Secondary breast cancer resource pack
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Included in this pack are two booklets, **Thinking about difficult choices and decisions about the end of life**, which you can find at the back of this pack and **Living with secondary breast cancer** which is in the pocket at the back of this pack.
Introduction

This pack is for anyone with secondary breast cancer. It may also be useful for family, friends or carers of someone with secondary breast cancer. It contains a lot of information that may be useful to you from the time you’re diagnosed, throughout your treatment and care.

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 breast care 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.

Don’t be afraid to ask your specialist team to repeat, or explain further, anything that you don’t understand. You may want to write down questions for them as well as keeping a note of their answers to refer back to. We’ve included some places in the pack for you to do this.

The pack aims to help you understand what secondary breast cancer is and the physical and emotional impact 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.

It talks about living with the disease and coming to terms with the future. It looks briefly at treatments and symptoms, and lists sources of help and support. There’s also separate information on advance care planning and decisions you may want to make about end of life.
This pack has three sections.

• A loose-leaf section that covers treatments for secondary breast cancer, symptoms and side effects, as well as tools that you may find useful for monitoring your condition and recording what happens at your clinic appointments.

• A booklet on living with secondary breast cancer. This looks at how you may feel after being diagnosed with secondary breast cancer and what effect this can have on your life and those around you.

• A small booklet – **Thinking about difficult choices and decisions about the end of life** – which you’ll find at the back of this pack. This is for if and when you want to start thinking about these areas.

Although receiving a lot of information when you’re newly diagnosed may not be easy, for some people, having information about what’s happening to them can provide a sense of hope. It can also be a way of taking back some control at a time when you may feel overwhelmed and powerless. We hope this pack addresses many of your questions and concerns.

You can find further information on secondary breast cancer and its treatment in our booklets:

• **Secondary breast cancer in the bone**
• **Secondary breast cancer in the lung**
• **Secondary breast cancer in the liver**
• **Secondary breast cancer in the brain**.

On page 41 of this pack there’s a list of ‘Secondary breast cancer words explained’ which may be helpful as you read through any information about secondary breast cancer.

If you have further questions or would like more information, you can call us free on **0808 800 6000** (for Text Relay prefix **18001**).

Our website **www.breastcancercare.org.uk** has an online discussion Forum and regular Live Chat sessions for people with secondary breast cancer. We also run Living with Secondary Breast Cancer meet-ups around the country for people to chat and share experiences with others with a secondary breast cancer diagnosis. You can find more details about support from Breast Cancer Care on page 51.
This pack is not aimed at people with local or regional recurrence, but some of the information may still be useful. Local recurrence is when the breast cancer comes back in the same breast near where the original cancer was. Regional recurrence (also called locally advanced) is when breast cancer spreads to areas around the breast such as the skin, the muscles on the chest wall, the lymph nodes under the breastbone (sternum) (called internal mammary nodes), between the ribs or the nodes above the collarbone (clavicle) (called supraclavicular nodes). Both of these types of recurrence will need further treatment, but they are not secondary breast cancer.

This pack has been designed with the help of patients from the Christie Secondary Breast Cancer Focus Group.
What is secondary breast cancer?
Secondary breast cancer occurs when breast cancer cells spread from the first (primary) cancer in the breast to other parts of the body. This may happen through the lymphatic or blood system. You may hear it referred to as:

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

Although secondary breast cancer can be treated, it can’t be cured. The aim of treatment is to control the cancer, relieve any symptoms and maintain a good quality of life for as long as possible.

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, on rare occasions, before the primary breast cancer has been diagnosed.

The most common areas breast cancer spreads to are the bones, lungs, liver and brain. Sometimes other parts of the body, for example the abdomen (belly), are affected. Where it spreads to and how many sites varies with different types of breast cancer and in different people.

When breast cancer spreads, for example to the bones, it is called secondary breast cancer in the bone. The cancer cells in the bone are breast cancer cells.

One of the 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 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. Your specialist will have an understanding of the likely progression of your secondary breast cancer and can talk to you about what you might expect. 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.
Professionals who may be involved in your care

You’ll be looked after by a team led by a cancer specialist (oncologist). The team may include people who were involved in treating your primary breast cancer, as well as other healthcare professionals such as a breast care nurse who specialises in secondary breast cancer or a nurse from the palliative and supportive care team (in this pack we call this a palliative care nurse).

We’ve provided a space on page 12 where you can record the names and contact details of healthcare professionals you come into contact with.

GP (General practitioner)
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 co-ordinating and delivering all nursing care and organising any equipment you may need, such as a commode or pressure-relieving mattress. Your district nurse can visit up to three times a day to help with practical nursing care and symptom control. Some district nursing teams offer a 24-hour service.

Palliative 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 patients and their 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 will assess what aids and adaptations you could have, such as stair rails and bathing aids, to enable you to be more independent in your home. 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 (see below). 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 adviser
A benefits adviser gives specialist advice and information on benefits, tax credits, grants and loans to help you to work out what financial help you could be entitled to.

Hospice
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 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.
You may find it helpful to record the names and contact details of the people caring for you:

**Oncologist (usually contacted through their secretary)**

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**Clinical nurse specialist (if applicable)**

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**Chemotherapy department**

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<th>Name</th>
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Radiotherapy department

Name

Telephone

Email

Physiotherapist

Name

Telephone

Email

Palliative care nurse/doctor

Name

Telephone

Email

District nurse

Name

Telephone

Email
Call our Helpline on 0808 800 6000

GP

Name

Telephone

Email

Social Worker (in the community, hospital or hospice)

Name

Telephone

Email

Benefits/Finance Adviser

Name

Telephone

Email

Others

It can also be helpful to have a record of who to contact if you have an urgent query or problem during the working day or out of normal working hours.

Urgent contact (daytime)

Urgent contact (night time)

Urgent contact (weekends)
Treatment
The aim of treatment for secondary breast cancer is to control and slow down the spread of the cancer, relieve symptoms and give you the best quality of life, for as long as possible.

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 characteristics of the cancer (such as oestrogen receptors – see page 18)
- your general health (and any other medical conditions).

Any recommendations for treatment should be discussed with you, taking into account your personal wishes. A number of different treatments are used to treat secondary breast cancer and your specialist will talk with you about your options.

As part of your treatment you may be asked if you’d like to take part in a clinical trial. Your specialist team will talk with you about what this might mean or, if you’re interested in taking part in a clinical trial, you can ask your team if there’s any that are appropriate for you. The Cancer Research UK website on page 52 has more information on clinical trials, including a list of current trials for secondary breast cancer and where they’re taking place.

**Decisions about treatment**

If you want to be involved in decisions about your treatment, you’ll need to know your options and what they might mean. It may be helpful to think about what would influence your decision to have a treatment. For example, an improved quality of life by not having to go for a particular treatment and experience its side effects may be more important to you than the possible benefits of that treatment.

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 (see ‘Getting the most out of your appointment with a healthcare professional’ on page 27). 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.
Some people consider asking for a second opinion. 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 will be able to discuss any impact this might have.

You may decide that you don’t want to be involved in making decisions about your treatment, or that you’re 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.

**Hormone therapy**

As the hormone oestrogen can play a part in stimulating some breast cancers to grow, there are a number of hormone therapies that work in different ways to block the effect of oestrogen on cancer cells. Hormone therapy will only be prescribed if the breast cancer has receptors within the cell that bind to the hormone oestrogen (known as oestrogen receptor positive or ER+ breast cancer).

This will usually have been tested using tissue from your primary breast cancer, but your doctor may discuss having a biopsy of the secondary breast cancer to re-test the hormone receptors. This will depend on your individual situation.

When oestrogen receptors are not found (oestrogen receptor negative or ER-) tests may be done for progesterone (another hormone) receptors. As oestrogen receptors play a more important role than progesterone 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.

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.

If your cancer is found to be hormone receptor negative, then hormone therapy will not be of any help to you.

For information about individual hormone therapy drugs and their side effects, see our range of booklets.

‘I was offered the option to try fulvestrant (Faslodex) and since then the cancer in the lung has gradually become smaller. I now have a three-monthly blood test and a six-monthly CT scan. Emotionally, life is like a rollercoaster. The knowledge that fulvestrant will not work forever leaves me on a knife edge every results time.’

Marie

‘I expected to be straight on to chemotherapy but am managing ok on letrozole. My oncologist is optimistic and CT scans show no increase in tumour size since I started.’

Shirley
Chemotherapy

Chemotherapy treatment for secondary breast cancer aims to control and slow down the growth of the cancer and 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 to some extent. Your specialist team will talk with you about the likely effect the chemotherapy will have on the progression of the cancer, as well as how side effects can be managed. This means that you should have a clear idea of what chemotherapy treatment may mean for you when you make your decision about treatment.

Chemotherapy is usually recommended for people with triple negative breast cancer. This means the breast cancer is oestrogen receptor negative, progesterone receptor negative and HER2 receptor negative (see below) and so hormone therapies and HER2 targeted therapies will not be of help to you.

You can talk to your chemotherapy nurse or clinical nurse specialist about chemotherapy and the drug(s) that you’ll be having. You can find more information on individual chemotherapy drugs on our website where you can also order or download our Chemotherapy for breast cancer booklet.

Targeted therapies (sometimes called 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.

The most widely-used targeted therapy is trastuzumab (Herceptin). You can read more in our Trastuzumab (Herceptin) booklet.

Only people whose cancer has high levels of HER2 (called HER2 positive or HER2+), a protein that makes cancer cells grow, will benefit from having trastuzumab. There are various tests to measure HER2 levels which will usually have been done using tissue from your primary breast cancer. Your doctor may discuss having a biopsy of the secondary breast cancer to re-test for HER2. This will depend on your individual situation.

If your cancer is found to be HER2 negative, then trastuzumab and other HER2 targeted therapies for secondary breast cancer will not be of benefit to you.
Some targeted therapies are not approved for use in the NHS and newer drugs are being investigated in clinical trials. Your specialist will be able to tell you more about whether they might be of benefit to you and whether there are clinical trials you could take part in. For more information about targeted therapies used to treat secondary breast cancer see our website

www.breastcancercare.org.uk

Bisphosphonates and targeted therapy for secondary breast cancer in the bone

Bisphosphonates are a group of drugs used to treat secondary breast cancer in the bone. Denosumab (Xgeva) can be given as an alternative to bisphosphonates. Denosumab is a targeted therapy specifically for secondary breast cancer in the bone. Bisphosphonates and denosumab work in slightly different ways but both reduce bone loss and make complications of secondary breast cancer in the bone, such as fractures, less likely to happen.

Bisphosphonates and denosumab are used in secondary breast cancer 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).

Complications of secondary breast cancer in the bone such as spinal cord compression and hypercalcaemia can be very serious. It’s important that you know the signs and symptoms to look for. You can read more detailed information about these on page 35 and in our Secondary breast cancer in the bone booklet.

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 (subcutaneous injection) into the thigh, abdomen or upper arm.

Radiotherapy

The aims of radiotherapy treatment for secondary breast cancer are 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) in the skin, neck or under the arm (axilla).
A course of radiotherapy treatment for secondary breast cancer is usually much shorter than for primary breast cancer. You may have a few treatment sessions, or sometimes only one, and it’s often used alongside other treatments. Side effects vary depending on which part of the body is being treated and what type of radiotherapy is used. For example, radiotherapy to the brain can cause hair loss.

**Surgery**

Surgery is rarely used to treat secondary breast cancer because it can be difficult to remove and there may be more secondary breast cancer elsewhere in the body. Although surgery will not cure secondary breast cancer, occasionally an oncologist will request a surgical opinion. 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.

**Palliative and supportive care**

Palliative and supportive care focuses on symptom control and support. It usually involves a team of healthcare professionals such as specialist nurses, doctors, social workers and physiotherapists. It’s an extremely important part of the care and treatment for many people with secondary breast cancer and can significantly improve quality of life for both patients and their families. It can be helpful at any stage of your illness and aims to prevent and relieve the symptoms and any other physical, emotional, social and spiritual effects of secondary breast cancer.

Some people use palliative 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.

Palliative care is commonly associated with end-of-life treatment but many people value having it much sooner and alongside their medical treatment to help control symptoms.

You can be referred by your specialist team, GP or breast care 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 re-referred at a later date. It can continue up to and including end-of-life care.
Complementary therapies

Complementary therapies are a varied group of treatments that are used alongside medical treatments and so differ from ‘alternative’ therapies, which are used instead of conventional medical treatment.

There’s been very little in-depth research into complementary therapies and so it’s hard to judge how useful they are and whether they could affect how breast cancer treatments work. However, many people believe they improve their general wellbeing and help them manage anxiety and stress and some other side effects of their cancer and its treatment.

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.

Therapies sometimes used by people with secondary breast cancer include: reiki, acupuncture, shiatsu, aromatherapy, massage, yoga and tai chi and hypnotherapy.

You can ask if there are any therapies available to you through your local hospital, hospice or cancer information centre. See our Complementary therapies booklet for more information.
‘I haven’t used any complementary therapies, but I do go to yoga classes and try to do relaxation in my own time and space.’

Shirley

‘I enjoy relaxation sessions, reflexology and acupuncture but don’t class them as alternatives to conventional treatments.’

Marie

‘I have had acupuncture to help with hot flushes and this helped reduce the frequency and severity of them. I also found that massage helped when I started to lose feeling in my fingers and toes.’

Anna

Thinking about stopping cancer 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 your condition
You should have regular hospital appointments to check how well you are physically and emotionally. You should also have the name and contact number of someone in your specialist team to get in touch with if you have routine or urgent concerns (both during working hours and overnight/weekends) or if you need to change an appointment.

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

Scans and x-rays may not 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 are likely to be monitored more frequently, depending on the requirements of the trial.

**Getting the most out of your appointment with a healthcare professional**

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 continuing symptoms or side effects and any questions you have. You might want to share any information from diaries, symptom charts or your patient record sheet (see the back of the pack).

2. **Take support**
   If you’re able to, 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. You can ask for a copy of the letter which is usually sent to your GP by your specialist if you’d like to re-read the information.

Patient record sheet
We’ve included a few patient record sheets (at the back of the pack) you can take to your appointments. They can help you monitor your condition, write down questions and take notes. If you’d like more copies you can download them from our website www.breastcancercare.org.uk/patient-resources
Questions you might want to ask your specialist

The following questions have been put together by the Secondary Breast Cancer Focus Group at The Christie Hospital as these are questions they found they asked their specialists. You might find them useful to take along to your appointments. You might not want to ask them at every appointment but they may be useful from time to time.

- Can you explain the blood test results to me?
- What do the results mean?
- Can you show me the CT scan and explain what is on it?
- Can you tell me more about the tumours? Where are they? Have they changed size?
- What is the aim of my treatment? What sort of side effects will I get? Will you give me something for these today?
- What other treatment options are there available?
- Can you tell me if there are any clinical trials I can join?
- Who else I can speak to?
- Can I see a/my nurse specialist?

You can ask your specialist to go over your plan, repeat information or explain any new terms to you. What matters most is that you understand what’s happening and why.

You can make notes on the patient record sheets provided.
Physical effects

Even though you’ve had a secondary breast cancer diagnosis, 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 and its treatment can cause many different physical symptoms and the more common ones are described below. Symptoms will depend on where the cancer has spread to in your body and how extensive it is. For more details of symptoms and treatments relevant to your particular diagnosis you may find it helpful to read our booklets on secondary breast cancer in the bone, lung, liver or brain.

Pain

Pain can be caused by the cancer itself or the treatment. Having pain that can’t be relieved is a fear for many people with secondary breast cancer.

People may also have pain from other conditions unrelated to their breast cancer, for example, arthritis. Pain can affect your ability to carry out everyday tasks and affect you on a day-to-day basis. Everyone’s experience is different, however most cancer-related pain can be controlled effectively.

Pain relief is a very important part of the care of anyone with cancer. Many people find that once their pain is under control they feel less anxious and can eat and sleep better.

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. 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. But 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 own 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.

Pain can be experienced in different ways and you may find you have more than one type of pain. To find the best way of treating your pain, you’ll need to try 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 nought to ten
- where the pain is, in one place or several
- 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 the pain 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 but we’ve included one at the back of this pack and you can download more copies from our website (www.breastcancercare.org.uk/patient-resources).

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 really 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 also think that needing to take morphine must mean that 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.
Doctors often use other drugs alongside pain relief. These include anti-inflammatory drugs, steroids and drugs used to help treat depression or epilepsy which can also help relieve certain types of pain.

Other treatments such as bisphosphonates/denosumab or radiotherapy for secondary breast cancer in the bone may also be used to relieve pain – see page 21, and our Secondary breast cancer in the bone booklet for more information.

It's very important that your pain is assessed regularly by your nurse or doctor to make sure it remains under control. It's useful to know who to contact if your pain changes or worsens. 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.

‘All I can say is don’t be a martyr: if you’re in pain, don’t just keep suffering. Palliative care can help alleviate this and it’s the best place to go for one-to-one care.’

Moira

Some medicines can affect your ability to drive. Since March 2015 it’s an offence to drive with certain 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 www.gov.uk/drug-driving-law

Is there anything else that might help?

Complementary therapies
There’s very little reliable research showing the effectiveness of complementary therapies. However, some complementary therapies, when used alongside conventional drug treatment, have been reported to be helpful in relieving symptoms such as stress and anxiety which may contribute to pain in cancer. See our Complementary therapies booklet for more information.
**Talking to others**

Many people find it useful to talk with others about their pain and how they’re coping. Learning from people who’ve had similar pain experiences, how it affected their lives and what they used to help relieve it can be very valuable. Pain is a topic discussed regularly on our online discussion Forum, Live Chat sessions for people with secondary breast cancer and at our Living with Secondary Breast Cancer meet-ups. For more information see page 51.

**Fatigue**

Cancer-related fatigue (extreme tiredness) is one of the most common symptoms experienced by people with secondary breast cancer. Everyone knows what it feels like to be tired sometimes, but cancer-related fatigue feels much more severe. It can come and go or be unrelenting and it can be distressing and frustrating.

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**

There are a number of common signs of fatigue which include:

- tiredness that is not related to any activity
- tiredness which 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 it can be difficult to describe.

It may have a significant impact on your ability to cope, your mood and your relationships. Fatigue can also affect your everyday activities and quality of life. Many people find that it stops them working, socialising and generally living life in the way they wish to. There are a number of things you can do to help manage your energy levels and reduce the effects of fatigue.
• It’s important to 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, which should improve the fatigue.

• Information and support can help you manage fatigue. You can ask to be referred to a specialist, such as an occupational therapist, in your local palliative care team who may be able to suggest adaptations or equipment that may help.

• You may need to accept that you can’t do everything you want to do and that some days will be better than others.

• Keeping a diary of your activities and energy levels can help you work out your patterns of fatigue. This can be useful when talking to your specialist team and when planning for day-to-day life. Your hospital may provide you with a fatigue diary to use or you can use the one provided in the back of this pack. You can also download more copies from our website – www.breastcancercare.org.uk/patient-resources

• Be realistic about what you can do. Prioritise your tasks and plan your days so you have a balance of activity and rest. It can be a good idea to stop any activity before you become too tired so that you keep some energy in reserve. By prioritising the things you have to do you can pace yourself throughout both your good and bad days.

• Prepare for a special occasion or days out by planning some additional rest before and after.

• Regular physical activity has been shown to improve energy levels and reduce fatigue. Short achievable periods of gentle strengthening exercises as well as short walks can help increase your appetite, give you more energy and improve wellbeing (see the booklet Living with secondary breast cancer at the back of this pack).

• Pain can worsen fatigue by affecting your ability to be active or to sleep well, or by reducing your appetite and lowering your mood. If your pain is not well controlled, talk to your specialist or palliative care team.

• Try to eat as well as you can so your body continues to get the nutrients it needs. If your appetite is poor, it may help to eat smaller amounts more often and drink plenty of fluids to keep hydrated. You could also ask to be referred to a dietician for advice.

• Being able to continue to do things for yourself is important for many people. However don’t feel guilty if you need to ask for help. Use offers of practical help from others as a way of managing your energy levels so that you can continue to do other things you enjoy.

• Counselling, talking therapies and complementary therapies can be helpful in relieving stress and anxiety which may contribute to fatigue.
For more information, Macmillan Cancer Support has a booklet called Coping with fatigue. Order it free from their website (see Further Support section on page 52).

**Breathlessness (dyspnoea)**

Breathlessness is a common symptom of secondary breast cancer. It can affect anyone with secondary breast cancer but is more likely if you have secondary breast cancer in the lung. Secondary breast cancer in the lung also increases the risk of chest infections which can cause breathlessness.

You may find breathing is uncomfortable or feel that you can’t get enough air into your lungs. This is often more noticeable when you are moving but some people experience breathlessness when they’re still or lying down.

Not being able to breathe properly can make you feel anxious and frightened. This can lead to a feeling of panic which can make your symptoms worse. There are several practical things you can do to help ease your breathlessness. Using a hand-held fan or sitting near an open window to get cool air on your face can be helpful. Learning relaxation and breathing techniques to use when you start feeling short of breath can also help. Your specialist team may refer you to a physiotherapist or a palliative care doctor or nurse to teach you breathing exercises which may also help.

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

Spinal cord compression is a risk for people with secondary breast cancer in the bone that has spread to the spine. Spinal cord compression can happen when a vertebra (spinal bone) collapses and puts pressure on the spinal cord.

Symptoms can include unexplained back pain, difficulty walking, numbness or pins and needles in the fingers, toes or bottom, or problems controlling urine and/or bowel movements. Spinal cord compression can have serious effects if not diagnosed quickly, so seek medical advice if you have any of these symptoms. We’ve produced an alert card that you can hand over to any healthcare professionals you come into contact with if you believe you may have symptoms of spinal cord compression.

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

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
You’ve been given this card because you have secondary breast cancer in the bone and are at risk of spinal cord compression.

If you develop any of the following symptoms, contact your local Accident and Emergency Department or a doctor or nurse from your specialist team straight away.

• Severe back pain, especially if it’s different from any other pain you experience and/or affects the top part of your spine or neck.
• Pain in the back that changes when you lie down, stand up or lift something, or prevents you from sleeping.
• Pain which starts in the back and goes around the front to the chest and towards the belly.
• Pain or numbness extending down a leg or arm.
• Difficultly walking or feeling clumsy or weak – especially in the arms and legs.
• Difficulties going to the toilet, problems passing urine or opening the bowels.
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.

Further copies of this card can be obtained from
www.breastcancercare.org.uk

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

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.

**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. Your 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.

**What causes problems with sleeping?**

The main causes are stress and anxiety resulting from your diagnosis and side effects of treatment.

- Anxiety can be related to many things. It could be uncertainty about the future or worries about relationships with friends and family and their expectations of you. Feeling anxious can stop you from getting to sleep or cause you to wake up early.
- Your sleep pattern may change if you’re having chemotherapy or taking steroids.
- Night sweats caused by the onset of the menopause or menopausal symptoms due to taking hormone therapies may disrupt your sleep.
- Other treatments such as pain relief can also affect your sleep pattern. If this happens, talk with your specialist or palliative care team about how and when to take your pain relief to try to improve this.
• Changes in your daily routine can also affect your sleep. Being diagnosed with secondary breast cancer can affect what you do on a daily basis. You may have stopped working and be getting up later which can disturb your regular sleep pattern.

• You may have less energy and as a result be doing less exercise which can affect your sleep pattern.

Many people worry or feel guilty that they may keep their partners awake when they’re unable to sleep. However there are some things you can do to improve your sleep pattern.

What can I do to improve my sleep patterns?
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. 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. Use or keep a sleep diary, so you’re aware of how extra sleep during the day affects your sleep at night.

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. Turn the light off when you go to bed.

Keeping a worry book allows you to write down your worries so that they can be put away to be dealt with or talked through with others during the daytime.

If you’re not asleep within 15 minutes after lying down 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.
Feeling sick (nausea) and vomiting

If you feel sick or are vomiting, it’s likely to be due to your cancer, its treatment or emotional side effects such as anxiety. In most cases it can be controlled. 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 them, although this usually wears off. You may be prescribed an anti-sickness tablet to take with your pain relief to prevent this happening.

Constipation

This may be caused by eating or drinking less, 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 will be able to prescribe these for you.

Diarrhoea

Treatment such as chemotherapy and radiotherapy to the abdomen (belly), spine (backbone) or pelvis may cause diarrhoea. Other drugs can also affect the digestive system and cause diarrhoea. If you experience regular diarrhoea, your body is unable to absorb water and nutrients from food as well as any medications taken by mouth. If the chemotherapy you’re receiving is known to cause diarrhoea, your specialist team may prescribe drugs to help control this.

Try to drink plenty 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 care team.
Poor appetite and weight loss

Sometimes people with secondary breast cancer are unable to 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 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 (see Further Support section on page 52).

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

Weight gain

You may find that you put on weight as a result of treatment, for example if you’re taking steroids or hormone treatment or doing less exercise. Putting on weight can affect you physically and also have an impact on how you feel about yourself. If weight gain becomes a problem for you, it might help to talk to your specialist team or a dietician 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. See the Living with secondary breast cancer booklet at the back of this pack for more information on exercise and secondary breast cancer.
Secondary breast cancer words explained

A

Abdomen: belly.

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 and/or body.

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. 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 examples of anthracycline drugs.

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

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

**Bevacizumab**: also known as Avastin, a targeted therapy that works by stopping the 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.

**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, which are also called cytotoxic drugs.
**Chest wall:** the muscles, bones and joints that make up the area of the body between the neck and the abdomen.

**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.

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

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

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

**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. One of a group of drugs called aromatase inhibitors.
F

Filgrastim: also known as Neupogen, a drug that promotes reproduction and maturing of white blood cells to treat or prevent neutropenia (a decrease in the number of white cells, essential for fighting infection).

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

- FISH negative (FISH-): normal levels are present.
- FISH positive (FISH+): excessive amounts are present, classed as HER2+.

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

Intramuscular (IM): an injection into the muscle.

Intravenous (IV): an injection into a vein.

Letrozole: also known as Femara, a hormone therapy. 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 (axilla) and surrounding area.

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.

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.

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

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

**Palliative treatment:** aims to control symptoms and slow down the progress of cancer, rather than cure it.

**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 is 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 is 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.

**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.

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

**Targeted therapies (sometimes called 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.

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

**Vinorelbine:** also known as Navelbine, a chemotherapy drug used to treat breast cancer.

**X-ray:** used to produce images of dense tissues in the body such as bone or lungs.
Other Breast Cancer Care publications

All our publications are available to order or download from www.breastcancercare.org.uk/publications Here you’ll also find more information about other secondary breast cancer treatments which may be available in clinical trials.

The following is a list of our print publications which you may find useful. You can tick the boxes for the ones you would like to receive and post the form off to us. Alternatively, call us on 0808 800 6000 and our we can send them to you.

**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)
- Fulvestrant (Faslodex) (BCC122)
- Goserelin (Zoladex) (BCC33)
- Letrozole (Femara) (BCC64)
- Trastuzumab (Herceptin) (BCC41)
- Tamoxifen (BCC20)

**Chemotherapy**

- Capecitabine (Xeloda) (BCC121)
- Chemotherapy for breast cancer (BCC17)
☐ Docetaxel (Taxotere) (BCC35)
☐ FEC chemotherapy (BCC96)
☐ Paclitaxel (Taxol) (BCC34)

**Other treatment**

☐ Ovarian suppression (BCC27)

**Health and wellbeing**

☐ Breast cancer and hair loss (BCC54)
☐ Complementary therapies (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)
☐ Your body, intimacy and sex (BCC110)

**Other issues**

☐ Breast cancer in families (BCC32)
☐ Breast cancer and your child’s school (BCC209)
☐ In it together: for partners of people with breast cancer (BCC120)

Name: ____________________________________________

Address: ____________________________________________

Postcode: ____________________________________________

Please send to: Breast Cancer Care Publications PO Box 33, Ross on Wye HR9 9WA.
Helping you face breast cancer

A diagnosis of secondary breast cancer can be overwhelming, and the support you need might feel like it’s hard to come by. We’re here to help. Meet other women with secondary breast cancer and get specialist information on topics relevant to you with our Living with Secondary Breast Cancer services. We can help you feel less alone and more in control to make confident decisions about your treatment, lifestyle and care.

Ask us
Our free Helpline is here to answer any questions about breast cancer and talk through concerns. Or you can Ask the Nurse by email via our website.

Free Helpline 0808 800 6000 (Text Relay 18001)
Monday–Friday 9am–5pm, Saturday 10am–2pm
www.breastcancercare.org.uk/ATN

Meet people like you
Come along to our free Living with Secondary Breast Cancer meet-ups for a chance to chat and share experiences with people who understand what it means to live with secondary breast cancer.

They’re also a unique opportunity to increase your knowledge as we run longer sessions with guest expert speakers every other month. Topics include pain management, fatigue, claiming benefits and side effects of treatment. Call 0345 077 1893 or visit www.breastcancercare.org.uk/lwsbc to find out more.

Talk to someone who understands
Exchange tips on coping with the side effects of treatment, ask questions, share experiences and talk through concerns at our website’s discussion Forum. There’s a dedicated area for people with secondary breast cancer – it’s easy to use and professionally hosted. Live Chat sessions exclusively for people living with secondary breast cancer take place weekly in a private area of our website. Each session is facilitated by an experienced moderator and a specialist nurse who can point you to sources of help and information. But for most people, being able to talk to others who know what you’re going through is what counts.
Further support
Cancer organisations

Cancer Research UK
Angel Building
407 St John Street
London EC1V 4AD

Telephone: 020 7242 0200
Freephone Helpline: 0808 800 4040
Website: www.cancerresearchuk.org

Cancer Research UK is the world’s leading independent organisation dedicated to cancer research. They provide a free information service about cancer and cancer care to people with cancer and their families. They also have information on clinical trials including a list of those currently taking place.
**Macmillan Cancer Support**

89 Albert Embankment  
London SE1 7UQ  

General enquiries: 020 7840 7840  
Helpline: 0808 808 0000  
Outside UK: 020 7091 2230  
Website: www.macmillan.org.uk  
Textphone: 0808 808 0121 or Text Relay  

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. Over the phone, its cancer support specialists can answer questions about cancer types and treatments, provide practical and financial support to help people live with cancer, and are there if someone just wants to talk. Its website features expert, high-quality information on cancer types and treatments, emotional, financial and practical help, and an online community where people can share information and support. Macmillan also funds expert health and social care professionals such as nurses, doctors and benefits advisers.

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**Marie Curie**

89 Albert Embankment  
London SE1 7TP  

Administration: 020 7599 7777  
Freephone Helpline: 0800 090 2309  
Website: www.mariecurie.org.uk  

Marie Curie Cancer Care provides high quality nursing, totally free, to give terminally ill people the choice of dying at home supported by their families.
Other organisations

**British Complementary Medicine Association (BCMA)**

PO Box 5122
Bournemouth
BH8 0WG

Telephone: 0845 345 5977
Email: office@bcma.co.uk
Website: www.bcma.co.uk

Produces a guide and a code of conduct for practitioners, and holds a register of practitioners.

**British Pain Society**

Third Floor, Churchill House
35 Red Lion Square
London
WC1R 4SG

Website: www.britishpainsociety.org/people-with-pain

A forum for patients and professionals offering information on all aspects of pain.

**Hospice UK**

Enquiry line: 020 7520 8200
Email: info@hospiceuk.org
Website: www.hospiceuk.org

Provides information on hospices and palliative care services in the UK and abroad.
About this pack

Secondary breast cancer resource 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 www.breastcancercare.org.uk/publications

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

Phone 0345 092 0808
Email publications@breastcancercare.org.uk
Living with secondary breast cancer
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Introduction

This part of the Secondary breast cancer resource pack is about living with the disease.

It covers how you may feel when you are diagnosed and what effect this may have on you psychologically and physically. It also looks at what effect this may have on those close to you.

We have also included some information on practical issues and how things like gentle exercise can improve how you feel. There’s also quotes from women living with secondary breast cancer and they talk about how they feel and what has helped them.

If you have any questions or just want to talk through your feelings you can call us free on 0808 800 6000. You’ll also find support on our website www.breastcancercare.org.uk/forum
Finding out

For many people diagnosed with primary breast cancer, the future feels uncertain. The fear that the cancer could come back may never go away completely. Being diagnosed with secondary breast cancer can be even more difficult because the hope of staying well is replaced with the realisation that a cure is no longer possible.

When you find out that your breast cancer has spread you may experience many different emotions. Reactions can include 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. Your mind may race ahead with worries about what’s going to happen to you. You may feel concern for people close to you or disappointment about plans that may not go ahead. You may also find yourself questioning the value of everything that you went through following your first breast cancer diagnosis. Although these feelings are normal, don’t be afraid to ask for support to help you manage them. For more information on places to turn for support, see ‘Further support’ on page 30.

‘My husband and I were both totally shocked to hear that the cancer had probably spread to my liver. The rest of the day is a bit of a blur. You feel shocked and devastated at first but this feeling will diminish over time and you will start to feel more normal.’

Anna
In the initial days or weeks following your diagnosis of secondary breast cancer, you may feel in turmoil and find it hard to think clearly. This is a stage that many people go through before reaching a point where they are able to start to take some control of their situation. However difficult this may seem, you can still have some control over how you manage the illness and deal with the emotional and practical issues that it brings.

**Coping in the first few days and weeks following diagnosis**

Talk about how you’re feeling. 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 and you can ask to be put in contact with one if you haven’t already. See page 27 of the main pack on getting the most out of your meeting with a healthcare professional.

You can also call us free on **0808 800 6000** and talk through any of 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 via our discussion Forum and Live Chat on our website www.breastcancercare.org.uk
Psychological effects

Feelings of sadness and loss are common with a diagnosis of secondary breast cancer. 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. You may find that people around you 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 or there may be strategies you can learn with support from a counsellor or psychotherapist who specialises in working with people affected by cancer. Seeing a counsellor or psychologist can give you the time and space to talk openly about your worries or things that you are unable to discuss with those closest to you. They may be based in your local hospital, hospice or in the community.

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 try 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 find going to hospital for my trastuzumab (Herceptin) every three weeks emotionally draining. It’s a constant reminder that I have cancer, so I’m trying to get the treatment at home instead.’

Jacqui

Anxiety and stress

Living with secondary breast cancer means 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. For some people anxiety can become so overwhelming that it results in panic attacks, causing further fear and worry. Sometimes continued anxiety can lead to depression. Your specialist team may talk to you about prescribing drugs to relieve the side effects of anxiety.

One way to cope with anxiety is to talk about your concerns with someone who can help. Your family and friends may offer sympathy and support, or you may want to talk to a trained professional who can teach you practical techniques that you can learn and use at home. These can help you feel more in control of your life. You may need to try a few 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. Some of these are listed below.

- 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.
- Counselling: one-to-one counselling takes place in a private and confidential setting. You’ll be able to explore feelings related to your
secondary breast cancer diagnosis – such as anger, anxiety and grief – making them easier to cope with.

• **Cognitive behavioural therapy (CBT):** can help you change negative patterns of thinking and behaviour. Unlike some techniques, it focuses on problems you’re having in the ‘here and now.’ Instead of exploring the causes of your distress or symptoms in the past, it looks for ways to improve your state of mind in the present.

• **Mindfulness:** focusing on the present moment to reduce stress and improve quality of life. This means noticing sights, smells, sounds and tastes, as well as thoughts and feelings from one moment to the next.

A few cancer centres offer mindfulness classes. These may include mindfulness-based cognitive therapy (MBCT), mindfulness-based stress reduction (MBSR), yoga, meditation, relaxation and breathing exercises along with some cognitive behavioural therapy (CBT) techniques. There may be other classes in your local area and a number of free podcasts, recordings and phone apps are also available for personal use. If you think you might benefit from any of these techniques, your specialist team or GP should be able to help you access them.

**Complementary therapies**
Complementary therapies such as aromatherapy, massage or reflexology can help you to relax and reduce stress and anxiety. See our [Complementary therapies booklet](#) for more information.

**Low mood and depression**
Depression is a common condition and may occur at different times in a person’s life. Depression is a broad term used to describe a range of feelings, from being low in spirits to having no will to live.

Some people become depressed because of the impact of breast cancer and this can happen at any stage during diagnosis and treatment. Being told you have secondary breast cancer, having more treatment and facing a shorter life expectancy can cause severe depression in some people. You may be more at risk of becoming depressed if you have previously experienced depression.

You may describe your mood as being ‘depressed’ when you feel low in energy and are generally feeling down and lacking in motivation. You may feel that the enjoyment has gone from your life and you can’t
imagine things getting better. Many people who are depressed find it
difficult maintaining their usual social contacts and so feel isolated
and unsupported.

If negative thoughts are having an impact on 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.

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

- 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.

You don’t have to ignore these feelings and struggle on. Realising that
there’s a problem and getting help is the most important thing you can
do. 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 admitting that you’re feeling
depressed or finding it hard to cope and you need help. Some people
find it particularly hard to seek professional advice but it can help to
relieve these symptoms and allow you to regain some control of your life.

What might help?
Emotional support from your family and friends and healthcare
professionals can help. Professional support such as counselling can
also be of benefit and your specialist team, palliative care team or GP
will be able to direct you to services in your local area.
Antidepressants
Antidepressant drugs may be recommended if you’re thought to be clinically depressed. 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.

Finding support
Joining a cancer support group to meet others with a similar experience may also be helpful. Your breast care nurse, chemotherapy or palliative care nurse or local cancer information centre will be able to give you the details of any appropriate support groups in your local area. Breast Cancer Care’s Living with Secondary Breast Cancer meet-ups are held at a number of 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. Call 0345 077 1893 or email secondaryservices@breastcancer.org.uk for more details. You can also search for support groups near you on the Macmillan Cancer Support website.

You can also call us free on 0808 800 6000 for information and support or you can email a Breast Cancer Care nurse through our website. All emails are treated confidentially. Visit www.breastcancer.org.uk/ATN to submit a short form that includes your question and a nurse will reply.

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 08457 909 090, or email jo@samaritans.org

The Mental Health Foundation has more information on talking therapies that you may find helpful. See the ‘Further support’ section for more details.
Living with secondary breast cancer

Each person’s experience of secondary breast cancer is unique and everyone will cope with their diagnosis and the impact it has on their life in their own way.

Having secondary breast cancer doesn’t necessarily mean that you’re going to have to make big changes; some people are able to carry on with their lives much as they lived them before their diagnosis. However, many people find that their diagnosis causes them to take time to think about their life and what’s important to them. Even if you want to carry on as before, your diagnosis will have some impact on the people around you, the things you do and how you see the future.

Living with uncertainty

For many people, the uncertainty of living with secondary breast cancer can be the hardest part. Some people feel that living in the present and making plans from day to day is easier than looking ahead. Others find that planning for the future helps them to feel more in control.

When you’re first diagnosed you may find it difficult to feel positive. But once you start to adjust to this new situation and find ways to cope, you may discover that you can feel more hopeful about the future. Unfortunately 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.
‘My husband took early retirement in order for us to bring forward some of the travel plans we had made for our retirement – mainly long haul travel, so that we can leave European and more local trips for when I can no longer travel as far. Also, travel insurance is a factor here.’

Marie

Relationships

Partners

If you have a partner, they will probably experience many of the same emotions as you. 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 result in changes to your relationship. These changes can bring you closer together but can also sometimes feel like a barrier between you. If you have been the main caretaker for the family, both you and your partner may find it difficult to adjust to you now being the one who needs 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 will cope, particularly if you have children. They may be feeling the full weight of responsibility for the family both 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 at home. Help and support is available in many areas for partners/carers. You can ask your specialist team or see ‘Further support’ on page 30. Your partner is 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.

You may both find it painful to show how you’re feeling or talk about your fears and this can make communication difficult at a time when talking openly is important. 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 are both feeling. Even in close relationships some people hide their emotions, perhaps to protect the other person or because they don’t want to appear weak. But don’t to be afraid to cry or be angry as showing how you’re feeling can help you cope.

**Sex and intimacy**

Your sexual relationship may also be affected by your diagnosis and treatment. Some people think that because you have secondary breast cancer you will not be interested in sex and intimacy. However for many people, being intimate with a partner can bring comfort. The physical changes and emotional impact of having secondary breast cancer, as well as the effects of treatment can affect how you feel about yourself and your sexual needs may change and vary depending on how well or tired you feel. If you’re upset by changes in your appearance you may not want to be physically close to your partner or your partner may be afraid of hurting you if they touch you. 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 pleasure.

By finding a way to talk to each other about your physical and sexual needs, you and your partner are more likely to be able to 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 or a counsellor. You may also find our booklet, *Your body, sex and intimacy* useful.

**Children and grandchildren**

If you have children and/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 to some extent 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, try to be open with your children so that they feel included. Not addressing it can leave them feeling more anxious.
How much children can understand about secondary breast cancer will depend partly 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 still find it hard to take in what you have told them and to respond straight away. They may need time to think about what you have said. Some 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 families is often available through schools, social workers or family liaison officers. Both parents and grandparents may also find our booklets Talking with your children about breast cancer and Breast cancer and your child’s school: communicating about your diagnosis and treatment useful, even though they aren’t specifically about secondary breast cancer. There are also other resources – see the ‘Further support section’ at the end of this booklet.
‘The thing my husband and I dreaded most was telling our daughters (aged 8 and 13) the news. We had always been honest with them about my primary cancer but felt that we couldn’t tell them everything we knew about secondary. We chose to tell them separately because we felt that their understanding would be on different levels and they may ask different questions. The reality of telling them was not as bad as we thought it would be – they did not have pre-conceived ideas of the future the way we did.’

Anna

‘Our son, who is 22 and was only 10 when I was first diagnosed, was very upset when we told him about the diagnosis and I have promised to keep him informed about any treatments and how I am doing. However, he seems to be getting on with his life quite normally, which I’m delighted about. He is due to spend a year in the USA as part of his university career and I was concerned he would be too worried about me to go, but he is intending to keep to his plans and leave in September – which I’m really pleased about. It makes life more normal for all of us.’

Shirley
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 who 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 used by other members of your family 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 will be provided with genetic counselling so that you understand the process and the impact the results may have. Our booklet, Breast cancer in families has more information.

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 find that some people 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, which many people prefer not to do. All these things may affect how people relate to you. Alternatively, you may feel overwhelmed by the support and concern from those around you.
Often people may simply not 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. This can make any isolation you’re already experiencing because of your diagnosis even worse. You may find that your family and friends need you to raise the issue, though this may feel unfair. If you can talk about how you’re feeling and what you need from them, they can begin to understand how best to support you. If you’re able to 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 than emotional support and you may feel that you don’t have anyone you can really talk to. Joining a support group may be a way of meeting people who understand what you’re going through. Some people find sharing experiences online helpful and you may consider Breast Cancer Care’s Forum or Live Chat sessions specifically for people with secondary breast cancer. If you prefer, you may be able to talk to somebody in your specialist team, perhaps a Macmillan nurse or palliative care nurse, or you could ask to be referred to a counsellor.

‘People responded very differently to the news, but one of the hardest things was trying to know what to say to them after I had told them. Some people changed the subject, some fell silent, others cried. The people who made it easiest for me were those who managed to listen without getting upset.’

Anna
‘People were generally pretty upset when I told them, and I felt I had to cheer them up by telling them there were lots of potential treatments and so on – but I did rather resent trying to make people feel better about it when I felt so awful!’

Shirley

If you’re on your own

Some people may not have as much support as they would like or need. You may live alone, or you may not have close family or your friends may not live nearby. You don’t have to manage completely on your own. Even 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 are part of. 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 also exist in many areas, and can provide this type of support. Your specialist team, GP or social worker may also be able to tell you about other sources of practical support which may be available to you. For more information see ‘Further support’ on page 30.

Making changes in your life

When you’ve had some time to think about the future and what your priorities are, you may decide that you want, or need, to make some changes to your life. These may be small changes, or more significant ones, but they can make a big difference to how you feel.

You may want to pursue an unfulfilled ambition or visit a place that you have always wanted to go to. It can be a time when you focus on what’s most important to you and the things you get most pleasure from. You may find you have a greater awareness and enjoyment of simple things,
such as spending time with friends or listening to music. You’ll probably find some days you have more energy than others, so try to use these days to do the things you really want to do. 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.

You can talk to your specialist team about planning a break in your treatment to allow you to plan a holiday or activity.

Some people choose to make changes to their lifestyle, for example by eating a healthier diet or trying to be more physically active. Sometimes you may have to make changes that you would not choose, perhaps because of the effects of the cancer, such as fatigue or pain limiting your mobility. It can be difficult to adjust to these enforced changes if you are used to being active and independent.

**Work**

For some people work is very important. This may be for financial or social reasons or because they need 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, perhaps by reducing your hours or changing your role. 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.
‘Going to work has really helped me. I have been lucky because the college where I work has been very flexible and let me do reduced hours. Work gives me a purpose and something to talk about which isn’t cancer. It also helps the children to see that I am still doing something that I used to do.’

Anna

Finances

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

Whatever your personal situation and level of income, you may be able to claim welfare benefits because you have secondary breast cancer. Some benefits are means tested (your entitlement depends on your income) and some act as a gateway to other types of help, so it’s important to find out what you are entitled to.

From April 2013 the Personal Independence Payment (PIP) started to replace the Disability Living Allowance for adults aged 16-64 with a long-term health condition or disability. Attendance allowance is paid to those aged 65 or over.

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 under special rules for people who it is thought may not live for longer than six months. But it’s impossible to say exactly how long someone will live when they have secondary breast cancer. You can talk to your GP, nurse or social worker about what you may be entitled to. For more information see Macmillan Cancer Support’s A quick guide to benefits and financial help leaflet or visit www.gov.uk. You can also get help
from a specialist welfare officer in your palliative care team or a benefits adviser by contacting Macmillan or Citizens Advice. The Money Advice Service also has lots of useful information. See page 30 for the details of the organisations mentioned.

‘My husband and I have both found that planning for the future helped us to feel less stressed.’

Anna

**Mobility**
If you’re under 65 you may also 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 www.gov.uk

**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 similar benefits from exercising, but you may need to take a little extra care.
Regular exercise may help to:

- increase fitness, strength, stamina and flexibility
- control weight (when combined with a healthy diet)
- boost the immune system
- reduce blood pressure
- reduce fatigue.

People who exercise, even gently, during treatment may tolerate treatments better and experience less pain, sickness, problems sleeping and fatigue. Your specialist team or cancer information centre will have information about any appropriate local support to get active.

**What is regular exercise?**

Regular exercise can help many people diagnosed with cancer improve their quality of life. 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 before starting any exercise it’s important to discuss it with your specialist team. You can begin gently and build up gradually. It doesn’t need to be 30 minutes all at once. There are many ways to include physical activity in your daily routine so joining a gym or attending classes is not necessary.

'Moderate intensity' usually means you breathe harder, become warmer and are aware of your heart beating slightly faster than normal. However, you should be able to talk and it should not 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. It’s important to listen to your body and stop straight away if it hurts or feels like you’re working too hard.

When choosing your exercise, try to focus on aerobic-type activities such as walking, swimming or cycling. However, less structured activities such as dancing and gardening can also be beneficial. You could also include some light toning or conditioning exercises such as stretching or low-impact yoga. The most important thing is to choose something you can safely enjoy.
‘Many people are of the opinion that the words ‘secondary’ or ‘spread’ imply an immediate death sentence. They don’t – I am living proof of this. To name just a few things I’m involved with, I ski, ramble and belong to walking groups. I go to Scottish dancing, I volunteer and I am actively involved in the U3A [University of the Third Age]!’

Marie

Exercise and secondary breast cancer in the bone
The most common effects of secondary breast cancer in the bone – bone weakening and fracture risk – are also seen in people with osteoporosis. In these people, regular exercise increases bone strength and reduces fracture risk. Research shows that regular weight-bearing exercise, such as walking, is the best choice for strengthening bones. As your bones are at a greater risk of fracture you should avoid high-impact activities, such as contact sports.

For people with secondary breast cancer in the bone that has spread to the spine, there is a potential risk of developing spinal cord compression. There’s more information about this on page 35 of the main pack. To reduce your risk, avoid activities that involve twisting the spine or large forward bends of the spine.

Exercise and secondary breast cancer in the lung
Breathlessness, coughing, pain, tiredness and loss of appetite can all be symptoms of secondary breast cancer in the lung(s). These symptoms are similar to those experienced by people with long-term respiratory diseases such as chronic obstructive pulmonary disease (COPD) and asthma. Research has found that when people with respiratory disease exercise regularly they are less breathless, have more stamina, are better able to perform everyday tasks and have a better quality of life.
There are a number of things you can do to avoid or reduce breathlessness. Firstly, avoid exercising in very cold or dry conditions as this makes it more difficult for your lungs to expand. Swimming can be ideal because the pool hall is usually quite warm and the air is damp. Secondly, always start your exercise session with a gentle warm up to get your body ready to exercise and to slowly increase how hard you’re breathing so your lungs have time to adjust to the new demands. Walking can also be helpful. However, it’s best to choose a route where you can take plenty of rest stops. You could also try ‘pursed lip breathing’. This involves pursing your lips and breathing in and out through the narrowed opening. This reduces the air pressure, making it easier for your lungs to expand and contract.

**Exercise and secondary breast cancer in the liver**
Some people with secondary breast cancer in the liver have no symptoms while others have a combination of pain, feeling sick, loss of appetite, hiccups, tiredness and fatigue. While physical activity may help reduce some symptoms it’s important to listen to your body and not push it too hard. Gentle regular activity is often most effective.

**Exercise and secondary breast cancer in the brain**
Depending on where exactly it is, the symptoms of secondary breast cancer in the brain may include headaches, feeling sick, blurred vision, seizures, weakness, dizziness or balance problems. While these symptoms may not prevent you from exercising, it’s important to choose suitable exercise to make sure you don’t put yourself at unnecessary risk of injury. For example, for people with balance problems an exercise bike may be better than cycling outdoors. If you suffer from seizures, always try to avoid exercising alone.

**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. Although you may already use your arm normally in everyday life, you may want to restart or take up some regular exercise.

In the past it was thought that exercise could make lymphoedema worse but recent evidence shows that it will not worsen any symptoms you may already be experiencing and may improve them.

However, if you’re considering starting or restarting exercise it’s a good idea to talk to your lymphoedema specialist about the type of exercise beforehand.

If you’ve been fitted with a lymphoedema sleeve, you should always wear it when you’re exercising, as long as it is comfortable to do so. If your compression garment is not comfortable, you should go back to whoever fitted it for you to get the fit checked.

See our Living with lymphoedema after breast cancer booklet for more information.
Faith and spirituality

Religious belief is an important part of many people’s lives and it can give them strength and comfort, particularly 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 is 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 are sure in your beliefs or are 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 inner comfort and strength from talking to people who share a similar outlook.
Helping you face breast cancer

A diagnosis of secondary breast cancer can be overwhelming, and the support you need might feel like it’s hard to come by. We’re here to help. Meet other women with secondary breast cancer and get specialist information on topics relevant to you with our living with secondary breast cancer services. We can help you feel less alone and more in control to make confident decisions about your treatment, lifestyle and care.

Ask us
Our free Helpline is here to answer any questions about breast cancer and talk through concerns. Or you can Ask the Nurse by email via our website.

Free Helpline 0808 800 6000 (Text Relay 18001)
Monday–Friday 9am–5pm, Saturday 10am–2pm
www.breastcancercare.org.uk/ATN

Meet people like you
Come along to our free Living with Secondary Breast Cancer meet-ups for a chance to chat and share experiences with people who understand what it means to live with secondary breast cancer.

They’re also a unique opportunity to increase your knowledge as we run longer sessions with guest expert speakers every other month. Topics include pain management, fatigue, claiming benefits and side effects of treatment. Call 0345 077 1893 or visit www.breastcancercare.org.uk/lwsbc to find out more.

Talk to someone who understands
Exchange tips on coping with the side effects of treatment, ask questions, share experiences and talk through concerns at our website’s discussion Forum. There’s a dedicated area for people with secondary breast cancer – it’s easy to use and professionally hosted. Live Chat sessions exclusively for people living with secondary breast cancer take place weekly in a private area of our website. Each session is facilitated by an experienced moderator and a specialist nurse who can point you to sources of help and information. But for most people, being able to talk to others who know what you’re going through is what counts.
Further support

Cancer organisations

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ

General enquiries: 020 7840 7840

Helpline: 0808 808 0000

Outside UK: 020 7091 2230

Website: www.macmillan.org.uk

Textphone: 0808 808 0121 or Text Relay

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. Over the phone, its cancer support specialists can answer questions about cancer types and treatments, provide practical and financial support to help people live with cancer, and are there if someone just wants to talk. Its website features expert, high-quality information on cancer types and treatments, emotional, financial and practical help, and an online community where people can share information and support. Macmillan also funds expert health and social care professionals such as nurses, doctors and benefits advisers.
Marie Curie

89 Albert Embankment
London SE1 7TP

Administration: 020 7599 7777
Freephone Helpline: 0800 090 2309
Website: www.mariecurie.org.uk

Marie Curie Cancer Care provides high quality nursing, totally free, to give terminally ill people the choice of dying at home supported by their families.

Penny Brohn Cancer Care

(formerly Bristol Cancer Help Centre)

Chapel Pill Lane
Pill
Bristol BS20 0HH

Telephone: 01275 370 100
National helpline: 0845 123 2310 or helpline@pennybrohn.org
Email: info@pennybrohn.org
Website: www.pennybrohnancancercare.org

Offers courses of varying lengths (led by experienced trained facilitators) for people with cancer and their supporters offering counselling, relaxation, imagery, meditation, art and music therapy, healing and advice on nutrition. Helpline offers emotional support and information on finding complementary therapists and support in your area.
riprap
Website: www.riprap.org.uk
A website for children and young people who have a parent with cancer.

The Haven
Effie Road
London SW6 1TB
Telephone: 020 7384 0099
Email: info@thehaven.org.uk
Website: www.thehaven.org.uk
Provides support, information and complementary therapies to help anyone affected by breast cancer to cope with the emotional impact of diagnosis as well as to help relieve the uncomfortable side effects of some medical treatments such as chemotherapy and radiotherapy. Its services are free of charge to anyone affected by breast cancer.

Other organisations

Be Mindful
Website: www.bemindful.co.uk
A campaign raising awareness of mindfulness meditation by the mental health foundation.
British Association for Counselling and Psychotherapy (BACP)

BACP House
15 St John’s Business Park
Lutterworth
Leicestershire LE17 4HB

Telephone: 01455 883 300
Email: bacp@bacp.co.uk
Website: www.bacp.co.uk

Aims to promote counselling and psychotherapy and raise standards. Produces a directory of counsellors and psychotherapists, also available online, and will send a list of counsellors and psychotherapists in your area.

British Complementary Medicine Association (BCMA)

PO Box 5122
Bournemouth BH8 0WG

Telephone: 0845 345 5977
Email: office@bcma.co.uk
Website: www.bcma.co.uk

Produces a guide and a code of conduct for practitioners, and holds a register of practitioners.
**British Red Cross**

UK Office  
44 Moorfields  
London EC2Y 9AL

Telephone: **0344 871 1111**

Email: **information@redcross.org.uk**


Provides support at home, transport and mobility aids to help people facing crisis in their daily lives.

**Carers Trust**

32-36 Loman Street  
London SE1 0EH

Telephone: **0844 800 4361**

Email: **support@carers.org**

Website: [www.carers.org](http://www.carers.org)

Providing local information, practical support and advice for carers including care and respite services.

**Carers UK**

20 Great Dover Street  
London SE1 4LX

Advice line: **0808 808 7777** Mon-Fri 10am-4pm

Email: **advice@carersuk.org**

Website: [www.carersuk.org](http://www.carersuk.org)

Advice for carers, people being cared for and professionals. Deals with a range of care issues including benefits, residential care, respite care and care in the community across the UK.
Citizens Advice
Advice line: 03444 111 444
Website: www.citizensadvice.org.uk

Provides free advice and information on a wide range of issues, including benefits, employment and money advice. To find your nearest office, look in your local telephone directory or visit the website.

Disabled Motoring
Telephone: 01508 489 449
Website: www.disabledmotoring.org/blue-badge/eligibility-and-use
Email: info@disabledmotoring.org

Campaigning for disabled drivers, passengers and blue badge holders, including information for those applying for a blue badge.

Gov.uk
Provides information on a range of public services including benefits and blue badge applications.
Website: www.gov.uk

Benefits information: www.gov.uk/browse/disabilities/benefits
Blue badge information and application: www.gov.uk/apply-blue-badge
Honey Rose Foundation

2-4 Cotham Street
St Helens WA10 1SL

Telephone: 01744 451 919
Fax: 01744 453 062
Email: lynn@honeyrosefoundation.co.uk
Website: www.honeyrosefoundation.co.uk

A national organisation providing special days for people aged over 40 facing cancer or other life threatening illness (for those under 40 see Willow Foundation).

Hospice UK

34-44 Britannia Street
London WC1X 9JG

Enquiry line: 020 7520 8200
Email: info@hospiceuk.org
Website: www.hospiceuk.org

Provides information on hospices and palliative care services in the UK and abroad.
The Lymphoedema Support Network

St Luke’s Crypt
Sydney Street
London SW3 6NH

Information and support line: 020 7351 4480

Email: adminlsn@lymphoedema.freeserve.co.uk

Website: www.lymphoedema.org

The national organisation providing advice and support to people with lymphoedema. Works for better awareness of lymphoedema by the medical profession and for appropriate and comprehensive standards of treatment and ongoing care for everyone affected.

Mental Health Foundation

Colechurch House
1 London Bridge Walk
London SE1 2SX

Telephone: 020 7803 1100

Website: www.mentalhealth.org.uk

Organisation that focuses on mental health and works across all age ranges, whatever condition or circumstance. Provides a range of free podcasts to help with relaxation and improve wellbeing.

Money Advice Service

120 Holborn
London EC1N 2TD

Telephone: 0300 500 5000

Website: www.moneyadviceservice.org.uk/en

Free and impartial money advice.
Silverline

19-23 Featherstone Street
London EC1Y 8SL

Website: www.thesilverline.org.uk

Helpline: 0800 470 8090

Free and confidential helpline providing information, friendship and advice to older people 24 hours a day, 365 days a year.

Willow Foundation

Gate House
Fretherne Road
Welwyn Garden City
Herts AL8 6NS

Telephone: 01707 259 777

Email: info@willowfoundation.org.uk

Website: www.willowfoundation.org.uk

An organisation providing special days for seriously ill young adults (16–40). Their website includes information on eligibility criteria and how to apply. (For those over 40 see The Honey Rose Foundation.)
Further reading

Secondary breast cancer books
Holding Tight, Letting Go: Living with Metastatic Breast Cancer
Musa Mayer. Pub Group West, 1997

Resources for parents and children
This list of resources is for parents with secondary breast cancer to help them talk with their children about their illness and future. They have all been read and briefly reviewed to try and help you find appropriate reading for you and your family. All are currently available from bookshops, libraries and online. It is also worth speaking to your local librarian or visiting your local cancer information centre, as many will stock and loan a variety of similar books. Amazon online also lists many of these books and booklets.

Books for parents or carers
Here are a range of books other people have found useful in talking to children about life-threatening illness and death. Some are cancer specific, others are more general.

Talking to children and teenagers when an adult has cancer
Macmillan Cancer Support, 2013

How To Talk So Kids Will Listen and Listen So Kids Will Talk
Adele Faber and Elaine Mazilsh. Piccadilly Press. 2013

As Big as it Gets: Supporting a Child When a Parent is Seriously Ill
Winston’s Wish, 2007

What happens when someone dies?
Jennie Armstrong. See Saw, 2014
Books for children

The Secret C: Straight Talking About Cancer
Julie Stokes. Winston’s Wish/Macmillan Cancer Support, 2009
Suitable for children 7-10 years.

When Your Mum or Dad Has Cancer
Ann Couldrick Sobell Publications. 1991
Suitable for children 7 and upwards.

A Monster Calls
Suitable for children 9 and over.

The Rainbow Feelings of Cancer
A Book for Children Who Have a Loved One with Cancer
Carrie Martin and Chia Martin. Hohm Press 2002

A Dragon in Your Heart
Most suitable for children aged 5 and over.

Water Bugs and Dragonflies: Explaining Death to Children
Doris Stickney. Continuum, 2007
Suitable for children aged 4-10.
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.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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

Donate online
You can give using a debit or credit card at www.breastcancercare.org.uk/donate

My details
Name ____________________________________________________________
Address _________________________________________________________
_________________________________________________________________
_________________________________________________________________
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_________________________________________________________________
_________________________________________________________________
Postcode __________________________
Email address _____________________________________________________

We might occasionally want to send you more information about our services and activities

☐ Please tick if you’re happy to receive email from us
☐ Please tick if you don’t want to receive post from us

We won’t pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG, 5–13 Great Suffolk Street, London SE1 0NS
About this booklet

Living with secondary breast cancer 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 www.breastcancercare.org.uk/publications

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

Phone 0345 092 0808
Email publications@breastcancercare.org.uk
Breast Cancer Care is the only UK-wide charity providing specialist support and tailored information for anyone affected by breast cancer.

Our clinical expertise and emotional support network help thousands of people find a way to live with, through and beyond breast cancer.

Visit [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) or call us free on 0808 800 6000 (Text Relay 18001).

**Central Office**
Breast Cancer Care
5–13 Great Suffolk Street
London SE1 0NS
Phone: 0345 092 0800
Email: info@breastcancercare.org.uk
Thinking about difficult choices and decisions about the end of life
Introduction

It’s not possible to accurately predict someone’s life expectancy after a diagnosis of secondary breast cancer. However, more and more people are living longer with the disease.

For some people the cancer becomes like a chronic illness – it doesn’t affect their day-to-day lives very much 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. Whatever your situation, you’ll need to come to terms with the fact that you may not live as long as you might have done if the breast cancer hadn’t spread. Whether you have months or years left to live you’ll almost certainly think about your death from time to time.

Many people are frightened more by the process of dying than by the thought of death itself. This is often linked to fears about loss of dignity and not being in control. Understanding how your symptoms can be effectively controlled and being aware of the support that will be available to you towards the end of your life can help remove some of the fear. Once you begin to consider these issues, however difficult they are, it may be easier to think about what you’ll leave behind and how things will be after your death. There’s no right or wrong way to deal with these fears. People may choose to consider the issues when they’re diagnosed, delay thinking and talking about them or decide not to think or talk about them at all.

‘My husband and I chat about the future sometimes although he finds it very hard to accept that I may only have a few more years with him. The hardest part is not knowing how long I will be in reasonably good health and also the feeling that, with secondary breast cancer, there are not a lot of options open to me.’

Jacqui
Being dependent

Many people fear they’ll lose their dignity and become dependent on others as they become more ill. Even if you’re physically dependent, you can still be involved in making decisions about the management of your disease and how you’re cared for. It can be difficult and painful to look ahead to this time but it may be helpful to think about where and how you want to be cared for. For example, some people will find that they can’t manage stairs but would like to remain at home, so consider sleeping in a room downstairs and what changes need to be made for this to happen. Others wish to be cared for in a hospice for the last few weeks or days of their life and may choose to familiarise themselves and their family with the surroundings and staff.

How you would like to be cared for

Family or friends involved in your care may also need to think about what impact it will have on them. Caring for someone at the end of their life can be emotionally and physically exhausting. There’s professional support available, so try to talk with family members or friends who are caring for you 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 so that when you and your family need them they’re not strangers.

Recently there have been many initiatives in healthcare which mean anyone diagnosed with secondary breast cancer will be able to talk with a doctor or nurse about what is important for them in terms of their care towards the end of life and where they might wish to die. There are many structures in place designed to improve care, for example the Gold Standards Framework, Preferred Priorities of Care and Advanced Care Planning or Advanced Decisions. Healthcare professionals are aware of these and can use them to discuss with you what’s important or any concerns you may have in advance of needing care.

If you have strong feelings about how you want to be cared for and where you want to be towards the end of your life, talk to your family, GP, or palliative/home care team. For some people making their wishes clear can help them feel more settled, safe and in control.
Making decisions

It can be very difficult to think and talk about how and where you would like to be cared for at the end of life and make any necessary plans. The checklist at the end of this section may help you start to think about what you would like, or you may find publications by Macmillan Cancer Support and Marie Curie helpful – see the ‘Further support’ section on page 14 for details.

You may need to consider making decisions about who will care for your family and any necessary financial arrangements.

You can talk these decisions through with your family, friends and those caring for you, to ensure you feel confident that you’ll be cared for and all arrangements will be made in the way that you wish. Remember you can change your mind about any of your decisions at any time.

Making sure your choices are known

You may want and 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.

The Mental Capacity Act applies to people aged 16 and over in England and Wales. Its aim is to protect people who cannot make decisions for themselves. This means that a person can plan ahead for a time when they may not be able to make choices on their own behalf. It makes clear who can make decisions on their behalf, in which situations or circumstances, and how they should do this. There are many parts to this act, including parts on Lasting Power of Attorney and advance decisions. The Adults with Incapacity Act relates to people in Scotland.
Lasting power of attorney (LPA)
A lasting power of attorney is when you appoint someone you legally trust to make decisions on your behalf or manage your financial, legal or health affairs in the future if you’re no longer able to do so. An LPA must be made while you are able to understand what it is and what it means for you. It’s only valid in England and Wales.

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 (see page 17).

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 (see page 18).

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.

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

These types of documents are called advance statements and advance decisions (previously known as living wills).

An advance statement is a general statement of 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. Writing down your preferences and wishes can enable you to feel more in control and be helpful to those caring for you.

An advance decision states that you want to refuse treatment. For example, you may choose that if your condition suddenly worsens and your breathing stops, you don’t want people 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 signed and dated in the presence of at least one witness who must also sign and date the instructions within it. For more information on how to complete an advance decision correctly, go to www.compassionindying.org.uk. Their details are at the back of this booklet.

An advance decision to refuse treatment must say exactly what treatment you want to decline and in which situations. 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. This means your wishes are known to the teams that you may be in contact with, day or night. 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 fully.

Advance statements and advance decisions can also let your family and friends know your wishes, so that they’ll know what you want.

You can get more information about advance statements and advance decisions from a social worker, GP or palliative care specialist team or at www.nhs.uk/Planners/end-of-life-care.

You can discuss your wishes with a healthcare professional such as your specialist, GP or nurse, or with family and friends. Remember that
your family and friends may see things differently to you. If possible, it’s good to have an honest and open discussion with your partner, relatives or closest friend in advance, so that they fully understand your choices.

**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 to keep you comfortable, it’s illegal for them to 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, putting their affairs in order is a positive thing to do. It can be a way of making sure your wishes are carried out after you have died.

If you have children, you may want to think about what you would like them to have when you’ve died. 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 so think carefully about what you leave them or what you 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 them to carry. There’s a list of organisations that provide information to help your children with bereavement on page 20.

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. 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.

When writing a will or amending an existing one, it’s usually best to use a solicitor who 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 at www.gov.uk/make-will.

The Society of Trust and Estate Practitioners and The Law Society (see page 20) have more information on how to write a will and where to find a solicitor.
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 the process of coming to terms with the fact that you are coming to the end of your life.

There’s useful information on funeral options, using a funeral director, and how to apply for help covering funeral costs at www.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 (see page 18) and commit their members to providing a high standard of service.

You do not need to use a funeral director if you don’t wish to. The Natural Death Centre (see page 19) can provide information and advice if you would like to arrange a funeral yourself. You may also find www.nhs.uk/CarersDirect/guide/bereavement/Pages/Arrangingafuneral.aspx useful.
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 toward the end of your life (for example, at home, in a hospice, hospital or care home)?

Do you want to write an advance decision (advance directive) (see page 6) 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?
Helping you face breast cancer

A diagnosis of secondary breast cancer can be overwhelming, and the support you need might feel like it’s hard to come by. We’re here to help. Meet other women with secondary breast cancer and get specialist information on topics relevant to you with our living with secondary breast cancer services. We can help you feel less alone and more in control to make confident decisions about your treatment, lifestyle and care.

Ask us
Our free Helpline is here to answer any questions about breast cancer and talk through concerns. Or you can Ask the Nurse by email via our website.

Free Helpline 0808 800 6000 (Text Relay 18001)
Monday–Friday 9am–5pm, Saturday 10am–2pm
www.breastcancercare.org.uk/ATN

Meet people like you
Come along to our free Living with Secondary Breast Cancer meet-ups for a chance to chat and share experiences with people who understand what it means to live with secondary breast cancer.

They’re also a unique opportunity to increase your knowledge as we run longer sessions with guest expert speakers every other month. Topics include pain management, fatigue, claiming benefits and side effects of treatment. Call 0345 077 1893 or visit www.breastcancercare.org.uk/lwsbc to find out more.

Talk to someone who understands
Exchange tips on coping with the side effects of treatment, ask questions, share experiences and talk through concerns at our website’s discussion Forum. There’s a dedicated area for people with secondary breast cancer – it’s easy to use and professionally hosted. Live Chat sessions exclusively for people living with secondary breast cancer take place weekly in a private area of our website. Each session is facilitated by an experienced moderator and a specialist nurse who can point you to sources of help and information. But for most people, being able to talk to others who know what you’re going through is what counts.
Further support and useful addresses

Cancer organisations

**Macmillan Cancer Support**

89 Albert Embankment
London SE1 7UQ

General enquiries: 020 7840 7840

Helpline: 0808 808 0000

Outside UK: 020 7091 2230

Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

Textphone: 0808 808 0121 or Text Relay

Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. Over the phone, its cancer support specialists can answer questions about cancer types and treatments, provide practical and financial support to help people live with cancer, and are there if someone just wants to talk. Its website features expert, high-quality information on cancer types and treatments, emotional, financial and practical help, and an online community where people can share information and support. Macmillan also funds expert health and social care professionals such as nurses, doctors and benefits advisors.
Marie Curie
89 Albert Embankment
London SE1 7TP

Administration: 020 7599 7777
Freephone Helpline: 0800 090 2309
Website: www.mariecurie.org.uk

Marie Curie Cancer Care provides high quality nursing, totally free, to give terminally ill people the choice of dying at home supported by their families.

Other organisations

British Humanist Association
39 Moreland Street
London EC1V 8BB

Telephone: 020 70324 3060
Fax: 020 703243061
Website: www.humanism.org.uk

The British Humanist Association (BHA) is the national charity working on behalf of non-religious people who seek to live ethical and fulfilling lives on the basis of reason and humanity. They have trained and accredited celebrants who conduct funerals and other non-religious ceremonies.
Compassion in Dying
181 Oxford Street
London W1D 2JT
Telephone: 0800 999 2434
Website: www.compassionindying.org.uk
Email: info@compassionindying.org.uk

Gov.uk
Provides information on a range of public services including benefits.
Website: www.gov.uk

Hospice UK
Enquiry line: 020 7520 8200
Email: info@hospiceuk.org
Website: www.hospiceuk.org
Provides information on hospices and palliative care services in the UK and abroad.
The Law Society

The Law Society’s Hall
113 Chancery Lane
London WC2A 1PL

General enquiries line: 020 7242 1222

Website: www.lawsociety.org.uk

Represents solicitors in England and Wales. They do not provide legal support for the public, but their members will be able to. Their website includes the facility to search for solicitors by postcode.

Office of the Public Guardian

PO Box 16185
Birmingham B2 2WH

Helpline: 0300 456 0300

Website: www.justice.gov.uk/about/opg

Email: customerservices@publicguardian.qsi.gov.uk

A government agency which can give information about Lasting Power of Attorney.
Office of the Public Guardian (Scotland)

Hadrian House
Callender Business Park
Callender Road
Falkirk FK1 1XR

Helpline: 01324 678300
Website: www.publicguardian-scotland.gov.uk
Email: opg@scotcourts.gov.uk

A government agency which can give information about Lasting Power of Attorney.

National Association of Funeral Directors

618 Warwick Road
Solihull B91 1AA

Telephone: 0121 711 1343
Website: www.nafd.org.uk
Email: info@nafd.org.uk

National Society of Allied and Independent Funeral Directors

SAIF Business Centre
3 Bullfields
Sawbridgeworth
Herts CM21 9DB

Telephone: 0345 230 6777
Website: www.saif.org.uk
Email: info@saif.org.uk
Natural Death Centre

In The Hill House
Watley Lane
Twyford
Winchester SO21 1QX

Website: www.naturaldeath.org.uk

Telephone: 01962 712690

A charity that gives free, impartial advice on all aspects of dying, bereavement and consumer rights. They give support on family-organised and environmentally friendly funerals, and run the Association of Natural Burial Grounds.

Scottish Legal Aid Board

The Scottish Legal Aid Board
Thistle House
91 Haymarket Terrace
Edinburgh EH12 5HE

Legal information helpline: 0845 122 8686

Website: www.slab.org.uk

Email: general@slab.org.uk

The non-departmental public body that manages legal aid in Scotland. Their legal aid information line can give Scottish residents information about legal aid and whether they qualify, as well as advice on where to find a legal aid solicitor or order their leaflets.
**Society of Trust and Estate Practitioners**

Artillery House (South)
11–19 Artillery Row
London
SW1P 1RT

Telephone: 020 3752 3700

Email: step@step.org

Website: www.step.org

Professional body for practitioners in the fields of trusts, estates and related issues.

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**Children’s organisations**

**Child Bereavement UK**

Clare Charity Centre
Wycombe Road
Saunderton
Buckinghamshire HP14 4BF

Telephone: 01494 568900

Support and information line: 0800 02 888 40

Email: enquiries@childbereavement.org

Website: www.childbereavement.org.uk

Produces resources and information for bereaved children and families.
Winston’s Wish

3rd Floor
Cheltenham House
Clarence Street
Cheltenham
Gloucestershire GL50 3JR

Telephone: 01242 515 157
Family line: 0845 203 0405
Email: info@winstonswish.org.uk
Website: www.winstonswish.org.uk

An organisation providing guidance and information for bereaved children and young people and their families.
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.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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

Donate online
You can give using a debit or credit card at www.breastcancercare.org.uk/donate

My details
Name __________________________________________________________
Address _______________________________________________________
______________________________________________________________
______________________________________________________________
Email address __________________________________________________

We might occasionally want to send you more information about our services and activities

☐ Please tick if you’re happy to receive email from us
☐ Please tick if you don’t want to receive post from us

We won’t pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG, 5–13 Great Suffolk Street, London SE1 0NS
About this booklet

This booklet 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 www.breastcancercare.org.uk/publications

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

Phone 0345 092 0808
Email publications@breastcancercare.org.uk
Breast Cancer Care is the only UK-wide charity providing specialist support and tailored information for anyone affected by breast cancer.

Our clinical expertise and emotional support network help thousands of people find a way to live with, through and beyond breast cancer.

Visit [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) or call us free on 0808 800 6000 (Text Relay 18001).

**Central Office**
Breast Cancer Care
5–13 Great Suffolk Street
London SE1 0NS
Phone: 0345 092 0800
Email: info@breastcancercare.org.uk