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'A great shock'

Julian Evans

If, as you open this book, you ache with grief: our very deepest sympathy.

Eight years ago my wife of 32 years died very suddenly; even an hour before her death neither of us realised how ill she was. Ben, my son, who has written several of the early chapters, heard the terrible news later that night. His mother had died and he didn't even know she had been taken ill and so no opportunity for final words, expressions of love, or a last visit. Phil, the author of Chapters 2 and 7, lost his mother from cancer at the age of 63, and, Clive, who has written Chapter 4, suffered the tragedy of his brother drowning when just 18 years of age.

The pain of loss, the yawning gap in one's life, the unsought and unwanted wrenching away is unbearable. It hurts and hurts and no book can make up for the heartache of bereavement. But we hope we can help you along the path all of us are, at some time or other, likely to tread. In particular we want to remove some of the obstacles, explain some of the things that puzzle, and outline what usually happens and what needs to

be done in the days, weeks and months following bereavement. We want to come alongside and share our experience at a time you are confronted with decisions and actions often wholly unexpected and unsought. We hope we may be of assistance as you travel your own path through grief.

The shock of loss

Whether sudden or long expected, the death of someone close comes as a shock. And shock affects us in all sorts of ways. Rachel, a close friend, knew for months that her husband's melanomas were life threatening. She felt prepared, and nursed him in the final days. But she said: "In the first few days after Peter died, I simply couldn't get warm. I felt chilly and cold all the time. Even now (speaking 10 days later) I can't settle, and flit from one thing to another." This is all very natural and very normal.

We are all different

Facing the death of someone close, whether a near relative or dear friend, will be different for each of us. The relationship is yours alone; no one else knows the intimacies, the shared experiences or, for that matter, the arguments and tensions there may have been. And, of course, the relationships themselves are many: death of a child, a spouse, a parent, a brother or sister, a work colleague, a close friend or a valued church minister to name but a few. Also the events and circumstances that have shaped our lives may have prepared some of us to cope better, from careers in the caring professions, religious ministry or the police, while for others life may have sheltered us from bereavement until now. But now our tranquillity is shattered, death has invaded and even overwhelmed.

We are different, too, in how we feel. No two of us share quite the same emotions, or upbringing, or network of friends. We are each unique. Our response to death: shock, numbness, initial disbelief, weeping or desperately wanting to, anger, despair or how we cope initially or later on may vary enormously, but this

makes it no less real or our emotions and reactions no less valid. There is no 'proper' way to grieve in our Western culture compared with some more structured societies or, indeed, with earlier times, but many of us do experience some of the same feelings which can be helpful to understanding the awful turmoil within.

The special circumstances

Unique, too, will be the circumstances of the death. While the cause might be all too familiar – a tragic car accident, cancer, the slow decline of someone old or facing terminal illness – the timing, the place, our relationship to the person, where we were when we got the news, the duties and responsibilities expected of us, all make for a unique situation of which you are at the centre. And there is the particular shock of a violent death or the grief that daily churns within of a missing person presumed dead.

Only a help

This short book covers both practical matters and emotional, physical and spiritual ones; in a way it's two books in one. All four of us as authors have provided input to the whole book. We have worked together on it coming from our different perspectives and have written chapters which retain our individual styles but with occasionally some repetition. Ben has led for Part 1, Julian for Part 2, Phil (a doctor) for the two chapters with a strong medical dimension, and Clive (a minister) the chapter on spiritual questions.

Bereavement and grief are personal and emotional and immediate. So we begin in Part 1 trying to untangle something of the web of feelings, emotions, and moods by sharing with you personal reflections and what experts say without, we hope, their detachment. We share, too, cameos and stories of others before you on this journey and many of our own experiences. All the

incidents in this book are true, but names have been disguised in some instances to protect anonymity.

The more practical issues are addressed in Part 2. They are very loosely ordered chronologically since some matters such as registering a death must be carried out within a few days, or arranging the funeral usually within a week or two, while other matters can often be left until later. Our subdivision of topics is for convenience, but which we hope is helpful for finding your way around what may be unfamiliar territory.

Using this book

There is no need to read this book from cover to cover. Just pick and choose chapters as you may need them.

A Help in Grief is not a manual, but an introduction. We have written it to offer help. At the back there is a list of helpful reading, organisations to contact for further advice and support, checklists of things needing doing (some find this helpful), and an index.

We are sorry if the detail is insufficient to meet every case. We hope the book can be a guide at least to indicate where to find out more. And we pray that we are just one of many helps you receive at this time; a time of pain and a time, perhaps more than any other, when we all need support and understanding.

Part One

The Emotional Journey
(Where is this taking me?)

1

Mourning & Grieving

Ben Evans

Your journey - body, mind and soul

Pain doesn't fit neatly into boxes, follow set patterns, or stick to anyone's time lines. Your pain, as with your loss, is unique. How you work through it will be different from how your siblings, children, parents or friends will. There are though challenges that most will probably face at some point and to some degree in their personal journey. This first half of the book hopes to help you through some of the more common that are felt. There is no right or wrong order in which to read the next few chapters so please pick and choose as and when you feel ready to do so. Here we give an outline of the chapters to follow so you know what to expect and perhaps which to turn to first. In all of them, we're speaking from our own experiences and from those who have kindly shared their stories with us.

The enormity of what has happened may take time to unfold, but the impact on your life will probably soon hit home – and so very hard when it does. Pain may seem to consume every corner of your life and prevent any thought of the future – let alone one in which happiness, excitement, and fulfilment exist.

However, emotions will be ever-changing and the death of someone close does not have to mark the end of everything – even though at times it may seem like this – but rather a monumental shift in how your life will look and feel. At some point you will laugh again, and at some point you will stop feeling drained. At some point you may even look back on your grief and see some good in it – when your family drew close around you, when your friends touched you with their generosity and thoughtfulness, or perhaps even when your beliefs or world view, though tested, survived the ordeal and came out the other side better equipped to cope with the challenges of life than before. But before you start to experience any of this, there will probably be a number of difficult twists and turns in your personal journey of grief. Our hope is that this book will be just one of many forms of support you're offered in the days, weeks, and years ahead.

Health matters

In Chapter 2, Dr Phil West looks at how grief and emotional pain can impact your health. Not only can the extreme heartache bring the expected exhaustion, but grieving can also present a number of less obvious challenges to your physical self that Phil sensitively guides you through. He advises not only as a medical professional (who through his work meets many suffering the physical effects of grief) but also as someone who has experienced such loss himself.

The emotional roller coaster

Chapter 3 walks you through some of the common emotional downs, and even some ups, of grieving. Whether it is anger, guilt, depression, loneliness or despair that you're feeling – or any mixture of these or others – these negative emotions are a great burden when you are already feeling fragile. Perhaps these feelings are mixed with some small sense of relief, or gratitude

for the difference your loved one made in your life, or the comfort that friends and family may now be bringing. Whatever emotions are being experienced, we don't try to offer any 'clever' mechanisms for dealing with them or restrictive guidelines on the different stages grief may take and the order in which your feelings should progress. Emotions are often unpredictable and illogical and reactions to grief are utterly unique to the individual and their circumstances. We hope that this chapter will bring some support through acknowledging something of what you might be feeling, alerting you to what emotional challenges may be lying ahead, and sharing something of our own journeys.

A bigger picture?

The spiritual challenges of losing someone you love is the purpose behind Chapter 4. Regardless of which religion, or none at all, Reverend Clive Anderson explores how the reality of death can certainly test how we understand the world around us and the point of it all. Whether you are someone of strong, shaky or no faith, losing someone close can take your beliefs on a journey in much the same way as your emotions. It is not for us to say whether your faith will be stronger, weaker or destroyed by the experience of death, but your faith will certainly be different once you emerge from the depths of your grief. As authors we are all, first and foremost, individuals who know what it is to have our beliefs refined and brought into focus by the shock of losing someone close. Chapter 4 highlights some of the challenges one's faith can experience, and how these challenges may work themselves out.

What about everyone else?

In Chapter 5 we offer help with the difficulties that interacting with others can bring for those who've been bereaved, but also for the people around them. Faithful friends and family may be

painfully distant and yet mere acquaintances, or even strangers, may show extraordinary acts of kindness and compassion. Returning to work, school, or any form of routine, can be an immense challenge and worse still can be Christmas, birthdays and anniversaries. Simply meeting up with friends or heading out to the shops can be tough because, when grieving, any form of social contact demands effort when previously it was effortless. There may also be new relationships that form – such as a parent who remarries after the death of a spouse. Or existing relationships may develop in an entirely new direction (for better or for worse) because the loss of someone you both knew has simply changed everything between you. As well as the challenges of dealing with those around you, perhaps making you feel you want to shut everyone out, grief can, conversely, leave some feeling isolated or alone and in need of reconnecting with the world outside their door. In all of these challenges of social interaction there will be surprises and frustrations and, as with any journey, it will take time for these to be understood and to settle.

We hope the first part of this book, as well as Parts 2 and 3, are a helpful and sensitive companion as you seek to work through your grief and understand what your loss means not only for the present, but also for the future.

Snowdrops

2

Health – what's normal and abnormal

Phil West

Standing on a veranda, outside a rural clinic in South Africa's KwaZulu Natal Province, I chatted to a local Christian pastor and explained that I was soon to return home as my mother had been diagnosed with cancer. He gave his condolences, assuming that she could not recover. He asked me her age and having replied that she was sixty-three years old, he seemed satisfied and commented that it was good that she had lived to an old age. Back in England, my friends and relatives were hopeful of successful treatment and dismayed at my mother's illness affecting her at such a young age. When she died, I was in my late twenties which seemed young to lose a parent in the UK. In South Africa, I had regularly seen people dying who were younger than me. There are huge cultural differences in the way people grieve, and what may be considered abnormal or inappropriate in one culture may be accepted as entirely normal in another.

Grief affects us in different ways

The way we grieve after a death is determined by our

relationships and attachments in life. My mother was also the wife of my father, aunt to my cousins, and sister to her siblings. She was a friend to many and a childminder to dozens of children over a period of decades. At her funeral, each of these relationships was represented and although we all grieved for the loss of the same person, we all grieved differently according to our loss.

Our perceptions of life and death, health and illness are shaped by our culture, our society and by our spiritual beliefs. Illness and death is always sad, but our expectations for our levels of health and life expectancy vary due to our own experiences of life, health and death.

What most people experience

Acute grief often resembles the symptoms of depression though most people who grieve do not suffer the loss of self-esteem that often occurs in depressive illnesses. These symptoms include sleep disturbance, lack of concentration and motivation and changes in appetite and libido (sex drive). Many people who are bereaved accept these symptoms as normal for their circumstances and over time most will recover from them without the need for regular medical help or counselling.

The English word '*bereavement*' probably derives from the Saxon word '*reave*' which means, 'to rob'. This emphasises the fact that although we refer to 'the loss of a loved one', there is often the feeling that a loved one has actually been taken from us. There is no 'right or wrong' way to grieve, but many people have tried to observe the processes that seem to commonly occur following the loss of a loved one. These observations can be helpful so that we may know what to expect as we grieve. An awareness of these processes is also useful to medical professionals to help them detect when the grieving process is outside of what may normally be expected.

Four phases in the normal mourning process have been

described by Dr C.M. Parkes, Consultant Psychiatrist and author[1]:

1. Numbness
2. Pining
3. Disorganisation and despair
4. Reorganisation

As people grieve they may move back and forward between these phases before completing the process. The process itself may take anything from a few months to several years.

Numbness may lead to an initial lack of emotion and expression. This can serve a useful purpose in that it may initially protect friends and relatives from the pain of loss. There may be initial shock and denial leading to behaviour as though the death has not really happened. The business of making arrangements after a death can provide an escape for some people which can help them delay actually facing what has occurred.

> "I keep expecting him to walk in through the front door. He was often away for short periods on business and I find myself thinking that he has gone away, but will be back soon. It hasn't sunk in yet…"

Numbness is generally short-lived, followed by intense pining for the deceased where there is often more acute distress, sometimes termed 'pangs of grief'. There may be associated anxiety and the feeling of a need to search for the loved one even though this is realised as illogical. This can produce tension and restlessness and it is common to analyse the time leading up to the death, to see if anything could have been done differently, either by medical professionals, the bereaved or the departed.

Anger may be directed at any of these people and, it may come as a surprise that it is often directed at the deceased person as to why they have left this life when they are needed and depended on.

Along with the more acute pining for the loved one, there develops the phase of disorganisation and despair. This is the time when symptoms, similar to depression are most likely to occur. Appetite, weight, short-term memory and concentration may all be reduced and it is not unusual to experience hallucinations of the deceased. These are most commonly fleeting visual hallucinations with brief glimpses of the person which are most likely to occur when going to sleep or immediately upon waking. Memories and thoughts of the loved one may remain very strong and can constantly fill the mind of the bereaved.

Although it is a cliché to say that 'time is a healer', it is true that as time passes a grieving person will usually find themselves entering the final stage of reorganisation. Symptoms of pining and despair may still arise though less frequently and less intensely. It may take several months for normal appetite to return and much longer before people feel ready for social contact. It is often in the second year following bereavement that people feel that they are recovering from their grief. Although they may have changed and their situation is different they gradually regain purpose and enjoyment in life.

But sometimes we get stuck.

Let me describe two examples where people have been unable to pass through the grieving process to the final phase of 'reorganisation'. These may be termed 'atypical' or 'abnormal grief reactions'.

Pining

An elderly man watched his wife of sixty years dying from a rapidly progressive lung condition over a period of several

months. Her final month was spent in the intensive care unit with tubes and machinery supporting and monitoring her. Attempts to reverse her disease process failed and he was with her until her death. In her final days he worried that she could not recognise him and at her death his lasting memory of her was of her distressed face. He grieved acutely for her and as weeks went by the intensity of his grief did not lessen. He was frequently tearful and recurrently saw the distressed and dying face of his wife.

It was suggested that the level of grief had become abnormal but he resisted suggestions that might help him feel better as he felt that to have relief from his mourning would in some way make him seem unfaithful to his wife. Under the care of his GP he started antidepressant medication to treat an abnormal grief reaction with features of depression and post-traumatic stress. He was also seen by a psychiatrist and made a slow but gradual improvement in his mental health over many months.

Anxiety and depression following bereavement - disorganisation and despair

A nurse in her fifties looked after her elderly mother at home during her final months. She cared for her diligently, but after her death felt guilty that she could have diagnosed elements of her illness which may have led to further treatment and temporary recovery. Her mood became lower and she had recurrent thoughts that she had failed her mother even though she had cared for her so well. Her self-esteem became poor and she lost confidence in herself, especially in her abilities to work as a nurse. She became increasingly concerned that when she returned to work, she would miss important signs in her patients as she believed she had done in her mother's case. She worried that she was developing an early dementia because her memory became poor and she was unable to think clearly.

The nurse's GP challenged her as to how many times in her

career she had missed important findings that had led to serious consequences for a patient? She could not recall one such incident. She was treated with antidepressant medication and referred for cognitive behavioural therapy* to challenge her unduly negative thoughts and help regain her self-confidence and self-esteem.

The bereaved often suffer increased physical illness

Following the death of a spouse or child, there is an increase in the risk of heart disease, especially in elderly widows or widowers. Our immune systems can become less active, making the bereaved more vulnerable to infection. There are also changes in the body's hormonal responses and natural steroid production. These are biochemical changes which are also found in people who are distressed or depressed for other reasons.

About 25 per cent of widows and widowers suffer clinical depression and anxiety during the first year of bereavement, but this risk decreases with time. There are a number of identifiable factors (listed below) that seem to increase the risk of psychiatric illness following bereavement. These may lead to unresolved grief or psychiatric illness of which the commonest are depression, anxiety, panic disorder and post-traumatic stress disorder.

1. Bereavements which are especially traumatic
    - Death of a spouse or child
    - Death of a parent (especially for young children or adolescents)
    - Multiple deaths (particularly disasters)
    - Deaths by suicide
    - Deaths by murder or manslaughter

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* Cognitive Behavioural Therapy, often abbreviated to CBT, is a psychological therapy which can be learnt from reading materials, online resources or face- to- face consultation with a psychologist or counsellor trained in the technique. It looks at the way our thoughts (cognitions) affect our feelings which in turn affect our behaviour. Negative thoughts and emotions can unduly affect our feelings and behaviour and by recognising and challenging excessively negative thoughts we can positively influence the way we feel and behave.

2. Bereavements occurring in those who are vulnerable due to:
   - Low self esteem
   - Low trust in others
   - Previous psychiatric disorders
   - Previous suicidal threats or attempts
   - Absent (or unsupportive) family

3. Other relationship factors:
   - Ambivalent attachment to the deceased (where there may have been a difficult relationship with a loved one)
   - Dependent or inter-dependent attachment to the deceased (where someone may have been especially reliant on another person or vice versa)
   - Insecure attachments to parents in childhood (particularly learned fear and learned helplessness) can lead to increased risk of psychiatric illness following any bereavement.

The grief of suicide

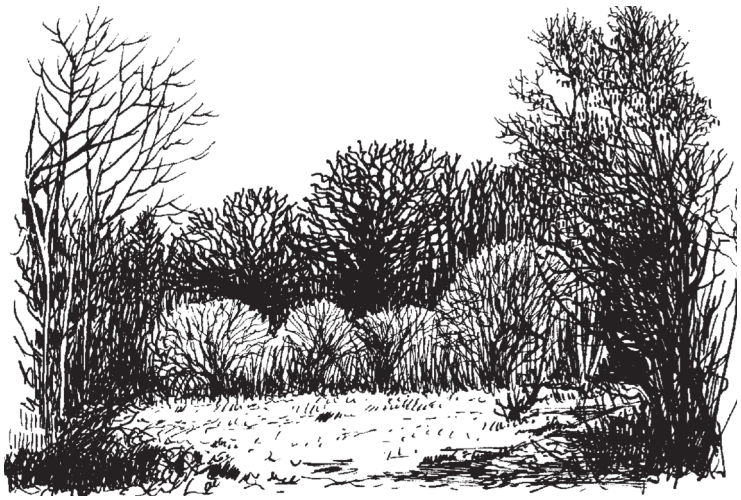
Sitting with the family of a man who had committed suicide earlier that day, was one of the most difficult times I have ever spent with patients. Three adult generations of his family were present and everyone in the room, me included, tried to work out what we could have done differently to save his life. There is little one can do or say in such a circumstance to bring any comfort to the bereaved. Suicide is perhaps the worst of deaths to grieve as the natural tendency is to examine the circumstances over and over again and try to relive it in a different way with a different outcome. Each family member tried to lay some blame on themselves and the only help I could offer was to encourage them to consider how they would view someone else in their situation.

We tend to be much harder on ourselves than we are with

other people and, not surprisingly, we lose any degree of objectivity. When feelings of excessive blame and failure persist, counselling and psychological interventions such as cognitive behavioural therapy can be of great help. These techniques teach us to restore balance to our way of thinking about a situation, helping us to recognise and remove our bias to the negative.

A final comment

The descriptions of the grieving process included in this chapter, including the greater detail outlined below, can only touch on the emotions and feelings that might arise. I hope that it may have been helpful to recognise what you have been going through, or to understand some of the things you might experience in the future. Perhaps the main help may be to know that you are not alone and that others have walked this path before. Your doctor will want to be able to help when they can, so do seek their advice if your troubles start to overwhelm.



A woodland glade

A little more detail about the grieving process

The rest of this chapter gives background to some of the research and theories around bereavement and grief. Not everyone will want to read on, but for some I hope it will be useful to understand how some of the modern theories have developed.

Some history

Sigmund Freud, sometimes termed the father of modern psychiatry, identified what he called 'Grief Work' in his essay 'Mourning and Melancholia'[2] in 1917. This is perhaps the first truly modern writing relating to grief and bereavement. He suggested four stages in working through the grieving process:

1. To truly recognise and accept loss
2. To mourn the loss, giving expression to grief
3. To perform the new tasks of life that the loss obliges us to take on
4. To look to a new kind of future

Freud implies the need for an active working through the grieving process, initially coming to terms with what has happened and eventually making adjustments to allow life to continue in a new way.

Dr Erich Lindemann, writing in the American Journal of Psychiatry in 1944[3], wrote of his observations regarding the symptoms that commonly occur in the bereaved. His work was largely based on those who lost loved ones in a fire in 1942 so his findings are biased towards those whose loss had been both unexpected and traumatic. The fire occurred at the Cocoanut Grove nightclub when someone lit a match to provide light while changing a light bulb and accidentally set alight a decorative palm tree. This went on to engulf the building killing nearly 500

people. Dr Lindemann's paper described a syndrome of grief characterised by the following five points:

1. Somatic (i.e. physical) distress
2. Preoccupation with the image of the deceased (including hallucinations)
3. Guilt (in not being able to have saved the deceased)
4. Hostile reactions (to those who may be trying to help)
5. Loss of normal patterns of conduct (lack of productive work despite restless activity)

He added a sixth point, which described the appearance of traits of the deceased in the behaviour of the bereaved.

It is not uncommon for the bereaved to believe that they have seen or heard the deceased after death. This may be at home in a familiar setting or it may equally occur in a crowd or even at a shopping centre.

Grief of the dying and of their loved ones

As well as describing the process of bereavement some have also tried to describe the process of grief that a terminally ill patient experiences. Dr Elisabeth Kubler-Ross described five stages of dying in her book *On Death and Dying* [4] in 1969:

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance

There are some similarities between the grief experienced by the terminally ill and that experienced by those who have lost a loved one. Those who have terminally ill relatives can experience aspects of these stages and may start to come to terms

with their grief even before the death has occurred. It is not uncommon to have a sense of relief when the death of a loved one occurs following a lengthy terminal illness, though this may be associated with guilty feelings. During a prolonged illness much of the adjustment to new roles may also have occurred prior to the death though there is often a big change moving away from the role as carer.

Trying to be practical

The idea of stages and phases may seem too passive a process for grieving. J.W. Worden in his counselling and grief therapy handbook proposed 'Tasks of mourning' which I find more akin to Freud's 'Grief Works' as they involve processes which need to be actively worked through. Worden has proposed the following tasks:

1. To accept the reality of the loss
2. To work through the pain of grief
3. To adjust to an environment in which the deceased is missing
4. To emotionally relocate the deceased and move on with life.

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