

Talking to children and teenagers when an adult has cancer





This booklet is about talking to children and teenagers when an adult has cancer. This could be a parent, grandparent, family member or friend.

The booklet explains how to tell a child or teenager about cancer.

It also helps you understand their reactions, and gives tips on how to help them cope.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

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

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

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



Patient Information Forum

About this booklet

This booklet is about talking to children and teenagers when an adult has cancer. This could be a parent, grandparent, family member or friend.

The booklet explains how to tell a child or teenager about cancer. It also helps you understand their reactions, and gives tips on how to help them cope. We hope it helps you deal with some of the questions or feelings you may have.

The following booklets could also be helpful:

- Talking about cancer this is for people who have cancer.
- Talking with someone who has cancer.

We have more information about ordering these booklets.

How to use this booklet

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

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

On pages 76 to 83, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse.

Quotes

In this booklet, we have included quotes from people with cancer, and their family and friends. These are from people who have chosen to share their story with us. This includes Sean, who is on the cover of this booklet. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

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

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.

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Talking about cancer

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Talking to children and teenagers

Talking to children and teenagers about cancer can be difficult at times. If you can talk to them in a way they can understand, they may cope better. We have some tips to help you talk to them.

Why talking can help

People sometimes feel they are protecting children by not telling them about a cancer diagnosis. It is natural to want to protect children from difficult news.

You may have worries of your own that stop you talking about it. You may feel that talking about cancer will make it feel more real when you are still struggling to accept it. But explaining what is happening may make things less unsettling for children.

Children often know when something serious is affecting the people they are close to. They may also notice changes in how the adults around them are feeling and behaving. It is important to give them the chance to talk about their fears and worries, and to ask questions. Talking about the cancer can help them feel more secure.

The benefits of talking

There are many benefits to talking to children and teenagers:

- Knowing what is happening may make them feel less anxious.
- It gives them a chance to talk about how they feel and to ask questions.
- It shows you trust them.
- You will not worry about them hearing your conversations with other people.
- It can make you feel closer and able to support each other.
- It might help them cope better with a difficult situation.

Telling the boys was my biggest worry. I didn't want to upset and scare them, but equally I wanted to be open and honest with them.

Victoria, diagnosed with ovarian cancer

The risks of not talking

It may be difficult starting to talk to children about cancer. But if you do not talk to them, they may:

- feel frightened because they do not know what is happening
- get the wrong idea about what is happening
- feel alone and worried with no one to talk to
- think they are not important enough to be included
- worry that they have done or thought something that has made someone unwell.

Children often find out about what is going on, even when you have not told them. For example, they may hear something from friends whose families know yours. They may wonder if they can trust you to tell them about important things.

Children also learn things from TV, the internet and conversations they hear. But this information is not always accurate. If you do not speak to them about what is really happening, they may continue to believe this information.

How children may react

Children can react in lots of different ways. How they understand and behave will depend on how old they are. You may have to repeat the things you tell them. This can be hard if you are finding it difficult to talk about the cancer.

Younger children may not understand what is happening, but they will notice changes to their routine. Teenagers or young people usually understand, but they may find it hard to talk about what is happening.



Preparing to talk to children

You will probably need time to cope with your own feelings before talking to children. You might first want to speak to one of the following healthcare professionals:

- a clinical nurse specialist (CNS) a nurse who gives information about cancer, and support during treatment.
- a psychologist someone who gives advice about managing feelings and behaviours
- a counsellor someone who is trained to listen to people's problems and help them find ways to cope.

Try to talk to children before they realise something has changed and start to worry. You can do the following things to prepare yourself:

- Have all the information you need and make sure you understand it.
- Think about the questions a child might ask.
- Think about the words you will use to explain things.

You could start by asking them what they already know. You may find they know more than you think.

I took the bits of advice I thought would work well for us and ignored the rest. Ultimately I think you know your own children best and what works for them. II

Victoria, diagnosed with ovarian cancer

Who should tell them?

It is usually best to have another adult there when you talk to children. This should be someone they know and trust, such as someone in your family or a close friend. But you may want to do it on your own.

Even if you are not the person telling them about the cancer, you may want to be there. This means you know what is being said and how the child reacts. Some people with cancer prefer not to be there themselves. You should do what feels right for you and the child.

Choose the right time and place

There may be places where you feel more able to talk to the child or children. Make sure it is somewhere they will feel able to talk too. You might want to tell them somewhere away from home. This might make it easier to speak openly, and when the conversation is finished you can both walk away. It might be a place you go back to every time you want to speak about cancer.

Try not to tell them just before bedtime, as they may not be able to sleep. If this is the only time you can talk to them, it is important to make them feel supported. Try to answer any questions they have before they go to sleep.

If there is more than 1 child, it might be best to tell them together, if you can. This prevents them feeling like others know more than them. If you are talking to children separately, do it as close together as possible. Some children may wonder why they were told last.

Try to avoid only telling older children, as this can be difficult for them to cope with.



How to talk to children

If you are the parent, you are the expert when it comes to your child. You know the best way of talking to them, how they might react and what support they will need. If you are not the parent or quardian, you should talk first to the person who is.

You might want to practise what you are going to say before you talk to them. But do not feel you need to have the perfect conversation. Children can ask questions you were not prepared for, and these may come hours or days later.

Try to find a time when you are feeling calm. The first conversation is just a starting point. You can then slowly give your children small, relevant pieces of information and reassurance.

If you can, let your child's reactions and questions direct the conversation. Listen and keep it as open as you can. Try to ask questions that will encourage them to say what they are thinking, rather than giving a 'yes or no' reply.

Be honest

It is best to be honest with children. If they think you are hiding something, they may think they are not being told the truth. Try to not make things sound less serious than they are.

Depending on the situation, you may be able to tell them that cancer is serious, but many people get better. You might be able to tell them that doctors are doing everything possible to help.

You may not be able to answer all their questions. Tell them you will try to find the answers and will tell them when you know.

Teenagers may react differently from younger children or adults when they are told someone has cancer. They may ask for more information about the diagnosis and what it means for family life. They may also need more time to work through their feelings.

As with younger children, it is best to tell teenagers the truth about the cancer and your treatment plan. Encourage them to ask any questions they have, and answer these gently but honestly. Remember teenagers value their independence, but they will still look to you for reassurance and support.

Starting the conversation

You will need to use words that children will understand. These will vary depending on their age. Here are some tips to help you through the conversation:

- Find out what they know and explain anything they are not sure about.
- Use simple, clear language and short sentences.
- Talk about what is happening now, rather than things that may happen in the future.
- Be prepared for them to react in different ways.
- Ask them if there is anything else they want to know.
- Repeat the information for younger children, especially those under 7. They may not understand or remember everything you tell them.

There are some useful books and resources that help explain cancer to children. It might help younger children to see pictures of a hospital.

You may also want to use our other information about cancer types and treatments to help explain cancer to older children. We also have easy read booklets with illustrations.

"Telling our children was probably the most difficult moment of going through cancer. My wife researched 'how to help children cope' on the Macmillan website and requested a booklet to help us tell our children in an open and honest way. "

Sean

Explaining cancer

Children need some information about the name of the cancer, where it is in the body and how it will be treated. You should try to prepare them for any physical changes that may happen. They may cope better with the changes if you are honest with them.

Here are some examples of how you can explain cancer to young children:

- 'I have a lump growing inside my body (explain which part)
 that shouldn't be there. It is called cancer and I'm going to
 have an operation to take it away. After that, the doctor will
 give me medicine, so the lump does not come back.'
- 'Gran has an illness called cancer. The doctor is giving her special
 medicine to help her get better. The medicine might make her
 feel sick or tired some days, but on other days she will feel fine.
 The medicine might make her hair fall out, but it will grow back
 when she finishes taking the medicine.'
- If your child asks you what cancer is, you can say 'Our bodies are
 made up of lots of tiny things called cells. They all have a different
 job to make our bodies work and keep us healthy. Cancer is when
 some cells in the body stop working properly and stop the healthy
 cells doing their jobs. The cancer cells can grow into a lump.'

Teenagers will often know what cancer is. They may have heard about it at school or have a friend with cancer. You could talk to them about what they know if you think that would help.

Teenagers or older children may look for information about cancer on the internet. You could help them understand whether the information they find is accurate and relevant.

You could show them:

- Macmillan's cancer information
- Hope Support Services
- Riprap a website for teenagers who have a parent with cancer.

Macmillan gave advice about talking to our kids. They said children often fear that they could catch the cancer, or worry that they are somehow responsible. I don't think we would have realised that, and it really helped us to address their fears.

Marina, diagnosed with lymphoma

Important points to tell them

Children, particularly those under 10 years old, often have worries about cancer. Children may need reassurance that:

- you cannot catch cancer from people it is okay to sit close, hug or kiss
- the cancer was not caused by something they did or thought
- there will always be someone to take care of them
- they can always ask you questions and talk to you about how they feel
- you will listen to their worries and try to help them cope.

How a child understands the information and reacts can depend on how old they are. They are usually able to understand more about illness as they get older, but this depends on the child. We have more information about how children may react at different ages.

I told them I had bowel cancer but the prognosis was good. With the use of a diagram I showed them where the tumour was and what the surgery entailed.

Sean

Children with additional needs

Children who have learning disabilities or learning differences, or who are neurodivergent, can find talking about change hard. But in most situations, they will cope better if they are involved and prepared.

Some children may think or learn in a different way to others. Try to use communication styles that the child is comfortable with.

- Plan what you want the child to know, and how much information you need to share.
- Pick a quiet space to talk.
- Talk slowly and clearly.
- Give a small piece of information and then stop.
- Give the child time to process each bit of information before talking again.
- If you need to repeat the information, use the same words.
 You might have to explain more than once, especially if you are having a long course of treatment.

If the child finds diagrams helpful, our <u>easy read booklets</u> may help with your conversations. They have simple diagrams about cancer, cancer treatment and life with cancer.

You could try using calendars that show your hospital appointments or visits, and your child's activities. This can help them see what is happening and when it will happen. It will help your child see how your treatment will fit in with their life. It will also remind them of the things that are staying the same.

Some children may want to know about any changes in routines. Try to keep their routine the same if possible. Keep things they are used to around them and explain what is happening every day.

It may also help to prepare them for possible physical changes. They may cope better if they have time to prepare. Reassure your child that they are coping well with the change.

It might be useful to talk to any teachers or support workers who are involved in your child's care.

The National Autistic Society has more information on helping children prepare for change.



Who else needs to know about the cancer

You may want to tell close family and other adults who your children know and trust. Let them know 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 can be helpful to talk with children about who else they think should know. For example, they might want a teacher, club leaders or their friends' parents to know. Older children may have strong feelings about who should or should not know so it may be helpful to talk to them first.

It is a good idea to tell nursery staff, schoolteachers and the school nurse. It will mean that they can be aware of the child's needs. It will also help them understand any unusual or difficult behaviour. Ask them to let you know if your child shows any changes in behaviour.

You could also ask them to support your child by giving them more one-to-one time. You can ask if your child can have some time with the school nurse or counsellor too.

At school, college or university

Older children or teenagers may not want to be seen as different from their friends. But it is important that certain people know and can be there to support them if they need it.

You should speak to your teenager before talking to their school or college. They may not want people to know, as this may be a place where things still feel 'normal'. Asking them will make them feel that you are telling them everything and including them.

Teenagers may be facing exams or coursework at school, college or university. Teachers or staff can offer support. They may also notice issues or changes in behaviours that are not shown at home.



Children's and teenagers' reactions

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Understanding children's and teenagers' reactions

How much children understand about cancer and how they react depends on their age.

Children are usually able to understand more about illness as they get older, but each child is different.

Babies and toddlers

Babies and toddlers will not understand what is happening. They will be aware of changes to their routine, or to who is looking after them.

How to help

- Try to keep their routines as normal as possible, especially if their main carers are not there.
- If possible, someone who knows the child well should care for them.
- Keep to familiar routines when you can, such as bedtimes, meals and nursery.

Children aged 3 to 5

Young children do not really understand illness. But they often notice physical changes, or changes in adults' emotions. They react to changes in their routine and to being separated from the people who usually care for them.

Young children may feel guilty that they have done something to cause the cancer. Or, if you are in hospital, they might worry that they have made you go away.

Some children in this age group may understand what illness is. They may worry that they will get cancer too.

This age group can become clingy and scared of being separated from the people who care for them. They may start to do things they have outgrown, such as:

- sucking their thumb
- wetting the bed
- talking like a baby
- having tantrums.

They may become guieter than usual or have bad dreams.

How to help

- Ask someone they know and trust to take care of them.
- Keep to everyday routines when you can.
- Stick to their usual boundaries. Do not be surprised if they start doing things they have outgrown.
- Let them know that the cancer is not their fault, and that they cannot get cancer from you.
- Use a doll, soft toy or simple drawing to explain where the cancer is or where an operation may be.
- Try to prepare them for any physical changes.

Children aged 6 to 12

At this age, children can understand more about cancer and its effects on the body. They often have fears they may not talk about. This includes worrying that the person with cancer is going to die. that they have caused the cancer, or that they can catch it.

They may try to be especially good and set high standards for themselves. You may see changes in their behaviour, concentration, schoolwork or friendships.

How to help

The suggestions for children aged 3 to 5 still apply to many in this age group. You may find the following tips helpful:

- Use books to explain the cancer and its treatment.
- Reassure them that many people with cancer get better, if this is appropriate.
- Make sure they keep up with school, other activities and friendships.
- Let them know it is okay to enjoy themselves.
- Give them little things to do to help out.
- Let their school know, so they can also offer support.

Teenagers

Teenagers usually understand what it means to have cancer, but they may not want to talk about it. They may find it hard to talk to you or show how they feel. It is important to encourage them to ask any questions they have and make sure they feel involved.

Some teenagers may be keen to help out. But they may have to take on more responsibilities at home at a time when they want to be more independent.

This can make them feel angry and guilty. Sometimes their behaviour may seem hurtful to themselves or others.

How to help

- Ask them what they think and talk to them like an adult.
- Help them understand that talking is a good way of coping. Encourage them to talk to someone close, such as their friends, a relative or a family friend.
- Make sure they keep up with friendships, activities and normal life as much as possible.
- Give them time and space to themselves when they want it.
- Keep to usual rules and limits these can be even more important now than before.
- Explain that they might need to help a bit more with things like cooking, tidying up or looking after younger children. Letting them help shows that you need and trust them. But reassure them you do not expect them to do everything, and that people will care for them too.
- Show them you appreciate their help.
- Tell them about information that may help, such as Riprap and Hope Support Services.

"As I recovered from surgery I was limited in what I could do with the children. Just being around them helped me, and I believe that seeing me at home recovering and feeling better by the day reassured them. "

Sean

When children need help

Children can have lots of different feelings and reactions. They can show their feelings through anger or 'bad' behaviour. A child may react to someone's cancer diagnosis with behaviour you would not normally accept.

Some children may have problems with eating, sleeping or bed-wetting, or problems at school. They may seem sad and withdrawn, or have physical symptoms like not wanting to eat, headaches or tummy aches.

These changes are not unusual. If they carry on, or if there is anything worrying you about the child, you can ask for help from:

- your GP
- teachers
- the school nurse
- social workers
- psychological services at your hospital
- local counselling services
- health visitors (for pre-school-aged children).

Your cancer doctor or specialist nurse can give you advice about counselling or psychological services to help you support a child.

You may be able to get help from social workers. In England, Scotland and Wales, social workers are accessed through your local authority (council). You can search for contact details of your local council online.

In Northern Ireland, social services are accessed through Health and Social Care Trusts. Visit the NI Direct website.



When teenagers need help

Being a teenager can be an emotional time. But this can be even harder if a family member or friend has cancer.

Some teenagers may not be comfortable talking about their emotions. They may prefer to express themselves through writing, art or music.

Remember that if they are not talking to you about how they feel, they may be talking to someone else. They may have support from their friends, or another adult such as an uncle, aunt or grandparent. It is important to make sure they have someone to speak to outside of the family.

Teenagers may feel more comfortable joining a support group than speaking to a counsellor. Visit macmillan.org.uk/localsupportgroups

They can also get online support from some organisations.



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Your feelings

How a family responds to a cancer diagnosis will depend on many different things. This includes the way they normally deal with feelings.

Showing your feelings

Some adults worry about showing their feelings or crying in front of children. But there are good reasons to show how you feel. Hiding your feelings takes energy and can make you feel even more anxious.

We have more information about dealing with anxiety in our booklet How are you feeling? The emotional effects of cancer.

Showing your feelings can make it easier for a child to show theirs. It is like giving them permission to do the same.

You might want to protect children from strong emotions. such as arguments between adults. But it is okay to cry in front of them sometimes, or to tell them you are sad or angry about your illness.

Let them know that crying helps you feel better, and there may be times when they need to cry. Let them know crying is not babyish, and that they do not have to be strong.

You can explain that feeling sad or angry is normal and it is okay to feel like this. This helps children accept these feelings as normal. Always let children know how much you love them. This might be through words, hugs or kisses. Sometimes children may be annoyed about not getting enough of your attention. Or you may feel irritated by them or lose your temper. But try not to be hard on yourself.

Family life can be hard to manage, even for people who do not have cancer. Your reactions may be affected because you are under a lot of stress

If you can, talk about this with other adults. Make sure you are getting enough support to help you cope. This can stop things becoming too tense.

You may think teenagers will find it hard to see you cry or hear about how you are feeling. But it is important to be honest about your feelings, as it will help them trust you. It may also make them feel they can be honest about their own feelings. This trust will make it easier for you to find out if they are coping.

Changes to family life

Try to keep family life as normal and stable as possible for children. This might not be easy, but there are things you can do that may help.

Changes to routines

Disruptions and changes to your usual routines are normal. But it is important that children know how their daily routines are going to change. Children, especially younger ones, like routine and depend on it. It helps them feel safe.

Tell them about changes in advance and make sure they always know:

- who is looking after them
- who will pick them up from nursery or school
- who is taking them to activities such as swimming lessons
- any other changes to their normal routine.

Even with planning, arrangements may have to change at short notice. Try to show your children that things can be flexible. Involve them as much as you can in any new plans.

Changes to teenagers' routines

Teenagers often want to help when someone in their family is ill. This could mean anything from washing up to going to hospital appointments.

Letting teenagers help in these ways can have many benefits, for you and for them. They may learn new skills and feel more mature.

At the same time, it is important to make sure they do not try to take on too much. Let them know that you might need their help, but they should keep focusing on their schoolwork too. They should also keep doing things they enjoy, such as seeing their friends.

In some families, teenagers will not need to do any more than they usually would. In others, they may have more responsibilities to take on.

Some teenagers become carers when a family member has cancer. A carer is someone who provides unpaid support to a family member or friend who could not manage without this help.

Spend time together

Life can be busy when you are coping with cancer. It is important to have some uninterrupted time with each other.

If possible, ask people to contact you by text or email rather than by phone. People often want to help or let you know they are thinking of you. But they do not usually expect you to reply, so do not feel you have to. You could also switch your phone off at mealtimes.

We have listed some ways you can spend time with each other at home, even when you do not have much energy.



Get help

You might want to ask people to help with childcare or take over some of the things you usually do. Try to choose people who the children feel safe, comfortable and familiar with. Below are some things you could do:

- Try to accept offers of help around the house. This can give you more time to spend with the children.
- Accept help from other families. They are often willing to look after the children after school or nursery.
- You could ask a relative or close friend to coordinate offers of help. They can help plan a rota system. You can use a calendar or chart, so you know who is helping when. There is an example of a rota in our booklet Looking after someone with cancer.
- Try to get extra help with childcare if you need it. We have more information at macmillan.org.uk/childcare

Keep to the usual rules

Even when life is going well, it is often hard to be consistent and set rules for children. It is especially hard when someone is coping with cancer and worried about children's reactions.

Children and teenagers need love and support, but they also need the usual discipline to help them feel secure. It is important to try to keep to your usual rules as much as you can. If you are worried about a child's behaviour and need support, help is available.



Effects of treatment

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Explaining cancer treatment

This section is about different cancer treatments, and how to talk about them with children and teenagers. Knowing about cancer treatment and its side effects can prepare children and help them feel less anxious.

If you are struggling to understand it all, it may help to talk to our cancer support specialists first. You can contact them by calling 0808 808 00 00. They can send you booklets about different types of cancer or cancer treatment. This may help you explain the treatments to children.

Surgery

You can explain that this is an operation. The doctor or surgeon will either remove the cancer or remove the part of the body where the cancer is.

If children visit someone after surgery, try to prepare them first. For example, if the person they are visiting will have drips or tubes, tell them:

- what they are for
- that they will only be there for a short time.

If children want to look at a scar, it is usually fine to let them see it. But it may be best to wait until the swelling and redness settle down. If they are reluctant or not interested, do not force them.

Chemotherapy

Explain that chemotherapy is medicine that destroys the cancer, or stops it growing.

It is helpful to tell children how chemotherapy may affect how someone feels. Let them know the following things:

- Chemotherapy can sometimes make you feel sick, but you can take tablets to help stop the sickness.
- Chemotherapy can make you feel very tired, so you will usually need lots of rest or sleep after having it.
- Your hair may fall out. If it does, you will be able to wear a wig, bandana or hat. Hair usually grows back again after the chemotherapy finishes.
- Germs do not cause cancer, but chemotherapy can make it easier for you to get a cold or infection.

Radiotherapy

You can explain that radiotherapy uses special invisible rays to destroy cancer cells in the part of the body that is being treated.

Depending on where you are having the radiotherapy, you can explain that it:

- can make the skin in the area being treated sore, or make it change colour
- makes you feel very tired, even after it is finished, so you will need to rest a lot.

Side effects

Children need to know that:

- side effects will usually go away when cancer treatment finishes, but it can take some time
- side effects do not mean you are getting sicker
- not everyone gets the same side effects.

If they notice you are unwell, children may worry the cancer is getting worse. Or if there are no side effects, they may think the treatment is not working.

Tell children that cancer treatment can be hard. Explain it is normal for people to feel sad or frustrated at times. But make sure they know it is not because of anything they have done. Try to help them feel involved. If they want to feel helpful, you could ask them to do little things to help around the house.

Changes to physical appearance

It is helpful to tell children in advance about any possible changes to how someone will look. Younger children, particularly those under 10, struggle most with this. Letting them know in a calm way is often the easiest way to explain things. Older children may feel embarrassed and want to avoid talking about it.

If you are struggling to explain this, you can ask someone else to talk to them. Or you can ask for more help on how to talk to them. You can call our cancer support specialists free on **0808 808 00 00**.



After treatment

After treatment finishes, children may expect things to get back to normal. They might find it hard to understand why might not happen.

People often continue to feel very tired and may still be coping with side effects. It is also common to feel anxious and isolated, and to miss the support available during treatment. This is normal - it takes time to adjust to life after treatment.

It may take time, possibly months, for people to get their energy back. It is a good idea to prepare children for this. It might help to tell them about any new changes to family life and routines.

You could involve them in things to help with recovery, such as:

- doing some exercise, like going for short walks, to help to build up energy levels
- eating well tell them about foods that are healthy to eat and encourage them to try them
- making sure you all get enough sleep explain how important this is for recovery as well as for their growth
- asking them to keep helping around the house, if they have been doing this.

Try to keep being open with children. Let them know you are there to listen and they can talk to you about their worries. They may worry about people staying well. Younger children will probably want lots of attention.

Explain that people can still get illnesses like colds, but this does not mean the cancer has come back.

It can help to talk about how:

- you have been through something hard together
- they have helped.

This can be very important for teenagers. Things usually start to get back to normal as daily life takes over from the cancer.

Cancer might have caused lots of difficulties, but it may also bring some positive things to family life. Being open and honest with children can make you feel closer. You can feel proud of how your children have learned to cope when things are hard.

Do not be afraid to say how proud you are of them. They may be more responsible, independent and sensitive to other people's needs in the future.

Spend time together

People may have cancer treatment as an outpatient or during a short stay in hospital. Or they may be at home coping with side effects or symptoms.

All this can disrupt family life and make it hard to have enough quality time with children.

In hospital

You may be worried that visiting people in hospital will be too stressful for children. But being separated from people they love may make them more anxious. Ask children if they would like to visit and let them decide.

At first, it may be easier for them to visit in a visitors' room or day room. Or there may be a canteen or cafe to go to.

You will need to be aware of what children may notice when visiting a hospital. There may be very unwell people being cared for nearby. For younger children, try to keep visits fairly short, for example up to 15 minutes. Remember that older children may want some time alone with the person during the visit.

Here are some other ideas for preparing children for a hospital visit:

- Explain what to expect. For example, tell them what a drip is, what it looks like and what it is for.
- Tell them about the different people who are there to help.
- Encourage older children and teenagers to bring a book, games console, tablet or laptop. Encourage younger children to bring a toy or colouring book.
- Make sure there are snacks and things you can do together. This could be a pack of cards or a book of word games.
- If children are overwhelmed or tired, have an adult ready to take them home.

It is important for children to keep in touch with people while they are in hospital. Some of the following ideas can be helpful:

- Try to arrange regular phone calls or video calls.
- Give them a photo of the person who is in hospital.
- Leave notes or a small gift for them to find at home, or send a card or letter.
- Young children could send drawings to the person in hospital.

Teenagers may want to come along to treatment sessions, if they are not in school time. It can help them understand the treatment process and ask any questions they have. It may be reassuring for them to understand how cancer treatment works.

At home

Here are some things people with cancer can do with children:

- Watch TV or films, or listen to music together.
- Play cards, board games or computer games.
- Look through family photos and make a photo album together.
- Allow them to help by bringing a drink or a book, or by tidying up.
- Save energy for the things you enjoy doing together.
- Getting out for some fresh air can be good for everyone. Exercise, even short walks in the park, can help increase energy levels and reduce stress.
- Ask the children to talk about what they have been doing at school or clubs.
- Plan something to do with the children in the future. This may make them feel like things will get easier soon.

If the children are younger:

- Use art or craft materials and things like Play-Doh® together. Drawing pictures can help children express their feelings.
- Read and write stories together. Writing a story about you becoming ill can help your children show how they feel.

Getting support

It is important to ask for help if you need it, and there is lots of support available. Your cancer doctor and specialist nurse can offer you support and advice. Your GP can also give you or your relatives emotional support.

Sometimes people need more advice and support. You may find it easier to talk to someone who is not directly involved. Your specialist nurse or GP can usually refer you to a counsellor, social worker or psychologist.

Our cancer support specialists on **0808 808 00 00** can tell you more about counselling. They can let you know about services in your area.

Social workers at the hospital may be able to:

- help you with finances
- find suitable childcare
- offer emotional support.

We have more information about help with childcare.

Support groups

You may find it helpful to join a support group. These can offer a chance to talk to other people in a similar situation to you or who are facing the same challenges. This can help you feel less alone. They can be a place to share experiences, ask questions and support each other.

Not everyone finds it easy to talk in a group. It may help to go once to see what the group is like and then decide. You might want to take someone you know with you for extra support.

We have information about cancer support groups across the UK. Or you can call us on 0808 808 00 00.



Online support

If you use the internet, you can join an online support group or chat room. There are:

- groups about different types of cancer
- more general groups where people chat about practical and emotional issues
- groups for carers, relatives and friends.

You can share your own thoughts and feelings by posting messages for others to read and reply to. Or you can just read other people's comments or posts.

These messages can sometimes be helpful. They can also be sad and difficult to read. It may help to know that other people feel like you do. You may feel less alone and learn how other people cope after treatment.

This might be helpful for you if you find it difficult to talk face to face. Online groups are also easy to leave. You do not need to say why you are leaving.

Our Online Community offers this type of support. It is quick and easy to join. You can talk to people in our chat rooms, blog about your experiences, make friends and join support groups. Visit macmillan.org.uk/community



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If the cancer does not get better

This information is for anyone whose cancer is not expected to get better and who would like suggestions for telling a child or teenager. If your situation is different, you may not want to read this section.

If cancer has come back or is not getting better, children may know or sense that things have changed. It is important to tell them what is going on.

It can be helpful to first ask the child what they understand about what has been happening. You can talk to them about this and then gently tell them about the current situation.

Give them step-by-step information about what is happening. For example, you could tell them the cancer has come back and more treatment is needed. Try to reassure them that the doctors will do everything possible to control it. Try to be as honest and hopeful as you can.

If treatment is no longer controlling the cancer, you will need to tell them that the person with cancer is going to get more ill. Children also need to know it is okay to talk about this. They might try to protect others by not talking, so it is important to let them know they do not have to do this.

Children often worry about who will care for them if a carer is no longer there. It can help to talk to them about this and reassure them that they will always be cared for.



Talking about dying

This information is for people with advanced cancer who only have a short time to live and want to prepare children for this.

Preparing children for the death of a parent, relative or friend is an incredibly hard thing to do. Some people may feel they know the best way to do this for their own family. But no one has to do it alone. It is usual to need a lot of support from family or close friends. The following professionals can help:

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

Before talking to a child, you may find it useful to practise the words you plan to use with another adult.

You may not feel emotionally strong enough to start any hard conversations. Just take your time and go at a pace that feels right. You may want to have this conversation in stages, so children can process it. You may want to completely avoid talking about what is happening. It is common to react to a hard situation this way. It can be a way of coping. But it can also make it harder for you and others to support and understand each other.

When talking about dying, it is best to be honest with children and use clear language. Talking openly allows you to find ways of helping children cope in the future. It will also let you talk about any issues you have.

What to say

Try to use simple language. This includes saying the words 'dying' or 'died' when you tell young children about death. Saying someone is 'lost' or has 'passed away' can be confusing. They may wonder why no one is looking for the person who has died.

Saying a person has 'gone away' may make a child feel they have been abandoned. Try not to use 'going to sleep' to describe dying. Young children may then be afraid of going to sleep.

Young children may need to be reassured that they are not responsible for someone's death. They can often find reasons to blame themselves.

It is difficult to describe to a child how someone will die, as no one can ever predict exactly what will happen. You will need to slowly explain what has happened and why, and what may happen next.

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

The way children understand and react to death can depend on their age and their level of understanding.

Babies and toddlers

Children under the age of 3 can sense that something very serious is happening, even if they cannot understand what death means. Children as young as 3 can grieve. Some children in this age group may slip backwards in some of their developing behaviours, for example toilet training or feeding.

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.

They may need to be reminded that the person who has died will not come back again. But they should also be reminded that they can still remember all the things they did with that person.

Children aged 6 to 12

Children aged 6 to 12 know about death. But, as with children of other ages, they may not always understand the emotions they feel. By about 8 or 9, children start 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.

Teenagers

Teenagers may find it harder than younger children to cope with the news that someone is dying. They are old enough to know this means a major change and loss in their life. They may cope in ways that are hard for you to understand or deal with. Some teenagers may refuse to talk about the illness. Others may try to become closer to the people around them. Some may get angry 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 there is no right or wrong way to feel at this time. They need to be told it is okay if their feelings change a lot.

It is important to make sure they get the support they need. We have details of useful organisations.

Questions children may ask

It might help to think in advance about questions children may ask, and how you want to answer them. There is not a right or wrong way. What is important is that the child feels able to ask questions and talk about how they feel.

Here are some examples of questions a child may ask, and suggestions of how you could respond.

'What will happen to me?'

'Daddy/Mummy/Granny/Grandad will still be here for you and will look after you. It is very important to us that you will be safe and looked after, so we have already talked about it.'

'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 is 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 is well and healthy at the moment and will be here to look after you.

'Is it my fault?'

'Nothing you did or said has made this happen.'

We have more information about helping a child prepare for the death of a parent in our booklet Preparing a child for loss.

Organisations such as Marie Curie have information about supporting children and teenagers when an adult is dying.

Cruse Bereavement Support has a special website for bereaved children and young people called Hope Again. It also has a free helpline at 0808 808 1677.

Winston's Wish also helps support bereaved children and young people.

Memory boxes

To help children remember, you might like to make a memory box. This is a container that holds special things. It might include photos, some favourite music, letters or a message recorded on a DVD.

Depending on their age, children can be involved in helping make their own memory box.

We have more information about memory boxes at macmillan.org.uk/ memory-box or in our booklet Preparing a child for loss.



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About our information

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

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

Order what you need

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

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

Online information

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

Other formats

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

- audiobooks
- Braille
- British Sign Language
- easy read booklets

- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

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

The language we use

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

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

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Call us on **0808 808 00 00**. We 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.

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

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

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 808 0000 or use the Relay UK app.

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

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

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit macmillan.org.uk/financialsupport to find out more about how we can help you with your finances.

Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing, to changes needed to your home. Call us on **0808 808 00 00** to find out more about Macmillan Grants.

Help with work and cancer

Whether you are 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

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on 0808 808 00 00 to speak to a work support adviser.

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Support for young people

Childhood Bereavement Network

Tel 0207 843 6309

www.childhoodbereavementnetwork.ora.uk

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

Hope Again

Helpline **0808 808 1677**

www.hopeagain.org.uk

Supports young people across the UK after the death of someone close. Has a private message service on the website.

Hope Support Services

Tel 0198 956 6317

www.hopesupport.org.uk

Supports young people between the age of 5 and 25 across the UK when a family member is diagnosed with a life-threatening illness.

Riprap

www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Ruth Strauss Foundation

www.ruthstraussfoundation.com

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

Teenage Cancer Trust

Tel 0207 612 0370

www.teenagecancertrust.org

A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

Winston's Wish

Helpline 0808 802 0021

www.winstonswish.org.uk

Helps bereaved children and young people throughout the UK re-adjust to life after the death of a parent or sibling.

Youth Access

Tel 0208 772 9900

www.youthaccess.org.uk

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

Emotional and mental health support

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

Cruse Bereavement Support

Helpline **0808 808 1677**

www.cruse.org.uk

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

National Autistic Society

www.autism.org.uk

Provides advice and guidance for people with autism and their families.

Samaritans

Helpline 116 123

Email jo@samaritans.org

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

UK Council for Psychotherapy (UKCP)

Tel 0207 014 9955

www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel 0734 047 1970

www.cancerblackcare.org.uk

Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline 0808 800 4040

www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel 0800 652 4531

www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel 0300 123 1801

www.maggies.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118**

www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline 0808 808 1010

www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**

<u>lgbt.foundation</u>

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

www.outpatients.org.uk

Supports and advocates for LGBTIQ+ cancer patients in the UK, inclusive of all genders or types of cancer. Also produces information, and runs a peer support group with Maggie's Barts.

Support for families and carers

Carers Trust

Tel 0300 772 9600

www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline **0808 808 7777**

www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland). You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

https://gov.wales/find-your-local-authority

NI Direct

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Advanced cancer and end of life care

Hospice UK

Tel 0207 520 8200

www.hospiceuk.ora

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

Marie Curie

Helpline 0800 090 2309

www.mariecurie.ora.uk

Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Natural Death Centre

Helpline 0196 271 2690

www.naturaldeath.org.uk

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

Your notes and questions

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by members of Macmillan's Centre of Clinical Expertise.

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

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

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 cancerinformationteam@macmillan.org.uk

Sharpe L, Curran L, Butow P, Thewes B. Fear of cancer recurrence and death anxiety. Psycho-Oncology. 2018;27:2559-2565. Available from https://pubmed.ncbi.nlm.nih.gov/29843188 [accessed September 2023].

www.nhs.uk/conditions/social-care-and-support-quide/help-fromsocial-services-and-charities/getting-a-needs-assessment [accessed September 2023].

www.mind.org.uk/information-support/helping-someone-else/ carers-friends-family-coping-support/support-for-you [accessed September 2023].

Can you do something to help?

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

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

5 ways you can help someone with cancer

1. Share your cancer experience

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

2. Campaign for change

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

3. Help someone in your community

A lift to an appointment. Help with the shopping.
Or just a cup of tea and a chat. Could you lend a hand?

4. Raise money

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

5. Give money

Big or small, every penny helps.

To make a one-off donation see over.

Please fill in your personal details	Do not let the taxman		
Mr/Mrs/Miss/Other	keep your money		
Name Surname	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.		
Address Postcode			
Phone Email Please accept my gift of £ (Please delete as appropriate)	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		
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support	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.		
OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro Card number Valid from Expiry date			
Issue no Security number	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 whact on our behalf.		
Signature	If you would rather donate online go to macmillan.org.uk/donate		
Date / /			





