

LIFE AFTER CANCER TREATMENT



**I choose to live here
and now, where I'm
healthy and I'm happy,
and I have a family
who love me.**

**Daloni, diagnosed with
womb cancer**



About this booklet

This booklet is about coping after cancer treatment finishes, 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 list on page 3 to help you.

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

On pages 86 to 90, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (see pages 91 to 92).

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 Daloni, who is on the cover of this booklet. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

For more information

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

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

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

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

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Contents

Finishing treatment	5
Your care after treatment	14
Managing treatment side effects	27
Lifestyle and well-being	48
Your feelings and relationships	59
Work, finances and travel	70
Further information	81



FINISHING TREATMENT

Preparing for the end of treatment	6
Beginning to recover	10

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 other people, treatment is about managing the cancer over a long period of time.

You may feel relieved when your treatment ends. 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 from a few weeks to a few months to adjust. You may also be thinking about positive changes you want to make. These might include focusing on your well-being (see pages 48 to 57) or planning things like a holiday (see page 75).

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 with another member of your healthcare team. They will tell you what to expect after treatment finishes. They will also ask about any concerns or specific needs you have.

Holistic Needs Assessment

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. You answer a set of simple questions about all areas of your life. This helps you identify any concerns you would like to talk about.

You can discuss these with a member of your cancer team. Together you can talk about possible solutions and make a plan. This makes sure your care is planned based on what is most important to you.

Our leaflet **Holistic needs assessment: planning your care and support** has more information (see page 82).

Personalised care and support plan

Your cancer team may write a care plan for you. It is based on any concerns you have discussed and 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.

HNAs, personalised care plans and end of treatment summaries 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.

Treatment summary

At the end of your treatment, your cancer team may create a summary of the treatment you have had. This may be after a certain phase of treatment, or after you finish all your treatment. It will describe the treatment you have had. It will also help you know what to expect. Knowing what happens next can help you adjust to life after your main treatment.

Your treatment summary will include information about:

- the cancer and treatment you have had
- possible side effects of treatment
- any symptoms to look out for
- 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.

You may hear some health professionals talk about personalised care or a Recovery Package. The Recovery Package combines all of the options above and also includes a cancer care review with your GP (see page 22).

Knowing who to contact

Your cancer team should give you details of who to contact after your treatment finishes. This may be a specialist nurse, or another member of the cancer team. They may be called your key worker.

Keep their contact details in your phone or somewhere safe.

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

What to ask your key worker

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

- how often will you have follow-up appointments (check-ups) and for how long – see pages 16 to 22
- about any blood tests, scans or other tests you may need and how often you might have these
- how to contact your healthcare team.

You may also want information about:

- how to manage any side effects or symptoms you have (see pages 28 to 38)
- symptoms to look out for that may be signs of cancer
- side effects of your treatment that may happen months or years after treatment ends (late effects) – see pages 39 to 43
- what you can do to stay healthy and well
- things you can do to reduce the risk of cancer coming back
- health and well-being clinics, events, or support for people with cancer in your area.

Beginning to recover

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

How you may feel

You may feel ready to get on with life after 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 might also find it difficult adjusting to not seeing your cancer team as often (see page 60).

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:

- going back to work or education (see pages 73 to 74)
- doing hobbies or exercise again
- seeing more of family and friends.

Try not to expect too much of yourself too soon. Recovery is a gradual process. Some days you may feel better than others. You will need time to build up your physical strength. You will also have to process what you have been through. Sometimes emotional recovery can take longer than physical recovery. But everything 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 (see pages 48 to 57). This could be to improve your well-being or to find ways of reducing stress.

Self-management

Self-management 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 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 key worker can provide a lot of information (see page 9). 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 to show you how to manage your health better. These are usually free.

We also have courses and workshops that can support you. HOPE (Helping to Overcome Problems Effectively) is a free short course on coping with a cancer diagnosis. We also offer a range of online courses. To find out more about HOPE and our online courses, visit learnzone.macmillan.org.uk

Your local Macmillan information and support centre can tell you if there are any local courses (see page 82).



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 going for a walk when you feel able or eating healthily most days. You can be flexible with yourself.

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. Recognise every success, no matter how small. You might also want to reward yourself for your hard work.

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.

YOUR CARE AFTER TREATMENT

Follow-up care	16
Knowing about symptoms	23



Follow-up care

After your main treatment ends, you usually still see your cancer team for regular check-ups. This is called follow-up care. How often you see them 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.

Types of follow-up care

There are different types of follow-up care. You usually have follow-up care at the hospital. This is usually with someone from your cancer team. These appointments may happen every few months in the first year after your treatment. 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 if this is needed, ask your cancer nurse or GP.

You will have fewer check-ups after the first year. You may not need to go to the hospital in the future.

You may have your follow-up care over the phone with a specialist nurse, instead of at a clinic. You may also have some follow-up care with your GP.

Your cancer team will discuss your follow-up care with you. You can decide together what is best for you.

Telephone clinics

Telephone clinics are a common and effective type of follow-up care. They are usually run by specialist cancer nurses. They can help you avoid long journeys to hospital and waits in hospital clinics. Having fewer hospital visits may also help you feel less anxious.

You may have regular telephone appointments with your cancer nurse. During these appointments, they may ask you some questions. Or you may be asked to contact your nurse if you need support or are worried about anything. If your nurse thinks anything needs to be checked, they will arrange this. You will still have any regular tests or scans you may need.

This type of follow-up care is sometimes called supported self-management (see pages 11 to 12). Your nurse will help you manage your health. They will provide 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 nurse or cancer team for help if you need it.

I currently have a Macmillan nurse who I see at my appointments. I am often in email contact with her about my appointments or upcoming scans. Often I will ask her to flag specific questions to my oncologist or ask advice about concerns I have.

**Jolene, diagnosed
with melanoma**

Your follow-up appointment

The aim of this appointment is to make sure everything is going well for you. It is also a chance for you to talk about any concerns you may have. The appointment helps your cancer doctor or nurse 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.

It is very important to go to your appointments. If you cannot go because you are not feeling well, tell the clinic. They can arrange another appointment for you.

You may feel worried before an appointment. Going back to hospital can be difficult after you have been through treatment. But it can also be a positive reminder that you 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 help, or a physiotherapist for advice about exercising.

Tips for getting the most from your 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 can help you remember what was said.
- Always tell your cancer doctor or nurse 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. Sometimes 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 finishes (see pages 48 to 57). For example, they may:

- suggest exercises to improve your movement
- tell you what symptoms to look out for
- explain how any treatment side effects or symptoms can be managed
- give you ideas to help you be more active and to improve your general health.

If you are taking any ongoing cancer drugs, for example, hormonal therapy, it is important to take them exactly as your cancer team explains. Do not stop taking them without getting medical advice from your cancer doctor (see pages 37 to 38).

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 practice nurse can offer support during and after treatment. If you have not seen them during treatment, it is a good idea to make an appointment when it finishes. Your cancer team will send them a report (treatment summary) about your treatment – see page 9. You should always tell your GP about any problems you need help with.

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

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

- recovering
- maintaining a healthy lifestyle
- work
- benefits and financial support.

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

Remember to keep going to any regular check-ups you have at your GP practice. These may include blood pressure checks or cervical screening. It is important to care for your general health.

Cancer care review

You may see your GP or practice nurse about 6 months after you have been diagnosed with cancer. This is sometimes called a cancer care review.

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 have had. If you have a personalised care plan (see page 7) or treatment summary (see page 8), take these with you. Your GP may already have been sent a treatment summary from your cancer team.

Your GP or practice nurse can help you understand which symptoms to look out for. They can also advise when you might need to contact your cancer team.

Your cancer care review is a chance to talk about:

- how you are feeling
- any changes in your concerns
- any new worries or concerns that you have.

Your GP can give you information and tell you what support is available in your area.

Even if your GP does not routinely do cancer care reviews, they can still give you support and advice.

Knowing about symptoms

Ask your cancer team if there are symptoms you should look out for after treatment finishes.

When treatment has finished, it is common to worry that every ache and pain 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 look out for
- possible late effects of treatment and their symptoms (see pages 39 to 43).

Knowing more can help you manage any worries you may have. Make sure you have any symptoms checked, even if you think they are not serious. Tell your cancer team if you have any new symptoms, or symptoms like those you had when you were diagnosed.

You can also see your GP if there is anything you are not sure about. You can have symptoms because of other things, not just the cancer. 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. Your cancer team can reassure you if your symptoms are most likely to be from your treatment. They can also arrange to see you if they need to.

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 if you have them. But they often get better with time.

Certain things may trigger these feelings, for example going back to 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 (see pages 60 to 63)
- finding ways of managing anxiety and stress
- doing activities you enjoyed before treatment, or starting new ones
- going back to work.

If you are still feeling worried or finding it difficult to cope, talk to your cancer team or primary care team. They can give you advice on ways to manage anxiety. They can also refer you to any extra support you may need.





MANAGING TREATMENT SIDE EFFECTS

Side effects of treatment	28
Late effects of treatment	39
Sex and fertility	44

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 finishes. 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 (see pages 39 to 43).

If you are still having hormonal therapy or another type of anti-cancer drug, you may have ongoing side effects.

Always tell your cancer doctor or nurse about side effects or any symptoms you have. There is usually something they can do to improve them. They can also give you advice on what you can do to help manage your side effects.

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 day-to-day 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 – 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
- eat healthily – 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 a low level 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 booklet **Coping with fatigue (tiredness)** – see page 82.

I do get tired, it does affect my life. I decided to go down to reduced hours at work, which helped a lot. Many people I speak to say they would give up work if they were in my position, but work is my normal.

Anthea, diagnosed with melanoma

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, which may be over 37.5° (99.5°F)
- suddenly feel unwell, even with a normal temperature
- have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

If you need to see someone who is not your usual cancer doctor or GP, explain that you have recently had, or are still having, cancer treatment (see pages 37 to 38). They might not know that you may be at an increased risk of infection or other side effects.

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

We have more information about chemo brain at **macmillan.org.uk**

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 treatment to help manage the pain. They can also refer you to a pain specialist.

You can also ask your cancer team if 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 in our booklet **Managing cancer pain** (see page 82).

Effects on the nerves

Some chemotherapy drugs 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 about managing peripheral neuropathy at [macmillan.org.uk](https://www.macmillan.org.uk)

Bowel and bladder side effects

Surgery and radiotherapy to the lower tummy (abdomen) area can cause bowel and bladder side effects. These may take a few weeks to get better after treatment finishes. But they can take longer to improve. If they do not get better, it is important to tell your cancer team.

Bowel side effects

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

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

Tell your cancer team if you have any of these side effects. 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) or blood or mucus in your poo. Tell your cancer team straight away if you have these side effects.

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.

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

Less common side effects can include:

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

Tell your cancer team straight away if you have these side effects.

Eating problems

Treatments to any part of your digestive system, for example the bowel, stomach or gullet, may affect the foods you can eat.

Treatment to your head or neck area can affect eating. Problems often improve over time as you adapt to changes. A dietitian or speech and language therapist (SLT) 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 see a dietitian. Getting enough energy and nutrition from your diet is very important for your recovery. There are different ways you can add more calories to your diet. These include supplement drinks.



PLEASE
SUGGESTION
HEAR PERFECT

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 refer you to a counsellor or psychologist. A talking therapy called cognitive behavioural therapy may help.

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 can help to talk to others who have been through something similar. You may find it helpful to join a support group.

We have further information on coping with changes to your body image in our booklet **Body image and cancer** (see page 82).

Effects of ongoing treatment

Some people may have ongoing treatment to either reduce the risk of the cancer coming back or help to control the cancer.

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

- hormonal therapy drugs
- targeted or immunotherapy drugs
- maintenance chemotherapy.

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 and not smoking (see pages 48 to 57). You can read more about this in our booklet **Bone health** (see page 82).

Immunotherapy drugs can cause serious side effects of the immune system. Side effects may still happen up to one year or longer after treatment finishes. You can read more information about these at **macmillan.org.uk**

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 a time, or your cancer team may reduce the dose. If you continue having difficult side effects, they may suggest changing the drug you are on.

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 look out for. Ask them if 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 on.

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 about different cancers and late effects at macmillan.org.uk

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.

We have further information about lymphoedema in our booklet **Understanding lymphoedema** (see page 82).

Follow the advice from your specialist nurse to reduce your risk. This includes looking after and protecting your skin in the area which 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.

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 happening in the long term.

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 can also cause heart problems. Some immunotherapy drugs can also affect the heart.

There are different drugs that can be used to manage any heart problems you may have.

We have more information in our booklet **Heart health and cancer treatment** (see page 82).

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

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 helps look after your heart and lungs (see page 48 to 57).

Effects on the bones

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

Radiotherapy to the pelvis area may increase the risk of small insufficiency fractures in the pelvis, but this is not common. We have more information in our booklets **Managing the late effects of pelvic radiotherapy in men** and **Managing the late effects of pelvic radiotherapy in women** (see page 82).

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

What you can do

You can look after your bones by:

- doing weight-bearing exercise like walking
- eating a healthy, balanced diet
- not smoking.

We have more information about looking after your bones and bone health on pages 51 to 52 and in our booklet **Bone health** (see page 82).

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 to see your dentist and oral hygienist regularly.

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.

We have more information in our booklet **Managing the late effects of head and neck cancer treatment** (see page 82).

Effects on the bowel and bladder

Radiotherapy to the lower tummy area (pelvis) can cause late effects on the bowel and bladder. These can often be managed or treated successfully. Some people may need to see a bowel or bladder specialist for more specialised help. There are different treatments available. We have more information in our booklets **Managing the effects of pelvic radiotherapy in men** and **Managing the effects of pelvic radiotherapy in women** (see page 82).

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.

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 experience 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 seeing a counsellor or sex therapist.

Body changes as a result 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 about sex and cancer at **macmillan.org.uk** and in our booklet **Cancer and your sex life** (see page 82).

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.

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

Some men may have changes in their levels of testosterone because of treatments they have had. 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. Your partner may be supportive and not have any problems with changes in your appearance.

Partners may sometimes mistakenly worry that they could catch the cancer, or that having sex could make the cancer worse. They may worry that you have lost interest in them or that 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, although sometimes it can take longer. Talking with your partner about any problems and concerns can reduce the possibility of any misunderstandings.

Fertility

Some cancer treatments can result in you not being able get pregnant or make someone pregnant (infertility). Sometimes this can be 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 about fertility and cancer in our booklets **Cancer treatment and fertility – information for men** and **Cancer treatment and fertility – information for women** (see page 82).

LIFESTYLE AND WELL-BEING

Improving your well-being after cancer treatment

50



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 form 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 can 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.

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.

Giving up smoking is not easy. Using a stop smoking treatment with help from an NHS support service or your GP gives you the best chance of success. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live. There are also support groups available for people trying to quit, as well as one-to-one support. Ask your GP for advice or contact one of the national stop smoking services.

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, such as going for a short walk, will give you more energy and make you feel stronger.

Some hospitals 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 you keep to a healthy weight
- improves your mood
- 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.

You can gradually build up how much activity you do. Doing too much too soon can make you feel more tired.

Aerobic activity helps to protect your heart. It can include 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 becoming more active.

We have more information in our booklet **Physical activity and cancer** (see page 82).

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** (see page 82).

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 see 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 gradually by eating a healthy diet and being more physically active. Try to be patient with yourself. These tips may help:

- only eat as much as you need
- eat lots of fruit, vegetables and wholegrains
- limit saturated fats and sugar.

Keeping to a healthy weight has lots of benefits. It reduces the risk of other medical conditions. We have more information in our booklet **Managing weight gain after cancer treatment** (see page 82).

Weight loss

If you have lost weight or are having difficulties eating, ask your cancer team for advice. There are different ways to add calories 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** (see page 82).

Follow sensible drinking guidelines

NHS guidelines suggest that both men and women should:

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

A unit of alcohol is:

- half a pint of ordinary-strength beer, lager or cider
- one 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**

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, stalls 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 look out for, 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 local physical activity groups.

Find ways to reduce stress

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

- talk about your feelings with family, friends, health professionals or people going through a similar experience
- do things you enjoy, such as spending time with family and 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.

We have more information in our booklet **Cancer and complementary therapies** (see page 82).

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





YOUR FEELINGS AND RELATIONSHIPS

Your feelings	60
Talking to someone or sharing your experience	64
Relationships	66

Your feelings

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

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.

Support groups and online social networks, such as our Online Community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)), let you talk to people who have been through a similar experience to you. You can use these groups and networks to find out what has helped them cope. Knowing you are not the only one who feels a certain way can be helpful.

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.

Uncertainty

Uncertainty about your future and worrying about the cancer coming back is hard to cope with. These worries usually get easier to manage as you focus on other things in your life. Thinking about things that you can control may 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.

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.

I did find myself in a very low place. I had a clear scan and should have been celebrating but I just felt really low. I was very lucky to have a supportive GP and when I told him how I was feeling, he said he wasn't surprised. He gave me medication and I had counselling which really helped me.

Daloni, diagnosed with womb cancer

Low mood and depression

Usually, sadness, low mood and anxiety 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 and 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 they will help.

We have more information in our booklet **Your feelings after cancer treatment** (see page 82).

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 have been, or are in, a similar situation. You can share your experiences and ways of coping. Support groups can help if you live alone. They can also help if you do not feel able to talk about your feelings with people close to you. You can go along to see what a support group is like before you decide to get involved.

You may find it helpful to join our Online Community (see page 84). 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.

On the Online Community I found women who had gone through very similar experiences to me. They were 2 years further on, saying “I’m alive.” At a time when I was really very frightened about my future, it was a huge weight off my shoulders to see these women living normal lives.

**Daloni, diagnosed
with womb cancer**

Relationships

Going through an experience like cancer can strengthen your relationships with people close to you. People often say they would not have coped without the love and support of family and friends.

But 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 see things more clearly.

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 primary care team for more advice.

We have more information about cancer for you and your partner in our booklet **Cancer and relationships: support for partners, families and friends** (see page 82).

Family and friends

Your family and 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 and 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** (see page 82).

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 your cancer experience. 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 if you cannot have children. You may be concerned if they will be able to give you the support you need.

But having a new relationship can be an enjoyable challenge. 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 your cancer experience. But it may be better to talk about it before the relationship gets serious.

WORK, FINANCES AND TRAVEL

Work	73
Travel	75
Financial help and benefits	77



I found it really helpful to have some great colleagues who I could talk to about what was happening to me. They were very supportive and continue to be during my recovery while I am off work.

Anne, diagnosed with womb cancer

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 and friends about how you feel so they can support you.

You may decide you want to do a different kind of job, or to 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 consider making reasonable adjustments (changes) to help your return to work.

Making reasonable adjustments

Both the Equality Act and the Disability Discrimination Act 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, such as 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 are in a wheelchair
- making sure you can get to the toilet easily.

We have further information about work and cancer in our booklets **Work and cancer** and **Self-employment and cancer** (see page 82). This includes advice on finances when you return to work and on finding a new job.

Travel

You may think about having a holiday after treatment. This can be something positive to look forward to. 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.

You may need to plan some things before you travel, for example taking medicines with you. Talk to your cancer doctor or 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, or targeted therapy drugs, you may be more sensitive to the sun. You will need to be very careful. Wear sun cream with a high sun protection factor (at least SPF 30) and cover up with clothing and a hat.

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 in our booklet **Travel and cancer** (see page 82).



Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

More information

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 one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see pages 88 to 89).

Our booklet **Help with the cost of cancer** has lots more information (see page 82).



FURTHER INFORMATION

About our information	82
Other ways we can help you	83
Other useful organisations	86
Your notes and questions	91
Can you do something to help?	95

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](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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](https://www.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
- eBooks
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](https://www.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**.

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. Our cancer support specialists can:

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

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

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

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.

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

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

Help with work and cancer

Whether you 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](https://www.macmillan.org.uk/work)**

Work support

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

Other useful organisations

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

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**

www.cancerblackcare.org.uk

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

Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)

Email **nurseline@cancerfocusni.org**

www.cancerfocusni.org

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

Cancer Support Scotland

Tel **0800 652 4531** (Mon to Fri, 9am to 5pm)

Email **info@cancersupportscotland.org**

www.cancersupportscotland.org

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

Maggie's Centres

Tel **0300 123 1801**

Email **enquiries@maggiescentres.org**

www.maggiescentres.org

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

Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 9.30am to 5pm)

Email **helpline@pennybrohn.org.uk**

www.pennybrohn.org.uk

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

Tenovus

Helpline **0808 808 1010** (Mon to Fri, 9am to 5pm, and Sat and Sun 10am to 1pm)

Email **info@tenovuscancercare.org.uk**

www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 9am to 5pm)

Email **bacp@bacp.co.uk**

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 their 'How to find a therapist' page.

Emotional and mental health support

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.

Financial support or legal advice and information

Citizens Advice

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

England

Helpline **03444 111 444**

www.citizensadvice.org.uk

Wales

Helpline **03444 77 2020**

www.citizensadvice.org.uk/wales

Scotland

Helpline **0808 800 9060**

www.cas.org.uk

Northern Ireland

Helpline **0800 028 1881**

www.citizensadvice.co.uk

Equipment and advice on living with a disability

Disabled Living Foundation (DLF)

Helpline **0300 999 0004** (Mon to Fri, 10am to 4pm)

Email **info@dlf.org.uk**

www.dlf.org.uk

Provides free, impartial advice about all types of disability equipment and mobility products.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 10am to 6pm)

Email **helpline@lgbt.foundation**

www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling.

The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel 020 7654 8000

Email enquiries@phe.gov.uk

www.ncras.nhs.uk

Tel (Ireland) 021 4318 014

www.ncri.ie

Scottish Cancer Registry

Tel 0131 275 7050

Email nss.csd@nhs.net

www.isdscotland.org/health-topics/cancerscottishcancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500

Email general.enquiries@wales.nhs.uk

www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028

Email nicr@qub.ac.uk

www.qub.ac.uk/nicr



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 Prof Tim Iveson, Macmillan Chief Medical Editor.

With thanks to: Dr Dennis Colligan, Macmillan GP; Professor Deborah Fenlon, Professor of Nursing; Professor Diana Greenfield, Consultant Nurse in Specialist Cancer Services; Alison Hill, Macmillan Director of Nursing for Cancer, Palliative Care and End of Life; Dr Pauline Love, Macmillan GP; Louise Smith, Macmillan Cancer Information Specialist and Survivorship Lead; Dr Claire Taylor, Macmillan Nurse Consultant in Colorectal Cancer; Avril Van der Loo, Macmillan Recovery Package Programme Manager; and Jane Wraight, Clinical Nurse Specialist.

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

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

European Society for Medical Oncology: Supporting self-management of patients and family members. 2019.

Macmillan Cancer Support. Providing personalised care for people living with cancer: a guide for professionals providing holistic needs assessments, care and support planning. 2019.

Maher, J et al. Implementation of nationwide cancer survivorship plans: Experience from the UK. *Journal of Cancer Policy*. 2018. Vol 15, pp 76-81.

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

Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

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

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

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



Registered with
**FUNDRAISING
REGULATOR**



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

This booklet is for anyone who has finished cancer treatment. There is also information for carers, family members and friends.

The booklet talks about the coping after cancer treatment. It explains about side effects, follow up care, emotional effects and making healthy lifestyle changes. It also has information about work and finances.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

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

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

**MACMILLAN
CANCER SUPPORT**

© Macmillan Cancer Support, July 2020. 9th edition. MAC11661_E09.
Next planned review July 2023. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. Printed on sustainable material. Please recycle.

