

A pathway and guide for professionals working with children and young people in Leeds who have been bereaved

Version 3 - November 2019

“Children and young people often report feeling alone and different following the death of someone important in their lives”

(BMJ Supportive and Palliative Care 2012;2:2-4)



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Produced by Charlotte Hanson, Office of the Director of Public Health, with contributions from colleagues from a wide range of services. Thank you for support in updating version 3 from Phoebe Lionakis, Graduate Local Government Officer.

- Version 1 - developed November 2016
- Version 2 - updated June 2017
- Version 3 – updated October 2019

Section 1: Introduction

Aims

This pathway aims to:

- Set out a citywide approach to addressing the needs of children/young people who have experienced bereavement.
- Describe the integrated pathway in Leeds for a child/young person who has been bereaved.
- Provide staff with clear guidelines about how to support a child/young person

The intended outcomes for Leeds are:

- A more open attitude to discussing death and bereavement.
- Grief responses normalised.
- Practitioners feel more confident to support children/young people and refer appropriately.
- Children/young people who have experienced bereavement feel less alone and different.

Scope

The pathway is aimed at practitioners within universal settings such as schools, Children's Centres, voluntary sector agencies or GP practices. The pathway focusses predominantly on supporting children who have lost a key family member or friend, as opposed to focussing on supporting a parent when a child dies.

Staff within Early Start Teams (working with 0-5 year olds) should also refer to the EST Bereavement Pathway specific to this service.

Prevalence

There is no formal system for recording of how many children are bereaved, so data tends to come from self-reported surveys.

In the Leeds 'My Health My School Survey' (2018-19) participants were asked about bereavement they had experienced within the last year.

- 3% (326) of Primary pupils surveyed said they had lost someone who lived in their house (e.g. parent or sibling) within the last twelve months, with 37.2% (3,890) losing a family member who doesn't live in the house within the last twelve months.
- 2.9% (204) of secondary pupils surveyed (2.9% of Year 7s (87), 3% of year 9s (88) and 3.3% of Year 11s (29)) said they had lost someone who lived in their

house (e.g. parent or sibling) within the last twelve months, with 38.8% (2,689) losing a family member who doesn't live in the house within the last twelve months.

The Childhood Bereavement Network also estimates numbers of bereaved children in each local authority using mortality statistics, census data and other sources. See box below.

Leeds

We estimate that each year, around **260** parents die in this area, leaving around **450** dependent children (aged 0 to 17).

We estimate that the current school-age population of children and young people (aged 5 to 16) in this area who have been bereaved of a parent or sibling at some point in their childhood is around **3140**

Source: <http://www.childhoodbereavementnetwork.org.uk/research/localstatistics.aspx>

Key Principles

- Grief is a normal process that is difficult, but should not be pathologised. It is important not to assume that all bereavement results in ongoing mental health issues for children and young people.
- Bereavement is not an issue to be dealt with once as it will continue to impact on the child / young person over time, especially as they moves through different developmental stages. Be aware that historical bereavement may be an underlying factor if child/young person is exhibiting emotional/ behavioural issues.
- Ideally children will access support from within their own family unit, so supporting the parents and the family as a whole is important.
- Local services such as schools and Children's Centres are well placed to offer support due to their existing relationships with families. However, referral to a specific bereavement support service is advised if a family is struggling to cope or the bereavement is particularly traumatic (for example, an unexpected death of a parent).

Section 2: Understanding Childhood Bereavement

Responding to death is something that affects everyone. The response is an individual process and is affected by a variety of factors. Grief is often seen as primarily emotional, but it is multi-faceted with physical, cognitive, spiritual and behavioural dimensions.

For children and young people, the impact on them can be profound and can run through a life course. Long term, there can be effects on their socialisation, some children report being bullied as a direct result of being bereaved, and it can also impact negatively on concentration and educational attainment.

Bereavement affects children and young people in different ways dependent on a variety of factors:

- How sudden the death was.
- The age of the child/young person.
- The support mechanisms and resilience of the child/young person.
- How it is handled – both by the family and by the others around the child/young person.
- The relationship the child/young person had with the person who died.
- The nature of the death.
- Previous experiences of bereavement and the number of bereavements experienced.

Common grief reactions in children (Dyregrov, 2008)

- Anxiety
- Vivid memories
- Sleep difficulties
- Sadness and longing
- Anger and acting out behavior
- Guilt, self-reproach and shame
- School problems

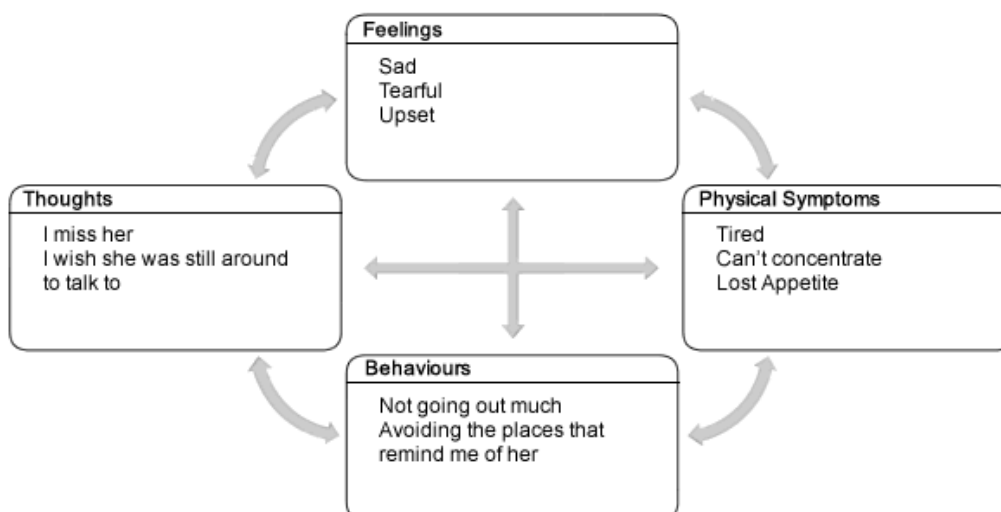
Some children might show regressive behaviour, social isolation, fantasies, personality changes, pessimism about the future, preoccupation with cause and meaning, and a sense of maturity and growth as a result of being bereaved.

It is normal for children and young people who are bereaved to react with physical responses, emotional responses and behaviour responses. Examples include:

- Being anxious.
- Open distress.
- Refusal to cooperate.
- Panic.
- Having vivid memories.
- Trouble sleeping.
- Feeling sadness.
- Feelings of anger against people and things.
- Feelings of guilt.
- Regressing to behaving like a younger child.
- Changing personality.
- School problems e.g. lack of concentration.
- Psychosomatic illness.
- Bed wetting.
- School refusal.
- More susceptible to being bullied.
- Any other signs of stress/change of mood – these may be expressed in unexpected ways e.g. nervous giggling, stoical bravery, untypical aggression, clowning around, or even total denial. These signs may show at the time or sometime after the death has occurred.

Not everyone has these feelings and, although they may be very strong and confusing, they are normal feelings which are associated with many bereaved people. Hopefully they will subside over time, and with reassurance from adults.

Cycles of grief:



Understanding of death

Children and young people process death differently to adults due to their cognitive development process.

'For adults, it feels like having to wade through rivers of grief, and they may get stuck in the middle of a wide sea of grieving. For children, their grieving can seem more like leaping in and out of puddles. First reactions may range from great distress to seeming not to be interested. One minute, they may be sobbing, the next they are asking: "What's for tea?" It does not mean they care any the less about what has happened.' - Winston's Wish

As children mature, their understanding of death also develops:

Birth to 6 months

Babies do not understand death but they can feel a sense of abandonment, demonstrated by anxious behaviour, inconsolable crying or disrupted feeding. This is particularly difficult if the baby's primary caregiver has died.

6 months to 2 years

Babies at this stage can now picture the primary caregiver internally even when they are not present so, if they die, the baby is aware of their absence and may become withdrawn and lose interest in playing or interacting. Young toddlers may also try to seek out the person.

2 years to 5 years old

Young children cannot understand abstract concepts and therefore struggle to understand that death is permanent and may expect the person to return. They may see death as a kind of sleep and worry about practical issues such as how the dead person will eat.

Children of primary school age

As a child moves through primary school, their understanding of death matures and they begin to realise that death is irreversible and inevitable (usually around age 7). Children may be anxious about their own death or death of a loved one. Children may imagine that their thoughts or actions caused the death. They may revert to acting like a younger child and struggle emotionally.

Children of secondary school age

Adolescents are already experiencing a period of change and struggles relating to puberty such as creating their own identity away from their parents/carers. Experiencing bereavement can compound these difficulties. Adolescents may inhibit their grief and become withdrawn and apathetic. They may take part in risk-taking behaviours to cope with feelings of anxiety and awareness of their own mortality.

Traumatic death

Death by suicide can result in emotions such as guilt, shame or self-blame. Families must cope with the aftermath of such a traumatic event whilst being under public scrutiny. Some people feel isolated by the stigma attached to suicide and struggle to talk about their feelings.

Encourage families to be open about the cause of death with children or young people, as hiding the truth can result in lack of trust and problems later on. Simple language such as 'daddy felt so sad that he made himself die' could be used. Children/young people are likely to worry that it was their fault or that others will take their own lives so support and reassurance is vital.

More information available here:

<https://www.childbereavementuk.org/explaining-to-a-child-that-someone-has-died-by-suicide>
<https://www.childbereavementuk.org/supporting-your-child-when-someone-has-died-by-suicide>

Death by violence is also extremely traumatic and can result in fear, anger, vengeance, blame, guilt and confusion. For children/young people there can be the realisation that the world is not a safe place leading to concerns about their own and others' safety. Families also have to deal with the police and media which can be extremely intrusive.

When talking about the death it is important to be honest but avoid emotive language such as 'stabbed' or 'murdered' as simpler words such as killed have less focus on the violent circumstances. If a child/young person witnesses the crime they are more likely to need professional support in the immediate aftermath and can be at risk of developing post-traumatic stress disorder.

Children with Special Educational Needs or Disabilities (SEND)

Grief is a normal emotional response to loss, including death and applies to all of us regardless of our abilities or disabilities, including SEND. Although grief is a universal emotion the experience of grief is individual and unique. It's important to note that

the experience of death and the subsequent grief can occur regardless of an individual's ability to understand a death.

There are differences in types of SEND needs, however there are characteristics to bear in mind when thinking of supporting people with SEND who have experienced a loss. A young person with SEND may understand the concept of death at a later stage than other children. Children do not need to have a full understanding of the concept of death to feel the loss and grieve; they will certainly be aware of that person's absence and of the changes in their own life that may result.

Children and young people with SEND may have additional needs in relation to communication which may make it difficult for them to communicate their feelings. Therefore, it is important to be sensitive to changes in their behaviour, as an indicator of grief. The life experiences of children and young people with SEND may make it difficult to deal effectively with their loss and grief. They may be shielded from the harsh realities of death to protect them but they are also then denied the opportunity to learn about life and death.

All children and young people, regardless of their circumstances, have a right to have their grief recognised, to hear the truth and to be given opportunities to express their feelings and emotions.

Section 3: Leeds Bereavement Pathway for Children and Young People

The Leeds Pathway was developed in line with the model set out in the National Bereavement Alliance document 'A Guide to Commissioning Bereavement Services in England' (Penny and Relf, 2017). This builds on the Three Component Model (NICE, 2004)

It states that grief is a normal reaction to bereavement and many people find that their inner resources, combined with support from family and friends, are sufficient to help them manage their distress and the life changes triggered by loss. However, some people experience traumatic stress reactions and need more targeted, or specialist, support.

There are 3 levels of need:

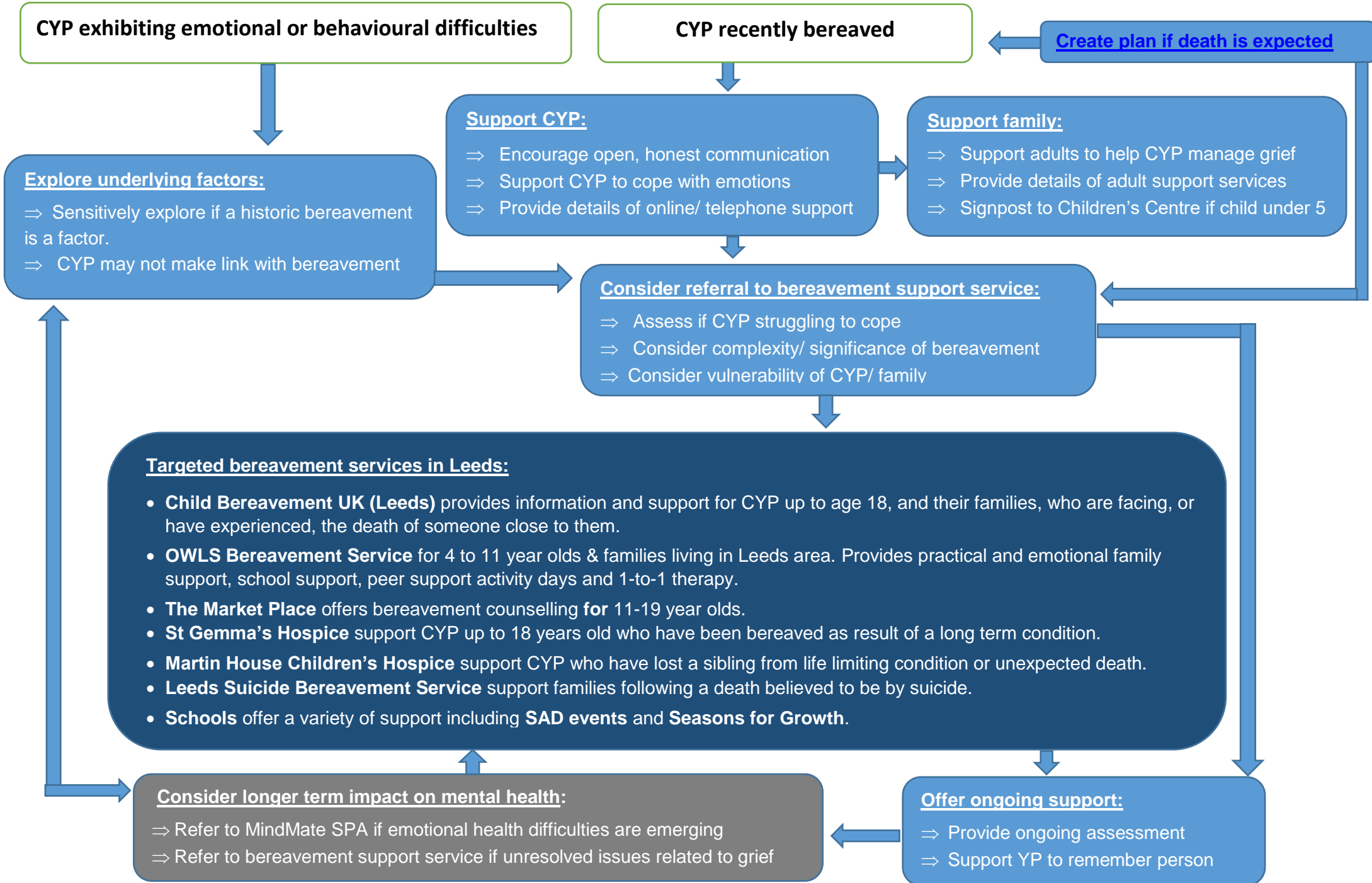
- 1. Universal** - Family friends and existing networks will continue to provide much of component 1 support, with information being supplied by health and social care professionals providing day-to-day care to families
- 2. Selective or targeted** - Some bereaved people who are seeking support at risk of developing complex needs may access social support (peer support groups, befriending etc or support from trained bereavement workers)
- 3. Indicated** - A minority of bereaved people with complex needs or prolonged/complicated grief and a high level of need may need support from specialist bereavement counsellors/practitioners. Others may require specialist mental health support with mental health problems which pre-date or are triggered by their bereavement.

The diagram overleaf sets out pathway and shows the different components of the model in different coloured boxes.

The following chapter gives detailed information about each section of the pathway. Each box in the pathway has a hyperlink to the relevant supporting section.

Leeds Bereavement Pathway for Children and Young People (CYP) version 3 2019

Universal = light blue
 Targeted = dark blue
 Indicated = grey



There are two entry points to the pathway;

Firstly when a child/ young person is bereaved and professionals are aware of this, the pathway sets out how to support them.

Secondly a child/ young person who has *not* recently experienced a bereavement, but may be struggling with their emotions or behaviour; in this case the pathway explores how a historic bereavement may be underlying this.

Create an individual plan if a death is expected

For those where the death is expected, such as after a period of illness, preparative work can be helpful. In these situations the child/young person may be accessing support from an organisation supporting the person who is dying (such as a hospice) so find out what (if any) support they are getting to ensure work is linked up. Improved communication between health and education sectors can support the child/young person throughout this time.

The Public Health Resource Centre stock a booklet called 'Preparing a child for loss', produced by Winston's Wish and MacMillan Cancer Support. It is for parents or guardians who are near the end of life to help them prepare and talk to a child or children about their death.

Support child/young person following bereavement:

Grief is a normal reaction to bereavement that is difficult, but should not be pathologised (i.e. treated as psychologically abnormal and indicating a mental health problem). An assumption that all bereavement results in mental health difficulties can lead to a fear of working with the child/young person and an instinct to refer immediately for specialist support.

Universal settings, such as schools, Children's Centres or voluntary sector agencies are well placed to support the child/young person following the death as they should already have a trusted relationship.

Children and young people who are part of the **Childhood Bereavement Network** have said that the following things can help:

- having the death acknowledged
- being given age-appropriate information about what has happened and what is going to happen
- having the chance to express their feelings and thoughts about the death
- being helped to remember
- taking part in opportunities to say goodbye and commemorate the person who has died
- knowing they are not to blame for what has happened
- meeting other children and young people who have been bereaved.

Encourage open and honest communication and avoid euphemisms:

Children learn how to talk about and react to death from adults. It can feel uncomfortable and be hard to know what to say, but talking openly and raising the subject can reassure them that it is ok for them to talk about it.

Use honest words such as death and dying but also recognise the terminology that the child uses for death. Phrases such as 'gone to sleep' or 'passed away' or words such as 'lost' may feel kinder but are misleading and will lead to confusion and complication, especially for younger children. If death has been referred to as 'falling asleep' it is logical for children to become fearful of sleeping or of going to bed or if it is referred to as 'losing someone', this implies that something is lost and could be found again.

When children ask difficult questions, there is no automatic need to give a long explanation. It is often best to start by asking: 'What do you think?', and then build on their answer. Give concrete information, for example, if they ask about the body it can be helpful to explain that when someone dies their body is like an empty shell they used to live in. If they ask about what happens when someone dies, then acknowledge that people have different beliefs and discuss what their family belief is.

Support child/young person to cope with emotions:

The child/young person may feel overwhelmed by emotions but reassure them that this feeling is normal and will pass. Sometimes the child/young person feels pressure to respond in a certain way so it is helpful to reassure them that everyone reacts differently and it is ok to cry or not to cry.

Suggest alternative ways for child/young person to express emotion such as via sport, punching cushions, drawing or keeping a journal. A normal routine can help children and young people to feel more secure and provide a sense of normality.

Encourage the bereaved child/young person to be themselves without feeling guilty (being with friends, time to play in a safe space outside of the home environment). Some children may feel that the death was their fault (for example, if they misbehaved) so reassure them that something else caused the death and it's not their fault.

Encourage child/young person to access support online or by phone:

MindMate is a Leeds website developed by the NHS. It has a page entitled 'Has someone close to you died?' within the 'Common Issues' section that you can suggest young people look at:

<https://www.mindmate.org.uk/im-a-young-person/coping-common-issues/has-someone-close-to-you-died/>

Child Bereavement UK run a national helpline - Helpline 0800 02 888 40 (Monday - Friday, 9am - 5pm)

Supporting Children with SEND:

The main difference between supporting children/ young people with SEND and those without is the ability to verbalise their feelings and emotions surrounding the bereavement. Children/ young people with SEND may exhibit more stark behavioural changes than those without, due to a possible inability to verbalise their feelings. Being aware of changes in their behaviour is important, as this would be the primary medium of expressing grief. It is vital that support is tailored to their level of functioning and allow them to process their grief with assistance when required, without minimising their grief due to ideas surrounding diminished mental capacity.

How individuals grieve is unique and the support they need for those around them will be need to be personalised however, here are some general guidelines for supporting children with SEND:

- Keeping to normal daily routines as much as possible, as many children/ young people with learning difficulties find any change difficult to manage.
- Using clear, concrete language, avoiding euphemisms and abstract ideas.
- Explain any predicted changes in routine in advance, giving details about who will be doing what and when.

The charity Child Bereavement UK (CBUK) has useful guidance including:

Guidance on supporting children with additional needs -

www.childbereavementuk.org/Handlers/Download.ashx?IDMF=7ea38390-75f9-4fb1-8917-2bd8fc5f3b2b

Guidance on supporting children with Autism Spectrum Disorder (ASD) -

www.childbereavementuk.org/Handlers/Download.ashx?IDMF=3b9e7799-f7f6-451b-b931-faca4ce76336

Support the family

Encourage adults to be honest to help children/ young people manage grief:

The response of those around them, particularly within their family, is important in helping the child/young person through the grief. If the family is not coping well with the loss then this means that the child/young person may also struggle. Reassure the parents/carers that it is ok for child/young person to see them cry as it gives the them permission to show their feelings. Siblings may react very differently to death and need different support

Families who have been bereaved usually want people to talk about the person who has died. It is ok to tell them you are sorry and even that you don't know what to say. You can't make it better for them and they would rather you said something than nothing.

Familial support when grieving for children/ young people with additional needs/ Learning Disabilities is especially important. The child/ young person can see who those around them deal with loss and can adapt by modelling their behaviour on those around them. This helps them to understand that emotional expressions of grief and loss are okay and perfectly normal.

Provide details of adult support services:

Professionals should consider how they can support the whole family. Ask the parents/carers what support they are getting and what their needs are. Often families require practical help as well as emotional in order to navigate the processes following a death in the family.

Some of the targeted Bereavement support services, including the Child Bereavement UK Leeds service and OWLS Bereavement Service, offer support to the family as a whole including offering practical support and help to liaise with schools etc.

If the adults also require support with their own grief there are a variety of local services – see Appendix 1 or there is an online directory on the Leeds Bereavement Forum website

<http://lbforum.org.uk/services/>.

Signpost to local Children’s Centre if family has child under 5 years old

When a younger child is bereaved the most beneficial thing is to ensure that parents/carers are receiving the support and encouragement to manage their own grief and support their child.

All practitioners can refer children under 5 to **Early Start Teams** by contacting the local Health Visitor Team or Children’s Centre. Children’s Centres are able to help families to support a bereaved child. This support is available at any stage of the bereavement process. Children’s Centres (as part of Early Start Teams with Health Visitors) have a key role in supporting all families who have children under 5 (not just those who have a child attending the Children’s Centre).

Second pathway entry point: Child/ young person is exhibiting emotional and behavioural difficulties

Explore underlying factors:

If a child/ young person is exhibiting emotional or behavioural difficulties, professionals may not immediately link this with a previous bereavement, but this should always be considered.

Historic bereavement refers to a loss that may have occurred several years ago. However, grief reactions in the child/ young person may be delayed or continue to affect them long after their loved one has died. The effects of a historic bereavement, especially a highly significant and or traumatic loss can persist for years and have severely detrimental effects on the child/ young person in some cases. This may happen when they received little to no support in the past whilst dealing with the death of a loved one.

Unexpected or traumatic deaths might be further complicated by the existence of conditions such as undiagnosed Post Traumatic Stress Disorder (PTSD). These effects can be seen in displays of concerning behaviour and difficulties with mood regulation. This could possibly include displays of emotion such as intense anger, withdrawal from activities, school refusal and misbehaviour at school or college. Adolescents may use drugs, alcohol and risky sexual behaviour to cope with feelings of loss surrounding a historic bereavement.

Intense feelings of grief may persist for longer periods of time for some people, especially if they are in what is considered to be a vulnerable group, including

someone with a history of mental health problems. Bereavement may worsen the symptoms of these conditions.

Sensitively explore if a historic bereavement is a factor:

If you observe or are informed that a child/young person is exhibiting difficulty managing their emotions, and is exhibiting concerning behaviour, explore as to whether a historic bereavement may be a factor. This can be done by having an open conversation with the child/ young person and their family, or by reviewing any information regarding their history that may be available.

Grief may endure for many years for some people, be delayed, or resume intensely due to other triggering life events, especially further deaths. Just because a bereavement happened many years ago, it doesn't make it any less painful, especially if they received little or no support at the time.

Child/ young person may not make link with bereavement:

Child/ young person may not realise or feel that a historic bereavement is a contributing factor to their emotional and behavioural difficulties, so exploring as to whether this is a factor should be done delicately and compassionately, taking any specific vulnerabilities into account. If a historic bereavement is identified as a factor, then appropriate support can be put in place for that child/ young person as per the pathway.

Consider referral to bereavement support service

Assess if child/young person is struggling to cope:

With support from family and the settings around them, most children/young people will be able to cope with their grief, especially if they are encouraged to talk about how they feel and about the person who has died.

There is no clear criteria to identify if a child/young person would benefit from accessing a targeted bereavement service, however if they are struggling to cope as a family in the weeks following a bereavement, or the grief seems to be enduring for a longer period and is having a lasting impact, discuss with the family about accessing a further support.

Consider complexity/ significance of bereavement:

An unexpected sudden loss of a parent or another significant person within a child or

young person's life, is undoubtedly going to have a huge impact on the child, so additional support from a targeted bereavement service is likely to be beneficial. . Children/young people who experience a parent dying from suicide have an increased risk of depression¹. Leeds has a specific service to support families following a death believed to be by suicide.

Consider vulnerability of child/young person:

Be aware that not all children/young people have strong family units offering support, or there may be existing mental health problems within the family or other complexities that impact on the child/young person's vulnerability and capacity to manage their grief. Furthermore, some children/ young people experience multiple loss/ bereavement which again increases their vulnerability and level of support required.

The following section has information about how to refer to the targeted bereavement services, set out firstly as a table with detail about each service, then a printable diagram that shows which services are available by age.

¹ Pitman et al, (2014) Effects of suicide bereavement on mental health and suicide risk. The Lancet Psychiatry, 1 (1) 86-94

Details of targeted bereavement services in Leeds:

Service:	Child Bereavement UK (Leeds)
Age range:	Children and families up to and including age 18
Bereavement type:	<ul style="list-style-type: none"> • Loss of a close family member. • All bereavement categories including sudden unexpected death.
Timing	<ul style="list-style-type: none"> • No time limit in terms of when the death happened. • Also offers pre-bereavement support.
Services offered:	<p>Face-to-face support: For children and young people up to the age of 18 and their families. We can provide support at schools, children’s centres, community hubs, or at our centre on Tunstall Road.</p> <p>Groups for families: Facilitated groups for bereaved families providing an opportunity for children and their adult carers to meet others and explore their feelings through creative activities.</p> <p>Groups for young people: Facilitated groups where 11-18-year-olds work together to advise us on developing resources to help others.</p>
How to contact:	<p>Enquiries are welcome directly from families. We also welcome referrals from other agencies if a family has agreed to have their contact details passed on to us. Please get in touch to find out more about what we offer.</p> <p>Tel: 0113 350 3598 Email: leedssupport@childbereavementuk.org Website: https://www.childbereavementuk.org/leeds</p>

Service:	OWLS Bereavement Service
Age range:	Children aged 4 to 11 and their families.
Bereavement type:	<ul style="list-style-type: none"> • Loss of a loved one. • All bereavement categories including sudden, traumatic or unexpected death. • No time limit in terms of when the death happened.
Timing	No time limit in terms of when the death happened.
Services offered:	<p>OWLS (Overcoming Worry, Loss and Sadness) is a free bereavement service for families living in the Leeds area, funded by donations to the Jane Tomlinson Appeal. We are committed to taking a holistic approach and will involve the whole family, including older children, if there are any.</p> <p>Family support: We provide psychoeducation on how children experience grief, access to OWLS Lending Library and digital resources, emotional assistance and signposting for adults supporting a bereaved child.</p> <p>Peer support activity days: OWLS peer support days are designed for children who have been bereaved to meet other children with a similar experience. As well as containing a therapeutic element, the events help children understand that they are not alone and enjoy a range of activities. Siblings older or younger than 4 to 11 are also encouraged to attend; parents and carers of bereaved children have the opportunity to meet and experience informal peer support at our activity days.</p> <p>1-to-1 bereavement therapy: Direct therapy in the form of Dramatherapy is provided to children most affected by grief. Dramatherapy is a branch of psychotherapy which uses creative expressive mediums to communicate and explore feelings.</p>
How to contact:	OWLS welcome referrals from families or professionals living or working in the Leeds area. If you are concerned about a child, or would like some advice, please get in touch. Tel: 0113 433 3737. Email: owls@janetomlinsonappeal.com Website: https://www.janetomlinsonappeal.com/owls

Service:	The Market Place Bereavement Counselling
Age range:	Young people aged 11-19 can self-refer to The Market Place bereavement counselling.
Bereavement type:	Any bereavement type.
Timing	No time limit in terms of when the death happened.
Services offered:	<p>The Market Place offers 6 sessions with a counsellor, who is trained and experienced in supporting young people who have experienced a bereavement or death of any kind.</p> <p>Young people can use their sessions to talk about what has happened, their feelings and how this is affecting them, and/or do activities with the counsellor. These include things like memory jars, memory boxes, memory books and using drawing and painting to share your feelings.</p>
How to contact:	<p>Contact 0113 2461659 to make a Bereavement Intro Session appointment. This is a one off appointment to come and find out more (11 or 12 year olds will need consent from an adult).</p> <p>Website: https://www.themarketplaceleeds.org.uk/services/counselling/</p>

Service:	Martin House Bereavement Support
Age range:	Open to all – children and young people can access support alongside parents/family members.
Bereavement type:	Death of a child or young person under the age of 25, including sudden or unexpected circumstances as well as life limiting conditions. Does not include still birth or miscarriage.
Timing	Referrals can be made up to two years after a child or young adult's death.
Services offered:	<p>Following the death of a brother or sister, children often express their grief differently from their parents and other adults. They do not always have the words to communicate the complex range of their feelings and tend to dip in and out of their grief. Experience has shown us that it can be helpful for them to have the opportunity to be in the safe and supportive environment of a group with other children whose brother or sister has also died.</p> <p>Our carefully planned and therapeutic activities, which also include family workshops and a residential weekend, give children the opportunity to explore and understand their grief, thoughts and feelings in relation to their brother or sister and their parents. Through fun games and activities, the death of their brother or sister is acknowledged.</p>
How to contact:	Tel - 01937 845045 or email communitybereavement@martinhouse.org.uk
Website:	https://www.martinhouse.org.uk/Our-Services/Information-for-families/Bereavement-Support

Service:	St Gemma's bereavement support
Age range:	Any age
Bereavement type:	Children bereaved following the death due to long term condition. Not just for those who have used the hospice.
Timing	Offers pre-bereavement work and no time limit regarding support after a death.
Service offered:	<p>Our Young People's Service has bereavement support workers who are trained and highly-experienced in working with bereaved children and young people.</p> <p>Support can be offered on an individual basis or by meeting together in a group for memory days or fun events. They can also signpost to other agencies, provide leaflets, advice and information</p> <p>The St Gemma's Young People's Service arranges all kinds of fun activities for children of all ages, to help them cope with their feelings and worries.</p> <ul style="list-style-type: none"> • We meet with children, young people and their families. • We sometimes do activities such as artwork or an activity book. We also talk about the person who is ill or has died. • We are used to talking about difficult things and don't mind if you get upset. • Sometimes groups of children and young people meet together to talk about how things are
How to contact:	You can refer yourself by ringing 0113 218 5500 or e-mailing familysupportteam@st-gemma.co.uk . Evening meetings can be arranged by prior appointment.
Website:	https://www.st-gemma.co.uk/young-peoples-service

Service:	Leeds Suicide Bereavement Service
Age range:	Any age – supported as part of the family.
Bereavement type:	You can use the service if you believe someone you care about has ended their own life, even if this has not been officially recognised or you haven't had an inquest.
Timing	No time limit in terms of when the death took place.
Services offered:	We provide 1:1, peer groups, family support and counselling. We know it can be difficult for family members to find ways to support each other after a suicide and that individuals can sometimes grieve very differently. Family support is flexible and we work in a number of ways with a mixture of family members. Our definition of family is not restricted to blood relatives and can include people you see as part of key support systems in your life. We also support young children through working with the family and have a range of playful and creative ways to talk about death and loss.
How to contact:	Referral form - https://www.leedssbs.org.uk/ 0113 3055803 info@leedssbs.org.uk Website: https://www.leedssbs.org.uk/our-support/family-support/

Service:	SAD Events
Age range:	4 to 19 year olds
Bereavement type:	Any bereavement type.
Timing	Not offered immediately following death. Offered 4-6 months after the death. . It can be requested 4-6 months following a bereavement where the child/young person, or their school and family, identify they may need additional support
Services offered:	Sad Events is a brief, three session, solution focused intervention for children and young people who have been bereaved. The sessions occur in the child/young person's school and the parent/carer and schools views are sought at the beginning and end. Sad Events practitioners include; Educational Psychologists, Targeted Services Staff and other educational professionals with experience of working with young people who have SEMH (social, emotional and mental health) needs.
How to contact:	Requests for the Sad Events intervention are made by the child/young person's school/setting who can contact the team on sadevents@leeds.gov.uk or 113 378 5163.

Service:	Seasons for Growth
Age range:	aged 6-18
Bereavement type:	Includes loss and change in a wider sense.
Services offered:	<i>Seasons for Growth</i> is an accredited bereavement and loss support programme for young people ages between 6-18 years old. It is a group based peer educational programme which runs over about 8 weeks. The programme is run in school with a small group of children/young people who are of a similar age and are experiences difficulties following a loss or a bereavement.
How to contact:	Some clusters have professionals trained to facilitate Seasons for Growth programmes. Speak to school to find out if available.

Targeted bereavement support for children/young people (CYP) in Leeds

Age of child:



Child Bereavement UK (Leeds) offer support for CYP who have lost a close family member. Tel: 0113 350 3598

Face-to-face support: For children and young people **up to the age of 18 and their families**.

Groups for families: Facilitated groups for bereaved families providing an opportunity for children and their adult carers to meet others and explore their feelings through creative activities.

OWLS Bereavement Service for 4 to 11 year olds & families. Tel: 0113 4333737. Provides family support, peer support activity days (designed to meet other children with a similar experience) and one-to-one Dramatherapy for children most affected by grief.

Groups for young people: Facilitated groups where **11-18-year-olds** work together to advise us on developing resources to help others.

The Market Place bereavement counselling for 11–19 year olds. Tel: 0113 246 1659. Up to 6 sessions with a counsellor who is trained and experienced in supporting young people who have experienced a bereavement or death of any kind. Includes activities such as creating memory boxes.

St Gemma's Hospice support **CYP up to 18 years old** who have been bereaved as result of a long term condition. Tel: 0113 218 5500. Offers individual or group support, such as memory days or fun events.

Martin House Children's Hospice support **CYP** who have lost a sibling (under 25 years old) from life limiting condition or unexpected death. Tel: 01937 845045. Offers therapeutic activities including family workshops and residential weekends. Referrals can be made up to two years after a child or young adult's death.

Leeds Suicide Bereavement Service support **families** following a death believed to be by suicide. Tel: 0113 3055803. Family support is flexible using a range of playful and creative ways to talk about death.

SAD Events is a 3 session solution focused intervention for **CYP aged 4-16** within some school settings. Available from 4 - 6 months after the death. Referral via pastoral staff to Cluster.

Seasons for Growth is an 8 week group programme focussing on loss & bereavement, available in some schools for **CYP aged 6 - 18**. Referral via pastoral staff to Cluster.

Children's Centres are able to help families to support a bereaved child **under 5 years old**. Contact Health Visitor or Children's Centre.

Age of child:



9. Offer ongoing support

Provide ongoing assessment

Universal services have an ongoing role to offer support, either if they child/young person is not accessing targeted bereavement support, or after this has finished. Regular contact offers a chance to assess how the child/ young person is coping on an ongoing basis, as it may take months or years for the child/young person to reach the stage of acceptance in which they feel able to enjoy their usual activities and not be overwhelmed by distressing emotions.

Traumatic deaths, such as murder, manslaughter, suicide or substance misuse, often result in police investigations, a post mortem, trials and court attendance. The processes surrounding these types of death can be complex and lengthy and may cause the child/young person to re-visit the circumstances and their grief time and time again, thus prolonging the grieving process.

Support child/ young person to remember person who has died

Many children/young people worry that they will forget the person who has died. The information sheet (from the charity Winston's Wish) suggests activities to do with the child, such as creating a memory box. This could include cards from the person, photographs, perfume or aftershave, jewellery or any other item that reminds the child/ young person of the person who has died.

<http://www.winstonswish.org.uk/wp-content/uploads/2013/10/Activities-to-do-with-a-child-that-has-been-bereaved.pdf>

The Public Health Resource Centre (details Appendix 2) stock some interactive resources from Winston's Wish that provide more detailed information about activities to help the child/young person remember the person.

As children/young people move through the different developmental stages they may re-experience grief as they understand that the person will never be returning. Be aware of potentially difficult dates relating to person who died (for example birthdays, inquest dates), and challenging transition times for the child/young person. Be aware of activities that may be upsetting such as making a 'Mother's Day' or 'Father's Day' card. Talk to the child/young person rather than automatically excluding them to find out what they would like to do. Ideas at www.winstonswish.org.uk/remembering-special-occasions/

10. Consider longer term impact on mental health

Refer to bereavement support service if unresolved issues related to grief:

Over time and with support from family and wider networks, many children/young people deal with their grief and are able to function well. However, if there are additional complexities or if the child/young person did not get support at the time, they may benefit from a referral to a targeted bereavement support service, even if time has passed (most services are available at any stage but check the criteria of each service as a few have restrictions about when someone can be referred)

Refer to MindMate SPA if emotional health difficulties are emerging:

If the child/ young person is displaying difficulties with their Social, Emotional or mental health alongside or triggered by their bereavement, it is possible to refer to the MindMate Single Point of Access. This is for all children/young people up to age of 18 who have a Leeds GP. The MindMate SPA provides access to the full range of services available in Leeds, dependant on the needs of the child/young person. SPA Contact details: **0113 376 0324** (9am – 5pm)

This would be appropriate if you feel that there are more complex issues and that a direct referral to a specific bereavement support service may not be the most appropriate option.

Historic Bereavements and Prolonged Grief Disorder (PGD):

Some children/ young people may experience what is known as Prolonged Grief Disorder (PGD) or Pathological Grief Reaction. This is an intense preoccupation with the loss, which may severely impact the social, mental and emotional functioning of the child/ young person.² Furthermore, PGD may coexist with clinical depression.³ The intense grief reaction must occur for at least 6 months after a bereavement but may also persist for years. Therefore, in a small minority of cases ⁴ a child/ young person may be suffering from PGD, as a result of a historic bereavement. If a professional suspects this is the case, then they should refer child/ young person for assessment via the MindMate SPA. Although, this will usually only occur in a very

² Melhem, Nadine M., et al. "Identifying prolonged grief reactions in children: dimensional and diagnostic approaches." *Journal of the American Academy of Child & Adolescent Psychiatry* 52.6 (2013): 599-607.

³ PGD is now defined as "PGD is characterized by core symptoms such as longing for and preoccupation with the deceased, along with emotional distress and significant functional impairment that persist beyond half a year after the loss of a significant other". Please see Killikelly C, Maercker A. Prolonged grief disorder for ICD-11: the primacy of clinical utility and international applicability. *Eur J Psychotraumatol.* 2018;8(Suppl 6):1476441. Published 2018 Jun 6.
doi:10.1080/20008198.2018.1476441

⁴ Ibid n8

small minority of cases. Also, PGD is a new condition listed in the ICD 11, so some professionals may not be aware of its existence yet.⁵

Signs and symptoms of PGD:

Prolonged grief disorder

- following the death of a partner, parent, child, or other person close to the bereaved,
- a persistent and pervasive grief response characterized by
 - **longing for the deceased**
 - **persistent preoccupation with the deceased**
 - **accompanied by intense emotional pain**, e.g. sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one's self, an ability to experience positive mood etc.
- the grief response has persisted for an atypically long period of time following the loss (**more than 6 months at a minimum**) **and**
- **clearly exceeds expected social, cultural or religious norms** for the individual's culture and context (...)
- Significant impairment in personal, family, occupational and other important areas of functioning



⁵ Ibid n9

Section 4:

Implementing the pathway at service level

This section gives suggestions about how services within Leeds can improve their practice around supporting bereaved children/ young people.

Normalise conversations about loss and death – Practitioners can support children / young people to build an age appropriate understanding of loss, separation and death by including it as a topic within everyday conversations. This helps to create a culture where death is not seen as a taboo topic. Sharing books about death and loss as part of normal story telling is important even when there hasn't been a death so that the child learns to talk about the range of feelings we all experience.

Promote children/young people's emotional literacy - Universal settings have a role in promoting emotional literacy so that children/young people are able to recognise, express and manage their feelings. This should build resilience for children/young people to draw on when they do experience bereavement or other losses. This sort of intervention can be from general discussions about loss and change or in more formal curriculum interventions focussing on building emotional literacy.

Review service capacity to support bereaved children - Use this pathway to review if your service is able to deliver appropriate support and is aware of how and where to refer. Consider running a themed team meeting or training session to raise awareness of the pathway. Approach the targeted bereavement support services will be able to

Review if a bereavement policy for your specific service is required. The pathway can be adapted to be service specific.

Keep up to date:

- Leeds Bereavement Forum produce an e-newsletter providing information of any local events or training sessions – <http://lbforum.org.uk/contact-us/>
- The Childhood Bereavement Network also produce a newsletter <http://www.childhoodbereavementnetwork.org.uk/>

Access training for staff:

MindEd - Loss and Grief – free 25 minute e-learning. This session addresses parental loss, grief in children and how to work with grieving children. It also covers loss of others by death or separation/divorce and the range of bereavement or mourning reactions - www.minded.org.uk/course/view.php?id=90

The **NHS Scotland animation** about how to talk to bereaved children is a useful tool to use in team meetings or to promote to staff - www.sad.scot.nhs.uk/video-wall/

Leeds Bereavement Forum | Basic Bereavement Skills for those working with Children, This half day training course is aimed at those working with bereaved children. The session introduces some of the basic theories about the grieving process and develops skills and awareness in a small group through exercises and discussion. Prices for start at £350 (for voluntary organisations). Courses can be adapted for specific groups of people as necessary to ensure that our training is as relevant to your organisation as possible - <http://lbforum.org.uk/training/>

Resources and support specifically for schools

Access crisis support following significant bereavement

Schools can contact the crisis line to gain support from a Senior Educational Psychologist following a bereavement in the school community. Tel: **0113 378 3645**. This is usually if a child attending the school or staff member has died, or there has been an incident that has a significant impact on the school, such as a traumatic death like a suicide or murder. Schools are offered support including advice about communications that go out to press and parents and support to liaise with other professionals working with the family.

Find out more about bereavement within your school

Carry out the 'My Health My School' survey which includes questions related to bereavement – this will allow you to find out pupil need. To register or to login if your school has already registered, visit www.myhealthmyschoolsurvey.org.uk. If you have any questions contact schoolwellbeing@leeds.gov.uk

Develop a bereavement policy

Schools have access to a prototypical bereavement policy that can be adapted to meet the needs of each school. This can also be accessed by schools with a service level agreement with the Health and Wellbeing Service, and is also provided as part of bereavement training for schools provided by the service.

Access training and support including the following:

The Health and Wellbeing Service offer grief and bereavement training to all school staff, in partnership with school Educational Psychologist team. This aims to

support staff in supporting pupils and families who have been bereaved. More information can be found at www.schoolwellbeing.co.uk.

Educational Psychology. Schools can offer a range of support through their PHSE curriculum. One intervention that schools can offer is Seasons for Growth (see Targeted Section). Training for facilitators to run the programme is usually offered yearly in the city. School staff who wish to access this training can book through Leeds for Learning. <http://www.leedsforlearning.co.uk> or contact **0113 3951039**

Child Bereavement UK - A free online training resource for schools. This comprehensive, free-to-access resource 'Supporting a bereaved pupil' has been developed by Child Bereavement UK in collaboration with the London Grid for Learning - <https://www.childbereavementuk.org/online-learning-for-schools>

Child Bereavement UK offers support and training to school staff supporting bereaved students.

OWLS School Support can present assemblies and workshops to children in Primary Schools, which provide a gentle introduction to the transition of life to death and give children the opportunity to reflect on grief and ask questions in a safe space. We can also deliver bespoke training to school staff, including grief psychoeducation, and offer practical strategies to support bereaved children in school. School support request forms are available to download from the website. Alternatively, contact OWLS Bereavement Service Co-ordinator on 0113 433 3737 or at owls@janetomlinsonappeal.com

Step by Step A Samaritans service that provides advice and practical guidance to help schools prepare for the repercussions of suicide or attempted suicide. The service is offered by specialist volunteers, called Postvention Advisors, who offer practical support, guidance and information on addressing the impact of suicide on the school community.

Email: stepbystep@samaritans.org Tel: **0808 168 2528**

Resources for professionals

The Public Health Resource Centre (PHRC) offers support to anyone in Leeds with a responsibility or professional interest in public health or promoting health and wellbeing. They stock a wide range of resources to support professionals who are working with children who have been bereaved, including guides to supporting teenagers with grief, supporting children who have been bereaved by suicide and picture books explaining loss for younger children.

Technorth, 9 Harrogate Road, Chapel Allerton, Leeds, LS7
3NB www.leeds.gov.uk/phrc

Useful websites:

- <http://www.childbereavementuk.org/>
- www.winstonswish.org
- www.childhoodbereavementnetwork.org.uk/
- www.achildofmine.org.uk/ A Child of Mine offers support for bereaved parents after the loss of a baby or child.
- www.cruse.org.uk/ CRUSE offers support, advice and information to children, young people and adults when someone dies.
- www.janetomlinsonappeal.com/owls
- www.samaritans.org/your-community/supporting-schools Samaritans is a mental health charity that supports schools, colleges, communities and other youth settings across the UK through postvention services, lesson plans and school talks.
- www.samaritans.org/your-community/supporting-schools/step-step/step-step-resources Samaritans aims to support a school in supporting grieving children and minimising the risk of further suicides.
- www.supportline.org.uk/problems/bereavement.php A confidential emotional support line for a variety of personal issues, including bereavement
- www.careforthefamily.org.uk/family-life/bereavement-support/bereaved-parent-support This website has an information including information on how to help bereaved parents. Download the free resource sheet "[How you can help bereaved parents](#)", for anyone supporting a bereaved parent, it is based on real-life experiences and contains some practical tips on helpful things you can say and do - and those things best avoided.

Appendix 1:

Support for bereaved adults

For full up to date details, Leeds Bereavement Forum provides a Directory of Bereavement Services in Leeds both online and as a booklet.

The Directory includes several specific search categories including children and young people, traumatic death and death of a child- <http://lbforum.org.uk/services/>

Email info@lbforum.org.uk for a hard copy of the booklet.

Face-to-face support in Leeds:

Cruse Bereavement Care

Cruse Bereavement Care offers support to bereaved people aged 18 and over to help them understand their grief and cope with their losses.

The type of support offered will be dependent on client need following assessment. Support ranges from information, signposting and advice via telephone and email to one to one support, provided by trained bereavement support volunteers. One to one support is provided at the York Place office or on the telephone.

As an inclusive service, Cruse strives to accommodate disabled people. This includes people with learning disabilities and dementia. The type of support offered considers the client's ability and comfort in participating in one to one sessions, based on a 'talking' based support model. Home visits can often be arranged for those unable to attend the York Place office due to disability or other personal reasons.

Call 0113 234 4150 - www.crusebereavementcare.org.uk

Leeds Suicide Bereavement Service | Compassionate support for people bereaved by suicide

Leeds Suicide Bereavement Service supports people who have been bereaved by suicide; whether that be of a close family member, friend, colleague or neighbour and whether you were affected by a suicide that was a few days, weeks or decades ago. We offer a range of support including individual peer support, group peer support, family support and counselling alongside annual events and memorials.

We offer family support and work in a number of ways with a mixture of family members. Our definition of family is not restricted to blood relatives and can include people you see as part of key support systems in your life. We also support young

children through working with the family and have a range of playful and creative ways to talk about death and loss.

Call 0113 305 5803 or email info@leedssbs.org.uk

Martin House Children's Hospice

Offers a community bereavement service for families who have lost a baby or child through a life limiting condition (ranging from babies diagnosed antenatally to young adults up to the age of 25) including those who have not previously accessed Martin House. It is usually for the parents of a baby or child who has died; support for other family members can also be arranged. The aim is to provide an opportunity to talk through feelings and find ways of coping within a supportive and confidential professional relationship. Referrals can usually be made up to 2 years after a baby or child's death, and each one will be considered on an individual basis.

01937 845045

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

Charlie's Angels Centre

Charlies-Angel-Centre Foundation offers many different kinds of support for bereaved parents & families.

We provide free services for anyone affected by the death of a child of any age (ranging from miscarriage to adult children) and for any reason, including stillbirth, termination, accidental, violent or suicidal death and death following acute or chronic illness. We also help families that are facing a prenatal diagnosis of fetal anomaly.

Whatever the cause of your loss, wherever you are in the UK, and whatever your circumstances we are here to help

www.Charlies-Angel-Centre.org.uk

St Gemma's Hospice Bereavement Service

The hospice continues to care for the patients' family and carers after death. Qualified bereavement counsellors and bereavement workers offer one to one sessions on site as well as regular bereavement support groups which incorporates a facilitated peer support approach. Home visits can be accommodated in exceptional circumstances. Referrals can be made by professionals or self-referral: the service is only available to those who are connected to someone cared for by the Hospice.

www.st-gemma.co.uk

0113 218 5500

SANDS (Stillbirth and Neonatal Death), Leeds

Leeds Sands are a group of bereaved parents who provide support for other parents and families who have suffered the death of a baby before, during, or shortly after birth. The support they provide is free of charge and is open to all bereaved parents, their families and friends, no matter how long ago the loss occurred.

www.leeds-sands.org.uk

General enquiries **07518 917 594**

Helpline: **020 7436 5881**

Helplines and Websites

Child Bereavement UK Support and information helpline

Provides confidential support, information and guidance to families and professionals. The professionally trained bereavement support workers are available to take calls 9am - 5pm Monday-Friday.

0800 02 888 40.

Cruse Bereavement Care

Provides support services for people who have been bereaved.

Our Leeds offices are open from Monday – Friday, from 10am -5pm. We offer appointments until 8pm on Wednesday and Thursday evenings for face to face sessions so you can still come to us if you work during the day.

You can call us on 0113 234 4150. Please feel free to leave a message with your name and contact number and someone will call you back as soon as possible.

You can also email us: leeds@cruse.org.uk

Cruse National helpline on 0808 808 1677 if you need to speak to someone urgently about your bereavement.

<https://www.cruse.org.uk/get-help/local-services/yorkshire-and-humber/leeds>

Bereavement Trust Helpline: Support for anyone who has been bereaved.

0800 435 455 6pm-10pm every evening

www.bereavement-trust.org.uk

Winston's Wish

The Winston's Wish Helpline is a UK-wide national helpline offering support, information and guidance to all those caring for a child or young person who has been bereaved. It is staffed by people with extensive experience, who have up-to-date knowledge of supporting bereaved children and their families.

The line is open from Monday to Friday between 9am and 5pm.

www.winstonswish.org.uk/

08452 030405

Websites/Helplines for specific groups:

If a child has died:

Child Death Helpline: - Helpline for anyone affected by the death of a child of any age. Advice, information, listening, befriending, referrals and face to face service by arrangement.

0800 282 986,

www.childdeathhelpline.org.uk

The Compassionate Friends: Helpline and support services run by bereaved parents. Support to parents and their immediate families after the death of a child/children of any age and from any cause.

0345 123 2304

www.tcf.org.uk

Elliot's Footprint:

Elliot's Footprint is a Leeds-based charity that helps families through child bereavement. They offer help and guidance whilst campaigning and fundraising for improved bereavement services.

www.elliotsfootprint.org/

The Lullaby Trust: Offer confidential support to anyone affected by the sudden and unexpected death of a baby or young toddler. This is available immediately or at any later time in your lives. This support is for families, friends, carers and professionals.

0808 802 6868

www.lullabytrust.org.uk

Violent death or suicide:

SAMM (Support After Murder and Manslaughter): Telephone support line for families and friends of homicide victims.

0121 451 1618 / 0845 872 3440

www.samm.org.uk

Survivors of Bereavement by Suicide: National Helpline and other support services run by a self-help group for people bereaved by suicide. Helpline provides listening support and will put people in touch with their nearest local group. Monthly group meetings in various locations. Bereavement pack and literature for survivors. Conferences and support days.

0300 111 5065

www.uk-sobs.org.uk

(Also see local face-to-face suicide bereavement service – details above)

Road traffic accidents:

BrakeCare: Helpline for people bereaved or injured in a road crash, listening ear and information on practical matters, and local counselling and trauma therapy services.

0808 8000 401

www.brake.org.uk

RoadPeace: Helpline providing practical and emotional support for people who have suffered bereavement or injury in a road crash.

0845 450 0355,

www.roadpeace.org

SCARD (Support and Care After Road Death & Injury): To alleviate distress to people who have been bereaved, injured or affected by road death or injury. Set up by a family who lost their 27 year old son in a car accident. Provide emotional and practical support, helpline, support groups, meetings and personal support.

Helpline: 0845 1235542

www.scard.org.uk