

Through Loss



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T H R O U G H L O S S

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The characters in this book do not represent any one individual. Rather, they are a fictional blend of stories and themes—similarities to individuals are entirely coincidental.

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EJB and CLS

DEDICATION

For whom the words 'nonfinite loss and grief' resonate.

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P R E F A C E

This book is about normalising the place loss takes in the lives of human beings. By demonstrating the pivotal place of loss—the normal place it occupies in development—we identify the nature of significant or traumatic losses and their interaction with development and biography. Our hope is that this book will help you to respect and validate the range of emotions and behaviours that have paralleled incidents of loss in your life. For many people, deep and cherished hopes, dreams and life plans have been replaced with sadness and the realisation of fears and dreads.

Looking back over your past will explain some of the reasons behind the routes that you have chosen to take in your life when you have been at a crossroads. An understanding of past development helps, but managing your current situation, finding better ways and seeking better outcomes for yourself is the primary aim of this book. An important part of that aim is to offer fresh insight into the responses of others, those individuals who may not have been able to stay with you through your losses, the friends who may have fallen by the wayside.

In saying this, we do not want to be prescriptive. We would prefer this book to be a useful manual that you feel you can return to, not only because it may provide some different ways of looking at your surroundings, but because it may help you to re-validate any natural recurrence of feeling states throughout

your life. We want it to reinforce the fact that the feelings you have are normal. We also want to explain grieving: what it involves; where it may sometimes take you; ways you can develop to contest some of its strength, intensity and relentlessness; ways of staying connected with other people; ways of living with the loss and grief that continues in the forefront of minds or as a backdrop to lives, or sometimes both.

This book is divided into three parts. Part I serves as a general introduction to the topic and to several fictional characters, whose journeys through loss and grief demonstrate key points, which are made progressively throughout the book. The three chapters in Part II provide an opportunity for readers to reflect on past encounters with loss and describe how early formative processes shape identities and personalities. Part III brings us face to face with present realities, emphasising the importance of self-preservation, and presents practical guidelines in adapting to loss.

We welcome the opportunity to share with you, in these pages, the meaning of loss and grief through the use of the word 'nonfinite'. We have found this word remarkably apt to describe what, perhaps, you too have discovered about loss and grief. It rules out the unrealistic idea of emotional acceptance, or of returning to the world as it used to be, to who we were before. It ushers in the more realistic possibility of adaptation to the world and self that is emerging. We would like to think that the word 'nonfinite' offers validation and explanation to those readers for whom the term resonates.

Part I

S E T T I N G
T H E S C E N E

CHAPTER 1

In the Company of Strangers

Looking back, there is no clear memory of when the load lifted a little for me, when small steps towards feeling that 'living with what had happened' was possible, was actually taking place within me. There came a time when talking about it became easier and sharing aspects of my load with others occurred without faltering. But this type of resignation was never secure. Being jolted back into that feeling of despair and being overwhelmed could be just around the corner again—feeling estranged, a type of glass veneer separating the conversation of friends, feeling absent even when present. That was at the beginning, a time when things felt insurmountable. Conversation that no longer seemed to have any point. Walking in a waft-like cloud. Time passing, yet at the same time, not moving at all for what seemed like many, many months. There were long days of extreme anxiety and gloom—still are sometimes. The shock, the sheer disbelief, feelings of protest: 'Why me? Sometimes a strong urge to be defiant: 'I'm not going to put up with this!' Then a cynical: 'Why not me? This sort of fits the general theme of what has gone on in my life'. Then despair

yet again surrounding the knowledge that the clock cannot be turned back—if only it could—and between times, a strange unaccountable feeling of surrender and a pause for unaccustomed, yet quieter reflection.

Rebecca

Does Rebecca's story, do her feelings, sound familiar to you? Her life had suddenly been taken out of her hands by a diagnosis of breast cancer leading to a radical mastectomy. These are very strong emotions that we are talking about. There are many people who experience these feelings relentlessly. Are there circumstances or events in your life that have triggered these feelings in you? Have you wondered how you would survive, or have survived? Are you trying to make sense of it all?

Let's take a journey of exploration through loss to try to unravel some answers to these difficult questions. First, we present examples of circumstances that have been known to trigger strong negative feelings and trace their impact when they become part of everyday life. Then we travel back into the past to identify those natural and instinctive aspects of life common to us all—our hopes, our dreams, our expectations, which determine much of our reaction to unfortunate or adverse circumstances. With the benefit of these insights, we consider the present and look ahead in anticipation of the emotional jolts that may be part of the future.

The following stories, and Rebecca's, are but a few of the many that could be told. In every case, there has been a loss accompanied by deep emotion. Illustrating a range of situations

that can evoke loss and grief, we turn next to a poignant scene as a relationship ends, complicated by the memory of a previous rejection.

Ian and rejection

And then out of the blue, no warning, she said she wanted it to be over—a separation, no second chances. Whoa—where did this come from? She'd given me no reason to believe things were this bad. She said: 'I did warn you, Ian! You are never here for me and Jack—it's all work, sport, television, computer games'. She went on and on. My thoughts left her. In what must have been a split-second, I found myself revisiting a time I had deliberately chosen to put out of my mind. I could see myself, a teenager, standing in the kitchen of my childhood home. I was shaking. I wanted them to stop—just leave me alone. As far as I was concerned, it was a bolt out of the blue, much like the present. Me, adopted? Yet my parents said they had told me when I was little. A mother who had chosen to relinquish me only two lousy days after my birth! She was too young, too broke, not married, hadn't told her parents. And my father? Cited 'unknown' on the birth certificate. And now another woman chooses to leave me and expects me to give up my child. Staring at the television, I tuned out. Turning briefly to my son who was sitting in front of me on the floor, the usual words tumbled out: 'Put your head down, Jack. I can't see the television!'

Belinda, Ron and baby Tom

Anticipating the birth of a first child is a time crammed with plans. It was no different for Belinda and Ron. So many discussions about how life would be: What name to choose? Which schools? Move house or add extension? So many hopes, dreams and plans. Belinda and Ron secured all checks for genetic anomalies, attended antenatal classes, and read numerous texts in preparation for parenting. The birth of Tom, however, followed no plan. It was a series of traumas for Belinda and Ron. Ending in a 'too late' emergency caesarian, Tom was diagnosed at birth with significant brain damage. It is difficult to quantify the enormous height Belinda and Ron had to fall to the reality that now stands in their path: Tom and they are living a very different life to any that they had envisaged. There are lots of difficult times. They feel disconnected from friends whose lives are following mainstream paths, who have little idea of the depth of emotions felt by Belinda and Ron. Unversed in what to say, many of their friends, and even their parents, make blunders. Belinda and Ron have become isolated in their grief. They are finding it hard to recover and make a place for plans in their lives.

Clare and her helium balloon

Clare is a three-year-old who has been treasuring her first helium balloon. All the way from the circus through the crowds on the long train trip home, she watched it bounce towards the sky, then the ceiling of the train, pulling it

towards her, then letting it bob away. Finally, she and her family reach home. Clutching the string of the bright helium balloon, Clare fumbles to change hands to open the gate of her front yard. In one irreversible, intense moment, her grip weakens, the string is free from her grasp, and she watches helplessly as her precious helium balloon floats slowly away, into the clouds. Drifting slowly, the helium balloon mesmerises her attention, making it all the more difficult to reduce her helplessness. From their earliest beginnings, individuals try to manage the intense feelings that characterise irrevocable loss. But for a three-year-old, there are no skills sufficient to manage this loss emotionally. Clare responds with unhar- nessed emotion—her body racked with pain, loss and disappointment. A long, drawn-out period of sobbing, screaming, choking, gulping, then running aimlessly through her garden, screaming ‘come back’, and into the house until eventually this terribly powerful feeling wanes and she lies face down on her bed sobbing. It went on too long, this unbridled emotion. There was nowhere for her to transfer her sorrow, her disappointment, her anger. Her feelings were left trapped in her body. No one else’s fault— just the normal, physical ineptitude of a three-year-old’s fine motor skills. Clare’s temperament and the strong emotion she experienced have left the event etched in her memory. Her family missed the essence of this loss for Clare, putting it down to a big fuss about nothing— perhaps an effort to secure attention.

Jesse and a disrupted adolescence

'What would you like to eat?' 'I don't care. You choose' was Jesse's mumbled reply. Was this reply surprising from a sixteen-year-old boy? Not really, for Jesse had just been told that the family would be moving yet again. They had shifted to different countries every four years or so, two of the locations involving the learning of a new language. This latest move came as a shock and was extremely difficult for Jesse. He thought the family had settled for good. He had established close and meaningful friendships since his early teens and he really enjoyed a sense of freedom within the neighbourhood. His parents tried to gloss over the losses involved for Jesse: 'It will be an adventure, a new room of your own, trips around the Continent'. Jesse did as he had always done and took the line of his parents, feigning excitement. He should be grateful! But following the last of a succession of going-away parties, and after his closest friend had hugged him 'goodbye', Jesse became aware of the tightness in his chest, his head throbbing and his jaw rigid and aching. Through a sleepless night, these physical sensations persisted. Arriving in England, they resurfaced, accompanied by a deep and painful longing for his home and friends. Frightened that he would forget that home and his friends, Jesse would lie in bed, picturing his street, his room and his friends. Leaving his peer group in this developmental period, a time when peers develop stories and memories together, represented a significant loss for Jesse. Often individuals who have been separated from this continuity cannot pick up where they left off;

nor can they develop a sense of history and continuity with new peers. This was so for Jesse. He was left with an innate sense of loss and feelings of disconnection right through into his adulthood.

Mary and her idealised father

It was not until Mary was in her mid-twenties that memories of her childhood started to change. Up till then, whenever she had been asked about her family, she had been full of praise—the carefree wonderful childhood, an idolised mother and father. Why had this all changed? Mary has two children, aged two and four years. Every week, she took them to her parents who would babysit them. It was in the interaction between her father and her children that Mary began to get glimpses of her own childhood. Watching her children with him, Mary became aware of the harsh, belittling language and the discipline he meted out. They walked on eggshells around him. Mary realised that they were terrified of her father. She began to confront her own childhood and her relationship with her father. How had he treated her? Through counselling and therapy, Mary slowly unfolded a different picture of her father. She learnt why she had feared adults and why she had not been able to develop self-esteem. Her life might have been so different! The loss of her idealised portrait of her father was very painful, and it was a shock. She was left with the confronting task of considering his love for her and her love for him. Could love exist in such a

relationship? Mary protested that she had been robbed of a loving, nurturing father. There were regular reminders of this loss in all the apparently rewarding father–daughter relationships that she witnessed in her girlfriends’ lives—seemingly so much happier than her own. She distanced herself and her children from him. Often Mary yearned for a different life—to turn back time and experience a loving relationship with a kind and nurturing father. On occasions, what she had missed out on made her feel angry. Could she ever be free of regret?

Marvin and a degenerative condition

Marvin was forty-eight years old when he was diagnosed with a degenerative condition. A successful doctor, he himself had frequently diagnosed serious illnesses in his patients. In the aftermath of the diagnosis, he reflected on how little understanding he had formerly had of the enormous adjustments that were part and parcel of chronic conditions and their treatment. From now on, he would live with a condition that would involve frequent checks, which meant his normal plans were left balancing precariously on the results of scans and blood tests. He could no longer give messages from inside his body just cursory interest. Now they were all considered with mounting suspicion. Knowing the effectiveness of the treatment brought little relief for Marvin. His body had failed him. What prospect was there of returning to a relaxed attitude to his life? The reality of the risk intruded

at odd times. Despite the monthly visit to specialists, Marvin is often struck by fresh shock and disbelief that this has happened at all, and to him? Unbelievable! And then a wave of emotion—fear or intense anxiety, lapsing into an overwhelming feeling of helplessness: ‘What made me think I was immune to becoming ill?’ He realises that he has lost that naive comfort and security, but he does not display his grief. He finds it excruciatingly difficult to play the role of the patient and avoids the topic with his colleagues and friends. Instead, he portrays the role of a doctor, resolute that nothing fundamentally has changed in his life. He defiantly hangs onto this image, while in his private moments, Marvin grapples with anxiety and fear.

How loss never ends

The circumstances described in these stories have a common thread—they describe a loss with a starting point, perhaps a realisation of a false hope, an awakening to a future beyond one’s control, a diagnosis, a new and changed world to contend with. For the young child **Clare**, it has meant experiencing how things disappear and how, sometimes, she cannot get them back. She has no alternative but to endure great emotional anguish. With her story, we are warned against too easily dismissing the meaning a particular, seemingly insignificant, loss has for an individual.

For sixteen-year-old **Jesse** there is no recourse but to manage his profound disappointment. The benefits his parents described about living in England can never replace his life back home.

He yearned for his home and his friends—the novelty of England was no compensation. Jesse is forced to experience emotional distress and come face to face with his inability to control his destiny. With no words to capture what he is feeling, this grief remains unshared. For **Rebecca**, life has become a roller-coaster ride, as Chapter 2 explains more fully.

While forty-eight-year-old **Marvin** privately grapples with a degenerative condition, he tenaciously holds onto the familiarity of his routines as a medical doctor. It is a continuous struggle that he refuses to share with others. Would this sharing make it all too real? **Mary** awakens to the fact that she has developed an idealisation of her father that she can no longer hold onto—not an uncommon realisation for children once they become adults and parents themselves. Memories come flooding back of her childhood, forcing her to wrestle with ambivalent feelings towards her father. Inevitably, her picture of him has altered forever.

Belinda and Ron provide an example of the loss of hopes and dreams that individuals embellish from childhood. And **Ian**? He may later be faced with many regrets about not spending time with his wife and child. Why didn't he see, hear, or heed the warnings? Perhaps the reason lies behind his entrenched need to protect himself from becoming too close to anyone. His early relinquishment by his birth-mother created a continuing theme in his later relationships.

In reading these comments, you may have become aware that the direct outcome of Clare's loss actually applies to all of our examples—all these individuals have encountered the irrevocable. For Rebecca and Marvin, it is trust in the integrity of their

health and body. For Mary, it is the idealised version she has held of her father–daughter relationship. Jesse has lost the comfort of home and the intimacy of peers during a sensitive and pivotal developmental period in his life. For Belinda and Ron, it is the expectations that surround the birth and parenting of a normal, healthy child. For Ian, it is the end of another significant relationship and the prospect of separation from his son. The irrevocability is only one dimension of their loss.

Each story unfolds into a continuing experience that gains in meaning and significance over time and links with previous experiences in life. Each retains a lasting impact, to a lesser or greater degree, and some are more obvious than others. It is obvious that life will not be the same again for Rebecca, Marvin, Belinda and Ron. Their losses are inescapably linked with a grief that ebbs and flows, subsiding and resurfacing as time presents changing perspectives on the original loss. For Ian, his loss inevitably reverberates with the continuing grief related to his earliest perceived rejection.

The lasting impact for Clare, Mary and Jesse is less obvious, but nevertheless it is indelible. The factors influencing this outcome are explored later, but for now the particular point to note is how significant their attachment was to what they lost. As a consequence, the two younger characters have become at risk in the event of future losses. Early in their development, they have experienced overwhelming emotions with little, if any, support in relation to a significant loss. And Mary? She will continue indefinitely to revisit surges of yearning and regret about her relationship with her father.

These stories may make you aware that the meaning and significance of loss, whether or not loss retains a continuing presence, has as much to do with the idiosyncratic developmental experiences and temperament of individuals as it has to do with the nature of the precipitating event or trauma. Have any of these stories touched aspects of your experiences? Does the term *nonfinite loss* resonate for you? It rules out the unrealistic idea of emotional acceptance, or of returning to the world as it used to be, to who we were before. It ushers in the more realistic possibility of adaptation to the world and self that is emerging.

The way forward

We invite you to take a personal journey back into the past, through the present, and on into glimpses of the future. Before any journey can be taken, a certain amount of information, guidelines and maps are basic requirements. Hence the introductory nature of Part I, with the stories to set the scene and then a description of the nature of loss and the ebb and flow of grief in Chapters 2 and 3. In preparation for our journey through Parts II and III, Part I conveys the pervasiveness of loss in human life: how the experience of loss can take us along different pathways; how a loss with a continuing presence is nonfinite; and how grief is very often the counterpart of nonfinite loss.

Inevitably, the material is sensitive; it is bound to stir up memories and touch on some personal issues. *Reflecting* on what is read is just a beginning of the process of reducing emotional pain. With the exception of this introductory chapter and the final chapter, you will find a summary section headed

‘Thoughts to ponder’ at the close of each chapter. These sections are designed to prompt useful memories and reflection. *Talking* about your reflections, thoughts and feelings with a friend or counsellor is another step in making the most of what this book has to offer. Another helpful way to look after yourself is *writing* about your thoughts and feelings in a journal. Giving substance to what we hold deep inside ourselves—what we have not had the opportunity to share—can be very powerful and therapeutic. Please do not underestimate this. Whatever is your preferred way of *artistic expression*, draw on it as you read this book.

CHAPTER 2

The Nature of Loss

Loss is an integral part of the lifelong learning process, shaping our identities and personalities. It is a theme from birth onwards, from leaving the mother's breast, to dummies, to bunny rugs, to the loss of first teeth, to room changes, to place changes, the exposure of the myths of Father Christmas, losing the special toy, the family dog—all woven into emotional memory, personality and biography. Many childhood losses common to us all are, because of their innate significance or time of occurrence, retained as vivid memories. Other highly charged emotional experiences can leave their mark by way of physical sensations or discomfort.

Losses that occur beyond childhood and throughout adulthood are often associated with life's major transitions: becoming independent; leaving home; changing jobs; an empty nest; retirement. The ageing process itself is replete with loss, and we all deal with disappointment and frustration surrounding unrealised expectations and the slow or sudden dismantling of assumptions.

'Loss in common', 'Loss uncommon', and 'Loss nonfinite' are terms that we have chosen to use for a limitless array of experiences across the lifespan. The framework these terms provide for

our journey into loss and grief is illustrated in Figure 1. It shows several potential outcomes of loss, depending on many factors including the nature of the loss itself. Figure 1 also illustrates the distinction between the common type of losses we are all likely to encounter and the uncommon losses, that is those that may or may not be part of our experience in life. In either type of loss, common or uncommon, the onset may be sudden, gradual, or expected, the effects on sense of self varying from salutary through indelible to traumatic. Before describing nonfinite loss fully, let's take a closer look at common and uncommon loss.

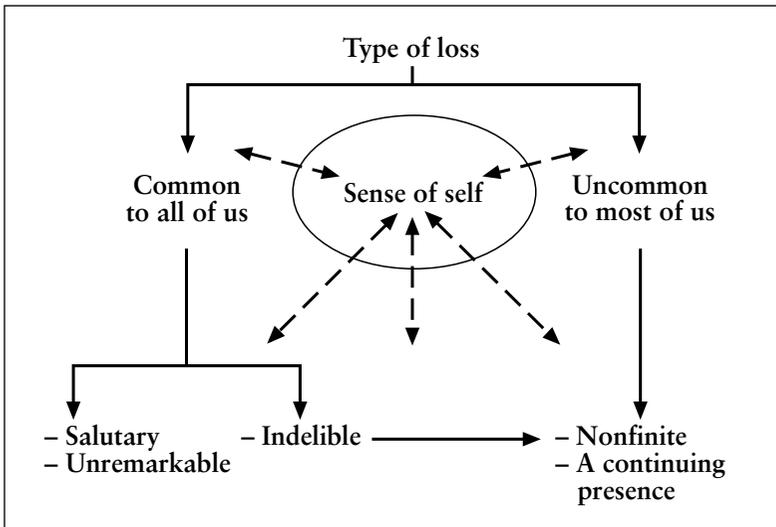


Figure 1 The spectrum of loss

Loss in common

Losses we have in common with most others are the kind of experiences every one of us can reasonably expect to encounter; they are an inseparable and integral part of growing up and

growing old. They can connect us with others, creating an understanding and empathy that even draws us to strangers. A nod of agreement, a silent or shared acknowledgment acts as a buffer: ‘Oh, I’ve had that experience, I know what you mean’. The impression that we are alone in feeling as we do evaporates.

An empathic connection with others provides a model of how to view our loss and helps us to manage our feelings. It is through such channels that our emotions are normalised. Sadly, this outcome is not always the case; a lack of synchrony with the experience of our peers can produce the reverse effect, casting an enduring shadow and causing feelings of isolation. Like Jesse, we may leave a certain secondary school before our peers; or we may experience a death long before our friends suffer a bereavement. Particular circumstances can rob us of the comfort of sharing even common experiences of loss. But there are the other losses—uncommon losses—that are even more likely to cast a shadow and to usher in more intense isolation.

Loss uncommon

As indicated in Figure 1, there is a direct link between uncommon and nonfinite loss. Uncommon losses are those not experienced by the majority of us, even though their rate of occurrence may be alarmingly high within the general population. Rebecca’s loss is a telling example—she is experiencing what has cautiously been termed ‘survivorship’ of cancer. She had never considered herself to be a candidate for such a condition. Sheer unexpectedness often accompanies uncommon loss: ‘I can’t believe this has happened to me!’

Uncommon losses come in many different forms and guises. Sometimes they stare us in the face; they cannot be ignored. Sometimes they creep up on us, maybe after we have attempted to camouflage the future, to kid ourselves. Surrounded by a relatively foreseeable genetic condition, such as haemophilia or Huntington's disease, family members might still judge themselves immune. Whatever form they take, there is a direct link between uncommon loss and nonfinite loss, as Figure 1 shows.

Table 1 lists some of the many forms that uncommon loss can take. It is just a selection—there may be others you want to add. And where does death—the most salient form of loss—fit into this equation, this terminology?

On bereavement

Perhaps you are questioning why suicide, untimely bereavement and violent death have been singled out from other deaths for inclusion in Table 1? These are personal encounters with death that are anything but common—deaths that are not expected in the normal course of events. In their wake are unanswered questions about the despair that surrounded the person who suicided; or the helplessness and horror of brutality and violence; or the senselessness of accidental death and the death of a child whose life is just beginning. They are momentous and life-changing losses that retain a continuing presence. They are best respected and understood as nonfinite loss.

Closure and resolution may be equally unreasonable expectations in the experience of bereavement in its more common forms. Who knows what factors come into play? Who knows

Table 1 Examples of uncommon loss

abandonment	injury to self, child, or significant other
adoption; fostering	life-threatening illness
alcoholism; drug dependency	lifestyle change
chronic unemployment	loss of childhood (e.g. caring for parents; work)
degenerative condition in self, partner, parent, or child	migration
developmental anomalies	psychiatric illness in self, partner, or child
disability in self, partner, parent, or child	psychic loss of father or mother
disappearance of a loved one	reason for being
disfigurement	relinquishment of a child or grandchild
disenfranchisement	separation or divorce affecting spouse, children, or grandparents
dislocation; refugee status; breakdown of cultural heritage	sexual abuse
emotional or physical abuse	suicide
failure at lifelong vocation or 'groomed-for' goal (e.g. ballet, gymnastics, sport, or a profession)	untimely bereavement
gender dysphoria or sexual identity	victim of crime, terrorism, war, natural disaster
infertility; impotence	violent death

what other losses there might be as an aftermath? Who knows what amount of personal threat a death may create? Who can judge or predict that a loss will be finite? There are so many aspects unique to an individual and particular situations that can influence the course of grief. For instance, death and dying often

demand traumatic decisions: the turning off of life-support machines, ‘no resuscitation’ orders, requests for organ donation. ‘No win’ choices can linger as agonising memories, perhaps declining in intensity over time, but nevertheless are likely to remain as a continuing presence.

Other significant factors about the possibility of closure in relation to bereavement include the level of support available, the resilience and health of the bereaved person, and cultural and familial matters, to mention but a few. Regardless of circumstances, and despite popular belief, there are no requisite periods of time to grieve. The idea of resolution is a difficult notion—let no one tell you otherwise. Perhaps no one knows this better than you do. Maybe your acquaintance with this knowledge came in the aftermath of a loss that left an indelible mark, if not for yourself, then for somebody close to you?

Loss nonfinite

Figure 1 illustrates how nonfiniteness can be the outcome of any loss experience, either due to the uncommon nature of the loss itself or to other determining factors surrounding a common loss. Follow the arrows to trace the pathways by which the shift into nonfiniteness may occur. See how there is a branching of outcomes in the aftermath of the more common type of loss? A salutary impact can foster the capacity to adapt, presenting little more than a fleeting nostalgia. A marked impact can, for various reasons, leave an indelible effect, sliding into nonfiniteness characterised by a continuing presence.

Loss as a continuing presence

Inevitably, nonfinite loss has an interminable effect on an individual's life. The characteristic continuing presence may be physical, psychological, emotional, or all of these; it is often difficult to describe precisely. The presence can be blatantly obvious or shadowy, but always there—above or below the surface. There are several explanations for this phenomenon. It may be because the loss itself:

- has shattered hopes and dreams, ideals and expectations held for life and the future;
- changes in meaning and gathers significance over time, often related to developmental stages;
- has involved a significant attachment;
- has no clearly marked conclusion.

It may also be because there is:

- recurrent psychological and physical pain, suffering and distress or grief;
- intense distress involving shame, self-consciousness, maltreatment, or fear of rejection due to mishandling by self or others.

And it may be traceable to sense of self when, for you:

- there is a continuing sense that something is missing in your life and your world;
- there is a self-perceived departure from mainstream experience, that is, away from, out of, the world that should have been, the world to which I felt entitled;

- there is a disconnection from customary ways of being with others;
- the lost object, person, place, or thing occupied a position integral to your sense of self.

At the root of these last four characteristics of nonfinite loss is the centrality of our being—our sense of self. By way of emphasis, sense of self is placed centre stage in Figure 1 and is defined for present purposes as an evolving and blending of life experiences with ‘Who I believe I am’ and ‘How I perceive that other people see me’. There is more to consider about sense of self, but first an illustration of how a relatively common loss can have an indelible effect, a continuing presence, a nonfiniteness.

An indelible effect

His dog, Mac, had provided Nathan with his first and only trustworthy, reliable relationship—an indelible, treasured memory. The death of Mac left a similar indelible impression:

‘Hands up who has lost a pet, a dog, cat, or mouse’ said the teacher. As nine-year-old Nathan’s head dropped and his body tensed, a sea of hands went up, and one by one Mrs Danby learnt the names, stories, and special places cats, dogs, mice play in the lives of her Grade 3 children. Nathan felt strange. Why couldn’t he talk about his dog like they did? Because Mac had been more than all those stories put together. His dog had felt different from theirs. Mac was more than a dog; Nathan had almost forgotten that Mac was a dog. Mac was his companion, his company, his only confidant; his licks were his contact and comfort. And when

Nathan's mother managed to lift herself from the couch in the lounge room, and he heard the familiar sound of the fridge door opening yet again, reaching to pat Mac's soft coat calmed him. Mac never changed ... until he ran out on the road ... The squeal of car brakes ... Mac lying so still. Nathan could not put his hand up to talk about his Mac.

Nathan's loss acquired a continuing presence—a nonfiniteness. Over time, through different developmental stages, his loss is likely to reveal itself: Nathan might continue an endless search to find another such trusted relationship throughout his life; he might take up some profession that allows him to demonstrate his feelings for animals. It is not unusual for a significant loss to be declared and represented in some form or manner. There are numerous possibilities. The outcome is not necessarily negative. In some cases, a loss of this nature develops into a theme that is central to a sense of self and who we later become.

Loss and sense of self

Sense of self is particularly vulnerable when it has not yet developed into a relatively consistent perception or when loss intrudes into our lives. Usually, sense of self begins to consolidate throughout later adolescence and young adulthood, but there are individuals for whom it remains fragile and mutable till much later on in life. Absorbing information about who we are and how other people perceive us is an ongoing part of our development. Unfortunately, we are prone to making large errors of judgement in our perception of how others perceive us and how we perceive them.

Threat of loss increases the margin for error—it weakens the sense of self. Under siege, we are beset by fear and anxiety, thrown off balance. We ask: ‘Who am I now that this has happened? How do people perceive me?’ Feeling isolated and different, the baseline has shifted for working out how we are now perceived. The confusion grows: ‘I wonder how my friends see me? I feel like a stranger to myself. Do I seem different to them?’

In the middle of a bustling supermarket, Alice, a middle-aged woman who bears the obvious effects of rheumatoid arthritis, hears a familiar voice: ‘You poor old thing! How are you?’ She stops in her tracks, quizzically considering this comment: ‘Is that how I appear to others? Do I really look like a person who prompts this comment? Is this just sympathy?’ Left feeling vulnerable, Alice tries to catch her reflection in the nearest shop window to reassure herself.

How we appear to others, and how others treat us, often undermines our sense of self, disturbing and destabilising a self-image that might only recently have gathered strength after shock or trauma. As happened for Alice, a sharp reminder of what about us is now different can, in an instant, undermine our self-image—we are weakened yet again. Fran’s story depicts how a childhood impression of ‘Who I am’ can lay the foundation for a nonfinite loss of sense of self.

Who am I?

It all began with Fran’s sense of being ‘special’.

‘You are my little princess,’ said her mother, and Fran felt like a princess. In the words and gaze of her parents and

just about everybody else, Fran was a special person, very precious. Eyes were always watching her, hands clapping her every effort, her adventures and stories intently listened to, her progress marked and revelled in. It is difficult for her to tell just when it all changed, but Fran believed that she was the centre of the world until, maybe, Year 7. After that, she no longer felt special. Eyes were diverted to others; the world was full of princesses in magazine pictures, the models, the superstars. It was a steep fall from a pedestal. From Year 7 onwards, her parents frequently made disparaging remarks about Fran—her hair, weight, skin, neatness. These ‘we are only trying to help you’ comments replaced her parents’ former admiration, approval and support. Overwhelming self-consciousness engulfed her. There was anxiety in every social setting—head down, shielding her face, so painfully awkward. Fran seemed to be pleading not to be noticed—‘Don’t move closer to me. Don’t stare at me.’

Around early adolescence, this praise and attention dropped away. No longer special, Fran’s sense of self was crucially undermined. She perceived that her parents no longer approved of her unconditionally. The obvious drop in parental support and positive regard during an anxiety-prone period of development resulted in an acute self-consciousness. One immediate outcome was her extreme social anxiety. She experienced a developmental loss that left an indelible impression likely to be experienced throughout her life as a fear that love is conditional. The discrepancy between her early self-image and her later reality was too sharp.

Discrepancy

What happened to Fran occurs for many individuals who, for one reason or another, experience a discrepancy with who they thought they were. This includes those who have been elite athletes, ballet dancers in their youth or, who through an accident, are forced to become familiar with a self that is totally different, disfigured, or disabled. It includes those whose family life is not what they had planned and those who have difficulty embracing the ageing process. Not surprisingly, there can be dissatisfaction with life and a bitterness about the success and attention that others attract in their lives. Maybe you are well acquainted with this feeling?

Individuals who sustain congenital disability or an injury at birth sometimes refer to an imagined time prior to birth when normality was theirs in the womb. In hindsight, an entitlement to an able body was lost, a life was irrevocably changed. Leading to an understandable grief for the life that might have been, a sense of self becomes overshadowed by a condition. The discrepancy between what might have been theirs and ‘what is’ is inescapable—the loss has a continuing presence and can feature as an impelling drive towards subsequent social advocacy and choice of vocation.

The sense of a discrepancy, that is, the sense that something is missing in one’s life, is inseparable from nonfinite loss. Being relinquished by birth parents, a childhood subjected to traumatic parenting that involves drugs, alcohol, or severe mental illness, or having been a victim of abuse are but a few stark examples of this loss. There is a feeling of having been cheated of a rightful destiny. A search for metaphors to convey loss and

incompleteness is inevitable: 'It's like a jigsaw piece is missing. There is a black hole, an emptiness. Do others feel like me?' The search for the elusive, shadowy jigsaw piece, the attributes of which can only be imagined, is a fathomless search. The life missed out on can never be road-tested. That searching is central to the grief described in Part II. But before leaving this chapter, let's return to some of the characters introduced in Chapter I. How do their stories relate to nonfinite loss? Perhaps they strike a chord with your story?

The stories revisited

Nonfinite loss applies to the losses of all the characters introduced in Chapter 1. The losses for **Rebecca**, **Marvin**, **Ian**, **Belinda** and **Ron** are uncommon; that is, they are not the kinds of loss that people generally encounter in life. Their hopes and expectations have been shattered, there are no clearly marked conclusions, and they struggle to know themselves as they now are, changed from how they had previously known themselves. Rebecca's story, in particular, forms the basis for further exploration in the following chapter, as we trace her grief.

The lasting impact of **Mary's**, **Jesse's** and **Clare's** experiences of loss may not be quite so self-evident. Yet Mary's psychic loss of her father, the gradual insight that he is not the father she had previously idealised, has brought an unending sense of grief into her life. There will also be psychological repercussions for Jesse. His story brings to mind adults who experience similar disruptions to their development. Their identity lacks a secure base, divided between places, with a resulting lack of any real sense of continuity. There can be an internal, learnt clock, a rhythm or

personal calendar that insists that they periodically pull up roots and move on, whether or not they want to. Or there can be an insistent urge to stay put, to put down roots and never leave. Perhaps this sounds familiar?

Clare's reaction to the loss of her helium balloon—a common enough childhood loss—reflects a combination of her temperament and immature defences. Her overwhelming despair indicates that she will develop a blueprint of this memory and, perhaps, a lasting fear of strong emotions and their effects. In later years, she might develop a somewhat blasé front, a protective façade, which conceals her sensitivity and vulnerability. She does not want to feel that fragmented again. She will fool lots of people. A common enough loss, but a lasting impact.

Not all children and adults will respond like the children and adults in the stories. For instance, some children will feel very little impact from the loss of a helium balloon. Especially if they are older, they may find a way to look at the balloon's flight as a way of providing them with emotional relief: 'The balloon is going up to heaven to be with Grandma'. Instead of feeling loss, they may marvel at its flight through the clouds. Who knows what meanings we can come up with to soothe ourselves in times of distress! The following thoughts to ponder serve as a summary of key points so far and are intended as a ready reference.

Thoughts to ponder

- Our early experiences of loss shape our identity and personality; they directly influence how we manage each loss experience that we encounter as adults.

- There are losses that are common to us all—relatively predictable and to be expected.
- There are losses that are uncommon—largely unpredictable and unexpected.
- Nonfinite loss has a continuing presence. This presence might be tangible; it might be amorphous.
- Nonfinite loss manifests itself in differing forms over time, sometimes difficult to detect or recognise for what it is—a lasting presence over a lifetime.
- The sense of self is particularly vulnerable when loss intrudes into life, especially when the loss coincides with a still-developing perception of self.

The way forward

To tease out the later effects of loss on adults, the losses that individuals experience in childhood are highly relevant. There are numerous factors determining whether a loss creates an indelible effect which, in turn, leads to nonfinite loss and nonfinite grief. Attachment, personality and parental approach are but a few of these factors. Forthcoming chapters are devoted to past, future and daily realities for adults. We now take another look at Rebecca's story to explore the ebb and flow of the grief associated with her nonfinite loss.

CHAPTER 3

The Ebb and Flow of Nonfinite Grief

Remember **Rebecca**? She was the first of the strangers to be introduced in Chapter 1. Did you notice how, in her story, there was a shift in intensity of feelings, and how, for instance, she had become less at the mercy of her feelings, experiencing moments of relief? The grieving she is going through is evoked by the experience of nonfinite loss in her life. Rebecca's loss has a vivid presence every day, physically, psychologically and emotionally. Her loss is obvious to her—she is left in no doubt about it. Her grief is inescapable. Awareness of the complexity of the process provides validation of the multitude of different feelings Rebecca is experiencing and lends insight into how she is managing her loss.

Threat and complexity

Certain natural reflexes are set in motion when we are faced with the possibility of irreversible loss. Against understandable hope and resistance to owning what has happened, the magnitude of the loss and its irrevocability involves a gradual process of realisation. Reality eventually wears down the resistance. In

some instances, the extent of the loss and its irrevocable nature are clear from the start: external bodily injury, obvious congenital defect, or a natural disaster, for example. When a loss is less obvious, the grief may be silent or obscure—and less easily recognised for what it is.

Many of you will relate instantly to a loss that collapses like a massive and immovable weight on top of you. A telephone call bearing shocking news, a serious accident, maybe a diagnosis of autism or schizophrenia delivered in a doctor's surgery, a verdict handed down in a custody dispute, or for some parents, the conviction of their child's criminal behaviour leading to a sentence of imprisonment. As is often recounted: 'There are no words in my language that can capture the desolation I feel'.

Remember **Mary's** gradual realisation of her lost relationship with her father? The same obscurity may occur with the insidious onset of syndromes and conditions—or with developmental losses that can only become clear with maturity. In these situations, there can be a lengthy, drawn-out dawning: a life-threatening illness, a life-altering disease, breakdown of a relationship, disappearance of a family member or significant person, sexual abuse or migration, for example. Whether clear or unclear from the start, there has been a threat to the world as it was, a threat to sense of self as it has formed or is still forming.

How has it been for you? An almost unbearable weight, clear from the start, or was it more insidious in its onset? Or have you had the impression that your experience involved both factors—at times clear, at other times surrounded by uncertainty? Perhaps your grief has been felt particularly on another person's behalf? There are bound to be individual differences and degrees of

response, dependent on circumstances, awareness, and the defences we employ against what we can handle, but patterns do emerge.

Powerful forces

The grieving can be described in terms of powerful forces: resistance, counteractions and reactions to firmly facing the unalterable nature of the loss. These forces impinge on our whole being—our bodies, our minds, our souls. They trigger a multitude of feelings; they entwine themselves around our thoughts, our cognitions; they take hold of our behaviour and force a range of physical reactions. They tap into our spiritual being. Our beliefs shaken, we plead and protest: ‘Why me?’ ‘Why her?’ ‘Why my child?’, and for some individuals: ‘Why, again?’ The search for meaning in life merges with the longing to make sense of the loss: ‘What have I done to deserve this? Is this loss just my bad luck—a curse?’ ‘How can I believe in God when something like this has happened to my child?’ For some, it may seal their lack of faith in God’s existence; for others, their faith is strengthened.

It is not surprising that the interaction of these forces can be utterly overwhelming. Who would choose to experience the anxiety and anguish that surround the helplessness to fix, to reverse or to eradicate what has happened; that is, to turn back time? Naturally, there are individuals who continue to cling to a false hope, who avoid coming face to face with the reality. For others, the threat is reinforced daily and is all too real, forcing acknowledgment of further and other associated losses. So much is this so, that the terms ‘griefwork’ and ‘reality testing’ are particularly applicable to the circumstances.

Figure 2 depicts the suffering and distress of the powerful forces that are the counterpart of loss and, in particular, of nonfinite loss. Not so readily depicted, however, is the ebb and flow—the nonfiniteness of the grief when the loss itself is nonfinite and negative in its impact. The loss is always there in some form or shadow. But so is the grief. Picture the elements in Figure 2 as rotating and interacting ceaselessly—like being in a vortex. Is it any wonder that a hostile contest is involved between the grieving person and these intense responses? How can one defend and protect oneself against such anguish and pain?

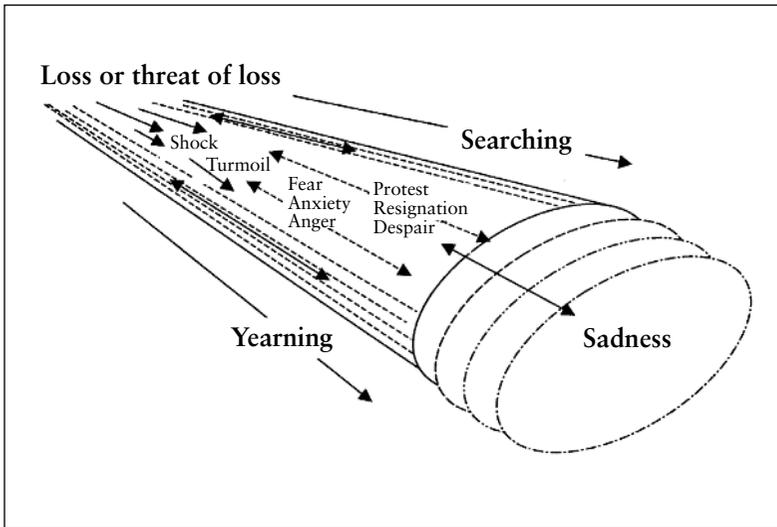


Figure 2 Nonfinite loss and the vortex of grief

Nonfinite loss and grief

The interactions and fluctuations of grieving shown in Figure 2 are the cyclic themes often encountered in living with nonfinite loss. Notice how two-way arrows lie between the responses? This indicates that the responses are not sequential and can

shift easily, sometimes momentarily expressed, or passing in some form or fashion. Picture a stream of thoughts and feelings, past and present memories, at times a churning whirlpool, blending and merging: ‘Where did that memory come from?’ At other times, you may be dominated by an all-pervasive current of feeling which surfaces in vivid dreams and nightmares. What alters over time is the intensity and frequency of these responses, or perhaps the intensity of the ‘drive’ or ‘need’ for them to be represented. They may become easier to control. Let’s explore them under four separate headings: Shock and turmoil; Fear, Anxiety and Anger; Yearning and searching; and Sadness.

Shock and turmoil

The first natural and widely recognised response to loss is one of shock. Even when loss has been anticipated, there inevitably comes a period in time—maybe short, maybe longer—when disbelief that this should happen, that this should happen to me, holds sway. As if to rescue us from the sheer weight of emotions, we are given a cloak of competence—automatic pilot, we run on rote. Lacking focus or concentration, we are a ‘third party’ in each and any social setting, physically there, emotionally not there—a strange feeling of not being entirely present. Plans may be put on hold. Sooner or later, the shock may dull and we may experience intermittent bouts of turmoil as our changed lives demand disruptions to once familiar ways of being or routines and patterns that we understood. Underneath, like electrical currents, sparking and shorting, instinctive responses of fear, anxiety and anger may jolt or immobilise.

Fear, anxiety and anger

What savage feelings these can be, as they gather force, peak, wax and wane—so powerful, capturing mind and body. There is fear of what lies ahead, anger at being robbed of what one thought one had or was entitled to in life, anxiety about what these changed circumstances mean for self and family—and will there be more change and threat? So strong, they are inescapable and demand attention—a response—an action to counter the feeling of being overwhelmed. In private moments, or when given permission or challenged, there may be *protest, defiance*: ‘I’ve been ripped off. I’ll not take it on board. It is unacceptable’.

Protest can take many forms. In cases of chronic and life-threatening conditions, remonstrations may be expressed against one’s body such as smoking, drinking, taking risks: ‘What’s the point?’ Hear the adolescents who have endured a childhood of medications and limitations: ‘Stuff the medications, the rules and regulations! Where has it got me?’

As the inevitable ‘new’ reality, often containing associated losses, continues to emerge, these responses are constantly revisited. The anxiety inevitably persists. The immensity and intrusion of the fear is unpredictable and sometimes immobilising. A sense of security has been seriously undermined and an uncharted present looms in its place: ‘What might now be in store? Can that secure base be reinstated? How?’ And paralleling the fear—the anxiety, the anger and the insecurity—is the constant yearning and searching, sometimes urgent, for whatever will turn the clock back to the time before this happened.

Yearning and searching

The sense that something is missing in life is often expressed in periods of deep yearning for what should have been and renewed searching for information in an attempt to find meaning in what has happened. There is an urge to research and track down solutions, sometimes in a valiant attempt to hold the loss in abeyance. These instinctive responses can be teased out in most situations of nonfinite loss. They are clearly evident in instances of adoption, migration and infertility. Through ruminations, dreams, fantasies, or actions, the grieving person continues to yearn for what has been lost. For the rest of life, attempts are made in strange and unique ways to recover the world as it once was, or the world as it should have been. For many, given the idealisation of their dreams, they remain just that, idealised dreams:

- A small suburban backyard is transformed into an English garden.
- An idealised childhood forces an adult to search for a farmyard house surrounded by lush green acres of land and the rhythmic sound of a milking machine.
- A middle-aged man dons the leather jacket and mounts a motorbike, travelling back in time to an unspent adolescence.
- A young adolescent girl, confined to a wheelchair, fantasises about waking and walking: ‘I send the message down to my legs each morning’.

For the mother of an adult child with a severe intellectual disability, her now-and-then dream of her child speaking to her is her way of creating the world as it should have been—a glimpse—at least for a few moments:

It is not as though I really think this would happen. He's twenty-one! But in this dream, it's just like he's normal, he speaks to me. I can lose myself in this dream. Wrenching myself awake is like walking into a nightmare. For most other people, it's just the opposite—they wake from the nightmare!

Sadness

And what of sadness, always not far under the surface for some; for others, still there, but under many layers? The sadness sometimes shows up as loneliness; wishing; private tears shed to moving songs and unhappy endings; a tightness held in the throat and chest; an emptiness hard to give an adequate name. Moments of *despair* and *resignation* are part of this underlying sadness, an inescapable part of unrequited yearning and searching. Despair: 'I am not strong enough to take this on! It is beyond me, I cannot bear watching this happen to my child!' Resignation: 'There is no choice in this story—it's a brick wall. I have no choice but to go on'. So, in many cases, the culmination of feelings—fear, anxiety, anger, yearning and searching—leads to a quiet and sad surrender. This place sees grief partnered with solitude and reflection.

Life goes on!

Would you place yourself somewhere with **Rebecca** in Figure 2 at this moment in time? Perhaps you have not been aware of, or 'felt', these feelings. Maybe you have felt them strongly in the past and have now found an inner strength so they are less pervasive.

Or your feelings may have been buried under the demands of your normal occupational and household responsibilities, immersed in the preoccupation of daily medical or physical regimes required by your condition or your child's condition. It is conceivable that, unbeknown to you, some feelings have been too confronting and you have side-stepped them, or found refuge from them in unavoidable responsibilities such as taking care of the needs of others—your children, your spouse, your parents—any task that will take you away from stopping, thinking, and feeling. Has your professional work played a part in this also?

Refuge from your anger, in particular, may have been especially sought out; after all, you may never have been comfortable with that emotion anyway? Blazing vitriolic language, driven from the depths of somewhere, a pumping heart-beat: 'Who is this?' It felt way out of control—not you! Where was it taking you? Did it remind you of anyone standing over you, their face contorted with rage when you were young and small?

Take a moment to ask yourself when you have expressed anger outwardly in your life. For many of us, that kind of behaviour is quite common and natural, even though probably distressing for self and others. But for you, maybe those feelings have always been held inside—perhaps without you ever realising this? Is it possible that anger is slipping out in other ways, maybe through aggravation or intense irritation at what were once petty and ignored incidents? Why so cross now? Are you intent on making sure your anger does not escape from you?

Clare was able to ventilate her anger, the depth and breadth of her feelings all slipped out, albeit overpowering in her case. But not everybody has the luxury of full ventilation of anger

and despair. There is a risk of hurting someone and, for some, maintaining appearances acts as a curb. Not many people can retreat into a cave, a private space, and spend time grieving the magnitude and personal nature of their loss. There are not many places or spaces that can absorb a cry of anguish from the depths of one's body, the cry over the injury to a loved one, the life facing us—our grief. How does the burden of unreleased emotion find an adequate way out? Would you, like many others, reply: 'We only have a small backyard. The neighbours would hear, I'd have to explain'. For the majority of people, what others would think holds sway; rather than lick our wounds, we hide them.

Conceivably, an accumulation of personal losses is stored over long periods of time. Often they blur into each other, indistinguishable in retrospect, and none receiving adequate emotional expression. Where does this private world of grief find expression? Perhaps your story is only told in nightmares or vivid dreams, while a 'hyped-up' busyness—faster and faster—protects you from the grimness of the reality?

Time to grieve?

Time to grieve? 'Hmm ...' we hear you say:

When would I have had time? Which aspect would I choose to grieve for? It's been one thing after another. It would take a lifetime. How far do you want me to go back in time? The beginning. You know, I've forgotten the beginning. What's the point of going back? Where do I start? I've got four kids. A husband who works 24/7. One car. A mother who is frail, needs shopping and lots of

company. Schedules, specialists, rosters, routines. How do I feel? I don't know anymore. Sad? Is feeling teary, sad? Tired, worn out? Yes.

Time to grieve? Me? I just continue working. There's no stopping it. There's no one else who can do it. I eat, sleep, and work. I can't remember what procedure I'm up to, time, days and dates. I just turn up at the hospital, get it over and done with, no big deal, time off, back again. It just goes around and around and in between I think about work. What do I feel? Nothing much. There's no point thinking about something you can't change. What would that achieve? It would just be worse. And there're always people worse off than me. Come to think about it, you know, I guess I've never really given it much time—this illness thing. I just get that treatment and get on with it. Do I ever lose control? It's strange you should ask that. I have and I did just the other day. This guy cut me off while I was driving. No way could I have left that alone! Pure rage pushed that accelerator—pedal down, and I tailgated him for ages. After a while the rage left. Looking back, I don't know what that was all about.

The treadmill

Look at Figure 3. Does that picture resonate with you? Maybe you are well aware that life's pace continues like a treadmill—it does not slow down. Maybe you cannot get off your treadmill? There are the constant needs of your children, your parents, your spouse, perhaps a sibling, animals to be fed, bills to be

paid, work must be done to earn money: ‘Time to get up, get on, pick up, make the appointments—another day. And what if I don’t sleep tonight? What if I can’t get up tomorrow? What if I can’t dull this pain? And what if things get worse, say the medicine does not work, or there are complications?’

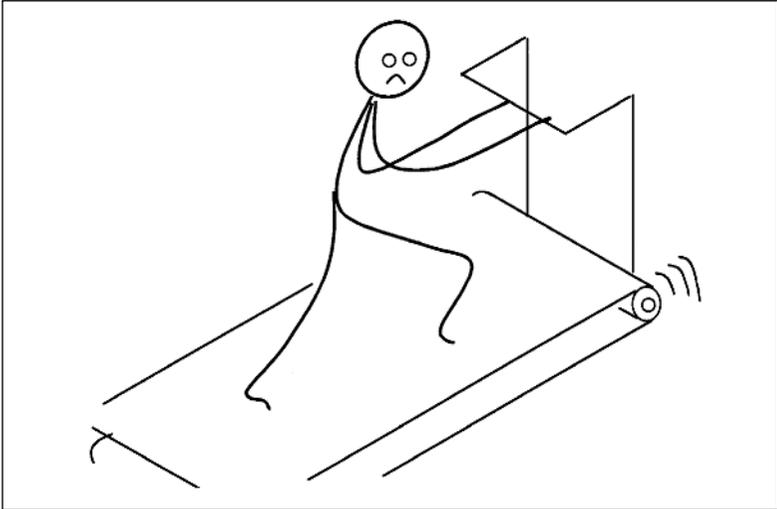


Figure 3 The treadmill

Even if you could get off your treadmill, you cannot imagine how you would get back on? It would be too fast for you then. Or perhaps you would not trust yourself enough to get back on? What does your treadmill look like? What burdens do you carry on your back or hold in your head? A familiar comment comes to mind: ‘If I had the choice, I’d escape. I’m frightened of this feeling. It comes up so often!’

The treadmill pays attention to the demands that accompany busy lives or the pain that never lets up. It reflects another layer of feelings that stand as an obstacle in the grieving of nonfinite

loss. Trapped, burnt-out, isolated, helpless, no one to talk to—an environment that cultivates recurring thoughts of having become just a condition: ‘I feel as though I have “sexually abused” written on my forehead, stamped on my mind’. Or an automaton: ‘Just a carer’, ‘Just a therapist and nurse’, ‘Just an angry mass of feelings towards self and those whom I love’. Pressure mounts, creating painful and confronting emotions such as guilt in experiencing ambivalence towards a loved one and sadness in recognising the limitations of being human.

Untenable pressure is clearly depicted in the nightmare of parenting a child whose psychiatric illness forces parents to concede that they cannot cope, or in the case of the elderly spouse, beside herself with weariness, who finds herself losing control and striking her bedridden husband of fifty years. Similarly, the carer—spouse, parent, sister, offspring—of an individual suffering from a cognitive disability who admits: ‘Love is not enough. Twenty-four hours a day, seven days a week brings out something in me that I am not proud of—I have become a bully. I would never ever have thought this was possible!’

Perhaps there is no relief either way. While extraordinary stress can drastically affect relationships, being on the receiving end of extraordinary levels of care and devotion can create feelings that are every bit as stressful and uncomfortable: ‘Am I worthy of such incredible devotion?’ ‘I can’t stand it, this neediness for so long. It’s driving me crazy—thank you, thank you, thank you—so many thank yous!’ Thus, the treadmill imagery is also applicable when there is a constant feeling of indebtedness and the obligation to be grateful, with a swinging in between the two; and an unremitting

undercurrent of sadness or bitterness about being so dependent. To have no choice in these circumstances tests patience and tolerance—often well beyond human limits. How to continue to receive and not able to reciprocate? How to be trapped for so long?

For those of you who are seeking solitude or searching for some peace of mind, it may be a comfort to know that it is possible to reduce the intensity and frequency of the surges of emotion that may be a feature of your life. That can and does happen. Remember when we spoke about **Rebecca** gaining a sense that she was no longer at the mercy of her cancer? For her, there have been fleeting periods of a strange inner blending or balance between what was and what is, between who she was and who she is now. Eventually, this balance might herald a shift towards a slow building up of a firmer personal emotional platform. Although this is not a secure position, there may be times at the helm; there may be moments of reprieve or calmness; there may be less general anxiety. These responses may, for you, signify a move towards an adaptation.

Adaptation

There is a very important adaptive outcome that extends beyond the responses described in Figure 2. Adaptation depends on finding ways to contest the strength, intensity and relentlessness of grief. Taking a wide and informed view of loss and grief is a starting point. It is part of the search for meaning in life—challenging, distressing, painful. This search can signify an energy at work—a spiritual dimension, a spirit we all possess. The same spirit that has reclaimed you at other times, in childhood, adulthood—maybe over recent years—is a driving force

curbing personal despair and feelings of being disconnected. The following thoughts to ponder are designed to offer support as you reflect further on nonfinite loss and grief.

Thoughts to ponder

- There are instinctive responses basic to human nature when we come under threat of loss.
- Nonfinite loss and grief involves cyclic, interacting responses to the loss.
- Shock and turmoil are natural and widely recognised responses to loss.
- Anxiety, anger and fear are relentless, instinctive, but spasmodic reactions to uncertainty and threat.
- Yearning, searching and sadness are natural to grieving.
- The point of temporary relief in the ebb and flow of grief is one of surreal-like tranquillity and calmness, a surrender and solitude.
- To grieve means to respect the place loss takes in our lives and to be able to express authentic emotion about that loss.
- Part of the search is to find a way forward, to comfort, to relieve, and maybe transform the relationship we have with our loss; that is, to adapt.

The way forward

Resorting to uncharacteristic behaviours is quite common and not surprising in people under stress. They represent an

endeavour to express emotional pain. They can occur and recur for people experiencing nonfinite loss, but in fact they are evident in human behaviour quite generally. It would be unrealistic not to expect there to be times when you become overwhelmed. You know that already! Usually, these will be times when feelings such as helplessness, or issues of dependency, being invisible, or being tired, force your feelings out.

In these circumstances, you may find yourself expressing what you feel by way of uncharacteristic behaviours. Often, just like in childhood, adults are unable to name the exact feeling they do feel and they sense that their personal dilemmas and feelings are far from understood. In these situations, a range of uncontrollable behaviours may surface. These can include withdrawal and isolating oneself; aggressive and destructive actions; thoughts or acts of hurting self; demanding attention; intensifying attachment behaviours; rejecting people to whom you are attached; drinking or substance abuse. You may be vaguely or painfully aware of having resorted to these behaviours in your childhood or as an adult?

Obviously, these behaviours amplify a person's distress. Within each person's biography, there are clues to their response to severe loss or to loss in general. And because each one of us has a different story to tell, no two of us will respond in quite the same way. Our journey in Part II takes us back into the past to consider what we learnt about loss in infancy, childhood, young adulthood, and right up to our present age.

In the meantime, another way of thinking about the responses triggered by nonfinite loss and grief is the multitude of feelings and the self-talk underlying these responses. *Being able*

to name one's feelings can temper the energy driving emotional and behavioural responses. Feelings range widely in intensity and in shades of meaning. The more accurately a feeling can be pinpointed, the more swiftly the intensity of that feeling is muted and validated. To this end, you may find it useful to scan the checklist of feeling words at the close of this chapter and maybe add you own. They are a few examples of the many words, both positive and negative, commonly used to describe the feelings experienced in adversity.

The ebb and flow of nonfinite loss and grief are depicted in Figure 2 as a vortex of constantly interacting and instinctive responses that trigger a multitude of feelings. By naming the underlying feelings, grief is given further and more precise definition. This naming can begin to alleviate some of the pain and distress you feel. You may discover, or rediscover, words that bring awareness of your inner strength and the richness of your surrounds. It is not always easy to put a name to those feelings. Table 2 has been included to assist in their identification. You may want to add to the list; or you may not, at this point, be able to identify any of the feelings as yours.

Checklist of feeling words

Table 2 Towards identification of feelings

abandoned	blue	despairing	explosive
abused	bombarded	detached	exposed
afraid	brave	determined	fallible
aggressive	broken	devastated	false
agitated	burdened	devoted	fearful
aimless	burnt-out	different	flat
alienated	calm	disappointed	foggy
angry	challenged	disconnected	fragile
apathetic	cheated	discouraged	freakish
apprehensive	comforted	diseased	frightened
ashamed	compassionate	dismayed	frozen
attacked	confused	dismissed	frustrated
avoided	courageous	disorientated	furious
awkward	crushed	dispirited	fuzzy
bad	cursed	distant	grateful
battered	damaged	dread	grey
belittled	dead	emasculated	guilty
betrayed	deceived	embarrassed	gutted
bewildered	defeated	encouraged	hardened
bitter	defiant	enraged	heartbroken
bizarre	depressed	envious	helpless
black	deprived	exhausted	hopeful
blamed	derided	exiled	hopeless

Table 2 Towards identification of feelings (continued)

horrified	numb	resolute	trapped
hostile	odd	responsible	traumatised
immense pain	out of control	robbed	tricked
impatient	outraged	rudderless	trusting
imprisoned	overwhelmed	scarred	unburdened
inadequate	panic-stricken	self-conscious	unlucky
incomplete	patient	shaky	useless
insecure	patronised	shattered	valued
insignificant	peaceful	sick	vanquished
inspired	persecuted	soothed	vicious
invisible	petrified	stuck	victimised
isolated	pitied	stunned	vindictive
jealous	powerless	suicidal	violent
jinxed	profound pain	superstitious	vulnerable
left-out	quiet	supported	weak
lifeless	reassured	tense	wiped out
lonely	reflective	terrified	wistful
lost	rejected	threatened	withdrawn
loved	relieved	tight	withered
morbid	remote	timid	worried
murderous	resentful	tired	worthless
mutilated	resigned	tormented	wounded

Part II

C O N S I D E R I N G
T H E P A S T

CHAPTER 4

Looking Back

Loss is an inescapable part of life. For all its common presence in our lives, a fear of loss remains deep down within us. In childhood, eruptions of anxiety frequently signal the pervasiveness of loss. Ideally, in the scheme of things, a child's first conscious experience of loss will be minor or incidental. But even minor changes to body and health can produce anxiety in a small and defenceless child. Take, for example, three-year-old John's first awareness of the dampness of perspiration on his skin: 'What is it? Will it stop? Am I melting?' Or Emily's first skin blemish: 'Will it return to normal?' Adults realise the blemish is a temporary experience; that is, it will not be an experience of loss. Handled with a minimum of fuss and calm reassurance, the child's anxiety can be defused. For how long? Perhaps until the child learns that this blemish is unremarkable, even evident on the skin of other children; that it is commonplace in life. The next blemish of the same nature may quietly slip past his or her surveillance.

The lessons we learn over time exert a great influence on how we deal with our *fear of loss* and of *actual loss* when it strikes. It is not difficult to contemplate the heightened states of distress a child endures when things do not get better, when they do not

go away, are perceived as odd, or the world continues to present itself as an unsafe place. This is the reality that we all contend with when we experience the ‘unfixability’ of nonfinite loss: ‘I keep hitting this brick wall. For once, I have nowhere to go with this—there is no choice!’ Typically, the loss must be endured, as Rebecca’s story illustrates. She has lost her previous trust in her health and life expectancy.

The ability to deal with this predicament is largely acquired through a mix of temperament, physical health, emotional and cognitive development, the support available, and what we learn about loss and grief throughout childhood. In the three chapters of Part II, we highlight the role biography plays in developing this ability to manage loss and grief. In particular, the vital role of parents and other adults in assisting infants and children to tame strong emotional states is emphasised. For now, the focus is on what we learn from experiences of loss in our early days.

Loss in infancy and childhood

Early on, in the absence of language, children’s bodies absorb their emotions. Depending on the power of the feeling, children can be almost swallowed up by unbearable affect. Frightened of what is happening inside their small bodies, they can become even more alarmed if the feelings explode and are out of their control—the trashing of the bedroom; the banging of the head against the floor of the shopping centre; the relentless punching of the sibling who takes the toy; the body writhing, kicking, protesting against the car door as the favourite playground flashes out of sight.

The capacity to handle strong feelings is a skill that is learnt gradually, under the guidance of parents and key caregivers. Suffice it to say, this can be an extraordinarily difficult parenting task, especially when children lack the capacity to communicate, are unable to use their bodies, or have menacing conditions that sap their confidence. Children who suffer from asthma, diabetes, arthritis, or other chronic conditions generally need an enormous amount of empathy and reassurance over long periods of time. In cases where a child has been rescued from abuse, a similar great deal of reassurance and forbearance is called for.

The challenge for all parents is to learn what their child is feeling, validate the feeling, and support the child's expression of that feeling—to hold the child together through times when he or she feels lost in strong emotion. Picturing Clare's emotional and physical experience, as she helplessly tracks the flight of her helium balloon, provides a good example of this terribly frightening state. Her inadequate defences as a three-year-old failed to protect her from the physiological and emotional experience of helplessness to retrieve her balloon—she had no ability to distract her attention or reframe the incident and reduce its intensity.

What might Clare's parents have done differently? Reams of parental words intended to play down the loss would only have added further emotional burden to a child of this age. For instance, her mother's or father's efforts to distract Clare will fall on deaf ears, possibly even aggravate the loss: 'Picture your balloon bravely moving through the sky to bring happiness to another little girl who may be unwell,' says Clare's mother.

Clare's response: 'I don't want any *other* little girl to have my balloon!' Now Clare must contend with the idea that someone else will enjoy her balloon! The parental words miss the point. Without belittling or dismissing her distress, Clare most needed comfort by soothing until the rush of emotions had passed.

What did you learn about loss and disappointment in your childhood? What might have stood you in less or better stead in the way you now handle your current losses as an adult? Tracing back biographically can produce fresh insights into your own innate capabilities. It draws attention to the central place that developmental experiences and learning have had on your capacity to manage loss and grief.

Loss-related experiences

Just where do the roots of the ability to tolerate loss and disappointment take hold? Everyone who faces loss, trauma and grief faces it with the capacities and experiences that have accumulated from their infancy and childhood. A pivotal early experience surrounds a child's awareness that the source of food, safety, comfort and reassurance relies on the proximity of Mum, Dad, or proxy. Regrettably, a number of infants are deprived of that proximity. Their parents may lack maturity, suffer emotional illness or drug and alcohol dependence. Possibly lacking positive parenting models themselves, these parents may be incapable of adequately responding to their own children. Such erratic care gives rise to separation anxiety, an intense anxiety and fear on the part of the child of losing one's source of nurturing and protection.

Proximity soothes anxiety—it is a guarantee against losing those all-important forms of sustenance. When a significant loss does occur, the need for proximity intensifies. Even in adulthood, a yearning for proximity to parental figures after an uncommon loss is not untypical. You may have found yourself looking to your parents during times of extreme distress? Even long after their death, you can draw on their words for guidance and comfort. For some of you, this need may have been all-consuming? For some, the need for proximity to parents has never waned and is present with or without personal distress.

Holding tight

From our earliest beginnings, we make an effort to manage the intense feelings that characterise loss. Watch a child waving her mother or father goodbye—the longer and more momentous the leave-taking, the more intolerable the experience for both. Experimenting with this anxiety-provoking experience of leave-taking customarily continues throughout development—the adolescent tackling it, and, in the main, the adult seeking it. A minority are never able to master it effectively.

Being able to handle loss and disappointment is the culmination of a long-developed honing of what is essentially a valuable skill. Frequently, unbridled feelings or tantrums do not become manageable until late childhood or early adolescence. Under certain extreme circumstances, they can be clearly observed at any age—child or adult, parents included. After all, stress plays an enormous part in the parenting role. Does the following scene sound at all familiar?

A young mum and dad are angry and stressed about managing Tom's temper tantrums, particularly in public. On this occasion, Dad complains about his four-year-old son's inability to 'hold it together' when he is not allowed to buy a novelty at the supermarket check-out: 'What an embarrassing pain in the neck he is—can't take no for an answer!' Dad exclaims loudly. 'You don't get those skills out of a weeties packet!' Mum retorts.

On this occasion, Mum's response was spot-on. But of course, not only fathers make these aggravated criticisms, mothers do too. In fact, it is very easy for adults to forget how difficult it is for a child to deal with loss and disappointment, to overlook the huge amount of emotional and physical constraint required when one loses something—or in Tom's case, is denied something he wants, for whatever reason unbeknown to him.

Loss recalled

Obviously, many experiences in infancy and early childhood are lost to memory, even as the learning proceeds. How many of the following loss-related experiences are you able to identify with in terms of your childhood relationships with significant others? The list is designed to illustrate how widely and easily loss invades childhood and young adulthood. As you read them, remember that these experiences do not necessarily carry adverse after-effects; but the items may help you to appreciate and respect the relationship you have developed with loss over the years:

- when, as a child, you were isolated and felt helpless and invisible;
- when, as a child, you could not rely on anyone for guidance or support;
- when, as a child, you were left, or lost, for a period of time not knowing where the significant caregiver had gone;
- when, as a child, you were shunted from one strange home to another;
- when significant caregivers were unavailable to soothe you and provide you with support;
- when significant caregivers magnified a loss situation and reacted with reprisals;
- when significant caregivers failed to validate sadness and anxiety;
- when significant caregivers failed to provide or re-establish containment, structure and routine;
- when an adult or peer embellished any of the features of a childhood loss, before you were old enough or emotionally ready to endure its meaning and significance, leaving you traumatised by too much information;
- when an adult or peer presented images that you were not ready or equipped to handle, not able to process the intensity of the thoughts and scenes that were provoked and feeling traumatised by the images;
- when an adult or peer disillusioned you about important symbols or icons that provided feelings of safety or support

before you were psychologically able to protect yourself, causing, maybe, a loss of faith in God, a loss of trust in significant adults, a loss of belief in fairies, magic, special toys, or cherished objects;

- when, as a child, you felt singled out as ‘different’, losing the joy and comfort of being like your peers or siblings;
- when, as a child, you lost being treated as ‘special’ after reaching a certain age.

Many of these experiences are an inevitable part of growing up. More often than not, they occur inadvertently, without malice or ill intent. As you reflect on your own ability to manage loss and disappointment in your life, consider the messages from the past that have strongly influenced you in that regard. Thinking back, maybe you remember a distressing episode, perhaps recent, when it was too late for you to hold yourself together, when you felt lost in strong emotion? And afterwards, looking back to that episode, there was a sense that there were two selves: one familiar and one only vaguely familiar. Harking back to your early childhood, this latter self was reminiscent of a child who felt way out of control. Was there someone there to support and reassure you through the eye of that storm of emotions?

Messages from the past

Most happenings that characterise childhood, like falling over, breaking things and seeking reassurance, are replete with interpretation and comments made by adults. Messages from the past are frequently mixed messages. Say, as a child, you made a mistake, for example you accidentally broke something, and an

adult attributed intent and blame that dismissed your feelings of sadness or regret. Or you saw through the expression of interest in you as feigned, recognising the adult's boredom or hastiness to return to an interrupted activity. Or your falling over was treated as clumsiness or a plea for attention. Or you misinterpreted the meaning of what was said, which is so easily done, when the words do not seem to match the nonverbal behaviour, or when apparently contradictory statements are made.

Confusion

Mixed messages are particularly telling when there is a loss involved, as the following incidents show. Notice how the 'mix' can be in the actual message or in the confusion the message generates. The confusion can mark the origin of what we have called 'knots'— the topic of the section that follows.

A child loses a toy. 'It's your own fault, you didn't look after it. It was only a toy anyway,' her mother remonstrates. What are the child's feelings? Fear, guilt, shame, embarrassment, sadness?

A young man contracts diabetes. 'It could have been worse, there are so many worse things!', his parents impatiently retort. What are his feelings? Shame? Being weak for feeling sorry for himself?

A child turns up at school with a leg in plaster and has to spend a great deal of time convincing her friends that she is not an attention-seeker. How does she feel? Anxious? Uncertain of herself and the part she played in the accident? All reflected in the self-talk: 'Am I a fraud?'

A girl contracts a high fever, her brother complains: 'She's done it again! She always manages to come up with something when I've got a special day happening for me. She makes these things happen!' How does the girl feel? Puzzled? Guilty? She wonders: 'Do I deliberately manipulate these things?'

And the glazed-over, far-away look in the parent's eyes as their daughter, yet again, relates the details of her recent lost romance: 'They say they are interested, but they don't take it in. They just don't get how much I am hurting'. Clearly their body language says, time's up.

We have all heard in one way or another so many confusing messages in childhood. In relation to gender too, there may well have been bias. A ten-year-old boy queries the reason a girl receives hearty praise from a teacher when they have both fallen over: 'Fifty house-points for you, Genie. I expected you to cry when you fell over, and you didn't. Well done!' Why no praise for the boy? According to this teacher: 'Girls are more sensitive than boys'. How come? The boy is left confused, somewhat resentful that girls get it so easy, but there is also a flickering of pride in being a male. On an even more sobering note, there are individuals who, as a result of mixed messages received, doubt the veracity of their own conditions: 'Did I do this for attention? Did I cause myself to get muscular dystrophy—is that possible?'

Often there are messages from the past that leave us in no doubt about their meaning or the intent behind them. They include overt derogatory labelling and behaviours that lead

directly to a loss of self-esteem. Ridiculing, teasing and bullying can occur in school settings and often characterise communication within some families. A sequence of behaviours from family members can target the expression of sadness in a child or sibling. A type of ganging-up is evident.

They would always try to talk me out of how I felt. My father and brothers would start ‘tickling’ me, and my sisters would roll their eyes. Relentlessly, they would tease me about my feelings. I’d always wind up sobbing. It was only then that whatever had started, finally stopped.

Sadly, messages from the past often have the effect of tying us up in ‘knots’: emotional knots, with internal feelings churned up inside; cognitive knots, with thoughts and self-assurance confused; and physical knots, which are the ones that dwell in the tension of our bodies, the result of pent-up feelings stored over a long period of time. It is likely, perhaps also for you, that knots of these kinds are not just experiences from the past but that they persist to the present day.

Knots

Knots are the emotional, cognitive and physical responses to messages, be they indirect or direct. They are apparent when we lose faith in ourselves, question our motives, are unsure of how we feel or how we should regard ourselves; in other words, in conflict with who we believe we are or what we think we deserve. They can lead to a deep insecurity. Julie is trying to tell her parents that she misses them and wants to leave boarding school. Her parents have just picked her up for the summer

break. As she sits in the back of the car, she pleads with her parents to stay at home. Her father describes his reaction and response to Julie's feelings.

She just goes on and on and on about how she feels homesick and misses us. What am I supposed to do? I listen for a while and then my impatience gets the better of me and I say: 'For goodness sake, will you just get off this bandwagon. Of course you miss us, that will pass—everyone goes through this. It's no worse than anyone else's situation. You are just trying to get your own way. You haven't given it a real go'. Julie generally just sobs. She tries to tell me that her homesickness is getting worse instead of better. I tell her to pull herself together. Then I change the subject completely. I say: 'Hey, how about that team of ours, how good was our win on the weekend!' It usually brings her round. I'm not sure why.

Where have Julie's feelings gone? She has worked out that her pleading is falling on deaf ears. More than likely, her feelings are being bottled up inside her. After all, such strong feelings cannot just evaporate. No doubt she is questioning the feeling of homesickness she experiences and the intensity of her feelings: 'Are my feelings over-the-top? Am I different from other boarders? What's wrong with me?' Although Julie knows how hard she has tried to put up with boarding school, she begins to doubt whether she has tried hard enough. And yet, there is still a pervasive longing that will not go away.

Hard to untangle

We are often left with labels and the automatic drawing on errant interpretations that were made by our parents. Emotional and cognitive knots are hard to untie. They sound something like this:

- ‘I don’t know what I feel. Happy? Sad?’
- ‘I can’t find words for how I feel.’
- ‘I sort of feel bad. I enjoy the attention Mum’s giving me while I feel like this.’
- ‘I should feel lucky. I’ve been so fortunate in so many ways.’
- ‘They’d think I was a whinger if I told them that I feel as though I’ve missed out on something.’
- ‘There are so many people worse off. I have no right to feel so sorry for myself.’
- ‘There’s so many things I should be grateful for. Why am I then feeling like this?’
- ‘I’d be a wet blanket if I told them what I really felt and they would get angry. It would ruin their hopes about the new treatment.’

There are likely assumptions resulting from emotional and cognitive knots formed in childhood that carry into adulthood. They explain why emotional expression can become difficult, even feared. They indicate the pervasive nature of our concern with how we are perceived by others—what they think of us. But do we really know what others think of us when we display strong emotions or claim a personal loss? Ironically, fear

surrounding the negative judgement of others clouds the capacity to judge this question without bias.

In fear of emotions

The anxiety stirred up by messages from the past not only ties us up in knots, it instils a fear of owning strong emotions, of expressing strong emotions, of pushing the limits of another's patience in listening, even of claiming a personal loss. These fears are based on assumptions—often misguided—of self in relation to others. Julie's self-talk illustrates how these assumptions can sound:

- 'Other people are 'fed up' with my emotions.'
- 'Other people are really thinking about something else when I express my emotions.'
- 'Other people have no idea of the depth of my experience.'
- 'Other people are making harsh judgements about me.'
- 'Other people do not really know me.'
- 'Other people do not really care.'
- 'Other people judge me as weak and self-centered.'
- 'Other people see me as a nuisance—a burden.'

Learnt fears

Let's see how these learnt fears may manifest themselves in adulthood. Fay desperately needed to share how she felt about her predicament. She made an appointment to see a counsellor,

but she was immediately up against her learnt fear of ‘imposing’ her troubles on anyone else. This is what transpires:

Telling her story, Fay stops mid-sentence, embarrassed and says: ‘I’ve been going on and on. I’m probably wasting your time. There’re lots of people you see worse than me. It sounds as though I am making it up—you’ll find it hard to believe! Even I find it hard to believe what has happened to me.

And observe the young man, Jonathon, holding himself together, possibly like **Marvin**, as he says as little as possible about a diagnosis of a life-threatening condition in his wife. He is not likely to return to the intensity of a one-to-one therapy session; he is afraid of breaking down—it is too hard to stay strong. It is even too hard to find a feeling, let alone find the right words to convey them. Does he believe his words are worth being listened to? Probably not. What would reassure him that it is safe to talk it through? That he would not be humiliated if he expressed himself? Where and how did he learn to fear his emotions?

The world can be so overwhelming. There are very real external dangers that permeate life, just as there are very real dangers that threaten life from within the human body. Learning about life is not all ‘beer and skittles’. It involves frustration, anger, disappointment, sadness and an abundance of anxiety. Without appropriate support, a fear of emotions is learnt, in turn creating difficulties in learning how to manage loss and grief. Fay, Julie and Jonathon illustrate some of the difficulties. This inability to manage loss-related emotions generates responses into adulthood that can cause a great deal of unnecessary hurt.

Take, for instance, the reaction of 50-year-old Neil to the reminder of the frailty of his once able mother and the loss her frailty holds for them both.

Watching his mother fall on a flight of steps into a restaurant and rushing to her aid, Neil feels emotional about her frailty and its meaning for both himself and her. He camouflages her aging along with his concern. While helping her up, he cracks a joke that makes her feel uncared for: 'Mum, no more drinks for you!'

This type of jocular comment is quite commonplace in families. Is it an attempt to cover up, to belie, the feelings of sadness underneath? It can be so hard to handle our emotions, all those knots, all those messages, all those fears. The following thoughts to ponder are designed as a quick summary of the main points made in this chapter. These points are quite sobering, but at the same time they are the reality for many men, women and children.

Thoughts to ponder

- Experiences in childhood dramatically shape how we view loss and manage loss and grief in our lives.
- The capacity to handle strong feelings is a skill learnt gradually, given adequate support and encouragement.
- Messages from the past can create benchmarks, superstitions and dread.
- Bullying, ridicule and teasing lead directly to a loss of self-esteem.

- Thoughts and emotions can become hard-to-untie knots in response to mixed messages.
- A great deal of rivalry surrounds the theme of attention. Parental, sibling and peer judgement surrounds the receiving of what is assumed to be ‘special’ attention.
- Perceptions and experiences surrounding loss can generate a fear of owning or expressing strong emotions.
- An ability to manage strong emotions acts as a bulwark in dealing with loss and grief.

The way forward

Having taken a look at how loss in infancy and childhood can often create difficulties in adulthood, it comes as a relief to know that learning to manage loss is a skill acquired by many of us as we mature. Yes, it is difficult to tackle our early learning—that persistent, negative self-talk and the judgements we make on ourselves and others. The achievement of validating our own losses is a habit that is often slow and arduous to learn, but it has its rewards.

Admittedly, there are features in our lives other than being emotionally expressive that contribute towards our ability to manage loss and grief; these are being alluded to progressively in this book. It is also quite possible to actively reduce the impact of undesirable influences as we grow up—the legacy is not totally irreversible. Skills can be developed later by deliberate choice, though not without a considerable amount of effort.

We continue to look back into the past in Chapter 5, as the learning experiences that cultivate a respectful approach to loss and grief are placed in juxtaposition with the experiences described in this chapter—those that stand in the way of managing loss and grief in our lives. The experiences to value are those that are constructive, insightful, supportive, nurturing, enriching, and generally to the advantage of the recipient. They have to do with competent models, strong support, adequate levels of comfort, mastery of self-talk, and a mature perspective on loss and grief issues as they affect children and adults across their lifespan. Unfortunately, not everyone is blessed with these advantages, creating less rather than better stead.

CHAPTER 5

In Less or Better Stead?

Learning to manage loss is often a hit and miss affair, like many things in life, seemingly reliant on luck. There is our start in life, whether we were anticipated and welcome, our nature, our genes, our health, the rhythm of our bodily functions, the happenings we encounter in infancy and childhood, the insight and well-being of our parents, the adversity or good fortune across the years. None of these experiences can be orchestrated—they are givens.

For young children, losing things is a daily occurrence that offers unavoidable training. Shoes are lost, hats, socks, toys, parts of toys, and even, sometimes in panic: ‘Mum! Dad! Where are you?’ How to tolerate and manage loss, disappointment, frustration and sadness? Not an easy task when memory is immature and there is much to learn and remember. Children need extensive reassurance that when something important is lost, their feelings of sadness are normal. The losses for which there is ample support and which do not create too much distress are valuable childhood lessons about how to cope with the experience of loss. In these instances, the sense of self and self-competence is likely to be strengthened.

An important role for parents is to convey to children that they are entitled to own sadness about things that they break or lose, or to feel intense disappointment and sadness when something that has been expected to happen does not eventuate. Along the path, such nurturing experiences help in the development and honing of skills to manage loss. These are in stark contrast to the experiences introduced in the previous chapter—those that teach a fear of emotions and their expression.

Those of us who have had the good fortune to be on the receiving end of emotional support and validation of feelings have a head start in dealing with loss—and no more so than when we live with a loss that is nonfinite, a continuing presence. By being able to give voice to our feelings, by claiming our loss and its pain—our grief—we gain the strength to contest the forces that otherwise threaten to overwhelm us. At the same time, we are able to soothe and reassure ourselves, debunk the harsh judgements of others, the disparaging self-talk, and the labels we may have been accustomed to from childhood.

What do enriching experiences entail? Which experiences impoverish? What has helped or hindered you in developing your relationship with loss and grief? Four formative experiences that have a prevailing positive effect on this relationship have been singled out for discussion. Generally, these experiences are acquired within the family of origin and extended family settings.

- positive *modelling* behaviour provided by parents and adults;
- the provision of *validation and emotional support*;
- the encouragement to draw on personal *sources of support*;
- *insightful handling of loss, grief and sadness*.

Modelling

In childhood, much of our emotional competence is learnt through imitation. The earliest imitation occurs through observing the range of emotions displayed by our parents and significant others in varying situations. Ideally, an end product is that loss and the emotions of sadness and grief are taken for granted as a natural part of life. As a child watches his or her parents move through their emotions, expressing and surviving their intensity, he or she learns that doing so is safe—you can come out the other end! Watching carefully, an important emotional script is being learnt. How do a mother and father react to their own experiences of loss and frustrations? How do they treat each other when either is grieving? How do they calm themselves?

Reassurance

Positive modelling provides children with the entitlement to express strong emotions and claim a personal loss, an ability to interpret their losses as not being ‘the end of the world’, that they will slowly feel a little better over time. This modelling is constructive and culminates in the internalisation of useful words, behaviours and skills that children can draw on to soothe themselves in times of personal distress. ‘What do you do when you are feeling very, very sad?’ the seven-year-old is asked. ‘I can hear the voice of my mother,’ he replies, ‘and I say with her when I feel sad: “Calm down, calm down, this feeling will pass—it will be all right”’. Learning early in life to self-soothe is an asset as life goes by.

An invisible shared emotional circuit runs between parents and their children. Grief is an emotion that may be expressed as an outpouring, or present as a silent atmosphere that besieges a family, a strained ominous atmosphere—closed doors, darkened rooms, phones not answered, no future plans, a shutdown of routine. Perhaps, in your house, there was an unspoken understanding that the death of a brother, sister, or grandparent must not be openly talked about. Whisper to your sibling and hold your feelings tight to yourself. This ‘no show’ approach to grief may have typified the emotional model that was presented in any situation that involved significant loss and disappointment, an emotional model that you were expected to adhere to—a ‘stiff-upper lip’ and ‘get over it’.

No reassurance

Losses that are camouflaged in childhood obviously have repercussions for the child. Parents unable to face their own emotions are full to the brim with grief that has not been adequately expressed. They avoid seeing sadness, grief and disappointment in their children. In maintaining this avoidance, parents feel compelled to entice their children to change their emotions, to replace sadness by providing things such as surprises, or rewards, like the promises made to **Jesse**. Fabricating the loss or change is intended to help the child feel special and grateful for the experience that is being offered: ‘None of your other friends get opportunities like you!’ says Jesse’s Dad. How confusing—no grief allowed! Of course, Jesse’s experience may involve pleasure, but the sadness, grief and lack of personal control over the course of events are valid feelings that require ventilation. What was it like

for you growing up? Can you remember such a confusing episode in your life? What might have particularly affected you?

Cheering a child up has its own range of problems. Instead of learning a tolerance of these strong painful emotions, attention is shifted to an object or act that will suppress the emotional pain and provide a commensurable distraction. Often this response is more about the parents' inability to tolerate the feelings that the child's sadness brings out in them. They may feel helpless, and this difficulty is nowhere more evident than in situations of parenting children with chronic conditions. An inability to come face to face with their own grief about the nature of their child's life commonly prevents some parents from managing their children's complex range of frustrations, including the personal grief of their children who, more than likely, may not have a childhood like their peers.

Understandably, rather than naming and experiencing the feelings for what they are, the issue may be forestalled by diversion or challenges: 'Look, you are so much better, braver than all of them!', 'Look at that other little boy, he has no use of his legs either', 'Nobody is good at everything!' When these children reach a counselling situation—often in early adolescence—it can be the first time that their loss has been legitimated and the word 'grief' has been used.

Unexplained grief

Perhaps grief was not talked about in your family? In times of significant loss, did strong, untamed and unexplained emotions erupt? Suddenly the understanding and compassionate parent

was transformed into every child's nightmare, alternately pre-occupied or frighteningly angry?

'Mum? Dad?' They looked right through me. Had I become invisible? And what about my grief? Mum said: 'That's different—you're too young'. So? No explanation or guidance here! There followed a tirade of hurtful remarks. Apparently, I had no idea what they were feeling! Apparently, I didn't really care anyway! After all, what would I understand? I recall many anxious moments wondering whether or not things would ever return to normal.

When emotional expression is rare, or confounded by a lack of reassurance and explanation, children learn to be frightened and wary of human beings whom they observe to be in emotional pain. With no prior scripts on how to handle these situations, they tend to avoid emotionally intense situations. In these instances, observing a parent cry may be unendurable for a child who is dependent on the brave front of the parent. Helplessness becomes ingrained: What to do? How to act? Provide comfort—how?

Children may find themselves with so much apprehension that they have no recourse but to want to run and hide—under the bed, behind the clothes in the cupboard, away, riding fast on a bike—not surprising responses when you consider what anxiety is like for children to handle. It is not just about small zaps of feeling uncomfortable: 'It feels like a balloon with a brick in it inside my tummy—but instead of bursting, it just feels as though it's *about* to burst' or 'It's like a million wasps inside my stomach'. Understandably, there is an attempt to wall off even

the possibility of acquiring competence to express how they change these emotions.

In adulthood, perhaps the ability to comfort is something you have sought to master, or perhaps your perceived incompetence in moments like these has reigned, and like others you have veered away from emotional pain: ‘I can’t go there’, ‘I feel incompetent’, ‘I would drown in that level of distress’, ‘My insides won’t let me go there—let alone my heart-rate!’

Emotional support

Teaching children words to match their feeling states eventually enables them to single out words to express those feelings. Accurately naming a child’s inner state and permitting the expression of emotions, conveys a mutuality of understanding—validation. Considerable reassurance is immediately offered: the adult has felt this feeling and survived. What if the child does not understand words? A parent can still use facial and physical expressions to show an empathy with the feeling being experienced by the child. For those children who develop speech, behaviours that they used to communicate feelings—tantrums, head-banging, biting—start to decrease.

Validation

In the event of loss, children who are emotionally supported and soothed through the intensity of the feelings, without parents amplifying or judging the response, are provided with a favourable environment for learning how to manage loss. Take, for example, two seven-year-old boys, both of whom experience

the death of their pet hermit crab. One of the children is reprimanded by his parents: ‘You have killed that crab. You took no care of him!’ It is unlikely that he will want another hermit crab! For the other child, the learning outcome is salutary; his sadness at the death of his pet is the central concern of his parents. He will not have learnt fear, guilt, or shame in relation to this loss, his confidence in self will not have been shattered. Later, when he is older and has developed stronger defences, he may revisit the part he played in the death of the hermit crab. He may be sympathetic toward himself, feel a certain nostalgia, and understand how his age at that point stood in his way.

The contrast in the lasting impact for these two children has much to do with concurrent factors; for them, it was the difference in parental approach to the issue and the provision of timely empathy—validation rather than blame. You might find it useful to reflect on the approach you grew up with and how that has influenced your life?

Punishment

Punishment, blame and labelling in childhood can have a devastating effect on how loss and grief are handled later in life. They influence expression of emotion and judgement of what is permissible in others. Regardless of their innocent origins, uncontrollable strong emotions in a child generally trigger a feeling of helplessness in parents. In public arenas, this behaviour ushers in shame or embarrassment for the parent. Rather than enduring these emotions, parents often automatically revert to whatever works quickest in the circumstances at hand, overlooking the child’s sense of loss and strong emotions:

- Banishment: ‘Go to your room’, ‘Go away’, ‘Stay outside’, ‘I’ll leave you here’;
- Derogatory labels: ‘You’re weak’, ‘You sound like a girl’, ‘You’re always whining’;
- Physical punishment, including smacks.

Being subjected to these off-the-cuff responses is humiliating. An additional burden of emotion transpires, a feeling of rejection, and, if put down in front of others, shame and humiliation envelops the child. The little boys and their hermit crabs demonstrate how this burden eventuated for the one, but not the other. Then there are the more complicated dressing-downs, those which infer that a behaviour has been intentional or manipulative—that it is about the seeking of attention, or conspiring to get one’s way. Tracing back to these behaviours often reveals the origin, for the child, of a disappointed expectation and loss of trust.

Labelling

Not surprisingly, ‘attention-seeking’ and ‘being manipulative’ are offensive labels throughout life. Most people are particularly concerned when their behaviours are seen in this light. Apart from belittling and dismissing the authentic feelings of another person, there is a rather tragic conundrum attached to this derogatory labelling. It is evident whenever a chronic condition or disability becomes the target.

A person’s chronic condition realistically requires attention, but it often excites rivalry and dogmatic judgement. For instance,

children are prone to regard their sibling's behaviour as attention-seeking: 'He finds doing that easy enough when Mum's not around!' It is complicated. Rivalry can produce skewed versions, but maybe there is some truth in it? Perhaps the sibling feels protected by the mothering? Sometimes at school, peers find ways of rejecting the validity and extent of the attention given by the teacher or the entitlement for special consideration. The child or adolescent with the chronic illness or disability instinctively knows about this fine line. If only this could be explained and understood—not likely!

It is quite common for people with chronic conditions to be fearful that their injury will be viewed with scepticism. This is particularly the case with respect to conditions that are not apparent to the naked eye, say the individual who is suffering from depression, lupus, diabetes, chronic fatigue and similar, somewhat inconspicuous, conditions. 'Looking all right' or 'being all right now and then' often distracts from the validation of a condition or from the validation of the effects of a traumatic experience, such as rape or sexual abuse.

Friends, peers and colleagues may validate the condition or trauma for a time, but the fear remains that they will eventually make negative or harsh judgements: 'He's not as bad as he says!', 'He's playing on it!', 'She babies her', 'I've known people to do better with that condition if they get serious about diet!', 'If she took up therapy there would be a difference!' Things can get worse as in an interpretation of perversity when a man relates the trials and tribulations of his illness: 'It's as if he is boasting about his difficulties—he just wants to feel special because of them!'

What's this about? Jealousy over illness or disability? For many onlookers, the idea of chronicity is hard to deal with, perhaps a leftover from those early beliefs in childhood: 'Things can be fixed or cured—they will go away'. 'Incurable', 'unfixable', 'for the rest of our life' are frightening words and realities to be safely distanced from at all costs. Small comfort here—learnt way back!

Comfort

Were you allowed to enjoy sources of comfort as a child? Children draw on attachment objects, wishes, dreams and fantasies to protect themselves from their feelings of being alone or dwelling on the prospect of unmentionable and awful futures: 'What happens to me if my Mum and Dad die?' In the darkness of the night, they pray to God; fondle a blanket; cuddle a teddy; slip into Mum and Dad's bed; perform a harmless ritual. They may draw on the company of a book or music—anything that stops the sense of being alone and the experience of feeling emotions too intensely. These adaptive behaviours are especially crucial when a child experiences an uncommon loss. In difficult times, when all else might be changing, they also provide continuity—something stays the same and can be relied upon. These behaviours are slowly relinquished, or perhaps become dormant as the capacity of an individual to be alone with the threats and losses in life increases.

In coping with loss, reassurance of the existence of a benevolent, protective world is particularly needed. In times of separation from significant others or places, certain objects act as substitutes for the missing person or thing. Children enduring traumatic loss

or dramatic changes in their life can also regress, seeking a closer attachment relationship with their parents, reducing their independence temporarily. In these periods of insecurity, children often make pacts with God or begin believing in God to find the necessary feeling of protection. These are all efforts at adapting to the anxiety surrounding the loss.

Be brave!

Frightened that their children may develop excessive dependency, some parents no longer permit them the comfort of sharing their bed, the cuddly presence of a precious toy, the warmth of a pet at the end of the bed, the dummy, or the blanket. They may prematurely disillusion the child about their imaginations, wishes coming true, and about heaven. Bravery well beyond their developmental stage is frequently expected of them: ‘You are too big a kid to still come into Mummy and Daddy’s bed’, ‘Be brave; you don’t need that old rug now—rugs are for babies!’ These approaches make it most difficult for a child to gradually build up skills to manage loss. Ideally, children are encouraged to be in charge of their own separation and weaning from these precious objects and behaviours.

So what happens when children are not permitted to wean themselves gradually from their attachment objects, their harmless rituals of distraction? What if parents undermine the efforts children make to calm and soothe themselves in times of loss and intense loneliness? What if a child becomes disillusioned about the protection a parent can offer? Children then endure too much anxiety, anxiety that can generalise to other areas of life. Or perhaps they become expert at pretending to be brave. The

accolades can be seductive, and praise can become more important than acknowledging innermost feelings: 'We'll just call on our big, brave boy when we are in trouble'.

Reaping helplessness and generating a further fear of emotions, withholding or preventing the efforts of children to calm themselves in their distress only undermines their ability to stand alone. A child whose parents deprived her of all comfort—they themselves are sources of her fear—develops a secret relationship. Forming her small hand into a fist, raising her thumb and forefinger, two fingers make the ears and mouth of her imaginary friend against the light of her bedside table the shadow cast on the wall was her 'Billy'. Picture her lying in bed, coming up with this reliable and constant source of comfort. Can you recall any losses of loved objects that created emotional distress for you? Was there a period in your childhood when you drew on fantasies, dreams, or rituals to help you cope with loss or the threat of loss?

Routines

Another source of comfort is the maintenance of routines. Routine has a central place in our lives. In our development, it provides predictability and enables mastery of the environment. Routines provide a platform of reliability, especially in times of stress. The less predictable the plans for the day, the greater the anxiety can be, for some people increasing dramatically in later years—the need to know what is happening, or the need to distract from difficult, confronting thoughts, or both?

Said seventy-year-old Mary to her neighbour as they met at the postbox: 'I love having our family to stay from interstate during the holidays, but there's a lot of upheaval that goes with it. I feel a bit at sea. We lose our routine. Ben and I like our routine!'

The magnitude of how a change of routine affects us is evident in our responses, most of which emanate from an underlying anxiety. Reliable structure during the upheaval often associated with loss reduces the emotional burden—it acts like a safe harbour. Compare the feelings that might surround an organised move from one house to another, with the desperate grab for belongings in a war-torn country or following an environmental disaster.

What do you do to soothe yourself in times of great distress? You might turn to a book? Or seek the company of your parents, or a friend? Or take to vigorous cleaning of the bathroom, meticulously ordering your kitchen cupboards, or building something with wood in the shed? These types of routines can allay the intensity and overpowering nature of strong emotions. Are these behaviours reminiscent of rituals or routines you drew on in your childhood or adolescence? Or, perhaps you have no idea how to soothe yourself? Emotional feelings just mount up only to overwhelm you—immersed in such states, you seem to have no clues about how to help yourself? Maybe you repeatedly find yourself turning to alcohol or drugs?

Capacity

If only the world could be designed to provide loss experiences that are commensurate with the emotional and cognitive capacities of a child to manage them. If only we could control the magnitude of losses we encounter in childhood. Without sufficient control, losses can outdo the capacity to cope. Those of us who experience losses that do not threaten the structures and reliability of our world or overwhelm our defences are indeed fortunate. Regrettably, many individuals are forced to manage loss that is well outside their emotional and cognitive capacity.

In some instances, a parent or adult amplifies a loss that would otherwise be thought about by a child in fits and starts over time. Unintentionally, and occasionally in an effort to debrief themselves, adults magnify the meaning and significance of either their own losses or a loss that the child has endured. Through talking about the loss repeatedly, describing graphic emotionally laden images, adults can overwhelm children with the topic. Too much information, too much vivid drawn-out description of people helpless, in danger, terrified, last breaths, no help on the way—just death. So bleak and negative!

When a grandparent or sibling dies, children can hear too much or see too much of hospital scenes, violent scenes, blood, needles, monitors. Bitterness and demeaning exchanges between divorcing or separating parents can spill over into the child's estimation of one of the parents: 'You'd be fooling yourself if you felt you really mattered to them!' So the child is forced to absorb the meaning and significance that the loss holds for the adults. Revisiting the loss and embellishing the

emotions involved in the loss engulfs the child. At these times, many children ask questions, but very young ones may have no idea what the answer will entail; the capacity to manage the experience in an age-appropriate manner becomes at risk. Often children take on the perspective, the emotional response, and the words of the adult; instead of their emotional distress being slowly eased, it is heightened.

So much

There is a lot of self-control required in containing a loss, particularly if the loss is extremely significant. Adults often forget that there is only so much emotional intensity that a child can absorb without feeling overwhelmed. Parent reprisals in response to their own emotions, such as ignoring the child or severely reprimanding about the immature and idiosyncratic way the child expresses strong emotions, introduces more emotional burden. Shame, embarrassment, anger and guilt are connected with the emotions surrounding the loss. The outcome is that the magnitude of the loss reaches proportions where the child is overcome with unbearable anxiety.

Was your childhood and adolescent experience of loss one where shame and humiliation were common parental responses? Or were your emotional and cognitive knots kept to a minimum through helpful guidance and wise handling? What did you learn about managing loss that perhaps shaped how you react today—to others and to your own losses?

Thoughts to ponder

- Childhood experiences of loss and grief continue to have a significant and intense impact on the way loss, or threatened loss, is approached psychologically.
- How loss and grief were handled or mishandled by significant others in our younger years influences our adult way of handling loss and grief.
- The inability of parents to tolerate the emotions of grief often leads them to camouflage or dismiss grief in their children.
- The memory of emotional experiences in childhood can be re-experienced throughout life if a situation triggers a similar theme.
- Fortunate individuals will not have encountered losses beyond their coping capacities in childhood.

The way forward

In our journey so far, we have been looking back at how early lessons about loss are absorbed and how the emotional skills to manage loss and grief are gained or not gained. These lessons have much to do with nurture. Awaiting further exploration, there are other crucial formative processes, those that involve taken-for-granted, youthful expectations about the future, hopes and dreams, and the events we learn to dread happening in our lives.

CHAPTER 6

Hopes and Fears

What might reasonably be expected to be a natural part of life's experiences? Is it reasonable to feel entitled to being healthy, able-bodied, to finding a partner, to being fertile, able to parent children—children that are also able-bodied and healthy—and finally to living with one's partner till a ripe old age, enjoying the children and grandchildren as they too live out their lives to the full? Is it reasonable, as a child, to expect unconditional love? For many lives, these expectations are the 'givens', the 'taken-for-granted's', the foundation blocks on which hopes, dreams and plans are safely constructed.

But not for everybody. Deprived of this foundation, many lives are lived quite differently. In these cases, the fragility and elusive nature of taken-for-granted expectations is often reflected in cursory, quite matter-of-fact comments: 'It's just the way things are', 'It's just not how it was supposed to be'; or in understandable protest: 'I've been robbed!' Underlying these comments is a natural grief that peaks in response to images of what should have been: happy couples in the street; boys and girls who swing on swings, ride bikes, laugh, and chase; friends who enjoy the givens. These images give substance to the loss—sharp and painful contrasts!

The world as it should be

In the Western world, we are likely to grow up and retain the idea that we are entitled to or deserving of certain things in life. Irrespective of age, a vision of the world ‘as it should be’ pervades many lives. Dreams and plans take numerous forms. They can be low-key, high-brow, simple, or extravagant, from ‘I just want to be a parent’, ‘I want to be famous’, ‘I want to cure the ills of the world’, ‘I will be a fighter pilot and rid the world of terrorism’, ‘I want to prove myself to my father’ to simply ‘I want to be happy—that will do me!’

All too swiftly, the world that was expected, hoped for, dreamt about, that plans were made around, can slip through one’s fingers, becoming instead the world that should have been. This shift is central to an understanding of the nonfinite nature of loss and grief. Perhaps you have had taken-for-granted expectations about your life that have been lost? For you, your loss may have become a continuing presence—a feature of a markedly changed life?

Our worlds are not so robust, after all. Our worst fears can be realised. The world we learn to dread exists largely behind the scenes hovering around us. Naively, many believe that this dreaded world happens to others, not to themselves. Occasionally, this cloak of self-protection falters: ‘What if that happened to me?’ Some anxiety creeps in! We seek reassurance: ‘It won’t happen to me, will it?’ Figure 4 depicts how our hopes hover above us—the world of our expectations and dreams—along with the coincident events we dread might happen to us.

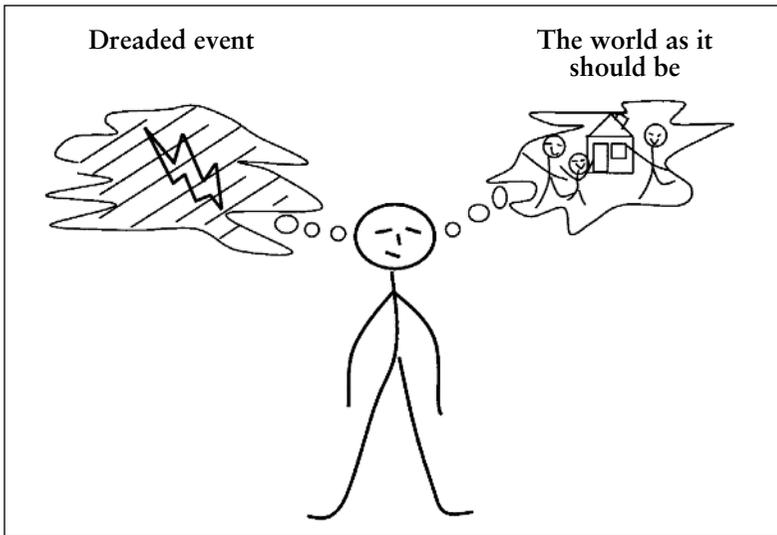


Figure 4 Hopes and fears

Dreams and dreads

Not all of us have had particular dreams or future plans of our own making. On a path predestined by father, mother, societal pressure, marriage, children, a safe, responsible job, there was no personal choice—it was just expected and went unquestioned: ‘It wasn’t my place to question it. I owed them’. With hindsight, a respected family tradition? Or a cause for regret, a lost opportunity to make a chosen contribution in life? Sonia was a young woman with very particular dreams of her own.

Sonia dreams about becoming a mother holding her baby, the colour co-ordinates of the pram, the proud introductions. She has been embellishing a picture that had its beginnings in her own experiences as a child. Being number

six of nine children, she had not felt special. It seems to her that a yearning to be needed and belong could only be met in a bond with a child of her own. This portrait has become central to her view of self, gaining further depth and meaning over time. It has become all-consuming—very precious.

Inevitably, such embellished dreams have the potential to falter or create unrealistic benchmarks. For Sonia, will a baby match her dreams? Can she meet her own expectations of how she might parent this child? The portrait she has painted may eventually have to be modified. Adjustments may have to be made between her dreams and what unfolds. This is true for most of us—there is likely to be a discrepancy between our dreams and what eventuates. There is a demand for us to make constant modifications, barely noticed fine-tuning, to make nostalgic relinquishments; or to turn full-circle, to contend with an entirely foreign version of self and life?

Let's imagine what Sonia's dreads might be: in all likelihood, fear of miscarriage, still-birth, or severe birth defect. Without the child of her dreams, there would be an enormous gap—a huge sense of loss. It would not just be the child, but also the idealised context surrounding the child. Sonia's sense of self and her connection with life is bound up within this context—a complex tapestry.

Let's go a step further: what if Sonia's long-nurtured dream were lost? What then? She must rethink large chunks of her world and her place in it. The world as it should be—that bonding with her own child—is replaced with her deep-down

dread of being alone. Lost between two worlds, her unenviable task is to absorb the reality, painfully fathoming the depths of what has happened and its meaning for her life. In a sense, she is asked to reinvent her self, to discover who she now is. We cannot begin to presume to know how long this would take. Figure 5 frames an aspect of what Sonia's plight would be.

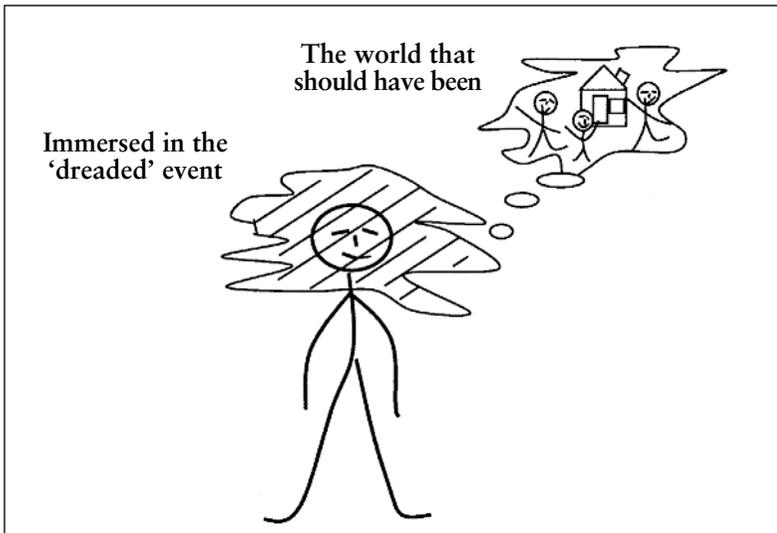


Figure 5 The dreaded world

A yardstick to measure the intensity of emotional responses to loss is provided by taking into account the significant role that hopes and dreams play in life's goals and pursuits. It allows us to see that a loss, seemingly insignificant to us, can be an immense loss for someone else. Who knows for how long in someone's life, a hope has been nurtured? Who can tell what dreams others have had to relinquish as they grow older? How many dreaded events have become a reality?

And what happens when children are born without the givens? A considerable period of time elapses before they take on board the fact that they are less fortunate than others. Ironically, in some cases, these children may have absorbed the idea that they have been chosen for this role, that they are very special. There comes a time when they admit that there is a part of themselves that they would reject if they could—a painful revelation, reality staring them in the face.

The origins of dread

We all fear losing something that is important to us. All of us have a subconscious relationship with what we dread happening to us—it does not often surface to be talked about in any depth. What we dread may range from our view of the life of those individuals who have lost a healthy, able body to being ‘left on the shelf’, to being a divorcee, with associated self-consciousness, shame and loneliness.

Perhaps in mid-life, it is the fear of not having the opportunity to make a meaningful life for yourself? Or how would it be if a particular goal did not come to fruition—just for a moment—can you imagine it? The hockey, basketball, soccer, football player who began their sport in very early childhood anxiously avoids the prospect: ‘I can’t even go there’. It is a common refrain, especially from individuals who have spent most of their life in its pursuit. How to reset the internal daily rhythm of training and practice without feeling lost?

Everyone attaches their own personal meaning and significance to the place words and events take in their lives. Certain expectations are instilled and the dreaded event may become one

of letting parents down or not proving something to them. Parents may pass on their own fears and convey standards about weight, intelligence, achievement and temperament. Inadvertently, children are set up to dread failure, or the dread of reliving earlier experiences of rejection drives a preoccupation with chasing success.

Learning to dread

Can you remember being the last child to be picked up from kindergarten or primary school? Or brought out in front of your classmates? Any limelight, positive or negative, is a dreaded prospect for many children. Being singled out on account of something about you that is negative is extremely relevant to the topic of nonfinite loss. Being different, being separated from peers, not being able to be included in childhood or adolescent school settings, or feeling isolated within the family setting generates a great deal of disconnection and emotional stress. Figure 6 depicts this theme as a cartoon.

Dread accumulates from early childhood. Images of people with disabilities, individuals who were stared at, chronic conditions, disfigurements, even the old skin of aging grandparents, hold firm places in the memory. Children, adolescents and adults recall the child who was least liked, isolated, held in contempt—the child ‘you would not want to be’—the child rejected, the child shunned, the child who was called a ‘spastic’, a ‘retard’, the child who could not keep up, the child who was not good at anything, whose father was in jail, whose grandfather had dementia and ‘spoke funny’, the child whose surname unfortunately rhymed with some rude word—you name it. Indelible memories!



Figure 6 Isolation

A recollection of who these ‘dreaded’ children were from your past may be forming. Or sadly, perhaps some memories about your own childhood are coming to light. Perhaps you, yourself, were isolated because there was something about you that made you different? Perhaps this explains adverse responses to notions of sympathy: ‘I don’t want anyone feeling sorry for me, for my life!’ What might this be about? Maybe sympathy from others forces you to come face to face with loss, or stirs up difficult emotions of bitterness and resentment.

Things that we dread can slip out unintentionally in conversation or turn up in nightmares. They may be envisaged in a daydream, or we may try to imagine what it would be like: ‘What would it be like to be that person?’, ‘What would I do in his situation?’ In our fear and ignorance, we query and usually doubt whether we could manage it: ‘I just know that I couldn’t

handle having a scarred face. I'd hate to be like that—people staring. I'd feel embarrassed. I wouldn't like the pity they would be feeling.'

The mere thought that there are situations in life, such as a relentless caregiving role that might press us to our limits and on occasion bring out the worst in us, is another prospect to be dreaded. Paul, the father of an adult child with a severe disabling condition, reproaches himself:

On some occasions, I find myself angry with him—not giving me an inch of time to myself. Sometimes my intolerance is unbearable and makes me wonder about who I was before this—and who I am now. After all, I am his father. I should not have these feelings.

Strangely enough, we can remain unaware of exactly what is important to our sense of self, until we are threatened with its loss. And when the loss becomes a reality, ironically, what we have lost becomes idealised; it becomes the key to what otherwise would have been a happy and contented life: 'If I had children, my life would be happy', 'If I had a partner, I would feel content'. Likewise, in retrospect, a loss suffered early in life may be regarded as the reason behind all the things that do not turn out right—a prevailing theme in one's life story: 'That would be right, it fits, from day one I've been rejected', 'I think I'm too scared to go along with being content, in case something goes wrong. I'm very wary of feeling pleasure. That way, there will be no more terrible shocks!'

Thoughts to ponder

- In the Western world, individuals grow up believing that they have an entitlement to a certain way of living and a certain future—taken-for-granted expectations.
- Taken-for-granted expectations form a foundation on which hopes, dreams and plans are constructed.
- Along with taken-for-granted expectations, hopes, dreams and plans can become inseparable from a sense of self—who we are.
- From childhood, individuals develop a relationship with what they might dread.
- If adversity has not struck in childhood, most of us keep a distance from the prospect of dreaded events happening to us.

The following points are for further reflection:

- What, in your life, have you most dreaded? What especially creates fear in you?
- Are there particular things about a dreaded event that you fear? Fear of rejection? Pain? Isolation?
- What do you actually ‘know’ about this dreaded event as opposed to what you assume to know about it?

The way forward

In examining taken-for-granted expectations, hopes and plans, and by tracing the origins of fear and dread, two pivotal learning experiences from childhood have been highlighted. It is inevitable that this formative framework has great bearing on an

individual's relationship with loss. It also explains the emotional intensity behind certain life experiences that might otherwise be discounted.

We have travelled back into the past quite extensively now and you have, maybe, done some painful and confronting personal review and soul-searching. The application to the present is the next step forward. To do this, we take a look at how loss can leave us feeling disconnected, how challenging it can be to face the crowd, even friends, and how nonfinite loss and grief can lead at times to extreme situations of trauma. But it is equally important to review the positive moments in our life, times when we have enjoyed wonderful support, and to recall our proven capacity to survive earlier experiences of loss in our life. After all, we have made it to where we are now.

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I N T E R L U D E

As promised when you first began this journey of contemplating loss and grief, Parts I and II have endeavoured to set the scene for reflection on past and present experiences. Numerous questions and thoughts to ponder have been raised in these pages. Perhaps there are aspects that have touched on your own experiences of nonfinite loss and grief, for instance, the characters introduced in Chapter 1, or maybe the Figures, or a particular chapter may have caught your attention.

You may wish to pause for a little while to consider how the past influences your life today, how your earlier hopes, dreams and expectations have had to be scaled down—or completely revised—as time went by. Over the years, days, months, you may have felt a lack of connection with friends and extended family, isolation, loneliness, feelings of being different, rejection—in short, a complex psychological climate may surround you. Thoughts and feelings—how we see ourselves and how we experience life—play a pivotal role in our sense of self.

By way of summary, Figure 1 on the spectrum of loss is revisited and expanded upon in Figure 7. It emphasises the interacting relationship between sense of self and common and uncommon losses. Note how the former type of loss can have a salutary effect or create an indelible effect, leading to the nonfiniteness characteristic of severe and traumatic losses. In drawing attention to the potential for individuals to be overwhelmed by either type of loss, the unique effects the experience may have for some people is reiterated.

In the way ahead, a few new stories allow examination in Chapter 7 of thoughts and feelings related to disconnectedness

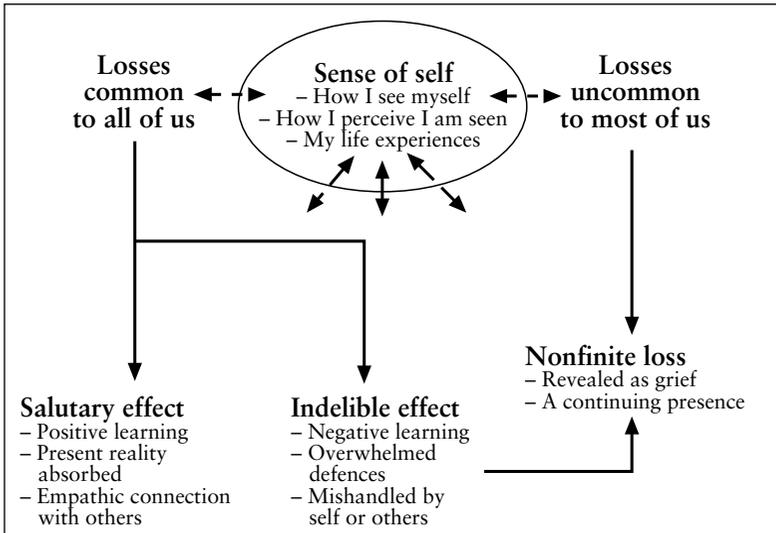


Figure 7 The spectrum of loss revisited

in day-to-day living. Then, the characters from Chapter 1 are reintroduced in Chapters 8 and 9 to describe the hurdles and obstacles they have faced and what ‘adaptation’ has meant for each of them. You might remember them well? To update their current situations:

Belinda and Ron are the parents of Tom, who has a chronic condition. We meet them again two years after his birth, as they wrestle with the nonfiniteness of their family situation.

Ian’s marriage had just broken up when we met him. We revisit him five years later and find him grappling with issues related to rejection. His aloneness had served to exacerbate his negative self-talk.

Marvin is the GP who is living with a degenerative condition. Four years on, his condition is bearing down on him, as the reality of his changed life becomes unavoidable.

Mary, as a young mum, began to 'see' her father in an unfamiliar light. Five years have passed, during which time she has gradually discovered an inner strength to manage her disappointment and disillusionment.

Jesse, the adolescent who was moved from pillar to post in his childhood, is ten years older. Often reflecting back on the peers with whom he shared his early adolescence but subsequently lost contact with, he regards those friendships as irreplaceable—an irrevocable loss.

Rebecca is three years down the track after surgery and aggressive cancer treatment. She has reached a point where she is now able to contemplate facing difficult questions about her future.

For Clare, the little girl who lost her helium balloon, twenty years have passed. Quite recently, a major loss of lifestyle forced an understanding of the indelible effect a loss in childhood can exert.

These characters share how they have teased out meaning from their losses through tangible expressions of their grief—how they have slowly found a 'best possible' adaptation to their new worlds. In addition to this sharing, the following imagery and metaphors are to be found in Part III:

- In **Chapter 7**, the imagery of the spiral is used to demonstrate the connectedness or disconnectedness experienced in life. Loss can be so difficult to share with other people; finding someone who really listens can make a world of difference.
- In **Chapter 8**, the focus moves from myths about and complexities in grieving to identifying strategies to lessen their impact. The terms ‘acceptance’ and ‘adaptation’ are contrasted.
- In **Chapter 9**, the closing imagery used is that of crossing bridges, building shelters and filling voids.

It is our hope that, at the conclusion of this book, readers will share with us a lasting and deep respect for nonfinite loss and grief and its impact on so many lives. It might reasonably be expected that an individual, in experiencing nonfiniteness over time:

- searches for the meaning of loss, gradually recognising that things must change because of the loss;
- may begin to perceive self, spouse, family and significant others differently;
- discovers discrepancies and experiences painful tension between what was and what is emerging as a new life;
- makes a series of compromises between the wish for ‘what was’ and ‘what might have been’, and reality;
- may discover a personal way of being by developing close relationships, responding to the needs of others, the use of humour, imagination, touch, expressive arts, music, mutuality, self-disclosure and the bonds often formed in grief.

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Part III

C O N N E C T I N G
P A S T , P R E S E N T
A N D F U T U R E

CHAPTER 7

The Spiral of Life

In an ideal world, life is experienced as a continuous flow rather than a succession of jolts and sudden surprises. Through a gradual weaving together of experiences, there is the emerging of a relatively consistent sense of self. This sense of self is not vague, it has a feeling of substance. But, we all know there is no such thing as an ideal world—life may produce not just a jolt but a succession of jolts. What happens when we experience jolts that are not simultaneously shared by our peers, or we experience a jolt that is outside the ordinary, strange or unfamiliar to our peers? As mentioned in the Interlude, there often emerges a disconnection, isolation, feelings of being different, lonely, rejected—a complex psychological climate with which to deal.

A shared reality

Shared understandings of the world and the synchrony of development and experience are important pylons throughout life. The loss of this common ground and common range of feelings can be unsettling, even traumatic. Bereft of those common comforts, solitude and nonfinite loss complicate grieving. Strong emotions can instantly set us apart:

- ‘I don’t think they get what I’m on about.’
- ‘Not one of my friends has experienced this.’
- ‘Acquaintances I make who are experiencing this, look and sound as though they are handling this much better than me.’
- ‘Am I the only one not handling it?’
- ‘I can’t seem to find the words to explain it.’

Shared realities and shared vocabularies give us the best chance to remain connected with others. Through shared realities, we sense a union with the flow of conversation and life that surrounds us; we contribute, are understood, and understand. This critical interpersonal connection—to be able to join in and share relevant feelings—is a bonding. Those of us who grow up experiencing shared sequential development with the majority of our peers, or in harmony with a family member, carry within ourselves a sense of connection. Not everybody enjoys that connectedness.

In or out of the spiral?

How our early learning develops and continues to influence our lives is depicted in Figure 8 as a spiral. Notice how the spiral conveys the continuity of life experiences—major transitions as we move from infancy through childhood and adolescence, on through adulthood and into old age. This passage provides a timetable that is taken for granted, an expectation of what should happen when. Falling in line with this timetable turns out to be central to a feeling of connection. This common range of life experiences not only allows a shared language, reality, and memory but also contributes to a sense of a continuity in self.

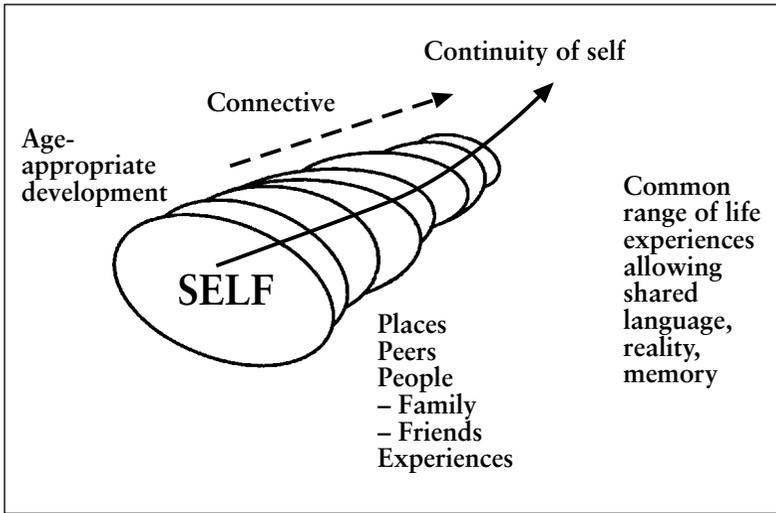


Figure 8 In the spiral

Continuity

A sense of continuity is likely to prevail when our life experiences do not fall outside the range of what would be expected as the normal vagaries of life. The experiences and feelings—emotional, psychological and physical—are in common with those of others; they do not fall on deaf ears, are not met with glazed or blank stares, do not find empty words or judgmental opinions, do not hasten a change of topic, and do not claim a familiarity that is obviously not there: ‘You have no idea!’ The spiral in Figure 8 also illustrates a continuous flow of interactions and experiences throughout life that provide relatively consistent feedback about who we perceive ourselves to be. Unfortunately, perceived continuity may not actually be continuous.

Discontinuity

Picture the painful disregard when traumatic news is anxiously shared with friends who fail to stop what they are doing: ‘Can you hold on to this, while I just get that phone?’ Or the reply is too glib: ‘He’s not worth all this—after all, you’ve said that yourself!’ What to do next? Whom to turn to? Try to manage alone! For those children and adults who experience circumstances beyond their control, events that set them apart from others, reality is less likely to be shared within the mainstream of life experiences. This sense of aloneness may have had its beginnings in childhood, as earlier chapters described. A range of daunting emotional and physical reactions are linked with the loneliness or isolation: ‘What I feel doesn’t seem to matter’, ‘Who am I?’, ‘What’s happening to me?’, ‘Is this normal?’, ‘Will it get worse?’, ‘I don’t feel like me’.

Not feeling the same, overwhelmed with anxiety and helplessness, there is a disruption to our familiar sense of self. Figure 9 illustrates this interruption as a break in the spiral—a disconnection with others and with aspects of who we were. It reveals how loss can gain a nonfinite presence in our lives, which is at the same time exacerbated by a lack of opportunity to maintain or develop a shared understanding. The combination of being forced to leave the common range of life experiences along with a deprivation in sharing can lead to a feeling of being ‘out of sync’ with one’s peers. There are likely to be individuals who have sensed no interruption to their lives. Instead, they judge themselves to have always been outside the spiral: ‘I’ve felt different from my peers all my life!’

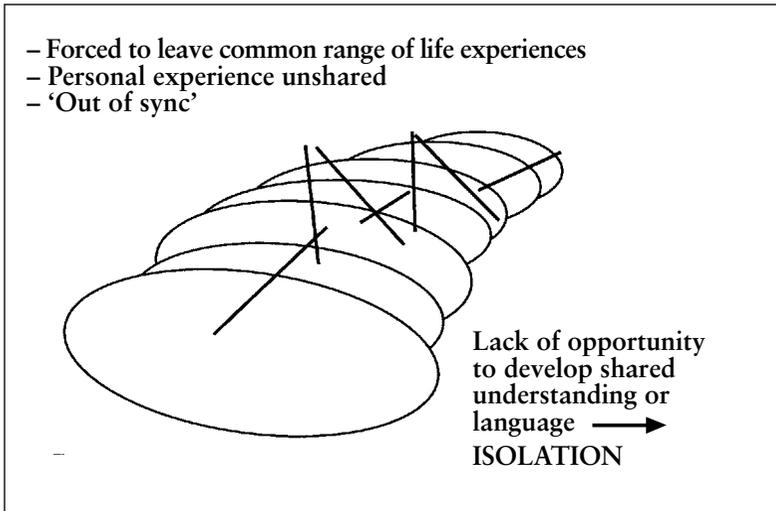


Figure 9 Out of the spiral

Fortunately, for many people, connections are maintained when loss threatens to overwhelm. Age, temperament and circumstances are important variables; background, particularly the loving support, guidance and strength of trusted others becomes paramount. There may be a like-minded friend, a character in a book that creates a vital link, music that captures the depth of feelings, art that simulates the colours that match the hope, the fears, the dreads, or landscapes that symbolise our moods. But sometimes these connections fail to avert the loneliness.

How to share an experience that falls outside the experience of your familiar friends, your family? Customary language intended to convey care begins to miss the mark and fall terribly short of the depth of feelings that is being experienced. Rightly or wrongly, individuals often perceive that they have burdened their family or friends once too often: 'I don't want to worry them any further. They have had to put up with enough!' And

when there is little, if any, support and understanding? What then?

Popular expectations of ‘recovery’, ‘getting over it’ and ‘acceptance’ seriously underestimate the anguish and the traumatic nature of the loss. These ignorant notions create anxiety. The ‘Why aren’t I moving? I must not be trying’ questions slowly and surely force grief underground. A number of further emotions can surround this quashing of feeling: shame, embarrassment about what may be perceived as self-indulgence or lack of progress; insecurity about the normality of continuing grief; resentment, bitterness, anger and self-doubt when loss is being belittled and dismissed.

In sync or out of sync?

It is not surprising that some individuals opt to appear in sync with mainstream. They have two selves—a self who manages the public face: ‘Everything’s fine!’, and a self who does not always manage—the private face that stays behind closed doors:

I long to get rid of this distance from people—friends, people at work—to talk about what’s really happening for us. How much longer can we go on, alone with our thoughts? My partner—long nights watching television; me—lying in bed, head crowded with jumbled thoughts of the day. We are really not coping. Stop! Make a phone call. Go to work. No time for intrusion of thoughts and feelings then. Faster, faster—that’s better; it all goes by quicker. If only they knew how tough it is to get anywhere—to maintain this appearance, to keep pretending nothing’s wrong. I should bring it up. It stands between

us. 'It'? I can't even say the word without feeling uncomfortable. I'm no good at this stuff—putting words together. I've got the feeling, but in words, it comes out wrong—a major blunder. You can't take back the words once they're out there. I dread the day it all comes out.

The public face often takes over. Staying well away from the sadness of life, this self excels in cocktail chatter, general banter, news items, updates on other people's family, routines and neighbourhood news: 'You'd hardly have guessed there was anything wrong' is the impression created:

I must try to look interested—put on a brave face—will it give me away? I feel so exposed sometimes. I duck questions about my life. No use talking about it—there's too much—all too serious. How are things going? What did you do on the weekend, and the holidays? How I hate those questions! I cover up with idle chatter—change the subject. Don't let on how hard it really is—pretend nothing's changed—I'm still one of them. What is authentic about me now? Not even the nod of my head!

And what might others be thinking—the close friends, the family?

Gee, we wish you weren't so hard to reach! We do not have the slightest idea how to get you to talk to us, and we don't pretend to really know how your life feels at the moment. Even the mere mention of counselling is thrown back in our face. It's not a put-down; it is nothing about weak and strong—or pity. It's about caring for you. And

our lives? You know, it's really hard for us to celebrate our lives now, when you no longer share aspects of them.

Here's another example:

I feel as though I'm letting you down. But there is only so much I have to give. Over the phone, I hear how hard it is for you—but there's nothing I can say that helps—I can't go over it any more. It feels as though my resources are running dry. I've come face to face with my own limitations. I know I am not contacting you as much as I should. It feels bad. I should talk to you about it. Perhaps I should be honest with you. How would you take it?

And then there are the acquaintances whose life experiences have kept them inside the spiral or who have continued to see only black and white—no in-between—who give up on you, lose patience with you: 'You never stop to think about others. There's so much worse'.

Me and myself

What happens when we are not able to share our thoughts and feelings? Personal isolation is perilous, breeding many casualties in relationships and futures. On our own, there is no reprieve from an incessant set of harrowing thoughts—rolling and twisting inward, losing perspective, and merging with reams of judgmental self-talk. Permitting no light, no lifting of mood, no changing perspectives, no testing of thoughts, and no relief, an unproductive heavy state of mind is likely to dominate—

somewhat like thinking in bed in the dark long hours, the world sleeping soundly, morning so far away.

So alone

Traumas often begin with the delivery of words that are personally terrifying: ‘We cannot find your son’, ‘The prognosis is not good’, ‘I am leaving you’, ‘Your father has been convicted’, ‘You have not been selected’. The words running around their heads, devastated individuals return to their homes, frequently on their own—maybe immobilised, perhaps a frantic phone call back to the heavy silence, alone. Despite life-altering information, family routines persist, take precedence. Individuals remain trapped in their private trauma. How to get free of it? Who can provide reassurance that things are not that bad? No one? There may be no such relief! Perhaps a frantic search for further information—the Internet, medical dictionaries, interrogate those people who may know more. Reassurance looks doubtful. Too much helplessness and hopelessness, a deluge of daunting information too difficult to decipher: ‘Where to from here? I am overwhelmed’.

All too easily, thoughts and fears become entangled with habitual self-talk from the past, while untested assumptions about the perceptions and thoughts of others invoke further isolation. Let’s see how these ruminations tend to circle round and round, in some cases the thoughts becoming interspersed with self-recriminations formed from childhood—back and forth—voices echoing from the past—arguing the point—a recalled incident involving a friend. Says me to myself:

Life goes on. Life has to go on. Life goes on—all around—as though nothing has happened. But life does not just go on! Life can't just go on. There are certain things in life that you can never get used to. I refuse to get used to this—there will be no placid acceptance! Why fight it, what's the point, these are the cards that I have been dealt! You waste your energy with your moaning! Less time looking back, more time getting on with it. The road ahead. 'What road? I can't find it. You're not trying! You're not going back to that again? You have been over and over it. I just sit here and sit here. This is all too dramatic—perhaps I'm dramatising—there are worse things. But maybe things are actually worse than I make out? I remind myself that this has happened. They are prescribed tablets, not pills—I'm not 'popping them', and I won't get hooked—I have never liked drugs. Why feel guilty? They're helping me—more than any of you. Me talking to me about being strong—then you talking to me about being strong: What do you know about what I feel, my life? What's going to happen to me? Time will heal. I should be feeling better. You're not trying! Try harder. It's getting worse. Mucking up your latest dental appointment—that's what we talked about last time. My head was nodding—perhaps you thought in agreement, but it was only my head—I wasn't there. I was thinking about the time when you had tried to hug me—how awkward it felt, and this gaping black empty hole inside me and how disconnected I had become from you. And how disconnected I had become from me.'

From the other side

Let's look at the reply, the thoughts of the close friend who talked about mucking up that dental appointment:

Likewise! I've lost out too, it's not just about you! I have lost you, your friendship, our friendship, our humour, the way you would listen to me when I had a problem. The mention of the dentist. What do I say? What to say? My banter, it all sounds petty, and the silences are long and I find it intolerable—I don't want to talk about the dentist. What if I say it will be okay—things will turn out all right? You'll get angry. You might turn into a rage. Will it make things worse? I turn myself inside out—part of me wants to avoid you—leave you. You think I don't see how you've changed? No way are you the same—how could anyone so hurt be the same—to me. To phone, to message you, to email you, drop in—which one? And I don't know that things will get better—I can't imagine how—I can't imagine telling you to your face that this is it? This is what you must face. I can't go there with you—certainly not all the time—I wouldn't be able to go on in my life if I delved too far into yours. I leant over to hug you that time. Did you notice? In my mind I had felt like comforting you—you looked so frail and frightened—you leaned back away from me. You probably don't remember. I wanted to give you sympathy—let you know I was here for you.

Could this be one of your friends? And what about the thoughts and feelings of parents or siblings:

Too much dwelling on this! Where's it going to get us? We've just got to get on with it. It's happened. It's a shock—

we're shocked too—it's not just you. It could have been so much worse. Surely it's worth taking some time out to think about that—some people do have it worse. My life, our life? It's been tough too—tougher than we can share with you. We've had to bear up. There're been ramifications for us. We've had responsibilities. Feeling sorry for ourselves just wasn't in it. What makes you think it should be different for you? You've got to get on with your life—it's time to accept it and get on with it.

Here's another example:

I'm not sure exactly what I feel. Sometimes it's tremendous sadness, and uneasiness—almost guilt that you had this happen to you and I didn't. I'm uncomfortable in my luck. Does that sound right? Why you? I watch you when you are not looking—you don't see these expressions. I lift myself. 'Life will go on. I'm behind you. I love you.' Seldom do I not feel this shadow on my life. Often this shadow becomes so black that I am driven to shout at you: 'Things are not that bad!' I think that's just me getting too much on edge—I must be shouting to reassure myself.

In public view

I dread going out these days. I just don't get it! How blatantly rude people are—eyes riveted on me, how I look, how I walk, how I talk. Necks turned, twisted—another glimpse. 'Haven't you seen enough? Why don't you take a photo and be done with it?' I scream out. In an instant, I am staring back at them, trying to stare them

out, to extinguish them. So childish, but it happens without me thinking. Then there's the trapped moments, standing in line, the public question for all the world to hear: 'I heard what happened to you?' Or: 'What happened to you?' How to answer? How to hold my fort? Or the forewarning that a conversation will pin you down into a public discussion of your private life: 'You are so strong through all this!' Me? I hold myself together: 'I've just been cast in this role—nothing more than playing a part!'

Feeling personally and publicly out of sync evokes an increased intensity of grieving for all concerned. The pitfalls are compounded, as other thought processes emerge:

- the 'should have beens' become more powerful and difficult to shrink;
- things that are dreaded become too dominant and hope is difficult to sustain;
- childhood self-beliefs become skewed towards the negative, with a belittling of personal abilities and no self-validation of the entitlement to one's feelings and thoughts;
- negative versions of one's life start to stack up and create feelings of helplessness.

You and the spiral

The image of the spiral is a useful depiction of the disorientation, self-talk and associated pitfalls that necessarily accompany grief. Pulling back into the spiral becomes particularly challenging when

the grief is associated with nonfinite loss, an especially difficult task if the perception of self is of having always been outside the spiral. Consider how each Christmas represents an occasion to come face to face with the gaps and voids in life—an occasion, like birthdays, to revisit one's loss and grief. The world that should have been, the conjured image, the map of our destiny, ourselves, our children, is a relentless and ineradicable image in our minds.

What's happening for you now? Are you outside the spiral? Do the following comments strike a chord with you: 'I don't feel like myself', 'I feel awkward around my friends', 'I feel out of sync with my body'. Is this 'being different' a feeling that is not unfamiliar for you? Have you kept too many of your thoughts and feelings to yourself? Have you decided not to burden your friends? 'I would not have known what to say. Why put it on them?'

Your current feelings may trigger memories of earlier times in your life when you felt isolated. Perhaps that 'in public view' reaction to staring is a good example? Maybe your life feels like a series of chapters without links. There may be useful comparisons that enable you to see how feelings and perspectives slowly change over time. Looking back on difficult periods in your life may remind you that you have managed to transform yourself before. There have been very lonely periods before when no pleasure was to be found, but you came through those times.

Think about the impressions you have about your loss and grief—maybe your own judgmental self-talk. How did you acquire this self-perception? How relevant are these thoughts to the present situation? What about the perception you have of the significant others in your life? What sort of judgements have you made of them? How many of these thoughts might be

linked to myths about self, others, the world? If you have been isolated with your thoughts and feelings for a long time, these perceptions are likely to need the objectivity of another person. Have you shared your thoughts and feelings, without fear of judgement, with a counsellor/therapist or a friend who is non-judgmental and a good listener?

Thoughts to ponder

- Sharing common experiences enables us to sense a union with others.
- A sense of continuity prevails when our experiences fall *within* the spiral of life.
- Feelings of isolation and disconnection are often associated with a break in the spiral.
- When we feel out of sync, our thoughts become entangled with self-recriminations.
- Our self-talk is often negative, without self-validation and reflecting our learnt attitudes.
- Grieving is made all the more difficult when we are alone with our thoughts and feeling.

The way forward

Sharing your story, an unabridged version, full of the sentiment and depth of emotion it evokes, may be the way forward for you. Often the events related to a personal trauma are jumbled up—difficult to pinpoint and relate as a sequence. There are some markers or distinct episodes that stand out, but many of

the frightening incidents along the way have become entwined and put on hold. Telling the story, putting together the sequence of times and events into chapters that link into a life story, captures and builds up the consistencies of self that may have been hidden from view.

You may choose to tell your story by means of various mediums, like writing and expressive art. You may seek validation and objective feedback from a listener of your choice—someone who can provide the affirmation that a personal trauma has indeed taken place, that grieving naturally parallels nonfinite loss, and that it is possible to reframe negative self-talk. Do you hesitate, concerned or fearful about what the listener thinks?

Take a moment to consider the assumptions you hold about listeners in general. Do you assume that they are bored, not really interested, that they want to escape, think you are full of self-pity, think that you just won't get on with it, that they pity you? These assumptions are not uncommon, nor is the anxiety of being identified as different and ostracised as an object of pity. A considerable period of time may have to elapse before you trust your chosen listener's concern and empathy enough to produce an uninterrupted, uncensored account.

There are obstacles as to how or whether you tell your story. Other obstacles and challenges to grieving over time are addressed in Chapters 8 and 9 and in the appendix to Chapter 8.

CHAPTER 8

Grieving over Time

Does it sometimes seem to you as if you have taken three steps forward, then you slip two steps back? Or maybe you have a tired or defeated impression that you have taken two steps forward and three steps back? Or do you just feel stuck? You have insight into how your earlier experiences in life have affected the way in which you handle your loss and grief? You have identified times when you have felt cut off—outside the spiral? You have attempted to deal with what that disconnection might mean for you? You have found a measure of emotional relief at times? But then the ‘should have beens’ crowd in and the old familiar messages from self or others drown out your progress: ‘Get over it or on with it’. Or ‘When will you have room to consider me?’, ‘You’re just running away from it’, ‘You are not trying hard enough!’

Obstacles

What is it that sometimes makes it so very hard to hold onto positive and self-supportive thoughts about our efforts and our lives? Why can it be so foreign to nurture ourselves? Why so difficult to use our insights in the reality we face today? Why so persistent the negative and judgmental messages we have inadvertently

taken on board—accusations of self-indulgence, weakness and feelings of guilt? Why so hard to tell our story? No easy answers to those questions—there are so many factors at work. But let's make a few notes about some realistic obstacles that stand in our way. Consider for a start:

- the *magnitude* of nonfinite loss, whatever its form, the way it continues, sometimes getting worse or accumulating new meaning and significance as time passes, or the way in which it is surrounded with uncertainty and threat;
- the *dread* that may hover around you;
- the *triggers* or constant reminders of 'what might have been';
- the *discrepancy* between previous hopes and expectations and today's reality, with the counterparts of loss and grief;
- the *learning from our past*—that becomes hard-wired into the way we look at things, judge ourselves, and automatically feel guilt;
- the *vortex of grief*—round and round, forwards, backwards—threat, shock again;
- the *treadmill of life*—demands and pressures both from inside and outside ourselves.

These are but a few of the possible explanations behind those soul-searching questions, some of which have been explored in earlier chapters. Some explanations hit home harder than others, depending on the individual circumstances. Perhaps one of the most trying aspects is that last one—those demands and pressures. They come from all sides—the physical, the emotional, the social, the spiritual—impossible to cover them all here.

Separating out the habitual ways of thinking about self and others has been known to offer some relief from the feelings of no control and goes some way to eliminating sources of further pressure. But the questions still remain: What are we going to make of these many demands? What are we going to do with them? How to make sense of them?

Myths

Beneath the surface of thinking about life and people, there are habits, attitudes, misinterpreted information, or lack of information; there are conjectures, assumptions, and there are unrealistic expectations. These expectations often surge forth quite easily from people whose life experiences have remained inside the spiral. They draw on the only vocabulary with which they are familiar. Invariably, the comments are based on myths:

- myths about ‘acceptance’ and ‘recovery’;
- myths about what the human condition is capable of handling;
- myths about other people and the quality of lives that they lead;
- myths that ‘public’ faces demonstrate what people really ‘feel’;
- myths that boys don’t cry and that expressing sentiment is weak;
- myths about the merit of finding answers and solutions quickly;

- myths that ceremony and memorials are only relevant to bereavement;
- myths about being the only one, the odd one out;
- myths that talking about loss and life does not change anything;
- myths that nobody cares.

Of course, the list of myths above is not complete. There are many more public myths, folklore-type myths that surround ceremony and public rituals. Many more personal myths may have been passed down through your family and its generations, types of understandings about behaviour and entitlements that are gleaned from sitting-around-the-dining-room-table type experiences. The impact of some of these myths has run like a thread through earlier chapters. For now, we are going to concentrate on unravelling several of the most troublesome issues.

Acceptance?

Take the myths surrounding acceptance and recovery. There is a popular and widespread notion about ‘getting over it’ and ‘getting on with it’ which overlooks the difficulty that living with loss and grief entails. This mistaken idea probably begins to penetrate thinking from infancy onwards, through childhood and into teenage years. Not only is it entrenched within public attitudes in general, but it occupies space in the minds of those who are experiencing nonfinite loss. They tell themselves: ‘I should be over these feelings of sadness—get a handle on things.’

Sadly, one part of self remains in unison with this mistaken belief. Similarly, this part of self concurs with a related myth that ‘grieving ends—or must end’, that not accepting equates with failure, self-pity, or self-indulgence: ‘What’s wrong with me? Am I playing the victim? After all, it’s been over twenty years of having various bouts of overwhelming sadness’.

It’s unacceptable

In fact, the idea of emotional acceptance and time-limited grief are in direct conflict with innate feelings about personal trauma. For many individuals, the word ‘acceptance’ conjures up a derision or dismissal of the loss itself. Instead, they yearn and need to say: ‘This loss is unacceptable’, ‘It is unacceptable that my child should have so diminished a life!’, ‘It is unacceptable that I have a body, eyes, limbs that do not work!’, ‘It is unacceptable that my children have been denied a father!’

There is a personal entitlement to this protest. Without such protest, the loss instantly becomes belittled—even obsolete. Could there be a worse possible outcome for anyone than to not be able to acknowledge a loss? Anger simmers beneath a calm exterior. The mere expectation of acceptance creates tension and anxiety; the ‘should be’ of accepting grapples with the deep-down knowledge that there has been untold suffering and that the wound remains. That ‘should-be’ is counterproductive to taming the pain of nonfinite loss and grief.

Before complying with the pressure of unrealistic expectations of others, or the expectations you place on yourself, it is especially important to check out the source of these expectations.

Have they come from someone who has experienced the very same reality as yours? Someone who had dealt with a life-threatening illness? Someone who has lost a parent in childhood? It may also be useful to reflect on whether the expectations you hold of yourself are rational and realistic. Have you questioned your perfect right to have feelings of loss and grief, waves of distress, in bouts, throughout your life? Sometimes it is difficult to respect this entitlement to grieve. Anticipating that this respect comes naturally, without a great deal of personal effort, would be a mistake. As several of the characters introduced in Chapter 1 have found, they need to continually remind themselves of their entitlement to grieve:

Belinda asks a question common to individuals living with nonfinite loss: 'How do I just get on with it? If I could, I would. Somehow I feel as though I must be failing! Ron interrupts: 'But in a sense, we have just got on with it—there has been no choice ... but I don't think this means that we have accepted what has happened to our son. Maybe, there's an acceptance intellectually—it has happened, but emotionally it's hard to imagine!'

Ultimately, for Ron and Belinda, the thought that the loss could ever be fully accepted belittles its magnitude and the strong and painful sentiments surrounding it. Ron feels that the mere expectation is offensive and disloyal to their son's loss. They look back at the moment in their lives, when it was put to them that their loss was indeed unacceptable: 'I still remember the silence that hung in the air in that counselling room—we immediately felt understood—here was a refuge'. According to Belinda and Ron, in this

moment, the vital and required respect for the significance and emotional wound behind their loss emerged. Someone had actually validated their entitlement to intense and prolonged grieving. At last, a deeply felt protest could be freely expressed: 'For our son, for us, this is unacceptable'.

Your entitlements

Life is permanently changed by nonfinite loss; in fact, life may frequently be threatening to end. Taking your entitlements seriously is a part of adapting to the reality of the situation. Adapting could be thought of as a process of pursuing a best possible outcome for yourself—your situation. How to adapt? How do I do that? A starting point is to reflect on the following facts:

- You are entitled to claim that an event in your life has been unacceptable, to protest loud and clear. That protest is central to grieving—it's okay.
- You are entitled to grieve.
- You are entitled to choose avenues of support that aid you in self-preservation—enable you to continue your efforts to keep up with life.
- You are entitled to search out a reliable and consistent professional person who can listen, validate and reframe circular thinking.
- You are entitled to require and request medication when the going gets too tough.
- You are entitled to feel a range of feelings instinctive and normal to being a human being.

Paradise lost?

Another all-too-consuming misconception that reinforces the myth about acceptance is that individuals who share our reality are ‘doing better’ than us:

They seem to handle it so much better than me. Some even make light of what has happened to them—crack jokes about their clumsiness—about enormous changes to their bodies and their lives!

Be suspicious—remember the difference between public and private faces? Often individuals are too fearful of acknowledging the depth of their loss in public arenas. Such honesty undoes them. They may feel like a burden to others, or it may bring the trauma too close for comfort—so they present a well-practised front: ‘It’s only now and then, I let down in front of someone—with some people, it’s harder than others’. And all those people who seem so much better off—trouble-free? Your impressions won’t always be right—there is no telling. There may very likely be hidden, private adversities. And is there any guarantee that they will remain scot-free for the rest of their lives? Curbing the tendency to make assumptions about other people’s lives and, in the process, idealising ‘what might have been’ was a difficult task facing Ian. Idealising can wane on its own, but frequently people need help with it—to shake free of it.

Symbols and triggers

Let’s look at Ian’s story five years on, as he grapples with some of these issues and finds ways to contest them.

Following the failure of Ian's marriage, he began talking with a counsellor. There had been lots of fall-out from his adoption that gradually became clear after his wife left him. Curiously, that marked the first time in his life that he had actually looked at it. Perhaps it was because the very idea brought up such unsettling feelings. Looking back, he realised that he must have always felt bitter about his beginnings. He recalled how his envy of children who physically resembled their parents had shadowed him all his life; he had constantly fantasised about a reunion and taking his own revenge by rejecting his mother and father. He had latched on, without a second thought, to 'whoever' demonstrated that they wanted him; he would often swing between obsessive ambition to crumpling under the weight of insecurity: 'Who am I? Am I wanted?' When grief was put to him, Ian responded: 'I guess that since finding out about my adoption, I have been grieving constantly'. Searching and yearning and turbulent anxiety had pervaded his life.

Idealising or romanticising what has been denied, or what one has been deprived of, sets up complex patterns and 'hard to fill' voids. Simultaneously, there occurs a visual scanning for what symbolises these ideals. This can become a habit, a painful routine, given form and substance in people, things, surroundings, like happy couples, loving families, healthy, able-bodied people. Sticking to this habit means that everything must fall short—there is a denigration of the life that stands in its place.

In all likelihood, there is a lack of awareness of how one-sided the visual perspective is or of the naivety that surrounds assumptions about the quality of other people's lives. Physical

resemblance between a child and parent was one such symbol for Ian. Symbols like this produce a cycle of painful, self-admonishing thoughts. Over time, the cycle kick-starts itself—the symbols act as triggers. Riveted to the trigger, a private exclamation in bitterness? Regret? Jealousy? Anger? Resignation? ‘Over there, that healthy body—that’s what I have lost!’ What has been denied or what one has been deprived of materialises in people and things.

Belinda and Ron have tended to idealise the lives of parents who have able-bodied children, children in playgrounds, keeping up, able to compete—not standing out alone. Ian is similarly affected, but for him it is more painful to observe what he believes to be the love between mother and child: ‘And then I’m in this mood—a state that can take days to get over’. Belinda and Ron agree that their state of mind is affected, but over the years it has become less difficult to shift. Perhaps this is because they are not as isolated with their thoughts as Ian is. **Marvin**, too, has wrestled with envy of other people’s seemingly uncomplicated existences. He admits: ‘I don’t like my feelings of jealousy, my lack of real enjoyment of the good fortune of others. I’ve become a person I don’t like!’

Reactions like these reflect what has been lost. They are part of grieving, they deserve respect. Over time they diminish—but never completely. To aggravate matters further, all these images are idealised, lifted up as a ‘paradise lost’, albeit, a paradise that cannot be put to the test. And sadly, the paradise confronts full on in scenes of friends who appear to have it all—to have not yet left the spiral. As a result, there may be a distressing distancing from them; for a short or long time, these friends may

be casualties of our nonfinite loss. How easy it is to forget, though, that aspects of their paradise are tenuous. It's risky to assume anything about other people's lives.

Lessening the impact

Are there symbols that trigger what you feel you have been denied in your life? It may be too daunting to list them at this point. Maybe down the track it could be useful, perhaps an emotional relief? Be as tough as you can in challenging assumptions and dismissing symbols that seem to emerge automatically. It was suggested to Ian that he could, when he felt ready, try to tame and redirect his habitual way of thinking. Breaking any habit involves challenges, repetition and persistence. For Ian, it meant questioning the validity of his thoughts, as well as the harsh assumptions he had made about his mother. How would he feel if he knew for sure that his birth-mother had given him up because there was no choice? Maybe the relinquishment was about unselfish love on her part—that Ian would be better off. In taking some control of his self-talk, Ian began to examine possible alternative views of his situation. For a start, he began to think seriously about his own son's reaction to his father's leave-taking—a very different reaction to Ian's own sense of rejection.

And for Belinda and Ron, how long would they select triggers related to paradise lost? They realised there were alternative adversities which were impossible to idealise—ones that revealed the other side of the coin; ones that provided some emotional relief concerning the trauma in their life, like the elderly woman over there, whose spouse barely comprehends who he is or what they are doing in the cafeteria; the middle-aged couple who

grapple with their son's schizophrenia; the single mother desperately trying to manage a child with behavioural problems amidst the stares of the supermarket patrons.

Moments of relief can be plucked from innumerable examples of the lives people lead. Use the contrasts if need be. Contrast, compare, single out the differences that make your world a little easier to bear—preferable to those 'out there'. Have you heard yourself muttering to yourself: 'I could not go through what she is going through—never!' That same person may be saying the very same thing about you and your particular trauma. We are all capable of empathising with other people's traumatic situations and comparing them with our own. This challenging form of self-talk can be surprisingly helpful. It reinforces and attests to our ability to bear up under the psychological weight that is upon us.

After hearing about a man who has had a stroke and lost the ability to know anything, a person suffering from motor neurone disease makes a remarkable statement: 'If there was a choice between me and him, I'd rather be me and know what was going on up to the very end'. What if the man with the stroke had the choice? Perhaps he would say 'I couldn't stand knowing what was happening to me. That would be more than I could bear!' No two people are alike.

In the final analysis, the realisation that bad things happen to lots of people becomes unavoidable.

Reflecting on the origin of your dreads can also be a source of relief and insight; for instance, Ron reflected on the origin of his ideas about disability:

You know, just like dreading that I would get a chronic illness that would set me apart from my friends in adolescence, I have actually dreaded having a disabled child—perhaps for the same reason. It is my dread that I am dealing with'. Ron realised that he needed to re-think his ideas about disability and his fear of being set apart from others.

Possibly, you too may have become aware that some of the fear involved in your loss is the fear of standing out and being stared at—an unwelcome experience beyond your control? Untangling present feelings from past learnings and experiences lessens the impact. Fortunately, the passing of time allows some reflection—you are no longer a child who is unable to interpret situations laterally. You are able to tell yourself differently. You are able to understand curiosity, bad manners, compulsive and compassionate interest. It may be worth making a mental note of how many steps forward you have made.

There is so much in nonfinite loss that can seem beyond control. Taking whatever control possible can temper a sense of helplessness and introduce a sense of resolve. Some attempts to gain control can backfire. For instance, many people cannot resist an instinctive urge to search and know more about what is to be faced in traumatic situations. This search is based on fear, anxiety and the need to be in charge of the situation. Deep down, it is also triggered by a need to find psychological relief—to know that there is a solution, that things are not that black. Unfortunately, this drive can lead to a flood of conflicting or unsettling information—a dead-end in itself. Resisting the urge to jump impulsively may be wise; in other

words, controlling the rate of information flow at a pace that is comfortable for you. Figure 10 illustrates the gradual absorption of information as distinct from a sudden deluge of too much information.

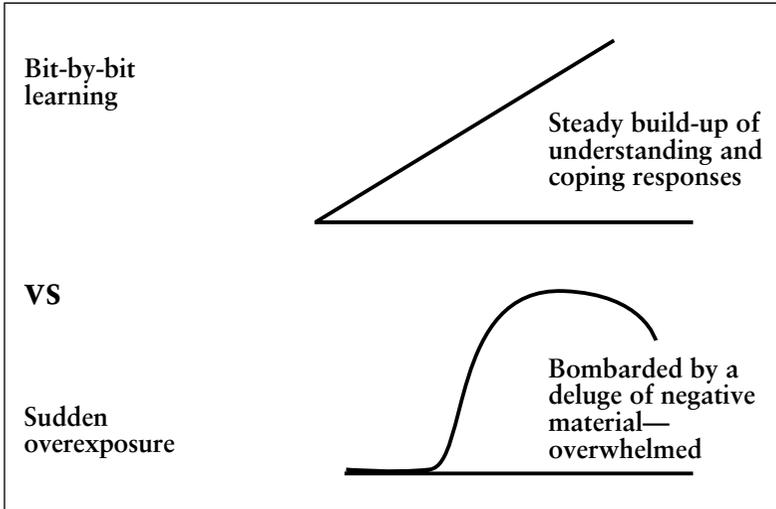


Figure 10 Information flow—gradual or sudden

Slow down

‘You know, in retrospect, I did it all wrong—I went against my own advice to patients.’ It is four years down the track for **Marvin**. How can his experience help others? Let’s see what he says:

Such difficult words to get your head around—this disease, this diagnosis business. Pictures, thoughts, endings flash into your mind—dependency, helplessness, pain, death. I always tell my patients to try not to overload themselves with the future, to wait until they are up

to the present. What do I mean? I have a great many patients who anxiously search out the future. What are they looking for? Maybe relief? Maybe a way to get their thoughts around things? Possibly a way out and away from what they have been told. Relief! Will there be relief? In this anxious state, they often cannot pace themselves, they cannot decipher what is relevant, they cannot employ their familiar defences. Instead, they become deluged with frightening information. Sometimes there's a fleck of gold in there. Perhaps that makes it worth it. Not for some—and certainly for many people—being able to trust the professionals they are under provides the best comfort. In my experience, and certainly now, I know that for each of us there is a time and sequence for each question—a pace we can take some charge of when the answers can be managed. So now I emphasise to my patients, listen to your anxiety, respect what you can handle. There is such a thing as too much information too quickly, particularly when we feel helpless and the threat is real. You may prefer not to know what lies ahead—the choice is yours.

There are individuals for whom questions always represent the potential for threat. In situations that cannot be 'fixed', with no promise of emotional or physical relief, it is feasible that questioning will be avoided from the start, or along the track: 'I have no need to know any more—it's over to the professionals', 'I don't want to hear anything that's not positive', 'I do not want any more hurt—no more brick walls', 'No more empty promises'.

In seeking the truth about the relationship she had had with her father in her childhood, **Mary**, like many others, had overwhelmed herself with information. A compulsive process, she asked relentless questions of her mother until the picture was close to complete. Long emails to her sister who was overseas confirmed and fuelled the story. Too much all at once. Falling from an idealised memory to a reality never before entertained, within a few weeks Mary experienced a psychological loss that altered who she thought she was. According to Mary, there were no remnants of a father–daughter relationship left. Mary’s anxiety escalated, eventually leading to a complete avoidance of her father. Mary began to question whether there was any integrity left at all to her memory—what memories could she trust?

All of us can take heed of these reflections. When individuals are experiencing precarious times, their foundations are fragile. Overwrought, it is impossible to selectively decipher and objectively consider the place of novel information in their story. Listening to too much gossip, reading too many stories, hearing too much ‘it could be worse’ stories—even asking questions when we are not ready to hear the answer can be overwhelming: ‘It was like the doctor just kept shooting bullets at me! I had not begun to imagine what all this entailed’.

Far better to side-step information that stimulates the incessant anxiety involved in the ‘what ifs’ that make it more difficult to process what is happening at the present time, or that provide further sensations of shock. Before lifting up the phone, emailing, sending the SMS, pausing to chat in the street, logging on to the Internet, or asking that question, be cautious.

Will this communication provide some relief or create further distress right now? Maybe, leave it for now.

Rebecca left it: for ages, she did not dare to ask questions about her prognosis. Only now has it dawned on her that she is ready to hear more: ‘What can I expect from this condition?’ she asks her doctor. Three years later, she is up to facing the present. Trust your intuition about yourself—there may come a time when you are ready—later on, perhaps?—that is, if it is in your hands. The following thoughts to ponder summarise the ground covered in Chapter 8.

Thoughts to ponder

- We often have unrealistic expectations of ourselves as human beings: our behaviours and thoughts are often based on folklore, family and public myths.
- The myth of acceptance and time-limited grief are in direct conflict with feelings we naturally have about personal trauma.
- Permission to claim that a life-changing event has been unacceptable, to protest loud and clear, is central to grieving.
- Refusing to idealise what we have been denied can lessen the impact of loss.
- Individuals who share our reality often hide their true feelings—they present a public face.
- Separating out the habitual ways of thinking about self and others offers some relief.

- Resisting the urge to find out things fast will re-establish some sense of control.
- Establishing a relationship with a counsellor/therapist or objective friend is essential to gaining adequate support.

The way forward

Crossing bridges and building shelters are commonplace activities in life. Bridges and shelters of a particular kind apply when nonfinite loss intrudes in life. In the concluding chapter, the characters from Chapter 1 relate what this means for them, as they continue their efforts to adapt to reality. But first, at the close of this chapter, there are illustrations of how self-talk can be recruited to combat some difficult situations and lighten the load of grief maybe a little—or maybe even a lot.

On self-talk and untangling knots

The following scenes are designed to illustrate the insidious relationship between popular myths and what we all too easily tell ourselves in given circumstances. Automatically, we resort to what we have been led to, or have come to believe about our acts, thoughts, and intentions—at times, we even battle with our entitlements. For each of the eight scenes, an example of self-talk precedes a description of the myth or myths likely to have triggered that line of thought and the problems the myths create or reinforce. These entries are followed by a ‘reframe’—a shift to seeing the situation in a different light, leading to a ‘refocus’—actively seeking alternative ways of handling self-reproach.

Scene 1: A carer, spouse or child is encouraged to seek some respite

What was said: *‘Me, have a break, use respite? You’ve got to be joking. I couldn’t do that. What would people think?’*

Myth: That people have limitless capacity, that they do not need nurturing, stress has no effect, respite means rejection, and everyone will judge you as not caring.

Myth: That I am not entitled to enjoy moments in life, when partner, child or parent is suffering so much.

Myth-related problems:

- (a) idealisation of what caring ‘should’ embrace;
- (b) a belief that caring for self is selfish, rather than self-preservation;
- (c) a dread of anticipated judgement and criticism.

Reframe: ‘If I am to continue in any role that involves overseeing ___’s well-being, it is essential to consider how to preserve myself.’

Refocus: ‘I need to replenish myself, to meet others in my situation and nurture my spirit with activities I enjoy.’

Scene 2: An individual with nonfinite loss talks about pretending otherwise

What was said: *‘I never tell it how it is to anyone! I’d be a whinger. I’d feel disloyal. I’d feel it was about my weakness—you name it. Either way, I always pretend.’*

Myth: That there is no one who will validate my feelings and respect the emotional climate that I am in.

Myth: Strong equates with no show of emotion and weak equates with being emotional.

Myth-related problems:

- (a) habitual putting-on of a public face, covering up;
- (b) veto of the right to express feelings;
- (c) belief that there is no one to turn to.

Reframe: ‘I am in a realistically complex and difficult environment. To be able to continue, I need to authenticate what I am feeling and tell it how it is and what I am going through.’

Refocus: ‘A recommended counsellor/therapist will enable me to express my real feelings and find myself.’

Scene 3: A person under enormous stress in a caregiving role seeks relief from guilt

What was said: *‘This will make you think that I am a horrible person, but sometimes I say the most dreadful things to him. The relentless demands can bring out the worst in me.’*

Myth: That people can continually take on a caring role day in, day out, without rest, nurturing, praise, or feedback that there might be light at the end of the tunnel.

Myth: That people in trapped situations will not become resentful of the freedom they have lost, the comfort and love from another person they may have lost.

Myth-related problems:

Unrealistic expectations of the human condition.

Reframe: ‘In many ways I too have lost aspects of my life. I am a human being and sometimes I express my frustration in ways that I regret later.’

Refocus: ‘On some days I do better.’

Scene 4: Nonfinite loss and grief get tangled up with the ‘shoulds’

What was said: *‘I should be over these feelings of sadness; it’s been twenty years!’*

Myth: That acceptance is possible.

Myth: That grieving is time-limited.

Myth-related problem:

Minimalisation of how loss affects people.

Reframe: ‘I am entitled to experience feelings of loss and grief in bouts, as waves of distress, throughout my life.’

Refocus: ‘I will respect those times.’

Scene 5: Coming to terms with unwanted attention

What was said: *‘Everyone is staring at me, and her. She’s so different. I want to shout at them: “Have you seen enough yet?”’*

Myth: That staring is an act of rejection, ignorance, social clumsiness, a human instinct like curiosity, or even evidence of a shared experience.

Myth-related problems:

- (a) questioning the genuine nature or naivety of some people’s interest;
- (b) reactivating dread of humiliation, embarrassment, shame.

Reframe: ‘This person most likely means no harm. I will try to communicate this to my child.’

Refocus: ‘How can I change this? I will make up a printed sheet that explains the condition and try to do my own educating of the public.’

Scene 6: Adverse circumstances set up yearnings

What was said: *‘I find myself staring at any couple and becoming jealous and bitter about what I have lost’.*

Myth: That what you see is what is.

Myth-related problem:

Idealisation of what you have lost and what they have.

Reframe: ‘Seeing couples shows me what I have lost and evokes grief in me.’

Refocus: ‘This is understandable, but I shall try to scan for examples of adversity in life other than my own.’

Scene 7: When depression takes hold

What was said: *'Getting out of bed is too difficult. What's the point anyway?'*

Myth: That times of depression are not reasonable, to be expected, or tolerated in this role/condition.

Myth-related problem:

Unrealistic expectations of emotional health.

Reframe: *'Naturally I am worn down. I often feel helpless and hopeless. It is probable that I have become depressed.'*

Refocus: *'I need to take this seriously, talk it over with my doctor and perhaps, for a short term, take medication and seek counselling that may provide support.'*

Scene 8: Seeking revitalisation

What was said: *'I often feel overwhelmed and desperate for someone to talk to—sometimes I wish I had a companion.'*

Myth: That human beings do not feel overwhelmed in situations of relentless caregiving.

Myth: That to yearn for companionship is disloyal.

Myth-related problem:

Unwarranted self-recrimination and guilt.

Reframe: *'It is reasonable to feel overwhelmed and yearn for a companion.'*

Refocus: *'A support group where I can share my concerns will revitalise me and help in the long run.'*

CHAPTER 9

Crossing Bridges and Building Shelters

Ron discovered two different meanings of the word acceptance: he distinguished between intellectual acceptance and emotional acceptance. For him, the latter implied a negation of his continuing grief—emotional acceptance was just not feasible. In contrast, intellectual acceptance pertains to the ‘knowledge’ that an event has taken place. It relates closely to adaptation, which involves acting in accordance with the world that now is, the emerging ‘new’ reality, doing what must be done in the here and now. In a sense, Ron felt that reality left **Belinda** and himself no choice but to adapt. From day one, their child’s condition has been life-threatening. The traumatic situation they found themselves in had to be taken on board as a matter of urgency.

Most individuals, one way or another, gradually do adapt to their loss. A herculean feat for some, for many it happens almost behind the back of busy lives—life does not stop and wait. For others, there remains a central struggle, a tug-of-war with an obstinate foe, a hurdle always in front of them. Let’s look at how

some of the characters introduced in Chapter 1 have fared. Are they adapting?

The stories revisited

Belinda and **Ron** have shown us the importance of finding validation for the intensity of their emotions and the significance of their loss. Without such affirmation, they would have found their grief overshadowed by self-doubts about their entitlement to grieve and by resentment that others fail to ‘see’ what has actually happened in their lives. Having struggled through the shocking aftermath of their trauma and gradually adapting to parenting a child with a chronic condition, Belinda and Ron continue, now and then, to protest that ‘it is unacceptable that Tom should be faced with such a diminished life’. Tom has had no choice but to adapt to the only life he has ever known; in the future, he will be entitled to protest that ‘it is unacceptable that I have a body that does not work!’

Clare is now in her twenties. She was the three-year-old who experienced unbearable emotion on losing her helium balloon—remember? Although managing her emotions has become easier over time, Clare has always been fearful of what lay beneath her calm exterior. Protecting this exterior had been arduous. Emotive music, nostalgic themes, deep and meaningful talks created too much anxiety: ‘I would feel as if caught in the midst of a thousand violins vibrating on the one note—it was a warning that my emotions may be unleashed—I’d be forced to crack a joke, change the topic—quick’.

Quite recently, Clare faced a hurdle of emotions that she could not avoid: she was faced with the loss of her home due to

financial difficulties. Given her fear of strong emotions, how would she adapt to such a significant loss in adulthood? Clare formed a trusting relationship with a therapist who provided a sanctuary for exploring her emotions. Through learning ways to modify her emotional and physiological responses to strong emotions, Clare felt able to acknowledge and sit longer with what were, for her, terribly uncomfortable feelings; she no longer felt as much urgency about changing topics or cracking jokes. Eventually, with the help of her therapist, she laid the foundation for reliving the emotional response that was etched in her memory. In a strange synchrony, she cried for her balloon, her home, and her many losses. In finding a way to personally master her emotions, Clare began adapting to loss in her life. On reflection, she offers an insight into her fear of emotions and the reframing she has made of her self-perception and self-talk: 'I always imagined that I would have fallen apart, not be able to stop crying, or end up hurting myself or someone else. Now, I have discovered that I am stronger than I thought'.

Rebecca and **Marvin** have adapted as well as can be expected to living with their conditions. On occasion, they are reminded of their continuing grief, but less so than in the beginning. Against this backdrop, Marvin speaks of the 'intolerable anxiety of the creeping weakening of his abilities'; Rebecca identifies peaks and troughs of anxiety surrounding what she describes as 'a Russian roulette that is played in check-ups and foreboding aches and pains'. At the same time, they both believe a life threatened and shortened by a condition is unacceptable to them—in moments of anguish they protest: 'Too young', 'Not enough time!', 'Too hard on my partner', 'I will miss out on having children', 'I miss my kids already—I can no longer protect them'.

Over time, and in retrospect, **Ian** has understood the part he played in his wife's departure and has adapted to living a life without her and his son. However, he continues to feel that it is unacceptable that his mother left him and is inclined to believe that she chose to reject him at birth, that he was unlovable. An ache deep in the pit of his stomach can, at times, still feel unstoppable. While **Jesse** has adapted to a childhood full of upheavals and leave-takings, **Mary** has adapted to a different version of her father. Yet both Jesse and Mary have reviewed their childhoods and consider that they are entitled to have moments of protest over what they lost out on in life—at times, they feel short-changed.

Bridging the gaps

There are some things in life that can never be accepted! But for all these characters, there is a difference between acceptance and adaptation. Life goes on despite what happened yesterday. The process of adapting has us in a headlock. In certain respects, living with loss forces adaptation. Working towards the best-possible outcome is incredibly hard work. It means conquering fears and dreads, redefining or modifying hopes and dreams, asserting control in the face of extreme difficulties. It means adapting. It means respecting the place grief will always have in your life. It means attempting to bridge the gaps or fill the voids:

- between the old and new you;
- between friends who have been important in the different lives you have touched on;
- between generations, family, parents, grandparents who are not familiar with the words to use or tacks to take in supporting you;

- between yourself and others who are in similar situations;
- between yourself and professionals who can enter a partnership with you, and offer support.

There are individuals for whom the need for acknowledgment and permission to grieve is the *only* route home for the best possible adaptation. This acknowledgment and granting of permission may stem from one's own inner resources, but, invariably, is strengthened by a supportive relationship. For many individuals, adaptation relies on a relationship that provides safe guidance in the management of emotions; for them, feelings are frightening: either too tightly bottled up, or an explosion that may hurt self and others. Finding a way to focus the customary self-talk of the past has much to do with bridging the gaps between the old and the new you that is emerging. Clare provides an example of seeking alternative ways of thinking about self, as do the scenes in the appendix to Chapter 8.

The inner psychological intensity that demands permission to protest against what has been lost, to represent the wound inflicted by nonfinite loss parallels the innate need to broadcast this protest—some need to do this anonymously—and to personally find a thing or act that signifies the loss, to communicate its permanent significance in one's life story. This may be likened to the need and drive for memorialisation in times of bereavement: What was he or she like? What special things did he or she mean to you? What did he or she accomplish in life? A memorial can be a source of solace—a shelter within which to reflect and find some peace of mind and to maintain a tangible link with what has been lost.

Memorials

The traditional domain of loss through bereavement—ceremony, memorials and testimonials—applies equally to nonfinite loss. But how to go about that without customary protocol and rituals in place to fall back on? And who or what has been lost when there remains a continuing presence? ‘Who I was? The opportunities I had—or might have had’, ‘If only my loss could be seen’, ‘If only people were aware of how long it takes for me to get out and about of a morning’, ‘If only they knew about my life, how difficult it is’. For others, it may not be quite so straightforward; talking about their personal lives is too revealing—so very unfamiliar—perhaps it seems almost disloyal—they feel more comfortable using their public face.

What happens if a loss goes unnoticed? What happens if there is no acknowledgement of grief? What happens if you do not attend to this part of your emotional life? Feeling unnoticed, listening to other people’s stories and not sharing your own story breeds the feeling that ‘I don’t count’ and kindles the related myth that ‘nobody cares’. This line of thinking is amplified and becomes entangled with grief. The outcome can be a noxious mixture of bitterness, resentment, anger, isolation, envy, fake feelings, lack of authenticity, lack of pleasure in the lives of others perceived to ‘have it all’, and a cutting off of communication that might otherwise repair and maintain supportive relationships.

Have you abdicated from disclosing to others what you really feel about your loss? Do you have a secret life? Why not share it with someone? It may be important for others to know your story—to be allowed to show that they do care. When individuals

lose aspects of themselves, they often need to share with someone ‘who they were’ before the loss incurred such changes: ‘I was in a thriving business’, ‘I served in the war,’ ‘I ran a busy office’, ‘I was a super-organised person’, ‘I was extremely attractive’, ‘I was an active sportsperson—though you’d never know it now’. Perhaps because there has been no actual bereavement, you have remained unaware what it might mean to represent the significance of loss in your life? Responding to this need was difficult for Belinda and Ron, given the absence of protocol or ceremony surrounding nonfinite loss. According to Ron: ‘It is such a quiet loss. I’ve been quiet about it’. And for Belinda: ‘It becomes lost in life’s routines—nobody has died—but yet, you know it actually does feel as though something has died—certainly something devastating has happened’.

Coming out

The value of representing or memorialising the loss, the parts of your self and your life that have been taken away, will surprise you. Does it seem strange that a ritual can provide such emotional calming and a sense that in some way your inside world has been given a face? This process can begin in counselling or group therapy, when there is an opportunity to be authentic about your feelings, their range and complexity. Unfolding your story and feelings can also be useful through journal writing, the collation of a photo album, the preparation of a tape, a tapestry that marks the sequence of your life story so far, expressive arts and crafts, including music, that tell the story and symbolise who you were then and now.

Dedicating time and advocacy to causes, building objects that symbolise what has happened, what you have been grappling with, or even who you were—these pursuits can provide invaluable personal testimony. Certainly, finding the metaphors or accurate words that are commensurate with the emotional pain and grief of this life experience helps.

Belinda found her memorial in words. She whispers sadly that her ‘heart has been broken. I picture a bruise on my heart that will not go away’. Ron could find no words. Instead, he searched for something that he could do or make. Eventually, there was both a nameless drive and countless hours of laboring his loss. From logs of old wood, he carved and sculptured a perfect miniature garden waterway, waterwheels, channels of water moving through bamboo grass settings—a vista for Tom, a measure of Ron’s grief.

Rebecca found the wearing of a chain around her neck provided tribute to her personal trial with cancer—the chain supported a small gold tiger—the face of her internal struggle.

Five years on, Mary, was initially ambivalent about a picture she found of her father holding her as a baby. His eyes were unmistakably full of love. It struck her deeply that then, at that time, she had indeed been treated lovingly—gently. Hard to believe, but that moment meant something. Eventually, this picture was framed, treasured in a very safe place.

Marvin felt deeply about all the losses that accompanied his slow wasting of abilities. Above all, Marvin grieved for the personal fulfillment he would miss in his career as a general practitioner. Hard for him to share this sadness; he felt he should be grateful for the opportunities he had been given. Setting up a scholarship research fund anonymously reflected the depth of these feelings and allowed Marvin to represent his lost future in a most tangible way.

For some individuals, a physical scar becomes their memorial. Years down the track, when asked if they would like the scars removed, they object loud and clear: ‘I would not have cosmetic surgery. This is a part of who I am, my story, my war-wounds if you like’. You may find this answer strange: ‘You’ve got to be kidding. Who would want reminders?’ But each person is different—there are numerous personal and unique ways to memorialise a loss. Finding the way that best suits you may remain hidden from your grasp for a period of time. Coming out—memorialising—gives substance and dedication to what has been lost—the loss gains representation. It lays the foundations for a bridge between the old and the new, the past and the present—a joining of the chapters in your life.

Perspectives on reality

Adapting to nonfinite loss involves distancing self from the old reality. Bit by bit, what was expected, even taken for granted prior to the loss, is whittled away. How does one sort out, or test, reality? What might have to be taken aboard, thrown overboard? What can be modified? What is there about you or the

changes in your life that might make adaptation easier for you? Circumstances often mean giving up or modifying the world that should have been more quickly for some than for others. There are those who see themselves as having been thrown overboard, with no advance notice to build a shelter of defence: 'Out of a clear blue sky—this disaster—no warning. The shock—enormous—I can't get over it'.

Awareness can come steadily with each passing day. For instance, Belinda feels that she has acquired far more awareness than Ron about Tom's condition. Even when she is not listening to diagnostic or assessment information concerning Tom, she is privy to an endless number of triggers on a daily basis when out and about, when chatting with friends. Ron is somewhat shielded by his workplace circumstances—he is away from home most days. Belinda finds his perceptions frustrating and confusing—often he contradicts her about what she sees as the reality of Tom's condition. Their differences in grieving sometimes create misunderstandings, dismay and feelings of being estranged from one another.

Differing perceptions of reality can occur between mothers and fathers, parents and children, siblings, between one set of circumstances and another, between individuals with dissimilar background experiences and formative processes. In one family who live under the same roof, expect a multitude of personal perceptions from several diverse vantage points: the optimist, the pessimist, the well-defended, the 'she'll be right', the 'what was that all about' young child, and the grandparent who forgets or does not fully understand. Bridging individual differences, and closing the gaps in perceptions of the world as it is, requires infinite understanding and patience.

Reality testing

Reality testing is about checking out the ‘real’ world. We actually do it all the time as a matter of course. Everyone’s reality hangs together a certain way; great comfort and control is drawn from the regular rhythm of life that can be expected—the places and people that commonly surround us—the familiar interactions. Each day usually throws up roughly the same scene; reality is not given a second thought. A serious personal event changes all this. Big chunks of what is familiar have to be reworked: how the world, me, others, everything now looks; so different from expectations, hopes and dreams. This rethinking is confronting, arduous, and evokes intense anxiety. Often by coming up with a range of thoughts and behaviours, relatively successful efforts can be made to slow down the realisation and soften what is a dawning personal crisis: ‘This will settle down’, ‘Professionals have been wrong before—they make mistakes’, ‘Things like this just don’t happen to me!’

For Marvin, his new reality is becoming unavoidable. He will soon have to face giving up work. His disease is moving quite quickly. His reflection in the mirror provides irrefutable evidence: ‘Is that old, sickly looking man really me?’ His peers regularly comment: ‘You’re looking tired, Marvin. Did you get a good sleep last night? Are you okay?’ As his psychological defences wear down, he reacts with immediate anxiety: ‘This must mean I don’t look okay; they see me as sickly too. Is it my pallor today, my eyes? What have they noticed in me?’ Around this time, he found relief through taking prescribed medication. It clipped the edges of his anxiety and enabled him to continue functioning in his chosen profession. He understood that taking medication was a reasonable thing to do.

Quite recently, Rebecca is choosing to avoid any disturbing encounters that might rock her boat. This is a challenge, for her body speaks to her via obscure aches and pains. Anxiety does not need coaxing! However, she is making a good fist of it with yearly check-ups now. It sometimes even slips from her mind that she is under threat from cancer. That cancer could be in the back of her mind strikes Rebecca as amazing. She would never have presumed it could be so of cancer sufferers, before she was ill: ‘Who would have thought that someone with cancer forgot about it, ever!’

Pacing

The amount of exposure an individual has to contrasts, comparisons, change and observer’s comments has a direct bearing on the starkness of their reality. Control can often be applied over the extent of this exposure, in a similar way to deciding when and whether it is the right time to seek information. Especially in the early days, it is useful to consider how much exposure to triggers is likely to be overwhelming. You can legitimately take part in looking after yourself, testing the new reality gently, and shaping the process. Saying ‘thanks, but no thanks’ to places or company that may overwhelm you on some days is about self-preservation. Check how you feel! You may not be up to handling stark contrasting images today. After recently separating from your partner, being number seven at the dinner party of couples may be one such occasion!

The pace at which perceptions are challenged is an individual matter, and largely dependent on the immediate circumstances. Control over the pacing is not always possible. Interaction with

the social environment often has the effect of fast-tracking the testing of reality, even though delaying the process may have served as a shelter. For others, the process is artificially controlled by the world of work; when this happens, an individual can become too shielded and eventually experience a shock far greater than would have taken place otherwise: ‘It was like really ‘seeing’ it for the first time. What was I thinking before? Where have I been? Were things really that bad all along?’ There is no protective shelter when this happens. Adaptation becomes just that much more difficult.

Building shelters

Adapting to nonfinite loss and grief involves not only crossing bridges, but also building shelters. These shelters are not always immediately apparent or available or within control. The following list serves as this journey’s closing thoughts to ponder and as glimpses of a possible way forward at some point. These shelters include:

- adequate support in every sense of the word;
- the emotional expression of grief;
- acknowledgement of an entitlement to grieve;
- being mindful of the compromises that must be made between the wish for ‘what was’;
- a paced reality testing;
- an information flow to match individual needs;
- a personal choice in the way to memorialise your loss—‘what might have been’—and the reality as it emerges;

- a recognition of the quietness and solitude that may be required by your loss;
- a diverting of hopes and dreams into thoughts that centre on the moment that is now;
- pleasure in finding a friend to depend on;
- trust in finding effective relief from pain, anxiety and depression;
- a sense of nobility in joining a fellowship of shared loss, suffering and fortitude;
- finding purpose and meaning in life;
- building and acknowledging networks of love and support.

In conclusion

The search for meaning that accompanies adversity, suffering, and sadness becomes a quest in many lives. Answers may or may not be found, but the questioning can be a powerful and creative force in itself. It signifies a source of energy—a strength of spirit to persevere through nonfinite loss and grief. The journey travelled in this book closes with a reflection from Rebecca, who found that strength of spirit:

In my childhood, I had always been led to believe that I was weak. But in living through loss and threat of greater loss, I have found proof that I am capable of suffering and prevailing. Nobody can remove this assurance—this reality—from me. My childhood image has now been replaced with an immense respect for myself.