



**Bereavement
Charter**
FOR SCOTLAND

A Bereavement Charter for Children and Adults in Scotland: Guidance Notes

Updated November 2023

#becausegriefmatters

Introduction

Over four years ago, a range of like-minded professionals and individuals came together to reflect on the nature of bereavement support in Scotland. We concluded that despite a lot of really good work happening, we could do more, and we could do better, and from that point on we undertook work to produce a National Bereavement Charter for Scotland.

Today, the need for such a Charter has become even more important due to the unique circumstances which resulted from the COVID-19 pandemic.

Today, the need for such a Charter has become even more important due to the unique circumstances we currently find ourselves in due to the COVID-19 pandemic. People who were bereaved were in some cases not able to be with a person as they approach the end of their life and many were isolated from their usual networks of support. The pandemic also changed the customary ways we were able to mark our grief. Traditional bereavement rituals and funerals changed with many people unable to attend funerals in the way that they might have in the past. Many deaths became sudden with little or no time to prepare. This has resulted in many people struggling to grieve.

It is therefore increasingly important that we understand not only the importance of bereavement support, but what that support needs to look like. Whilst accepting that every death is unique and that the way we each come to terms with a death is individual, this Charter and Guidance attempts to describe what good bereavement support can look like and what difference it can make.

The Charter does not claim to be the end

of the story or to have all the answers. It is an evolving document designed to ensure that we get better at talking about grief and bereavement care. It is offered in part to help the discussion but also to guide us by describing good bereavement support at its best.

Many of us will have experienced the death of someone close to us. We may have had to do the hard work of grieving on far too many occasions. Whilst we recognise that grief is normal, and that many people will cope with bereavement through the help and support of family or friends, some may struggle to find a path through and a sense of balance when the waves of absence and grief overwhelm.

Bereavement is the sense of feeling robbed and bereft. For no matter how expected or anticipated a death or loss is, its ache is still sore, its pain is still raw, its touch is a cold beyond description.

This sense of lost-ness is beautifully conveyed in the original word for 'bereavement' from the Old English -'bereafian' which denotes a sense of deprivation, of being robbed by someone, of being seized or grabbed out of living and life.

We have lots of evidence to show that as a society in Scotland we have lost the cultural and societal ability to deal with dying and have misplaced our skills at working through loss in bereavement.

A Bereavement Charter for Children and Adults in Scotland: Guidance Notes

We believe that bereavement support is a fundamental right of what it means to be a citizen in modern Scotland. That is why we have framed the Charter very explicitly in human rights terms.

Human rights at their heart are statements underpinned by law which describe what it means to be human, how we relate to others who are different from us, and how we can make decisions and determine priorities when society is being challenged.

Human rights are rarely black and white, more often they sit within the multiple competing convictions and priorities which are involved in modern living and decision-making. That is why when we consider bereavement, they have a particular resonance and application.

In Scotland we have a long history of ensuring that human rights sit at the very centre of what we do as a society and the way in which we should seek to support one another.

At this present time there is active consideration of embedding the United Nations Convention on Economic, Social and Cultural Rights (ESCR) into Scottish law. This will potentially enshrine into Scottish law the 'right to health'. Health is viewed as the right to not just physical health, but to mental, emotional and psychological health and wellbeing. The right to health is considered fundamental to the ability of a person to achieve and realise all their other human rights.

The authors of the Charter believe that a core element of what it means to be well and healthy is our ability to deal with the emotions and feelings which occur before and after the death of someone.

Therefore, how we are supported to deal with death, dying and bereavement is intrinsic to our ability as citizens to achieve the right to health and, by extension, all our other human rights.

Good bereavement support is not an optional extra, it is fundamental to a society basing its character on dignity and human rights. Good bereavement support renews and restores, it can give a sense of purpose and direction, for many it is what has literally saved their lives.

An initial short animation was launched in September 2021 to help health & social care professionals support the implementation of the Charter: <https://vimeo.com/592277288>

There is a short film further summarising the rationale for the development of the Charter available at: <https://vimeo.com/395685686>

**Dr Donald Macaskill,
Chair of the Bereavement Charter
Development Group
November 2023**

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How to use the Charter

The Charter is designed to be used by any organisation and/or individual in whichever way they feel is appropriate. Our hope is that you use the Charter and that it starts a serious conversation about bereavement support across Scotland.

One of the things we would like to see happen is that the Charter is displayed in as many places as possible. Please consider displaying it in your place of work, business or social/recreational space.

Everyone in Scotland needs to be talking about bereavement; we all need to be thinking about how we can support others. We will help to achieve the aims of the Charter and create the Scotland which supports those who are bereaved if we give real visibility to the Charter and its accompanying Guidance.

So please display the Charter:

- If you are in your local café or supermarket
- If you are in a pub or restaurant
- If you are in your dentist's or doctor's waiting room
- If you are in a hospital, prison or police station
- If you are in a nursery, school or university
- If you are in a club, theatre or museum
- If you are at a local concert or music festival
- If you are on a bus, train or plane

In fact, wherever you go and whatever you do, we would love for the Bereavement Charter to be seen.

The ways of using the Charter are endless. This is **your** Charter, please use it and tell us what you are doing by emailing bereavement@scottishcare.org

Ways you could use it

There are many ways in which you might consider using the Charter:

- Talk about its content to friends and family
- Take one sentence and think about what it means for you as a person
- If you have family, think about what it means for them and those who matter to you
- If you are an employer, consider what its terms might mean for the support you give your staff
- If you are a teacher, think about ways in which you could create a lesson plan around the Charter to encourage conversations about grief
- If you are a commissioner of care, think about how you can change your services to allow carers to talk about these issues with those they support
- If you run the local Students Union, you might want to hold a dedicated session on the Charter
- If you are a supervisor in your workplace, talk through the issues with the staff you manage as a matter of routine
- If you are an events organiser in a museum or cinema, think about organising an event which focuses on the issues raised in the Charter
- If you run a café, think about holding a Death Café which can focus on bereavement
- If you run a walking club, think about how you could walk and talk bereavement
- If you are a journalist, why not write a piece or record a story about the Charter
- If you are a politician, consider how you can make the achieving of its aims easier

Charter statement explanations

Below are some more detailed explanations about many of the statements in the Charter.

People should be treated with compassion, empathy and kindness:

When an individual is experiencing grief, it is vital that there is understanding of the pain and confusion they may be feeling.

Treating others with compassion and kindness involves being willing and able to demonstrate to others that you recognise the importance of their grief and feelings, while acknowledging that every person is unique and will experience grief in their own way.

This means that you cannot make assumptions around how an individual will experience and deal with their bereavement and loss. Sometimes people shy away from talking to someone who is bereaved as they worry about saying the wrong thing or causing further upset. However, there is no single right thing to say. Listening to and talking with individuals about their feelings and demonstrating your understanding shows you care and want to support them.

Empathy is vital in understanding these complex emotions and enables you to imagine how you would feel under the same circumstances. Although we all have our own individual ways of coping with heightened emotion we can draw on our own feelings and experiences when giving support to others.

We all need to feel that our emotions are important and understood by others particularly when difficult emotions are being displayed, such as anger at a loss. We can understand when people are in

physical pain, so it is equally important to be able to understand that emotional pain can have just as much of an impact on those experiencing grief.

Pain of any type results in us finding it harder to cope with our daily lives and can have an impact on how we deal with situations and react to others. Through displaying our understanding of each individual's feelings of grief, and supporting them where possible, we give validation of their emotions and show that we understand and have empathy for their loss. Treating others with compassion during difficult times creates a society that values each other and understands the importance of supporting each other during bereavement.

People should have their wishes, choices and beliefs listened to, considered and respected by all:

It is especially important that we feel listened to and respected, and feel that our personal wishes, choices and beliefs are considered when we are experiencing grief and loss. Every individual will find their own experience of grief different and will rely on their personal beliefs to understand and process their feelings and emotions.

When we talk about person-centred care, it is about knowing each individual and taking time to discover their personal opinions, wishes and choices. It is those personal beliefs which will shape the decisions they make regarding their day to day lives.

People can have a more positive bereavement experience when they are able to follow the wishes of the dying person as closely as

possible especially around the particulars of their death and funeral arrangements.

It is important to recognise that others may have different experiences and understand how, for example, a person's religious, faith and spiritual beliefs may impact their grief. We live in a varied and multicultural society that includes people from all nationalities who have a variety of beliefs with an impact on how they view and talk about death, dying and bereavement.

It is also important to recognise that we cannot make assumptions based on those beliefs but should instead use them to guide us to understand the individual and to have conversations around their personal wishes and choices.

Where possible, every individual has the right to choose their own end of life care and this includes having opportunities to talk about their death and how this is affecting them. It is only by opening up these conversations that we will become more experienced when dealing with death and bereavement and create situations where people feel confident to discuss their own individual needs when dying and when dealing with bereavement.

Grief, bereavement and death are recognised as a natural part of life:

Bereavement or being bereaved is a time after someone has died. Grief is the emotional response to bereavement and can begin before someone dies. As grief is unique to everyone, there is no one way of responding. Death is something that happens to everyone and is a natural part of living; everyone who lives will also die, so it is right that it is understood that we should be supported and given the opportunity to talk openly about death and how it impacts our lives.

Accessing support (including emotional, practical, financial, social, and spiritual) is seen as a right:

As an individual wishing to exercise your right to bereavement support, you should be able to access the support that best meets your individual needs, when you need it.

This will inevitably mean that this looks different for each person. It is important that you have the right information at the right time and are able to feel supported to grieve in a way that helps and protects you. This support will look very different for every individual. Organisations, employers and others should be careful not to assume that they know what best suits an individual.

For some it might mean knowing what to do in a very practical sense: how to fill in the many forms that seem to accompany the death of an individual; what to do about notifying public authorities and others when a death happens; what the stages are after someone has died for you to undertake particular practical tasks.

For some the support needed might be financial. This is not just about making practical arrangements around pensions, insurances and benefits. Many hundreds of individuals are placed into real poverty when someone in their family dies. This might for instance be because of the sheer expense of paying for a funeral or the fact that the main bread-winner in the family has died, or the reality that you are left with bills to pay and have no source of income because you are off work. Good bereavement support meets the practical and financial needs of people who are bereaved.

It may be the case that you need support which recognises the emotional and psychological changes and impacts you are experiencing following the death of someone you know or someone in your community. Good bereavement care should be able to signpost you to organisations and individuals who can support and assist you in dealing with the often confusing and conflicting range of emotions and feelings you are having.

For many individuals, dying and death raise profound questions about the nature of human existence, and so the right to good bereavement care recognises the importance of validating, valuing and enabling someone to express their religious and/or spiritual needs and questions. Spiritual care is intrinsic to achieving good bereavement support for many individuals.

Efforts are made to ensure that adequate bereavement support is accessible to everyone:

When someone in your life dies you should receive information that you can read at any time about bereavement and how you might feel. This will be relevant to you and in a format that you can readily access. People will understand that whilst you might not feel that you want support at the present time, you might want support in the future and the information will tell you how you can do that.

You will be able to have confidence and trust in the information provided and the support listed. For example, depending on your preference you may receive a booklet, or a list of electronic resources such as websites or apps. If you are a child or young person, you will receive age appropriate information.

People have space and time to grieve:

People will understand that your feelings of grief may change and develop over time but that there is no time limit. You may still have occasions when you need time to think and grieve long after a death.

Caring for someone who has then died can be difficult and feelings of grief and loss during bereavement may not only be about the person who has died but about the caring relationship and the purpose, meaning and routines that go with that.

It is important to:

- Talk to others about how you are feeling; remain connected with family and friends; find people who are in a similar situation; join groups either in person or online
- Be aware of triggers of dates, transitions and events that may spark off feelings of grief and prepare yourself for how it will make you feel
- Be honest with yourself; let yourself experience these feelings and take some time to work through them in a way that helps you
- Ask for help and tell the person that what you are feeling is grief and bereavement and that you need support with it

It is recognised that bereavement might affect all aspects of a person's life (e.g. relationships, school, and workplace):

Grieving can be a lifelong process for some people with no time limit as to if, or when, the grieving will come to an end. It is therefore important that the impact that grief may have on you is acknowledged and respected by whoever you encounter in life, e.g. through relationships, work or education.

For example, many people believe that the first year is the most difficult following a bereavement and can expect people to “be over it” after a set time. However, as grief is so unique to everyone, we need to be mindful that someone may have grief responses many years after they have been bereaved, with thought given to events that may trigger grief reactions e.g. birthdays, anniversaries, cultural celebrations etc.

Grief and bereavement can begin before death and can be life-long

It is common and expected to experience grief and bereavement when someone in your life dies. However, you can also have feelings of grief and a sense of bereavement when the person you care for is still alive.

For example, if they are terminally ill or severely incapacitated, we can grieve for the person they used to be, and for all the hopes for the future that have now disappeared. There are many triggers and experiences for grief before death and it is important that these are acknowledged and accepted as normal parts of everyday life.

Additional guidance for bereavement in specific circumstances

The following sections show the potential impact of different types of death. These will be reviewed frequently and updated with additional sections being added.

Pregnancy and baby loss

Parents may experience loss in a variety of circumstances during pregnancy or after birth including stillbirth, neonatal (newborn) death and sudden unexpected death up to 24 months. Women, partners and siblings often find family, friends, employers, schools and even healthcare staff can treat the loss of a baby very differently from other bereavements.

People may react by saying or implying that the loss of a baby, especially an early pregnancy loss, does not really count - 'you can always have another'. This attitude is a cultural issue where people believe a baby is not an individual, a real person, so will not be much missed and families can recover quickly whereas in reality their bereavement has only just started.

When a baby dies there may be very little evidence of the baby's existence and there are few, if any, shared memories, which can make grieving a very isolating experience. This can complicate the grief and families may worry about some of the emotions and feelings they are experiencing.

Whilst parents may find themselves grieving at the same time, their grief may take different forms. This can put a strain on a relationship and a significant number of parents experience isolation, anxiety and depression in the following months and longer term.

Emotions can be hard to manage around anniversaries, family celebrations and when expecting a subsequent baby. The death of a baby can also lead to the loss of hopes, dreams and expectations parents had for the future.

Families may find it difficult to look after other children at home as they may be experiencing unresolved grief which can have a major impact on their ability to function and carry out daily tasks.

It is important that parents find support to try and make sense of their grief so they can explore ways of integrating their loss into their life – many learn ways to honour their baby.

For families who have experienced a sudden, unexpected death of a baby or infant, the involvement of the police and procurator fiscal and lengthy investigations and review processes can be particularly distressing.

 **Links to further information
and sources of support**

Miscarriage Association

<https://www.miscarriageassociation.org.uk/>

National Bereavement Pathway for
Pregnancy and Baby Loss

<https://nbcpathway.org.uk/>

Sands, Stillbirth and Neonatal
Death Charity

<https://www.sands.org.uk/>

Scottish Cot Death Trust

<https://scottishcotdeathtrust.org/>

Twins Trust Charity

<https://twinstrust.org/>

Antenatal Results & Choices (ARC)

www.arc-uk.org

Bliss – for babies born premature or sick

www.bliss.org.uk

Children and young people

Many children and young people will experience bereavement, through the death of a parent, sibling, grandparent or friend. Children can also face the loss of a loved animal or pet which can be as significant for them as the death of a relative or friend.

Children, young people and grief

People are often anxious or reluctant to talk about death and dying with children and young people. Many people still believe that children do not grieve or that because they are young, they are resilient and will “get over it”. Whilst many children are resilient, we need to understand the impact on a child’s life following the death of a significant person in their lives.

For children to grieve well and have the best chance for coping with their grief and avoiding potential difficulties in adulthood, it is important that they feel supported, with access to available help at a time they need it. Children often experience similar feelings to adults but may show these differently. For example, very young children may be sad for only short periods of time. This can be misunderstood as not caring or not understanding but may be to do with their short attention span and protecting themselves from difficult and confusing feelings.

The importance of support

When a child or young person is bereaved, they might experience a range of emotions. These might include feelings such as, sadness, confusion, worry, guilt or regret and anger. Sometimes they can blame themselves for the death and can need reassurance that this isn’t the case. Most children and young people can be supported well with their grief with the care and support of family, friends and trusted adults. Most children will not require specialist intervention.

What children and young people understand about death and how they react

The age of the child or young person affects how much they understand about death. Children and young people’s reactions will be affected by their understanding of death, and by their experiences and circumstances.

Age and stage	Understanding	Common reactions
Babies and infants	<ul style="list-style-type: none"> ▪ Can't understand what death means ▪ Can be affected by emotions of people around them 	<ul style="list-style-type: none"> ▪ Can become unsettled and cry more than usual ▪ Can become clingy and restless ▪ May not feed or sleep in the same way as before
Toddlers to school age	<ul style="list-style-type: none"> ▪ Expect the dead person to return – do not understand that death is lasting ▪ Have a tendency to 'magical thinking' believing that their behaviour might somehow have caused the death 	<ul style="list-style-type: none"> ▪ Go back to behaving like a younger child (e.g. thumb sucking, bed-wetting) ▪ Not have the words to say how they feel so show feelings in their behaviour ▪ Ask lots of questions over and over again as they try to understand what is happening ▪ Become anxious and upset when separated from those closest to them, as they are afraid that others may also leave them ▪ Be sad only for short periods of time
Five to nine	<ul style="list-style-type: none"> ▪ Begin to understand that death is permanent ▪ Be afraid that someone else important to them will also die 	<ul style="list-style-type: none"> ▪ Ask lots of questions ▪ Worry about the person who has died (e.g. what are they doing now? How do they eat or sleep?) ▪ Still not be able to put their feelings into words ▪ Feel guilty and believe they might have done something to cause the death, (e.g. "... if I hadn't been angry with x...) ▪ Behave differently (e.g. becoming anxious or withdrawn, or becoming difficult, becoming aggressive or showing off)

Age and stage	Understanding	Common reactions
<p>Nine to twelve</p>	<ul style="list-style-type: none"> ▪ Understand that death is permanent ▪ Be afraid that they might die ▪ Be afraid that someone else important to them will also die ▪ Be anxious about how their life will change 	<ul style="list-style-type: none"> ▪ Find it difficult to talk about and share their feelings ▪ Behave differently (e.g. becoming anxious or withdrawn, or becoming angry or guilty) ▪ Become isolated or unhappy at school and find school friendships difficult ▪ Not want to go to school ▪ Experience physical symptoms (e.g. headache, upset stomach)
<p>Teenagers / young adults</p>	<ul style="list-style-type: none"> ▪ Adolescence at any time is a period of change, the addition of a bereavement on top of this can make life even more difficult for young people. <p>As teenagers making the transition from childhood to adulthood, they can struggle with issues of identity and want to establish their independence from adults and belong with others of their own age.</p> <p>They will:</p> <ul style="list-style-type: none"> ▪ Understand that death is permanent ▪ Be anxious about how their life will change ▪ Have similar feelings to those of adults 	<ul style="list-style-type: none"> ▪ Not want to be different and so may not be able or willing to talk about or share their feelings ▪ In trying to establish their independence may be reluctant to ask adults for help or support ▪ Look for and find support through social media ▪ Change their behaviour (e.g. becoming isolated or withdrawn, may take risks or become involved in anti-social behaviour)

How to support children and young people who are bereaved

Preparing and including children and young people and offering choice

The best support we can offer children is to give preparation, inclusion and choice. The more that children are prepared and provided with information that is age appropriate and timely, the more this will help them to make informed choices and feel listened to and respected and part of what is going on. For example, giving them the opportunity to attend a funeral (see below).

- Tell children and young people about the death as soon as possible and in a way that they will understand. Children do not need every detail at once, the information can be given in stages to prevent overwhelm. Give basic, concrete information and allow time for the child to ask any questions that can help guide your conversation;
- Use clear language so that there can be no misunderstandings
- For example, use the word ‘died’ rather than ‘passed away’ or ‘gone to sleep.’ Saying that someone has ‘passed away’ can be confusing and ‘gone to sleep’ can make children afraid of sleep. Even the term “heart attack” may give rise to images of violence
- Check that the child has understood what you said, this might need to be repeated a few times to help support understanding
- Give plenty of reassurance, support and affection and keep routines as normal as possible
- Continue to talk about the person who has died and share your feelings (for example, don’t be afraid to say that you too are feeling sad or that you miss the person)

Thinking about the funeral

Give children and young people the opportunity to go to the funeral. Before making a decision on behalf of the child, it can be helpful to explain to children what a funeral is and to allow them to decide if they would like to attend. Even for very small children this event will be part of their life story about the person who died.

Children will benefit most from a clear explanation of what might happen at a funeral. Using clear factual words will lessen their confusion and help them to make their decision. It can be helpful to show them pictures of key parts of a funeral; for example, the place the funeral will take place, the hearse or funeral cars, the coffin (reminding them that the person has died and cannot feel anything anymore because their body has stopped working can help children feel less scared about the person being in the coffin).

Small pieces of information at a time will ensure they don’t become overwhelmed. On the day, having someone beside them to accompany them so they can have the option to leave if they need to can be helpful.

Education and information

Children who are bereaved need, and have a right, to have any questions they might have in an honest age-appropriate way to give them information that clearly explains what has happened, why it has happened and what will be happening.

Always answer questions kindly but honestly and if there is something that you do not know – say so.

The need for support from schools and colleges

Children who are bereaved need understanding and support from their teachers and peers without having to ask for it. Good practice would suggest that all teachers are trained in understanding childhood bereavement as mandatory so that more children can be supported in school. It is important to tell the school about the death, however it is important to have a conversation with children about this and about how they would like the news shared.

Sometimes families ask the school “not to mention the death” in the belief this will avoid pain for the child, but that may not be helpful, since schools can be a valuable source of support.

Support throughout childhood

Many people believe that if a child is bereaved at a very young age as a baby or toddler, they won't remember the person and so they will not or cannot grieve, when in fact they can and will. Even if they cannot speak, they know that something is wrong and that someone important is missing from their life, so they grieve the loss of a relationship with that person. Later they grieve how life might have been if the person hadn't died, and they grieve the loss of memories – that connection with the person who died.

Children may need support for their grief from a variety of different people at different times throughout their childhood depending where they are at in terms of their grief.

How a child understands information about a death at one age may be completely different at another age. For example, how a child understands the meaning of death at age five will be different to how they understand this by the time they are ten.

Children and young people who are bereaved can feel like they have no control over anything. Giving them appropriate information to help make informed choices can support them to regain some sense of control and to feel included. This can help them manage their grief. This might be about attending the funeral, how they can be supported in school, and where they can access information about what help is available to them, so they are able to identify support and decide whether they want to engage with it.

Links to further information and sources of support

Other services, for example, the NHS, hospices, police, funeral directors and faith leaders should have a basic understanding of how children grieve as this can impact how information reaches children at the time of a death.

If we start here and everyone understands that children do grieve, this can have a huge impact on how they cope with grief throughout their childhood and into adulthood.

If you need to refer a child or young person, a list of each area with support services available will help here. [At A Loss](#) has lists of available supports in areas in Scotland.

CHAS (Children's Hospices Across Scotland)

<https://www.chas.org.uk/>

Childhood Bereavement Network

<http://www.childhoodbereavementnetwork.org.uk>

Child Bereavement UK

<https://www.childbereavementuk.org>

Richmond's Hope

<https://www.richmondshope.org.uk/>

St Columba's Hospice

<https://stcolumbashospice.org.uk/>

The Compassionate Friends

<https://www.tcf.org.uk/>

Cruse Bereavement Care Scotland
(includes children and young people's service, as well as adults)

<http://www.crusescotland.org.uk>

At A Loss

<https://www.ataloss.org/>

Children and young people with learning disabilities or with profound and multiple learning difficulties (PMLD)

The needs of bereaved children with additional difficulties are the same as those of any child. Ensuring they receive appropriate support and understanding can require some additional thought and preparation from the adults caring for them.

It is sometimes assumed that children and young people with additional difficulties need more protection from hearing about death and dying than other children, or that they will not understand, and that it might minimise anxiety and unnecessary upset if the news about a bereavement is withheld. However, it is important that the loss is acknowledged in a way that is both supportive and understandable to a child with learning disabilities.

Having a learning disability does not mean they cannot understand a bereavement or be affected by it. Like most children and young people, they will progress normally through their grieving experience, although some of their understanding and reactions may be similar to those of a younger age-group. Some may appear to cope well at the time of the death and then continue to grieve over the weeks, months and years that follow the bereavement.

All children can struggle with the concept of death and its permanence. Children with learning difficulties may find this particularly hard to grasp and having visual explanations is important, particularly for children with autism spectrum disorders.

Most children and young people with a learning disability will have some form of communication difficulty and this can have a significant impact on their ability to understand what has happened and on their ability to express their thoughts, feelings and opinions.

Showing a physical example to highlight the difference between dead and alive can be helpful.

You can help them to understand what dead means by looking outside for a bug that has died and one that is alive and talking to them about how we can tell if something is alive or dead or you might buy a dead fish from the supermarket and compare it to one that's alive. Highlighting that even when put into a bowl of water the dead one will not move, breathe, eat or swim. Using concrete words like died and dead will be most helpful. Try to use concrete words like "Mum has died" rather than "we have lost mum". It can also be helpful to reassure the person with a learning disability that the death was not their fault. This can be helpful for all children.

It might help to explain a funeral by using as many examples as you can, such as pictures of funerals and coffins to aid understanding about what happened to the person who died. It might also be helpful to support and encourage the person to visit the grave or a special place of remembrance if they want to. As you might need to repeat the information numerous times it might be helpful to make a story book for retelling the information.



A Bereavement Charter for Children and Adults in Scotland: Guidance Notes

Some might have difficulty understanding spoken language and might have difficulty understanding unfamiliar words and concepts. They may be able to talk about how they are feeling through speech, signs or symbols. Others might use non-verbal means of communication and this might be expressed through changes in their behaviour. Many people with PMLD can rely on facial expressions, vocal sounds, body language and behaviour to communicate.

Children and young people who have a more severe learning disability might respond in the main to the absence of the person and to any change in their routine. Try to encourage routine activities as routines provide a sense of stability during emotional times.



Links to further information and sources of support

MND Scotland

<https://www.mndscotland.org.uk/>

PAMIS (promoting a more inclusive society)

<http://pamis.org.uk/>

PAMIS Speaking Up – Being Heard Resource

<https://pamis.org.uk/site/uploads/pamis-resources-multisensory-storytelling.pdf>

Macmillan – Going to a funeral when someone dies (Easy Read booklet)

<https://be.macmillan.org.uk/Downloads/CancerInformation/Easyread/MAC16311Going-to-a-funeral-when-someone-dies.pdf>

Macmillan – What can help you feel better when someone dies (Easy Read booklet)

<https://be.macmillan.org.uk/Downloads/CancerInformation/Easyread/MAC16345What-can-help-you-feel-better-when-someone-dies.pdf>

Marie Curie – Feelings you might have when someone dies (Easy Read booklet)

<https://www.mariecurie.org.uk/blog/feelings-you-might-have-when-someone-dies-a-new-booklet-on-grief-for-people-with-learning-disabilities/259254>

Down's Syndrome Scotland – Let's talk about death (Easy Read booklet)

<https://www.dsscotland.org.uk/wordpress/wp-content/uploads/2016/02/Lets-Talk-about-Death-2012.pdf>

Children and young people in contact with the justice system

This section refers both to the experiences of children and young people involved in offending behaviours as well as children and young people who are involved indirectly, such as through the sentencing and/or imprisonment of a parent or other close relative.

Children and young people who are involved in offending behaviours have often experienced a higher rate of bereavement than young people in the general population. Children in contact with the justice system have also experienced a higher rate of traumatic, multiple and parental/caregiver deaths. This is not to say that bereavement causes crime, but that a relationship can be observed.

One of the reasons for this might be because factors that can be associated in some way with involvement in offending are similar to those that increase the risk of premature death and bereavement, such as: poverty and inequality; parental substance misuse; parental mental ill health; and family and community violence. Or there may be a more direct association, in that children who are already vulnerable may find it more difficult to cope with bereavement, or something in the nature of their bereavement experiences might make it more likely that they will experience further difficulties and challenges in the future.

The reality is likely to be somewhere in between. For example, responses to grief can include anger, withdrawal, irritability and difficulty concentrating.

Young people who have experienced multiple and traumatic losses, and other adverse events, are also more likely to experience depression, self-harming and suicidal behaviours, substance use and other risk-taking behaviours. In home, school, or other settings if these symptoms are understood to be part and parcel of grieving, then allowances can be made, and appropriate supports offered.

However, if these symptoms are interpreted simply as poor behaviour, then the response from family, school or other services may look very different, meaning that opportunities to support the young person are missed and could result in them coming into conflict with authority or the law.

Since some vulnerable children may have already been in trouble, or may tend to act out their grief and distress (such as we see in some young males) then there is an even greater risk that other people will misinterpret their symptoms and behaviour as being anti-social or criminal rather than a sign of distress. Therefore, awareness raising amongst professionals is critical – bereavement and even repeated bereavement may not readily surface in individual assessments and may need intensive work and building of trust.

Children separated from parents and other close family through imprisonment experience feelings and behaviours akin to bereavement and, according to some research, even more detrimental feelings of grief and loss.



Imprisonment of a household member is also one of the ten Adverse Childhood Experiences (ACEs) proven to increase risk of poor outcomes in later life. Bereavement due to a death can also create barriers for children with a parent or close family member in prison who may not be taken to see someone in person who is terminally ill or who has passed away in custody. In addition, a death may be one additional adversity for children already feeling stigmatised, isolated, and unsupported.

How to support children in contact with the justice system who are bereaved

Children in conflict with the law are still children, regardless of their behaviours. Children with family members who are sentenced or imprisoned are also still children, regardless of the stigma attached to them by the behaviour of others. Thus, the advice on supporting children and young people that is provided in this guidance is appropriate for all children. However, there are a few considerations that might be helpful, and at times necessary, to be kept in mind when working with children and young people in contact with the justice system.

The extent and nature of the deaths experienced by young people means that some may need additional support with their grief. However, children who are vulnerable or who have experienced adversity in childhood may not always have sufficient family or social networks to draw upon for support and may find it more difficult to form safe and trusting relationships with professionals or other sources of support because of their childhood experiences.

Professionals may need to take more time to build relationships and safe spaces, or to adapt methods and resources to meet the needs of children.

Children who end up in care or custody as a result of their or others' offending behaviours also face a unique set of circumstances associated with loss and bereavement. First, the reception into care or custody can be experienced as traumatic and represents a huge and additional loss for young people who may have already experienced a multitude of losses, including bereavements and family breakdown.

Acknowledging and naming the extent of loss that these children have experienced, including losses caused by reasons other than death or by their contact with the justice system is important.

Children who are separated from their family and support networks may feel isolated in their grief and, depending on any potential level of restriction, may not be able or allowed to participate in shared grief experiences and rituals such as visiting people who are terminally ill or attending funerals or gravesides.

Recording important dates, such as anniversaries and birthdays, will ensure that potential triggers can be prepared for, and young people can be supported. Visits should be permitted where possible.

Where visits or direct participation in rituals is not possible, then the use of technology (such as the streaming of funerals, or video calls to terminally ill relatives) and creative ways to develop and support rituals and memorials within the custodial or care setting should be considered.

It is important to ask children about **who** is important to them, as permission to participate in key rituals is often limited to immediate family members, whereas children frequently report wider networks of family and friends that have been significant in their upbringing.



A Bereavement Charter for Children and Adults in Scotland: Guidance Notes

Being in care or custody, or even on a court or Children's Hearings System order in the community, can also disrupt and restrict children's preferred ways of coping with loss and grief. For example, children may not be able to distract themselves by going for a walk, visiting significant places, looking through old photographs or listening to songs that remind them of someone. It can also be difficult for a child in care or custody to find private and safe spaces where they can express their grief. As a result, many children may choose to 'put on a front', which can cause professionals and others to overlook their distress.

Professionals in the justice system should consider how any restrictions in place (including court orders in the community, as well as care or custody) will affect an individual's ability, and right, to grieve.

Links to further information and sources of support

When People Die: Stories from Young People

<https://discovery.dundee.ac.uk/en/publications/when-people-die-stories-from-young-people>

Trauma, Bereavement and Loss: Key learning and messages from research and practice

<https://cycj.org.uk/wp-content/uploads/2019/09/Key-Messages-from-TBL.pdf>

Bereavement and offending behaviours: A role for Early and Effective Intervention (EEI)?

<https://cycj.org.uk/wp-content/uploads/2019/10/Bereavement-and-EEI-1.pdf>

Persistent Offender Profile: Focus on Bereavement

<https://cycj.org.uk/wp-content/uploads/2014/05/Bereavement-Paper-CJSW-Briefing.pdf>

The ripples of death: Exploring the bereavement experiences and mental health of young men in custody

<https://cycj.org.uk/wp-content/uploads/2014/05/Factsheet-25-in-template-final.pdf>

The trauma, bereavement and loss experiences of women in prison

<https://cycj.org.uk/wp-content/uploads/2019/07/Here-and-Now-Females-FINAL-Report.pdf>

Talking about death with children and young people

<https://cycj.org.uk/wp-content/uploads/2016/11/Info-sheet-56.pdf>

Our Lives with Others: An evaluation of trauma, bereavement and loss developments at HMYOI Polmont

<https://cycj.org.uk/wp-content/uploads/2016/11/Our-Lives-with-Others-Evaluation-Report-.pdf>

Understanding ambiguous loss in young people involved in offending

<https://cycj.org.uk/wp-content/uploads/2015/08/Info-sheet-40.pdf>

Ambiguous Loss. Scottish Journal of Residential Child Care

<https://core.ac.uk/download/pdf/195293914.pdf>

Grief involving children and adults with learning disabilities, and other long-term, life-limiting or degenerative conditions

If you are a family member caring for a child or adult affected from birth or early years by a learning disability or a severe physical disability, life-limiting or degenerative condition, you will share a number of feelings with those caring for and grieving for adults with later onset degenerative diseases. But you will also face some specific challenges.

Learning disabilities and other long-term conditions

A learning disability refers to a lifelong condition affecting cognitive or intellectual development and capacity, to the extent that the person will usually require at least some level of support with daily functioning and life skills.

Other conditions which may require regular additional carer support, depending on their severity, include physical disability or sensory impairment from birth or after illness or injury. Some conditions result from abnormal development before birth, or have genetic causes such as Down's syndrome. In other cases, young people can be affected by degenerative conditions such as Muscular Dystrophy. And of course some people (though not all) with conditions such as Cerebral Palsy or neurological conditions such as Autism may also have learning disabilities or communication difficulties.

Conflicting feelings in carers and family members during the caring journey

If you are a close family member of a young person requiring regular support, you will no doubt have a number of conflicting feelings.

There will be times of joy and love and fun demonstrated in the close bond between you, but often it can be interspersed with periods of grieving as you realise the life you imagined for this young person growing up will be very different in reality. You may be their sibling, parent or grandparent. In all these cases, the typical things you expected to do with them may be impossible or substantially different, requiring considerable modification.

This can be hard and lead to a sense of loss and a feeling of missing out, both for your own life and that of the young person. You can particularly feel loss at the milestones normally recognised in life which may not be available to them, or when you witness the achievements of other children of their age and realise that the gap is widening.

Cycles of grief and loss in the caring journey

Although young people with disabilities can develop and show progress over the years in many respects, quite a number may continue to depend on varying degrees of support. In the case of more severe conditions, as you continually have to adjust and remodel your previous expectations, you can experience feelings of loss and grief for the life that can never be, and for the dreams that cannot be fulfilled - grief which often may not be recognised, understood or acknowledged by those around you or sometimes even by professionals.

In fact, you may find yourself moving in and out of periods and cycles of grief over a sustained, significant period of time.

In addition, caring for a young person in the family with a physical or intellectual disability or life-limiting condition can be hard work and all-consuming, resulting in you giving up your own identity, work and interests outside the home. Also as young people grow up and move into adolescence or become adults, it can be increasingly difficult for carers to manage any physical disabilities, particularly with degenerative conditions.

Foster carers and their families can also give wonderful support to youngsters with disabilities, often forming a bond that lasts long into adulthood. However, the families and foster families may eventually face the necessity of having the person move into residential care. This point can again bring feelings of grief and loss on both sides of the relationship, which should be recognised and appropriate support identified.

Helping people with learning disabilities and other conditions to cope with bereavements and other loss

Eventually the situation may arise where adults with learning disabilities or other life-limiting conditions will themselves experience a significant bereavement, for example when one of their friends dies, and even more so if their main family carer dies. This can be an extremely disturbing time for them, due both to their grief and to the challenges and additional losses accompanying the bereavement.

These can include at the very least disruption of routines, but often it also involves major changes to their whole life structure, such as change of main carer (the one person who knows them most fully), possibly moving home, or perhaps moving into residential care for the first time, and losing contact with any previous support arrangements or activities and clubs.

The right to grieve

Even if they have previously moved into residential care, people with learning disabilities are likely to require considerable individualized support to cope with the loss of a significant person in their life. It is important not to hide the truth from them, as this does not help avoid pain, but simply adds to their confusion if a family member or main carer is suddenly no longer there. They have the right to grieve and also to be supported if possible through the experience of rituals and events such as funerals which aid this.

People with learning disabilities may experience intense grief reactions, which can trigger anxieties in carers. Again, through open communication and planning of all those who are invested in their care and wellbeing, sensitive responses will support healthy grieving, and give reassurance to carers. Bereavement organisations and charities are able to support the grieving process in some children and adults with learning disabilities and other conditions, but where direct support is not possible, they can support and advise the carers involved.

When the person dies: effects of bereavement on family members and carers

When the person being cared for dies after a long or difficult illness, it is understandable if the bereavement causes family and friends to feel conflicting emotions, such as sadness and relief, and perhaps guilt and anger. And as professional carers also develop a relationship with the person and their family, they too become bereaved on the death, although grief in non-family carers is often not recognized.

However, it is important that everyone involved has the right to bereavement support that meets their needs.

Links to further information and sources of support

MND Scotland

<https://www.mndscotland.org.uk/>

PAMIS (promoting a more inclusive society)

<http://pamis.org.uk/>

PAMIS Speaking Up – Being Heard Resource

<https://pamis.org.uk/site/uploads/pamis-resources-multisensory-storytelling.pdf>

Macmillan – Going to a funeral when someone dies (Easy Read booklet)

<https://be.macmillan.org.uk/Downloads/CancerInformation/Easyread/MAC16311Going-to-a-funeral-when-someone-dies.pdf>

Macmillan – What can help you feel better when someone dies (Easy Read booklet)

<https://be.macmillan.org.uk/Downloads/CancerInformation/Easyread/MAC16345What-can-help-you-feel-better-when-someone-dies.pdf>

Marie Curie – Feelings you might have when someone dies (Easy Read booklet)

<https://www.mariecurie.org.uk/blog/feelings-you-might-have-when-someone-dies-a-new-booklet-on-grief-for-people-with-learning-disabilities/259254>

Down's Syndrome Scotland – Let's talk about death (Easy Read booklet)

<https://www.dsscotland.org.uk/wordpress/wp-content/uploads/2016/02/Lets-Talk-about-Death-2012.pdf>

Adults with profound and multiple learning difficulties (PMLD)

Many people with profound and multiple learning disabilities experience challenges with communication and difficulties in how they can experience the world and interact with others. Many of them cannot use words to communicate. They can also have problems with their sight and their physical disabilities may make mobility and using their limbs difficult. In addition, they may have a number of health-related problems, such as respiratory illness.

Parents will typically care for their son or daughter with PMLD into their elderly years and carry a vast amount of knowledge and skill about their son or daughter's condition and treatment.

Many people still believe that individuals with PMLD cannot experience grief because they lack the understanding of death. This is why many do not receive the support they need following a bereavement. If we think about how attentive caregivers must be to the physical needs and emotional wellbeing of these individuals (especially after a lifetime of experience), we may get a sense of how difficult it must be for a person with PMLD to be separated from their accustomed caregiver, through death or otherwise.

Carers can find it difficult to know how to respond to the many responses someone with PMLD may show when bereaved: crying, looking around for the person who has died, self-injury, despair and in some cases a worsening of their health problems such as developing a respiratory illness.

However we respond to the experiences of loss in people with PMLD, it necessarily involves approaches that respect how loss impacts on the body whilst also understanding the communicative limitations of people with PMLD. Multi-sensory and body-based approaches can facilitate this and have been described in the [Speaking Up - Being Heard](#) resource from PAMIS, a charitable organisation supporting families of people with PMLD.



Links to further information and sources of support

PAMIS (promoting a more inclusive society)

<http://pamis.org.uk/>

PAMIS Speaking Up – Being Heard resource

<https://pamis.org.uk/site/uploads/pamis-resources-multisensory-storytelling.pdf>

Grief involving dementia and other degenerative conditions in adults

Grief before bereavement

When you care for someone with a degenerative condition, you may experience feelings of loss and grief for a considerable time before they die, as well as after the actual bereavement. This can make it feel as if you lose them twice over, once due to their condition deteriorating, and again when they die.

Not only do people in this situation often fail to understand that the difficulties they are experiencing over an extended period are caused by a situation of very real grief and loss, professionals too often fail to recognise it.

Triggers of grief

These feelings of grief and loss-in-life can be experienced at any point, whether randomly, now and again, or constantly. They may be triggered at the point where there is a diagnosis or at a transition point such as moving into care or hospital and also at the point of death.

Degenerative diseases

All degenerative diseases present challenges for both the people affected and for carers. Some conditions primarily affect physical capacities, sometimes with devastating consequences, such as Motor Neurone Disease (MND).

Some conditions such as Parkinson's have a noticeable physical effect but may also have an impact on some cognitive functions. Other conditions such as dementia primarily target the brain and cognitive functions, although with physical consequences as the disease progresses.

The increasing burden

A very difficult aspect with a degenerative illness is that the caring burden becomes much heavier as the person's mobility and physical abilities decline. In the case of dementia, where the main carer is frequently the spouse or partner, this can often be at a time when that person too is becoming elderly and less able (although early onset dementia does exist, but is less common).

When patient aids such as wheelchairs and hoists become an integral part of the daily routine, normal life as you knew it seems to slip further and further away, emphasizing the loss.

Challenges of dementia and cognitive decline

Furthermore, if you are a family member (whether or not in a caring role), or a close friend, of someone with cognitive deterioration over a period of time, you will find that their personality can change, and they can lose familiar parts of their identity - what makes them who they are. You grieve the loss of the person as they were. They might not be able to have the same conversations as before or do the things they used to love doing.

Changing roles and loss of connection

As the condition of your family member or friend worsens and communication becomes increasingly difficult, one of the most painful aspects is that despite enduring bonds, you feel the loss of the connection you had with that person. They may be your partner, parent, sibling, other family member, friend or colleague. In all these cases, the previous role you had with them may be reversed

and you miss having that person to rely on or interact with. With cognitive decline, it can feel like you're losing shared memories you built together - or even that you are being deprived of the opportunity to build memories for the future.

Further deterioration

As memory deteriorates further, the person may no longer remember dates or events special to you both, such as anniversaries, and most painfully they may eventually not even know who you are or understand where they are. This can be particularly painful and hard for families to deal with, especially if the person still looks and sounds the same as before.

In some cases, the burden of caring falls unevenly on one member of the family e.g. where one sibling may be looking after the entire caring needs of an elderly parent, while the other siblings, possibly in different parts of the country, can pursue a normal life without additional responsibilities.

Overwhelming demands

Sometimes the caring role can become so overwhelming that you may not have the time or energy to deal with your own grief or to remember the importance of looking after your own health and well-being. In such cases, the support of family members, friends and colleagues can become immensely valuable, as well as the recognition on your part as carer that trying to look after your loved one on your own night and day without support or respite is exceedingly difficult. That is when exhaustion might affect your own personality and patience.

When the caring role ends

One further aspect is that even though the caring role can be all-consuming and exhausting, when the person dies, or even moves into residential care, it can have a big effect on the family. This is especially true where a family member who has been the main carer has put their own life and interests completely on hold, and submerged their own identity. Then they are suddenly cut adrift, without a purpose, while perhaps a previously busy house becomes empty.

The caring journey and conflicting emotions

Looking after someone with a degenerative condition or prolonged health issues is stressful, and it can be extremely difficult to stay on an even keel whilst also remaining patient and positive. The person affected by the condition can equally become frustrated and angry, or be affected by low mood. In dementia, for example, this clearly can have an impact on the sense of grief and loss which both of you may be experiencing already, thus causing friction in the relationship.

It is understandable to experience conflicting feelings during the caring journey although it can also be a signal to reach out for extra support from your circle of friends and family, or from medical and social care services.

Emotions after bereavement

However, contradictory emotions can also surface after bereavement, particularly with degenerative illnesses, when it is normal for feelings of relief to accompany the sadness. In addition there may be guilt or anger, leading to a difficult mix of emotions. If these are distressing, it often helps to talk about it.

Effects on health of carers - need for support

Therefore overall, people can find their mental and physical health can be severely affected by this prolonged journey of inherent grief for many years before an actual bereavement takes place, as well as subsequently.

This is something we need to recognise whether as friends, as a society or as employers, remembering that this kind of grief requires its own support over the longer term.

Effects of the bereavement on external carers

Finally, carers who are not family members can also be greatly affected when the person they have been looking after dies. It is natural for even professional carers to develop a relationship with the person and their family. This means that carers also become bereaved on the death along with the family, although grief in non-family carers is often not recognised.

However, it is important that these carers also have the right to bereavement support that meets their needs. This may be provided in several ways, for example through the employer, General Practitioner, or specialist bereavement services. It is therefore essential for professional carers, as well as family members, to have their grief recognised with due regard to their own well-being, to allow them to carry out their important caring role without the risk of burnout.



Links to further information and sources of support

Tide (together in dementia everyday)
<https://www.tide.uk.net/resources/>

Dementia Matters
<https://www.dementiamatters.net/>

Alzheimer's Research UK
<https://www.alzheimersresearchuk.org/>

Age Scotland – Dementia
<https://www.ageuk.org.uk/scotland/information-advice/health-and-wellbeing/dementia/>

Bereavement following suicide

A death by suicide is usually sudden, often unexpected and may be violent. These factors and others can increase the degree of shock and trauma experienced compared to many other types of bereavement.

Bereavement by suicide can bring an intensity and range of emotions and physical reactions which may be unfamiliar, frightening and uncontrollable. Emotional reactions are often complex, and people may find that they are experiencing a bewildering range of feelings including guilt, anger, shame, rejection, sadness and fear. People who have been bereaved by suicide may become vulnerable to thoughts of suicide themselves.

If the person witnessed the death or found the body, they may suffer from flashbacks or nightmares. This can also happen even if the person did not see it themselves but cannot stop imagining what happened – and imagination may be worse than the reality.

Most people bereaved by suicide are troubled by two big questions – “Why did the person take their life?” and “Could I have somehow prevented it?”. Also, perhaps they may dwell on what they said or did not say or what they did or did not do.

These are impossible questions and thoughts to resolve, and eventually the person may have to either accept that they will never know or settle on an answer which they can live with. It is natural that the bereaved person will take some considerable time in exploring these questions and it is an important part of the grieving process.

There is still a stigma attached to suicide, rooted in centuries of history and this generates misplaced associations of weakness, blame, shame or even sin or crime. This stigma can prevent people from seeking help when they need it and others from offering support when they want to.

There may be a desire to deny that the death was a suicide, perhaps driven by cultural values or from a sense of denial or shame. This can create further confusion in an already complex situation. It may also be that the person who is bereaved avoids other people and may struggle to share their own feelings because they are fearful themselves of what they are experiencing and of the reaction of others. They may not want to upset other people or they may worry about how to answer questions such as “How did (s) he die?”.

In addition, when someone dies by suicide, it can be difficult to maintain privacy. There may be emergency services at the scene and visits from police. There may also be unwanted media attention.

Whilst family and friends are often a great source of support, they can also be a source of tension and conflict. Sometimes families struggle to communicate, protective instincts kick in and they may be worried about causing more pain or about having a different view or feeling to others. In addition, different people express their grief in different ways, some keeping it more internal than others, possibly leading to accusations of someone “not caring”.

Existing tensions and difficulties in family relationships can surface as a result of the death. Some people cope with their pain by blaming another person – this may go as far as excluding them from the rest of the family, denying them the opportunity to attend the funeral and withholding information about the investigation.

When dealing with the suicide of a friend, colleague or family member, it is important to find support to make sense of what has happened, to help with the intense feelings of grief, and reduce the feelings of isolation that the loss can provoke. The pain of suicide loss can't be eased quickly but there are things that can be done that will help and organisations that specifically assist people bereaved by suicide. These are listed below.

Those affected by suicidal thoughts are advised to:

- Contact their GP or
- Visit www.suicide-prevention.org.uk or
- Call NHS 24 on 111 or
- Call Breathing Space on 0800 83 85 87 (6pm - 2am weekdays and Friday 6pm through to Monday 6am at weekends) or
- Visit the [Samaritans website](http://www.samaritans.org) or dial the Freephone number 116 123 (available 24 hours a day) for confidential support

 **Links to further information and sources of support**

Scottish Government: Suicide prevention action plan: every life matters

<https://www.gov.scot/publications/scotlands-suicide-prevention-action-plan-life-matters/>

Petal (people experiencing trauma and loss)

<http://www.petalsupport.com/>

SAMH, After a Suicide

https://www.samh.org.uk/documents/After_a_suicide.pdf

Survivors of Bereavement through Suicide

<https://uksobs.org/>

Papyrus – preventing young suicide

<https://www.papyrus-uk.org/>

Postvention: Supporting the wider community after a suicide

Studies estimate different numbers of people who may be affected by a suicide. This ranges from a very conservative estimate of six immediate family members up to a much higher estimate of 135 individuals being exposed to the impact of an individual's suicide. In Scotland there were 805 probable suicides registered in 2020. Based on the above estimates this would mean that in one year many hundreds of people will be affected by suicide and could benefit from support after a suicide.

Family members and those very close to the deceased are likely to be more strongly affected than those whose relationships were more distant. Some writers describe this as a continuum of 'suicide survivorship'.

The continuum ranges from those who are exposed to a suicide without experiencing an impact on their life, to those who feel affected or distressed by it, to those who experience intense short or long-term grief reactions. Within this continuum a distinction is made between what is termed "suicide survivorship" and "exposure to suicide". The former applies to the bereaved who had a personal and close relationship with the deceased such as a family member or close friend. The latter applies when someone did not know the person who died personally but is exposed to the suicide through other means such as their work, hearing from other people or media reports.

Examples of this would include the suicide of a celebrity or someone who has personally witnessed or been present at the death of a stranger such as a train driver or police officer.

The notion of continuum does provide a way in which we can begin to consider the range of responses that may be experienced across different relationship types, from close family members and friends to those indirectly exposed to suicide. All have been impacted by suicide and should feel able to seek and receive the help and support they need.

The term postvention is now used to describe bereavement support following a suicide. The challenge of postvention is to ensure that every person affected gets the right support and this requires a collective, planned multi-agency response. Many organisations have developed or offer postvention guidance or programmes.

Some of these postvention programmes are focused on specific settings such as schools. For example, the Samaritans Step by Step resource <https://www.samaritans.org/scotland/how-we-can-help/schools/step-step/step-step-resources/> and Papyrus Building Suicide-safer Schools <https://www.papyrus-uk.org/>

Other initiatives aim to provide support to the broader community such as the guidance provided by Public Health England, Support after a suicide: A guide to providing local services, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/590838/support_after_a_suicide.pdf

Organisations like Survivors of Bereavement by Suicide (sobs) will assist organisations in developing postvention plans

<https://uksobs.org/>

The Princes Responsible Business Network have also developed a postvention toolkit for employers:

<https://www.bitc.org.uk/wp-content/uploads/2019/10/bitc-wellbeing-toolkit-suicidepostventioncrisismanagement-mar2017.pdf>

Programmes like these highlight the importance of providing the right support at the right time. We now know that the impact of suicide goes beyond the immediate family and friends, and given that those impacted by suicide are at risk of suicide themselves, only further highlights the importance of postvention efforts as pivotal components of any suicide prevention programme.



Links to further information and sources of support

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<https://www.papyrus-uk.org/>

Public Health England: 'Support after a suicide: A guide to providing local services'
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/590838/support_after_a_suicide.pdf

Making Suicide Prevention Everyone's Business: The annual report of the National Suicide Prevention Leadership Group: Scotland
<https://www.gov.scot/groups/national-suicide-prevention-leadership-group/>

Coping when someone dies by Suicide
<https://www.cruse.org.uk/get-help/traumatic-bereavement/coping-when-someone-dies-suicide>

Sudden and traumatic death

What is “traumatic death”?

Trauma often results from an event, series of events, or set of circumstances where an individual perceives that they are at risk of physical or emotional harm or where there is a threat to life, which can result in lasting adverse effects on the individual’s functioning and mental, physical, social, emotional or spiritual wellbeing.

Trauma refers to an emotional response to a deeply distressing event (or series of events) which overwhelms a person’s ability to cope.

A traumatic death refers to the sudden, unexpected shocking death of a person or a death which takes place in horrific circumstances.

Factors that are known to increase the risk of a death being experienced as traumatic

A traumatic response may be more likely when a death occurs without warning or where the circumstances of the death are particularly distressing. For example:

- accidental death (e.g. from a road traffic accident)
- suicide
- the death of one’s child
- death in horrific circumstances
- occasions when the body is not recovered, or is damaged
- multiple deaths
- death due to violence
- death due to the fault of others, from carelessness or negligence
- death resulting from the actions of others, whether intentionally or unintentionally

Other situations which may contribute to a traumatic response to a death include where the survivor witnessed the death or survived when others were killed or felt their own life was also threatened. Witnessing a death or circumstances surrounding a death that trigger previous traumatic memories from the person’s life may also increase the risk of a traumatic response.

Additional Factors

However, it isn’t only the specific nature of the death that can make it traumatic, but also other factors:

- how the person understands what has happened
- their previous trauma history
- the strategies that people tend to use to cope with adverse life events e.g. self-care strategies, physical exercise, talking to family members etc.
- their pre-existing mental health and wellbeing
- substance use
- the nature of the relationship with the person who has died, e.g. feeling a sense of responsibility for the person’s wellbeing, feeling particularly close to that person, the importance placed on the relationship with that person
- how the person feels about the availability and type of support accessible to them

The COVID-19 pandemic has also brought increased challenges. For months people have been faced with accounts of tragic loss of life often under very difficult circumstances, highlighted by continuous news headlines, statistics, and images of intensive care wards.

Being bereaved is a lonely time, but it has been made even more difficult by isolation and restrictions due to the pandemic. This has also produced a combination of unreality and anguish, with families cut off from their loved ones in hospital and during end-of-life, and unable to view the body or perform full funeral rites. In some cases, this has resulted in trauma in those who are bereaved.

What are the effects of traumatic deaths?

Traumatic deaths can lead to increased distress as sufferers have to deal with a combination of grief and trauma, generally contributing to more intense, extensive and prolonged symptoms.

It is important to remember that every bereavement is unique for each person. There is no specific “right way”, and there are no “absolutes” such as definite stages or timescales; in fact, it can take quite a lot of time (often much more than one thinks). However, even without trauma, people grieving do tend to experience some of the following common reactions and emotions in various combinations:

- disbelief, numbness or emptiness
- sadness, feelings of loss and pain
- longing
- wanting to be alone and/or wanting to speak to someone
- anger
- blame and/or guilt
- anxiety and/or depression
- difficulty in thinking clearly
- problems with memory
- unable to take pleasure in ordinary things
- wishing to be no longer here/alive
- physical symptoms e.g. aches and pains, chest or stomach pains, disturbance in sleep or appetite, exhaustion

- problems from additional losses due to the bereavement – e.g. loss of home, income, children’s school, main caregiver for disabled or elderly, loss of faith

In the context of a traumatic death, any of these reactions may become more extreme or continue for longer. People may experience emotional outbursts or prolonged sobbing. They may have intense anger and possibly a heightened need to blame someone else, or themselves, for the actions taken or lack of action.

A traumatic scene may replay endlessly in people’s imagination, or alternative scenarios go round and round in their mind. The shock or grief may be overwhelming, so that people cannot function. They may also have crippling feelings of anxiety or depression and fear or panic attacks. These can leave people unable to cope with the responsibilities of daily life or think of the future.

“Resolution” – Going Forward and Finding Support

Bereavement is a natural part of life and usually the feelings of grief and pain start to fade after some time as people process the feelings and gradually come to accept or integrate the death. They find a growing ability to focus on the life ahead, realising that they can move forward while still keeping memories of their loved one with them.

They may continue to miss them, feel sad when thinking about them but are able to function and find joy in life at the same time as the grief is no longer overwhelming, preoccupying or disabling. It is about staying connected with the deceased without their physical presence. This is in contrast to a more enduring form of grief often described as complex grief where the loss and grief continues to have a significant impact on a person’s day to day functioning.

However, trauma often disrupts this natural grieving process, leading to a more complicated grief. People may continue to feel completely stuck, distressed and overwhelmed on a prolonged daily basis. In addition to intense pain, they find that any previous assumptions about the world being a safe and predictable place have been shattered, leading to a sense of insecurity and unreliability.

When this happens to someone, it is a sign that additional support could be of benefit. People should not hesitate to seek extra help, as it is available.



Links to further information and sources of support

Bereavement Information and suggestions on coping:

- Cruse Scotland Bereavement Care – [crusescotland.org.uk](https://www.crusescotland.org.uk) for articles on coping with bereavement.
- [NHSinform.scot](https://www.nhs.uk/information) – see “Bereavement Support”
- [Mind.org.uk](https://www.mind.org.uk) – see “Bereavement”
- [Clearyourhead.scot](https://www.clearyourhead.scot) – for mental health and wellbeing tips during challenging times

Bereavement Support is available from the following:

- Your GP
- Cruse Scotland Bereavement Care [crusescotland.org.uk](https://www.crusescotland.org.uk) for live webchat or Free Helpline: **0808 802 6161**

Additional support in times of any distress or crisis:

- Samaritans: Freephone **116 123**
- Breathing Space: Freephone **0800 83 85 87**

Bereavement following substance use

Grief is a complex emotion and while there are common feelings that may be expected when someone feels grief everyone's experiences will be different, and they will find different ways to work through their grief. When substance use has been a factor in a person's death this can further compound the complexities of grief.

Some additional complexities of bereavement following substance use include:

- Every death as a result of substance use is premature and preventable
- The circumstances around the death are often troubling and unsettling (e.g. died alone, not pleasant environment, etc.)
- Feelings of guilt that the friend or family member didn't 'do more' to help
- Potentially difficult or broken relationship preceding the death
- Loss of hope that they will get better and get into recovery
- Involvement with police following the death
- Stigmatising media coverage

Disenfranchised Grief

Due to the behaviours of the person who died, friends and family are often met with stigmatising responses rather than sympathy and support. This can leave families feeling that their grief is not acknowledged as being legitimate (also called "disenfranchised grief") and they can feel shame in talking about their loved one, or even about the death. This can make the grieving process more complicated. It also means they cannot find support which may lead to feelings of isolation.

" I used to tell people my son died in a car crash – people have sympathy for that. They didn't look at me with as much judgement. When I told people he died from drugs, I felt they judged him – and me – more and couldn't sympathise as much. Almost like he deserves it. "

A family member

The stigma and stigmatising language that surrounds substance use has a profound impact on the grieving process for family members. Labels such as 'addict' can dehumanise the deceased person, further exacerbating the unacknowledged feelings of loss.

Secondary Losses

In addition to the grief experienced by the death of a loved one, people may also experience what is referred to as 'secondary losses'. Families often find that they have been coping with the frustration, stress and pain of the person's substance use for a long time. They may feel that they 'lost' the person they knew many years before due to their substance use behaviour. Families often say they felt the death was inevitable having experienced non-fatal overdoses or witnessing their loved one's increasing substance use. Grief can be felt before and after the loved one's death.

As with any loss, it is important that bereavement following substance use is acknowledged and met with kindness and respect. Language is very important and ensuring the bereaved person is not subjected to stigmatising labels is essential.

 **Links to further information
and sources of support**

Alcohol Health Alliance

What to do when you are bereaved through alcohol harm - Alcohol Health Alliance (ahauk.org)

<https://ahauk.org/what-to-do-when-you-are-bereaved-through-alcohol-harm/>

Scottish Families Affected by Alcohol & Drugs

<https://www.sfad.org.uk/support-services/bereavement>

Scottish Families Affected by Alcohol & Drugs – Sudden and Unexplained Deaths booklet

<https://www.sfad.org.uk/content/uploads/2018/10/Sudden-and-Unexplained-Deaths-Booklet-Web-Version.pdf>

Bereaved through substance use guidance

<https://www.bath.ac.uk/publications/bereaved-through-substance-use/attachments/bereaved-through-substance-use.pdf>

Supporting care workers

Regardless of place of work, role or professional background there are a range of people who have an important part to play in the support and care of the dying and the deceased.

Care workers may develop relationships with those they look after and following their death may experience grief in the same way they would do following the death of others in their life. This grief may be especially distressing when the death of people they look after happens on a regular basis, where a large number of deaths occur over a short period of time or when a death is perceived as untimely or traumatic.

However, this grief and distress is not always recognised, acknowledged, and understood by society, employers, colleagues, families and friends. Nevertheless, the emotional burden of caring may trigger stress responses in workers and over time may lead to moral injury¹ if they feel they are unable to look after those in their care to the best of their ability due to the competing demands of their job.

This is especially true when workers are faced with complex situations during a global pandemic when care organisations may struggle to provide the infrastructure to enable optimal care provision. It is therefore of vital importance that workers receive the support that meets their needs following the death of a person they have cared for to allow them to remain well and to continue to provide optimal care to others.

Developing a supportive organisational culture

Taking a proactive, organisational approach to supporting the wellbeing of workers both before and after a death of someone they have cared for is key.

An organisational culture where open and honest conversations about death, dying and bereavement are seen as normal, rather than to be avoided, is crucial as it gives workers permission to talk about their feelings and emotions.

This in turn may allow workers to be more open about their feelings when someone they have cared for dies and to understand that what they are experiencing is normal. National organisations such as [Good Life, Good Death, Good Grief](#) provide guidance on how organisations can become more open to talking about death and dying and have sources of information to help take this forward.

Opportunities for reflection

As part of a continued understanding of how the death of someone who has been cared for affects workers, it can be helpful for a care team to reflect on the past and remember the person who has died.

This allows workers to see the individuality of grief responses and for the team to support each other in difficult times.

¹ e.g. the damage done to a person's moral compass when that person perpetrates, witnesses, or fails to prevent acts that go against their moral beliefs, values, or ethical codes of conduct.

One way of enabling workers to come together to reflect on a death is to embed a daily team wellbeing huddle into the working day. In these time-protected sessions, the emotional impact of care enables the team to review challenges that may be faced by all workers who have been involved in a specific situation.

For example, within its staff wellbeing hub, NHS Lothian provides guidance that can be used to stimulate team discussions of recent care events.

Another organisational or team approach to help workers cope with the death of someone they have cared for is the ability to share memories of the deceased with other workers and with the deceased's family and friends. Organising and/or taking part, either as an organisation or a team, in an event related to a national festival such as **'To Absent Friends'** can create dedicated time and space to allow workers and others to come together to share memories of those who have died.

This provides the recognition that grief affects all of those who are bereaved in different ways but also creates a shared identity and understanding.

Organisational guidance to support worker wellbeing

In recognition of the emotional burden of caring, The Institute of Health Care Improvement (IHI) supports a proactive approach to professional support and has developed the **'The Joy in Work'** programme. This provides a range of guidance documents on how to develop a dynamic workplace in which carers feel well supported physically, emotionally secure and feel motivated to provide the best care they can.

IHI has recently developed recommendations to promote emotional wellbeing when working in very difficult circumstances called **'Psychological PPE'** which can be used by both managers and individuals to promote wellbeing within the workforce.

In a similar vein, and in recognition that workers respond to traumatic work events in different ways, NHS Scotland developed a national wellbeing hub for health and social care workers affected by major incidents.

The National Wellbeing hub offers a range of guidance for organisations and individual workers on how to access evidence-based psychological care. The National Wellbeing approach to promoting "psychosocial recovery" is underpinned by the principles of Psychological First Aid (PFA). PFA is a well-respected and evidence-based process that provides individuals with the support they need to develop "resilience" following distressing events.

In summary, care organisations may be in the public, private, independent or charitable sectors and as such the way they support workers who are bereaved needs to be tailored to meet the needs of both the organisation and the bereaved person.

However, as bereavement is a common reason for poor emotional and physical health, which may lead to increased sickness absence, having a compassionate and understanding approach to supporting workers is beneficial for the health and wellbeing of the worker, the wider care team and the organisation as a whole

 **Links to further information
and sources of support**

Good Life, Good Death, Good Grief
– Scottish bereavement friendly
workplaces toolkit

https://www.goodlifedeathgrief.org.uk/content/workplace_home/

Institute for Healthcare Improvement
(IHI) - Joy in work Programme

<http://www.ihl.org/Topics/Joy-In-Work/Pages/default.aspx>

NHS Lothian team huddle template

<https://staff.nhslothian.scot/COVID-19/StaffWellbeing/StaffWellbeingHuddleTemplate.pdf>

NHS Scotland Wellbeing Hub

<https://www.NationalWellbeing.scot/>

Support Around Death - Bereavement
in the workplace

<https://www.sad.scot.nhs.uk/bereavement/dealing-with-bereavement-in-the-workplace/>

To Absent Friends

<https://www.toabsentfriends.org.uk/>

An example of how to record the
outcomes of wellbeing huddles from
North Manchester General Hospital

<https://www.pat.nhs.uk/Coronavirus/North%20Manchester/Wellbeing%20Huddles.pdf>

National wellbeing hub for
professional care givers

<https://www.NationalWellbeing.scot/>

Workplace training

https://www.goodlifedeathgrief.org.uk/content/workplace_training/

<https://www.cruse.org.uk/training>

“The Joy in Work”

<http://www.ihl.org/resources/Pages/IHIWhitePapers/Framework-Improving-Joy-in-Work.aspx>

Remote and rural considerations in bereavement

Almost everyone will, in the course of their lives, be bereaved. The death of someone that you love, were friends or a colleague with, or cared for and the grief that accompanies it are probably the most difficult things that we will ever have to deal with.

Everyone who has been bereaved will grieve in their own way. There is no blueprint for it and that makes writing about it very hard because we can only ever deal in generalisations. Having said that it can be helpful to have things in mind to help us try to understand what is going on.

One of those items which may have a bearing on bereavement is location. Where we live at a time of bereavement may shape how we deal with it and there are particular things to be aware of when we live in remote and rural areas of the country.

The death of an individual is naturally devastating for their family and friends. However, in a small community where so many may have known the person the death may affect a far greater proportion of the population than in other areas. There may be a sense of communal grief as the community mourns the loss of a person they may have grown up with or seen every day. The funeral may become a focal point for the expression of the collective grief that is shared, possibly, by a whole community.

Most people, regardless of where they live, will be able to work through their grief with the help of those closest to them, families and friends.

Sometimes that is hard to do, and further support may be necessary and a great help to work things through. In remote and rural parts of the country that help may not be easily accessed because of the distances involved or transport issues. However, bereavement support can be accessed by telephone and on-line, although it is important to be aware of connectivity issues such as the cost of broadband in areas which often have lower than average incomes and also the reliability of the service.

Living in a small community can have great advantages at a time of bereavement. There are the practical ones such as people leaving pans of soup for those who are bereaved and emotional ones such as not having to explain to others that you are grieving because so many people will know what has happened. Paradoxically, it is harder to be anonymous and privacy is something that is afforded by your neighbours in a conscious act of empathy and compassion.

In remote and rural places issues of confidentiality can be a little challenging. Healthcare staff living in the same communities as those they care for are unable to say anything about the people they attend and yet everyone may have seen the ambulance arriving at a person's door.

Bereavement can be bewildering. However, with the help of those who are close to you, and the compassion of those you live amongst and an awareness of some of the potential pitfalls, bereavement can be weathered and grief worked through.

Anticipatory Grief

In this section we explore what anticipatory grief is, what lies behind the phrase ‘a good death’, the anticipatory grief of carers and lastly the experience of children and young people.

When a person is diagnosed with an incurable, life limiting illness it throws them and their family and friends into a very uncertain and emotional situation. Consequently, in the time between the diagnosis and the expected death family members and friends will experience varying levels of emotional, physical, and spiritual distress as they try to make sense of their situation. For instance, individuals trying to comprehend how the expected death of a loved one might affect their own future may experience what is called ‘anticipatory grief’.

It is suggested that experiencing ‘anticipatory grief’ may help enable an individual to begin to adjust to their life without their loved one before they actually die. This in turn may help them cope better with their bereavement. Nevertheless, not everyone can imagine a life without a loved one as the very thought of this causes them distress. Individuals who do not experience anticipatory grief do not appear to be more adversely affected in their post death grief than those who do.

It is recognised that there are many other reasons why some people may be less able to cope with their eventual bereavement following the expected death of a loved one. For instance, individuals may experience a range of concurrent life events such as a change in role/relationships, a physical or mental illness or care giver burden. Such happenings may trigger grief responses so

what an individual may be experiencing is the grief related to current losses, ‘anticipatory grief’, or a combination of these. Consequently, consideration of other losses that family members and friends experience during the illness journey is required to fully understand their pre-death grief responses and meet their support needs.

A Good Death

Most people have an idea of what they think a ‘good death’ may or may not be, based on their values, belief systems and life experiences. As such, the term can vary in meaning not only in individuals but also across societies/groups. For instance, a good death in Western Societies is usually represented as one that is expected and planned for, occurs in their preferred place and when the dying person is able to be with others of their choosing. A good death in Western Societies may also be also viewed as one that is peaceful, dignified and pain free. This philosophy is based on the Western beliefs of individualism and autonomy where people should be free to make choices about themselves in life but also in death.

There are also groups that bring together people with varying values and belief systems who will always have different views on what a good death may be. An example of this is health and social care organisations who employ people from all walks of life. However, in care settings the personal views of professionals around what might be considered to be a good death are also influenced by their professional training, codes of conduct and organisational policies and procedures. For instance, it is understood that for many hospital professionals a hospital death is considered the best place

to die as this ensures that physical suffering is minimised, and people die in a quiet and dignified way. However, this may not match with the views of the dying person, families, and friends, where their rites and rituals cannot be upheld or where there is little opportunity for the dying to have choice in what they would like within organisational routines.

Consequently, regardless of the philosophies and ideologies outlined here the dying person, their family members and friends and their care team may well differ in their view of what a good death may be. It is therefore important to determine what a good death means to each dying person and their family as end-of-life care providers have only one chance to get this right. This is especially important as it is understood that a death that is not in keeping with the view of a good death of the bereaved may affect their ability to cope with their bereavement.

Upaid carers and anticipatory grief

Those who care for family, friends and neighbours with a life shortening or terminal illness can experience grief and bereavement long before the person they are caring for dies. This is a common example of 'anticipatory grief'.

Anticipatory grief can take many forms and carers can experience it in different ways. It can include feelings of loss as the cared for person's physical health declines, including loss of intimacy, and companionship. The nature of the relationship can change moving from one based on a personal relationship, for example husband and wife, to one that is balanced more toward carer and patient resulting in grief for the loss of what went before. Carers can also feel grief at the impending death of the person they are caring for, especially when they are in a close

relationship, such as a spouse.

For some, the sense of loss can come from changes in the behaviour and personality of the person they are caring for as their cognitive function declines. Carers can feel the person they once knew is gone, even though they are physically still there, leading to feelings of loss and grief.

The sense of grief ahead of a death felt by a carer can also be about the loss they experience in relation to themselves including the loss of identity, social opportunities and networks, as well as freedom and independence, and feelings associated with a 'lost' future.

Anticipatory grief can impact on those caring for people with any condition, including terminal cancer or heart failure, and is commonly seen among those caring for someone experiencing significant cognitive decline, such as dementia. 50-80% of carers of someone with dementia can experience anticipatory grief.

Anticipatory grief can be constant, consistent, but also come in waves of differing severity. It can have significant negative consequences for the carer including affecting their physical, mental, and psychosocial health with increased levels of depression and anxiety. Many carers can become overwhelmed by anticipatory grief.

Anticipatory Grief for a pregnancy and baby

The news that your child is going to die is arguably one of the most painful things that any parent will ever hear. When families are experiencing anticipatory grief for a child or a baby not only do they experience the pain of the subsequent loss of that child, but also the loss of a future that they had planned for that

child.

Helping when a baby is expected to die before, during or shortly after birth

Compassionate conversations and plenty opportunities to talk to those who can support the family is helpful as they start to process this news. Ways in which we can help adults prepare for the death of their baby:

- **Making memories:** families should be supported to make memories while their baby is still in utero as this might involve playing music, reading and talking to the baby and buying keep sakes.
- Encourage families to make memories when their baby is in hospital, both before and after their baby has died. This may be taking photos and videos, reading stories or playing music as well making casts of hands and feet.
- Clear conversations with families regarding the options of delivery and care, including whether their baby could be taken home.
- **Anticipatory care planning:** it is important that this should be done gently and through a series of ongoing conversations and not in one conversation to fill in a document
- **Being able to talk:** access to professional and psychological support if needed through peer support or counselling may be helpful to support their exploration and feelings of anticipatory grief. This should be during anticipatory grief period and following the loss.
- Consider the needs of each member of the baby's family, including parents, siblings, grandparents and extended family and give support where necessary.

Helping when a child has a life shortening

condition

Families where a child is diagnosed with a life shortening condition often go through a series of losses. Loss of the present as everything changes, loss of the future as it looks so different to what they had imagined and the knowledge that their child will die.

There are many things that help families that are anticipating the loss of their child:

- **Making memories:** Opportunities to make memories with the child and as a family is important in how the family remembers the time that they have with their child, however short
- **Include making memories with others:** Making memories with other people in your social and support circle is important in anticipatory grieving as this also allows the family to have other people to talk to about their child after they have died that can share those memories with them.
- **Keeping hope alive:** often families don't know how long their child will live and hope for what they can achieve together is as important as preparing for the death of their child
- **Anticipatory Care Planning:** although keeping the hope alive for the child is important it is helpful to balance this with managing considerations for end of life care and what a family may wish to do when their child does die
- **Knowing the options:** Being knowledgeable about end of life care, and care after death is important in supporting the family to make informed choices – like do they wish to take their child home until the funeral? Families often don't know what their options are so it is helpful if they can be guided through what choices they have

- **Finding a tribe:** Often the isolation of having a child with a life shortening condition is one of the things that families can find the most stressful. Finding other people in a similar circumstance or that have a child with the same or similar condition can help in anticipatory grieving.

Anticipatory Grief – Children and Young People

Supporting a child or young person when someone has a palliative illness, or is dying, is a difficult thing to do, especially as the adults around the young person are often experiencing anticipatory grief too.

Here are some things that can help:

Preparation

Helping children prepare for a death is important as it helps them to make sense of the situation and can help children grieve better after the person has died. Ways in which we can help children prepare are:

- **Legacy work:** eg, keep sakes, memory work, continuing connections etc
- **Advanced Care Plans:** Involving children in this helps children to know what is happening and can help with their anxiety.
- **Explanation:** of what is happening, or might happen, can help children to understand what is going on and this can help them not to make assumptions or reach wrong conclusions.
- **Age appropriate language:** thinking about the language we use so that it makes sense to a child can be helpful as sometimes we can make assumptions that children might understand things that they don't. This will differ depending on their age and stage of development.
- **Routine:** Helping children know what is happening and when can help children to

feel safe and secure.

- **Being able to talk:** helps the child to be able to make sense of what is happening, to understand their feelings and to ask questions. It's ok though if they don't want to talk.

Choice

Different children make different decisions about how much they want to know about and how much involvement they want to have.

Choice should be informed: and requires explanation of different concepts – for example, would they like to visit someone where they are being cared for? This might need further explanation of what the place is like, how the person might be and how they might feel. This helps children make the choice that is right for them.

Lack of choice can often affect ongoing relationships as it can often become blame that a child wasn't allowed to be involved and can be directed to those that are seen to have made the decision for them.

Adults can find this difficult, especially when children might have a lot of questions that they are asking to help them understand. However, being able to help children by giving explanations and providing information lessens their distress and supports better bereavement experience.

Giving children a choice in who they can talk to and where they can find them (especially within an education setting) can be really helpful. Often having someone to talk to out with the situation can be helpful.

Inclusion

Children almost always know more than we

think they do when someone is very ill or dying.

Adults sometimes feel that it will protect children to not share how ill someone is, or that they are dying. Children who are not included are likely to worry more and often make something up in order to try to make sense of the behaviour of others around them.

When children are not included this can cause children to have more questions and possibly some fears about illness and dying. Making death a part of life will help children understand what is happening and can assist them with managing their grief. Often when children aren't included their grief can feel out of sync with those around them which can feel very confusing.

Opportunity for a goodbye is important for children. This doesn't have to be in person, some might choose to draw a picture or write a letter, but having the opportunity to say what they need to say is important.

Anticipatory Grief is hard for everyone involved and often is uncharted territory that we don't know how long will last. Helping children find their way through this is important for not only their own grief but the adults around them too. Preparation, Choice and Inclusion will support better grieving for everyone.

References

Tara Dehpour & Jonathan Koffman
(2023) Assessment of anticipatory grief
in informal caregivers of dependants
with dementia: a systematic review,
Aging & Mental Health, 27:1, 110-123,
DOI: 10.1080/13607863.2022.2032599

 **Links to further information
and sources of support**

Good Life, Good Death, Good Grief
<https://www.goodlifedeathgrief.org.uk/>

Age UK – Ageing in coastal and rural
communities
<https://www.ageuk.org.uk/our-impact/policy-research/ageing-in-coastal-and-rural-communities/>



General links to further information and sources of support



Breathing Space

<https://breathingspace.scot>



Cruse Bereavement Care Scotland

For all ages and any type of
bereavement

<http://www.crusescotland.org.uk>



Good Life, Good Death, Good Grief

<https://www.goodlifedeathgrief.org.uk>



Marie Curie

<https://www.mariecurie.org.uk/help/support/bereaved-family-friends>



mygov.scot

Death and bereavement
<https://www.mygov.scot/births-deaths-marriages/death-bereavement>



National Records of Scotland

How to register a death
<https://www.nrscotland.gov.uk/registration/registering-a-death>



NHS Inform

Death and Bereavement

<https://www.nhsinform.scot/care-support-and-rights/death-and-bereavement>



Samaritans

<https://www.samaritans.org>



Scottish Care

<https://scottishcare.org>



Sue Ryder

<http://www.sueryder.org>



Support around Death

Website for health and social
care professionals

<http://www.sad.scot.nhs.uk>



What to do when someone dies

<https://www.mygov.scot/when-someone-dies>

A Bereavement Charter for Children and Adults in Scotland

This Charter provides a set of statements which describe how in Scotland we can support a person or a group of people experiencing bereavement. Good bereavement care is a human right. This Charter is underpinned by a desire to make sure that in Scotland, we do all that we can to support people who might be experiencing difficulties following the death of someone they know or somebody in their community. It is the responsibility of everyone within Scotland to ensure that this is achieved. These are our statements:

IN SCOTLAND, PEOPLE WHO HAVE BEEN BEREAVED SHOULD

- Be treated with compassion, empathy and kindness
- Have their wishes, choices and beliefs listened to, considered and respected by all

SCOTLAND SHOULD BE A PLACE WHERE

- Grief, bereavement and death are recognised as a natural part of life
- There is an open culture which is supportive of people having the opportunity to grieve
- Accessing support (e.g. emotional, practical, financial, social and spiritual) is seen as a right
- Efforts are made to ensure that adequate bereavement support is accessible for everyone
- People have space and time to grieve
- It is recognised that bereavement might affect all aspects of a person's life (e.g. relationships, school, workplace)

IN SCOTLAND, PEOPLE ARE SUPPORTIVE OF FRIENDS, FAMILY AND COMMUNITY MEMBERS WHO HAVE BEEN BEREAVED, WHICH MEANS THAT

- People's needs and grief reactions are recognised and acknowledged as being different at different times
- Grief and bereavement can begin before death and can be lifelong
- People who have been bereaved should feel supported to talk about the person who has died if they wish to
- Bereavement and grieving can be experienced by the whole community and not just by individuals
- There is help to know where to refer or signpost people to for additional support

The Charter and additional information can be found at www.scottishcare.org/bereavement

A Bereavement Charter for Children and Adults in Scotland Frequently Asked Questions

This Charter provides a set of statements which describe how in Scotland we can support a person or a group of people experiencing bereavement. Good bereavement care is a human right. This Charter is underpinned by a desire to make sure that in Scotland, we can do all that we can to support people who might be experiencing difficulties following the death of someone they know or somebody in their community. It is the responsibility of everyone within Scotland to ensure that this is achieved. These are our statements:

What is the Charter?

The Charter provides a set of statements which describe how people and communities who are bereaved in Scotland can be supported. The Charter is accompanied by further Guidance that gives additional information for specific groups and individuals.

Who is the Charter for?

The Charter is for everyone in Scotland, and it will hopefully make a difference to the experience of people who are facing death, dying and bereavement in their community.

What might the Charter mean to me?

Death is something that happens to everyone and is a natural part of living. Every person is unique and will find their own experience of grief different. Many will rely on their culture, beliefs and other sources of support to understand and process their feelings and emotions. The Charter should help to support people and give them the opportunity to talk openly about death, dying and bereavement and how it impacts on all our lives.

Why was the Charter created?

This work has been brought about by a desire to make sure that in Scotland, we can do all that we can to support people who might be facing difficulties following the death of someone they know.

Who was involved in the creation of the Charter?

A number of professionals and individuals across a wide range of backgrounds developed the Charter, over a period of eighteen months, to describe what Scotland could be like if we really support those who are experiencing the death of someone. We consulted widely on the content of the statements during this time.

Who is the Charter owned by?

The Charter is owned by everyone and not by those who created it. It is a Charter for everyone who experiences death, dying and bereavement in today's Scotland.

Why base the Charter on human rights principles?

The Charter is based on human rights principles as a set of values which means that you are treated with respect and dignity, that your voice is heard, and that if you are facing difficulties, you are able to find a means by which those difficulties can be met.

Where might I find more information on the Charter and guidance?

These are available at:

www.scottishcare.org/bereavement

Bereavement Charter Mark

Organisations can earn the Bereavement Charter Mark by taking actions to make their organisation more supportive of bereaved employees. Having the charter mark on your website demonstrates that you are working to make your community a place where people who are bereaved feel supported by the people around them.

The Bereavement Charter Mark is currently available to:

- Employers

We are working to develop resources to enable other communities and organisations to apply for the Bereavement Charter Mark, including:

- Community Groups
- Schools
- Care Homes
- Faith communities

Apply for the Bereavement Charter Mark

To display the mark, an organisation must first agree to meet certain criteria. More information about how to apply for the Bereavement Charter Mark is available at the links below:

- [Information for Employers](#)





Bereavement Charter FOR SCOTLAND

We wish to acknowledge thanks to those individuals who created content, edited and updated this document. The following logos are representative of the organisations involved:

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- care inspectorate
- CHAS Children's Hospices Across Scotland
- Childhood Bereavement Network
- Cruse Bereavement Care Scotland
- Healthcare Improvement Scotland | ihub
- Scottish Families Affected by Alcohol & Drugs
- Sands
- National Bereavement Alliance
- NHS Highland
- NHS Lothian
- MND Scotland Supporting people affected by Motor Neurone Disease
- NHS Education for Scotland
- NHS Fife
- NHS Forth Valley
- NHS Greater Glasgow and Clyde
- families outside
- University of Strathclyde Glasgow
- Northumbria University NEWCASTLE
- Scottish Ambulance Service Taking Care to the Patient
- Scottish Care Voice of the independent care sector
- St Columba's Hospice Care
- Sue Ryder palliative, neurological and bereavement support
- tide together in dementia everyday
- University of Glasgow
- UNIVERSITY OF THE WEST OF SCOTLAND UWS