MACMILLAN CANCER SUPPORT

LIFE AFTER CANCER TREATMENT





About this booklet

This booklet is for people who are preparing for life after treatment. It has information on follow-up care, managing treatment effects and making healthy lifestyle changes.

For some people, the end of treatment means they are not likely to need any further cancer treatment. While for others, their treatment may be about managing the cancer over a long period of time.

You may still have side effects and be coping with mixed feelings. You will probably need time to find out what is now normal for you. It can take from a few weeks to a few months to re-adjust.

You will usually feel relieved when treatment is over and keen to get back to everyday life. You might be able to now take back some control over your life and choices. You may be thinking about positive changes you can make. For example, this could be focusing on your well-being or planning new things you want to do. You can still get support from health professionals, cancer organisations and self-help groups. You also have valuable experience to share with others.

We hope this information helps you cope with the challenges you may be facing and to live well after treatment. If you find this booklet helpful, you could give it to your family and friends. They may also want information so they can understand how you are feeling and how to support you.

How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on page 3 to help you.

On pages 81 to 87, there are some contact details of other useful organisations. If you want to write down notes or questions, there is space on pages 88 to 89.

Quotes

Throughout this booklet, we have included quotes from people who have finished their cancer treatment. Some of them are from people who have chosen to share their experiences with us by becoming a Cancer Voice. Visit macmillan.org.uk/cancervoices to find out more. Some names have been changed.

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**, Monday to Friday, 9am 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.

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FINISHING TREATMENT

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Preparing for the end of treatment

As you come to the end of your treatment, you usually have a discussion with someone from your cancer team. Your discussion will usually be with your specialist doctor or nurse, or another health professional. They will talk to you about what to expect after treatment finishes. They will also ask you about any concerns or specific needs you have.

In some hospitals, this discussion is called a Holistic Needs Assessment (HNA). You answer a set of questions about all areas of your life, to see whether you have any concerns. You then have a discussion with a member of your healthcare team, to talk about the issues you have and think of possible solutions.

You may have a **care plan** created based on your HNA. A care plan explains how you will be supported now and in the future, and other services that may be useful. You should be given a copy that you can share with other members of your healthcare team. You can update your care plan whenever you need to.

Some hospitals create a document called a **treatment summary**. It usually includes:

- the treatment you have had
- what to expect after treatment
- any follow-up care or tests you need (see pages 16 to 21)
- contact details of your cancer team.

You will be given a copy to keep and the hospital should send another copy to your GP.

Holistic Needs Assessments, care plans and treatment summaries are not standard practice in all hospitals. But more hospitals are doing them. It may happen in the ways we have described, or it could be done in a more informal way. You will always have the chance to talk to someone from your cancer team before your treatment ends. It is a good idea to prepare for this and think about what you would like to ask.

You may hear some health professionals talk about the Recovery Package. This is a term that combines all the options above. It also includes a Cancer Care Review (see page 8) with your GP and information about any health and well-being events. It is aimed at improving your quality of life during and after treatment.

We have more information about HNAs, care plans and treatment summaries in our leaflet Your support and follow-up care. See page 76 for information on how to order this.

Having a Cancer Care Review

You may see your GP or practice nurse about six months after you have been diagnosed with cancer. This is sometimes called a Cancer Care Review. They will talk to you about the cancer and the treatment you have had. They can help you understand which symptoms to look out for and when you might need to contact your cancer team for advice.

It is a chance to talk about how you are feeling, if your concerns have changed and any new worries that you have. Your GP can tell you about the kind of support that is available in your area. If you have a care plan or treatment summary (see page 6), take these with you when you see your GP.

Even if your GP does not routinely do Cancer Care Reviews, they can still give you support and advice.

Getting support

Ask who your main contact will be when you finish treatment. This person is sometimes called your **key worker**. They may be your clinical nurse specialist (CNS) or another member of your cancer team. You can contact them if you have any concerns about the cancer or treatment. Store their contact details in your mobile phone or somewhere you can find them easily.

You could also see your GP to let them know you are coming to the end of treatment and talk about any concerns you may have. Knowing what to expect can help you to adjust to life after treatment. Some things you may want to ask include:

- how often you will have regular reviews or check-ups and how long for (for example, 1 to 2 years or longer)
- what regular blood tests, scans or tests you may need and how often will they be done
- are there any signs or symptoms you should look out for and let your cancer team know about (see pages 22 to 23)
- how to contact your team quickly (directly or through your GP) if you are worried.

You may also want information and advice about:

- managing any side effects or symptoms you have
- any late effects (side effects that can happen months or years later) of the treatments you have had, and anything you can do to reduce the risk of these (see pages 34 to 37)
- anything you can do that may reduce the risk of the cancer coming back
- what you can do to stay generally healthy and well (see pages 43 to 51)
- if there are any health and well-being clinics or events, physical activity or survivorship programmes you can attend.

'I had 18 months of treatment and when you get to the end, everybody around you thinks, "Oh, you're better now". But in fact, that's just the start of it."

Adam

Beginning to recover

Although you may feel ready to get on with life after treatment, it is common to have mixed feelings. You may have days when you feel anxious or uncertain about the future or less positive about your health.

Recovery is a gradual process. Some days you will feel a little better than others. You need time to build up your physical strength and to process what you have been through.

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

Things that can help you during recovery

- Pace yourself so that you save your energy for the things you really want to do.
- Let your family and friends know how they can help.
- Try to eat healthily (see pages 48 to 49).
- Think about ways to reduce stress (see page 51).
- Get the right balance of resting and being active (see page 46). Sitting or lying down too much can make you feel tired for longer.
- Talk about how you feel. If you need extra support, contact a support group (see page 57) or ask your hospital team or GP to refer you to someone who can help.

Setting goals

How quickly it takes to get back to doing everyday things depends on your type of cancer, treatment and general health. Try not to rush things. Think about your recovery as small, achievable goals you can manage and build up. For example, a goal could be going for a walk or trying to eat healthily most days. You can be flexible with yourself.

Setting goals, whether big or small, and working towards achieving them can bring different benefits. It can help you to focus on what you can do and help you to feel more in control. As you achieve a goal, your confidence will start to grow. Remember to notice every success, no matter how small. For example, you might want to reward yourself by doing something you enjoyed before you had cancer.

You may need to push yourself to do things you are less confident about doing, such as going out. Start with simple things like a short walk with family or friends, or going to a cafe. Over time, you will gradually find yourself getting back into the routine of everyday life. Other things will start taking over and cancer will become less of a focus for you. You may go out more and see friends, go on holiday, get back into sport or hobbies, or go back to work. There is more information about going back to work on pages 64 to 67.

> 'Take it easy and one day at a time. Remember how far you have come and what you have dealt with. Then slowly, your confidence will start to increase.

Karin, Online Community member

Changes to your outlook on life

Your cancer experience may change your outlook on life. Or you may find you think about things differently than you did before. Some people decide on what is important to them and make new priorities. You may discover new interests or decide to make lifestyle changes to improve your well-being or to find ways of reducing stress in your life (see pages 43 to 51).

> 'My whole outlook on life has changed. Rather than thinking things like, "How much do I want to work and earn?", I now think, "How much do I need to earn and do I want to do that?"."

Sandra



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Follow-up care

How often you see your cancer team for follow-up care (check-ups) after treatment depends on different things. This includes the type and stage of the cancer, the treatment you have had and your individual needs. It also depends on the arrangements at the hospital you attend.

Types of follow-up care

There are different types of follow-up care. Most people are followed up at the hospital with their cancer doctor, surgeon or nurse. These check-ups are usually every few months in the first year. After the first year, you will have fewer check-ups. You may not need to continue going to the hospital in the future.

Some people may have their follow-up over the telephone with a specialist nurse (see page 20), instead of going to a clinic. Or you may be asked to contact your healthcare team when you need support or have a new problem or concern. If you are offered this type of follow-up care, always make sure you contact your nurse if you are worried about anything. If you don't get in touch, they will assume that you are fine. Other people may just see their GP for follow-up appointments.

Your cancer doctor or nurse will usually tell you the type of follow-up care you will have. You may decide together what would be best for your situation.

What you can do

Your cancer team may give you advice on what you can do after treatment finishes. For example, they may suggest doing certain exercises to improve movement, or being more physically active (see page 46). They may also tell you what symptoms to look out for.

If you are taking any medicines, for example hormonal therapy, it is important to take it exactly as your cancer team explains.

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.

Macmillan offers courses and workshops to support you. There are a range of online courses, including HOPE (Help to Overcome Problems Effectively). This is a free, short online course that looks at ways to manage the impact of living with and beyond cancer. To find out more about HOPE and sign up for our online courses, visit learnzone.org.uk

Your local Macmillan information and support centre, or a cancer support group, can tell you if there are any local courses. Visit macmillan.org.uk/inyourarea to find an information and support centre or a support group near you.

Your follow-up appointment

The aim of your follow-up appointment is to make sure everything is going well and find out if you have any concerns. The appointment helps your doctor or nurse notice any possible problems early on. 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 been experiencing.

If you want more information about your treatment or follow-up care, you can ask for copies of the letters your cancer team sends to your GP. You can also ask for your treatment summary (see page 6) to be sent to you.

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 a difficult reminder of what you have been through. But it can also be a positive reminder that you are getting back to everyday life. People are often reassured after their visit.

Be open and honest with your doctors and nurses. They need information from you to give you the best care. Your cancer team can refer you to other services if you need specialist help. For example, you may be referred to a psychologist or counsellor for emotional help, or a physiotherapist for advice on exercising.

Tips for getting the most from your appointment

- Write down your main questions before your appointment. You can also write down the answers when you are there, if it helps you remember them. There is space on pages 88 to 89 to write down any questions or information.
- Take someone with you for support and to help remember what was said.
- Always let your doctor or nurse know about any on-going or new symptoms, or other health worries. Try to be open and honest with them.
- Tell them how you are coping with your feelings. They can give you advice or direct you to the right place for support.
- Let them know about any prescribed or non-prescribed medicines you are taking. This includes vitamins, minerals, or herbal or complementary medicines. Occasionally, these can interfere with other drugs, including some anti-cancer (cytotoxic) treatments.

Nurse-led telephone follow-up

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

You may have regular appointments when your nurse phones you and asks some questions. Or you may have an arrangement where you contact your nurse if there is anything you are worried about.

You will still have any regular tests or scans if you need them. If your nurse thinks anything needs to be checked further, they will arrange for you to see your cancer doctor immediately.

This type of follow-up is sometimes called self-management. Your nurse will give you information to help you manage your health. This could include information on:

- side effects (see pages 27 to 41)
- symptoms to look out for (see pages 22 to 23)
- what you can do to keep healthy (see pages 43 to 51)
- places to get support.

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

Your GP

Your GP can offer support during and after treatment. If you have not seen your GP during treatment, it is a good idea to make an appointment with them when it finishes. Your cancer team will send them a report about your treatment. It is always worth telling your GP about any problems you need help with.

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

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

- recovering (see pages 11 to 13)
- maintaining a healthy lifestyle (see pages 43 to 51)
- work (see pages 64 to 67)
- certain benefits and financial support (see pages 68 to 71).

The GP surgery may also be able to support people close to you.

Remember to continue going to any regular checks you usually have at your GP surgery. These may include blood pressure checks or cervical screening for women. It is important to look after your general health.

Be aware of symptoms

When treatment has finished, it is common to worry that every ache and pain you have is linked to cancer. You will still be getting used to what now feels normal for you. You will also get the usual aches and pains that most people get. This means it can be 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 that may develop because of your treatment and what the symptoms are (see pages 34 to 37).

Knowing more can help you put things into perspective. Always make sure you get your symptoms checked, even if you think they are not serious. Let your cancer doctor or nurse know if you have any new symptoms or similar symptoms to 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 due to 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 (check-up) appointment to contact your cancer doctor or nurse. Make sure you have their contact numbers to get in touch with them. They can arrange to see you or reassure you if the symptoms are most likely to be from your treatment.

Although it is important to be aware of changes in your body, constantly checking for symptoms or changes can make you feel more anxious. People may do this when they are finding it hard to cope with uncertainty and worrying about the cancer coming back (see page 24). If you find yourself doing this, talk to your doctor, specialist nurse or GP.

> 'If I find anything abnormal on my body or if I have a cough, whatever it might be, my immediate reaction is, "Oh my god, is this coming back again?"."

Charlie

Worrying about cancer coming back

Worrying about the cancer coming back and struggling to cope with feelings of uncertainty is common after treatment. It can be hard to deal with but often gets better as you recover. Certain situations may trigger these feelings. For example, this could be going back to the hospital for a test, or reading or hearing something about cancer in the news.

There are different ways to help you manage worry and uncertainty. For example, try to focus on what you can control and do now rather than worrying about things that may never happen. This could include:

- getting involved in your recovery and focusing on your well-being (see pages 43 to 51)
- talking about your feelings and getting support (see pages 54 to 57)
- finding helpful ways of managing anxiety and stress (see page 51)
- getting back into activities you enjoyed before or starting new ones
- going back to work (see pages 64 to 67).

You can also talk to your doctor, specialist nurse or GP. They can give you advice on ways to manage your worries.

We have a leaflet called Worrying about cancer coming back that can help you deal with your worries. See page 76 for ways to order this.





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Side effects of treatment

Although your treatment is over, you may still be coping with side effects from your treatment. In this section, we have included some examples of possible side effects after treatment. We also have more information about the different types of cancer and cancer treatments. See page 76 for ways to order this information.

After treatment, some people may also be adjusting to permanent body changes (see page 32) because of treatments such as surgery.

If you are still taking hormonal therapy or a targeted therapy drug, you may have on-going side effects (see page 33). These drugs can be given for a few years or longer to reduce the risk of the cancer coming back.

Treatment side effects usually gradually go away after treatment finishes. But some take weeks or even months to improve. Occasionally, certain side effects become permanent or they may develop months or years after treatment. These are called late effects of treatment (see pages 34 to 37).

Always let your cancer doctor or nurse know 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 (fatique)

Most people are very tired when treatment finishes. You may find it hard to do simple day-to-day things. You might also have trouble concentrating on anything for long. This can last for a few weeks or months, or occasionally longer. This will gradually get better.

Plan your day and pace yourself so you have time to do the things you most want to do. Try to get a good balance between getting plenty of rest and being active. Taking some gentle exercise can help reduce tiredness (see page 46). You can gradually increase how much you do as you get used to exercising.

Our booklet Coping with fatigue has lots of tips that may help you manage tiredness. See page 76 for information on how to order this.

> 'I set myself goals to deal with fatigue. I started off doing little things, like tasks around the house. Just bits at a time. Slowly, my fatigue started to improve.

Denton

Pain

Occasionally, cancer treatments can result in on-going (chronic) pain. Surgery or radiotherapy may limit your movement or damage nerves in the treated area. This can cause pain or discomfort that may take weeks or sometimes months to improve.

If you are in pain, let your cancer team know. They may be able to prescribe drugs or a treatment to control the pain. They can also refer you to a pain specialist if needed. A referral to a physiotherapist may help to make sure you have as much movement as possible. An occupational therapist may also be able to help by providing splints to support painful joints. They can also give you some aids or equipment to help make it easier to do certain things at home.

It is important to keep up with any exercises you have been asked to do. This can prevent problems with pain in the future. Contact your physiotherapist or doctor if you are having difficulties doing your exercises.

We have a booklet called **Managing cancer pain**, which you may find helpful. See page 76 for ways to order this.

Peripheral neuropathy

Some chemotherapy drugs can damage the nerves in your feet, leas, hands and arms. This is called peripheral neuropathy. You may notice numbness or tingling and have difficulty with tasks, such as doing up small buttons. Always tell your doctor or nurse if you have these symptoms. They can prescribe drugs to control nerve pain and give you advice on how to manage it.

Peripheral neuropathy may gradually improve when treatment is over, but for some people it can be permanent.

Bowel and bladder side effects

Treatment with surgery or radiotherapy to the lower tummy area (pelvis) can cause side effects such as diarrhoea or needing to pass wee (urine) more often. These may take up to a few weeks after treatment has finished to go away. Tell your doctor if they don't improve.

Follow any advice you have been given at the hospital about changing your diet. If you have diarrhoea, you should drink plenty of fluids. Your doctor can prescribe drugs to control diarrhoea.

With bladder side effects, it is important to drink plenty of fluids. Drink at least 2 to 3 litres (3.5 to 5.5 pints) of fluids a day. Your doctor can prescribe anti-inflammatory drugs to help improve 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. If you have had treatment to your head or neck area, it may have affected the way you eat. These problems often improve over time as you learn to cope with them.

Always ask a dietitian on your cancer team to advise you about eating difficulties. Getting enough energy and nutrition from your diet is important to help you to recover. There are different supplement drinks you can take. Some of these are available on prescription. If your weight has changed during treatment. you may want to look at ways of getting to a healthy weight.

Our booklet **Eating problems and cancer** may help you. See page 76 for information on how to order this.

Concerns about body image

Coping with changes in how your body looks or works because of treatment effects can be difficult. It can affect how you see and feel about your body image. Body image is the picture in your mind of how your body looks and works. It can also affect your self-esteem, your confidence and how you feel about yourself sexually. It is important to let your cancer doctor or nurse know if you have concerns about your body image. There are different ways they can help and support you.

If you have a partner, you may worry about their reaction. It helps to try to talk as openly as you can with each other. You may both need some time to adjust. Sometimes it can help to talk to a psychologist, a counsellor or a support group. You can ask your doctor or nurse to arrange this for you.

Our booklet **Body image and cancer** has more information. See page 76 for ways to order this.

'After I had my mastectomy, I felt very strange. It didn't feel like it was my body. It took a little while to get myself to look in the mirror.'

Heather

On-going treatment effects

After treatment is finished, some people may have on-going treatment, for example with a hormonal therapy or a targeted therapy drug. These treatments may be given to reduce the risk of the cancer coming back. If you have side effects, some may improve within a few months of starting the drug. Others can usually be managed in different ways.

Always talk to your cancer doctor or nurse about any side effects, especially if they are affecting your quality of life. It is very important that you do not stop taking any on-going treatment without talking to your doctor first, as it may affect the success of your treatment. They can usually suggest ways to help or make changes to the way you take the drug. If these do not work, they may suggest changing the drug.



Late effects of treatment

Late effects of treatment are side effects that can develop many months or years after treatment finishes. Or they may be side effects that carry on for longer and don't go away.

Your doctor or specialist nurse can explain the risk of any possible late effects of your treatment. You can ask for advice on possible signs or symptoms to look out for. They can also tell you if there is anything you can do to help reduce the risk of certain late effects. This could include not smoking, keeping to a healthy weight and being more physically active (see pages 45 to 49).

It is very important to tell your doctor about any new symptoms you get or if the symptoms you have don't improve.

We have included examples of some possible late effects. We have not listed them all. Visit macmillan.org.uk to find more information about late effects. You can also call us on **0808 808 00 00** to order the information you need.

Lymphoedema

Radiotherapy or surgery to lymph nodes may cause a swelling called lymphoedema. There is a higher risk of lymphoedema if you had both treatments. Lymphoedema usually affects an arm or a lea, but can also affect other parts of the body. It depends which area was treated

Follow the advice from your nurse to reduce your risk. This includes looking after and protecting the skin in the area at risk of lymphoedema. If you notice any swelling, always ask your doctor or nurse to check it. The earlier lymphoedema is diagnosed, the easier it is to manage and treat successfully.

Effects on your heart

Certain cancer treatments may increase the risk of different types of heart problems in the future. Many people who have these drugs or treatments do not develop any heart problems. You can ask your doctor or nurse if there is a possible risk of this late effect with the treatment you have had.

There are things you can do to help look after your heart health. Stopping smoking is very important. Being physically active and keeping to a healthy weight will also help to look after your heart.

Chemotherapy drugs

Drugs called anthracyclines are the most common drugs to affect the heart. They include:

- doxorubicin (Adriamycin®)
- epirubicin (Pharmorubicin®)
- daunorubicin
- idarubicin (Zavedos®)
- mitoxantrone.

Some other chemotherapy drugs may also affect the heart.

Targeted therapy drugs

The following targeted therapy drugs can cause different types of heart problems:

- trastuzumab (Herceptin®)
- bevacizumab (Avastin®)
- imatinib (Glivec[®])
- sorafenib (Nexavar®)
- sunitinib (Sutent®).

Hormonal therapy drugs

Hormonal therapies are usually used to treat breast or prostate cancer. They can increase your risk of heart problems. They include:

- tamoxifen
- anastrozole (Arimidex®)
- letrozole (Femara®)
- goserelin (for breast and prostate cancer).

Radiotherapy given close to the heart

Radiotherapy is only a possible risk if you have it to the left breast or the middle of the chest. Improvements in radiotherapy techniques mean this is less likely to be a problem.

Effects on the bones

Hormonal therapy drugs can also increase the risk of bone thinning (osteoporosis) and fractures. Having pelvic radiotherapy may also increase the risk of getting small fractures in the pelvis. Weight-bearing exercise, such as walking and resistance exercise, and a healthy balanced diet can help to look after your bones.

Effects on the head and neck

Radiotherapy to the head and neck can cause late effects. For example, it can cause a dry mouth because you have less saliva or saliva may be stickier. Some people may lose their sense of taste. A dry mouth can often be managed by taking artificial saliva products and having sips of water often. Using a sodium bicarbonate mouthwash may help clear thick saliva.

After treatment, it is important to follow the 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.

Both surgery and radiotherapy can affect eating and speech. Specialist health professionals, such as dietitians and speech therapists, can help with changes to eating and speech.

Effects on the bowel and bladder

Radiotherapy to the lower tummy area (pelvis) can cause late effects of the bowel and bladder. These can often be managed or treated successfully. If the symptoms don't improve, your doctor can refer you to a bowel or bladder specialist.

Some people may have changes to their bowel habit, such as diarrhoea or constipation. Changing your diet to reduce foods high in fibre can often help manage bowel problems. You can also take medicines to help control diarrhoea or constipation.

Effects on the bladder can mean you need to pass wee (urine) more often and some people may get some leakage. Drinking plenty of fluids and keeping to a healthy weight can help to relieve pressure on your pelvic floor. Bladder training and pelvic floor exercises can also help.

Second cancer

Certain cancer treatments may slightly increase the risk of developing another cancer in the future. But the chances of this happening are low and the benefits of treatment will far outweigh any risk. Your doctor or nurse can give you more information about this.

Sex and fertility

Changes to your sex life

After treatment is over, you may experience difficulties with your sex life. Anxiety, tiredness, and other side effects may mean sex is the last thing on your mind. Some cancer 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 cancer or its treatments have changed your appearance because of cancer, this can cause concerns about your body image (see page 32). Changes to how your body looks or works may make you feel less feminine or masculine and affect your sex life. Over time and with the right support, people often find they are able to adjust. Your specialist nurse and other health professionals can support you. They can explain ways you can manage body changes and where to get support.

Let your doctor or nurse know if you are having problems. They may be able to reassure you or give you advice. Some people may find it helpful to talk to a sex therapist.

Sometimes it can help to talk to a psychologist, a counsellor or a support group (see page 57). You can ask your doctor or nurse to arrange this for you.

Visit macmillan.org.uk/sex for more information about how cancer treatment can affect your sexuality and sex life.

Effects on women

Some treatments can bring on an early menopause, which can cause symptoms such as hot flushes, vaginal dryness and loss of sex drive. Radiotherapy to the pelvis can cause vaginal dryness and narrowing of the vagina caused by scarring, which can affect your sex life. Your specialist nurse or radiographer will usually talk to you about ways of trying to prevent narrowing, such as using vaginal dilators. You can also buy creams or lubricants to improve dryness and make having sex more comfortable. There are also creams or gels that your doctor can prescribe.

There are different ways to manage menopausal symptoms. Your specialist nurse can give you advice. If you do not have a cancer that is dependent on hormones to grow, hormone replacement therapy (HRT) may be suitable for you. You can talk to your cancer doctor or nurse about this.

> 'There is sex afterwards, there are relationships, and there's love afterwards. You may be a different person and you may have a different approach to things, but it gets better.'

Helen

Effects on men

Surgery or radiotherapy to the pelvic area or on-going hormonal therapy may cause difficulties getting or keeping an erection. Your doctor can prescribe drugs to help with this or refer you to a specialist clinic. If you cannot take these drugs or if they do not work for you, there are other methods that can help with erections, such as vacuum pumps.

Some men may have changes in their levels of testosterone because of treatments they have had. This may cause difficulties with energy levels, mood and affect your sex life. You can ask your cancer doctor about having your hormone levels checked. Sometimes it is possible to have hormone replacement therapy (HRT), unless you had a cancer that is hormone dependent, such as prostate cancer.

If you have a partner

If you have a partner, you may worry about their reaction to a body change. 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 your changed appearance.

Partners may sometimes mistakenly worry that they could 'catch' the cancer, or that having sex could make the cancer worse. Or they may feel you have lost interest in them or that your feelings 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 don't feel like having sex.

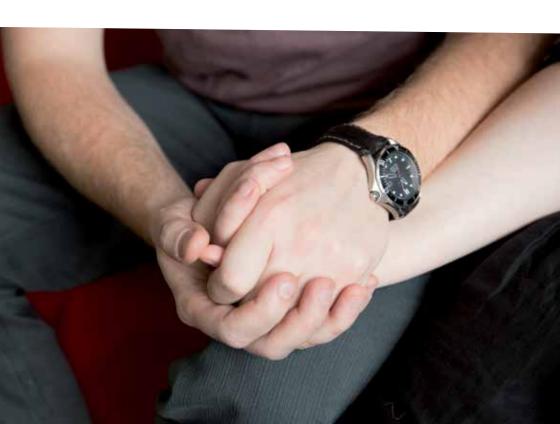
Difficulties often gradually improve as you recover from treatment, although sometimes it may take longer. Talking about problems and concerns about your sex life with your partner can help to sort out any misunderstandings. It can also reassure you that your feelings for each other have not changed.

Fertility

Some cancer treatments can result in not being able to father a child or get pregnant (infertility). Sometimes this can be temporary, but in some people it will be permanent. Your cancer doctor or nurse will talk to you about the effects of your treatment on your fertility.

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

We have more booklets about fertility for men and women. See page 76 for information on how to order these.





LIFESTYLE AND WELL-BEING

Improving your lifestyle after treatment

44

Improving your lifestyle after treatment

After treatment and as part of your recovery, you may decide to think about ways to improve your well-being and long-term health. Your cancer team and GP can give you advice on this. You could ask if there are any health and well-being clinics or events in your area. These may be run by volunteers and Macmillan professionals, or by some hospitals. They can give you support and advice on diet, lifestyle and adjusting to life after treatment.

We have included a few suggestions on some changes that can have a positive effect on your health and well-being.



Stop smoking

If you smoke, stopping is the healthiest decision you can make. Smoking increases your risk of heart disease, stroke and developing new cancers. Smoking can also make some late effects of treatment worse, such as bladder or bowel problems (see page 37).

Giving up smoking is not easy. Using a treatment with help from an NHS support service or your GP gives you the best chance of success. There are support groups available for people trying to guit, as well as one-to-one support. Ask your GP for advice, or contact one of these national stop smoking services:

- In England, visit nhs.uk/smokefree or call the free Smokefree National Helpline on 0300 123 1044 (Monday to Friday, 9am to 8pm, and Saturday and Sunday, 11am to 4pm).
- In Scotland, visit canstopsmoking.com or call the free Smokeline on 0800 84 84 84 (Monday to Friday, 8am to 10pm, and Saturday and Sunday, 9am to 5pm).
- In Wales, visit **stopsmokingwales.com** or call the free Stop Smoking Wales Helpline on 0800 085 2219 (Monday to Thursday, 8am to 8pm, Friday, 9am to 5pm, and Saturday, 9am to 4pm).
- In Northern Ireland, visit want2stop.info

We have more information about stopping smoking. Order our booklet Giving up smoking from be.macmillan.org.uk or visit macmillan.org.uk/smoking

Be more active

Gradually being more physically active is an important part of your recovery. It can also improve your long-term health and well-being. During treatment, people are often less active than usual. This can make you feel more tired and your muscles lose some strength. Even a little regular physical activity, such as short walks, will help give you more energy and make you feel stronger. It can also help reduce stress and anxiety. You can gradually build up how much activity you do. Make sure you don't do too much as this can make you feel more tired.

Some hospitals have exercise programmes for people recovering from treatment. Your doctor or specialist nurse can tell you what is available in your area. Your cancer doctor, nurse 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 can help look after your bones and your heart. It reduces the risk of heart disease, stroke, diabetes and bone thinning (osteoporosis). Regular physical activity and keeping to a healthy weight may also reduce the risk of certain cancers coming back and getting another new cancer.

Aerobic activity, such as fast walking, running, skipping, cycling, dancing and swimming, can help to protect your heart. This may also help reduce the risk of late effects developing (see pages 34 to 37).

Hormonal therapies and early menopause due to cancer treatments can increase the risk of bone thinning (osteoporosis). Weight-bearing exercises, such as walking, dancing or resistance training, help keep bones and muscles strong.

We have more information and a range of tools on our website to help you get more active - visit macmillan.org.uk/beactive



Eat healthily

Eating healthily will help your recovery and give you more energy. It can also help to keep your weight healthy. If you have eating difficulties, get advice from a dietitian or your specialist nurse before making any changes.

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)
- only a limited amount of red meat and processed meat
- some milk and dairy foods, such as cheese, butter and yoghurt
- just a small amount of foods high in fat, salt and sugar.

Treatments such as surgery to the bowel or radiotherapy to the pelvis may cause changes in how your bowel works. For some people, this may mean a diet high in fibre (fruit and vegetables) may not be suitable. If your treatment has affected the way you eat, follow the advice from your cancer team or dietitian.

Changes to your weight

Some cancer treatments may cause changes to your weight. This can be upsetting and for some people it can cause concerns about their body image (see page 32).

Some people gain weight during chemotherapy or as a side effect of hormonal therapies. Others may lose weight because of symptoms, treatments or their side effects. After treatment, try to focus on eating healthily to help your recovery. If you are worried about your weight, ask your GP or a dietitian for advice.

If you need to lose weight, it is important to do this gradually and along with being more physically active. Try to be patient with yourself. Following the tips below may help:

- Only eat as much food as you need.
- Eat a healthy diet with lots of fruit, vegetables and wholegrains.
- Limit saturated fats and sugar in your diet.

Keeping to a healthy weight has lots of benefits and reduces your risk of other medical conditions. It may also help to reduce the risk of certain cancers coming back.

If you have lost weight and are having difficulties eating, it is important to get advice from a dietitian. There are different ways to add calories to food. There are also nutritional drinks and powders you can have to help build up your weight.

Our booklet Healthy eating and cancer has tips on how to eat well and maintain a healthy body weight. See page 76 for ways to order this.

Stick to 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 three 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, or a single measure (25ml) of spirits.

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



Find ways to reduce stress

After treatment, finding ways to reduce stress and anxiety in your life can be helpful. Talking about your feelings with family, friends, a health professional or other people who have been through a similar experience can help.

Doing things you enjoy, such as spending time with family and friends, socialising or relaxing activities, can help to reduce stress. Recovery takes time, so try to be aware of your limits. Try to ask for help from others when you need it.

Regular physical activity, such as walking, can help reduce stress and anxiety. Some complementary therapies, such as relaxation, meditation and voga, may also help. They may be available at your cancer treatment hospital or through cancer support groups.

'I take care of myself now and I wouldn't have done that before. I enjoy life so much more and notice the little things, like the leaves falling or snow outside.'

Thom

'Spending a lot of time on your own, you learn a lot about yourself – about how strong you are as a person.'

Amrik, diagnosed with Hodgkin lymphoma in 2010



YOUR FEELINGS AND RELATIONSHIPS

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Your feelings

Even though your treatment is over, you may have many different and confusing feelings. This is common and many of these feelings will become easier to manage with time.

In this section, we have included some of the common feelings you may have. We have more information in our booklet **Your feelings after cancer treatment**. See page 76 for ways to order this.

Feeling alone

You might feel alone because you are no longer in regular contact with your cancer team. You can get in touch with your key contact at the hospital or talk to your GP if there is something worrying you.

There are lots of different ways you can get help. Support groups or online social networks, such as our Online Community, mean you can talk to people who have been through a similar experience. You can also find out what has helped them cope. Knowing you are not the only one who feels like this can be helpful. See page 79 for more information.

'Cancer messes with your emotions. It took me a few years before I started to feel like the real me coming back again.'

Lynda, Online Community member

Uncertainty

Uncertainty about your future and worrying about the cancer coming back (see page 24) is often the hardest thing to cope with. It usually gets easier as you gradually focus on other things in life other than the cancer. Getting on with the things that you can control may help. For example, you can:

- organise your own day
- do activities you enjoy
- get involved in your own care
- make the most of your health.

Finding ways to help you relax, such as relaxation therapy or meditation, may also help. Our booklet Cancer and complementary therapies has more information.

Anger

It is normal to feel angry about cancer and the effects of treatment. You may be dealing with infertility, menopause, changes in your appearance or effects on your sex life.

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
- taking regular exercise
- breathing or relaxation therapy.

If you are finding it hard to talk to anyone, or if you continue feeling angry, you could ask your doctor or nurse about speaking to a counsellor.

Guilt

Some people feel guilty or blame themselves or others for the cancer. Others may feel guilty because they have survived cancer when others have not. It is not usually possible to know exactly what has caused a person's cancer. Remember, the cancer is not your fault. Try to talk about these feelings and focus on caring for yourself and getting the support you need.

Sadness or depression

Usually, feelings of sadness, low mood, anxiety or anger lessen over time. If they don't get better, you probably need more support.

Signs of low mood or 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 or finding it difficult to concentrate
- symptoms like a dry mouth, a racing heart (palpitations) or difficulty sleeping.

If you think you may be depressed, talk to your family and friends. You may also want to tell your doctor or nurse. They can refer you to a counsellor or psychologist. They may prescribe anti-depressant or anti-anxiety drugs if they think this will help you. Taking regular physical activity can also help to improve low mood (see page 46).

Talking to someone or sharing your experience

Talking about your emotions can help reduce feelings of stress, anxiety and isolation. You also have valuable experience that can help others who are going through a similar situation.

Support groups or online support

Support groups offer a chance to talk to other people who have been or are in a similar situation. You can share experiences and ways of coping. They can help if you live alone or don't feel able to talk about your feelings with the people close to you. You can go along to see what a support group is like before you decide to get involved.

Our Online Community is a social networking site where you can talk to people in our chat rooms, blog about your experiences, make friends and join support groups. You can also share your feelings and get support from others.

See page 79 for more information about support groups and our Online Community.

> 'I meet with a counsellor once a week to deal with my depression. There is light at the end of the tunnel, but you may need help to see it.'

Anna, Online Community member

Relationships

Going through an experience like cancer can strengthen relationships with the people close to you. People often say that they would not have coped without the love and support from family and friends. But it is also often a stressful time and can put a strain on close relationships. Partners, family and friends will also have their own feelings to cope with. But they may try to protect each other by not being open about their fears and concerns.

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

Partners

If you have a partner, your relationship with them may become stronger. Because it can also be a stressful time, misunderstandings are not unusual. You might have different ways of expressing your feelings. Even couples who have been together for a long time won't always know how their partner is feeling.

Talking openly and listening can help you to understand each other. Although some people find it easy to talk about their feelings, not everyone is comfortable with this. Partners may show their feelings in other ways. This might include things like:

- touching your hand or putting their arm around your shoulder
- spending time with you
- doing practical things to show they care for you.

If there are difficulties in your relationship that are affecting your everyday life, it may help to speak to a professional counsellor. You can ask your cancer nurse, doctor or GP for more advice.

Our leaflet **Cancer**, you and your partner has more information. See page 76 for ways to order this.

Family and friends

You may sometimes feel that your family and friends don't understand if you are not feeling positive about getting on with life. Sometimes people have unrealistic expectations and think things will go back to how they were within a few weeks. After treatment, it can take everyone a little time to sort out their feelings and know what to expect.

Tips to help you talk to family and friends

- Be honest about how you feel. Explain that coping does not mean being positive all the time.
- Tell them about the physical effects you are still dealing with. Mention that recovery can take time.
- Let them know what you can do and what you cannot do yet, so they know what to expect.
- Ask for their emotional support and help with practical things.
- Start to plan things you enjoy doing together, such as going for a walk, having a meal or seeing a film.

Children

How children react to your illness depends on their age and level of understanding. They often need a lot of reassurance. Try to talk openly and honestly with them, but don't give too much information at one time or in advance.

Tips to help you talk to children

- Help them to understand that recovery can take time by explaining any treatment effects you are dealing with, and tell them what you still cannot yet do.
- Look for ways of getting them involved in your recovery, such as going for walks or helping with small things around the house.
- Keep to usual boundaries for behaviour and tell teachers at school what is happening so they can give extra support. Look out for any signs that they are behaving differently.
- If teenagers are finding it hard to talk to you about how they feel, encourage them to talk to someone close, such as a relative or family friend.

We have a booklet called **Talking to children and teenagers** when an adult has cancer, which may help you cope. See page 76 for ways to order this.

New relationships

If you are not in a relationship, you may worry about finding or starting one after cancer.

Cancer does not stop you from having relationships. Your experience may have made you a stronger person with more to offer in a relationship. But it is natural to worry about how the person may react when you tell them you have had cancer or how they will deal with body changes. For example, it can be difficult to talk about any sexual difficulties or to tell someone you cannot have children. You may also worry whether the person will give you the support you need.

A new relationship may be one of the challenges you want to face in a positive way. These tips might help:

- Get involved in activities you enjoy and where you can meet other people. This can help improve your confidence.
- Get advice from other people who have been through a similar experience. You could try social networking.
- You may want to wait until you feel comfortable before you tell someone new about your experience with cancer. But it may be best to talk about it sooner before the relationship gets serious.

We have videos on our website about coping with your feelings and how cancer can affect relationships. Visit macmillan.org.uk/ copingwithcancervideos



WORK, FINANCES AND TRAVEL

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Going back to work

For many people, returning to work is a big step in their recovery. It can bring back 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.

Decisions about returning to work after treatment will depend on different things. This includes your recovery and the work you do. Some people may also need to go back for financial reasons. But if possible, don't push yourself to go back too soon. Talk to your family and friends about how you feel so they can support you.

Some people may decide they want to do a different kind of job, or stop working altogether.

There are different ways your employer can support you when you return to work. They usually understand that it is a stressful time and try to be supportive. You and your manager could agree on a return-to-work plan. Make sure you are fully involved in any discussions. The law says your employer must consider making reasonable adjustments (changes) to help you – see next page.

> 'My advice is don't rush going back to work. If you have an understanding employer, they will help you until you are ready."

Mark, Online Community member

Making reasonable adjustments

Under the Equality Act 2010 and the Disability Discrimination Act 1995, employers are required to make reasonable adjustments to make sure you are not disadvantaged compared to other non-disabled people in your workplace. If you have or have had cancer, the law considers you to be disabled. If you are treated less favourably because of the cancer, it is discrimination.

Examples of reasonable adjustments include:

- a phased (gradual) return to work
- flexible working arrangements, such as part-time working, flexible start or finish times or working from home
- extra breaks, to help you cope with tiredness
- allowing you to do 'light duties' for a time
- time off for medical appointments
- making sure the environment is suited to your needs, such as toilet facilities you can get to easily or suitable access if you are using a wheelchair.

You may find you cope better if you plan to return gradually (phased return) and build up to your usual hours. You can agree this with your manager or HR department. You and your manager can also decide on the important parts of your role. You can choose what to focus on until you feel stronger.

Talk to your manager or HR department as soon as you can about any possible changes, such as flexible working, that would help you return to work. If your workplace has an occupational health adviser, you can usually refer yourself or ask your manager to refer you. An occupational health adviser will give you independent work-related health advice based on your situation. They can recommend adjustments to help you carry on working. They also help you to return to work after you have been off for a period of time

We have more information to help you manage cancer at work:

- Visit macmillan.org.uk/work to read the information online.
- Visit **be.macmillan.org.uk/work** to order free information.
- Call us on **0808 808 00 00** to order the information you need.

Finding a new job

Looking for a job can be a positive sign of recovery. But you may also wonder if you have to tell an employer you have or have had cancer.

The Equality Act 2010 means employers should only ask questions about your health in limited situations during the recruitment process. In Northern Ireland, employers can ask job applicants about their health but cannot discriminate against you because of a disability.

However, it is also important not to mislead a possible employer. So if you are pressed for an answer about your health, it may be best to be open about the cancer. But this is your decision. If you do not get the job because of this, you may be able to bring a discrimination claim against them.

Before an interview, practice how to answer any questions about your health. If you are asked about gaps in your work history, explain that you were dealing with some health issues. Tell them you are now ready to get back to work and emphasise your relevant skills and strengths.

There are different organisations that can help people with a disability to find work:

- If you live in England, Scotland or Wales, visit gov.uk/lookingfor-work-if-disabled
- If you live in Northern Ireland, visit nidirect.gov.uk/articles/ employment-support-information

Finances

It is not unusual to have money difficulties because of cancer. You may also have concerns about insurance or a mortgage.

After cancer treatment, it can be more difficult to get life insurance, car insurance or travel insurance. This can be difficult to cope with, but there is support to help you. Our financial team can give you guidance on insurance, pensions, mortgages and tax.

Being able to get insurance depends on your type of cancer, its stage and how long ago you finished treatment. You will usually be offered a higher premium (the amount of money you need to pay for insurance) than average. Our financial guides can give you information on the different types of insurance that can be affected by cancer. This includes health, life, car and travel insurance.

There are also different organisations that can put you in touch with an insurance broker or a financial adviser. Our financial guides can advise you on who to contact. Call our support line on **0808 808 00 00** to speak to a financial guide.

Benefits and financial help

There are different benefits you may be able to claim. Our welfare rights advisers can help you apply. They can also give you advice on other financial support that is available, such as Macmillan Grants (see page 80).

You may also be able to meet a Macmillan welfare rights adviser in your area. Visit macmillan.org.uk/inyourarea to see where this service is available near you.

Other organisations, such as your local Citizens Advice, can also help (see page 85 for contact details).

Statutory Sick Pay

If you are employed but unable to work, you can usually get Statutory Sick Pay (SSP). Your employer will pay SSP for up to 28 weeks. The weekly rate is currently £88.45 a week. Many employers run their own sick pay scheme with more generous payments and terms than the statutory minimum.

Before SSP ends, find out whether you can get a benefit called Employment and Support Allowance (ESA) – see page 70.

Employment and Support Allowance

This benefit is for people under retirement age who cannot work because they are ill or disabled.

There are two types of Employment and Support Allowance (ESA):

- contribution-based you can get this if you have made enough National Insurance contributions
- income-related you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit has started replacing income-related ESA in England, Scotland and Wales.

ESA is currently paid at a basic rate of up to £73.10 a week for the first 13 weeks. Some people may need an assessment to see how their illness limits their ability to work. This is called a work capability assessment.

If you qualify for ESA, after 13 weeks you are placed in either the work-related activity group or the support group. If you are waiting for, having, or recovering from cancer treatment, such as chemotherapy or radiotherapy, you are placed in the support group. You get a smaller extra weekly payment in addition to the basic rate. You do not need a work assessment.

If your ability to work is limited, but not severely, you are placed in the work-related activity group. You get a smaller extra payment in addition to the basic rate. This benefit is paid for up to a year. After this, it stops unless you claim and qualify for income-related ESA (or Universal Credit), or ask to be placed in the support group and are accepted.

More information

We have more information on benefits and financial support:

- Visit macmillan.org.uk/benefits to read the information online.
- Visit **be.macmillan.org.uk/finances** to order free information.
- Call us on 0808 808 00 00 to order the information you need.



Trave

You may be thinking about planning a holiday after treatment. This can be something positive to look forward to and 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 give any side effects time to improve.

You may have some things to think about and plan for 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. 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 a high sun protection factor (at least SPF 30) and cover up with clothing and a hat.

Travel insurance

You may find that it is 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 travelling after cancer treatment and travel insurance. Visit macmillan.org.uk/travel or call us on 0808 808 00 00 to order the information you need.





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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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available at macmillan.org. uk/information-and-support There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

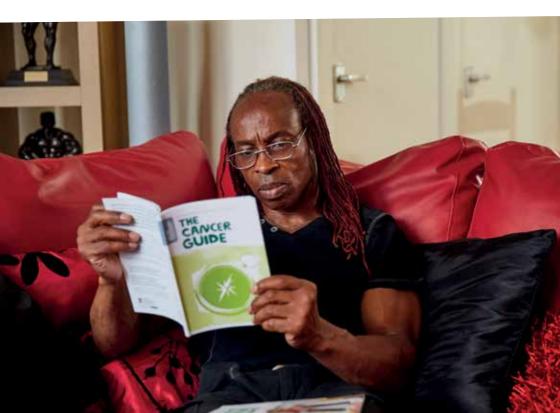
Find out more at macmillan. org.uk/otherformats If you'd like us to produce information in a different format for you, email us at cancerinformationteam@ macmillan.org.uk or call us on 0808 808 00 00.

Help us improve our information

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open Monday to Friday, 9am 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'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

Talk to others

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

Support groups

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

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

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.

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

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit macmillan.org.uk/ financial support to find out more about how we can help you with your finances.

Help with work and cancer

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

> Macmillan's My Organiser app This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

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 **Email**

info@cancerblackcare.org.uk www.cancerblackcare.ora.uk Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

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, including a

free helpline, counselling and links to local support groups.

Cancer Research UK Helpline 0808 800 4040 (Mon to Fri, 9am to 5pm) 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 (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 various 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 a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus Helpline 0808 808 1010 (Daily, 8am to 8pm) **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.

General health information

Health and Social Care in Northern Ireland www.hscni.net

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

Healthtalk

Email info@healthtalk.org www.healthtalk.org www.healthtalk.org/youngpeoples-experiences (site for young people)

Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS.UK www.nhs.uk

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

NHS Direct Wales www.nhsdirect.wales.nhs.uk NHS health information site for Wales.

NHS Inform Helpline 0800 22 44 888 (Daily, 8am to 10pm) www.nhsinform.scot NHS health information site for Scotland.

Patient UK www.patient.info

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

Counselling

British Association for Counselling and **Psychotherapy (BACP) Tel** 01455 883 300 Email bacp@bacp.co.uk Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at itsgoodtotalk.org.uk

UK Council for Psychotherapy (UKCP) Tel 020 7014 9955 Email info@ukcp.org.uk www.psychotherapy.org.uk Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind Helpline 0300 123 3393 **Text** 86463 Email info@mind.org.uk www.mind.org.uk Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans **Helpline** 116 123 Email jo@samaritans.org www.samaritans.ora Samaritans branches are located across England, Scotland, Wales and Northern Ireland. Gives confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial 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 in the phone book or one of these websites:

England Helpline 03444 111 444 www.citizensadvice.org.uk

Scotland Helpline 0808 800 9060 www.citizensadvice.org.uk/ scotland

Wales Helpline 03444 77 2020 www.citizensadvice.org.uk/ wales

Northern Ireland Helpline 0800 028 1181 www.citizensadvice.co.uk/ nireland

Department for Work and Pensions (DWP) **Personal Independence** Payment (PIP) Helpline 0345 850 3322 **Textphone** 0345 601 6677 (Mon to Fri, 8am to 6pm) Carer's Allowance Unit **Tel** 0345 608 4321 **Textphone** 0345 604 5312 (Mon to Thu, 8.30am to 5pm, Fri, 8.30am to 4.30pm) www.gov.uk/browse/ benefits

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

Support for people living with a disability

Disability Rights UK Tel 0207 250 8181

(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)

Email enquiries@ disabilityrightsuk.org

www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Scope

Helpline 0808 800 3333 (Mon to Fri, 9am to 5pm) Email helpline@scope.org.uk www.scope.org.uk

Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for older people

Age UK

Helpline 0800 055 6112 (Daily, 8am to 7pm)

www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030 (Mon to Fri, 10am to 10pm, and Sat 10am to 6pm) **Email** helpline@labt.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.

Support with sight loss

Royal National Institute of Blind People (RNIB) Helpline 0303 123 9999 (Mon to Fri, 8.45am to 5.30pm) Email helpline@rnib.org.uk www.rnib.org.uk Offers support and advice to blind and partially sighted people in the UK.

Support with hearing loss

Action on Hearing Loss Helpline 0808 808 0123 (Mon to Fri, 9am to 5pm) **Textphone** 0808 808 9000 SMS 07800 000 360 Email information.line@ hearingloss.org.uk www.

actiononhearingloss.org.uk Offers support and practical advice to people in the UK with hearing loss and tinnitus.



You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.

YOUR NOTES AND QUESTIONS

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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

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With thanks to: Dr Denis Colligan, Macmillan GP; Dr Jackie Dominey, Macmillan GP; Natalie Doyle, Nurse Consultant; Dr Debbie Fenlon, Associate Professor in Cancer Care; Dr Dorothy Goddard, Consultant Breast Radiologist and Macmillan Advisor Breast Cancer Survivorship; Alison Hill, Trust Lead Cancer Nurse; Dr Pauline Love, Macmillan GP; Dr Nicola Robinson, Macmillan GP; Louise Smith, Macmillan Cancer Information Nurse Specialist and Centre Manager – Project Lead Survivorship; Dr Claire Taylor, Macmillan Lead Nurse, Colorectal Cancer; 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, contact cancerinformationteam@macmillan.org.uk

Sources

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

Linda, J and Shulman, L. Follow-up care of cancer survivors: challenges and solutions. Lancet Oncology. 2017; 18: e19-29.

Murchie P, et al. Determining cancer survivors' preferences to inform new models of follow-up care. British Journal of Cancer. 2016. 115: 1495-1503.

Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

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

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

Don't let the taxman keep your money

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

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

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

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

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

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

Security number

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Signature

Date

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

REGULATOR

This booklet is for people who are preparing for life after treatment. It has information on follow-up care, managing treatment effects and making healthy lifestyle changes.

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

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

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



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Information Standard

This organisation has been certified as a producer of reliable health and social care information.

Certified member

www.theinformationstandard.org