

Worrying about cancer coming back



About this booklet

This booklet is for anyone who is worried about cancer coming back after treatment. It suggests things that might help you manage worry and uncertainty. This booklet also has information on where to get support and help.

How to use this booklet

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

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

At the <u>end of the booklet</u>, there are details of other organisations that can help.

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

Quotes

In this booklet, we have included quotes from people who have been affected by cancer. These are from people who have chosen to share their story with us.

To share your experience, visit <u>macmillan.org.uk/shareyourstory</u>

For more information

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

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

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, interactive PDFs, easy read, Braille, large print and translations. To order these, visit <u>macmillan.org.uk/otherformats</u> or call <u>0808 808 00 00</u>.

Contents

Worry and uncertainty	4
Talking and getting support	6
Being aware of your thoughts	12
Write down your feelings	14
Taking control	16
Follow-up appointments and tests	20
Following advice	22
Focusing on your health	24
What to look out for	32
Managing stress and anxiety	34
Looking ahead	42
About our information	44
Other ways we can help you	46
Other useful organisations	50

Worry and uncertainty

You might feel relieved when you finish cancer treatment. But you may also worry whether treatment has worked and what might happen in the future.

Sometimes the aim of treatment is to cure the cancer. But doctors may not use the word cure. This is because some cancers do come back. Everyone's cancer and treatment are different. Sometimes treatment may get the cancer under control, but doctors 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 uncertainty. They can feel as if they have very little control over their lives. But these feelings can get better over time.

We have more information about the different feelings you may have in our booklets:

- Your feelings after cancer treatment
- How are you feeling? The emotional effects of cancer.

Coping with uncertainty

It can help to know that feelings of worry and uncertainty are normal. You may always have some of these feelings after a cancer diagnosis. This may be hard and can take time to accept. But help and support are available. You might find it helpful to focus on what you can control right now. This can help you manage any concerns about what might happen in the future.

Things you can control right now might 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 - visit <u>macmillan.org.uk/help</u>

Some of these suggestions may not work for you. There is no right or wrong way to cope.



Talking and getting support

Many people find it helpful to talk about cancer and how it is affecting them. You may find the idea of talking 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 right 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
- your GP
- your specialist nurse
- a religious or spiritual leader.

Your doctor or nurse may be able to refer you to a psychologist or counsellor. Some organisations like <u>Mind</u> can offer this type of support too.

You might find <u>self-help groups</u> or <u>online communities</u> useful. This can be a good option if you find it hard to talk to your partner, family members or friends.

You can also speak to one of our cancer support specialists on $\underline{0808\ 808}$ $\underline{00\ 00}$ (7 days a week, 8am to 8pm).

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 and cares 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.
- Having a lot of concerns can feel overwhelming. Talking can ease the pressure and make you feel better.
- 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 can seem. It can be a big relief to say your feelings out loud.
- Talking can help you process how you are feeling. This can help you make important decisions. When you have to make decisions, you often think you know what other people are thinking or feeling. But they may surprise you with their views, and help you to make tough decisions.

Self-help and support groups

Joining a self-help or cancer support group can have many benefits. These may include:

- gaining a sense of community and knowing that you are not alone
- listening to and learning from the experiences of others
- participating in activities to support your well-being
- sharing common feelings and coping strategies
- making new friends, being more confident and enjoying yourself.

Some groups are for people with a specific type of cancer. For example, there are breast cancer care groups and laryngectomy groups. There are also support groups for families and carers.

It may help to attend a meeting and discover what the group is like before you decide to join. You might want to take someone with you.

Slowly, positive effects have become noticeable. People have started mentioning that I am oozing confidence, and I am beginning to emerge from my cocoon.

Lizzy, diagnosed with oesophageal cancer

What to expect at a support group

Each cancer support group is different. Some groups are made up of a few people who meet regularly at someone's house. Others are much larger and might have a meeting room.

You can expect a warm welcome from someone who has been in the group for some time. You will be introduced to other members and have the chance to tell them about yourself. You do not have to talk about anything you do not want to talk about. It can take a few visits before you feel comfortable enough to talk about personal things.

Most groups provide training in listening skills for group leaders. This means they will be able to listen in a positive, caring way. Meetings could include an activity, a social event or a talk from a guest speaker.

You may be able to access support services through the group. These might include complementary therapies, counselling or bereavement support.

Most groups are free. Some may charge for drinks and snacks, or accept donations for any support services they offer.

Contact the organiser if you have any questions about how the group works. They can tell you:

- what to expect
- how big the group is
- common discussion topics and activities.

How do I find a support group?

You can search for groups in your area by visiting <u>macmillan.org.uk/</u> <u>supportgroups</u> or by asking someone from your healthcare team. You can also call our cancer support specialists on <u>0808 808 00 00</u>.

<u>Life after Cancer</u> can help you find support groups after cancer treatment. There may be many groups in your area. You can try different groups to find one that works for you.

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 if you find it difficult to talk face to face. Online groups are also easy to leave. You do not need to explain 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 <u>macmillan.org.uk/community</u> "I used the Macmillan Online Community to vent my worries to others who'd been in my situation. I still go on now just to read what others have posted and to see if I can help someone else. "

Sarah, diagnosed with thyroid cancer

Being aware of your thoughts

It is common to have some negative thoughts when you are coping with cancer. But sometimes this can become 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 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 focusing on the negatives and forgetting the positives?

Some types of cognitive behavioural therapy (CBT) suggest it can help to take notice of your thoughts and then try to get some distance from them. This means that when you have an unhelpful or anxious thought, you acknowledge it and then let it go from your mind.

Some people find that writing their thoughts down helps them do this.

This may also help you see if there is a pattern of negative thoughts. For example, if 1 thing goes wrong, you may feel that everything else will go wrong too. It might help to think about this differently.

You could try to change negative thoughts into more balanced thoughts. For example:

- Negative thought: The cancer will come back and I will not be able to cope with more treatment.
- Balanced thought: 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.

We have more information about <u>cognitive behavioural therapy (CBT)</u> and how it can help you manage your problems better.

Getting help

If you are in crisis or having suicidal feelings, you can call **999** and ask for an ambulance to take you to your local A&E (emergency department). Or you can call <u>Samaritans</u> on **116 123** at any time of the day or night.

You can also call the Macmillan Support Line so they can direct you towards services that can help.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.



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. Some people like to write down things that went well in their day.

You might want to write down how you are feeling, but you may not be sure where to start. You can try using our Good days/Bad days tool. You can use this to write down what makes a day good or bad for you.

We all have days when both good and bad things happen. There is space on the opposite page to write any next steps to help you have more good days. Review 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?

This thinking tool was written by people affected by cancer. You can find more tools, stories and help using the tools by visiting <u>thinkaboutyourlife</u>. <u>org</u>

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

Good days	Bad days
I slept well.	I woke up at 3am and felt tired for the rest of the day.

Next steps

Write down my worries before I go to bed.

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.

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 online and in print, and shared on social media. Some of this information can be wrong or misleading. This is called misinformation.

There are a lot of incorrect beliefs about cancer and cancer treatment. It is important to get information that comes from a source 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 whether 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, whether online or in print, it can help to search for the Patient Information Forum (PIF) Tick:



The PIF Tick means that the information is based on up-to-date evidence and follows strict guidelines.

Some health information videos on YouTube also have a blue panel under them. These panels are applied to videos that have been identified as reliable sources of information.

For example, videos from the NHS have the following blue panel under them:



We have information in a range of formats about cancer, cancer treatments and living with cancer. You can order our information by visiting <u>be.macmillan.org.uk</u> or by calling our cancer support specialists on <u>0808 808 00 00</u> (7 days a week, 8am to 8pm).

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 Information and Support Centres near you by visiting <u>macmillan.org.uk/inyourarea</u>

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 situations.

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 <u>what to expect after treatment</u> 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-term and long-term recovery
- your follow-up plan, including how often any appointments or tests will be
- symptoms to be aware of
- who you should contact if you are worried about any late effects of treatment.

It is important to go to your appointments. Tell your specialist nurse or cancer doctor about new or ongoing symptoms or side effects.

You may be offered a Holistic Needs Assessment (HNA) during treatment. This is where someone from your cancer team talks to you about your feelings and concerns. These can be physical, emotional or practical concerns.

They can then offer you the best advice and support. They may give you a personalised care and support plan. If you are not offered an HNA and would like one, you can ask someone from your healthcare team about it.

You may also be offered a treatment summary. This describes the treatment you had and gives you information about follow-up appointments. A copy is sent to your GP.

We have more information in our booklets:

- Life after cancer treatment
- Holistic Needs Assessment: Planning your care and support.

Follow-up appointments and tests

After treatment, you may have follow-up appointments or telephone calls. 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.

Follow-up appointments are also a chance to talk about any concerns you may have. You can always contact your healthcare team between appointments. If you are worried about anything, you do not need to wait for an appointment.

You may not have regular follow-up appointments. Instead, your specialist nurse or cancer doctor may ask you to contact them if you have any symptoms or concerns. Your healthcare team will talk to you about symptoms you should be aware of.

Not having regular follow-up appointments may cause anxiety. Talk to your cancer doctor or specialist nurse if you are worried about this.

Get the most from your visit

At follow-up appointments or for telephone calls, it might be helpful if you:

- write a list of questions and things you want to talk about before the appointment
- bring someone with you for support
- bring something to do while you are waiting, such as a book to read or a way to listen to music.

Sometimes it can be hard to remember everything you talked about during an appointment. You or the person with you might want to write notes during your visit. Or you can ask your doctor or nurse to write down the main points.

You could also ask whether you can record the conversation so you can listen to it afterwards. You can check that you will receive a copy of the letter that gets sent to your GP.

If anything was not clear, ask the doctor or nurse to explain again. They will be happy to answer your questions and make you feel less worried. If they understand your concerns, they can offer you the right support. If you forget something or think of other questions, you can always contact them afterwards.

You might want to take some time afterwards to discuss things with someone you feel comfortable with, such as a friend or family member.

We have more information in our booklet <u>Ask about your cancer</u> <u>treatment</u>.

Following advice

Your healthcare team may give you advice on what you can do to help your recovery.

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

If you are taking drugs to reduce the risk of the cancer coming back, it is very important to keep taking them. Talk to your healthcare team if you have any questions or concerns about ongoing treatment. They would rather know so they can best help and support you.

Always let your specialist nurse, cancer doctor or GP know about any side effects so they can help. They may be able to change the treatment to a different one. Your pharmacist can also offer help and support.



Focusing on your health

During and after cancer treatment, there are things you can do to improve your general health and well-being. Focusing on your well-being can help you feel involved in your care and recovery. As well as improving your physical health, it may also support your mental health.

There are many benefits to being physically active and eating healthily. It can reduce the risk of conditions such as heart disease and diabetes. It might reduce the risk of late effects from some types of cancer treatment – for example, heart and bone problems.

We have more information about how to keep your bones healthy during and after cancer treatment in our booklet <u>Bone health</u>.



Eat well

Having a healthy, balanced diet is one of the best things you can do for your general health. Eating well can help you feel like you are taking control of your health and well-being.

Eating well can help you:

- keep or rebuild your strength
- maintain a healthy weight
- have more energy
- increase your sense of well-being.

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

There is a lot of misleading information about cancer and diet. This is called misinformation. It is always good to check information with your healthcare team. They can help and support you.

You may have different needs relating to your cancer type, or from effects of cancer treatments. It is always best to check with your healthcare team. They can give you advice that is suitable for you. A general, well-balanced diet should include:

- 5 portions of fresh fruit and vegetables a day
- meals with high-fibre starchy food such as potatoes, bread, rice and pasta
- protein-rich foods, such as chicken, oily fish, eggs, nuts and pulses (such as beans and lentils)
- dairy (such as cheese and yoghurt) or dairy alternatives (such as soya) that contain calcium
- plenty of fluids (at least 6 to 8 glasses a day).

Try to use unsaturated spreads and oils, and use small amounts. Also, try to eat smaller amounts of:

- foods that are high in fat, salt and sugar
- red and processed meat (such as bacon, ham and sausages)
- pickled or smoked food.

If you are concerned about your weight, talk to your GP or practice nurse. They can advise you on the right weight for your height. This is called body mass index (BMI). They can also give you advice if you need to lose or gain weight.

We have more information in our booklets:

- Healthy eating and cancer
- The building-up diet
- Eating problems and cancer.

You can order our booklets and leaflets for free. Visit <u>be.macmillan.org.uk</u> or call us on <u>0808 808 00 00</u>.





"Gardening really does have so many benefits, both physically and mentally. ,,

Lara, diagnosed with breast cancer

Be physically active

When you are living with or after cancer, being physically active can help you feel better. Sometimes it can be hard to know when and where to start. You may worry that you are too tired or there are things you should not do. You can ask your healthcare team what might be suitable.

Whatever exercise you are able to do is better than not exercising at all. Exercise helps the brain produce chemicals that improve mood and reduce stress. These are called endorphins. Exercising can feel like you are doing something positive for your health and well-being.

Being physically active can:

- help you feel less tired and improve your sleep
- help with side effects of cancer treatment
- improve your mood and help support your mental health
- manage your weight
- improve your fitness, strength and balance
- improve your bone health and help your heart and lungs we have more information in our booklet <u>Bone health</u>
- reduce the risk of other health problems, such as high blood pressure and diabetes.

Getting active with others can help, such as taking regular walks with family, friends or a walking group. You could ask your healthcare team about joining a cancer rehabilitation programme so you can exercise with other people with similar experiences. Gardening or other outdoor activities can improve your mood too.

We have more information about physical activity and cancer in our booklet <u>Physical activity and cancer</u>.

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. Many people find they stay awake, often worrying about the same thing each night.

You can try to improve your sleep by doing things such as:

- going to bed and getting up at the same time every day
- relaxing for 1 hour before bed, by taking a bath or reading a book – try to avoid looking at your mobile phone, tablet or computer, and avoid watching television
- being physically active during the day, but not exercising for at least 4 hours before bed
- making sure your bedroom is dark and quiet
- avoiding alcohol, smoking and drinks that contain caffeine (such as tea and coffee) for 6 hours before bed.

If worry and anxiety are keeping you awake, talking to someone may help. <u>Writing down your worries</u> before going to bed can help clear your mind. Breathing and relaxation exercises may also help reduce anxiety and stress. If sleep problems are not improving, talk to your GP or pharmacist.

Sleepio is an app that you can access for free if you have cancer. It uses guided cognitive behavioural therapy (CBT) techniques to help improve your sleep. For more information, visit <u>sleepio.com</u>

We have more information about how cancer can affect sleep on our website. Visit <u>macmillan.org.uk/</u> trouble-sleeping



Stop smoking

If you smoke, stopping 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.

The <u>NHS</u> has more information about giving up smoking.

Follow sensible drinking guidelines

NHS guidelines recommend that people:

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

A unit of alcohol is a:

- half pint of ordinary-strength beer, lager or cider
- small glass (125ml) of wine
- 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.

Drinkaware has more information about alcohol and drinking guidelines. Visit <u>drinkaware.co.uk</u>

Avoid recreational drugs

Recreational drugs can affect your health and relationships. Tell your healthcare team if you use recreational drugs. Some recreational drugs can affect your prescribed medication. If you are worried about this, or you need help and support, talk to your doctor or nurse.

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 out for.

It is useful to know about the side effects of any ongoing treatment and any possible late effects of treatment. 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 the problem will go away. You can contact your cancer doctor or specialist nurse between appointments. They can often reassure you and explain what is causing the symptoms. 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 anxious or worry more. Talk to your cancer doctor, specialist nurse or GP if you are doing this or thinking about it a lot of the time.

It may help to talk to one of our cancer support specialists on the Macmillan Support Line.

Call the Macmillan Support Line free on <u>0808 808 00 00</u>, 7 days a week, 8am to 8pm.





Managing stress and anxiety

Stress and anxiety are normal reactions to difficult life events. But living with stress and anxiety can be hard. There are things you can do to help manage your stress.

You may want to try:

- talking to someone this may be your friend, partner, family member, doctor, nurse, or a professional counsellor or psychologist
- focusing on your breathing breathe in slowly and deeply through your nose and slowly out through your mouth
- practicing mindfulness paid apps such as <u>Headspace</u> and <u>Calm</u>, and free apps such as <u>Healthy Minds Program</u> can help
- closing your eyes and listening to your surroundings, or to music
- moving, especially outdoors even a short walk can help with anxiety
- carrying on with your hobbies and interests, if you can
- keeping a diary or journal this can help you recognise things that trigger your anxiety
- <u>complementary therapies</u> such as yoga, meditation, massage or reflexology.

We have more information in our booklet <u>Cancer and complementary</u> <u>therapies</u> and on our website at <u>macmillan.org.uk/complementary</u>-<u>therapies</u> Feeling stressed or anxious is normal if you are dealing with cancer. If you feel your anxiety is getting worse, speak to:

- your GP
- your specialist nurse
- a psychologist or counsellor.

They can help you find ways of coping with it. Some people with anxiety also have depression. Speaking to your healthcare team is the best way to get the help you need.

You may find it helpful to contact <u>Anxiety UK</u>. You may also find that it helps to join a <u>support group</u>.

We have more information about talking therapies on our website. Visit <u>macmillan.org.uk/talking-therapies</u>

Make time to relax

One way of coping with stress is making time to relax. Doing things you enjoy and being with family or friends can help distract you from 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.

There are <u>relaxation techniques</u> you can use to help you relax and cope with stress. These include meditation, yoga, regular physical activity and massages.
"A friend suggested I might like to help restore an old boat. It was a chance to get out and I could do as much or as little as I wanted. I have a feeling of achievement and it helped a lot with depression. "

Lizzy, diagnosed with oesophageal cancer

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, depression or other health problems.

The way we think and behave can have a powerful effect on how we feel. People who are anxious or depressed often have unhelpful patterns of thinking and behaviour. These can lead to the problem getting worse. CBT helps you change these negative patterns.

The therapist will help you:

- recognise the negative thoughts
- find ways to change them
- 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 for Behavioural and Cognitive Psychotherapies (BABCP) website – visit <u>babcp.com</u>

Mindfulness and meditation

Mindfulness is being aware of your thoughts and feelings in the present moment. 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. You can search for mindfulness apps online.

Mindfulness-based cognitive therapy (MBCT) uses the techniques of mindfulness with some cognitive behavioural therapy (CBT) to help you change how you think. MBCT was developed to support people in chronic pain and has been used in cancer support.

MBCT is usually taught as an 8-week course, either in groups or individually. Some centres in the UK offer MBCT classes from the NHS. You can also learn MBCT online at <u>bemindfulonline.com</u>

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. Mindfulness classes are available from:

- the <u>NHS</u> ask your doctor about what is available in your area or at your hospital
- Every Mind Matters you can find a free mind plan and tips to help deal with stress and anxiety at <u>nhs.uk/every-mind-matters</u>
- Mind courses are available throughout England and Wales
- Buddhist Centres courses are available in England, Scotland and Wales
- <u>Aware NI</u> the national depression charity for Northern Ireland runs courses in mindfulness
- a private practitioner search for a certified mindfulness teacher at <u>bemindfulonline.com</u>.

You can learn more by visiting <u>mentalhealth.org.uk/publications</u> and choosing 'How to look after your mental health using mindfulness'.

Some cancer support groups or organisations may offer relaxation, massage, aromatherapy or reflexology. You can ask your cancer doctor or specialist nurse whether 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 <u>nhs.uk</u>

You might find it helpful to visit <u>anxietyuk.org.uk</u> There are also many 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.

Complementary therapies

Complementary therapies are used with, or as well as, conventional medical treatments.

Conventional medical treatments are those used by doctors to treat cancer, such as chemotherapy. Complementary therapies do not claim that they can treat or cure cancer.

People might use complementary therapies to improve their physical or emotional health. Or they may use them to reduce cancer symptoms or the side effects of cancer treatments.

There are many types of complementary therapies, including:

- mind-body therapies, such as yoga, meditation and hypnotherapy
- massage and other touch therapies, such as reflexology
- acupuncture
- therapies using herbs and plants
- therapies using supplements or diet.

If you are thinking of using a complementary therapy, always check with your doctor. Some therapies have been scientifically tested to check how effective and safe they are, and whether they have side effects. But it is often difficult to know how effective a complementary therapy is.

We have more information about complementary therapies in our booklet <u>Cancer and complementary therapies</u>.

Some hospitals, hospices and support groups provide complementary therapies alongside cancer treatments, such as chemotherapy or radiotherapy.

Some Macmillan Information and Support Centres offer free complementary therapies to people with cancer. Find your nearest Information and Support Centre at <u>macmillan.org.uk/inyourarea</u>

We have more information about complementary therapies on our website. Visit <u>macmillan.org.uk/</u> <u>complementary-therapies</u>



Looking ahead

Your worries about the cancer coming back may never go away completely. At times, it may feel overwhelming. It is important to talk to someone if you feel like this. It is still possible to live a full life with the right <u>help and support</u>.

Going back to work or starting to do the things you did before are important steps forward. We have more information about work and cancer in our booklet <u>Work and cancer</u> and on our website at <u>macmillan</u>. <u>org.uk/work</u>

Having cancer can lead to positive life changes. Sometimes it can focus your mind on what is important to you. This can include spending more time with the people you care about or making time for the 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 or dancing. Or you may join a walking group. You do not have to be good at these activities to enjoy them. You can search for 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 moving forward.

" My parents raised me with the attitude to never give up, and that is certainly my attitude with cancer. I have good days and bad days, but I just need to take each day as it comes. "

Nick, diagnosed with bowel cancer

About our information

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

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

Order what you need

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

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

Online information

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

Other formats

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

- audiobooks
- Braille

- interactive PDFs
- large print
- British Sign Language
- translations.

easy read booklets

Find out more at macmillan.org.uk/otherformats

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

The language we use

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

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

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Call us on <u>0808 808 00 00</u>. We are open 7 days a week, 8am to 8pm. You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to <u>macmillan.org.uk/talktous</u>

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

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Help with energy costs

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

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing, to changes needed to your home.

Call us on 0808 808 00 00 to find out more about Macmillan Grants.

Help with work and cancer

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

Work support

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

Talk to others

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

Support groups

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

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 <u>macmillan.org.uk/community</u>

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

Macmillan healthcare professionals

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

Other useful organisations

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

Counselling

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

Tel 0330 320 0851

www.babcp.com

Promotes the practice, theory and development of cognitive behavioural therapy (CBT) in the UK and Ireland. You can search for therapists on the 'Find a therapist' page.

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300

www.bacp.co.uk

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

Relate

www.relate.org.uk

Offers a range of services to help with couple and family relationships. Available face to face, by phone and online.

Relate NI

www.relateni.org

Offers counselling services to support people and their relationships across Northern Ireland. Available face to face, by phone and online.

Relationships Scotland

Tel 0345 119 2020

www.relationships-scotland.org.uk

Provides relationship counselling, family mediation, child contact centres and many other forms of family support services across all of mainland and island Scotland.

UK Council for Psychotherapy (UKCP)

Tel 0207 014 9955

www.psychotherapy.org.uk

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

Emotional and mental health support

Anxiety UK

Infoline **0344 477 5774** Text **0753 741 6905** <u>www.anxietyuk.org.uk</u> Provides help, information and support for people with anxiety, stress and anxiety-based depression.

Aware NI

Tel 0289 035 7820 (Belfast) or 0287 126 0602 (Derry/Londonderry)

www.aware-ni.org

Has 23 support groups across Northern Ireland run by trained volunteers, for people with depression and bipolar disorder, and their carers.

Be Mindful

Tel 0127 332 5136

www.bemindfulonline.com

Delivers mindfulness-based cognitive therapy (MBCT) through a series of online modules.

Breathing Space

Tel 0800 838 587

www.breathingspace.scot

A free, confidential phone-based and web-based service for people in Scotland experiencing low mood, depression or anxiety.

Inspire

Tel 0289 032 8474

www.inspirewellbeing.org

A network of emotional, psychological and social well-being support services throughout Northern Ireland.

Lifeline

Tel **0808 808 8000** Textphone **18001 0808 808 8000** <u>www.lifelinehelpline.info</u> Crisis response service for people in distress or despair in Northern Ireland.

Mental Health Foundation

www.mentalhealth.org.uk/podcasts-and-videos

Provides free well-being podcasts through its website. These include relaxation and mindfulness exercises.

Mind

Helpline **0300 123 3393**

www.mind.org.uk

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

Rethink Mental Illness

Tel 0808 801 0525

www.rethink.org

Provides mental health advice and information by phone and through its website.

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.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org

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

Cancer Black Care

Tel 0208 961 4151

www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**

www.cancerfocusni.org

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

Cancer Research UK

Helpline 0808 800 4040

www.cancerresearchuk.org

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

Cancer Support Scotland

Tel 0800 652 4531

www.cancersupportscotland.org

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

Life after Cancer

www.life-aftercancer.co.uk

Runs support groups for people who have finished cancer treatment, to increase their physical, mental, emotional and social well-being.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

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

Maggie's

Tel 0300 123 1801

www.maggies.org

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

Penny Brohn UK

Helpline **0303 300 0118**

www.pennybrohn.org.uk

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

Riprap

www.riprap.org.uk

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

General health information

Drinkaware

www.drinkaware.co.uk

Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net

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

NHS.UK

www.nhs.uk

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

NHS 111 Wales

<u>111.wales.nhs.uk</u>

The NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** <u>www.nhsinform.scot</u> The NHS health information site for Scotland.

Patient UK

www.patient.info

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

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**

<u>lgbt.foundation</u>

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

OUTpatients (formerly Live Through This)

www.outpatients.org.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBTQI+ cancer experiences. Runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel 0300 772 9600

www.carers.org

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

Carers UK

Helpline **0808 808 7777**

www.carersuk.org

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

Your notes and questions

Disclaimer

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

Thanks

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

With thanks to: Dr Timothy Anstiss, Doctor and Trainer; Dr Alison Farmer, Clinical Nurse Specialist in Psycho-Oncology; Dr Kathrin Hicks, Clinical Psychologist; Matt Loveridge, Clinical Nurse Specialist; Dr Louise Robinson, Clinical Psychologist; Azmina Rose, Macmillan Cancer and Support Lead; and Dr Elizabeth Stamp, Lecturer in Health Psychology.

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

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

Sources

Below is a sample of the sources used in our information about cancer and emotions. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Maheu C, Singh M, Tock WL, Eyrenci A, Galica J, Hébert M, et al. Fear of cancer recurrence, health anxiety, worry, and uncertainty: a scoping review about their conceptualization and measurement within breast cancer survivorship research. Frontiers in Psychology. Published 12 April 2021. https://doi.org/10.3389/fpsyg.2021.644932 [accessed November 2022].

National Institute for Health and Care Excellence (NICE). Common mental health problems: identification and pathways to care. Clinical guideline [CG123]. Published 25 May 2011 www.nice.org.uk/guidance/cg123 [accessed November 2022].

National Institute for Health and Care Excellence (NICE). Depression in adults: treatment and management. NICE guideline [NG222]. Published 29 June 2022 www.nice.org.uk/guidance/ng222 [accessed November 2022].

Can you do something to help?

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

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

5 ways you can help someone with cancer

1. Share your cancer experience

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

2. Campaign for change

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

3. Help someone in your community

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

4. Raise money

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

5. Give money

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Fmail

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



Date

Do not 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 l aive.

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 would rather donate online go to macmillan.org.uk/donate



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

This booklet is for people who are worried about cancer coming back after treatment. We hope you find this booklet helpful in coping with some of the feelings you may have.

This booklet also gives information about where to get support and help.

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

For information, support or just someone to talk to, call <u>0808 808 00 00</u> or visit <u>macmillan.org.uk</u>

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, interactive PDFs, easy read, Braille, large print and translations.

To order these, visit <u>macmillan.org.uk/otherformats</u> or call our support line.



© Macmillan Cancer Support, November 2023. 4th edition. **MAC14215_E04_R**. Next planned review November 2026. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. Printed on sustainable material. Please recycle.