

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

#becausegriefmatters

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Introduction

Eighteen months 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.

The Charter has been produced as a result of many discussions and debates, of much consultation and engagement, and is offered in sincerity as a support to all those who struggle with the death of someone they know or someone in their community.

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 are bereaved may not have been able to be with a person as they approach the end of their life and may be isolated from their usual networks of support. It has also changed the customary ways we are able to mark our grief. Traditional bereavement rituals and funerals have changed with many people now unable to attend funerals in the way that they might have in the past. Many deaths have become sudden with little or no time to prepare.

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.

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.

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

Dr Donald Macaskill, Chair of the Bereavement Charter Development Group 14th April 2020



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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. We would like you to 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.

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 dentists 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.

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 could hold a 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 focusing 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

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

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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 kindness and empathy 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 out of fear of worrying about saying the wrong thing or causing further upset. However, there is no right thing to say and listening to and talking with individuals about their feelings and demonstrating your understanding you can 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 form results in us finding it harder to cope with our daily lives and can 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 when bereavement is experienced.

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

It cannot be emphasised enough the importance of feeling listened to, respected and having personal wishes, choices and beliefs considered when 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 on their grief. We live in a varied and multicultural society that includes people from all nationalities who have a variety of beliefs that will 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 on 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 every single 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, and 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, be it through e.g. 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 have feelings of grief and bereavement when the person you care for is still alive and these feelings can last all through their life and long after the person dies. 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

These will be reviewed frequently and updated as required. There are links to <u>further information</u> <u>and sources of support</u> at the end of this document.

Pregnancy and baby loss

Parents may experience loss in a variety of circumstances during pregnancy or after birth including neonatal 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 is little or no 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 play a big part in 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 and many learn ways to honour their baby.

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



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 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. 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	 Can't understand what death means Can be affected by emotions of people around them 	 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	 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 	 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	 Begin to understand that death is permanent Be afraid that someone else important to them will also die 	 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
Nine to twelve	 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 	 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)
Teenagers / young adults	 Adolescence at any time is a period of change, the addition of a bereavement on top if this can make life even more difficult for young people. 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. They will: Understand that death is permanent Be anxious about how their life will change Have similar feelings to those of adults 	 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)

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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
- Use clear language so that there can be no misunderstandings (e.g. 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). Check that the child has understood what you have said
- 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 (e.g. don't be afraid to say that you 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 what a funeral is to children 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. Small pieces of information at a time will ensure they don't become overwhelmed.

Education and information

Children who are bereaved, need, and are entitled to, receive answers to their questions and 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.



Support throughout childhood

Many people believe that if a child is bereaved as a baby or toddler, that, as they don't remember the person, they will not or cannot grieve for them, when in fact they can and will. They grieve the loss of a relationship with that person. 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 dependant on 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 5, will be different to how they understand this by the time they are 10.

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 engage with it.

Other 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. The Childhood Bereavement Network has lists of available supports in areas in Scotland (please refer to the 'Links to further information and sources of support' section on page 28).

Additional information and details of support services are available at the end of this document.



Children and young people 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, in general this is not helpful.

Having a learning disability does not mean they cannot be impacted by or understand a bereavement. Like most children and young people, they will progress normally through their grieving process. 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 are 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 and because of this there will be an emphasis on helping them to develop a cognitive understanding, with a need to balance this with creating space for exploring emotions.

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, breath, 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 child with a learning disability that the death was not their fault.

You might explain a funeral by burying the dead bug or fish. Use as many real-life 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 child 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 take photos of the dead fish/bug/ and make a social story book for retelling the information. If it's possible you can make the book telling the story of the person that died, including funeral pictures.



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 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.

Remember it's important to acknowledge a death regardless of a child's capacity to understand it.





Children and young people in contact with the justice system

Children and young people who are involved in offending behaviours have often experienced a higher rate of bereavement than children and 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 them more vulnerable to negative outcomes.

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 risktaking 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 lead them to come into conflict with authority or the law. For vulnerable children who may have already been in trouble, or who tend to act out their grief and distress then the risk of misinterpreting symptoms is greater. 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.

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. 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 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 be removed from shared grief experiences and rituals such as funerals or attending gravesides. Recording important dates, such as anniversaries and birthdays, will ensure that potential triggers can be prepared for and young people can be supported. 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.

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. Many of these places can also be difficult for a child to find private and safe spaces in which they can express their grief and 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.





Adults with profound and multiple learning difficulties (PMLD)

People with PMLD are typically non-verbal in their communication, presenting with many complex health problems combined with sensory and motor limitations.

If we consider the high dependency needs of these individuals, the skill and knowledge involved in their care and the patterned nature of that care, we may appreciate the extent to which their bodies can be affected by the loss of a caregiver. People with PMLD are at risk of not receiving the support they need at times of loss; the perception that they lack the cognitive capacity necessary to experience loss often precludes them from accessing psychotherapeutic support.

Many people with profound and multiple learning disabilities cannot use words to communicate, can have problems with their sight and their physical disabilities make 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 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 needs of these individuals, we may get a sense of how difficult it must be for a person with PMLD to be separated from this caregiver, through death or otherwise. Loss of the relationship is loss of that attuned care for the body. Loss is felt in the body.

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.

It is clear that however we respond to the loss experiences of people with PMLD, it necessarily involves approaches that respect how loss impacts on the body but also the communicative limitations of people with PMLD. Multi-sensory and body-based approaches can facilitate this and have been described in a Bereavement and Loss Resource developed by PAMIS (promoting a more inclusive society), a charitable organisation supporting families of people with PMLD.

Staff training is key because we know that bereavement support for this group will be sensitive to the needs of the individual when staff feel they have the knowledge, skills and confidence in their caring role.



Learning disabilities and degenerative neurological conditions such as dementia

Some examples of when you may feel grief and bereavement when a person is still living is when you are caring for someone with a degenerative neurological condition such as dementia or caring for someone with a learning disability.

Throughout and after your time caring for someone with dementia you can experience feelings of loss and grief. You can grieve the loss of the person as they were. Their personality can change, and they can lose familiar parts of their identity – what makes them who they are. They might not be able to have the same conversations as before or do the things they used to love doing. It sometimes feels like you are losing the person twice, once due to their condition deteriorating and again when they die.

You can grieve the relationship you had with them, they might have been your partner, your parent, your sibling, a member of your family or your friend. Now the previous role you had with them may be reversed, and you miss having that person to rely on. It can feel like you are losing shared memories of a life you built together. Or you can grieve memories that you haven't had the chance to make yet.

You can experience these feelings when you are witnessing deterioration in the person's condition, when they lose certain abilities such as speech and mobility. Or when you realise that the situation is not going to get better, you might feel helpless and that you are failing because there is nothing you can do to stop it. The caring role can become so overwhelming at times that you do not have the time or energy to face your own grief.

These feelings can be triggered randomly; you may experience them now and again, or constantly. You may feel them at the point where there is a diagnosis made or at transition points into care or hospital, or at the point of death – and they can last for a significant amount of time.

Grief can be triggered when the person forgets a memorable date, like a birthday or anniversary, or they no longer understand or connect the significance of that date, which they did in the past.

Losing the connection you had with the person, when they are unable to recognise you or remember different parts of your life together, whilst they still look like and sound like the person you knew is extremely painful and hard to deal with.

You can suddenly be overwhelmed with grief when you see the apparently normal life of people going on around you and you realise that you don't have that anymore and will never have the future you pictured with that person or do the things you talked about or planned.

As well as grieving for the person you care for, you can grieve the loss of your own identity. You can feel like you lost the parts of you that made you who you are; your job, your relationships, your hobbies and your purpose,



as you have taken on the new identity of being a carer. There can come a point when you lose that new identity of being a carer too, when the person you care for moves into a care home or when they die. You can grieve your identity in relation to others; your whole family can be affected. These losses can isolate you and make you feel very alone.

If you are caring for a person with a learning disability you may share some of the feelings and experiences similar to the ones mentioned above. However, you may have been caring for the person since they were born and the life that you imagined for your child growing up will be very different.

You may feel grief and loss at popular milestones in their life which they struggle to meet or when you see other children at the same age achieving things you hoped your child would at that age.

The person may be your sibling, your parent or your grandparent and the typical things you expected to do with them might not be possible or may be different to how other people do it. Your relationship with them might be different to other ones you see around you and that can be hard. Your expectations will change, and you will make adjustments which may trigger feelings of grief and bereavement which are not recognised or understood by others around you.

You will find yourself coming in and out of periods and cycles of grief over a sustained, significant amount of time and that might not end.

Additionally, it is recognised that as a carer (who is not part of the family), who has supported and cared for someone who has died, you will have developed a relationship with the person and their families. This means that you will also become bereaved on their death along with the family, although grief in carers is often not recognised. However, you also have the right to bereavement support that meets your needs. This may be provided in several ways through your employer, General Practitioner and other bereavement services. It is important for you to keep well in your bereavement to allow you to continue with your important caring role.



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. Those affected by suicidal thoughts are advised to:

- Contact their GP or
- Visit <u>www.nhsinform.scot/campaigns/</u> <u>suicide</u>
- Call NHS 24 on 111
- Call Breathing Space on 0800 83 85 87 (6pm – 2am weekdays and Friday 6pm through to Monday 6am at weekends)
- Visit the <u>Samaritans website</u> or dial the Freephone number 116 123 (available 24 hours a day) for confidential support

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 them 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 from 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.

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.



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 unacknowledged (disenfranchised grief) and feel shame in talking about their loved one. This can make the grieving process more complicated. Families may feel they cannot talk about the death, which in turn 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.



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 those 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.

Nevertheless, this grief and distress is not always recognised, acknowledged, and understood by society, employers, colleagues, families and friends. However, the emotional burden of caring may trigger stress responses in workers and over time lead to moral injury 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 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 reflecting on the past and remembering the person who has died as a care team can be helpful. This allows workers to see the individuality of grief responses and for the team to support each other in difficult times. 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 PRoMIS hub offers a range of guidance for organisations and individual workers on how to access evidence based psychological care. The PRoMIS 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

The following list of resource links will be amended and updated as required.

GENERAL

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 <u>https://www.mygov.scot/births-deaths-</u> 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-supportand-rights/death-and-bereavement

Samaritans https://www.samaritans.org

Scottish Care https://scottishcare.org Sue Ryder https://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

CHILDREN AND YOUNG PEOPLE

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



CHILDREN AND YOUNG PEOPLE IN CONTACT WITH THE JUSTICE SYSTEM

Children and Young People's Centre for Justice

Trauma, Bereavement and Loss: Key learning and messages from research and practice <u>https://cycj.org.uk/wp-content/</u> <u>uploads/2019/09/Key-Messages-from-TBL.pdf</u>

Children and Young People's Centre for Justice

Bereavement and offending behaviours: A role for Early & Effective Intervention (EEI)? https://cycj.org.uk/wp-content/ uploads/2019/10/Bereavement-and-EEI-1.pdf

Children and Young People's Centre for Justice

Persistent Offender Profile: Focus on Bereavement <u>https://cycj.org.uk/wp-content/</u> <u>uploads/2014/05/Bereavement-Paper-CJSW-</u> <u>Briefing.pdf</u>

Children and Young People's Centre for Justice

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-templatefinal.pdf

Children and Young People's Centre for Justice

The trauma, bereavement and loss experiences of women in prison <u>https://cycj.org.uk/wp-content/</u> <u>uploads/2019/07/Here-and-Now-Females-</u> <u>FINAL-Report.pdf</u>

Children and Young People's Centre for Justice

Talking about death with children and young people

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

Children and Young People's Centre for Justice

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

Children and Young People's Centre for Justice

Understanding ambiguous loss in young people involved in offending <u>https://cycj.org.uk/wp-content/</u> <u>uploads/2015/08/Info-sheet-40.pdf</u>

The Howard Journal of Crime and Justice

The Ripples of Death: Exploring the Bereavement Experiences and Mental Health of Young Men in Custody <u>https://onlinelibrary.wiley.com/doi/</u> full/10.1111/hojo.12064

University of Dundee

When People Die: Stores from Young People https://discovery.dundee.ac.uk/en/ publications/when-people-die-stories-fromyoung-people

University of Strathclyde

Ambiguous Loss https://core.ac.uk/download/pdf/195293914. pdf



LEARNING DISABILITIES AND DEGENERATIVE NEUROLOGICAL CONDITIONS SUCH AS DEMENTIA

Alameda County Public Health

Supporting people with disabilities coping with grief and loss – Easy Read Booklet http://www.acphd.org/media/121165/grief_ and_loss.pdf

Down's Syndrome Scotland Let's talk about death https://www.dsscotland.org.uk/wordpress/ wp-content/uploads/2016/02/Lets-Talkabout-Death-2012.pdf

Macmillan Going to a funeral when someone dies – Easy Read Booklet http://be.macmillan.org.uk/Downloads/ CancerInformation/Easyread/ MAC16311Going-to-a-funeral-whensomeone-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-betterwhen-someone-dies.pdf

MND Scotland Supporting people affected by Motor Neurone Disease https://www.mndscotland.org.uk

PAMIS Promoting a more inclusive society http://pamis.org.uk

Tide Together in dementia everyday https://www.tide.uk.net/resources

PREGNANCY AND BABY LOSS

Miscarriage Association https://www.miscarriageassociation.org.uk

National Bereavement Pathway for Pregnancy and Baby Loss <u>https://nbcpathway.org.uk</u>

Stillbirth and Neonatal Death Charity (SANDS) <u>https://www.sands.org.uk</u>

Scottish Cot Death Trust https://scottishcotdeathtrust.org

Twins Trust Charity https://twinstrust.org

Antenatal Results & Choices (ARC) http://www.arc-uk.org

Bliss for babies born premature or sick http://www.bliss.org.uk

BEREAVEMENT FOLLOWING SUICIDE

NHS Inform Choose Life, Suicide Prevention in Scotland <u>https://www.nhsinform.scot/campaigns/</u> <u>suicide</u>

Papyrus Preventing young suicide https://www.papyrus-uk.org

Petal People experiencing trauma and loss <u>http://www.petalsupport.com</u>

Public Health Scotkand Suicide prevention overview <u>http://www.healthscotland.scot/health-</u> topics/suicide/suicide-prevention-overview

SAMH

After a Suicide <u>https://www.samh.org.uk/documents/</u> <u>After_a_suicide.pdf</u>

Survivors of Bereavement through Suicide https://uksobs.org

SUPPORTING CARE WORKERS

Cruse Bereavement Care Workplace training https://www.cruse.org.uk/training

Good Life, Good Death, Good Grief Scottish bereavement friendly workplaces toolkit https://www.goodlifedeathgrief.org.uk/ content/workplace_home

Good Life, Good Death, Good Grief Workplace training https://www.goodlifedeathgrief.org.uk/ content/workplace_training

NHS Northern Care Alliance

Looking After You – Standard Operating Procedure for the Daily Wellbeing Huddles at North Manchester General Hospital (NMGH) https://www.pat.nhs.uk/Coronavirus/ North%20Manchester/Wellbeing%20Huddles. pdf

Bereavement

Charter FOR SCOTLAND

PRoMIS

National Wellbeing Hub For people working in Health and Social Care <u>https://www.promis.scot</u>

Support Around Death

Bereavement in the workplace <u>http://www.sad.scot.nhs.uk/support-</u> <u>around-death-news/2020/may/dealing-with-</u> <u>bereavement-in-the-workplace</u>

To Absent Friends A people's festival of storytelling and remembrance https://www.toabsentfriends.org.uk



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 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:

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 <u>www.scottishcare.org/bereavement</u>



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

The Bereavement Charter Mark is available for use by organisations that wish to indicate their wish to endorse or show their support for the Bereavement Charter for Adults and Children in Scotland.

The Mark is offered in the sizes small (100px), medium (500px), and large (1000px) in PNG image format, at the links below.

Bereavement Charter mark small (100px)

Bereavement Charter mark medium (500px)

Bereavement Charter mark large (1000px)

All organisations wishing to make use of the Charter Mark image(s) should email the NHS Education for Scotland's Bereavement team – this is to help the Charter Development Group track how widely it is being used. We're also available for any queries on its use.

Email:

SupportAroundDeath@nes.scot.nhs.uk

Additionally, if you require a different format (for instance to incorporate the Mark in professional design or printing), please email the address above and we can provide additional formats.





This guidance document was developed by a coalition of individuals and organisations

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