

TALKING TO CHILDREN AND TEENAGERS WHEN AN ADULT HAS CANCER



**We encouraged them
to ask any questions
and to talk openly
both with us and
their friends.**

**Sean, diagnosed
with bowel cancer**



About this booklet

This booklet is about talking to children and teenagers when an adult has cancer. It is for parents with cancer, but it can also be used by other adults, such as partners, grandparents and family members.

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.

We also have other booklets about talking about cancer that could help:

- **Talking about cancer** (for people who have cancer)
- **Talking with someone who has cancer.**

See page 60 for information about ordering these booklets.

How to use this booklet

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

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

Quotes

In this booklet, we have included quotes from people with cancer, and their family and friends. Some are from Sean, who is on the cover of this booklet. Others are from people who have chosen to share their story with us, or from the website **healthtalk.org**. To share your story, visit **macmillan.org.uk/shareyourstory**

For more information

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

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

If you are deaf or hard of hearing, you can contact our support line using the Next Generation Text Service (NGT) by dialling **18001 0808 808 00 00**, or use the NGT Lite app

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

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MERVAN
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TALKING ABOUT CANCER

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Why tell children?

Parents sometimes feel they are helping protect their children by not telling them about a cancer diagnosis.

Trying to protect children from difficult news, worry and distress is natural. But children often know when something serious is affecting their family. They may also notice changes in how you and other adults around them are feeling and behaving. Not knowing what is happening may cause some children more distress. This may have a negative impact on your relationship with them.

'I came home that night and I told them straight away, because I didn't feel the need to keep anything a secret. I wanted them to share in the things that the family was going through – I thought that was very important.'

Nicholas

It is important to give children the chance to talk openly about their fears and worries. Talking about the cancer can help them feel more secure. It also lets them ask questions and tell you how they feel about it.

You may have concerns that delay or stop you explaining what is happening. This is normal. You may be struggling to accept the situation yourself. The thought of coping with a child's distress on top of everything else may seem overwhelming. Or you might worry about how it will affect your family life. You may worry that cancer will become the focus, instead of things like school and exams.

The benefits of talking

There are many benefits to being open with children and teenagers:

- Knowing what is happening may make them feel more secure and less worried.
- They can ask questions, say how they feel and talk openly to you.
- It shows you trust them and you can be open with them.
- It can make you all feel closer. Your children can help support you, and you can help support them.
- It might help them cope better.

If you do not talk

Wanting to protect children from difficult news is natural.

But if you do not talk to them, they may:

- feel frightened, because they do not know what is happening
- feel alone with lots of worries and no one to talk to
- worry that something they have done or thought has caused the cancer
- think they are not important enough to be included
- imagine something worse than what is actually happening
- think cancer is too terrible to be talked about.

Children often find out about what is happening even when you have not told them. For example, they may find out through friends whose families know your family. Finding out like this can have a negative effect on their relationship with you. They may wonder if they can trust you, or other adults, to tell them about important things.

Children also pick up 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.

Telling your children

You will probably need time to cope with your own feelings before you talk to your children. You might want to speak to your specialist nurse or a counsellor first. But if you can, try to talk to your children before they notice things and start to worry.

Try to be as prepared as you can. You could get together all the information you have and make sure you understand it. You may want to think about:

- the questions a child might ask
- the words you could use to explain things.

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

'We did our best to reassure them that everything was going to be ok and it was ok to talk openly about this and ask whatever questions they wanted.'

Sean

Who should tell them?

If you are a two-parent family, it is usually best if you both talk to your children together. But this can depend on how you usually talk as a family.

If you are a single parent, you may feel able to, and want to, tell your children on your own. Or you could talk to them with someone close to you, who your child knows and trusts. You could also ask your specialist nurse or a counsellor to be there with you.

If you are not doing the talking, you might want to still be there. That way, you will know what has been said and how your child has reacted. But some parents prefer to let their partner or another adult tell the children and not be there themselves. You should do whatever feels right to you.

'My wife helped me to explain more in detail the situation we were in. Once the message got through to them, they were also very, very helpful in making me feel at ease.'

Mo

The right time and place

Choose a time and a place when your children are most likely to listen and feel relaxed, and where you will not be interrupted. There may be places where you and your children feel more able to talk. Try to find somewhere they will feel able to express their feelings.

If you have more than one child, it is best to tell them together if you can. This means they will not feel like their siblings know more than them. If you are telling them separately, do it as close together as possible. Some children may wonder why they were told last.

Try to avoid only telling the older children, as this can put a burden on them.

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 your cancer.

Try not to tell them just before bed time, 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.

'We decided to tell our children on the Saturday, so that there was no school to worry about for a couple of days.'

Sean

How to tell them

As a parent, you are the expert when it comes to your child. You know the best way to communicate with them, how they might react and what support they might need.

If you want to, you can 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 fairly 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 children's reactions and questions direct the conversation. Listen and keep it as open as you can. Try to ask open questions. These will encourage them to express what they are thinking, rather than giving a one-word reply.

Some examples of open questions are:

- 'Tell me about...'
- 'How can we...?'
- 'What do you feel about...?'

Be honest

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

Depending on your 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 you and your doctors are doing everything possible to make you well again.

'With the use of a diagram, I showed them where the tumour was and what the surgery entailed.'

Sean

If you cannot answer all their questions, it is fine to say you do not know. You can say you will try to find out and tell them when you know.

Teenagers may react differently from younger children or adults when they are told a parent 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. Try to 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 your children will understand. These will vary, depending on how old they are (see pages 24 to 27). Here are some tips to help you through the conversation:

- Find out what they know and correct any misunderstandings.
- Use simple, straightforward language and short sentences to explain what is happening.
- Try to talk about the current situation, rather than things that will happen in the future.
- Be as specific as you can. Children worry more when things are not clear, or if they hear adults whispering.
- Ask them if there is anything else they want to know.
- Take the conversation at your child's pace and be prepared for them to react in their own way.
- Repeat the information for younger children, especially those under seven. They may not understand it all the first time.
- Try to explain how their lives and routines are likely to be affected (see pages 34 to 35).

There are some useful books and resources that help explain cancer to children (see page 67). You may also want to use our other information about cancer types and treatments to help explain cancer to older children (see page 60).

Explaining cancer

You can tell your children the name of the cancer, where it is in the body and how it will be treated. 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.'
- 'I have an illness called cancer. The doctor is giving me medicine to help me get better. The medicine might make me feel sick or tired some days, but on other days I will feel fine.'
- 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.'

Older children and teenagers 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. They may find it helpful to visit the Macmillan website, **macmillan.org.uk**, Hope Support Services (see page 64) or Riprap (see page 66). Riprap is a website for teenagers who have a parent with cancer. There are also other sources of online support (see page 64).

Teenagers may already know what cancer is. They may have learned about it at school or have a friend with cancer. Some of their friends may have family members who have had cancer. You could ask them about what they know if you think that would help.

Important points to explain

Children, particularly those under 10 years old, often worry about things like causing the cancer or catching it. Children need reassurance that:

- nothing they did or thought caused the cancer
- cancer is not like a cold and you cannot catch it – it is okay to sit close, hug or kiss
- 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.

We have more information about how children and teenagers might react to the news on pages 24 to 27.

Children with learning disabilities

Children with learning disabilities can find change hard. But in most situations, they will cope better if they are involved and prepared. You are closest to your child, so you and your family can decide how much information you need to share. Remember to explain any possible changes to routines, and also any physical changes you might go through. You might be scared of telling your child. But it is likely that they will cope better with any changes if you are honest and open with them.

You could try using calendars or timelines that show your appointments or when you will be in hospital, 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.

Using visual supports can help explain what is happening. You might have to explain more than once, especially if you are having a long course of treatment.

Try to keep their routine the same. Keep things they are used to around them and explain what is happening every day. 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.

If your child has autism, the National Autistic Society has more information – visit **autism.org.uk**

Who else needs to know?

You will probably want to tell your 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. Also let your children know who you are going to tell and why.

It might be helpful to talk with your children about who else they think needs to know. For example, this could be a teacher, a club leader or their friends' parents. Older children may have strong feelings about who should know, so it is good to talk to them first.

It is a good idea to let nursery or school teachers and the school nurse know. This way, they can be sensitive to your child's needs. They can also understand any unusual or difficult behaviour. Ask them to let you know if your child shows any signs of worrying 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.

'We talked to the school and we talked to some of her friends' parents, so that the messages she was getting from them was, "Yes, mummy's not very well, but she is going to get better soon".'

Patricia

Some 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. This may be one of the few places where things still feel 'normal'. So at first, they may not want to let people know. Asking them will also make them feel that you are telling them everything and including them.

Teenagers may have exams or coursework at school, college or university. If they are finding it hard to keep up with their studies, it might be a good idea to speak with one of their teachers. You could find out if any support is available or whether they can extend your child's deadlines.

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

'My wife messaged the schools and the parents of their closest friends, so that everyone was aware.'

Sean



CHILDREN AND TEENAGERS' REACTIONS

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How children and teenagers might react

What children can understand and how they might react depends on how old they are. They can usually understand more as they get older. But this depends on the child. Remember each child is different and will react in their own way.

Babies and toddlers

Babies and toddlers will not understand what is happening. But they may be very aware of changes to their routine, and especially changes to who is looking after them. Try to create an environment that is as familiar and consistent as possible, especially for when you are not there. If possible, choose someone to care for your child who knows them well. Keep to usual routines when you can.

Children aged 3 to 5

Young children will not really understand about illness. But they may notice tensions and any emotional or physical changes in the adults around them. They may react to changes in their routine and to being separated from you.

They may also believe that wishing or hoping can make things happen. They might feel guilty that they have done something to cause the illness. If you are in hospital, they might worry they have made you go away.

Older children in this group are starting to understand what illness is. They may worry they will get cancer too.

This age group can become clingy and scared of being separated from their parents. They may start to do things they have outgrown, like thumb-sucking, bed-wetting, talking like a baby or having tantrums. They may become quieter than usual or have bad dreams.

How to help

- Use a doll, teddy or simple drawing to explain where the cancer is. You could also explain the area of the body where you might have treatment.
- Ask someone they know and trust to take care of them when you are not there.
- Keep to usual routines when you can.
- Let them know the cancer is not their fault and they cannot catch it.
- Try to set usual limits and boundaries, but be prepared for them to start doing things they have outgrown.

Children aged 6 to 12

At this age, children can understand more detailed explanations about cancer and how it affects the body. They might have fears they do not tell you about. They may worry you are going to die, that they have caused the cancer, or that they can catch it. They may try to be especially good, setting impossibly 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 too:

- You could use books (see page 67) to explain the cancer and its treatment.
- If it is appropriate for your situation, reassure them that many people with cancer get better.
- Make sure they keep up with school, other activities and friendships.
- Let them know it is okay to enjoy themselves and have fun.
- Give them little things to do to help. This will help them feel involved.
- It might be a good idea to let their school know, so they can also support your child.

Teenagers

Teenagers usually understand about cancer, but they might 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 might want to help out. But they may also want to be more independent and spend less time in the house. Having more responsibilities at home can make them feel angry and guilty at the same time. Sometimes their behaviour may seem hurtful to themselves or others.

How to help

- You could suggest some sources of information that may help. There are organisations that can help, including Riprap (see page 66) and Hope Support Services (see page 64). We also have a list of helpful books and resources (see page 67).
- Ask them what they think and try to include them as you would include an adult.
- Help them see that talking about feelings is a positive and mature way of coping. You can also encourage them to talk to someone close. This could be their friends, a relative or a family friend.
- Encourage them to 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 if you can. 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 siblings. Letting them help shows you need and trust them. But also reassure them you do not expect them to do everything and that people will care for them too.
- Show them you appreciate their help.

When children need help

Children can have lots of different emotional reactions. They might show their feelings through anger or bad behaviour. 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 a poor appetite, headaches or tummy aches.

These changes are common. But if they continue, or if you are worried about your child, you can ask for help. People who can support you and your child include:

- your GP (family doctor)
- 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 nurse can give you advice about counselling or psychological services to help you support your child.

You may also be able to get help from social workers. You can access a social worker through:

- your local authority (council) if you live in England, Scotland or Wales – visit **[gov.uk/find-your-local-council](https://www.gov.uk/find-your-local-council)**
- your local Health and Social Care Trust if you live in Northern Ireland – visit **nidirect.gov.uk**

When teenagers need help

Teenage years are already a time of emotional ups and downs. But knowing a family member has cancer can make things even harder.

Some teenagers may be less comfortable talking about their emotions. They may prefer to express themselves through writing, art or music. Remember that if they are not telling you how they feel, it does not always mean they do not have anyone to speak to. They may well have the support of 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. We have more information about support groups on page 62. They can also get online support from some organisations (see pages 64 to 66).



YOU AND YOUR FAMILY

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Your feelings

You and your children are unique. How you all respond to the situation will depend on many different things. This includes the way your family normally deals with feelings.

Showing your feelings

Some parents worry about showing their feelings or crying in front of their children. But there are good reasons to show how you feel. Hiding your feelings also takes up 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** (see page 60).

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

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

Let them know that crying helps you feel better, and there may be times when they need to do the same. Try not to let them think crying is babyish, or that they have to be strong. You can explain that feelings like sadness and anger are normal and it is okay to show these. This helps your children accept these feelings as normal. This means they are less likely to be frightened of them or feel it is wrong to have them.

Always let your children know how much you love them through words, hugs and kisses. Sometimes your children may feel resentful about not getting enough of your attention. Or you may feel irritated by them or lose your temper. 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 heightened because you are under a lot of stress.

If you can, talk about this with your partner or family. Try to make sure you are getting enough support and time out to help you cope. This can stop things at home 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

It can help if you try to keep family life as normal and stable as possible for your 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 your children know how their day-to-day 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 when you are not there
- who will pick them up from college, school or nursery
- who is taking them to activities such as swimming lessons
- any other changes to their normal routine.

Even with planning, sometimes arrangements 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 are often keen to help when someone in their family is ill. This could mean anything from doing the washing-up to going to appointments with you.

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.

We have more information for young carers aged 12 to 18 in our booklet **A guide for young people caring for someone with cancer** (see page 60).

Have family time

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

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 your family at home, even when you do not have much energy (see page 48).

Getting help

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

- Try to accept offers of help as much as you can. This can allow you to spend time with your children.
- Accept help from other parents. They are often willing to look after the children after school or nursery.
- You could ask a relative or close friend to coordinate the help that has been offered. 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** (see page 60).
- Try to get extra help with childcare if you need it.

Keeping to the usual limits

Even when family life is going well, it is often hard to be consistent and set rules and limits for your children. It is especially hard when you are coping with cancer and are worried about your 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 family rules as much as you can. If you are worried about your child's behaviour and need support, help is available (see pages 28 to 29).

'They're very adaptable and they're very resilient. And they were okay, as long as we tried to keep their routine as normal as possible.'

Tim



EFFECTS OF TREATMENT

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Explaining your cancer treatment

This section is about the cancer treatments you may have, and how to talk about them with children and teenagers. Knowing about your treatment and its side effects can prepare children and help them feel less anxious. What they may need to know will depend on their age (see pages 16 to 19).

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**. We can send you booklets about the type of cancer you have or its treatment. This may help you explain the treatments to your children.

Surgery

Explain that this is an operation and the doctor or surgeon will either remove the cancer or remove the part of the body where the cancer is.

Before your children visit you in hospital, try to prepare them for how you might be after the operation. For example, if you will have drips or tubes, tell them what they are for. Explain that you will only have them for a short time to help you get better.

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 not interested or seem like they do not want to look, do not push them.

Chemotherapy

Explain to them that chemotherapy is medicine that destroys the cancer, or stops or slows down the growth of cancer cells.

It is also helpful to tell children how chemotherapy may change your routine and how it may make you feel. Let them know the following things:

- Chemotherapy can sometimes make you feel sick, but you will take another medicine 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 and, if it does, you will be able to wear a wig, bandana or hat. You can reassure them that your hair will grow 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

Explain to them that radiotherapy uses x-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 a bit red and sore
- it 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 your treatment finishes, but it can take some time.
- side effects do not mean you are getting sicker
- not everyone gets the same side effects.

Some children may worry the cancer is getting worse if they see you unwell. Or they may think the treatment is not working if you do not get side effects.

Tell your children that treatment can be hard. Explain it is normal for you to feel sad or frustrated at times. But reassure them it is not because of anything they have done. Try to help them feel involved. You could ask them to get you a drink, or to do little things to help around the house if they want to.

Changes to your physical appearance

It is helpful to tell children in advance about any possible changes to your appearance. Younger children, particularly those under 10 years old, 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 cope with this yourself, you may prefer someone else to explain it 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, your children may expect things to get back to normal. They might find it hard to understand why that is not always simple.

You might 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 you had during treatment. This is normal – it takes time to adjust to life after treatment.

It may take time, possibly months, for you to get your energy back. It is a good idea to prepare your children for this. Try to be positive about the things you can do now treatment has finished. It might help to tell them about any new changes to family life and routines. For example, tell them if you will be picking them up from school or if you will not go back to work for a while.

Tell them if you are still getting support from the hospital, a support group or online. You could involve them in things you are doing to help your recovery, such as:

- doing some exercise, like going for short walks, to help to build up your 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 your recovery and for their growth
- asking them to keep helping around the house, if they have been doing this.

Try to keep being open with your children. Let them know you are still there to listen and they can talk to you about their worries.

They may be worrying about you staying well. Younger children will probably still be clingy. Tell them you will be going to the hospital for check-ups to make sure you are well. Explain that you can still get day-to-day 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
- how they have helped you get better.

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

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

Spending time together in hospital and at home

You may:

- be having treatment as an outpatient
- need short stays in hospital
- 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 your children.



In hospital

You may be worried that seeing you in hospital will be too stressful for your children. But being separated from you may cause them more anxiety. Ask your children if they would like to visit you and let them decide.

At first, it may be easier for them to see you in a visitor's room or day room. Or there may be a canteen or cafe you can take them to.

You will need to be aware of what your child may see in hospital. There may be very unwell people being cared for nearby. For younger children, try to keep visits fairly short (up to 15 minutes). Remember older children may want some time alone with you.

Here are some other ideas for how you can try to prepare your children for a hospital visit:

- Make sure they are prepared for what they are likely to see and explain things to them. 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 you. Show them things like the call button, so they know you are being looked after.
- Encourage older children and teenagers to bring a book, handheld games console, tablet or laptop. Encourage younger children to bring a toy or colouring book.
- Make sure you have snacks and things you can do together. This could be a pack of cards or a book of word games.
- If they are overwhelmed or tired, ask the adult who is with them to take them home.

Keeping in touch with your children while you are in hospital is also important:

- Try to have a regular time to call home if possible, or when they can call or text you.
- Make sure they have a photo of you while you are away if they would like one.
- It can be nice to leave notes or a small gift for them to find when you are in hospital.
- If you have internet access in hospital, you could send them an email. Or you can speak with them over an online video chat service such as FaceTime or Skype™ – **skype.com**
- You could also leave them a voicemail, or send a card or letter.
- If you feel well enough, you could set up a website or blog to keep them updated.
- If your children are younger, you could read a story with them over the phone. Or you could ask them to send you a drawing they have done.

Teenagers may want to come along to treatment sessions. You should encourage them to do this if they want to, and if the treatments 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 have a better idea of how your treatment works.

At home

Here are some things you can do with your children, even if you do not have much energy:

- Watch TV or DVDs together.
- Play cards, board games or computer games.
- Listen to music together.
- Look through family photos and make a photo album together.
- Allow them to help by bringing you a drink or a book, or by tidying up.
- On days when you are feeling better, save energy for the things you enjoy doing as a family. They do not have to be expensive or out of the ordinary. Your children will appreciate that you are spending time with them.
- Getting out for some fresh air can be good for everyone. Exercise, even short walks in the park, can help increase your energy levels and reduce stress.
- Ask the children to show you what they have been doing at school or other activities they have been involved in.
- If you feel well enough, plan something to do with your children in the near future. This may make them feel like things will get easier soon.

These tips may be useful if your children are younger:

- Use art materials and things like Play-Doh® together. Drawing pictures of family life 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. It may also show any misunderstandings they have.

Getting support

There is lots of support available for you and your family. It is important to ask for help. Talk to someone, such as your GP, if you feel you are not getting enough support.

Health professionals

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 (see page 60).

Support groups

You may find it helpful to join a self-help or support group. These can offer a chance to talk to other people in a similar situation to you, and facing the same challenges. This can help you feel less alone and more normal. 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 (see page 62). 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. There are more general groups where people chat about practical and emotional issues. There are also 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 **community.macmillan.org.uk**

Other organisations

We have details of other useful organisations that can help you (see pages 64 to 66).

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 prefer not to read this section.

If your cancer has come back or is not getting better, your 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 your children what they understand about what has been happening. You can then gently correct any misunderstandings and slowly 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 you need more treatment. Try to reassure them that you and your 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 you are going to get more ill. Children also need to know it is okay to talk about you not getting better. They might try to protect you 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 you are 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 their children.

Preparing children for the loss of a parent is an incredibly hard thing to do. Some people may feel they know the best way to do this for their own family. But you do not have to do it alone. It is usual 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. You may find it useful to practise the words you plan to use with another adult.

If you are feeling unwell or low, you may not feel emotionally strong enough to start any hard conversations with your family and friends. Just take your time and go at a pace that feels right. You may want to have this conversation in stages, so your children can process it. You may want to completely avoid talking about what is happening. Or, if you have a partner, you may find they do not want to talk about it. 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 your family to support and understand each other.

Even when talking about dying, it is best to talk openly and honestly with your children and use clear language.

Talking openly allows you to find ways of helping your children cope in the future. It will also let you show how much you care for each other and talk about any issues you have.

What to say

Try to use straightforward language. This includes saying the words 'dying' or 'died' when you tell young children about death. Saying a parent 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 (see below and opposite).

Very young children (aged under 3)

Children under the age of 3 can pick up 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.

Young children (aged 3 to 5)

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

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.

Older 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 their parents. Some may get angry with you 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 (see pages 64 to 66).

Questions children may ask

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

Here are some examples of questions your 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 me to make sure 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 made me ill.’

We have more information about helping a child prepare for the loss of a parent in our booklet **Preparing a child for a loss** (see page 60).

Organisations such as Marie Curie have information about supporting children and teenagers when an adult is dying. Cruse Bereavement Care has a special website for bereaved children and young people called Hope Again. It also has a free helpline – call **0808 808 1677**. Winston's Wish also helps support bereaved children and young people. We have details of useful organisations on pages 64 to 66.

Memory boxes

Some people want to help their children connect with memories of the things they have shared. You might like to make a memory box. This is a container that holds special things belonging to you. It can be a way of passing on memories to your children. It might include photos, some favourite music, letters or a message recorded on a DVD.

Depending on their age, children can be involved in making their own memory box to remember you.

We have more information about memory boxes on our website at **macmillan.org.uk/memorybox**



FURTHER INFORMATION

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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 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
- eBooks
- 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**.

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

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.

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

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** 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**

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 (Monday to Friday, 8am to 6pm).

Other useful organisations

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

Support for children and teenagers

Childhood

Bereavement Network

Tel 020 7843 6309

Email cbn@ncb.org.uk

www.childhoodbereavementnetwork.org.uk

A national, multi-professional group of organisations and individuals working with bereaved children and young people. Has an online directory you can search for local service.

Hope Support Services

Tel 01989 566317

Email [help@](mailto:help@hopesupportservices.org.uk)

hopesupportservices.org.uk

www.hopesupportservices.org.uk

Supports 11 – 25-year-olds when a family member is diagnosed with a life-threatening illness.

Winston's Wish

Tel 08088 020 021

Email info@winstonswish.org.uk

www.winstonswish.org.uk

Helps bereaved children and young people rebuild their lives after a family death. Offers practical support and guidance to families, professionals and anyone worried about a grieving child.

Youth Access

Tel 020 8772 9900

(Mon to Fri, 9.30am to 1pm and 2pm to 5pm)

Email admin@youthaccess.org.uk

www.youthaccess.org.uk

National membership organisation for young people's information, advice, counselling and support services (YIACS). Find your local Youth Access service via the website.

Counselling, bereavement and emotional support

Association for Family Therapy and Systemic Practice (AFT)

Tel 01925 444414

www.aft.org.uk

Promotes effective family therapy, systemic services and high standards of professional training and practice. Search for a family therapist on its website.

Barnardo's

Tel 020 8550 8822

www.barnados.org.uk

Produces resources that are specially designed to help children face family bereavement or separation, including booklets, a board game and memory books.

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

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

Cruse Bereavement Care

Tel 0808 808 1677

www.cruse.org.uk

Provides bereavement counselling, information and support to anyone who has been bereaved, including children and young people. Has a network of branches across the UK. Also runs the Hope Again website for young people, which includes information and forums where visitors can share their experiences. Visit **hopeagain.org.uk**

Relate

Email relate.enquiries@relate.org.uk

www.relate.org.uk

Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and more.

Relationships Scotland

Infoline 0345 119 2020

(Mon to Fri, 9.30am to 4.30pm)

Email enquiries@relationships-scotland.org.uk

www.relationships-scotland.org.uk

Provides relationship counselling, mediation and family support across Scotland.

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.

Samaritans

Helpline 116 123 (24 hours a day, 365 days a year)

Email jo@samaritans.org

www.samaritans.org

Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential, non-judgemental emotional support for people experiencing feelings of distress or despair, including those that could lead to suicide.

UK Council for Psychotherapy

Tel 020 7014 9955

Email info@ukcp.org.uk

www.psychotherapy.org.uk

Holds the national register of psychotherapists, psychotherapeutic counsellors and listening practitioners.

Books and other resources

These books and resources may support you with talking to children and teenagers about cancer. You can order these publications by searching for their titles online.

Books

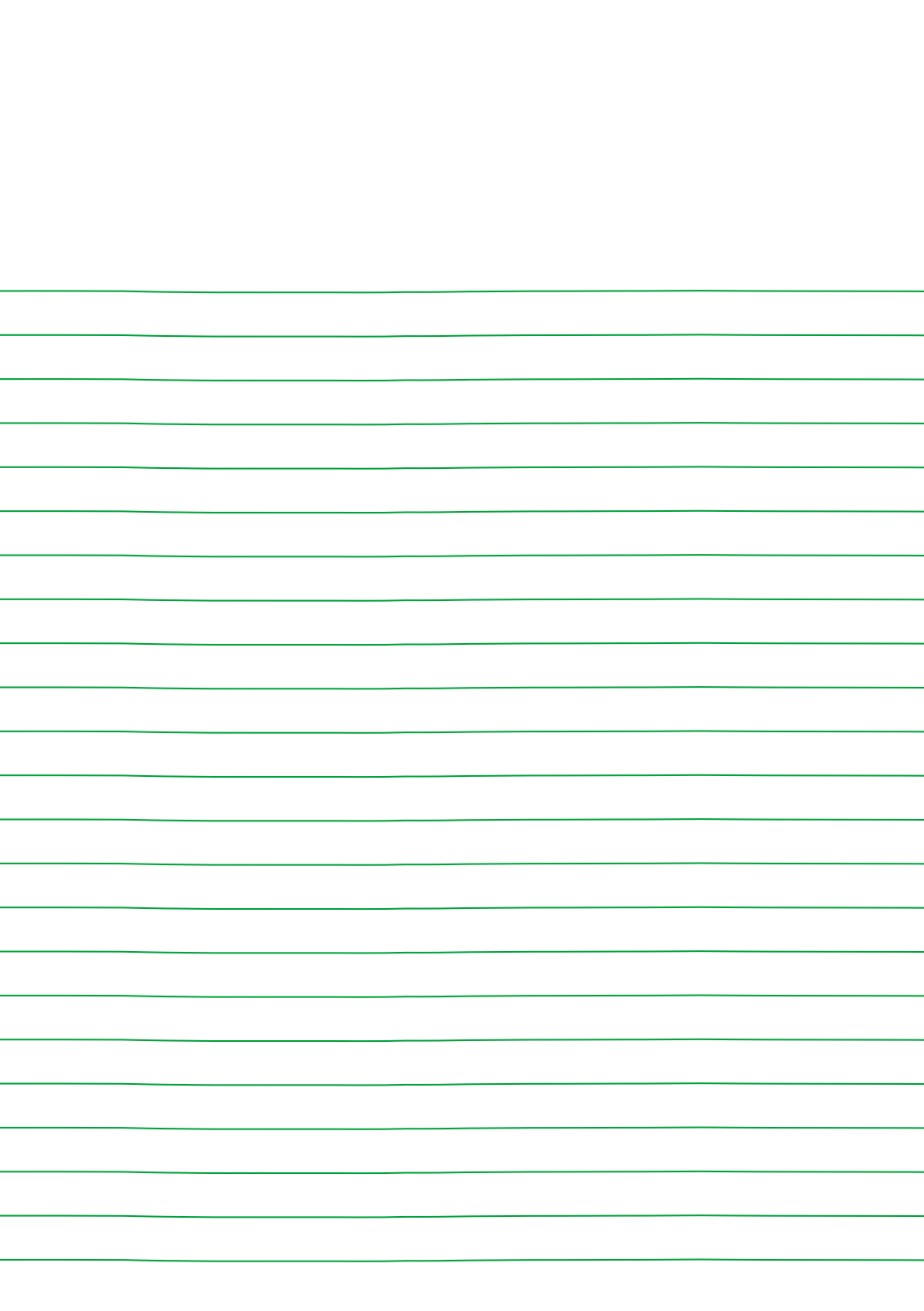
- **Stories about surviving cancer** – Jane Bingham
- **Artichoke hearts** – Sita Brahmachari
- **A monster calls** – Siobhan Dowd, Patrick Ness
- **Life on the refrigerator door** – Alice Kuipers
- **Milo and the restart button** – Alan Silberberg
- **My parent has cancer and it really sucks** – Maya Silva
- **The secret C: straight talking about cancer** – Winston's Wish

Resources

- **Mummy's lump** – Breast Cancer Care
- **Talking with your children about breast cancer** – Breast Cancer Care
- **When your parent has cancer: a guide for teens** – National Cancer Institute (USA)
- **Milly's bug-nut** – Winston's Wish

YOUR NOTES AND QUESTIONS

A series of horizontal green lines for writing notes and questions. The lines are evenly spaced and extend across the width of the page, providing a structured area for student input.



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.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Prof Tim Iveson, Consultant Medical Oncologist and Macmillan Chief Medical Editor.

With thanks to: Diana Borthwick, Clinical Nurse Specialist; Jamie Cargill, Lead Nurse, Teenage and Young Adult Cancer; Shirley Crofts, Clinical Nurse Specialist and Clinical Psychologist; Liz Egan, Macmillan Working Through Cancer Programme Lead; Dr Joy Hall PhD, Psychosexual and Relationship Therapist; Elaine Heywood, Macmillan Counsellor; Darren McKinley, Teenage and Young Adults Project Manager, Teenage Cancer Trust; Helen Moorey, Clinical Nurse Specialist; Michelle Pengelly, Supportive Care Lead Nurse; and Dr Louise Robinson, Consultant Clinical Psychologist.

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

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

Sources

We have used a number of sources in this publication. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

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Don't let the taxman keep your money

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

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

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

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

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



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

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

This booklet is about talking to children and teenagers when an adult has cancer. It is for parents with cancer, but it can also be used by other adults, such as partners, grandparents and family members.

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.

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

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

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

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