This booklet honours all the families who have shared their grief with us, their emotion and struggle which showed us how they "Learn to live with grief."

We wish to thank all those who have supported the development of this booklet. The bereavement and walking groups of Accord, the volunteers and Staff who shared their opinions which helped shape some of the content of this booklet.

Thank you

You have been given this booklet because someone in your life has died. Grief is the emotional response when someone dies and is a very individual experience. What is helpful for one person could be unhelpful for someone else. Although this booklet cannot tell you how to grieve, we hope it will be helpful in giving you a better understanding of grief and support you to manage your expectations.



EARLY LOSSES

The losses you experience have started at the point illness is diagnosed, as life can never be the same again. This leads to people learning to live a new 'norm'. This can be a very short or a long period of time which can influence your grief.

Illness brings out different coping strategies in different family members, which can lead to misunderstanding at times. Often the emotions that are experienced before someone dies can be hidden away. There can be no time to express feelings due to the caring role. You may be holding back trying to protect the person who is ill, other family members and sometimes yourself.

It can be challenging to acknowledge the changes that you are experiencing at that time. It might only be after the person you were caring for dies that you have time to process some of these emotions.



REMEMBER: There is no right and wrong in this situation, grief is unique.

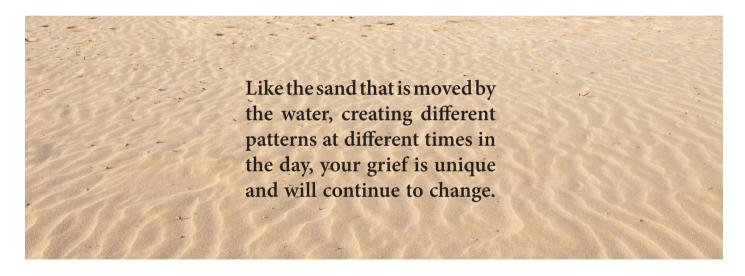
As grief is unique and individual to each, so is the journey towards the end of life. People's experience of illness and death are all different, for some diagnosis and death can come in a matter of weeks and for others this will be much longer. This will also affect how you grieve. Despite being given the information that someone in your life will die, the end can still leave you feeling a degree of shock.

We encourage you not to get into comparing your experiences to other people's as this will never be comparing like for like, whether that is thoughts, feelings or behaviours. Everyone has their own experience they are trying to make sense of.

No matter how many times in our life there is loss, each death will be a unique individual experience based on the relationship you have had with that person.

Grief is the price we pay for loving people. Even if a relationship has become more difficult or estranged there once was love and care for a relationship to have formed.

When someone dies and the relationship had held difficulties, this can impact the grief. Any hope there may have been to make the relationship different is also lost.

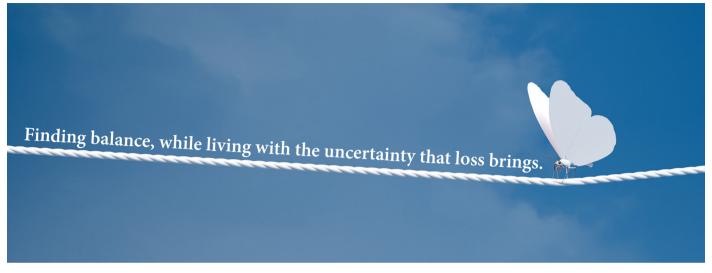




REMEMBER: You have never done this before.

GRIEF RESPONSES.

Living and grieving go side by side, you can't do one without the other. There are many challenges that grief brings, finding balance between thoughts and emotions could be one of them. Sometimes the emotional coping strategies that you use in everyday life don't always support grief. This could leave you feeling in a lost and frightening place, which may make you question many areas of your life.



It can be common to FEEL:

- Unable to concentrate
- Irritable or angry
- Frustrated or misunderstood
- * Anxious, nervous, or fearful
- 🌞 Like you want to 'escape'
- Guilt or remorse

- Uncertain
- Numbness
- Exhausted
- Loneliness, a sense of emptiness
- A deep sadness, that can be felt as a physical pain

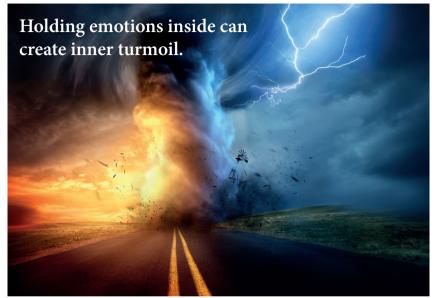


Common THOUGHTS can be:

- This is not really happening.....
- Why.....
- How 'should' I be
- I must be strong for those around me.....
- What will people think if I.....
- I must sort everything as....
- Could I have done something different
- * If only

Common BEHAVIOURS can be:

- Crying for long periods or not being able to cry
- Trying to keep very busy or feeling too exhausted to do the things you normally do
- Struggling to sleep or struggling to get out of bed
- Forgetfulness
- Confusion
- Social withdrawal / not wishing to be alone
- Not taking care of yourself, e.g. not eating



The thoughts, feelings and behaviours you may experience can have a physical effect on your body which you may not expect. It can be surprising how physical grief can be. Grief can be felt like a knot in the stomach or heaviness in the chest. Thoughts can

often go round and round like a hamster in a wheel. Some struggle with certain emotions such as anger. We are often encouraged not to show our anger, but like any emotion as long as it is not destructive to you or others, expressing your anger can be helpful, i.e. many a task is completed by working through anger, finding a safe private space to express this.

After someone dies there may be many things you need to attend to. Contacting family and friends, arranging a funeral and all things associated, exploring how the funeral will be paid for. Dealing with the changes that have to happen i.e. names on bills, title deeds, joint accounts all take emotional

and psychological energy. In order to support your emotional and psychological needs you may find yourself wishing to keep busy or allowing family and friends to take a more active role to support you at this time.



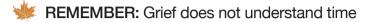


REMEMBER: 'Should' is an internal expectation you place on yourself.

The depth of your grief can feel overwhelming at times. Sometimes you may fear this pain will never ease. You may place expectations on yourself of how you think you 'should' be and often these are unrealistic and unhelpful in supporting yourself through your grief.

THE REALITY OF THE LOSS

The further away you go from the point that someone dies the sense of the loss can become a greater reality. This may contradict the belief that 'time heals grief.' However what is missing from this is the fact that you are **learning** to live with multiple losses which takes time to understand.



Experience suggests that at times people can show and feel emotions and other times hold back. Learning to live with this huge change can mean you need time out from your grief. Trying to find a balance between living and grieving may feel like a struggle. It can be supportive to allow yourself



some time out from your grief that does not leave you feeling guilty. This can help you to get on with living while grieving, managing all the changes you face.



REMEMBER: There are multiple losses when someone dies which you are learning to live with - some of these can be hidden.

CHANGES

As well as experiencing the emotion of grief, the death of someone can have other impacts on your life. You may need to learn a new task that once was done by the person who died e.g. learning to deal with financial matters, or

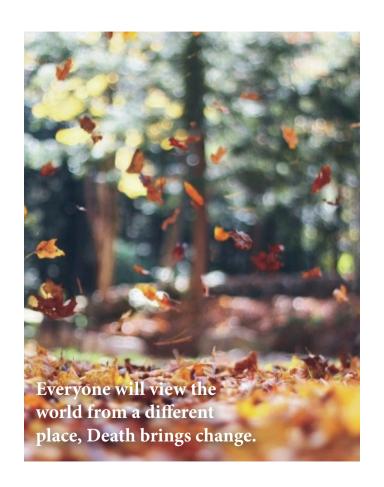
cooking or gardening. When someone in your life dies it can have an impact on identity and on family structure, e.g. attending a family event will be different.



Acknowledging your and others emotions in these circumstances can support the situation. You may find those around you are frightened to upset you and likewise you may avoid conversations. You may find it actually more helpful, when ready, to have these conversations and share your thoughts and feelings with family and friends.



REMEMBER: People cannot support you if they don't know what you are thinking and feeling



GRIEF CYCLES

It can be helpful for you to be aware that the grieving experience has a beginning which continues throughout life in cycles, not as a forward path where you check things off as you go along. Many of the thoughts, feelings and behaviours encountered can



be like climbing a spiral staircase where things can look and feel like you are going round and round in circles, yet you are actually taking one step at a time. There can be times where you believe you have gone back to the beginning of your grief; however grief can make you revisit emotions many times. It may feel similar to what was previously experienced but it will be different.



REMEMBER: Be realistic with the expectations you have of yourself. This grief is a new experience.

As every relationship is unique, so too will be the grief experience, i.e. partner, parent, child, grandparent, friend....

RELATIONSHIPS

The grieving process can impact other personal relationships. While we initially share our grief with those around us, as time passes it may start to feel that you are alone with your grief. People who you expected would always be there for you may disappoint, and others who you didn't have any expectations of may step up and be the support you need.

Sometimes people find it difficult to maintain social connections or struggle to share emotions with friends and family i.e. always responding 'I'm fine', when asked how you are. There can be a fear of judgement,

worry of it being awkward for others or you can have a perception that others don't really want to know how you are really feeling. Holding on to your thoughts and feelings could have an impact on your health.

Not sharing with people how things are for you can contribute to a feeling of loneliness where you feel no one really understands. Some people in your life may not understand your grief and may say things that feel insensitive or inappropriate. Unless you share your feelings with them, they will never have the opportunity to learn how to best support you.

People often think others will be fed up listening to them, remember others do not live with your pain and will hear you from their own perspective. Consider what you need at this time and remember you can always change your mind. Even if you find it too difficult to connect with some people in the early stages of your grief you can reach out to them at a later time, when you feel ready.



REMEMBER: Whatever we feel in a moment doesn't last forever, it will change.

OCCASIONS

Special occasions or anniversaries may be challenging but consider what you want and need and who you can ask to support you during these times. Having conversations explaining your concerns fears or worries can support you to engage in social situations sooner.



LIVING IN THE PRESENT

There are three aspects to life, what was, what is and what if - past, present and future. What we are able to manage, is to try and hold the 'what is' (the present). Acknowledgement that what has happened is in the past and cannot be changed can be difficult. 'What if' is often



about focusing on the future that you have not lived and cannot until it arrives i.e. 'what if I cannot cope with an up and coming situation' rather than staying with 'what is'.

The present moment is one thing you can deal with and pay attention to. Focusing on the worries of the future can be a way of avoiding the pain of the present.



REMEMBER: While the past can be important to think about and can inform us, using energy looking at what was takes it away from what is.

What is coping? Often people who are grieving say 'I am not coping', but what does this really mean? Reflecting back on how you actually have managed to deal with all you have, can sometimes be helpful.

Acknowledging that despite the emotional overwhelming feelings of grief there is still an ability to function at some level.

Grief can be like putting your world under a magnifying glass which makes everything appear bigger, thoughts, feelings, behaviours, family situations and life in general. Things that would normally have been like 'water off a ducks back' now cause struggle where we catch, we hold, we allow it to soak into the very being of who we are and often this can be out of proportion because of our view of the world through our grief.

CONTINUING TO LOVE

An important thing to remember is as human beings we strive to continue the bond with those who have died and this can take many different forms. Speaking to a picture, having a hug from a cardigan, a bench in their memory, acknowledging birthdays and other special days, can bring comfort as well as sadness. To try and ignore takes a huge amount of energy, the fear of judgment can often lead you to question the choices you make. However everyone needs to find their own unique way, so long as it causes no harm to you or others.





REMEMBER: The person you have cared about has died but love remains.



The book has never been written that can tell somebody how to grieve, however we hope this booklet will help to make sense of a world that has changed for you forever. Being patient and kind to yourself and those around you, through this really difficult part of your life's journey is really important. Continue to share with those who can offer support.

Helpful Telephone Numbers

Breathing Space: 0800 83 85 87

Samaritans: 116 123

Patient and Family Support Team at Accord: 0141 581 2014

www.childbereavementuk.org

www.winstonswish.org.uk

www.tcf.org.uk - support after the death of a child at any age

www.accordhospice.org.uk



