

**MACMILLAN**  
CANCER SUPPORT

# WORRYING ABOUT CANCER COMING BACK



# About this booklet

**This booklet is for anyone who has had treatment for cancer and is worried about the cancer coming back.**

It suggests ways to help you manage worry and uncertainty. This booklet also has information and advice on where to get support and help.

## How to use this booklet

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

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

On pages 45 to 47, there are some useful addresses and websites. There is also space to write down questions and notes on page 48.

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

## Quotes

In this booklet, we have included quotes from people affected by cancer. Some are from our Online Community ([community.macmillan.org.uk](https://community.macmillan.org.uk)). The others are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://macmillan.org.uk/shareyourstory)

## For more information

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

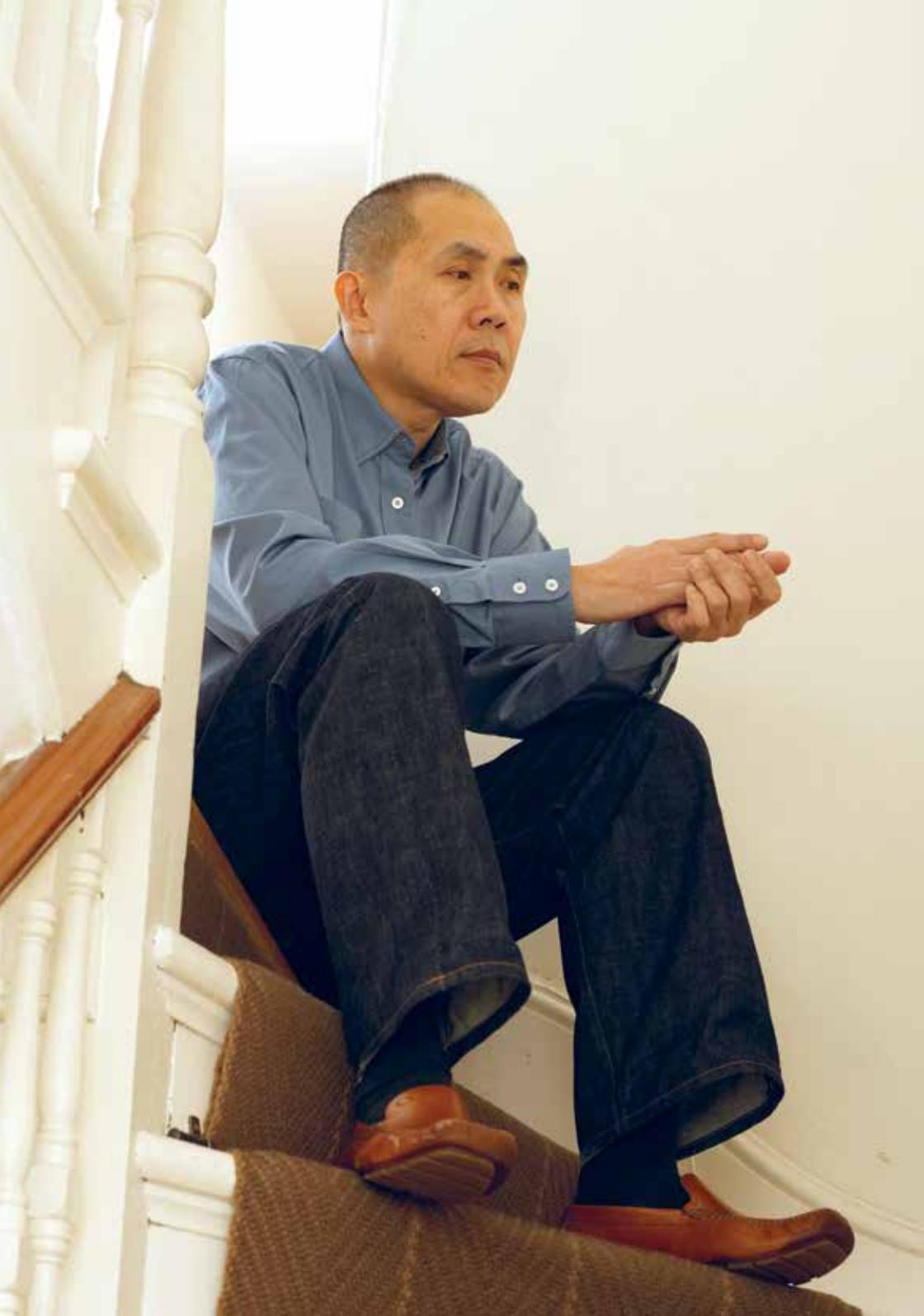
If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

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# Worry and uncertainty

You will probably feel relieved when you finish cancer treatment. But you may also find yourself worrying about whether it has worked and what might happen in the future.

For many people, the aim of treatment is to cure the cancer. But doctors may not say the word cure. This is because some cancers do come back. Everyone's cancer and treatment is different. For some people, treatment may get the cancer under control, but they know it may come back in the future.

Most people who have been through cancer treatment live with some worry and uncertainty. This does not mean they are not coping with life after treatment.

Some people find it hard to cope with these feelings of uncertainty. They may feel as if they have very little control over their lives. These feelings often get better over time.

## Coping with uncertainty

There are ways to help you manage worry and uncertainty. Knowing that you may always have some of these feelings and what they are normal can help. This may be hard and can take time. But there are people who can help you with this.

One way of managing your worries is trying to focus on what you can control right now. This can help you to manage any concerns about what will happen in the future.

It can include:

- talking about your feelings
- getting support
- being involved in your own health and well-being
- following advice from your healthcare team
- knowing when you need help and where to get it.

Some of these suggestions may not work for you. There are no right and wrong ways to cope.

*'Just be kind to yourself, take one day at a time, stay in the moment, and I bet that soon you will notice you have made baby steps forward. Your old life might never come back, but that doesn't mean you can't enjoy a new one.'*

**Greg**

## Situations that may worry you

You may find there are some situations that make you worry more. Sometimes you may feel worried, but not know exactly why. This can make it hard to talk about.

These situations vary. Everyone worries about different things. But some common worries are:

- hospital appointments or tests – you may worry you will get bad news or it may bring back memories of your diagnosis or treatment
- noticing a new or different ache, pain or other symptom
- reading or hearing about cancer in magazines, newspapers, films, TV programmes or online
- hearing someone else's cancer has come back or that they have died – this could be someone you knew or even a celebrity in the news.

Knowing what makes you worried can help. Worry and anxiety are common reactions, but there are helpful ways to manage these feelings. For example, try not to compare yourself with others. No two cancer experiences are the same, even if they are the same type of cancer.

A new symptom could be nothing to do with cancer. You may get the normal aches and pains everyone gets. Or they could be caused by treatment side effects. We have more information on symptoms or signs to be aware of (see pages 32 to 33). Always check any new symptoms with your GP, cancer doctor or specialist nurse. This can help with feelings of worry and anxiety.

## Talking and getting support

Many people do not like talking about cancer and how it is affecting them. You may find the idea of talking upsetting or uncomfortable. But talking to someone about how you feel can help you cope with your emotions. It is often the first step in helping you feel better. Talking about things can make you feel supported. It can also help you make decisions that are best for you.

You may want to talk to someone you know well. This could be a partner, family member or friend.

Or you may find it easier to talk to someone you do not know well. This could be your cancer doctor, GP or specialist nurse, or a religious or spiritual leader. Your doctor or nurse may be able to refer you to a psychologist or counsellor. Some organisations like Mind can offer this type of support too (see page 47 for contact details).

You might find self-help groups or online communities useful, such as **community.macmillan.org.uk**. This might be a good option if you find it hard to talk to the people close to you. You can also speak to one of our cancer support specialists on **0808 808 00 00**, 7 days a week, 8am to 8pm.

You may find our booklet **Talking about cancer** helpful (see page 40).

## How talking can help

There are a few ways that talking may help you:

- You may feel more supported and less anxious. Knowing someone else understands, cares and is there for you can reassure you that you are not alone.
- It can help you understand your feelings. When you keep everything inside, your thoughts often feel confusing. Talking can make your thoughts clearer.
- Talking allows you to express how you are feeling. Having a lot of concerns can feel overwhelming. Talking can ease the pressure and make you feel better.
- It helps you to know that your feelings are normal. You may feel guilty, weak or angry after a cancer diagnosis. Having someone listen to you without judging can reassure you that your thoughts are normal.
- Talking puts things into perspective. The more you worry about something, the worse it seems. It can be a big relief to say your feelings out loud.
- It can help you make important decisions. Talking can help you process how you feel about things. When you have to make decisions, you often think you know what other people are thinking or feeling. But sometimes they may surprise you with their views and help with tough decisions.

## Self-help and support groups

Joining a self-help or support group can have many benefits. They give you a chance to talk to other people. These people may be in a similar situation to you or facing the same challenges. Talking to them can help you feel less alone and more normal. Support groups are a place to share experiences, ask questions and support each other. You may also feel able to discuss the cancer and how it affects you more honestly than you could with friends or family.

Some groups offer support for people with different types of cancer. Other groups are for people with a specific type of cancer. For example, there are breast care groups and laryngectomy groups. Support groups can also help carers, family and friends cope with what is happening. They can learn how to help you and how to take care of themselves.

Carers may find our booklet **Looking after someone with cancer** helpful (see page 40).

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

## Online support

If you use the internet, you can join an online support group or chat room. There are groups about different types of cancer. There are more general groups where people chat about practical and emotional issues. There are also groups for carers, family members and friends.

You can share your own thoughts and feelings by posting messages for others to read and reply to. Or you can just read other people's comments or posts. These messages can sometimes be helpful. They can also be sad and difficult to read. It may help to know that other people feel like you do. You may feel less alone and learn how other people cope.

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

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

# Being aware of your thoughts

It is common to have some negative thoughts when you are coping with cancer. But sometimes this becomes your usual way of thinking. You may start to ignore positive things and focus on the negative thoughts. This can affect your mood and confidence, making you more anxious.

Being aware of negative thoughts and how they affect you can help you change the way you think.

## Challenge unhelpful thinking

Try asking yourself the following questions:

- Is what I am thinking right – is there proof?
- What would I say to a friend who had these thoughts?
- Am I jumping to conclusions or getting things out of proportion?
- Am I seeing the negatives and forgetting the positives?
- What would be the effect of thinking about things more positively?

It might be helpful to write down your thoughts. This may help you see if there is a pattern of negative thoughts. For example, if one thing goes wrong, you may feel that everything else will start to go wrong too. It might help to think about this differently.

You could try to change negative thoughts into more balanced thoughts. Here is an example:

### **Negative thinking**

'The cancer will come back and I will not be able to cope with more treatment.'

### **Balanced thinking**

'My cancer doctor told me there is a very good chance the cancer will not come back. But if it did, I have already coped with treatment and I could probably do it again.'



# Write down your feelings

Some people find it helps to write down how they are feeling. Keeping a diary, journal or online blog can be a way of expressing how you feel without having to talk about it.

You might want to write down how you are feeling but are not sure where to start. You can try using our good days, bad days tool on the opposite page. You can use this to write down what makes a good or a bad day for you. We all have days when both good and bad things happen. There is space to write any next steps to help you have more good days. Look at your lists and ask yourself:

- What can I do to have more good days?
- Is there anything I can do to make sure I have fewer bad days?

The thinking tools on pages 15 and 16 were written by people affected by cancer. You can find more tools, stories and help using the tools by visiting **[thinkaboutyourlife.org](http://thinkaboutyourlife.org)**

Writing things down does not work for everybody. Some people prefer to paint, draw or play music.



**Good days**

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**Bad days**

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**Next steps**



Hopes



Fears

**Next steps**

# Taking control

Learning about the cancer and its treatment can make you feel more in control. It can help you understand your condition and make decisions. It can also help you feel more involved in your care.

Having the right information can help when you speak with your cancer doctor, family, friends or work colleagues. Telling people what you really think and feel helps them understand what is important to you.

You may find the writing tool on the opposite page helpful.

Some people want a lot of information. Others may only want to know the basic facts and prefer to leave the details to their doctor. Tell your cancer team what you prefer. Everyone has their own ways of coping. It is okay to do what is best for you.

## Getting the right information

There is a lot of information available on the internet and in print. Some of this information can be wrong or misleading. There are a lot of incorrect beliefs about cancer and cancer treatment. It is important to get information that comes from a source that you can trust and is up to date.

Ask your specialist nurse or cancer doctor where to find the best information. If you are not sure if something you have read is reliable, check with your nurse or doctor. They are in the best position to answer your questions because they know about your situation.

When you are reading information, look for the Information Standard logo. This means that the information is based on up to date evidence and follows strict guidelines. You can see the Information Standard logo on the back cover of this booklet

You can get information from Macmillan (see pages 40 to 44). We have information in a range of formats about cancer, cancer treatments and living with cancer. You can order our information by visiting **be.macmillan.org.uk** or by calling our cancer support specialists on **0808 808 00 00**.

You can also go to a local Macmillan information and support centre to talk to experts and trained volunteers. They can give you support and answer your questions. You can search for groups or cancer information centres near you by visiting **macmillan.org.uk/inyourarea**

## Making sense of statistics

Statistics about cancer can be difficult to understand. If you want to know more about the chances of the cancer coming back, talk to your specialist nurse or cancer doctor. They may be able to give you statistics about it.

Statistics about surviving cancer are based on large numbers of people. Everyone is different, so statistics cannot predict what will happen to you as an individual. Your situation may be different from other people's.

Although doctors cannot predict exactly what will happen to you, they may be able to give you some general facts. They will base this on:

- the stage of the cancer
- how the type of cancer you have usually behaves
- the treatments you have had
- the evidence they have available to them.

If you read any statistics that worry you or you cannot understand, talk to your cancer doctor or specialist nurse.

## Before treatment finishes

Knowing what to expect after treatment may help you adjust and feel more in control. You may want to talk to your specialist nurse or cancer doctor about:

- what to expect
- what you can do to improve your short and long-term recovery
- your follow-up plan, including how often any appointments or tests will be
- symptoms to look out for
- who you should contact if you are worried about any late effects of treatment.

It is okay if you do not want to know all of this. The important thing is to go to your appointments. And tell your specialist nurse or cancer doctor about new or ongoing symptoms or side effects.

You may have a Holistic Needs Assessment (HNA) during treatment. This is where someone from your cancer team talks to you about your feelings and concerns. They discuss any side effects you have and explain how you may feel during and after treatment. They can then offer advice and support on how to cope. You might find our leaflet **Holistic Needs Assessment: Planning your care and support** helpful (see page 40).

You may also be offered a Treatment Summary. This describes the treatment you had and gives you information about follow-up appointments.

# Follow-up appointments and tests

You may worry about going to the hospital or clinic for follow-up appointments or tests, but it is very important to go. Many people feel reassured after their follow-up appointments. It also gives you a chance to talk to your cancer doctor about any concerns you have.

Your cancer doctor or specialist nurse will ask you how you have been. They can also check any problems you are having or possible signs that the cancer has come back. If the cancer does come back, finding it earlier may make it easier to treat. Treatment may cure certain cancers that have come back.

Instead of regular appointments, you may be asked to contact your specialist nurse or cancer doctor if you have any symptoms or concerns. There are also symptoms you should look out for (see pages 32 to 33).

Some people feel less anxious if they have fewer hospital visits. But other people miss the routine of having appointments, or the relationships they had with hospital staff. Talk to your cancer doctor or specialist nurse if you are worried about this.

## Get the most from your visit

You might find going to appointments or having tests easier if you:

- write a list of questions or things you would like talk about
- have someone with you for support and so you can talk to them about what was said later
- bring something to distract you while you are waiting, such as music or a book
- plan to do something you enjoy afterwards.

When you feel anxious, it can sometimes be difficult to understand what your doctor or nurse is saying. You or the person with you can write notes during your visit. Or you can ask your doctor to write down the main points of the conversation. You could also ask if you can record the conversation so you can listen to it afterwards.

If you are not sure about anything, ask your doctor to explain it in simple, clear language. Otherwise you may worry afterwards about what they said. Tell your doctor or nurse as much as you can and be honest. If you tell them how you have been feeling, they can support you better. Sometimes you might think of questions after the visit. Write these down for your next appointment. If it is urgent, you can telephone the clinic and speak to your doctor.

We have more information about asking about your cancer treatment in our booklet **Ask about your cancer treatment** (see page 40).



## Following advice

Your cancer team may give you advice on what you can do to help your recovery. Other healthcare professionals can also give you support and advice.

If you have ongoing side effects, your cancer team may explain how to manage these. They may show you how to do some simple checks for signs that the cancer has come back. Or they may tell you about signs or symptoms to look out for. They may also give you advice on lifestyle factors, such as smoking, diet and being active.

You may be taking drugs to reduce the risk of the cancer coming back, for example hormonal therapies. If you are, it is very important to keep taking them. Not taking these can increase the chance of the cancer coming back.

Always let your specialist nurse, cancer doctor or GP know about any side effects that you are worried about. They can often help with these, or they may be able to change the drugs you are taking. Talking to your pharmacist about your medicines can also be helpful.

This may seem like a lot to deal with after treatment. But it is important to follow the advice from your cancer team and make it part of your normal routine.

# Focusing on your health

During and after cancer treatment, there are things you can do to improve your general health and well-being. This can make you feel more in control of what is happening to you. If you feel that your emotions are building up, focusing on your well-being can help you release the tension.

Looking after your health is important. There are many benefits to being active and eating a healthy diet. It helps reduce the risk of illnesses such as heart disease and diabetes. It also helps reduce the chance of developing some late effects, as certain treatments increase the risk of heart disease or bone problems later in life.

'I've been learning to accept that who I was 4 years ago is different to who I am now. Now I avoid stress and try to remain relaxed and take each day at a time.'

**Jacqueline**

## Eat well

Having a healthy, balanced diet is one of the best choices you can make for your overall health. Many people find making a positive change like eating well helps give them back a sense of control. It can also help you feel that you are doing the best for your health.

Eating well and keeping to a healthy weight will help you:

- keep or get back your strength
- have more energy
- increase your sense of well-being.

There is no evidence that eating a particular diet can cure a cancer. But a healthy, balanced diet can help reduce the risk of new cancers and other diseases, such as heart disease, stroke and diabetes.

A well-balanced diet should include:

- 5 portions of fresh fruit and vegetables a day
- foods high in fibre, such as beans and cereals
- some protein-rich foods, such as chicken, fish, nuts and pulses (like beans and lentils).

Try to eat less:

- red and processed meat
- salt
- pickled or smoked food.



If you are concerned about your weight, talk to your GP or practice nurse. They can tell you the right weight for your height. They can also give you advice if you need to lose or gain weight.

We have more information about healthy eating and cancer, and managing your weight after cancer treatment (see page 40).

## Be physically active

When you are living with or after cancer, being physically active can have a positive impact on you. We have a **Move More** pack that can help you get started (see page 40). Being active can:

- reduce tiredness and some other treatment side effects
- reduce anxiety and depression
- improve your mood and quality of life
- strengthen your muscles, joints and bones
- improve your heart health
- reduce the risk of other health problems.

At first, you might be nervous about increasing your activity, especially if you have not been active for a while. You may worry that you are too tired, or you may not know where to start. It is important to remember that some exercise is better than none. Physical activity encourages the brain to produce chemicals that improve mood and reduce stress. These are called endorphins. It will also help you feel more in control, because you are doing something positive for yourself.

You could exercise with family or friends. For example, you could all go for regular short walks. Or you could join a cancer rehabilitation programme and exercise with other people. They may understand you and what you are going through. It can also help your mood if you are active outdoors in fresh air and sunshine. You could try gardening or joining a walking group.

## Get enough sleep

Most people need around 8 hours of good-quality sleep a night.

Cancer can make you worried and anxious. This may affect your sleep. We have more information on our website (see page 40). Many people find they stay awake, often worrying about the same thing each night.

There are some things you can do to try and improve your sleep, such as:

- going to bed and getting up at the same time every day
- being physically active during the day
- making sure your bedroom is not too hot, cold, light or noisy
- having a snack before bed
- avoiding drinks that contain caffeine and alcohol in the evening
- not using a mobile phone, tablet or computer or watching television for an hour before bed.

If worry and anxiety are keeping you awake, talking to someone may help. Writing down your worries before going to bed can help clear your mind. Breathing and relaxation exercises may also help reduce anxiety and stress.

## Stop smoking

If you smoke, giving up is one of the healthiest choices you can make. Stopping smoking reduces your risk of heart and lung disease, bone thinning (osteoporosis), and smoking-related cancers. It may also reduce the chances of cancer coming back.

We have more information about giving up smoking when you have cancer online and in our booklet **Giving up smoking** (see page 40).

## Follow sensible drinking guidelines

NHS guidelines recommend that women and men:

- do not drink more than 14 units of alcohol a week
- have a few alcohol-free days each week.

A unit of alcohol is:

- half a pint of ordinary strength beer, lager or cider
- 1 small glass (125ml) of wine
- a single measure (25ml) of spirits.

Alcohol is linked with an increased risk of some cancers. It can also cause weight gain. Following sensible drinking guidelines is good for your overall health.

There is more information about alcohol and drinking guidelines on the Drinkaware website. Visit **[drinkaware.co.uk](https://www.drinkaware.co.uk)**

## Avoid recreational drugs

Recreational drugs can affect your health and relationships. Taking recreational drugs can also change the effect of some of the drugs prescribed by your doctor.

Talk to your doctor or nurse if you are worried about this or need support. It is important to be honest with them about using these drugs.



## What to look out for

After treatment, it is common to worry that every ache and pain is cancer. Your friends, family or partner might worry about this too. You will also be getting used to what is now normal for you. This can make it harder to know what to look for.

It is useful to know about the side effects of any ongoing treatment and any possible late treatment effects. This can help you cope with any worries about changes or new symptoms. But it is always important to get any new symptoms checked, even if you think they are not serious.

Always let your cancer doctor or specialist nurse know if you have:

- new symptoms or side effects that do not get better
- symptoms similar to the ones you had when you were diagnosed
- general symptoms, such as losing weight, feeling tired, or losing your appetite
- constant worries about possible symptoms
- problems sleeping
- trouble coping emotionally.

Do not ignore your concerns and hope that the problem will go away. You can contact your cancer doctor or specialist nurse between appointments. They can often reassure you and explain if the symptoms are likely to be because of treatment. They can arrange for you to have tests if needed. You can also ask your GP for advice.

Constantly checking yourself for symptoms or signs can make you worry more and make you anxious. Talk to your cancer doctor, specialist nurse or GP if you are doing this or thinking about it a lot of the time. Try to focus more on your recovery and well-being. You can read more about focusing on your health on pages 25 to 31.

It may help to talk to one of our cancer support specialists. Call the Macmillan Support Line for free on **0808 808 00 00**, 7 days a week, 8am to 8pm.

# Managing stress and anxiety

Living with stress and anxiety can be hard. There are things you can do to help manage your stress and cope with the physical symptoms. For example:

- if you feel like talking, talk to someone who is a good listener – this may be a friend, partner or family member, your doctor or nurse, or a professional counsellor or psychologist
- think about your breathing – breathe in slowly and deeply through your nose and slowly out through your mouth
- put on music you enjoy and close your eyes – this can help you feel calmer
- do some physical activity – even a short walk can help with anxiety
- keep a diary of what makes you anxious – this can help you avoid those situations if possible
- try activities or treatments such as yoga, meditation, massage or reflexology – these may help you relax and manage your anxiety.

**'Exercise and being outdoors is incredibly helpful to me. Art and weaving have also been so important to me as reflective time.'**

**Carol**

We have more information in our booklet **Cancer and complementary therapies** (see page 40).

If you feel your anxiety is getting worse, speak to your GP, specialist nurse or a psychologist or counsellor. They can help you find ways of coping with it. Many people who have anxiety may also have depression. Speaking to your healthcare team is the best way to get the help you need (see page 38).

You may find it helpful to contact Anxiety UK (see page 47 for contact details). You may also find it helps to join a support group. You can find groups near you at [macmillan.org.uk/inyourarea](https://www.macmillan.org.uk/inyourarea). We have more information on talking therapies (see pages 37 to 38).

## Make time to relax

One way of coping with stress is making time to relax. Doing things you enjoy and being with people you are close to can distract you from the things you are worrying about. It can help you feel more positive. Making time for activities you enjoy can also help you relax. You may want to start a new hobby or try an activity you have always wanted to do.

## Try relaxation techniques

There are relaxation techniques you can use to help you relax and cope with stress. These include meditation, yoga, regular physical activity or having a massage. We have more information in our booklet **Cancer and complementary therapies** (see page 40).

Some cancer support groups or organisations (see page 45) may offer relaxation, massage, aromatherapy or reflexology. You can ask your cancer doctor or specialist nurse if these are suitable for you.

Relaxation exercises can help you learn to relax your breathing or your body. You can find more information on stress and anxiety on the NHS website (see page 46). You might also find it helpful to visit Anxiety UK's website (see page 47). There are also many DVDs, CDs, online apps or podcasts you can use at home. You can ask your GP about relaxation exercises. They may be able to refer you to a healthcare professional who can show you how to do them.

## Talk with a professional

Sometimes it helps to talk to a counsellor or psychologist if you feel very low or anxious.

Some people find talking therapies help them deal with their feelings and find ways of coping. Your hospital or GP practice may have their own counsellors.

**'My advice would be to try and get some counselling organised with someone who is qualified. They will listen in a non-judgmental way.'**

**Glynis**

Or you can ask your specialist nurse, cancer doctor or GP if counselling or psychological support is available. The British Association for Counselling and Psychotherapy can also give you details of counsellors in your area (see page 46 for contact details).

## **Cognitive behavioural therapy (CBT)**

Cognitive behavioural therapy (CBT) is a talking therapy. It can help you manage your problems better by changing the way you think and behave. It can be used to treat anxiety, panic attacks or depression, or other health problems.

The way we think can have a powerful effect on how we feel. People who are anxious or depressed often have negative patterns of thinking and behaviour.

These can contribute to the anxiety or depression. CBT helps you to change these negative patterns.

The therapist will help you recognise the negative thoughts and help you find ways to change them. They will also help you find out which things give you a sense of satisfaction and pleasure.

You can ask your cancer doctor, specialist nurse or GP about any local support services that are available to you. You can also search for therapists on the British Association of Counselling and Psychotherapy (BACP) website (see page 46).

CBT and other types of therapy are available on the NHS. There are also online CBT programmes that you can do on your own.

## Mindfulness

Mindfulness is a way of becoming more aware of your thoughts and feelings. It uses techniques like meditation, breathing exercises and yoga to help you focus on what is happening at that time. It can help you change the way you think about things. This can help reduce stress and anxiety.

Mindfulness-based Cognitive Therapy (MBCT) uses the techniques of mindfulness with some CBT to help you change how you think.

Some centres in the UK offer MBCT classes on the NHS. You can search for Mindfulness apps online. You can also learn MBCT online at **[bemindfulonline.com](http://bemindfulonline.com)**

Acceptance and Commitment Therapy (ACT) also uses mindfulness. It focuses on accepting what you cannot control or change, while still doing things that will improve your quality of life.

## Know if you need more help

The worry or fear of cancer coming back may make you feel very anxious or depressed, or cause panic attacks. If you feel like this a lot of the time, or if it gets worse, talk to your doctor.

Sometimes it can be difficult to know if you are depressed or to talk about your feelings. Other people may notice and suggest that you might need help.

If you or someone close to you thinks you need help, speak to your GP, cancer doctor or specialist nurse. They can give you advice and refer you to a psychologist or a counsellor. They may also ask you how you feel about taking medicines that help treat depression or anxiety. There are also other organisations that can help you (see pages 45 to 47).

# Looking ahead

Having something to look forward to can help you feel less worried and more positive about life. Your worries about the cancer coming back may never go away completely. It may be difficult at times. But it is still possible to live life fully, with the right help and support.

The things you did before the cancer will slowly start to fit back into your life. Going back to work or starting to do the things you did before are important steps forward. We have more information on work and cancer (see page 44).

Although you would not have chosen it, having cancer may change you in positive ways. You may think again about what is important to you and focus on your relationships with family, friends or a partner. Or you may decide to do things you have always wanted to do.

Having plans can help move your focus away from the cancer. Doing something new can help distract and relax you. Some hobbies help you express your feelings – for example, learning to play a musical instrument or painting. You may decide to be more active. For example, you may start cycling, doing yoga, dancing, or join a walking group. You do not have to be good at these activities to enjoy them. Look out for any groups or classes in your area. Find something you enjoy and feel comfortable with.

When you feel ready, you may decide to do some volunteer work. You could try to find something that matters to you or makes you feel part of your community.

These are all different ways to help you feel you are getting back control of your life.

# 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](https://www.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.

## Online information

All of our information is also available at [macmillan.org.uk/information-and-support](https://www.macmillan.org.uk/information-and-support)

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](https://www.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](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

## Help us improve our information

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

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

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



# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

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

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

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

## Information centres

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

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

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://www.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](https://www.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](https://www.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.

## Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit [publications.macmillan.org.uk](https://www.macmillan.org.uk/publications) and search 'book reviews'.

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

Mal

## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out

more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

## Help with work and cancer

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

### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

### Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

# Other useful organisations

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

## Cancer support organisations

### Cancer Support Scotland

**Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

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

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

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

### Macmillan Cancer Voices

**[www.macmillan.org.uk/cancervoices](http://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

**Tel** 0300 123 1801

**Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

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

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits.

Also offers emotional and social support to people with cancer, their family, and friends.

### Penny Brohn UK

**Helpline** 0303 300 0118

(Mon to Fri, 9.30am to 5pm)

**Email**

[helpline@pennybrohn.org.uk](mailto:helpline@pennybrohn.org.uk)

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

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

## General health information

### Health and Social Care in Northern Ireland [www.hscni.net](http://www.hscni.net)

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

### NHS UK [www.nhs.uk](http://www.nhs.uk)

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

### NHS Direct Wales [www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

NHS health information site for Wales.

### NHS Inform Helpline 0800 224 488 (Mon to Fri, 8am to 10pm, and Sat and Sun, 9am to 5pm) [www.nhsinform.scot](http://www.nhsinform.scot)

NHS health information site for Scotland.

## Counselling

### British Association for Counselling and Psychotherapy (BACP) Tel 0145 588 3300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)  
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at [itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)

### UK Council for Psychotherapy (UKCP) Tel 0207 014 9955 **Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk) [www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)

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

## Emotional and mental health support

### Anxiety UK

**Infoline** 0344 477 5774

(Mon to Fri, 9.30am to 5.30pm)

**Text** 0753 741 6905

#### Email

support@anxietyuk.org.uk

**www.anxietyuk.org.uk**

Provides help, information and support for people with anxiety, stress and anxiety based depression.

### Mind

**Helpline** 0300 123 3393

(Mon to Fri, 9am to 6pm)

**Text** 86463

**Email** info@mind.org.uk

**www.mind.org.uk**

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

### LGBT Foundation

**Tel** 0345 330 3030

(Mon to Fri, 10am to 10pm, and Sat, 10am to 6pm)

**Email** helpline@lgbt.foundation

**www.lgbt.foundation**

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

### Samaritans

**Helpline** 116 123

**Email** jo@samaritans.org

**www.samaritans.org**

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



## Disclaimer

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

## Thanks

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

With thanks to: Karen Bowes, Specialist Palliative Care Nurse; Michelle Buono, Education Nurse; Mark Cawley, Lead Nurse Palliative and End of Life Care; Shirley Crofts, Clinical Nurse Specialist and Clinical Psychologist; Christopher Hewitt, Consultant Clinical Psychologist; Elaine Heywood, Macmillan Counsellor; Matt Loveridge, Clinical Nurse Specialist; Annabel Price, Psychiatrist Associate Specialist Director for Palliative Care; Louise Robinson, Clinical Psychologist; Helen Sanderson, Thinkaboutyourlife.org; and Susan Williamson, Senior Research Fellow.

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

We welcome feedback on our information. If you have any, please contact **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

## Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

Butow P, et al. Fear of cancer recurrence. In Holland J, et al (eds). *Psycho-Oncology*. 3<sup>rd</sup> edition. Oxford University Press. 2015.

Lebel S, et al. Addressing fear of cancer recurrence among women with cancer: a feasibility and preliminary outcome study. *Journal of cancer survivors*. No. 8, p 485 to 496. 2014.

Mind. Anxiety and panic attacks. 2017. [www.mind.org.uk](http://www.mind.org.uk) accessed February 2018.

Mind. Wellbeing. 2016. [www.mind.org.uk](http://www.mind.org.uk) accessed February 2018.

# 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](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other \_\_\_\_\_

Name \_\_\_\_\_

Surname \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

Postcode \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Please accept my gift of £ \_\_\_\_\_

(Please delete as appropriate)

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

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

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Security number

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Signature \_\_\_\_\_

Date / / \_\_\_\_\_

## Don't let the taxman keep your money

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

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

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

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

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



If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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

**This booklet is for people who have had treatment for cancer and are worried about the cancer coming back.**

**We hope you find this booklet helpful in dealing with some of the feelings you may have. This booklet also gives information and advice about where to get support and help.**

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

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

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

**MACMILLAN  
CANCER SUPPORT**  
**RIGHT THERE WITH YOU**

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<p>Certified member</p>	<p><a href="http://www.theinformationstandard.org">www.theinformationstandard.org</a></p>

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