

MACMILLAN
CANCER SUPPORT

PREPARING A CHILD FOR LOSS



In partnership

**WINSTON'S
WISH** **WW**

Giving hope to grieving children



She came home from school and we sat down and explained to her truthfully that Daddy was not going to get better.

Denise, whose husband Andy died of cancer in 2009

This booklet is for parents, grandparents, 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.

Jointly developed by Macmillan Cancer Support and Winston's Wish, it has information on how your child might understand and react to the idea of death, what language you might like to use, and where you can find more support during this difficult time.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

**MACMILLAN
CANCER SUPPORT**
RIGHT THERE WITH YOU

© Macmillan Cancer Support, April 2018. 2nd edition. MAC15372_E2_N.
Next planned review 2020. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. Printed on sustainable material. Please recycle.

 The Information Standard	This organisation has been certified as a producer of reliable health and social care information. www.theinformationstandard.org
Certified member	

What's this logo? Visit macmillan.org.uk/ourinformation

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 begin to 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. These people will be able to help you and your family now and in the future. You don't 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 a shocking and emotional time. We hope that the suggestions in this booklet are helpful, but you may have different ideas about how to approach your children. That is perfectly okay. 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.

On page 60 there is space for you to write down any notes or questions you might have for your doctors, nurses, or other healthcare professionals supporting you through this time.

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

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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

How to use this booklet

The booklet is split into sections to help you find what you need. You don't 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.



'I think we have to prepare them for what is inevitable so they can handle it better when that time comes.'

Alan



Contents

Your feelings about your death

7

Talking to your children about your death

11

Help and support

35

After your death

43

Further information

49



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 cope with your own feelings about being told you will not recover from cancer. It will be hard to talk to your children about what is happening when you are still trying to manage your own emotions.

If you are feeling unwell or low, you may not feel emotionally strong enough to begin any difficult conversations with your family and friends. Take your time and go at a pace that feels right. 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 with a difficult situation. 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 (see page 58). You can speak about whatever is on your mind. Some people find online support a good source of help too (see page 40).

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 be a way of practising how you are going to tell your children about what is happening to you and them. You may find it useful to try out the words you plan to use with another adult. You could also think about the kind of questions your child may have and plan your answers.

'The doctor told us it was terminal. As you can imagine, we were absolutely devastated. Our little boy Oscar was only two at the time.'

David



TALKING TO YOUR CHILD ABOUT DEATH

How children understand and react to death at different ages	12
Talking about dying	16
Telling your children	20
Questions children may ask	30
Answering children's questions	32

How children understand and react to death at different ages

The way children understand and react to death can depend on their age and their level of understanding. 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 aches. There may also be changes in their behaviour.

You may find yourself becoming upset or tearful when having difficult conversations with your children. But that is okay. It can help children to see that sometimes adults cry too when they feel upset.

Child Bereavement UK has information about how children of different age groups grieve (see page 55). They have also worked with bereaved young people to develop an app for teenagers.

'Be prepared to have your child say, 'All right' and walk off and go and watch the telly. That's okay, because that is their way of dealing with it.'

Carol

Very young children (aged under three)

Children under three can pick up that something very serious is happening, even if they cannot understand what death means. Children as young as three can grieve. Some children in this age group may slip backwards in some of their developing behaviours, for example toileting or feeding.

Young children (aged 3 to 5)

Children aged 3 to 5 may have heard about dying, but they may not understand what it means. For example, they may imagine that a dead person will come back or is living somewhere else.

How you can help

- 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 everyday 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 are asking to do this.
- Tell someone you trust at playgroup 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 eight or nine, 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. Their worry is more likely to be that death is frightening or painful.

How you can help:

The suggestions for children aged 3 to 5 will still be helpful to many children in this age group.

- Use books to talk about the end of life (see pages 58 to 59).
- Encourage them to keep up with school work, activities they enjoy and friendships.
- Let them know it is okay to enjoy themselves. It is also okay to be sad.
- Give them small tasks to do to help out. For example, they could put flowers in a vase or bring you a glass of water.
- Explain the situation to their teacher. You may also want to explain what is happening to a few parents of their close friends, who you know they trust. They can also offer support.

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 may cope in ways that are difficult for you to understand or deal with. Some teenagers may refuse to talk about the illness. Others may try to become closer to their parents. Some may get angry with you or your partner in ways that seem thoughtless. They may then feel guilty about how they have acted. 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 change a lot.

How you can help:

- Ask them what they think and, if they want to be, include them in the same way as you would include an adult.
- 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.
- Give them time and space to themselves when they want it.
- Tell them about useful sources of information and support (see pages 50 to 59).
- Encourage them to keep up with their friendships, activities, and normal life as much as possible.
- Keep to usual rules and boundaries. These can be even more important now than before, as they can help teenagers feel safe.
- It might help to gently remind them that their behaviour may affect any younger children in the family.

Talking about dying

Preparing children for the loss of a parent is an incredibly hard thing to do. You will know the best way to do this for your own family. 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 such as social workers, palliative care nurses, doctors, counsellors, and psychologists can also help you (see pages 36 to 37).

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, but only 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.

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. It is important to explain things in language that children can understand.

Tell them that everyone, including the doctors, nurses, and yourself, have 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.

Be prepared for the possibility of children asking 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.

'There is a difficult balance between protecting them and letting them be kids, and being honest with them.'

Ben

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. They 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 ask questions that are important to them.

Check their understanding

Be aware of what your children may hear when you are talking to other adults. It can be frightening for children to understand some but not all of the facts that they overhear. Children are imaginative, and in stressful situations using that imagination can sometimes scare them. 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.

'The most important thing was to keep her updated and informed all the way through. I felt that if we hadn't done that, she would have heard it from somebody else or heard talking on the telephone, and it would have been the most dreadful thing to hear.'

Carol

Telling your children

Many parents want to protect their children when there is a serious illness or death in the family. They 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. Go at their pace and give them plenty of time to talk. 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 about cancer and its treatment to your children. 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 has a booklet called **As big as it gets – supporting a child when someone is seriously ill** (see page 59). They also have a booklet called **The Secret C**, which explains cancer in simple terms (see page 58). 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 close 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 do 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.

'Her Grandma and I told Grace about her Daddy on the day that we were told at the hospital. She came home from school and we sat down and explained to her truthfully that Daddy was not going to get better. He was going to come home and be looked after by me and the doctors and nurses.'

Denise

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. The 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 able to express their feelings. Turn off any distractions, such as phones and the television. If possible, sit so that you can all see each other clearly.

If you have more than one child, it is best to tell them together if you can. This stops them feeling that their brothers or sisters know more than they do, and perhaps wonder why they were told last. If you are telling them separately, do it as close together as possible.

'I always gave our son time to ask questions during normal bedtime routines. The hard questions sometimes come out of the blue when you are least expecting them.'

Kate



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.

You can practise what you are going to say beforehand and think about some of the questions they may ask. But don't 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 (see pages 30 to 31). And remember, 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 directed 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. 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 about what is happening at this time.

Children with learning disabilities

Children with learning 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.

When explaining things, 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 the same. Keep things that they are used to around them and reassure your child that they will continue to be looked after.

It might be useful to involve any support workers involved in your child's care.

There are organisations that can help and provide further support (see pages 55 to 58).

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.

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 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.

'As we walked in, I think it was apparent that both Claire and I were visibly shaken and upset. So we sat down and we said, we are never going to hide anything from Danielle, and we told her. We said, "Mum's cancer is back, but unfortunately they are not going to be able to cure it this time".'

David

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 take it in or understand.
- Children need to know who will look after them when you die and how their lives and routines are likely to be affected.
- 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:

- 'Tell me how you think things are going.'
- '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?'

As the conversation continues, it is worth checking what your child has heard and how much they understand.

For example, you could ask:

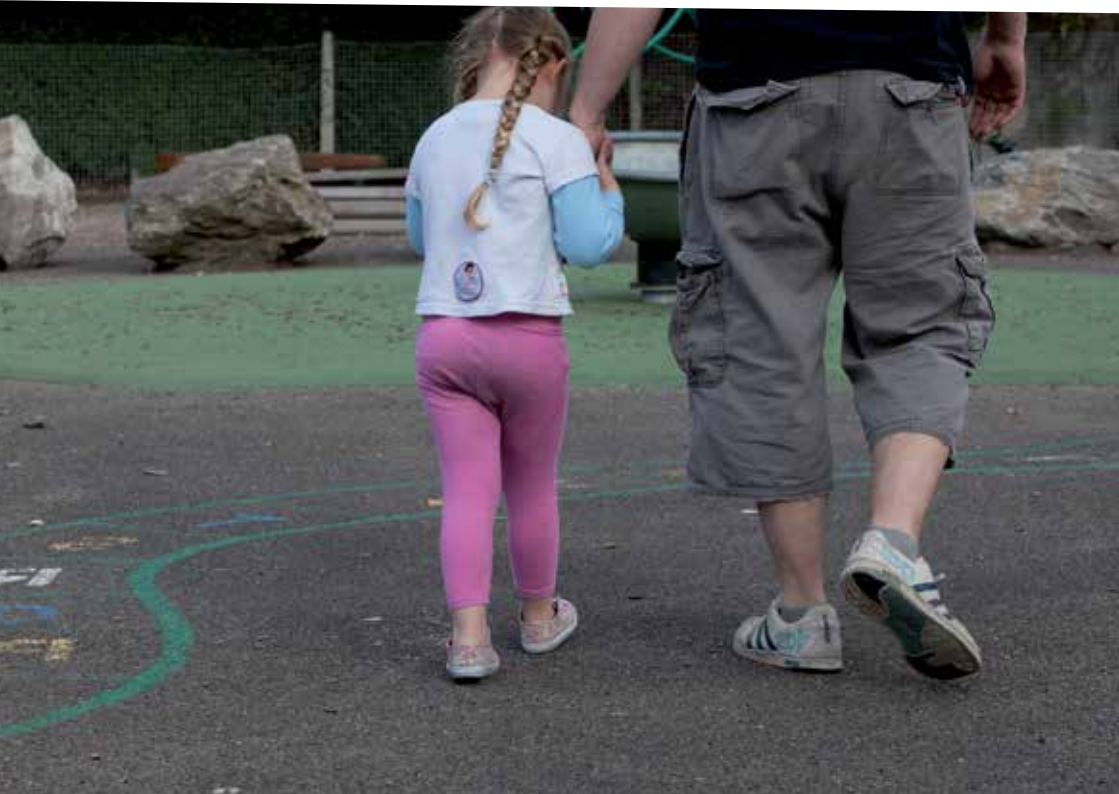
- 'How do you feel about what I have told you?'
- 'How can we look after each other?'
- 'If you had to explain this to your (favourite toy/pet/friend/teacher), what would you say?'

'Be easy on yourself and trust your instincts. You need to balance your needs with those of the ill person and those of each child. They do not always match. Be ready for unexpectedly frank questions from your child.'

Kate

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. 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 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's very important to me to make sure you will be safe and looked after. We have talked about it and made plans for what will happen.'

Will I get cancer?

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

Am I going to die too?

'You can't catch cancer. Most people die when they are old and their bodies get worn out. It's very unusual and sad for someone young to be so ill that the doctors cannot make them better.'

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 it will happen or exactly what will happen. Children need to have gradual explanations about what has happened and why, and what may happen next. Again, if you don't 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.

Sometimes, the cancer or the side effects of treatment can change a parent. For example, strong painkillers may cause drowsiness. It is important to keep talking to the children as the situation changes. 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 either the child or the parent prefers not to have visits in the hospice, communication can still happen through texts, phone calls or voicemails, Skype, or FaceTime.

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

Our booklet **End of life: a guide** has more information, which you may find helpful. You can get a copy by calling the Macmillan Support Line on **0808 808 00 00** or by visiting **be.macmillan.org.uk**

Child Bereavement UK produces information about supporting children when a parent is not expected to live (see page 55).

If you do talk about appointing a guardian for your children, it is worth talking to them about who they would prefer. **Plan If** is a campaign launched by the Childhood Bereavement Network (CBN) (see page 55). 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.



HELP AND SUPPORT

Getting support

36

Getting support

Support is available for you and your family. But it is important to ask for help or to talk to someone like your doctor if you feel you are not getting enough support or the right kind of support.

Health professionals

If you are the person with cancer, your cancer doctor and specialist nurse 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 offer different services to support you and your family. You can use these services even if you do not want to go into the hospice. They will also offer support for your family after you have died.

Support from Macmillan

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

We have some easy read booklets that use simple language and pictures (see pages 58 to 59). They can be useful for anyone who finds it hard to read. The booklets are about care at the end of life and after someone dies.

Other organisations

Organisations such as Winston's Wish or Marie Curie provide information about supporting children and teenagers when an adult is dying (see pages 56 to 58). You can also look for local bereavement services near you at the Childhood Bereavement Network (see page 55). Your local hospice may also be able to support you and your children.

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 and club staff to be aware of the cancer diagnosis in the family and of any additional help and support the children may need. Tell the teachers or group leaders what you have told your children. It is important that your children get the same message from everyone. Let your children know who you are going to tell and why.

It is also important to tell nursery or school teachers, and the school nurse. They can be sensitive to your child's needs, and it will help them understand any unusual or difficult behaviour. Explain exactly what your child knows and what sort of support you think they may need.

Teenagers may be facing exams or coursework at school, college, or university. They may be finding 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.

You should speak to your teenager before contacting the 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.

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.

'School were very considerate of needing time off when necessary and would listen to any concerns I had when I dropped her off at school – so they knew if she was tired, upset or needing a shoulder to cry on.'

Denise

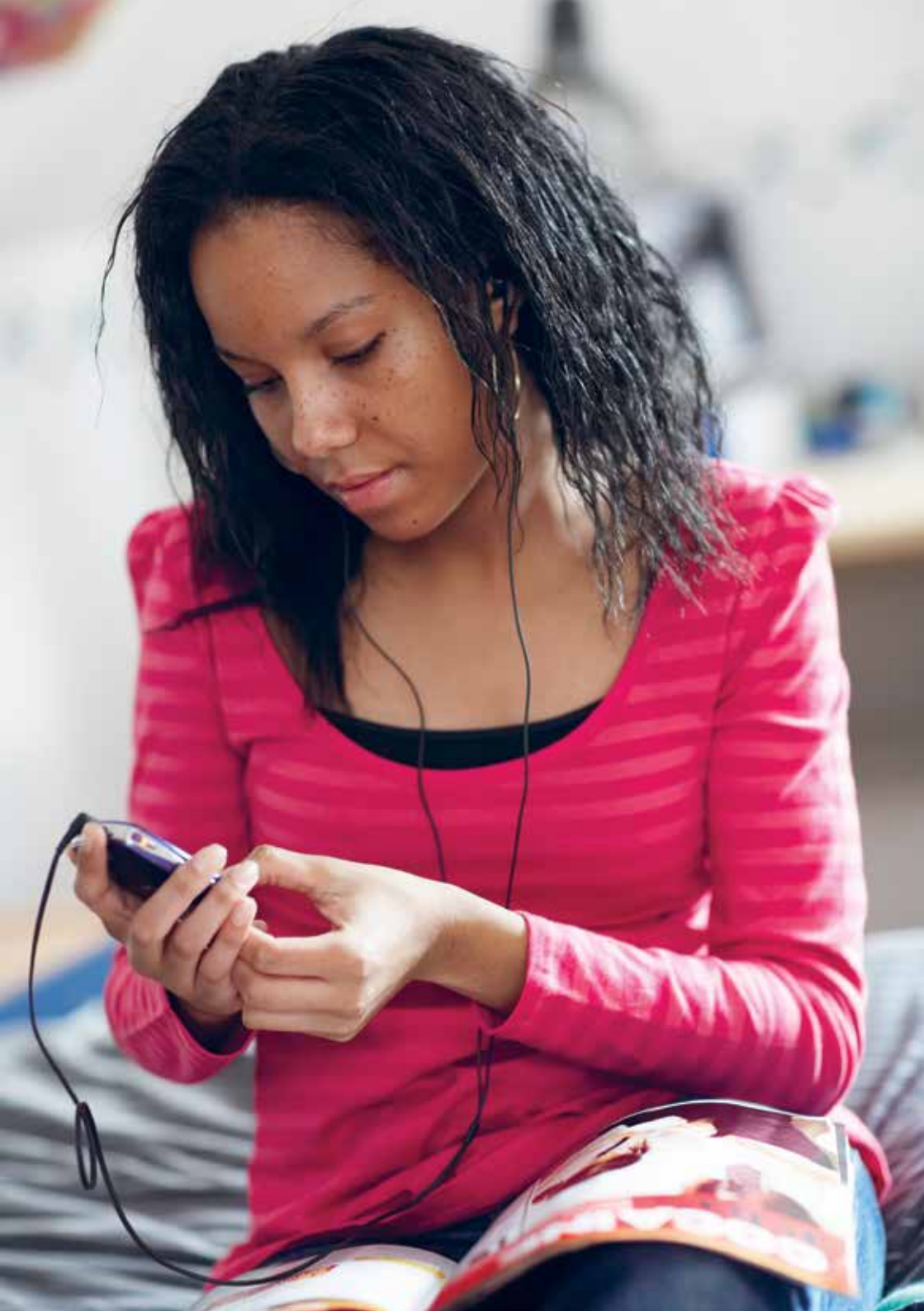
Online support and useful websites

Teenagers in particular may look for information about cancer on the internet. 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 rather than speaking to a counsellor.

The websites **hopesupport.org.uk** and **riprap.org.uk** might also be helpful. They are for teenagers who have a parent with cancer. You can also use them to search for other useful organisations that can help you.

Cruse Bereavement Care has a website (**hopeagain.org.uk**) for bereaved children and young people, as well as a free helpline (**0808 808 1677**).

Child Bereavement UK has a website (**childbereavementuk.org**) with information and support for bereaved children, young people, and families. They also have an app called **Grief Support for Young People** and a free helpline (**0800 02 888 40**).





‘Making a memory box helped tremendously for both of us. We still use them to help us on our low days.’

Denise, whose husband Andy died of cancer in 2009

AFTER YOUR DEATH

Memory boxes	44
Going forward	46

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 (see page 58).

Creating a memory box can be a sad thing to do. But it can also be satisfying 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 can feel overwhelming. It can be difficult to know where to start. You may find it helpful to have a member of your family or a close friend there to support you and help you gather the objects you want to put in your memory box. You may want to write a letter for the future, saying how much you love your 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 can send you more information on making a memory box. Call us on **0808 808 00 00**.

Winston's Wish has an activity book called **Muddles, Puddles and Sunshine**, which has lots more ideas and activities that your partner or child's guardian could do with your child. This may help them understand their thoughts and feelings after your death. You can order a copy of this, and other helpful books, from Winston's Wish or online (see pages 58 to 59).

'Having a memory box helped me to cope better after losing my dad. At first when I opened it, it made me sad. Now as time has gone by, I can smile when I open my memory box.'

Siana, 14

'We use the memory box to support others who are having the same experience of loss. The activities enable you to release your thoughts, emotions and fears in a safe way.'

Denise

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 who are helping you manage your illness. Hopefully this booklet can help you at these different stages. There are also organisations that help and support you and your loved ones during your illness and after your death (see pages 55 to 58).





FURTHER INFORMATION

About our information	50
Other ways we can help you	52
Other useful organisations	55
Your notes and questions	60

About our information

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

Order what you need

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

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you'll also find videos featuring real-life 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
- eBooks
- large print
- translations.

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

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

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets, and fact sheets.

If you'd like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk. You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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 free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://www.macmillan.org.uk/talktous)**

Information centres

Our information and support centres are based in hospitals, libraries, and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://www.macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

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's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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](https://www.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](https://www.macmillan.org.uk/community)

The Macmillan healthcare team

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.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares, and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing, and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants, and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Child bereavement support organisations

Child Bereavement and Trauma Service (CHUMS)

Tel 01525 863924

Email info@chums.uk.com

www.chums.uk.com

CHUMS tries to meet the needs of children and their families following the death of someone close. They offer support in a variety of ways to children, young people, and their families across Luton and Bedfordshire.

Child Bereavement UK

Tel 0800 02 888 40

Email support@childbereavementuk.org

www.childbereavementuk.org

Supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement.

Childhood Bereavement Network (CBN)

Tel 020 7843 6309

Email cbn@ncb.org.uk

www.childhoodbereavementnetwork.org.uk

A national federation of organisations and individuals working with bereaved children and young people. CBN has set up a campaign called Plan If (www.planif.org.uk) aimed at all parents. Plan If helps you ensure that your children have the right conditions to provide stability and security if you were to die while they are still young.

Cruse Bereavement Care

Tel 0808 808 1677

(Mon and Fri, 9.30am to 5pm,
Tue to Thu, 9.30am to 8pm)

Email info@cruse.org.uk

www.crusebereavementcare.org.uk

Provides bereavement counselling, information, and support to anyone who has been bereaved, with a network of branches across the UK.

Cruse Bereavement Care Scotland

Tel 0845 600 2227

(Mon to Wed, 10am to 8pm,
Thu, 10am to 9pm, Fri, 10am to 4pm)

Email support@crusescotland.org.uk

www.crusescotland.org.uk

Provides bereavement support to people throughout Scotland.

Grief Encounter

Tel 020 8371 8455

Email contact@griefencounter.org.uk

www.griefencounter.org.uk

Grief Encounter helps families address difficult issues such as death and helps them make sense of the hurt and confusion.

Hope Again

Helpline 0808 808 1677

(Mon to Fri, 9.30am to 5pm)

Email hopeagain@cruse.org.uk

www.hopeagain.org.uk

Hope Again is the youth website of Cruse Bereavement Care. It is a safe place, where young people who are facing grief can share their stories with others.

Jigsaw South East

Tel 01342 313895

Email info@jigsawsoutheast.org.uk

www.jigsawsoutheast.org.uk

Jigsaw South East offers grief support to children and young people who have experienced the death of a significant family member. In partnership with Macmillan, it also provides support to children and young people who have a family member with a life-limiting condition.

Marie Curie

Tel 0800 716 146

(Mon to Fri, 9am to 5pm)

Email supporter.relations@mariecurie.org.uk

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

Rainbows Bereavement Support GB

Tel 0161 6242269

Email rainbows.gb.dc@btconnect.com

www.rainbows.gb.org

A national charity aiming to make a positive impact on the lives of children, young people and adults grieving a significant and often devastating loss in their lives.

Riprap

www.riprap.org.uk

A website for teenagers who have a parent with cancer. They can learn more about cancer, read stories, and share their experiences. Experienced cancer professionals answer emails sent through the site.

Widowed and Young (WAY) 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

Tel 020 7520 8200

Email info@hospiceuk.org
www.hospiceuk.org

Provides information about living with advanced illness. Has a directory of hospice services in the UK and free booklets.

The Natural Death Centre

Helpline 01962 712 690

Email rosie@naturaldeath.org.uk

www.naturaldeath.org.uk

Offers independent advice on aspects of dying, funeral planning, and bereavement.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300

Email bacp@bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Support for young people

Youth Access

Tel 020 8772 9900

(Mon to Fri, 9.30am to 1pm,
then 2pm to 5.30pm)

Email admin@youthaccess.org.uk

www.youthaccess.org.uk

A UK-wide organisation providing counselling and information for young people. Find your local service by visiting youthaccess.org.uk/find-your-local-service

In partnership with

Winston's Wish

Helpline 08088 020 021

Email info@winstonswish.org

www.winstonswish.org

Winston's Wish believe that bereaved children need support to make sense of death and rebuild their lives. They provide a helpline, email service, and face to face support.

Books and other resources

You can order these online or from the charity mentioned. We also have some easy read booklets that uses simple language and pictures, get these from macmillan.org.uk/otherformats. They can be useful for anyone who finds it hard to read. The booklets are about care at the end of life and after someone dies.

Books for adults with life-limiting illness

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

Books for children whose parent is seriously ill

- **The Secret C** – Winston's Wish
- **Flamingo Dream** – 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
- **The 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 & Alex Barber

Other resources

- **Stepping Stone Postcards** – Childhood Bereavement Network
- **Muddles, Puddles and Sunshine** – Winston's Wish
- **Making a Memory Box: Activity sheet** – Winston's Wish
- **Memory boxes** – Macmillan Cancer Support
- **Grief Encounter Work Book** – Dr Shelley Gilbert
- **Beyond the Rainbow: A Workbook for Children in the Advanced Stages of a Very Serious Illness** – Marge Heegaard
- **Standing on His Own Two Feet: A Diary of Dying** – Sue Grant



You can search for more organisations on our website at [macmillan.org.uk/organisations](https://www.macmillan.org.uk/organisations) or call us on 0808 808 00 00.

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 our Senior Medical Editor, Dr Viv Lucas, Consultant in Palliative Care. With thanks to: John Holland, Chartered Educational Psychologist; Wendy Lewis-Cordell, Bereavement Support Practitioner; Anne McGee, Macmillan Project Manager; Alison Penny, Childhood Bereavement Network Coordinator; Cyndi Taylor, Training, Publications and Merchandise Co-ordinator, Winston's Wish; and Amanda Thaxter, Operations and Development Director, CHUMS Mental Health and Emotional Wellbeing Service.

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

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

Sources

We've listed a sample of the sources used in the publication below. If you would like further information about the sources we use, please contact us at: **cancerinformationteam@macmillan.org.uk**

Cancer.Net. www.cancer.net/coping-with-cancer/managing-emotions/grief-and-loss/helping-grieving-children-and-teenagers (accessed July 2017).

Chalmers A. When a parent is not expected to live: supporting children. Childhood Bereavement UK. 2014.

Dying Matters. www.dyingmatters.org/page/resources-talking-about-death-and-dying (accessed July 2017).

Royal College of Psychiatrists. Bereavement. July 2017.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there 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.



Share your cancer experience

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

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.

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?

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

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

□□□

Security number

□□□

Signature _____

Date / / _____

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

- I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ