

DIAGNOSED WITH BREAST CANCER: WHAT NOW?

BREAST
CANCER
NOW The research &
support charity

We're here

2 Call our helpline on **0808 800 6000**

About this booklet

If you've been diagnosed with primary breast cancer, it's normal to worry about what happens next.

This booklet explains how to get the information you need about your breast cancer and how to find support. You'll also find tips on how to cope emotionally in the coming weeks and months.

It also covers treatment for primary breast cancer. You may find it useful to read our **Treating primary breast cancer** booklet, which has more information about the different types of treatments for breast cancer.

You don't have to read this booklet from cover to cover if you don't want to. You can pick out the sections that are helpful to you now and come back to the other sections when you feel ready.

If you'd like to talk to someone about how you're feeling or have questions about any of the information in this booklet, we're here. Call our free helpline on **0808 800 6000** or email Ask Our Nurses through our website **breastcancernow.org**

Diagnosis and the early days

There's no right or wrong way to feel after you've been diagnosed with breast cancer.

It can be hard to concentrate or carry out normal everyday activities. Some people have physical symptoms such as loss of appetite, diarrhoea or difficulty sleeping.

The days and weeks immediately after a diagnosis can be particularly emotional and may feel overwhelming. Your feelings may change day to day or even hour to hour. It's usual to have times when you feel very low, followed by times when things seem more positive.

If you're feeling overwhelmed, it can help to talk to your GP. They can offer support and medication that can help in the short term.

If you're finding it hard to cope

Many people find it easier to talk to someone other than family or friends.

Our helpline offers the chance to talk openly in a safe and confidential space. Our helpline nurses are used to talking to people who are finding it hard to cope after a breast cancer diagnosis. They can also talk to you about your treatment and what to expect, as well as relevant services or information.

Call our helpline free on **0808 800 6000**.

If you prefer to ask a question in writing, you can email our nurses. Visit breastcancernow.org/contactnurses to find out more.

You can also post your question in the Ask Our Nurses section of our forum forum.breastcancernow.org

Dealing with stress and anxiety

It's common to feel stressed and anxious after a diagnosis of breast cancer.

This may be your first experience of anxiety, or you may have had anxiety in the past. Your diagnosis, or waiting for more tests or results, could make this worse.

Some people find they're more anxious at quieter times, such as during the night or when they're alone.

It can be tempting to turn to any usual coping methods, such as alcohol, when you're feeling stressed or anxious. However, this can often make you feel worse.

There are many ways to reduce stress and anxiety, including:

- Distraction – focusing on things around you, or a hobby or interest, to shut out negative thoughts
- Relaxation, visualisation, mindfulness and meditation – you can use these separately or together to reduce stress and tension
- Exercise – regular physical activity, whether it's a brisk walk or yoga, can help clear your mind and reduce your stress levels
- One-to-one counselling – explore feelings which can be related to your cancer diagnosis, making them easier to understand and cope with
- Cognitive behavioural therapy (CBT) – can help you to change patterns of thinking and behaviour that may be stopping you from moving forward

If you think you might benefit from these techniques, your breast care nurse or GP may be able to advise you on how to access them.

You can find information about mindfulness, relaxation and exercise on our website **breastcancernow.org**

You can find out more about reducing stress and anxiety on the NHS website (NHS.UK) or Anxiety UK (anxiety.uk.org.uk)

Telling people about your breast cancer diagnosis

Telling family and friends

Telling your family and friends you have breast cancer can be very difficult.

Who you tell and how you tell them is a personal decision.

You may only want to tell a few people or ask others to help you pass the information on.

It can be helpful to start with the basic facts about your diagnosis and treatment options, and let the conversation progress naturally from there.

If you have social media, such as Facebook, or WhatsApp you could let people know in a private group. This means you won't have to repeat yourself to different people. Make sure you're clear about who they can tell if you don't want everyone to know.

You may worry about how your friends and family will react. Some people may be upset and worried, some might feel uncomfortable, and others may struggle to take it in.

It may feel like people avoid talking to you about your cancer, but they might just be worried about upsetting you if they mention it.

It can be helpful to discuss your feelings with those close to you and let them know how they can help you.

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Telling children

If you have children, telling them you have breast cancer can feel very daunting.

Evidence suggests that children are less frightened if they know what's happening, even if they don't fully understand.

Children are very good at sensing when something is wrong and can usually tell when you're upset or worried. They can often tell if something seems different and may start worrying and guessing what it might be. So it's best to tell them sooner rather than later.

Your children's understanding and reaction is likely to depend on their age and personality. The best approach is to keep things simple and avoid complicated explanations.

You can find more information about talking to children in our **Talking with children about primary breast cancer** booklet or on our website breastcancernow.org

Talking to your employer

You don't have to tell your employer about your diagnosis and treatment if you don't want to. But your employer does have a duty to make reasonable adjustments to your role or working environment to help you do your job. If you don't tell them about your diagnosis and treatment, it may be difficult for them to know what adjustments to make.

You cannot lose your job or be treated less favourably for having breast cancer.

You have the right for any information you do provide to be kept private and only discussed with other people with your permission.

Some people find it helpful to tell their team. Others prefer to tell close colleagues, and some prefer not to tell anyone. How much information you give about your breast cancer to people at work is a personal decision.

Work and breast cancer

Some people continue to work, sometimes with reduced hours, and others give up work temporarily or permanently. Everyone is different and what works for some people may not work for you.

If you're self-employed you may worry your diagnosis and treatment will affect your business. You may not be entitled to the same support that an employed person has. However, you may have more flexibility to decide your work hours and taking time off for hospital appointments.

For some people, work can provide normality, while others decide to concentrate on treatment and recovery. Speak to your treatment team about how your diagnosis and treatment may affect your daily life.

You may find the organisations below helpful if you want more information about working when you've been diagnosed with breast cancer:

- Macmillan Cancer Support (macmillan.org.uk)
- Working with Cancer (workingwithcancer.co.uk)

Getting the information you need

It can be difficult to take in everything you're told when you first hear you have cancer.

You may only remember a small amount of what's said to you at first. You may need time and help to get the facts straight, understand what they mean and to ask questions that are important to you.

At your appointments

If you're worried about forgetting information you're told in your clinic appointment, or just want to make sure all your questions are answered, you can:

- Ask for a copy of your clinic letter
- Take someone with you to appointments who can listen and help you remember what was said
- Make a list of questions and take it with you to your appointment
- Take notes during your appointment
- Ask your doctor if you can record the conversation, so you can listen back later
- Check who to call if you have questions after your appointment (for example, your breast care nurse)

The people who have the most information about your cancer are those in the treatment team looking after you.

If you're unclear about something you're told, ask to have it explained again. You can ask whoever you feel most comfortable with. This may be your breast care nurse or someone else in your treatment team. If they don't know the answer, they should be able to find it out for you.

Your breast care nurse

Most people will meet a breast care nurse during the early days of diagnosis and treatment. They are there to offer support and information to you and your family.

It's useful to have the contact details of your breast care nurse so you know how to get in touch with them.

Often, they will be able to spend some time with you, helping you understand your options and supporting you.

Once treatment has finished, you can usually continue to contact your breast care nurse if you have any worries or concerns, or need ongoing support, even if this is many years after you've been diagnosed. For some people this may mean asking their GP to refer them back to their treatment team.

Any information you receive should be accurate and relevant to you and the features of your cancer. For example, a treatment that's right for one person with breast cancer may not be right for another.

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Finding information you can trust

Everyone's different when it comes to the amount of information they want.

Knowing about the possible treatments can help you decide what to do next if you're offered a choice. However, some people find this overwhelming. You may prefer your treatment team to decide the best approach to your treatment and what information you need.

Many people use the internet to look for information. You may want to do this alone or with a partner, friend, or family member.

Be aware that some sites can be unreliable, so our website **breastcancernow.org** is a good place to start. You can send written questions to our nurses through the Ask Our Nurses section of the website.

It can also be helpful to focus on trustworthy websites that reflect UK practice, such as NHS.uk, Macmillan Cancer Support, Cancer Research UK and other recognised UK charities.

If you don't have access to the internet, or prefer not to use it, we have a range of printed publications. Our helpline is also on hand if you would like further information or to talk to someone. You can call for free on **0808 800 6000**.

Many hospitals also have a cancer information centre that can provide a wide range of information, support and details of other local support services.

Having treatment

Your treatment team will discuss your treatment options with you and prepare a treatment plan.

Your pathology results

A doctor called a pathologist will look at the tissue removed during a biopsy or surgery under a microscope. Other tests will also be done on the tissue to get more information.

The results give details about the breast cancer that helps determine the treatment you're offered.

For more information to help you understand your results, you can read our booklet **Understanding your pathology results**.

Types of breast cancer treatment

Most people are recommended a combination of treatments. These may include:

- Surgery
- Chemotherapy
- Radiotherapy
- Hormone (endocrine) therapy
- Immunotherapy
- Targeted therapy
- Bisphosphonates

You can find out more about the different treatment options in our booklet **Treating primary breast cancer**.

There's more detailed information in our booklets on chemotherapy, radiotherapy and individual hormone therapy, targeted therapy and bisphosphonate drugs.

You can also find information on all these treatments on our website.

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Making decisions about treatment

You can take some time to think or talk things over before you make any decisions about your treatment.

A few days spent making sure you have all the information you need about your treatment won't make any difference to the outcome. It may help you feel more in control of what's happening.

It can help to talk through decisions with someone else. Some people prefer to talk to a partner, family member or close friend. Others may feel more comfortable talking with someone in their treatment team such as their breast care nurse. You can also call our free helpline on **0808 800 6000** to speak to one of our nurses.

Questions to ask your treatment team

Questions you might want to ask your treatment team include:

- Why is this the best treatment for me?
- How does my treatment work?
- When will my treatment start?
- How long will I have treatment for?
- What are the possible side effects?
- Who can advise me about managing side effects?
- Are there any long-term side effects?
- How will the treatment affect my everyday life?
- Where will I need to go for treatment and how long will I be there?
- Will I need to take time off from work?

Clinical trials

You may be asked if you want to take part in a clinical trial.

Clinical trials are research studies involving people. They are voluntary and aim to improve diagnosis, treatment, side effects and quality of life.

Clinical trials might involve:

- Looking at ways to reduce the likelihood of getting breast cancer
- Improving ways of diagnosing breast cancer (such as breast screening)
- Testing new cancer drugs to find out more about them and any side effects
- Testing new treatments to see if they work better than current treatments
- Testing current treatments in different ways to reduce side effects
- Finding new ways to combine treatments to see if they work better
- Looking at the effect a treatment has on everyday life (quality of life)
- Looking at whether additional psychological support makes a difference

Whether you're asked to take part in a clinical trial will depend on the features of your cancer and the criteria of the trial.

You can find out more information about clinical trials on our website **breastcancernow.org** or on the Cancer Research UK website.

Side effects of treatment

Many breast cancer treatments have side effects.

If you're having surgery, getting information about your operation and what to expect afterwards can help prepare you. Our booklet **Your operation and recovery** may help.

Extreme tiredness (cancer-related fatigue) is a very common side effect of breast cancer treatment and may continue after your treatment has finished. You can find more information on coping with fatigue on our website **breastcancernow.org**

Treatments such as chemotherapy and hormone therapy can cause menopausal symptoms like hot flushes. You may find our booklet **Menopausal symptoms and breast cancer** useful.

You can find out more information about side effects of specific treatments on our website.

While side effects can get better with time, they can still be upsetting. If you're worried about any side effects, talk to a member of your treatment team. They may be able to advise you on how to manage side effects.

Getting the support you need

Practical support

Many people want to carry on doing as much as possible during their treatment. However, side effects of treatment can often make it more difficult to continue with everyday tasks.

Friends and family are often keen to help with practical tasks such as:

- Shopping
- Cooking
- Childcare
- Dog walking
- Driving
- Gardening

If you live alone, or don't have close family or friends nearby, you may not have as much support as you would like.

Often, people you don't know that well are willing to help in times of need. They may be neighbours, colleagues, friends of friends, or members of your church or any other social group. You may find it difficult to ask, but people are often keen to help if they know how.

Ask your breast care nurse or local cancer information centre if there are any local organisations that provide practical support.

Financial support

Money concerns, whether permanent or temporary, can be particularly stressful at a time when you feel less able to cope.

Many people with breast cancer don't claim benefits because they don't know what they're entitled to, are too embarrassed to ask for help, or find the system complicated.

You can find more information about financial support and benefits when you have breast cancer on our website breastcancernow.org

Emotional support

Sometimes it can seem like no one really understands how you feel. But talking to other people in a similar situation may help.

Breast cancer support groups can provide a sense of community, an opportunity to share your experiences and learn different ways of coping.

To find out about a support group in your area, ask your breast care nurse or contact your local cancer information centre.

Support at Breast Cancer Now

Someone Like Me

Someone Like Me can match you to a trained volunteer who's had a similar experience to you.

They can talk to you by phone or email, listen to your concerns and provide support.

Forum

Through our online forum (forum.breastcancernow.org) you can exchange tips, ask questions, share experiences and talk through concerns.

Dedicated areas for popular topics make it easy for you to find what you're looking for.

The forum is simple to use and professionally hosted. There's always someone online, whether you're feeling anxious or just need to hear from someone who understands.

Younger Women Together

Younger Women Together gives tailored support if you've been diagnosed with primary breast cancer between the ages of 18 and 45. It also give you the chance to meet people your age who understand what you're going through. Younger Women Together events happen online and in person.

The future

For some people, the last hospital-based treatment is the goal they focus on, and getting there can feel like a real achievement. But some people also feel isolated, low or anxious when hospital-based treatment has finished and regular appointments stop.

Our booklet **After breast cancer treatment: what now?** explains what happens after hospital-based treatments end. It includes information on follow-up care, how you might feel after treatment ends and coping with worries about cancer coming back. It also has information about the signs and symptoms to be aware of after treatment.

Our **Moving Forward** booklet contains information and tips to help you adjust to life after treatment.

Our Moving Forward course gives you the tools you need to adjust to life beyond primary breast cancer. This course happens online and in person.

We're Breast Cancer Now, the research and support charity. However you're experiencing breast cancer, we're here.

Life-changing support

Whoever you are, and whatever your experience of breast cancer, our free services are here. Whether you're worried about breast cancer, dealing with a diagnosis, working out life with or beyond treatment – or someone you love is.

World-class research

We support over 290 of the brightest minds in breast cancer research. They're discovering how to prevent breast cancer, live well with the disease, and save lives. Every day, they get closer to the next breakthrough.

Change-making campaigns

We fight for the best possible treatment, services and care for everyone affected by breast cancer, alongside thousands of dedicated campaigners.

Could you help?

We don't get any government or NHS funding for our support services or health information. So, we rely on donations and gifts in wills to make our vital work happen. If you'd like to support us, go to breastcancernow.org/give

ABOUT THIS BOOKLET

Diagnosed with breast cancer: what now? was written by Breast Cancer Now'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:
Email health-info@breastcancernow.org



You can order or download more copies from
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We welcome your feedback on this publication:
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We make every effort to ensure that our health information is accurate and up to date, but it doesn't replace the information and support from professionals in your healthcare team. So far as is permitted by law, Breast Cancer Now doesn't accept liability in relation to the use of any information contained in this publication, or third-party information included or referred to in it.

We're here

Information you can trust, support you can count on

Whatever breast cancer brings, we're here for you.

Whether you're looking for information about breast cancer or want to speak to someone who understands, you can rely on us.

Call **0808 800 6000** to talk things through with our helpline nurses.

Visit **breastcancernow.org** for reliable breast cancer information.

Breast Cancer Now

6th Floor
The White Chapel Building
10 Whitechapel High Street
London E1 8QS



Patient Information Forum

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