MACMILLAN CANCER SUPPORT

Preparing a child for loss

"Harvey's sessions with his counsellor really helped him. It gave him a place where he could be completely honest about how he felt, whatever his feelings were."

Katie, aunt of Harvey, who lost both his parents

About this booklet

This information is for parents or guardians who are near the end of life. It aims to help you prepare and talk to a child or children about your death. Partners, grandparents, and close family members may find it useful too. It may also help you talk to children who are already dealing with the death of a family member.

This booklet is written with the childhood bereavement charity Winston's Wish. It is a practical guide to help you have some of the hardest discussions you will ever have.

We include details of some people and organisations who can support you as you prepare to talk to your children about what is happening (pages 48 to 49 and 58 to 61). These people will be able to help you and your family now and in the future. You do not have to face this difficult time alone.

You will find suggestions on how to:

- tell a child or teenager you are going to die soon
- understand their reactions
- help them cope
- explain what is likely to happen.

Finding out that a diagnosis is terminal is shocking and emotional. We hope that the suggestions in this booklet are helpful, but you may have different ideas about how to approach your children. There is no right or wrong way to cope with this situation.

Even with support, discussions can be distressing for you and the children, or they may not go as you had planned. The important thing to remember is that you are trying to do the best you can in really difficult circumstances.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 58 to 63, there are details of other organisations that can help.

There is also space to write down any notes or questions you might have for your doctors, nurses, or other healthcare professionals supporting you through this time (page 64).

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

Quotes

Throughout this booklet, we have included quotes from families affected by the loss of a parent. Some are from Katie, who is on the cover of this booklet. Others are from people who have chosen to share their experience with us.

To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

Your feelings about your death	7
Talking to your children about your death	11
Help and support	37
After your death	45
Further information	51

Your feelings about your death

Coming to terms with your own death 8

Coming to terms with your own death

Before talking to your children, you may need some time to process your own feelings about being told you will not recover from cancer. If you are finding it particularly hard to manage your own emotions, it will be harder to talk to your children about what is happening.

If you are feeling unwell or low, you may not feel emotionally strong enough to begin difficult conversations with your family and friends. You may want to avoid any discussion about what is happening.

Or, if you have a partner, you may find that they do not want to talk about it. This may be their way of coping. But it can make it harder for you and your family to support and understand each other.

Try to talk to the different members of your healthcare team about what is likely to happen in the coming weeks or months. If you have a partner or close family or friends supporting you, try to talk to them about your feelings and concerns.

If you prefer to talk to someone outside your situation, you can call the Macmillan Support Line on **0808 808 00 00** or contact Winston's Wish (page 58). Some people find online support a good source of help too (pages 54 to 57).

Talking things through with someone can help you to make sense of the options you and your family have at this painful time. It can help you plan how you are going to tell your children about what is happening to you and them. You may find it helpful to practice what to say to your child with another adult first. You could also think about the kind of questions your child may have and plan your answers.

Talking to your children about your death

Children's understanding of death at different ages 12

Talking to children about dying 19

Telling your children 24

Questions children may ask 32

Answering children's questions 34

Children's understanding of death at different ages

The way children understand and react to death can depend on their age and their level of maturity. It may be helpful to know how your children might react before you talk to them. Emotional reactions in children and teenagers can also appear as physical symptoms, such as headaches or stomach (tummy) aches. There may also be changes in their behaviour.

You may find yourself becoming upset or tearful when having difficult conversations with your children. This is normal and can help children understand that sometimes adults cry too when they feel upset. It can help your child know it is okay for them to cry and express their emotions.

"When Harvey's mum died, Winston's Wish talked to us and gave us some information. It was very difficult as he was only 2. There were no questions like 'Where's Mummy gone?'"

Katie

Very young children (aged under 3)

It can be difficult to know how much a child under 3 understands about death. They are likely to sense that something very serious is happening, even if they cannot understand what death means.

Their grief might show in behaviour changes. Some children in this age group may go back to an earlier stage of development. For example, a child who is on solid foods may only want to drink out of a bottle, or potty-trained children may stop using the toilet.

You may find the following tips useful when supporting very young children:

- Ask for support from healthcare professionals on how you can plan for the changes in your child's life and future care.
- Try to arrange for your child to spend as much time as possible with the person or people who will be caring for them in the future.
- Write down what your child does or does not enjoy so they can continue in a routine that works for them. For example, you could make a list of the music, food or books they like.

Young children (aged 3 to 5)

Children aged 3 to 5 may have an awareness of separation and death, but they may not understand what it means in the way older children do.

For example, they may imagine that a dead person will come back or is living somewhere else. Children may show some changes in behaviour.

They may be upset one moment and then behave as they usually would in the next moment.

You may find the following tips useful when supporting young children:

- Keep reminding children that you do not want to die and leave them. But explain that when it does happen, you will not be able to come back.
- Keep to daily routines when you can.
- Let them know that the cancer is not their fault.
- Reassure them that they cannot catch the cancer from you.
- Ask someone that you and the children know and trust to keep a special eye on how they are coping and feeling. Tell the children who you will be asking to do this.
- Tell someone you trust at playgroup, nursery or school what is happening, so that extra support can be arranged.

Older children (aged 6 to 12)

Children aged 6 to 12 know about death, but they may not always understand the emotions they feel. By about 8 or 9, children begin to understand death more like adults do. But they may still believe that if they are very good, the person who has died may come back.

They are more likely to worry that death is frightening or painful. Children in this age group have more vocabulary to understand their thoughts and feelings. Some will share how they feel, but others may become more withdrawn.

You may find the following tips useful when supporting older children:

- The suggestions for children aged 3 to 5 will still be helpful to many children in this age group.
- Use books to help talk about the end of life (pages 48 to 49).
- Let them know they can ask questions, and talk to them about the best people to answer them.
- Suggest that they write, draw or paint to express how they feel.
- Encourage them to continue with schoolwork, activities they enjoy and friendships.
- Let them know it is okay to enjoy themselves, and also to be sad.
- Give them small helpful tasks to do. For example, they could put flowers in a vase or bring you a glass of water.
- Explain the situation to a teacher (pages 40 to 41). You may also want to explain what is happening to a few parents of your child's close friends, who you know they trust. They may also want to offer support.
- If you are able to have a short walk, it may help to talk while walking. Or find a time when you are sitting side by side, such as on a car journey. This may help if your child struggles with serious conversation face to face.

Teenagers

Teenagers may find it harder than younger children to cope with the news that someone is dying. They are old enough to know that this means a major change and loss in their life. They are likely to experience confusion and shock. They may feel numb to begin with, then have a delayed reaction.

They may cope in ways that are difficult for you to understand or deal with. This might include:

- expressing anger
- missing school
- risk-taking or anti-social behaviour.

Some teenagers refuse to talk about what is happening. In this situation, it may help to leave them to talk when they are ready. Others may try to become closer to their parents. They may get angry with you or your partner in ways that can seem thoughtless. They may then feel guilty about how they have acted or blame themselves for you becoming ill. Or they may feel bad about spending time with their friends.

Teenagers need to know that there is no right or wrong way to feel at this time, and that it is okay if their feelings keep changing.

You may find the following tips useful when supporting teenagers:

- Ask them what they are most worried about. Sometimes their biggest worries are something that you can reassure them about.
- Ask them if they want to be included in any talks or discussions about your situation, in the same way as you would include an adult. This might depend on the age of the teenager.

- Make sure that they know someone is available to listen if they need support at school and at home. Support may also be available from those involved in supporting the dying parent, such as healthcare professionals.
- Help them see that talking about feelings is a positive and mature way of coping. Encourage them to talk to someone they are close to, such as their friends, a relative, a family friend or a trusted teacher.
- You could also ask if they would prefer to talk to a counsellor. It can be easier to talk to someone more removed from the situation.
- If they struggle with talking about how they feel, suggest they write a journal or poem, or draw or paint about how they feel.
- Give them time and space to themselves when they want it.
- Tell them about useful sources of information and support (pages 48 to 49 and 58 to 63).
- Encourage them to keep up with their friendships, activities and normal life as much as possible. Remind them that it is okay to have fun and do things they enjoy.
- Keep to usual rules and boundaries. These can be even more important now than before, as they can help teenagers feel safe.
- If your teenager is using alcohol or drugs as a way to cope, their GP or other members of your healthcare team can suggest the best support services for them to access. Young Minds has more information to support you and your teenager (page 63). Visit **www.youngminds.org.uk**

Winston's Wish (page 58), Hope Support Services (page 63) and Child Bereavement UK (page 58) have information about how children grieve at different ages.

" When my brother was diagnosed with cancer, Winston's Wish gave me advice on how to talk to the children about what was happening. He died 9 months later. Harvey was just 4 years old. "

Katie

Talking to children about dying

Preparing children for the loss of a parent is an incredibly hard thing to do. You know your child best, so will have some idea of the best way to talk to them. But talking over the different ways of approaching this can be helpful.

You do not have to do it alone. You may need a lot of support from family and close friends. Professionals can also help you, such as:

- palliative care nurses
- doctors
- social workers
- counsellors
- psychologists.

Sometimes, your closest relatives are so distressed themselves that they may not be able to understand the best way to help you or your children. And family members may have different views about when and how to talk to the children.

It might help you to involve them in your discussions with professionals, when you are ready to do this and are clear about what you want.

Be honest and open

Being honest and including children in what is happening is usually the best approach. It is natural to want to protect children from painful experiences. But we know that adults who had someone close to them die when they were young often wish they had been told what was happening. They knew something was wrong, but everyone told them the opposite, or would not talk to them at all.

This can be very confusing and just as upsetting as knowing what is really happening. It can also affect how someone copes with their grief after someone dies.

When talking about dying, talk openly with your children and use clear, age-appropriate language. This allows you to find ways of helping your children to cope in the future. It will also give you the chance to show how much you care for each other. It is often easier for children to hear information in small chunks, rather than all at once. You may need to repeat simple messages several times.

Tell them that everyone, including the doctors, nurses and yourself, has done everything possible to keep you living, but there is no medicine that can make you better. Explain that it will soon be your time to die.

It is also important to let your child know they will be included in any ceremonies held after your death, such as at the funeral. This will help them to feel they are helping and are involved. For example, younger children may have limited understanding, but may want to make a card.

Some children may ask what happens to people once they have died. How you approach this will depend on your own beliefs. It may be helpful to think in advance about your answer to this kind of question.

Use clear language

Use simple words such as 'dying' or 'died' when you tell young children about death. Try not to use phrases that may confuse them. For example, saying that you will be 'going away' or 'going to a better place' may make a child feel that you are abandoning them. Try not to use 'going to sleep' to describe dying, because young children may then be afraid of going to sleep.

Also encourage the people who will talk to your children after you die to use clear language. Saying a parent or guardian is 'lost' or has 'passed away' can be confusing – children may wonder why no one is looking for the person who has died.

Talking honestly and clearly about what is happening helps your children to feel more secure at an upsetting time. Young children can often find reasons to blame themselves in ways that you would not expect.

Being honest with them helps to reassure them that they are not responsible for someone's death. You will also be giving them the chance to talk about how they are feeling and get answers to questions that might be important to them.

Check what your child understands

Be aware of what your children may hear when you are talking to other adults. Make sure you are somewhere children cannot hear you.

It can be frightening for children to understand some but not all of the facts that they overhear. Children are imaginative – in stressful situations, they may imagine far worse than what is actually happening. This is particularly true if they are trying to make sense of what is happening without talking to you directly. It is a good idea to check their understanding every now and then.

This is especially important if you think they may have accidentally overheard a conversation not meant for them. If you are not sure they have understood words and ideas you have used when talking to them, ask them what you have said.

"Winston's Wish gave us advice about giving the children simple pieces of information. And not to talk about my brother being 'poorly' because then they'll think that every time someone is poorly, they are going to die."

Katie

Telling your children

When there is a serious illness or death in the family, it is normal for parents to want to protect their children. For example, they may think that if they do not talk about it, their children will not be affected or need to worry. But it can often be more helpful to talk about what is happening, so that children feel included and valued.

If your child trusts you to tell them what is really happening, it is likely that they will feel able to ask any questions that are worrying them. But some children may not want to talk very much. They may need time to express themselves in a non-verbal way. Go at their pace and give them plenty of time to talk and express themselves. You know your children best. Trust your instincts on when and what to tell them.

Make sure you have all the information you need first and that you understand it. Talk to your doctor or specialist nurse about anything you do not understand.

You may already have talked to your children about your diagnosis and the treatment. You may have prepared them for the possibility of treatment not working. Try to talk to them before they notice things and start to worry.

Winston's Wish (page 58) has a booklet called **As Big As It Gets – Supporting a child when someone is seriously ill**. It also has a booklet called **The Secret C**, which explains cancer in simple terms. These may help you to work out how you want to explain things to your children.

Who should tell them?

If you are a two-parent family, it is usually best to tell your children with the other parent. But this can depend on how you usually talk as a family. If you are a single parent, you may want to do it on your own. Or you might prefer to do it with someone who your child knows and trusts, or a healthcare professional you trust. Do whatever feels right for you and your child.

You may find it too difficult to tell your children yourself. If you are not the one telling them, it is a good idea to be there so you know what has been said. Your children can then see that everyone knows what is happening and there are no secrets. But some parents find it too difficult and prefer to let their partner tell the children, and not to be there themselves.

Rarely, some types of cancer can affect how someone thinks or communicates – for example, a brain tumour. In this case, the parent affected by cancer might not be able to be fully involved in the conversation.

The right time and place

Choose a time when you are feeling fairly calm and when you usually feel at your best. It should be at a time when your children are most likely to listen and feel at ease. If it is during school term time, the start of a weekend is better. Children can then take some time to think about what you have told them and ask questions.

Try to find a place that is quiet and private. It should be somewhere you and your children can talk freely and where you will not be interrupted. Make sure it is somewhere they will feel safe to express their feelings. Turn off any distractions, such as phones and the television.

If you have more than 1 child, it is best to tell them together, if you can. This stops them feeling that their siblings know more than they do, and perhaps wonder why they were told last. If you are telling them separately, try not to leave too much time between conversations.

How to tell them

You are the expert when it comes to your child. You know best how to talk with them, how they might react and what support they will need. Every family will have had different experiences. Some children will not have experienced a loss of any kind. Other children may have been to a relative's funeral or been through the death of a family pet.

The thought of talking to your children about dying will feel very emotional. It may help to talk to a friend, healthcare professional or counsellor before you talk to your child. This allows you to prepare and practice what you want to say and how you will say it. It will also give you a chance to think about some of the questions they may ask.

But do not try too hard to have the perfect conversation. If you plan too much, a question from your child may surprise you. Children can ask questions you were not prepared for, and these may come hours or days later.

We have examples of some questions your child may ask (pages 32 to 33). It is okay to say 'I don't know the answer to that right now. But I will try to find out for you'. The important thing is that they feel their concerns have been heard.

The first conversation can be a starting point. Allow the conversation to be led by your children's reactions and the questions they ask. Listen and keep it as open as you can.

It can be helpful to find out what your child understands first. You can do this by asking them to tell you what they think has been happening. From this starting point, you can gently correct anything they are confused about. You can then gradually tell them what is happening at this time.

Appointing (choosing) a guardian

If you talk about appointing a guardian, it is a good idea to talk to your children about who they would prefer. Plan If is a campaign launched by the Childhood Bereavement Network (page 59). It encourages all parents to put plans in place in case they die before their children grow up. It has instructions on how to appoint guardians in different situations and helps you to make these difficult decisions.

Children with special educational needs or disabilities

Children with special educational needs and disabilities can find change hard. Some may find death difficult to understand. Usually, they will cope better if they are involved in a situation and are prepared for it.

As you are closest to the child, it is up to you and your family to decide how much information needs to be shared. You might be nervous about telling your child, but it is likely that they will cope better if you are honest with them.

A child's understanding of death will differ depending on the child's developmental stage and whether they have experienced a death before (pages 12 to 17). Winston's Wish has some more information about this (page 58).

When explaining about what is happening, you might find it helps to use visual supports such as photographs, drawings, symbols and images. You might have to explain things or answer questions more than once.

If possible, try to keep your child's routine and surroundings the same. Reassure your child that they will always be looked after.

It might be useful to include any support workers involved in the child's care, so that you can all communicate in a consistent way about what is happening.

There are organisations that can help and provide further support (pages 58 to 63).

Be honest

It is best to be honest with children. If they think you are being vague or hiding something, they will find it hard to believe they are being told the truth. You can be honest but still provide reassurance about how they will be supported.

Teenagers may react differently from younger children or adults when they are told a parent is dying. They may ask for more information and may need more time to work through their feelings. They may appear not to react. Or it can seem as if they do not care. You may think this means they are coping, but that is not always the case. It can take time for them to take in what they have been told and connect with how they feel.

It is best to encourage them to ask any questions they have, and to answer these gently but honestly. Remember that although teenagers want to be independent, they will still look to you for reassurance and support (pages 16 to 17).

Making a start

You will need to use words your children will understand. This will depend on their age. Here are some suggestions to help you through the conversation:

- Find out what they know and correct anything they are confused about.
- Use simple, clear language to explain what is happening.
- Be as clear as you can – children worry more when things are not clear.
- Ask them if there is anything else they want to know.
- Take it at the child's pace and be prepared for them to react in their own way.
- Be ready to repeat the information for younger children, as they may not understand.
- Children need to know who will look after them when you die and how their lives and routines are likely to be affected.

"My mum always kept me up to date and made sure I knew everything."

Grace, whose dad died when she was 8

Once you have explained the situation, it might help to try and ask your child some open questions. This can encourage them to express their thoughts and feelings.

For example, you could ask:

- Is there anything worrying you right now that we could talk about?
- How are you feeling?
- How do you think I am doing?
- What would you like to know today?
- Is there anything that you feel would help you to cope?

As the conversation continues, it is worth checking what your child has heard and how much they understand. For example, you could ask:

- How do you feel about what I have told you?
- Is there anything you want to ask or know about?
- How can we look after each other?
- If you had to explain this to your favourite toy/pet/friend/teacher, what would you say?

Questions children may ask

It may help to think in advance about the kind of questions your children may ask, and about how you want to respond. There is no right or wrong way to answer.

Sometimes you will not know the answer. Instead, you can focus on how difficult it is to cope with uncertainty and what might help them to cope.

We have some suggestions here, but you will have your own ways of explaining things to your family. What matters is that your children feel included and able to ask questions and talk about how they feel.

What will happen to me?

'Daddy/Mummy/Granny/Grandad will still be here for you and will look after you. It is very important to me to make sure you will be safe and looked after. We have talked about it and will include you in making plans for what will happen.'

Will I get cancer?

'Cancer is not like a cold and you cannot catch it. It is okay to sit close to Mummy/Daddy/Granny/Grandad and hug or kiss them.'

Am I going to die too?

'Everyone dies at some point, but most people die when they are old, when their bodies get worn out.'

Is it my fault?

'Nothing you did, said or thought made me ill. It is no one's fault.'

Who will look after me if Daddy/ Mummy/Granny/Grandad dies too?

'If something happens to Daddy/Mummy/Granny/Grandad, we can arrange for someone you know well to become your guardian and they will look after you.'

Answering children's questions

It is difficult to describe to a child how someone will die, as no one can ever predict exactly when or how it will happen. Children need gradual explanations about what has happened and why, and what may happen next. Again, if you do not know the answer, it is okay to say so. But explain that you will talk to someone who might be able to answer their questions.

At times, it may feel difficult to find the right words. But supporting a child is not just about what you say. Sometimes, the most comforting thing can be a hug or simply having a cry together. Just talking together shows how much you value them.

> **"It was tough for our son to see his Dad getting weaker and weaker – and sometimes coming home from school to be asked to get medicines ready."**
>
> Ounal, who lost her husband Jamie

If it is difficult to talk

Sometimes, the cancer or the side effects of treatment can affect how you would normally communicate as a parent. For example, strong painkillers may cause drowsiness. It is important to keep talking to children as the situation changes. Or a family member, friend or healthcare professional can explain why you might find it hard to talk for too long.

If a parent is going to go into a hospice, you may want to prepare your children before visiting. You could show them the hospice's website or some photographs. If a child or parent prefers not to have visits in the hospice, you can communicate through texts, phone calls, videocalls or voicemails.

Other sources

Older children may want to know more about what happens when someone is dying and need more detailed information.

We have more information in our booklet **A guide for the end of life** (page 52) and at **macmillan.org.uk/endoflife**

Child Bereavement UK produces information about supporting children when a parent is not expected to live (page 58).

Help and support

Getting support 38

Getting support

Support is available for you and your family. If you need more support, it is important to ask for help. You can talk to your doctor or another healthcare professional about this.

Healthcare professionals

Cancer doctors and specialist nurses can offer support and advice. You can also talk to your GP if you need emotional support, whether you are the person with cancer or a relative. Sometimes it is easier to talk to someone who is not directly involved. Your specialist or GP can usually refer you to a counsellor or psychologist.

Your local hospice will have different services to support you and your family. You do not need to be in the hospice to be able to use these services. They can also offer support for your family after you have died.

"It was a comfort to know that I could talk about my dad and not have everyone go silent because they didn't know what to say. Now, I know that it is okay to have bad days and to still feel deeply sad, but I also know that I have ways to remember my dad and that he won't be forgotten. "

Grace, whose dad died when she was 8

Schools and clubs

When a child has a parent with terminal cancer, they are likely to have complicated emotions.

It is very important for school or nursery teachers and school club staff to be aware of the cancer diagnosis in the family and of any additional support children may need. Tell the teachers what you have told your children. It is important that children get the same message from everyone.

If children know the school is aware, it can help them feel less alone. You could also tell the school nurse. They will be able to help with emotional support for your child. Let your children know who you are going to tell and why.

Explain exactly what your child knows and what sort of support you think they may need. This will help teachers understand any unusual or difficult behaviour and be sensitive to your child's needs.

Teenagers may be facing exams or coursework at school, college or university. They may find it difficult to keep up with their studies. It is important that their teachers or tutors know what is happening so they can offer extra support.

If your teenager has exams coming up, you could talk to their teacher about how they are coping and what can be done to support them during the exams. In some situations, exam marking might be adjusted to take into account what your teenager is going through emotionally.

You should speak to your teenager before contacting their school. School or college may be one of the few places where things still feel normal, and they may be hesitant about letting people know. Asking them will also show them that you are telling them everything and including them. You can reassure them that the school will be sensitive to their needs and keep the information confidential.

It is important to speak to their school or college about how they are coping. Teachers or staff can offer support, and they may notice issues or behaviours that are not always apparent at home.

"I wanted my schoolmates to know how hard it was, but I never wanted them to feel the hurt I was feeling."

Grace, whose dad died when she was 8

Support from Macmillan

You can visit Macmillan's Online Community at **macmillan.org.uk/community** and chat with others in a similar situation. Or you can call our cancer support specialists for free on **0808 808 00 00**. They can tell you more about counselling and services in your area.

Our easy read booklet **Your feelings when someone dies and what can help** uses simple language and pictures (pages 52). It can be useful for anyone who finds it hard to read.

"It's been tough, especially with 3 kids. The Macmillan respite team was great. Everybody clicked into motion and we got everything we needed."

Richard, who lost his wife Vicky

Other organisations

Lots of organisations exist to support children, young people and families through bereavement (pages 58 to 63).

Online support for teenagers

Teenagers may look for information about cancer online. You or your doctor could help them understand whether the information they find is accurate and relevant to your diagnosis. Some teenagers may feel more comfortable joining an online support group than speaking to a counsellor.

Hope Support Services (page 63) might also be helpful. It is for teenagers who have a parent with serious illness such as cancer. You can also use it to search for other useful organisations that can help you.

After your death

Memory boxes 46

Going forward 47

Books and other resources 48

Memory boxes

A memory box is a container to hold special things belonging to you. It can be an important way of passing on memories of treasured times to your children. The things in the box can help a child hold on to their memories and build new ones as they get older. Depending on their age, children can be involved in making their own memory box. You could begin to put together a memory box for your child, or you could start to make one with them.

Some organisations, such as Winston's Wish, sell specially made boxes with pockets to hold objects in place (page 58).

Creating a memory box can be upsetting. But it can also be positive to do something that will help your child to connect with memories of you and the times you shared. It also gives you a chance to reflect on your own memories.

Deciding to make a memory box may feel overwhelming, especially if you have more than 1 child. It can be difficult to know where to start and can take up a lot of your energy. You may find it helpful to have a member of your family or a close friend there to support you. They can help you gather the objects to put in your memory box.

You may want to write a letter for the future, saying how much you love your child or children (mentioning them individually) and talking about specific memories you have shared with them. Or you could make a video or sound recording, or buy something special as a keepsake.

We have more information on making a memory box on our website. Visit **macmillan.org.uk/memorybox**

Going forward

Talking about death and dying with a child who is facing loss is one of the hardest things anyone is likely to do. We hope the information here has given you and your family some ideas on ways of approaching this sad and difficult task.

You are likely to want to talk to your children in stages. You can get help from your close family and friends, and the healthcare team that is helping you manage your illness.

We hope that this booklet can help you at these different stages.

There are also organisations that can help and support you and your loved ones during your illness and after your death (pages 58 to 63).

Books and other resources

Our easy read booklet **Your feelings when someone dies and what can help** uses simple language and pictures (page 52). It can be useful for anyone who finds it hard to read.

Winston's Wish has an activity book called **Muddles, Puddles and Sunshine** (page 58). It has lots of ideas and activities that your friends and family could do with younger children, to help them understand their thoughts and feelings after your death. Some of these books are about bereavement rather than serious illness, but they may still help.

Books for children whose parent is seriously ill

- **The Secret C** – Winston's Wish
- **Flamingo Dream** – Donna Jo Napoli
- **No Matter What** – Debi Gliori
- **When Someone Has a Very Serious Illness** – Marge Heegaard
- **When Dinosaurs Die** – Laurie Krasny-Brown
- **Always and Forever** – Debi Gliori
- **Michael Rosen's Sad Book** – Michael Rosen
- **The Memory Tree** – Britta Teckentrup
- **The Copper Tree** – Hilary Robinson and Mandy Stanley
- **Is Daddy Coming Back in a Minute?** – Elke Barber and Alex Barber
- **Why Do Things Die?** – Katie Daynes

Books for adults with an illness that cannot be cured

- **As Big As It Gets** – Winston's Wish
- **Late Fragments** – Kate Gross

Other resources

- **Stepping Stones postcards** – Childhood Bereavement Network (page 59)
- **Making a memory box: Activity sheet** – Winston's Wish
- **macmillan.org.uk/memorybox** – Macmillan Cancer Support
- **Grief Encounter workbook** – Dr Shelley Gilbert
- **Beyond the Rainbow: A Workbook for Children in the Advanced Stages of a Very Serious Illness** – Marge Heegard
- **Standing on His Own Two Feet: A Diary of Dying** – Sue Grant

Further information

About our information 52

Other ways we can help you 54

Other useful organisations 58

Your notes and questions 64

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **orders.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- interactive PDFs
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **informationproductionteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Child bereavement support organisations

This information was developed in partnership with:
Winston's Wish

Helpline **0808 802 0021**
www.winstonswish.org
Winston's Wish is a charity that supports bereaved children and young people, their families, and the professionals who support them, by helping them face the future with hope.

Child Bereavement UK

Tel **0800 028 8840**
www.childbereavementuk.org
Supports families, children and young people up to the age of 25 to help rebuild lives when a child grieves, or a when a child dies.

Childhood Bereavement Network

www.childhoodbereavementnetwork.org.uk
A UK-wide group of organisations and individuals working with bereaved children and young people. Has an online directory where you can find local services.

Child Bereavement and Trauma Service (CHUMS)

Tel **0152 586 3924**
www.chums.uk.com
CHUMS supports children and their families following the death of someone close. Offers support across Luton and Bedfordshire, and has services for young people in Kent and Medway, and Herts and West Essex.

Cruse Bereavement Support

Tel **0808 808 1677**
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Cruse Scotland

Tel **0808 802 6161**
www.crusescotland.org.uk
Provides bereavement support to people throughout Scotland.

Fruitfly Collective

www.fruitflycollective.com
Supports children, adults and families affected by cancer. Provides toolkits to help children or young people who have a parent diagnosed with cancer.

Grief Encounter

Tel **0808 802 0111**
www.griefencounter.org.uk
Supports children and young people following the death of someone close.

Hope Again

Helpline **0808 808 1677**
www.hopeagain.org.uk
Designed for young people by young people, Hope Again is part of Cruse Bereavement Support. It supports young people across the UK after the death of someone close. It also offers a private message service on the website.

Jigsaw South East

Tel **0134 231 3895**
www.jigsawsoutheast.org.uk
Offers grief support to children and young people through the loss of a loved one. Supports families across Surrey, parts of West Sussex, Kent and surrounding areas.

Ruth Strauss Foundation

www.ruthstraussfoundation.com
Provides emotional support for families to prepare for the death of a parent.

Widowed and Young (WAY)

Tel **0300 201 0051**
www.widowedandyoung.org.uk
A UK-wide support network to help young widows and widowers rebuild their lives after the death of a partner.

Advanced cancer and end of life care

Hospice UK

www.hospiceuk.org
The national charity for hospice and end of life care. Provides information about living with advanced illness. Has a directory of hospice services in the UK and free booklets.

Marie Curie

Tel **0800 090 2309**
www.mariecurie.org.uk
Marie Curie nurses provide free end of life care to people in their own homes, or in Marie Curie hospices. They also provide emotional and clinical support over the phone and online.

Natural Death Centre

Helpline **0196 271 2690**
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning, and bereavement.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
The professional association for members of the counselling professions in the UK. Has an online therapist directory where you can search for a counsellor or psychotherapist by location, service or specialism.

Support for young people

Hope Support Services

Tel **0198 956 6317**
www.hopesupport.org.uk
Supports young people aged 5 to 25 when a loved one has a serious illness, including cancer. Provides a monitored Facebook group and online 1 to 1 support sessions.

Young Minds

www.youngminds.org.uk
A national charity supporting children's and young people's mental health.

Youth Access

Tel **0208 772 9900**
www.youthaccess.org.uk
A UK-wide organisation providing counselling and information for young people.

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date, but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team, in partnership with Winston's Wish. It has been approved by Dr Vivian Lucas, Consultant in Palliative Care.

With thanks to: Dr John Holland, Chartered Educational Psychologist; Wendy Lewis-Cordwell, Bereavement Support Practitioner; Alison Penny, Director, Childhood Bereavement Network; and Letizia Pernia, Winston's Wish.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **informationproductionteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our information about preparing a child for loss. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

Bergman, A-S et al. When a parent dies – a systematic review of the effects of support programs for parentally bereaved children and their caregivers. BMC Palliative Care. 2017; 16:39. Available from bmcpalliatcare.biomedcentral.com/counter/pdf/10.1186/s12904–017-0223-y.pdf [accessed October 2023].

Estroff Marano, H. How Losing a Parent Affects Young Children: Some carry the parent inside them, and benefit from it. Psychology Today. 2022. Available from www.psychologytoday.com/gb/blog/experimentations/202202/how-losing-parent-affects-young-children [accessed October 2023].

Rapa E, et al. Experiences of preparing children for a death of an important adult during the COVID-19 pandemic: a mixed methods study. BMJ Open 2021;11: e053099. Available from bmjopen.bmj.com/content/bmjopen/11/8/e053099.full.pdf [accessed October 2023].

Wray A, et al. BMJ Supportive & Palliative Care 2022;0:1–12. Doi:10.1136/bmjspcare-2022–003793 Available from spcare.bmj.com/content/bmjspcare/early/2022/11/15/spcare-2022–003793.full.pdf [accessed October 2023].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, money advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps.
   To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

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Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN CANCER SUPPORT

This booklet is about preparing a child for loss. It is for parents or guardians who are near the end of life. It aims to help you prepare and talk to a child or children about your death. Partners, grandparents, and close family members may find it useful too.

This booklet is written with the childhood bereavement charity Winston's Wish. It is a practical guide to help you have some of the hardest discussions you will ever have. We include details of people and organisations who can support you as you prepare to talk to your children.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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Patient Information Forum

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