

# Secondary breast cancer in the brain



This booklet describes what secondary breast cancer in the brain is, what the symptoms are and the treatments used.





## **This information is by Breast Cancer Care.**

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

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

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

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **[breastcancercare.org.uk](https://breastcancercare.org.uk)**



Secondary breast cancer in the brain happens when cancer that started in the breast has spread to the brain.

We hope this booklet answers some of your questions about your condition and helps you discuss your options with your specialist team.

We suggest you read this booklet with our **Secondary breast cancer resource pack**, which contains information that may be useful from the time you're diagnosed and throughout your treatment and care. It also covers the physical and emotional impact of living with secondary breast cancer and the support available.

## What is secondary breast cancer in the brain?

Secondary breast cancer occurs when breast cancer cells spread from the primary (first) cancer in the breast to other parts of the body, such as the brain. This may happen through the lymphatic or blood system. Sometimes it can happen a number of years after a primary breast cancer diagnosis.

Secondary breast cancer in the brain is not the same as having cancer that starts in the brain. The cells that have spread to the brain are breast cancer cells.

When breast cancer spreads to the brain, it can be treated but cannot be cured. Treatment aims 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.

You may hear this type of spread described as metastatic breast cancer, metastases, advanced breast cancer, secondary tumours, secondaries or stage 4 breast cancer.

## Outlook

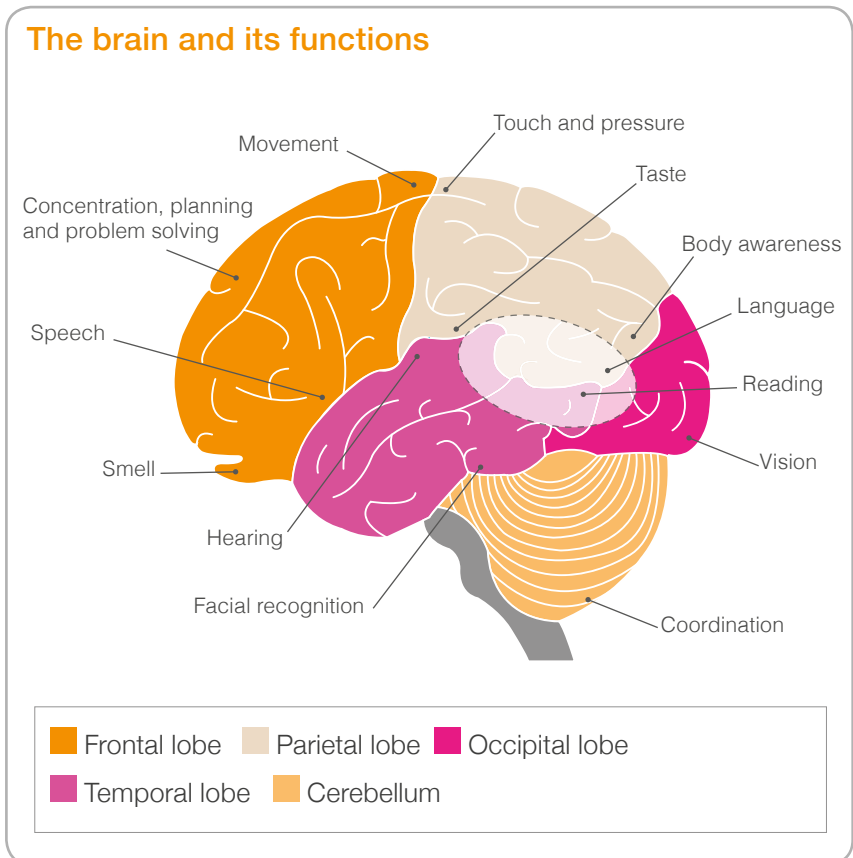
Following a diagnosis of secondary breast cancer in the brain, many people want to know how long they've got to live. As treatments improve, more and more people are living longer after a diagnosis of secondary breast cancer. However, life expectancy is difficult to predict as each person's case is different and no two cancers are the same.

Your specialist can talk to you about the likely progression of your secondary breast cancer. You may worry if their answers are vague, but

it's difficult to accurately predict how each person's illness will respond to treatment.

## The brain

The brain is the control centre for the body's functions such as speech, movement and thinking. It controls all our thought processes, feelings and emotions, and how we behave. It also controls vision, coordination and balance, how we understand our surroundings, how we learn, and our memory.



## Symptoms

There are a number of symptoms of secondary breast cancer in the brain. As different parts of the brain are responsible for different functions in the body (for example speech or movement), your symptoms will depend on which area of the brain is affected. Symptoms can range from mild to severe, depending on how much of the brain is affected by the cancer. It's important to report any new or ongoing symptoms to your specialist.

Symptoms include:

- headache
- nausea (feeling sick) and vomiting (being sick)
- weakness or feeling numb down one side of the body
- unsteadiness or loss of balance
- seizures (fits)
- difficulty with speech
- problems with vision
- changes in behaviour
- confusion
- memory problems

Symptoms will vary from person to person. These symptoms are explained in more detail on page 15.

## What tests might I need?

Your specialist will examine you and discuss any symptoms you have. You may need one or more of the following tests to help confirm a diagnosis of secondary breast cancer in the brain.

### Neurological examination

A neurological examination is a series of simple tests that provide information about the nervous system. Your specialist may look in your eyes with an instrument called an ophthalmoscope to see if there is swelling at the back of the eyes caused by pressure from the brain. They may check your arms and legs for changes in feeling and strength, and changes in your reflexes. They may look at your balance and how you are walking.

### CT (computerised tomography) scan

You may have a CT scan. This uses x-rays to take detailed pictures across the body. It's also known as a CAT scan.

### MRI (magnetic resonance imaging) scan

This scan uses magnetism and radio waves to produce a series of images of the inside of the body. There is no radiation dose from an MRI scan. It provides a different type of picture of the brain than a CT scan, so your doctor may want you to have both types of brain scan. Some people find being in an MRI scanner claustrophobic – if you are worried you can discuss this with your GP or the radiographers who operate the scanner.

### Brain biopsy

In most cases your specialist will be able to tell if you have secondary breast cancer in the brain from your symptoms and scans, but occasionally it's necessary to have a biopsy. This involves removing a small piece of tissue from the brain, under general anaesthetic, to be examined under a microscope.

### Tumour marker tests

Some people have a blood test for tumour markers. These are proteins found in the blood which may provide more information about how you're responding to treatment or if the cancer is progressing. There is some debate about the accuracy of measuring tumour markers so they are not used by all specialists.

## Leptomeningeal metastases

Leptomeningeal metastases (also known as carcinomatous meningitis) develop when secondary breast cancer spreads to the membranes (tissues) surrounding the brain and spinal cord. The leptomeninges are the two innermost layers.

Symptoms of leptomeningeal metastases are similar to those of secondary breast cancer in the brain, but may be less obvious and more difficult to diagnose. It's usually diagnosed following an MRI scan, but you may also have a lumbar puncture (a needle inserted into the spine) to obtain a sample of fluid for examination under a microscope. This fluid is cerebrospinal fluid (CSF), a clear fluid that surrounds and supports the brain and spinal cord.

Treatment usually includes steroids, radiotherapy and/or chemotherapy. Chemotherapy may be given using a technique called intrathecal chemotherapy. This treatment delivers drugs directly into the fluid surrounding the brain and spinal cord to treat the cancer.

As with secondary breast cancer that occurs in other parts of the brain, supportive and palliative care (controlling symptoms when cancer can't be cured) is an extremely important part of treatment and can significantly improve quality of life for patients and their families.



## What treatment might I be offered?

Your treatment may include:

- steroids
- radiotherapy
- stereotactic radiosurgery (SRS)
- surgery
- hormone (endocrine) therapy
- targeted (biological) therapy
- chemotherapy

These treatments can be given alone or in combination.

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

- how many tumours you have
- which parts of the brain are affected
- whether the cancer has spread elsewhere in the body
- any symptoms you have
- what treatment you've had in the past
- the features of the cancer
- whether you've been through the menopause
- your general health

Your specialist should discuss any recommendations for treatment with you and take into account your wishes. They will talk with you about your options, explain what the aim of treatment will be and help you weigh up the potential benefits against the possible side effects you may have.

Sometimes, when breast cancer has spread to the brain, oncologists ask the advice of the neuro-oncology multidisciplinary team. This is a team of doctors, including neurosurgeons, neuro-oncologists, clinical nurse specialists and radiographers, who specialise in treating brain tumours with treatments including neurosurgery (an operation) or stereotactic radiosurgery (SRS – a special type of highly targeted radiotherapy). Your care would continue under your usual breast oncologist, but with involvement or advice from the other team.

## Steroids

Steroids are made naturally in the body, but can also be produced artificially for use as medicines. Steroid drugs such as dexamethasone are used to reduce swelling and pressure around the secondary breast cancer in the brain, and can relieve symptoms such as headache and nausea. They are sometimes prescribed before you have any investigations because they can begin to relieve your symptoms quickly.

The steroids are given as tablets, in high doses at first. Your dose may be increased or decreased at different times, depending on your symptoms and any treatment you have had.

It is very important not to stop taking steroids suddenly, so make sure you don't run out.

Some of the more common side effects of steroids in high doses are:

- indigestion (when taken on an empty stomach)
- thrush (candidiasis) in the mouth
- increased appetite
- sleeplessness (when taken later in the day)
- mood swings
- weight gain
- muscle weakness

Taking steroids with food will help avoid side effects such as indigestion, and you will usually be given a tablet to protect your stomach lining. Not taking steroids after 6pm can help prevent sleeplessness.

If you are concerned about any of these side effects, it may be helpful to discuss this with your specialist hospital team or palliative and supportive care team.

In the UK, if you take steroids for more than three weeks you will be given a blue 'steroid card'. As there can be a number of side effects with steroids and you shouldn't stop taking them suddenly, always keep hold of the card and show it to any doctor or nurse treating you.

## Radiotherapy

This is the most commonly used treatment for secondary breast cancer in the brain. It involves the use of high energy x-rays to destroy cancer cells. It may be given as whole brain radiotherapy or stereotactic radiosurgery.

## Whole brain radiotherapy

Radiotherapy may be given to the whole brain if there are a number of areas of secondary breast cancer in different areas of the brain, or if there is disease involving the meninges (the covering of the brain). See 'Leptomeningeal metastases' on page 8 for more information.

Whole brain radiotherapy may also be given following surgery or stereotactic radiosurgery (see below). It's usually given in daily doses over one to ten days, but this can vary.

Fatigue (extreme tiredness) is a common side effect of radiotherapy and it can be particularly noticeable when radiotherapy is given to the brain. For more information about fatigue, see page 16.

Hair loss is another common side effect of radiotherapy. Hair usually starts to grow back three to four months after treatment has finished, although it may not grow back completely and can grow back unevenly. For more information see our **Breast cancer and hair loss** booklet.

Whole brain radiotherapy can cause changes to the brain tissue. After treatment you may experience symptoms such as problems thinking clearly, difficulty managing tasks you previously found easy, and poor memory or confusion. For most people these symptoms settle over time. An occupational therapist can help you to manage everyday tasks – you can ask your GP if you'd like to be referred.

## Stereotactic radiosurgery (also known as stereotactic radiotherapy)

Stereotactic radiosurgery (SRS) is a very precise radiation treatment that may be considered for people with a single or limited number of small secondary cancers in the brain. It may also be given in combination with surgery or whole brain radiotherapy.

This treatment allows high doses of radiation to be delivered with extreme accuracy to targeted areas, avoiding the surrounding healthy brain tissue. Because of this, stereotactic radiotherapy treatment has fewer side effects than whole brain radiotherapy. Treatment can be given in a single or small number of visits.

Stereotactic radiosurgery may be delivered using a number of different types of treatment machines, including a Gamma Knife, CyberKnife, or a modified linear accelerator. Stereotactic radiosurgery is a specialist treatment that is not available in all hospitals – you may need to travel to a different centre.

Your specialist team will tell you if it might be suitable for you.

## Surgery

Although surgery will not cure secondary breast cancer in the brain, occasionally an oncologist may ask the opinion of a neurosurgeon (a specialist brain surgeon who treats diseases and conditions affecting the nervous system). Surgery is more likely if there is a single or very few areas of secondary breast cancer in the brain that can be safely accessed by the surgeon.

If surgery is an option, your specialist will discuss the potential improvement to your quality of life alongside assessing your general health, fitness and the extent to which secondary breast cancer is affecting your whole body.

Surgery for secondary breast cancer in the brain is a very specialised treatment and is often followed by a course of radiotherapy. Your specialist team will tell you if it might be suitable for you.

Surgery may also be used to relieve pressure on the brain.

## Blood brain barrier

The blood brain barrier is a natural filter within the body that protects the brain from harmful chemicals. It only allows certain substances through from the blood to the brain tissues. Because of the blood brain barrier some drugs (for example, chemotherapy) may not be as effective in treating secondary breast cancer in the brain as they are in other parts of the body. Your specialist team will be able to discuss this with you.

## Hormone (endocrine) therapy

Hormone therapy is used to treat breast cancers that are stimulated to grow by the hormone oestrogen. These cancers have receptors within the cell that bind to the hormone oestrogen, and are known as oestrogen receptor positive or ER+ breast cancers.

The tissue from the biopsy or surgery for your primary (early) breast cancer will have been tested to see if it is ER+. If you have had a biopsy of your secondary breast cancer in the brain then this will be tested to find out if it is ER+.

If you'd like more information about these treatments, we have booklets about individual hormone therapies.

## Targeted (biological) therapies

This is a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow. For information on targeted therapies see our website [breastcancercare.org.uk](http://breastcancercare.org.uk)

The most widely used targeted therapy is trastuzumab (Herceptin). Only people whose cancer has high levels of HER2 (called HER2 positive) will benefit from having trastuzumab. HER2 is a protein that makes cancer cells grow. The tissue from the biopsy or surgery for your primary (early) breast cancer will have been tested to see if it is HER2 positive. If you have had a biopsy of your secondary breast cancer in the brain then this will be tested to find out if it is HER2 positive.

For more information, you can read our [Trastuzumab \(Herceptin\)](#) booklet.

## Chemotherapy

Chemotherapy is treatment aimed at destroying cancer cells using anti-cancer drugs (also called cytotoxic drugs), and is sometimes used to treat secondary breast cancer in the brain. If chemotherapy is an option, your specialist team will discuss this with you.

For more general information about this type of treatment, see our [Chemotherapy for breast cancer](#) booklet or our booklets on individual chemotherapy drugs.

## Availability of treatments

Some treatments for secondary breast cancer may not be routinely available. You may still be able to access these treatments in other ways.

Macmillan Cancer Support has information about what you can do if a treatment isn't available. You can find it on their website [macmillan.org.uk](http://macmillan.org.uk) or by calling 0808 808 00 00.

It can be frustrating and distressing if a treatment you and your cancer specialist feel could benefit you isn't routinely available. For help and advice about accessing a treatment, you can speak to your specialist team. You can also call our Helpline on **0808 800 6000** to talk through your concerns.

## Clinical trials

Many breast cancer trials look at new treatments or different ways of giving existing treatments, such as surgical techniques, chemotherapy, targeted therapies or radiotherapy. Your specialist may talk with you about a clinical trial, or if you're interested in taking part in clinical research you can ask them if you're eligible for a clinical trial.

For more general information on clinical trials see our website or [cancerresearch.org.uk](http://cancerresearch.org.uk) for listings of current clinical trials.

## Palliative and supportive care

Palliative and supportive care focuses on symptom control and support. 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 patients and their families.

Palliative care is usually associated with end-of-life treatment. However, people value having it at any stage of their illness, alongside their medical treatment, to help prevent and relieve symptoms such as pain or fatigue. It can also help with the emotional, social and spiritual effects of secondary breast cancer.

You can be referred by your specialist team, GP or breast care nurse depending on your situation.

## Managing symptoms of secondary breast cancer in the brain

### Seizures (fits)

A seizure is a short-term period of abnormal activity in the brain. Usually the person will lose consciousness and their muscles will twitch. It can happen without warning and can be very frightening to watch. Seizures may also happen without much movement – instead, the person may stare into space or be unable to talk. Sometimes only the hand or leg will jerk – this is called a partial seizure.

Most seizures pass quickly and are not necessarily a medical emergency. However, there are different causes of fits so tell your GP or specialist team if you start having them. They can usually be managed with medication.

### Nausea and vomiting

If you experience nausea (feeling sick) or vomiting (being sick), it may be due to your secondary breast cancer in the brain or elsewhere in the body, its treatment or emotional side effects such as anxiety.

It's important for your doctor to try to find out 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. In most cases, nausea and vomiting can be controlled and treated with anti-sickness drugs, steroids or benzodiazepines (drugs that work on the brain and nerves to produce a calming effect).

### Pain

Pain relief is a very important part of the care of anyone with secondary breast cancer. Once pain is under control, many people feel less anxious and can eat and sleep better.

Some people may experience headaches that can occur due to the build-up of pressure within the brain caused by the area(s) of secondary breast cancer. These might be different to headaches you've had before (they may get worse, continue for days or not go away completely). However, most pain can be relieved or controlled with steroids and pain relief. You can also be referred to a healthcare professional who specialises in pain management.

There are many different types of pain relief and often a combination of drugs will be needed. It's very important that your pain is assessed regularly by your nurse or doctor to make sure it stays under control. It's useful to know who to contact if your pain changes or gets worse. 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 long-term pain that gets worse or doesn't improve with treatment.

You can read more about managing and monitoring pain caused by secondary breast cancer in our **Secondary breast cancer resource pack**, or visit our website [breastcancercare.org.uk](http://breastcancercare.org.uk)

## Fatigue (extreme tiredness)

Cancer-related fatigue 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 can feel much more severe. It can come and go or be continuous, and this can be distressing and frustrating. It has many causes, from psychological ones such as the stress of coping with the diagnosis, to physical ones such as the side effects of treatment, particularly radiotherapy to the brain, or progression of the cancer.

Fatigue may have a significant effect 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 want 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 and may improve the feelings of fatigue.

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 doctor and when planning for day-to-day life. Your hospital may provide you with a fatigue diary or you can find one in our **Secondary breast cancer resource pack**. You can also download copies from our website [breastcancercare.org.uk/patient-resources](http://breastcancercare.org.uk/patient-resources)



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

- plan your days so you have a balance of activity and rest
- try to do small amounts of physical activity each day; even just a short walk can help
- accept that you may have good days and bad days
- prepare for a special occasion or days out by planning some additional rest before and after
- try to eat well. 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 dietitian for advice
- accept offers of practical help from other people to save your energy for things you enjoy

Macmillan Cancer Support has a booklet called *Coping with fatigue*. Order it free from Macmillan's website [macmillan.org.uk](http://macmillan.org.uk) or call 0808 808 00 00.

## Blood clots

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

You may be at risk of a blood clot forming known as a deep vein thrombosis (DVT). People with a DVT are at risk of developing a pulmonary embolism. This is when part of the blood clot breaks away and travels to the lung.

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

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

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

## Physical activity

Although there has 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 have been positive and there is no reason to believe that people with secondary breast cancer would not have similar benefits from exercising. However, 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 and between treatments may tolerate treatments better and have less pain, sickness, problems sleeping and fatigue.

### What is regular exercise?

Regular exercise can help many people 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 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 without joining a gym or going to exercise classes.

'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.

## Exercise and secondary breast cancer in the brain

Depending on where exactly the secondary cancer is in your brain, your symptoms may include headaches, sickness, 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.

For information on exercise and secondary breast cancer see our [Secondary breast cancer resource pack](#).

## Driving

If you drive, you are required by law to tell the Driver and Vehicle Licensing Agency (DVLA, or DVA in Northern Ireland) that you have secondary cancer in the brain. If you have been diagnosed with secondary breast cancer in the brain you will not be allowed to drive again until you have their approval. Once you have given up your licence, DVLA medical advisers will decide if a licence can be issued back to you and how long after your diagnosis this will be.

You can call the DVLA on 0300 790 6806 or use their email service via the website [gov.uk/contact-the-dvla](https://www.gov.uk/contact-the-dvla)

If you have secondary breast cancer you can apply for a Blue Badge. This will allow you to park closer to your destination, whether you are the driver or the passenger. You can apply at [gov.uk/apply-blue-badge](https://www.gov.uk/apply-blue-badge)

## Living with secondary breast cancer in the brain

Knowing that your cancer has spread to your brain can cause a range of emotions. There may be times when you feel very isolated or overcome by fear, anxiety, sadness, uncertainty, depression or anger.

Sometimes symptoms may not improve. This can be frustrating and make you feel low in mood, and you may need help from the people closest to you. Some people want support from professionals – you can talk to your breast care nurse, palliative care nurse (who may be a Macmillan nurse), hospice or home care specialist nurse. They will have a good understanding of the specific needs of people with secondary cancers and will be familiar with different ways of coping and adapting to the diagnosis. They also have specialist knowledge in helping with pain and symptom control and can arrange for you to talk to a counsellor or psychotherapist.

If you're not in regular contact with a palliative care nurse or Macmillan nurse, you can ask for a referral to be made through your hospital team or GP. You could also contact the Breast Cancer Care Helpline on 0808 800 6000 to talk through your concerns and find out what support is available in your area.

### Finding support

Breast Cancer Care's Living with Secondary Breast Cancer meet-ups take place monthly in locations throughout the UK.

Whether you have questions about pain management, treatments and side effects, or just want to talk openly to others who have had a secondary diagnosis, these sessions can provide you with helpful information and support in a relaxed environment.

For more information about Living with Secondary Breast Cancer, visit [breastcancercare.org.uk](https://breastcancercare.org.uk) or call **0345 077 1893**.

You can also chat to other people living with secondary breast cancer on our online discussion Forum [forum.breastcancercare.org.uk](https://forum.breastcancercare.org.uk)



## 4 ways to get support

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



Speak to trained experts, nurses or someone who's had breast cancer and been in your shoes. Call free on **0808 800 6000** (Monday to Friday 9am–5pm, Wednesdays till 7pm and Saturday 9am–1pm).



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



Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at **[breastcancercare.org.uk](https://breastcancercare.org.uk)**



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

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

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

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.

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

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

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



# About this booklet

**Secondary breast cancer in the brain** 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:

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

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **[breastcancercare.org.uk](https://breastcancercare.org.uk)**

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