WE ARE MACMILLAN. CANCER SUPPORT

End of life

PREPARING A CHILD FOR LOSS



About this booklet

This information aims to help you prepare and talk to a child or children about your death. It's for parents or guardians who are near the end of life. 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'll find suggestions on how to:

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

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

On page 45 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.

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's 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're trying to do the best you can in really difficult circumstances.

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

Alan

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Coming to terms with your own death

You may need some time to cope with your own feelings about being told you will not recover from cancer before talking to your children. It will be hard to explain to them 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 you may find that your partner does not want to talk about it. It's not unusual to react to a difficult situation this way. It can be a way of coping. But it can also 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 express your feelings and concerns.

If you prefer to talk to someone outside of your situation, you can call the Macmillan Support Line on 0808 808 00 00 or Winston's Wish (see page 43 for details). You can speak about whatever is on your mind. Some people find online support a good source of help too (page 31).

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're going to tell your children about what is happening to you and them. You may find it useful to rehearse the words you plan to use with another adult. You could try to 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

How do 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.

> 'Be prepared to have your child say, "Alright" and walk off and go and watch the telly. That's okay, because that's 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 under three may slip backwards in some of their developing behaviours, for example toileting or feeding.

Young children (aged 3-5)

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

How to help:

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

Older children (6-12)

Children aged 6–12 know about death but, as with children of all ages, they may not always understand the emotions they feel. By about nine, children begin to understand death more like adults do. But they may still believe that if they are very 'good' their parent or guardian may come back. Their worry is more likely to be that death is frightening or painful.

How to help:

- The suggestions for children aged 3–5 will still be helpful to many children in this age group.
- Use books to talk about the end of life (see page 44 for some examples).
- Encourage them to keep up with school, other activities 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 (see pages 29–30 for more information). You may also want to explain what is happening to a few parents of their friends, who you know they trust. They can also offer support.

Teenagers

Teenagers often find it harder than younger children to cope with the news that someone is dying. They're 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, while 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've acted, or feel bad about spending time with their friends.

Teenagers need to know that there's no right or wrong way to feel at this time and that it's okay if their feelings change a lot.

How to help:

- Ask them what they think and, if they want to be, include them in the same way as you'd 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 (see pages 36–44).
- 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 on their younger siblings.



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 very difficult time can be helpful. You don't have to do it alone and it's not unusual to 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 page 27 for more details on who you can talk to.

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. 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.

Being honest and including children in what's happening is usually the best approach. It's natural to want to protect children from painful experiences. But we know that adults who lost someone close to them when they were children often wish they had known more about what was going on at the time. 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 language. This allows you to find ways of helping your children to cope in the future. It will also give you the opportunity to show how much you care for each other. It is often easier for children to hear information in small chunks, rather than all in one go. You may need to repeat simple messages several times. What is important is to explain things in language that children can understand.

Emphasise that everyone – the doctors, nurses and you 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.

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.

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

Ben

By talking honestly about what is happening, you are helping 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. Opening up to them helps to reassure them that they're not responsible for someone's death. You will also be giving them the chance to talk about how they're feeling and ask questions that are important to them.

Be aware of what your children may hear when you are talking to other adults. It can be very 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. This is particularly true if they are trying to make sense of what is happening without talking to you directly. It's a good idea to check their understanding every now and then. especially 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'd 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 serious illness or death happens within a family. They think that if they don't talk about it, their children will not be affected or need to worry. However, 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, they will feel able to ask any questions that are worrying them. 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 don't understand. You may have already explained what cancer and its treatment is to your children. You may have prepared them for the possibility of treatment not working. Try to talk to them before they pick up on 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. They also have 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. See page 43 for details on how to contact Winston's Wish.

Who should tell them?

If you're a two-parent family, it's usually best to tell them with the other parent – but this can depend on how you usually talk as a family. If you're 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.

You may find it too difficult to tell your children yourself. If you're not doing the telling, it's 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 (for example a brain tumour) can affect how someone thinks or communicates. In this case, the parent affected by cancer might not be able to be fully involved or take a lead in the conversation.

'Her Grandma and I told Grace about her Daddy on the day that we were told at the hospital that he was terminal. 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're 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's during term time, the start of a weekend is better. They can then take some time out, reflect on what you've 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 won't be interrupted. Make sure it's somewhere they'll 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's best to tell them together if you can. This prevents them feeling that their siblings know more than they do. If you're telling them separately, do it as close together as possible. Some children may wonder why they were told last.

'I always gave our son time to ask questions during normal bedtime routines etc. I hope this gave him an easy way to raise issues. The hard questions sometimes do 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 how best to talk with them, how they might react and what support they'll need. Every family will have had different life 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're 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 throw you. Children can ask questions you weren't prepared for, and these may come hours or days later. See pages 24-25 for some questions your child may ask.

See the first conversation as 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 you child understands. You can do this by asking them to tell you a bit about what they think has been happening. From this starting point, you can gently correct any misunderstandings. You can then gradually tell them about the current situation.

Be honest

It's best to be honest with children. If they think you're being vague or hiding something, they'll find it hard to believe they're being told the truth.

It's fine to say you don't know if you don't have all the answers to their questions. Tell them you'll try to find out and will tell them when you know.

Teenagers may react differently from younger children or adults when they're 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. This can be mistaken for resilience. It's best to encourage them to ask any questions they have, and to answer these gently yet honestly. Remember that although teenagers value their independence, they'll 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're never going to hide anything from Danielle, and we told her. We said, "Mum's cancer is back, but unfortunately they're not going to be able to cure it this time."

David



Making a start

You'll need to use words your children will understand. These will vary, depending on their ages. Here are some suggestions to help you through the conversation:

- Find out what they know and correct any misunderstandings.
- Use simple, clear language to explain what's happening.
- Be as specific as you can. Children worry more when things aren't clear.
- Ask them if there's 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've 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 at the moment that we could talk about?'
- 'How are you feeling?'
- 'How do you think I'm 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. Some examples of these questions are:

- 'What do you feel about what I've 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 a unique child. They don't always synchronise – be ready for unexpectedly frank questions from your child.'

Kate

Questions children may ask

It may help to think about questions your children may ask in advance, and about how you want to respond. There isn't a right or wrong way. 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'll be safe and looked after, so we've already talked about it.'

Will I get cancer?

'Cancer isn't like a cold and you can't catch it. It's 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're old and their bodies get worn out. It's very unusual and sad for someone young to be so ill that the doctors can't make them better.'

Will other people I love die too?

'Daddy/Mummy/Granny/Grandad are well and healthy at the moment and will be here to look after you.'

Is it my fault?

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

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

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

It's 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's okay to say so. But explain that you will talk to someone who might be able to answer their questions.

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 hospice, you may want to prepare your children before visiting. You could show them the hospice's website or some photographs.

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



Our booklet End of life: a guide has more information, which you may find helpful.

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). 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. See page 42 for more information

Getting support

There is a lot of support available to you and your family. It's important to ask for help or to talk to someone like your doctor if you feel you're not getting enough support.

Health professionals

If you're the person with cancer, your cancer specialist and your specialist nurse can offer support and advice. You can also talk to your GP if you need emotional support, whether you're the person with cancer or a relative.

Sometimes it's easier to talk to someone who's not directly involved. Your specialist or GP can usually refer you to a counsellor or psychologist who can help.

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.

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. 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. They are available online or we can send you some copies.



Other organisations

Organisations such as Winston's Wish or Marie Curie (see page 43) provide information about supporting children and teenagers when an adult is dying. You can also look for local bereavement services near you at childhoodbereavementnetwork.org.uk Your local hospice may also be able to support you and your children

You'll find information about different organisations and useful websites on pages 41-43.

Schools and clubs

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

It is 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. Let teachers or group leaders know what you've told your children. It is important that your children get the same message from everyone. Let your children know who you're going to tell and why.

It's a good idea 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. If they're 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, it is good to speak to their teacher about how they are coping and if any extra measures can be put in place to support them during the exams.

You should speak to your teenager before doing this. 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 reaffirm their trust that you're telling them everything and including them.

It may be important to speak to their school or college about how they're coping. Teachers or staff can offer support, and they may notice issues or behaviours that aren't 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 (see Hope Again on page 42).

Memory boxes

It can be difficult for young children to hold on to memories. A memory box can be an important way of passing on memories of treasured times to your children. A memory box is a container to hold special things belonging to you. 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 building 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.

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 and may make you laugh as well as cry.

'Activities like making a memory box helped tremendously for both of us. We still use them to help us on our low days and 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

Deciding to make a memory box can feel overwhelming, and it can be difficult 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.

Winston's Wish have an activity book called Muddles, Puddles and Sunshine which has lots more ideas and activities that your partner could do with your child, to help them understand their thoughts and feelings after your death.

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, with the help of 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 different organisations that will be able to help and support you and your loved ones, during your illness and after your death.

'Children are amazing. My boys have come out the other side. Life will never be the same again, the pain never goes away but you learn to live with it.'

Vanessa



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.

All of our information is also available online at macmillan. org.uk/cancerinformation 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. No one should face cancer alone.

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 Monday-Friday, 9am-8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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

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 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

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

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.

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 advice

Our financial auidance team can give you advice 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/ financial support 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

> Macmillan's My Organiser app This 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 and Trauma Service (CHUMS)

Wrest Park Enterprise Centre, Enterprise Way, Wrest Park, Silsoe, Bedforshire MK45 4HS 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

Clare Charity Centre, Wycombe Road, Saunderton, Buckinghamshire HP14 4BF **Tel** 01494 568900 Email support@ childbereavementuk.org

childbereavementuk.org

www.

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)**

8 Wakley Street,

London EC1V 7QE **Tel** 020 7843 6309 www.childhoodbereavement network.org.uk

A national federation of organisations and individuals working with bereaved children and young people. It involves, and is actively supported by, all the major bereavement care providers in the UK, CBN has also set up a campaign called Plan If (www.planif.org.uk) which is 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

PO Box 800. Richmond TW9 1RG **Tel** 0844 477 9400 (Mon-Fri, 9.30am-5pm) **Email** helpline@cruse.org.uk Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch at cruse.org.uk/ cruse-areas-and-branches

Grief Encounter

The Lodge, 17 East End Road, London, N3 3QE Tel 020 8371 8455 **Email** contact@griefencounter. org.uk

www.griefencounter.org.uk

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

Hope Again Helpline 0808 808 1677 **Fmail**

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

East Court Mansion, College Lane, East Grinstead, West Sussex RH19 3LT 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

London, SE1 7TP

89 Albert Embankment,

Tel 0800 716 146 (Mon-Fri, 9am-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

Werneth Grange, Grange Avenue, Oldham OL8 4EL **Tel** 0161 6242269 Email rainbowsgb.dc@ btconnect.com www.rainbowsqb.orq 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.orq.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.

3rd Floor, Cheltenham House,

Winston's Wish

Clarence Street, Cheltenham, Gloucestershire GL50 3JR Helpline 08452 03 04 05 www.winstonswish.org.uk Winston's Wish believe that bereaved children need support to make sense of death and rebuild their lives. They provide a Helpline, online forums and publications alongside support for children, young people and their families in the South West, South East and North West.

Books and other resources

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

For adults with life-limiting illness

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

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 fact sheet Macmillan Cancer Support
- Grief Encounter work book Dr Shelly Gilbert

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 thirdparty 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 Sara Booth, Associate Lecturer, CUHNHSFT, and our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

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Sources

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

Cancer.Net. Helping grieving children and teenagers. Accessed July 2015. Chalmers A. When a parent is not expected to live: supporting children. Childhood Beregvement UK, 2014.

Dving matters. Talking to children about dying. Acessed July 2015. Royal College of Psychiatrists. Bereavement. May 2015.

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 keep your money Mr/Mrs/Miss/Other Do you pay tax? If so, your gift will be worth 25% more to us – at no Name extra cost to you. All you have to Surname do is tick the box below, and the tax office will give 25p for every Address pound you give. Postcode I am a UK taxpayer and I would like Macmillan Cancer Phone Support to treat all donations **Email** I have made for the four years prior to this year, and all Please accept my gift of £ donations I make in the future, (Please delete as appropriate) as Gift Aid donations, until I I enclose a cheque / postal order / notify you otherwise. Charity Voucher made payable to Macmillan Cancer Support I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each OR debit my: tax year, that is at least equal to the tax that Visa / MasterCard / CAF Charity Charities & CASCs I donate to will reclaim on my aifts. I understand that other taxes such as Card / Switch / Maestro VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of Card number 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, Valid from Expiry date 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. Security number Issue no In order to carry out our work we may need to pass your details to agents or partners who act on our behalf. Signature

Don't let the taxman

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

Date

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

This booklet is for parents who are near theend of life. It aims to help you talk to your children and prepare them for loss.

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. It describes what language you might use, and where you can find more support during this difficult time.

WE ARE MACMILLAN. CANCER SUPPORT

Questions about cancer?
Call free on 0808 808 00 00
(Mon–Fri, 9am–8pm)
Visit macmillan.org.uk



Call 08452 03 04 05 (Mon-Fri, 9am-5pm, Wed, 7pm-9:30pm) Visit winstonswish.org.uk

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