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Supporting Children

**A SUPPORTIVE GUIDE FOR PREPARING A CHILD
OR TEENAGER FOR THE LOSS OF A LOVED ONE**

Introduction



This booklet offers guidance and support to parents, guardians and extended family members who have children who are experiencing the end of life care of a loved one while in hospital. We would like to acknowledge that this is an emotional and upsetting time for both you and your family.

DEATH IS AN INEVITABLE PART OF LIFE AND GRIEF IS A UNIVERSAL HUMAN PROCESS.

Naturally we want to shield children from pain. Giving a child difficult news about a serious illness or death is not easy at a time when you can be overwhelmed by grief yourself. It's normal to be unsure about what to say, and how to find the words your child can understand.

WE CANNOT SHIELD CHILDREN FROM THE REALITY OF DEATH OR THE PAIN OF LOSS, HOWEVER WE CAN HELP THEM TO PREPARE FOR THE LOSS, THUS EQUIPPING THEM TO BE BETTER ABLE TO COPE.

In this booklet we offer simple guidance and give ideas on how to explain this upsetting news to your child, how to involve your child when visiting your family member, when your family member has died and finally what bereavement supports are available.

If at any time you need assistance, please speak to a member of staff. This includes the medical social work team, palliative care team and pastoral care team.

For more information and emotional support you can also contact the Irish Childhood Bereavement Network supported by the Irish Hospice Foundation:

Telephone: 016793188



SHOULD I TELL MY CHILD THAT SOMEONE THEY LOVE HAS A SERIOUS ILLNESS?

Telling a child that someone close to them has a serious illness and is going to die is not easy. But it can help them if you do talk about it. Some adults find it difficult to tell a child or young person that someone close to them is seriously ill. You may still be processing the news yourself. It can be especially hard when you know the person won't get better.

How telling a child might help them

If children are told that someone close to them is seriously ill, it can help them to understand what's happening, and it might make them feel less lonely and worried about the situation.

If children notice that something is wrong, they may start to search for information themselves. This might lead to them getting the wrong information or misinterpreting the situation. For example, they could overhear information from someone else.

IT'S BETTER FOR INFORMATION TO COME FROM SOMEONE THEY KNOW AND TRUST.



Talking openly and honestly about the person's illness may also help the child to speak about the things they are worried about. It can provide opportunities to spend time together as a family, and it gives you and the child the chance to share your feelings. It can also help them to be more prepared for when the person dies.

Telling a child that someone is seriously ill might also help them to feel more in control, as it can give them the chance to be more involved in making decisions. For example, whether they would like to see the person in hospital or not.

ACKNOWLEDGING THE ‘Small Goodbyes’

Some of the changes that result from their loved one’s illness may feel like losses to your child. We call these “small goodbyes.” Small goodbyes may be different for each child depending on their previous relationship and interactions with the loved one who is very ill. Different small goodbyes may occur as your loved one’s illness progresses. Try to acknowledge them as they occur. Grieving the small goodbyes is part of anticipatory grief. Examples of small goodbyes include:

Not being able to do the things they once did with their love one who is ill

Not being able to see them as much

Not having them come to special events like school plays, sporting events, etc.

Changes in how active or involved the person is in a child’s daily routines

Dougy.org



GETTING SUPPORT WITH TELLING THEM

Telling a child or young person that someone is seriously ill can be very emotional. It is important to take some time to think about what you will say. You may be able to get support with telling them from a family member, friend, or a professional like a social worker.

WHAT DO CHILDREN UNDERSTAND ABOUT DEATH AND DYING?

Age Appropriate Information

In this booklet, we refer to using age appropriate words and language when talking to children about death and dying. How much a child or young person is able to understand about the person's illness and death may depend on how old they are, their stage of development and any previous experiences of illness or death they have had. Children may also fluctuate in and out of their grief. Some children may be the same age but will be at different stages of development. It's important to give them information which is appropriate to their age and level of understanding.



0-2 Years

Although infants do not understand death, they know when things have changed, and may react to a person's absence. This may show in clinginess and distress. Support them by maintaining the child's routine and making them feel secure.



2-5 Years

The child does not fully understand death. They don't realise death is permanent and will happen to everyone. They may worry that something they said or did have caused the death, and need to be reassured that it wasn't their fault. Children at this age often ask the same questions over and over again. Support the child by encouraging them to ask questions, and answering them openly and simply.



5-8 Years

Children gradually learn that death is final and that all people will die at some time. This may make them worry that other people close to them will also die. It can help children to talk about these fears. We can't promise children that no-one will ever die, but we can help them to feel safe by telling them that they will always be looked after. More curious children in this age group often ask direct questions about what has happened the body as they are trying to understand. These questions may be difficult for a grieving adult to hear and answer. It may help the grieving adult

to know that these can be developmentally appropriate questions for the child's age. Children may blame themselves in some way for the death and can engage in 'magical thinking'; filling the gaps when information has not been given to them. Support the child by encouraging them to talk about and express their feelings, no matter what those feelings are. Children require an honest explanation of death and require permission to talk and cry if needed. Provide plenty of physical and verbal expressions of love.



8-12 Years

This age group understands that death is irreversible, universal, and has a cause. Grief can express itself through physical aches and pains, changed and challenging behaviours. Encourage the child to talk but realise they may find it easier to confide in teachers, friends or trusted people. Gentle adherence to routines can give helpful stability at such an emotional and sensitive time of change. Discuss any changes to family roles, maintain boundaries and routines.

WHAT DO CHILDREN UNDERSTAND ABOUT DEATH AND DYING?

Age Appropriate Information



Adolescence

Adolescence is a time of great change. Teenagers struggle with issues of identity and independence as they try to bridge the gap between childhood and adulthood. Adolescents need clear and accurate information at the time of a death. Adolescents fully understand the concept of death. They know it is final and inevitable. However, confusion arises as they struggle with the many emotions, thoughts and mood changes that the death creates while trying to remain similar to their peers. They may feel responsible for assuming a parental role in the family. Avoid burdening them with adult responsibilities and include them in discussions concerning role changes in the family

Irish Childhood Bereavement Network

TELLING A CHILD THAT A LOVED ONE WILL DIE



WHO SHOULD BE INVOLVED IN TELLING THE CHILD?

A familiar person to your child (parent or guardian) who cares for your child every day is the best person to communicate this news. If you don't feel comfortable telling the child on your own, it's OK to have someone with you. Recognising your own worries and fears may be an important first step in feeling ready to involve your child.

WHERE AND WHEN SHOULD I TELL THEM?

There is no set way to tell a child or young person that someone they love is going to die. Every family and every situation is different.



Conversations about death are
steps in a journey.



Once you tell a child that their loved one is going to die, you may need to have **ongoing conversations** as the child takes in and processes the information. However children, especially younger children, think more immediately. They think in the present. If the person is expected to live long months or longer, it may be too soon to tell them that their loved one is going to die. It may be more helpful to say that they are very sick and cannot be cured.

FINDING THE WORDS; What to say

Everyone was talking about my Dad being unwell, but nobody explained what the illness was, nobody named it, I came to my own conclusion that it was cancer.

Roisin

- Decide in advance what information you want to give, and in what words: both depend on the age of the child and their ability to understand what is said. Children of different ages will need different levels of information.
- A useful start can be to say you want to talk to them about the person who is very sick.
- Children often notice changes in the appearance of an unwell person and the daily routine. Check what the child already understands about the person's condition, and the conversation can build from there.
- Let them know you will be as honest and include them in what is going on and that you may not know all the answers.
- Be as honest as you can about what is happening to the person.
- It is usually helpful to say the name of the illness. Children need to hear that nothing they say and do can cause the illness.
- Listen to your child. Be kind and reassure your child that they are loved and cared for.
- Use simple, familiar words and communicate clearly without being rushed. Give age appropriate information in gradual amounts and in simple language.

I wanted to remain hopeful, but it's important that they know the truth about what's happening.

David

Honesty is needed. Being honest and explaining the facts to me was so important.

Roisin

- Books or drawings of the body may be helpful to explain a condition.
- Children cannot infer meaning as adults do, and so need concrete language. Vague words confuse children.
- Reassure them that no one is to blame for the illness.
- Allow time for the information to be understood. This will give you a sense of how much they understand.
- If children are not told the truth about what is happening, then they will make up their own version of the story, which can cause misunderstanding and upset. (Additional information may be accessed through www.childhoodbereavement.ie)
- We can involve our social work team, palliative care team. Pastoral care team as appropriate, who can advise and support you.

explain it truthfully no matter how hard it might be for you

Daniel

- Children are frequently exposed to concepts of death and dying in the media, whether it's something they see or hear on the news, or social media. For example, cartoons where a character dies and the next week is magically alive again. Children may know or have heard of a friend whose family member died or was ill. Yet, if no one has openly talked about these topics with them, children often have significant misinformation and misconceptions.
- Validate your child's emotions: Remind your child that it is okay to have any feelings regarding their loved one. Modeling your own emotions and coping strategies can be a great way to normalize anticipatory grief. For example, "Mammy is feeling really sad about ____ dying. I'm going to take a walk; would you like to come?"

Easy access to the internet meant my children looked up information about their grandparent's illness as they didn't want to ask me in case she upset me

Elaine

TO VISIT OR Not to Visit

Children should be encouraged to spend some time with their loved one who is receiving end of life care. This will help them make sense of what is happening and to feel involved.

- It is important to give your child the opportunity to visit, regardless of their age.
- Explain what to expect to the child, what their loved one might look like, if they will be asleep or awake, prepare your child for changes in their loved one's environment, if there will be medical equipment, noises.
- Allow your child to be involved e.g. getting a glass of water.
- Keep the visit short for younger children.
- Encourage photos, blankets and any other familiar items from home to be brought in.
- Make family handprints or memory boxes if you wish (the social work team may be contacted to assist).
- Your child may not want to visit. Validate your child's wishes not to visit. It's okay to not want to visit. Help maintain a close link by encouraging sending cards, photos, to make and send drawings or pictures, phone calls or video calls.
- Inform your child when the loved ones illness is unlikely to improve.
- Allow time to say goodbye, the child can be supported to tell the person they love them, read to them, hold hands or lying in the bed with them



I wasn't prepared for what I would hear, see or smell.

Roisin

SUPPORTING A BEREAVED CHILD with Autism Spectrum Disorder

There is no one size fits all formula, you know your child best

Marcie

- All children are individuals-all children with autism are individuals. Therefore, we cannot provide one scenario of what a bereaved child will 'look like' or one way we should help them when they are grieving. The same applies to a bereaved child with ASD (Autism Spectrum Disorder).
- The information shared will depend on the child or young person's level of understanding and age. It is also important to consider how this information is going to be presented as it may differ to what a child or young person who has autism may need.
- Some children and young people with autism may need an explanation about the cause of death and help to rationalise that they are unlikely to die soon and that other people important to them are unlikely to die soon. Explaining to the child or young person that whilst some people do die when they are young; they may have an accident or have an illness, but this is not common. For some, a visual representation of the facts may be helpful.

Ask me if I want the information and then give me the information in a way I can understand

Conor

Do not have an expected timetable on how your child might respond

Marcie



AFTER DEATH HAS OCCURED

It is important to tell your child when someone important in their lives has died, and ideally, this is done by someone who is closest to them. All bereaved children and young people have the need for information, explanation and reassurance.



- Tell your child as soon as possible, in a place where they can be supported and away from distractions.
- Use clear simple language that they can understand, for example: 'I have something very sad to tell you. Grandad has been very sick for some time, and now he has died'.
- Use clear words such as 'he has died' as these are easier for children to understand than 'lost', 'passed away', 'gone to sleep'. It is important to explain to your child what dead means, that the body has stopped working, no longer able to talk or breath.
- Allow time together for comfort, support and any questions they may ask.
- Answer questions honestly, and keep explanations short, clear and appropriate for their age and understanding.
- Discuss spending time with their loved one and allow them the opportunity to do so. Reassure them that they may change their mind at any stage. Let your child guide you in relation to time spent with their loved one.
- Prepare them for when they spend time with their loved one- they will feel cold, look pale and no longer be able to talk or breath.
- You may need to repeat information, especially with a young child. It is ok to show your emotions and to explain that you are sad because the person has died.
- Talk about the plans for the days ahead, including who will take

them to school. If you need to leave them, tell them when you will be home, or who will be looking after them. This will help them feel secure.

- Our hospital is aware of the needs of diverse religious communities and cultures in our healthcare settings. Please feel free to ask any member of staff if there are any specific religious/spiritual requirements that you may wish to avail of.



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ENCOURAGE

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Acknowledgements

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References

Irish Childhood Bereavement network

The Dougy Center

Barnardos Children's Bereavement Service

Child Bereavement UK

Bereavement Support

barnardos.ie

rainbowsireland.ie

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childhoodbereavement.ie



hospicefoundation.ie

