

A practical guide to living with and after cancer

# TALKING TO CHILDREN AND TEENAGERS WHEN AN ADULT HAS CANCER



# About this booklet

**This booklet aims to help you talk to children of any age, including teenagers, about cancer. It focuses on parents with cancer, but it can also be used by other adults, such as partners, grandparents and close family members.**

Not all the information here will be relevant to your situation. Many people with cancer can now be cured, or live longer with it. But we have also included a section for when the person with cancer is not going to recover.

It gives suggestions about how to:

- tell a child or teenager you have cancer
- understand their reactions
- help them cope
- explain cancer treatments
- deal with changes to your family life.

Talking to children and teenagers about cancer can be a hard thing to do. Being honest and including them in what's happening is usually the best approach. When the time comes, many parents find the conversation more natural and less traumatic than they expected.



Most of the information in this booklet is relevant to teenagers as well as children. However we've highlighted information that's particularly relevant to teenagers in panels like this one.

In this booklet we've included comments from people who have talked to their children about cancer, and from a teenager whose parent had cancer, which you may find helpful. Some are from members of our Online Community (**[macmillan.org.uk/community](https://macmillan.org.uk/community)**). Others are taken from the website **[hearttalk.org](https://hearttalk.org)**

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm.

If you're hard of hearing you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **[macmillan.org.uk](https://macmillan.org.uk)**

We've listed the details of some other useful organisations on pages 67–70, and included some helpful books and resources on page 71. There is also space on page 72 to write down any notes or questions for your doctor or nurse.

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

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# TALKING ABOUT CANCER

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# Why tell children?

Parents sometimes feel that by not telling a child or teenager about a cancer diagnosis, they are protecting them.

Trying to protect children from difficult news, worry and distress is natural. But not explaining what's happening may make them feel more vulnerable. It's important to give them the chance to talk openly about their fears and worries. If they overhear things, they may interpret things wrongly.

Children know when something serious is affecting the family and people they are close to. They'll notice unusual comings and goings, phone calls and hushed conversations. They may also pick up on changes in how you and other adults around them are feeling and behaving.

'After my first appointment I told my children. I didn't want them to hear me discussing my diagnosis in hushed tones, and felt I should tell them the truth at the earliest possible stage.'

**Sharon**

Understandably, you may have concerns that delay or stop you explaining what's happening. You may feel it will bring home the reality of the situation, when you're still struggling to come to terms with it yourself. The thought of coping with a child's distress on top of everything else may seem overwhelming. Or you may worry that family life will be disrupted and that cancer will become the focus, instead of things like school and exams.

## The benefits of talking

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

- Knowing what's going on may make them feel more secure and less anxious.
- It gives them permission to talk – they can ask questions, say how they feel and talk openly to you.
- It shows you trust them and that you don't feel you need to guard what you say all the time.
- 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 with difficult situations in life.

## The effects of not talking

Wanting to protect children from difficult news is natural. But if you don't talk to them, they may:

- feel frightened because they don't know what's going on
- feel alone with lots of worries and no one to talk to
- worry that something they've done or thought has caused the cancer
- think they're not important enough to be included
- imagine something worse than the reality
- think cancer is too terrible to be talked about
- misunderstand situations and get the wrong idea about what's happening.



Children often find out about what's going on even when they haven't been told – for example through friends whose families know each other. Finding out like this can have a negative effect on their relationship with their parent(s). They may wonder if they can trust you, or other adults, to tell them about important things.

Children also pick up things from the television, internet and overheard conversations, but this information isn't always accurate. If you don't speak to them about what's really happening, they may continue to believe this information.

'When I was diagnosed, my son was five and daughter eight years old. My son would not talk about things, but demonstrated his fears by a change in his behaviour. My daughter was older, and wanted to talk about her fears. Both children needed to be reassured that this illness was not their fault.'

**Swati**

# Telling your children

You'll probably need time to cope with your own feelings before talking to your children. You might want to speak to your nurse specialist or a psychologist or counsellor before talking to your children. Try to talk to them before they pick up on things and start to worry.

Be as prepared as you can. Make sure you have all the information you need and that you understand it. You may want to think about the questions a child might ask and the words you will use to explain things.

Find out what they already know. You can sometimes get very worried about telling them something and then find out they know more than you think.

## Who should tell them?

If you're a two-parent family, it's usually best to tell your children along with the other parent – but this can depend on how you usually talk as a family. If you're a single parent, you may feel able to, and want to, do it on your own. Or you could do it along with someone close who your child knows and trusts. You could also ask your nurse specialist or a psychologist or counsellor to be there.

Even if you're not doing the telling, it's still a good idea to be there so you know what's been said and how the child has reacted. However, some parents do prefer to let their partner tell the children and not to be there themselves. You should do whatever feels right to you.

## The right time and place

Choose a time and a place when your children are most likely to listen and feel at ease, and where you won't be interrupted. There may be places where you and your children feel more able to talk. Make sure it's somewhere they will feel able to express their feelings.

If you have more than one child, it's best to tell them together if you can. This prevents them feeling like their siblings know more than them. If you're 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 place a burden on them.

'I found it quite easy to talk to my children about it. Although I did make the mistake of not telling everybody everything right at the start, because I thought the youngest one was too young.'

**Lucia**

Avoid telling them just before bed time, as they may not be able to sleep. If it's unavoidable, make them feel supported and answer any questions they have before they go to sleep.

You might want to tell them somewhere away from home. It 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.

## How to tell them

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

If you want to, you can practise what you're going to say beforehand and think about some of the questions they may ask. But don't try too hard to have the perfect conversation. If you plan too much, a question from your child may throw you. Children can ask questions you weren't prepared for, and these may come hours or days later.

Choose a time when you're feeling fairly calm. See the first conversation as a starting point. It's the beginning of an ongoing process of gradually giving your children small, relevant pieces of information and reassurance.

Allow the conversation to be directed by your children's reactions and the questions they ask. Listen and keep it as open as you can. Try asking questions that encourage them to express what they're thinking, rather than a one word or two-word reply.

Some examples of openers are:

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

## Be honest

It's best to be honest with children. If they think you're being vague or hiding something, they may find it hard to believe they're being told the truth. Don't make things sound less serious than they are. But, depending on your situation, you can be hopeful and let them know that although cancer is serious, many people get better. Tell them that you and your doctors are doing everything possible to get you well again.

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



Teenagers may react differently from younger children or adults when they're told a parent 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, teenagers will benefit from being told the truth about the cancer and your treatment plan. It's best to encourage them to ask any questions they have, and to answer these gently but honestly. Remember that although teenagers value their independence, they'll still look to you for reassurance and support.

## Starting the conversation

You'll need to use words your children will understand. These will vary depending on their ages (see pages 22–25). 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's going on.
- Keep information relevant to the current situation, rather than things that will happen in the future.
- Be as specific as you can – children worry more when things aren't clear, or if they hear adults whispering.
- Ask them if there's anything else they want to know.
- Take it at the child's pace and be prepared for them to react in their own way.
- Repeat the information for younger children, especially those under seven, as they may not take it in or understand.
- Children also need to understand how their lives and routines are likely to be affected (see pages 32–33).

There are some useful books and resources that help explain cancer to children (see page 71). You may also be able to use our other information booklets about cancer types and treatments to help explain cancer to older children.

To order any of our booklets, call the Macmillan Support Line free on **0808 808 00 00** or visit **[be.macmillan.org.uk](https://be.macmillan.org.uk)**

## Explaining cancer

Children need some information about 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's called cancer and I'm going to have an operation to take it away. After that, the doctor will give me medicine so that the lump doesn't 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 other days I'll feel fine.'
- If your child asks you what cancer is – '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.'

'Telling my daughter was one of the worst things I had to do. I thought, "How do you explain cancer to an eight-year-old?" I think she was glad we told her, as children pick up on things and often think it's worse than it is.'

**Kate**



Teenagers in particular may look for information about cancer on the internet. You or your doctor could help them understand whether the information they find is accurate and relevant to your diagnosis. They may find it helpful to visit the Macmillan website ([macmillan.org.uk](http://macmillan.org.uk)), Hope Support Services ([hopesupport.org.uk](http://hopesupport.org.uk)) or Riprap ([riprap.org.uk](http://riprap.org.uk)). Riprap is a website for teenagers who have a parent with cancer. We've listed some other sources of online support on pages 67–70.

Teenagers may know what cancer is from experience. They may have been taught about it at school or have a friend with cancer. Some of their friends may have family members who've had cancer. You could talk to them about what they know if you think that would help.





## Important points to get across

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 isn't like a cold and you can't catch it – it's okay to sit close, hug or kiss
- 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'll listen to their worries and try to help them cope.

'I made the decision to be honest and open with my children. I always promised I'd tell them the truth. It made it open for them to ask me anything that was worrying them – and they have.'

**Louise**

## Children with learning disabilities

Children with learning disabilities can find change hard. But in most situations, they will cope better if they are involved in a situation and are prepared for it. As you're closest to the child, it's up to you and your family how much information you think needs to be shared. Remember to explain any possible changes in routines and also physical changes that you might go through. You might be scared of telling your child, but it's likely that they'll cope better with the changes if you are honest with them.

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 the child see how your treatment will fit in with their lives. It will also remind them of the things that are staying the same in their lives.

Using visual supports can help explain what is happening. You might have to explain your situation more than once, especially if you are having a long course of treatment. Try to keep their routine the same. Keep things that 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 involve any support workers involved in the child's care.

The National Autistic Society has more information (see page 70).

## Who else needs to know?

You'll usually want to tell your close family and other adults who your children know and trust. Let them know what you've told your children – it's important that your children get the same message from everyone. Let your children know who you're going to tell and why.

It's usually helpful to have a conversation with your children about who else needs to know, for example a teacher, club leaders or their friends' parents. Older children may have strong feelings about who should and shouldn't know, so it's good to talk to them about this.

It's a good idea to let nursery or school teachers and the school nurse know. It will mean that they can be sensitive to your child's needs, and will help them 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, or you can involve the school nurse or counsellor.

'We noticed early on that when I have a major hospital event, the children's academic performance can deteriorate, and the school has played its part in handling that.'

**David**



Some teenagers don't want to be seen as different from their friends. But it's important that certain people know and can be there to support them if they need it.

Teenagers may be facing exams or coursework at school, college or university. If they're finding it difficult to keep up with their studies, it may 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.

You should speak to the teenager before doing this. School or college may be one of the few places where things still feel 'normal', and they may be hesitant about letting people know. Asking them will also reaffirm their trust that you're telling them everything and including them.

It may be important to speak to their school or college about how they're coping. Teachers or staff can offer support, and they may notice issues or behaviours that aren't always apparent at home.

Macmillan has a toolkit called **Talking about cancer**. It's aimed at helping teachers discuss cancer openly and honestly with 9–16-year-olds. The pack contains everything teachers need to give young people the facts about cancer. It includes lesson plans and DVD clips. The toolkit can be ordered from **macmillan.org.uk/teachingpack**



# CHILDREN AND TEENAGER'S REACTIONS

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# How children and teenagers might react

Children's understanding and emotional reactions can depend on how old they are. They're usually able to understand more about illness as they get older, but this depends on the child. Some younger children may understand things more easily than older children.

## Babies and toddlers

Babies and toddlers won't understand what's happening. They will be aware of changes to their routine, and especially changes to who's looking after them. Try to create an environment that's as familiar and consistent as possible, especially for when you're not there. If possible, choose someone to care for your child who knows them well and is able to look after babies and toddlers. Keep to familiar routines when you can.

## Children aged 3 to 5

Young children don't really understand illness, but they pick up on tensions, changes in adults' emotions and physical changes. They 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've done something to cause the cancer. Or, if you're in hospital, they might worry that they've made you go away.

Older children in this group are beginning to understand what illness is, and they may worry that they'll get cancer too.

This age group can become clingy and scared of being separated from their parents. They may start to do things they've 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, where you'll have an operation, or both.
- Ask someone they know and trust to take care of them.
- Keep to everyday routines when you can.
- Let them know that the cancer isn't their fault and they can't catch it.
- Set usual limits and boundaries, but don't be surprised if they start doing things they've outgrown.

'My children are old enough to understand what's happening, but also find it difficult. The youngest is worrying about losing me and is becoming clingy. The eldest is a teenager and likes to work things through on his own. We know he'll come to us when he wants to.'

Liz



## Children aged 6 to 12

At this age, children can understand more detailed explanations about the cancer and its effects on the body. They often have fears they may not mention to you. This includes worrying you are going to die, that they've 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:

- Use books to explain the cancer and its treatment (see page 71).
- Reassure them that many people with cancer get better.
- Make sure they keep up with school, other activities and friendships.
- Let them know it's okay to enjoy themselves.
- Give them little things to do to help out.

## Teenagers



Teenagers usually understand what's going on in terms of the cancer, but they can be reluctant to talk about it.

They may find it hard to talk to you, or show how they feel. It's 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 find that when they want to be more independent and spend less time in the house, they have more responsibilities at home. This can make them feel angry and guilty at the same time. Sometimes their behaviour may seem hurtful to themselves or others.

## How to help

- Tell them about sources of information that may help. See pages 67–70 for details of some useful organisations, such as Riprap and Hope Support Services. There is also a list of helpful books and resources on page 71.
- Ask them what they think and include them in the same way as you'd include an adult.
- Help them see that talking about feelings is a positive and mature way of coping. Encourage them to talk to someone 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 out a bit more with things like cooking, tidying up or looking after younger siblings. Allowing them to help shows that you need and trust them. But reassure them you don't expect them to do everything and that people will be there to care for them too.
- Show them you appreciate their help.

# When children need help

Children can have lots of different emotional reactions. They can show their feelings through anger or bad behaviour. Your child may react to your illness with behaviour you wouldn't 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 going off their food, headaches or tummy aches.

These changes aren't necessarily unusual, but if they carry on, or if there's anything worrying you about your child, you can ask for help.

People who can offer you and your child support are:

- 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 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 at **gov.uk/find-yourlocal-council**. In Northern Ireland, social services are accessed through Health and Social Care Trusts – visit **nidirect.gov.uk**



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

Some teenagers may be less comfortable speaking about their emotions directly, and prefer to express themselves through writing, art or music. Remember that if they aren't telling you how they feel, it doesn't necessarily mean they don't have anyone to speak to. They may well have the support of their friends, other adults, or both, such as an uncle, aunt, grandparent or other relative. It's 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. They can also get online support from some of the organisations listed on pages 67–70.



# 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 different factors, including the way your family normally deals with 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 or bottling up your feelings also takes up energy and can make you feel even more anxious. You can read more about this in our booklet **How are you feeling? The emotional effects of cancer**. Showing your feelings can make it easier for your child to show theirs – it's like giving them permission to do the same.

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

**Ben**

## Showing your feelings

Children may need to be shielded from strong outbursts of emotion, such as arguments between adults. But it's okay to cry in front of them sometimes, or to tell them you're fed-up or angry about your illness.

Let them know that crying helps you feel better and there may be times when they'll need to do the same. They shouldn't think crying is babyish, or that they have to be strong. Explain that feelings like sadness and anger are normal and it's okay to show these. This helps your children accept these feelings as normal, rather than be frightened of them or feel that it's 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. Don't be hard on yourself. The demands of children can be difficult to manage at the best of times. Your reactions may be quite normal or heightened because you are under a lot of stress.

Talk this over with your partner or family to try to make sure you're getting enough support and time out to help you cope. This can stop things at home becoming too tense.



Every teenager will react differently to a situation. You might think that your teenager will find it hard to see you cry or hear about how you are feeling. But it's 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 the children. This isn't easy, but there are things you can do that may make it easier.

## Changes in routines

Disruptions and changes in routine are to be expected, but it's important your children know how their day-to-day routines are going to be affected. Children, especially younger ones, like and depend on routine – it helps them feel safe. Tell them about changes in advance and make sure they always know:

- who's looking after them when you're not there
- who will pick them up from college, school or nursery
- who's taking them to activities such as swimming lessons
- any other changes to their normal routine.

Sometimes, even with planning, arrangements have to change at short notice. Try to show your children that things can also be flexible, and involve them as much as you can in any new plans.



Teenagers are often keen to help out when someone in their family is ill. This could mean anything from doing the washing-up to going with the person to appointments.

Allowing teenagers to 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's important to make sure they don't try to take on too much. Let them know that while you might need their help, they should also carry on focusing on their schoolwork and doing things they enjoy, such as seeing their friends.

In some families, teenagers won't 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.**

## Have family time

Life can often be busy when you're coping with cancer, so it's 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're thinking of you. But they don't usually expect you to reply, so don't feel you have to. You could also switch your phone off at mealtimes.

On pages 46–47 we've listed some ways you can spend time with your family at home, even when you don't have much energy.

## Getting help

Ask people to look after your children or take over some of the things you usually do. Choose people who your children feel safe, comfortable and familiar with. Younger children need consistency, so if possible it's a good idea to have the same person helping.

- Don't be reluctant to accept offers of help, especially when it frees you up to spend time with your children.
- Other parents are often willing to help by looking after the children after school or nursery.
- Ask a relative or close friend to coordinate the help that's been offered. A rota system can often be worked out, and you can use a calendar or chart to keep track of who's helping when.
- Get extra help with childcare if you need it. We have more information about help with childcare – visit **macmillan.org.uk/childcare**

## Keeping to the usual limits

Even when family life is going well, it's often hard to be consistent and to set rules and limits for your children. It's especially hard when you're coping with cancer and are worried about your children's reactions to your illness. Children and teenagers need love and support, but they also need the usual discipline to help them feel secure. It's important to try to keep to your usual family rules. If you're worried about your child's behaviour and need support, help is available (see pages 26–27).





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# Explaining your cancer treatment

This section is about the cancer treatments you may have, and how to talk about these with children and teenagers. Knowing about your treatment and its side effects can prepare children for what to expect and help them feel less anxious. What they'll need to know will depend on their age (see pages 22–25).

If you're struggling to take it all in, 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, which may help you explain treatments to your children.

## Surgery

Explain that this is an operation and the doctor or surgeon will either:

- remove the cancer
- remove the part of the body where the cancer is.

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

If children want to look at a scar, it's usually fine to let them see it. But it may be best to wait until the swelling and redness settle down. If they're not interested or seem reluctant to look, don't push them.

## Chemotherapy

Explain to them that chemotherapy is either:

- medicine that destroys the cancer
- medicine that stops or slows down the growth of cancer cells.

It's also helpful to tell children how the chemotherapy may change your routine and how it may make you feel. Let them know that:

- chemotherapy can sometimes make you feel sick, but that you'll take other medicine to stop the sickness
- chemotherapy can make you feel very tired, so you'll usually need to get lots of rest or sleep after having it
- your hair may fall out and, if it does, you'll 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 don't cause cancer, but chemotherapy can make it easier for you to catch a cold or infection.

## Radiotherapy

Explain to them that radiotherapy is either:

- the use of x-rays or a laser beam to destroy the cancer
- strong x-rays given to the part of the body where the cancer is to destroy the cancer cells so they can't grow.

Depending on where you're 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's finished, so you'll need to rest a lot.



## Side effects

Children need to know that side effects will usually go away when your treatment is finished, but that this is often gradual. They should also know that side effects don't mean you're getting sicker, and that not everyone gets the same side effects. Some children may worry that the cancer is getting worse if they see you unwell, or they may think that the treatment isn't working if you don't get side effects.

Tell your children that treatment can be hard and that it's normal for you to feel down or frustrated at times, but it's not because of anything they've done. Help them feel involved by asking them to get you a drink or to do little things to help around the house. But remember not to ask them to do too much if they don't want to.

## Changes in physical appearance

Children usually cope well if they're told in advance about any changes in your appearance. Younger children, particularly those under 10 years old, struggle most with this. Letting them know in a matter-of-fact way is often the easiest way to explain things. Older children may feel embarrassed and want to avoid talking about it. If you're struggling to cope with it yourself, you may prefer someone else to explain it to them, or to get further help (see pages 26–27).

# After treatment

After treatment, your children may expect things to get back to normal. They might find it difficult to understand why that's not always simple.

You'll probably feel very tired and may still be coping with side effects. It's also common to feel anxious and isolated, and to miss the support you had during treatment. This is normal and it takes time for everyone to adjust to life after treatment. Our booklet **Life after cancer treatment** has more information.

It's a good idea to prepare your children for the fact that it's going to take time, possibly months, for you to get your energy back. Be positive about the things you can do now treatment is over. Tell them about new changes to family life and routines – for example, if you'll be picking them up from school or if you won't be going back to work for a few months.

'It was really helpful to have play dates and weekends organised for my son. I'm so grateful to a couple of mums in my village who regularly had my son to play with their kids. He comes home happy and tired.'

**Anne-Marie**

Tell them if you're still getting support from the hospital, a support group or online. Get them involved 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 carry on helping around the house.

Keep being open with your children. Let them know you're still there to listen to them and that they can talk to you about their worries. They may be worrying about you staying well, and younger children will probably still be clingy. Explain that you'll be going to the hospital for check-ups to make sure you're well. They'll need to know that you can still get everyday illnesses like colds, but that this doesn't mean the cancer has come back.

Acknowledge that you've been through something difficult together and how they've helped you to get better. This can be particularly important for teenagers. Things usually gradually get back to normal as everyday life takes over from the cancer.

Despite all the difficulties, cancer may 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 difficult, and don't 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.

# Time together – in hospital and at home

You may:

- be having treatment as an outpatient
- need short stays in hospital
- be coping with side effects or symptoms at home.

All this can disrupt family life and make it difficult 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'd like to visit you and go with what they want.

'I didn't want my son to see me in hospital with all the tubes in me. Somebody suggested I take him along when I was booking in. Then he could see me in my bed and he'd know where I was when he didn't see me for the next few days.'

**Barbara**

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

You'll need to be aware of what your child may see in hospital, especially if there are very unwell people being cared for nearby. For younger children, keep visits fairly short (up to 15 minutes) and remember that older children may want some time alone with you.

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

- Make sure they're 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's for.
- Tell them about the different people who are there to help you. Show them things like the call button, so they feel more secure about you being looked after.
- Encourage older children and teenagers to take along a book, handheld games console, tablet or laptop. Encourage younger children to take a toy or colouring book.
- Make sure you've got snacks and things you can do together, such as a pack of cards or a book of word games.
- If they're overwhelmed or tired, ask the adult who's with them to take them home.

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

- Have a regular time to call home, or when they can call or text you.
- Make sure they have a photo of you while you're away if they'd like one.
- Leave notes or a small gift for them to find when you're in hospital.
- If you have internet access in hospital, send them an email or speak with them over an online video chat service such as Skype™ (**skype.com**) or FaceTime.
- Leave them a voicemail, or send a card or letter.
- Set up a website or blog that you can use to keep them updated.
- If they're younger, read a story with them over the phone or ask them to send you a drawing they've 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 aren't 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 ideas for things you can do together when you want to spend time with your children, even if you don't have much energy.

- Watch TV or DVDs together.
- Play cards, board games or computer games.
- Listen to music together.
- Look through family photos and create a photo album together.
- Allow them to help out by bringing you a drink or a book, or by tidying up.
- On days when you're feeling better, save energy for the things you enjoy doing as a family. It doesn't 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. It's great for your children and also helps them let off steam.
- Set aside some time for the children to show you what they've been doing at school or other activities they've been involved in.
- If you feel well enough, plan something to do with your child 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 about 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 reveal any misunderstandings they have.







# Looking after yourself

Whatever your situation, taking care of yourself and getting enough support will help you cope. On the next few pages, there are some suggestions about how you can do this.

Getting enough rest is important, as your body uses up more energy than usual when you're coping with treatment or stress, or both. Rest gives your body time to recover. Try to get enough sleep and pace yourself so you don't overdo things.

Even if you don't feel like it, try to eat healthily. This gives you more energy to feel better and improves your general health. Try to eat:

- plenty of fruit and vegetables
- more high-fibre foods, such as wholegrain bread and pasta, beans and oatmeal
- more protein, like chicken and fish or nuts and fruits if you are vegetarian.
- less red and processed meat
- less saturated fats, like pastries, samosas, cakes and cheese.

We have more detailed information about exercise and eating well after cancer treatment. Call our cancer support specialists on **0808 808 00 00**, or visit **macmillan.org.uk**

It's good to be physically active as well. Even short walks can sometimes help you feel less stressed and sleep better. It's great for the children as well.

## Getting support

There's lots of support available to you and your family. It's important to ask for help or to talk to someone, like your GP, if you feel you're not getting enough support.

### Health professionals

If you're the person with cancer, your cancer specialist and specialist nurse can offer support and advice. You can also talk to your GP if you need emotional support, whether you're the person with cancer or a relative. Occasionally people need more advice and support, and sometimes it's easier to talk to someone who's not directly involved. Your specialist or GP can usually refer you to a counsellor, social worker or psychologist who can help.

Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and 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 at **[macmillan.org.uk/childcare](https://www.macmillan.org.uk/childcare)**

## Support groups

Self-help and support groups offer a chance to talk to other people who may be in a similar situation and facing the same challenges as you. Joining a group can be helpful if you live alone, or don't feel able to talk about your feelings with people around you. The first meeting is usually the hardest one. Not everyone finds talking in a group easy, so it might not be for you. Try going along to see what the group is like before you decide.

You can call us on **0808 808 00 00** or visit **macmillan.org.uk/supportgroups** for information about cancer support groups across the UK.

## Online support

Many people find support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experiences, ask questions, and get and give advice based on your experience. Our Online Community (**macmillan.org.uk/community**) is a social networking site where you can chat to people, blog your journey, make friends and join support groups.

## Other organisations

You can find details of other useful organisations on pages 67–70.

# If the cancer doesn't get better

This information is for anyone whose cancer is not expected to get better and who would like suggestions about how to tell a child or teenager. If your situation is different, you may prefer to continue reading from the next chapter (go to page 61).

Many people with cancer are cured, or live with the cancer for many years. Even when a cancer is advanced, people may live with it for a long time.

If your cancer has come back or isn't getting better, your children may know and sense that things have changed. It's important to tell them what's going on.

It can be helpful to first ask the child what they understand about what's been happening. From this starting point, you can gently correct any misunderstandings and gradually tell them about the current situation.

Give them step-by-step information about what is happening. Tell them that the cancer has come back and you need more treatment to control it. Reassure them that you and your doctors will be doing everything possible to keep it under control. Try to be honest but still offer hope.

If treatment is no longer controlling the cancer, you'll need to tell them that you are going to get more poorly. Children also need to know that it's okay to talk about you not getting better. They might try to protect you by not talking, so it's important to let them know they don't have to do this. Children often have worries about who will care for them if you're no longer there. It can help to talk to them about this and reassure them that they'll always be cared for.

## Talking about dying

The information over the next few pages 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 how best to do this for their own family. But you don't have to do it alone and it's 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 rehearse the words you plan to use with another adult.

If you are feeling unwell or low, you may not feel emotionally strong enough to begin any difficult 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 that your children are able to take it in. You may want to avoid discussions about what is happening altogether. Or, if you have a partner, you may find that they don't want to talk about it. It's common to react to a difficult situation this way – it can be a way of coping. But it can also make it harder for you and your family to support and understand each other.

Even when talking about dying, it's still best to talk openly and honestly with your children and to use straightforward language. Talking openly allows you to find ways of helping your children to cope in the future. It will also give you the opportunity to show how much you care for each other and to sort out any issues you have.

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 that they've been abandoned. Try not to use 'going to sleep' to describe dying, because young children may then be afraid of going to sleep.

Young children often need to be reassured that they're not responsible for someone's death, as they can often find reasons to blame themselves.

It's difficult to describe to a child how someone will die, as no one can ever predict exactly what will happen. Children need to have gradual explanations about what has happened and why, and what may happen next.

Older children may want to know more about what happens when someone is dying. We have a booklet called **End of life: a guide**, which you may find helpful.

A child's understanding of death generally depends on how old they are:

### **Very young children (aged under three)**

Children under three can pick up that something very serious is happening. They don't understand that death is permanent and may confuse it with sleep. However, like children of any age, they can grieve and might start behaving differently.

## Young children (aged 3 to 5)

Children aged 3 to 5 may have heard about dying, but don't really understand what it means. They may imagine that a dead person will come back or is living somewhere else.

They often need to be reminded the person who has died will not come back again, but that they can still remember all the things they did together.

## 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 nine, a child's worry is more likely to be that death is frightening or painful.

## Teenagers



Teenagers often find it harder to cope than younger children with the news that someone is dying. They're old enough to know that this means a major change and loss in their life. They may cope in ways that are difficult for you to deal with, such as refusing to talk about the illness. Others may adapt and try to become closer to you. Teenagers need to know that there's no right or wrong way to feel. They may get angry with you and then feel guilty about how they've acted, or feel bad about spending time with their friends.

It's important to make sure they get the support they need. Cruse Bereavement Care (see page 69) provides information about how teenagers understand death, and can offer support.



## Questions children may ask

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

**'Am I going to die too?'**

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

'Will other people I love die too?'

'Daddy/Mummy/Granny/Grandad 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.'

Our booklet **Preparing a child for loss** has more information that you may find helpful.

Organisations such as Marie Curie Cancer Care (see page 68) provide information about supporting children and teenagers when an adult is dying. Cruse Bereavement Care (see page 69) 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 (see page 70) also helps support bereaved children and young people.



## Memory boxes

Some people want to help their children connect with memories of the things they've shared. You might like to make a memory box. This is a container that holds special things belonging to you, and 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.

We have more information about memory boxes that we can send you. You can also read this information online – search for 'memory box' on the Macmillan website ([macmillan.org.uk](http://macmillan.org.uk)).

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

**Siana, 14**



A practical guide to living with oral and other cancer

# SIDE EFFECTS OF CANCER TREATMENT

WE ARE CANCER RESEARCH

# UNDERSTANDING THYROID CANCER (PAPILLARY AND FOLLICULAR AND PAPILLARY)

# YOUR RIGHTS

NEAR THYROID CANCER

# CANCER

# 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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available online at **macmillan.org.uk/cancerinformation**. There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- ebooks
- large print
- translations.

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

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



## Help us improve our information

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

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

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





# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

## Talk to us

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

### Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

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

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

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres.

There, you can speak with someone face to face.

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

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://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 guidance team can give you advice on mortgages, pensions, insurance, borrowing and savings.

### Help accessing benefits

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

### Macmillan Grants

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

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

## Help with work and cancer

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



### Macmillan's My Organiser app

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

# Other useful organisations

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

## General cancer support organisations

### Cancer Black Care

79 Acton Lane,  
London NW10 8UT  
**Tel** 020 8961 4151

#### Email

[info@cancerblackcare.org.uk](mailto:info@cancerblackcare.org.uk)

**[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)**

Offers information and support for people with cancer from ethnic communities, and their friends, carers and families.

### Cancer Focus Northern Ireland

40–44 Eglantine Avenue,  
Belfast BT9 6DX

**Helpline** 0800 783 3339  
(Mon–Fri, 9am–1pm)

**Email** [hello@cancerfocusni.org](mailto:hello@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

### Cancer Research UK

Angel Building,  
407 St John Street,  
London EC1V 4AD

**Tel** 0300 123 1022

**[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)**

Has patient information on all types of cancer and has a clinical trials database.

### Cancer Support Scotland

The Calman Centre,  
75 Shelley Road,  
Glasgow G12 0ZE

**Tel** 0800 652 4531

**Email** [info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

[www.cancersupportscotland.org](http://www.cancersupportscotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

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

### **Maggie's Centres**

20 St James Street,  
London W6 9RW

**Tel** 0300 123 1801

**Email** enquiries@  
maggiescentres.org

**www.maggiescentres.org**

Provides information about  
cancer, benefits advice,  
and emotional or  
psychological support.

### **Penny Brohn Cancer Care**

Chapel Pill Lane, Bristol  
BS20 0HH

**Helpline** 0845 123 2310

(Mon–Fri, 9.30am–5pm,  
Wed, 6–8pm)

**Email** helpline@pennybrohn.org

**www.pennybrohn  
cancercare.org**

Offers a combination of  
physical, emotional and  
spiritual support, using  
complementary therapies  
and self-help techniques.

### **Riprap**

Maggie's, The Stables,  
Western General Hospital,  
Crewe Road,  
Edinburgh EH4 2XU

**www.riprap.org.uk**

Developed especially for  
teenagers who have a parent  
with cancer.

### **Tenovus**

Head Office,  
Gleider House,  
Ty Glas Road,  
Cardiff CF14 5BD

**Helpline** 0808 808 1010

(Mon–Sun, 8am–8pm)

**Email** info@

tenovuscancercare.org.uk

**www.tenovus.org.uk**

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

### **Advanced cancer and end-of-life care**

#### **Marie Curie**

89 Albert Embankment,  
London SE1 7TP

**Helpline** 0800 090 2309

(Mon–Fri, 9am–5pm)

**Email** supporter.relations@  
mariecurie.org.uk

**www.mariecurie.org.uk**

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

## Counselling, bereavement and emotional support

### Barnardo's

Tanners Lane, Barkingside,  
Ilford, Essex IG6 1QG

**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.

### Childhood

#### Bereavement Network

8 Wakley Street,  
London EC1V 7QE

**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 that you can search for local services.

### Cruse Bereavement Care

PO Box 800, Richmond,  
Surrey TW9 1RG

**Tel** 0844 477 9400

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

**Email** helpline@cruse.org.uk

**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 ([www.hopeagain.org.uk](http://www.hopeagain.org.uk)) for young people, which includes information and forums where visitors can share their experiences.

### Hope Support Services

Unit 8C, Alton Business Park,  
Alton Road,  
Ross on Wye  
HR9 5BP

**Tel** 01989 566317

**Email** help@

hopesupportservices.org.uk

**www.hopesupport.org.uk**

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

### **Samaritans**

Chris, PO Box 9090,

Stirling FK8 2SA

**Tel** 08457 90 90 90

**Email** jo@samaritans.org

**www.samaritans.org.uk**

Provides 24-hour confidential, non-judgemental and emotional support for people experiencing feelings of distress or despair, including those that could lead to suicide. Service provided by phone, email or letter.

### **Winston's Wish**

3<sup>rd</sup> Floor, Cheltenham House,

Clarence Street,

Cheltenham GL50 3PR

**Tel** 08452 03 04 05

**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 concerned about a grieving child.

### **Support for young carers**

#### **Include Programme at the Children's Society**

Ground Floor, Unit 4,

Wessex Business Park,

Wessex Way SO21 1WP

**Tel** 01962 711511

**Email** include@

childrenssociety.org.uk

**www.youngcarer.com**

This programme provides information for young carers and those who support them across the UK. Find information about local young carers and projects in your area via the website.

#### **National Autistic Society**

393 City Road,

London EC1V 1NG

**Tel** 020 7833 2299

**Email** nas@nas.org.uk

**www.autism.org.uk**

The leading UK charity for people with autism (including Asperger syndrome) and their families. Provides information, support and pioneering services, and campaigns for a better world for people with autism.

# Books and other resources

## 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
- **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
- **What's up with Bridget's mum? Medikidz explain breast cancer** – Medikidz
- **What's up with Tiffany's dad? Medikidz explain melanoma** – Medikidz
- **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 text entry.

## 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's Cancer Information Development team. It has been approved by Dr Tim Iveson, Consultant Medical Oncologist and Macmillan Chief Medical Editor.

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## Sources

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

American Cancer Society. *Helping children when a family member has cancer: dealing with a parent's terminal illness*. Available from [www.cancer.org/treatment/childrenandcancer/helpingchildrenwhenafamilymemberhascancer/dealingwithaparentsterminalillness/dealing-with-a-parents-terminal-illness-teens](http://www.cancer.org/treatment/childrenandcancer/helpingchildrenwhenafamilymemberhascancer/dealingwithaparentsterminalillness/dealing-with-a-parents-terminal-illness-teens) (accessed November 2015).

Cancer.net. *Talking with your teenager*. Available from [www.cancer.net/coping/relationships-andcancer/talking-about-cancer/talking-your-teenager](http://www.cancer.net/coping/relationships-andcancer/talking-about-cancer/talking-your-teenager) (accessed November 2015).

Corner J, Wagland R. *Text analysis of patients' free text comments: final report*. 2012. National Cancer Survivorship Initiative. University of Southampton.

Finch A, Gibson F. How do young people find out about their parent's cancer diagnosis: a phenomenological study. *European journal of oncology nursing*. 2009. 13: 213–222.

Kennedy VL, Lloyd-Williams M. How children cope when a parent has advanced cancer. *Psycho-oncology*. 2009. 18: 886–92.

Lindqvist B, et al. Factors associated with the mental health of adolescents when a parent has cancer. *Scandinavian journal of psychology*. 2007. 48: 345–351.

Niemelä M, et al. A systematic narrative review of the studies on structured child-centred interventions for families with a parent with cancer. *Psycho-Oncology*. 2010. 19: 451–61.

Semple CJ, McCance T. Parents' experience of cancer who have young children: a literature review. *Cancer nursing*. 2010. 33(2): 110–8.

# 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.

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More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way,  
call Macmillan on 0808 808 00 00  
(Mon–Fri, 9am–8pm) or visit [macmillan.org.uk](http://macmillan.org.uk)

Hard of hearing? Use telephone  
0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available.  
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