

Living with Bereavement

Steven Lissaman
5th June 1957 – 2nd February 1970

‘My Childhood Friend.’

Living with Bereavement is dedicated to the memory of my childhood friend, Steven Lissaman.

In the 1960’s and 70’s I was living in Coventry in foster care. My neighbours, Steven and his family became a very important part of my childhood. When I was 12 years old Steven died as the result of a road traffic accident.

At that time a young curate, Simon Stevens, was working at the Coventry and Warwickshire Hospital where Steven died. Simon was very supportive to the family and in particular to me. It was as a result of his work at the hospital that he founded the worldwide organisation, The Compassionate Friends.

www.compassionatefriends.org

Stevens’s death was devastating for all of us, I’m sure that the support that we received at that time was of huge benefit and instrumental in the way that I was able to manage my loss, at a time when children were the forgotten mourners.

A note from Alex,

I wrote ‘Living with Bereavement’ in 2003, I believe it was ahead of it’s time. I wrote it because I wanted to give the bereaved a voice. I was working in several different places at the time but I constantly came across the same struggle, the struggle to express the real feelings and the struggle to understand.

At the end of the book, I have added an excerpt to introduce you to my latest work,

‘Just As I Am – Just As You Are.’

Best Wishes,

Alex.

Introduction

Human beings regardless of our cultural religious or historical backgrounds are united by one common bond; the need to communicate, and to know that they are not alone. The recognition that something they experience has also been experienced by another is both reassuring and a huge relief.

I spend much of my time confirming to those who grieve that they are not losing their minds and that the thoughts and feelings they are experiencing in grief are usual. (I hesitate to use the word 'normal', as everyone sets their own criteria as to the true meaning of that word.) There are large unspoken about and unexplored areas of communication, even in today's technical, forward thinking, fly on the wall society, and I hope by reading this book you will find a greater ability to communicate with the bereaved.

Many bereaved people use imagery or metaphors to describe their feelings as they can feel that this is the only way they can communicate the true depth of their grief and loss to us. Sometimes, particularly where deep emotions are involved, commonly used words are not enough. When one of my clients described her grief as a bubble I was aware of her sense of relief that she had found an image that exactly described her feelings. We don't want to be misunderstood; we work hard at enabling those that we wish to communicate with to understand.

Many Grieving individuals don't talk about how they really feel; there are too many things left unsaid and thoughts that are not shared. The bereaved might feel an unspoken pressure to conform and to avoid being seen as a nuisance. Their most overwhelming fear is that those in authoritative roles may label as unstable.

I hope that attitudes will change towards grief and towards the bereaved and that in some small way my work may contribute towards and activate greater understanding and communication. This would alleviate further anxieties not only for the bereaved but for their helpers and those who wish to support.

Messengers and Helpers

One of my clients described the experience of bereavement like this.

“Once I had a puzzle, a jigsaw puzzle, a picture complete. I knew its pieces – how they fitted with me. I knew its shape and colour and I planned its future and size.. Suddenly it’s as though someone had taken everything I knew and shaken it, thrown it up into the air and I ‘m left with pieces. Some of them are familiar but they no longer fit as they did, part is missing and it can never be the same”

This use of language clearly describes this person’s sense of disconnection. It wasn’t enough to say “I feel lost” or “I can’t put my life back”; the image instantly and vividly conveys the sense of isolation and loss.

Death does change everything, and we cannot fix it or prevent it, but we can learn how to communicate with those who find themselves in that place, where their life has been changed by death forever.

There are those who say that you cannot know or understand any experience unless you too have been through it .I disagree.

We are all individuals, and our experiences of life and death are as individual and unique as we are. How we manage any situation will not only depend on our current situation and emotional capacity but on other aspects and influences at that time .It is impossible for any one person to truly know how another feels. Understanding of others comes not from your own experience but from the ability to be with them to hear and empathise. To take all that they have to say, and to accept their words as they are, avoiding the urge to interpret them by your own measure or judgement. The stages of grief have been spoken and written about many times, but I wonder how useful it is to refer to the experience as though there is a plan or mapped

route to follow or to guide you through these stages. Often people are confused or feel that they aren't 'doing it right' the stages being interpreted by them as set tasks that must be carried out in order to move forward.

I spend much of my time confirming that they are 'doing it' properly and that there is only one way – their way.

Each person's passage through grief is unique, but contained within it are threads that can be connected to the experience of others. Our use of language, what we say, how we talk and more importantly how we listen, are the foundation of real communication.

This first chapter is written for people who, either by nature of their work or through circumstance find themselves communicating with the bereaved.

The messengers who deliver the news of a death to a family have a traumatic job indeed and whilst acknowledging their feelings and anxieties.

This chapter is about understanding how it feels to be the person receiving the news.

“I was doing my ironing, I saw the police car pull up outside and I thought, oh, someone's in trouble. It didn't cross my mind that it could be me, not even when he came up the path or knocked at the door. I thought – it must be for next door, he had a strange look on his faceI don't really remember all he said just that he was sorry and that my husband had been killed in a accident .I thought he was joking .I thought he had got the wrong house. The lady police officer with him told me to sit downI felt like things were very confused, muddled , I felt like I was disconnected in a bubble , like I wasn't in the right life suddenly. I know that sounds strange. I remember thinking that they were wrong and my body felt totally numb. I think I made the tea .We chatted but I can't remember what about except that the policeman seemed so young and I did say I was sorry that he had such an awful job”

People are going about their everyday business and are unaware of the shattering news that they are about to receive. On receipt of the news, the shock may be so great that it almost unacceptable. They may continue to do whatever they are doing at the time. The providers of the news may find the recipient offering them comfort. At one level the recipient of the news is aware of what is being said, but at another so shocked that they are incapable of taking in information. This can give the messenger / helper a false impression that, although shocked, the recipient is accepting and able to understand.

*“After the police went I couldn’t remember everything they’d said and I felt anxious, panic that I had to do things, but might not remember everything. I couldn’t recall things and it still felt so unreal
‘Like I’m talking to you now, but I’m distant behind glass”*

The use of language, awareness of reaction and the ability to hear what is not being said is the key to communication. Speaking slowly without effect or drama, using the simplest and shortest phrases/language and adding detail as the family request it. Writing down any instructions or details is very useful too.

In my experience once the family are alone they will revisit being told and may not be able to recall details that have been given, this state of shock can cause many reactions. They may appear to be very organised seeking to gain control over what feels to be and is an uncontrollable situation/experience. They may seem efficient Lucid and in some instances supportive to others. They may continue with their work or whatever they were doing at the time.

A police officer told me:

“I arrived at the house. The mother was mowing her grass. I told her about her daughter’s death and after a short time she said before she could do anything else she would have to put her lawn mower away or her husband would go mad if he came home and saw that she left it out.”

The enormity of the news, the shocking revelation and its unreality, create a protective bubble around the bereaved, a bubble that separates them from reality and acceptance.

It should never be assumed that reaction will occur in a certain way or can be interpreted as anything other than a variation of shock. In some instances there may be euphoria a kind of excited need to tell others.

“After the police had gone I phoned my brother. I just said I hope you are sitting down Joe.Then I kind of blurted it out excitedlyJohns dead. Afterwards I regretted telling him because I suddenly thought what if it’s not true.”

There may be anger with the messenger or at the deceased, or guilt. The bringer of this news may appear to be at the calm centre of this trauma, while the bereaved struggle with accepting and taking in all that they have been told.

“I heard what the police Officer said but I felt he was talking about someone else. I began to feel a sense of unreality of being disconnected, like I was in this bubble, seeing everything hearing it but not part of it. I phoned my children's school and told them, I arranged for them to be collected – I think the police offered but my neighbour went .I phoned my sister. I remember I was supportive to her shock but I felt disconnected from my own. After they went I couldn’t remember it or all they’d said. The person I wanted most to talk to, to help me – my husband, wasn’t there.”

The descriptions of being behind glass or in a bubble are in my experience, commonly used. The confirmation that others too feel this way enables and relieves the sense of isolation.

Sometimes professionals and family members can become too protective, it can be tempting to withhold information in the belief that it could be more damaging.

“I wanted to see my son but the police officer said I shouldn’t. He was my son; I wanted to know how he had died. I needed to hold him to be with him but the funeral director said it might be better not to.”

When I asked why he felt unable to insist, he replied “*I didn’t want to be a nuisance.*”

There seems to be a feeling that, once a loved one dies, the body becomes the property of the hospital or funeral director. In cases of death where there are suspicious circumstances or where there may be an autopsy, the body will not be released to the family and remains in possession of the coroner. (These are not the occurrences that I refer to when I say that it is not unusual for the bereaved to feel that their loved one has been taken from them in an unspoken way.) They feel unable to touch or hold or ask questions. One lady told me that her husband was wrapped up in a sheet at the hospital with only his face visible. She said she felt unable to touch him, she said it felt too clinical and that she was aware that if she disturbed the sheet, they would know she had done so and might not like it.

In the same way preparation for viewing of a body might also need consideration.

In some hospitals and hospices after death the body is prepared and laid out, eyes closed and in some cases clothing changed.

In some religions there are of course certain procedures to follow, these will be understood by the loved ones, but in many cases the loved ones want extra time with the deceased soon after death and some do not want the body to be further tampered with.

I feel that we need to address our own needs and consider why we want to present the dead as more appealing. To be mindful that our efforts may not be wanted or appreciated by everyone, its simple we need to ask the close loved ones what they want.

We can, as individuals only reach our own conclusions by drawing on our own experiences. What one person may find sickening or unbearable, another may not. By protecting the bereaved from details that we

find too difficult to stomach or distressing we may hinder them from their acceptance and in some cases send them along the road of potentially damaging fantasies, which could, at some later stage, cause them regrets for allowing themselves to be pressurised in to agreeing to decisions that others deem best for them.

It is of vital importance that some thought be given at this stage to the 'real' reasons for withholding any information, and exploration of the fear of outcome behind any decision. It can be tempting to rescue, to feel the need to cover up details and avoid facing the extra distress that revelations might cause.

It frequently feels to me as though the bereaved are in a deep dark pit, reaching them can seem impossible. The immediate urge is to rescue, the reaction, to throw in a ladder, urge them to climb out into daylight. Tell them things are better once they get out; recall stories of others who have survived it.

How hard we work at rescue, why? Because we think it is all we can do. The recognition of death is too painful and our knowledge of death the impact, on all aspects of the lives of those who are left, makes us want to be the one who helps them to survive.

I climb down into that pit, I hear their story, I accept their words, thoughts, feelings, the bizarre, and the frightening parts that they fear to share fear being misunderstood or crazy. This is where they need to be.

There may be a deep need to care for the emotionally devastated to tuck them up, make them safe, protect them from reality, to offer hugs and hush their anguished words, stem their flow of tears. This care can cause the bereaved to become the pleaser, to deceive, hide their real thoughts and feelings thus isolating themselves.

To the outside world they appear to be 'doing well'. Oh how we use that phrase around the bereaved. The "doing well blanket" the blanket of pressure that we wrap them in so tightly that we suffocate their deepest

feelings. These are the scary feelings, the thoughts, memories, fantasies that often lay hidden whilst in the company of caring family or friends, but which in isolation, in the lonely hours, emerge and are lived through.

It is rather like sitting on the lid of an over full box, eventually, it becomes so full that it cannot be contained and its contents spill out uncontrollably.

“They ask how I am. I want to say.this is indescribable. I feel like someone’s ripped my insides out, I feel so raw it’s a real pain a stabbing in my chest, in my heart, I feel like I have been skinned alive, I feel like

I just want to die.

I reply ...Oh you knowI’m doing ok.

They say “Great! Time heals”.....they are relieved.”

We ask **“How are you?”** and secretly hope you’ll say **“Fine”** It is rare to ask anyone at any time **“How are you?”** and get the response **“Well, actually I feel like total shit!”**

There is, it seems, unspoken rules to our communications which revolve around acceptable response. It is acceptable to say “I’m fine” but too scary or risky to tell the truth if it’s anything other than **“Fine.”**

“I went to see my husband. My brother said I shouldn’tI didn’t want to upset him so I went alone. The funeral director tried to say he thought I shouldn’t, I felt angry. That I had to find strength to argue my case, in the end I promised not to lift the small cloth over my husbands face .The funeral director came into the room with me. I felt like a child. Like I couldn’t be trusted. I felt like he was watching me. I felt I couldn’t say my goodbye.”

This is a clear example of non- communication.

The bereaved person feeling afraid to ask, to have a need explained or a wish fulfilled, the question, the need, stays within and they often feel they must hide or excuse their sorrow, their need, they must appear coherent, and managing or even apologetic.

They may fear that those who are professional or informed may judge them, find their questions tiresome, or in some way strange. Too much is left unsaid.

How can we change this?

By changing our reaction to the bereaved, communicating with them; listening to their words and to what they are saying and not placing our own interpretations on those words. We need to inform the bereaved of the facts in simple language that can be easily absorbed and allow them their choices. Allow space for them. We have to encourage them to absorb and manage as much as they feel able to at the time and support them in a non-intrusive way. In making these changes you are not attempting rescue but giving something far more beneficial, crucial to the process, acceptance and holding. This is demanding both physically and emotionally, but if yours is a mission to assist then you must refrain from covering up rescuing or hushing their words .There is also a need for balance. There may be time limits and official procedures that need to be addressed and maintained and if you can achieve the balance between these things the sense of holding will be in place and the bereaved will not feel that all control is gone from their life.

Whilst working in a secondary school with bereaved teenagers, I observed that teachers were hesitant to give the bereaved youngsters homework or to ask them to complete tasks as 'they were grieving'. The teenagers did need time to grieve, but they also needed security and confirmation that tasks have to be completed and that life does continue. In the same way, grieving adults must be encouraged to make decisions and choices and allowed to undertake and complete tasks.

When someone dies the world does change and we may feel out of control, leading to a sense of powerlessness and insecurity. All that we knew and had thought would be forever has gone. It is of vital importance then, that some sense of that ability to decide, to plan, is, if only in some small way restored.

After the initial news of a death the household may become very active, with visits by those involved, official paperwork to attend to, and funeral arrangements to make. All this happens at a time when the minds of the bereaved are in shock and in a dreamlike unreality. They may feel enclosed within the bubble of grief and on automated function. You may feel the need to assume responsibility for any arrangements that need to be made. However, whilst it may be necessary to assist with some practical tasks, the most crucial and beneficial thing is to simply be there to listen. Allow the bereaved to talk repetitively about their experience and feelings and encourage their involvement with decisions and arrangements. There may be feelings of a need to organise things quickly. It is often said or thought that once the funeral is over everyone will feel better and life will return to normality, but it should not be forgotten by the helper that this is the last goodbye of the loved one. Nothing should be done in urgency. Time should be taken to talk and discuss with those involved how this farewell should be, and assisting them as far as possible with arrangements.

The bereaved often tell me that they can't remember the funeral and they feel cheated that such an important day passed in a blur and is lost as they were so numb and unable to take in all that was happening. There may be frustration or anger with those who helped with arrangements, or towards those professionally involved.

“I didn't think much at the time, I was disconnected, I feel I let him down; I left him to the care of someone he didn't know. I am worried that they didn't know him; he was a very private man. I feel intruded upon. I wish I had been there to see to him myself.”

A sense of deserting the loved can be present. When I enquire why they didn't ask the funeral director whether they could be there and participate in the preparation. I am often told that they wanted to, but felt scared that the funeral director might think them weird or morbid or crazy.

There may be concerns about the state of the body because of injury or decomposition but it should not be forgotten that this is the loved one of the bereaved; they do not see what we, who are more detached, see. Neither is it unusual for the bereaved to say initially that they don't want to see the deceased, and then to change their minds, but feel they cannot ask later.

“I left him at the hospital, I wish I'd brought him home; I wish I'd had more time with himI didn't want to be a nuisance”

The need to give ongoing care to the deceased loved one is very real and it can feel like the unspoken taboo and secrecy that still exists around funeral parlours prevent this and keep out the bereaved.

Years ago when someone died, the body was often brought home and laid out by the family. In some cultures today preparation of the body is undertaken by family members and this in my experience and opinion can be beneficial to the bereaved, it enables them to physically embrace their loved ones death and to extend their care to the body. It is not unusual to want to take photographs or a lock of hair, or to feel the need to hold on to every last part before the final goodbye. Many people tell me they longed to take a photo but felt an unspoken restriction, like this may be refused to them. How is it as a society we find it acceptable to watch on television the funerals of the famous and yet find the videoing of the funeral of our loved ones still taboo?

Gentle reassurance that whatever they want is ok and that there are no do's or don'ts, death, is, after all as individual as those experiencing it's impact and how it is managed by each individual will depend on that individuals emotional, physical and psychological background and life experience.

I wrote earlier of the sense of shocked unreality and how it may prevent the bereaved from taking in information although they may appear to be listening. Writing down, using simple terms and clear instructions can be of huge assistance: as can leaving a list of numbers by the telephone ,easily accessible and perhaps a list of things that need to be attended to and of things that are being attended to and by whom. Make any information accessible and easy to understand .It is important where possible to offer choices although the response may be of indecision. Allow space and time and avoid the temptation to succumb to your own feelings of wanting to protect or spare them the added trauma. It is fundamentally important in this intimate involvement with the newly bereaved, to lay one's own self aside , to be non-judgemental and to offer regard and respect for their wishes ; To be part of their journey through grief and not the driving force.

Panic Attacks, Anxiety and Phobias:

Anxiety is often apparent in the early days and can manifest in many ways .Fear of going out is not unusual, or an overwhelming sense of panic once outside, or desire to get away. It is useful to talk through and plan any outings. Discuss where and when you are going and how you intend to get there. Whether they might meet people they know and if this happens how they might wish to manage it. I call this safety netting. Putting in place something that gives a sense of security, reassurance, at a time when everything may feel rocked, unsafe and insecure .You can't change what has happened, but you can assist in its manageability by trying to pre-empt potential emotional triggers and situations. It's also important that pressure is not put upon the bereaved to continue with a task that adds anxiety.

“I had been to order the flowersit seemed so unreal. I needed to get some shopping too and I was ok at first but then I felt this rush of fear. I felt like I had to run to get out to get homeit was really scary.”

Often anxieties are unexpected, or may seem bizarre and therefore are left unspoken, leaving the bereaved to struggle with feelings in isolation.

“I had been fine on the morning of the funeralI had this sense of peace of calm. I was able to think. I even managed to talk to a neighbour and I felt in touch after the last few days where I had felt so disconnected then it happened. We were in the car behind the hearse and I began to panic .I wanted to get out. I felt stifled like I couldn’t breath .I just wanted to get away .I kept my face turned towards the window and felt every bone in my body so tense I thought I’d snapit was like being trapped.”

The sense of being trapped, fear of being out of control and on display with no escape may also cause of anxiety. Someone else described his anxiety of being afraid people would think he didn’t care, as he couldn’t cry, he tried, but felt totally numb, empty, all cried out.

“I felt anxious angry with myself a fraud that they were watching me and I wanted to cry but I couldn’t. I was sitting in the chapel thinking I don’t look like a mourner if I don’t cry they will think I’m ok. ”

“I had planned all that I wanted to say.but as I tried to speak it wouldn’t happen I felt overwhelmed I couldn’t stop sobbing, I felt exposed, on show like I had let her down.”

These very different experiences share a similar pattern: The expectation to behave or react in a certain way and the feeling of being observed and of exposure. In grief there is vulnerability .The usual protective guards that we have in place help us to mask those feelings we wish to control or manage, are no longer

accessible. The feelings of vulnerability and fragility can be all consuming. The day of the funeral often passes in a haze of making conversation but not participating in the ritual, or actually feeling part of it. Again the bubble like containment, often described as though it is a film.

“It feels like I am watching a film. I know I am there but I don’t feel part of it”

The bereaved may find they are supporting others who cling tearfully to them, exhibiting their own grief and seeking comfort. This can feel overwhelming and as though they must be there for these mourners .If safety netting can be put in place prior to the funeral it can be of great benefit to know that there is a place for the bereaved to take time out. That it’s ok to have some time and space to his or herself.

After the funeral, the sense of loss and reality can be suddenly present and there may be a need to talk through the day, revisiting events over the last few days. It is usual to be repetitive, necessary for them to feel heard. This can cause anxiety for the listener.you may not know what to say, how to respond, this too is normal, but by listening and accepting you are helping the bereaved to work through the experience, this process helps them to make some sense of it .

It’s also very useful to be honest, to tell them when you don’t know what to say, this in itself is often received with relief. There are many thoughts and feelings that the bereaved feel unable to voice or share, for example, the fear of what others may think. There may be concerns about the body of the deceased and if it has been buried about its safety.

“I couldn’t bare itI hadn’t expected to feel like that at the graveside. Someone gave me some dirt to throwI couldn’t throw dirt on my baby. It felt brutal I wanted them to stop. I wanted to lift him out and take him home. ”

This feeling of wanting to care, to bring the body home, is very common and when this is confirmed as being quite usual there is relief.

A grieving mother told me that she just couldn't tell anyone, not even her husband that she had felt a desire, for some time, to dig up their dead child. It was very emotionally challenging for her she knew she couldn't do it, but at the same time she longed for her child, to have those remains to hold and to care for them. The thought of the cold and the wet and the decomposer troubled her, but she felt unable to share her thoughts and fears. We explored her feelings and afterwards she went home and told her husband who began to sob and said it was a huge relief, because he had also felt that way and had those thoughts.

Well-meaning family and friends can unwittingly exert pressure on the bereaved person to pack up the belongings of the deceased soon after the funeral. There is no time limit on when or how these tasks are done. Reassurance that nothing needs to be done at speed and that they can be done in their time and at their own pace is often much needed. The bereaved may gain comfort from wearing the clothes of their loved one or carrying them around or sleeping with them. Their sense of loss can increase when the smell of their loved one begins to fade from precious items of clothing or from the room. Changing the bedding where the deceased slept can be unbearably hard. One bereaved husband changed the bedding immediately afterwards:

“It was just too painful to sleep in her smell knowing she was gone”

A mother told me that she couldn't move or change anything in her child's room after he had died and often got into the bed where she felt closeness and comfort in the smell of her child. To those less involved, to observers of these behaviours they can seem bizarre or be distressing. Confirmation to the bereaved that they are usual and acceptable for now, is all that may be needed. I say 'for now' as the importance of boundaries and limitations cannot be underestimated. It is also important that the sense of security that life does continue after a death is part of the healing process, although, the getting back to life can in itself can create vast areas of emotion, guilt, anger and vulnerability.

“About a week after the funeral I decided to go back to work .I got ready that morning it was incredibly hard I had to make myself get up and dress. Just as I was leaving the house I saw a neighbour, she waved, it seemed normal, too normal. I waved back she approached I began to feel anxious. Then she saidI’m glad to see you getting back to normal. Normal. Normal can never exist again for me. I felt guilty like she thought I was over it, like it must seem to everyone that I’m over it. I wanted to scream out.it’s not normal my daughter is dead .I needed to go to work but I felt like I was deserting my grief, I felt vulnerable and exposed.everyone in the street knows she’s dead. What were they thinking?”

The action of going back to work may be extremely hard; there can be unexpected triggers. The workplace itself can be a trigger

“.....the last time I sat in that chair he/she was alive.”

A teenager, whose mother died suddenly, told me he felt guilty for being the centre of attention and for liking the attention .At the same time not wanting to share his feelings, he feared being unable to recover them if he let them out and that would make him feel vulnerable.

The diversity of feelings within grief are enormous and confusing for the bereaved. The fear of letting go, of becoming uncontrollably distressed or overwhelmed by emotion and of being unable to recover the person he or she used to be. There may be feelings of anxiety about being asked and anger with those who don’t ask, frustration that no-one is asking or seems concerned about their feelings, or that people are disinterested.

Managing a return to life after bereavement is physically and emotionally draining, this coupled with the deep grief work being undertaken can leave the bereaved mentally exhausted. Simple tasks become increasingly harder and physical symptoms may be apparent. Loss of appetite, inability to concentrate, and disinterest in the world /life in general.

As weeks pass the bereaved become more aware of the enormity of their loss and as the cushion of shock slips away they are left with reality and eventually acceptance. The pressure to be ' doing well' or 'getting

over it' increasing. Opportunity to talk about their loved one becoming less frequent .A sense of isolation manifests around them.

Other events may cause additional trauma, such as attendance at an inquest.

The experience of revisiting the day of the death without preparation and support can be extremely traumatic. Hearing the detailed accounts of their loved ones last hours and moments can move the bereaved backwards, without the bubble of numbness or cushion of shock they are exposed to the impact of their loved ones death and of it's reality. There may be unexpected information and revelations known only to the family, these may be aired in public and disclosed to the press. This may cause huge distress, anger frustration and grief. Some coroners are aware of these aspects and impacts of inquests and of how use of language can be tailored to be sensitive to the grieving family. Unfortunately not all police officers, coroners, medical staff or coroners' assistants are aware and sensitive to these issues and can be the cause of added anguish. Preparation for the attendance of inquests is as I have said advisable, there are agencies that offer this support.

There are other events within families where the absence of the deceased is more obvious and confirmation of the reality of the death is there for the family in a very striking way.

Family celebrations and anniversaries of the death are times when the bereaved may feel extremely anxious, the importance of talking through pre planning, 'safety netting', cannot be emphasised enough. Sometimes the bereaved are not asked what they might like to do, they may be cajoled along with ideas and ways that they can participate, ways that enable them to join in, little attention may be given to whether they actually want to join in and there may be fear about them not joining in. The need to jolly those out of grief to get lives back to 'normal', could be more to do with our own sense of security and our need, to move things to how we feel they ought to be, to be comfortable. This is, of course impossible as life has changed

and will never be the same again. People are changed by death and it is only by accepting that change is permanent that grief becomes a little bit more manageable.

There is a need for everyone to be educated about death and about its impact on individuals, not only from a medical or textbook psychological or analytical stance but also from a personal and humane angle. It isn't enough to offer condolences or a listening ear. It's not enough to accept the standard phrase "I'm doing okay" because it's easy, because it releases us from struggling to find the right words and perhaps facing our own inadequacy, clumsiness, or embarrassment. Knowing that you are not alone in your experience can be a huge comfort. I often connect to my clients by using the experience of another, a thread of it, a language that seems common and understood between those who grieve. Those I work with often accept the description of life as a puzzle and its devastation and missing pieces.

"That's it.That's how I feel."

A father whose teenage child died suddenly, told me ...

"...I felt like I'd got some clay I made this vase it took ages moulding it and it was almost ready to fire to be something I could look at and see finished but then it was dropped.smashed and gone. "

By using these visual illustrations the bereaved are able to communicate with me. To describe something of how they feel. We may be lost for words and worried that anything we say or do would be inadequate or insufficient. But there is, I believe in all of us, the ability to communicate with a person at the time of greatest emotional need and to find words where so often it feels there cannot be any.

Death of a Parent

Most of us hope that we will live a long and healthy life, ideally coming to an end when we are too old to care and hopefully gently in our sleep. We accept, because we have to, that with age our bodies will deteriorate and that we may become infirm, unable to do the things that we were once able to. If we are well, healthy and have lived a moderately healthy lifestyle we may expect to achieve a 'ripe old age' From my personal perspective I say this and think of somewhere around my mid late 90's.

As we grow older we push what we feel is old further from ourselves. Life is a process and in the expected order of life we accept that our elderly relatives, grandparents and parents will die leaving us behind. If our parents are elderly, losing the senses and faculties that give quality to their lives, if we have had to nurse, or be involved in the care of an elderly parent, there may be a sense of relief when life ends. For many though, the relief may go hand in hand with a deep sense of sudden loneliness. These feelings are rarely shared, because, when ones parents are elderly and one is middle aged and a perhaps a parent oneself, society gives little regard to the loss. It is expected, the norm and order of life.

Whilst our parents are alive we are children, when they die no matter our age we are orphaned. Even though throughout our lives there is the unspoken acceptance that our parents will die one day it seems far away in the distance.

A 60 year old man whose parents had died recently, said:

"I am an orphan now, I feel alone, my roots are goneMaybe I am next, I am moved up a notch, I am the old one in the family now.

It isn't that they are gone so much but that I am left behind. The world is changing too quickly and my most stable and familiar are gone. I am relieved for them, my mother was sickly for years and feared dying painfully – it was a blessing that she slipped away gently in her sleep.

The deep loss felt by this gentleman after the death of his parents is not at all unusual or unique, but rarely talked about. We somehow expect a person who has a family of his own and whose parents are in their late eighties to relinquish being the child, to let go with ease.

I remember the funeral of my father-in-law's mother, we, the younger generation all being in our twenties and thirties gathered together afterwards in the same social way that we might at a wedding, or other family social event. Some spoke of Nana's great age, she was ninety three, others recalled memories of her living in a certain house where they had visited, but of this group the thought seemed to be that as nana had lived a long life it was acceptable that she had died. My husband's parents and their siblings also grouped together, chatting and reminiscing; there were a few tears, but there was, it seemed an acceptance, this was the expected order, her longevity seemed to make her death easier to bear.

On the other hand, perhaps the expectation may have created an unspoken pressure for older children, my husband's parents, to sit on their grief. How would it affect younger generations if the children of the elderly deceased were to express their loss, their grief, their fear, their sense of being left parentless? What could we offer?

Our expectation is that perhaps with age, comes the acceptance of death.

During the last century two world wars brought with them tragic loss of young life. Perhaps in those bygone days there was no time to indulge in grief. With so much loss and a need to survive, the focus became getting on with life, moving on. This attitude towards death and loss would have affected our parents and grandparents; they may have grown up to show 'a stiff upper lip' and exhibit 'backbone'. Perhaps these ways of thinking have influenced our present day behaviour and reaction to death, dying and bereavement. The pressure to be doing well, to say, "I'm ok" and the awkwardness of asking and not knowing what to say, so we say nothing.

We are changing, becoming more aware of feelings, the 'big boys don't cry' and 'stiff upper lip' are, thank goodness finally becoming less frequently used, less acceptable statements.

Whilst our mother or father is alive no matter their age we have an anchor to our childhood, a place to go to, although there may be little that our aged parents can offer, their presence on the earth confirms that we are not only parents, middle-aged, grandparents, but we are still someone's child.

"I wish people, friends family even could understand how I feel, My dad died young well in his 60's but mum lived on to her 90's. When my dad died I was 38, people were more supportive they were interested in how I was, There were some who when they learned his age 62, said oh well he was getting onLike it was ok. I wasn't ready for his death I still needed him there. Now my mum has died I just feel so lostShe was senile but she was there. I could go to visit her and somehow her being there gave me a sense of securitythis sounds silly I mean I'm almost 70, but no-one seems to be interested even my children it's like it doesn't matter because mummy had a good innings as they say and that makes it acceptable. It's like I'm suddenly faced with my own age my own mortality and it does feel just as painful as when my dad died."

For many children as their parent's age and deterioration, illness and inability set in there is often a dilemma 'what to do about mum or dad?' If there are siblings this might be discussed and the care shared. Some parents have made arrangements for themselves and taken time to plan for their future, for possible care that may be needed. However with spiralling costs of care homes and closures of many council run homes here in the UK, children may be faced with caring for an elderly parent themselves. This a dedicated and exhausting task, a task of commitment and can be the cause of resentments not only for the carer but from other family members who may have to adjust their lifestyles in order to facilitate an elderly relative.

"I promised my father that I would always care for my mother, he died of cancer at the age of 70. My mother lived alone until she was in her mid-eighties but after a fall I felt that she needed more constant on hand care. My children were at university and we, my husband and I decided to convert a downstairs room for her. I never knew how much it was going to impact my family. At first it was manageable,

mother could do some things alone but she became forgetful and confused and it meant we couldn't leave her .I felt guilty if I went anywhere .It caused so much trouble within the family especially between my husband and I .When mum became incontinent it was so hardI had to wash her down sometimes more than four times a day and sometimes she didn't recognise me and would be quite aggressive .I began to wish her deadit was awful I loved my mother so very much but I didn't recognise the person she was becoming . Eventually we let her go into a care home where she died. Now I cannot forgive myselfI let my father down and I wanted my mother to die because I was selfish. It's all so destructive.”

It is not uncommon for the elderly parent to be the cause of many problems within the family. Where there are siblings it isn't unusual for the death of parent to leave many arguments and unresolved issues in its wake.

“My sister hardly ever visited but since our mother died she seems to visit our parents' house a lot and is always talking about items of furniture that she'd likeI feel bitter about this because it was me who cared for mother for the last ten years .I made so many sacrificesIt's not fair.”

“My brother is bullying me over the sale of our parent's homeHe wants his share of the monies now. I feel like it's all too soon.”

“My elder sister and I have argued since the day my father died we even argued about the funeral arrangements.”

Most children have their parents with them throughout their childhood and into adulthood and beyond. The issues raised by death of a parent will differ according to the age of the child and of course the impact can vary depending on how the parent died.

When a parent dies suddenly or unexpectedly there are many issues to be addressed, not least the circumstances of death. Sudden death is usually as a result of accident, heart failure, illness, suicide or in rare cases murder.

A teenage boy suffered huge trauma when his mother died suddenly and unexpectedly from a brain haemorrhage .Not only was he shocked and traumatised by his mother's sudden death, but he was overwhelmed with guilt and self-blame.

“I feel really guilty, Mum said she had a headache that morning and asked me to bike to the shop to get painkillers. I refused and went out with friends to play football. When I got home mum was in bed really ill. I called a neighbour but by the time he arrived my mum had died .It's my fault”

He was initially unable to accept that his mother's death couldn't have been prevented, even if he had been to the shop and bought the pain killers as she had asked.

When a child is old enough to understand the circumstances of parental death there is often , in my experience , a reversal of role, just as a parent when a child dies the child looks to themselves for reasons , reproaching themselves for any 'bad' behaviour and becomes caught in the should have, would have, could have trap. The feelings that they didn't save their parent, that they didn't or couldn't protect them. It is of the utmost importance that children are given the opportunity to talk honestly and frankly about the experience of the death of their parent. To be heard, even when the thoughts and feelings are scary, and, or uncomfortable to hear, or observe, or when there is temptation to fix or make the child feel better.

It is tempting to tell the teen, who feels responsible, because he wouldn't go to get tablets for his mother, that he isn't in any way to blame, to hush his words and to try to ease his grief and self-reproach. This however is not useful. We cannot stop this lad from having such thoughts, telling him not to feel guilty will not prevent or ease his private anguish. Allowing him space and time, a safe place to work through his private stuff, will enable him to eventual acceptance, alongside realisation, that his mother's death was not preventable.

Children may also experience a sense of desertion and rejection. The parent didn't fight hard enough for life,

“If he’d loved me he wouldn’t have left me.”

“If she’d really cared about my sister and I she’d have fought harder for life.”

“Why it didn’t happen to someone else’s mum? What did I do wrong?”

“I feel really angry with my dad because he seems to think its ok that he’s going to die.”

A mother, who was told she had terminal illness, spent much time discussing her anticipated decline and death with her children. The children observing their mothers bravery felt that just as she and their father appeared to be managing and accepting, so should they. The outward display of ‘doing well’ of accepting all that was to come quietly, enabled everyone, including the mother, to believe that it would be ok. Afterwards there were comments such as *“she did ever so well for the kids – so brave, so strong.”* Such statements placed the bereaved children under immediate pressure

to play the ‘being strong game’ ‘to accept’ the death thing that was to take their mother forever, like it was just another life’s mystery and to embrace it quietly for everyone’s sakeWHO IS EVERYONE ? Why US of course, the left behind, the observers, the helpers, friends, neighbours, and acquaintances. It’s so much easier for us to believe the children are doing well.

One of the children told me:

“I was so angry with myself , my dad , the doctor , God , My mum her sister , everyone even my best friend because I wanted it to be her mum .,I wanted to scream at my mum to stop it ,How could she leave me . My dad said don’t cry in front of mum it upsets herWe have to be strong .I wanted to die with her. We were pretending it was ok. I cried every night and every morning I thought will she die today. Once I heard dad and mum crying together I went into the room and they stopped and I felt excluded so alone we never talked about it .Mum tried to act like it was some place she was goingan adventure I felt she left us long before she died .No one knows how it is for me and they don’t want to know.”

In this family the children were not allowed to attend the funeral. Whilst the husband/father was surrounded by supportive well-meaning family and friends, the children were farmed out and told to be brave for their dad and not to make a fuss. In the presence of others the children, believing it to be a fitting tribute to how well their mother managed her illness and death, played the parts of 'doing ever so well' children. So began their self-denial.

In my experience those who are terminally ill alongside working through their own needs, anxieties and fears about illness and death often feel they must make the acceptance of it and manageability easy for their families. They invest time planning and putting affairs in order, and in some cases grasp death by the throat appearing in control until eventually overcome by it. Children can and do feel left out and unacknowledged.

Their fear and loss unaddressed, often denied the grieving with the dying parent for all that they will not share. Children's grief can feel too great, too big and overpowering. It says we fail; we cannot as adults fix everything. It steals away the security we wish our child to have, the belief in us as adults, that we can protect, mend and take away the scary stuff of life

It's distressing to observe the rawness of a child's grief, too real perhaps? Hence so often, too often, we fail. How foolish we are to believe that by not involving them, by not acknowledging them we make it easier for them to bear. Children see and feel as we do and in so many ways, in my experience, they are more sensitive, they have not yet learnt to close down, or cover up. The child has little life experience to draw upon and in the very young little understanding.

Telling a young child that his or her parent has gone to be a bright star, or to heaven to be with God also says it's better there, better than being here, better than being your parent. It is vitally important that children be told, regardless of the belief system, that there are no choices about death, that a mother or father would much prefer to stay with their child than to die, that the child has not been rejected or deserted.

“When my dad was ill my mum and dad talked about it a lot. My dad told me he loved me so many times. He talked about his pain too and his fear and sometimes we just cried together. I was 11 when he died and although watching him so ill was sad and distressing I also knew he couldn’t live on and I knew how it really was. I felt part of it and my mum and me and my two brothers comforted each other. Its two years now and we talk about dad a lot and all he went through. I know he couldn’t live on and all he went through makes it easier in some ways to accept his death”

Clearly the family sharing of the experience of this teenager’s father’s death though painful and traumatic also enabled acceptance. The honesty between the close members of family afforded them the opportunity to communicate, to say things that perhaps might not have been said and importantly for the parent and child to share their grief together.

When a parent dies and the child or children are young, there is a need for the remaining parent and or close family members to keep open the channels of communication, and availability of memorabilia, so that as the child grows and develops understanding ,he or she can ask for and receive knowledge of the deceased parent .Time may seem far longer for the young , by this I mean that a year to a child of 11 will present many changes not only in every day or obvious expected ways, but in less noticeable subtle ways too. A child whose parent dies when they are 11 will not only be managing the obvious pain and grief that the death has brought, but alongside it, the massive changes to his/her growth, abilities and understanding. The way that a child of 11 is communicated with and the needs of a child of 11 are very different t to the needs and communication skills that are apparent in the 13 year old.

As adults we do not change as quickly in this physical and mental way. When we experience bereavement we can be pretty sure that it will affect us in one way and that our memory of the person and of the death will remain constant. Children are often and rightly given information at the level that we perceive that they are capable of understanding. A child may be told about a parent’s death and given what we believe they need at the time. However, in the succeeding months the child is developing and may need more information as the development proceeds.

Whilst working at a secondary school with bereft teens, I worked with many youngsters who were experiencing a need, to revisit and explore their parents death as they grew older .Their needs, comforts they required at the time of the death, were not the same as the needs as they grew older, as time passed they all seemed to say the same thing –

“I knew my parent had died, but I didn’t realise then that it is forever.”

A year to a child of 11 is an incredibly long time and over a 2 or 3 years the changes that occur to the child are quite phenomenal. A teenager whose mother died when she was 11 told me:

“It’s been 3 years since my mum died and I try to remember her but it’s really difficult, There are things I want to ask about mum but we don’t talk about her often and I don’t feel I can ask things When I try to remember her I can’t think of enough memories .I don’t want my auntie to be upset or to think she hasn’t done a good job looking after me .I think she thinks I’m over it but I know I’ll never get over it .In fact sometimes I feel worse than I did and I can’t believe it’s three years since mum died”.

Another teenager told me:

“It was 5 years ago but I was just a little kid then. I can’t tell the family that I’m grieving what I know I’ve lost nowthey seem to be over it but I feel liked as I’ve got older I’ve woken up to it . My dad’s death has affected everything sometimes I feel so low just thinking about everything I’m missing with him and I struggle to get a picture of him in my head or the sound of his voice .No-one seems to realise how I feel. When dad died I kind of got through but as times passed and I’ve changed I’ve needed more. My mum has started to rebuild her life and I want her to be happy but I feel like I need to talk more nowIt’s a very lonely place to be”

Clearly we need to be aware of the needs of children who are bereaved and to be aware that for them the passage of time isn’t a healer as it might be for the adult, with growth and knowledge it may bring further anguish .My experience of bereaved children is that they are largely unacknowledged. What we may feel is protection can be exclusive and isolating and that their grief may need extensive space and time to revisit as

changes occur. Change and lack of power after the death of a parent can also cause the child who may feel that their feelings are selfish, or too demanding, to withdraw and outwardly to appear to be doing, what those around feel, most comfortable with, 'DOING WELL'

“When my parents died in a car crash I was 13 years old. My elder sister and her partner and their two children came to live at home and look after me. At first it was ok but then my sister’s partner started to change things in the house and no-one asked me. I felt like they had moved in on my ,angry that they didn’t seem aware of how I felt Guilty because everyone said they’d done a very unselfish thing coming to look after me so I could stay in the house and at the same school and near my mates. After a couple of months my sister decided to start moving things and brought a lot of her own furniture and things .They did let me keep one or two things that belonged to mum and dad but most of their stuff was taken away. It’s three years since my parents died and I still feel out of place, lost, sometimes feel like my life died when mum and dad died, like that’s another life and now I am existing in one that doesn’t fit .My Sister gets really irritated with me and says I should be grateful, more appreciative but I want to tell her that I feel like an intruder in my own homeIt doesn’t even look the same. Soon I will leave school and get a jobI feel alone , no-one knows or understands when parents die it changes everything forever and the ripples just go on .I seems that people think after 3 years I should be over it or at least feeling differently but I still feel shocked , sometimes I think it can’t be true . Sometimes I sit very still in a room and try to hear them, the familiar sound of mum in the kitchen or dad watching TV. Then I get distressed because I can’t remember them the sound of them. The other day I thought when dad died I was only about 5 ft. now I’m 6’2if dad were here I’d be taller than him – that’s hard to imagine .”

When a parent dies there are many changes in store for the child. Some obvious to all, but others often occurring within the child’s world and not apparent to the remaining parent or caregivers, until the child speaks them. Some children do not speak at all, bearing their grief alone. My observations of grieving children are that they seem to be able to dip in and out of it , one moment immersed in it’s all consuming painful reality and in the next playing a techno game or engrossed in a TV programme. This swift mood

change may to some observers seem fickle or may be perceived as lightweight grieving. In my experience this IS simply how grief is and however the individual reacts to their personal loss is acceptable and needs acknowledgement and validation. It's ok to do it your way.

Younger children are capable of decision making, they benefit from being involved and given choices where possible.

Allow space, time for them to begin to adjust to a situation that has rocked their very core of security. It is vital that in the rush to give comfort and protection we do not exclude or cause stifled emotions. Gentle acceptance of their individual experience and a willing, non-judgemental ear for as long as they need it, alongside the security and continuum of life disciplines, required tasks, education and other boundaries, offer balance. The child's world is progressive it changes daily. Experiences cause them to develop and grow and for some, traumatic experiences can cause stunting of growth. This is reversible as long as the child has the opportunity within a safe trusting relationship to explore and embrace all that the experience of grief brings to them.

A child who has experienced the death of a parent needs ongoing opportunity to address what the death of their parent means, to adjust as they grow to its on-going impact.

"I've listed my losses since my mum diedThey are huge but they need to be because she was my mum and that's how it is"

My response to this simply –

"Yes and for you that's exactly how it is."

Death of Spouse or Partner

The relationship between two people is unique and the death of a person within that relationship and the feelings experienced by the remaining partner are as individual as the relationship itself. We all hide our true feelings beneath a shell, only showing people the parts of us that we wish them to see, but it is only to our chosen partner do we reveal the real person beneath the façade, and the whole truth about our relationship is only known to the two of us. We assume that we know a great deal about the lives of family and friends because we may have known them intimately for many years, but sometimes we can find ourselves shocked by revelations about the private lives of people who we thought we knew well. Many bereaved partners have told me that they feel that assumptions have been made about their relationship by those on the periphery and other people's perspective on their relationship can appear judgmental or devaluing. Our assumptions and interpretations may cause the remaining partner to feel unable to share their grief and innermost feelings and become isolated. It may difficult for the husband whose wife died of terminal illness to talk about his sense of relief, or the partner in a new relationship to feel acknowledged as an important part of the deceased person's life.

In this chapter I hope to explore the diversity of grief for bereaved partners. When a partner dies, whether they are young or old, the hopes, dreams and plans for the couple's future are brought to an end. For young and old alike, the death of a partner is the confirmation of mortality.

Death comes in many guises, and where it is sudden or unexpected the bereaved partner may have to cope with many personal emotions, the grief of other family members and the sense that much has been left unsaid. It does not seem to matter how expected or planned a beloved partner's death is, its arrival can bring the sense that life is unfinished or passed too quickly. Men and women manage their grief in different ways and the differences in how they grieve are enormous. There may also be secret areas in the life of the deceased which were not disclosed to partners or family members, undisclosed financial affairs, debts and in some circumstances unknown loved ones or other families whose presence is only revealed

after the death. Discovery of such hidden secrets can greatly add to the burden of grief of the surviving partner as they often feel they cannot discuss them with anyone, but have to keep the knowledge locked inside themselves to be taken out and examined only when they are alone and vulnerable.

A male client whose wife of fifteen years was diagnosed with terminal cancer told me that he felt he lost her the day her illness was confirmed.

“I felt out of control - this sense of not being able to do anything to help her or change things, that we were both heading towards something so scary and there was nothing we could do. I felt angry, angry at her and at the doctors, angry that our lives were about to be messed up big time. I wanted to get away from it and, I feel ashamed to say it, I wanted her to die quickly. I didn't want her to go on dying slowly while I observed. I was scared of what lay ahead but not so much of after her death, strangely that didn't seem to come to mind much. I was scared of going through her illness with her. As time went by I felt excluded, she began this journey towards death and I was just there, not able to offer much at all, and as more doctors and nurses became involved I felt useless, I talked to her about our lives, everyday stuff, but I couldn't join in her conversations about death. I felt angry that she seemed to accept it although I knew there were no choices. As she grew more sickly she spent more time in hospital where she befriended other people who seemed more able than I to communicate with her. I started to go out with the children alone. Our lives began to change. Before her illness I thought she would need me but there was nothing that I could do for her”.

The confirmation of his wife's illness brought with it a realisation that this wasn't something that could be resolved. He felt trapped by the illness and afraid of his own limitations. His anger that life had suddenly changed and the future that they planned was not going to happen. He was isolated by a sense of powerlessness and loss of control and ashamed of his vulnerability and fear of what was to come. His observations were that his wife had become part of a world from which he felt excluded and that medical professionals were now part of her life and that the other patients were now her familiar and new social

contacts. She had planned her funeral, talked about her hopes for the family after her death and appeared to be 'doing death well'. This led her husband to feel frustrated and more useless because he couldn't stop this death thing that had slipped unexpectedly through the back door whilst they were busy living. He couldn't protect her from it, bargain with it or change places with her. There were days when he wanted to leave and never come back, days when he wanted to shake her and make her fight it and days when he wondered if it would be her last. The family were riding an emotional rollercoaster and no-one knew when or how it would stop.

“As my wife grew more ill there was an air of impending death in the house, sometimes I felt I could smell it, touch it. Friends visited less frequently. I felt isolated and alone, nurses were a welcome relief with their cups of tea and sensitivity but I couldn't tell them how I really felt. As my wife became more incapable I wished her dead. I looked at her once and thought ‘Who are you?’ She didn't look like my wife anymore. Letting her go to a hospital was not easy. I felt so guilty as they took her away, she had wanted to die at home but I couldn't go on with it any longer and although I felt guilty, there were feelings of relief. It was coming to an end. For the next few days I sat with her, I felt guilty for not crying, for not desperately wanting her to keep going, I remember praying on every breath that it would be her last.

After she had gone it seemed suddenly too soon. I began to think all about how for most of the time I had distanced her and her death. I started to think about all I didn't do or hadn't said, I missed her. Sometimes I long for the closeness of her I know it sounds bizarre but I have climbed into the wardrobe just to smell her clothes”.

The impact of discovering that your partner has a terminal illness is a shocking and often isolating experience. The need to understand and accept what is happening alongside the fear and the knowledge of the changes to come maybe overwhelming. Often the focus is on the person who is terminally ill and

partners and other family members can feel alone and disregarded. The feelings that they are experiencing may be alien to them and emotions such as anger, resentment and self pity may feel too awful to share. Another husband talked about feelings of freedom after his wife's death, his contemplations about his attractiveness to other women and a sense of excitement that he might meet someone else swiftly followed by huge feelings of guilt because it felt like he was being unfaithful.

“I think I got used to my wife not being here quite quickly and I feel guilty for that. I felt a sense of pleasure being able to do things and consider only myself. I missed her of course but I felt ok alone. In the beginning I tried to keep things the same, the garden, the household chores but after a while I started to move things, change things and do things my own way. I enjoyed the changes.”

“I feel guilty about the garden mostly because my wife loved it so and it was neat but gardening was never my thing, I mean I only did it to please her. I sometimes wonder what the neighbours think”

The change from 'we' to 'me' can be a very emotionally complicated process. Often within relationships couples give up parts of themselves in order to gain togetherness so when a partner dies there is conflict between the need to be the same, to continue without the partner and keep things going in their absence and with the need to find oneself. When death occurs in any circumstances it creates a permanent change within those it touches. The most common thoughts are on the bereaved person's diversity of feelings - on the one hand feeling lost and needing continuity to keep the sense of security that existed because of the established relationship, but on the other hand the finding of new interests which are pertinent to you alone.

“My husband bought this chair; he loved it and used to fall asleep in it every night in front of the telly. I never liked it, monstrous thing, it isn't even that comfy. I really want to get rid of it but I have this feeling that if I do, I'm going against him. My daughter says ‘Oh Mum, you can't get rid of Dad's special chair’.”

“My wife said she wanted me to move on, maybe find someone else, not to be alone. It's like she's given permission but I still have these feelings of guilt. I was going to take off my wedding ring but it felt like I was leaving her and all our marriage stood for behind.”

“I always wanted to travel but my partner wouldn't; now I can and I'm trying to get courage to go alone”.

“My husband and I had a rocky marriage, we argued most days, I miss him so much. I wish we hadn't spent so much time arguing, but I also feel guilty because I feel better without those arguments.”

The feeling of guilt is frequently experienced by those who are bereaved. The self-recriminations of ‘should haves’, ‘would haves’, ‘could haves’, ‘wish I had said’ and the ‘wish I hadn't said’.

“I was too busy that day, she said she didn't feel well but I said ‘Oh get up and get about you'll feel better then’. I didn't kiss her goodbye; I didn't tell her I loved her. I just stuck my head round the bedroom door and said ‘You'll feel better if you get up’, then I said something ‘Like see you later’ and left. If I'd taken more care, if I'd waited with her, if I'd been there, if, if, if. I ask her sometimes ‘Just come back. It'll be different’. I know that sounds stupid but sometimes I think it's all a cruel joke.”

This husband felt that by leaving his wife, by ignoring her symptoms of illness, he was responsible for her death but even if had he stayed his wife would not have survived the sudden, massive heart attack that killed her. Bargaining with a deity or begging for the return of the loved one is also common. The immediacy of being alone, the lonely future stretching far, far ahead and the cessation of all hopes, dreams or plans for the future are all that seem to be available to the bereaved partner at that time.

It is a common assumption to think that all deaths are mourned and a devastating blow to the surviving partner. One wife told me that although she gave the impression of a grieving widow, she actually was glad her husband was gone from her life.

“My husband was a bully, for years he was aggressive and made our lives miserable. I often fantasized about life, without him how much better it would be to be rid of him. I will cash the insurance policies, sell everything and do what I've always wanted, to make a new life with my sister in Australia. I won't have to argue for a divorce any more”.

This client experienced deep feelings of guilt because she was not as devastated by the loss of her husband as other people assumed she was. We spent many sessions working through her turbulent relationship with her husband and her frustration and anger with herself for not dealing with it while he was alive. Another common assumption made by ‘outside’ people is that elderly people who have been married for many years accept the death of a partner as a natural occurrence and therefore the bereaved partner is not the recipient of as much consideration and understanding as a younger widow/widower. People justify these assumptions using such phrases as ‘Oh well, he/she was 70, 80, 90, he/she had a good innings’. A client of 80, whose husband died unexpectedly whilst asleep, told me.

“We were together forever, I can't quite believe it was 63 years, it has flitted by all too soon. I can't imagine going on without him, no amount of time would have been long enough for us. I wasn't ready for it yet and I want to slap those who keep saying he had a good innings.”

Society treats the young widow very differently from the older widow, but who is more deserving of our compassion? The young widow gains sympathy for her perceived loss and for the years she did not have with her husband. The older widow is the recipient of such comments as ‘Well, you had a long time together’, but which of them is going to find grieving easier or death more acceptable? The older widow has a confirmation of the finality of life and her sense of isolation and loneliness can seem unbearable. Her

family's lack of regard and understanding caused her greater distress and depression all largely unacknowledged because after all 'they had had a good innings'!

Who is the judge of how long is a 'good innings'? Does age alters the depths of emotion and feelings? Do we become less sensitive to loss when those we love and are long standing parts of our lives take their leave and depart? Does age bring quiet acceptance of our own mortality? If we were married for a hundred years would that make letting go easier? It may be the nagging suspicion that perhaps the aged do not march joyfully on leaving those they love behind and that those they love do not willingly accept their passing that keeps us uttering such banal statements as 'he had a good innings' or 'life was very difficult for her after the last stroke', all too often assumptions are made and the true feelings of those grieving the loss of their cherished partner are neither heard or acknowledged. A loving partnership can also involve those who were not married but committed within a relationship and following the death of one partner, the surviving partner can often find their position disregarded. In law perhaps the blood family of the deceased person may take precedence as 'next of kin', but both emotionally and morally a partner needs to have their links with the deceased person acknowledged and considered. A young fiancé of a woman killed in an accident told me

"I had no say at all about anything. I wanted to arrange the funeral and I wanted her buried nearby but her family made those decisions. I feel angry that they said 'You're young; you'll meet someone else. Thank goodness you weren't married or there weren't any children'"

Words of comfort and hope for the future offered by people who are meaning to be kind can unintentionally trivialise the depth of commitment between the partners. They may be trying to be positive and show the bereaved person that there is a future for them laying it before them with enthusiasm and optimism, but who are they trying to reassure? Themselves, maybe? The focus for the grieving partner in this relationship was the loss of his beloved fiancée and he still needed to acknowledge his loss of being part of a couple and the loss their future together. Well-meaning people trying to comfort a bereaved person sometimes say 'Well, at least they didn't have children', not realizing that this the lack of a tangible proof

that once there was someone who loved them enough to have a child with them, is yet another twist of the knife in the raw wound of grief. It can be thought that a future life may be less complicated because the couple didn't have family and the assumption that youth gives the bereaved time to heal and they may find it easier to make a future if they carry no outward baggage from the past. This may be true, but in the immediacy of their grief, the thought of any future, let alone with a new partner is unthinkable.

“When my partner died I felt as though everything went with him, I know this might sound strange, but I'm also grieving the children we often talked about having. We used to talk about the future and having a family, we even gave the children, we hoped one day to have, names - I feel they have died too. I can't tell anyone this they'd think I was crazy”.

Partners of the deceased often struggle to gain recognition of their place within the life of their loved one. The devaluation of the relationship can cause added anguish and create a greater need for acceptance. Sometimes there is no recognition or acceptance of the partnership from the relations of the deceased.

“We were together for just over a year, we'd just moved in together. I feel as though I'm not important. My girlfriend's family said they are coming to collect her things, I feel powerless”.

A married client who had been having an affair with another woman told me

“I feel like this is my punishment, I have been denied everything”.

He was faced with grieving alone, unable to share his loss with anyone and clearly felt that his deceit was to be punished by death of the woman he loved and exclusion from the closed circle of shared grief. Secrets are often revealed about a person after their death, most often by reading a diary and revelations about thoughts and feelings both past and present can be either comforting or the cause of added distress to the bereaved partner and their family.

“After her death I started to go through old photos and keepsakes. I knew she kept a diary but I wasn't expecting it to be so intimate or so revealing. Initially I found comfort in her words but there were also graphic accounts of arguments, her thoughts about me, and her anger and, in some passages, her hatred and plans to leave me. These were very distressing. I feel angry with her for dying and for not being here to talk this through - I'm just left to deal with it”.

It is very important to not only face the impact of any negative discoveries but also to accept them. It is also necessary to have balance and for the bereaved partner to realise that some of the writings in the diaries were loving and comforting for him whilst others caused him distress. The reality was that this was the truth about this relationship as the deceased saw it. As human beings we often focus on the negative aspects of a situation and place the positive aspects as those of less importance.

Those who are emotionally devastated cannot find the capacity to rationalise alone, often erring on the side of self-recrimination. It is very beneficial to encourage exploration of the whole relationship accepting both the imperfections and the glorious moments that create a balance of perspectives.

Sex and New Relationships

There are many instances where newly bereaved clients have disclosed rather shamefacedly, that they felt the need for sexual satisfaction within a very short time of the death of a partner and felt guilty for having thoughts at such a time.

“I feel so ashamed that after my wife's funeral I relieved myself by masturbating. I went to bed and just had this need for comfort. I haven't masturbated for ages, but it felt overpowering, afterwards I felt guilty. I seem to need this like a comforter”.

“I don't understand why I have this need, sometimes when I think about my wife I feel guilty and if I think about other things – fantasise, I feel guilty too.

These feelings and actions are not unusual or disturbing as the craving for comfort is, I believe, the driving force behind the sexual need. Young children often rock or caress their genitals when they are distressed which seems to provide fulfilment of their need for comfort. These feelings can resurface when we feel threatened, stressed or traumatised and all of these emotions are very strong during the period of grieving and self gratification can be comforting. Sometimes clients disclose that they have sought the comfort from another person and feel deep regret or confusion about their need and actions. Attachments can be formed to those involved, for instance with nurses who may have been closely involved with the dying person and are perceived having a sympathetic and caring nature. They may become the confidante of the very private and personal thoughts of the surviving partner and consequently may become a focus of their attention. The bereaved are vulnerable and often emotionally insecure and their need for contact with others can be misinterpreted and lead to complicated situations that they do not have capacity to manage at that time.

“I nursed my husband at home until he died. His brother and I had never been close and I certainly never thought of him in any way other than as my brother-in law. In my husband’s last days I found his brother so supportive. After his death I longed to be held and I don’t quite know how or why but I ended up with my brother-in law. He stayed over with me and I just so needed the affection.

Now I feel guilty, I don’t know how to live with myself, I just feel like I’ve sullied my husband’s memory”.

“I was so lonely, my neighbour, a single mum had been amazing while my wife was in hospital. She’s a really lovely person. I did find her attractive - who wouldn’t? When my wife was ill she sat with me till the early hours, just keeping me company, and I knew I was getting attached to her. I even fantasised about asking her out. Anyway we have slept together just once and straight away afterwards I regretted it. I feel like I’ve been unfaithful, but I needed someone so much. Now I can’t bear to see her, it’s all too unmanageable”.

When we are in crisis and vulnerable to our emotions we may be unable to think as clearly as we usually do. We may make decisions that we regret. It needs to be remembered that the period following the death of a beloved partner is a time of immense emotional turmoil and these are not 'normal' times and that our needs and desires can be in a confusing jumble. Those that are the focus of attention of a bereaved partner need to be aware of this and whatever their needs at this stage, concern and regard for the vulnerability of the bereaved still need to be the main motivating factor whilst in their company. Jumping into an intimate encounter or relationship with a bereaved person whilst in the early days of their loss can be the cause of greater devastation and added complications and anguish, not only for those immediately involved but also for the extended family.

Family and friends may sit in judgement on the remaining partner. There can be complete confusion about how things ought to be. Often friends and family try to jolly the bereaved out of grief, invitations here and there and introductions to new friends. However the partner who takes a new partner may be judged and talked about as though he/she are doing this so soon, but what and in whose opinion is 'too soon'?

The Victorians had a set period for mourning to show 'proper respect' to the dead. The length of mourning depended on your relationship to the deceased. The different periods of mourning dictated by society were expected to reflect your natural period of grief. Widows were expected to wear full mourning for two years. Everyone else presumably suffered less – for children mourning parents or vice versa the period of time was one year, for grandparents and siblings six months, for aunts and uncles two months, for great uncles and aunts six weeks, for first cousins four weeks. These days there is no set length or correct pattern to a period of mourning and if you are bereaved, then yes, you do need time, space and support followed by a gentle introduction back to a different and perhaps intimidating life which, for you, has changed from the familiar ways of the past. If this future does include a new partner, as long as this happens in your time and when you are ready, then welcome the opportunity.

Supporting a bereaved partner

If you take the decision to support the bereaved partner then you need to first ask yourself why you are seeking to support this person, be aware of your own personal needs and be guarded about your motives. The bereaved person needs to work through their feelings before they are capable of thinking about another relationship, so even where you feel physically attracted to them try to use your capacity to manage your feelings thus allowing time for this person to complete their pathway through the grieving process. If you hope the relationship will eventually develop, it will benefit from time, space and a more emotionally solid foundation.

“I met my partner almost a year after my wife’s death. I feel very anxious about any sexual relationship. I enjoy cuddling her but I just feel it's wrong to take it further, I don't think I am capable of sexual intimacy with anyone else. I do fancy her but I just feel like I'm being unfaithful. Also, I know it sounds silly but I keep thinking of my wife watching me and I don't want to hurt her. I sometimes get aroused but can't bring myself to orgasm either, it just feels wrong”.

Just as increased sex drive is not unusual after bereavement, the anxiety and stress which are usual at this time can cause a lack of sex drive or impotency. Feelings of guilt and unfaithfulness and thoughts about the deceased partners and feeling that he/she may be watching them are also usual and often unspoken for fear of being ridiculed. The communicating of these thought and feelings to a trusted friend or counsellor can help tremendously with the manageability of grief and self permission to live alongside loss.

Single Parenting Children

“I am trying so hard to keep things together; I try not to get upset in front of the children. At first I just kept busy but now I'm finding hard to get motivated. Sometimes I feel angry with her for leaving us, for leaving me with the kids. I can't do it all alone. Then I get angry with myself”.

“I feel so totally alone, I cry at night when my kids are in bed. I can't let them see me cry, I think they'd be scared if they knew how I feel. I'm worried too about money and how we're going to manage. I sometimes wish I could just walk away. It's so hard much harder than I ever thought it would be without him. I don't want people to know I'm not doing as well as they think”.

Becoming a single parent through bereavement is incredibly hard, physically, mentally and emotionally. Many newly bereaved partners tell me they feel exhausted, that they hide their emotions fearing letting their children see their devastation and that they are anxious about coping, doing things the right way and appearing to be managing. The stifling of feelings and the constant anxiety drains their energy and adds to their sense of isolation. Sometimes the remaining parents feel they have to keep things to a certain standard, fulfil the role of the deceased parent and go beyond the needs of their bereaved child in order to compensate. They fear communicating their own grief because often they fear letting go, losing control of themselves and not being able to recover. The pressure to see their children through grief is their main priority. Sometimes overprotection of children and the belief that the children should not see the bereaved parent's distress can be cause of breakdown of real communication within the family.

Children are often more aware than we realise, and they too can hide their feelings in order to protect the remaining parent. This quickly becomes a vicious circle, the children trying to protect their parent, the parent trying to protect their children and thus no-one speaks.

“My Dad seems to be ok; he doesn't talk much about Mum. He sometimes cries but never in front of us. My aunties say we must all be strong. I never talk much about Mum because it just upsets everyone but I would like it if Dad and I could talk about her, even if we are sad”.

By allowing children to see our pain and our grief we reassure them that they too can express their feelings. They do not have to protect us from their scary grief and by observing that sadness in others is acceptable,

they too can share their own feelings. It is important for families to communicate and for the deceased parent to be talked about and to mourn their death. We cannot protect those we love from death or from feeling its impact, but by communication we can help them to manage and accept their loss.

Making Changes

Changes do happen. We are often not aware of the small, subtle everyday changes until suddenly they have happened and we realise that something is no longer as it was when our loved one was alive. Making changes can feel very uncomfortable; some changes may be inevitable and necessary for the everyday management /function of the family. Other changes may be made by choice and these are often cause mixed feelings, on one hand there may be pleasure in change and on the other guilt because those changes take a little more of the loved one away.

“After my husband’s death I decided we ought to move nearer to my parents. We had only moved to this area because of his work. I longed to be near my Mum and Dad; I needed their support with my baby.

I wish I hadn't rushed it now. I feel alien in our new home and I miss familiar things. It feels like my whole world has changed”.

“I decided to redecorate our room. I don't know why but I just wanted to pack up my wife’s things and change everything. I feel lost now like I've pushed her out completely and I miss the sense of her in our room”.

Sometimes well-meaning family or friends may instigate change believing that it can help the bereaved partner. The choice, the decision to change, needs to be thought through carefully and nothing done in haste. It is vitally important that remaining partners and children are consulted about any change and that they are comfortable with it.

“In spite of the attempts of family and friends and their kind offers to sort through my wife’s clothing I am not ready to do it. I want to keep her things where they are, our children like to see her things around. We talk about her, we miss her, we know that she was here with us. I know a time will come when we are ready but why don't others allow us to just be as we are”.

Why do we try to encourage the bereaved pack up their loved one’s possessions? Why do we believe they'll feel better for it? Is it our own awkwardness about the belongings of the dead that causes us to rush to offer to pack them for others? The physical evidence of their existence, the coat or shoe that will never be worn again, the bag or briefcase that will no longer be carried, they all remind us that their owner is no longer here, that they are gone. It does perhaps enforce the fact that we are only a friend or family member, we can only observe the grief of the family and that we cannot make it better or make the grief go away. So, we encourage the packing up, the moving on, we discourage the lingering and bring out the ‘doing well blanket’. Oh good, they've changed the house, gone on holiday, bought a new car – they seem to getting over it, they appear to be ‘doing well’, and that is comfortable, we can accept that, we have helped them achieve **our** goal – getting on with their life. But, of course, the truth is that we cannot run from the pain of bereavement. Holidays, cars, decorating and change do not make it easier or go away. It is time, measured in seconds, minutes, hours, day, weeks months and years, and only time coupled with the opportunity to communicate and feel heard will eventually help the bereaved work their way through the turmoil of grief towards the relative calm of acceptance.

When a Child Dies

Death before Birth

The confirmation of pregnancy can be the most fulfilling and exciting moment of a woman's life. The feelings of anticipation and expectation generated at this time are unlike any she has experienced prior to this moment. Some pregnancies are not so welcome and for some the news may be devastating. They may decide to terminate the pregnancy, either for reasons of a personal nature or on medical advice. Some women experience a sense of relief following their termination, but for others it may be an emotionally painful experience. Whatever the decision or circumstances, all women need the opportunity to acknowledge their feelings and address any issues raised by the decision.

When a woman is glad to be pregnant and happy with her condition she begins to plan for her child and for the bright and exciting future ahead for her and her family. The baby growing inside her has already been given a personality and more of the expectant mother's attention will be paid to the other people's children, as in her own mind she relishes her impending motherhood. Some expectant mothers feel an almost instantaneous connection with their growing child and clients who miscarried early at 10 or 12 weeks have told me that they already knew in their minds what sex their baby was and how they would look.

Miscarrying a baby is a traumatic experience, both emotionally and physically and many women often feel further distress by hearing their baby referred to as a 'foetus', a 'cluster or bunch of cells', a 'miscarriage' or a 'missed abortion'. The medical professionals usage of correct but insensitive language can make the grieving mother feel disregarded and forgotten in her need to acknowledge the little life that was developing inside her. She may be experiencing feelings of failure, guilt, self-blame and redress.

“When I started bleeding, I went to bed, I tried tilting my body so that my lower half was higher, I thought that might hold him in. I couldn't stop it, I just bled and I felt so alone. I sat on the loo just crying. It seemed too awful that my baby was disappearing down the toilet. The doctor said he'd admit me for a scrape. That word felt so brutal. No-one talked about my baby like he was a baby, but to me he was very real. I used to look at

books photographs of developing babies and think “Ah this week his little hands are growing”. I don’t think anyone knew what to say, someone said it’s probably for the best I felt alone. I kept thinking “Why me - what had I done wrong?”, then I thought it was because I’d had a drink at my friend’s wedding . It was only one drink but I wish I’d been more careful. I called my baby Steven. I can’t just forget him. Giving him a name makes it easier somehow, like although everyone else thinks he was just a blob, I regarded him, loved him, wanted him and I won’t forget him.’

The misuse of language can cause added pain and distress to the bereaved parents and in particular, the mother. Words of support offered by well-meaning friends and family such as “You’ll have another baby”, or “It’s nature’s way “makes the mother feel that her loss is not being recognised as a bereavement and her grief often remains unexplored and in isolation. The hormone levels in her body are still telling her that she is pregnant and her body’s return to a pre-pregnancy state can take several weeks and cause side effects.

“I was thrilled when I was pregnant It was my first time and I felt so special. I was so shocked when the doctor said he couldn’t see a heart beat on the scan and in one moment my world was devastated. I wanted to get home and be with my partner but the doctor admitted me for a D&C (Dilation & Curettage). I had never had one of those before. He said I’d had a missed abortion I didn’t understand his language really. I was admitted to hospital and in the next bed to me was a woman who was pregnant with twins and on the other side was a young girl who had had a termination. I was in the middle. I was alone and I had to wait until morning for them to take me to theatre. I felt like everything was out of control and I had no choice. I didn’t ask too many questions because I thought they’d think I was a nuisance. Strangely I didn’t feel any different ... I still felt pregnant. I wondered if they’d made a mistake. I was shaking and sobbing as I went down to theatre and I felt totally patronised by the nurses who referred to me as a big, brave girl. Afterwards a doctor said my baby had died at least two weeks before and that this happens sometimes I should go home and in a while try again.

What about my babywhere was it, I felt pretty helpless and as if asking anything was inappropriate. It was important though for me to know about my baby. I couldn't see it but I wanted to know where they had disposed of it. I was haunted by these thoughts of it being kept in a jar somewhere. I felt very low. I couldn't talk to anyone about it and as days went by I began to feel as though I was engulfed by black. I lost interest in everything and I couldn't cry. I felt numb. A vicar came to see me and I told him I wanted to know about my baby. I was 14 weeks gestation when it died. The hospital told him that they put the remains of my baby in the sluice. I was very distressed but then the vicar said the sluice would eventually go to the sea and in that I found a little hope. I was depressed for almost a year and life lost its joy for me. I will never forget how I felt. I have two children aged 15 and 13 now, but I feel I really had 3 and still think of that baby and the life it never had".

Many thoughts and feelings are so often left unspoken and the lack of acknowledgement and importance may lie beneath the surface causing resentment and stress within the relationship. Whilst acknowledging that both partners are affected by the death of their unborn child, it is the feelings of the woman governed by the hormones released in her body during pregnancy, who suffers the ongoing symptoms that can affect her in ways that her partner may not be able to understand or relate to. Some women may yearn to be pregnant again almost immediately and experience a sense of frustration if she is told by her doctors to wait a while or if her partner seems hesitant.

"After we lost the baby my partner was really supportive for the first few weeks but after that I could tell he was getting fed up with me talking about it. I was still feeling so empty so sad and so very cheated. He said he felt sad – sorry that we weren't going to have the baby after all but that we would have a baby one day. I really wanted to talk about this baby, the one I was expecting. I know people say, that they aren't babies at 14 weeks, but I felt like mine was. I was sure it was a boy and I used to look at pictures in magazines and

try to imagine what he'd look like. I felt I'd lost my child and no-one really wanted to know. In the end I just kept my feelings in. It took ages for me to fall pregnant again and I have a daughter now aged three but I want my unborn child to be acknowledged too."

For some couples the desire for a child can become the focus of their life and this often brings added stresses and pressures to the relationship, and in particular to the sexual aspect of the relationship where anxieties about conception can create impotence and cause once enjoyable and relaxed lovemaking to feel contrived, planned and clinical.

"We used to have such a fantastic sex life it was spontaneous and exciting . Since losing our baby we have been trying for another and 'doing it 'at certain times – I've been taking my temperature and keeping a chart so we know when I'm ovulating. My partner often finds arousal difficult. I have felt like we are not as close I didn't expect this to happen and now he says he thinks we should stop thinking about another baby for a while I can't. It's causing lots of arguments. No-one seems to understand".

The loss of a baby in the early weeks also often causes the expectant mothers to blame themselves or experience a sense of failure. It is important to explore these feelings and to validate the experience and its impact on the mother, the relationship and the ripple effect on all areas of life.

"I had just attended my first ante-natal class I was 14 weeks and my friend was also pregnant, we had planned to do so much together and life seemed complete. When I lost the baby, she was upset and afraid for herself. I felt angry that she was concerned about herself, her pregnancy. It seemed so unfair that this happened to me. She stopped coming round – she told my husband that she found it hard that she felt guilty for still being pregnant. I was glad that she stopped calling. I didn't want to hear about her or see her getting bigger. It was like part of my life was taken away My plans. Also I noticed

other pregnant mums and thought 'Why couldn't it have been you?' I felt guilty about that and angry too".

Often for the mother this might be her first experience of loss and the extent and depth at which she is impacted will depend not only on the level of support and understanding she receives but on past experiences. Her recovery may be helped or hindered by the care she receives at this crucial time. Bereavement can often cause other fears to rise to the surface and may be a trigger for the release of past emotional turmoil. On the Internet there are several websites where the unborn are remembered and grieved. Many women express their innermost thoughts and feelings on these websites, women whose babies have not survived into life and are holding their feelings of loss within themselves. They write of their grief at the lack of society's acknowledgement of their child's existence and death, the lack of understanding of friends, family, neighbours and work colleagues during the struggle to come to terms with their loss and their overwhelming feelings of emptiness because some mothers feel that a part of them has died with their child. All deaths both before and after birth needs acknowledgement and acceptance for only then can those who are bereaved feel they have permission to mourn.

"I started to get this really bad pain in my stomach. I phoned the doctor, he said It sounded like food poisoning and if I wasn't better in 24 hours to call him again. Within a few hours I knew I was having contractions, I was 7 months pregnant. I phoned my husband, but by the time he got home they had stopped. I went to my doctor he couldn't find a heart beat and admitted me to hospital. My baby had died but I had to deliver it.

I was so shocked and I couldn't believe that my baby had died. I thought they had made a mistake. I was hoping that once labour started they'd tell me it was ok. I had lots of pain relief and the staff at the hospital were very kind after just a few hours my baby son slipped silently into the world. He looked perfect. I didn't want them to take him to perform an autopsy but they said they would need to establish why he died. I was horrified that my baby was going to endure yet more, his perfect little body. I was so alone, so useless and

cheated. The hospital took photos of him for me and I named him but they didn't offer anything else. I left him at the hospital and I often wonder what they did with him".

In many hospitals there seems to be the assumption that the reason why a patient doesn't ask a question it is because they do not want to know the answer. My experience is that often the patient does want to know but perhaps does not know how to ask for information. They are frightened that these capable and efficient people who are caring for them may think they are a nuisance, that they are morbid or strange and that they may not like them if they make a fuss. All of these comments have been said to me at some time during counselling sessions.

All people are individuals with their own ways of feeling and behaving, but yet we expect them to all conform to acceptable and emotionally straight jacketed behaviour at a time of enormous mental and physical turmoil and distress. Perhaps it is because we are afraid that if we experience the real and raw emotion of another person's distress, we will be unable to control or contain our feelings which will then escalate and magnify beyond our control.

Some hospitals are only too aware of the depth of grief and distress experienced by bereaved 'death before birth' parents and are willing to spend time with them and try to answer their questions honestly without recourse to jargon and consider their requests sympathetically. Unfortunately though there are many hospitals who suffer staff and money shortages so they have neither the time or facilities to provide this comfort to bereaved 'death before birth' parents who leave the hospital taking a huge number of unanswered questions and confused thoughts home with them.

Birth and Death

In some circumstances a woman who has had a healthy pregnancy may tragically lose her child during labour or due to complications in vitro (inside the womb) her child dies just prior to or during labour.

For these mothers the complications and trauma of giving birth and watching their baby die are so very distressing and many tell me that they felt alone, misunderstood and unsupported. The mother is often

returned to the maternity ward where she may then endure the added distress of hearing other mothers give birth and the cries of their healthy and living babies.

Most hospitals now recognise and accept that the bereaved parents may wish to be with their stillborn baby and for them to have time alone in this way is extremely important. Many hospitals encourage mothers to hold their deceased baby, take photos, hand prints or footprints and allow the parents private time with their child. It is not unusual for mothers to want to dress their baby, cuddle it and love it. The tangible evidence of photographs, handprints or footprints gives the parents in the months and years ahead, confirmation of their child's existence and that their experience was real.

“Everything was fine with the pregnancy; I had been so well and felt really good unlike my first pregnancy where I felt ill most of the time. When I think back I did feel uncomfortable about going over my date. I was a little anxious but my GP said it was fine and I did feel good. Things just went so very wrong. I still don't know exactly what happened. It seems the cord was around my baby's neck and she died before they could deliver her. Afterwards I held her, so tiny and perfect. I dressed her and wrapped her in the little pink outfit and blanket that I had hoped to take her home in. I felt very calm at the time, I remember thinking it was a dream. I tucked her under my arm and slept, when I woke up I thought 'I've had my baby' and I felt excited, then I started to realise that she had died and there she was alongside me, blue and cold. The worst part was leaving her there in the hospital. I put her tiny body into her crib and said goodbye but I just couldn't bear to leave her. Looking at her lying there I tried to take in every detail. I thought I have to make this last me a lifetime. I told her I was so sorry and I loved her. Finally a nurse and my husband took my arms and turned me away I could barely walk. The pain with each step that I felt as I left her alone there in the hospital was agonising, my heart really felt as though it were breaking.”

Leaving hospital can be a mixture of complicated feelings. The expectant parents had entered the building with the expectation of new and family life. The building may now feel like a place of limbo and disconnection where the reality of all that has happened has still to be accepted. It can feel safe within the hospital. The reality of going home without the baby can be overwhelming. Leaving hospital empty armed and childless is the first, full impact of reality. Some parents have told me that they would have liked to have taken their baby home with them.

“I wanted to bring her home, to keep her at home until the funeral. I just wanted her to feel wanted, not discarded ‘Baby Jones’. I wanted my little girl to have known that she had a home, a crib, a room, a family. It felt bizarre to think this. I didn’t mention it not even to my husband. A long while after he said he thought about that too, but we both didn’t share our thoughts because we felt that they would be thought of as morbid, that the hospital would refuse us the right or that they might think we were crazy”

Many bereaved parents have told me of their feelings of not having any rights, of their baby becoming in some way the property of the hospital or funeral director, of being unable to ask for more time with their child and of wanting to do as they wish with their baby including taking it home.

There must come a time when we, as a community of considerate and caring people, start to help our fellow human beings to work through the acceptance of the death of their loved one and their tragedy in their own way without inflicting on them our assumptions or judgements. In some hospitals counselling/support services are available and it is beneficial to the bereaved parents for them to have an opportunity to talk through their feelings both before and after leaving hospital. Where this service is not available supportive and listening family and friends can be of huge assistance.

It is very important to recognise that the couple whose child has died have experienced circumstances which are beyond their control and where they had no choices whatsoever. It is therefore essential that they are encouraged to make choices and to feel that some areas of their life are still within their control, even in these early grief stricken days where the energy to make choices and decisions may be limited .

There may also be many issues surrounding mother and child care during the final stages of gestation and in labour e.g. on-going investigations and legal procedures and evidence may need to be sought by solicitors and other professionals. This coupled with the trauma, the tragic death, stresses and anxieties can affect the relationship between the couple. Feelings of resentment, failure, guilt, anger and depression are all usual, but communication between the couple can become fraught and there are many issues that may cause a vast change in the relationship. The loss of the way things were and the lack of hope for the future coupled with the loss of self.

“I go over and over it, I comb through every detail, I lay in bed every night thinking it through, sometimes I try to focus on one of the doctors or a nurse, I wonder did they cause it to happen? I think about my wife and sometimes I blame her for not being more able, if she had worked harder at the delivery. I hate myself for blaming anyone but there has to be an answer - doesn't there?”

I feel a failure, I let my baby down, I should have told them to perform a caesarean, I should have known, I should have protected my baby. I hate the nurses - when I think it through I keep hearing this one nurse talking about a night out and I feel angry that she was not as involved with me .

“I want to hate the midwife who made a mistake in my delivery but I can't. Right now I feel so sad it's like my heart beats pain and is heavy”.

The couple may at first be comforting to each other; both feeling isolated and lost within their nightmare but as time passes their individual feelings of loss rise to the surface.

“I feel cheated. At first I felt grief for our baby, now I feel grief for me. I don't feel the same anymore about anything and my world feels uncertain. I feel lost”.

“I couldn’t talk to her, tell her what I really felt it was too devastating too punishing. I hated her, but I felt such sadness for her too, all at the same time. It was totally unexplainable to feel such deep feelings of hate and resentment for the woman I loved and felt so devastated for. I also felt I’d let her down, failed to protect her. In my hating feelings, I wanted to leave her, to run away from it all. We couldn’t have any more children now I had always wanted a large family. All I had planned and worked for was stolen. I often looked at her and thought she had changed. I couldn’t understand the diversity of my feelings, I felt like I didn’t want her near me. Not only had she changed emotionally but physically she put on a lot of weight and she wasn’t bothered it seemed about how she looked. I felt less of a man. I felt people thought I was a failure. I thought they were secretly blaming me. She was a living reminder of what we’d been through. At the same time I felt totally sad for her, protective of her vulnerability and, though unable to show it, a deep sense of love and guilt too for all she’d been through

Our relationship was changed forever; we had been so very excited about the baby, so happy, in love, a future that seemed great. Now we were devastated, lost and unable to communicate. I was so angry at everything but unable to put it anywhere”.

“At first we were close; there was a time, for a while, of huge understanding. I felt cared for, he was so attentive and comforting.

But then it started to change, I felt it was my fault, I also felt angry with him for not doing more at the birth but I knew in reality there was nothing. I felt empty, loveless, like when our baby died part of me died too. He didn’t want to talk about it. I used to go and sit by the crib and gaze for hours trying to remember every detail of our baby. My hospital bag was still unpacked, I just couldn’t put things away. He used to get irritated with me, I felt like everything died with our baby - even us. There seemed to be no hope”.

The death of the baby had changed everything for this couple. Initially they were able to comfort each other and the support and understanding of those involved enabled them to grieve openly. It was acceptable for them to be shocked, tearful and at a loss, but as time progressed the divisions in their once easy relationship became more apparent as the reality of their baby's death affected every part of their life. Family and friends of the couple can help by making themselves available and simply listening to them talk. Professional grief counselling, either individually or as a couple, will be of huge benefit and slowly the two people may start to talk and listen to each other and once again become a couple with shared experiences. Everything has changed and it is important that this is acknowledged so the relationship can move forward.

The death of a child is so life changing and the pressures felt by the child's parents are so enormous that many couples cannot see the way forward together. A separation following bereavement is not uncommon, the bereaved couple who may be experiencing an overwhelming sense of failure as parents, now have to cope with appearing as a failure as a couple as well. They may try and protect family and friends from the truth and become burdened with the added stresses of putting on an appearance of managing their circumstances and emotions. Their feelings are very real, but their difficulty is in accepting the lack of control or choice in the recent turmoil of their life. Even the couples who are able to talk openly to each other about their emotions and manage to retain their relationship need acknowledgement of their trauma and its ongoing ripple effect and to enable them to forge, on the foundations of this communication, a stronger and closer bond.

Experiences change us and alter our perceptions. The death of someone we loved makes us question all that we trust and hold dear. Plans are changed as future hopes come crashing down around our ears. Death is common to each and every one of us, but each experience is unique and creates change within us, and it is important that this change is recognised and used positively and not allowed to cloud our vision and hopes for the future.

Funerals

Where the parents hold religious convictions, most church leaders will visit the parents if requested and, in most cases, a blessing can be given to the baby. The bereaved parents then have the difficult task of

arranging the funeral and also the dilemma of who to invite. It can feel uncomfortable for those invited to such a funeral, especially where other couples are expectant or have infants or small children and can sometimes create a break down in relationships with friends. It is important that the bereaved parents do things the way they wish and are able to do whatever gives them comfort. The most helpful family member or friend will be the one who asks 'What do you want to do and how can I help you to do it?' If the couple wish to bring their baby home the funeral director will advise them about keeping their baby until the funeral. Keeping the baby at home can be extremely beneficial as it provides the parents with private opportunity to be with their child. It takes away the feeling that the child belongs to the hospital or that they might be being observed or judged. It permits other members of the family, especially siblings, to share time with the baby and an opportunity, depending on their age and understanding, to grasp what has happened.

Preparing the baby and experiencing feelings of wanting to make him or her comfortable or cosy are usual. Special outfits can be chosen and it can be a comfort to the mother to care for her child in this way.

Photographs might be taken and letters written and placed in the baby's casket. Parting with the baby should not be a rushed event and parents encouraged and allowed as much private time as they feel they want. No amount of time is ever enough, but they will be aware of eventually having to say goodbye to their child.

The parents may find comfort in the funeral service and the presence of family and friends, but in the coming weeks and months the reality of their loss will become stronger and it is at this time that more support may be needed. For many parents the first anniversary of their baby's death can be incredibly painful. There are other areas of their lives too that will be emotional, the birth of new babies to friends, christenings, family occasions, the first birthdays of any children born to other couples at the same time as their little one and watching other children grow coupled with thoughts of how their child might have grown up and looked. Their grief is not only for the loss of their child but also for their future and their hopes and dreams.

Friends and family, by being aware of these emotional milestones in a bereaved couple's life and by making themselves available in supportive, listening roles, will help the couple move through their grief

towards an acceptance of their loss and to carry on with the life that had turned out differently from their original plans.

Infant Death

“My baby was always happy and contentedshe slept. I blame myself, although the hospital says it wasn't my fault but I should have known something was wrong.... why didn't I know? I read about other mothers who say things like they just knew. I keep thinking about her lying there, dying all alone and I never comforted her. It is so painful. I hate myself. I feel so lost, my world has changed forever. I can't talk about her. Sometimes I think the hospital will call me to go and get her, it's been a mistake, and she's ok. I look for her in other people's prams I still want to buy her things. I think other people think I did something wrong I think I did something wrong. The emergency service came, the police came and I felt they thought I'd caused it. My husband says he knows it isn't my fault but I think he is only saying that, I go over it bit by bit I think about everything all the time but there isn't an answer. I don't want to be with other people's babies in case something happens, and I feel envious of others too. So jealous - I think why couldn't it have happened to you? I don't like myself for thinking that. I want to talk about it over and over, but other people tell me not to keep doing it to myself they don't understand, they just think they do. This has crucified me I feel so alone and empty”

This mother believed that she had neglected her daughter, pleased to have a cup of tea before tending her child and then overwhelming guilt that she didn't check her child more closely and thoughts that if she were a 'good mother' she might have known something was wrong. Her failure for not saving ,or protecting her daughter. Her guilt for the times that she had left her baby crying, for the times she'd felt over tired and found mothering hard work. She was re-examining every action to try to discover what she did wrong and she needed to say all this and for it to be heard and validated.

‘Don’t keep doing this to yourself’, ‘Don’t keep going over it’, ‘Don’t dwell on it’, ‘It isn’t your fault’, ‘You couldn’t know’ – statements that are all so kindly meant and often said, with the best intentions in the world, to those who are experiencing this trauma. It is very difficult to look and to really see, to listen and to really hear and not offer a solution, for there is no solution or easy way through the pain.

Acknowledging the pain, being able and willing to hear the story time and time again without seeking to give advice or to offer consolation are not the easiest ways of helping the bereaved mother, but giving her your presence and support at this time is the most valuable and enabling assistance you can offer.

You cannot prevent a mother from blaming herself for the death of her child by telling her so. Let her acknowledge her feelings, be present while she voices her thoughts and fears again and again so that she herself can hear them and begin, very slowly, to put them into some semblance of understanding until eventually finding her own way through these paths of pain and self-reproach.

Sudden Accidental Death

In some instances accidental death could have been prevented. A mother called to the phone and distracted whilst her three year old left the garden and was subsequently hit by a vehicle and died. The parents who bought their son a motorbike ,on which he died, the parents who allowed their child to go on a camping trip with friends and where she drowned. We have all read and heard of such incidents. We all make decisions that, with hindsight, we knew may have put our loved ones into a potentially life threatening situation. It is the good fortune of those of us whose children survive such situations that we have the opportunity to think ‘I could have lost him/her’. We never think that dashing quickly to another room to get a towel whilst our babe is playing in the bath could find us attending his/her funeral in a week’s time or that leaving our precious child playing for one moment whilst we answer the phone could provide the opportunity for him to run into the road and be killed. This is only brought forcibly home to us when we either experience such a tragedy or when it occurs to people we know. We cannot take protect our children from every danger at every moment of that child’s life. All parents whose children have died in any situation blame themselves. The feelings of being unable to protect their child are overwhelming and the guilt for not foreseeing the outcome of a decision is torturous.

'My daughter died in a house fire. It was my fault, my husband told me to turn off the Christmas tree lights before leaving for work. They looked so pretty I left them on. When I got a call in the early hours to say there had been a terrible accident at home, I knew it was my fault. I think of my daughter screaming in pain as she burnt although my husband was home and he tried to get to her, he said she wasn't screaming, they say she died of smoke inhalation. I just can't stop hearing her screaming for me. I let her down, I caused her death'.

How tempting to tell this mother it wasn't her fault and that she didn't cause the fire to make it easier for her bear or for ourselves to hear. No words, make the fact that the lights were faulty, and she made a choice to leave them, can ease the pain of knowing that her decision caused the loss of her child's life. There is only one way to assist this mother. There is no rescue, and it is vital that those feelings of wrapping this mother in the hush of comforting words are restrained. There is a need for this mother to talk about her daughter's death, to retell and revisit its painful experience and to face her own accusation, if she had turned off the lights it would not have happened. In revisiting she works through the painful and different aspects of it, by enabling her to say what she really thinks and feels without attempting to rescue, to tell and retell the story to someone who listens without judgement, to talk of her guilt and self-punishment she begins to work through it, to process it and to eventually accept and hopefully to manage some parts of it.

'I always felt something would happen. He was a special child always funny and loving and very adventurous, it's strange really, I know it sounds strange but I knew something was going to happen to him'

Often parents tell me that they had thought about losing this child, that they had felt that something might happen and struggled to communicate to me the strong sense of something different about this child, perhaps this child was more adventurous, more daring and caused its parents to fear they could not always protect their child .

'He was always in trouble of some sort or another, I was always worrying about his safety, I'd shout at him to take care and he'd say ' Yeah, yeah Dad, give it a rest'. I went to his grave and I said 'You see - I told you, now look what you've done'. My wife blames me, I know she does. I didn't want him to have a bike either, not really but he was settling down not so mad and he wanted it so much. It's my fault, I shouldn't have given in' .

'When the doctor told me it was a routine op I believed him. I was a bit tearful though when she went to theatre, I had a feeling, just a sad feeling inside. I wish I'd said 'No, don't do it now'. I'll never forget the look on her beautiful little face as they put her asleep. It's my fault. I let them do it'.

So many parents believe that they should have known or been able to stop their child's death. They struggle to come to terms with and to justify the choices they made at the time. Offering solutions or answers and trying to give a 'feel better' factor can prevent the bereaved parents from voicing their innermost feelings and thoughts. These raw and anguished emotions only multiply and fester if they are trapped within the person, by releasing them in the form of words and perhaps, actions, such as frenetic cleaning of the house or gardening, in the presence of a person who can listen and accept and not judge or console are the parents' first steps towards a clarity of thought regarding their loss.

The Feelings of Parents

The word 'child' or 'children' conjures up the image of a young person, but if you are 60, 65, 70 even and your parents are still alive, you are still their child! Every parent who loses a child, no matter how old the child or how they died, share similar feelings of guilt and failure because they did not or could not protect their child from pain or death, or, in some cases, because they were not present when their child died, We all hope that if we were to experience such a tragedy in our family that the parents would support each other during their shared grief.

These are the words of many parents, whose children of different ages died.

‘The pain is so great that when it overwhelms me I rock from side to side, I bang my head on the floor and against the wall. I hit the pillow, I pinch and punch myself, I pull my hair but it doesn’t relieve the pain I feel.

I scream out to anyone, to God, space, WHY? I sob, my nose runs, my eyes swell, I want to wrap myself in sackcloth and ashes. I feel jealous, envious of others whose lives are still intact.

I feel a sense of comfort when I hear of others going through this pain, though I would not wish it on my enemy. I feel guilty for feeling envious.

Everything in my life is changed; everything has lost its meaning. I don’t recognise my life or myself anymore. I am afraid, I am afraid of my future. I long with physical pain for the past. Change disturbs me, it distresses me. The world is changing too quickly, it isn’t the world my child knew, each day something changes, I don’t want change, I want things to stay the same. I don’t want to move forward. Friends – no-one can understand I cannot tell them, they will think I’m going crazy. In my moments of complete anguish I feel crazy”.

“I am aloneit’s like I’m on another plane, in an alien world. I want comfort. Others say they understand but I know they can’t. Time drags quickly. I am not aware of its passing but it seems so slow”.

“In every part of my life there is a memory. He loved beef burgers I cannot bear to cook them now or to throw them out. I want to wear my pain so that the world will bow its head as I pass and acknowledge that my child has died”.

The Relationship

Often women tell me that their husbands don't talk and refuse to listen or that they feel rejected, unloved, alone and angry. Men tell me they hurt, that they are afraid to let out their 'real' feelings, that they feel a need to be strong.

There are, in my experience, huge differences in the way that men and women who experience a shared bereavement handle their emotions. It is common for there to be marital difficulties after the death of a child. Any death can create division between couples and where there are already difficulties the problems may become exacerbated and consequently, some couples can separate. Women often lose the desire for sexual intimacy, whilst men may seek comfort through closeness, but there may be guilt that they have indulged in sexual intimacy so soon after the death.

The heightened emotions and tensions within the relationship can be relieved by sexual intimacy and a release for feelings that have been contained.

“It sounds odd but whilst we were making love I kept thinking could our child see us?”

“I felt awful afterwards how could we make love while our child lay in the chapel of rest?”

“Making love was a release, afterwards we sobbed together ...it was almost like we needed the release to enable us to be close enough to share our feelings”.

There are many thoughts and feelings that are too intense to share, even in the closest of relationships. Parents don't talk openly about their grief with each other or outside of their relationship because the feelings are so very painful and intense that they do not know where to start and are concerned that those they tell will not be able to understand or find the capacity to hear their pain which to them is too overpowering. Between partners it is often about protection of each other and of self.

“I don’t think my husband feels like I do, he says he doesn’t want to talk about it or keep going over it. He gets angry when I cry and says I have to ‘Get my act together’. He says that he can’t stand it, he even said maybe we should separate. It feels like everything is going to pieces, I just feel so alone”.

“What good is talking about it? It won’t change anything, I am trying to survive it but it feels like I’m crucified. My wife cries all the time, she is always trying to talk about it but it scares me, if I start to talk, if I really think about it, I don’t think I’ll get back”.

“Sometimes I’m just doing my work and I start crying I think ‘My God it’s really true’, and I just feel like my insides are falling out”.

“If I tell my wife or husband how I really feel it will scare them, they won’t be able to manage it on top of everything else and some of the things I think are just too unbearable. Also if I begin to talk about it I might not be able to manage it, it feels like it might drag me too far down and I’ll never recover”.

Grief brings with it so many intense feelings, anger, despair, anxiety, guilt, hate, blame, jealousy. One of my clients told me she wanted to tell other mothers how unfair it felt that they still had their child or to shout at a mother who was smacking her child. She had anxieties about other friends and their children aroused feelings of envy.

“The part of me that genuinely shared in the joy of others died with my child. I can’t talk about these feelings, I’m ashamed of them but they are there. I have this hard lump in my chest, it isn’t like I can touch it, but it’s there, a weight, a stone. The pain is unbearable.

If anyone knew how I think they wouldn’t like me ... I don’t like myself”.

The bereaved are often the protectors, they are too aware of the inability of those around them to understand and hear their pain which often forces them to keep it locked inside them. They think their thoughts and feelings are too shocking to voice for fear of being judged.

*“Why did it have to be my child, why me, why us? Why not *****, my sister’s child, he is a handful”.*

“Why did it have to be our son, we have three daughters I wouldn’t chose any of them but why wasn’t it one of the girls?”

It is not unusual for couples/parents to blame each other or to feel resentments towards each other about the death, the past, the present and to have little hope or thought for the future. It can feel selfish or inappropriate to grieve for loss of self or to feel anger that a relationship with a partner has changed. Old grievances and unresolved issues may rise to the surface as the parents struggle to survive whilst their world is collapsing around them.

“He never wanted children I know secretly he’s glad”.

“I didn’t get on with our sonwe argued most of the time. I told him I couldn’t wait for him to leave home – now he’s gone forever”.

I blame himmy husbandhe wasn’t watching our childlike he should have, if he had been it wouldn’t have happened”.

Alongside their individual feelings, the feelings for each other within their relationship there may additional pressures. There may be the grief of other children to support or if their deceased child was adult there may be a partner or wife /husband and grandchildren to consider. In my experience each parent may feel that

they are the principal support mechanism. Men often don't express their feelings openly and try to support their female partners by trying to instill a sense of continuity or normality within the home often by returning to work.

“I have to go back to work... I don't like the thought that others may see me going back to work and think I'm ok, that I'm over it, but if I don't go back I might lose my job and we have bills to pay. Work has been very good they gave me 6 weeks off but I am scared that I might lose my job. Money is worrying meI wish it wasn't, sometimes I think 'What's money now', but I have to pay the funeral costsit's just so unbearable”.

“He was our baby, a beautiful baby always laughing, giggling, contented. When I went to the hospital and saw him he looked like he was asleep he had that contented look, it's hard to believe he had died so violently in that crash. His hands were damaged though because he was thrown over the handle bars of his bike. I wanted to hug him, to kiss him, to tell him I was there but I couldn't, his wife was there and I felt excluded, denied my son. I felt in the way. I had to hold on to my feelings so that we could support his wife”.

There are many different aspects to the feelings of ownership, not only of the deceased person, but also of their remains. This can also extend to the details of what and how events happened and once other people know, the lack of privacy this causes equates to a lack of intimacy and a lack of control. The pain of the mother of the man who died in a crash was increased because she was not able to touch her son or have her space and time with him. She felt unable to share these feelings with anyone as she wanted to appear supportive of her daughter in law and was concerned that others would think her selfish or disregarding of her daughter in law and of her daughter in law's position as next of kin to her son. This was the beginning of resentments that over time festered beneath the surface.

“I felt like I had no rights, everyone seemed concerned about my daughter in law.

He was my baby, my son, my child but because he was older I was forgotten. I had to

ask for information I felt excludedso alone .When he was little and he hurt himself I would kiss him better I still felt I wanted to kiss him better. Instead I stood by his side – no one said I couldn't touch him but I knew it wasn't my place”.

It isn't unusual for parents of older children to feel excluded. The loss of an older child can present them with many other issues.

“We feel guilty, we are in our seventies he had his life ahead of him it should have been us first”.

“I feel so alone now, the grandchildren don't visit us as much either, it's as though when our daughter died the whole family died with her”.

Equally, the partners of the deceased may feel that the parents have too much involvement and the deep feelings of exclusion and lack of ownership can create huge breakdowns in communication.

Regret

In some circumstances the relationship with the child was difficult.

“Our daughter changed when she was 15, she became a person that we didn't know, couldn't relate to and we didn't like her much. Some nights she didn't come home and we'd go out looking for her. Our lives were so awfulwe never knew what would happen next. She stole from us and would tell lies all to feed her drug habit. Last time I saw her she said she hated meshe wished we'd just go away leave her alone. Now she's goneI feel I failed her”.

“I had a row with my eldest son, 23, last time I saw himI told him it would be better for us if he just stayed out of our livesI wish I hadn't said that now”.

In all families there are times when there is friction between its members, where parents question their decision to marry and have a family and whether they will be able to survive the family emotional rollercoaster. Children grow and develop and move away from the family unit. They become influenced by the outside world and begin to develop their own thoughts, values and opinions which may be alien to those of their parents. This can be the catalyst for a breakdown in communication between parents and children. Both parents in the instances quoted have been left with a very mixed emotional response to their bereavement.

They felt guilt because they felt that they would be better off if they had never had their child, that life would be easier without them and the problems brought to the family by their existence and also because they feel relief that it is over, that rows and disagreements will no longer occur, and no more worry because what they always feared for this child has happened and guilt for all that has been said in the heat of the moment and more guilt for all the words of love and support that were left unsaid. They felt anger that their child has finally inflicted this unending pain on them and that others may condemn them if they feel any form of relief.

“We were always on this rollercoaster. I half expected this to happen one dayI feel like we finally have gone over the edge”.

“It feels so unfair, after all the trouble we’ve had in the family. He was just beginning to come through it, just starting to talk to us to be my friend. I feel I lost the opportunity to make it right between ushe’ll never know how much I loved him”.

There is nothing that can be offered to these families except a listening ear, allowing these parents to express their feelings and their regret, anger and sadness without fear or judgement. By talking and retelling their story, they begin to make their path through their pain, face their worst thoughts and to begin to put their feelings into a more logical form. It’s really not about rescuing or feeling better, it is about allowing them to survive the immediate torment of the bereavement and interment and manage the days,

weeks and months following their loss and allowing them to slowly develop a more positive aspect on their life.

Searching For the Child

“I am concerned about where my child is, I know it sounds crazy, I know she is dead, gone - and I don't have a religious belief, I wish I did. I worry about her being ok. I worry that she might be alone, lost somewhere, It's all so big, too big. I mean how could she be gone just like that?”

The need to know that a child is alright, although the parents know that their child is dead may sound irrational, but is a very real and common need. They contain this need within themselves and often will not speak of it which contributes to their sense of isolation and belief that they are going crazy.

I noticed a black bird in the garden the other day it looked different from other birds, I know this sounds ridiculous, but my son always loved the birds in the garden ... I was thinking could it be him?”

The search for the child, the longing for some contact that might confirm that they are still around, safe and well is a natural need. It is painful it is to accept that someone you loved, who has been with you, that you have held, loved, laughed and cried with can be gone forever leaving only memories. These feelings are often expressed in the early weeks and months of bereavement, when the realisation of the permanence of the child's absence is just too powerful. Searching for and believing that they have seen their child is also usual in bereaved parents. A religious belief may offer some comfort, but for those without a belief there may be fear about their child's whereabouts. There may be pressure to have a belief from many, different well-meaning friends or family 'God only takes the best' 'He's in heaven with Jesus' are common examples. There may be some feelings of anger with God or the parent's Supreme Being, 'Why me?', 'How can this be acceptable, my child belongs here with me, not with God'. Some bereaved parents seek

comfort in spiritualism or visit clairvoyants in their desperate need to know that all is well, when actually all feels far from well. Their desperate need can also manifest in dreams or nightmares.

“I see my child but when he sees me he runs away, I call to him please come back, but he just keeps looking over his shoulder and running I wake up so anxious and sobbing”.

“I dream that it’s a mistake, I’m holding my child in my arms and telling everyone ... look she’s back not dead at all. In my dream I feel such relief and then I wake up and, for a moment, I feel ‘Oh, thank God it’s not real’ I feel so light, well relief, like a weight is lifted from me, then it’s there, I realise the truth, she is dead and I feel beaten to the ground”.

It is not abnormal to experience dreams such as these and some parents tell me that when they see their child or hold them in dreams, though distressing, they gain comfort from them, but where the child is running away or is crying or calling for the parents, the parents often say that after such traumatic dreams they feel empty.

“I feel drained after those dreams, I feel like I’ve emptied my grief and for a while the feeling is manageable”.

“I long to dream of my child, but have dreamt nothing, feel cheated that he doesn’t come to me Give me a sign. I speak to him, I ask him to just let me knowbut nothing “.

You cannot offer these parents comfort, you cannot offer them any hope or take away their pain, all you can do is listen or sit with them, often in silence, offering companionship in the deep, dark pit of grief.

“I worry about the pain my child went through when she died, I wanted to ask about it but no-one would say. I know she was crying for me but I wasn’t there, she died in a freak accident, a tree fell on her. I got there too late. I think about her in such pain, it’s like I need to feel it with her. I feel like I let her down. I can’t bear to think about her alone, lying there beneath the tree but it’s all I think about”.

“My grief comes in waves, like an ocean. Sometimes it’s just still, calm at other times it’s deep, dark and so rough and the waves are so high I feel I’ll drown. I never know how it is until I’m in it”.

For some parents who are present at the time of their child’s death, such as at a road crash, their deep shock, trauma and hysteria can to onlookers seem unmanageable and in some circumstances they may be removed from the scene by attending services. In my experience this is only useful if there is an immediate danger, vehicle fire for instance or where the scene presents a further risk of injury. Those parents that I have worked with that were denied access to their child in those final moments are further traumatised by that denial and are often left with overwhelming feelings of desertion and total loss of control, privacy and choice .

“I was there but I didn’t hold my child , I was screaming at the paramedics to do something, my wife was kept back by police I was taken to a police car nearby, all I wanted to do was get to my little girl but they wouldn’t let me. I could hear my wife screaming but they wouldn’t let her near either.

Even when we were at the hospital we weren’t allowed to see her right away, we felt we had deserted her”.

“At the hospital we were not allowed to touch our child, he was kept in a room I think, my husband identified him but we only saw him through a window. It was so awful, we wanted

to hold him, to love him, to let him know we were there but they said we couldn't do that yet, we felt that he belonged to them"

The feeling that their child was taken from the parents not only by death but by those in official roles are common. Parents frequently tell me that they felt they couldn't ask what happened, or that touching or moving their dead child was not permitted and that in some way their child was no longer theirs and their desire to be with their child might be viewed as strange or morbid.

"Our daughter in her coffin, she looked so different lying flat like that. I hadn't seen her like that before, I remember thinking about sleeping beauty, yes, that's how she looked. She had bandages on her arms. I wanted to look at her arms to see why but I felt them watching me so I didn't touch her. I kissed her forehead but even that felt intrusive. I wanted to take her nose piercing for myself but I was scared to touch her and scared to ask the funeral director in case he said no. I didn't tell my husband either, I didn't tell anyone how I just wanted to pick up her broken body and hug her and bring her home".

"I went to see our boy every day at the funeral home. It made it easier that we could still see him although he looked different. I wish we could have brought him home but I didn't think they'd let us".

I cannot tell you how many times parents have said these things to me. Why can we not ask the bereaved what they want? What do we think they are going to do with the body? Secrete it away somewhere, never parting with it? Parting is painful and distressing but by being given space, privacy and time to spend in private goodbyes the parting is made more manageable.

Unspoken thoughts

"I worry about my child's body. I think about it under the ground especially when it's wet. I wanted to ask someone how long it would take before it decomposed, but I think they'll think I'm morbid".

“I worry about my child being safe in his grave, I don’t like it that he is so far away, I wish I could have buried him in my garden”.

“I try to go to the grave every day. Once a dog ran over my daughter’s grave and I felt so angry with the owner, I felt my child had been disregarded”.

“I put balloons and teddies on my child’s grave but someone took them”.

“I feel like our child is alone in the cemetery, I wanted to keep the ashes at home but my husband said it would distress visitors”.

“I went to get my child’s ashes, there didn’t seem to be enough. I’ve read that sometimes you don’t get the right ones but I was scared to ask anything”.

“My child was cremated, I don’t know what happened, I’d like to know”.

“I didn’t see my child, he drowned and the funeral director said It might be better not to see him, I wanted to but I was afraid and I felt the funeral director might insist”.

“My daughter’s body was never found, I sometimes think when I’m driving - is she there? I am always searching”.

“It’s like being in a pool, sometimes I am staying afloat but mostly I feel I’m drowning”.

“My child was in the hospital, they did an autopsy, I saw he had a cut by his throat I wanted to know what they had done to him, no-one told me and my husband said it would only distress us more. What could distress us more?”

What could distress these parents more than the unknown? Often the unknown is more frightening, more painful than the reality. If they don't ask, don't tell. If they don't ask, does it mean that they don't want to know? Is it our fear of upsetting the parents or are we worried about our own inability to communicate. In some circumstances the death may be reported by the media, in the press and on TV. When this happens lack of privacy and intrusion are often felt and parents can feel that they have lost their child to the general public and that their grieving has to be done under the public's gaze.

“All those things written about us, details about our child's death were written for everyone to read, it feels like people we don't even know know all about us, we aren't private anymore. I think about them, they're not really bothered or able to understand how it is for us, like we were before. They probably think 'Oh, how awful, poor people'. It always happens to others, stuff like this – we are the others now”.

“It feels like they have some ownership on us and everything they know about it feels like a piece of it is taken from us. Like we have nothing left that is ours and ours alone”.

When a child has died traumatically, in an accident or has been the victim of murder, details are often revealed to the press and alongside the information given by police there will be added information about the family, the child's life or the story behind the child's death.

Families often find this intrusion difficult to manage and many are further distressed by reports and concerned about the reactions of those who may know them. There is little that can be done about reports and information made public but a great deal can be achieved by forward planning and talking through possible reports and reactions, thus aiding the manageability of situations and avoid additional trauma

Your Child's Room

I have written on numerous occasions throughout this book about the individuality of grief and the diversity of feelings experienced by each and every individual. I have also acknowledged that males and females grieve differently, setting aside cultural, religious and genetic backgrounds. Alongside the differences of

gender is each parent's individual relationship with their child. This can often be the cause of added stress and misunderstandings, resentments, blame and anxieties.

“After our daughter died I used to sit in her room for hours, just breathing in the smell of her. Sometimes I'd take her clothes from the cupboard and bury my face in them just to get a sense of her, a familiar piece of the realityyes, she was here. I sometimes got into her bed too and that is where I did a lot of my crying. I always waited until I was alone in the house then I'd give myself permission to go to pieces. I couldn't bear the thought of anyone moving her things or taking them. I'm so grateful that my husband didn't try to stop me, although a friend expressed concerns about my behaviour, she couldn't understand. It wasn't about shrine building, it was about accepting and letting go of her slowly in my own way. It was five years before I felt able to begin to change her room and ready to put her things away”.

“I came home from shopping and found boxes outside the door, my husband and parents had cleared our child's room whilst I was out. I was devastated, I couldn't believe that they would do that, did they think that if they stripped his room I'd be better?”

“I felt this need to pack up my son's things after we came back from hospital after he'd died. My husband sat there in his room on his bed. I washed his clothes and ironed them, it was as though I needed to do it although I knew he'd never wear them again. I put his shoes and coat in a suitcase under the stairs. I can't bear to look at them. I don't know when I'll move the rest of his things - is there a time limit?”

“My son committed suicide in his room. The police went into everything, it felt so intrusive, and we have just left it like that for now. People keep offering to sort it out for us but we aren't ready to do it yet”.

For some parents the room was not the focus of their grief and for others the room was a significant focus, a place where they felt their grief was permitted. Some put their child's possessions away quickly and sometimes that's alright, others find comfort in surrounding themselves with the room and belongings of their child, taking comfort and releasing their grief in the smell and feel of the child around them. Some close the door and cannot bring themselves to cross the threshold. Change is not easy to manage and a task such as changing the bedding or washing the clothes can be overwhelmingly painful.

“Two weeks after my daughter’s funeral I was at home alone and decided to go to her room. I began to tidy up, I was ok, a bit tearful, but managing it until I took the sheets off her bed, as I put them into the washing machine I thought ‘That’s the last time she’ll ever sleep in those sheets’. It felt like I was washing her away”.

Is there a right way to be? In the early days it is a case of getting by in which ever way you can. By the minute, by the hour if that is what it takes. It's allowed to close the door on your child's bedroom, leaving it just as it is so you can spend time in the room in the early days. It is also important to recognise the choices of other family members, if the room was shared for instance it is important to ask the sharer how they might like to see the room change or stay the same. Some families decide to change the use of the room to something else, again, time, space and consideration for all involved is essential. Decorating the room can be as hard as changing the bed linen or packing up toys and belongings as by physically changing something from the way it was is a final confirmation that the child will not be returning to their bedroom. Some parents feel they are deserting their dead child by getting on with their lives.

“It was almost a year before we decorated the room, it was incredibly hard. We felt like we were leaving part of him behind, moving on, removing him. Our daughter has the room now, but it’s hard not to keep calling it Johns room”.

When clients ask me about change, when and how to do it, I suggest that they think about what they want to change. It is all about giving yourself permission to do something your way, if it feels too hard - it's ok

as maybe it is not the right time yet. There are no hard and fast rules that say you must clear out the belongings and make changes until you feel able to do so. It will never be easy but in time it becomes more manageable. Keeping memory boards, a journal or memory box with a few favourite items is a way of keeping memories together and easily accessible and can be useful in enabling you to progress through the grieving process.

Sometimes, in the early days it can be tempting to want to give others a memento of your child. Of course you can do this, but sometimes it's better to wait a short while as it can feel right to give something away one day but the next wish you hadn't done so.

Moving On?

“I am finding even small changes hard to live with, it feels as each day goes by something changes and the world as my son knew it has changed so much even in a few months. You don't notice change normally but now I feel like I'm moving on from him”.

It can be incredibly difficult to express and manage the feelings that can be evoked by change.

It may sound crazy but I don't want to cut the grass, I know my child stood on that grass and it's another feeling like there's this blackboard with her life on it and slowly it's being wiped out”. “

These are not crazy thoughts, but thoughts that have not been expressed in the open, but felt, thought and feared in the mind and in isolation in some degree by each and every bereaved person with whom I have either worked or who has contacted me. Bereaved parents are also very conscious about what people on the outside think of them.

“Do they think we are okover itmoving on?”

“If we go out do they think ‘Ah life's back to normal now?”

“We had to get a new car after the crash, a neighbour saw us out and said ‘ Oh, lovely cardid you win the lottery?’ Before I could answer he said ‘Nice to see you getting

better'. I know he didn't think about any of his words, but it caused me so much distress, anger and frustration that actually no-one understands how we really are".

"We have new neighbours. They'll never know our child. I want to put a huge photo outside saying 'I used to live here'" .

The diversity of feelings experienced by the bereaved are complicated. On the one hand they want the world to acknowledge the loss of their child and their grief and on the other resenting the intrusions into their privacy. They feel anger that those that have no understanding of the depth of their grief and perhaps offer words of comfort in what may feel hurtful or inappropriate ways.

"I was doing the garden when a neighbour came over. I felt very anxious like my chest was getting so tight. She said 'I'm so sorry to hear about your little one', I said 'Thank you', all the time my chest tightening like a fist was there squeezing it. I said something about the weather, she said it was nice to see me out and getting on, then she said 'You have other children don't you?' and I said 'Yes' and she said 'Oh well then, they'll keep you busy'. It's not the first time that I've felt like it's ok because after all, I've got my other children".

The hurt was not intentional but said by way of offering something positive. As a society our reaction when faced with someone who has been recently bereaved is to bring out the 'doing well' blanket, to offer our condolences alongside some promise of brighter days so reassuring the bereaved that they will get over it. Are we really reassuring ourselves? The realisation that bereavement is that it cannot be got over easily but in time it may become, on some days, a little easier to live with. However, the acknowledgement that the death has changed things permanently may just be too incomprehensible and uncomfortable for those less involved to accept. For each and every person there is always the knowledge that in one moment some tragic event could impact on your life and steal away your children leaving devastation in its wake and causing unforeseen and unimaginable changes. The most immediate change is to the family, their relationship with each other and with the outside world. This reality is often felt but undisclosed by the

bereavedwhy? Our society has no time for circumstances that cannot be healed or cured, not even by the passage of time, it makes all of us feel vulnerable, exposed and out of control. What is the old saying? What cannot be cured must be endured. That is what we expect the bereaved parents to do, to endure their loss and grief, preferably in privacy and out of our sight so we do not have to suffer alongside them and face the reality of mortality.

Family Dynamics

When a child dies the dynamics within the family are changed. A child who was once an elder or younger sibling may now be an only child and children who have lost an only sister or brother now become the 'only' boy or the 'only' girl.

Parents who lose a child can transfer their understandable anxieties to the children they still have, trying to offer those children the protection and love they may feel they did not give the child who died.

“We were a very laid back family, relaxed. Now I feel anxious all the time and I don’t like the children to be away to long or to go out alone. I know it’s hard on them but I’m scared something might happen”.

The feelings of loss of control, the anxieties caused by the upheaval to what was once a secure and stable family relationship are overwhelming. The effect on the family can be extremely destructive as each person tries to manage their own grief and still present a positive outer image for the other members of the family. Parents often feel the need to keep their remaining children close to them and remaining children may feel resentful of this new and restrictive regime and lack of freedom. There may be arguments and outbursts of anger that previously were never experienced by the family. Disagreements and pressure from other family members can cause additional anxieties to the grieving parents and these in turn can contribute to a breakdown in the relationship and their ability to communicate with each other.

Parents may feel responsible for the death or may blame each other or other family members. There may be feelings of animosity towards older family members, who are still alive, when the younger member has died.

“I feel angry with my husband’s mother she has all these health problems, if anyone should be dead it should be her. Now she is even worse, I feel angry that she is using our son’s death to get more attention“

It is not unusual for feelings like these to be present or for previous grievances unconnected to the death to become magnified and become the focus of the emotional impact of the death. Grandparent’s health is often greatly affected by the trauma caused by the death of a grandchild. It can create many issues for them – not least that the perceived order of things has been changed, the younger dying before the elder, and they may find themselves feeling guilty for living. Where once a family may have been sympathetic to the older person’s ailments now these may be triggers for feelings of deep resentment.

“My mother was always complaining of this pain or that pain and it used to cause problems because I felt that I ought to give her lots of consideration, we were very close. My husband said that she was an attention seeker, many of her ailments began when my father died 10 years ago. I felt sorry for her, the children used to get irritated as sometimes plans had to be changed to facilitate my mother’s needs. Then last year she was diagnosed with terminal cancer. I devoted so much time to her care and I resented my family for not being more generous. If I had not been at my mother’s that day our daughter wouldn’t have been driven by her friend and wouldn’t have died. Now I can’t feel the same about my mother, I resent her for being here and, you know, I also resent that she is going to die soon and escape this agony. My husband and I hardly speak, he blames me for our daughter’s death, I blame myself. My mother says ‘It should’ve been me I want to die’, I think she feels guilty but I feel so angry when she says that too, because she is going to die and will be with my daughter. I feel I’ve lost my daughter, my family, my mother and myself. I don’t know what to do anymore, our son has left home, no-one seems to understand, my husband is so distant. What’s life about?”

For this mother all relationships within her family were changed by the sudden death of her daughter in a car crash. The impact of her daughter's death had changed every relationship. Feelings of resentment towards her mother, guilt for feeling resentment coupled with guilt for feeling responsible for her daughter's death. Feelings of anger, distress at her loss of relationship with both husband and remaining child.

“I blame my son for the death of my grandchildren, he was too laidback, he allowed them to do anything they wanted, he wouldn't listen. Yes, I blame him and I want him to know but I can't say it. I don't visit much and I know they are finding it hard to be together, I think my daughter in law blames him too”.

Disconnecting from the family isn't unusual and often after the death the extended family find their feelings so overwhelming that they choose to have less contact while they come to terms with these emotions, but this can add to the isolation felt by the grieving family.

“I can't talk to my husband about how I'm feeling, he keeps saying we have to move on, but I'm not ready, he goes to church and takes our other son but I can't go there, I hate God for this”.

Everyone manages their unique experience of grief differently

“My mum doesn't want to go out or do anything with me, I feel like saying ‘My sister's dead but I'm alive!’” ,

“My parents are separating. I hate my brother, even in death he is the cause of family problems. When is it going to end?”

“This is too painful. I wish I'd never had children, stayed on my own. I want to leave my wife and get away from this”.

“We can't communicate, every time we try to talk we end up arguing, then crying and it feels like everything is falling apart”.

If the family are to survive this together it is essential that they communicate and that each member of the family has the opportunity to talk as much or as little as they feel able. Parents need to share their grief and do not attempt to conceal it in order to protect the remaining children. Each person in the family needs to feel able to voice the feelings, thoughts and fears they hold inside themselves even the youngest children who are often forgotten or feel they must be strong because that is what 'grown ups' do.

The Death of a Sibling

The death of a brother or sister will affect the remaining brothers or sisters differently according to their age and their understanding of death. Circumstances play a large part in how the remaining sibling or siblings come to accept the death, for example, a child who has a long history of terminal illness will have had a very different relationship with his or her siblings who may from a very early age have been exposed to the reality that this child may not live a long life. Sudden accidental death, because of its unexpected nature, will have a different effect on siblings. There are however similarities in the needs of all bereaved children, the need to talk and for people to listen to them.

“My brother Tom was playing in the road and he was run over by a car and he died. I don't think people can come back when they die. It's scary, I don't want to die”.

Children are often left with fantasy about death. Much of the information they already have comes from films or television in which the nature and permanency of death is glossed over. Parents are naturally consumed by their grief for their deceased child and it is not unusual for the living children to become their defenders, protectors of their parents and indeed it is not unusual for this task to be conferred on them by well-meaning relatives or friends.

“Don't let Mummy or Daddy see you cry, you must be brave/ be good/ be strong”.

Statements such as these are offered in belief that they are helpful, but the pressures on a sibling can be overwhelming, the pressure to be good, to be strong, to get on with life and in some cases to be perfect in

the absence of the sibling. There may be guilt for living when their brother or sister is dead or self-blame and often anger or jealousy.

There may be fear about death, especially when the remaining sibling is very young and their understanding of finality of death is limited. They may fear that, like their sibling, they too may die. Some families have religious or cultural beliefs and these alongside other stories may be offered to the remaining children as comfort.

“Tom has gone to be a bright star for Jesus”.

“I don’t want Tom to be a starI was a good boy too and I want to be a star”

“I don’t want Tom to be a star because he will be lonely and I can’t play with him now”.

Some well-meaning, comforting platitudes said to surviving small children may be misconstrued as rejection. Often parents tell them that their dead sibling was extra special and chosen to be an angel and most of us have heard the statement ‘The good die young’. Do they? Does this mean that we who grow old are bad? Of course not. But the horror of death, particularly the death of a child leaves all of us looking for a reason why. The reality is not easy to accept and the change in the perceived order of life can cause great insecurities for both young and old alike. Reality, unlike fantasy has an end. Fantasy can become unmanageable and is governed only by the limitations of one’s mind.

Small children are often left without support. Their ability to communicate may be limited by their experience, age and understanding. It is important that even the very young are invited to talk about their feelings and to share their thoughts about death and dying with someone who will listen and accept all their words. It is sad that a young child’s life may be affected by death. Childhood is seen as a time of innocence and naivety, and the loss of both of these seemingly desirable experiences early on is upsetting but it can create experiential growth, death need not always be destructive. Children have the ability to dip in and out of emotion, one moment immersed in grief the next playing happily. It is important that

questions are answered when asked and that they be answered honestly, but taking into account the child's ability to comprehend the answer.

“When our son Tom died he was 11, our younger son, Joe, was 6. We let Joe go and stay with his grandparents, we were so shocked and Joe didn't understand, not really. I remember being really angry with Joe because on the way back from the funeral directors we passed a fairground. Joe said ‘Oh look Mummy, a fair, after Tom's funeral can we go?’ I was so angry, it was as though he didn't understand, of course he didn't but we somehow thought he would”

Even though Joe had been told about his brother's death, it didn't mean that he understood. He appeared to be aware of all that was happening, he was present when they talked to the police and he saw how distressed his parents and other family members were. He knew that Tom wasn't there and he felt a sense of deep sadness around. The house although busy with unusual amounts of visitors had a different feel to it. He was aware of having more attention but unable to make sense of it all. He became scared at night when he was alone and afraid that others might leave him, he thought that it might be his fault and he looked for Tom wherever he went. Joe's parents found dealing with his emotional needs whilst going through their own grief incredibly difficult. In such circumstances, external support is invaluable and a place where Joe could talk openly and explore his feelings and thoughts would benefit both Joe and his parents. When Frank (23) died in a freak accident at work his sister Joanne (15) was devastated

“I was 15 when Frank died. I remember coming home from school and there being a lot of cars outside the house. I just knew something was wrong everyone was there, my uncles, aunts and grandparents. I went into the house and my aunt said ‘It's Frank, he's had an accident at work, he's dead’. I was really shocked, I shouted for Mum but they wouldn't let me in the front room. My uncle said could I go with him to the shop to get tea and milk and stuff. I was just shocked. I can't remember much, but going into the shop I told someone and it felt unreal. I didn't talk much to Mum or Dad, I tried to make tea for

them and they just sat there staring. No-one really asked if I was ok. I cried so much, but only when I was alone. I sat in Frank's room too and I begged him to come and for it to be a dream. Our house was so busy I wanted people to go away but they kept coming round. I didn't go to school but I can't remember what I did. I wore his tee shirt. Mum and Dad went to see him at the funeral directors, I said I didn't want to and now I wish I had because I felt like I let him down. At the funeral I was with Mum and Dad but I felt alone and I really needed Frank to be there, he always looked after me.

Things have changed so much at home, Mum said she wants to just die. I feel that sometimes but sometimes I feel angry that Frank died and our life has changed, sometimes I want to shout 'Frank's dead but I'm still here!' Recently I have felt angry with him for causing all this, it's not fair".

Joanne was largely forgotten amidst the grief and shock of Frank's death. Quite quickly she began to fit into the role of carer to the family and her own grief became contained inside herself, but mixed with her feelings of loss and of deep sadness were resentment, anger and in turn, guilt. Over a period of time she became depressed due to the lack of opportunity to release these pent up emotions which bubbled and fermented inside her.

Martina was 11 when her twin sister drowned whilst on holiday. Martina was swimming with her sister, Natalia but could not save her.

"I don't remember what happened but I think it was my fault, I should have saved her. I think it should have been me who drowned because Natalia was a better swimmer. I sometimes think other people like the family think it should have been me too because she was a special person".

It is not unusual for a child to feel responsible, less important or devalued following the death of a sibling. They may believe their sibling to be far more special or more loved than themselves because grieving and

shocked parents often make casual comments declaring how special, gifted and beautiful the deceased sibling was unaware of the vulnerability and feelings of inadequacy these can cause in the living children. The feeling that the deceased sibling has been elevated to an unattainable position and that they are forever being compared with them can begin to grow even in very young children, who may be told by mourning parents how wonderful their sister or brother was.

In some cases, parents may decide to have more children.

“I never knew my sister, she died two years before I was born in a road accident. I have always felt like the family compare me or look for her in me, this sounds silly, but it’s true. Once I did something and my aunt said that I did it in just the same way as my sister. I have felt like I’ve had to almost be someone I don’t know”.

Children who are left to face life without their siblings need a great deal of support in safely exploring both positive and negative feelings that are usual in such circumstances. They need reassurance that they too are worthwhile people in their own right, that they are loved for themselves and that they are important to their parents. They need to have these points emphasised to them time and time again, not just in the period of time after their siblings’ death but as they mature, and hopefully, they will slowly start to believe that they too have a value as a member of the family and are not just a poor substitute for their dead brother or sister.

Sudden, Violent Traumatic Death.

This Chapter is written for those of you whose loved ones have died in traumatic circumstances, either in an accident, through acts of violence, terrorist attack, suicide or murder.

The experience of a sudden unexpected death impacts in a very different way to the experience of expected death, where to some extent there may be some degree of emotional / mental preparation.

Although there are similarities of grief, recognisable reactions, the circumstances of how the loved one died will impact and affect the grieving.

In Chapter 1, I wrote about the reaction to news of sudden death: the shock and devastation the numbness.

In this chapter I hope to expand on and contribute to greater understanding of this trauma. Hopefully you can reassure those who have been bereaved that they are not going mad or losing their mind. Bizarre and irrational thoughts at this time are usual and many people in the same situation feel like that.

The story of the death, what happened? How it happened? Where did it happen? How much suffering was caused and experienced by the loved one? These are the main areas that the families of those who died a sudden death will explore often in isolation and in those lonely hours. Lying awake, through the night, trying to piece together parts of all that has happened, and those bits that they cannot remember, or recall. There are often fantasies about the loved ones death and added fantasy of the loved one surviving.

“I often think about my husband’s last moments, I try not to but I can’t get my mind away from it .Sometimes he is calling for me , he is in need and I’m not there sometimes I work at trying to put myself there with him and I fantasise about all of the things I’d do to help him . Sometimes I fantasise that I rescue him. I dream about him calling me too. The reality is he died alone on a roadside and though they say they think his death was instant I know he must have felt somethinghad thoughts and it tortures me.

It is normal to need to keep going over the details. Many people have told me that they find it difficult to talk about their thoughts and feelings for several reasons:

They don't want to be a nuisance.

The things they want to say are too horrific, or may be thought of as morbid, others may think they are losing their minds.

They think that they ought to be getting on, getting over it.

They must protect their remaining loved ones.

Where the death has been caused by disaster or terrorist attack, or where there are several deaths of unrelated persons, the bereaved are often carried along on a wave of public attention and the camaraderie of group and organised care, which in the immediate aftermath provide support and comfort. At this time however the families are in shock. They may seem fully involved and participating, but it is afterwards that the sense of belonging fades. The group disperses; they go to their separate homes and to reality. Then their real feelings emerge. These emotions can be diverse, changing direction from one moment to the next .

“There was a nurse who was just so amazing she listened and I was able to talk and talk sometimes I feel nothing but gratefulness towards her and then this other feeling emerges, I feel angry that she was there, that I shared my stuff so willingly and though I can remember her face, I will do forever, I can't remember everything I said and so now I feel like she knows my stuffI don't like to feel angry with those who help but sometimes I do.”

“I regret talking to the pressI feel like it's not my story anymore it's everyone'speople I don't know things about me .To them I'm just news.”

The vulnerability of the bereaved and of those who are in trauma and shock is often exploited .They have the deep need, a driving force to keep telling the story of what happened, over and over again in an attempt to make sense of it, to work it through, put it together ...get the whole picture .This exposure can leave them with overwhelming feelings of exploitation and lack of ownership, of the story of their loved ones death.

“I feel cheated that my husband is a number.

I feel cheated that his death is part of a huge death it's lost amidst the event .Does this sound selfish? In some ways I gain comfort from other families – they know how it is but sometimes I just want to stand up and shout his name and tell the world this is who died.”

“The difference is the world will go on, they talk in public speeches about braverythey call my husband a hero. I feel angry that it's all so public and that they will move on but I can't things will never ever be the same.”

The observation of public of death through disaster or human act, the leaving of flowers and sending of cards and letters, the grouping and get together, is short lived and in a few months the families are left with the reality of life without their loved one and sometimes the feeling of being forgotten by people who had surrounded them and seem to care about them only a short while ago.

In some circumstances the family/ loved one may be present at the death. The trauma of observing or being part of the horror causes them further distress, panic, uselessness, anxiety .Surviving a crash or event where others including loved ones have died can be the cause of tremendous guilt, powerlessness and self-blame. In some circumstances family may be present but restricted by emergency services, or medical staff, from being with their loved one and in time the memory of this will also cause distress.

“I was at the scene but the police wouldn't let me near, I could see my daughters legs and her bike .At one point I am certain I heard her call out ‘mummy’ but the police officer was holding me back I remember pleading to be let go to her but they took me in a police car behind the ambulance. When we arrived at hospital they took me to a room, I kept asking about my daughter it seemed like ageswhen my husband arrived they told us she had died. I wanted to know where when but the time on the death certificate indicates she died in hospital – why wasn't I with her .I think she died at the roadsideI feel I let her down .I know she called me It haunts me.

Now I feel so angry with them for denying me being with her.”

There may be many reasons why family may not be allowed immediate access to their loved one .Sometimes the reasons are practical or for safety, or legal reasons i.e. scene of a crime , sometimes it may be deemed by the ‘professionals’ involved to be just too distressing ,or awful for the family to witness. In chapter one I have written about the importance of offering the family choices. Of keeping information truthful and of offering it without drama or effect, the bereaved are initially in a state of shock. Such considerations as using simple words and not medical or legal jargon, writing down information and offering and providing opportunities for the bereaved to request information as they wish – all ways of helping them to absorb the circumstances of their loved ones death .People have told me that they were given information verbally but couldn’t recall it and didn’t like to keep asking for repetition as they didn’t want to be a nuisance.

In the circumstances of murder the body will be held as evidence and may not be immediately released to the family .Families may find official procedures bewildering, restricting and confusing. The importance of Police liaison or other supportive agency at this time cannot be underestimated.

Suicide

“Every day I wake up asking myself the same question – WHY?”

Families and loved ones of those who choose to end their own lives are all faced with the unanswerable question why? Even in those families where the deceased may have left notes, or attempted suicide before it might be hard to understand why someone they love took his or her own life. Suicide is often felt by those left behind as a reflection on them, a sign of failure to keep their loved one alive, failure to help them and alongside this the hurtful feeling of rejection.

Sometimes suicide is committed with no obvious prior warning and comes as a complete shock to the family / loved ones. Sometimes the threat has been present for a while or there has been depression and attempts before the act has succeeded.

“Our son was ill for quite a few years, he was suffering depression and was receiving medication, Recently he had been receiving treatment that seemed to be doing him some good and we felt that he just might be getting better .On the morning of his death he phoned me and he sounded very chirpy he said he was looking forward to coming home at the weekend. It was a total shock when the police came and told us that he had taken his life .He had hung himself .I feel like I failed himI should’ve known he was going to do itI am tortured by the thought that he died alone, that he must have been so much more depressed, unhappy than we knew .I feel physical pain that my son went through it aloneI will never forgive myself.”

Many children and adults contemplate suicide at some time in their lives. Those that consider it do not always follow through. In my experience there are no set patterns, the reasons can be many, a broken relationship, low self-esteem, loneliness and no-one to tell, the sense of despair in the lonely hours or feeling that life is not ever going to be how you want it to be. Unable to see an alternative, life seeming bleak, a future too frightening to face .a call for help, where actions speak louder than words

“If they know I want to die because of this they’ll take notice, they’ll be sorry when I’m gone”

The need to know ones value but irrationally believing that there will be acknowledgement of how much the individual means once they are gone: irrational because of course they will not be there to experience it. Suicide may feel like the only option for the teen who believes themselves to be ugly or whose acne has caused them to feel life is not worth living .The child that is bullied may be seeking release from tormenting peers or the child that fears failure or believes that they are not ever going to achieve anything good in life, may seek an escape.

“My daughter was a happy girlnever a problem always funny and lively until she became the focus of a group at school who over a period of time destroyed herself esteem with their comments and verbal abuse / bullying .

She became introvert and refused to go anywhere without us .She said she would be better off deadI never for one moment thought those words were so seriously felt. I said something likedon't be sillythis is a phase, they are jealous of you .I said all those things that I felt were true, helpful and encouraging. Sometimes I got angry with herjust before she died I went to her room and said” Is this it thenyou going to let those girls win stay in your roomnever go out . I shouted at her to pull herself together.

When I got back from a shopping trip the house was quiet and I thought thank goodness she's gone outI even thought, perhaps my shouting had done it finally made her get it together .

I didn't go to her room until supper timeI went to put her laundry away and I couldn't open the door .She had pushed her bed against the door and earlier that day maybe not long after my shouting she hanged herselfshe didn't leave a note” .

On reflection this mother felt she had failed her daughter: Why hadn't she recognised the depth of her daughters despair and why hadn't she known how serious it was?

She suffered the torments of should haves, would haves, and could haves. Had she failed her child? Do we as a society fail those who choose to end their lives?

Perhaps with the benefit of hindsight it is easy to see how we might have reacted differently, but I have no doubt that the person who is seriously intent on suicide will eventually succeed. So where does this leave those left to manage life without their loved one. Unlike other types of death it leaves most with overwhelming feelings of guilt, failure and unanswered and unanswerable questions .Asked by anyone how their loved one died there is often added anxiety of how the truth may be received .The word 'suicide' is an unforgiving word; the very mention of it may cause the enquirer discomfiture, the fear of probing further, it

raises unsaid and unspoken thoughts. The bereaved know those thoughts. Is suicide a statement of reflection on family? Does a person's choice to die reflect the family's failure to help him or her through the trauma he or she experienced, and ultimately were unable to face?

What is the stigma -My child committed suicide, did I fail him /her?

We can only work within our experience of the present, the mother whose child hanged herself because of bullying hadn't failed her child at all. She had practised her parenting skills to the best of her ability; she had listened, talked, encouraged and tried to boost her child.

“My ex-partner threatened to kill himself several times and there were two attempts. The first time I raced up the motorway to be with him he had overdosed but called paramedics himself. Afterwards we got back together and things did improve but deep down I knew I'd only got back with him because I felt responsible. I began to feel very depressed and after a visit to my gp was on medication. I became more down he became aggressive and at that point I wanted to leave. He said if I left he'd kill us both and on one occasion tried to drive the car off the road, after this I left him .I was called at work they said he'd tried to cut his wrists . Again I went to see himI felt so guilty because this time I wished he'd died .I tried to keep friends with him but he seemed unpredictable sometimes rational and accepting of our separation and of friendship, at others he'd threaten me or talk of ways he could kill himself. I was so depressed by it all that I had to give up work my life was collapsing. I felt trapped by him no escapeevery night I'd pray he would do it. Then he did. He took an overdose and drowned himself. At first I was so relieved and glad a weight lifted but now I feel responsible, guilty and I'm tormented by thoughts about it and a note he left saying he didn't want to live without me and he was sorry. To be honest I feel relieved but don't like myself for feeling it and I know those who know him blame me”

For some people, the relief of no longer living with the threat of another person's suicide is enormous. These feelings mixed with grief for loss of the person, are complicated, confusing, difficult to talk about and express. .

*“My daughter was a cutter she began self-harm about five years ago, at around 13 years old .I took her to see so many specialists sometimes it felt like things were better but then it would go downhill again. It was like riding an emotional rollercoaster. Our family lived on the edge never knowing what next .I tried so hard to keep her going but she seemed unreachable the last six months of her life were hell for all of us and when she took her life I felt thank God it’s over . I remember standing by her coffin at the chapel of rest and looking at hershe looked peaceful at last. I miss her so much it’s incredibly painful but I am relieved that for all of us it’s over;
It’s so isolating to feel relief and grief together.”*

In my experience the separation of the positive and negative aspects of life and death for those living on after suicide need to be expressed and accepted. I wrote in chapter 1 about our need when talking with the bereaved to make better, to offer positive thoughts and words and to disregard the negative. It is tempting to tell the bereaved loved ones of a suicide, that they have no blame and to hush their words with kind soothing remarks and actions But, in my experience this serves only to push inwards the unspoken words and thoughts and isolates them further.

“I feel, I know I am to blame, I know everyone thinks I could have done more although they don’t say it. I sometimes feel I want to wear a board sayingMy partner suicide it’s my faultthat’s what I think they are thinking.

“Some days I feel so angry with her for doing this. I think she was selfishWe needed her how could our mother not want to live for us?”

“My partner was diagnosed with terminal illnessshe was afraid of dying slowly and I know this was her way of controlling it. I know she didn’t want us to suffer it with her .I feel she did it for us , I

understand it but I wish she had shared it with us I wish we had known how she felt and I think about her dying alone and it tortures me”.

“I feel so very ashamed; I can’t grieve my son’s death because in choosing to kill himself he killed an innocent driver too. I cannot allow myself to grieve for him .I miss him so muchWhy did he do this? Why didn’t he tell me, Why didn’t he talk to me. I could have helped him. I would have been there more. I should have known. Why?”

“I am haunted by his last moments ...how much did he suffer. When I think about it, Oh my God its torture.”

Suicide, death by choice, has so many stigmas attached to it. It is this combination of stigmas and the sense of being judged that makes the bereaved feel isolated. There is fear of being labelled and being the focus of misinformed often cruel and judgemental gossip. The pain felt by the bereaved and their grief alongside those unanswered questions can be overwhelming .Sometimes the belief that they are to blame and the overwhelming guilt because of it .Did he/she really mean to do this? Could it have been a mistake?

“I don’t know whether I believe in God but it troubles me because someone said that suicide is a crime in God’s eyes and suicides cannot be buried on consecrated ground The minister at our church was very kind and supportive but I worry about my childit sounds bizarre to say that because I don’t know if there is a God or not.”

*“Someone said that it was disgusting that my husband killed himself.
I feel so ashamed I don’t want people to know.”*

Sadly suicide is so often seen as a reflection on a family and their life together, and this can add to the stigma. Most coroners are cautious to record death by suicide. Families are often fearful of such public statement. They may believe, if death is recorded as suicide then they will have to live with the unanswered questions and uncertainty forever.

“If the cause of death is publically recorded as suicide I will have to live with that forever.”

Once recorded the families are left with no alternative but to face the truth. There is no more of the grey area, where it may be said their loved one died by accident. The desire for death, rejection of life stares them brutally in the face and brings with it in so many cases, the suspicion of personal rejection.

(Since this book was published in 2004 there has been much debate about death by choice and you will find more on this subject on the website along with details of agencies offering support.

Death by Murder

“Our daughter was beautiful, she was an angel. The thought of someone violating her, of her suffering of not being able to get help, of us not protecting her crucifies us every minute of every day. No-one can ever know how it tortures us and how it has destroyed our lives My husband and I have separated, he says it’s the guilt. He couldn’t live with it because he thinks we should have saved her. I feel dead, completely dead, I don’t want to live, but I fight it because if I give in her murderer has won”

“He will come out of prison one day but we are imprisoned forever, she’s gone forever. Her children will never know her. People offer words, they try to offer hope, and they think they understand but no-one understands or can know this unless they have lived through it. This is hell”

“My husband was attacked by a gang, he was kicked so violently that it caused him trauma and he died. They write about it in the newspapers. Everyone knows , and when they meet me they say they are sorry but no-one can offer me anything that can come near to stopping this pain .I have nightmares about his death and sometimes I think I might know his killers and I fear for my safety . I can’t begin to tell you how this has changed me. I am destroyed”.

When a loved one is murdered, the impact this has on those who cared about them is different from that by any other cause of death. The death of a loved one at the hand of another, violently, can cause deep and ongoing trauma for families. Those bereaved by murder are tortured by revelations of how their loved one died, and how they may have suffered. Added media attention and publicity means that they are exposed to and immersed in public attention, often insensitively. Many of us will recall observing the shocked families of murder victims appealing for help on television and reading their stories in newspapers.

At that time it’s likely that the shocked family are carried along by the police press and public and the whole business of attention. They may lose their own identity and are now identified by what they have been through. The emphasis is usually on how well they are coping or how brave the family are .They may be treated as heroes , the brave and courageous family of murder victim x . They are interviewed on TV and their vulnerability is often exploited by those keen to produce a good media story, thus creating an unspoken pressure on them to remain dignified.

The initial attention may give them a sense that their grief has been acknowledged, the publicity and attention they receive showing them that people care ,but, as time passes and the attention fades, they are left to face the reality of bereavement by murder and they can feel deserted and forgotten as their story becomes ‘old news.’

“At first we didn’t feel alone, letters arrived daily ... too many to read some days. But it seemed that so many people were out there, shocked by our sons murder. And wanting to let us know they cared.

“After the trial and the newspaper reports and a few occasional public statements we were finally alone and it was then that our hell began. It felt unbelievable that our son wasn’t coming home. I had kept

every article, videoed every interview on TV and we (my husband and I) went over and over it all . No matter how many times we did, it didn't make sense. It felt unreal, inconceivable, the worst thinking about the pain he endured, and we weren't there for him.”

There are many emotions experienced by the family of a murder victim, pity forgiveness perhaps, but more likely rage, anger thoughts of revenge, Revenge may be thought about or planned, but not spoken of. It is usual for all who's loved ones die at the hands of another to feel vengeful at some time or other. These feelings can be the cause of added anxieties within families and need to be heard, rationalised and explored.

“My wife says that feeling the way I feel is eating away at who I am, who I was. I will never be the same again. This person murdered my son and I want to see him. I want to seek him out. I will wait for him to be released and I will find him, that is my purpose in life,”

“I felt bitter, twisted with hatred for seven years after my husband died, I planned how I would hurt his killer, I fantasised about it and I was consumed by it .It changed me and then I realised that he was killing me too and everything our family meant. I had to let it go, let go of my rage so I could survive it, though I'll never forgive him”

“I cling to my faith, I hope that my God will punish this person – it's all I have”

The families and friends of murder victims may experience a deep sense of helplessness and self-torture, reliving in their imaginations the last moments of their loved ones, frustrated by their inability to protect and defend the victim from this evil deed. Their eventual realisation, that, no matter what punishment the killer may receive, it will not heal their grief, or compensate them for their loss, eventually leads them towards acceptance.

There seems little to offer the parents of a murdered child , the children of a murdered parent , or the bereaved partners , siblings ,grandparents and other loved ones., Only a place for them to openly and

unashamedly share their thoughts and feelings without having to consider the sensitivities of the listener, their anguish needs to be acknowledged and accepted . We have to try to avoid the temptation to try to fix or compensate what, in reality, we cannot. They need to feel that they can express their rage openly, if they wish to, at another human being for taking away the life of someone they loved and to work through all aspects and emotions that may eventually help them to manage.

'Dear Alex.....'

At Bereavement UK we work voluntarily and receive emails daily from people all over the world. They seek reassurance, the opportunity to tell their story, share their intimate feelings and most importantly to feel acknowledged.

The website has changed since the writing of this book, the letters here are now 10 years old but today's letters follow similar themes.

I would like to thank each and every individual who generously gave their permission for use of the following letters. Small details have, with permission been changed in order that the identity of the authors be protected.

Email support is still free of charge and available on the Bereavement UK website.

Thank you.

All of the letters that I receive are as individual as the people who write them, but many of them address similar concerns or feelings, so I have grouped them together under the most commonly expressed views for the readers ease of reference.

Waiting to Die

This might sound odd to anyone who has not experienced a close bereavement, but a lot of bereaved people use this expression. Many grieving people feel this way but are unable to express it. Not being able

to voice a feeling is extremely isolating and can leave you thinkingI must be going crazy or I must be the only person to think this way. One of my clients once said

“I think, one day further from my child being alive but one day nearer to being with him”

Another person said;

“Before this happened I used to think “what if they were to tell me I had a terminal illness, only a short time to live? I’d be devastated, I’d fight it. But since her death in some ways I’d be gladit would mean release from this pain, a way out.”

These thoughts and feelings are, as I have discovered usual, but often unspoken. People who have not been through this experience might be unable to comprehend or be horrified that such words can be said and be thought acceptable. ‘Waiting to die ‘as an escape from pain and from a life that has changed so much and is no longer recognisable as your own, does not mean that you are going to take your own life. The two are very different. Comments such as ***“I cannot live without him or her”*** or ***“I feel my life is finished”*** are descriptions, communications of feelings that are so deep, so intensely painful that living on can seem intolerable.

Sometimes risks may be taken crossing roads or doing things that before may have caused deep anxiety or fear.

“I used to fear flying, but now I just thin –what the hell. In fact if something happens I will not have to endure this agony”

They may feel as if the joy and colour in life have been stripped from it, but alongside this the bereaved survive.

Dear Alex

You know I never thought anyone else had these feelings but me , I used to tell my husband after our child died of Leukaemia that I was ready to die too . Before her death I was always afraid of dying but since she's gone I am ready .sometimes I just need to be near her .I miss her so much that I'm ready – not fearful .Does that make sense ?I don't know . I would never take my life; I wouldn't do that .It's just how I feel.

From Bess

Dear Alex

I feel just like this, I am facing the prospect of having Cancer and yes it scares me but somehow it's different now that my son died .The problem I have the most is the hurt and agony the ones around me feel .I came in from work yesterday to find my wife sobbing, she is so fearful of what might happen if I die. I could only tell her I'm not going to – she won't get rid of me that easy. If she didn't hurt so much, if I could take away her pain it wouldn't be so hard.

From M

Dear Alex

It just seems peaceful kind of 'I don't care if death comes' I don't fear it any longer My family would never understand it, this feeling I have. I have this feeling from suffering loss, it so helps to know others think and feel this way, that I'm not crazy, that it's ok. For the most part I think society judges the unacceptable as self-pity.

Thanks for reading

KK

Dear Alex

The loss we experience as parents affects us in ways I could never have imagined or thought possible. After losing my daughter Kristina in 2001 I look at it totally differently. She was 20 when she died living

without her is hell. There's no place left to go but to be with her and some days I think sooner rather than later. I have no fear of death, some days it's just not soon enough .No I'm not crazy, I just miss her.

From Krissy's Mom

Dear Alex

I thought I was alone 'til I read that others feel as I do. My 18 year old committed Suicide 2 years ago .I often feel I just want to die .Sometimes I think my husband and remaining children would get over it . Reality always comes back to roost though and I would never want to hurt my family, put them through that. It just keeps going one day after another. I feel no joy, happiness I am empty .I am on anti-depressants and I feel I want to cry most of the time. I cannot tell you how thrilled I am to think this is normal. I thought no-one thought like me – had these thoughts .Many times individuals have tried to comfort me and tell me I will be with my son for eternity , I replyEternity is until the day I can hold him in my arms againThat is eternity.

Thank you.

From C

Hope

Has this really happened? Is there any hope?

People who have not experienced a close bereavement may not understand this kind of hope. How can there be hope when a loved one has died? However, this feeling of hope is a very common feeling experienced by many who have been bereaved .People often tell me that during the first few months of bereavement, they experience a sense of hope that their loved one may return to them, that what has happened is not real, that they are caught in some nightmarish situation, that it is all a mistake and will soon return to how it was before, back to normal.

Sometimes the bereaved try to re-enact an event , or repeat behaviour , or may try to keep things the same. If no changes are made, time may stand still and they may somehow find a way back to how things were , recover the past and their loved one.

These feelings of hope can be comforting and can form part of the grieving process and journey towards acceptance. In between these feelings there may be other more easily talked about feelings of anger, guilt and despair coupled with moments of joy. This confusing and diverse rollercoaster of feelings, thoughts and emotions is an exhausting time for the bereaved.

The sense of hope doesn't grow from disbelief although it may seem so to an observer. It is the desire for the situation to be unreal, the mind's battle towards eventual acceptance of the unacceptable. This language of grief at its very core being

'I know my child is dead but I hope.'

Dear Alex

Well, I know she is gone. I know it, but for some reason, inside, I am programmed to wait for her before I can begin preparing Christmas. Does it sound crazy? Am I absolutely bonkers? I know she isn't coming again – I went and decorated her grave for Pete's sake !In a few moments of sanity I even bought some presents for out of town people I need to send to , but I never mailed them. They just sit here on December 18th unmailed. My baking ingredients are purchased but I cannot bake I turn on the oven a few times daily but nothing goes in it.

Why can't I stop this feeling that she will come, walk in the door any minute, signal the beginning of Christmas? I feel it so strongly, any moment she'll call and I can start.

From Marilyn

Dear Alex

I am very concerned about my friend. Her daughter died six months, but my Mum told me ago, but my Mum told me she still waits for her to come. Sometimes she sits on the sofa and waits. She hopes to hear her daughters familiar rat tat on the door and her voice as she arrives. It is difficult to talk to her she says she knows Deirdre is dead, but she hopes.

Please, if you can explain this, if we can understand what she is feeling I might be able to help her a little.

Thank you

Julia

Dear Alex

I am a bereaved father. My only son Joey died just before Christmas. I don't think there's a moment when I don't think about him, but the feeling of anticipation at times is huge. I frequently anticipate seeing him, hearing him outside and his familiar voice. I can't talk about this to anyone; I fear they'd think I was crazy. I hope you can help me.

Thanks Tom

Anguish and Shock

Dear Alex

Today I am experiencing all of this –

Today I could lie on the floor of concrete and push my face deep into it as I could. Most days I do ok but we all know we will never experience the joy of a perfect day again.

After six years of living without the awesome smile of my Elizabeth I still experience the same pain as in the beginning. I just hide it better after so many years of practise. Those words about wanting everyone who passes us to know hit me so hard, how sad to have a wish like that. As hard as I try I cannot get through this day without tears. Thank you for this book it is a comfort to know others feel the same

Dear Alex

When they told me he had died , my world began to shake , the room was spinning , I can't remember it all but I know I knelt on the floor with my arms over the chair. I have this pain across my chest like being crucified, my heart ripped out. I begged them to say it was a mistake.

There were moments when I felt in control, almost stony, absent feelings and I could put words together and make arrangements, even supporting others. People said I was doing well, like praise. I felt like I should be doing more. I went out at night looking but I can't say what for. I blame myself, I let him down, I should have been there, I failed, I need to be strong but I don't know how.

Sometimes I have thought about dying, escaping the pain. I won't do it because I can't put the family through anymore.

Sometimes it just hits me, he really is dead. Sometimes I hold it in, afraid that if I let it out – start to cry I'll never stop

I don't know how life will be now, I think about years ahead. I envy the elderly because for them life may soon be over. I know nothing any more, just existing

Thanks for reading

Hanna.

Worries about Burials and Cremations

Dear Alex

My daughter died 18 months ago and we decided to have her buried close to my parents, her grandparents, who died ten years and eight years ago. At first I gained a sense of comfort from knowing that she was near my parents and if I ever thought about her grave and the dark and cold I would think about how much my parents loved her and the fact that they were nearby helped. Lately though, I've felt more concerned about my daughter. I can't stop thinking about her lovely smile, and all that may be going on beneath the soil. I'm thinking about the destruction of her, the decomposition and it's torturous. I know this sounds silly, but it's bad enough to bear that she's dead without thinking about further damage. Please tell me if my thoughts are normal

Thank you

Stevie

My Reply;

Yes others do have these thoughts. Sometimes there are concerns about the weather , about cold or rain , and on several occasions people have told me they have felt compelled to clear snow from their loved ones grave or had thoughts about the grave being wet. The sense of transferred claustrophobia... fantasising about the deceased being trapped below ground or being afraid is also not unusual. The hardest part of acceptance is the reality that she is dead, she is not experiencing these elements that are disturbing you and that by retrieving the remains you cannot bring back his life. I wonder is this more about the need to have her back, the deep loss and need to care for her still?

I feel you would certainly benefit from good professional support and urge you to seek this as within a trusted relationship the opportunity to explore these thoughts and feelings in greater depth will be beneficial.

Dear Alex

I have tried to find some answers myself but it seems there is a lot of secrecy about death and when I have attempted to talk about it friends and family seem horrified and try to distract me by changing the subject. I'd like to know what happens to the body when it's cremated. My husband was cremated and I have just received his ashes, I don't think there are enough. Also can I be sure they are his?

My Reply;

The process of cremation is the disposal of human remains by burning at an extremely high temperature. Nothing is removed from the coffin prior to cremation and dressings provided on the coffins used for cremation such as handles are of disposable material. Items such as mobile phones, photo frames and jewellery will usually be returned to the family pre cremation these items are not crematable. Once the cremation process is completed any remaining ash and bone are removed from the cremator and scanned through a scanner to remove any metal content. The remains are then placed into a machine that grinds them to dust. Finally the dust / ashes are transferred to either a

plastic bag or urn before being returned to the family. Bodies are never cremated with other bodies and the ashes you receive will be of only one person. Yes it does seem impossible that a whole person can be reduced to a small amount of powder. You are not alone in thinking these thoughts but I offer my confirmation that this is how it is.

Dear Alex

My wife died a year ago and is buried. I often think about her beneath the ground and I can't get the thoughts out of my head once they start Can you please tell me how long it takes for a body to decompose completely? I don't know why I am in need of this information .Am I being morbid, or do others feel this way?

My Reply:

Decomposer begins soon after death and progresses until there is only solid matter such as bones left which in certain conditions and with the passage of time will also reduce.

If the body has been embalmed and, depending on the degree of embalming that has taken place decomposer may take longer. Ground conditions also impact the speed at which decomposer progresses,. If the ground conditions are wetter, the decomposer will be quicker. I have been told that in many cases by around 18 months the body will have mostly decomposed.

In answer to your final question. No you are not alone in having these thoughts. Although some feel it is morbid. I believe it is quite usual to want to know these things, being able to talk about and ask such questions and to receive appropriate information can be a positive move towards manageability.

Dear Alex

My family are arguing about my daughters ashes. (She died of illness and was cremated a year ago) My ex – her mother , wants to place her ashes in a local cemetery but I would like to scatter them in a place where we spent many happy hours together .Someone suggested we split them , Is it an acceptable thing

to do ? I mentioned this to a family member and she was horrified but frankly my ex-wife and I are ok with it. Your thoughts on this would be greatly appreciated

Tony

My Reply;

I believe that whatever you as individuals feel is right for you is the right thing to do. No, it isn't at all unusual for families to split or share the ashes of their loved one particularly where families may be separated. It, may be difficult for those who are not as closely involved or who have never experienced a death to fully understand the needs of the bereaved. What's really important is that you do whatever gives you comfort, it sounds like you had a very special relationship with your daughter and leaving something of her at your special place sounds fine.

Just As I Am – Just As You Are (c) Alex James

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‘A Cup of Tea with Auntie’

When one of my clients described a session with me as feeling like ‘a cup of tea with auntie’, I believe what she meant was that it was comfortable, reassuring, familiar and allowed her to be just as she was at that moment in time. There was no air of falseness but simple warmth a place in which she could be herself and express and explore her feelings – I am pleased that my clients found in me a friend, genuineness and a sense of being held.

When I say I love my clients I mean it. I feel connected to them, I get to know them well and the relationship between us facilitates not only a huge depth of acceptance, but also of trust and empowerment.

Today we are driven to provide statistics, aims, objectives, to tick boxes and to prove our worth, not by the quality of the relationship with the client but by the form that measures in static fashion, whether they feel better and hey, if all the boxes are ticked in the correct way it proves that great work is achieved and is therefore worthy of more funding.

The face of the client, the individuality of each session can so easily fall by the wayside in favour of ‘one size fits all’ stats. There isn’t time to sit and listen, just because someone needs to talk, because we have a schedule to fulfil. So, to hell with love and passion for our work, let’s reinforce those boundaries, protect ourselves from our clients and serve them only with the fifty min hour and move on to the next. I don’t know about you but as a counsellor I have frequently felt under this pressure.

Over the last ten years I have met and worked with many different people. Meeting all of these people and sharing their journey’s, enabled me to recognise that actually most of them didn’t need counselling in the ‘professional more boundaried’ way, they wanted something else. A space to share, they didn’t want to be dissected, or psychologically assessed. Most, simply wanted to know, that their experience of grief was ‘normal’ and that others felt the same.

I, like most came into this work because I care, I want to help others. I feel passionate about my fellow human being. Over years I have seen so many others like myself come to the work with this sense of care, only to fall into theoretical techniques and boundaries, confining their natural capabilities for human connection.

Is it really so wrong to hug a client or to touch their hand?

Fear of inappropriateness should surely not exist if you're working in an intuitive and professional way.

Is there a place for both? Does being professional mean keeping such tight boundaries?

I believe that we are entering a new age of therapy. It often feels to me as though we are in a sort of in-between stage, teetering on the edge of new ideas and yet clinging to older more familiar methods.

There is I am sure, much yet to be learned about the power of positivity, holistic therapies and the human mind with regard to all aspects of wellbeing and indeed of terminal illness.

I coin this new phase 'The Human Phase.' It allows for less conventional and more creative relationships, where holistic therapy, creative art, music, movement, meditation and animal assisted interactivity, unite to engage the whole person.

I have worked supporting individuals and families for over thirty years; it is over time that I have grown to recognise the differing needs of individuals with regard to the therapeutic relationship. It seems to me that there are several key ingredients to a useful relationship between the client and the support. It is those ingredients that I wish to explore with you, to share the ways in which your clients might benefit from this way of working.

Years ago in this country (UK), people tended to stay put, working and living in an area where it wasn't unusual for families to live close to each other. There weren't large supermarkets and people shopped locally, providing them with opportunities to chat to shop owners and give updates on family news etc. Children were known by neighbours and less traffic meant they could play together in streets and back yards.

The sense of community, of having the support of close family, neighbours and friends meant that people were not so isolated. There was always someone ready to listen and old sayings such as 'a trouble shared is a trouble halved' carried a lot of truth.

There was a sense of belonging, people knew about the misfortunes of others and often pulled together to help. Sadly, today this sense of belonging and of close knit community is deteriorating and in some cases has been lost. Families live miles apart and it's not unusual for neighbours not to know each other. Large supermarkets with express DIY checkouts mean speed, but also no personal exchange. People rarely work and live in the same locality and for those living away from their original roots, life can be very insular with a lack of support or place to chat. We live vicariously through TV entertainment soaps and realities. How can this be healthy?

Human beings need community; we thrive on feeling included and on a sense of belonging. We can observe this when a disaster occurs and how when given the opportunity people pull together, there can be a sense of euphoria, being part of something for the common good. People often say how much they liked this community feeling and how since a disaster they strive to continue to keep the relationships made with those they previously didn't know.

There is in each of us a need to feel loved, wanted, important, included, heard and understood. As I mentioned earlier, I have spent many years working with the bereaved in differing agencies and in different ways. I travelled around a lot too, as an independent person, just finding out what services were available and how they were offered. I spent time listening to the individuals and families that came to me or wrote to me for support, I also spent time talking to and listening to the professionals, wishing to offer support. Out of the many conversations, I've begun to see a picture of how we are struggling. How the bereaved and vulnerable are really feeling and how those who wish to help often lose their way encumbered by red tape policies and procedures.

When I wrote *'Living with Bereavement'* it was ahead of its time. We were only just beginning to think about how we could help and talk more openly about death and dying. Over the past ten years things have slowly begun to change.

Shortly after writing *'Living with Bereavement'* I was offered a job in a hospice working with families, pre and post bereavement. This was a challenging opportunity and gave me a greater insight into the work, not only with the bereaved but with the terminally ill.

There were so many services on offer to the bereaved, but I felt there was a place for something more. I wanted to offer a less structured approach, less boundaried, to freely give my clients time and space to express themselves.

Fortunately the hospice was quite forward thinking and allowed me the opportunity of building a service for children and their families that was quite unique.

In my new offering *'Just As I Am, Just As You Are'* I invite you to join me as I explore and share with you some of my innovative ideas and experiences. The richness of relationships that I've achieved with the terminally ill and the bereaved, their thoughts and ideas of how they might be best assisted (this might be useful if you work in this field) and ideas for the terminally ill, about living and continuing bonds with those they love. Hopefully, a book for everyone will put us all on the same page and activate and encourage greater communication – which is really what it's all about, isn't it?

The connection with ease to another human being can sometimes be as simple as 'a cup of tea with auntie.'