

Supporting children when someone they love is seriously ill and has a poor prognosis.



East Cheshire Hospice
Where people come to live

A message from Jane Burton, Counsellor, Children and Family Services.

East Cheshire Hospice is following government and PHE advice relating to the covid-19 pandemic and have taken the necessary action to reduce the spread. This means that out-patient services are currently restricted, with very limited face to face meetings available.

We are all finding and adjusting to new ways of working and we are currently able to offer support to families by telephone and webcam and email.

I have put together this information leaflet to answer some of the most frequently asked questions. There is also a resource list at the end. I offer it as support for you and your loved ones at this difficult time.

Jane (updated August 2020)

Anticipatory Grief

These are the emotions that are experienced before an impending death. They can be really confusing because you are grieving for a loved one who is still alive.

It is not just adults who have these feelings; children do too. Each child will react differently and their developmental level will affect their understanding of the situation. As children grow and mature, so does their understanding of death, dying and loss.

“If you are old enough to love, you are old enough to grieve”

-Alan Wolfelt

Examples of how children may experience anticipatory grief

1. Physical symptoms. eg tummy ache, headache.
2. Clingy behaviour and feeling insecure.
3. Changes in sleep patterns – difficulty in going to sleep, nightmares, sleeping less or more than usual.
4. Changes in behaviour. Eg hitting out, withdrawing.
5. Regressive behaviour – may return to bedwetting, thumb sucking or carrying round a special toy or blanket.
6. Variety of feelings – sadness, anger, fear, guilt, anxiety, confusion.
7. Inability to concentrate.

When someone is seriously ill, there are often many changes that affect both them and those around them. Even if adults choose not to change their words or behaviour, children are very perceptive. They pick up on the emotional state of the adults around them, including the adult's own grief process.

They will notice changes in –

- Daily routines for themselves and their carers. Eg meal times, bed times, hobbies
- Moods
- Usual family routines
- Finances
- Family members roles and responsibilities

Changes are unsettling and ‘not knowing’ what is happening can be part of the reality of serious illness for adults and children alike. Being open about your own feelings helps validate your child’s feelings and helps them understand what they are going through is normal.

The many types of loss

When someone is seriously ill, there can be many feelings of loss



Grieving these losses is real and normal. Notice them and discuss them. Just like adults, children need the opportunity to process their emotional response to loss and express them in healthy ways. Avoiding topics that might make children sad may deprive them of an opportunity to practice these skills that aid in their healing process.

Children are naturally curious

In the absence of the truth, children often make up their own version of events. Children deal with changes by **magical thinking**. This may cause a child to assume responsibility for someone's illness or death by thinking that their thoughts or actions are somehow to blame. It can be a little like superstitions in adults. Eg if I walk under a ladder something bad will happen. This is normal for young children. Eg If I give mummy my teddy, she will get better, or because I shouted and told him to go away, grandad got ill and went to hospital.

Concerns that children often have

- What is happening to my loved one?
- How will this affect my life?
- Who will take care of me?
- Was it my fault?
- Will this happen to me/you/other people in my family?

To help reduce stress and tension for everybody, you can help prepare your child for change in the following ways:-

- ❖ Explain the changes that are happening. If you are able to do this before they happen, that is even better.
- ❖ Be honest. Children need to know who is ill and the name of the illness because they may hear these words being used and it is better that they are not confused. Also explain, to the best of your knowledge, your best understanding of what might happen next.
- ❖ Use language they understand. You know your child best and you can use language appropriate to their level of development.
- ❖ You do not have to give all this information at once. It will depend on the age of your child, their previous experiences and their maturity. Tell them at a pace that suits them.
- ❖ If you or your child feel overwhelmed, take a break. Explain that you have these feelings and you will take a break and talk more later. Then be sure to do this when you feel ready.
- ❖ Avoid language that has other meanings (Euphemisms) as this can cause confusion e.g. granny has gone to sleep, daddy has lost his battle.
- ❖ It's OK not to have an answer for everything. Telling a child that you are not sure of the answer, how you might find out and returning with an answer when you have one is much better than making up an answer.
- ❖ Children may not have the words or social emotional skills to express all of the complicated feelings associated with grieving. Use books, games, stories, songs, drawings and play to help explain things. Children learn and express themselves through play, so allowing them to be active is a helpful way to help them through this process.
- ❖ Be prepared for children to ask the same question repeatedly. This is normal and usually means they are trying to make sense of things.
- ❖ Don't worry if you are upset as you tell them. You are showing your child that it is OK to cry.
- ❖ Equally, if your child seems disinterested, bored or as if nothing has happened, remember that children cope with difficult news in a variety of ways.
- ❖ Involve children in decision-making, however small. It gives them some sense of choice and control. It can be simple things like which game you will play or what they wish to wear that day or bigger decisions eg whether they wish to visit a parent in hospital.
- ❖ Check their understanding. Correct any misunderstandings.
- ❖ Check in to see if your child has any worries about new changes.

“If there ever comes a day when we can't be together, keep me in your heart, I'll stay there forever.”
- Winnie the Pooh



Remember - It's OK that you don't feel prepared to help a child grieve. No one has all the answers or the perfect response to every situation.

It's OK to ask questions yourself or seek support.

We are here to help within the current resources we have available. It is best to send me an email and then I can arrange a suitable time to call.

Resources

Books

For younger children

- Goodbye Mog by Judith Kerr
- Duck, Death and the Tulip by Wolf Erlbruch
- Badgers Parting Gift by Susan Varley
- When Dinosaurs Die – a guide to understanding death by Laurie Krasny Brown and Marc Brown
- Always and Forever by Debi Gliori
- No matter what by Debi Gliori
- Cinnamon Roll Sunday: a child's story of anticipatory grief by Jennifer Allen
- The Invisible String by P Karst
- The heart in the bottle by Oliver Jeffers
- Sad by Micheal Rosen

For older children

- Charlotte's web by E B White
- Grief is a thing with feathers by Max Porter
- Still here with me; teenagers and children on losing a parent by Suzanne Sjoqvist
- The grieving teen by Helen Fitzgerald
- A monster calls by Patrick Ness
- Goodnight Mr Tom by Michelle Magorian
- Dancing at the pity party; a dead mom graphic memoir by Tyler Feder

How to start a conversation with children

- As big as it gets – published by Winston's Wish
- When someone has a very serious illness by Marge Eaton Heegaard

Websites

National services that are also still running to support children either online or by telephone

Kooth <https://www.kooth.com/>

Childline <https://www.childline.org.uk/>

National bereavement support for young people. There are also loads of resources for carers on these websites too.

- Winston's Wish - <https://www.winstonswish.org/>
- Child bereavement UK - <https://www.childbereavementuk.org/>
- The young person's branch of Cruse – <https://www.hopeagain.org.uk/hope-again-about-us>

Young Minds have some great resources online too for dealing with grief and loss and anxiety. They also have a parent's helpline.

<https://youngminds.org.uk/find-help/feelings-and-symptoms/grief-and-loss/>

<https://youngminds.org.uk/find-help/conditions/anxiety/#where-to-get-help>

Widowed and Young <https://www.widowedandyoung.org.uk/>

NSPCC <https://www.nspcc.org.uk/keeping-children-safe/support-for-parents/>

Videos

How to support your child with bereavement

<https://www.youtube.com/watch?v=4u7p5a0lcQo>

How to help bereaved children understand grief

<https://www.youtube.com/watch?v=Y9rqJlbQDpk>