# Life after cancer treatment





# **About this booklet**

This booklet is about coping after cancer treatment ends. including managing side effects, follow-up care and making healthy lifestyle changes. It is for people who are preparing for life after cancer treatment

We hope it helps you deal with some of the questions or feelings you may have.

### 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 contents <u>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 end of the booklet there are details of other organisations that can help. If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

### **Quotes**

In this booklet, we have included quotes from people who have finished cancer treatment. These are from people who have chosen to share their story with us. This includes Lara, who is on the cover of this booklet.

To share your experience, visit 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 <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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK 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 <a href="macmillan.org.uk/otherformats">macmillan.org.uk/otherformats</a> or call 0808 808 00 00

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# Finishing treatment

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# Preparing for the end of treatment

For some people, the end of treatment means they are not likely to need any more cancer treatment. For others, treatment is about managing the cancer over a long period of time.

When your treatment ends, you may feel relieved. But you may still have side effects from treatment and other emotions to cope with. You will need time to find out what is now normal for you. It can take time to adjust. You may also be thinking about positive changes you want to make. These might include focusing on your well-being or planning some things to look forward to.

Towards the end of your treatment, you usually have a discussion with someone from your cancer team. This may be with your cancer doctor, specialist nurse or another member of your healthcare team. They will tell you what to expect after treatment ends. They will also ask about any concerns or specific needs you have.

Holistic Needs Assessments, personalised care plans and <a href="mailto:end-of-treatment summaries">end-of-treatment summaries</a> are not standard practice in all hospitals. But more hospitals are doing them. They may happen in the ways we describe, or more informally. You will always have the chance to talk to someone from your cancer team before your treatment ends.

## **Holistic Needs Assessment (HNA)**

In some hospitals, the discussion with your cancer team is called a Holistic Needs Assessment (HNA). You may have already had an HNA when you were first diagnosed.

During an HNA, you answer some simple questions about all areas of your life. This helps you to identify any concerns you would like to talk about. You can then discuss these with a member of your cancer team. Together you can talk about possible solutions and make a personalised care plan. This makes sure your care is planned based on what is most important to you.

We have more information about HNAs in our booklet Holistic Needs Assessment: Planning your care and support.

#### Personalised care and support plan

Your cancer team may write a care plan for you, based on any concerns you have discussed. It explains how you will be supported now and in the future. It also lists services you may want to use. Your cancer team should give you a copy so you can share it with other healthcare professionals.

Your needs and concerns may change over time. You can have another HNA and make a new care plan at any time.

### **Treatment summary**

At the end of your treatment, your cancer team may create a treatment summary. This may be after a certain phase of treatment, or after you finish all your treatment.

It will describe the treatment you have had and helps you understand what to expect next. Knowing what happens next can help you adjust.

Your treatment summary will include information about:

- the cancer and treatment you have had
- possible side effects of treatment
- · any symptoms to be aware of
- details of follow-up appointments and tests you may need
- contact details for your cancer team.

Your cancer team will give you a copy of your treatment summary. They will also send one to your GP. If you are not given a copy and would like one, talk to your cancer team.

## **Knowing who to contact**

Your cancer team will give you details of who to contact after your treatment ends. This may be a specialist nurse or another member of the cancer team. They may also be called your key worker. Or it may be a member of another healthcare team, depending on your situation. Keep their contact details in your phone or somewhere safe.

You could also tell your GP that you are approaching the end of treatment. You can talk to them about any concerns you may have.

### What to ask your specialist nurse

Knowing what to expect can help you adjust to life after treatment. For example, you may want to know:

- how to contact your healthcare team
- how often will you have follow-up appointments (check-ups) and for how long
- how often you might need blood tests, scans or other tests, and who will arrange them.

You may also want information about:

- how to manage any side effects or symptoms you have
- side effects of your treatment that may happen months or years after treatment ends - these are called late effects
- symptoms to be aware of that may be signs of cancer
- what you can do to <u>stay healthy and well</u>
- health and well-being clinics, events or support for people with cancer in your area
- if there is anything you can do to help reduce the risk of cancer coming back.

# **Beginning to recover**

As you begin to recover, you might have many different emotions and practical challenges to cope with.

## How you may feel after finishing cancer treatment

You may feel ready to get on with life after cancer treatment. But it is also common to have mixed feelings. You may have days when you feel anxious or uncertain about the future. Or you may feel less positive about your health. You may feel tired from dealing with your emotions.

Many people find it hard at first not meeting with their cancer team as often. It is important to remember that although you might not meet them as often, you can contact them if you need to. You can also talk to your GP about anything that is worrying you, or if you need more support. You could also visit a local cancer well-being and information centre.

The time after treatment is a period of change. You are finding out what is now normal for you. Some people call this their 'new normal'. You need time to find out and adjust to what this means for you.

You may be thinking about getting back to the things you did before treatment. For example, this could include:

- going back to work or education
- doing hobbies or exercise again
- spending more time with family or friends.

Try not to expect too much of yourself too soon. Recovery is a gradual process and can have ups and downs. Some days you may feel better than others. You will need time to recover your physical strength. You will also have to process what you have been through. Sometimes emotional recovery can take longer than physical recovery. But things should improve with time and the right support.

### Changes to how you view your life

Your cancer experience may change your outlook on life. You may find you think about things differently now. You might think about what is important to you and change your priorities. You may discover new interests or make certain lifestyle changes. This could be to improve your well-being or to find ways of reducing stress.

## **Self-management**

<u>Self-management</u> means taking an active role in your own care. This may help you feel more in control of what is happening to you. You may already be doing some of the things we mention here, and you may feel you are as involved as you want to be.

When self-managing, you work with your cancer team to improve your health and well-being. This means learning more about your condition and how it affects your life. It is important to know when you need support or information, and who or where to get it from. You need to be able to plan ahead and set goals for the future.

Your specialist nurse or key worker can give you lots of information. They can help you find the best people to talk to when you need support or advice. Your healthcare team can help you with self-management. They may know about training courses that can help you manage your health. These are usually free.

Help to Overcome Problems Effectively (HOPE) is a course to help people after cancer treatment. It was developed by Hope for the Community and Macmillan Cancer Support. It is a 6-week selfmanagement course that is run online.

You can learn more and book onto a course on our website. Visit macmillan.org.uk/hope-programme

Your local Macmillan Information and Support Centre can tell you if there are any local courses. Visit macmillan.org.uk/in-your-area to find the nearest Information and Support Centre or call 0808 808 00 00.

## **Setting goals**

How long it takes to get back to doing everyday things usually depends on:

- the type of cancer
- your treatment
- your general health.

Try not to rush things. Think about your recovery as a set of small, achievable goals that you can work towards. For example, this could be doing some gentle exercise like going for a walk when you feel able. Or it could be trying to eat healthily most days.

You can be flexible with yourself. To start, you may want to think about setting short-term goals. Once you are ready, you can think about some longer-term goals you would like to achieve.

Setting goals and working towards them can have different benefits. They help you focus on what you can do and may help you feel more in control.

As you achieve a goal, your confidence will grow. You might also want to reward yourself for your hard work. Try not to be upset if you miss some of your goals. What is important is that you are trying. The HOPE course has support for people setting goals after cancer treatment. For more information, visit <a href="mailto:macmillan.org.uk/hope-programme">macmillan.org.uk/hope-programme</a>

You may need to push yourself to do things you feel less confident about. Start with simple things like meeting up with family or friends. Over time, you will get back into the routine of everyday life.

Other things will start taking over and cancer will become less of a focus for you. As time passes, you may:

- · go out more
- see friends
- go on holiday
- · start doing hobbies again
- go back to work.

# Life is my journey and now I take my time.

Gina, diagnosed with breast cancer



# Your care after treatment

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# Follow-up care

After your main treatment ends, your cancer team will usually arrange for you to have check-ups or any scans you may need. This is called follow-up care. How often you have these appointments depends on different things, including:

- the type and stage of the cancer
- the treatment you have had
- your needs and wishes
- the arrangements at the hospital you go to.

Good cancer care must prepare patients through treatment and for life after cancer, so people feel they have all the tools they need to carry on after treatment has ended.

Elohor, clinical nurse specialist, skin cancer

## Your follow-up appointment

The aim of this appointment is to make sure everything is going well for you. It is a chance for you to talk about any concerns you have. The appointment helps your cancer team notice any possible problems early.

They may examine you and do some simple tests, such as taking a blood sample. They will usually ask questions about your recovery and any side effects or symptoms you have. They can give you advice and support on how to manage these.

It is important to attend your appointments. These may be in-person, phone or video appointments. If you cannot attend because you are not feeling well, tell the clinic. They can arrange another appointment for you.

You may feel worried before an appointment. But your cancer team will support you. For some people, going back to hospital for face-to-face appointments can be difficult. But for others, it can be a positive reminder that they are returning to everyday life. You may feel reassured after your visit.

Your cancer team can refer you to other services if you need specialist help. For example, they may refer you to a psychologist or counsellor for emotional support, or a physiotherapist for advice about exercising.

## Ways of having follow-up care

There are different ways of having your follow-up care.

# Appointment with your cancer doctor or specialist nurse

You may have regular face to face appointments at the hospital.

Or you may have virtual appointments over video call or phone call.

The appointment will usually be with someone from your cancer team. Your cancer team will discuss your follow-up care with you. You can decide together what is best for you. Sometimes you may have some of your follow-up with your GP.

In the first year after your treatment, the appointments may happen every few months. As time goes on, the appointments will happen less often. You may be asked to have a blood test or scan before an appointment. This helps make sure your results are available for the appointment. If you are not sure whether this is needed, ask your cancer team.

#### **Shared care**

Shared care is when your follow-up care is shared between your cancer doctors or specialist nurses and your local hospital or GP. For example, you may have tests and scans at your local hospital. Some GPs have an agreement with the hospital to share your follow-up care.

### Self-management

Some people have supported self-management follow-up instead. This is when you are supported by your nurse and cancer team to manage your health.

You may have regular phone appointments with your specialist nurse or someone else from the cancer team. Or you may be asked to contact the cancer team if you are worried about anything or if you need support.

If they think anything needs to be checked, they will arrange this. If you need regular tests and scans, they will be arranged for you. You will also have direct access to your cancer team if you need it. They will give you information on:

- side effects
- symptoms to look out for
- what you can do to keep healthy
- where to get support.

Self-management allows you to be more in control of your care. But you can always contact your cancer team, GP or other healthcare professionals for help if you need it.

## Tips for getting the most from your follow-up appointment

- Write down any questions before your appointment. You can also write down the answers to help you remember them.
- Take someone with you. They can support you and help you remember what was said.
- You can ask for copies of any letters so that you can keep track, or ask for a treatment summary.
- Always tell your cancer team about any ongoing or new symptoms, or other health worries.
- Tell them how you are coping with your feelings. They can give you advice or direct you to the right place for support.
- Tell them if you are taking any prescribed or non-prescribed medicines. This includes vitamins, minerals, or herbal or complementary medicines. These can affect other drugs, including some cancer treatments.
- Be honest with your cancer team. This helps them to give you the best support.

#### What you can do

Your cancer team can give you advice on what you can do after treatment ends. For example, they may:

- explain how any treatment side effects or symptoms can be managed
- suggest exercises to improve your movement
- tell you what symptoms to be aware of.

If you are taking any ongoing cancer drugs, such as hormonal therapy, it is important to take them exactly as your cancer team explains. Do not stop taking them without getting advice from your cancer doctor.

Knowing more about your condition and recovery will help you get the most benefit from your treatment. Follow the advice from your cancer team and make it a part of your usual routine.

### Your GP and primary care team

Your GP and other members of the primary care team can support you during and after treatment. The primary care team may include your GP, practice nurse, and other health and social care professionals who work in the community.

If you have not met with them during treatment, it is a good idea to make an appointment when it finishes. Your cancer team will send them a report about your treatment - this is called a treatment summary. You should always tell your GP about any problems you need help with.

Some GPs have an agreement with the hospital to share your follow-up care. They may also prescribe some of the drugs you need. They may be part of your shared follow-up care.

Your GP is responsible for your general health. They can also give you emotional support and advice on:

- recovering
- · maintaining a healthy lifestyle
- work.

Your GP practice may also be able to support people close to you.

It is important to care for your general health. Remember to keep going to any regular check-ups at your GP practice - for example, blood pressure checks or blood tests. It is also important to take part in NHS screening.

#### Cancer care review

You may have an appointment with your GP or someone else from the primary care team after you have been diagnosed with cancer. This is sometimes called a cancer care review.

A cancer care review is usually done within 12 months of being diagnosed. The review may happen a few months after being diagnosed. or sometimes after your treatment has finished. But you can ask for a cancer care review at any point.

Your primary care team may get in touch with you first, by phone or by sending you a letter. Or you can contact them. The cancer care review can be done face to face, over the phone or through a video call (virtually).

Your primary care team will check whether you have any concerns or need any more information or support. They will talk to you about the cancer and the treatment. You may have a Holistic Needs Assessment (HNA). This is a discussion and assessment with someone from your healthcare team.

We have more information about HNAs in our booklet Holistic Needs Assessment: Planning your care and support.

This helps to make sure you are getting the right support for the things that are most important to you.

Your cancer care review is a chance to talk about:

- · how you are feeling
- any new worries or concerns that you have
- any changes in your concerns
- what can help you manage and cope with these concerns
- what support is available in your area.

If you have a personalised care plan or treatment summary, take it with you. If you have completed your treatment, your GP may already have a treatment summary from your cancer team.

Your primary care team can help you understand which symptoms to look out for. They can also advise when you might need to contact your cancer team.



# **Knowing about** symptoms

When treatment has finished, it is common to worry that every symptom you have is linked to cancer. You will still be getting used to what is now normal for you. You will also get the same aches and pains as most other people. This can make it hard to know what you need to pay attention to.

Ask your cancer team about:

- any symptoms you should be aware of
- possible late effects of treatment and their symptoms.

Knowing more can help you manage any worries you may have. Tell your cancer team if you have any new symptoms, or symptoms like those you had when you were diagnosed.

If there is anything you are not sure about, you can also visit your GP. Your GP can check your symptoms and refer you for advice if needed. You do not have to wait until your follow-up appointment to contact your cancer team. Make sure you have their contact numbers so you can get in touch with them if you need to.

If your symptoms are most likely to be from your treatment, your cancer team can reassure you. They can also arrange to meet you if needed. If you have been fully discharged by your cancer team, you can contact your GP about any concerns.

It is important to be aware of changes in your body. But constantly checking for symptoms or changes can make you feel anxious.

You may do this if you are finding it hard to cope with uncertainty about the cancer coming back. If you find yourself doing this, talk to someone from your cancer team or your primary care team. They can get you the support you need.

### Worrying about cancer coming back

Worrying about the cancer coming back is common after treatment. Many people struggle to cope with feelings of uncertainty. It can be hard to deal with these feelings. But they often get better with time.

Certain things may trigger these feelings – for example, going back to the hospital for a test or hearing something about cancer in the news.

You can manage worry and uncertainty in different ways. Try not to worry about things that may never happen. Instead, you might find that focusing on what you can control and do now can help. This could include:

- getting involved in your recovery and focusing on your well-being
- talking about your feelings and getting support
- finding ways of managing anxiety and stress
- knowing what your triggers are
- doing activities you enjoyed before treatment, or starting new ones
- going back to work.

If you are feeling worried or finding it difficult to cope, talk to your cancer team, GP or practice nurse. They can give you advice on ways to manage anxiety. They can also refer you to any extra support you may need. Some charities also run programmes on helping people with fear of recurrence.

We have more information in our booklet <u>Worrying about cancer coming back</u>.



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# Side effects of treatment

Although your treatment has finished, you may still be coping with some side effects.

Side effects usually go away after treatment ends. But some take weeks or months to improve. Sometimes, certain side effects may become permanent. Others may also develop months or years after treatment. These are called late effects of treatment.

Some people may have ongoing treatment, such as hormonal therapy or other types of anti-cancer drugs. In this situation, you may still be dealing with some ongoing side effects.

Always tell your GP, cancer doctor or nurse about side effects or any symptoms you have. There is usually something they can do to improve them. They can talk to you about ways to manage your side effects.

"Your own well-being is crucial to getting through your cancer journey. You have to take care of your health, so your body can recover. "

Alan, diagnosed with bowel cancer

### **Tiredness**

It is normal to feel very tired when treatment finishes. This can last for a few weeks or months after treatment. Sometimes, it can last longer. You may find it hard to do everyday things and have trouble concentrating. For most people, this gets better over time.

To help manage tiredness (fatigue), you could:

- spread chores over the week and do not be afraid to ask for help
- plan your day pace yourself so you have time to do the things you want
- try to keep to a regular sleep routine
- try to eat a balanced diet this will give you more energy
- do some gentle exercise this can help reduce tiredness.

If it does not improve, you can ask your cancer team or GP for a blood test. This will check for other possible causes of your tiredness. For example, it may be caused by having low levels of red blood cells (anaemia).

Your cancer team can also advise you on what help is available. For example, they may recommend a physiotherapist or occupational therapist who can give you advice. Your cancer team can also tell you about any rehabilitation services at your hospital or in your community.

We have more information in our booklets Coping with fatigue (tiredness), Physical activity and cancer and Healthy eating and cancer.

### Increased risk of infection

Some people may have a higher risk of infection because of the treatment they have had. This is usually temporary. Your white blood cells and immune system help your body fight infection. Some cancer treatments can weaken these. This is more likely if you:

- have had a stem cell transplant
- are having ongoing treatment (maintenance) with a cancer drug that increases your risk of infection
- have had your spleen removed in this case, the risk of infection is permanent and you will have to take antibiotics for the rest of your life.

Your cancer team will tell you what to do to reduce your risk of infection. This will depend on your treatment. Always follow their advice. This may include avoiding crowds, staying away from anyone who has an infection and being careful about eating certain foods.

Keep the hospital contact numbers with you. Call them straight away if you:

- develop a high temperature over 37.5°C (99.5°F)
- suddenly feel unwell, even with a normal temperature
- have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery or shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) often or discomfort when you pee.

If you need to talk to a healthcare professional who is not part of your usual cancer support team, explain that you have recently had, or are still having, cancer treatment. They might not know that you may be at an increased risk of infection or other side effects.

We have more information online at macmillan.org.uk/infection

The effects that the cancer had on me and my family were (and still are) far-reaching.

Paula, diagnosed with breast cancer

#### Cognitive changes (chemo brain)

After cancer treatment, you may find you have:

- changes in memory
- difficulties with concentration
- problems thinking clearly.

Doctors call these cancer-related cognitive changes (CRCC). These symptoms are also called chemo brain. This is because they were first linked with chemotherapy. Chemo brain can also affect people who have had other cancer treatments.

If you have these symptoms, talk to someone from your cancer team. They can check if your symptoms are caused by something else - for example, anaemia, medicines you are taking, or anxiety.

Different ways of coping with cognitive changes include:

- using things such as sticky notes and phone alerts to help you remember things
- doing memory exercises such as crosswords, word games and number puzzles
- keeping to simple and regular routines or hours of work, if possible
- avoiding distractions such as TV or radio noise when you are concentrating.

We have more information online at macmillan.org.uk/chemo-brain

#### **Pain**

Surgery and radiotherapy may limit your movement or damage nerves in the treated area. This can cause pain or discomfort that may take weeks or months to improve. If you have been given exercises to do, it is important to do them.

If the pain does not improve, tell your cancer team. They can prescribe drugs or other treatments to help manage the pain. They can assess your pain and refer you to a pain specialist if you need it.

You can also ask your cancer team whether a referral to a physiotherapist would be helpful. A physiotherapist can advise you on managing the pain and keeping as active as possible.

Your cancer team may also be able to refer you to an occupational therapist. They can provide splints to support painful joints, or equipment to make it easier to do certain things at home.

We have more information about managing pain in our booklet and audiobook Managing cancer pain, and online at macmillan.org.uk/pain

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





#### Effects on the nerves

Some cancer treatments can affect the nerves in your feet, hands and lower legs. This is called peripheral neuropathy. It may cause:

- tingling or numbness (pins and needles) in your hands or feet
- difficulty doing fiddly tasks for example, fastening buttons
- problems with your balance.

Tell your cancer team if you have any of these symptoms. They can advise you on the best way to manage them. Your doctor may prescribe drugs to control nerve pain. Physiotherapy can also help with balance problems.

Usually, peripheral neuropathy improves when chemotherapy is over. But sometimes it is permanent.

We have more information at macmillan.org.uk/peripheral-neuropathy

#### Bowel and bladder side effects

Surgery and radiotherapy to the lower tummy (abdomen) area can cause bowel and bladder side effects. Some drug treatments may also cause ongoing bowel problems.

These may take a few weeks to get better after treatment ends. But they can take longer to improve. If they do not get better, it is important to tell your cancer team.

We have more information at macmillan.org.uk/bladder-bowel-problems

#### **Bowel side effects**

After treatment ends, you may have side effects such as:

- diarrhoea
- constipation
- needing to empty your bowel (poo) urgently
- tummy cramps
- wind

If you have any of these side effects, tell your cancer team. Follow any advice your cancer team gives you. This may include:

- taking anti-diarrhoea tablets
- taking medicines to help constipation
- drinking lots of fluids
- changing your diet.

Less common side effects can include:

- leaking small amounts of poo (bowel incontinence)
- blood or mucus in your poo.

If you have these side effects, tell your cancer team straight away.

#### Bladder side effects

After treatment finishes, you may have side effects such as:

- passing urine (peeing) more often than usual
- passing urine during the night
- feeling the need to pass urine urgently
- a burning feeling when you pass urine.

Follow any advice your cancer team gives you. It is important to drink 2 to 3 litres (3½ to 5½ pints) of fluids each day. Concentrated urine can irritate the bladder and make side effects worse. Drinking more fluids will make your urine less concentrated.

If your symptoms get worse or you have a high temperature, contact the hospital straight away. They can check your urine for any infection.

Less common side effects can include:

- leaking small amounts of urine (incontinence)
- blood in your urine.

If you have these side effects, tell your cancer team straight away.

#### **Eating problems**

If you have had treatment to any part of your digestive system, such as the bowel, stomach or gullet, it may affect the foods you can eat.

Treatment to the head or neck area can affect eating. Problems often improve over time as you adapt to changes. Your GP or cancer team can refer you to a dietitian or a speech and language therapist (SLT). They can advise you about any foods or drinks to avoid.

If you are losing weight, it is important to talk to your cancer team. They can give you advice or arrange for you to visit a dietitian. Getting enough energy and nutrition from your diet is very important for your recovery.

We have more information in our booklets **Eating problems and cancer**, The building-up diet, and Healthy eating and cancer.

#### Changes to your body image

Treatment can affect how you see and feel about your body (body image). This can make you feel anxious and affect your confidence. Talk to your cancer team if you feel like this or are finding it difficult to adapt to changes in your body. They can give you advice on what may help. Or they may refer you to a counsellor or psychologist.

If you have a partner, you may worry about how they might react to your body changes. Try to talk as openly as you can with each other. You may both need time to adjust. Sometimes it helps to talk to others who have been through something similar. You may find it helpful to join a support group, or the Macmillan Online Community at macmillan. org.uk/community

We have more information in our booklet Body image and cancer.

#### **Effects of ongoing treatment**

Some people may have ongoing treatment to either:

- reduce the risk of the cancer coming back
- help to control the cancer.

You may have ongoing treatment with the following types of drugs:

- hormonal therapy drugs visit macmillan.org.uk/hormonal-therapy
- targeted or immunotherapy drugs visit macmillan.org.uk/targetedtherapy
- maintenance chemotherapy visit <u>macmillan.org.uk/chemotherapy</u>

Side effects of ongoing treatment may improve within a few months of starting the drug. Others can usually be managed in different ways. If you are taking hormonal therapy drugs, you are more at risk of bone problems. You can help look after your bones by:

- doing regular exercise, such as walking
- eating healthily
- not smoking.

We have more information in our booklet Bone health.

Immunotherapy drugs can cause serious side effects of the immune system. Side effects may still happen up to 1 year after treatment ends. Sometimes they happen even later.

Always talk to your cancer doctor or nurse about any side effects, especially if they affect your quality of life.

Do not stop your ongoing treatment without talking to your cancer team. If you stop taking the drugs, this may affect the success of your treatment.

Your cancer team can usually suggest ways to improve any side effects you might have. You may need to stop taking a drug for some time, or your cancer team may reduce the dose.

If you continue having difficult side effects, they may suggest changing the drug.

> I sometimes went to the Information and Support Centre. There were really helpful leaflets and they had wig fittings, too. It was just really nice having it there - like a common room you could go to any time you wanted.

Lara



# Late effects of treatment

Late effects are side effects that do not go away after treatment. They can also be side effects that do not happen until months or years after treatment.

Your cancer team can tell you about the risk of any late effects of your treatment. They can tell you which signs and symptoms to be aware of. Ask them whether there is anything you can do to reduce the risk of these happening. They may also tell you if there are any regular tests you can have to find problems early.

Tell your cancer team if your side effects do not improve after treatment, or if you get new signs or symptoms. If needed, they can arrange tests to check your symptoms.

We have more information at macmillan.org.uk/late-effects-of-treatment

#### Lymphoedema

Radiotherapy or surgery to the lymph nodes may cause swelling called lymphoedema. This usually affects your arms or legs (limbs). But it can affect other parts of the body, depending on which area was treated.

To reduce your risk, follow the advice from your specialist nurse. This includes looking after your skin in the area that was treated. If you notice any swelling, get it checked by a doctor straight away and tell your cancer team. The earlier lymphoedema is diagnosed, the easier it is to manage and treat successfully.

We have more information in our booklet Understanding lymphoedema and online at macmillan.org.uk/lymphoedema

#### Effects on the heart and lungs

Certain cancer treatments may increase your risk of developing different heart and lung problems in the future. But many people who have these drugs or treatments do not develop any effects. If you are worried, you can ask your cancer team if your heart or lungs are likely to be affected in the long term.

#### Radiotherapy

Radiotherapy to the middle of the chest or the left breast may increase the risk of heart problems. Radiotherapy to treat lung cancer may cause lung changes, such as scarring. Newer radiotherapy techniques aim to lower the risk of these problems.

#### **Cancer drugs**

Different cancer drugs may cause heart problems. These problems may include high blood pressure and abnormal heart rhythms. If you are at risk of these side effects, you will usually have checks on your heart before treatment. You may also have checks during and after treatment.

Chemotherapy drugs called anthracyclines may also affect the heart.

These include doxorubicin (Adriamycin®) and epirubicin (Pharmorubicin®). Targeted therapy drugs such as trastuzumab and pertuzumab (Phesgo®) can also cause heart problems. Some hormone therapies and immunotherapy drugs can also affect the heart.

Different drugs can be used to manage any heart problems you have.

Chemotherapy drugs such as bleomycin can affect the lungs. Targeted and immunotherapy drugs may cause lung inflammation. This is called pneumonitis. If you have breathlessness or a cough, contact your doctor straight away.

We have more information at macmillan.org.uk/treatments-and-drugs

#### What you can do

There are things you can do to help look after your heart and lungs. Not smoking is very important. Being physically active, eating healthily and keeping to a healthy weight also help look after your heart and lungs.

We have more information about managing the late effects affecting the heart and lungs at macmillan.org.uk/late-effects-of-treatment

#### Effects on the bones

Hormonal therapy to treat breast or prostate cancer can increase the risk of bone thinning - this is called osteoporosis. This may mean you are more likely to get a break (fracture) in a bone.

Radiotherapy to the pelvic area may increase the risk of small insufficiency fractures (stress fractures) in the pelvis, but this is not common. You can read more in our booklet Understanding pelvic radiotherapy.

If you have pain or aching in the bones, tell your cancer team. It can be caused by many different conditions, but it is important to get it checked.

#### What you can do

You can look after your bones by:

- · doing weight-bearing exercises, such as walking
- · eating a healthy, balanced diet
- not smoking.

We have more information in our booklet Bone health.

#### Effects on the head and neck

Radiotherapy to the head and neck can cause late effects to your mouth and throat. These may include:

- a dry mouth because you have less saliva
- thicker or stickier saliva
- a loss of sense of taste.

Using artificial saliva and having frequent sips of water can help with a dry mouth. Using a sodium bicarbonate mouthwash may help clear thick saliva.

It is important to follow any advice you have been given. Keeping your teeth and mouth clean can also help. You will need regular visits to your dentist and oral hygienist.

Surgery and radiotherapy can affect eating and speech. Specialist health professionals can help with any changes to eating and speech. These may include dietitians and speech and language therapists (SLTs).

We have more information in our booklet Managing the late effects of head and neck cancer treatment.

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



#### Effects on the bowel and bladder

The pelvis is the lower part of the tummy (abdomen) between the hips. Radiotherapy to the pelvis can cause late effects on the bowel and bladder. These can often be managed or treated successfully. Some people may need to consult a bowel or bladder specialist for more specialised help. There are different treatments available.

You can often manage late effects on the bowel by changing your diet. This could include reducing how much high-fibre food you eat. You can take medicines to control diarrhoea or constipation.

Pelvic late effects on the bladder may mean you need to pass urine (pee) more often. You may also leak a small amount of urine (incontinence). It is important to drink lots of fluids and avoid things that can irritate the bladder - for example, caffeine and alcohol. Stopping smoking can also help with effects on the bowel and bladder.

If you have problems with bowel or bladder control, ask your nurse for a referral to a continence adviser. They can talk to you about pelvic floor exercises or bladder training to help bladder control. Keeping to a healthy weight will also help. This relieves pressure on your pelvic floor.

We have more information in our booklets Managing the bladder late effects of pelvic radiotherapy and Managing the bowel late effects of pelvic radiotherapy.

#### Second cancer

Certain cancer treatments may slightly increase the risk of developing another cancer in the future. But usually, the benefits of treatment will far outweigh any risk. Your cancer team can give you more information about this.



# Sex and fertility

Cancer treatment may affect your sex life in different ways. It may also affect your ability to get pregnant or make someone pregnant (fertility).

#### Changes to your sex life

After treatment, you may have difficulties with your sex life. Anxiety, tiredness and other side effects can affect your sex drive (libido). Some treatments may affect your ability to have sex or how you feel about yourself sexually. There are different ways of managing these changes to help improve sexual difficulties.

If you have problems, do not be embarrassed to tell a member of your cancer team. They may be able to reassure you. They can also give you advice on working with a counsellor or sex therapist.

Body changes because of treatment can also make you feel less confident and affect your sex life. Your cancer team can give you advice. Over time and with the right support, people are usually able to adjust to any changes.

We have more information in our booklet Cancer and your sex life and online at macmillan.org.uk/sex-and-cancer

#### Early menopause

Some cancer treatments can stop the ovaries producing hormones and cause an early menopause. This can cause symptoms such as:

- hot flushes
- mood changes
- vaginal dryness
- changes to your sex drive.

There are different ways to manage menopausal symptoms. Your nurse can give you advice. For example, they may suggest using different creams, gels or lubricants to improve vaginal dryness.

If you do not have a cancer that is dependent on hormones to grow, hormone replacement therapy (HRT) may be suitable. Talk to your cancer team about this.

We have more information at macmillan.org.uk/menopausal-symptoms

#### Vaginal dryness or narrowing

Radiotherapy to the pelvis can cause vaginal dryness and narrowing of the vagina. This can affect your sex life. Your cancer team will talk to you about ways of preventing narrowing, such as using vaginal dilators.

There are also creams, gels and lubricants to improve dryness and make sex more comfortable. Ask your specialist nurse or radiographer for advice.

#### **Erection problems**

Surgery or radiotherapy to the pelvic area or ongoing hormonal therapy may cause difficulties in getting or keeping an erection. This is sometimes called erectile dysfunction (ED). Your doctor can prescribe drugs to help with this. They can also refer you to a specialist clinic.

#### Changes in testosterone levels

Treatments may cause changes in testosterone levels. This may affect your:

- energy levels
- mood
- sex life.

You can ask your cancer team to check your hormone levels. If you do not have a cancer that is dependent on hormones to grow, it may be possible to have testosterone therapy.

#### If you have a partner

If you have a partner, you may worry about their reaction to any changes in your body. It helps to try to talk as openly as you can with each other.

Partners may sometimes mistakenly worry that:

- they could catch the cancer
- having sex could make the cancer worse
- they might hurt you
- you have lost interest in them
- your feelings may have changed.

You and your partner may need some time to work things out. There are intimate, affectionate ways of showing how much you care for someone, even if you do not feel like having sex.

Difficulties often gradually improve as you recover from treatment. But sometimes it can take longer. Talking with your partner about any problems and concerns can reduce the possibility of any misunderstandings.

We have more information in our booklet Cancer and relationships: Support for partners, families and friends.

#### **Fertility**

Some cancer treatments can result in you not being able get pregnant or make someone pregnant. This is called infertility. Sometimes this is temporary. But for some people, it may be permanent. Your cancer team will talk to you about the effects of treatment on your fertility.

Losing your fertility can be very upsetting to cope with, whatever your situation. Some people find it helpful to talk with a trained counsellor. Your doctor or nurse can arrange this if you would like it.

We have more information in our booklet Cancer and fertility.

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





# Lifestyle and well-being

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"My second life, as I call it, has been a very tricky one. But it is still a blessing. I am proud of who I was, who I am and who I am becoming. I am proof there is life after cancer. "

Dylan, diagnosed with testicular cancer

# Improving your well-being after cancer treatment

After treatment, you may decide to think about ways to improve your well-being and long-term health. This could be part of your recovery. Your cancer team and GP can give you advice about this.

You could ask if there are any health and well-being clinics or events in your area. These could give you support and advice on diet, lifestyle and adjusting to life after treatment. There are different things you can do that may have a positive effect on your health and well-being.

#### Be more active

Gradually doing more physical activity is an important part of your recovery. It can also improve your long-term health and well-being.

During treatment, you may be less active than usual. This can make you feel more tired. It can also make your muscles lose some strength. Doing a small amount of physical activity regularly will give you more energy and make you feel stronger. This includes going for a short walk.

Some hospitals, cancer charities and leisure clubs have exercise programmes for people recovering from treatment. Your cancer team can tell you what is available in your area.

Your cancer team or GP can advise you on the type and amount of exercise that is safe for you to do. Some people may need to take special care when exercising.

Being more physically active:

- helps look after your bones
- helps manage tiredness (fatigue)
- helps you keep to a healthy weight
- improves your mood and emotional well-being
- reduces stress and anxiety
- reduces the risk of bone thinning (osteoporosis)
- reduces the risk of heart disease, stroke and diabetes
- reduces the risk of certain cancers coming back, or of getting another cancer
- increases your confidence.

You can slowly increase how much activity you do. Doing too much too soon can make you feel more tired. We have more information in our booklets Bone health and Coping with fatigue (tiredness).

#### Types of exercise

Aerobic activity helps to protect your heart. This includes fast walking, running, skipping, cycling, dancing and swimming.

Weight-bearing exercises help keep bones and muscles strong. These can include walking, dancing, and resistance and strength exercises such as lifting small weights.

Some types of exercise may not be suitable for you. Make sure you get advice from your cancer team before you start getting more active.

We have more information in our booklet Physical activity and cancer.

#### Eat healthily

Eating healthily helps your recovery and gives you more energy. If your treatment has caused eating problems, follow the advice of your cancer team or dietitian

For most people, a healthy balanced diet includes:

- lots of fruit and vegetables
- plenty of starchy foods (carbohydrates), such as rice, potatoes, bread, pasta and couscous
- wholegrains rather than refined (processed) grains
- some protein-rich foods, such as meat, fish, eggs, nuts and pulses (like beans and lentils)
- some milk and dairy foods, such as cheese, butter and yoghurt
- a limited amount of red meat and processed meat
- a small amount of foods that are high in fat, salt and sugar.

Some treatments may cause changes in how your bowel works. These include surgery to the bowel or radiotherapy to the pelvis.

For some people, this may mean a diet that is high in fibre (fruit and vegetables) may not be suitable. We have more information in our booklet Healthy eating and cancer.

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



#### Changes to your weight

Some cancer treatments may cause changes to your weight. After treatment, try to focus on eating healthily to help your recovery. If you are worried about your weight, ask your cancer team for advice. They can arrange for you to visit a dietitian if needed.

#### Weight gain

Some people gain weight during chemotherapy or when taking hormonal therapies. If this happens, you may find it upsetting. It may also affect your body image.

If you need to lose weight, it is important to do this slowly. You can do this by eating a healthy diet and being more physically active. Try to be patient with yourself and set realistic goals. Keeping to a healthy weight has lots of benefits. It reduces the risk of other medical conditions.

#### Weight loss

If you have lost weight or are having difficulty eating, ask your cancer team for advice. There are different ways to add calories and more nutrients to food. There are also nutritional drinks and powders to help increase your weight. Some of these can be prescribed by your doctor.

We have more information in our booklet The building-up diet.

#### **Stop smoking**

If you smoke, stopping is the healthiest decision you can make. It can reduce the side effects of some treatments. Stopping can also help you to heal faster after surgery.

Smoking increases your risk of heart disease, stroke and developing new cancers. It can also make certain late effects of treatment worse. These can include bladder and bowel problems.

It is not always easy to quit smoking. It may take you a few tries. But there are lots of tools and resources to make stopping easier. The first steps are:

- asking your cancer doctor, nurse, GP or other healthcare professional for advice
- contacting your local stop smoking service.

You are 4 times more likely to quit if you have specialist support from a stop smoking service and use:

- products such as nicotine replacement therapies
- medicines to manage cravings.

The NHS has a lot of information and support to help you stop smoking. Look on the <u>NHS website</u> for the country where you live.

### Follow sensible drinking guidelines

NHS guidelines suggest you should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units you drink in a week over 3 or more days
- try to have several alcohol-free days every week.

#### A unit of alcohol is:

- ½ 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 lead to weight gain. Following sensible drinking guidelines is good for your overall health.

There is more information about alcohol and drinking guidelines at drinkaware.co.uk.



#### Skin safety in the sun

Some cancer treatments can make your skin more sensitive to the sun. This includes radiotherapy, some types of chemotherapy, targeted therapy and immunotherapies. It is always important to protect your skin in the sun to help reduce the risk of skin cancer.

There are many things you can do to protect your skin:

- Stay out of the sun when it is strongest. This is usually between 11am and 3pm.
- Wear clothing made of a close-weave fabric. This will give you more protection against the sun.
- Keep your arms and legs covered by wearing long sleeves and trousers. Wear a wide-brimmed hat to protect your face, neck and ears.
- Always wear sunglasses in the sun.
- Use a suncream with a high sun protection factor of SPF 30 or above whenever you are exposed to the sun. Follow the instructions on the bottle and re-apply it as recommended.
- Choose a suncream that protects against ultraviolet A (UVA) and ultraviolet B (UVB) radiation. It should have at least a 4-star UVA protection rating and be at least SPF 30.
- Make sure you use enough suncream. About 6 to 8 teaspoons is enough to cover most adults.
- Do not use suncream instead of covering up or staying in the shade. You might think that if you use suncream, you can stay in the sun for longer. But the best protection is to cover up and to stay out of direct sunlight. There is no such thing as a safe suntan.
- Never use a sunbed or sunlamp. If you like to look tanned, use fake tan.
- If you use a sunbed for treatment of a skin condition, your dermatologist may advise you to stop using it.

If you are not often outdoors or in the sun, ask your specialist doctor or GP to check your vitamin D levels. Vitamin D is important for general health and can become low in people who avoid the sun or are indoors most of the time. You may need to take vitamin D supplements if your levels are low

#### Health and well-being clinics

You may be invited to a health and well-being clinic. At the clinic, you can find out more about healthy living and local support that is available.

There are usually different workshops and talks. They happen in a hospital or in the community and usually last a few hours.

Health and well-being clinics can be a good way to meet people in a similar situation to you. They usually provide information about:

- eating well and having a healthy lifestyle
- possible long-term effects of treatment
- emotional effects and how to get help if you need it
- signs and symptoms to be aware of, and who to contact if they happen
- claiming benefits and other financial support
- getting back to work or education
- local services, such as support groups and physical activity groups.

#### Find ways to reduce stress

Finding ways to reduce stress and anxiety can be helpful. It may help to:

- talk about your feelings with family, friends, a health professional or people going through a similar experience
- do things you enjoy, such as spending time with family or friends, or getting back to hobbies you did before treatment
- do regular physical activity, such as walking, cycling and swimming
- try complementary therapies, such as relaxation, meditation and yoga.

Find out what suits you best. Your recovery will take time, so know your limits. Try to ask for help when you need it.

Being around nature and plants is the most healing experience.

After 5 minutes of gardening, I feel completely relaxed and engrossed, and I forget about the outside world.

Lara

# Trying to get good sleep

Sleeping well can help with recovery after cancer treatment. If you are having trouble sleeping, there are things you can do that may help.

#### Tips for a better night's sleep

- Go to bed and get up at about the same time every day.
- Try not to sleep late into the day after a sleepless night, as this can lead to a disrupted sleep pattern.
- Try to do gentle exercise like walking, as this can help you feel naturally tired and ready for sleep.
- Try a relaxing routine before bed. Having a warm bath or shower, reading a book or listening to soothing music might help.
- Make your bedroom a relaxing place to be. Create an area that is dark, quiet and comfortable, but not too warm.
- Be aware of how naps affect you. Some people find that daytime naps help them sleep better at night, while others sleep less well after them.
- It may help to write down any worries before you go to bed so that you can try to forget about them until the next day.
- Alcohol and caffeine can stop you from falling asleep. Try to cut down on alcohol and avoid caffeine close to bedtime.

We have more information online at macmillan.org.uk/trouble-sleeping



# Your feelings and relationships

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# **Your feelings**

You may still have lots of different and complex feelings after your treatment has ended. This is common. These feelings usually get easier to manage over time. Ask someone from your cancer team for advice if you are finding it hard to cope.

We have more information in our booklets Your feelings after cancer treatment and Talking about cancer.

# Feeling alone

You may feel isolated because you no longer have as much contact with your cancer team. It can take time to get used to this. But you will still usually have regular check-ups. If something is worrying you, you can contact your cancer team at the hospital. You can also talk to your GP or practice nurse, or find a local health and well-being clinic.

Support groups and online social networks, such as our Online Community, let you talk to people who have been through a similar experience. You can use these groups to find out what has helped them cope. Knowing you are not the only one who feels a certain way can help.

Visit the Online Community at macmillan.org.uk/community

# **Uncertainty**

It can be hard to cope with uncertainty about your future, and you may worry about the cancer coming back. These worries usually get easier to manage as you focus on other things in your life. Getting back into some kind of routine can help. Thinking about things that you can control may also help. For example, you could:

- organise your day
- · do activities you enjoy
- get involved in your care
- make lifestyle changes that improve your health and well-being.

Finding ways to relax may also help. These could include relaxation therapy, meditation or yoga.

Now I try to enjoy and experience every moment. It is important to enjoy where you are at. When I had cancer, I did not know if I had that time.

LJ, diagnosed with acute myeloid leukaemia

# **Anger**

It is normal to feel angry about cancer and the effects of treatment. You may be dealing with difficult side effects such as infertility. menopause or changes in your appearance.

Try to talk to people about how you feel. It may help to explain that you are angry at the illness and not at them. Finding ways to help you relax and reduce stress can also help. This can include:

- talking about or writing down how you feel
- doing regular exercise
- breathing or relaxation therapy.

You may find it hard to talk to people close to you. If this happens, you can ask your doctor or nurse about speaking to a counsellor.

# Guilt

Some people feel guilty. They may blame themselves or others for the cancer. Other people may feel guilty for surviving cancer when others have not.

It is not usually possible to know the exact cause of the cancer. Remember, it is not your fault. Try to talk about your feelings. Be kind to yourself and get the support you need.

# Low mood and depression

Sadness, low mood and anxiety usually get better over time. If they do not, you may need more support.

Signs of low mood and possible depression include:

- feeling sad or hopeless most of the time
- losing interest in things you used to enjoy
- feeling numb, overwhelmed or out of control
- constantly focusing on worries
- finding it difficult to concentrate
- finding it difficult to sleep
- physical symptoms like a dry mouth or a racing heart (palpitations).

If you think you may be depressed, talk to your family or friends. You should also tell your doctor or nurse. They can refer you to a counsellor or psychologist. They may also prescribe anti-depressants or anti-anxiety drugs if they think it will help.

We have more information in our booklet Your feelings after cancer treatment.

# Talking to someone or sharing your experience

Talking about your emotions can help reduce feelings of stress. anxiety and isolation. You also have valuable experiences that can help others in a similar situation.

# Support groups or online support

Support groups offer a chance to talk to people who are, or have been, in a similar situation. You can share your experiences and ways of coping. Support groups can help if you live alone, or you cannot talk about your feelings with family or friends. You can attend a support group meeting before you decide to get involved.

We can help you find a support group in your area.

You may find it helpful to join our Online Community. It is a social networking site where you can:

- talk to people in our chat rooms
- blog about your experiences
- make friends
- join support groups
- share your feelings
- get support from others.

Visit macmillan.org.uk/community

You look the same, but you are not the same. The old you is still there, but you are a new person. I have a new perspective – life is for living and loving.

Gina, diagnosed with breast cancer

# Relationships

Going through an experience like cancer can strengthen your relationships with people close to you.

Cancer is often stressful and can put strain on close relationships. Partners, family and friends will have their own feelings to cope with. They may try to protect each other by hiding their fears and concerns.

Talking about your feelings may make it easier for others around you to do the same. It can help you to understand each other's emotions better and think more clearly.

Before my diagnosis, I was strong-minded and independent. So it was a big step to accept emotional support, and an even bigger challenge to admit that I needed it.

Thom, diagnosed with colon cancer

## **Partners**

If you have a partner, your relationship with them may become stronger. But in any relationship, it is still possible to have misunderstandings. You might have different ways of expressing your feelings.

You can understand each other better by talking openly and listening. Some people find it easy to talk about their feelings. But not everyone is comfortable with this. Partners may show their feelings in other ways. They may do practical things to help you, or spend time with you.

If relationship difficulties affect your everyday life, it may help to speak to a counsellor. You can ask your key worker or your GP for more advice.

We have more information in our booklet Cancer and relationships: support for partners, families and friends.

# Family or friends

Your family or friends may expect you to be positive and want to get on with life. They may think things will quickly go back to how they were before. These expectations are usually unrealistic. It can take time to deal with your feelings and adapt to what is now normal for you. When talking to family or friends, it can help to:

- be honest about how you feel explain that coping does not mean being positive all the time
- tell them about any physical effects you have explain that recovery takes time
- tell them what you can and cannot do yet this will let them know what to expect
- ask for their support tell them practical things they can do to help
- plan activities you enjoy doing together such as going for a walk, having a meal or watching a film.

# Children

How children react to your illness depends on their age and level of understanding. Try to talk openly and honestly with them. But do not give them too much information at one time or in advance.

## Tips to help you talk to children

- Help them understand that recovery takes time. Tell them what you cannot do yet.
- Look for ways of involving them in your recovery, such as going for walks or helping with small things around the house.
- Set boundaries for their behaviour. Tell teachers what is happening so they can give extra support if it is needed.
- Look for any signs of changes in their behaviour.
- Teenagers may find it hard to talk to you about their feelings. If this happens, encourage them to talk to someone close, such as a family member or family friend.

We have more information in our booklet Talking to children and teenagers when an adult has cancer.



# **New relationships**

If you are not in a relationship, you may worry about finding or starting one. It is natural to worry about how someone may react when you tell them about the cancer. But cancer does not stop you from having relationships. Your experience may have made you a stronger person with more to offer.

You may worry about how a possible partner may react to any changes to your body. Or you may worry about whether you can have children. You may be concerned about whether a possible partner will be able to give you the support you need.

But having a new relationship can be enjoyable. Take time to recover first and decide when it is the right time for you.

The following tips might help:

- Do activities you enjoy where you can meet other people this can make you feel more comfortable and improve your confidence.
- Talk to people who have had similar experiences before starting new relationships - they can give advice. You could also try using social networks.
- Wait until you feel comfortable before telling a possible partner about vour cancer experience. But it may be better to talk about it before the relationship gets serious.





# Work, finances and travel

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# Work

For many people, returning to work is a big step in their recovery. It can bring a sense of normality, financial stability, routine and social contact. Some people may have worked during treatment, possibly with reduced hours. If you are self-employed, you may also have continued to work.

Deciding whether to return to work after treatment will depend on different things. This includes your health and the sort of work you do. Some people may need to go back for financial reasons. If possible, do not push yourself to go back too soon.

Talk to your family or friends about how you feel so they can support you. Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

You may decide you want to:

- do a different kind of job
- reduce your hours
- · stop working altogether.

If you decide to return to work, there are different ways your employer can support you. You and your manager could agree on a plan for your return to work. Make sure you are fully involved in any discussions. The law says your employer must make reasonable adjustments (changes) to help you return to work.

In terms of employment benefits, I went to Macmillan. The woman there was amazing. She told me all the information I needed and the number I needed to call. She also gave me her email and phone number in case I needed any help. ,,

# Making reasonable adjustments

Both the Equality Act 2010 and the Disability Discrimination Act 1995 say that employers must make reasonable adjustments to help you return to work. The adjustments might be to your workplace or your job. These laws make sure you are not treated differently to people at your workplace because of cancer.

There is no fixed description of what a reasonable adjustment should be. It depends on things like how much the adjustment will benefit you and the possible effect on your employer's business.

Reasonable adjustments could include:

- a phased return to work
- different working hours for example, part-time working, having a flexible start or finish time, or working from home
- extra breaks to help you cope with tiredness
- easier tasks than normal
- time off for medical appointments or rehabilitation
- making sure you have suitable access if you use a wheelchair
- making sure you can get to the toilet easily.

Our booklets have more information that may be helpful:

- Work and cancer
- Self-employment and cancer
- Your rights at work when you are affected by cancer.

There is also lots more information online at macmillan.org.uk/work

# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to at <a href="mailto:ma

We also have information for carers in our booklet <u>Working while caring</u> for someone with cancer.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- <u>nidirect.gov.uk</u> if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on 0808 808 00 00. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from <u>Citizens Advice</u> if you live in England, Scotland or Wales, or <u>Advice NI</u> if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

# **Macmillan Grants**

Macmillan Grants are small, one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call 0808 808 00 00 or visit macmillan.org.uk/grants

## Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

If you are thinking about buying insurance or making a claim, our financial guides can help. You can call them on 0808 808 00 00.

"The most useful thing was the financial information and advice. You don't know what you are entitled to, but the benefits adviser was so confident and knew exactly how to help. "

Lara

# Trave

Planning a holiday after treatment can give you something to be excited about. It can also help with your recovery. It may be best to wait for a few weeks after your treatment, so you feel less tired. This will also allow time for any side effects to improve.

Before you travel, you may need to plan how you will take medicines with you. Talk to your cancer doctor or specialist nurse before you make any plans. They will give you advice on whether it is safe for you to travel or how long you should wait.

They can also give you a letter to take with you about the treatment you have had. You can show this letter to healthcare providers if you become ill. Some travel insurance providers may ask for a doctor's letter to show you are fit to travel.

It is always important to take care in the sun. But if you have had radiotherapy, chemotherapy, immunotherapy drugs or targeted therapy drugs, you may be more sensitive to the sun. You will need to be very careful. Wear suncream with a high sun protection factor (at least SPF 30) and cover up with clothing and a hat.

We have more information in our booklet Travel and cancer.

# **Travel insurance**

You may find it more difficult to get travel insurance after treatment for cancer. It is likely to be more expensive and can take longer to arrange. It is a good idea to give yourself extra time to get organised.

We have more information about travel insurance in our booklet. Travel and cancer. Our Online Community forum on Travel insurance may also be helpful. Visit macmillan.org.uk/community

Your local Macmillan Information and Support Centre may also be able to help - visit macmillan.org.uk/inyourarea

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





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# **About our information**

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

#### Order what you need

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

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.

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 macmillan.org.uk/ information-and-support 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
- British Sign Language
- easy read booklets

- interactive PDFs
- large print
- translations.

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 macmillan.org.uk/ourinfo



# 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. Call us on 0808 808 00 00. 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.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 **808 00 00**, or use the Relay UK.

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 <a href="macmillan.org.uk/talktous">macmillan.org.uk/talktous</a>

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 0808 808 00 00 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 macmillan.org.uk/financialsupport 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 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.

#### 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 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

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

#### **General cancer support organisations**

#### **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.

#### **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.

### **Emotional and mental health support**

#### **Breathing Space**

#### Tel 0800 838 587

#### www.breathingspace.scot

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

#### **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.

#### 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.

#### **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 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**

#### 111.wales.nhs.uk

The NHS health information site for Wales.

#### **NHS Inform**

#### Helpline 0800 224 488

#### www.nhsinform.scot

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

#### labt.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.

#### **OUTpatients (formerly called 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 LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

### Financial support or legal advice and information

#### **Advice NI**

Helpline 0800 915 4604

www.adviceni.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

#### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

#### **England**

Helpline 0800 144 8848 www.citizensadvice.org.uk

#### Scotland

Helpline 0800 028 1456 www.cas.org.uk

#### Wales

Helpline **0800 702 2020** www.citizensadvice.org.uk/wales

# 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 Macmillan's Centre of Clinical Expertise.

With thanks to: Lisa Castellaro, Macmillan Haematology Clinical Nurse Specialist; Annabelle Cracknell Jones, Radiographer and Macmillan Senior PSFU Allied Healthcare Professional; Professor Diana Greenfield, Consultant Nurse and Honorary Professor: Dr Pauline Love, Macmillan GP; Louise Smith, Macmillan Deputy Lead Cancer Nurse; and Avril Van Der Loo, Macmillan Personalised Cancer Care Lead.

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 life after cancer treatment. If you would like more information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk

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Vaz-Luis I, Masiero M, Cavaletti G, Cervantes A, Chlebowski RT, Curigliano G, et al. ESMO expert consensus statements on cancer survivorship: promoting high-quality survivorship care and research in Europe. Annals of Oncology. 2022;33(11): 1119-1133. Available from www.doi. org/10.1016/j.annonc.2022.07.1941 [accessed April 2023].

# 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?

#### Raise money 4.

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	Do not let the taxman		
Mr/Mrs/Miss/Othe	er	keep your money		
Name		Do you pay tax? If so, your gift will be worth 25% more to us - at no extra cost to you. All you		
Surname				
Address		have to do is tick the box below,		
Postcode		and the tax office will give 25p for every pound you give.		
Phone		I am a UK tax payer and		
Email		I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the		
Please accept my (Please delete as a	=			
I enclose a cheque Charity Voucher m Macmillan Cancer	ade payable to	last 4 years as Gift Aid donations until I notify you otherwise.		
OR debit my: Visa / MasterCard Card / Switch / M	,	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 tha I give.		
Card number				
Valid from	Expiry date	Macmillan Cancer Support and our trading companies would like to hold your details i order to contact you about our fundraising campaigning and services for people affect by cancer. If you would prefer us not to use		
Issue no	Security number	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.		
Signature		If you would rather donate online go to macmillan.org.uk/donate		
Date / /				







# This booklet is for anyone who is preparing for life after cancer treatment. There is also information for carers, family members and friends.

The booklet explains about side effects, follow-up care, emotional effects and making healthy lifestyle changes. It also has information about work and finances.

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 Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

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Patient Information Forum