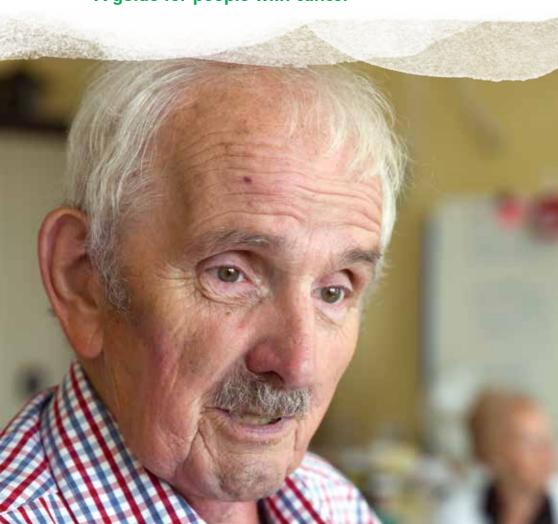
A practical guide to living with and after cancer

# TALKING ABOUT CANCER

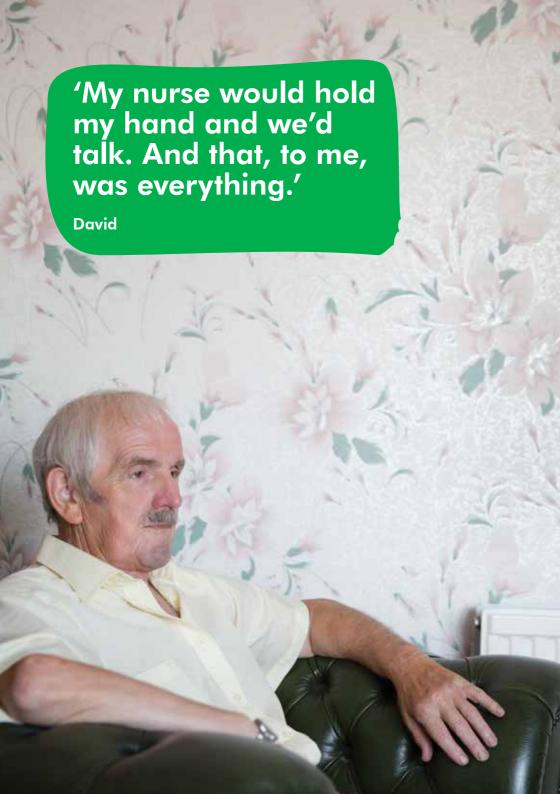
A guide for people with cancer



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#### About this booklet

#### This booklet aims to help you talk to other people when you have cancer and ask for the support you need.

It's common to find it uncomfortable or even upsetting to talk about cancer. The suggestions in this booklet can help you talk to the people in your life. You may be guite surprised – and pleased - with the changes that can be brought about simply by talking.

#### Who is this booklet for?

This booklet is for people with a cancer diagnosis. It aims to help you:

- understand the benefits of talking and who you can talk to
- understand common problems in talking about serious issues and ways to overcome them
- appreciate how your family and friends may also be feeling and how best to talk to them
- feel more confident talking to children and teenagers about cancer
- think about how much you want to share at work and the support you should expect to receive
- find a practical way of talking to healthcare staff to get the information and support you need.

This booklet gives you some general guidelines you may find helpful. But how you talk to people about the cancer will depend very much on your personality and how you usually talk to the people around you.

Don't worry if the examples we use in this booklet don't fit in with your own style of communication – you can adapt them to suit you.

Throughout the booklet we've included comments from people affected by cancer. Some are from David, who is on the cover of this booklet. Others are from **healthtalk.org** Some are from members of our online community at macmillan.org.uk/community Others are from people who've chosen to share their experiences with us by becoming a Cancer Voice. To find out more you can visit macmillan.org.uk/cancervoices

We hope this booklet makes you feel more comfortable about asking for what you want and need to know, and helps you to talk about your feelings if you want to.



#### Family and friends

It can also be difficult for family members, partners and friends to talk about what's happening when someone close to them has been diagnosed with cancer.

We have a range of booklets that give advice on how to talk and listen to a family member or friend who has cancer and how to provide support.

#### These include:

- Be there for someone facing cancer
- Looking after someone with cancer
- Lost for words how to talk to someone with cancer
- When someone close to you has cancer.

Your family and friends can also visit source.macmillan.org.uk to view simple, practical tips from people who have first-hand experience supporting someone with cancer.

#### Young people

We have a range of resources for young people aged 12-25 living with cancer. Our booklet The cancer guide for young people offers tips from young people who have lived with cancer.

#### **Further information**

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

Turn to pages 91–100 for some useful addresses and websites.

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



## TALKING ABOUT CANCER

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# After being diagnosed with cancer, you may find the idea of talking about it upsetting or uncomfortable. It may be taking you some time to come to terms with your diagnosis.

Trying to put how you are feeling into words may feel overwhelming. But talking about how you feel and what you need can help you make the right decisions and feel supported.

Many people don't like talking about their own needs because they don't want to seem needy, demanding or selfish. Or they may want to protect other people from being upset by their news.

However, there will often be friends and relatives who really want to help. Try starting a conversation with them and saying what you need. Even if you just want them to listen to you. You may be surprised at how willing they are to support you. By asking for someone else's support, it shows that we value them.

It's important to realise that there isn't a 'right' way to cope with cancer. But it is important to think about which people need to know about your diagnosis and the best way to talk to them about it. This can help you to get the support you need at home, at work and from your healthcare team.

#### The benefits of talking

Talking can help you cope with uncertainties or difficulties that may lie ahead. It can give you support and help you have some control over your situation.

#### Talking may help you to:

- Understand how you're feeling and why. When everything is inside our heads, our thoughts often feel confusing. Putting our thoughts into words forces us to clarify what they are.
- Express how you're feeling. Having a lot of concerns can make our heads feel like a pressure cooker. Talking can ease the pressure and make us feel better.
- Feel reassured that your feelings are normal. We may feel guilty, weak or ashamed for some of our thoughts or actions following a cancer diagnosis. Having someone listen to us without judgement can reassure us that our thoughts are normal. Often, this is enough to relieve many negative feelings we have towards ourselves.
- Put things into perspective. The more we think about something, the bigger that problem can get in our minds. It can be a big relief once your emotions are out in the open.
- Find the answer to a problem. Talking to another person can bring up solutions we have not thought of. Sometimes it just gives us the time or opportunity to think of one ourselves.
- Make important decisions. When we have decisions to make that affect others, we often assume we know what other people are thinking or feeling. But sometimes they may surprise us with their views and help make tough decisions easier.
- Feel more in control of your feelings and situations. Talking helps to clarify our feelings and to find solutions. This increases our confidence for dealing with further difficult issues and conversations that may arise in the future.

- Feel more supported and less anxious. Knowing someone else understands, cares and is there for us helps reassure us that we are not going through difficult times alone.
- Build bonds with your family and friends. People close to us want to feel that they are important to us. Talking about personal issues with them and including them in important decisions makes them feel valued.

#### Who can you talk to?

The best person to talk to is probably whoever you usually talk to about important issues or difficult problems. This could be anyone - your partner, your closest friend, a member of your family, a work colleague, a counsellor or a religious leader. It may be somebody who is going through a similar experience.

#### Family, friends and colleagues

Some people have a close circle of family and friends who can give them a lot of support. Or close relationships with work colleagues.

See pages 18–25 for tips on telling family and friends about your diagnosis and asking for support. See pages 68-73 for advice on talking about cancer at work.

But even with a supportive circle of people around you, it can be difficult to talk about cancer. You may feel isolated and that only people who've had cancer can understand how you're feeling. Sometimes, people find it easier to speak to someone they don't know.

Other people may have disagreements in their family or have friends that live far away. They may work alone or not get along with people they work with. In this case, you may feel there is no one for you to talk to.

Whatever your situation, there are a number of groups, organisations and healthcare professionals that can help you.

#### **Support helplines**

You may find it helpful to contact an organisation that runs a telephone helpline service for people with cancer. These helpline services are often run by healthcare professionals.

#### **Macmillan Support Line**

You can contact the Macmillan Support Line, Monday-Friday, 9am-8pm. You can call to talk about a cancer diagnosis, to discuss money worries, for advice about work or simply for someone to listen to you talk. Our team includes:

- cancer information support officers they can answer your questions about cancer or treatment, or be someone to chat to
- welfare rights advisors they can give advice on claiming benefits
- financial guides they can advise on financial matters including mortgages, pensions, insurance and savings.

#### Other support lines

If you need to talk to someone when our phone service is closed, you can contact any of these 24-hour services.

For medical help or advice:

- In England call NHS 111 on 111.
- In Scotland call NHS 24 on 111.
- In Wales call NHS Direct Wales on 0845 4647.
- In Northern Ireland it varies by region (see page 95).

#### For emotional support:

Call Samaritans on 0845 790 9090 (UK-wide).

#### Counselling

It can sometimes help to talk to a counsellor, especially if you feel very low. Counsellors are trained to listen and help people talk through their problems.

They won't give advice or answers, but will help you find your own answers. Talking one-to-one with a trained counsellor can help you sort out your feelings and find ways of coping with them. This can be very helpful, particularly if you aren't able to discuss your feelings and emotions with people close to you. Some people find it easier to talk to people who aren't involved with them or their care.

GP practices and hospitals often have their own counsellors or can refer you to one. The British Association for Counselling and Psychotherapy can also give you details of counsellors in your area - see page 91 for details.

#### **Support groups**

Most areas of the UK have cancer support groups. These are usually led by people with cancer, sometimes with support from a healthcare professional. Other members of the group may be in a similar position to you. A group usually includes people with different types and stages of cancer. You may find this wider experience helps you see your own problems from a different perspective.

Our cancer support specialists on 0808 808 00 00 can tell you about support groups in your area or you can find them on our website macmillan.org.uk

Some people find groups very helpful and form close relationships with other members. However, others get embarrassed or uncomfortable when talking about personal issues with strangers. If groups aren't for you, don't worry.

#### **Online support**

If you use the internet, you may want to join an online support group or chat room. There are a number of these groups and some are aimed at particular types of cancer, while others are more general. They're easy to join and you can 'talk' to other people in real time. If you prefer, you can stay anonymous and just read other people's emails or posts. These messages can be both uplifting and sad.

This can be very helpful, as you can find that other people have similar thoughts, emotions and experiences. It can make you feel less alone, and help you learn how to cope with your treatment and live with cancer. Online groups are easy to leave, without any need for personal contact or explanations.

Our online community at macmillan.org.uk/community lets you talk to people in our chat rooms, blog your experiences, make friends and join support groups. You can share your own thoughts and feelings, and get support from others.

#### **Macmillan Connected Buddies**

If you prefer to talk one-to-one with someone, we can help you find someone who can relate to what you are going through. You can then chat on Skype, through instant messaging or by email, for free and in confidence. For more details, visit macmillanconnected.org.uk

#### Barriers to talking about cancer

Being diagnosed with cancer is a life-changing experience for most people. It can have a huge effect on your emotions, as well as on the practical aspects of your life.

Many people used to see cancer as something that shouldn't be talked about. But things have changed a lot, and cancer is now widely talked about in magazines, on TV and on the radio.

However, there are several reasons why talking about the cancer may be difficult:

- You may be afraid that you'll lose control of your feelings. Or that the person you are talking to will. Before you can talk about how you feel to other people, you may want to work out your feelings for yourself. (See pages 28-41 for tips on managing difficult feelings.)
- Your family and friends may find it difficult to talk about the cancer because they are struggling to accept your illness. (See pages 18–25 for advice on talking to family and friends.)
- Some people may never have had a serious illness themselves or known anyone who has. They may be unsure of what you want and need, or how to ask you. (See pages 24–25 for tips on asking for support.)
- You may be afraid of losing your job or being discriminated against at work. (See pages 68-73 for information on talking about cancer to your employer.)
- You may feel your healthcare team are too busy to talk about your feelings. (See pages 76-83 for information on talking to healthcare staff.)

• You may live alone or have no one close to talk to. (See pages 10-13 for advice on who you can talk to if you don't have family and friends nearby.)

#### If you don't want to talk

Some people don't want to talk about their thoughts or feelings, or about the cancer and its treatment. They'd rather just get on with life, and find that doing normal, everyday things and not discussing the cancer is the best way for them to cope.

#### Dealing with family and friends

While you may not want to talk about the cancer, remember that people you care about may want to. Try to be open and honest with your family and friends. Let them know that it's hard for you to talk and there may be a limit to how much you feel able to share.

If a family member or close friend wants to talk about the cancer when you don't, this can cause conflict. See pages 48-49 for tips that can help you resolve conflict in your relationships.

It is up to you how much you want to talk about your diagnosis. For example, if you're going out to enjoy yourself with your friends, don't be afraid to tell them that you'd rather not talk about cancer today or that you'll bring up the issue if you want to discuss it.

However, not talking about the cancer at all can cause problems if it goes on for weeks or months - making it difficult to make decisions about treatment or your employment situation. This can delay the start of your treatment, cause financial difficulty and worsen relationships. See page 29 for information on denial.



# TELLING YOUR FAMILY AND FRIENDS

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#### Telling family and friends about a cancer diagnosis can be difficult. Although you may feel very alone at this time, it's important to remember the cancer also affects them.

They will be worried about you because you are an important part of their life. They may also be concerned about the changes you may have to make to your working life or education, and the financial impact of this.

You may worry about how your family or friends will react. Will they withdraw from you? Will they blame you? You may feel guilty about the effect of the cancer and its treatment on the lives of your family and friends.

Some people feel guilty because they think they have caused the cancer themselves in some way. In most cases it's not clear what's caused someone's cancer. There is no reason to blame yourself.

See pages 52–55 for extra advice on relationships and sexuality.

#### Taking someone to hospital appointments

Having someone come with you to hospital appointments can make conversations with family and friends much easier. It gives your partner, family member or friend a chance to ask questions directly to the doctor and take notes of important information.

If you are feeling shocked or upset, you may struggle to do these things for yourself. This can lead to frustrations when trying to tell other people. When someone comes with you, there is less pressure on you to answer questions and repeat what your doctor has said. The person who came with you can also tell anyone else you would like to know.

#### Telling the news

If you have told your family and close friends you have been going for cancer tests, they may be waiting to hear the results. This may make you feel under pressure. You may feel forced into talking about the cancer before you are ready. If this is the case, it can help to tell your family and friends you need some time for the news to sink in before you are ready to talk about it in detail. See page 15 for advice if you don't want to talk.

People usually tell their spouse or partner first, then other family and close friends. It's also important to tell any children you have, which might require more preparation depending on their ages.

Other family members or friends may say nothing because they are afraid of saying the wrong thing. You may have to bring the subject up.

#### Before the conversation:

- Make a list of who you want to talk to in person.
- Take a notepad to make a note of questions that come up so you can ask your healthcare team.
- Think about how much you want to share in the first conversation. You may want to tell them the kind of cancer you have and which treatments you may need. If you don't feel ready to talk any more at this stage, you can say you need a break and you will talk more at a later time.
- Try to get the setting right. Make sure the television is turned off, the room is quiet, you are sitting comfortably and you can see each other's face easily.



#### Practical tips for the first conversation

- Introduce the subject gradually. You should do this in a way that comes most naturally to you. But if you are struggling to find the words, you could try saying something such as:
  - 'This is going to be difficult, but I need to tell you something.'
  - 'I've had some bad news, but there's a good chance that everything will be okay after I've had treatment.'
  - 'You know I've been feeling unwell for a while. I've had some tests and they've found out what's wrong.'
- Tell them in the way that feels best for you. Sometimes it's easier to give the news over the telephone, through a letter or by email rather than face-to-face. It may be the only option if you're a long distance away.
- Ask what they already know and add to it. This can prevent you from repeating information.
- Give the information in small chunks. Start with a few sentences and check the other person understands what you're saying before you carry on. You can ask things such as, 'Does that make sense?'
- Don't worry about silences. You, your family member or friend may sometimes not know what to say. Holding hands, hugging or just sitting together can often say more than any words. If you find a silence makes you feel uncomfortable, break it with a simple question such as, 'What are you thinking about?'

- Say what you need to say. You may want to be positive and cheerful to make your family member or friend feel better. This is fine if your situation looks okay. But if you're really worried about the future, it's important they know so they can support you.
- Be truthful. It's better for your family and friends to know the truth than find out the seriousness of your situation later on. This can lead to them feeling hurt and upset that they haven't been there for you. Tell your relatives or friends if things seem uncertain and it's difficult to know whether your treatment will be successful. This will help them support you better.
- Accept and ask for support. Family and friends will often offer their support. Don't try to cope alone if they can help. If you cannot think of anything at that moment, thank them and tell them you may come back to them at a later date. If they haven't offered support, don't be afraid to ask. See pages 24–25 for tips on asking for support.
- Ask for help to tell others. Explaining the cancer diagnosis to people can be exhausting. You can choose someone you trust to tell more distant family members or friends. Let them know what information you're happy for them to share.

These tips can help make a difficult conversation a bit easier. Talking about your situation can help your friends to support you in the future, and may also help you to not feel so alone. The act of talking can also make you feel better, as though a weight has been lifted off you, even if nothing has changed.

'When I was diagnosed, I was lucky to have a really good friend who just let me talk all evening.'

Anne



#### Reactions

It can be difficult to deal with other people's emotions and reactions to the news you have cancer. Some people around you may find it difficult to accept the news. They may:

- not know what to say
- avoid you
- tell you, 'Don't worry everything will be okay'
- refuse to let you talk about your fears and say, 'That isn't going to happen.'

Or they may respond strongly and:

- push you to talk when you aren't ready
- try to make decisions for you or argue about your decisions
- be overly emotional.

See pages 44–49 for practical tips on dealing with the reactions of other people.

Our booklet Lost for words is written for relatives and friends of people with cancer. It looks at some of the difficulties people may have when talking about cancer and suggests ways of overcoming them.



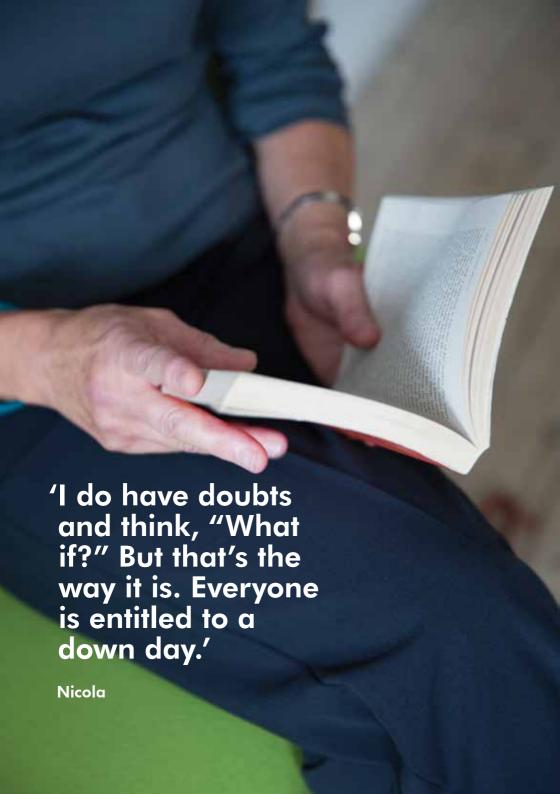
#### Practical tips when asking for support

- Tell the person that you want to talk about the cancer. This lets your listener know that what follows is important to you.
- Think about which issues are most important to you. You may feel as though there's a lot on your mind, but when you focus your thoughts you might find that there are only two or three things that you really want to discuss.
- If you can, try to tell the person about what in particular is worrying you. You may find it easier to narrow down what's worrying you by taking the conversation in stages. You could start by saving something general, such as, 'I'm worried about how things are at the moment.' This can make it easier to then focus on particular problems.
- Say if you've been worrying about something a lot. This lets the person listening to you know how important the issue is to you and they can focus on that.
- Asking the other person if they understand may help you feel listened to. You could use any phrase you like to do this, such as, 'Do you see what I mean?' or, 'Does that make sense to you?' If you've agreed for some things to be done, you may also want to sum up what's been said at the end of the conversation.
- It's okay to go back to small talk. You don't have to discuss serious issues all the time. Just chatting about everyday things can also help you feel that normal life still goes on.

The tool on the next page may be useful to note down the areas in your life where you want support. We've listed one here as an example.

This table is a person-centred thinking tool, taken from thinkaboutyourlife.org, which was developed by cancer survivors. The website has examples, stories and support to help you use the tool.

| What is important to me | How best to support me                 |
|-------------------------|--|
| To carry on working     | Ask how you can help<br>with housework |
|                         |  |
|                         |  |
|                         |  |
|                         |  |
|                         |  |
|                         |  |
|                         |  |



### MANAGING YOUR FEELINGS

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It's normal to feel a range of emotions when you are diagnosed with cancer. Each person deals with diagnosis and treatment differently, and there's no right or wrong way to feel.

Some feelings can make talking to other people difficult. We list these on the next pages.

#### Shock and disbelief

The first reaction to being told you have cancer is often shock. You may:

- not believe what's happening
- be unable to concentrate on what someone else is saying or asking
- be able to only take in small amounts of information at a time
- have to keep asking for information to be repeated
- feel numb.

If you are in a state of shock or disbelief, you may be unable to express any emotion. This can make talking to family and friends difficult. Some people find that talking about the news can help them to accept the reality. But other people need more time to think about it before they can accept it. Only then are they ready to talk about it.

#### **Denial**

Shock and disbelief usually wear off as things become more real. But some people cope with the news they have cancer by pretending it's not happening. This may be the only way they know how to handle the news. You may:

- not want to talk about the cancer or its treatment.
- continue with your life like nothing has happened.

This is a normal reaction to distressing or difficult situations. If you feel you're in denial, or if someone close to you points it out, don't blame yourself or feel you must hurry to overcome it. Tell your family and friends that you gren't ready to talk about the cancer yet and that you need more time. People should respect that this is your way of dealing with things for now, while you adjust to your situation.

Denial can become a problem if it goes on for many weeks or months. In extreme cases, it can stop people from doing things they need to do, like going for treatment or sorting out their finances. It can also cause problems if family members need to discuss certain issues but the person refuses to talk about it.

If you feel your denial is causing problems with treatment, finances or relationships, you should seek help. There is a list of organisations on pages 91–92 that can help. If you are a family member or friend, don't try to force the person into facing their situation. Offer to go with them to see their doctor or a counsellor.

#### Anger

Anger can occur when you are diagnosed or any time during and after treatment. Cancer is a big interruption in your life and it's natural to feel angry at that. Fear often gets expressed as anger. So if you have angry feelings, think about whether they are being caused by fear and uncertainty.

Anger and frustrations are often difficult to control. They may be directed at people close to you, or those who are treating you. Sometimes you may resent the fact that you have cancer while other people are healthy. You may also feel out of control and vulnerable. See page 39-41 for ways to feel more in control.

It's important you find a positive way to express your anger. Uncontrolled anger can cause problems in your relationships with family, friends and healthcare staff. Holding back your anger can lead to depression.

'When I was going through the worst times, I used to write down all the good things that had happened each day in a notebook, one page per day. It really helped me to focus on the positives that were still there in my life.'

**Bronwen** 



#### Practical tips to manage anger

- Identify your anger.
- Talk to someone about what is making you angry.
- Find a safe way to express your anger. For example, writing a journal or blog, doing physical activity, beating a pillow, or yelling out loud.
- Don't let anger build up you risk expressing it in an unhealthy way.
- Don't take your anger out on others. This makes it more difficult for them to support you.
- Try not to hide other feelings with anger these may be sadness, fear or quilt.
- Look out for warning signs and try calming techniques like counting to ten, deep breathing or walking away from a situation.
- Be calm and assertive when telling someone that something is making you angry. They are more likely to listen to you if you are not shouting (see pages 48-49 for tips on resolving conflict).
- Consider counselling if you are still struggling to express anger in a positive way.

The tool on the next page can help you to record things that have made you angry and things that have had a positive impact on your day.

The person-centred thinking tool is from **thinkaboutyourlife.org**, which was developed by cancer survivors. The website has examples, stories and support to help you use the tool.



I went for a walk and slept well that night



#### **Bad days**

I felt tired and snapped at my partner

#### **Next steps**

Try to go for a short walk every other afternoon

#### Guilt

Some people are naturally shy or just not used to talking about personal issues. If this sounds like you, then you may find it difficult to talk about your feelings at a time when it could really help you.

You may avoid talking about your own needs and emotions because you:

- don't want to seem demanding, needy or attention-seeking
- don't want to worry those close to you
- feel guilty about the disruption the cancer will cause to other people's lives.

However, there will often be relatives and friends who really want to help. Try to start a conversation with them and say what you need – even if you just want them to listen to you. You may be surprised at how willing they are to support you.

By asking for someone else's support, it shows that we value them. Often they will feel happy knowing that you're comfortable enough to talk with them about what's on your mind.

If you find it difficult to talk about your feelings with the people close to you, you may want to contact one of the support organisations listed on pages 91–92. They have people who you can talk to in confidence. Or you can speak to our cancer support specialists on 0808 808 00 00.

#### Fear of loss of control

Many people are concerned about losing control of their feelings. You may:

- be unsure about how you will react when you talk to other people
- want to stay strong for other people
- be worried that crying will make you seem weak and distress the people you love
- be worried that you won't be able to stop crying.

When dealing with something as difficult as cancer, it's natural to need to cry and it's fine if you do. Know that after a time you will naturally stop crying. This may be only for short periods at first, but these will get longer.

Sometimes the other person may also get upset and cry with you. Crying together can give both of you a real sense of relief and bring you closer together.

People react differently to similar situations. Some may not cry. Just as it's okay for someone to cry, it's also okay if they don't.



#### Talking about your feelings

Some people find it easy to talk about their feelings. However, many people aren't used to doing this and can feel uncomfortable.

If you, or a family member or friend, have strong emotions and don't talk about them, it can make it hard to talk about anything. So if either of you feels angry, afraid, embarrassed or sad, your conversation will feel difficult until one of you talks openly about your feelings. If you're able to, try saying something like, 'I'm sorry I seem in such a bad mood today, but I've just been told that...' You may then suddenly find that it becomes much easier to talk.

> 'I had a handful of low days, when I'd cry all day. But if I hadn't had my friends and family there, and my daughter to pick me up and keep me going, then it would've been so much worse."

Colleen

The tool on the next page can help you to write down some of your feelings. You may find it useful to clarify what you're feeling. You may also use it as a starting point for a conversation.

The person-centred thinking tool is from **thinkaboutyourlife.org**, which was developed by cancer survivors. The website has examples, stories and support to help you use the tool.



# **Hopes**

I can work flexible hours during treatment



# **Fears**

I'm worried people will treat me differently

# **Next steps**

Talk to my manager about my situation



# Practical tips for dealing with your emotions

- Always accept any strong feelings whether they are your own or those of someone you're close to.
- Always try to describe your feelings and not simply act on them. For example, if you say, 'I'm feeling really angry today because...', this can start a conversation. But if you show your anger by being sharp and irritable, it can make talking more difficult.
- It's okay to feel any way you like. The way you feel is the way you feel – emotions are not right or wrong. But if you try to cover up strong feelings, problems can become more difficult to solve.
- Don't be afraid to tell the other person how much they mean to you. We don't often do this. But when there's a crisis, it's really worthwhile to tell the other person how you feel about them.
- Don't be afraid to say you're unsure. If you don't know how you feel, or if you don't know what's going to happen or how you're going to cope, it's fine to say so.
- Words are not always needed. Holding someone's hand, hugging them or simply sitting together in silence can often mean as much as, or more than, words.
- Everybody has some regrets in their life. Don't feel that you're not allowed to talk about yours. More than any other emotion, regret can be reduced when it's shared. This may strengthen the bond between you and those close to you.



#### Humour

A lot of people are unsure about whether they should use humour when talking about difficult subjects. This is a really personal thing and depends very much on how you and the people close to you normally interact with each other.

Humour can be helpful in some situations, but it may be best to use it carefully so that it doesn't seem as though you don't understand the seriousness of the situation. Humour can be a useful way of coping as it can help make situations less frightening. If joking about things has been part of the way you've coped with challenging things in the past, it may help you now. If, on the other hand, you haven't used humour in this way before, it may not be helpful.

# Taking control of your situation

It is often easier to talk about something when we feel in control of the situation. Cancer can take this feeling of control away. This can feel very threatening and frightening.

To get back a feeling of control, you could:

- try to find out answers to any questions you have
- think about how you are going to deal with issues.

When people feel more in control, they often find it easier to talk about the cancer to other people.

The tool on the next page can help you to think about the decisions you need to make and the people who need to be involved in these decisions.

The person-centred thinking tool is from thinkaboutyourlife.org, which was developed by cancer survivors. The website has examples, stories and support to help you use the tool.

| Decisions I<br>need to make             | Who I want to<br>be involved                 | Who makes the final decision |
|---|--|------------------------------|
| need to make Should I carry on working? | be involved  My doctor, partner  and manager |                              |
|   |  |                              |

# **Getting information**

Learning about the cancer and its treatment can give you back some feeling of control by helping you know what to expect. You can ask your doctor or nurse to tell you about the cancer and its treatment, or you can get information from some of the organisations listed on pages 93-96.

Many people find it helps to focus on the present and not look too far ahead. Try to take each day as it comes and avoid thinking about 'what ifs' and 'maybes'.

See pages 79–81 for advice on getting information from your healthcare staff and other reliable sources of information.

#### **Complementary therapies**

Complementary therapies include relaxation, visualisation and meditation. These can help some people cope with cancer and give a feeling of being in control. Some hospitals offer complementary therapies as part of their cancer services. You can ask if any therapies are available at your hospital. We have a booklet called Cancer and complementary therapies, which you might find helpful.

# Writing

Some people find it helpful to keep a diary, journal or online blog where they can write down all their thoughts, feelings and frustrations. Some people also write down their feelings about any good or positive things that happen to them. Keeping a diary can help you work through various problems. Some people find it can give them back a sense of control and perspective and help them deal with emotions and difficult situations. Creative writing may also help you to relax and express your feelings.

You can set up an online blog on Macmillan's online community. Visit macmillan.org.uk/community



# DEALING WITH REACTIONS

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| Fear of your reaction | 44 |
| Avoidance             | 45 |
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How people react when you tell them about the cancer may depend on many different things. These include what experience they have of cancer and how well they cope with fear and anxiety.

Some people will be keen to support you. They may even want to talk about things before you are ready (see page 15 for advice if you don't want to talk). But you may find the news makes other people uncomfortable.

# Lack of experience

Many people have no experience of talking to, or supporting, someone with cancer. They may be unsure of what you want and need. They may be too embarrassed to ask if they think they should already know. You may have to bring up the subject.

# Fear of your reaction

People may worry about how you'll react if they bring up the subject of the cancer. They may be scared of upsetting you. They may think they won't know what to do if you cry or get upset. But if you're open and able to talk about your situation and feelings, you can let people know what support you need.

#### **Avoidance**

They may have no idea what to say, but may feel like that they should know. So, because they don't know what to say, they may avoid you altogether or simply say very little. This can be hurtful and disappointing.

Other people may only be able to talk about helpful and positive things. This may frustrate you if you feel you need to talk about your fears.

You may find that other people go into denial and that they cope with the situation by pretending that it's not happening. Again, this can be upsetting when you need their support.

> 'Most people find talking about cancer very difficult. But for fear of saying the wrong thing they say nothing - which is extremely upsetting. So if you're not sure what to say, just say hello, but don't be a stranger.'

**Chris** 

# Practical tips for dealing with the reactions of other people

- Acknowledge their feelings. Remember that the person cares about you, but may be struggling to accept the cancer or doesn't know the best way to help. You may feel resentment that you have to deal with their feelings when you are trying to cope with the cancer yourself. But try not to push them away or brush their feelings aside as it is likely to make things worse.
- Always try to respond to their feelings. If you're good at recognising how people might feel, it can help to identify their emotion and what caused it. This can be guite simple, such as, 'When I talk about the cancer you look really upset' or, 'I know you are feeling very helpless and taking control is your way of coping, but...'
- Don't be afraid to say how you feel too. For example, 'I think both of us are finding this awful' or, 'I know you're worried about what could happen and so am I.' The more aware you both are of each other's feelings, the better the communication will be. Arguments are common. If you get into an argument, see our section about resolving conflict on pages 48-49.
- Try not to compete with their feelings. Reminding the other person that you feel worse can make them feel like you don't acknowledge their feelings.
- If a person is avoiding talking, gently ask them to listen. Tell them that they don't need to respond right now, but you would just like them to listen. See pages 24-25 for tips on how to ask for support.

• Ask for more time. If you are being forced to talk before you are ready or if you are finding it difficult to deal with emotional people. Then come back to them at a later date. See page 15 for information if you don't want to talk.

With some honest discussion and time, you may find that your relationship becomes supportive for both you and the other person. The tool on page 25 may help you to talk to family and friends about how they can support you in practical ways.

However, some people may not be able to support you in the way you would like. They may need more time to deal with their own feelings. Or you may have to accept they cannot help and find other sources of support. See pages 10-13 to find out who else you can talk to.

You'll learn to assess people's reactions, and to focus on those who are willing to talk to you and be supportive. If some people find it hard to discuss your illness or react in a way that isn't helpful, you may just want to talk about everyday issues. This can also be useful as it gives you time to talk about things other than cancer.

Your family and friends may find it useful to visit source.macmillan.org.uk to view simple, practical tips from people who have first-hand experience supporting someone with cancer.

# Resolving arguments

When dealing with cancer, people are often worried and nervous, and arguments can happen. For these reasons, it's possible there will be times when you won't always agree with your family or friends, colleagues or with a member of your healthcare team.

# Practical tips to help you manage disagreements

- Try to describe your feelings rather than acting on them. For example, say you feel anary instead of shouting.
- Try to accept emotions yours and the other person's.
- If you can't agree on an issue, you can 'agree to disagree'.
- Don't assume you know what the other person thinks or wants ask them.
- Give the other person a chance to also talk about how they feel - even if you disagree.
- Avoid 'all or nothing' words such as 'always' and 'never'. For example, 'You never listen to me' or, 'I always call you.' These words make the other person defensive.
- Avoid criticising someone's character say how their actions made you feel instead. For example, instead of saying, 'You are thoughtless – I have to remember everything', try saying, 'I feel overwhelmed and stressed when I have a lot to remember.'
- Talk about the issue with someone else. You may find a solution by seeing things from a different point of view.

- Try to see the other person's side of the argument. They may feel bad about the conflict and seeing this may help you feel less angry.
- Write down some of your feelings. This can help you to put things in perspective.
- Contact a counselling service. If you're unhappy about personal issues or your home life, it may be helpful to talk to a counsellor.

Many of these arguments can be resolved with time. But some people find themselves getting very angry with others. See pages 30-31 for tips on managing anger.

Visit healthtalk.org to watch videos of people talking about their cancer experiences and how they coped with other people's reactions.



# RELATIONSHIPS AND SEXUALITY

| If you're in a relationship | 52      |
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| If you're single            | 54      |
| Sexuality                   | <u></u> |

# Cancer can have a big impact on relationships and sexuality whether you have a partner or are single.

There are many things you can do to help you cope with your situation.

# If you're in a relationship

How cancer affects your relationship with your partner may depend on how long you have been together, how long you have had cancer, how it affects your day-to-day life and how well you understand the changes you and your partner are going through.

If you live with your partner, their life is likely to be affected the most by the cancer.

For any couple, talking is important to work through issues such as money, work and, if you have children together, childcare. This is even more important after a cancer diagnosis.



Our booklet, Cancer, you and your partner aims to help you with issues you and your partner may face.



# Practical tips for talking to your partner

- Let your partner know how they can support you. (See pages 24–25 for tips on asking for support.)
- Ask your partner to come with you to hospital appointments. You will feel supported and your partner will feel valued as they have the chance to ask questions. This can make later conversations easier.
- Remember that your partner will be greatly affected by your illness too. A cancer diagnosis affects both partners, so let them talk to you about how they feel as well. If your relationship is strong, it can be a great source of strength for both of you.
- Talk together as a team. Trying to protect each other from bad news or difficult feelings will create distance in the relationship. If one partner feels they have to always be strong for the other one, anger and resentment can build.
- Talking is only one way to communicate. Facial expressions, body language, gestures and tone all contribute to how we express our thoughts, feelings and ideas.
- Write down your feelings. Share these with your partner. The tool on pages 35–36 may help with this.
- Nurture your relationship. Spend time together and plan fun activities. It's important to maintain a normal routine for your relationship.
- Find support outside of the relationship. It may also be helpful for you or your partner to talk to others in a similar situation. You can do this on Macmillan's online community

at macmillan.org.uk/community You may also want to speak to a counsellor or go to a support group, either on your own or with your partner. See pages 12–13 for more information.

Strong emotions can often make talking difficult. See pages 48-49 for tips on dealing with them and resolving conflict in your relationship.

We've included the contact details of useful organisations such as Relate and Relationships Scotland on pages 91–92. They may be able to offer you relationship counselling.

Your partner may also be your carer. A carer is anyone who provides unpaid support to a family member or friend who could not manage without this help. If your partner is your carer, this can also have a big impact on your relationship.



# If you're single

If you're single, you may or may not feel like this is the right time to start a new relationship. If you do want to start a new relationship, it may be difficult to decide what to tell a new partner about the cancer, and also when to tell them. It's best to be open with the other person and make time to discuss your situation.

If you think that you need some help, you can find support from family, friends or one of the organisations on pages 91–92.

You can also call our cancer support specialists on 0808 808 00 00.

# Sexuality

Cancer and its treatment can have a big impact on your sexuality. If you're in a relationship or starting a new relationship, it's best not to ignore talking about this. If you had an active sex life before the illness, it will probably be affected by the diagnosis or its treatment. This can be caused by many factors, such as the physical effects of the cancer or its treatment, and the emotional impact of living with cancer.

If you have a partner and feel they are distant from you, try telling them this as gently as you can. You may need to focus more on sensuality than sexuality at this time. Using touch can be an important way of telling someone how you feel and help you communicate emotions that are not easily expressed in words. Try to explain your needs and discuss what can be done by either or both of you. A simple discussion can make a big difference and will help both of you to understand how the other is feeling. Remember to pick a time to talk when you will not be interrupted.

Our booklets Sexuality and cancer – information for women and Sexuality and cancer – information for men discuss how cancer and its treatments can affect your sexuality, sex life and relationships.



# TALKING TO CHILDREN AND TEENAGERS

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# You naturally want to protect your children from upsetting news. So talking to them about the cancer can be especially difficult.

You may think not telling your children will help you to protect them. But children know when something serious is affecting their family. Not knowing what is happening can cause them more distress. And this can have a negative impact on your relationship with them.

Children will often cope better with an adult's cancer if they're told what's going on in a way they can understand.



We have a booklet called Talking to children when an adult has cancer, which you may find helpful.

# Benefits of talking to your children and teenagers

- They feel safer when they know what's going on.
- It gives them the chance to talk about how they feel and to ask you questions.
- It shows you trust them. It also shows they can trust you.
- You don't have to guard your words or hide what's happening.
- Being honest can help to make your family closer.

- You are able to support your children. And your children can be a valuable support to you.
- They will learn how to cope when life isn't going to plan.

# Negative effects of not talking to your children and teenagers

Not talking to your children or teenager about cancer may mean they:

- Feel frightened as they don't know what's happening.
- Feel alone with no one to talk to.
- Worry they caused the problem.
- Feel they are not important enough to be included or trusted.
- Think cancer is something that shouldn't be talked about.
- Imagine something worse than the reality.
- Lose trust in you.

# How to tell children or teenagers

Decide who is the best person to tell your children. This can depend on how you usually talk as a family. But it's a good idea to be there yourself so you know what's been said.

Choose a time and place where your children can listen and you won't be interrupted.

Try to tell your children together if you have more than one child. This will prevent them worrying that their siblings know more than they do. It can also prevent the older children feeling burdened.

Avoid telling them before bedtime as they may not be able to sleep. And make sure they have time to ask you questions.

You'll need to use words your children will understand. These will vary, depending on their ages.

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 not things that will happen in the future.
- Be as specific as you can children worry more when things aren't clear.
- Ask them if there's anything else they want to know.
- Take it at the child's pace and be prepared for them to react in their own way.
- 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.

# Explaining cancer to children and teenagers

How you explain cancer and your treatments to your children will depend on their age. Here's an example 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.'

Older children and teenagers may find it helpful to visit macmillan.org.uk, hopesupportservices.org.uk or riprap.org.uk - a website for teenagers who have a parent with cancer. More sources of support are listed on pages 98–99.

They may also find information about cancer from other websites. You or your doctor could help your children to understand whether the information is accurate and relevant to your diagnosis. Let them know they can come to you with any questions.

# Important points to get across

- 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.

# Who else needs to know

You will usually want to tell other adults who your children know and trust. This may include your close family and friends, your children's teachers and their friends' parents. Have a conversation with your children about who needs to know before you tell other people. This can help them to trust you.

Let your children know who you're going to tell and why. Older children or teenagers may not want to be seen as different to their friends or classmates. But it's important that other people know so they can support them if they need it.

Let the other people know what you have told your children. It's important that your children get the same message from everyone.

We have a Talking about cancer toolkit, which is 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.

# Reactions

Children can react in lots of different ways. Their understanding and behaviour will depend on how old they are.

Be prepared to repeat the information. Children may ask for important information to be repeated, perhaps many times. If the subject is painful to you, then you may feel irritated. But when children ask for repetition, it's not because they aren't listening or are trying to hurt you – they simply need to hear the information again. So try to be patient. Repeat the information, but be sure that you say the same things as you did before.

Younger children may not understand what's happening but they will be aware of changes to their routine. Try to keep their environment as familiar and consistent as possible. Reassure them that many people with cancer get better. Give them little ways to help out.

Younger children can be scared of being separated from their parents. They may start to do things they have outgrown, such as bed-wetting, thumb-sucking or having tantrums.

Teenagers usually understand what's happening, but may find it hard to talk to you or show how they feel. They may struggle with having to do more at home when they want to be more independent. They may feel angry and guilty.



# Practical tips for talking to teenagers

- Tell them about useful sources of information, books and websites, such as Riprap (see page 94) and Hope Support Services (see page 98).
- 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. If they feel they can't do this, but do want to talk, they may want to talk to a counsellor. See page 12.
- 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. But tell them that you'll let them know when they're doing enough.
- Show them you appreciate their help.

Allowing teenagers to help out shows them you need and trust them. Talk to them about it first and don't allow them to take on too much responsibility.

You may find the tool on the next page helpful to explain to your child or teenager how you may act and why. This lets them know you are not upset because of something they did and the best way they can support you.

# Tool for children or teenagers

The person-centred thinking tool is from **thinkaboutyourlife.org**, which was developed by cancer survivors. The website has examples, stories and support to help you use the tool.

| Situation                              | Explanation                         | How you can support me |
|--|-------------------------------------|------------------------|
| I got angry at you for<br>making noise | I'm angry at the<br>cancer, not you | Give me a hug          |
|  |                                     |                        |
|  |                                     |                        |
|  |                                     |                        |



# TALKING AT WORK

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# Whether you are employed or self-employed, you may worry about telling people you work with about the cancer.

You will need to think about the best work arrangements for you during and after treatment. It is important to know your rights in the workplace and what help is available.

# Talking to your employer

Many people worry about telling their employer that they've been diagnosed with cancer and need to have treatment. You may worry that your employer won't support you and that they may be prejudiced or discriminate against you.

Although it helps to tell your employer that you have cancer, you don't have to do so by law. However, if you don't tell your employer, and the cancer and its treatment affect your ability to do your job, this could cause problems.

Some people worry that their employer will sack them or find an excuse to make them redundant if they tell them they have cancer. However, employers shouldn't do this. Anyone who has or has ever had cancer is protected by the Equality Act 2010 in England, Scotland and Wales, or the Disability Discrimination Act 1995 in Northern Ireland. These acts make it unlawful for employers to discriminate against people with a disability.

Both acts state that employers should make reasonable adjustments to remove any substantial disadvantage to employees as a result of their condition. You may be able to suggest adjustments that could help support you.

Also, if your employer doesn't know about the cancer and its effects, it will make it more difficult for them to make any necessary adjustments for you at work. In fact, in some cases, your employer's lack of knowledge may mean they're not legally required to make any adjustments.



If you are employed, our booklet Your rights at work may be helpful.

You can talk directly to your line manager, human resources manager, occupational health adviser or trade union, or to all four. If carrying on as normal is important to you, tell your employer so that they can support you in continuing with your work.

However, if you can't go on working normally because of the cancer or its treatment, then let your employer know. Arrangements can then be made to alter your work or give you time off as necessary.

## Asking your employer questions

Some questions you might like to ask your employer include:

- Can I work out with you what we'll tell everyone at work about the cancer and its effect on my work situation?
- How can my job be adjusted so that I spend less time on tasks that cause me extra discomfort?
- Where can I find information about any company/organisation policies that relate to my situation?

Our leaflet Work it out includes a list of questions that people affected by cancer can use in conversations with their GP, healthcare team, other advisory services and employer. You can order the booklet free at **be.macmillan.org.uk** or by calling our cancer support specialists on **0808 808 00 00**.

### Your right to sick pay and time off

Your employer or human resources department will be able to give you information about your organisation's sickness policy and how much paid and unpaid time off you're entitled to. Talking to your employer about your need for time off will mean they can support you in the best way possible.

Our booklet Work and cancer gives more information about employment rights and coping with the effects of treatment at work.

## Flexible working

Most employers are willing to change duties and working hours so employees with cancer can keep working if they want to. However, some employers may find it difficult to understand what's needed, or they may be unable to accommodate flexible working. It's helpful to have regular update meetings with your line manager to discuss your condition, how you're getting on at work and any difficulties you may be having.

# Occupational health

Your workplace may be able to provide an occupational health adviser. Occupational health advisers draw on their clinical knowledge and an awareness of the specific duties and demands of your role.

# **Employee assistance programmes**

Some employers run employee assistance programmes that aim to help you deal with any personal problems that may be affecting your work. Your manager should be able to tell you whether your workplace has one.

#### **Buddy system**

Some people may find it hard to talk to their manager about cancer and the problems or concerns it's causing for them at work. You may feel it would help to ask someone at your workplace to be your 'buddy' or mentor.

Choose someone you're comfortable with, or perhaps someone who's had cancer themselves. This arrangement would need to be agreed between you, your buddy and your manager(s).

# Talking to your colleagues

Talking about cancer can be very difficult. You may worry about how your colleagues will react – for example, whether they might withdraw from you. Or you may worry that talking about the cancer might make things awkward for yourself or your colleagues.

Some people may avoid you because they don't know what to say and are afraid of saying the wrong thing. You can help them by bringing up the subject and showing that you're willing to talk about the cancer.

Telling your colleagues can help, as they then know what to expect. For example, if fatigue affects your moods or concentration, it gives them the opportunity to support you.

# If you don't want to tell colleagues

Some people prefer not to tell colleagues they have cancer. You may not want to tell them so that you can keep one area of your life as normal as possible. This is a good way of coping for some people.

However, sometimes the effects of the cancer or cancer treatment (for example, if your hair falls out), and the need to take time off, make it impossible not to tell your colleagues.

Your colleagues may also be aware from your behaviour that something's wrong, and may feel uncomfortable if they don't know what it is.

# Risk to colleagues

There are many myths and misunderstandings about cancer. Some of your colleagues may worry that they can catch cancer. But cancer can't be passed on like an infection, and the people you work with have no risk of catching cancer.

Some people may also worry that they could be harmed if you're having treatments such as chemotherapy or radiotherapy. Again, there's no risk to your colleagues. Chemotherapy is broken down in the body and can't harm anyone you come into contact with. Radiotherapy treatment from an external machine doesn't make you radioactive. Even if you've had internal radiotherapy, the radiation will only affect a small area of tissue in your body around the cancer and won't affect anyone you come into contact with.

If you find it difficult to discuss these issues with your colleagues, you can ask your line manager to help you. You may also find it helpful to talk in confidence to our cancer support specialists on 0808 808 00 00.

# If you're self-employed

As a self-employed person, you may feel there are fewer people who you can talk to. This can feel isolating. You can call the Macmillan Support Line on 0808 808 00 00 to discuss emotional issues. You can also talk to one of our financial guides to discuss the practical needs of your business. It can also be helpful to find someone who works in the same field as you who can give you advice on your business.

When you are self-employed, other people or businesses may rely on you to deliver your goods or services. They may also rely on your payments. They may need to know you have cancer. You will have to balance your feelings about telling people with the needs of your business. For example, if the cancer affects your ability to drive, you could be fined if you don't tell the DVLA about it. On the other hand, some people may not need to know. It's your choice whether to tell them or not.

While it can be hard to tell people about the cancer, it can mean they will be able to give you support, both practically and emotionally. If you can, it may help to take some time to think about the pros and cons of telling people.

Our booklet Self-employment and cancer gives advice on the support there is available to help you continue with your business.



# TALKING TO HEALTHCARE STAFF

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# Most conversations between you and your doctors or nurses will probably go smoothly.

However, your feelings and fears may make it difficult for you to ask your medical team the right questions and to remember their answers.

# Conversations with healthcare staff

It's common for people to sometimes feel they're not getting the information or support they need.

# Practical tips when talking to healthcare staff

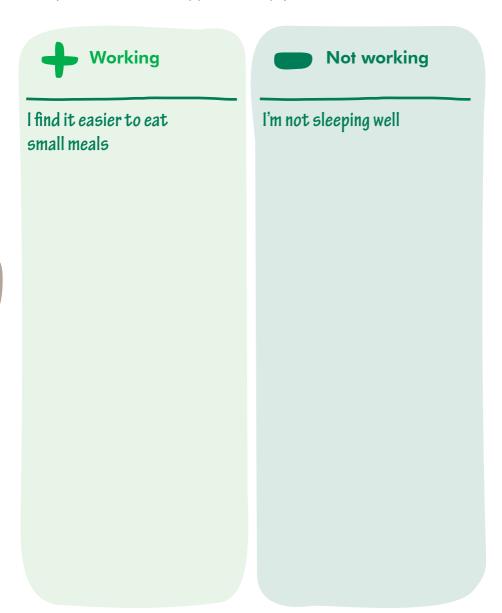
- Think of the most important questions before you meet with your doctor.
- Write down the important points on a piece of paper that you can take with you. Nobody will mind you writing things down or making a list of questions you want to ask. Some people are happy for you to record the discussion, so you can listen to it later. You can also ask your medical team for a copy of any letters summarising the details of your discussion with them.
- Take a relative or friend with you to appointments. They can help you remember things that the doctor says, and questions you want to ask but may forget.
- Be honest and factual when describing problems. Don't play down symptoms. Also talk about how you feel, including feelings of anxiety or depression. Even if they cannot help you themselves, they should refer you to someone who can help.

- Use your own language. Your doctors or nurses may use medical terms, but you don't have to. Using terms that you only partly understand may cause problems as the health professionals may think you know more than you do.
- Ask for simpler explanations. It's okay to say you don't understand the terms used. Ask the medical professional to explain things in a simpler way.
- Say if you're embarrassed. Medical symptoms and problems can be embarrassing. They're often the kind of personal things we don't want to talk about. When you start talking, you can say, 'I'm sorry, this is embarrassing to talk about, but...'
- Make sure you understand. Summarise the doctor's words and say, 'So you're saying that...' or 'If I've got that right, you mean that...' This makes it clear how much you've understood. It will encourage your doctor or nurse to explain things more clearly.
- Remember, you'll have other chances to ask questions. You could make another appointment to ask your questions if you don't cover everything in the first discussion, or if you're given surprising news that changes the questions you wanted to ask. You may also be given a phone number for a nurse specialist you can phone if you've forgotten to ask a question or if you don't understand something.

The tool on the next page may help you to think about things that are going well or could be improved with your treatment.

Our leaflets Getting the best from your cancer services and Ask about your cancer treatment may help you to think of questions you'd like to ask your doctors or nurses. Order online at be.macmillan.org.uk or call 0808 808 00 00.

The person-centred thinking tool is from thinkaboutyourlife.org, which was developed by cancer survivors. The website has examples, stories and support to help you use the tool.



# **Getting information**

Some people want to know as much as possible about their illness. This can help them explain things to their family and friends, and helps them during talks with their medical team.

Sometimes you may have a choice of treatments. In this situation it's helpful to ask your doctor to explain all the benefits and disadvantages of each treatment so you can make the right choice for you.

You may find our booklet Making treatment decisions helpful. Call 0808 808 00 00 or visit be.macmillan.org.uk to order a copy. You can also discuss your treatment choices with our cancer support specialists by calling the same number.

For some people, having more information helps them feel involved in their care and more in control generally (see pages 39-41). Other people prefer not to know all the details of their illness and want to leave treatment decisions to their doctors.

However, you need to have a certain amount of information to be able to give consent to your treatment. It's best if you explain how you feel to your healthcare team so they know how much information to give you.

Talking to your healthcare team about what you think and feel will help them focus on the issues that are important to you. Then you'll really benefit from conversations with your medical team.



# Reliable sources of information

You may sometimes find it difficult to get all the information you need from the doctors or nurses looking after you.

Your own healthcare team is in the best position to help you and answer your questions because they have the most information about your particular situation, the cancer and your general health. (See pages 76-79 for information about talking to healthcare staff.) However, there are many other sources of support and information. It's important to get information from a reliable source, which is up to date and relevant to your situation.

We produce a variety of booklets, leaflets and audio CDs, which are updated regularly. To order, visit be.macmillan.org.uk or call 0808 808 00 00. Alternatively, you can view our cancer information online at macmillan.org.uk/cancerinformation

Many people still believe myths about cancer, for example that cancer can never be cured. And some well-meaning people may want to tell you about awful experiences of cancer that aren't relevant to your situation at all. If this happens to you, let the person know that you feel uncomfortable hearing about other people's bad experiences and you'd rather get the information you need from the healthcare professionals.

You can get reliable information from our cancer support specialists on 0808 808 00 00 or the other organisations listed on pages 93-96. These organisations often provide a helpline, booklets and audio resources.

# Problems with your healthcare team

If you're unhappy with the care you receive from your healthcare team, try to talk about your worries with them as sensitively as you can. If you can say what you're unhappy with and how it affects you, they can hopefully change the situation so that it gets better.

If your disagreement is about your treatment at the hospital, you can contact the Patient Advice and Liaison Service (PALS), who can help sort out any problems. You can also write a formal complaint, which the hospital will respond to.



# **Dealing with uncertainty**

It isn't always possible to get definite answers. You may have to accept that uncertainties are common. When the conversation is about things that threaten your health or your future, you may think that your doctor or nurse knows what's going to happen but won't tell you. Usually, that isn't the case.

There is often a lot of uncertainty with cancer treatment. Even if statistics show that a treatment has been successful in the past. doctors don't know how well it will work for you. It may help you cope better if you can understand how your progress will be measured. For example, you can ask, 'So you can see from the x-rays if the treatment is working?'

Uncertainty can be one of the hardest things to deal with. It can make you feel angry, irritable and frightened, which can sometimes cause tension with people around you.

Talking to family, friends and healthcare professionals about how you feel can help. See pages 24-25 for tips on asking for support. Some people find it useful to talk about things with a counsellor. Your local cancer information centre or cancer support group may have a counsellor who you can talk to (see pages 12–13). Or your doctors and nurses can help you contact one.

Focusing on things in your life that you can control may help to reduce your anxiety. See pages 39-41 for ideas on how you may take control of your situation.



# 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
- large print
- translations.

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

# Help us improve our information

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

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

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



# Other ways we can help you

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

# Talk to us

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

# **Macmillan Support Line**

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

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

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

#### Information centres

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

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

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

# Talk to others

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

# Support groups

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

# Online community

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

# The Macmillan healthcare team

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

'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 advice

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

# Help accessing benefits

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

# Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit macmillan.org.uk/ financial support to find out more about how we can help you with your finances.

# Help with work and cancer

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

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

# Other useful organisations

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

# Counselling and emotional support

**Association for Family Therapy & Systemic Practice (AFT)** 

7 Executive Suite, St James Court, Wilderspool Causeway, Warrington, Cheshire WA4 6PS Tel 01925 444414 www.aft.org.uk

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

**British Association** for Counselling and **Psychotherapy (BACP)** 

BACP House, 15 St John's Business Park, Lutterworth LE17 4HB Tel 01455 883300 Email bacp@bacp.co.uk www.bacp.co.uk

Promotes awareness and benefits of counselling, and signposts people to appropriate services. You can search for a qualified counsellor on the website

# Relate

Premier House, Carolina Court, Lakeside, Doncaster DN4 5RA **Tel** 0300 100 1234 www.relate.org.uk

Offers counselling and support to help people of all ages, backgrounds and sexual orientations to strengthen their relationships.

# **Relationships Scotland**

18 York Place, Edinburgh EH1 3EP Tel 0845 119 2020 www.relationships-scotland. org.uk

A Scottish charity created when Relate Scotland merged with Family Mediation Scotland. Provides sex and relationship therapy, relationship counselling and family support. Has a helpline and can suggest local services for young people.

# **Samaritans**

Chris, PO Box 9090,

Stirling FK8 2SA Tel 08457 90 90 90 Email jo@samaritans.org www.samaritans.org Provides 24-hour confidential, non-judgemental emotional support, for people experiencing feelings of distress or despair, including those which could lead to suicide. Service provided by phone, email or letter.

# **UK Council for** Psychotherapy (UKCP)

2<sup>nd</sup> Floor, Edward House, 2 Wakley Street, London EC1V 7LT **Tel** 020 7014 9955 Email info@ukcp.org.uk www.psychotherapy.org.uk Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

### Youth Access

1–2 Taylors Yard, 67 Alderbrook Road. London SW12 8AD Tel 020 8772 9900 (Mon-Fri, 9.30am-1pm and 2-5pm)

# **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.

# **General cancer** support organisations

#### Cancer Black Care

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

info@cancerblackcare.org.uk www.cancerblackcare.org.uk

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

# **Cancer Focus** Northern Ireland

40-44 Eglantine Avenue, Belfast BT9 6DX Tel 0800 783 3339 (Mon-Fri, 9am-1pm) Email hello@cancerfocusni.org 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 www.cancerhelp.org.uk **Tel** 0300 123 1022 Has patient information on all types of cancer and has

# **Cancer Support Scotland**

a clinical trials database.

The Calman Centre, 75 Shelley Road, Glasgow G12 0ZE Tel 0800 652 4531 Email info@ cancersupportscotland.org www.cancersupport

# scotland.org

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

# **Macmillan Cancer Voices** www.macmillan.org.uk/ cancervoices

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

# Maggie's Centres

2<sup>nd</sup> Floor Palace Wharf. Rainville Road, London W6 9HN **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, Pill, Bristol BS20 OHH **Tel** 01275 371 100 (Mon-Fri, 9.30am-5pm) **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

Att Pauline Hutchinson, University of Sheffield, Sykes House Office, St Luke's Hospice, Little Common Lane, Sheffield S11 9NE 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 Tel 0808 808 1010 (Mon-Sun, 8am-8pm) 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.

# General health information

# **GP Out-of-Hours Service** - Northern Ireland

A support service for medical help and advice. Lines open weekdays, 6pm until your GP surgery opens the next morning, Sat-Sun open 24 hours.

**Belfast Health and Social** Care Trust

Tel 028 9074 4447

**Dalriada Urgent Care** Tel 028 2566 3500

South Eastern Health and Social Care Trust **Tel** 028 9182 2344

Southern Health and Social Care Trust Tel 028 3839 9201

**Western Urgent Care Tel** 028 7186 5195

# **Health and Social Care** in Northern Ireland www.hscni.net

Provides information about health and social care services in Northern Ireland.

# Healthtalk **Email**

info@healthtalkonline.org www.healthtalk.org www.youthhealthtalk.org (site for young people)

Has information about cancer, and videos and audio clips of people's experiences.

# **National Cancer** Institute - National Institute of Health - USA www.cancer.gov

Gives information on cancer and treatments.

# **NHS Choices** www.nhs.uk

The UK's biggest health information website. Has service information for England.

# **NHS Direct Wales** www.nhsdirect.wales.nhs.uk

NHS health information site for Wales

# **NHS Inform** www.nhsinform.co.uk

NHS health information site for Scotland.

# **Patient UK** www.patient.co.uk

Provides people in the UK with information about health and disease. Includes evidencebased information leaflets on a wide variety of medical and health topics. Also reviews and links to many healthand illness-related websites.

# **Ulster Cancer Foundation**

40-44 Eglantine Avenue, Belfast BT9 6DX Helpline 0800 783 3339 (Mon-Fri, 9am-5pm) **Email** infocis@ulstercancer.org www.ulstercancer.org

Provides a range of services to people with cancer and their families, including a free telephone helpline, which is staffed by specially trained nurses with experience in cancer care.

# Financial or legal advice and information

#### **ACAS**

Euston Tower, 286 Euston Road. London NW1 3DP **Tel** 0300 123 1100 (Mon-Fri, 8am-8pm, Sat, 9am-1pm)

# **Text Relay**

18001 0300 123 1100

# www.acas.org.uk

Provides information, advice, training, conciliation and other services for employers and employees to help prevent or resolve workplace problems.

# **Benefit Enquiry Line** Northern Ireland

Tel 0800 220 674 (Mon-Wed and Fri, 9am-5pm, Thu, 10am-5pm)

# **Textphone** 0800 243 787 www.nidirect.gov.uk/moneytax-and-bfits

Provides information and advice about disability benefits and carers' benefits.

# Citizens Advice

Provides advice on a variety of issues, including financial, legal and employment queries. Details for your local office can be found on theses websites:

- **England and Wales** www.citizensadvice.org.uk
- **Scotland** www.cas.orq.uk
- Northern Ireland www.citizensadvice.co.uk

You can also find advice online in a range of languages at advicequide.org.uk

**Department for Work** and Pensions (DWP) **Disability Living Allowance** Helpline 0345 712 3456 **Textphone** 0345 722 4433 **Personal Independence Payment Helpline** 0345 850 3322 **Textphone** 0345 601 6677 Carer's Allowance Unit 0345 608 4321 **Textphone** 0345 604 5312 www.gov.uk/browse/benefits Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

### **GOV.UK**

# www.gov.uk

Has comprehensive information about social security benefits and public services.

# **Labour Relations** Agency (NI)

2-16 Gordon Street Belfast BT1 2LG Tel 028 9032 1442 (Mon-Fri, 9am-5pm) Email info@lra.org.uk

# www.lra.org.uk

Provides an impartial and confidential employment relations service to those engaged in industry, commerce and the public services.

**Money Advice Scotland** Tel 0141 572 0237 www.moneyadvice scotland.org.uk

The Money Advice Service Tel 0300 500 5000 (Mon-Fri, 8am-8pm, Sat, 9am-1pm)

# **Typetalk**

18001 0300 500 5000

# www.moneyadvice service.org.uk

Runs a free financial health check service

and gives advice about all types of financial matters. Has an online chat service for instant money advice.

# **National Debtline** (England, Scotland and Wales)

Tricorn House, 51–53 Hagley Road, Edabaston, Birmingham B16 8TP **Tel** 0808 808 4000 (Mon-Fri, 9am-9pm, Sat, 9.30am-1pm) www.nationaldebtline.co.uk A national helpline for

people with debt problems. The service is free, confidential and independent.

# Personal Finance Society -'Find an Adviser' service www.findanadviser.org

Use the website to find qualified financial advisers in your area.

# Unbiased.co.uk Email contact@unbiased.co.uk www.unbigsed.co.uk

On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.

# Support for young people

# **CLIC Sargent**

Horatio House, 77-85 Fulham Palace Road, London W6 8JA Tel 0300 330 0803 www.clicsargent.org.uk Provides clinical, practical, financial and emotional support to children with cancer.

# **Hope Support Services**

375 High Road, London N22 8JA **Tel** 01989 566317 Email help@ hopesupportservices.org.uk www.hopesupport.org.uk Supports young people when a close family member is diagnosed with a lifethreatening illness. Online and face-to-face help is available.

# **Teenage Cancer Trust**

3<sup>rd</sup> Floor, 93 Newman Street, London W1T 3EZ **Tel** 020 7612 0370 **Email** 

hello@teenagecancertrust.org www.teenagecancertrust.org

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

# Support for older people

# Age UK

Tavis House, 1-6 Tavistock Square, London, WC1H 9NA Tel (England and Wales) 0800 169 6565 Tel (Scotland) 0845 125 9732 Tel (Northern Ireland)

0808 808 7575 (Daily, 8am-7pm)

www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

# Support for carers

**Carers Trust (Princess Royal Trust for Carers in Scotland)** 32–36 Loman Street. London SE1 0EH Tel (England)

0844 800 4361

Tel (Scotland) 0300 123 2008

Tel (Wales) 0292 009 0087

Email info@carers.org

www.carers.org and www.youngcarers.net

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

**Carers UK** Tel (England, Scotland, Wales) 0808 808 7777 Tel (Northern Ireland) 028 9043 9843 (Wed-Thu, 10am-12pm and 2-4pm) **Email** advice@carersuk.org www.carersuk.org Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

> You can search for more organisations on our website at macmillan.org.uk/organisations, or call us on 0808 808 00 00.

# Disclaimer

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

# **Thanks**

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

With thanks to the original authors: Dr Robert Buckman, Medical Oncologist, and John Elsegood, Behavioural Scientist.

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# Can you do something to help?

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

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



# Share your cancer experience

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

# Campaign for change

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

# Help someone in your community

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

# Raise money

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

# Give money

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

Call us to find out more 0300 1000 200 macmillan.org.uk/getinvolved

#### Please fill in your personal details keep your money Mr/Mrs/Miss/Other Do you pay tax? If so, your gift will be worth 25% more to us – at no Name extra cost to you. All you have to Surname do is tick the box below, and the tax office will give 25p for every Address pound you give. Postcode I am a UK taxpayer and I would like Macmillan Cancer Phone Support to treat all donations **Email** I have made for the four years prior to this year, and all Please accept my gift of £ donations I make in the future, (Please delete as appropriate) as Gift Aid donations, until I I enclose a cheque / postal order / notify you otherwise. Charity Voucher made payable to Macmillan Cancer Support I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each OR debit my: tax year, that is at least equal to the tax that Visa / MasterCard / CAF Charity Charities & CASCs I donate to will reclaim on my aifts. I understand that other taxes such as Card / Switch / Maestro VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of Card number tax on every £1 that I give. Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, Valid from Expiry date campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. Security number Issue no In order to carry out our work we may need to pass your details to agents or partners who act on our behalf. Signature

Don't let the taxman

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

Date

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

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

Hard of hearing? Use textphone 0808 808 0121, or Text Relay. Non-English speaker? Interpreters available. Braille and large print versions on request.

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