

This project is part of

**St Clare
Hospice**



A guide to helping children facing loss



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How to help children facing loss


You're probably reading this booklet because you are involved in the care of a child who is close to someone who is seriously ill, or has died. This may well be a difficult time for you; you may be managing many things at once both practically and emotionally. You may have concerns about how best to help a child during this stressful time.

Most people find speaking to a child about illness and death an extremely difficult thing to do. Yet when they do speak to them, they often report that it went well and although they may have been putting it off - they feel relieved when they have done it.

This booklet is designed to guide and support you to talk to your child about illness and death - giving you confidence in what to say to your child, and what are normal questions for them to ask, and ways of reacting to death - dependent on their age.

At St Clare Hospice, we are here to support you for as long as you need us. Please share this information with your family and friends.

Here for you

 **01279 773722** Child & Family Therapist

 **01279 773762** Patient & Family Support team

Bereavement Support Helpline

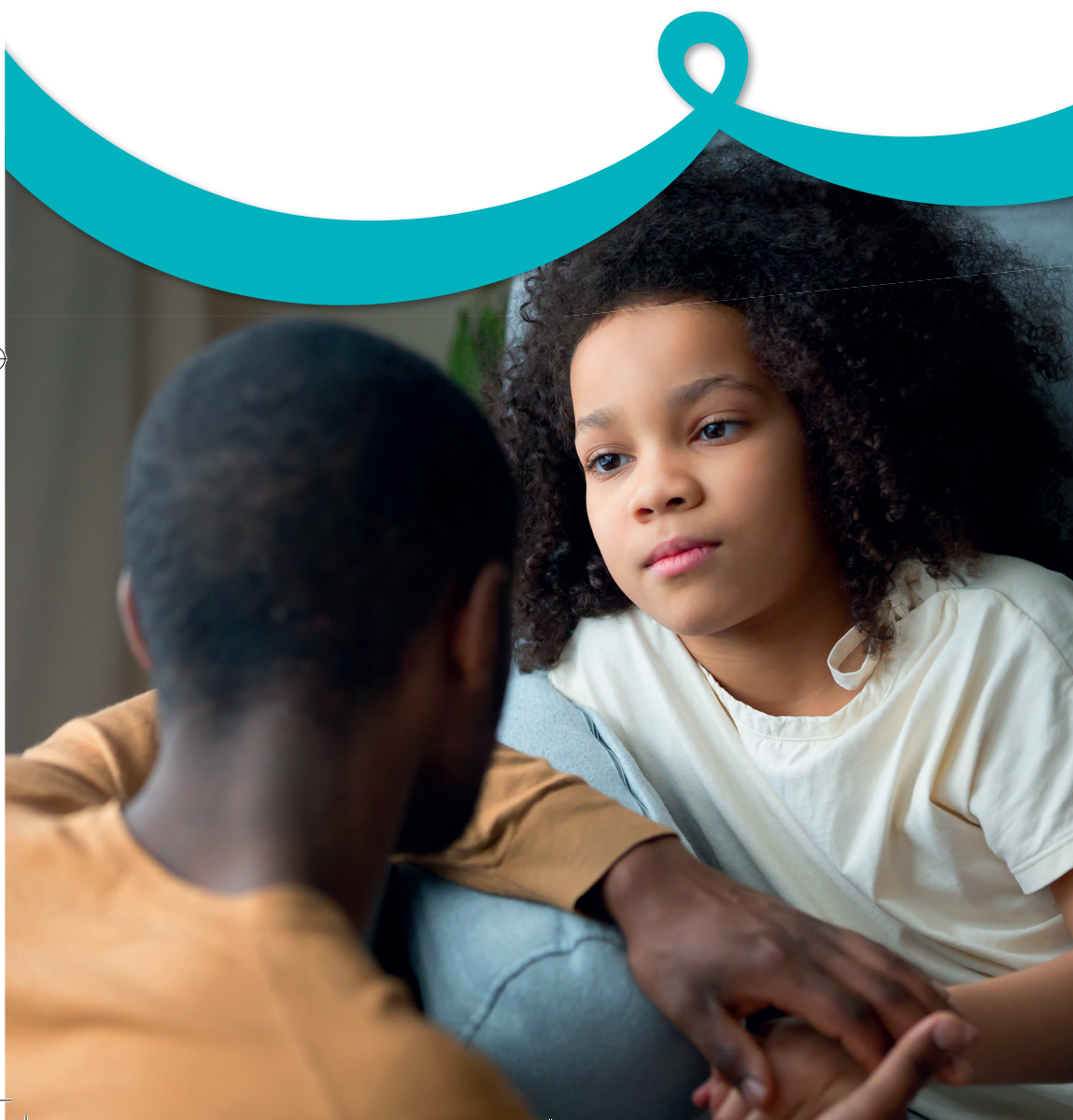
Call us on **01279 967670** between 9am - 5pm, Monday to Friday for a listening ear, information on what to do after a death, and sign-posting to other services.

Useful websites

- winstonswish.org.uk
- cruse.org.uk
- stclarehospice.org.uk
- griefencounter.org.uk
- hopeagain.org.uk

Section One

Speaking about illness



Telling a child about someone having a serious illness can be a really difficult thing to do. Parents often say that they do not want to spoil their children's childhoods; that they do not know what words to use; and that they want to protect their children from being upset.

But, if children and young people are not told about what is happening, they may feel left out and resentful if they later find out that things were kept from them. Speaking to your child about illness, dying or loss, means you are able to control the information they are getting.

Often, children need information broken down into stages, and need it repeated several times over a period of time

Some words and sentences you may find useful are:

- I have some news to tell you...
- The doctors have told me that... has a serious illness called...
- They have told me that they cannot make it better, and that means... will/might die

Be open and honest

It is better to use clear, accurate words that describe the situation, such as 'cancer' or 'serious illness' and, if it is incurable, 'dying'. Overall, being open and honest will allow clear communication to take place.

It's ok to cry

It's ok to get upset, and if you cry that is also ok. You are showing your child that they can be upset, and show their feelings too.

Invite questions

It is important to let your child know that they can ask questions. Younger children may ask repetitive questions about what you've told them.

No one's fault

You might want to say that the person with the illness doesn't want to die. And that it's no one's fault. Children can worry that they are to blame, or that the person is choosing to leave them.

Section Two

Questions children may ask



It's natural for children to have lots of questions, and here are some examples of things that they might ask about cancer, serious illness, and dying. We've also provided some answers that you might find it helpful to use.

The important thing to always remember is to be open and honest. Try to be direct and use plain language.

Say 'died' and 'dead' instead of 'passed away,' 'lost' or 'gone to sleep' to avoid confusion. Children understand words very literally and it may make them think their loved one will come back, or it may make sleeping sound dangerous. You may need to check that they have understood what you meant.



Questions about serious illness

Why do people get seriously ill?

No one really knows why some people get serious illnesses, like cancer, and some people don't. Doctors and scientists are working very hard to understand serious illnesses better. Often illness is nobody's fault.

Why isn't there a cure for some illnesses, but ways to cure others?

No one really knows why some people get serious illnesses like cancer. There are lots of treatments out there to help treat cancer, and other illnesses, and some illnesses can be cured – but not always. Doctors are working very hard to find a cure for serious illnesses and cancer.

Will I get seriously ill?

Most serious illnesses and cancer are not contagious, and you cannot 'catch it' from anyone. There are some things which can make some illnesses more likely, such as smoking or alcohol.

Research done by doctors shows that some kinds of illnesses are more common in families, but it doesn't mean that you will get seriously ill if your Mum/Dad/Grandparent did. If you're worried about this, you can talk to your doctor.

Is my Mum/Dad/Grandparent in pain?

Sometimes people with serious illness can be in pain. Doctors and Nurses can give medicines to try and make the pain stop.

What is Morphine?

Morphine is a type of medicine which is used to help treat pain. It can be taken as a tablet or syrup, and is sometimes given by injection.

How does a syringe driver work?

A syringe driver is a pump which is used to give medicines over 24 hours. It is often used to ease pain, and to stop people from being sick.

Questions about death and dying

What happens in your body when you are dying?

When someone is dying their body gradually becomes weaker, and they get sleepy and eat and drink less, and don't talk to you as much. They may be confused as well. It's ok if they want to rest and sleep, because their body is telling them to do that. This doesn't mean that they are in any pain or discomfort.

Am I going to die?

Yes, one day. Everyone dies eventually, but it probably won't be for a long time. People usually die when they are very old.

If this question has been triggered by the death of someone the child knew, you can say: "You won't die just because someone you know has died."

What is death?

Death happens when someone's body stops working. They no longer breathe, eat or drink. Their body goes cold and stays very still. They cannot feel pain anymore. When someone dies nothing can bring them back to life.

Why do people die?

Someone's body might have been damaged by a bad accident, or they might have had a serious illness that doctors couldn't make better.

When do people die?

Most people die because they are very old and their body is worn out. But not everyone who dies is very old.

Is death forever?

Yes. When someone dies nothing can bring them back to life.

Questions about what happens after death

You may want to adjust your answers based on your own specific religious or spiritual beliefs.

What is a funeral?

Funerals are special ceremonies that give family and friends who cared about the person who died a chance to come together to remember them, to say goodbye and celebrate their life.

What happens at a funeral?

The body of the person who died is usually put in a special box called a coffin. Music is often played and people usually speak about the person who has died. The body of the person who died may be buried in the ground. Sometimes instead of being buried, people are cremated. This is when a body is turned into soft ashes.



Will being buried or cremated hurt?

The person who died won't know that they're in a coffin or that they have been buried and if they are cremated it won't hurt. That's because after death their body cannot feel, hear or see.

What do people wear to funerals?

People dress up smartly as a mark of respect to the person who has died. People sometimes wear black or dark clothes to go to a Christian funeral. However some people don't like to do this, and the person who died may have said that they didn't want people to wear dark clothes. In different cultures, different colours are worn. For example, Hindus wear white to funerals.

Will people cry at the funeral?

Many people cry at funerals because they feel sad. However, there can also be happier moments when people remember the person who died and things they did together.

Can I go to the funeral?

(If you're ok with them going) Of course you can go to the funeral, but you don't have to.

Questions about spiritual beliefs

What happens after death?

No one knows for certain what happens after someone dies. Different people have different ideas and beliefs although many share some of the same ones.

Do people have a soul? What is a soul?

As well as a physical body, some people believe that we have a soul or spirit, which makes us who we are. They believe the soul is always there, even when our body is dead.

Where do you go when you die?

Some people believe that a person's soul or spirit goes to heaven or somewhere like Jannah or paradise. In heaven, their body is free from pain and they are no longer ill. Other people believe that when you're dead there is nothing more.

If (the person who died) is in heaven, why are they buried?

Their body, which is the physical part that doesn't work anymore, is buried. It's their soul that is in heaven.

Can (the person who died) see me from heaven?

Some people find it comforting to think (the person who died) is watching and looking after them from above.

Can I telephone heaven? Why can't I put an extra long ladder up to heaven?

Heaven is not like places on earth – you cannot phone or go there.

Why did God/Allah/Jehovah let (the person who died) die?

This is a question that many grown-ups can't answer either. People who believe in God believe that everything happens for a reason. This means there's a bigger plan to everything that happens that only God knows about. This can be difficult for people to understand, especially when it's so painful. Other people find it comforting.

Things to say, and things not to say

When talking to a child about death and dying, we need to try and choose our words carefully. Things like using simple and direct language, being honest, listening carefully and trying to understand what the child means, are a good place to start. It can be better to be led by their questions, and what they want to know.

Things to say

“What do you think...?”

“No one knows for sure, but I believe that...”

“Grown-ups find that difficult too.”

“Do you understand what I mean by...?”

“What do you mean when you say...?”

Things to try and avoid

“Grandma has passed away” – which sounds as if she may come back.

“People only die when they get old” – which is untrue.

“I’m sorry you’ve lost your Grandad” – which sounds as if he might be found somewhere.

“Joe has gone to sleep” – which makes it sound as if sleeping is dangerous.

Section Three

Supporting a child through grief



Grief is a natural reaction to loss and is always an individual experience. There is no 'right' way to grieve. A child's way of expressing grief can be different to an adult's, and so it can be helpful to understand the reactions and emotions they may experience.

Often, adults want to protect a child from pain, but we can support them in their sadness. Children need to be involved in what is happening. It is best to be open and honest with them, in a way they understand.

How a child may react to death

How a child may react to the death of someone close to them is dependent on a number of factors, including:

- How old they are
- How they understand death
- Their level of emotional development
- The relationship they had with the person
- How the death affects their own personal routine and environment
- How the adults around them are affected by the death
- What opportunities they have to express their feelings

Children are individuals. They go through stages of physical, emotional, mental and social development. However, each child will develop at their own speed and in their own way. This is true with grief. There is no wrong or right way to grieve, and it can be expressed in a number of ways.

Common feelings children may experience

Shock

Initially, as with adults, children may enter a period of shock. The child may seem unaffected by the death, or appear to go on with daily life. They might go on mechanically, smiling on cue, or they might withdraw and gaze into space for long periods of time.



Denial

The child may deny that the person is dead – **‘Mum isn’t really dead.’**

They can seem numb or lost. This may happen if they have not been involved in the funeral, or not been given an explanation of what being dead means.

Anger

They may feel that their world has been shattered, or destroyed – **‘Why did the doctors let Mum die?’** or **‘Why did Dad leave me? It’s not fair.’**

Remember, they have good reason to feel angry. Their world has been turned upside down. Let them know that you can also feel angry about the situation sometimes too. This will show them that their feelings are normal.

Panic

Death can evoke separation anxiety and strong feelings of abandonment – **‘What’s going to happen to me?’**, **‘Who’s going to look after me?’**, **‘I don’t want to go to school.’**

Children can feel frightened, out of control, confused, angry and unsafe.

Guilt

Children can often feel guilty, even about things that are nothing to do with the death – **‘I was cross with Mum and that’s why she died.’**

Anxiety

Children can worry about what caused the illness and death – **‘What made Mummy die? Can I catch it?’, ‘Will it happen to me too?’**

Children can worry about their own health – **‘Does my headache mean I have a brain tumour?’**

Sadness

Children can feel sad and lonely. They may feel that they are different from other children. They might feel isolated from other family members. These are normal grieving reactions that a child might experience.



Common behaviours children might show

A child's grief is often more easily seen in their behaviour than in what they say. Often their behaviours will come and go. A child could be playing one moment and deeply unhappy the next. This might seem confusing, or that the child is unaffected by the death, or simply behaving badly and being naughty. But this is all normal behaviour for a grieving child.

Regression

Children can regress to an earlier stage of development. They may start sucking their thumb, or wetting the bed, talking in a baby voice, or having temper tantrums.

Separation anxiety

A grieving child may be clingy and anxious about being left, saying **'Don't leave me!'**

They may become reluctant to go to school, for fear of something happening whilst they are away from home.

If a child sees a parent distressed, they may be reluctant to leave them on their own. Sometimes a child can take on the role of the parent, parenting other children or adults and taking responsibility.

Concentration and confidence

It may be hard for the child to concentrate. Their overall performance might be affected, and they may lose confidence and self-esteem.

Sleeping and eating

Sleeping problems can occur. A child may develop a fear of the dark, or difficulty sleeping. They may have disturbed nights or nightmares. Often eating patterns are altered too, eating more or less than usual.

Moods and behaviours might be changeable with some children more withdrawn, others more aggressive.

How to help a child through grief

It is very hard to see your child in emotional distress. You may feel that it is unfair that your child is going through this situation.

By being alongside them and sharing with them, you will be able to give them the tools they need to deal with their loss.

“Most of all, children need to feel safe, supported and accepted.”

Talk about the death

Children need clear information about the death and its causes, in a way that they can understand, and according to their age.

You might say - ‘The doctors tried very hard to make him better but in the end they couldn’t.’ ‘Her body was hurt so badly by the illness/cancer/accident that it wouldn’t work anymore.’

For younger children, you can explain that when someone dies their heart stops beating and they stop breathing. You can show them how to feel for their own heart beat and show them how we breathe. Explain to the child at their level, how their body works. They can then begin to understand how a body can stop working.

Give reassurance

Children need to know they’re going to be cared for, and by whom. They need extra reassurance, extra physical contact and cuddles.

They may be worried about things like who will make their dinner and who will take them to school now.

Be honest and open

They need to know that they didn't cause the death, as sometimes they hold fears that they have. Children are often more resilient than we give them credit for. With correct, honest, clear information, they can begin to make sense of what has happened. But with half truths, they will find it harder.

They need to be able to trust the adult caring for them. Answer their questions honestly, and if you don't know the answer, it is ok to say so.

Express emotions

Children need opportunities to express their grief, have their feelings accepted and learn that they are normal. They may need permission to cry, and they will learn this by seeing others cry, and sharing their grief with them.

“Adults should not be worried about showing they are hurt and upset too.”



Continue a routine

Continue with some activities that are routine and familiar, like going to school. Avoid big life changes where possible, such as changing school or moving house.

Space to talk

Children need someone to listen to their worries, and it may be helpful to have this space with someone outside of the family.

The companionship of other children, especially if they have been bereaved themselves, can help.

It's important to speak to their school, so that their teacher can support them. It might help if someone is identified within their school, who they can go and talk to if needed. If they are due to change school within two years of the death, inform their new school of the bereavement.



Ways to remember

Children need ways to remember the person who has died, to keep them in their life, and to stay connected. You could let them choose something which reminds them of the person who has died.

Making a scrap book, memory box, or a photo album can also help. It could be made together as a family, or they could do it on their own. Activities like this give a chance to reflect on what has happened, and to ask more questions if they need to.

Important dates like birthdays are good to remember. Visit special places that hold memories, have a birthday cake or meal, or visit the person's grave.

Section Four

Age related reactions to death

Age 0 – 2 years

| Common reactions | How you can help |
|--|---|
| Feeding and sleeping difficulties | Following normal routine is important |
| The child will pick up on grief feelings around them | Continue to meet the child's needs for food, warmth, rest, play and comfort |
| A sense of loss is felt | Lots of play and distraction can help |
| Separation from a loved one can cause anxiety | |
| There can be an anxiety when strangers are present | |

Age 2 – 5 years

| Common reactions | How you can help |
|--|---|
| The child jumps in and out of grief e.g. sad one minute, goes out to play the next | Try to give yourself time and space to consider the child's needs |
| The child may be tearful if faced with separation from a carer, fearing abandonment. This may be shown by crying, kicking, biting and holding on | Give time for play |
| The child may think they caused the death, or made it worse, through bad behaviour. They may worry about who will care for them | Remember to give the child praise |
| Sleep problems may occur | Follow normal routines and activities, including usual ways of disciplining |
| May think dead people continue to do everyday things | Be factual about death in a simple way. Avoid making up stories |

Age 5 – 9 years

| Common reactions | How you can help |
|---|---|
| The child may be withdrawn, sad, lonely and in a low mood | A child in this age range generally wants to know what is happening. Give short, factual, honest explanations - without looking too far into the future |
| The child may personify death e.g. a person or monster that takes them away | Keep routine as normal as possible and continue with activities and and friendships outside of the home |
| The child may act in an angry way, causing problems at home or school. On the other hand, they may become compliant or be a 'perfect' child | Allow short-term regression and dependence, as this will comfort the child |
| The child may fear that illness or death are contagious | |
| Regression may happen if the child is feeling stress and anxiety | |
| The child may get confused with explanations about death e.g. the purpose of the coffin, cremation and burial | |
| The child may develop an interest in the causes of death e.g. sickness, violence and old age | |

Age 9 – 11 years

| Common reactions | How you can help |
|---|--|
| The child may show sadness, loneliness and low mood, or become the 'perfect' child | Play, stories and drawing can often help the child reveal their inner feelings and fear |
| Anger may be acted out at home or school | Give the child short and factual explanations of what is happening as each stage is reached in the illness and death, without projecting too far into the future |
| A sense of morality has developed i.e. a strong sense of good and bad behaviour | Keep to normal routines as much as possible |
| There may still be some 'magical' thinking e.g. 'It's my fault because I shouted at Mum and said bad things to her' | Allow short-term regression and dependence |
| The child asks more about what happened | Give the child positive feedback and praise where appropriate |
| The child may begin to have an interest in the biological factors of death | |
| The child may have more of an interest in the spiritual aspects of death | |
| Worries about who will care for them are common | |

Age 12 – 15 years

| Common reactions | How you can help |
|---|---|
| The young person will think more like an adult | They may need adult guidance around the grief process and with coping skills |
| They understand death as inevitable, universal and irreversible | Try to give as much comfort as possible |
| They may be withdrawn, sad, lonely and have a low mood | Include the young person in family activities, and in negotiating clear rules |

Age 12 – 15 years (continued)

| Common reactions | How you can help |
|---|--|
| They may act out of anger and be hostile – rejection of some adults may happen | Allow them private space and quiet time to talk |
| There may be a reluctance to talk about the issues | They may need someone outside of the family to talk to |
| They may cover up fears and emotions with joking and sarcasm | Take their feelings seriously |
| There may be a regression and a return of dependence, or on the other hand, the young person may spend a lot of time away from home, wanting independence | Encourage them to have time with their friends |
| Involvement in risk activities may occur e.g. experimenting with drugs or alcohol | |

Helpful books for children

- **Always and Forever** by Alan Durrant – 3+
- **Badger’s parting gifts** by Susan Varley – 4+
- **What does dead mean? A book for young children to help explain death and dying** by Caroline Jay and Jenni Thomas – 4+
- **Water Bugs & Dragonflies – Explaining death to young children** by Doris Stickney – 5+
- **Muddles, Puddles and Sunshine** by Winston’s Wish – 5+
- **Michael Rosen’s Sad Book** by Michael Rosen – 5+
- **Duck, Death and the Tulip** by Wolf Erlbruch – 7+
- **Vicky Angel** by Jacqueline Wilson – 9+
- **Bridge to Terabithia** by Katherine Paterson – 9+

Section Five

How St Clare can help



The Echo Project – Supporting children, young people and families facing loss

The Echo Project is for children, young people and families facing loss and bereavement. It is run by a team of Children, Young People and Family Therapists and offers a range of support to children and young people under the age of 21 years.

It is for all those living in West Essex and East Hertfordshire and no previous connection with St Clare Hospice is required.

The Echo Project offers:


- Support through facing an illness
- Bereavement support
- Training for parents, carers and schools
- Family days


Bereavement support

We offer specialised support for children and young people who are struggling with grief and loss after the death of their loved one. We offer a range of services which include:

- **One-to-one therapy** – using methods such as art, play, music, drama and memory work
- **Bereavement groups** – offering a space to meet other young people experiencing loss
- **Family therapy** – for a family to come together with a counsellor

Here for you

 **01279 773722** Child & Family Therapist

 **01279 773762** Patient & Family Support team

Bereavement Support Helpline

Call us on **01279 967670** between 9am – 5pm, Monday to Friday for a listening ear, information on what to do after a death, and sign-posting to other services.

About St Clare Hospice

St Clare Hospice is a charity providing specialist palliative care to improve the lives of people affected by a life-limiting illness in West Essex and the borders of East Hertfordshire.

Our approach to care enables people, their families and carers, to make the most of every moment together, no matter how long they have left to live, supporting them whether at home or in the Hospice.

It costs around £5 million each year to provide our vital services, and with limited NHS funding we need to fundraise most of this. We therefore rely on our local community to help us raise money each year so we can continue being there for local families facing one of the most difficult journeys in life.

To donate visit stclarehospice.org.uk/donate



Our service covers

- Harlow
- Epping Forest
- Uttlesford
- East Hertfordshire border

♥ St Clare Hospice is located here

🏠 Our shops are located here

Here for you:

01279 773700
Main Reception
(Monday to Friday,
9am to 5pm)
01279 773773
24 Hour Advice Line



stclarehospice.org.uk
Registered Charity No. 1063631

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