with Jewish approaches to death, very helpful. I was also delighted to find, by chance, Thomas Harding’s saga *Legacy* (Harding, 2019) as an audiobook. This multigenerational nonfiction saga of the fortunes of a Jewish family, from European roots to world prominence, is not the sort of book I would usually read in print form, but I was transported by listening to it as an audiobook. The reasons I chose to listen to the book were, first, that I knew it dealt with the history of the Lyons Corner Houses in London, about which my mother spoke a great deal, from her postwar experience there; and, second, that I was interested to see how (or whether) a successful writer tackled the problem of writing a Jewish family saga without falling into tired triumphalist trope. I believe Harding does succeed, and the way in which he discusses both success and challenges of his family, helped me think about how to avoid writing my own memoir as a hackneyed tale of overcoming adversity. (Whether I succeeded as Harding did, of course, is not for me to judge).

Another important way in which I researched for the memoir was through listening to popular music. Despite the fact that my parents loved music, we did not have a record player when I was a child (an example of a strain of self-denial in both my parents, I think), but my mother clearly loved popular music, and my parents had a much-prized 78rpm record of Mario Lanza singing *Matinata*, which they could never play, but held on to. In preparing for writing the memoir, and during the writing itself, I listened repeatedly to The Andrews Sisters, Edmundo Ross and His Orchestra, Xavier Cugat, and Doris Day, amongst others, all loved by my mother, who I am sure was not the only mother of my generation who sang Doris Day’s famous *Que Sera* to her children. I do not have any hard evidence for this, but for me, it felt that listening to these songs provided me with emotional access to my memories of my mother. There is of course an extensive research field into research and emotion (Juslin & Sloboda, 2011), but my listening to music as part of researching my book was occasioned by emotion on my part, and not by an academic interest in the field of music research. One experience of listening which I believe influenced my writing is something I do not mention in the book. It is of listening, after so many years to a favourite of my mother’s, which is Doris Day singing *Teacher’s Pet*. This was a song my mother used to sing, and some of the words are:

Teacher's pet (pa dum pa dum pa dum)
I wanna be teacher's pet (pa dum pa dum)
I wanna be huddled and cuddled as close to you as I can get
(That's the lesson we're guessin' you're best in)

Mm, teacher's pride (pa dum pa dum)
I wanna be teacher's pride (pa dum pa dum)
I wanna be dated, paraded, the one most likely at your side
(Ya got a burnin' yearnin' to learn)

I wanna learn all your lips can teach me
One kiss will do at the start (are you really?)
I'm sure with a little homework
I'll graduate to your heart (to your heart)

Teacher's pet (pa dum pa dum), I wanna be teacher's pet (pa dum pa dum)
I wanna take home a diploma and show Ma that ya love me, too
(That ya love me, too)
So I can be teacher's pet long after school is through
(<https://genius.com/Doris-day-teachers-pet-lyrics>)

I was astonished, in this #MeToo historical moment (O'Neil, Sojo, Fileborn, Scovelle, & Milner, 2018; Tamba, 2018), at how this song so clearly advocates sexual relationships between adolescent girls and male teachers, and I felt a pang of sadness that I could not discuss this with my mother. I do not know what she would have said, but I am confident she would have had a strong opinion about this, as about everything else.

As many memoirists do, I imagine, I looked at family photographs in preparation for the memoir, and also looked at many images online. As I mention in the memoir itself, the postcards on the wall of the Anne Frank house had a strong effect on me, and led me to explore not only the images themselves, but also issues about memorialization, which I deal with briefly in the book but would like to explore more at a later date. I was struck, looking on the Anne Frank House website, of the huge amount of work involved in creating the image of authenticity
(<https://www.annefrank.org/en/museum/anne-frank-collection/conservation-and->

[management-anne-frank-collection/conserving-anne-frank-collection/picture-walls-secret-annex/](#)). As a writer, I am interested in the artifice involved in producing something which is read by others as “true”. This is clearly a concern of many writers, as I have indicated earlier, but, for me, this issue took on a material reality as I watched the video on the Anne Frank House website of restorers labouring to remake Anne Frank’s picture wall into as “genuine” a representation as possible. As I discuss later, the questions of “genuineness” and “authenticity” re-merged as issues for me as I engaged with ethical questions around the memoir.

In summary, my reading practices, and my practices of culling materials from a range of media or imaginaries, are experienced by me as unsystematic and not especially efficient. This is in keeping with my viewing myself as a bricoleur rather than as a systematic archivist. In the section which follows, I discuss briefly some challenges I faced regarding what to take out of, or not to include in, the memoir.

I took out the part

Part of the work of writing any work is commonly not only putting on the page what will be in the final product, but, also, deciding what needs to be recast and what needs to be left out altogether. The decision to cut parts out of a written document is often painful, and I am not sure that as writer I would ever have the strength, as J M Coetzee has done, for example, with a manuscript entitled, appropriately enough, *The burning of the books*, to work on a book for a full year and then abandon the manuscript (Attwell, 2015). Coetzee’s abandoned book, written at the height of apartheid in 1974-5, dealt explicitly with censorship and with the life of a censor. I had not thought, before reading this, that there is in fact an ironic level of commonality between what censors do and what authors must do in order to make their work accessible to readers. And then, of course, there is the reality of many stories never written and never told – and here I think of the phantom articles and books not written by my mother, clearly, to me, a talented writer.

The editing process is in its nature rather violent symbolically, and it is not by mistake that “killing your darlings” is often used to describe editing, or that a contemporary literary journal has the title *Kill your darlings*. In my teaching of academic writing I often cite Jessica Greenbaum’s poem *I took out the part*, which I reproduce here:

I took out the part
Where I compared a letter
Travelling steadily in its envelope
To the live pig I saw, travelling
Calmly in a basket
Atop the head of a woman
Riding a bicycle down the street in Bali. Too much
I figured. Juliet's "happy dagger" came in
A little later on, and I took that out. I took out
Mention of the elephant's
Foot pad, how it expands "like a bag of jelly"
When pressure is applied, meaning
The weight of the elephant. I might have been
Packing for your transcontinental
Bike ride, because I deemed superfluous
The woodpecker's tongue reaching
Back and curling around the
Jackhammered brain like a skein of Bubble Wrap
Which I learned about from Patty. And
I nixed the image of the lake's crust
Made from crests on a windy day
Or how we practice on fireworks
Saying, Oh, that's like a pink weeping willow
Hallucinating a geranium, or, Hercules just
Hit a line drive up to the moon.
I decided against Steve's paraphrase
Of Brecht, "It's hard to describe the trees
When police are in the forest," and also
The old gag about LPs being like gasoline
Puddles that go up and dizzy us
With their fumes, and of middle age
Rotating us out of Earth's orbit, stars like
A corrupted computer file
And the forgetful mind, a red-topped
Tupperware when we were young

Now without gravity or capacity like the shallow
Teacup and you calling my name
Like a soliloquy of wildflowers
Spilled and gone, I took all that out.

(Greenbaum, 2019), first published in *The New Yorker*, 21 April, 2014

When I began work on this memoir, I worried, as I usually do, that I did not have enough to write about – that what I had, essentially, was an essay but not a whole book. In the event, the final version is longer than I anticipated, and needed some pruning. I thought I would write about my mother and popular music (as I have mentioned briefly above) and that I would use more references to music than I did in the final memoir. There are many other examples of evocative details which I did not end up using in the book.

When I had a penultimate version of the memoir, I shared it with my children and with my close cousin Pamie, who was very attached to my mother. Louise, my wife, had read every word as I was writing and editing. Pamie was deeply affected by the book (which I greatly appreciated) but she was very concerned about something that I mentioned from my mother's past. I had included discussion of a traumatic experience my mother underwent in order to establish part of the argument of the book – that I was too close to my mother in some ways, knew too much about her private life, and this had an impact on the way in which I cared for her at the end. This point, about the arc of care from being cared for in childhood and then caring for ailing parents, as I have mentioned, is undeveloped in the literature on death and dying, and it was very important to me to make through the book. The incident I described was important in itself, in that I wonder about the impact of this trauma on my mother's mental state when I was a child, but, for this book, more important was the fact that I and my immediate family know about it. My cousin Pamie, who is not at all one to shy away from difficult feelings and discussion of them, was, I think, herself upset by learning of the incident. More pertinently though, she asked me if my sister knew of the incident, and I do not know the answer to this. Pamie was concerned, and rightly so, that both my sister and my other cousins, whose reactions to the manuscript I discuss later, could be upset by learning about this incident. When Pamie mentioned this to me, I could immediately see there was a problem,

but, I am somewhat embarrassed to admit, I also worried that if I took out this part of the book I would lose the impact of an important narrative arc in it.

In the event, I returned to the memoir and I did the work necessary to remove discussion of this incident and, I hope, to deal with the narrative arc in another way. I was struck here by my initial reaction to Pamie's comment (for which I am very grateful indeed) as more focussed on the integrity of the work I was creating than on feelings of people I care for deeply, including my sister. This is an issue I discuss in more detail in the next section.

The biggest omission from the memoir, though, was what I had planned as a whole chapter. During my time of researching and writing the memoir, I read Elsa Joubert's memoir *Cul-de-sac* (Joubert, 2019), published in Afrikaans as *Spertyd* when Joubert was 95 (Joubert, 2017), and beautifully translated by Michiel Heyns. This is what Couser (Couser, 2009) would call a "Somebody memoir", as Joubert is a celebrated South African author. Her most famous book, *Die swerfjare van Poppie Nongena* (Joubert, 1978) received global acclaim, and in fact the W W Norton edition, published in the USA, has printed on the front cover the words "The internationally acclaimed story of one woman's struggle against apartheid". The book also led to heated debate not only about its subject matter, but also about where it stands on, or across, the very shaky and fluid boundaries between fiction, memoir and biography (McClintock, 1990; Schalkwyk, 1986), boundaries which are of interest to memoir scholars (Couser, 2011; Yagoda, 2009). In the controversy following the publication of *Poppie Nongena*, Joubert was quoted as saying that the book was "apolitical" (McClintock, 1990), even though it was a book written by a white woman about the experiences of a black woman on the wrong end of the horrors of apartheid. I was reminded of this controversy when I read *Cul-de-sac*. At one level, this memoir is deeply personal, and indeed, both a "Somebody memoir" and what Couser (2009) calls a "Some body memoir", dealing as it does with the difficulties of being very old – the physical decline, the deaths of loved ones and friends, the constriction of the world as moving around becomes more and more difficult. There is no question in my mind that part of the appeal of what to me is one of the most affecting books I have read in my life, lies in its small, and diminishing, very personal canvas. But for me the book is also profoundly political, forcing the reader to confront the politics of ageing and debility. I doubt that there will be any controversy about *Cul-de-sac*, though, as there was about *Poppie Nongena*, precisely because of the continued

invisibility in society of disability and ageing issues (L. Swartz, Bantjes, Lourens, & Watermeyer, 2020; L. Swartz et al., 2018).

I was so affected by reading *Cul-de-sac* that, after long negotiations with intermediaries, including members of Joubert's family, I was lucky enough to meet Joubert and to have tea with her. I was not completely sure why it was so important to me to meet Joubert, and indeed, in email correspondence with her through a family member, I described myself as a 65-year-old fan boy wanting to meet a rock star. As soon as I had met and spoken with Joubert, however, I was convinced that the encounter would form an important chapter in the third part of the memoir. I had not anticipated this when I arranged to meet with Joubert, so I had to inform the ethics committee at the university of this change of intention, and the ethics committee agreed that I could use the material. There were many things I envisaged myself writing about Joubert, who in some ways reminded me of my mother – at the age of 97, she was unsentimental, thoughtful, and very direct. She had a lot to say about the experience of ageing. For me, there was another layer of interest in writing about this encounter – Joubert, for me, represented the writer my mother had never become. There were markers in the furnishings in Joubert's apartment of social class which differentiated her from my mother, but the flashing grey eyes in a very old face, and the directness in speaking of difficult things, reminded me of my mother in many ways.

When it came to the memoir, however, I realised (somewhat painfully) that this encounter, meaningful though it was for me, would detract, as I was telling it, from the central concerns of the third part of the book and it did not fit anywhere else easily either. So, as Greenbaum would say, with this, and with much else, I cut out the part.

Ethics, big and small⁴⁵

In the 1970s, Philippe Lejeune published in French the volume that in English translation was entitled *The autobiographical pact* (Lejeune, 1975, 1989), a work which was to prove foundational for memoir studies (Couser, 2018; Eakin, 2018). I do not have the space here to go into the many discussions of this pact and its

⁴⁵ For proof of formal ethical approval of this dissertation project, please see the Appendix at the end of this dissertation.

definition, but the essential aspect of it seems to be the tacit agreement between author and reader that, the name of the narrator of the text, and that of the protagonist are the same, and signify the same person (Blowers, 2000; Kam, 2018). This neat formulation of identity between narrator and protagonist has, of course, been troubled, not least by authors who point out that the “I” being written about and the “I” doing the writing are not really the same, with Richards using the words “Writing the othered self” (Richards, 2008). In her foreword to a recent text on autofiction in English (Dix, 2018), Grell writes:

To write from the self is to perform an experimental act (not just a gesture) in search of lost time, so that it is rewritten, relived by the hand that traces the lines, types on a computer keyboard, corrects the errors. What makes a person an author is that this person speaks to others of a life experience, reflects on it and transforms it in style into a book. Modern narcissism is no longer mired in the despair of ever being able to attain its own image. The post-Freudian modern narcissist knows that it will never do so. Unless it accepts seeing itself in fragments in all the pools of water that are found along the way and that always reflect on other climes, other environments, other men and women, other moments of lived experience.

(Grell, in Dix, 2018 p. vii)

Despite the rise of postmodernism and autofiction, however, and of acknowledgement that memory is constructed in the present rather than retrieved from the past (Conway & Pleydell-Pearce, 2000; McAdams, 2001; Williamson, 2019), the pact as outlined by Lejeune seems to be at the basis of much discussion of ethics and life writing. For example, Couser (Couser, 2011), in considering ethics in life writing returns repeatedly to the controversy around *A million little pieces* by James Frey (Frey, 2003), a book I very much enjoyed reading, and, in retrospect, was grateful to have read before the controversy broke. According to Couser (2011), Frey had written the book as a novel but had had no trouble having it published and becoming a best-seller as a memoir. When it emerged that certain parts of the memoir had been grossly exaggerated or fabricated, many, including, famously, Oprah Winfrey, disavowed Frey. The autobiographical pact had been shattered, and this was widely viewed as a serious ethical breach. What was violated here was an implicit, but fundamental, agreement between author and reader, and for this the author was widely castigated.

This contractual arrangement between author and reader, it seems to me, is at the heart of much of the concern regarding ethics in memoir. But there is also the smaller and more intimate ethical question of how the memoirist portrays real people in a text. In his essay on Doris Lessing's autobiographical writings, J M Coetzee (Coetzee, 2002) is rather definitive on the relative inability of memoir or autobiography to tell the "truth" as well as fiction can, a position he moderates and develops somewhat in his discussions with the psychoanalytic psychotherapist Arabella Kurtz (Coetzee & Kurtz, 2015), as excerpted at the beginning of this section of the dissertation. For me as a memoirist, what I term the "smaller" ethical question of my relationship with people I mention by name in my books, loo much larger than bigger questions of the autobiographical pact, or the validity of memory. And I have no doubt, from my writing, that there can be a tension between the two layers of ethical concern.

After *Able Bodied* was published, I was on a panel with two other authors at a literary event. We were all asked how we deal with the ethics of representing other people, and possibly hurting them, in service of our writing. One of the panellists was a very successful memoirist in terms of book sales, and she responded that because her books had helped many people, this outweighed any hurt she might have caused to individuals in the telling. At the time, I disagreed volubly with her, secure, as I was, that every person named in my book, except in passing, had been consulted before I published the book, and had agreed to the publication. In fact, most of the people mentioned by name were delighted with the book, and where I said negative things about people I changed names and details so they would not be recognisable. I still hold in the main to the view I held at that time – that it is not necessarily ethical to weigh the ultimate good a memoir can do against the harm it can cause real people, but I have had to face my own smugness in this regard.

A few years ago, I was involved in a long and painful ethical dispute about an arts-based PhD which had been awarded by Stellenbosch University. I chaired a subcommittee of the Research Ethics Committee, in a process which was hotly contested and for a long time (Horn, Van Niekerk, Theron, Swartz, & Le Grange, 2016; Lüdemann, 2017; Stolp, 2012, 2016; Walton, 2017). One of the key ethical questions about the work was whether the PhD student, in what I thought was a very well-written and interesting dissertation (Stolp, 2012), had breached ethics principles by writing about people who were easily identifiable in the dissertation without their

having known that they were participants in practice-based research. I, and others, believed that this ethical breach had in fact occurred, though this view was not held by everyone. In personal correspondence from a person with interest in the matter, I was accused of censorship. I think that if I had not been part of the case and had not looked so carefully at the dissertation and other materials, and another person had played the role I played, I would probably from the outside have also thought that this person was practising censorship. The whole experience forced me to think much more carefully about the complexity of my own ethical positioning.

Given this experience, it was important to me to try to behave as ethically I could in relation to my own arts-based PhD. Just as occurred in the Stolp matter, I would be writing about people without their permission, and there was no way I could get permission in advance for me to record my memories of interactions with people. In consultation with the Research Ethics Committee at the university I resolved that where people or their close relatives were named in the memoir, I would send them a copy of the draft and ask for their comments. I would not guarantee that I would change the memoir in line with what they said, but I would consider what they said. In addition to this, where I could, I have changed names and details in the memoir, but I could not do this for members of my and my mother's family. As promised to the Research Ethics Committee, I did send the draft to members of my immediate family, to my sister and her children, and to all my first cousins for their commentary. Not all have responded, but interestingly, all those closest to my mother (my sister, my wife, my children, my nephews) have all responded favourably to the memoir as did my closest cousin, Pamie, whose comments on my excluding some traumatic detail I have discussed earlier.

As I have indicated in my memoir, it was important to my mother to stay on good terms with extended family members even when there had been rifts and ruptures in the past. Nevertheless, I was worried about the response to the draft of a cousin with whom my mother had had conflict but had worked hard to reconcile with. As matters transpired, I had good reason to worry. Within a matter of days of receiving an 80000 word draft from me out of the blue, I received a 1600 word email from this cousin, followed (thus far) by two further emails. My cousin⁴⁶ expressed displeasure

⁴⁶ I have decided in this paragraph not to identify the cousin by gender, on the remote chance that this dissertation is read by people who know the cousin. I prefer not to use "he/she" as a pronoun, and the pronoun "they" for one person has come to be associated with people who identify as nonbinary or gender queer, which is not the case with my cousin. I have followed this convention for discussion of all the cousins

at my book and at the inaccurate and disrespectful way in which I had portrayed our family, but most of what was written across the three emails concerned detailed allegations about my father's duplicity and dishonesty going back fifty years, my mother's meanness and lack of gratitude, my sister's rudeness and haughtiness, and my many failings as a man. It was as though a floodgate of resentment and bitterness had opened, and the litany of allegations was clearly well-rehearsed (and well-formulated). My own close family was completely unrecognisable to me, and the allegations so preposterous, so far-fetched, and so lacking evidence that consciously I rejected them out of hand, but I was unable to sleep for a few nights. I was not surprised from what I know of this cousin, with whom my mother had worked so hard to reconcile, that this was the cousin's view of my family. I also knew that this cousin has argued and broken off relationships with many people I know and respect. Ironically enough, what I read as what I think my cousin designed to be the *coup de grace* at the end of the longest email I received from this cousin was the line, "The bottom line is that your mom never got over her wretched childhood". The irony here is that this is one of the points I hope I made in the memoir – that we all carry our childhoods into our adult lives. What the cousin was citing as a damning, final criticism of my mother (until the next email), I view as part of the reality of life for everyone – including my cousin and me. In fact, I have no way of explaining to myself the bitterness and aggression from my cousin than to think, characteristically I suppose, given my profession, that something must have gone very wrong in this cousin's early relationships.

Despite all of what was contained in the three emails, this cousin indicated to me that it was my business if I went ahead with the memoir as is, and the cousin also offered "regards and best wishes" to my family. Given the extreme nature of the response, coming as it did from a person who I know has difficult relationships with many people, it was relatively easy for me to discount the feedback, though there are small things I have changed in response to it. More concerning to me was feedback from other cousins. Some issues raised were matters of political belief – cousins differed with me, for example, on my views on Israel. Others, though, were more personal. One cousin was clearly upset with my portrayal of sibling relationships in my mother's family of origin, but was generous and kind in our subsequent correspondence, and if

who responded, with the exception of my cousin Pamie, who is named in the memoir and in this reflective section.

anything I feel the disagreements this cousin was kind enough to express, led to our becoming closer than we had been before I sent her the memoir.

Most concerning to me was what I read as a very carefully-worded short email from a cousin of whom I have always been very fond. The email read:

Dear Les

Thank you for a copy of your manuscript.

Am disappointed that you feel the need to disparage members of the family.

That being said, it is your story to tell.

Hope you all keep well in this crazy time.

Love (name)

I thought this email was absolutely fair, completely clear and direct, and honest feedback from a cousin my mother would describe as “no fool”. I read no retaliation in the email, just a clear statement of hurt. I did not expect this cousin to respond, because I thought that what had been said had been said absolutely clearly and forcefully, but I did write back immediately asking for more detail on where I had been seen to be disparaging. With a generosity I did not expect (but for which I am very grateful), the cousin did reply, and we had what I experienced as a warm exchange of emails about the family, the anxiety which is a feature of the lives of many of us, and other matters. In general, I am very lucky to have the cousins I have.

Before the cousin who wrote the short email above had written back to me, though, I was faced with a reality about myself which I did not particularly want to see. I had the choice to delete all references to family members (and to this cousin’s parents) in the book. And though I did go back and soften a few things, I realised that as a writer I was not as different as I would like from the writer who said she did not mind hurting others as long as this was for the greater good. I realised that where I had used incidents involving real people as, from my perspective, affectionate and loving bits of comedy in a book which also has a serious purpose, these funny stories were not read as funny by everyone – they were experienced as disparaging and hurtful. I knew that I would tweak bits of those stories as best I could to cause least offence, but I also knew that I was not going to omit some of what other readers had told me were among the best parts of the book. In short, what I perceived to be the quality of my book was more important to me than the hurt feelings of relatives whom I am never likely to see again, given that they are all much older than me and live on the

other side of the world. A part of me can wriggle out of all of this by saying that they read the book incorrectly – that my fondness for them and their families should be clear. I can also say, with ample justification, that I believe that I am much harsher in my judgements of myself and my mother than I am of others in the book. I think these things are true. But I cannot escape admitting that to have oneself or a member of one's extended family reduced to a comic bit part in a drama in which they never appear as fully realised characters, but rather as context to explain others, may well be experienced as demeaning and disrespectful. I am more ruthless as I writer than I had realised. None of my interlocutors has asked me to change anything in the text, so technically I have ticked an ethical box, but I have learned something about myself which in some ways I would rather not know.

There is one other issue related to ethics which struck me about feedback I received. As a matter of course where I was mentioning people in the book (especially, but not exclusively, disparagingly) whose identities were not central to the story, I used pseudonyms or changed details. A number of family readers set me straight as to the "real" names of people I was referring to, suggesting I correct the errors of naming. I had to acknowledge, following this feedback, that despite everything I know about memory and memoir and the ethics of life writing, some people who read memoir, and possibly most, have an expectation that every detail presented in a nonfiction text will be "true". This issue has of course been extensively discussed in memoir studies (Couser, 2011; Lejeune, 1989), but it feels far less abstract to me when I am told that I am not remembering the name of a person known to one of my readers. I also had to think about what some of my dissembling in order to protect identities could lead to. One of my readers was convinced that he knew the identity of someone I did not name but was key to the plot, and about whom I hid information so the person was not recognisable. My reader seemed confident that he had identified a person correctly, based on misleading information I had given in order to protect identities. I was tempted to respond by saying that my reader had been thrown off the scent, but I decided against this as I did not want to get into a situation in which I would reveal the identity of somebody whose identity I wished to hide.

In the big picture of the ethics of life writing, these concerns about who in my extended family knows what about whom, are probably rather trivial. But it is these issues over which I have lost sleep. My memoir, in its inception and writing, has

been strongly influenced by the ethics of care field (B. Fisher & Tronto, 1990; Narayan, 1995; Tronto, 1993), which argues that ethical responsibilities are constituted by and through relationships. I am in a relationship with my readers whether I want to be or not, and this makes my consideration of their welfare a key consideration. Similarly, the ethics of care approach, along with other approaches which depend on feminist theory, does not believe that the local and the relational aspects of ethics are less important than normative “big picture” ethics which focus on individual rights and responsibilities rather than on relationships (Bozalek et al., 2014). It is something of a balancing act to consider the ethical issues of a memoir in the abstract (or as read by somebody who does not know the people being written about) against the feelings of those whose relationships have in part constituted the story. Before I completed this memoir, I had underestimated quite how difficult this balancing act may be.

Concluding thoughts: The work of my memoir

When I decided to register for a degree of which my memoir was a substantial part, my primary motivation for doing this was essentially pragmatic – I knew that I would not be able to complete the book without some help, and this was a way to get help. I did not realize at the time that I was, through reaching out for help and allowing myself to be in the vulnerable situation of student, enacting something which is a concern of the book. I was allowing myself to accept care, and allowing others to see that I needed it. This is something I discuss in the memoir itself.

There is another layer to this, though. By registering for a degree in creative writing, I was forcing myself to engage with literature on writing, and memoir in particular. I have found this part of the writing much more challenging than I had anticipated. I had, or felt I had, no language for talking and thinking about writing. I have had to read more and learn more than I had anticipated, and I am especially grateful for the supervision I have received in this regard. But given the space constraints and the constraints of my understanding of the fields in which I am engaging, I am aware of how partial my treatment of complex issues has been in this part of the dissertation. There is much more to learn and much more to say – so part of the work of the memoir has been to open me up to a world of thinking about writing, about ethics, about communicating about difficult topics. I am well aware of my novice status as a

scholar in the nominal field in which this dissertation will be examined – English studies. I do not by this wish to discount what I do know and what I bring to the field from other disciplines, but I feel excited about how much more I have to learn.

The concluding chapter of Couser's introductory text on memoir (Couser, 2011), the title of which I have purloined and altered slightly for this chapter, makes a strong argument that fiction as a genre allows for more inventive work than does memoir, generally speaking. Couser also suggests that fiction writers who also write memoir tend in the latter genre to produce work which is less exciting and interesting technically. Nevertheless, one thing, as Couser agrees, that memoir and life-writing do, is that they narrativise lives. Lives are not simply "out there" to be remembered or spoken of. Narratives create and constitute the lives themselves. I have told stories about myself and my family all of my life, many of them funny. One of the people kind enough to read the manuscript of the memoir said to me in an email, "I'm really struck by how many 'funny' stories (told and retold at various gatherings) carried a sea of pain". The memoir has, I think, given me a way of situating all the funny stories in a more reflective context. I remain more convinced than ever that I am a privileged person who has lived and continues to live an unusually fulfilling life, and I think much of that has to do with my parents. But through the writing of the memoir, some of the pain of which shocked me, I have become more convinced than ever that what makes joy all the more sweet is understanding and accepting that which is difficult and hurtful. I cannot separate this belief from my writing or from my training in a particular school of clinical psychology. Nor do I want to. For me, the memoir has done its work of allowing me to come into being in a different way.

The ultimate work of memoir is in whether, and how, it is read. At this stage I do not have a publisher for the book and, given the times we are living in, there is a good chance that I will not find a publisher. So I may well have to think of finding other ways of disseminating the book. As I psychologist, I have often wished that I could write a best-selling self-help book. But this is not my way. There are some excellent self-help books, but I believe that people can learn more from stories than from trying to go through steps others prescribe to them. I would like this book to have some use to others. Some of my readers thus far think that the book does this work, but they are all people who know me, and not part of the world out there. This is something to see in the future, if people do read the book.

I write these words in the midst of a lockdown owing to the coronavirus epidemic. One of my daughters is preparing written materials for public education support for a health NGO; the other has sewed masks for health workers to use; my wife is supporting patients and staff through her work at a large state hospital. I have my name on a list to offer online support to health workers and hospice workers. We are early in the pandemic, and I am not sure how large the wave will be or when it will break. Everything is provisional, frightening, and unreal. In this context, what is the work, or the use, of my memoir? In some ways, the memoir feels completely useless, self-indulgent, and irrelevant – the writings of a very privileged man in a very privileged time. This may well turn out to be true. But I hope that the issues I discuss in the memoir – issues of care, of relationships, of the inevitability and the wonder of vulnerability and how we live through it – may continue to be of relevance in what feels like an unimaginable world to come. Whatever happens, this will be a world which will be narrated into life and changed through narration. Even if my story ceases to matter, I remain more convinced than ever that stories matter.

References

- Adichie, C. N. (2009). The danger of a single story. TED Talk.
https://www.ted.com/talks/chimamanda_ngozi_adichie_the_danger_of_a_single_story?language=en
- Agassi, J. (1969). Privileged access. *Inquiry*, 12(1–4), 420–426.
- Ain, C. T., Sabir, F., & Willison, J. (2019). Research skills that men and women developed at university and then used in workplaces. *Studies in Higher Education*, 44(12), 2346–2358.
- Al-Majed, A., Al-Kathiri, F., Al-Ajmi, S., & Al-Hamlan, S. (2017). 21st century professional skill training programs for faculty members--A comparative study between Virginia Tech University, American University & King Saud University. *Higher Education Studies*, 7(3), 122–131.
- Alter, A. (2017). *Irresistible: The rise of addictive technology and the business of keeping us hooked*. New York: Penguin.
- Attwell, D. (2015). *JM Coetzee and the life of writing: Face to face with time*. Oxford: Oxford University Press.
- Bantjes, J., Lochner, C., Saal, W., Roos, J., Taljaard, L., Page, D., ... Kessler, R. C. (2019). Prevalence and sociodemographic correlates of common mental disorders among first-year university students in post-apartheid South Africa: implications for a public mental health approach to student wellness. *BMC Public Health*, 19(1), 922.
- Bantjes, J., Saal, W., Lochner, C., Roos, J., Auerbach, R. P., Mortier, P., ... Stein, D. J. (2020). Inequality and mental healthcare utilisation among first-year university students in South Africa. *International Journal of Mental Health Systems*, 14(1), 5.
- Bantjes, J., & Swartz, L. (2017). The cultural turn in critical suicidology: What can we claim and what do we know? *Death Studies*, 41(8), 512–520.
<https://doi.org/10.1080/07481187.2017.1333355>
- Bashonga, R., & Khuzwayo, Z. (2017). “This thing of the victim has to prove that the

- perp intended to assault is kak!": Social media responses to sexual violence on South African university campuses. *Agenda*, 31(3–4), 35–49.
- Bechdel, A. (2007). *Fun home: A family tragicomic*. New York: Houghton Mifflin Harcourt.
- Bechdel, A. (2013). *Are you my mother?* New York: Random House.
- Blowers, T. (2000). The textual contract: Distinguishing autobiography from the novel. In A. Donnell & P. Polkey (Eds.), *Representing lives: Women and auto/biography* (pp. 105–116). New York: Springer.
- Boehmer, E. (2016). Reading between life and work: Reflections on 'JM Coetzee.' *Textual Practice*, 30(3), 435–450.
- Boice, B. (1997). Which is more productive, writing in binge patterns of creative illness or in moderation? *Written Communication*, 14(4), 435–459.
- Bosanquet, A. (2019). Academic writing from the depths: An autoethnographic and organisational account. In L. Thomas & A. Reinertsen (Eds.), *Academic Writing and Identity Constructions* (pp. 97–113). New York: Springer.
- Bosmajian, H. (1998). The orphaned voice in Art Spiegelman's *Maus I & II*. *Literature and Psychology*, 44(1/2), 1-22.
- Bozalek, V. (2017). Slow scholarship in writing retreats: a diffractive methodology for response-able pedagogies¹. *South African Journal of Higher Education*, 31(2), 40–57.
- Bozalek, V., & Boughey, C. (2012). (Mis) framing higher education in South Africa. *Social Policy & Administration*, 46(6), 688–703.
- Bozalek, V., McMillan, W., Marshall, D. E., November, M., Daniels, A., & Sylvester, T. (2014). Analysing the professional development of teaching and learning from a political ethics of care perspective. *Teaching in Higher Education*, 19(5), 447–458.
- Breet, E., Botha, J., Horn, L., & Swartz, L. (2018). Academic and scientific authorship practices: A survey among South African researchers. *Journal of Empirical Research on Human Research Ethics*, 13(4), 412–420.
<https://doi.org/10.1177/1556264618789253>

- Brokerhof, I. M., Ybema, J. F., & Bal, P. M. (2020). Illness narratives and chronic patients' sustainable employability: The impact of positive work stories. *PLoS One*, *15*(2), e0228581.
- Carel, H. (2019). *Illness: The cry of the flesh* (3rd ed.). Oxford: Routledge.
- Cartel, M., Boxenbaum, E., & Aggeri, F. (2019). Just for fun! How experimental spaces stimulate innovation in institutionalized fields. *Organization Studies*, *40*(1), 65–92.
- Cerrato-Lara, M., Castelló, M., García-Velázquez, R., & Lonka, K. (2017). Validation of the Writing Process Questionnaire in two Hispanic populations: Spain and Mexico. *Journal of Writing Research*, *9*(volume 9 issue 2), 151–171.
<https://doi.org/10.17239/jowr-2017.09.02.03>
- Chang, H. (2016). Autoethnography in health research: Growing pains? *Qualitative Health Research*, *26*(4), 443–451.
- Chast, R. (2014). *Can't we talk about something more pleasant?: A memoir*. New York: Bloomsbury Publishing USA.
- Coetzee, J. M. (1992). *Doubling the point: Essays and interviews*. (D. Attwell, Ed.). Cambridge, MA: Harvard University Press.
- Coetzee, J. M. (1997). *Boyhood: a memoir*. New York: Vintage.
- Coetzee, J. M. (2002). *Stranger shores: essays, 1986-1999*. New York: Random House.
- Coetzee, J. M., & Kurtz, A. (2015). *The good story: Exchanges on truth, fiction and psychotherapy*. New York: Penguin Random House.
- Collett, K. S., van den Berg, C. L., Verster, B., & Bozalek, V. (2018). Incubating a slow pedagogy in professional academic development: An ethics of care perspective. *South African Journal of Higher Education*, *32*(6), 117–136.
- Conway, M. A., & Pleydell-Pearce, C. W. (2000). The construction of autobiographical memories in the self-memory system. *Psychological Review*, *107*(2), 261.
- Couser, G. T. (2004). *Vulnerable subjects: Ethics and life writing*. Ithaca, NY: Cornell University Press.

- Couser, G. T. (2009). *Signifying bodies: Disability in contemporary life writing*. Ann Arbor: University of Michigan Press.
- Couser, G. T. (2011). *Memoir: an introduction*. New York: Oxford University Press.
- Couser, G. T. (2018). Philippe Lejeune: An American(ist) appreciation. *European Journal of Life Writing*, 7, CP79–CP84.
- Crumb, L. (2019). Integrating feminist narrative therapy, person-centered therapy, and rational emotive behavioral therapy: A short-term case study. *International Journal of Integrative Psychotherapy*, 9, 56–72.
- Cuijpers, P., Auerbach, R. P., Benjet, C., Bruffaerts, R., Ebert, D., Karyotaki, E., & Kessler, R. C. (2019). The World Health Organization World Mental Health International College Student initiative: An overview. *International Journal of Methods in Psychiatric Research*, 28(2), e1761.
- Dahne, J., Lejuez, C. W., Diaz, V. A., Player, M. S., Kustanowitz, J., Felton, J. W., & Carpenter, M. J. (2019). Pilot randomized trial of a self-help behavioral activation mobile app for utilization in primary care. *Behavior Therapy*, 50(4), 817–827. <https://doi.org/https://doi.org/10.1016/j.beth.2018.12.003>
- Dix, H. (Ed.). (2018). *Autofiction in English*. New York: Springer.
- Docrat, S., Besada, D., Cleary, S., Daviaud, E., & Lund, C. (2019). Mental health system costs, resources and constraints in South Africa: a national survey. *Health Policy and Planning*, 34(9), 706–719.
- Eakin, P. J. (2018). Philippe Lejeune turns eighty. *European Journal of Life Writing*, 7, CP19–CP24.
- Egner, J. E. (2019). “The disability rights community was never mine”: Neuroqueer disidentification. *Gender & Society*, 33(1), 123–147.
- Eriksson, G., & Machin, D. (2020). Discourses of ‘Good Food’: The commercialization of healthy and ethical eating. *Discourse, Context & Media*, 33, 100365. <https://doi.org/https://doi.org/10.1016/j.dcm.2019.100365>
- Faccio, E., Turco, F., & Iudici, A. (2019). Self-writing as a tool for change: the effectiveness of a psychotherapy using diary. *Research in Psychotherapy: Psychopathology, Process and Outcome*, 22, 256-264.

- Faulkner, S. L. (2017). Writing practice: A narrative poem. *International Review of Qualitative Research*, 10(3), 238–241.
- Felstiner, M. L. (2005). *Out of joint: A private & public story of arthritis*. Lincoln: University of Nebraska Press.
- Fisher, A. W. (2011). We love this trainwreck! Sacrificing Britney to save America. In D. Negra & S. Holmes (Eds.). *In the limelight and under the microscope: Forms and functions of female celebrity*. (pp. 303–332). New York: Continuum Books.
- Fisher, B., & Tronto, J. (1990). Toward a feminist theory of caring. In E. K. Abel & M. K. Nelson (Eds.), *Circles of care: Work and identity in women's lives* (pp. 35–62). New York: SUNY Press.
- Frank, A. W. (2000). Illness and autobiographical work: Dialogue as narrative destabilization. *Qualitative Sociology*, 23(1), 135–156.
- Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.
- Franssen, G. (2019). The celebrityization of self-care: The celebrity health narrative of Demi Lovato and the sickscape of mental illness. *European Journal of Cultural Studies*, 23(1), 89–111. <https://doi.org/10.1177/1367549419861636>
- Freud, S. (1957). Mourning and melancholia. In *The Standard Edition of the Complete Psychological Works of Sigmund Freud, Volume XIV (1914-1916): On the History of the Psycho-Analytic Movement, Papers on Metapsychology and Other Works* (pp. 237–258).
- Frey, J. (2003). *A million little pieces*. New York: Doubleday.
- Fricke, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford: Oxford University Press.
- Garland-Thomson, R. (1996). *Freakery: Cultural spectacles of the extraordinary body*. New York: NYU Press.
- Garland-Thomson, R. (2005). Feminist disability studies. *Signs: Journal of Women in Culture and Society*, 30(2), 1557–1587.
- Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, 26(3), 591–609.

- Garland-Thomson, R. (2012). Review of Swartz, *Able-Bodied: Scenes from a curious life*. *Disability Studies Quarterly*, 32(4).
- Genz, S. (2015). My job is me: Postfeminist celebrity culture and the gendering of authenticity. *Feminist Media Studies*, 15(4), 545–561.
- Gertler, B. (2017). *Privileged access: Philosophical accounts of self-knowledge*. London: Routledge.
- Goodley, D., & Tregaskis, C. (2006). Storying disability and impairment: Retrospective accounts of disabled family life. *Qualitative Health Research*, 16(5), 630–646.
- Graefer, A. (Ed). (2019). *Media and the politics of offence*. London: Springer.
- Grealy, L. (1994). *Autobiography of a face*. New York: Houghton Mifflin Harcourt.
- Green, J. (2018). Unveiling the storied lives of teachers through qualitative bricolage. *Qualitative Research Journal*, 18, 316–329.
- Greenbaum, J. (2019). *Spilled and gone: Poems*. Pittsburgh: University of Pittsburgh Press.
- Hall, A. (2015). Zip zip my brain harts: Disability, photography and auto/biography. *Journal of Literary & Cultural Disability Studies*, 9(3), 265–276.
- Hall, N. C., Lee, S. Y., & Rahimi, S. (2019). Self-efficacy, procrastination, and burnout in post-secondary faculty: An international longitudinal analysis. *PLOS ONE*, 14(12), e0226716. <https://doi.org/10.1371/journal.pone.0226716>
- Hansell, J. (2000). Mourning and melancholia in superego development and resistance to change. *Journal of Clinical Psychoanalysis*, 9(2), 255–277.
- Harding, T. (2019). *Legacy: One family, a cup of tea and the company that took on the world*. London: Heinemann.
- Hartman, Y., & Darab, S. (2012). A call for slow scholarship: A case study on the intensification of academic life and its implications for pedagogy. *Review of Education, Pedagogy, and Cultural Studies*, 34(1–2), 49–60. <https://doi.org/10.1080/10714413.2012.643740>
- Hassan, N. R., Swartz, L., Kagee, A., De Wet, A., Lesch, A., Kafaar, Z., & Newman, P. A. (2018). “There is not a safe space where they can find themselves to be

- free”: (Un)safe spaces and the promotion of queer visibilities among township males who have sex with males (MSM) in Cape Town, South Africa. *Health and Place*, 49. <https://doi.org/10.1016/j.healthplace.2017.11.010>
- Heyns, M. (2002). *The children's day*. Johannesburg: Jonathan Ball.
- Horn, L., Van Niekerk, A., Theron, T., Swartz, L., & Le Grange, L. (2016). Power and ethics in humanities research: A response to Stolp. *Acta Academica*, 48(2), 1-15.
- Hunt, X., Swartz, L., Braathen, S. H., Carew, M., Chiwaula, M., & Rohleder, P. (2019). Shooting back and (re) framing: challenging dominant representations of people with physical disabilities in South Africa. In P. Chappell & M. de Beer (Eds.), *Diverse Voices of Disabled Sexualities in the Global South* (pp. 33–53). New York: Springer.
- Hunt, X., Swartz, L., Braathen, S. H., Jordan, C., & Rohleder, P. (2019). (Re) presenting the self: Questions raised by a photovoice project with people with physical disabilities in South Africa. *Disability & Society*, 1–26.
[DOI: 10.1080/09687599.2019.1649125](https://doi.org/10.1080/09687599.2019.1649125)
- Hurst, D., & Greenhalgh, T. (2019). Knowing in general dental practice: Anticipation, constraint, and collective bricolage. *Journal of Evaluation in Clinical Practice*, 25(6), 921–929.
- Ingelby, D. (Ed.). (1980). *Critical psychiatry: The politics of mental health*. London: Pantheon Books.
- Johnson, H. M. (2006). *Too late to die young: Nearly true tales from a life*. London: Macmillan.
- Joubert, E. (1978). *Die swerfjare van Poppie Nongena*. Cape Town: Tafelberg.
- Joubert, E. (2017). *Spertyd*. Cape Town: Tafelberg.
- Joubert, E. (2019). *Cul-de-sac*. Cape Town: Tafelberg.
- Juslin, P. N., & Sloboda, J. (Eds.). (2011). *Handbook of music and emotion: Theory, research, applications*. Oxford: Oxford University Press.
- Kahr, B. (2018a). *Coffee with Freud*. London: Routledge.
- Kahr, B. (2018b). *Tea with Winnicott*. London: Routledge.
- Kahr, B. (2019). *On practising therapy at 1.45 am: Adventures of a clinician*. London:

Routledge.

Kam, T. (2018). Comic thanatography: Redrawing agency, dialogism, and ethics in Can't We Talk About Something More Pleasant? *Inks: The Journal of the Comics Studies Society*, 2(2), 215–235.

Kamler, B., & Thomson, P. (2004). Driven to abstraction: doctoral supervision and writing pedagogies. *Teaching in Higher Education*, 9(2), 195–209.
<https://doi.org/10.1080/1356251042000195358>

Karellou, J. (2019). Enabling disability in higher education. A literature Review. *Journal of Disability Studies*, 5(2), 47–54.

Kidd, I. J., & Carel, H. (2017). Epistemic injustice and illness. *Journal of Applied Philosophy*, 34(2), 172–190.

Kincheloe, J. L. (2005). On to the next level: Continuing the conceptualization of the bricolage. *Qualitative Inquiry*, 11(3), 323–350.
<https://doi.org/10.1177/1077800405275056>

Kittay, E. F. (2009). The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy*, 40(3-4), 606–627.

Klevan, T., Karlsson, B., & Grant, A. (2020). Conversational autoethnography, mentoring and the New Public Management academy. In J. Moriarty (Ed.), *Autoethnographies from the neoliberal academy: Rewilding, writing and resistance in higher education*. Oxford: Routledge.

Klevan, T., Karlsson, B., Turner, L., Short, N., & Grant, A. (2018). Aha! "Take on Me's": bridging the North sea with relational autoethnography. *Qualitative Research Journal*, 18, 330–344.

Kombuis, K. (2006). *Raka: die roman*. Cape Town: Human & Rousseau.

Lawrence, D. H. (2014). *Studies in classic American literature (originally published 1923)*. (E. Greenspan, L. Vasey, & J. Worthen, Eds.). Cambridge: Cambridge University Press.

Leibowitz, B., & Bozalek, V. (2018). Towards a slow scholarship of teaching and learning in the South. *Teaching in Higher Education*, 23(8), 981–994.
<https://doi.org/10.1080/13562517.2018.1452730>

- Lejeune, P. (1975). *Le pacte autobiographique*. Paris: Le Seuil.
- Lejeune, P. (1989). *On autobiography*. Minneapolis: University of Minnesota Press.
- Lim, C. T., Tadmor, A., Fujisawa, D., MacDonald, J. J., Gallagher, E. R., Eusebio, J., ... Hagan, T. (2017). Qualitative research in palliative care: applications to clinical trials work. *Journal of Palliative Medicine*, 20(8), 857–861.
- Littlewood, R. (1991). Against pathology: The new psychiatry and its critics. *The British Journal of Psychiatry*, 159(5), 696–702.
- Loughlin, M., Buetow, S., Cournoyea, M., Copeland, S. M., Chin-Yee, B., & Fulford, K. W. M. (2019). Interactions between persons—Knowledge, decision making, and the co-production of practice. *Journal of Evaluation in Clinical Practice*, 25(6), 911–920.
- Lourens, H., & Swartz, L. (2016). 'It's better if someone can see me for who I am': stories of (in)visibility for students with a visual impairment within South African Universities. *Disability and Society*, 31(2).
<https://doi.org/10.1080/09687599.2016.1152950>
- Lüdemann, W. (2017). Power and ethics in humanities research: another response to Stolp. *Acta Academica*, 49(2), 1–10.
- Malouff, J. M., & Schutte, N. S. (2019). The efficacy of interventions aimed at reducing procrastination: A meta-analysis of randomized controlled trials. *Journal of Counseling & Development*, 97(2), 117–127.
- Maslej, M. M., Srikanth, N., Froentjes, L., & Andrews, P. W. (2020). Why does expressive writing affect emotion? Considering the impact of valence and cognitive processing. *Canadian Journal of Behavioural Science / Revue Canadienne Des Sciences Du Comportement*, 52(2), 85–96. <https://doi-org.ez.sun.ac.za/10.1037/cbs0000167>
- McAdams, D. P. (2001). The psychology of life stories. *Review of General Psychology*, 5(2), 100–122.
- McClintock, A. (1990). "The very house of difference": race, gender and the politics of South African women's narrative in Poppie Nongena. *Social Text*, (25/26), 196–226.
- McDougall, K., Swartz, L., & Van der Merwe, A. (2006). *Zip zip my brain harts*. Cape

Town: HSRC Press.

- McWilliams, N. (2011). *Psychoanalytic diagnosis: Understanding personality structure in the clinical process*. New York: Guilford Press.
- Menand, L. (2009). Show or tell. *The New Yorker*, 8, 106–112.
- Mintz, S. B. (2001). Writing as refiguration: Lucy Grealy's "Autobiography of a face." *Biography*, 24(1), 172–184. Retrieved from <http://www.jstor.org/stable/23540316>
- Mkhwanazi, N. (2016). Medical anthropology in Africa: The trouble with a single story. *Medical Anthropology*, 35(2), 193–202.
- Moore-Gilbert, B. (2014). Time bandits: temporality and the politics of form in Palestinian women's life-writing. *Journal of Postcolonial Writing*, 50(2), 189–201. <https://doi.org/10.1080/17449855.2014.883178>
- Morris, P. (2019). When I was seventeen. In S. Farquhar & E. Fitzpatrick (Eds.), *Innovations in narrative and metaphor* (pp. 29–37). Springer.
- Mountz, A., Bonds, A., Mansfield, B., Loyd, J., Hyndman, J., Walton-Roberts, M., ... Hamilton, T. (2015). For slow scholarship: A feminist politics of resistance through collective action in the neoliberal university. *ACME: An International E-Journal for Critical Geographies*, 14(4).
- Mulvihill, T. M., & Swaminathan, R. (2017). *Critical approaches to life writing methods in qualitative research*. London: Taylor & Francis.
- Murray, R. (2014). 'Snack' and "binge" writing: Editorial for *Journal of Academic Development and Education*. *The Journal of Academic Development and Education*, (2), 5–8.
- Naldemirci, Ö., Britten, N., Lloyd, H., & Wolf, A. (2020). The potential and pitfalls of narrative elicitation in person-centred care. *Health Expectations*, 23(1), 238–246.
- Narayan, U. (1995). Colonialism and its others: Considerations on rights and care discourses. *Hypatia*, 10(2), 133–140.
- Ndlovu, H. (2017). Womxn's bodies reclaiming the picket line: The 'nude' protest during #FeesMustFall. *Agenda*, 31(3–4), 68–77.
- O'Neil, A., Sojo, V., Fileborn, B., Scovelle, A. J., & Milner, A. (2018). The #MeToo movement: An opportunity in public health? *The Lancet*, 391(10140), 2587–

2589.

Ortner, S. B. (1972). Is female to male as nature is to culture? *Feminist Studies*, 1(2), 5–31.

Petersen, I., Fairall, L., Bhana, A., Kathree, T., Selohilwe, O., Brooke-Sumner, C., ... Lund, C. (2016). Integrating mental health into chronic care in South Africa: the development of a district mental healthcare plan. *The British Journal of Psychiatry*, 208 (s56), s29–s39.

Phelan, J. (2016). Local fictionality within global non-fiction: Roz Chast's *Why can't we talk about something more pleasant*. *Enthymema*, 16, 19–31.

Posel, D. (2010). Races to consume: revisiting South Africa's history of race, consumption and the struggle for freedom. *Ethnic and Racial Studies*, 33(2), 157–175. <https://doi.org/10.1080/01419870903428505>

Pychyl, T. A., & Flett, G. L. (2012). Procrastination and self-regulatory failure: An introduction to the special issue. *Journal of Rational-Emotive & Cognitive-Behavior Therapy*, 30(4), 203–212. <https://doi.org/10.1007/s10942-012-0149-5>

Quayson, A. (2005). Postcolonialism and postmodernism. In H. Schwarz & S. Ray (Eds.), *A companion to postcolonial studies* (pp. 87–111). Oxford: Blackwell Publishing Inc.

Rabe, L. (2019). *Om tot verhaal te kom: Verwerk trauma en verlies deur skryf terapie*. Cape Town: LAPA Uitgewers.

Remnick, D. (2016, October). Leonard Cohen makes it darker. *The New Yorker*, 1–7. <https://doi.org/https://www.newyorker.com/magazine/2016/10/17/leonard-cohen-makes-it-darker>

Richards, R. (2008). Writing the othered self: Autoethnography and the problem of objectification in writing about illness and disability. *Qualitative Health Research*, 18(12), 1717–1728.

Richards, R. (2015). Celebrities and spiritual gurus: Comparing two biographical accounts of kidney transplantation and recovery. *African Journal of Disability; Vol 4, No 1 (2015)DO - 10.4102/Ajod.V4i1.151* . Retrieved from <https://ajod.org/index.php/ajod/article/view/151>

Richards, R. (2019). Shame, silence and resistance: How my narratives of academia

- and kidney disease entwine. *Feminism & Psychology*, 29(2), 269–285.
- Rijkeboer, M. M., Daemen, J. J., Flipse, A., Bouwman, V., & Hagenaaars, M. A. (2020). Rescripting experimental trauma: Effects of imagery and writing as a way to reduce the development of intrusive memories. *Journal of Behavior Therapy and Experimental Psychiatry*, 67, 101478.
<https://doi.org/https://doi.org/10.1016/j.jbtep.2019.04.004>
- Rottenberg, C. (2014). The rise of neoliberal feminism. *Cultural Studies*, 28(3), 418–437.
- Rozental, A., & Carlbring, P. (2014). Understanding and treating procrastination: A review of a common self-regulatory failure. *Psychology*, 5(13), 1488.
- Schalkwyk, D. (1986). The flight from politics: An analysis of the South African reception of 'poppie nongena'. *Journal of Southern African Studies*, 12(2), 183–195.
- Schneider, M. (1987). Omnipotence and idealization as contributory factors in a failure to mourn. *Psychoanalytic Psychotherapy*, 3(3), 211–224.
- Schnitker, S. A., & Richardson, K. L. (2019). Framing gratitude journaling as prayer amplifies its hedonic and eudaimonic well-being, but not health, benefits. *The Journal of Positive Psychology*, 14(4), 427–439.
- Schuldiner, M. (2002). Writer's block and the metaleptic event in Art Spiegelman's graphic novel, "Maus". *Studies in American Jewish Literature (1981-)*, 21, 108–115.
- Scully, J. L. (2018). From "She would say that, wouldn't she?" to "Does she take sugar?" Epistemic injustice and disability. *IJFAB: International Journal of Feminist Approaches to Bioethics*, 11(1), 106–124.
- Shakespeare, T. (2013). *Disability rights and wrongs revisited*. London: Routledge.
- Silvia, P. J. (2007). *How to write a lot: A practical guide to productive academic writing*. Philadelphia: American Psychological Association.
- Simplican, S. C. (2017). Feminist disability studies as methodology: Life-writing and the abled/disabled binary. *Feminist Review*, 115(1), 46–60.
- Sims, A. C. P. (1981). Research and the Royal College of Psychiatrists. *Bulletin of*

the Royal College of Psychiatrists, 5(3), 45–46.

Smit, A., Coetzee, B. J., Roomaney, R., Bradshaw, M., & Swartz, L. (2019). Women's stories of living with breast cancer: A systematic review and meta-synthesis of qualitative evidence. *Social Science & Medicine*, 222, 231–245.

Sousanis, N. (2015). *Unflattening*. Cambridge, MA: Harvard University Press.

Spiegelman, A. (1992). *The complete Maus (Books 1 and 2)* (Rereleased). New York: Pantheon Books.

Steel, P. (2007). The nature of procrastination: A meta-analytic and theoretical review of quintessential self-regulatory failure. *Psychological Bulletin*, 133(1), 65–94. <https://doi.org/10.1037/0033-2909.133.1.65>

Steiner, J. (2005). The conflict between mourning and melancholia. *The Psychoanalytic Quarterly*, 74(1), 83–104.

Stolp, M. (2012). Contemporary performance practice of art music in South Africa: A practice-based research enquiry. Unpublished PhD dissertation, Stellenbosch University.

Stolp, M. (2016). Response to the Academy. *Acta Academica*, 48(2), 16–17.

Stupnisky, R. H., Hall, N. C., & Pekrun, R. (2019). The emotions of pretenure faculty: Implications for teaching and research success. *The Review of Higher Education*, 42(4), 1489–1526.

Swartz, L. (1998). *Culture and mental health: A southern African view*. Cape Town: Oxford University Press.

Swartz, L. (2007). The virtues of feeling culturally incompetent. *Monash Bioethics Review*, 26(4), 36–46.

Swartz, L. (2014). Five challenges for disability-related research in sub-Saharan Africa. *African Journal of Disability*, 3(2), 1–6. <https://doi.org/10.4102/ajod.v3i2.149>

Swartz, L. (2018). Representing disability and development in the global south. *Medical Humanities*, 44(4), 281–284.

Swartz, L., & Bantjes, J. (2016). Disability and global health. In *Disability in the Global South* (pp. 21–33). Springer.

- Swartz, L., Bantjes, J., Lourens, H., & Watermeyer, B. (2020). Disability: The forgotten side of race science. In J. Jansen & C. Walters (Eds.), *Faultlines: A primer on race, science and society* (pp. 143–158). Stellenbosch: African Sun Media.
- Swartz, L., Hunt, X., Watermeyer, B., Carew, M., Braathen, S. H., & Rohleder, P. (2018). Symbolic violence and the invisibility of disability. *African Safety Promotion: A Journal of Injury and Violence Prevention*, 16(2), 21–30.
- Swartz, L., & Kilian, S. (2014). The Invisibility of Informal Interpreting in Mental Health Care in South Africa: Notes Towards a Contextual Understanding. *Culture, Medicine and Psychiatry*, 38(4), 700–711. <https://doi.org/10.1007/s11013-014-9394-7>
- Swartz, L., & Marchetti-Mercer, M. (2018). Disabling Africa: the power of depiction and the benefits of discomfort. *Disability & Society*, 33(3), 482–486. <https://doi.org/10.1080/02684527.2017.1400240>
- Swartz, S. (2018). *Ruthless Winnicott: The role of ruthlessness in psychoanalysis and political protest*. London: Routledge.
- Tambe, A. (2018). Reckoning with the silences of# MeToo. *Feminist Studies*, 44(1), 197–203.
- Thomson, P., & Kamler, B. (2016). *Detox your writing: Strategies for doctoral researchers*. London: Routledge.
- Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. New York: Psychology Press.
- van der Heijden, I., Abrahams, N., & Harries, J. (2019). Additional layers of violence: the intersections of gender and disability in the violence experiences of women with physical disabilities in South Africa. *Journal of Interpersonal Violence*, 34(4), 826–847.
- Vohs, K. D., Redden, J. P., & Rahinel, R. (2013). Physical order produces healthy choices, generosity, and conventionality, whereas disorder produces creativity. *Psychological Science*, 24(9), 1860–1867.
- Wahl-Jorgensen, K. (2018a). Media coverage of shifting emotional regimes: Donald Trump's angry populism. *Media, Culture & Society*, 40(5), 766–778.

<https://doi.org/10.1177/0163443718772190>

- Wahl-Jorgensen, K. (2018b). Towards a typology of mediated anger: Routine coverage of protest and political emotion. *International Journal of Communication*, 12, 2071–2087.
- Walton, C. (2017). Right to reply: Of ethics and incompetence. *Acta Academica*, 49(1), 1-1.
- Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M., & Priestley, M. (Eds.) (2006). *Disability and social change: A South African agenda*. HSRC Press.
- Wendland, C. L. (2019). Physician anthropologists. *Annual Review of Anthropology*, 48(1), 187–205. <https://doi.org/10.1146/annurev-anthro-102218-011338>
- Whitburn, B., & Goodley, D. (2019). Storying disability's potential. *International Journal of Inclusive Education*, 1–14.
- Williamson, J. (2019). The art of memory. *The Lancet Neurology*, 18(6), 527–528.
- Willison, J., Sabir, F., & Thomas, J. (2017). Shifting dimensions of autonomy in students' research and employment. *Higher Education Research & Development*, 36(2), 430–443.
- Woodiwiss, J. (2015). What's wrong with me? A cautionary tale of using contemporary 'damage narratives' in autobiographical life writing. In K. W. Shands, G. G. Mikrut, D. R. Pattanaik, & K. Ferreira-Meyers (Eds.), *Writing the self* (pp. 183–192). Stockholm: Elanders.
- Yagoda, B. (2009). *Memoir: A history*. New York: Penguin.
- Zembylas, M. (2015). 'Pedagogy of discomfort' and its ethical implications: The tensions of ethical violence in social justice education. *Ethics and Education*, 10(2), 163–174.
- Zembylas, M., & Boler, M. (2002). On the spirit of patriotism: Challenges of a 'pedagogy of discomfort.' *Teachers College Record*, 104(5), 1–27.
- Zembylas, M., & McGlynn, C. (2012). Discomforting pedagogies: Emotional tensions, ethical dilemmas and transformative possibilities. *British Educational Research Journal*, 38(1), 41–59.

Appendix

Ethical approval documentation



NOTICE OF APPROVAL

REC: SBER - Initial Application Form

31 May 2019

Project number: 10107

Project Title: How I lost my mother: Care, death, and the politics of invisibility

Dear Prof Leslie Swartz

Your REC: SBER - Initial Application Form submitted on 5 May 2019 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
30 May 2019	29 May 2020

GENERAL COMMENTS:

The REC is in agreement with the applicant that the risk level of this project is medium. However, results may well provide valuable information and hence the risk/cost-benefit is considered acceptable.

Once the work is complete, the researcher will make the draft manuscript available to those who he mentions in the work, and ask for any comments or feedback. If he receives any objections to publishing the work, he will try to change some details or will approach the REC for further advice as to how to proceed. The researcher is well acquainted with ethical issues specific to life writing, and the REC can be confident that this process will be handled sensitively. The researcher is therefore advised to notify the REC of any problems that arise with regard to negative reactions from those he will write about.

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (10107) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Investigator CV (PI)	CV of Prof L Swartz 2019	24/04/2019	1
Research Protocol/Proposal	Leslie Swartz proposal for REC	03/05/2019	1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.

The Research Ethics Committee: Humanities complies with the SA National Health Act No.61/2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

- 1. Conducting the Research.** You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.
- 2. Participant Enrollment.** You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use.
- 3. Informed Consent.** You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents/process, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.
- 4. Continuing Review.** The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the REC approval of the research expires, it is **your responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur**. If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.
- 5. Amendments and Changes.** If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.
- 6. Adverse or Unanticipated Events.** Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouche within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.
- 7. Research Record Keeping.** You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC
- 8. Provision of Counselling or emergency support.** When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.
- 9. Final reports.** When you have completed (no further participant enrollment, interactions or interventions) or stopped work on your research, you must submit a Final Report to the REC.
- 10. On-Site Evaluations, Inspections, or Audits.** If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

Principal Investigator Responsibilities

Protection of Human Research Participants

As soon as Research Ethics Committee approval is confirmed by the REC, the principal investigator (PI) is responsible for the following:

Conducting the Research: The PI is responsible for making sure that the research is conducted according to the REC-approved research protocol. The PI is jointly responsible for the conduct of co-investigators and any research staff involved with this research. The PI must ensure that the research is conducted according to the recognised standards of their research field/discipline and according to the principles and standards of ethical research and responsible research conduct.

Participant Enrolment: The PI may not recruit or enrol participants unless the protocol for recruitment is approved by the REC. Recruitment and data collection activities must cease after the expiration date of REC approval. All recruitment materials must be approved by the REC prior to their use.

Informed Consent: The PI is responsible for obtaining and documenting affirmative informed consent using **only** the REC-approved consent documents/process, and for ensuring that no participants are involved in research prior to obtaining their affirmative informed consent. The PI must give all participants copies of the signed informed consent documents, where required. The PI must keep the originals in a secured, REC-approved location for at least five (5) years after the research is complete.

Continuing Review: The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the REC approval of the research expires, **it is the PI's responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur**. Once REC approval of your research lapses, all research activities must cease, and contact must be made with the REC immediately.

Amendments and Changes: Any planned changes to any aspect of the research (such as research design, procedures, participant population, informed consent document, instruments, surveys or recruiting material, etc.), must be submitted to the REC for review and approval before implementation. Amendments may not be initiated without first obtaining written REC approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

Adverse or Unanticipated Events: Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the REC within **five (5) days** of discovery of the incident. The PI must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants.

Research Record Keeping: The PI must keep the following research-related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence and approvals from the REC.

Provision of Counselling or emergency support: When a dedicated counsellor or a psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

Final reports: When the research is completed (no further participant enrolment, interactions or interventions), the PI must submit a Final Report to the REC to close the study.

On-Site Evaluations, Inspections, or Audits: If the researcher is notified that the research will be reviewed or audited by the sponsor or any other external agency or any internal group, the PI must inform the REC immediately of the impending audit/evaluation.



NOTICE OF APPROVAL

REC: SBER - Annual Progress/ Final Report

10 March 2020

Project number: 10107

Project Title: How I lost my mother: Care, death, and the politics of invisibility

Dear Prof Leslie Swartz

Your REC: SBER - Annual Progress Report submitted on 23 January 2020 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
29 May 2020	28 May 2021

GENERAL COMMENTS:

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (10107) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	Leslie Swartz proposal for REC	03/05/2019	1
Default	shouting loud for REC	23/01/2020	1
Informed Consent Form	no consent for REC	23/01/2020	1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.