

A practical guide to living
with and after cancer

WORRYING ABOUT CANCER COMING BACK

**WE ARE
MACMILLAN.
CANCER SUPPORT**

This information is for anyone who has had treatment to cure cancer and is worried about it coming back. We make suggestions to help you manage your worries, uncertainties and fears about cancer coming back. We've also included information on where to get help if these feelings become difficult to cope with.

This leaflet talks about:

- **worry and uncertainty**
- **situations that may trigger worry**
- **talking and getting support**
- **getting involved in your own care**
- **follow-up visits and tests**
- **focusing on your well-being**
- **knowing if you need more help**
- **looking ahead.**

One of the biggest and most common worries people have after treatment is that the cancer might come back. It's normal to feel anxious about the future after treatment has finished.

But feeling worried, uncertain and even fearful a lot of the time may stop you fully enjoying or getting on with your life. Some people can become anxious or depressed and may need professional help. You may already have noticed situations that trigger these feelings and found helpful ways of coping with them.

Worry and uncertainty

You will probably feel relieved when you have finally completed treatment to get rid of the cancer. But you may find yourself worrying about whether it has worked and what might happen in the future. It's natural to feel like this.

For many people, treatment will cure the cancer and it will never come back. Some people may want to know if they need to wait a number of years to be confident the cancer is cured. Or they may ask if there is a time when the cancer is more likely to come back and what can be done if it does.

Even when your doctor is reassuring, it's normal to still worry. Most people who have been through cancer treatment live with some worry and uncertainty. This doesn't mean they are not coping with life after treatment.



Rather than worrying about things that may never happen, focus on what you can do now.

However, some people find it harder to cope with feelings of uncertainty. They may feel as if they have very little control over their lives. How uncertain or worried you are can depend on things such as your age, whether you have ongoing treatment side effects, and how you deal with life in general.

There are ways to help you manage worry and uncertainty. Realising that you will always have some of these feelings can be a good place to start. This may be hard and can take time, but there are people who can help you with this.

Focusing on what you can control right now is one way of managing your worries. It can help you to stop dwelling on future 'what ifs'. Rather than worrying about things that may never happen, concentrate on what you can influence and do now. This can include:

- talking about your feelings
- getting support
- becoming more involved in your own care
- following advice from your cancer team
- focusing on your well-being
- knowing when you need help with overwhelming feelings and where to get it.

When we talk about your cancer team we mean the main people that have been involved in your cancer care. This usually includes your cancer doctor (oncologist), surgeon, specialist nurse, or other health professionals such as your physiotherapist, pharmacist, or dietitian.

There are no right and wrong ways to cope.

Some of the suggestions we make may not fit in with your way of coping. There are no right and wrong ways to cope. You can adapt the suggestions in the ways that you find most helpful.

Situations that may trigger worry

You'll probably find there are certain situations that trigger your feelings of worry and uncertainty. These can differ from person to person. Sometimes worry might feel more like a vague sense of dread. Recognising situations when you feel like this can help.

For example, you may worry that the doctor will give you some bad news when you're due for a follow-up visit or test. Or it may bring back memories of being diagnosed or of having treatment.

Another example could be hearing of a person you know whose cancer has come back or who has died. This could be someone you went through treatment with or perhaps a celebrity with the same type of cancer as you.

Any of these situations may trigger worries about your cancer coming back. But no two cancers are alike, even if they are the same type. So comparing yourself with others is not usually helpful.

Another situation that can trigger worry is having a new pain or symptom. You will still get everyday aches and pains after cancer treatment. A new symptom could be nothing to do with the cancer. Or it could be a late side effect of treatment or a side effect of a drug you're taking.

It's important to get any new pain or symptom checked by a member of your cancer team if it continues. If you do nothing, you are likely to carry on feeling anxious.

Worrying that the cancer may come back is a natural reaction. However, some people get caught up in a cycle of worry. For example, a person with an ache or pain that's already been checked may still worry the cancer has come back. They may keep checking themselves for new symptoms. This can make them feel very anxious in the long run.

Worrying about the cancer coming back is natural. But worrying about a situation all the time can be unhelpful.

Talking and getting support

Some people feel that they need to look as if they are coping well. They feel they must put on a brave face or protect other people's feelings. But people close to you usually want to know how you really feel so that they can support you. Sometimes they may find it hard to talk to you about their own feelings if you do not talk to them about yours. It can be lonely for everyone involved if you are all protecting each other.

Talk to someone you trust and feel comfortable with. If you find it hard to talk to people close to you, tell your cancer team or GP. They can refer you to a psychologist or counsellor.

Talking about your worries or uncertainties helps you to:

- get them out in the open and stop you from going over things repeatedly
- understand your feelings and put them into perspective
- work out if you need to act on them, for example by contacting your cancer team to stop worries from growing bigger in your mind
- feel closer to the people you talk to.

**Talk to
someone
you trust
and feel
comfortable
with.**



Join a support group or online community

You may find it useful to talk to someone in a similar situation. Sometimes just realising that other people have similar thoughts and feelings can help you feel more able to cope.

You can get involved in a support group and attend their meetings. Some organisations or support groups offer buddy systems. Some offer counselling or complementary therapies.

You can also ask questions and get support from others through the internet. You can visit Macmillan's community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community) to talk about your experiences with other people.

Remember that other people's experiences may not be relevant to your situation. If you find sharing your own experience or reading other people's makes you more anxious, it's probably better to get support in another way.

Write it down

Writing about what is happening to you can help you express your deepest feelings privately. You might find that it helps give you a sense of control. Sometimes keeping a diary or journal can help you work through various problems.

Reading it back can help you become more aware of your thoughts and feelings. It can also help you identify what the real issues are for you, what triggers them and what has helped you to cope.

Try to include the good or positive things that have been helpful as well as the things you find difficult.

Getting involved in your own care

It can help to know more about the cancer and its treatment. Getting involved in your health care helps you focus on the things you can control. You'll know what to look out for and what to do if problems come up.

It can help to know about:

- what your follow-up plan is – for example, how often your appointments are
- any tests you need and when you will have them
- symptoms to look out for and who to contact – your cancer team or GP
- any common late effects of the treatment you had
- what you can do to improve your well-being and recovery.

Some people prefer not to be this involved. Everyone has their own ways of coping and it's okay to do what's best for you. The main things are to keep your appointments and to let your doctor or nurse know about new or ongoing symptoms.

Follow-up visits and tests

You may find going back to the hospital for follow-up visits or tests difficult. It's normal to want to avoid situations that make you feel anxious or bring back difficult feelings. But many people feel reassured after follow-up visits.

If cancer comes back, finding it early can make it easier to treat.

Going for your visits and tests is an important part of looking after yourself. Your doctors can check whether there are any signs that the cancer has come back (recurrence) or has spread. Your cancer team also need to know if you have any side effects or symptoms, and how you're coping emotionally.

If cancer comes back, finding it early can make it easier to treat and treatment may work better. In some cancers, treatment may cure a recurrence.

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

- have someone with you and let them know how you're feeling
- have something to distract you while you're waiting, such as music or a book
- write a list beforehand of what you want to talk about with your cancer team
- plan something enjoyable to do afterwards.

Having fewer hospital visits may make some people less anxious and help them move on after treatment. Instead of routine appointments, some people are asked to contact their nurse specialist or cancer doctor if they have any symptoms (see below) or concerns. If necessary, they will be seen urgently. This is sometimes called supported self-management or patient-triggered follow-up. It means you are more in control of your care.

Before your treatment finishes, your nurse will explain what will happen after treatment ends. They may tell you about symptoms to look out for, and what you can do to help your recovery. You will still have any regular tests or scans that you need.

Getting the most from your visit

When you feel anxious, it can be difficult to take in what your doctor or nurse is saying. As well as having your list of questions, you can write notes on what happened and what was said during your visit. If someone goes with you, they can help you by going over what was said later. You can also ask your doctor if you can record your conversation so you can listen to it afterwards.

If you're unsure of 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 about your health and don't play anything down. Try to be open with them about how you have been feeling emotionally. This way they are in a better position to support you.

**Follow
the advice
from your
medical staff**

Your cancer team may give you advice on what you can do and what to look out for after your treatment finishes. You may have ongoing side effects that you need to manage. Or your nurse may have shown you how to do some simple checks and explained how to recognise anything that is not now normal for you.

This might seem like too much to deal with after going through your treatment and you might just want to have a break from it all. But it's important to follow the advice from your cancer team and make it part of your routine. Getting to know what is normal for you now can help you feel more in control.

If your doctor has prescribed drugs – for example, hormonal therapy – to help reduce the risk of the cancer coming back, it's very important to keep taking them. Not taking your treatment can increase the risk of the cancer coming back.

If you have troublesome side effects always let your cancer nurse or doctor know. They can often help with these or if necessary change you to a different drug.

Symptoms or signs to look out for

After treatment, it's common to worry that every ache and pain is linked to the cancer. You'll also still be getting used to what now feels normal. This makes it harder to know what to pay attention to and what to ignore.

Always let your doctor or nurse know if you have:

- any new or unusual symptoms that don't go away
- symptoms or side effects that don't improve over time
- symptoms similar to ones you had when you were first diagnosed
- general symptoms, for example losing weight, going off your food or feeling more tired than usual, for no obvious reasons.

You can get in touch with your cancer doctor or nurse in between visits.

Remember that you can get in touch with your cancer doctor or nurse in between appointments. They can reassure you or explain if your symptoms are likely to be linked to your treatment. They can also do some tests if needed.

You may not always be able to speak to your cancer team when you need to. It may help to contact the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

You may feel you don't want to be a nuisance by mentioning symptoms you think seem minor. But by not mentioning them you'll continue to worry, so it's always better to get them checked. Knowing the side effects of any ongoing treatment and any possible late treatment effects can help.

There may be certain symptoms linked with your type of cancer coming back. You can ask your doctor or nurse about these. This may help you to know what to look out for and stop you worrying unnecessarily.

Checking yourself for symptoms can be a good way of noticing a cancer that comes back. However, for some people, checking themselves can become their main focus and take up most of their time. This is unhelpful and can cause them to worry more and feel very anxious. Focusing on other aspects of well-being may be more helpful – see pages 16–22.

Make sense of statistics

Statistics about cancer can be difficult to understand.

Your cancer doctor is the best person to talk to if you want to know more about the chances of the cancer coming back. Doctors may know from trials how many people benefit from a treatment but they can't predict exactly what will happen to you. They may be able to give you some general guidance based on the stage of the cancer, how it tends to behave and the treatments you've had.

Some people try to find this information for themselves. Cancer survival statistics are based on large numbers of people. They help doctors decide which treatments are the most effective overall. But everyone is different so statistics can't be used to predict what will happen to an individual. There may also be factors that make your situation different from the usual.

Ask your doctor if any statistics you've seen seem unclear. It may be best to ask them in the first place so they can give you statistics based on your situation.

Get reliable information

There is a lot of information available on the internet and in print. It is important to make sure any information you read is from a reliable source. A lot of information now has the Information Standard logo on it. This means that the information is based on evidence and is produced according to strict quality control guidelines. You can see the Information Standard logo on the back cover of this leaflet.

If you're not sure whether something you've read is reliable, check with your doctor or nurse or contact the Macmillan Support Line free on **0808 808 00 00**.

Make sure any cancer information you read is from a reliable source.

Focusing on your well-being

Many people want to make positive life changes after cancer treatment. You should make sure that any changes you make to improve your health and well-being are achievable. These changes can help you to feel better, speed up your recovery from treatment and improve your health.

Nowadays many people can be cured of cancer or are living longer with it. So it's important to look after your long-term health. This includes stopping smoking, being physically active, keeping to a healthy weight, eating healthily and sticking to sensible drinking limits.

Looking after your health helps reduce the risk of conditions like heart disease and diabetes. It can also reduce the risk of getting a new cancer. Some cancer treatments can slightly increase the risk of problems, such as heart disease or bone problems, later in life. So it is important to do what you can to take care of yourself.

Give up smoking

If you're a smoker, giving up is the healthiest decision you can make. Stopping smoking reduces your risk of heart and lung disease, bone thinning (osteoporosis) and smoking-related cancers. You'll also feel better, look better and save money.

Our booklet *Giving up smoking* can give you some helpful tips. We can send you a copy. Your GP, local pharmacist or hospital can also help you to stop smoking – ask them about support and services in your area.

**Be
physically
active**

Short walks, gardening, or taking the children to the park all count towards being active. You can start gently and build up the amount of physical activity you do. Whatever your age or level of fitness, there is some kind of activity you can try. It's good for your emotional and physical health. It also gives you more energy, reduces stress, helps you to feel better and you can do it with other people – family, friends or in a class with a group.

Our booklet *Physical activity and cancer treatment* has more information about this.

**Keep to
a healthy
weight**

If you're concerned about your weight, talk to your GP or practice nurse. They'll be able to tell you the right weight for you and give you advice if you need to lose weight. They can also help if you are having difficulty eating or maintaining your weight. Being active and eating healthily (see over) will help you keep to a healthy weight.

Our booklets *Weight management after cancer treatment*, *Eating problems and cancer* and *The building-up diet* have helpful tips.

Eat healthily

This will help you to feel better and give you more energy. It's a good choice you can make for your overall health.

A well-balanced diet should include:

- five portions of fresh fruit and vegetables a day
- foods high in fibre, such as beans and cereals
- more chicken and fish (especially oily fish).

Try to eat less:

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

Stick to sensible drinking guidelines. The UK government recommend women don't drink over 14 units of alcohol a week and men don't drink over 21 units a week. A unit is half a pint of ordinary strength beer, lager or cider, one small glass (125ml) of wine or a single measure (25ml) of spirits.

We have a booklet called *Healthy eating and cancer*, which has more information about this.

Reduce stress and practice relaxation

Living with the stress of cancer in your life can be very tough. It may take some time to adjust to. Although we can't always avoid stressful situations, we can choose how we respond to them. Research studies suggest that we can learn better ways of managing stressful situations, including worries about cancer.

Making time to relax can help you cope with stress.

One way of coping with stress is to make time to relax. Relaxing can be as simple as having a meal with friends or family, going for a walk, enjoying a bath, listening to music or watching a film. These can all help you to reduce your overall anxiety levels. Doing things you look forward to and being with people you're close to, can distract you from your worries. This can help you to enjoy the present and look forward in a more positive way.

It can help to learn new ways of relaxing and coping with stress. These might include meditation, yoga or having a massage.

Some people like to learn specific relaxation techniques. Maggie's Centres offer courses for these. See page 25 for details.

Some complementary therapists can offer relaxation as part of the treatment. Hospitals or cancer support groups sometimes offer relaxation, massage, aromatherapy or reflexology. You can try some out and find what suits you.

Mindfulness is an approach that can help you change the way you think about different experiences and so reduce stress and anxiety. It helps you to pay attention to the present moment using techniques like meditation, breathing and yoga. You are encouraged to become aware of your thoughts and feelings, without making judgements about them.

A specific technique is called Mindfulness-Based Cognitive Therapy (MBCT). It uses the meditation, yoga and breathing techniques of mindfulness along with some Cognitive Behavioural Therapy techniques to help you change thought patterns. Cognitive (thinking) therapy focuses on the 'here and now' difficulties and looks for ways to change your current state of mind so that your thoughts are more positive.

There are a few centres in the UK that offer classes on MBCT on the NHS. Other techniques to help address worries about cancer coming back are currently being researched.

Our booklet on complementary therapies has more information about relaxation and other ways to cope with stress.



Find a creative outlet

Taking up a new hobby can help to distract you and help you relax. Some hobbies can help you express your feelings – for example, learning to play a musical instrument or painting. Other activities may include gardening, dancing, knitting, joining a choir, photography or drawing. You don't have to be specially trained in these activities or be creative to benefit from them. Explore different ideas and see if there are any groups or classes in your area. Find something that you feel comfortable with and that you enjoy.

Help others and volunteer

If you feel up to it, there are lots of opportunities to volunteer and help out. If you prefer to do something that isn't cancer-related, find something that matters to you or makes you feel part of your community. Having a new commitment with goals for the future can help you to shift your focus away from any worries you have.

Knowing if you need more help

The worry of cancer coming back can sometimes be overwhelming. Some people find they repeatedly have the same worries and thoughts that their cancer will come back. This can make them feel constantly anxious or even depressed.

Feeling anxious all the time can be very hard. You may start to avoid social situations and this can lead to you feeling isolated. You may also have feelings of sadness and a low mood. If these feelings do not improve or get worse, it may mean that you are depressed.

Sometimes, it's difficult to know if you're depressed. It can also be hard to admit that you're depressed and to talk about it. Other people may notice and suggest that you might need help.

If you or someone close to you thinks you may need help with anxiety or depression, speak to your GP, specialist doctor or nurse at the hospital. They will listen and offer advice or refer you to a counsellor or psychologist. Your doctor may prescribe medication to help. This may only be needed for a short time.

There is more information about depression and anxiety in our booklet *How are you feeling? The emotional effects of cancer*. There are also organisations that can help you (see page 25).

Looking ahead

Having a sense of purpose in your life can help you shift your focus away from worrying and onto a positive outlook about life. Everyone does this differently. Some people like getting involved in a new activity. Others focus more on their everyday life such as family and friends.

The worry that your cancer may come back is something that may never go away completely. But while it may be tough at times, it is possible to live life to the full with the right help and support.

You might find it useful to read our booklet called *Life after cancer treatment*. It has more information about the emotional and practical issues you may face after cancer treatment.

Further information

We have more information about cancer types, tests, treatments and living with and after cancer. We also have details of other helpful organisations and support groups in your area. You can contact us using the following details:

Get in touch

Macmillan Cancer Support

89 Albert Embankment, London SE1 7UQ

General enquiries 020 7840 7840

Questions about cancer? Call free on **0808 808 00 00** (Mon–Fri, 9am–8pm)

Alternatively, visit **macmillan.org.uk**

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

Non-English speaker?

Interpreters available.

www.macmillan.org.uk

**Who
you can
contact
for help**

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

BACP House, 15 St John's Business Park,
Lutterworth LE17 4HB

Tel 01455 883 300

Email enquiries@bacp.co.uk

www.bacp.co.uk

Aims to promote awareness and availability of counselling and to signpost people to appropriate services. Has a database on the website where you can search for a qualified counsellor.

Maggie's Centres

1st Floor, One Waterloo Street,
Glasgow G2 6AY

Tel 0300 123 1801

Email enquiries@maggiescentres.org

www.maggiescentres.org

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

Disclaimer

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Thanks

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Sources

We've listed a sample of the sources used in this publication below. If you'd like further information, please contact us at bookletfeedback@macmillan.org.uk

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Can you do something to help?

We hope this leaflet 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

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I enclose a cheque / postal order /
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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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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



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

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

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

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

Together, we are all Macmillan Cancer Support.

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

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

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