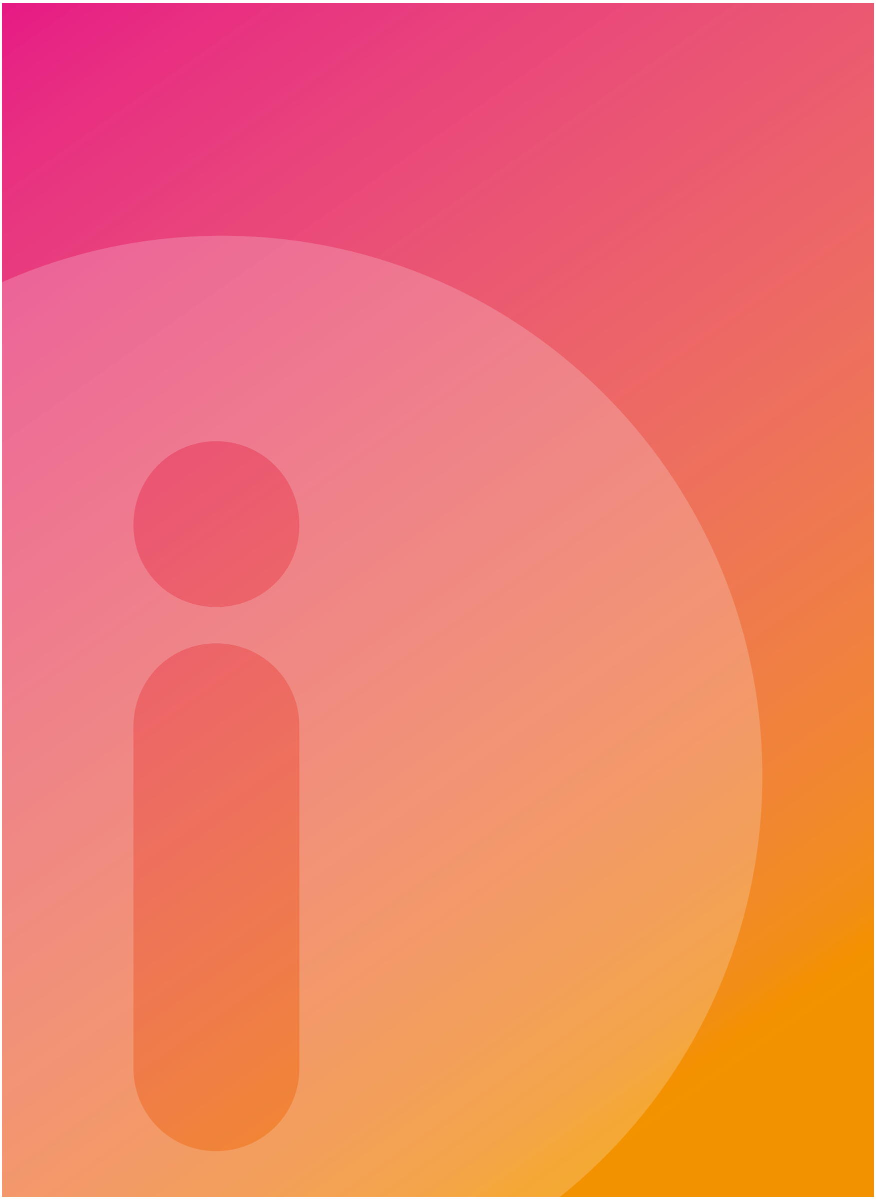
Secondary breast cancer

Information pack

breast cancer care



This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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Are you living with secondary breast cancer?

Sometimes it's hard to find anyone who understands what it's like to live with this diagnosis. Our Living with Secondary Breast Cancer sessions give you a chance to meet and share experiences with people who understand what you're going through because they're going through it too. Facilitated by a counsellor, you'll also be able to ask questions and hear from expert speakers about a range of topics.

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'It changed my life completely. I have become more relaxed and confident about dealing with secondary breast cancer.'

For more information call us on **0345 077 1893** or email **secondaryservices@breastcancercare.org.uk**

The breast cancer support charity
Call free on **0808 800 6000** or visit **breastcancercare.org.uk**

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About this pack

This pack is for anyone with secondary breast cancer. It contains information that may be useful to you and your family, friends or carers when you're diagnosed and throughout your treatment and care.

The pack aims to help you understand what secondary breast cancer is and the physical and emotional effects it can have on you and those around you.

It can also help you monitor your condition and get what you need out of your appointments with your specialist team.

What's in the pack?

This pack has four main parts.

1. The first part of the pack explains what secondary breast cancer is, looks at treatments and side effects, and has information about monitoring and coping with the physical effects of your condition.
2. The second part of the pack is called **Your needs and concerns with secondary breast cancer**. This looks at how to make sure your needs are met, from emotional and practical needs to concerns about relationships, work and finances, and health and wellbeing.
3. There's a **Personal organiser** to help you record symptoms or side effects from treatment, which you can take with you to hospital appointments. You can also record appointment details and names and contact details of people involved in your care.
4. Finally, a small booklet called **Planning ahead: choices and decisions about the end of life** is for if and when you want to start thinking about these things.

Further information

This pack is about secondary breast cancer in general.

We also have booklets called:

- **Secondary breast cancer in the bone**
- **Secondary breast cancer in the lung**
- **Secondary breast cancer in the liver**
- **Secondary breast cancer in the brain**

Our individual booklets explain the symptoms, treatments and physical effects when breast cancer has spread to these areas.

You can find the same information online at **breastcancercare.org.uk** where we also have information about secondary breast cancer that has spread to the skin.

To find out how to order our publications, turn to page 85.

Finding support

A diagnosis of secondary breast cancer is life changing, but support is available.

Our website **breastcancercare.org.uk** has an online discussion Forum, as well as regular Live Chat sessions for people with secondary breast cancer.

We also run Living with Secondary Breast Cancer meet-ups around the country.

You can call our free confidential Helpline on **0808 800 6000** for information and support.

While this pack is relevant for anyone with secondary breast cancer, younger women or men who have secondary breast cancer may have specific information or support needs. Our Helpline staff can discuss any concerns you have and tell you where to find support.

You can find more details about support from Breast Cancer Care on page 84.

About secondary breast cancer

What is secondary breast cancer?

Secondary breast cancer occurs when breast cancer cells spread from the primary (first) cancer in the breast to other parts of the body.

Breast cancer cells can spread to another part of the body through the lymphatic system or the bloodstream.

You may also hear secondary breast cancer referred to as:

- metastatic breast cancer
- metastases
- advanced breast cancer
- secondary tumours
- secondaries
- stage 4 breast cancer

Usually secondary breast cancer occurs months or years after primary breast cancer. But sometimes it's diagnosed at the same time as the primary breast cancer or before the primary breast cancer has been diagnosed.

Which areas of the body can it affect?

The most common areas breast cancer spreads to are the:

- bones
- lungs
- liver
- brain

Sometimes other parts of the body, such as the skin or abdomen (belly), are affected.

Where it spreads and to how many sites varies with different types of breast cancer and in different people.

When breast cancer spreads to the bones, for example, it's called secondary or metastatic breast cancer in the bone. The cancer cells in the bone are breast cancer cells.

Can it be treated?

Secondary breast cancer can be treated, but it can't be cured.

Treatment aims to control the cancer, relieve any symptoms, and maintain health, wellbeing and a good quality of life for as long as possible.

What's my prognosis (outlook)?

One of the first things many people with secondary breast cancer want to know is how long they've got to live.

As treatments have improved, more and more people are living much longer after a diagnosis of secondary breast cancer. However, life expectancy is difficult to predict as each person's case is different and no two cancers progress in the same way.

For some people the cancer becomes like a chronic illness – the illness and treatment don't affect their day-to-day life very much for a long time, and they deal with problems as they arise. For others, it's more difficult, with constant rounds of treatment needed to control their disease and its symptoms.

Your specialist can talk to you about the likely progression of your secondary breast cancer. You may worry if their answers are vague but it isn't possible to accurately predict how each person's cancer will respond to treatment.

Coping with a diagnosis

A diagnosis of secondary breast cancer often comes as a very big shock.

In the days or weeks after your diagnosis, you may feel in turmoil and find it hard to think clearly.

You may experience many different emotions, including disbelief, denial, shock, anger, fear, numbness and helplessness. Your emotions may swing from one extreme to the other or change from one day to the next.

Many people go through this stage before reaching a point where they're able to start taking some control of their situation. However difficult it may seem, you can have some control over how you manage the illness and deal with the emotional and practical issues it brings.

You can find more information on coping with the emotional effects of a diagnosis on page 57.

Talking about it

Talking about how you're feeling can often help you cope in the early days. You may be able to do this with family and friends, but many people find this very difficult.

Talking with a specialist nurse can often help. You can ask to be put in contact with one if you haven't already.

You can also call us free on **0808 800 6000** to talk through your concerns with our expert team.

It can help to be in touch with people who are in a similar situation. You can make contact with other people with secondary breast cancer through our online discussion Forum, Live Chat on our website **breastcancercare.org.uk** or Living with Secondary Breast Cancer meet-ups (see page 84).

Treating secondary breast cancer

Professionals who may be involved in your care

Your specialist treatment team

You'll be looked after by a team led by a cancer specialist (oncologist).

Everyone diagnosed with breast cancer should have access to a specialist breast care nurse who's there to provide them with information and support. Some people will have a secondary breast cancer nurse specialist.

You can talk to your specialist nurse or a member of your specialist team about any questions or concerns you have about your disease or treatment, or the information in this pack. If you don't know who to contact with questions or concerns, ask your oncologist.

Don't be afraid to ask your specialist team to repeat, or explain further, anything you don't understand. You may want to write down questions for them and keep a note of their answers to refer back to. You could use the organiser provided in this pack.

GP

Your local doctor has overall responsibility for your healthcare while you're at home and works with other health and social service professionals, who you can contact through your GP.

District or community nurse

While you're at home, the district nurse is usually responsible for coordinating and delivering all nursing care and organising any equipment you may need, such as a commode or pressure-relieving mattress.

Your district nurse can help with practical nursing care and symptom control. Some district nursing teams offer a 24-hour service.

Palliative and supportive care team/home care team

These teams are based in the hospital, hospice or community. They can help you with managing symptoms and can provide support for you and your family, friends and carers.

Teams may include specialist nurses (who may be Macmillan nurses), doctors and others such as psychologists, social workers or physiotherapists.

Community-based teams will visit you in your home and some offer a 24-hour on-call service.

Occupational therapist

An occupational therapist can assess what aids and adaptations you may need, such as stair rails and bathing aids, to help you be more independent in your home. They can also help with managing symptoms such as fatigue.

Your district nurse or GP can organise a referral for you.

Social worker

A social worker can assess what welfare benefits you may be entitled to and help you apply for them. They can arrange social services and other practical help. Some social workers offer counselling, particularly those based in hospices or palliative care teams.

Social services

This department is part of the local council. It can provide practical information and support, such as home carers to assist with things like washing, dressing and shopping. It can also provide other services such as meals on wheels. In some areas you may have to pay for these services.

Benefits and finance adviser

A benefits adviser gives specialist advice and information on benefits, tax credits, grants and loans to help you work out what financial help you could be entitled to. They can also provide information and advice on things like insurance, household bills and pensions.

Hospices

Hospices are there to support you and your family and to help you live with secondary breast cancer. Their services are free.

They usually have an inpatient unit where you can stay for a short time if you need help with managing symptoms or respite care, and then go home again. The hospice usually has a home care team and often a day unit where you can meet other people.

Many hospices offer counselling and a range of complementary therapies. You may want to visit your local hospice to find out more about its services. Some people choose the hospice as the place they want to be when they die.

Marie Curie or Hospice at Home nurse

These nurses provide hands-on care for people with secondary cancer in their own homes. Depending on your needs, they may stay with you day or night or both. This service can be organised by your district nurse or GP.

What is the aim of treatment?

The aim of treatment for secondary breast cancer is to:

- control and slow down the spread of the cancer
- relieve symptoms
- maintain health and wellbeing
- give you the best quality of life for as long as possible

Decisions about treatment

When making decisions about how best to treat you, your specialist team will consider factors such as:

- where the secondary breast cancer is in the body
- how extensive it is (how many sites and how large)
- any symptoms you have
- what treatment you've had in the past
- the features of the secondary cancer (such as oestrogen receptors – see page 21)
- your general health and any other medical conditions you have

Your specialist team should discuss any recommendations for treatment with you and take into account your wishes.

A number of different treatments are used to treat secondary breast cancer and your specialist will talk with you about your options.

If you want to be involved in decisions

If you want to be involved in decisions about your treatment, you'll need to know your options and what they might mean. When your specialist is talking with you about your treatment options, it's a good idea to have a list of questions ready that may help you make your decision.

You may want to take time to discuss things with your family, friends or different members of the specialist team. You may also want to bring a family member or friend to your hospital appointments.

It may help to think about what would affect your decision to have a particular treatment, such as its possible side effects or whether you would have to make regular trips to hospital to have it.

If you don't want to be involved in decisions

You may not want to be involved in making decisions about your treatment or you may be happy for your specialist team to guide you. There shouldn't be any pressure on you to be involved if you don't want to be. However, your team will need to gain your consent for treatment. This will involve discussing the planned treatments with you so that you understand the aim of the treatment and any potential side effects.

A second opinion

Some people consider asking for a second opinion about treatment options from another specialist. You can ask your specialist team or GP to refer you to another specialist who may be in the same hospital or elsewhere.

The second opinion may not be different from the first one and sometimes the time taken to get a second opinion may delay your treatment slightly. Your specialist can discuss any effect this might have.

Treatments for secondary breast cancer

Several different types of treatment may be given for secondary breast cancer. The following treatments may be given alone or in combination.

Hormone therapy

The hormone oestrogen can stimulate some breast cancers to grow. A number of hormone therapies work in different ways to block the effect of oestrogen on cancer cells.

In secondary breast cancer, hormone therapies are used to control and slow down the growth of the cancer and they are usually the first treatment recommended. You'll usually take hormone therapy for as long as it continues to keep your cancer under control.

If you've had hormone therapy in the past you can still have it again. The drug you're prescribed will depend on a number of factors, including whether you have gone through the menopause and how much time has passed since your diagnosis and treatment for primary breast cancer.

Testing for oestrogen receptors

Hormone therapy will only be prescribed if your breast cancer has receptors within the cell that bind to the hormone oestrogen, known as oestrogen receptor positive or ER+ breast cancer.

Invasive breast cancers are tested for oestrogen receptors using tissue from a biopsy or after surgery. When oestrogen binds to these receptors, it can stimulate the cancer to grow.

For many people this will have been tested using tissue from their primary breast cancer. However, in some people the oestrogen receptors may have changed during the development of the secondary breast cancer. Because of this your doctor may discuss having a biopsy of the secondary breast cancer to retest the hormone receptors. This will depend on your individual situation.

If your cancer is oestrogen receptor positive, your specialist will discuss with you which hormone therapy they think is most appropriate.

If oestrogen receptors aren’t found

If oestrogen receptors are not found it is known as oestrogen receptor negative or ER-.

Sometimes tests may be done for progesterone (another hormone) receptors. The benefits of hormone therapy are less clear for people whose breast cancer is only progesterone receptor positive (PR+ and ER-). Very few breast cancers fall into this category. However, if this is the case for you your specialist will discuss with you whether hormone therapy is appropriate.

If your cancer is hormone receptor negative, then hormone therapy will not be of any benefit.

For information about individual hormone therapy drugs, including their side effects, you can order our booklets:

- **Tamoxifen**
- **Letrozole (Femara)**
- **Anastrazole (Arimidex)**
- **Exemestane (Aromasin)**
- **Fulvestrant (Faslodex)**

See page 85 for information on how to order our publications.

Chemotherapy

Chemotherapy is treatment that destroys cancer cells using anti-cancer drugs.

Chemotherapy for secondary breast cancer aims to control and slow down the growth of the cancer. It can also help relieve some symptoms.

A number of different chemotherapy drugs are used to treat secondary breast cancer. The treatment you’re recommended will depend on what drugs you’ve had before and how long ago.

All chemotherapy drugs have some side effects that may affect your quality of life. Your specialist team will talk to you about the likely effect the chemotherapy will have on the progression of the cancer, the possible side effects and how they can be managed.

If you have triple negative breast cancer, chemotherapy will usually be recommended. Triple negative means the breast cancer is oestrogen receptor negative, progesterone receptor negative and HER2 receptor negative (see page 24), so hormone therapies and HER2 targeted therapies will not benefit you.

You can talk to your chemotherapy nurse or clinical nurse specialist about chemotherapy and the drug or drugs that you'll be having.

You can find more information on chemotherapy drugs used to treat secondary breast cancer on our website **breastcancercare.org.uk** including:

- docetaxel
- paclitaxel
- eribulin
- vinorelbine
- capecitabine
- gemcitabine
- cisplatin
- carboplatin

You can also order our **Chemotherapy for breast cancer** booklet.

See page 85 for information on how to order our publications.

Targeted (biological) therapies

This is a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow.

In secondary breast cancer they aim to control and slow down the growth of the cancer. You'll usually be given targeted therapy for as long as it continues to keep your cancer under control.

Some targeted therapies are not approved for use in the NHS and newer drugs are being investigated in clinical trials (see page 28). Your specialist can tell you more about whether they might be of benefit to you and whether there are clinical trials you could take part in.

HER2 targeted therapy

HER2 is a protein that makes cancer cells grow. People whose cancer has high levels of HER2 (called HER2 positive) are likely to be offered HER2 targeted therapy.

There are various tests to measure HER2 levels, which will usually have been done using tissue from the primary breast cancer. However, in some people the HER2 levels may have changed during the development of the secondary breast cancer. Because of this your doctor may discuss having a biopsy of the secondary breast cancer to retest for HER2. This will depend on your individual situation.

The most common targeted drug used for HER2 positive breast cancer is trastuzumab (Herceptin).

Other targeted drugs used to treat HER2 positive secondary breast cancer include:

- trastuzumab emtansine (Kadcyla)
- lapatinib (Tyverb)
- pertuzumab (Perjeta)

If your cancer is found to be HER2 negative, then trastuzumab and other HER2 targeted therapies will not be of benefit to you.

Other targeted therapies

Other targeted therapies used to treat secondary breast cancer include:

- abemaciclib (Verzenio)
- everolimus (Afinitor)
- palbociclib (Ibrance)
- ribociclib (Kisqali)
- denosumab (Xgeva)
- bevacizumab (Avastin)

For more information about trastuzumab you can read our booklet **Trastuzumab (Herceptin)**. See page 85 for information on how to order our publications.

For more information about other targeted therapies used to treat secondary breast cancer, see our website **breastcancercare.org.uk**

Bone-strengthening therapy

Bisphosphonates and denosumab are drugs used to treat secondary breast cancer in the bone. Bisphosphonates and denosumab work in slightly different ways to reduce bone loss and make complications of secondary breast cancer in the bone less likely to happen.

Bisphosphonates and denosumab are used to relieve bone pain and reduce the risk of fractures and spinal cord compression (when the bones in the spine fracture or collapse causing pressure on the spinal cord). They also help safely control the level of calcium in the blood so that it doesn't become too high (hypercalcaemia).

Spinal cord compression and hypercalcaemia can be very serious, so it's important you know the signs and symptoms to look for (see page 43).

Bisphosphonates can be taken as a tablet (orally) daily, or given into a vein (intravenously) usually every three to four weeks. Denosumab is given once every four weeks as an injection under the skin of the thigh, abdomen or upper arm.

Our **Secondary breast cancer in the bone** booklet has more information about these drugs and their side effects.

Radiotherapy

Radiotherapy for secondary breast cancer aims to control the cancer and relieve symptoms such as pain. Radiotherapy carries on working after the treatment has finished, so you may not feel the benefits from it until one or two weeks later.

It's most commonly used when the cancer has spread to the bones or brain, and for regional recurrence (locally advanced breast cancer) in the skin, neck or under the arm.

A course of radiotherapy for secondary breast cancer is usually much shorter than for primary breast cancer. Depending on which area of the body is being treated, it may include the use of specialist and precise techniques such as stereotactic radiotherapy, also known as radiosurgery.

You may have a few treatment sessions or sometimes only one, and it's often used alongside other treatments.

Electrochemotherapy

Electrochemotherapy, sometimes called ECT, is a treatment for cancers that affect the skin such as secondary breast cancer that has spread to the skin (skin metastases). It's a local treatment, which means it won't treat any other areas of secondary breast cancer inside the body.

It combines a low dose of a chemotherapy drug and electrical impulses, which are given directly to the area or areas being treated using an electrode. Using electrical impulses allows the chemotherapy to work in the treated areas only, with little or no effect in other areas.

The dose of the chemotherapy drug is much lower than when it's given to treat the whole body. This low dose of the chemotherapy drug isn't effective in treating cancer cells when used alone. But the electrical impulses change the outer layer of the cancer cells in the treated area by opening up gaps on their surface for a short time. This means that the chemotherapy drug can enter the cancer cells more easily. Once the gaps close the chemotherapy is sealed inside the cells.

You can read more about skin metastases and electrochemotherapy on our website **breastcancercare.org.uk**

Surgery

Surgery is not commonly used to treat secondary breast cancer, as it's unlikely to be able remove all of the cancer cells in the body. This is especially the case if the cancer has spread to more than one part of the body.

However, although surgery will not cure secondary breast cancer, occasionally an oncologist will ask the opinion of a specialist surgeon. This is more likely if the secondary breast cancer is very small, only at one site and easily accessed.

Surgery is also used to improve symptoms. For example, orthopaedic surgery can strengthen and repair weakened or fractured bones.

Side effects of treatment

Treatments for secondary breast cancer cause side effects. Everyone reacts differently to treatment and some people experience more side effects than others.

Before starting treatment, ask your specialist team what side effects you may experience and what steps will be taken to try to reduce these.

Some side effects may settle down within a short time of starting the treatment. However, it's important to report any side effects you notice to your specialist team so they can help you manage them as well as possible.

Many people find it useful to talk to other people who've had similar experiences about their side effects and how they manage them.

Managing side effects is discussed regularly on our online discussion Forum, Live Chat and at our Living with Secondary Breast Cancer meet-ups (see page 84).

Complementary therapies

Some complementary therapies are thought to improve the side effects of medical treatments without affecting the way they work. However, others could reduce the effectiveness of medical treatments or cause other side effects. Because of this, it's essential you talk to your specialist team before you begin any complementary therapy.

For more information on complementary therapies, see page 80.

Clinical trials and research studies

Clinical trials and research studies are very common in secondary breast cancer. They aim to find new or better treatments. They may also look at using existing treatments in different ways.

Taking part in a clinical trial may give you access to a new treatment or a new way of receiving treatment that may otherwise not be available.

All clinical trials are regulated to make sure everyone receives at least the standard of treatment that would have been recommended if they hadn't been taking part in the trial.

Clinical trials for people with secondary breast cancer often look at new drug treatments. They might also study new doses or regimes of drugs, new ways of measuring response to treatment, or new types of palliative and supportive care to control symptoms such as pain, breathlessness or nausea.

A research study could also be a survey of patient attitudes toward treatments, or finding out how treatment affects quality of life.

As part of your treatment you may be interested in, or may be asked if you'd like to take part in, a clinical trial. Your specialist will talk with you about this, or you can ask if there are any trials that are appropriate for you.

Clinical trials can take place at all stages of treating secondary breast cancer.

Clinical trials are written with a specific set of instructions, called a protocol, that specify why the study should be done and exactly what kind of patients the study will focus on (for example breast cancer type, previous treatment or general health).

You can search for current trials for secondary breast cancer on the following websites:

- UK Clinical Trials Gateway **ukctg.nihr.ac.uk**
- NHS Choices **nhs.uk**
- Cancer Research UK **cancerresearchuk.org**

Availability of new cancer treatments

Sometimes a treatment for secondary breast cancer may not be routinely available on the NHS, but you may still be able to access it.

It can be expensive to receive treatment outside the NHS, so it's important to speak to your specialist to make sure it's the best treatment option for you.

To get treatments unavailable on the NHS you can:

- apply to your local health body – this will depend on where you live
- apply to The Cancer Drugs Fund (in England) or other funding bodies
- pay for your own drugs or treatment
- consider using co-payment options
- contact your local member of parliament

Palliative and supportive care

People often think of palliative care as being associated with end-of-life treatment, so are worried when it's mentioned as part of their care.

However, palliative and supportive care also focuses on symptom control and support. Many people benefit from having advice from a palliative care team much sooner, alongside their medical treatment. It can be helpful at any stage of your illness to prevent and relieve symptoms and help you deal with any other physical, emotional, social and spiritual effects of secondary breast cancer.

Palliative care usually involves a team of healthcare professionals such as specialist nurses, doctors, social workers, physiotherapists and occupational therapists.

Many people access palliative and supportive care for specific symptom control, such as relieving pain or improving fatigue. Others may access complementary therapies or psychological support for themselves or their families.

You can be referred by your specialist team, GP or specialist nurse depending on your situation. Your needs and those of your family will be assessed by the palliative care doctor or nurse, who may see you at the hospital, hospice or in your own home. If palliative care input is no longer needed, you can be discharged but be seen again when required. It can continue up to and including end-of-life care.

Taking a break from treatment

Unlike treatment for primary breast cancer which comes to an end, most people diagnosed with secondary breast cancer will be on treatment continually.

For many people it can be difficult to continue with daily routines while trying to manage the ongoing side effects of treatment. Because of this your specialist team may suggest a break from treatment. Alternatively you may wish to take a short break for a special occasion or a longer break to recover from the effects of treatment. Whatever the reason, your specialist team can talk this through with you and explain the possible effect on your condition.

Thinking about stopping treatment

Many people reach a point when they decide not to have any more cancer treatment. This is often because the side effects from treatment are significantly reducing their quality of life, and they prefer to have supportive care and symptom control only.

This is never an easy decision to make. Sometimes people feel under pressure to have any treatment offered. Family and friends may also find it hard to accept their loved one has stopped having cancer treatment. It’s a very personal decision, so if you don’t want to carry on with treatment, try not to feel guilty about something that you feel is the right step for you.

Whatever you decide it shouldn’t make any difference to the care and support available to you.

Monitoring and coping with your condition

Regular appointments

You should have regular hospital appointments with your specialist team to check how physically and emotionally well you are. They should ask how you're feeling, if you have any new symptoms and how you're managing your day-to-day activities. This is a very important way for your specialist team to assess your condition and any changes that may have happened.

You should also have the name and contact number of someone to get in touch with if you have routine or urgent concerns (both during working hours and at night or the weekend) or if you need to change an appointment.

Blood tests

You may have blood tests while you're at the hospital to check if anything has changed.

Some people have a blood test for tumour markers, which may help monitor how your breast cancer is responding to treatment. Tumour markers are substances found in the blood. However, these tests are not widely used because doctors don't agree on how reliable they are. They're rarely used on their own to make decisions about starting or changing treatment.

Scans

Scans may not always be routinely done, but may be planned by your oncologist to see how the secondary breast cancer is responding to a new treatment or if you have new or worsening symptoms. If you're taking part in a clinical trial you may have scans more frequently, depending on the requirements of the trial.

Getting the most out of your appointments

Feeling comfortable with your specialist team can make a positive difference to how you feel about your treatment and care. Some things may be hard to discuss but being prepared for your hospital appointments and knowing what information you need to get from them may help.

1. Prepare for your appointment

Write a list of what you want to discuss, including how you're feeling physically and emotionally, any new or lasting symptoms or side effects and any questions you have. You might want to share any information you've recorded using the organiser included in this pack.

2. Take support

If you can, go with a family member, close friend or someone you trust. They can support you, listen to the information you're given and make notes you can read later. You may also find it helpful to talk to your supporter later and discuss any decisions you have been asked to make about your care.

3. Say what you want to say

It helps healthcare professionals to care for you effectively if they know what your concerns are and what information you would like. Don't be afraid to say what's on your mind.

4. Get answers to your questions

Healthcare professionals know that it's important for a patient's wellbeing to have their questions answered. If you don't feel you've had an answer to your question, or don't understand any information you've been given, ask again.

Sometimes it's not possible to give a definite answer to a question, but your healthcare professional should be able to explain why if this is the case.

Getting copies of letters about you

After most appointments with your specialist team, a letter will be sent to your GP or other healthcare professionals involved with your care, to update them on your treatment and wellbeing.

You’re entitled to copies of letters about you from healthcare professionals. It may also be possible to supply these in a different language, large print or as an audio recording.

Some people find that having copies of letters following their appointments helps them gain a better understanding of their secondary breast cancer and their treatment. Other people may not want written information about their illness as they may find it upsetting.

Ask your specialist team how to request copies of letters if you want them.

Coping with physical effects

Even though you have secondary breast cancer, you may feel well and have no symptoms for a long time.

When you develop symptoms, treatment aims to improve these so you can carry on doing the things you enjoy for as long as possible.

Secondary breast cancer can cause many different physical symptoms and the more common ones are described in this section. Symptoms will depend on where the cancer has spread to in your body and how extensive it is.

For more details of common symptoms and treatments, you may find it helpful to read our online information or booklets on secondary breast cancer in the bone, lung, liver or brain, and visit our website for information on secondary breast cancer that has spread to the skin.

Pain

Pain can be caused by the cancer or its treatment.

Having pain that can't be relieved is a fear for many people with secondary breast cancer. While everyone's experience is different, most cancer-related pain can be controlled effectively.

Pain relief

Pain relief is a very important part of the care of anyone with cancer. Knowing what's causing the pain, who to talk to about it and what's available to manage it can help you cope better and make a difference to your quality of life. Many people find that once their pain is under control they feel less anxious and can eat and sleep better.

A number of healthcare professionals are experts in pain management and can help.

Many people see their GP or oncologist for help managing their pain. If your pain is not under control, you may benefit from the advice of palliative care experts who specialise in pain and symptom control. These may be specialist nurses or doctors in the community who can often visit you in your home. You can ask your GP or specialist to refer you. Some hospitals and hospices have clinics for pain and symptom control which you can be referred to.

Describing your pain

Pain can be experienced in different ways and you may have more than one type of pain. To find the best way of treating your pain, you'll need to describe it to your doctors. Keeping a pain diary can help you do this. You should note down:

- how bad the pain is on a scale of 1 to 10
- where the pain is
- when and how often the pain occurs and how long it lasts
- what the pain feels like, for example a stabbing, nagging or burning sensation
- what makes it worse or better and what has relieved it in the past
- what medication you took, how effective it was and anything else that may have relieved the pain

Your hospital may provide you with a pain diary, or you can use the **Personal organiser** in this pack.

Three-step approach

Your doctor or nurse will probably recommend a frequently used three-step approach to pain control.

This starts with mild pain relief taken regularly and moves on to moderate and strong pain relief, often morphine-based, when necessary. Because different types of pain respond to different pain relief, your doctor may use a combination of short- and long-acting pain-relieving drugs. These can be given in many different ways.

Whatever pain relief you're given, it's important it's used as prescribed. If you wait until you're in pain before you take it, you may be in pain unnecessarily.

People are sometimes frightened of taking morphine-type pain relief because they think they'll become addicted to it or build up a tolerance so that it becomes less effective. Some people think that needing morphine must mean their cancer is getting worse. In fact, morphine-based pain relief is extremely effective for controlling many types of pain.

Morphine is used at many different stages of the disease and it doesn't necessarily mean that the cancer is getting worse or that you'll need to take morphine forever. Occasionally people develop side effects from taking morphine and your doctors may recommend switching to a different pain relief of a similar strength if this happens.

Other drugs, treatments or therapies

Doctors often use other drugs alongside pain relief. These include anti-inflammatory drugs, steroids and drugs usually used to help treat depression or epilepsy, which can also help relieve certain types of pain.

Other treatments, such as bisphosphonates, denosumab or radiotherapy, may also be used to relieve pain in secondary breast cancer in the bone.

When used alongside conventional drug treatment, some complementary therapies have been reported to be helpful in reducing symptoms such as stress and anxiety which may contribute to pain in cancer patients. See our **Complementary therapies, relaxation and wellbeing** booklet for more information.

Keeping pain under control

It's important that your pain is assessed regularly by your nurse or doctor to make sure it remains under control.

Let your specialist team, palliative care team or GP know if you experience a change in the type or location of pain, a new pain or a long-term pain which gets worse or doesn't improve with treatment.

Some medicines can affect your ability to drive. Since March 2015 in England, Wales and Northern Ireland it's an offence to drive if you have certain prescription drugs (including morphine and some drugs used to treat anxiety or insomnia) above a particular level in the blood, whether or not your driving is impaired. For more information go to gov.uk/drug-driving-law

If you're not sure whether you should drive while on your current drugs, talk to your doctor or pharmacist.

Fatigue (extreme tiredness)

Cancer-related fatigue is one of the most common symptoms experienced by people with secondary breast cancer.

Fatigue has many causes, from psychological factors such as the stress of coping with the diagnosis, to physical ones such as the side effects of treatment, loss of appetite, medication, disturbed sleep, or progression of the cancer.

Signs of fatigue

Common signs of fatigue include:

- tiredness that is not related to any activity
- tiredness that doesn't go away or keeps returning however much rest or sleep you have
- feeling weak, as though you have no strength
- sleeping more or difficulty sleeping
- feeling confused, lack of concentration or unable to focus your thoughts
- breathlessness or feeling light-headed
- feeling irritable, sad or depressed

Managing your energy levels

Fatigue is difficult to assess and measure and can be difficult to describe to other people. Many people find that fatigue stops them working, socialising and generally living life in the way they want to.

There are a number of things you can do to help manage your energy levels and reduce the effects of fatigue.

- **Tell your doctor or palliative care team** about the fatigue so you can be fully assessed. Causes such as difficulty sleeping or anaemia can be treated.
- **Ask to be referred to a specialist**, such as an occupational therapist, in your local palliative and supportive care team who may be able to suggest adaptations, equipment and ideas that may help you manage fatigue.
- **Keep a diary of your activities and energy levels** to help you work out your patterns of fatigue. This can be useful when talking to your specialist team and when planning for daily life. Your hospital may give you a fatigue diary or you can use the organiser in this pack.
- **Be realistic about what you can do** and pace yourself. Prioritise tasks and plan your days so you have a balance of activity and rest. Stop any activity before you become too tired so you keep some energy in reserve.
- **Prepare for a special occasion** or days out by planning some additional rest before and after.
- **Do some physical activity**. Some gentle strengthening exercises and short walks can help increase your appetite, give you more energy and improve wellbeing.
- **Get pain under control** (see page 36) as pain can worsen fatigue by affecting your ability to be active or to sleep well.
- **Eat as well as you can** so your body continues to get the nutrients it needs. If your appetite is poor, eat smaller amounts more often and drink plenty of fluids to keep hydrated. You could ask to be referred to a dietitian.
- **Ask for help**. Use offers of practical help from others so you can continue to do the things you enjoy.
- **Counselling, talking therapies or complementary therapies** can help relieve stress and anxiety, which may contribute to fatigue.

Macmillan Cancer Support has a booklet called Coping with fatigue.

Breathlessness (dyspnoea)

Breathlessness is a common symptom that can affect anyone with secondary breast cancer, but is more likely if you have secondary breast cancer in the lung.

Breathlessness isn't harmful but can be distressing and frightening, which can make your symptoms worse.

You may find breathing uncomfortable, or feel that you can't get enough air into your lungs. You may experience breathlessness when you're still or lying down, but it's often more noticeable when you're moving.

Breathlessness can happen for different reasons. For example, it can happen if you have a chest infection, or if the lymph channels in the lung are affected by the cancer and become inflamed or blocked (known as lymphangitis). Antibiotics and steroid drugs such as dexamethasone or prednisolone are sometimes used to help. Other drugs, such as morphine or antidepressants, can also be prescribed.

Relieving breathlessness

There are several practical things you can do to help ease breathlessness. Cooling your face with cold water, using a hand-held fan or sitting near an open window can help.

Physiotherapy can be helpful, as can using relaxation and breathing techniques when you start feeling breathless. Your GP or specialist team may be able to refer you to a physiotherapist or to a palliative and supportive care team to teach you breathing exercises. Some palliative care services, for example at your local hospice, provide groups, classes and clinics for this purpose.

You may find exercise can help relieve breathlessness (see page 77).

Breathlessness is not usually caused by a lack of oxygen, so giving oxygen has not been found to be a helpful treatment for breathlessness.

For more information see our **Secondary breast cancer in the lung** booklet.

Nausea and vomiting

If you feel sick (nausea) or are being sick (vomiting), it's likely to be because of your cancer, its treatment or emotional side effects such as anxiety.

In most cases nausea and vomiting can be controlled using anti-sickness medication. It's important for your doctor to find the cause so that it can be managed effectively. You can help your specialist or palliative care team decide what treatment will work best by keeping a record of what makes it worse or when it happens.

Some pain relief can cause nausea and vomiting when you first start to take it, although this usually wears off. You may be prescribed an anti-sickness tablet to take with your pain relief to prevent this happening.

Constipation

Constipation can be caused by eating or drinking less than usual, lack of exercise and some drugs, including chemotherapy and some pain-relieving drugs.

Try to eat fresh fruit and vegetables and other high-fibre foods such as wholemeal bread or bran. Increasing the amount of water you drink, including some fruit juice in your diet, and daily exercise may also help.

Laxatives can help relieve the constipation, especially if you're on regular pain relief. Your GP, specialist team or palliative and supportive care team can prescribe these for you.

Diarrhoea

Treatment such as chemotherapy and radiotherapy to the abdomen (belly), spine or pelvis may cause diarrhoea. Other drugs can also affect the digestive system and cause diarrhoea.

If you have regular diarrhoea, your body can't absorb water and nutrients from food as well as any medications taken by mouth.

If the chemotherapy you're having is known to cause diarrhoea, your specialist team may prescribe drugs to help control it.

Try to drink plenty of fluids during the day, avoid foods high in fibre, eat little and often and don't eat fatty foods.

If the diarrhoea doesn't settle, tell your specialist team or palliative and supportive care team.

Poor appetite and weight loss

Sometimes people with secondary breast cancer can't eat as much as usual. This means they have difficulty maintaining their weight as well as providing the body with energy.

Poor appetite can be due to the effects of the cancer, treatment or anxiety. Some people don't feel hungry or feel full after only eating a small amount. Others experience nausea or vomiting after eating.

If you have problems eating, the following tips may help:

- eat smaller amounts often rather than trying to eat a large plateful of food at set mealtimes
- add high-energy ingredients and foods containing protein to your meals. For example, add cream or butter to mashed potatoes and vegetables, grated cheese to soups, and syrup or jam to porridge or desserts
- avoid strong-smelling foods that may put you off your meal
- snack on high-calorie foods and drinks such as chocolate, cake, crisps, nuts or milkshakes to give you energy
- take your time eating, and if you have a dry mouth have a glass of water at hand
- some people find having a small alcoholic drink, such as a glass of wine, before a meal increases their appetite

For more information, Macmillan Cancer Support has a booklet called The building-up diet. Order it free from their website macmillan.org.uk

If you still aren't eating enough or you're losing weight, talk to your doctor or nurse about dietary supplements or ask to speak to a dietitian for specialist advice. In some circumstances you may be prescribed medication to help stimulate your appetite.

Weight gain

You may put on weight as a result of treatment, for example if you're taking steroids or hormone treatment or if you're doing less exercise.

If weight gain becomes a problem for you, it might help to talk to your specialist team or a dietitian who can advise you about diet and monitor your weight. If you want to exercise, speak to your specialist team to find out if there are any limitations on the type or intensity of exercise you can do.

There's more information on exercise on page 77

Emergencies

Blood clots

People with breast cancer have a higher risk of blood clots. Their risk is higher because of the cancer itself and some treatments for breast cancer. Having secondary breast cancer also increases the risk.

Blood clots can be harmful but are treatable so it's important to report symptoms as soon as possible.

If you experience any of the following symptoms contact your local A&E department, GP or specialist team straight away:

- pain, redness/discolouration, heat and swelling of the calf, leg or thigh
- swelling, redness or tenderness where a central line is inserted to give chemotherapy, for example in the arm, chest area or up into the neck
- shortness of breath
- tightness in the chest
- unexplained cough (may cough up blood)

Hypercalcaemia (too much calcium in the blood)

Bone releases calcium and other proteins that make the bone structure strong. Secondary breast cancer in the bone can alter the bone structure so that too much calcium is released into the bloodstream. This is called hypercalcaemia.

If the calcium level in the blood is too high you may get symptoms such as:

- feeling sick (nausea) and vomiting
- constipation
- drowsiness
- feeling very thirsty
- weakness and confusion

Hypercalcaemia can be serious if not diagnosed quickly, so seek medical advice if you have any of these symptoms. For more information see our **Secondary breast cancer in the bone** booklet.

Febrile neutropenia

A number of drugs used to treat secondary breast cancer can cause neutropenia. This is when the white blood cells that fight infection in the body fall below a certain level. Not having enough white blood cells can increase the risk of getting an infection.

The number of white blood cells usually returns to normal before your next cycle of treatment.

Having a high temperature with neutropenia is known as febrile neutropenia and could be a sign of an infection.

As infection can spread quickly it's important to contact your hospital immediately if:

- you have a high temperature (over 37.5°C) or low temperature (under 36°C), or whatever your specialist team has advised
- you suddenly feel unwell, even with a normal temperature
- you have any symptoms of an infection, for example a sore throat, a cough, a need to pass urine frequently or feeling cold or shivery

When necessary, you should be given a 24-hour contact number or told where to get emergency care by your specialist team.

Spinal cord compression

Spinal cord compression is a risk for people with secondary breast cancer in the bone that has spread to the spine. It can happen when:

- a vertebra (spinal bone) collapses and puts pressure on the spinal cord
- cancer grows in or near the spine, putting pressure on the spinal cord

The spinal cord is a bundle of nerves that runs from the brain to the lower back, and is protected by the vertebrae.

Symptoms can include:

- severe or unexplained back pain which may also be felt around the front of the chest and belly
- pain in the back which changes when you lie down, stand up or lift something
- difficulty walking
- numbness or pins and needles in the fingers, toes or bottom
- problems controlling urine or bowel movements

Spinal cord compression alert card

If you've been diagnosed with secondary breast cancer in the bone, you may want to keep this card with you.

For patients

Having secondary breast cancer in the bone means you're at risk of spinal cord compression.

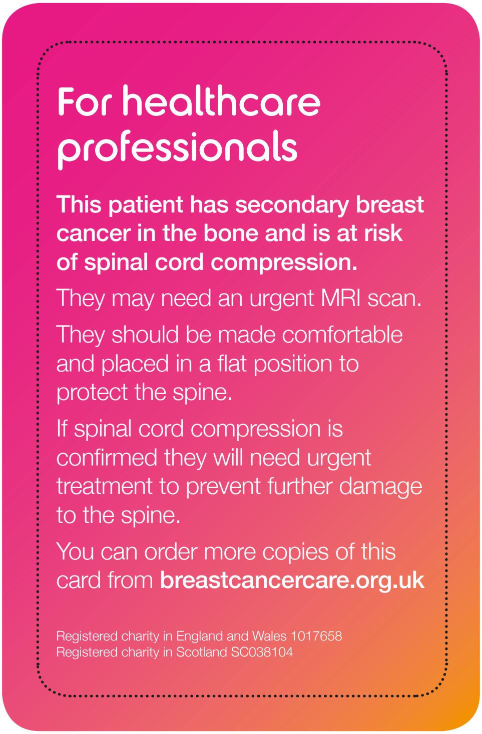
Contact your local A&E department or your specialist team straight away if you have any of these symptoms:

- severe or unexplained back pain which may also be felt around the front of the chest and belly
- pain in the back which changes when you lie down, stand up or lift something
- difficulty walking
- numbness or pins and needles in the fingers, toes or bottom
- problems controlling urine or bowel movements

It’s important to know who to contact at the hospital if you have any of these symptoms at any time. Spinal cord compression can have serious effects if not diagnosed quickly, so seek medical advice without delay to reduce the risk of any long-lasting effects.

Spinal cord compression is usually treated with radiotherapy and steroids. Some people may have surgery. A combination of all three treatments may also be used.

We’ve produced an alert card that you can hand to any healthcare professionals you come into contact with if you believe you have symptoms of spinal cord compression.



For healthcare professionals

This patient has secondary breast cancer in the bone and is at risk of spinal cord compression.

They may need an urgent MRI scan.

They should be made comfortable and placed in a flat position to protect the spine.

If spinal cord compression is confirmed they will need urgent treatment to prevent further damage to the spine.

You can order more copies of this card from **breastcancercare.org.uk**

Registered charity in England and Wales 1017658
Registered charity in Scotland SC038104

Secondary breast cancer words explained

A

Abdomen: belly.

Abemaciclib: also called Verzenio. A targeted therapy used to treat ER positive, HER2 negative secondary breast cancer.

Abraxane: a chemotherapy drug used to treat breast cancer.

Adriamycin: also known as doxorubicin. A chemotherapy drug used in breast cancer. One of a group of chemotherapy drugs known as anthracyclines.

Advanced breast cancer: breast cancer that has spread beyond the breast and the lymph nodes under the arm to other parts of the body. Also known as secondary, stage 4 or metastatic breast cancer.

Adverse effect: an undesired or harmful side effect of a treatment.

Alopecia: loss of hair from the head or body.

Alternative therapy: treatments used instead of conventional treatments like chemotherapy and radiotherapy.

Anaemia: a condition where there are too few red blood cells. It may cause symptoms including tiredness, shortness of breath and weakness.

Anastrozole: also known as Arimidex. A hormone therapy and one of a group of drugs called aromatase inhibitors.

Anthracyclines: a group of chemotherapy drugs commonly used to treat breast cancer. Doxorubicin and epirubicin are both anthracycline drugs.

Anti-emetics: drugs given to reduce nausea (feeling sick) or vomiting (being sick).

Aromatase Inhibitors: a group of hormone therapies used to treat post-menopausal women with oestrogen receptor positive (ER+) breast cancer.

Ascites: build-up of fluid between the two layers of the peritoneum (a membrane which forms the lining of the abdomen).

B

Bevacizumab: also known as Avastin. A targeted therapy that works by stopping cancer cells from developing their own blood supply (angiogenesis). This can help to stop the cancer from growing.

Biopsy: removal of tissue to be looked at under a microscope.

Bisphosphonates: a group of drugs used to treat the effects of secondary breast cancer in the bone.

Blood count: the number of red blood cells, white blood cells and platelets in a sample of blood.

Bone marrow: spongy, soft tissue found in the centre of bones where red blood cells, white blood cells and platelets are made.

Bone metastases: also known as secondary breast cancer in the bone. Cancer cells that have spread from the breast to the bones.

Bone scan: a test to help identify any abnormalities such as tumours, infection or fractures in the bones.

Brain metastases: also known as secondary breast cancer in the brain. Cancer cells that have spread from the breast to the brain.

C

Cannula: A small plastic tube through which drugs are given into a vein, usually in the arm or hand.

Capecitabine: also known as Xeloda. A chemotherapy drug used to treat breast cancer, given as a tablet.

Carboplatin: a chemotherapy drug used to treat breast cancer.

Cardiotoxicity: damage to the heart muscle causing the heart to become weaker and less efficient in pumping. May be caused by some chemotherapy and targeted therapy drugs.

Cyclin-dependent kinases (CDK): a group of enzymes (proteins) involved in helping control when cells grow and divide.

CDK inhibitors: a group of targeted (biological) therapies including palbociclib, ribociclib and abemociclib, often used alongside hormone (endocrine) therapy.

Cell: the tiny structures that make up the tissues of the body. A cell is too small to be seen by the naked eye.

Cell proliferation: an increase in the number of cells as a result of them multiplying and growing.

Chemotherapy: treatment aimed at destroying cancer cells using anti-cancer drugs.

Chest wall: the muscles, bones and joints that make up the area of the body between the neck and the abdomen.

CISH (chromatic in situ hybridisation): a way of measuring the amount of HER2 on breast cancer cells.

Complementary therapies: treatments used alongside conventional medicines. They aim to improve wellbeing.

Cisplatin: a chemotherapy drug used to treat breast cancer.

CT (computerised tomography) scan: also known as a CAT scan. A type of scan that uses x-rays to take detailed pictures across the body.

CyberKnife: see stereotactic radiotherapy.

Cyclophosphomide: a chemotherapy drug used to treat breast cancer.

D

Denosumab: a targeted therapy used to treat the effects of secondary breast cancer in the bone.

D-DISH (dual-color dual-hapten brightfield in situ hydridization): a way of measuring the amount of HER2 on breast cancer cells.

Docetaxel: a chemotherapy drug also known as Taxotere. One of a group of chemotherapy drugs called taxanes.

Drug resistance: cancer cells' ability to resist the effects of a drug.

E

EGFR (epidermal growth factor receptor): proteins on the surface of cells. When there are higher than normal levels (known as over expression) on cancer cells, they stimulate growth.

Embolism: when blood flow is blocked, usually by a blood clot or air bubble.

Endocrine therapy: see hormone therapy.

Epirubicin: a chemotherapy drug used to treat breast cancer. One of a group of chemotherapy drugs known as anthracyclines.

Epoetin: a treatment for anaemia (low red blood cell count).

Eribulin: also called Halaven. A chemotherapy drug used to treat breast cancer.

ER status: ER positive (ER+) means the breast cancer has oestrogen receptors. ER negative (ER-) means the breast cancer doesn't have oestrogen receptors (see oestrogen receptors).

Everolimus: also known as Afinitor. A targeted therapy used to treat secondary breast cancer and given with the aromatase inhibitor exemestane.

Exemestane: also known as Aromasin. A hormone therapy and one of a group of drugs called aromatase inhibitors.

F

Filgrastim: also known as Neupogen. A drug to treat or prevent neutropenia (a decrease in the number of white blood cells, which are essential for fighting infection).

FISH (fluorescence in situ hybridisation): a way of measuring the amount of HER2 on the breast cancer cells.

Fluorouracil: also known as 5FU. A chemotherapy drug used to treat breast cancer.

Fraction: each radiotherapy treatment is known as a fraction. Treatment involves several fractions given over a few days or weeks.

Fulvestrant: also known as Faslodex. A hormone therapy used to treat postmenopausal women with secondary breast cancer.

G

Gamma knife: see stereotactic radiotherapy.

Gemcitabine: also known as Gemzar. A chemotherapy drug sometimes used for treating breast cancer.

H

HER2 (human epidermal growth factor receptor 2): a protein involved in the growth of cells. Around 15–20% of breast cancers have higher than normal levels of HER2 (known as HER2 positive) which stimulates them to grow.

Hickman line: also known as a skin-tunnelled catheter. A fine silicone tube through which chemotherapy drugs are given. It’s put into a large vein through a small cut in the chest wall, and can stay in place for several months.

Hormone therapy: drugs that work in different ways to block the effect of oestrogen on cancer cells. Only used if breast cancer is hormone receptor positive.

Hypercalcaemia: higher than normal levels of calcium in the blood. Can be caused by secondary breast cancer in the bones.

I

Immunohistochemistry (IHC) hybridisation: a way of measuring the amount of HER2 on breast cancer cells.

Immunosuppression: reduced ability of the body to protect against infection and disease. Can be caused by chemotherapy.

Immunotherapy: a type of targeted therapy that uses the body’s immune system to help it fight cancer.

Intramuscular (IM): an injection into the muscle.

Intravenous (IV): an injection into a vein.

L

Letrozole: also known as Femara. A hormone therapy and one of a group of drugs called aromatase inhibitors.

Lymphoedema: swelling of the arm, hand or breast area caused by a build-up of lymph fluid in the surface tissues of the body. It can occur as a result of damage to the lymphatic system, for example because of surgery and/or radiotherapy to the lymph nodes under the arm and surrounding area.

M

Metastases: see secondary breast cancer.

Methotrexate: a chemotherapy drug given to treat breast cancer.

MRI (magnetic resonance imaging) scan: uses magnetic fields and radio waves to produce a series of images of the inside of the breast. An MRI doesn’t expose the body to radiation.

N

Neutropenia: when the number of white blood cells falls below a certain level; may happen as a side effect of chemotherapy. If there is also a high temperature (above 38°C), it is known as febrile neutropenia.

O

Oestrogen receptors: proteins within cancer cells that bind to the hormone oestrogen and stimulate the cancer to grow (may be abbreviated to ER, from the US spelling estrogen).

P

Paclitaxel: also known as Taxol. A chemotherapy drug used to treat breast cancer. One of a group of chemotherapy drugs known as taxanes.

Palbociclib: also called Ibrance. A targeted therapy used to treat ER positive, HER2 negative secondary breast cancer, and one of a group of drugs called CDK 4/6 inhibitors.

Palliative care: focuses on symptom control and support when cancer cannot be cured. Usually involves a team of healthcare professionals such as specialist nurses, doctors, social workers and physiotherapists.

Palliative care consultant: a doctor who specialises in palliative care.

Palliative care nurse: a nurse specially trained to provide palliative care.

Peripherally inserted central catheter (PICC): a tube put into a vein in the arm through which chemotherapy drugs are given. It stays in place throughout the course of treatment.

Pertuzumab: also called Perjeta. A targeted therapy used to treat HER2 positive breast cancer.

PET (positron emission tomography) scan: a type of scan that produces a three dimensional image giving details on both the structure and function of organs or tissue being looked at, sometimes combined with a CT scan.

Portacath: also called an implanted port. A thin, soft, hollow tube made of plastic that's put into a vein. The tube is attached to a rubber disc (port). Chemotherapy drugs are given into the port which is usually placed under the skin on the chest.

Prognosis: the likely outlook of a disease, whether it's likely to be cured and the person's life expectancy.

R

Radiotherapy: the use of high energy x-rays to destroy cancer cells.

Remission: when the signs and symptoms of a disease partly or completely disappear. It may be temporary or permanent.

Ribociclib: also called Kisqali. A targeted therapy used to treat ER positive, HER2 negative secondary breast cancer, and one of a group of drugs called CDK 4/6 inhibitors.

S

Secondary breast cancer: breast cancer that has spread beyond the breast and the lymph nodes under the arm to other parts of the body. Also known as advanced, stage 4 or metastatic breast cancer.

Side effects: unwanted effects of treatments.

Spinal cord compression: pressure on the spinal cord and nerves. It can be caused by the cancer growing in, or spreading into, the bones of the spine and can result in permanent damage to the spinal cord.

Stage: the size of the cancer and how far it has spread.

Stereotactic radiotherapy (also known as radiosurgery): a precise radiation treatment used in secondary breast cancer. May also be referred to as Gamma Knife or CyberKnife.

Supportive care: see palliative care.

T

Tamoxifen: a hormone therapy drug used to treat oestrogen receptor positive breast cancer.

Targeted (biological) therapies: a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow.

T-DM1: also called Kadcyla. A targeted therapy used to treat HER2 positive breast cancer.

TENS machine: a small portable device that uses adhesive skin pads to deliver small electrical impulses to help relieve pain.

Terminal: a term often used when someone is approaching the last few weeks or days of life.

Thrombosis: occurs when blood forms a clot. If the clot occurs in a major vein, the condition is known as a 'deep vein thrombosis' or DVT.

Trastuzumab: also called Herceptin, a targeted therapy used to treat HER2 positive breast cancer, and one of a group of drugs called monoclonal antibodies.

U

Ultrasound scan: uses high frequency sound waves to produce an image.

V

Vinorelbine: also known as Navelbine. A chemotherapy drug used to treat breast cancer.

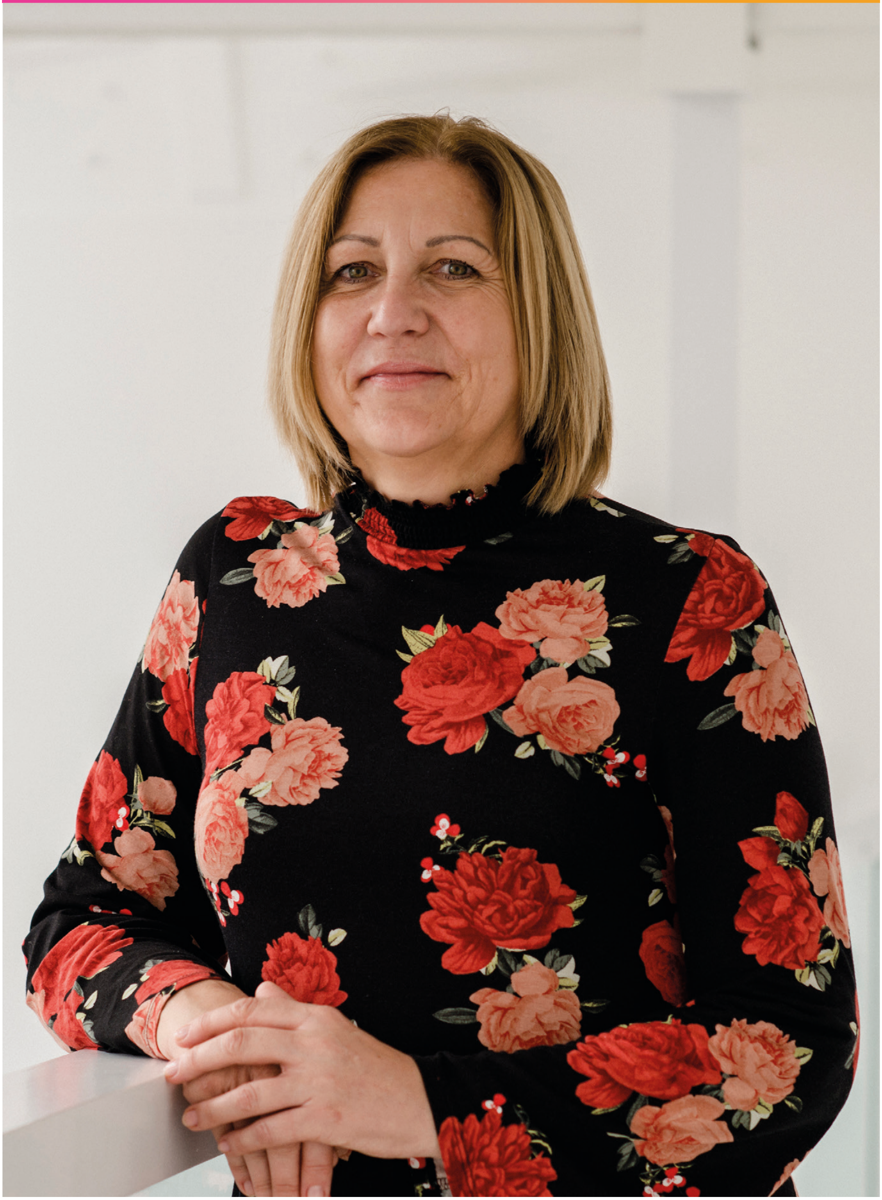
X

X-ray: used to produce images of dense tissues in the body such as bone or lungs.

Your needs and concerns

with secondary breast cancer

breast cancer care



A diagnosis of secondary breast cancer will affect many areas of your life.

You may have many different needs and concerns. Whether they're physical, emotional, practical or financial, identifying them is important as it means your team can help you get the appropriate support at the right time.

There are many healthcare professionals and services available to address your needs and concerns.

Holistic needs assessment (HNA)

A holistic needs assessment (HNA) helps you to think about your needs and concerns across all areas of your life and find possible solutions.

You may be offered an assessment by your nurse specialist or another member of the specialist team around the time of your diagnosis. If an HNA is not offered, you can ask for one at any time.

An HNA usually includes a:

- checklist or simple set of questions to identify concerns
- discussion with a healthcare professional who has the experience and skills to deal with your concerns
- written plan of care

The questions may be asked on a paper form or electronically, and you may be asked to complete the assessment at home before attending an appointment to discuss your plan of care. Remember that these are your concerns so you can choose what you discuss.

You can then agree a plan of care to address your concerns, which could be written down for you to take away.

If your needs change, they can be reassessed using the HNA.

Benefits of an HNA

An HNA can help you:

- get support and information specific to your needs
- prioritise your most important concerns
- be referred to relevant organisations and services for help
- plan ahead from your diagnosis

If you haven't already had an HNA, there's an example of an HNA checklist in the **Personal organiser** included in this pack. This can help you start to think about any concerns you may have, so you can share them with a member of your specialist team.

Emotional concerns

Most people with secondary breast cancer find their mood is affected by many things. Symptoms of the cancer, side effects from treatment, thoughts about the future, issues at home or the impact of the disease on relationships can all have an effect.

Feelings of sadness and loss are common. Suddenly you're facing an uncertain future and your life plans and goals have changed.

People react in different ways – some experience low mood from time to time while others feel hopeless.

People around you may encourage you to be positive and to 'fight' the cancer. For some people, adopting a 'fighting spirit' enables them to cope with their diagnosis. But it's hard to be positive all the time and pressure from other people can sometimes make you feel inadequate and guilty.

You'll develop your own ways of coping. However, if you need help you can talk to your specialist team.

> Enjoy each day. Do not worry about what might be.
>
> **Elisabeth**

Living with uncertainty

For many people, the uncertainty of living with secondary breast cancer can be the hardest part.

Some people find living in the present and making plans from day to day easier than looking ahead. Others find that planning for the future helps them to feel more in control.

With the right information and support, many people are able to feel more confident about how to cope and make decisions about their care and treatment.

However, there will almost certainly be days when you don’t feel this way. Even though it may be hard, try to think about your future. It may not be the future you would have wished for yourself, but you can still think about what your goals are and how you would like to plan the coming months or years.

You may find some of the techniques described in the next section on anxiety and stress helpful in coping with uncertainty.

Anxiety and stress

There will probably be times when you’re anxious or stressed, and this is natural.

Anxiety can show itself in many ways, such as mood swings, being irritable or unable to eat or sleep properly.

We can all deal with a certain amount of stress and tension but it can get on top of us if we don’t learn how to manage it.

One way to cope with anxiety is to talk about your concerns with someone who can help. Your family and friends may listen and offer sympathy and support, but often it can be difficult to share your true thoughts with those close to you.

You may want to talk to a trained professional who can teach you practical techniques that you can use at home. These can help you feel more in control of your life. You may need to try a few techniques before you find one that works for you. You can ask your GP or specialist team to be referred to a professional who can help you.

There are various techniques and talking therapies specifically designed to help you cope at a difficult time, including:

- **distraction:** learning to focus on the things around you so you can shut out negative thoughts
- **relaxation, visualisation and meditation:** can be used separately or together to reduce stress and tension, relax the mind and body and help improve wellbeing
- **mindfulness:** focusing on the present moment to reduce stress and improve quality of life. A few cancer centres offer mindfulness classes. There may be other classes in your local area, and a number of free podcasts, recordings and apps are also available. Your specialist team or GP should be able to help you access them
- **cognitive behavioural therapy (CBT):** can help you change negative patterns of thinking and behaviour. It focuses on problems you're having in the 'here and now,' instead of the causes of your distress or symptoms in the past, and looks for ways to improve your present state of mind
- **counselling:** one-to-one counselling takes place in a private and confidential setting. You can explore feelings related to your secondary breast cancer diagnosis – such as anger, anxiety and grief – making them easier to cope with
- **acceptance and commitment therapy:** aims to help people lead a full and meaningful life by accepting what is out of their personal control and make changes to improve their lives

Some people find complementary therapies, such as aromatherapy, massage or reflexology, help them relax and reduce stress and anxiety (see page 80).

You may feel extremely tired and not want to do very much at all. This is a normal reaction to a stressful situation, but it can help to plan to do something you enjoy every day. Simple things like a short walk with a friend or loved one can make a difference.

> I make sure I have something fun or positive to do every day.
>
> **Jane**

Depression

If negative thoughts are affecting your day-to-day life and don't go away within a few weeks or keep coming back, it may indicate that you're depressed. Depression can happen at any stage during diagnosis and treatment of secondary breast cancer.

Symptoms of depression can include:

- loss of enjoyment and interest in everyday things and experiences
- loss of interest in your appearance
- persistent thoughts such as 'I can't be bothered' or 'What's the point?'
- withdrawing from others (not going out or socialising)
- feeling persistently tearful and irritable
- difficulty concentrating
- difficulty sleeping or wanting to sleep all the time
- loss of appetite or overeating
- feelings of very low mood or suicidal thoughts

If you or those close to you are worried because you have some of these feelings, talk to your GP or specialist team, who can refer you to a counsellor, psychiatrist or psychologist for help and support.

It's particularly important to seek help quickly if you're feeling very low or thinking about taking your own life.

There's nothing to be ashamed of in admitting that you're feeling depressed or finding it hard to cope and need help. Some people find it hard to seek professional advice, but it can help relieve these symptoms and allow you to regain some control of your life.

Talking therapies

There are several different types of talking therapy that are used for depression, including counselling and cognitive behavioural therapy (CBT). See page 59 for more details.

> Do not be afraid to share your concerns with family and friends.
>
> **Elinor**

Antidepressants

Antidepressants are drugs used to treat depression. It usually takes around two to six weeks before you notice the effects and start to feel an improvement in mood, although it may take longer to feel the full benefits. Antidepressants can be an extra support during a particularly difficult period.

Support groups

Joining a cancer support group to meet other people with a similar experience may be helpful. Your breast care nurse, chemotherapy or palliative care nurse or local cancer information centre can give you the details of any support groups in your local area.

Breast Cancer Care's Living with Secondary Breast Cancer services are held at locations around the country. They provide the opportunity for people with secondary breast cancer to chat and share experiences with others with a secondary diagnosis. See page 84 for more information.

Further support

You can call our Helpline free on **0808 800 6000** for information and support, or you can email a Breast Cancer Care nurse through our website or ask them questions through our online Forum.

Samaritans provides confidential, non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair. You can call them on 116 123 (UK) or email jo@samaritans.org

The Mental Health Foundation has more information on talking therapies that you may find helpful. See page 87 for more details.

Getting information

Receiving a lot of information at a difficult time is often not easy. But some people find having information about what's happening to them a helpful way of regaining control.

Many people feel more confident about managing their symptoms and side effects if they understand more about their disease, the risks and benefits of treatments and how they work. You can ask a member of your specialist team to explain or repeat anything you don't understand.

Keeping a record of the names of healthcare professionals and how to contact them can help you get information when you need it. Sometimes people hesitate to contact members of their healthcare team as they know they're busy. However, it's important to contact someone if you have any new concerns so that they can be addressed. Your team will especially want to hear from you if you're concerned that your cancer may have spread, either in its current area(s) or to other parts of the body. See the **Personal organiser** in this pack for symptoms to report to your team.

Finding information about local and national support services makes a difference to the way many people cope, whether they need support immediately or keep it for the future. Local cancer information centres, usually based in hospitals, provide a lot of information about local professional and volunteer services.

Breast Cancer Care's free Helpline can also answer any questions about secondary breast cancer, as well as listen to and talk through your concerns.

We also have a wide range publications and online information. You can request any of our publications through our Helpline or order online.

> Breast Cancer Care was the one-stop shop for me. I found all my information from them. I also found my breast consultant and breast cancer nurse to be fabulous.
>
> **Mandy**

Relationships

A diagnosis of cancer can affect your relationship with those closest to you, and many people worry how their loved ones will cope.

Your partner

If you have a partner, they will probably experience many of the same emotions as you.

Every relationship is different and the concerns and needs of partners differ widely. However, they'll be worried about you being ill and what your cancer means for your relationship now and in the future.

The fact that you're ill may lead to changes to your relationship. These changes can bring you closer together but can also sometimes feel like a barrier between you. If you've been the main caretaker for the family, you and your partner may find it difficult to adjust to the fact that you may need care. You may feel worried about this and even fear you will become a burden.

At the same time your partner may be wondering how they'll cope, particularly if you have children. They may be feeling the full weight of responsibility for the family now and in the future. Your partner may need to continue to work but may feel torn as they want to spend more time with you. They are also bound to think about a future when you're not there and may feel guilty or sad about planning for this or even just imagining it. But such thoughts are normal.

Help and support are available for partners or carers. Your specialist team or local cancer centre can tell you what's available in your area.

Partners often need personal space and time to themselves to help them cope. Encouraging your partner to think about their own needs and to get support for themselves may also help. It can often help them support you better too.

> My husband and I have always been honest and realistic about the future. I like this as it helps me plan and be as practical as I always have been.
>
> **Susan**

Communicating

Being able to talk openly with your partner is important, even though it's natural to want to protect them from any distress or sadness. You may both find it painful to show how you're feeling or talk about your fears and this can make communication difficult. It's worth bearing in mind that once you start, talking may be easier than you imagined.

You'll probably have lots to discuss and you may need to make time and space to talk to each other about practical things, as well as how you're both feeling. Even in close relationships some people hide their emotions, but don't be afraid to cry or be angry as showing how you're feeling can help you cope.

Sex and intimacy

Your sexual relationship may be affected by your diagnosis and treatment.

Some people think that because you have secondary breast cancer you won't be interested in sex and intimacy. However, for many people being intimate with a partner can bring comfort and improve wellbeing.

The physical and emotional impact of having secondary breast cancer and its treatment can affect how you feel about yourself, and your sexual needs may change depending on how well you feel. If you're upset by changes to your appearance, you may not want to be physically close to your partner. Your partner may also be afraid of hurting you if they touch you.

Menopausal symptoms caused by taking hormone therapies, such as vaginal dryness, can make sex difficult or painful. A number of treatments are available to help with vaginal dryness. For more information, you can read our **Menopausal symptoms and breast cancer** booklet.

Talking to each other about your physical and sexual needs can help you deal with any tensions or changes in this area of your relationship. Many people find it helpful to talk through the physical changes and emotional impact of secondary breast cancer with their specialist nurse, a member of their specialist team, counsellor or therapist.

If you're not interested in sex but you still want to be physically close, kissing, hugging or cuddling may be alternatives. You may find that massage is a comforting way for you and your partner to give and receive physical comfort and pleasure.

Family and friends

It can be painful to tell those around you about your diagnosis when you're struggling to come to terms with it yourself.

You may be overwhelmed by the support and concern from those close to you.

However, some people may find it particularly difficult to cope with. They may be worried about what's going to happen to you and frightened about you dying. It can also make them think about their own death. All these things may affect how people relate to you.

Often people simply don't know what to say or how to behave. Friends may stop calling you, sound uncomfortable when they do or keep their distance because they think you won't want company or to hear their news.

You may feel friends and family don't understand the support you need. If you can talk to them about how you're feeling and what you need from them, they can begin to understand how best to support you. If you can share your goals and wishes, they may be able to help you make them a reality and enjoy helping you achieve them.

Practical help may be easier to find from friends than emotional support. Joining a support group may help you meet people who understand what you're going through. Some people also find sharing experiences online helpful – you could try Breast Cancer Care's online Forum or Live Chat sessions for people with secondary breast cancer. If you prefer, you may be able to talk to somebody in your specialist team, such as a specialist nurse or palliative care nurse, or you could ask to be referred to a counsellor.

> 'At first family and friends do not realise that you have an incurable illness which can worsen at any time even although you appear to be well. '
>
> **Elinor**

Children and grandchildren

If you have children or grandchildren, they may have already seen you go through treatment for primary breast cancer.

How you tell them that the cancer has come back will depend on how you managed this when you were first diagnosed, and how you and your family deal with intimate or serious issues.

If children are not told what's happening they can become scared and confused. They can sense that something is wrong and may notice changes in how you look and behave or overhear conversations between adults. Although you may find it difficult, research has shown that including children in what's happening can be very valuable to the way they and the family cope.

How much children can understand about secondary breast cancer will depend on their age, so try to explain the situation to them as simply as you can. Young children are more likely to ask direct, difficult questions that adults avoid, such as: 'Are you going to die?' Try to be as truthful as you can and don't make promises you may not be able to keep.

Even if your children are adults, they may find it hard to take in what you've told them and to respond straight away. They may need time to think about what you've said.

Some children find it helpful to know they can talk to you, whatever their age. Young children and adolescents may also want to talk with another trusted adult.

With grandchildren, it's more likely that their parents will tell them about your diagnosis, but they may ask you questions at some stage so it's a good idea to be prepared. It can be helpful for everyone to agree a similar approach to take with any children in the family.

If needed, extra emotional and practical support for children is often available through schools, palliative care services, social workers, local services or family liaison officers. Both parents and grandparents may also find our booklet **Talking with your children about breast cancer** useful, even though it isn't specifically about secondary breast cancer.

> I have two teenage boys. I think I tried to protect them too much at first from what was really happening to me. This is what upset them the most when they deduced the truth about me. Now I'm so glad we are honest with each other and it is so much easier to support one another.
>
> **Susan**

Worries about your family history

Around 5% of breast cancers are due to an inherited altered gene. If you're concerned this may be the case for you, and you have not discussed this before, talk to your specialist team. They can refer you for an assessment.

Genetic testing involves taking a blood sample from you or another living relative who has been diagnosed with breast cancer. You can consider having a blood sample taken whether or not family members have decided if they also want to be tested.

With your permission, blood can be taken and stored to be tested at a later date or after your death if necessary. If an altered gene is found, other blood relatives can then be tested for the same altered gene, either then or at some point in the future.

Whether or not you have a blood sample taken for genetic testing is entirely up to you. If this is something you're considering, either personally or as a family, you'll be given genetic counselling so that you understand the process and the impact the results may have. Our booklet **Family history, genes and breast cancer** has more information.

Practical concerns

It can often feel as though there's a lot of information available about your breast cancer, but much less about where practical support is available.

While family and friends may offer some practical help, this may not be enough. Some people live alone or don't have close family or friends nearby.

It can be useful to know about support services you can access to help you maintain your quality of life.

Regardless of the amount of support you have, people you don't know that well are often willing to help. They may be neighbours, colleagues, friends of friends, members of your church or any other social group you're part of.

Getting practical help

You may find it difficult to ask, but in times of need people are often keen to help however they can. There may be everyday things they can do, like shopping, cooking or driving you to a hospital appointment.

Voluntary services, such as the British Red Cross and the Carers Trust, can provide practical support in many areas. You may also be able to get help with other household duties such as cleaning and managing pets.

Your specialist team, GP, social worker or local cancer information centre may be able to tell you about other sources of practical support.

> If you are struggling with household chores ask family and friends for help or ask if there are any services you could use to help. There are often volunteer schemes that provide help with simple things like shopping and hoovering.
>
> **Julie**

For some people, being referred to an occupational therapist can help them continue to be independent. They can tell you about practical aids that can be supplied by local social services or through voluntary services such as the British Red Cross.

Prostheses and wigs

If you have or need a breast prosthesis or wig, the process for getting or replacing these depends on arrangements in your local area.

Our booklets **Breast prostheses, bras and clothes after surgery** and **Breast cancer and hair loss** have more information.

Mobility

If you're under 65, you may be entitled to claim help for mobility problems.

The Blue Badge scheme provides parking concessions for people with severe mobility problems who have difficulty using public transport. It can help the holder park close to a destination, whether they are a driver or passenger.

People with secondary breast cancer are often eligible, depending on their circumstances. You can apply for a Blue Badge through your local authority and online at GOV.UK

Employment

Employment and money can be big worries after a cancer diagnosis. For many people, work is important for financial reasons. But it can also be important for social reasons, because it gives them a sense of purpose or because they want to carry on as normally as possible.

If you're finding it difficult to cope at work, it may help to talk to your employer about making some adjustments.

Secondary breast cancer is a recognised disability. This means you have the right to ask your employer to make adjustments for you, such as flexible working, including working shorter days or part time, or changing your role.

Balancing work and treatment is not always easy. If you're worried that your employer might not be sympathetic or that you might be at risk of losing your job, you may want to talk to an adviser about your employment rights.

Many palliative care teams and hospices have specialist welfare officers who can advise you on employment issues. Your company may have an occupational health adviser or a human resources department, you may belong to a trade union, or you can contact your local Citizens Advice.

If you're self-employed, you may feel particularly worried about carrying on working and running your own business. Being self-employed may mean you don't have colleagues to cover if you're unable to work, but could offer the flexibility to make changes to your work pattern.

Stopping work

You may choose to give up work completely or take early retirement to focus on spending time with family and doing other things you enjoy.

Some people aren't able to work because of their symptoms or the effects of treatment.

It can be helpful to talk to your employer about any employment benefits you may be entitled to, such as your pension, as well as reviewing any insurance policies, personal critical illness or mortgage protection you have. Any income they may provide could help you decide if you are able to stop working.

If work has played an important part in your life, you may wish to find different ways to be active within your community and maintain social contact such as volunteering or campaigning.

Whatever your situation, it can be helpful to talk to a financial adviser.

> On my diagnosis I gave up work as a GP. I needed to concentrate on myself, my treatment and my family. As time has gone on I have taken up some voluntary jobs and this has given me a renewed sense of purpose.
>
> **Susan**

Carers' rights

Carers' rights at work are protected by law. If someone is caring for you as a result of your diagnosis, they may be entitled to ask for flexible working arrangements to help them find a balance between work and their caring responsibilities.

You can find information about rights at work on the Macmillan Cancer Support and Carers UK websites.

Financial concerns

Your financial situation may be affected by your illness, particularly if you have to stop working.

Insurance

If you have any insurance policies, such as critical illness cover or mortgage payment protection, check to see whether you're entitled to any payments. An independent financial adviser may be able to help review your financial situation.

Benefits

You may be able to claim welfare benefits because you have secondary breast cancer. Some benefits are means tested, which means your entitlement depends on your income.

If you're 16–64, you may be eligible for Personal Independence Payment (PIP), which can help with some of the extra costs caused by long-term ill health or disability. PIP has replaced Disability Living Allowance (DLA).

If you're 65 or over, you can apply for Attendance Allowance.

An individual assessment will be done to work out the level of help you can get. Your award will be regularly reassessed to make sure you're getting the right support.

PIP and Attendance Allowance are available more easily and quickly for people who are not expected to live longer than six months. It's impossible to say exactly how long someone will live when they have secondary breast cancer, but you can talk to your GP, nurse or social worker to find out what you may be entitled to.

If you're under 65 you may be entitled to help for mobility problems.

For more information about benefits, see Macmillan Cancer Support's Help with the cost of cancer booklet or visit GOV.UK

You can also get help from a specialist welfare officer in your palliative care team or a benefits adviser from Macmillan or Citizens Advice. The Money Advice Service also has lots of useful information.

Prescription charges across the UK

People in England being treated for cancer are entitled to all their prescriptions free of charge. To show you're eligible for free prescriptions you need to apply for an exemption certificate (FP92A) from your GP or hospital.

The certificate means you won't have to pay any charges for prescriptions for five years. You can renew your application after five years if you're still having treatment for:

- cancer (including tamoxifen and other hormone therapies, and lymphoedema garments)
- the effects of cancer (including pain relief and effects directly related to cancer that didn't exist before the cancer diagnosis, such as a change in mental health)
- the side effects of cancer treatment (including all side effects of chemotherapy or late effects caused by radiotherapy)

If you have to pay a prescription charge while you're still waiting for your exemption certificate, ask the dispenser for an NHS receipt (FP57). This is also a refund claim form.

People aged 60 and over don't have to pay NHS prescription charges in England and don't need to apply for the certificate.

In Wales, Northern Ireland and Scotland, prescription charges have been completely abolished.

> I sought financial advice from an advisor at my local hospital.
>
> **Claire**

Physical concerns

A diagnosis of secondary breast cancer and its treatment can mean you have a number of different symptoms and side effects.

Symptoms of the cancer

It may be a long time before you develop any symptoms from the cancer which have an effect on your daily life.

The symptoms you have can depend on the areas of the body the cancer has spread to. However, symptoms like fatigue are often experienced wherever the cancer is.

You can read about coping with the physical effects of secondary breast cancer on page 35 of the first part of this pack.

Our individual booklets on secondary breast cancer in the bones, liver, lungs and brain include information about managing the specific symptoms of secondary breast cancer in these sites.

Side effects of treatment

Side effects from treatment will vary according to the type of treatment you're having.

Common side effects include:

- pain
- nausea and vomiting
- effects on the digestive system
- poor appetite
- weight gain or loss
- hair loss and thinning
- mouth and dental problems
- skin and nail changes
- problems with concentration and memory
- tingling in hands or feet (peripheral neuropathy)
- menopausal symptoms

Talk to your specialist or palliative care teams about managing side effects. They can offer expert advice and help on how to best control them.

We have detailed information on treatments, their side effects and how to manage them on our website at **breastcancercare.org.uk**

> My main symptoms are nausea from the chemo and bone pains from my mets, both addressed thoroughly by my specialist with trials of different medications. Now I just need to take the medications regularly.
>
> **Susan**

Personal appearance

The side effects of treatment for breast cancer, whether temporary or permanent, can seriously affect the way you view your body.

Many women describe feeling they've 'lost' who they were before cancer, including their femininity or attractiveness. Men with secondary breast cancer may also feel different about their body.

Yet many people fear that compared to the life-threatening nature of their illness, body image issues are seen as trivial. This can mean they're reluctant to seek help in dealing with them. Healthcare professionals also often don't cover this topic in consultations.

If you need help with issues related to your appearance or body image, don't be afraid to ask. You can be referred for practical help, for example with hair loss, or emotional support from counselling or psychology services.

Ask us

You can call our Helpline free on **0808 800 6000** for information and support on managing symptoms, side effects or body image.

You can also email a Breast Cancer Care nurse through our website or ask them questions through our online discussion Forum.

Social concerns

Having secondary breast cancer presents many challenges. Managing side effects, making choices about treatment and having ongoing tests can take up a lot of time. So it can sometimes be difficult to continue to do the things you've always done.

For some people, a diagnosis of secondary breast cancer can affect how they relate to the people around them and in their community, as well as their ability to socialise and do the things they enjoy. They may avoid certain people, places or gatherings.

However, withdrawing from your social life may make you feel more isolated or that your diagnosis is stopping you doing the things you enjoy. Social and emotional issues can be difficult to talk about but can lead to problems like depression.

Keeping connected with people and taking up opportunities to join in activities when possible can help increase your confidence and improve your sense of emotional wellbeing.

Continuing with hobbies and interests, meeting family and close friends, planning enjoyable activities and accepting social invitations may feel hard at first. You may feel anxious about other people's reactions, but these feelings should gradually improve over time.

You might find it helpful to talk with other people about how their diagnosis has affected this aspect of their lives and how they manage this. You can connect with other people through our online discussion Forum, Live Chat or Living with Secondary Breast Cancer services (see page 85).

> Before I was diagnosed I had the energy to go out and do things I enjoyed. Once I was diagnosed and on treatments monthly I suffered with fatigue. The days I feel OK I always try to go out and do something whether it just be seeing a friend for an hour or going out somewhere for an evening.
>
> **Claire**

Travel

Many people with breast cancer can and do enjoy travelling. Travel insurance is essential for a holiday as it covers cancellation and medical expenses if you need treatment abroad. For more information about travel insurance, see our website.

Macmillan Cancer Support has information about travel online at macmillan.org.uk as well as a booklet called Travel and cancer.

Health and wellbeing

Some women choose to make lifestyle changes after a diagnosis of secondary breast cancer.

Healthy eating and exercise are important parts of living with secondary breast cancer and have been shown to have a range of benefits.

Diet

Eating healthily is important for everyone, but if you've been diagnosed with breast cancer you may become more aware of what you eat and drink.

Knowing what to eat while having treatment for secondary breast cancer can be difficult. Your appetite and taste may change, or you may put on or lose weight.

Research evidence about diet and cancer changes all the time and can be confusing. There's no scientific evidence that people with secondary breast cancer should follow a special diet, or that a particular diet can make a difference to your outlook. However, a healthy, balanced diet can help give you energy and improve your mood.

If you need help, you can talk to your doctor or nurse, or ask to speak to a dietitian for specialist advice.

Our booklet **Diet and breast cancer** looks at how treatment may affect your diet and how to eat a healthy, balanced diet.

> I have a positive addiction to walking for many reasons including giving me a healthy appetite, boosting my mood with fresh air, helping my leg pain and a good excuse to meet with a friend and chat while we pace along.
>
> **Susan**

Physical activity

Although there's been little research into the benefits of exercise for people with secondary breast cancer, several studies have looked at its effectiveness for people with primary breast cancer.

The results of these studies have been positive and it's likely that people with secondary breast cancer will experience very similar benefits from exercising. But you may need to take a little extra care.

Regular exercise may help to:

- improve your mood
- increase fitness, strength, stamina and flexibility
- control weight (when combined with a healthy diet)
- boost the immune system
- reduce blood pressure
- reduce fatigue
- meet other people if you join a class or club

People who exercise, even gently, during treatment may tolerate treatments better and experience less pain, sickness, problems sleeping and fatigue.

Before starting any exercise it's important to discuss it with your specialist team. Your specialist team or cancer information centre will have information about any appropriate local support to get active.

> I have found Tai Chi helpful for relaxation of body and mind.
>
> **Elinor**

What is regular exercise?

Guidance suggests 'regular exercise' means 30 minutes of moderate-intensity exercise at least five days a week.

This can be a lot initially if you’re new to exercise, so begin gently and build up gradually. It doesn’t need to be 30 minutes all at once.

'Moderate intensity’ usually means you breathe harder, become warmer and are aware of your heart beating slightly faster than normal. A brisk walk is a good example. You should be able to talk and it shouldn’t feel as if you’re pushing yourself too hard.

If you’re currently receiving treatment you may need to exercise at a slightly lower level. Listen to your body and stop straight away if it hurts or feels like you’re working too hard.

Choose aerobic-type activities such as walking, swimming or cycling. However, less structured activities such as dancing and gardening can also be beneficial. There are many ways to include physical activity in your daily routine so joining a gym or attending classes isn’t necessary. The most important thing is to choose something you can safely enjoy.

You could also include some light toning or conditioning exercises such as stretching or low-impact yoga.

Exercise and secondary breast cancer

You may need to take extra care when exercising depending on which areas are affected by secondary breast cancer.

Our individual booklets on secondary breast cancer in the bone, liver, lung and brain have information on choosing activities and precautions you might need to take. See page 85 for more information on ordering our publications.

Exercise and anaemia

People who are anaemic often get tired easily and may become breathless when they exert themselves. If this happens, you may need to be more cautious when you begin exercising and build up gradually.

There’s no particular type of exercise that offers any special benefit for people with anaemia as this type of breathlessness is due to your blood's reduced capacity to carry oxygen, rather than your ability to get air into your lungs.

Exercise and lymphoedema

Lymphoedema is swelling of the arm, hand or breast area caused by a build-up of lymph fluid in the surface tissues of the body.

If you're considering starting or restarting exercise, it's a good idea to talk to your lymphoedema specialist beforehand about the type of exercise. Research shows that exercise is a good way of managing the swelling because movement of the muscles encourages lymph fluid to move away from the swollen area.

See our **Living with lymphoedema after breast cancer** booklet for more information.

Alcohol

People who've had a breast cancer diagnosis are recommended to follow the NHS guidelines for alcohol intake. These state women and men should drink no more than 14 units of alcohol a week.

Your specialist team can give you specific advice about how much alcohol it's safe to drink.

Smoking

Smoking causes a range of health conditions. If you want to stop smoking, there are lots of programmes to help. Speak to your GP or practice nurse for advice.

Problems with sleeping

Problems with sleeping are common and often distressing for people with secondary breast cancer.

You may not be able to sleep or find that you're sleeping too much. Sleep often becomes disrupted around the time of diagnosis and this can continue for a long time after. Sleep patterns may settle down and return to normal or they may change or continue to be disrupted.

How to improve your sleep

Try to get into a routine of going to bed and getting up at the same time every day. Look at how much sleep you get on average each night and go to bed at a time that allows you to get the sleep you need. Many people believe that if they have a bad night's sleep they should go to bed early the next night, but this can make the problem worse.

For people who have difficulty sleeping, the bedroom can become a place of stress and anxiety, which can make it harder to get to sleep. Strengthening the link between your bedroom and sleeping can help. Don’t use the bedroom for other activities like watching TV.

Some people find that keeping a worry book helps. The idea is to write down your worries so you can put them away to be dealt with during the daytime.

If you’re not asleep within 30 minutes of going to bed, get out of bed and, if possible, go to another room until you feel tired enough to go back to bed.

Avoid stimulants such as coffee or tea in the evening, have a light evening meal and reduce your alcohol intake. Doing some gentle exercise during the day may also help you sleep at night.

If you have difficulty sleeping, keep a sleep diary to record this. Record how much sleep you have and when, if you have difficulty getting to sleep or wake in the night, as well as how you feel after your night’s sleep. Talk to your specialist nurse or GP so they can suggest ways of managing your sleep pattern.

Complementary therapies

Complementary therapies are used alongside conventional breast cancer treatments. They differ from ‘alternative’ therapies, which some people use instead of conventional medical treatment.

There’s been very little in-depth research into complementary therapies, so it’s hard to judge how useful they are and whether they could affect how breast cancer treatments work.

However, some people believe they help with the side effects of breast cancer and its treatment, improve their general wellbeing and help them manage anxiety and stress. For others, having complementary therapies is about taking time out to do something for themselves and feeling more in control.

With the right therapy and therapist, you may find that complementary therapies can offer much needed extra support. You can ask if there are any therapies available to you through your local hospital, hospice or cancer information centre.

Complementary therapies sometimes used by people with secondary breast cancer include:

- relaxation
- meditation
- mindfulness
- reiki
- acupuncture
- shiatsu
- aromatherapy
- massage
- yoga and tai chi
- hypnotherapy

For information on finding a complementary therapist see our **Complementary therapies, relaxation and wellbeing** booklet.

Spiritual concerns

Religious belief is an important part of many people's lives and can give them strength and comfort during difficult times. If you have a religious faith, you may find that it helps you cope with your diagnosis. On the other hand, this may be a time when you question your faith because of what's happening in your life.

You may have never had a religious belief or be unsure what you believe, but find yourself thinking and questioning now.

Whether you're sure in your beliefs or looking for answers, you may choose to talk to a religious leader of your chosen faith.

People who don't have a religious faith may still lead their lives according to a particular set of values and beliefs. These beliefs give them a sense of self and of their place in the world and can be thought of as their spirituality. You may find that you gain comfort and strength from talking to people who share a similar outlook.

You may also find it helpful to speak with a hospital chaplain, or local religious leader such as a vicar, priest, rabbi or imam. Often people talk over their concerns or wishes about end of life. It may also be important to you to have access to facilities such as a chapel or prayer room, should you need to spend time receiving care in hospital or a hospice.

For some people, faith or beliefs shape their decisions about the treatment and care they want to receive.

> I have faith in myself and my loved ones, that’s all I need to keep me going.
>
> **Mandy**

Language and cultural concerns

Communication is very important in all areas of healthcare.

It’s common for people with secondary breast cancer to feel anxious about their health, the tests and treatment they may have, and what the future holds.

Good communication can help reduce anxiety. This includes being able to get the right information and support, and making sure that language and communication needs don’t stop people receiving the same quality of care as other people.

If information is needed in a different language, hospitals can arrange translator services at appointments. This can help patients, carers and healthcare professionals get the most out of the consultations, and can make sure accurate and important information about treatment and care is provided. Some hospitals also provide written translation services.

Interpreting services such as sign language, braille or large text documents can also be provided for patients with sensory difficulties.

It’s important that your specialist team are aware of your wishes so they can respect these when discussing and planning your treatment and care. These may be part of your cultural or religious background or your individual personality or beliefs. For example you may want to be addressed in a particular way, or ask that particular medicines or blood products are not given to you.

Cultural beliefs and rituals are also often very important towards the end of life. You can discuss your wishes with those caring for you so that they are fully informed and can record these.

Standards of care for people with secondary breast cancer

Breast Cancer Care has developed the following standards of care for people with secondary breast cancer.

Anyone living with secondary breast cancer should be able to expect:

Information and support

- high-quality information and support from a clinical nurse specialist, who's skilled and knowledgeable in treatment and care of people with secondary breast cancer
- a clinical nurse specialist who will act as a point of contact, be an advocate, help coordinate treatment and care planning, and refer to relevant support services
- a comprehensive assessment of emotional, physical and information needs, especially when first diagnosed, if the cancer progresses and if treatment changes
- to be made aware of and referred to supportive, health and wellbeing services
- to be referred to specialist services for expert financial and employment advice

Treatment and care

- to be given a clear and personalised plan of all aspects of their treatment and care
- to have their treatment and care reviewed when necessary by an experienced team of healthcare professionals – for example with a holistic needs assessment (HNA)
- good communication between all members of the hospital and other healthcare teams, including their GP

Palliative and supportive care

- to be given information on the benefits of local palliative and supportive care services
- support and guidance on talking to those closest to them about the impact of living with secondary breast cancer
- advice and support on planning end-of-life care

A more detailed version of the Standards of care are available on our website **breastcancercare.org.uk**

Support for living with secondary breast cancer

A diagnosis may feel overwhelming and isolating, and information on your particular concerns may be difficult to find. But we can help.

From connecting you with others in similar situations to providing emotional support and the latest information, we're here for you.

Living with Secondary Breast Cancer

Come to a Living with Secondary Breast Cancer session and meet other women in a similar situation. You'll be able to share experiences with people who understand what you're going through.

The monthly sessions are facilitated by a counsellor and every other month you'll hear from a guest speaker who's an expert in their field.

Meet-ups take place across the UK and you can attend as few or as many as you like. Check our website for upcoming dates and locations and if you don't see an event that works for you, get in touch

- visit **breastcancercare.org.uk/lwsbc**
- call **0345 077 1893**
- email **secondaryservices@breastcancercare.org.uk**

Online Forum

For support day or night, chat to other people with a secondary breast cancer diagnosis in our friendly community

- visit **forum.breastcancercare.org.uk**

Secondary Live Chat

Join our weekly Live Chat sessions exclusively for people living with secondary breast cancer.

In a private chatroom, you'll have the opportunity to talk about whatever's on your mind. Each session is facilitated by an experienced moderator who can point you to sources of help and information. There are also monthly themed sessions with a clinical nurse specialist on topics that you may find relevant to your diagnosis.

- visit **breastcancercare.org.uk/talk-together**

Our publications

Breast Cancer Care has publications on a wide range of topics. You can order them free:

- online at **breastcancercare.org.uk/publications**
- by calling our Helpline on **0808 800 6000**
- by ticking the boxes below next to the publications you would like, and sending this form to **Breast Cancer Care, PO Box 33, Ross-on-Wye HR9 9WA**

You can see our full range of publications on our website at the address above.

Types of secondary breast cancer

☐ Secondary breast cancer in the bone (BCC30)

☐ Secondary breast cancer in the brain (BCC56)

☐ Secondary breast cancer in the liver (BCC36)

☐ Secondary breast cancer in the lung (BCC40)

Drug treatments

☐ Anastrozole (Arimidex) (BCC31)

☐ Exemestane (Aromasin) (BCC46)

☐ Goserelin (Zoladex) (BCC33)

☐ Letrozole (Femara) (BCC64)

☐ Tamoxifen (BCC20)

☐ Trastuzumab (Herceptin) (BCC41)

Chemotherapy

☐ Capecitabine (Xeloda) (BCC121)

☐ Chemotherapy for breast cancer (BCC17)

☐ Docetaxel (Taxotere) (BCC35)

☐ Paclitaxel (Taxol) (BCC34)

Other treatment

☐ Ovarian suppression and breast cancer (BCC27)

Health and wellbeing

☐ Breast cancer and hair loss (BCC54)

☐ Complementary therapies, relaxation and wellbeing (BCC55)

☐ Diet and breast cancer (BCC98)

☐ Living with lymphoedema after breast cancer (BCC5)

☐ Menopausal symptoms and breast cancer (BCC18)

☐ Osteoporosis and breast cancer treatment (BCC75)

Other issues

☐ Family history, genes and breast cancer (BCC32)

☐ Talking with your children about breast cancer (BCC50)

Name:

Address:

Postcode:

We never give your information to other organisations to use for their own purposes.

Useful organisations

Emotional concerns

Anxiety UK
anxietyuk.org.uk
08444 775 774

Supports people living with anxiety and anxiety-based depression.

British Association for Counselling and Psychotherapy (BACP)
bacp.co.uk

Information about counselling, and search for a therapist in your area.

Mental Health Foundation
mentalhealth.org.uk

Provides information and publications about mental health issues.

NHS Moodzone
nhs.uk/Conditions/stress-anxiety-depression

Information and tips on coping with stress, anxiety and depression.

Samaritans
samaritans.org
116 123

Samaritans offers a safe place to talk, whenever you like.

UK Council for Psychotherapy (UKCP)
psychotherapy.org.uk

Information about psychotherapy, and search for a therapist in your area.

Getting the information you need

Breast Cancer Care
breastcancercare.org.uk
0808 800 6000

For information about all aspects of breast cancer and its treatment.

Cancer Research UK
cancerresearchuk.org

You can search for clinical trials on the Cancer Research UK website.

Hospice UK
hospiceuk.org
020 7520 8200

Information about hospice care, and find a hospice.

Macmillan Cancer Support
macmillan.org.uk
0808 808 00 00

Can give comprehensive information about finances, benefits, work and other practical issues.

Marie Curie
mariecurie.org.uk
0800 090 2309

Information and support for people living with a terminal illness and their families.

UK trials gateway
ukctg.nihr.ac.uk

Search for clinical trials.

Relationships

Carers UK
carersuk.org
0808 808 7777
Information and help for carers, including financial issues.

Child Bereavement UK
childbereavementuk.org
0800 02 888 40
Offers support for families when a child is facing bereavement.

Fruit Fly Collective
fruitflycollective.com
Provide toolkits for children and young people whose parents have cancer.

Hope Support Services
hopesupport.org.uk
01989 566317
A charity supporting young people when a loved one is seriously ill.

The Osborne Trust
theosbornetrust.com

Provides practical and emotional support to children and young people when a parent is having treatment for cancer.

Relate
relate.org.uk
0300 100 1234
Offers relationship counselling throughout the UK.

riprap
riprap.org.uk

A website especially for teenagers who have a parent with cancer.

Winston's Wish
winstonswish.org
08088 020 021

A charity that offers support for bereaved children.

Practical concerns

Age UK
ageuk.org.uk
0800 055 6112

Information and advice on everything from money and legal matters to health and wellbeing.

British Red Cross
redcross.org.uk

Can provides support at home, transport and mobility aids.

Blue Badge scheme
gov.uk/apply-blue-badge

Helps those with severe mobility problems who have difficulty using public transport to park close to where they need to go.

Carers Trust
carers.org

Offers help and advice to carers, including information on money and benefits.

Disabled Motoring UK
disabledmotoring.org
01508 489 449

A charity that supports disabled drivers, passengers and Blue Badge holders.

Find your local council
gov.uk/find-local-council

Search for your local council online, to find out about local services.

Independent Age
independentage.org
0800 319 6789

Information about money, health, support and care for older people.

Work and finances

GOV.UK
gov.uk

Information about benefits, eligibility and how to apply.

Money Advice Service
moneyadviceservice.org.uk
0800 138 7777

Free and impartial money advice, set up by the government.

Macmillan online financial support tool
finance.macmillan.org.uk

Online financial support guides, including benefits, travel insurance and pensions.

Turn2us
turn2us.org.uk

Helps people in financial need gain access to welfare benefits, charitable grants and other financial help.

StepChange
stepchange.org

The UK's leading debt charity, helping people with debt problems take back control of their finances.

Physical concerns

British Pain Society
britishpainsociety.org
020 7269 7840

Has information and publications for people living with pain.

The Daisy Network
daisynetwork.org.uk

Support and information for people facing an early menopause.

Look Good Feel Better
lookgoodfeelbetter.co.uk
01372 747 500

A charity that helps women manage the visible side effects of cancer treatment.

Lymphoedema Support Network
lymphoedema.org
020 7351 44 80

Provides information and support to people with lymphoedema.

Menopause Matters
menopausematters.co.uk

A website offering information about the menopause, menopausal symptoms and treatment options.

Women's Health Concern
womens-health-concern.org

The patient arm of the British Menopause Society (BMS).

Social concerns

Cinnamon Trust
cinnamon.org.uk
01736 757 900

Can offer help if you have difficulty looking after pets.

Ellie's Friends
elliesfriends.org

Provides free gifts to people having or recovering from cancer treatment.

The Grove Bournemouth
thegrovebournemouth.co.uk
01202 552233

Hotel offering a holiday retreat for people with cancer and other life-threatening illnesses.

HoneyRose Foundation
honeyrosefoundation.org.uk
01744 451 919

Grants special wishes to adults over 40 with cancer.

Odyssey
odyssey.org.uk
0345 363 2207

Offers five-day residential events for people who have been treated for cancer.

Paul's Fund and Paul's Place
pauls-fund.co.uk/pauls-place
01271 891 076

Provides holiday breaks to young adults with a terminal or life-limiting illness.

The Silver Line
thesilverline.org.uk
0800 4 70 80 90

Free confidential helpline providing information, friendship and advice to older people.

Something to look forward to
somethingtolookforwardto.org.uk

A website that lets people with cancer and their families access free gifts.

Willow Foundation
willowfoundation.org.uk

Organises special days out for seriously ill 16 to 40-year-olds.

Health and wellbeing

Association of UK Dietitians
bda.uk.com

Information about nutrition, and find a dietitian near you.

Breast Cancer Haven
breastcancerhaven.org.uk

Offers complementary therapies, exercise classes, talks and other support to people with breast cancer.

British Complementary Medicine Association
bcma.co.uk

Information about complementary therapies, and find a therapist.

Complementary & Natural Healthcare Council
cnhc.org.uk

Find a complementary therapies practitioner.

Maggie's
maggiescentres.org
0300 123 1801

Offers free practical, emotional and social support to people with cancer and their families and friends.

NHS Smokefree
nhs.uk/smokefree

Free support to help you quit smoking.

Penny Brohn UK
pennybrohn.org.uk
0303 3000 118

Charity that aims to help people live as well as possible after a cancer diagnosis.

Walking for Health
walkingforhealth.org.uk

Find a health walk scheme near you, and information on walking with cancer.

Spiritual concerns

The Art of Dying Well
artofdyingwell.org

Practical and spiritual support from the Catholic Church of England and Wales.

The Retreat Association
retreats.org.uk
01494 569 056

National Christian organisation offering help through retreats, spiritual direction, resources and events.

Younger women's concerns

Younger Breast Cancer Network
facebook.com/YoungerBreastCancerNetwork

Private Facebook group for women 45 and younger with breast cancer.

Shine Cancer Support
shinecancersupport.org

Support for people in their 20s, 30s and 40s who've had a cancer diagnosis.

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Four ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone or read more about breast cancer, here’s how you can.

Speak to our nurses or trained experts. Call our free Helpline on **0808 800 6000** (Monday to Friday 9am–4pm and Saturday 9am–1pm). The Helpline can also put you in touch with someone who knows what it’s like to have breast cancer.

Chat to other women who understand what you’re going through in our friendly community, for support day and night. Look around, share, ask a question or support others at **forum.breastcancercare.org.uk**

Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at **breastcancercare.org.uk**

See what support we have in your local area. We’ll give you the chance to find out more about treatments and side effects as well as meet other people like you.
Visit **breastcancercare.org.uk/in-your-area**

We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

Donate online

Donate using your debit or credit card **breastcancercare.org.uk/donate**

Donate by post

Please accept my donation of **£10/£20/my own choice of £** ☐

I enclose a cheque/PO/CAF voucher made payable to **Breast Cancer Care**

Name ______________________________

Address ______________________________

____

______________________ Postcode ______________

Email address ______________________________

Telephone ______________________________

In addition, we'd love to keep you updated about our work and provide you with other opportunities to get involved with Breast Cancer Care. Please tell us how you would like to hear from us (by ticking these boxes you confirm you are 18 or over)

☐ I'd like to hear from you by email
☐ I'd like to hear from you by text message or SMS
☐ Please do not contact me by post
☐ Please do not contact me by telephone

We never give your information to other organisations to use for their own purposes. To change your preferences, or find out more information on how we use your data, please view our privacy policy at breastcancercare.org.uk or contact supporter services on 0345 092 0800.

Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG,
Chester House, 1–3 Brixton Road, London SW9 6DE

Code: LP

About this booklet

Secondary breast cancer information pack was written by Breast Cancer Care's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.

For a full list of the sources we used to research it:

Phone 0345 092 0808
Email publications@breastcancercare.org.uk

You can order or download more copies from breastcancercare.org.uk/publications

We welcome your feedback on this publication: breastcancercare.org.uk/feedback

For a large print, Braille, DAISY format or audio CD version:

Phone 0345 092 0808
Email publications@breastcancercare.org.uk

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When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

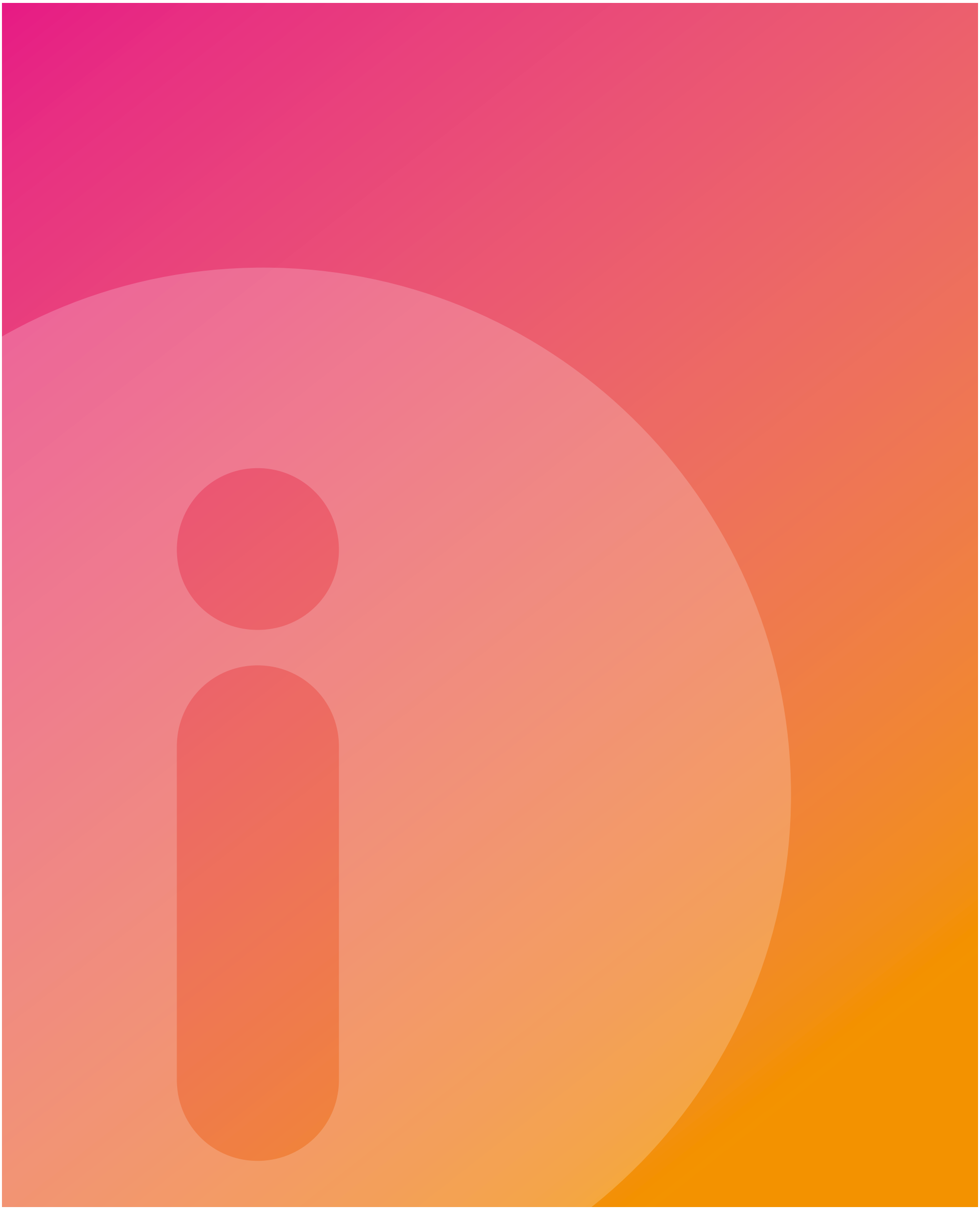
Central Office
Chester House
1–3 Brixton Road
London SW9 6DE
Phone: 0345 092 0800
Email: info@breastcancercare.org.uk

Registered charity in England and Wales 1017658
Registered charity in Scotland SC038104
Registered company in England 2447182

Planning ahead

Choices and decisions about the end of life

breast cancer care



This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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Why plan ahead?

Making choices or decisions about the end of life is not easy. There's no right or wrong time to think about these things. Some people consider the issues when they're diagnosed with secondary breast cancer, while others delay thinking and talking about them or decide not to think or talk about them at all.

Planning how you want to be cared for in future can help you receive the care you want. Writing down your preferences can also be helpful for both loved ones and the healthcare professionals caring for you.

Making your wishes clear might also help you feel more settled, safe and in control.

Putting your affairs in order, for example by making a will, can be a way of making sure your wishes are carried out. Some people find putting their affairs in order clears their mind of some concerns, leaving them free to make the most of the here and now.

Planning ahead also helps some people come to terms with the fact that they're approaching the end of life.

This booklet mentions several organisations that can help with planning ahead. You'll find their contact details on page 12.

Your future care

It can be very difficult to think, talk and make plans about how and where you would like to be cared for at the end of life.

The list of questions on page 11 may help you start to think about what you would like. Other organisations like Macmillan Cancer Support or Marie Curie have publications you may find helpful.

How and where you want to be cared for

Many people worry about becoming dependent on others as they become more ill. It can be painful to look ahead to this time but it may be helpful to think about where and how you want to be cared for.

Some people want to remain at home so think about what changes they might need to make for this to happen. For example, if you can't manage stairs, you might be able to sleep in a room downstairs instead. You can also talk to your GP, palliative care team or district nurse about any equipment or care you might need to allow you to stay at home.

Other people are cared for in a hospice or nursing home in the last few weeks or days of their life and may choose to familiarise themselves and their family with the surroundings and staff.

Who to talk to about your care

You can talk to your family, GP, or palliative or home care team about how and where you'd like to be cared for, as well as any cultural or religious considerations that would be important to you towards the end of your life.

Remember, you can change your mind about any of your decisions at any time.

Professional support is available for you as well as for friends and family involved in your care. Try to decide together what services you and they might make use of.

If you feel you'll need support at a later date, it can be a good idea to talk to your GP about making contact with services that are available to help in your area. This way, when you and your family need them you're not dealing with strangers. This might include local community palliative care and district nursing services.

Writing down your preferences

Usually you will talk with your doctor and nurses about what treatments you wish to have.

If possible, it's good to have an honest and open discussion with your partner, relatives or closest friends in advance, so that they fully understand your choices.

Some people write down their choices in advance so that if they become unable to discuss things or make decisions, the doctors will still know what their wishes are. It can also let your family and friends know what you want.

Advance statement

An advance statement is a general statement about your views and wishes. It can be used to record the care you would prefer and can include non-clinical things, such as your food preferences or religious beliefs.

An advance statement is not legally binding. However, your doctors and nurses should take it into account when they're caring for you.

Advance decision

An advance decision states that you want to refuse certain treatment. For example, you may choose that if your condition suddenly worsens and your heart stops, you don't want doctors to try to restart it (resuscitate you).

In England and Wales, an advance decision is legally binding under the Mental Capacity Act 2005 and must be respected by your doctors. In Scotland and Northern Ireland, an advance decision isn't legally binding. However, it must be taken into account by the medical team and others making decisions on your behalf. In Scotland, an advance decision is also known as an advance directive.

To be legally binding, an advance decision must be written down, signed and dated in the presence of at least one witness who must also sign and date the instructions within it.

An advance decision to refuse treatment must say exactly what treatment you want to decline and in which circumstances. It can only be made by someone aged 18 or over (16 in Scotland) with the mental capacity to make the decision. You can change your mind and rewrite your advance decision at any time.

A copy of your advance decision to refuse treatment should be kept in your medical and nursing notes. You may also be advised to provide further copies for the ambulance service, out-of-hours doctor, and district nursing and palliative care services. You will need to keep an up-to-date copy of this at home, in a place that can be easily seen in case you become very unwell and are unable to communicate.

You can find information on how to complete an advance decision correctly on the Compassion in Dying website (see page 12).

Lasting power of attorney (LPA)

You may need to make important decisions in the later stages of your illness. Usually you can talk with the doctors and nurses looking after you about what you want, but there may come a time when you can't make decisions or communicate easily.

A lasting power of attorney (LPA) is a legal document valid in England and Wales. An LPA is when you legally appoint someone you trust to make decisions about your property and financial affairs, and/or your health and welfare at a time in the future when you can no longer do so. An LPA must be made while you're able to understand what it is and what it means for you.

Once you've made an LPA, you need to register it with the Office of the Public Guardian, which can take 8–10 weeks. There's a cost to register an LPA. If you're receiving certain benefits or have a low income you may be exempt from paying the registration fee or only have to pay part of it. You can get more information about registering an LPA from a social worker or the Office of the Public Guardian.

If you're unable to make a decision about your treatment and have no family or friends to represent your views, medical staff are required to appoint an independent mental capacity advocate (IMCA) to represent your interests.

Scotland

In Scotland the legal document that appoints one or more people to make decisions on your behalf about your care and treatment, should you become incapable, is called the welfare power of attorney (WPA). The WPA has to be registered and there may be a fee to do this. You can get more information about WPAs from a social worker at the hospital, and the Office of the Public Guardian, Scotland.

Northern Ireland

In Northern Ireland it's currently not possible to appoint other people to make decisions about your care and treatment on your behalf.

Assisted dying or voluntary euthanasia

Currently under UK law, any action that speeds up a person's death is illegal. Although your doctor and nurses can make sure you have enough pain relief and other medications to keep you comfortable, they cannot give you more than you need with the intention of ending your life more quickly.

Putting your affairs in order

Thinking about life going on after you have died can be sad and painful for you and those around you. But for some people, putting their affairs in order is a positive thing to do. It can be a way of making sure their wishes are carried out after they have died.

Writing a will

It's normal to think about what will happen to your possessions after your death. Making a will is a thoughtful and effective way of taking care of the people you love, as it can spare them the difficult decisions and financial problems that can happen if you don't make your wishes clear.

When writing a will or amending an existing one, it's usually best to use a solicitor. They will be able to help with the wording to make sure your wishes are clear.

There's useful information on how to write a will, what should be included, where to keep it and how to update it on the GOV.UK website gov.uk/make-will

The Society of Trust and Estate Practitioners and The Law Society have more information on how to write a will and where to find a solicitor.

Letters or memory boxes for children

Some people write letters to their children, particularly if they're very young, or put together memory boxes containing messages or things that have a special meaning. These can be very precious to a child whose parent has died.

Think carefully about your child and what you want to leave them or write. Your child will know you loved them but writing this in a letter and explaining you didn't want to leave them can be helpful for them in the future.

Be careful not to ask too much of a child; telling them to do well in their exams or be strong can be a heavy burden for some children to carry.

There's a list of organisations that provide information to help children with bereavement on page 12.

Planning a funeral

Some people choose to plan their own funeral. This may be a difficult thing to do, but it can be part of how someone comes to terms with the fact that they're approaching the end of life. It can also be reassuring to know that things have been organised for your loved ones and that they know what your wishes are.

There's useful information on funeral options, using a funeral director, and how to apply for help covering funeral costs on the GOV.UK website gov.uk/after-a-death

Usually people arrange funerals through a local funeral director. Details of funeral directors can be found online or you may know of a local firm in your area. It's important to ensure that the funeral director you choose belongs to either the National Society of Allied and Independent Funeral Directors or the National Association of Funeral Directors as they each have a code of conduct for their members to follow. These codes are available on their websites and commit their members to providing a high standard of service.

You do not need to use a funeral director if you don't want to. The Natural Death Centre can provide information and advice if you would like to arrange a funeral yourself.

Bereavement support for your family

Many people worry about support for their family once they have died. Knowing there's support in place can be a great comfort.

Palliative care teams can often provide bereavement support to families of people who have been in their care, including children and young people.

GPs can also refer people for bereavement counselling, even if someone died a long time ago.

Other national and local services are able to offer support, advice and information face to face, by telephone or email, or online.

Financial support

Bereavement Support Payment provides accessible financial help for spouses and civil partners in the difficult period after a family death.

Bereavement Support Payment replaces Bereavement Payment, Bereavement Allowance and Widowed Parent's Allowance, and is available to people of any age up to state pension age. It is not taxed.

To find out more visit gov.uk/bereavement-support-payment

Advance care planning – questions to think about

- What information do you need about your illness and what may happen to you?
- Where would you prefer to be cared for towards the end of your life (for example at home, in a hospice, hospital or nursing home)?
- Do you want to write an advance decision to refuse treatment or resuscitation?
- Do you wish to arrange lasting power of attorney?
- Have you made or updated your will?
- Are there any spiritual or religious practices that you wish to be carried out before or at the time of your death, or after you have died?
- Who do you need to ask to make sure this happens?
- What funeral arrangements would you like to be made?
- Who do you want to make the arrangements? Do you wish to plan anything yourself or with your loved ones?
- Do you want to be cremated or buried?
- Do those looking after your affairs know where to find all the necessary documents?
- Is there anything that you want done for the people that you love?
- Do you wish to leave letters/messages/memory boxes or recordings for loved ones?

Useful organisations

Compassion in Dying
compassionindying.org.uk
0800 999 2434

A charity that helps people prepare for the end of life.

Cruse Bereavement Care
cruse.org.uk
0808 808 1677

Offers support, advice and information to children, young people and adults when someone dies.

Gingerbread
gingerbread.org.uk

Provides information and help to single parent families, including information about bereavement.

GOV.UK
gov.uk

Has information about lasting power of attorney, writing a will, planning a funeral and bereavement support.

Hospice UK
hospiceuk.org
020 7520 8200

Provides information about hospice care and lets you search for hospice care providers.

Humanists UK
humanism.org.uk
020 7324 3060

National charity working on behalf of non-religious people. Provides humanist funerals.

Law Society
lawsociety.org.uk

Its website has a section called ‘For the public’ which includes information on how to write a will. You can also search for a solicitor.

Office of the Public Guardian
gov.uk/government/organisations/office-of-the-public-guardian
0300 456 0300

Make and register a lasting power of attorney (England and Wales).

Office of the Public Guardian (Scotland)
publicguardian-scotland.gov.uk
01324 678398

For information about power of attorney in Scotland.

Macmillan Cancer Support
macmillan.org.uk
0808 808 00 00

Has information about planning for the future with advanced cancer.

Marie Curie
mariecurie.org.uk
0800 090 2309

Provides information and support for people living with a terminal illness.

National Association of Funeral Directors
nafd.org.uk
0121 711 1343

Has information on arranging a funeral and lets you search for registered funeral directors.

National Society of Allied and Independent Funeral Directors
saif.org.uk
0345 230 6777

Provides funeral advice and allows you to search for registered independent, local funeral directors.

Natural Death Centre
naturaldeath.org.uk
01962 712 690

Help, support, advice or guidance planning a funeral.

Society of Trust and Estate Practitioners
step.org/advice-information
020 3752 3700

Information on how to write a will and lasting power of attorney.

Winston's Wish
winstonswish.org
08088 020 021

A charity that supports bereaved children.

Notes

Notes

Four ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone or read more about breast cancer, here's how you can.

Speak to our nurses or trained experts. Call our free Helpline on **0808 800 6000** (Monday to Friday 9am–4pm and Saturday 9am–1pm). The Helpline can also put you in touch with someone who knows what it's like to have breast cancer.

Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at **forum.breastcancercare.org.uk**

Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at **breastcancercare.org.uk**

See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you.
Visit **breastcancercare.org.uk/in-your-area**

We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

Donate online

Donate using your debit or credit card **breastcancercare.org.uk/donate**

Donate by post

Please accept my donation of **£10/£20/my own choice of £** ☐

I enclose a cheque/PO/CAF voucher made payable to **Breast Cancer Care**

Name ______________________________

Address ______________________________

____

______________________ Postcode __________

Email address ______________________________

Telephone ______________________________

In addition, we'd love to keep you updated about our work and provide you with other opportunities to get involved with Breast Cancer Care. Please tell us how you would like to hear from us (by ticking these boxes you confirm you are 18 or over)

☐ I'd like to hear from you by email
☐ I'd like to hear from you by text message or SMS
☐ Please do not contact me by post
☐ Please do not contact me by telephone

We never give your information to other organisations to use for their own purposes. To change your preferences, or find out more information on how we use your data, please view our privacy policy at breastcancercare.org.uk or contact supporter services on 0345 092 0800.

Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG,
Chester House, 1–3 Brixton Road, London SW9 6DE

Code: LP

About this booklet

Planning ahead: Choices and decisions about the end of life was written by Breast Cancer Care's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.

For a full list of the sources we used to research it:

Phone 0345 092 0808
Email publications@breastcancercare.org.uk

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breastcancercare.org.uk/feedback

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Phone 0345 092 0808
Email publications@breastcancercare.org.uk

Health & care information you can trust
The Information Standard Certified Member

Edition 5, next planned review 2020

When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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