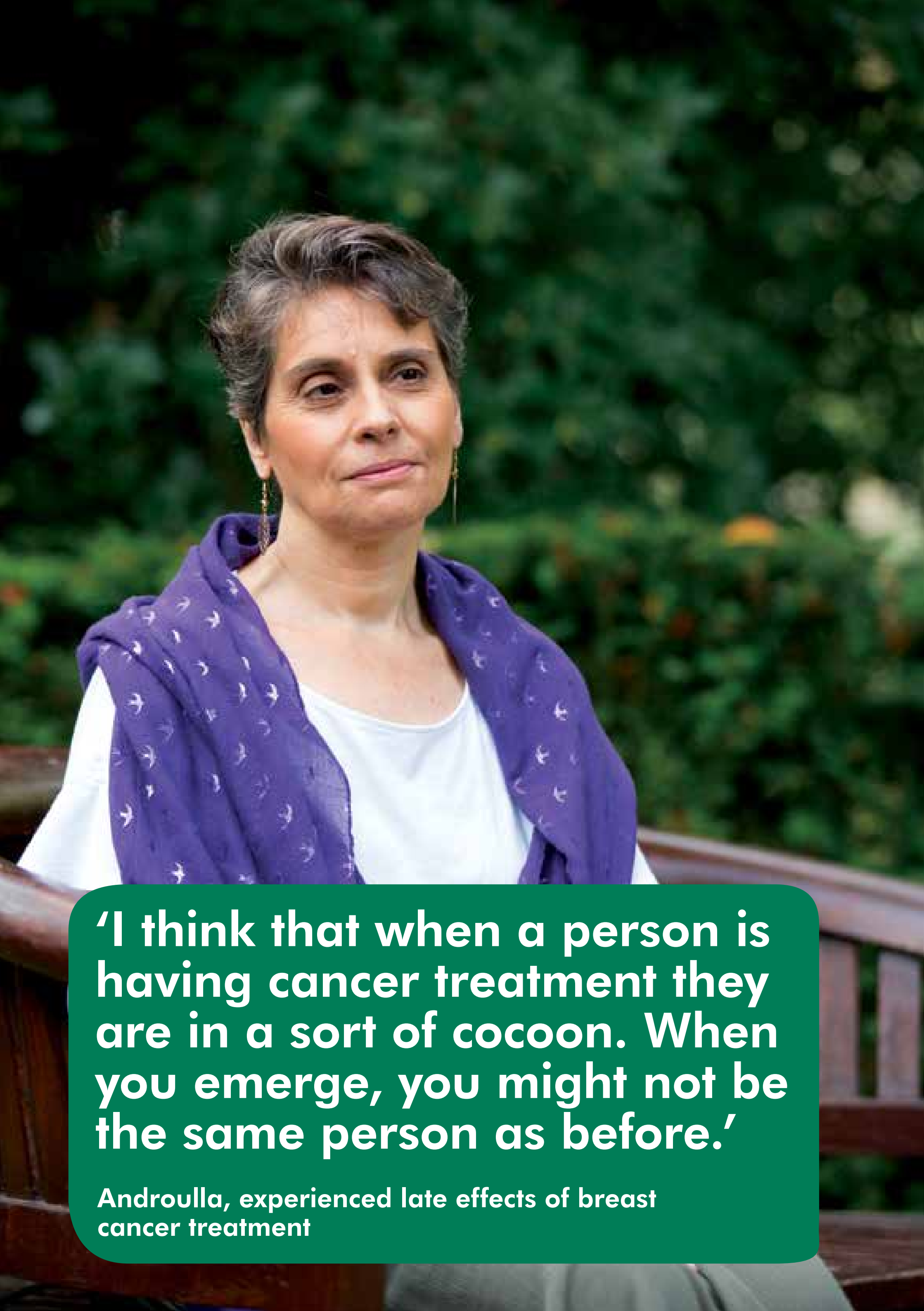
A practical guide to living with and after cancer

MANAGING THE LATE EFFECTS OF BREAST CANCER TREATMENT



> ‘I think that when a person is having cancer treatment they are in a sort of cocoon. When you emerge, you might not be the same person as before.’

Androulla, experienced late effects of breast cancer treatment

About this booklet

This booklet is about the possible long-term or late effects of breast cancer treatment. These are side effects that continue for 6 months or longer after treatment, or delayed side effects that develop months or years after treatment. In this booklet, we use the term late effects to describe long-term and late effects. The booklet is for anyone who has late effects of breast cancer treatment.

The booklet describes the possible effects of treatment and how they can be improved or managed. It also includes information on positive lifestyle changes, which can help reduce the risk of developing some late effects. There is also information about coping with some of the sexual and emotional difficulties that you may experience.

Although this booklet is written for women, some of the information may help men who have late effects of breast cancer treatment. Breast cancer in men is rare. We have more information about this in our booklet **Understanding breast cancer in men** (see page 110). However, treatments for breast cancer are similar for men and women. So men may also experience some of the side effects described in this booklet.

If you have late effects, we hope this booklet will help you know who can help you and what can be done. It also suggests some positive ways to help yourself.

How to use this booklet

The 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 5 to help you.

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

At the end of this booklet, there are details of other organisations that can help (see pages 115 to 124).

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

We have included quotes from people affected by the late effects of breast cancer treatment, which you may find helpful. This includes Androulla, who is on the cover of this booklet. Some quotes are from our Online Community, at **community.macmillan.org.uk** Others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory** Some names may 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/otherformat**s 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.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**

Contents

LATE EFFECTS AND BREAST CANCER TREATMENT

Long-term and late effects

Most women have side effects during treatment for breast cancer and for a few weeks after treatment ends. Usually, these side effects get better slowly and then stop. But sometimes side effects do not go away. Or they can develop months or years after treatment.

There are two commonly used terms for these side effects:

- long-term effects
- late effects.

Long-term effects begin during, or shortly after, treatment. They last for more than 6 months after treatment has finished. They may go away on their own, with symptoms getting better over 1 or 2 years after treatment. Or they may be permanent.

Late effects are a delayed reaction to treatment. They do not appear during treatment, but can happen months or even years later.

In this information, we use the term late effects to describe both long-term and late effects.

There are many things that can be done to manage or treat late effects. It is important that you do not feel you have to cope with them without getting help.

Late effects may be minor and not affect your daily life much. Or, they may be more difficult to live with and affect your daily life more. There are usually a lot of things that can help you cope with them to live life as well as you can. This information talks more about ways to cope. Some late effects improve over time and may eventually go away on their own.

Talking to your doctor

If treatment side effects do not go away after treatment, or if you develop late effects, always let your cancer doctor or specialist nurse know.

Give your doctor as much information as you can about your side effects. The more they know, the better they can help you. You may feel embarrassed talking about urinary problems or difficulties with your sex life. But doctors and nurses are used to having these conversations, so there is no need to worry.

Some late effects may be similar to the symptoms you had when you were first diagnosed. This can be scary, and you may worry the cancer has come back.

The breast care team will assess your symptoms. They will explain whether they could be caused by treatment. They will also talk to you about what can be done to manage them. You may be referred to a doctor who specialises in the late effects of treatment.

Sometimes symptoms are caused by other conditions not related to the cancer or its treatment. Your doctor may arrange tests to find out more about the cause of your symptoms.

Remember that you can contact your specialist nurse if you have any concerns. This is true even if you no longer have follow-up appointments with a doctor. You can also contact your GP.

You may need support from your family, friends or a support organisation (see pages 115 to 124). You can also talk to one of our cancer support specialists on **0808 808 00 00**.

> ‘After my treatment ended, I felt like a watered down version of myself. Aside from the physical changes to my body, I felt I had changed.’
>
> **Androulla**

Side effects from breast cancer treatments

The main treatments for breast cancer are:

- surgery
- radiotherapy
- chemotherapy
- hormonal therapy
- targeted therapies.

Surgery and radiotherapy

Surgery and radiotherapy to the breast, especially involving the armpit, can cause:

- pain in the breast, chest, arm and shoulder
- limited movement of the shoulder or arm
- swelling of the arm or breast (lymphoedema – see pages 28 to 31).

Women who have had part of the breast removed and have had radiotherapy may find the treated breast shrinks slightly over time. If this happens, the breasts will be different sizes.

Chemotherapy

Chemotherapy may cause:

- an early menopause (see pages 73 to 83)
- changes in sensation, such as pins and needles or numbness in your hands and feet (see pages 21 to 22).

Hormonal therapies

Hormonal therapies can cause:

- side effects similar to menopausal symptoms, including hot flushes and thinning of the bones (osteoporosis – see pages 47 to 51)
- joint pain (see pages 53 to 54)
- vaginal bleeding.

Other treatments

Bisphosphonates (bone strengthening drugs) can cause problems with the teeth and jaw.

Targeted therapy drugs such as trastuzumab (Herceptin®) and some chemotherapy drugs can cause changes in the way the heart works.

Other changes

Cancer treatments can also cause more general changes in how you feel. You may:

- be more tired than usual for several months after treatment (see pages 34 to 39)
- have difficulty concentrating or remembering things (see pages 86 to 89).

These effects are usually mild and get better over time. But some can be permanent.

Treatments for breast cancer are constantly improving. Better treatments mean that women are now living for longer. As treatments develop, we are learning more about late effects and how they can be managed. Doctors and researchers are trying to make sure people get the best treatment for them, with as few side effects as possible.

> ‘After the last radiotherapy appointment, I have had regular check-ups. I am feeling good. I still get tired, but I am staying busy and just getting on with things.’
>
> **Zoe**

BREAST AND ARM CHANGES

What changes might happen?

Surgery and radiotherapy to the breast can cause a number of changes. These can include:

- changes to the appearance of the breast
- pain and changes in sensation
- problems with movement or strength
- swelling of the arm (lymphoedema), if the armpit is treated.

Always let your cancer doctor or specialist nurse know if you have any of these symptoms. They can give you advice on the different ways that these effects can be managed. Your doctor may also refer you to other specialists who can help.

Changes to the appearance of the breast

Changes caused by surgery

After any type of breast cancer surgery there will be a scar. The amount of scarring will depend on the type of surgery you have and how well it heals. Most scars fade with time and become less obvious.

Stretching and massaging the scar area every day during the first year after surgery can help to reduce scarring. Ask your cancer doctor or specialist nurse for more advice.

Women who have a breast removed (mastectomy) may find it hard to accept the change in their appearance. It may change how you feel about yourself (your body image) and affect your sex life. It may also result in problems with depression. Some women choose to have breast reconstruction. You may need support adjusting to the changes. Having only a small part of the breast removed (wide local excision) will cause fewer changes in the appearance of the breast. This may be easier to adjust to.

We have booklets about body image and cancer, the emotional effects of cancer, and breast reconstruction. See page 110 for ways to order.

Breast reconstruction

Breast reconstruction is surgery to make a new breast shape after a mastectomy. It is also sometimes used to improve the shape of the breast after a wide local excision.

After breast reconstruction, there are sometimes dents or irregularities in the outline (contour) of the new breast. It may be possible to fill in these dents using fat cells removed from the tummy area (abdomen) or thighs. This technique is called lipomodelling. The fat cells are removed using gentle liposuction. The whole fat cells are then separated and injected into the breast.

For some women, breast reconstruction can help to restore self-confidence and feelings of femininity and sexual attractiveness. There is not a time or age limit on when the operation should be done. But you will need to be fit enough for the surgery. Many women have reconstruction years after their initial breast operation. Your cancer doctor or specialist nurse can discuss this with you. They can also arrange a referral to a specialist breast cancer surgeon or a plastic surgeon.

Changes caused by radiotherapy

Colour

After radiotherapy, the skin of the breast may change colour. It may become darker with a blue or black tinge. It may also be more sensitive. It is important to protect the area from strong sunlight by covering up with clothes or using a suncream with a high sun protection factor (SPF).

Blood vessels

Sometimes blood vessels under the skin can become dilated. This is called telangiectasia. It can cause lots of thin red lines. This changes how the breast looks, but it should not cause any other problems. Rarely, prominent blood vessels in the skin of the breast or chest can be a sign of more serious conditions. Always talk to your doctor about any changes.

Appearance and size

After radiotherapy, some women develop a hardening or thickening of the breast tissue. This is called fibrosis. The breast may also shrink slightly over time. This can cause the breast to become harder and smaller than it was.

Breast shrinkage is worse in women who smoke. Your doctor may strongly advise you to give up smoking. Sometimes after radiotherapy, the breast may be red and swollen. This usually goes back to normal over a few weeks or months.

If you notice changes to the appearance or feel of your breast, it is best to have them checked by your doctor or specialist nurse.

Breasts often get bigger with age or weight gain. But if you have had radiotherapy, the treated breast will not always grow to match the other breast. Keeping to a healthy weight can help the breasts stay more the same size.

If the breasts are very different sizes, some people choose to have surgery to reduce the size of the larger breast. The size of the treated breast can also be increased, using fat injections. Your cancer doctor or specialist nurse can tell you more about this.

Some people choose to use a partial breast prosthesis (shell) to help make the breasts look more even under clothing. A breast prosthesis is an artificial silicone insert. It fits over the smaller breast and can be worn inside one side of a bra. Breast Cancer Care has information on different kinds of prostheses. You can find their contact details on page 115.

Pain and changes in sensation

Changes caused by surgery

Surgery can cause changes in sensation in the chest area, the armpit, and the shoulder and arm on the affected side.

These can include:

- sharp, shooting or burning pain
- aching pain
- sensitivity to touch or to the cold
- numbness or pins and needles.

These symptoms happen because the nerves in the chest area or armpit are cut or injured during surgery. These symptoms are common, particularly after surgery to remove all the lymph nodes in the armpit. Symptoms usually improve with time, but in some cases they may take months or years to get better.

If you have an aching in the breast, wearing a supportive sports bra during the day and a soft bra with no underwire at night may help. You may find that bras with adjustable straps, soft seams and full cups are more comfortable.

We have a booklet called **Managing cancer pain** that you may find helpful (see page 110).

Describing your symptoms clearly will help your doctor to prescribe the right painkiller for you. Simple painkillers such as paracetamol, or anti-inflammatory drugs such as ibuprofen, can often control the pain. But if you have nerve pain (shooting or burning pain), you may need other types of painkillers.

Changes caused by radiotherapy

Very rarely, radiotherapy to treat breast cancer can damage the nerves in the shoulder. This is called brachial plexus neuropathy. It can cause problems with pain and numbness. In extreme cases it can cause loss of movement. As radiotherapy techniques have improved, this problem is now very rare.

Although this condition cannot be reversed, the symptoms can be improved with drug treatment and physiotherapy. Physiotherapy involves doing exercises to strengthen the muscles and keep them supple. The physiotherapist will also be able to show you how to use slings or splints to support your arm, if needed.

If you are unable to work because of damage to your arm, you may be entitled to some benefits. Our booklet **Your rights at work when you are affected by cancer** may be helpful. We also have a booklet called **Working while caring for someone with cancer** that might be helpful. See page 110 for ways to order these.

Movement and strength in your arm and shoulder

Radiotherapy and surgery, especially to the armpit, can affect the range of movement and strength in your arm or shoulder. This may change your ability to do everyday activities, such as household tasks or your work. It may also interfere with some types of exercise, such as swimming or tennis.

After breast surgery, a physiotherapist usually gives you exercises that will help you recover shoulder movement. Doing these will help your arm and shoulder movement slowly improve after treatment.

Tips to help improve movement and strength

See a physiotherapist

Ask your doctor to refer you to a physiotherapist. They will assess you and show you some exercises to improve movement and strength. If your problems continue, the physiotherapist may be able to give you different exercises. Having good posture is also important. Your physiotherapist can give you advice on this.

Tell your doctor if you have pain

Talk to your doctor if you have pain. Problems with pain may mean that you are not using your arm or shoulder properly. This can make things worse. Your doctor can also prescribe painkillers to help improve movement and relieve stiffness.

Relax your muscles before exercise

Take painkillers half an hour before you exercise, or have a warm bath. This can help relax your muscles. If you still cannot do your exercises, or you find them painful, then stop.

Avoid doing things that cause pain

If it hurts to reach out and lift or carry heavy things with the affected arm and shoulder, avoid doing these things. Use a shopping trolley instead of a basket, shop online and get heavy things delivered. Try to make sure that objects you use often are low down and easy to reach.

See an occupational therapist

If you are having difficulty doing daily tasks, ask your doctor to refer you to an occupational therapist (OT). They can assess your needs and suggest aids or equipment to help you.

Accept offers of help

Let people know what kind of practical help you need. They could help you with things like shopping, taking the rubbish out or mowing the lawn.

Ask about complementary therapies

Complementary therapies such as relaxation or deep breathing exercises may be helpful. Ask your doctor, nurse or physiotherapist for advice on these. We also have a booklet called **Cancer and complementary therapies** that may be helpful (see page 110).

> ‘You do start very slowly getting back to your fitness levels but it is also psychological. You have to get out of that bubble, get back into the world again and see other people. It is also about realising what you can do.’
>
> **Jill**

Cording

After surgery to remove lymph nodes in the armpit, some women develop cord-like structures under the skin on the inner arm. This is called cording or axillary web syndrome. We do not know exactly why cording happens. It is thought to be caused by inflammation and scarring of the tissues that surround the lymph vessels, blood vessels and nerves.

Cording is fairly common in women who have had most of the lymph nodes removed from the underarm. This is called an axillary lymph node dissection (ALND). It happens less to women who have had just 1 or 2 lymph nodes removed in a sentinel lymph node biopsy (SLNB).

You may be able to see or feel the cords when you lift your arm to shoulder height or above your head. There may be one thick cord or several smaller cords. They can cause a painful sensation and tightness that can reduce the range of movement of your arm and shoulder. This can affect your ability to do many daily activities.

Cording may develop within a few days of surgery, but it can develop a few weeks after surgery. Sometimes it appears many months later.

Managing cording

It is important to keep your arm and shoulder moving when you have cording. This helps prevent further tightness, which can cause more serious problems with movement.

The following tips may help:

- Ask your doctor to refer you to a physiotherapist. They can teach you exercises to gently stretch the cords and improve movement. Your specialist nurse may also be able to help you.
- Gentle massage to the area may help reduce pain and tightness. Your physiotherapist or specialist nurse may do this for you. They can also show you how to do it yourself.
- Apply a warm, moist heat pad. The physiotherapist may do this for you. It is important not to use it for too long each time, as heat can increase the risk of lymphoedema (see pages 28 to 31).
- If you have pain that stops you moving the arm and shoulder, ask your doctor for some painkillers. They may give you an anti-inflammatory painkiller, such as ibuprofen.

Cording usually gets better slowly over a few months. But it can last longer. Sometimes it can come back, but this is rare. If the cording continues, surgery can sometimes be done to improve symptoms.

Lymphoedema

Lymphoedema (swelling) of the arm, hand, or breast, can develop at any time after treatment for breast cancer. Surgery to remove the lymph nodes in the armpit, or radiotherapy to the nodes, can change the way that lymph fluid drains from the arm.

Lymphoedema is more likely to happen if you have had all or many of your lymph nodes removed, and have also had radiotherapy to the armpit. It usually develops gradually. It can develop months or years after treatment. If you have had just 1 or 2 of the lymph nodes removed (a sentinel lymph node biopsy), the risk of getting lymphoedema is low. If you are not sure about what type of lymph node surgery you have had, your specialist nurse can tell you.

We have a booklet called **Understanding lymphoedema** that you may find helpful (see page 110).

‘I do exercises on the affected breast to move the fluid onto the good side, where it drains away as normal.’

Suki

Reducing the risk of lymphoedema

It is thought that some things may cause swelling in someone who is at risk of developing lymphoedema. For example, overuse of a limb may cause inflammation. Having a skin infection may also increase the risk.

The following things could help reduce the risk of infection and help prevent lymphoedema. If you already have lymphoedema, following this advice may stop it getting worse.

Look after your skin

It is very important to keep your skin clean and well moisturised. This reduces the risk of inflammation and infection. It is also important to protect your skin from cuts and grazes, insect bites and sunburn.

Look out for early signs of infection

See your GP immediately if you develop any signs of infection. Signs may include having a high temperature, or your limb becoming red, hot or swollen.

Try to keep active

Regular exercise and physical activity will help encourage lymph fluid to drain. Ask your physiotherapist or nurse for advice about exercise.

Keep to a healthy weight

The risk of lymphoedema is higher if you are overweight. Your GP can tell you what your ideal weight should be. You can also ask your GP or a dietitian for advice and support on eating healthily.

Take care when travelling

It can help to use a suitcase on wheels so you do not have to carry a heavy bag. Protect your skin from the sun by covering up with clothes or using suncream with a high sun protection factor (SPF). Use an insect repellent to prevent bites. Avoid getting travel vaccinations in the affected arm.

Avoid injections

Avoid having any injections or blood taken from the affected arm.

Treating and managing lymphoedema

Lymphoedema is a long-term condition but the earlier it is diagnosed, the more effective and straightforward treatment is. If you notice any swelling in your arm or chest, always get it checked by your doctor or nurse.

If lymphoedema is diagnosed, you will be referred to a specialist lymphoedema nurse, breast care nurse, doctor or physiotherapist for an assessment. You may be seen at a specialist lymphoedema centre.

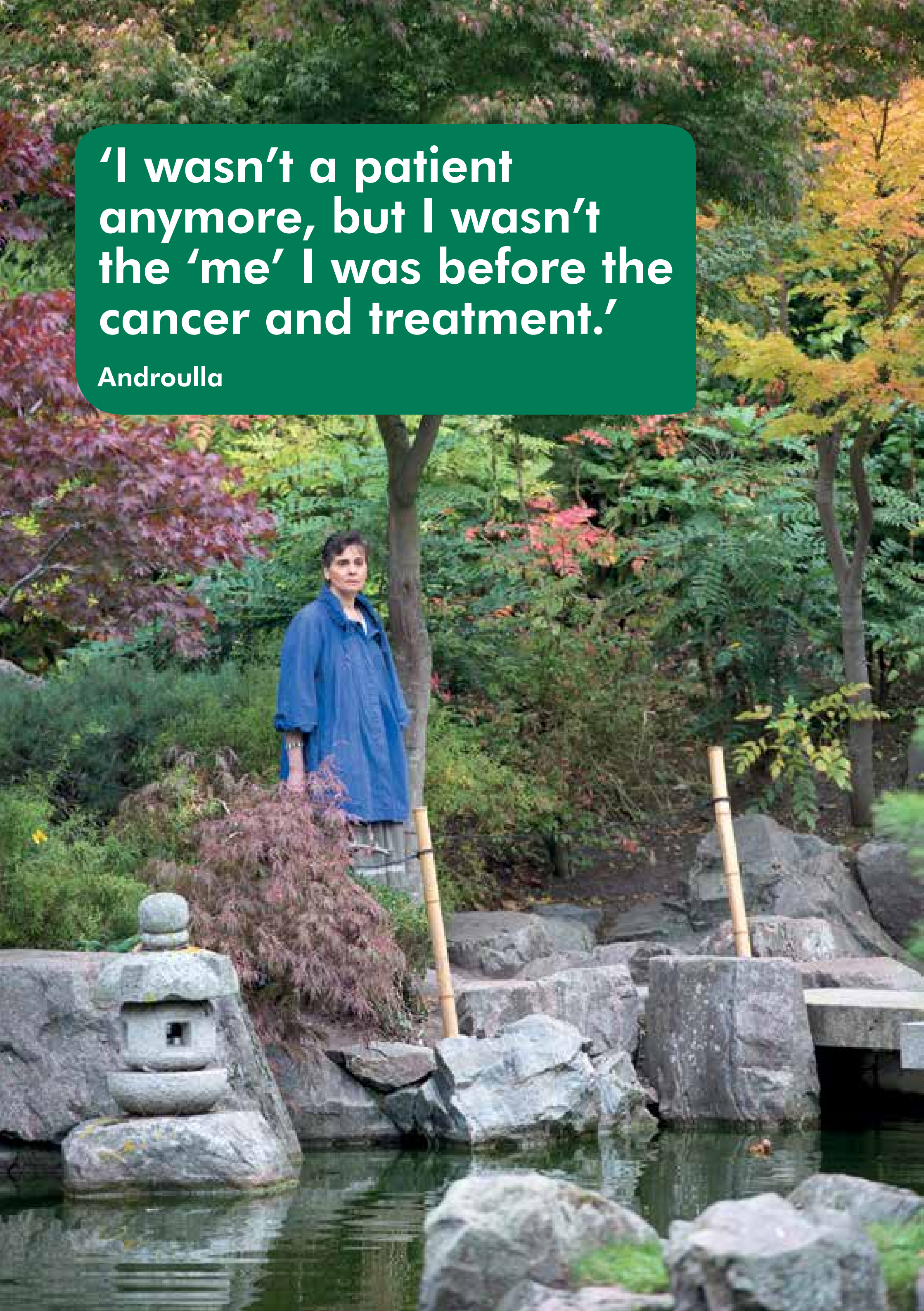
Treatment aims to reduce and control swelling, relieve discomfort and prevent more build-up of fluid.

Treating lymphoedema involves:

- skin care to prevent injury and infection
- exercises including limb positioning and movement to help drain fluid
- support using compression sleeves or bandages that help stop fluid from building up
- self-massage or a specialised type of massage called manual lymphatic drainage.

> ‘I have a glove and a sleeve, and the lymphoedema nurse showed me daily self-drainage exercises that help. It is another thing to cope with but it is a question of keeping it under control and being careful about scratches and insect bites.’
>
> **Zelie**

> ‘I wasn’t a patient anymore, but I wasn’t the ‘me’ I was before the cancer and treatment.’
>
> **Androulla**



OTHER PHYSICAL EFFECTS

Tiredness or fatigue

Tiredness is probably the most common side effect of breast cancer treatment. It is common for tiredness to last for months after treatment is over. For some people, it may last for 1 or 2 years.

Some people feel very tired and exhausted most, or all of the time. This is known as fatigue. Some of the more common effects of fatigue include:

- difficulty doing simple things, such as brushing your hair or getting dressed
- feeling you have no energy or strength
- difficulty concentrating and remembering things (see pages 86 to 89)
- difficulty thinking, speaking or making decisions
- feeling breathless after light activity
- feeling dizzy or lightheaded
- difficulty sleeping (insomnia)
- losing interest in sex (see pages 69 to 72)
- feeling low in mood and more emotional than usual.

Fatigue can affect the way you think and feel. Even things you usually enjoy, such as reading or watching TV, can be difficult.

We have a booklet called **Coping with fatigue** that you may find helpful (see page 110).

You may find fatigue affects your relationships. You may need to rest more, meaning you might spend less time with friends and family. Or you may avoid going out or being with friends because it makes you very tired. But there are things you can do to improve fatigue.

Possible causes

Recovering from cancer treatments can take time. For some people, tiredness continues while they are taking hormonal therapies. Hormonal therapies may be given for several years.

Sometimes fatigue is also related to problems such as:

- depression
- sleep problems
- pain
- anaemia
- thyroid problems.

The most important thing is to tell your doctor or nurse how you are feeling. Do not pretend everything is okay. Tell them what your fatigue is like when it is at its worst.

It is important to find out if there is a particular cause of your fatigue. This will help you find a suitable treatment. Your doctor can take blood samples to find out if you have anaemia (a low number of red blood cells), or to find out if your thyroid gland is underactive. Both these conditions can be treated with medicines.

Fatigue is a common symptom of depression. It is not unusual to feel depressed, anxious or stressed after treatment for cancer. If you think you are depressed, talk to your doctor or nurse. You and your doctor will be able to work out if your fatigue is caused by depression. Your doctor can then refer you to a counsellor to help you with how you are feeling. They may also prescribe antidepressants.

Sleep problems or pain may be causing your fatigue or making it worse. Improving these will help you feel better. Coping with pain is tiring and affects the quality of your sleep. Always let your doctor or nurse know if you have pain that is not controlled.

> ‘They got me to keep a fatigue diary. You record your tiredness and write a note about your activity. It helps identify the things that make you tired’.
>
> **Ronni**

Tips to help with fatigue

Keep to a normal sleep routine

Going to sleep at the same time every evening and waking up at the same time every morning can help. Try not to sleep late into the day, even after a sleepless night.

Eat a healthy diet

Eat as healthily as possible. This can help you feel better. It may also give you more energy.

Get support

Accept help from family, friends and carers. They will usually be happy to help. It is useful if you can tell them exactly what would help you most.

You could make a list of tasks you would like help with. This could include practical help such as taking out the rubbish, or things like setting up direct debits to pay bills. If you have internet access, you could do grocery shopping online and have it delivered.

Keep active

Regular exercise can help to reduce fatigue and increase your energy levels. It can also help you sleep better and can improve anxiety and depression.

If you have not been very active in the past or for a long time, it is best to start slowly. Try to get a balance between being active and getting some rest. You could start by going for short walks and gradually build up.

We have a booklet called **Physical activity and cancer** that can help you get started (see page 110).

Ask your doctor about complementary therapies

Complementary therapies may help to reduce stress and anxiety, and may improve fatigue. Relaxation, counselling and psychological support are available at many cancer treatment centres.

Find ways to cope with concentration problems

Problems with concentration and memory are common when you have fatigue. This can be frustrating to deal with. But there are ways of coping with concentration and memory problems. See pages 86 to 89 for more information.

Talk to your children

If you have children, it can be difficult to cope when you are feeling very tired. You may sometimes feel that you are letting your family down. It might help to explain to your children that you feel tired often and will not be able to do as much with them as before. Try to plan activities with them that you can do sitting down. If they are old enough, you could involve them in some household tasks.

Ask for and accept help from people you trust to help look after your children sometimes. For example, they might be able to take them to and from school or childcare.

Our booklet **Talking to children and teenagers when an adult has cancer may also be useful** (see page 110).

Talk to your employer

You might find that you cannot carry on working or that you need to reduce your hours. There may be things that your employer can do to help. This may be changing your hours or making other reasonable adjustments. If your job is physical, they might be able to find you lighter work within your role.

> ‘I finished treatment a year ago and struggled with fatigue. It is a balance between getting exercise and not doing too much. It gradually improved. I have a strategy now.’
>
> **Ronni**

Effects on the heart

Some treatments for breast cancer may increase the risk of developing heart problems, usually many years later. Most people will never experience any effects on the heart. But it may help to understand more about how you can take care of your heart.

The most important risk factor for developing heart problems is pre-existing heart disease, including high blood pressure. Women at risk are carefully monitored before and during their treatment to find out if their treatment needs to be changed.

We have a booklet called **Heart health and cancer treatment** that you may find helpful (see page 110).

Chemotherapy

The standard chemotherapy treatment for early breast cancer usually includes drugs known as anthracyclines. For example, you may be given drugs like epirubicin or doxorubicin. Research shows that these drugs are good at reducing the risk of breast cancer coming back.

In a small number of people, treatment with anthracyclines may cause slight damage to the heart muscle. Because these changes are small, they usually do not cause any symptoms straight away. But they may lead to an increased risk of developing heart problems much later in life.

Radiotherapy

Radiotherapy to the chest has a very small risk of damaging the heart muscle, or the major blood vessels around the heart. This can only happen if you had treatment to the left breast. This is because the heart is on the left side of the chest. Radiotherapy is now very carefully planned so that the heart is either completely outside the area being treated with radiation, or only a small part of the heart is inside the treatment area. This means the risk of developing any heart problems is now very low.

Hormonal therapy

Hormonal therapy drugs, called aromatase inhibitors, may increase the risk of high cholesterol. This can cause heart problems.

An early menopause

Having an early menopause because of your treatment may increase the risk of heart problems. This is because oestrogen and progesterone help protect the heart.

Targeted therapy

Trastuzumab (Herceptin®) can cause changes in the way the heart works, particularly in women who already have heart disease. This means you are not given this drug if you have a certain type of heart condition. You have tests before treatment to check your heart. You also have regular tests throughout and after treatment.

If heart problems happen during treatment with trastuzumab, they are usually temporary. This means they improve with medication and get better after treatment finishes.

Possible symptoms

Possible symptoms of heart problems include:

- feeling your heart beating fast, hard or irregularly
- pain or discomfort in your chest
- getting breathless, for example when climbing stairs
- feeling weak or dizzy
- getting tired very easily
- swollen feet and lower legs.

These symptoms can be caused by lots of other things. But it is still important to let you doctor know if you develop any of them. If these problems happen many years after treatment, you may need to tell them which cancer treatments you have had This will help them find the right help for you.

If you have heart problems, your doctor will refer you to a heart specialist (cardiologist).

What you can do to keep your heart healthy

Making small changes to your lifestyle may help reduce your risk of developing heart problems. If you already have problems, small changes can help to reduce your risk of further problems.

The British Heart Foundation has lots of information and advice about keeping your heart healthy. You can find their contact details on page 116.

Keep active

This can help your heart healthy and has other benefits too. Keeping physically active can:

- help you keep to a healthy weight (see pages 55 to 56)
- reduce your risk of bone thinning (see pages 47 to 59)
- reduce stress
- improve fatigue
- help you look and feel better.

There is some evidence that regular exercise may help to reduce the risk of breast cancer coming back. There is also evidence that it reduces the risk of getting some other cancers.

Eat healthily

Eating healthily helps protect your heart. It also helps you maintain a healthy weight.

Try to eat:

- at least 5 portions of fresh fruit and vegetables a day
- protein like chicken and fish, especially oily fish
- high fibre foods
- less saturated fat like pastries, cakes and cheese
- less red and processed meat
- less salt.

Drink less alcohol

Too much alcohol can cause heart problems. It is also high in calories. Sticking to sensible drinking guidelines is good for your general health. Current guidelines recommend that women drink no more than 14 units of alcohol per week. It is also good to have a few alcohol-free days each week.

Give up smoking

If you smoke, stopping is the healthiest decision you can make. It is one of the major risk factors for heart disease. Stopping smoking also reduces your risk of developing lung disease, bone thinning (osteoporosis) and smoking-related cancers. You will also feel and look better.

Effects on the lungs

Radiotherapy can change the cells that line the lungs and cause a hardening and thickening of the tissue. This is called fibrosis. This can cause problems with breathlessness months or years after treatment. However, this is a rare side effect because radiotherapy is carefully planned and ways of giving it have improved.

If you already have a chest problem such as asthma, or if you smoke, the symptoms can be worse.

Some women get inflammation of the lung (radiation pneumonitis) 1 to 3 months after radiotherapy. This causes symptoms such as:

- breathlessness
- a dry cough
- chest pain.

However, the condition usually improves so the symptoms will go away. You should always talk to your doctor if you develop new symptoms.

Treatment for lung problems

Treatment will depend on your situation. You may need to make some lifestyle changes. For example, it is best to give up smoking and keep to a healthy weight. Your doctor or specialist nurse will give you advice and support about this.

You may be given inhalers that contain drugs to help open up the airways. These are called bronchodilators. Or you may be given steroids. These can be given as tablets or inhalers to reduce inflammation. If you have an infection in the lung, you will be given antibiotics.

What you can do to keep your lungs healthy

Making small changes to your lifestyle can reduce your risk of developing lung problems. The British Lung Foundation has lots of information and advice. You can find their contact details on page 116.

Give up smoking

If you smoke, the most important thing you can do is to stop. It is also important to avoid being exposed to other people's smoke (passive smoking). Stopping smoking has lots of benefits.

Keep to a healthy weight

Keeping to a healthy weight improves breathing problems.

Do some breathing exercises

You can ask to be referred to a physiotherapist who can teach you deep breathing exercises and give you advice on exercise. This can help you breathe better and improve breathlessness.

Effects on the bones

Bone thinning

After the menopause, all women have an increased risk of bone thinning (osteoporosis). But after breast cancer treatment, some women are at a greater risk. This is because some treatments can reduce the amount of oestrogen in the body. Oestrogen helps to keep bones healthy and strong.

Treatments for breast cancer that can increase the risk of bone thinning are:

- chemotherapy, especially if it causes an early menopause
- hormonal therapy with aromatase inhibitors such as anastrozole, exemestane or letrozole
- ovarian ablation to stop the ovaries from working by removing them, having radiotherapy, or using drugs called LHRH analogues, such as goserelin (Zoladex®).

Before treatment with an aromatase inhibitor, national guidelines recommend that women have their bone health (density) checked. This is done using a DEXA scan. This uses an x-ray with a very low dose of radiation. DEXA is short for dual energy x-ray absorptiometry.

The scan only takes about 15 minutes. You lie on a couch while the scan is done. You do not need to have any injections for this scan. You also do not have to undress, as long as there is no metal, such as zips, in the area being scanned.

Your bone density can be monitored during and after treatment. Depending on the results, you may be prescribed calcium and vitamin D supplements or bone strengthening drugs called bisphosphonates. These help to minimise the risk of problems.

If you have a family history of osteoporosis, ask your cancer doctor or specialist nurse about using bisphosphonates to help prevent osteoporosis.

Radiotherapy damage to bones

Rarely, radiotherapy weakens the bones in the treatment area, such as the ribs and collarbone.

Radiotherapy can reduce the blood supply to bones. This makes them thinner and increases the risk of a bone breaking, but this is very rare. If you have any symptoms, such as bone pain, always talk to your doctor. Usually the symptoms are caused by something else, but it is important to get them checked.

Treatment might involve taking painkillers or anti-inflammatory drugs. Sometimes calcium supplements, vitamin D or bisphosphonates and antibiotics are given.

We have a booklet called **Managing cancer pain** that we can send you (see page 110).

What you can do to keep your bones healthy

Regular exercise, a healthy diet and stopping smoking can help to keep your bones healthy. The National Osteoporosis Society can give you more information about the prevention of osteoporosis and treatments. Breast Cancer Care also has a helpful leaflet. Their contact details can be found on page 115.

Keep active

Physical activity makes your bones stronger. Regular weight-bearing exercise is best. Examples of this kind of exercise are:

- walking or hiking
- climbing stairs
- dancing
- gentle weight-lifting.

Swimming is good for general health, but it is not as good for bone health as these other activities. This is because your bones are not supporting your weight while you swim.

If you already have osteoporosis, avoid exercises that put too much strain on your bones, such as jogging.

A physiotherapist or your specialist nurse can give you further advice about exercise after breast cancer.

Get enough calcium and vitamin D

It is important to make sure that you get enough calcium and vitamin D in your diet.

Good sources of calcium include:

- low-fat dairy products
- eggs
- green, leafy vegetables, such as kale
- nuts
- whole fish, such as whitebait and sardines.

Vitamin D is essential to help the body absorb calcium. It is found in oily fish, eggs and food with added vitamins, but we mainly get it from sunlight.

Most people get enough vitamin D by being outside in the summer months. If you have dark skin, you need more sunlight to make vitamin D.

A well-balanced diet and safe exposure to enough sunshine usually gives you the calcium and vitamin D you need. If you are not getting enough calcium or vitamin D, taking supplements may help. Your specialist nurse can advise you about this.

Drinking too much alcohol can interfere with the balance of calcium in your body, so it is best to follow sensible drinking guidelines.

Give up smoking

If you are a smoker, choosing to stop is a decision that will benefit your health. Stopping smoking has lots of benefits. It is also important to avoid being exposed to other people's smoke (passive smoking).

Effects on the joints

Pain in the joints (arthralgia)

Women taking aromatase inhibitors (such as anastrozole, letrozole and exemestane) may have joint pain and sometimes muscle pain. This is probably caused by a decrease in oestrogen levels. Joint pain is also a common symptom of the menopause.

Pain is most common in the hands and feet, but can also happen in the knees, hips, lower back and shoulders. It may be there all the time or it may come and go. Some women notice that their joints are stiffer in the morning, when they first get up.

If you have recently started taking an aromatase inhibitor, the pain may get better over the next few months as the body adjusts to changes in hormone levels. Aromatase inhibitors are very good at reducing the risk of breast cancer coming back. You should not stop taking your treatment without talking to your cancer specialist. There is usually something that can be done to improve the pain.

Treatment for joint pain

Doctors can prescribe several different painkillers for joint and muscle pain. These include:

- simple painkillers, such as paracetamol
- anti-inflammatory painkillers, such as ibuprofen
- opioid painkillers, such as codeine or morphine for severe pain.

If the pain is difficult to cope with, your doctor may suggest changing the type of aromatase inhibitor you take. If that does not work, they may suggest you take tamoxifen instead. Tamoxifen causes fewer problems with joint pain.

Small studies suggest that for women with lower levels of vitamin D, taking vitamin D3 supplements may improve symptoms. Talk to your doctor before taking a supplement.

Research is going on to discover if a drug called glucosamine may help some women with joint pain from aromatase inhibitors. Glucosamine is often used to treat arthritis. You can buy it over-the-counter in shops and pharmacies, but it is not suitable for everyone. For example, it is not suitable for women with diabetes, because it may change your blood sugar levels. Talk to your GP or cancer doctor before taking this drug.

What you can do about joint problems

It is important to talk to your doctor or specialist nurse if joint or muscle pain is a problem for you. Your doctor can prescribe drugs to help control the symptoms and find other ways of improving them.

See a physiotherapist or occupational therapist

If you are having lots of problems with pain, your doctor can refer you to a physiotherapist. They can give you more advice and treatment.

If you are having difficulty doing daily tasks, you can also ask to be referred to an occupational therapist (OT). They will be able to assess your needs and suggest aids and equipment to help you.

Some things that might help joint problems include the following:

Keep active

Doing regular exercise to strengthen the muscles around your joints. This can help to keep them flexible and reduce pain. Non-weight-bearing exercises, such as swimming and cycling, may feel more comfortable than other types of exercise.

Try acupuncture

Acupuncture may help to reduce pain from joint symptoms for some women. Some hospitals and primary care practices offer acupuncture on the NHS. The needles should not be used on the arm of the affected side.

Ask your doctor about complementary therapies

Complementary therapies such as massage may be helpful for some women. Some hospitals offer massage on the NHS. It is very important to talk to your cancer doctor or specialist nurse before starting complementary therapies. They can talk to you about any possible harmful impacts they could have on your cancer treatment, and about any possible side effects.

Weight gain

After breast cancer treatment some women find that they have gained weight. This can happen because:

- chemotherapy or another treatment has caused an early menopause
- you are taking steroids, which are often given with chemotherapy
- you are having hormonal therapies
- you are less active during treatment and eat a less healthy diet.

Losing weight can be difficult. Even keeping to a healthy weight is sometimes hard. But there are lots of benefits. It reduces the risk of getting heart problems and other illnesses such as diabetes. There is evidence that keeping to a healthy weight after the menopause helps reduce the risk of breast cancer coming back.

What you can do to help manage your weight

Try to keep your weight within the normal range for your height. Your GP or practice nurse can advise you on your ideal weight.

Eat a healthy diet

Reduce your calorie intake by eating less fat and sugar. It is important to eat a balanced diet to make sure you get all the nutrients you need to keep your body healthy. Ask your GP or a dietitian for advice and support.

Keep active

Choose a type of exercise you enjoy. For most people, it is safe to do exercise. But get advice from your GP before you start. They may be able to refer you to exercise groups run by fitness trainers. If you are a member of a gym, you can ask for supervised help from a trainer.

Keep to a healthy weight

Avoid losing weight too quickly to help maintain a healthy weight. Losing weight slowly and eating well is healthier, and you are more likely to stay a healthy weight in future. Aim to lose 1 to 2 pounds (0.5kg to 1kg) a week. Be patient with yourself. To help you lose weight, try to:

- only eat as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- eat less fat and sugar
- drink less alcohol or stop drinking, if you drink
- be more physically active.

Peripheral neuropathy

Peripheral neuropathy (also called neuropathy) is damage to nerves that carry messages between the brain, the spinal cord and the rest of the body. Nerve damage can cause symptoms such as pins and needles, numbness or pain in the hands and feet. For a few people, this may lead to problems with balance and walking.

Treatment with the chemotherapy drugs docetaxel or paclitaxel is the most common cause of peripheral neuropathy in women who have had breast cancer. Surgery and radiotherapy to the breast may also cause nerve damage.

After treatment has stopped, most women find that their symptoms slowly get better as the nerves recover. This usually takes several months. But for some women, the nerves do not completely recover and some nerve damage is long-term. Many women still find that their symptoms get better over time.

Managing nerve pain

There is not a drug or treatment that can repair damaged nerves. But nerve pain (neuropathic pain) can often be treated. There are also things you can do to help yourself.

Treating nerve pain

Nerve pain can be treated in different ways. Non-steroidal anti-inflammatory drugs (NSAIDs) are often used. This includes drugs like ibuprofen. Some drugs change nerve impulses. This helps relieve nerve pain. Drugs that can do this include:

- some antidepressants
- some heart drugs
- some anticonvulsants, which are drugs used to treat epilepsy
- drugs such as morphine.

If your pain is difficult to treat, you can ask for a referral to a pain clinic where there is expert help available from specialist doctors and nurses.

Transcutaneous electrical nerve stimulation (TENS) is a treatment that may also help. It uses pads that give off small electrical pulses. These are put on the skin. They stimulate nerves close to the pain. This may block pain messages from the nerves to the brain. It is unlikely to cause side effects.

Acupuncture may also be helpful. It uses very fine needles that are placed through the skin at particular points. It is not clear exactly how this works, but it may help to block pain messages being sent to the brain. Some hospitals and GP surgeries offer acupuncture on the NHS. The needles should not be used on the arm on the affected side.

We have more information about different ways in which pain can be treated and complementary therapies.

Other support

A physiotherapist will be able to offer treatment and advice for problems with balance or walking. If you are having difficulty carrying out daily tasks, you can ask to be referred to an occupational therapist (OT). They can assess your needs andsuggest aids and equipment to help you.

If your symptoms continue for more than 6 months and you find walking or doing daily activities difficult, you may be able to get financial help. You can contact our cancer support specialists on **0800 808 00 00** for more information. We also have more information on our website. Just visit **macmillan.org.uk**

What you can do to help manage peripheral neuropathy

It is important to protect your hands or feet and try to reduce your risk of accidents and falls. Here are some tips:

- Keep your hands and feet warm. It may help to wear gloves and warm socks in cold weather.
- Do not walk around barefoot. Check your feet regularly for any problems.
- Always wear well-fitting shoes or boots.
- Wear gloves when doing household chores, gardening or DIY.
- Always use pot holders and oven gloves to avoid burning your hands when cooking.
- Before baths or showers, test the temperature of water with your elbow to make sure it is not too hot.
- Make sure rooms are well lit so you do not hurt yourself. Always put on a light if you get up during the night.
- Keep areas that you walk through free of clutter and things you could trip over, such as loose rugs.

Diabetes

Some hormonal therapies used to treat breast cancer can slightly increase your risk of developing diabetes. Diabetes is a condition where the amount of glucose in the blood is too high. Glucose is a type of sugar that our bodies use for energy.

Most women will not get diabetes because of their cancer treatment. But it may help to know the symptoms of diabetes so you can get them checked if they develop. Usually the benefits of hormonal therapies outweigh the small risk of diabetes. Your doctor or specialist nurse can talk to you about this.

Symptoms of diabetes

Diabetes can cause the following symptoms:

- passing a lot of urine (peeing), especially at night
- feeling very thirsty
- feeling very tired
- losing weight for no obvious reason
- itching in the genital area or getting thrush a lot
- cuts and wounds that take a long time to heal
- blurred vision.

These symptoms can be caused by many other conditions. But you should always talk to your GP if you have any of them.

FERTILITY, SEXUALITY AND THE MENOPAUSE

Effects on fertility

Some breast cancer treatments can affect your ability to have children (fertility). Not being able to get pregnant and have children is called infertility.

Some women do not have problems getting pregnant naturally after treatment. This is especially true for younger women. The risk of infertility increases with age and how close you are to your natural menopause. Infertility may be temporary or permanent, depending on the treatment you have had and your age.

Infertility can be very difficult to deal with, especially if you wanted to have children or add to your family. It can be particularly hard when you are already coping with cancer. Having a family may feel like an important part of moving on with life after cancer.

Pregnancy after treatment

Doctors usually advise that you wait at least 2 years after treatment before trying to get pregnant. This is usually because:

- the first 2 years after treatment is when the cancer is most likely to come back
- it gives you time to recover from treatment.

Pregnancy raises your natural hormone levels, so it is important to talk to your specialist nurse first if you are planning to get pregnant. However, recent research has shown that pregnancy after breast cancer does not increase the risk of the cancer coming back. This is true even if the original cancer had hormone receptors (oestrogen positive).

Your cancer doctor or specialist nurse can advise you on the risk of the cancer coming back and how safe pregnancy is in your situation.

You should not get pregnant if you are continuing to take hormonal or targeted therapy drugs, as they may harm the developing baby.

How treatments may affect fertility

Hormonal therapy

Women taking tamoxifen often find that their periods change. Your periods may stop, or become less regular, heavier or lighter. If your periods stop, they usually start again when you stop taking tamoxifen.

Even if your periods stop, it is still possible to become pregnant. Tamoxifen can affect an unborn baby, so it is not safe to become pregnant while taking it. It can also increase the chances of a multiple pregnancy, such as twins or triplets.

Tamoxifen is usually prescribed for up to 10 years. Depending on your age when you start taking tamoxifen, this may be an issue if you want to get pregnant. It is important to talk this over with your cancer doctor.

Drugs such as goserelin, which are used to stop the ovaries from working (known as ovarian suppression), cause temporary infertility. Your period will usually start again about 6 months after treatment finishes.

The side effects of hormonal therapy are similar to the effects of menopause. Women in their 40s may go through the menopause without knowing it while taking hormonal therapy.

Chemotherapy

Some chemotherapy drugs may temporarily or permanently stop your ovaries producing eggs.

Some women may go into the menopause immediately after treatment, especially if they are close to their natural menopause.

If your periods do not come back after a few months, your cancer doctor can do blood tests. These can show if you have gone through the menopause.

If you are in your 30s and you stop having your periods, they will usually come back. This is particularly true if you are under 35. It may take a few months or up to 2 years. Some young women do not stop having periods at all. The younger you are, the more likely it is that you will still be fertile after chemotherapy.

Chemotherapy reduces your egg supply. This means that even if you get your period after treatment, your menopause may start earlier than it would have without cancer treatment. It is important to consider this if you are thinking about having a family.

Referral to a fertility clinic

If you have had chemotherapy and are having difficulty getting pregnant, ask your doctor to refer you to a fertility specialist. You can usually be referred after 6 months of trying to get pregnant. This is because of your risk of an early menopause. The fertility specialist will talk to you about possible options for you.

There are different ways of becoming a parent. You might consider egg donation, surrogacy or adoption.

If you had eggs or an embryo (a fertilised egg) frozen and stored before treatment, you can have fertility treatment later on. This may result in a successful pregnancy.

Becoming infertile can be very hard to live with – whether or not you already have children. You may find it helpful to talk through your feelings with a trained counsellor. If you need more specialised help, your doctor can arrange this for you.

We have booklets about sex, relationships and fertility for men and women. See page 110 for ways to order.

Contraception after treatment

Check with your cancer doctor or specialist nurse if you are not sure whether you need to continue using contraceptives to prevent pregnancy. You will be advised not to take the contraceptive pill or use coils (IUDs) containing hormones. This is because they could encourage breast cancer cells to grow. Your cancer doctor or specialist nurse will give you more advice about this.

Sexuality

How breast cancer can affect your sexuality

Breast cancer and its treatment can affect your sex life and your body image. Body image is how you think and feel about your body and how you think others value you.

Sexual difficulties can happen as a result of the physical and emotional effects of cancer and its treatment. You may lose interest in sex, feel unattractive, or worry that you will never be able to be sexually active. For some people, these problems continue long after treatment has finished.

Try not to think that sex is never going to be as important in your life as it was before. Bringing sex back into your life can involve a period of adjustment for you and your partner.

After treatment, some women continue to have problems with their body image and self-esteem. Others may be left with a low sex drive (libido) or have sexual difficulties as a result of the physical effects of treatment. Usually, women find that they overcome most difficulties with time.

Many people find it difficult to talk about sexual issues because they feel embarrassed or self-conscious. Your doctor or nurse specialist will be used to talking about these things. They can advise you about where to go for specialist help and support.

Changes in your appearance

If you feel less confident and attractive because your operation has changed your appearance, it may be possible to have further surgery. Breast reconstruction (see page 18) or surgery to change the shape of your breast can help restore your self-confidence.

Many women have reconstruction done years after their first breast operation. You can discuss this with your cancer doctor or specialist nurse. They can also arrange a referral to a plastic surgeon.

If you use a prosthesis (false breast) but it is no longer a good fit, you may feel less confident about how you look. You can have a reassessment, even if your prosthesis is still in good condition. Sometimes new prosthesis styles have been developed.

Even getting a new bra fitted in a different style can improve how you look and feel. Breast Cancer Care has helpful information about prostheses, underwear and clothing. See page 115 for their contact details.

> ‘Everyone is expecting me to go back to normal, but every time I look in the mirror I know it can never go back to exactly how it was. And I find that hard.’
>
> **Toni**

Tiredness (fatigue)

You may feel too exhausted to have sex during treatment and for a while afterwards. Most women find that this slowly improves. But sometimes it can last for months or longer. If you are very tired, it might help to have sex differently. For example, it might help to try a less energetic position.

Menopausal symptoms

You may have vaginal dryness and hot flushes. These can make having sex difficult and reduce your sex drive. Using gels and creams can help lessen discomfort during sex. Managing hot flushes and other menopausal symptoms may help to improve your sex drive.

Discomfort or pain

If you have problems with pain, this may lower your sex drive. You may have pain in your chest and shoulders after surgery or radiotherapy. Managing the pain may improve your desire to have sex. It may help to support painful areas with pillows and avoid positions where your weight rests on your chest or arms.

You and your partner

The emotional effects of treatment and cancer can also reduce your sex drive. Surgery to remove part or all of the breast can cause changes to how you see yourself. If you have a partner, you may feel insecure and worry if they will still find you sexually attractive.

These anxieties may cause problems between you and your partner. They may also make you feel anxious about new relationships. A partner may struggle with the changes at first. Or they may not have a problem with your changed appearance. It can be helpful to try to discuss how you both feel.

If you are feeling self-conscious about how you look, talking with your partner about how you feel can help you feel more confident. Partners are often concerned about how to express their love physically and emotionally after treatment.

If you do not feel like having sex, cuddles, kisses and massages can be affectionate and sensual ways of showing how much you care for someone. If you feel very self-conscious, you might prefer to have sex partly dressed, or in low lighting.

Let your cancer doctor or specialist nurse know if you are having problems with your sex life. They may be able to reassure you about your concerns or get you some help. You can also call us for a confidential chat on **0808 808 00 00**.

Our booklet **Cancer, you and your partner** may also be helpful. (see page 110).

Menopausal symptoms

Some breast cancer treatments can affect the way the ovaries work. This can cause an early menopause for some women. It can also cause side effects similar to menopausal symptoms. Sometimes these effects do not last long.

Before the menopause, the ovaries produce the hormones oestrogen and progesterone. These control a woman's period. During the menopause, periods gradually stop as the ovaries stop producing these hormones. This usually happens naturally for most women between the ages of 45 and 55.

Chemotherapy may cause an early menopause. This is more likely to happen in women who are closer to their natural menopause.

Hormonal treatments may cause menopausal symptoms or a temporary menopause. This is because these treatments block the effects of oestrogen on breast cancer cells, or reduce oestrogen in the body. Surgery that removes the ovaries will lead to a permanent menopause.

Managing menopausal symptoms

There are different ways to reduce menopausal symptoms. Choosing the right method for you will depend on:

- your personal preferences
- the possible risks and benefits of each approach
- the type of symptoms you have
- how severe your symptoms are
- what other treatments you are having.

We have more detailed information about breast cancer and menopausal symptoms on our website. Visit **macmillan.org.uk** for more information.

Hot flushes and sweats

This is the most common menopausal symptom. Hot flushes can vary from a mild feeling of warmth in the face to a heavy night sweat.

It is difficult to stop hot flushes and sweats, but how often they happen and how bad they are can often be reduced. Using more than one method often works best.

Ways to manage hot flushes include:

- keeping a record of when you have flushes to see whether something triggers them - to help you avoid them
- wearing natural fabrics, such as cotton
- dressing in layers, so you can remove clothes if and when you need to
- using cotton sheets or fabrics and pillows that are designed to keep you cool in bed
- having layers of bedding that you can easily take off during the night
- keeping the room temperature cool or using a fan
- having cold drinks rather than hot ones
- drinking less alcohol
- if you smoke, stopping or smoking less
- losing weight, if it is suitable for you to
- trying complementary therapies, such as controlled breathing or yoga.

Medicines for hot flushes

There are different medicines that your doctor can prescribe to help you have fewer and less severe hot flushes and sweats. These include:

- low doses of some antidepressants
- the anti-epilepsy drug gabapentin
- clonidine, that is used to treat high blood pressure or migraines.

These medicines are not recommended for all women. They may affect how your breast cancer treatment works. Your doctor or specialist nurse can give you more information.

Hormone replacement therapy (HRT)

HRT is not usually recommended after breast cancer because it contains oestrogen, which may increase the risk of the cancer coming back. Breast cancer guidelines also do not recommend non-oestrogen types of HRT, such as tibolone (Livial®).
Low dose progestogens (megestrol acetate, norethisterone and medroxyprogesterone acetate) are not recommended either.

Rarely, if a woman's symptoms are severe and nothing else helps, HRT may be prescribed. This is only done after careful discussion with your cancer doctor and nurse specialist. They will help you understand the possible risks and benefits.

Complementary therapies for hot flushes

Some women find that complementary therapies help reduce hot flushes.

Some complementary therapies may interfere with your breast cancer medicines. Talk to your cancer doctor or specialist nurse if you are thinking of starting a complementary therapy.

Here are some types of complementary therapy:

Acupuncture

This is the practice of putting sterile needles through the skin at specific points in the body. There is some evidence that it may help reduce the number and severity of hot flushes. The needles should not be used on the arm of the affected side.

Hypnotherapy

This is the practice of encouraging a positive state of mind. This may help reduce the length and severity of hot flushes, but it is unlikely to be available on the NHS.

Controlled breathing techniques

This is the practice of paced breathing or a yoga technique called Sheetali. It can be an effective way of managing flushes.

Evening primrose oil

This is an oil made from the seeds of primrose flowers. It may be helpful, although it is expensive. A few small research studies have shown that it might help. But there is no strong evidence that it works.

Sage

The sage plant can be used to make tablets or tea. Some women find taking sage tablets or tea helps reduce hot flushes. But there is no strong evidence that it works.

Homeopathy

This is the practice of using tiny amounts of substances that would normally produce the symptoms being treated. It is used by some women. But there is no strong evidence that it works.

Plant oestrogens

Plant oestrogens (phytoestrogens) such as black cohosh and red clover, can have a weak oestrogen-like effect. So doctors do not recommend them for women who have had breast cancer.

Vaginal dryness

Having a low level of oestrogen can cause vaginal dryness and itching. It can make having sex uncomfortable or painful.

Vaginal creams or lubricants can help to rehydrate the walls of the vagina. They can reduce discomfort, especially during sex. Not all products are the same. Some products may cause skin irritation.

You may need to try more than one product to find out which works best for you. Your doctor or specialist nurse can give you more information about which products are safe and suitable for you. You can buy them in chemists or online. Some creams may damage condoms and diaphragms, so you may need to use another form of contraception to avoid pregnancy.

Hormone-based treatments

Some vaginal treatments contain a small amount of oestrogen. The long-term risks of using products containing oestrogen after breast cancer are unknown. However, some breast specialists think very little oestrogen is absorbed. So they may prescribe hormone-based treatments for short periods of time. However, hormone-based vaginal treatments are not recommended for women taking an aromatase inhibitor, such as anastrozole, exemestane or letrozole.

It is important to talk to your doctor or specialist nurse before you use any products containing oestrogen. The hormonal therapy drug tamoxifen can cause vaginal discharge. Let your doctor or specialist nurse know if this happens.

Urinary problems

During the menopause you may pass urine (pee) more often. You may also have some urine leakage and be more likely to get urine infections. Urine infections are also called urinary tract infections or UTIs.

Speak to your doctor if you develop symptoms of a UTI. Symptoms include:

- cloudy or smelly urine
- pain or discomfort when passing urine (peeing).

It is important to drink enough fluid each day to keep your bladder healthy. You should try to drink at least 2 to 3 pints (1½ litres) of fluid a day. If you do not drink enough, your urine will become concentrated. This can irritate the bladder. You will also be more likely to develop a UTI.

If you have problems with urine leakage, doing regular pelvic floor exercises can help. These exercises strengthen the muscles that hold urine in the bladder. Your nurse or doctor can explain how to do these exercises. Or you can get more information from the Bladder and Bowel Community (see page 115).

Difficulty sleeping

You may have difficulty sleeping because of hot flushes, sweats or anxiety. The following suggestions may help you to relax and sleep well:

- Have a bedtime routine. This could include having a warm drink, brushing your teeth or reading in bed. This will help your brain know that it is time to sleep.
- Sleep for the right amount of time. Too much time in bed can affect the quality of your sleep. Try to go to sleep at the same time each evening and wake up at the same time each morning.
- Get out of bed if you cannot sleep. You could try reading, or listening to some soothing music. Wait until you feel tired again, and then go back to bed.
- Try breathing exercises and relaxation techniques. Or listen to relaxation CDs or podcasts.

Psychological effects

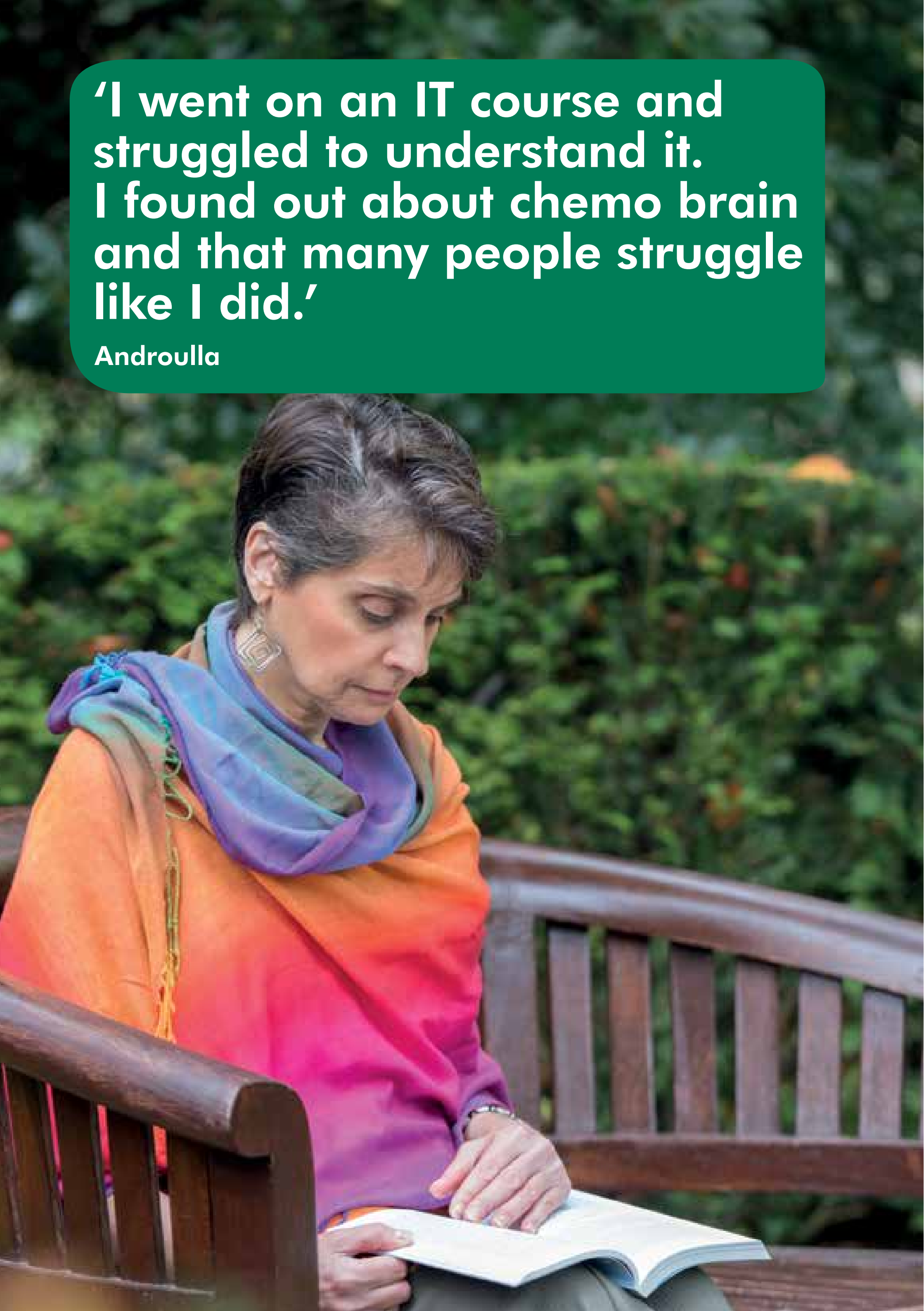
The psychological effects of menopausal symptoms can be hard to cope with when you are already dealing with cancer.

These effects can include:

- a low sex drive
- mood swings
- lack of confidence
- loss of concentration and memory
- feeling very emotional or anxious.

Many women find it helpful to talk through their feelings with family and friends, or their doctor or nurse. A number of organisations provide support to women going through menopause. Some women may find counselling helpful. Your doctor or nurse can give you more advice.

> ‘I have been on hormone treatment for 5 years, and some of my ups and downs can be put down to that. But a lot of it is the shock of settling, now that active treatment has finished.’
>
> Bethan



‘I went on an IT course and struggled to understand it. I found out about chemo brain and that many people struggle like I did.’

Androulla

EFFECTS ON CONCENTRATION AND MEMORY

Concentration and memory problems

After treatment for breast cancer, some women have difficulties concentrating and remembering things. Doctors call this cognitive impairment.

It is also sometimes called chemo brain or chemo fog. But these changes can also happen with other cancer treatments, such as hormonal therapy.

Changes in memory or concentration are usually mild. They often get better within a year of finishing treatment. But they can sometimes go on for longer, or have a bigger impact on your daily life.

Examples of these difficulties include:

- difficulty concentrating and focusing (mental fogginess)
- feeling mentally slower than before
- trouble remembering things you would usually remember, such as names or events
- mixing up dates and appointments
- not being able to find things
- difficulty doing more than one thing at a time (multitasking)
- finding it hard to remember the right word.

If you are having these problems, talk to your doctor. They will look for possible causes for your symptoms. They may arrange for you to have tests and scans. For example, you might have a blood test. There may be other things that are linked to your symptoms. It might be possible to treat these, which could help.

An early menopause may result in similar symptoms, or make them worse.

Hormonal therapies, such as tamoxifen may also affect your memory and concentration. Aromatase inhibitors, such as anastrozole, letrozole and exemestane may have the same effect.

Feeling extremely tired (fatigue) is a common side effect of cancer treatment. It can cause problems with concentration and memory. Improving fatigue may help improve these problems. See pages 36 to 41 for more information about fatigue.

Anxiety, stress and depression can all cause problems with memory and concentration. Treatment to help anxiety or depression may improve your memory and concentration.

Pain or other symptoms can make it difficult to focus on anything else. Treatment and finding ways to manage pain and other symptoms may improve your concentration.

What you can do to help with concentration and memory

It is important to take care of yourself. Get plenty of rest, but balance this with regular activity. Being more active improves fatigue and sleep problems. Feeling less tired could improve your concentration and memory. Gentle exercise like walking is a good way to get started.

Some women also find activities like yoga, meditation, reading and complementary therapies helpful. These activities can help you relax and feel less anxious.

Tell your family and friends about the difficulties you are having. They can support you and help you find ways of making life easier.

> ‘I told close family and friends that if I hesitated in conversation, it wasn’t because I wasn’t listening, I just needed to get the right word. They were very supportive.’
>
> **Sylvie**

There are some things you can do to improve your symptoms:

- Keep notes of anything important. This could include conversations with your doctor or specialist nurse and questions you want to ask them.
- Have a daily routine and try to keep to it.
- Try to do one thing at a time. When you are trying to concentrate, minimise distractions such as background noise.
- Use tools to help your memory. These could include diaries, planners, calendars, post-it notes or lists.
- Keep things in the same place. You are more likely to know where they are, even if you do not remember putting them there.
- If you need to take something with you when you leave the house, put it near the front door.
- Use a dosette box (pill organiser) to store your medicines. This will help you take the right dose of medicine.
- Try crosswords, word puzzles or sudoku to help your concentration. Or you could try doing simple maths in your head. For example, you might do this when you are calculating your change.
- Keep a diary of times when your concentration or memory problems are worse. You can then plan to do things that require concentration when you will find it easiest.

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is normal to find it difficult to cope with some of your feelings months or even years after treatment. It can be especially hard if you have late effects. These feelings often become easier to cope with over time and with the right support.

Feeling alone

You might find some late effects embarrassing or difficult to talk about. This can make you feel isolated. You may feel more alone if you do not know anyone else with the same difficulties. You may also feel isolated as you begin to have less contact with the hospital.

Uncertainty

You may worry that some of your late effects are a sign of the cancer coming back. After cancer treatment, it is also common to feel anxious about aches and pains that you would not have worried about before. It can help to know more about your late effects and where you can get support if you are worried.

Anger

You might feel angry about your illness. It is understandable that you may feel very upset about the cancer. This is especially true if you are coping with late effects of treatment. You do not need to feel guilty for feeling this way. You might find that it helps to tell yourself and the people close to you when you are feeling angry. Your family and friends may think your anger is directed at them, when it is really directed at your illness or late effects. Keeping strong feelings to yourself may make you feel depressed. You can talk to your doctor about seeing a counsellor.

Depression

Coping with the late effects of treatment can be physically and emotionally difficult. This can sometimes make people feel depressed. Signs of depression include:

- feeling low in mood
- having no interest in, or getting no enjoyment from, things that you normally would enjoy
- feeling helpless or hopeless.

If you think you may be depressed, talk to your doctor. They can refer you to a counsellor or psychologist, or prescribe a course of antidepressant drugs for you.

Our booklet **How are you feeling? The emotional effects of cancer** has more detailed information that you may find helpful (see page 110).

Relationships

Your experience of cancer may have improved and strengthened your relationships with people close to you. The support of family and friends may have helped you cope.

But cancer is stressful, and this sometimes affects your relationships. Any problems usually improve over time, especially if you talk openly with each other.

Family and friends

You may sometimes feel that your family and friends do not understand if you are not feeling positive about certain things. You may feel they do not realise how much the effects of treatment are affecting your life. Talking openly about how you are feeling will help them understand you better and give you the support you need.

Our booklet **Talking about cancer – a guide for people with cancer** has useful tips on how to talk to family and friends (see page 110).

Children

Deciding what to tell your children or grandchildren about your late effects can be difficult. The way your illness affects children often depends on their age. An open, honest approach is usually best.

Explain the late effects that you are coping with. You may want to find ways of getting them involved in managing them, such as going for walks with you. Tell them what you can do and help them to understand that recovery takes time.

Teenagers may find it particularly difficult because they are going through a lot of emotional changes themselves. At a stage when they want more freedom, they may be asked to take on more responsibilities. It is important that they can go on with their normal lives as much as possible and get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them. This could be a relative, friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk**, which is for teenagers who have a parent with cancer.

Our booklet **Talking to children and teenagers when an adult has cancer** has helpful advice (see page 110).

Your partner

Some couples become closer because they have shared the experience of cancer. But cancer can put a lot of strain on a relationship. Problems sometimes develop, even between close and loving couples who have been together for a long time. If a relationship was already difficult, the stress of a major illness may make things worse. The changes caused by some late effects may also be difficult to cope with. You may both need time to adjust.

You may both assume you know what the other person is thinking, but you may not always be right. Talking openly about your feelings and listening can help you understand each other's point of view.

We have a booklet called **Cancer, you and your partner** that you may find helpful (see page 110).

GETTING HELP AND SUPPORT

How and when to get help

You do not have to wait until your next check-up to contact your doctor or any other health professional. Let your doctor or specialist nurse know as soon as possible if:

- you have physical or emotional problems because of the cancer treatment
- you think that your symptoms have come back.

Even if you are just feeling nervous or worried, tell your doctor so you can get support. After going through cancer, it is natural for your body to feel different, and for you to feel differently about your body. Aches and pains that you would not have worried about before may now make you wonder if the cancer has come back. This is a common reaction.

Your GP or cancer specialist can assess your situation and refer you to the appropriate services. You can get physical and emotional support services through the NHS. Voluntary organisations can also offer a range of support services. Your doctor or nurse can arrange these for you during an appointment at the hospital.

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 110). For more information, visit **macmillan.org.uk/work**

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 110).

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 and 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 cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

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

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 110). Our Online Community forum Travel insurance may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

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 page 121).

Our booklet **Help with the cost of cancer** has lots more information (see page 110).

FURTHER INFORMATION

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.

Online information

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 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** 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**

My Organiser app

Our 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.

Cancer specific support organisations

Bladder and Bowel Community

Tel 0192 635 7220
Email help@bladderbowel.org
www.bladderandbowel.org
UK-wide community that provides information and support for anyone affected by bladder and bowel conditions, as well as their families and carers.

Breast Cancer Care

Helpline 0800 800 6000 (Mon to Fri, 9am to 5pm, and Sat, 10am to 1pm)
Textphone 0808 800 6001
Email info@breastcancercare.org.uk
www.breastcancercare.org.uk
Provides information, practical assistance and emotional support for anyone affected by breast cancer. Specialist breast care nurses run the helpline. Also offers a peer support service where anyone affected by breast cancer can be put in touch with a trained supporter who has had personal experience of breast cancer.

Breast Cancer Haven

Tel 020 7384 0000 (London)
Email info@thehaven.org.uk
www.breastcancerhaven.org.uk

Havens are day centres providing support, information and complementary therapies before, during or after cancer treatment. They have a network of centres across the UK. Details of other UK Haven centres are on the website.

Breast Radiotherapy Injury Rehabilitation Service

Tel 0122 547 3481
www.rnhrd.nhs.uk/175

A highly specialised national service for anyone experiencing pain from injury following radiotherapy for breast cancer.

British Heart Foundation

Helpline 0300 330 3311 (Mon to Fri, 9am to 5pm)
www.bhf.org.uk

National charity providing information and advice to people with heart and circulatory problems. Also gives advice on keeping your heart healthy.

British Lung Foundation

Helpline 0300 003 0555 (Mon to Fri, 9am to 5pm)
www.blf.org.uk

National charity providing information and advice to people affected by lung disease. Run support groups and a web community.

National Osteoporosis Society

Helpline 0800 800 0035
Email nurses@nos.org.uk
www.nos.org.uk

UK charity dedicated to improving the diagnosis, prevention and treatment of osteoporosis. Offers a wide range of services to people concerned about osteoporosis.

The Daisy Network

Email info@daisynetwork.org.uk
www.daisynetwork.org.uk

Support group for women who have ovarian failure. The website gives information about premature menopause and related issues.

General cancer support organisations

Cancer Black Care

Tel 0208 961 4151
Email info@cancerblackcare.org.uk
www.cancerblackcare.org.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
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.

Irish Cancer Society

Tel 1800 200 700
(Mon to Fri, 9am to 5pm)
Email cancernurseline@irishcancer.ie
www.cancer.ie
Has a freephone cancer helpline staffed by nurses trained in cancer care. You can also chat to a nurse online and use the site's message board.

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 300 0118
(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/young-peoples-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 88
(Mon to Fri, 8am to 10pm, and Sat and Sun, 9am to 5pm)
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 evidence-based 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 0145 588 3300
Email bacp@bacp.co.uk
www.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 0207 014 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 (Mon to Fri, 9am to 6pm)
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.org
Samaritans branches are located across England, Ireland, Scotland and Wales. Provides 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

Benefit Enquiry Line Northern Ireland

Tel 0800 022 2450 (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone 0289 031 1092
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

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 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.citizensadvice.org.uk/scotland

Northern Ireland

Helpline
0289 023 1120
www.citizensadvice.co.uk

Civil Legal Advice

Helpline 0345 345 4345
(Mon to Fri, 9am to 8pm, and Sat, 9am to 12.30pm)
Minicom 0345 609 6677
www.gov.uk/civil-legal-advice

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP)
Helpline 0800 121 4433
(Mon to Fri, 8am to 6pm)
Textphone 0800 121 4493
Carer's Allowance Unit
Tel 0800 731 0297
(Mon to Fri, 8am to 6pm)
Textphone 0800 731 0317
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.

Money Advice Scotland

Tel 0141 572 0237
Email info@moneyadvicescotland.org.uk
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

National Debtline (England, Wales and Scotland)

Tel 0808 808 4000
(Mon to Fri, 9am to 8pm, and Sat, 9.30am to 1pm)
www.nationaldebtline.org
National helpline for people with debt problems. The service is free, confidential and independent. Has an online chat service with an expert debt advisor.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Personal Finance Society - 'Find an Adviser' service

www.thepfs.org/yourmoney/find-an-adviser
Use the website to find qualified financial advisers in your area of the UK.

The Money Advice Service

Helpline
0800 138 7777 (English)
0800 138 0555 (Welsh)
(Mon to Fri, 8am to 6pm, and Sat, 8am to 3pm)
Typetalk
18001 0800 915 4622
Email enquiries@moneyadviceservice.org.uk
www.moneyadviceservice.org.uk
Runs a free financial health check service and gives advice about all types of financial matters across the UK. Has an online chat service for instant money advice.

Unbiased.co.uk
Helpline 0800 023 6868
Email contact@unbiased.co.uk
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Equipment and advice on living with a disability

British Red Cross
Tel 0344 871 11 11
Textphone 020 7562 2050
Email contactus@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK
Tel 0330 995 0400
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.

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.

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 a 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
Helpline 0345 330 3030
(Mon to Fri, 10am to 10pm, and Sat, 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.

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 our Senior Medical Editors: Dr Russell Burcombe, Consultant Clinical Oncologist; Professor J Michael Dixon, Professor of Surgery; and Dr Rebecca Roylance, Consultant Medical Oncologist.

With thanks to: Dr Dorothy Goddard, Consultant Breast Radiologist; Catherine Richmond, Therapy Radiographer; Dr Richard Simcock, Consultant Clinical Oncologist; and Dr Virginia Wolstenholme, Consultant Clinical Oncologist.

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 further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Agrawal S. Late effects of cancer treatment in breast cancer survivors, South Asian J Cancer. Apr-Jun; 3(2): 112-115. 2014.

National Institute for Health and Care Excellence (NICE). Early and locally advanced breast cancer: diagnosis and management. July 2018.

National Osteoporosis Society (NOS). Breast cancer treatments and osteoporosis. January 2016.

Stubblefield MD. Chapter 152: Rehabilitation of the cancer patient in DeVita Hellman and Rosenberg's Cancer: Principals and practice of oncology. Lippincott Williams and Wilkins (10th edition). 2014.

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.

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

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Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about the possible late effects of treatment for breast cancer. It is for anyone who has side effects that have continued for 6 months or longer, or has developed late side effects months or years after treatment.

The booklet describes the possible effects of treatment and how they can be improved or managed. It also has information about emotional, practical and financial issues.

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**

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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