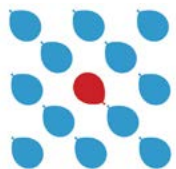




SAYING
GOODBYE



balloons

HELPING CHILDREN,
YOUNG PEOPLE AND FAMILIES
DEAL WITH BEREAVEMENT

Second Edition

“

In my grief support we made a journal and a memory box and stuff and this was just great as I wouldn't have done it on my own plus when we did it we just talked and talked

”

*Bereaved child
aged 12*

“

I think that talking with a support person can help you to make sense of all the stuff that it is hard to make sense of on your own

”

*Bereaved young person
aged 17*

“

At first I didn't feel the same with my friends and they seemed scared to talk to me about even ordinary things. I found it helpful to share this with my GSW and together we looked at if this might change and what I could say and stuff so that I felt I wasn't just losing my friends

”

Bereaved young person aged 15



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*Thanks to the families we have
worked with who have provided
tremendous insight through
sharing their experiences.
You have contributed more
to this book than you know.*



Balloons is a small charity working across Exeter, East and Mid Devon. Balloons provides support for children, young people and their families before an expected death, or following the death of someone significant in their lives. Our aim is to inform, guide and support them while they manage the impact of that death. The work of Balloons is carried out by a professional, multi-skilled team of staff and trained volunteers. We are a free service and we rely entirely on donations and grants.

For more info please visit www.balloonscharity.co.uk



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Grief is not a disorder, a disease or a sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief is to grieve.

”

Earl Grollman



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INTRODUCTION

Saying Goodbye offers advice and guidance for adults on how to help children and young people deal with an expected death in the family and how to cope after the death of someone significant.

Evidence shows that children who are given the option to be involved with the end of life process make an emotionally healthier transition into adulthood; whereas children who are shielded from the process are more likely to experience problems later in life.

Making assumptions and decisions about death on behalf of children and young people can complicate the grieving process and create additional distress. This booklet aims to help prevent and reduce some of this unnecessary upset by providing useful information and guidance. It also hopes to promote open and productive communication. After all, when emotions are being stretched to their limit it can be difficult to know how and where to begin to help others to cope.

Remember, this is just a guide. It is not possible to get everything right for everyone. Young people may be resistant to those who are trying to help them. They will almost certainly be more resilient than you imagine; but children are not resilient in a vacuum. It's a tough task, to work through pre- and post-bereavement issues with children, and we can only try our best.

The writers of Saying Goodbye have a lot of experience in hospice work, nursing, providing therapeutic support to children and young people and working alongside families through the bereavement process.

We sincerely hope you will find this booklet useful and wish you comfort on your journey.

SUPPORTING FAMILIES IN THE PRE-BEREAVEMENT PHASE



WHY SHOULD CHILDREN BE TOLD?

'Pre-bereavement' is the term given to that period of time between the diagnosis of a life-limiting illness and the time of that person's death. Because this period can last from days to years, because it can be unclear whether death is inevitable, and because circumstances can often change without warning, it can be a time for not communicating fully with the young people involved. Adults may find the circumstances hard to deal with and feel the need to offer factual answers, so understanding how to explain a frightening situation to a young child can be a difficult challenge.

It is important to understand that you should never deny a child the opportunity to grieve. A child may hold back their emotions for different reasons, but what is certain is that any strong emotions that aren't let out will find another outlet. Repressing emotions is an unhealthy thing for anyone to do but could have an especially negative effect on a child in the long term. Unheard sadness can become anger, unexpressed anger can become depression, and so on.

Here are some of the most common consequences of unexpressed grief. Some will be short term whereas others will develop in the long term as a coping mechanism:

- immature behaviour
- being 'clingy'
- anger
- depression
- withdrawal/introversion from family and peers
- inability to focus or concentrate
- sleeplessness, nightmares, night terrors and/or sleep walking
- having little energy
- bedwetting
- eating problems
- violence and bullying behaviour
- risk-taking behaviour
- self-injury
- unhealthy fascination with death

It is commonly thought that, by not sharing this potentially traumatic time with children, we're protecting them from unnecessary pain and heartache. In fact the opposite is true. Research and experience in this field has shown that many of the following beliefs are unfounded:

"IT IS BEST TO TELL A CHILD NOTHING UNTIL IT'S CLEAR WHAT'S GOING TO HAPPEN?"

We often underestimate a child's ability to deal with change. Children are in fact incredibly adaptable when given the opportunity. As adults we may feel under pressure to know all the answers, however, the conclusion to many life events are uncertain. By acknowledging and sharing our uncertainty with our children, we can provide a realistic example of dealing with the here and now. If a young person is not given information they may try to make sense of the situation from their own understanding and will misinterpret and imagine all sorts of things in order to try and join together all the little bits and pieces. Young minds can be very creative; more often than not what they imagine will be far more distressing to them than honest facts, no matter how small.

"THEY ARE TOO YOUNG TO UNDERSTAND WHAT'S GOING ON"

All humans are born able to express four emotions: anger, fear, sadness and joy. These are our primary emotions that, just like primary colours, are the foundation for all other emotions. Therefore each child will understand the gravity of any given situation in their own way if given information in an age appropriate way. Even if a child is two years old, they will not be two forever. As they develop so will their ability to revisit and review life events and since bereavement is an event of enormous impact, they will revisit it time and again throughout their life



“THERE IS NO NEED TO UPSET THEM AS WELL”

Young people will pick up on what is going on around them. They will become hypersensitive to atmosphere, adult conversation and emotion. If we show our children that it is best to avoid or hide our own distress, they in turn will hide and cover up their feelings. We cannot protect children from feeling and when someone close to us is dying all humans, no matter what their age, have the right to express their upset, confusion and grief.

“I HAVE ENOUGH TO DEAL WITH WITHOUT HAVING TO COPE WITH THEIR RESPONSES AS WELL”

This is often a huge predicament. In the short term imparting distressing information may heighten emotions within young people, just as it does in adults. Working through these emotions openly as a family will, in the long term, help you understand both yourself and those around you. Young people with a positive emotional attachment to the dying person will need ways in which to express their affection. They also want to feel needed and that they have been helpful in some way. Being honest and inclusive with your children will help build the foundation on which compassion, consideration, tolerance and understanding between you all can develop.



Being honest and inclusive with your children will help build the foundation on which compassion, consideration, tolerance and understanding between you all can develop.

INTRODUCING THE CYCLE OF LIFE AND DEATH TO YOUNGER CHILDREN

Introducing the cycle of life and death to a child can be a challenge. As adults we are more than aware of the emotional consequences when someone we know or love is dying. Children between the ages of two and five are not sufficiently mature to associate the scientific concept of death to the actual experience of loss through death. However, at this stage children can be naturally curious and will ask many questions and this is a good time to show children, through nature, that things die. This will then provide some understanding that death is irreversible.

Be careful not to overload them with too much detail. If you provide a child with the basic information they will soon come back with questions if they need to know any more. Try to pick a time when you are not feeling overwhelmed yourself so that you can get the information across sensibly. If you do get upset, remind your child that dying can be sad and that it's OK to be sad.

The following list has been designed for you to use either as a conversation starter or as an example on which you can build.

FACTS

Everything has a beginning, middle and an end. Let's think of some examples together: a piece of string, a book, a sound, etc.



We live in a natural world and are a part of nature. Living and dying are a part of nature. Living and dying are a part of the world we live in.

EXAMPLES

Seasons come and go; explain what happens to most trees in spring, summer, autumn and winter.

Use flowers in the home, garden or park to demonstrate that flowers begin as seeds; some seeds grow into flowers, some never do; some flowers have buds on them; some buds turn into flowers, while some buds die before they have the chance to turn into flowers. All flowers will eventually die; and you could explore with your child what the difference is between a flower that is alive and a flower that is dead.

A frog lays its eggs in the pond; some of these eggs get eaten by other creatures in the pond, some of the eggs turn into tadpoles; some of the tadpoles turn into baby frogs; some of the baby frogs die because they cannot get enough food or are not very strong; some of the frogs live for a long time and get very old, but one day they will also die.

Use anything around you to illustrate the cycle of life and death: spider's webs with flies.

When a family pet dies, the way in which the family responds can lead to conversations about more relevant topics:

- Death happens all the time
- It is different from sleeping
- Dead things feel different to things that are alive
- Dead things do not feel anything anymore
- When something is dead it does not come back to life
- What do we do with our pet now it has died?
- How can we remember our pet?

There are many books that can assist adults to broach the subject of death and dying which can get the questions flowing, some less direct than others. For more information see the Useful Resources pages at the end of this book and visit the Balloons website:

www.balloonscharity.co.uk

EXPLAINING LIFE-LIMITING ILLNESS

The term 'life-limiting' can apply to any illness that is incurable and is going to shorten a person's life expectancy. Older children especially might want to understand the terms they hear being used.

The following terms are commonly used to describe these types of illness, but they all have slightly different meanings.

A '**chronic**' illness means that a person can be ill for a long time, slowly becoming more unwell. It can often take many years to impact on the quality of their life.

A '**terminal**' illness means that the person cannot get better and that they have reached the final stage of life and are expected to die.

'**Palliative**' means that the illness has reached the stage when it is no longer curable. Treatment may continue to help with symptoms that are causing discomfort and can help the person to live a better quality of life for a little longer.

During a period of pre-bereavement (time before the death) a person may suffer from any of the above illnesses. It is usually when a person reaches the 'palliative' stage that we recommend that children are informed.

Sometimes a serious illness or accident causes someone to become so acutely unwell that they are not expected to live. In these situations there will probably be a short period of time before their death. However little time you have, please remember to try to include the children. It only takes minutes to talk to them and tell them what's happening. Those few minutes can make a difference to them for the rest of their lives.

One of the major differences between a life-limiting illness and a sudden death is that there is a valuable period of time before death for the children to be prepared and for families to work together, sharing their sadness and their worries.

From the time that someone is first told that they will not get better until they are approaching the end of their life, you will probably notice some (or all) of the following:

- They will become weaker and may well need to spend more time resting and sleeping.
- They won't need to eat the big meals that they did before they were ill. They can get all the energy they need from nutritious drinks and small snacks.
- Sometimes the medication they are prescribed can have an effect on their behaviour and personality, making them sleepy, confused or even aggressive. This can be really difficult for children to deal with.
- Their appearance will probably change as they lose weight.
- They may become jaundiced (yellow) if they have any problems with their liver.

Changes to appearance and behaviour can be very distressing and frightening to children. If they shy away from having contact with the sick person, you should try to listen to their fears.

TELLING THE CHILDREN

When you are preparing to talk to your children about the expected death of someone close to them, it might be a good idea to talk to the medical staff beforehand. Ask them to explain the illness so that you understand enough to answer any questions honestly. Remember that the children will have their own understanding and experience of how the illness has impacted on the life of the person concerned, and their own lives, up until this time.

For younger children you may find it useful to use examples from the life cycle of trees and plants or to read Doris Stickney's book, 'Waterbugs and Dragonflies'.

Older children may want to understand more about which part of the body is affected. Drawing a simple outline of a body and identifying the affected organs may help.

If a child is old enough to understand in more detail it might be helpful to explain that our bodies depend on all the vital organs working together in harmony. For example, the lungs have to be able to take in enough oxygen so that the heart can pump it around the body, via the blood, to all our cells – muscles, tissues, bones and organs. We have to be able to use and excrete whatever we eat or drink, so we need to have a healthy liver, kidneys, and a working digestive system. If any of these organs stop working properly the person's condition will quickly get worse.

So it may seem, for instance, that the cancer tumour is just in the lungs but in reality the lungs are only one part of a whole system.

Simple explanations are best and they can be built on as the illness progresses. As the person's condition deteriorates and it becomes obvious that they are dying, an explanation such as, "The doctors are doing everything they can to make 'dad' better, but sadly there is no cure for what he has so they are making him as comfortable as they can", might help them to accept what they see.



TELLING YOUR CHILD

This conversation will undoubtedly be one of the most difficult things you will ever have to do, but just remember how important it is to prepare your child. Keeping the truth from them creates even more anxiety and fear. Including them gives them the opportunity to ask questions and address their fears, and helps them to find ways to cope.

WHEN?

As soon as you are aware that the person is not expected to live tell them if the person is going into hospital for a scan or a check up with the consultant. Tell them if the results aren't good. It's important for them to know that everything is being done to make the person well, but sometimes things are out of your control.

Children can be told that there is no cure. 'Mum' may slowly become more and more unable to lead the life she did when she was well.

It is important that the person who is ill is allowed to live positively until they die. In some cases of incurable cancer, and certainly with degenerative conditions such as Motor Neurone disease, life expectancy may be for another 12 months or much more. If this situation applies to your family then you will need to give enough information so that your child is aware, but don't waste a year or more anticipating and preparing for the death rather than enjoying sharing life together.

WHO IS BEST TO TELL THE CHILDREN?

It could be the person who is ill, if they are physically able. In any case it should be someone known and trusted by the child such as the other parent, a grandparent or close family friend.

The doctors or nurses involved in the person's care, or the family GP, will also be available to offer advice.

SETTING THE SCENE:

- Know all the facts. If need be, speak to the medical team beforehand to make sure you know the situation well enough to answer any questions honestly.
- Choose your time carefully: avoid bedtime, or before an important event such as an exam. Often weekends are good as they provide enough time to digest the information and begin thinking of questions.
- Give some warning, say something like, "After breakfast I want to talk to you all about dad".
- Tell family and friends that you don't want to be disturbed at that time and why.
- Silence your mobile phone, unless you are expecting an important call from the hospital.
- Avoid times that are already fraught with arguing and conflict.
- If possible, aim to tell all of your children together. That way they will all have the same information. However, be prepared to answer questions on an individual basis according to each child's developmental age and understanding.

WHAT TO SAY?

- An important starting point is to establish what the child already knows and understands
- Find out what they know by asking something like, "What do you think is wrong with 'Dad'? Have you noticed any changes?"
- Explain that what you have to tell them is very difficult for you, but you feel it's very important that they understand why 'Mum' isn't getting better
- Accept that you will probably get upset in front of them. Don't struggle to hide your tears; this will give the children the message that it's OK to show your grief
- Tell them that, even though it does make you sad and upset talking about how sick 'Dad' is, it's really important to talk to each other. Talking and crying is good to share
- Tell them in simple language what the illness is. Older children might be interested in medical detail and you can discuss that with them later, but younger children will not understand, or may be frightened by it. So try to pitch your talk so that the youngest can understand what you are trying to tell them.
- Listen to their questions and try to answer truthfully

- Do not give false hope
- Tell them what you expect will happen to 'dad' over the next few days/weeks/months
- Give them time to think about what you've said, and ask them if they've understood? It may help to ask them to explain what they've heard.
- Tell them that they can talk to you anytime they are worried
- Do not push them to communicate if they're not ready
- Listen to your child
- Always leave the door open for further discussions and questions. Your child won't have been able to process all the information you've given them first time. They may not have understood anything other than 'Dad' is dying
- If they don't want to listen to what you need to tell them, let them go but find a quiet time later that day to sit one-to-one with them and listen to their fears. Let them set the pace
- Acknowledge that they will probably get very upset; it's only natural. That's why it's best for them to be told by someone they trust enough to reach out to for a hug.
- Children may ask the same question over and over again. However frustrating, this is a normal way for children to process important information.
- Discuss and plan how you are going to manage and support each other, as well as the person who is terminally ill.

Every child is different and may respond differently to the news that someone significant in their life is dying. They will express their emotions and fears according to their age and development, and also as an individual. They may burst into tears, sit stony-faced, refuse to accept that you have told them the truth, or even blame you for what is happening. It is really important that you try to accept that their response is all they are capable of giving at that time. Try to remain as calm as you can and know that with reassurance, patience and time you will survive this together.

NOTIFYING THE SCHOOL OR NURSERY

School can play an important part during pre-bereavement and after since it offers stability and normality at a time of uncertainty and sadness.

Your child may not wish anyone at their school to know that they have a terminally ill relative. But we recommend that you do let them know so that they will be able to offer the support and understanding your child needs, and not just dismiss them as behaving badly. Here are some of the reasons why:

- Your child may be distracted, tired or tearful.
- They may have problems with tasks such as homework.
- Hospital visits may make them late for school, so flexibility over attendance may be needed.
- They may not wish to participate in some subjects that could cause distress.
- There may be changes in appearance or behaviour that are out of character.

If possible, try to obtain your child's consent and let them identify the person they want you to tell, like their class teacher, head teacher, close friends or other pupils. Try to explain why an adult needs to be told: so that the child can get help and be supported.

It's a good idea for both parents (if possible) or, if not, the 'well' parent, or a close friend, to visit the school and talk to the staff. That way you can discuss what role you would like them to fulfil, both pre- and post-bereavement. Lunch and playtime assistants can play a vital role in observing behaviour, for instance a child whose parent is deteriorating rapidly may become withdrawn or lose their appetite. Try to involve your child for at least the summary of this meeting.

Keeping up good communication is important. Here are some points to consider:

- Identify someone at the school/nursery that you could contact in a hurry if, for instance, you were delayed at the hospital or you were sending someone else to the school to collect your child.
- For younger children consider using a contact book to send messages to and from school to home.
- Establishing email contact or text messaging between the parent and an identified adult is a quick, easy and reliable way to send information.
- Your child may take comfort from taking a favourite toy in their school bag, or something small or tactile that belongs to the sick parent. If this is the case, then inform their class tutor to avoid any misunderstanding or confiscation of the toy.
- Make sure the child knows who is collecting them from school.
- If they have after school activities they wish to continue – and this should be encouraged – make sure you confirm beforehand who is taking and collecting your child.

It may be difficult for your child to invite their friends back to play or have tea, especially if the sick parent is being cared for at home, but time out with friends needs to be encouraged and facilitated if possible.

Whether or not they should take time off school will depend on how sick the relative is. If you're only looking at days or weeks, it might be appropriate to spend that time at home/by the hospital bed. Or perhaps consider school for mornings or afternoons only so that you can have time with the ill person.

Leaving someone who is very ill may be upsetting for the young person. This may be demonstrated by a stomach-ache, headache or by the child simply saying they don't want to go to school. When time is short giving them a choice is really important.

TIME TOGETHER DURING THE ILLNESS

This section is about how you can involve your child in practical ways that not only bring comfort to the dying person, but also create a real feeling of doing something valuable that they will look back on later in life and take comfort from. The later section, 'Memories that children can create', suggests ways you can create lasting keepsakes and memories.

Children should not be overloaded with tasks and responsibility, but should be allowed to offer and carry out the simple tasks that give them and the sick person pleasure.

Here are some of the things that you could suggest that your child might like to do:

OLDER CHILDREN:

- Offering and making drinks
- Creating appetising snacks like chopped fruit or cheese and biscuits
- They could be shown how to do simple hand massage
- Read aloud from the newspaper or a novel
- Helping in practical ways like assisting the patient to walk to the bathroom, or taking them for short rides in a wheelchair
- Washing the person's hands and face if they are unable to do so independently
- If the patient suffers from anxiety or breathlessness, young people can be shown strategies that can help

YOUNGER CHILDREN:

- Brushing hair
- Telling stories
- Drawing pictures
- Fetching or carrying small items
- Sharing what they've done that day
- Cuddling up together

Sometimes the symptoms and the appearance of someone very sick can be distressing to children (and adults).

They should not be forced to spend time with the sick person.

Be aware that the young person may not wish to be left alone with the sick person and something untoward could happen, such as choking or an acute bout of breathlessness, that could frighten them. If they do not want to visit give them other ways to feel usefully involved, maybe they could write or draw messages to them instead. Find simple tasks that they could share with you, such as picking a few flowers from the garden that you could jointly place by the bedside.

SHOULD THE SICK PERSON BE NURSED AT HOME OR IN HOSPITAL?

This is a decision that many families have to face. The majority of people, when asked, would prefer to die at home where they feel comfortable and at ease. There are both advantages and disadvantages associated with either choice. What is most important is that this situation is discussed as a whole family unit. This may not be a straightforward decision because what the sick person wants may not be in the best interests of the rest of the family.

If the prognosis is short and there are just a few weeks or months left, then it may be essential to make sacrifices. However, if the prognosis is for a longer term then you may need to reach a compromise in order to respect everyone's feelings.

AT HOME

The advantages for the children of having the sick person at home are:

- Privacy
- Keeping to the usual routine, which is especially important for very young children
- Children can be involved as much, or as little, as they wish
- No restriction on who or when someone visits
- Easier for children to be helpfully involved
- They are not separated from either the sick parent or another relevant family member who would otherwise be spending time at the hospital

Disadvantages for the children are:

- Pressure on the children to spend time in the 'sick' room
- No escape from death and dying
- When space is limited, often the living area is taken over as the 'sick' room, reducing the places that children can be involved in normal activities
- Restricts social activities like having friends home from school
- Lack of privacy (or inclusion) due to friends and family visiting
- After the death they may be frightened to go back into the room where the person died

IN HOSPITAL**The advantages for children of having the sick person in hospital are:**

- The anxieties and responsibility for delivering care to the sick person is taken on by hospital staff
- You have free time to spend with the children doing 'normal' family activities, or to talk openly

Disadvantages for the children are:

- Lack of privacy
- Restricted visiting times
- Distance from home
- It may be more difficult for them to be actively involved
- Less able to communicate one to one
- Separation from sick parent
- Separation from other family members who are spending time at the hospital

If the sick person is being looked after in hospital then you may wish to take something with you to occupy younger children during visiting times, like homework, a game, a book, drawing things. You can always take in something to eat or drink that you've made especially for the patient as well as snacks for younger children.

**QUESTIONS CHILDREN MAY ASK****WHY DO PEOPLE DIE?**

Dying is part of life. All living things – plants and animals, as well as people – have their place and are part of the natural world. Like all other living things, though, people grow old or ill and reach the end of their life. This is called death, or dying.

WHERE DO DEAD PEOPLE GO?

Some people believe that when someone dies, the spirit of that person lives on. This part of us is not like a heart or brain or any other part of us that doctors have to take care of. It is the part that can sometimes feel like a voice inside us. It helps us feel love, happiness and all the other feelings we have. It never gets sick or wears out, and it is invisible to the eye. Some people call this part of us the soul. Lots of people all over the world believe that when they die their spirits or souls live on.

WHY CAN'T DOCTORS AND HOSPITALS STOP SOMEONE FROM DYING?

Many times they do. Yet sometimes, even though they have tried their best, someone dies. Doctors try to help people live long, healthy lives. Because of what doctors have learned, people live much longer now than they did when your grandparents were children. Hospitals help people too. Doctors and nurses work in hospitals to try and help sick and injured people feel better. However, sometimes the sickness or injury cannot be put right, no matter how hard the nurses and doctors try.

DOES DEATH HURT?

Doctors tell us that death is not usually painful. Dying is almost always quiet. When someone dies in an accident, they often feel no pain at all because death comes so quickly. When someone is sick or hurt for a long time before death, special medicines can usually take away much of the pain.

WHEN SOMEONE DIES, ARE THEY BEING PUNISHED?

Death is never a punishment. It is almost always natural. Time or illness can wear out important parts of our bodies. Usually after many, many years, these parts cannot work anymore. People die when these parts, the heart for example, stop working.

We have very strong bodies that usually last a long time. Sometimes sickness makes them stop working before a person becomes old. This is still not a punishment though, it is simply because important parts of their body wear out, don't work properly or stop working altogether.

WHY DID SOMEONE I LOVE HAVE TO DIE? WHY COULDN'T IT HAVE BEEN SOMEONE ELSE?

Sometimes death doesn't seem fair. Of all the people in the whole world, why did this one special person have to die?

Almost everyone, no matter who they are or where they live, is loved by others. Almost everyone will be missed by others when they die. Right now someone just like you somewhere else in the world is asking the same question: why did someone I love have to die? But just like we are all born, we will all have to die. This is the way of life for all things that live.

IS DEATH LIKE SLEEPING?

People who are dead look as if they are sleeping but dying is nothing at all like sleep.

People and even animals sleep to rest the hard-working parts of the body and stay healthy. Sleep also gives our bodies time to store up strength.

Think of how good you feel after sleeping. You feel good because your body is rested and ready for another day. When we are asleep our bodies are still alive. We dream and can be woken up by sounds or feelings. A dead person cannot do any of those things, they do not feel, hear, see or smell anything and will feel no pain. When someone dies their body stops working. It is not resting, its job is over.

WHY DO SOME PEOPLE DIE WHEN THEY ARE VERY YOUNG?

Sometimes, but not very often, a child will die. Illness can make this happen. So can a very bad accident. A young person's death makes us feel especially unhappy. We feel it isn't fair. We feel that everyone should live a long, happy life. We know that we will miss a young friend, or sister, or brother more than we might miss anyone else. We may even feel sad because we sometimes argued or fought with that person.

Even though that child's life was not as long as yours will be, it was mostly a happy life, because of loving friends and family like you.

All these feelings are normal. Every person has them, just as you may. But not all of our feelings will be unhappy ones. We can have other feelings too. We can remember happy things as well, like nice things we did together. Even if you did argue sometimes, it is important to remember that all friends and family love each other too.

GROWN-UPS ARE BIG AND STRONG. WHY DO GROWN-UPS DIE BEFORE THEY GET OLD?

Most grown-ups are strong and healthy and will live until they are very old. Sometimes, though, a grown up's heart or other important part of their body stops working. Being big and strong doesn't always help.

It is not the person's fault. It is not your fault. Remember this too: it is likely that no other grown-up you love will die before they become very old.

WILL I EVER SEE THE PERSON WHO HAS DIED AGAIN?

When someone dies they do not come back to life again. This is why people become so sad when someone they love dies. They miss the person who is gone. Right now you miss someone who has died. Maybe you will always miss them. But you will probably not always feel as sad about it as you do now.

Not all people think the same. Some people believe that when they die they will meet the people (and sometimes even the animals) they love, that have died before them. What do you think?

HOW DO I STOP FEELING SO SAD?

It is natural to cry and feel sad when someone you love dies. You miss them. You may feel lonely. You may feel confused too. Most people, not just children, feel the same way when someone they love dies.

Right now you are trying to understand more about death. This will take some of your sadness away. It helps to ask questions. It also helps very much to tell your family and friends how you feel. It helps most of all not to pretend. If you are sad, don't pretend you are not. If you aren't sad, don't feel bad about it or try to make yourself feel that way. We are all different in our own special way.

HOW LONG WILL I LIVE?

No one knows how long he or she will live. We do know that we will not live forever. Imagine how crowded the world would be if people lived forever! We know that when we grow old, death gets closer. This does not mean that people worry all their lives about growing old and dying. As we grow older, we learn more about living and dying.

Sadness is something like the pain you feel when you hurt yourself, but it is a hurt of the mind not the body. At first it hurts very much. But it will either hurt less each day or you will learn to live with the hurt.

HOW LONG DO YOU THINK WILL YOU LIVE?

Hopefully, a long, long time.

DO PEOPLE DIE BECAUSE THEY ARE UNHAPPY?

Unhappiness can sometimes make us feel sick for a while. Sometimes people who are very unhappy can get different types of illnesses but almost no one dies just because they are unhappy.

Remember the times when you have been unhappy? Sooner or later you feel better again. You are able to smile and laugh again. Everyone goes through times like this. It has nothing to do with dying.

WHAT ARE FUNERALS FOR?

One of the nicest things about being a person is that we are able to feel love for another person. This doesn't end when that person dies. Funerals can help us to cry and say our goodbyes to someone we love. They are for sharing loving feelings about someone who has died. They give us the chance to remember with others the goodness and joy that person brought to our lives and give us our own chance to say goodbye. Going to a funeral will help you to understand and share with others some of the sadness that we all feel. It also helps us to see how much other people care too.

WHAT HAPPENS TO A PERSON'S BODY WHEN THEY DIE?

When people die they don't need their bodies and cannot feel pain any more. After someone dies we put their body in a coffin, which is a container made especially for them. This container can be made from lots of things, wood, cardboard, wool and willow are just a few. They are then taken to a cemetery. These are special places where we can say goodbye to the person we love. A cemetery is a quiet place where we can come and think about the person we loved. After we have said our goodbyes, their coffin is put into the ground.

Some people prefer to be taken to a crematorium after they have died. Here their bodies are made into ashes, which can then be scattered or buried in a special place. This might be in the gardens at the crematorium, or in a wood, on a hill or wherever the person who has died especially liked to be.

CREATIVE WAYS TO ENCOURAGE COMMUNICATION

Sometimes, as grieving adults, it can be very difficult to find the words to express how we feel. Children and young people also experience this difficulty. This could be for a variety of reasons:

- Confusion – they have not yet worked out what it is they are feeling
- Overwhelmed – due to the depth of feeling they cannot find the words to describe how they feel
- Developmental issues – they may not have the ability to express themselves verbally
- Ignorance – they may not have received enough factual information to feel they are making any sense of their feelings
- Guilt – they may feel that explaining how they feel will cause upset, so they stay quiet to protect those they love
- Shame – what they feel may be so unrelated to the feelings being expressed around them that they cannot contemplate sharing it

Our brain does not always store memories as words since it is influenced by all our senses. The mind stores information as images, smells, sounds, tastes and textures. Luckily there are many nonverbal ways through which we can encourage our child to explore, find, sort out, explain and release feelings, no matter what age they are.

HERE ARE A FEW IDEAS TO INSPIRE YOU:

Reading, writing and storytelling

Reading books, or being read to, can also help young people to identify how they may be feeling. There is plenty of choice and you can read about some of them on the Balloons website (see the Useful Resources section at the end of this book).

Writing a diary, a letter, poem or song are private ways for young people to express themselves.



Creating stories can also help, no matter how unrealistic the tale is. Stories can be written, spoken or even acted out with the use of toys or puppets. The most important thing is that the story is completely child directed and the adult's role is simply to encourage the development of the story by asking questions like: "What happened next?"; "What did she say?"; "Tell me a bit more". Not all stories have happy endings and it is important for it to end the way the young person wants it to.

Metaphor is the language of the right brain. It works through symbol, sound and image and is a wonderful communication vehicle for all ages. Asking a child or adolescent how they feel often ends with an "OK" or a "don't know". If you ask a young person if they were an animal (or sweet, tree, noise, smell, etc.), what would they be, you will be amazed at the results. The important thing is to not read into it what you think they mean but to then ask them, "So, tell me about..." After all, what means one thing to someone will mean something else to another.

There are many books you can purchase full of photocopiable activity pages; however it is not difficult to create your own. For instance, draw a wall and on it draw five doors. Put one sign on each door: Angry Room; Sad Room; Happy Room; Room of Questions; Scary Room. Ask your child to pick a door and tell you what is behind it. Try to encourage them to be as detailed about the contents of the room as they are able. When you use activity sheets it is helpful to try and have uninterrupted, quality time.

Physical activity

Sporting activities require focus and discipline and provide a distraction or temporary escape for the busy mind. This time out can also be used to release stored up feelings such as unexpressed anger. All these activities require complete focus: running, dancing, rugby, football, tennis, squash, swimming, martial arts.

General day-to-day activities can be used to switch off or to focus on angry or sad thoughts. These are all helpful activities: throwing stones into water; throwing glass bottles into the bottle bank; ripping up newspapers as they are placed in the recycle bin; singing loudly to a favourite song (remember their idea of good music may not be yours); watching a really sad film; playing computer games; or even using something as simple as colouring, cutting out and sticking.

Play board games. Snakes and Ladders can be adapted so that when you go up a ladder you have to say something you love, like or enjoy about yourself or someone else and when you go down a snake you say the opposite. Many games can be used in this way.

Whole beings

Our body is not separate from our mind. Both communicate to and through each other, to make us a whole being. You can help your child to work out what they feel by looking at the way their body is responding. For instance, when we feel excited we may get butterflies in our stomach; if afraid our legs may turn to jelly; when upset we may feel tight in our chest and feel like there is a lump in our throats; being angry may make us hot and twitchy and increase our heartbeat. Recognising this is useful for young people who find it difficult to name what they feel.

Relaxation during this difficult time is as important for the family as communication. It is often seen as a luxury but during stressful times it is essential that all concerned have time out. A bath or a walk on the beach, a good book, or favourite TV programme can help you to relax together.

Try squeezing clay, playing with water, playing with sand, kneading bread dough, making biscuits and icing faces on them to express feelings. These are all tactile activities that can assist relaxation.

Stress levels will also affect sleep. As soon as the body begins to relax, the mind kicks in. One exercise you can use to promote relaxation is called muscle tensing. You can do this standing, sitting or laying down, as long as you are comfortable. It can be fun to learn this as a family and then it can be used individually:

1. Start with your feet. Tense your muscles in your toes and feet, screwing them up as tightly as possible until you can no longer hold it then let the muscles go all together
2. Then move up into your calves, include your feet, and do the same.
3. Slowly add other body parts in order, i.e. knees then thighs, until you reach your face
4. The final tense should include the whole of your body, mouth, eyes, tongue, arms hands, etc. Hold it as long as you can then let go all at once.

If you still feel tense then repeat the exercise again

Helpful aids

As a family, it can be helpful to find general ways of communicating feelings without words. For instance, make a feeling chart to go on the wall and each morning you all record how you are starting the day and in the evening how you are ending it. This will help you to be aware of each other's needs.

Draw or paint different facial expressions on pebbles and use them to share feelings.

Making worry dolls is a great idea for the under tens. They can be made from dolly pegs and clothed by wrapping wool around them or drawing on them. Felt clothes and stick-on eyes can make them easier to identify with. The idea is that the young person shares their concerns with the worry doll before going to sleep, then places it under their pillow. The worry doll will then take away their worries whilst they sleep.

How Balloons can help

We have lots of ideas for creative family activities which you can do together. Undertaking shared activities can be a very special experience for families and if it would be helpful to discuss this further then we would love to hear from you.

CREATING LASTING MEMORIES

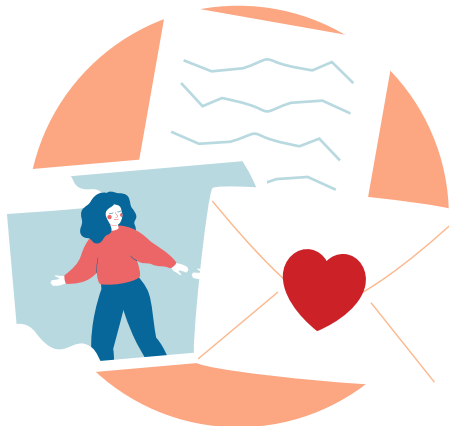
LEAVING A LEGACY

It can be really difficult to think of positives at a time like this, but having time before someone special dies means there is an opportunity for that person to leave a legacy that may help their child emotionally when they are no longer there.

Feel assured that thoughts and acts that show a bereaved child they have been truly thought about are invaluable and can never be taken away. The reality is that the absence of a loved one will impact upon a child every time they have a significant life event, but they can still be a part of those occasions.

The following are some ideas from people who have been determined to remain a proactive part of their children's lives after their deaths by leaving each person they wanted to say goodbye to:

- a letter
- a poem
- a recording of their voice
- video messages
- birthday cards
- a special token that reminds them of the deceased (ask them what they value, their answer may surprise you)



Think about what important events will be missed and ensure that there is a presence somehow. Arrange for a letter or speech for special occasions such as:

- when the going gets tough
- passing a driving test
- graduation
- wedding day
- birth of grandchildren

MEMORY BOXES

Making a pre-bereavement memory box is something that can be done in isolation for someone but can also be done with them. The more open and honest the discussion is about pre-bereavement, the easier the adjustment and acceptance will be for the young person. Knowing they were loved and respected will comfort them deeply. It may also be helpful for the sick person to hear what they are going to miss. Share as much as possible in the time available so that 'parent' and child continue to learn about each other right up until the very end. You can buy a variety of special boxes, or you can make one and decorate it together. Doing something constructive can help the communication flow; each time something is placed in the box, talk about what it represents.

Ideas to include in a pre-bereavement memory box are:

- A special film enjoyed together.
- Photos of a life before the child and of a life together
- Letters
- Poems
- Small gifts exchanged with each other
- A lock of hair
- Pictures and cards made or given to each other
- A tape of favourite music
- A favourite perfume
- Tokens from places visited together
- A piece of jewellery

Family portraits can be a great source of comfort and provide another way of capturing memories.

A plaster cast of hands can be used to console a child. When they miss their 'parent' they can place their hand in the cast and speak to it as if they were with them.

Baby books are also a wonderful record of milestones that occur early on in life. Those who are leaving behind a very young child may wish to consider entries that describe how they felt when they first set eyes on them and held them in their arms and so on.

This is especially important as it is rare for a child under the age of two to have their own memories to call on.

There are also websites and apps that help to record memories, making a lasting video legacy. See useful resources for further information on apps.

These tasks will not be easy to undertake. Making an end of life clearer to a child inevitably results in a self-confirmation of having to say goodbye. There is no shame in being open, honest and real about emotions. Sharing them will give permission to those who are trying to 'keep it together' to show their emotions. Try being together, crying together and remembering together.

MEMORIES CHILDREN CAN CREATE

There are many ways in which a child can store memories of their special person. Memory boxes, memory jars and memory books are a few examples. When children create anything to do with memories they need to be done on an individual basis so that they are special to the individual child.

Appropriate questioning can be used to assist a young person to store memories. You might include the little things like: what was their favourite meal; did they have any funny habits; what did they like to do; what were they good at; what were they not so good at; did they have a special name for you?

Memory boxes

When you are helping a child under five with a memory box it is important to be aware that as they grow older they will find it more difficult to recall memories of their own. With this in mind it may help them to include some stories and memories from other close people around them. They may need help to record them appropriately for their box.

For examples of what to place in the box see page 39.



Memory jars

For this activity you will need some coloured chalk, table salt, spoon and a jar. It is important with younger children that the rim of the jar is not too narrow, to avoid spillage and frustration. For older children use any glass container that can be sealed to make something more visually satisfying.

1. Crush a coloured stick of chalk with a rolling pin until it is a fine powder and place it in a bowl or plastic container
2. Mix table salt into it until you have the colour and amount you want
3. Do this with each colour separately until there is a good range to choose from
4. Think of memories as the activity takes place and record them on a mobile phone or other device or write them down
5. Then choose a memory, think of a colour to represent it and spoon some that colour salt into the jar
6. Use larger amounts for the most significant memories, letting it land however it falls
7. Try to be careful not move the container too much as it will flatten or mix the salt
8. Continue to do this with your memories until the container is full
9. Top the jar up as much as possible so that when the lid is put on the salt cannot move
10. Transport the jar carefully to the place you would like to put it

11. Memory books (and photograph albums)

These can take the format of a scrapbook, providing pages of information and souvenirs that can be viewed by the young person. It can be divided into sections. Here are some that others have found useful.

- _____ before I was born
- Before _____ was ill
- Whilst _____ was ill
- After _____ died
- My special memories of _____

Other activities

Making patchwork comforters and covers from the clothing of someone special is a lovely way to keep that person close to you. There may be occasions where outfits spring to mind and can bring back memories of that time. These could be created as a family.

Bunting could also be created in the same way. Then when there are family events that your special person would have attended, the bunting could be placed in a room to represent them.



Create a Christmas decoration that represents the person you are missing. A small object belonging to them, like a cufflink or earring could be included in it. Every year it can serve as a small but loving memorial.

DEALING WITH THE DEATH

Having the opportunity to say goodbye or telling someone that you love them before they die can be very important. Unfortunately, it is very hard to predict the exact moment it is likely to happen.

Pre-bereavement time is not just about the last few hours of someone's life, it's about making use of the months, weeks, or days that you have together. That's why it's so important to make the children aware that someone is dying and give them the opportunity to say what they want to say whilst they have that chance. What they want to say will very much depend on the relationship that they have had with that person. For example, they may need the opportunity to express anger and disappointment or ask personal questions to make sense of their experiences and relationship. When someone dies suddenly that opportunity is denied.

It can be a really positive experience for children to be present at the time of death; however, there may be exceptional circumstances when your healthcare professionals may advise against this.

Prepare them for the changes they may see:

- They may look paler
- Their hands may feel colder to touch
- Breathing may be more laboured or noisy
- Some people can become agitated and restless, but the nursing staff can usually give an injection to help relieve this
- They may be semi-conscious, still able to hear when you talk to them although they may not respond
- They may be receiving oxygen. As the person becomes weaker the need for oxygen lessens, so removing the oxygen mask means you can get physically closer and be able to touch or kiss the patient's face
- There may be catheters or drains in place to improve the person's comfort
- They may be receiving pain relief and other symptom control via a portable syringe driver. The nurse can explain how this works, plus any other questions the children may have

Most people leave this world peacefully, slipping into a state of unconsciousness.

WHAT CAN THE CHILD DO?

- Sit quietly holding the patient's hand or doing a gentle hand massage. If the patient is restless this can help to calm them
- Talk, sing, read a poem or from a book, say a prayer or play a piece of music. Hearing is the last sense to disappear
- Freshen the patient's lips with sponges dipped in water, juice or mouthwash solution
- Wash their hands and face. Comb their hair
- Hold the phone to their ear if anyone important is absent and is calling to say "goodbye"
- Lie on the bed beside them and cuddle or hold them if they wish to. This is easier in the privacy of your own home, but if this is their mum or dad, they must be given the opportunity to do what they feel they want to. They will never have this chance again

As the illness develops from the palliative stage to the terminal stage, children may be much more reluctant to leave the close proximity of home or the hospital. Hospices and most hospitals have the facilities to make up extra beds or offer you overnight accommodation if you wish to stay.

If you are managing to care for the person at home, you may have access to out-of-hours support in the form of Marie Curie night sitters. Your GP or district nurse can arrange this for you.

As the illness progresses, or if symptoms such as nausea or pain become more difficult to control, it may not be possible for the person's illness to be managed at home. Juggling everyone's best interests and wishes can be incredibly difficult for the 'well' caregiver to do, they can only do their best. Take advice from your GP or palliative care specialist nurse if you need it.

Hospital wards and hospices that are used to caring for people with terminal illnesses are usually geared to accommodate children and should welcome them to the ward. Extended visiting times and staying overnight can often be arranged.

Usually mobile phones are allowed in hospitals. If your child cannot, or does not wish to visit, they can text or ring. If they are away at university, or just too far away to make it back in time to see the sick person, you can place the phone to the patient's ear and your child can say their goodbyes even if the patient is too poorly to respond.

WHEN DEATH OCCURS

Should children view the body? It's often a difficult decision for parents to make. There is no right or wrong answer but if the death was peaceful then the children should be given the option to see the body if they wish to do so, provided that they are prepared for the changes they will see.

- The most obvious things will be the colour and the temperature of the skin. Hands will feel cold when the child holds them, or the cheek when they kiss them goodbye
- Even tiny babies can be involved in saying goodbye. It may seem unimportant at this time, but it will be an important memory for them in later years when you are able to say, "We put you in 'Dad's' arms," or, "You gave 'Mum' a kiss goodbye"
- Children of any age can help choose the clothes that mum will be buried in, or help the nurses to brush her hair
- Children may wish to spend as little time as possible in the presence of the dead person or they may wish spend time talking to them. Be guided by what's best for your child, by what they want not what other people think is appropriate

- The child may ask if the person who has died is 'asleep'. Answer truthfully and try to explain that death is not like sleep. "They may look as if they are asleep, but when you are asleep you still breathe, and your body is warm because you are just resting. When you die your body isn't able to breathe, feel or respond anymore"
- Allowing children to see and touch the dead person lets them see the changes for themselves and helps them to come to terms with the fact that the 'person' is no longer there, that it is just the body
- They may ask you what has happened to the dead person. "Where have they gone to now?" Your answer will depend on your religious beliefs, the age and developmental stage of your child. You might want to request our information sheet on this which gives more information
- The part of the person that makes them special and unique is how they looked, the way they laughed or smiled, their voice. Lots of these characteristics will live on in our memories, and indeed often in the faces and the mannerisms of the children they've left behind

SUPPORTING FAMILIES IN THE POST-BEREAVEMENT PHASE

Much of what we have outlined in the previous section on the pre-bereavement phase is also relevant and useful when supporting children and young people post-bereavement.



SHOULD YOUR CHILD ATTEND THE FUNERAL?

If they wish to do so after being prepared for what they will see and do. For them to be given the choice is the most important thing as it will have an impact on their perspective for years to come.

They cannot make an informed choice unless they know what to expect. Funerals are naturally sad but they also provide an opportunity for people to come together to celebrate someone's life.

IF YOUR CHILD WISHES TO ATTEND:

- Speak to your funeral director about services that involve/ include young people
- Ask their advice about explaining the difference between cremation and burial. Sometimes it's possible for children to visit the crematorium beforehand to understand more about the process
- Recruit another significant adult to help you support your child during the service
- Let your child choose the person they would like to sit next to. If they'd prefer not to have to sit right at the front where they might feel everyone is watching them, then that's perfectly all right
- Older, more confident, young people might wish to read or say something special about the person
- Younger children can be given paper and crayons and asked to draw pictures
- If there are several children attending, and space allows, create an area with writing and craft materials where they can draw, write or paint farewell messages to the deceased. These messages can be given to family members afterwards
- They can take something special to hold during the service, for example a special keepsake from the deceased or a favourite toy
- If useful, please feel free to contact us to request the Balloons information sheet on funerals

HOW THEY CAN BE INVOLVED, WHETHER OR NOT THEY GO TO THE SERVICE

Just because a child doesn't wish to be present at the funeral service, doesn't mean that they should miss out on being part of the preparations and the time together afterwards.

- They can help to design and create the service sheets
- Choose the hymns and readings
- Choose the flowers and the type of coffin
- Help to decorate the coffin
- Choose a theme or colour that people might like to wear. For example they might like everyone to wear their mum's favourite colour
- At the gathering afterwards children can help by handing around refreshments

Provide a memory book for the guests to write down their favourite memories of the deceased person. This is a lovely keepsake for the family.

Tell your child it's perfectly OK to laugh and have fun. The deceased person wouldn't have wanted you to be sad all the time.

If the deceased person is going to be buried, then you can usually put other articles into the coffin with them, like a special teddy that a child feels will 'look after' dad, letters, photos etc. However, if they are going to be cremated there are a lot more restrictions on what can be included. Ask your funeral director to tell you what's permitted.

If a child has set their heart on including something not allowed, then consider taking a photo of the young person holding the toy/ article and placing the photo into the coffin. Poems, letters and pictures are all excellent ways for young people to express their feelings and give them the opportunity of saying what's in their hearts but may not have been voiced.

If you can choose a venue with an outdoor area, it will provide a place for young people to 'escape' to and to take time out with their friends.

GRIEF IN DEVELOPMENTAL STAGES

Adults often mistakenly think that children do not mourn because they may not demonstrate their grief in the same way as adults. The way that they mourn, and their understanding of death and dying, depends on their cognitive and emotional development. They will model their responses from their experience of others around them. If you hide your tears from them, they may well hide theirs from you.

Children dip in and out of grief. They need to escape and will come back to it when they can cope with the feelings. For example, they may be inconsolable one minute, then outside playing and laughing with friends the next. They need to feel that it's OK to play and act normally; it does not mean that they have forgotten the deceased person, or that they don't care.

Below is a rough guide to children's reactions to the death of a parent or someone close to them. These developmental stages may well overlap or merge into each other.

UNDER THREE

Children under the age of three may not be able to speak well enough to express how they are feeling, but they can show very definite signs of anxiety at being separated from someone they love by calling out for that person who is no longer there, or doing things out of character.

AGE 3-5

They probably won't be able to grasp the permanency of their parent's death for several months. One day they may tell you that their daddy is dead, the next they will ask if he's picking them up from school. Children at this age make sense from repetition, so they may ask you the same question again and again or re-enact the event through play. This can be upsetting for the carers but it is completely normal. They are likely to suffer from separation anxiety if their primary caregiver is absent from their sight.

AGE 6-8

They are beginning to understand that death is permanent, although they still hope and believe they may in some way reverse it (magical thinking). They may even blame themselves in some way for causing the death. It's so important to listen to a child who feels this. Giving them a simple explanation of what really caused it, or reassurance that nothing they said or did made it happen, will have tremendous benefits for a child.

AGE 9-11

They need to have details about the death – how, when and why – to help them accept the reality of the situation. School is an important place to escape to. If teachers and friends are aware, they can have a really positive role in supporting and enhancing their healing process. They may demonstrate disruptive or bullying behaviour, or become withdrawn and become bullied. They may have dreams or nightmares about the deceased. They may find it difficult to express themselves, so therefore need opportunities to talk about their feelings.

Younger children may also be concerned about your safety and theirs; they may become over protective, clingy or revert to childlike behaviour such as tantrums or bedwetting.

AGE 12-14

The teenage years can be notoriously difficult in a regular household but in a bereavement situation they are even more likely to be emotionally withdrawn, avoiding having to acknowledge and deal with the grief of others as well as their own. Their peers are very important to them at this time and they may choose to spend more time out from the family and the grief situation. Teenagers show their grief in different ways. Some are more likely to openly talk and cry with friends, other are more inclined to hide their feelings and some channel them into aggressive behaviour.

AGES 15-17

These young people are more likely to demonstrate their grief in a similar way to the adults close to them. They may deal with the situation by taking on more responsibility within the household or shield their family from their own grief by confiding in friends and appearing aloof. They are usually reluctant to grieve openly so will either bottle up their tears or find their own private space.

It is important to remember that as children mature into young teenagers and then into adulthood, their understanding of their loss and how it impacts on them develops. It can mean that they need time to adapt to these changes by discussing them with someone they trust, which may not necessarily be the remaining parent. Going to a new school, to college, getting married, having their own child are all times when a loss can be more acutely felt.

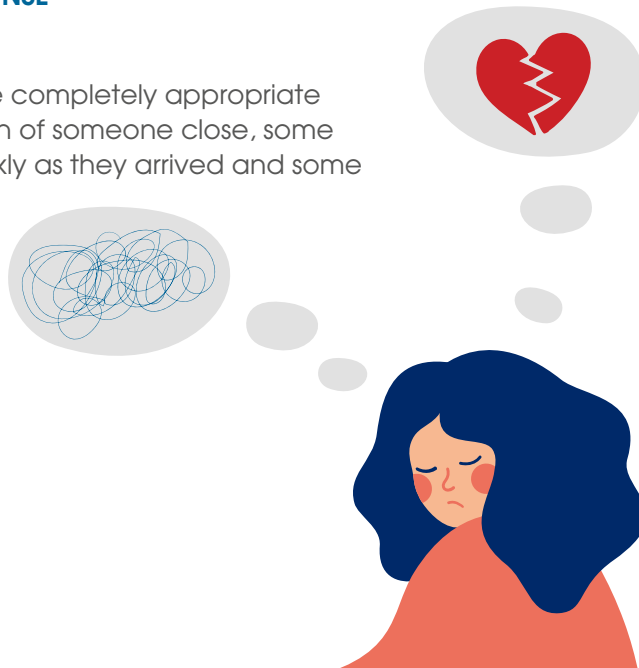
COMMON GRIEF RESPONSES

A brain's response to grief can traumatise, comfort, preoccupy and protect grieving children. It is extremely important when acknowledging reactions to grief, not to judge or measure by our own experiences. Children have their own individual relationships, and understanding, which will affect how they respond. They will revisit their grief time and again through the following years, each time they do so, making sense from their new level of understanding.

Grief responses fall into four categories:

1. **FEELINGS**
2. **PHYSICAL SENSATIONS AND REACTIONS**
3. **THE BRAIN'S RESPONSE**
4. **BEHAVIOURS**

All of the following are completely appropriate responses to the death of someone close, some will disappear as quickly as they arrived and some will hang around.



FEELINGS

Sadness; anger; guilt; anxiety; shock; helplessness; lethargy; loneliness; yearning; relief; numbness; fear; apathy; isolation; joy; abandonment.

PHYSICAL SENSATIONS AND REACTIONS

Tight chest; tight or sore throat; dry mouth; frequent swallowing; headaches, breathlessness; stomach upsets; muscle weakness; loss of appetite; jumpiness. Other physical responses associated with stress such as bedwetting; facial tics; eczema; stammering.

THE BRAIN'S RESPONSE

Disbelief; confusion; being in another world; sense the presence of, or hearing, the person who has died; hallucinations; flashbacks; staring into space.

BEHAVIOURS

Sleep disturbances; absent mindedness; not wanting to eat; overeating; sighing; social withdrawal; clinginess; calling out; dreaming of the deceased; restlessness; repeating events; repeating questions; crying; disruptiveness; aggressiveness; overactivity; avoidance of reminders; idolising the dead person; not wanting to enter the home; not wanting to leave the home; not wanting to leave other loved ones; possessiveness of people and objects; rejecting offers of help and affection.

Reactions children are surrounded by will influence how they respond. If they are in an environment where crying is either private or not acceptable then a child may display aggression as an alternative, since being told off is better than being ridiculed.

WHEN TO SEEK PROFESSIONAL HELP

There is no textbook time when significant grief will stop or disappear. Some theorists suggest three years as an average but as one child so simply stated:

“Why do people think it should be easier to not have a dad for four years than it is to not have a dad for three?”

I can see her point entirely, can't you?

Grief does not go away, we just learn to live with it and adapt our lives around it. Most children and young people will be able to experience grief without additional support if they have someone close to them who will encourage, listen, accept and respect what is being felt and shared. However, sometimes children will prefer to talk to a stranger for fear they will make things worse for the person they care for.

Seek professional help when:

- A child is clearly stating that they want to talk to someone else about their grief
- Responses in the four categories of grief begin to dominate and create significant changes in a young person's personality
- Other adults around you start commenting upon, or sharing concerns, about the way your child is now responding
- The best way to support your grieving child is to ensure that you have enough support and information yourself. Remember, you are grieving as well.

If you have any concerns about your child there is no harm in contacting a grief support service to discuss whether they feel your child's responses could benefit from some additional and more specialist support.

If you do not know where to start looking for such a service, then speak to your GP, hospital, school, or hospice. Failing that, contact one of the national organisations such as the Children's Bereavement Network (details in the Useful Resources section on page 56), they will point you in the right direction.

KEY THINGS TO REMEMBER

- You can only do your best
- No one is perfect, knows all the answers or just what to say. We all get it wrong sometimes
- Your children will see that you are trying your best to do what's right for them.
- Not telling creates anxiety, fear and misunderstanding
- They will almost certainly cry and be upset, but it's better that they cry with you than cry alone
- Evidence shows that children who have been included at this time are much less likely to suffer from complicated bereavement issues later in life
- They will be able to look back at this sad, but precious time knowing that they were able to contribute something special
- Involve the school/nursery
- Talk to friends and recruit their help and support
- Set aside times for visitors to call or visit
- Allow plenty of time to just be a family
- Always leave the 'door open' for your child's next question
- Don't press them if they don't want to talk
- Try to address their fears and concerns
- Try not to make promises you may not be able to keep. For instance, your partner may wish to die at home, but in reality this may prove too difficult to manage. Don't feel guilty; you can only do your best
- Children grieve and respond to distressing situations in different ways from adults
- Just because they may cry one minute, then laugh and play the next, does not mean that they don't care
- Children deal with information according to their understanding and cognitive development. Children with additional or specific learning and educational needs will need to be given simple explanations that you can revisit and expand on in time
- Each stage in your child's development will spark new questions. Be aware that this is normal behaviour, and necessary for them to be able to make sense of the situation

SUPPORTING BEREAVED CHILDREN & YOUNG PEOPLE WITH ADDITIONAL NEEDS

You may be supporting bereaved children and young people who have additional needs. Sometimes people assume that children with additional educational needs should not be involved in the grieving process, either because they need to be protected from it or because they are not able to understand what is happening. The key thing to remember is that grief is universal – it doesn't just impact on certain sections of society; everyone can grieve, and everyone deserves support.

At Balloons we believe that you are best placed to judge the individual needs of your child, and it is certainly the case that children with additional needs might actually be more vulnerable if excluded from mourning. What's important is understanding your child's individual needs and responding to them as best you can. You will already have a history of supporting your child through upset, and you will be able to use the lessons learned through that to support them whilst they are grieving.

Sometimes, the additional challenges come about because the child is unable to understand what death really means, and they may find it difficult therefore to process an appropriate response.



We have found a book published by Winston's Wish in 2020, written by Sarah Helton – *We All Grieve* – extremely useful. It is a book that can be used by both families and professionals. It provides the information, resources and confidence to talk about death and support all bereaved children. The book covers a broad range of SEND, including Autistic Spectrum Disorder and Profound Multiple Learning Difficulties, and aims to support families, SEND schools, mainstream schools, hospices (child and adult), social care services, day centres and residential care providers all over the UK. It looks at how children with SEND are affected by a bereavement and how those around them can support them to develop the child's understanding of death and loss. It also offers information, practical suggestions and ideas for activities, as well as where to find other support. The book is available to buy from the Winston's Wish website. There are of course other books available which we can recommend.



Alongside this – we can support you with tailored ideas and information. You can contact us on our support line, or email us, and together we can explore how best to support your child with additional needs. We can provide practical ideas as well as encouragement and support.

It is important that together we acknowledge the importance of supporting grieving children with additional needs.

USEFUL RESOURCES

BOOKS

There are many books that assist families and young people experiencing grief. For more information about specific resources please look at our website - www.balloonscharity.co.uk

Time To Go: Alternative Funerals by Jean Francis
iUniverse.com - ISBN 9780595318599

Before I Die by Jenny Downham
The story about the wish list of a 16 year old with only months to live.
David Fickling Books - ISBN 978-0385613460

The Day the Sea Went Out and Never Came Back by Margot Sunderland & Nicky Armstrong. *A story about a dragon going through the grieving process* - Speechmark Publishing Ltd - ISBN 978-0-86388-463-4

Grief Encounter Workbook by Shelley Gilbert
A workbook to encourage conversations about death between children and adults. - Grief Encounter Project - ISBN 978-0-954834-0-3

Mayfly Day by Jeanne Willis and Tony Ross
A story about the one and only day a Mayfly lives - Andersen Press - ISBN 978-1-84270-492-9

The Natural Death Handbook, 4th edition edited by Stephanie Wienrich and Josefine Speyer - Random House - ISBN 9781844132263

Straight Talk About Death for Teenagers by Earl A. Grollman
How to cope with losing someone you love - Beacon Press - ISBN 978-0807025017

We Need to Talk About the Funeral by Jane Morrell and Simon Smith
101 practical ways to commemorate and celebrate life - Accent Press - ISBN 978-1906125011

When Dinosaurs Die by Laurie Krasny Brown and Marc Brown
A guide to understanding death - Little, Brown - ISBN 978-0-316-11955-9

When Uncle Bob Died by Althea
A conversation starter about many different family members dying. Drawn from the experiences of a class of children - Happy Cat Books - ISBN 978-1-903285-08-4

Words to Comfort Words to Heal compiled by Juliet Mabey
Poems and meditations for those who grieve - Oneworld Publications - ISBN 978-1851681549

We all Grieve – Sarah Helton, Winston’s Wish

USEFUL CONTACTS AND WEBSITES

The Bereavement Advice Centre
Support and Advice for people about what to do after a death.
T. 0800 634 9494
www.bereavementadvice.org

British Humanist Association
A national charity working on behalf of non-religious people. The website includes information about Humanist Funerals and Memorials.
T. 020 7079 3580
www.humanism.org.uk

Care for the Family
Provides a Bereaved Parents Network, supporting bereaved parents with events, resources and training.
T. (029) 2081 0800
www.careforthefamily.org.uk

Child Bereavement Charity (Trust)
For children and young people’s bereavement support services in your area.
T. 01494 568900
www.childbereavement.org.uk

The Child Death Helpline
For anyone affected by the death of a child.
T. 0800 282986
www.childdeathhelpline.org.uk

Childhood Bereavement Network
For children and young people’s bereavement support services in your area.
T. 020 7843 6309
www.childhoodbereavementnetwork.org.uk

Balloons

Provides pre and post bereavement support for children and young people aged 5 to 25 in Exeter, Mid and East Devon.

T – 01392 982570

www.balloonscharity.co.uk

Compassionate Friends

Bereaved parents offering friendship and understanding to other bereaved parents.

T. 0845 123 2304

www.tcf.org.uk

Contact-a-family

Support and information for parents caring for a child with any disability, long term illness or special need.

T. 0808 808 3555

www.cafamily.org.uk

CRUSE Bereavement Care

For adult bereavement support services, and support for young people in For funeral advice.

0845 230 1343

www.nafd.org.uk

Partnership for Children

Good mental health for children, helping your child cope with bereavement.

T. 0208 974 6004

www.partnershipforchildren.org.uk

SIBS

For brothers and sisters of disabled children and adults, with any disability, long term illness, or life limiting condition.

T. 01535 645453

www.sibs.org.uk

Natural Death Centre

Information on 'green' funerals and arranging a funeral yourself.

T. 0871 288 2098

www.naturaldeath.org.uk

WAY Foundation

provides a self-help social and support network for those widowed up to the age of 50, and their families.

www.wayfoundation.org.uk

Winston's Wish

Support for those caring for children affected by the death of a parent or a sibling, and for the children themselves.

T. 08452 03 04 05

www.winstonswish.org.uk

APPS, BLOGS AND SOCIAL MEDIA

There are a range of organisations who provide apps and content on Social Media which many people find helpful. A few are suggested below.

Apart of Me

A mobile game to help children and young people cope with life-limiting illness, death and loss. Aimed at 11+

<https://www.apartofme.app/>

Record me Now

The RecordMeNow App lets you make a lasting video legacy for loved ones. The app is question-prompting and video-recording. It is private and free.

RecordMeNow – Free personal legacy app

Smiles and Tears

An app for young people developed by charity Nelson's Journey

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

The Good Grief Trust

Useful information, helplines, advice and encouraging stories from others.

Home – The Good Grief Trust

Grief Encounter

Website, Live chat and helpline for bereaved children and young people

Home SUPPORTING BEREAVED CHILDREN & YOUNG PEOPLE - Grief Encounter

SAYING GOODBYE

offers advice and guidance for adults on how to help children and young people deal with an expected death in the family and how to cope after the death of someone significant.

The booklet will be of great help to adults going through this most difficult and painful time. It will also be a useful resource for professionals working with pre- and post- bereaved families.

Saying Goodbye has been written and published by Balloons. Balloons is a small charity working across Exeter, East and Mid Devon. Balloons provides support for children, young people and their families before an expected death, or following the death of someone significant in their lives. The work of Balloons is carried out by a professional, multi-skilled team of staff and trained volunteers. We are a free service and we rely entirely on donations and grants.

If you would like to make a donation towards the cost of this booklet, we suggest £3.00 to £5.00. Donations can be made via our website

www.balloonscharity.co.uk

