



# BEYOND HOSPITAL-BASED TREATMENT FOR EARLY BREAST CANCER: WHAT'S NEXT?

This material is intended to a global audience for educational purposes only. It could contain information not applicable in your country. It does not replace the discussion with your healthcare professional: be sure to ask your healthcare professional about any question or concern you may have.

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# Introduction

This booklet is for people who have finished, or are coming to the end of, hospital-based treatment for early breast cancer.

This booklet gives you information about:

-  What early breast cancer is
-  The emotional impact of ending hospital-based treatment for early breast cancer
-  The impact of ending hospital-based early breast cancer treatment on your body
-  Relationships and everyday life
-  Further support

Please note that while breast cancer can also occur in men, this is rare and this booklet therefore features and refers more to women than men.

Although we have tried to cover everything that you might need to know about ending hospital-based treatment for early breast cancer, don't be afraid to ask your doctor for more information on anything in this booklet or any other questions you might have.

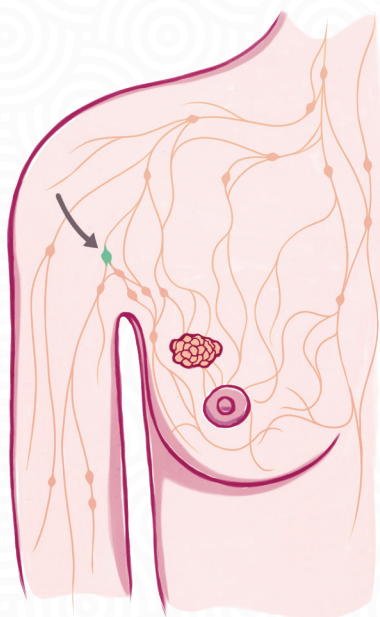


**Pierre Fabre**



# WHAT IS EARLY BREAST CANCER?

Early breast cancer, also known as localised breast cancer, is breast cancer that has not spread beyond the affected breast, including the nearest draining lymph node chains, where the cancer began.<sup>1</sup>



Not all early breast cancers are the same. When doctors look at different factors to diagnose specific types of breast cancer, they look at:<sup>2</sup>

- The size of the tumour
- How fast it is growing
- If the local lymph nodes are affected
- If hormones (oestrogen or progesterone) play a role in helping the tumour grow (hormone receptor-positive tumours)
- If the tumour expresses the HER2 protein

You can find more information about the different types of breast cancer in the 'My guide to early-stage breast cancer' booklet, or by talking to your doctor.

Some time ago, you and your doctor would have decided on your treatment for early breast cancer, based on the type of breast cancer you were diagnosed with. It might have included one or a combination of the following:<sup>2</sup>



**Surgery/  
plastic surgery**



**Chemotherapy**



**Radiotherapy**



**Hormonal  
therapy**



**Targeted  
therapy**



## What does 'ending hospital-based treatment for early breast cancer' mean?

Hospital-based treatment for early breast cancer is challenging, and coming to the end of your treatment is a huge achievement. You've probably been looking forward to this moment for a while and it's normal to experience a mix of emotions!



FOR MANY PEOPLE THE IMPACT OF A BREAST CANCER DIAGNOSIS ONLY REALLY STARTS TO SINK IN AFTER HOSPITAL-BASED TREATMENT HAS ENDED.

YOU MIGHT FEEL RELIEVED OR HAPPY THAT IT'S FINALLY OVER, FEEL WORRIED OR SAD ABOUT WHAT YOU HAVE BEEN THROUGH, OR HAVE FEARS ABOUT THE CANCER COMING BACK.



As you begin to have less contact with your healthcare team (see page 71) you may also find that you have lots of questions about your physical wellbeing and what happens next, such as:



At first, many people find that the way they feel, and the questions they have, change on a daily basis. This can be difficult to deal with, especially if you thought your life would quickly go back to normal after your treatment.



## What is 'the new normal' after hospital-based breast cancer treatment?

MOST PEOPLE FIND THAT THEY HAVE TO ADAPT TO A NEW WAY OF LIVING AFTER TREATMENT - YOU MIGHT HAVE HEARD THE TERM 'THE NEW NORMAL'.

Everyone's 'new normal' will look different and finding your own 'new normal' can take some time. Your 'new normal' might be very similar to the life you led before breast cancer, or you may decide to make some changes from now on. Your 'new normal' will probably depend on how you feel physically, and emotionally too.

This booklet will help you understand some of the emotional and physical changes you might experience after hospital-based treatment for early breast cancer, and how these can impact your everyday life and relationships. It will suggest some ideas for managing these changes and address possible concerns you may have, to support you as you move forward after treatment and gradually find your personal 'new normal'.



# ENDING HOSPITAL-BASED TREATMENT FOR EARLY BREAST CANCER: MANAGING THE EMOTIONAL IMPACT






After your initial early breast cancer diagnosis, you may have found that the people around you were especially supportive, and you might have been kinder to yourself too!

However, as you come to the end of hospital-based treatment, it can be common to feel pressure (from yourself and the people around you) to feel happy and put your breast cancer diagnosis behind you. In reality, you may feel that treatment is anything but over if you are still experiencing its impact on your physical and mental health. During a time like this, it's important to understand how you may be feeling and focus on looking after your emotional wellbeing!



This section explains some of the common emotional concerns you may be struggling with after ending hospital-based treatment and provides some tips that may make it easier to cope.

## **You may be feeling worried about:**

-  Living with uncertainty and the fear that the cancer could come back
-  Coping with depression, stress and anxiety
-  Getting less support from your healthcare team in the future
-  The impact of breast cancer on your body image
-  The impact of breast cancer on your family, work and personal routines

## Coping with uncertainty

Although ending hospital-based treatment can be a huge relief, you may also be left worrying about how well the treatment has worked and if your cancer will come back. Most people who have been through breast cancer treatment live with some worry and uncertainty. In fact, it's one of the most common concerns for people who have finished treatment for cancer.<sup>3</sup> The thoughts and feelings can be quite overwhelming at first, but often they get better with time, and you can also learn to cope with them better through various stress reduction techniques.<sup>3</sup>

Most breast cancers are unlikely to come back.<sup>4</sup> However, the risk of breast cancer returning is different for everyone and depends on a number of factors including the size, type, grade and features of the cancer and whether the lymph nodes were affected or not.<sup>5</sup> Your healthcare team may be able to talk to you about the factors impacting your own risk of a recurrence, but it is important to remember that no one can say for certain whether your cancer will come back or not!



## Understanding risk

When your healthcare team talk to you about risk, they may talk about two different types of risk: **absolute risk** and **relative risk**.

**Absolute risk** is the risk of developing a disease over a period of time. Everyone has an absolute risk of developing various diseases.

For example, if one in every ten people goes on to develop a disease, this would be a 1 in 10 risk. This could also be written as a 10% risk or a risk of 0.1.<sup>6</sup>



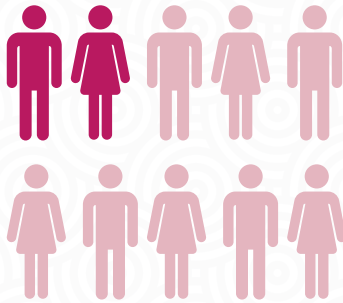
## Relative risk

Relative risk compares the risk of the same event between two different groups of people: one with and one without a particular characteristic (such as an additional risk factor or a specific biological characteristic).

For example, you could compare the risk of developing a disease among people who drink alcohol versus in people who don't. In this case, alcohol represents an additional risk factor. Let's assume the absolute risk of developing the disease among people who **don't** drink alcohol is 2 out of 10 (or 20%).

Now, if the relative risk of developing the disease increases by **50%** for people who **do** drink alcohol compared with people who don't drink alcohol, this means that a further 50% of two people, i.e. one extra person, will develop the disease among those who drink alcohol. This then brings the absolute risk for this group to 3 out of 10 (or 30%).

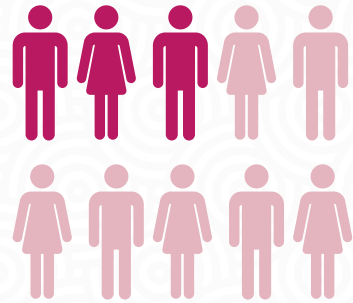
### PEOPLE WITHOUT THE RISK FACTOR



**50%**  
increase  
in relative  
risk



### PEOPLE WITH THE RISK FACTOR



The notion of relative risk can also be used to talk about the impact of a treatment on a given risk.

In this example, suppose the absolute risk of people developing a particular condition is 4 out of 10 (or 40%). Now, let's assume a treatment exists which reduces the relative risk of developing the condition by 75%. This means that the number of people developing the condition will be reduced by 75%, i.e. by 3 out of 4 people. As a result, the absolute risk of developing the condition for people taking this treatment is reduced to 1 out of 10 people (or 10%).<sup>6</sup>

### PEOPLE NOT RECEIVING TREATMENT



**75%**  
decrease  
in relative  
risk



### PEOPLE RECEIVING TREATMENT



An important thing to keep in mind when considering risk is that it is determined on a statistical basis and describes the likelihood of events happening for a group of people – it is not possible to calculate individual risk.<sup>6</sup>

## Coping with the fear of cancer coming back

From an emotional point of view, there are some things that you can do that might help you manage your fears about your cancer coming back, including:

-  **Focusing on what you can control right now:** Simple things like being active and sticking to a routine can help to give you a sense of control over your life
-  **Getting involved in your own health and well-being:** Being informed, following advice from your healthcare team, and knowing where to get help when you need it can also help give you a sense of control
-  **Learning to challenge unhelpful or negative thinking:** It can be helpful to remember that these are just thoughts and not facts, and learning how to challenge these thoughts may help you to feel less stressed by them
-  **Trying not to compare yourself to others:** Hearing about other people's experiences of cancer coming back can be alarming but remember everyone's cancer and experience of cancer is different
-  **Expressing yourself:** Talking or writing about your feelings can help you to process and let go of them. Writing down things that you are happy or satisfied with on a daily basis can help improve your self-esteem. You could talk to a friend, support group, psychologist, counsellor, or whoever you feel most comfortable with



From a physical point of view, there is some evidence that certain lifestyle changes may reduce the risk of cancer returning; these include:



**Staying active<sup>7</sup>**



**Stopping smoking<sup>8</sup>**



**Reducing alcohol intake<sup>9</sup>**



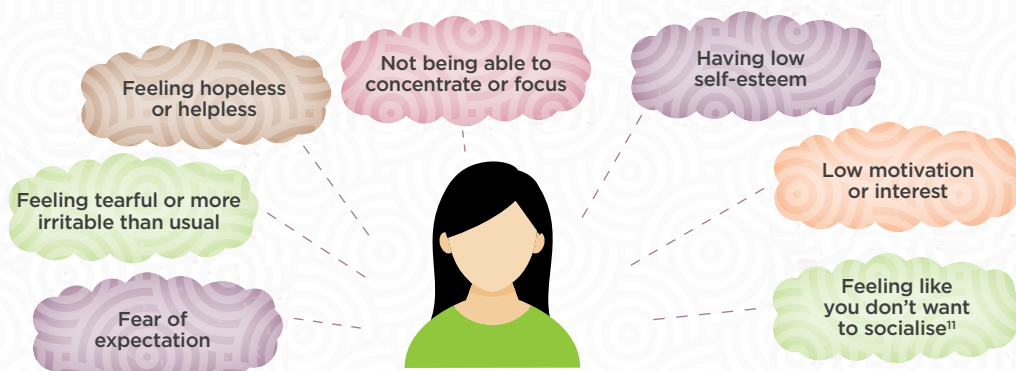
**Maintaining a healthy weight<sup>10</sup>**

Making these changes is good for your general health and wellbeing too – they may help you feel more in control, worry less about the cancer returning and lower your general stress levels! You can find more information about lifestyle changes on page 24 of this booklet.

## Coping with depression, stress and anxiety

Following your breast cancer diagnosis and treatment, you have probably experienced sadness, low mood, and moments where you felt anxious or stressed. The side effects of treatment can continue after the treatment has ended, or you may be on some types of treatment for a number of years, which can also impact how you feel.

So, it's normal to still have 'bad' days after your hospital-based treatment has ended. Some of the feelings you may experience include:



Many of these feelings are a normal response to trauma, and cancer is a major life-changing event! But, if they go on for too long, they can lead to depression or anxiety. Most people who experience depression or anxiety after breast cancer start to feel better with time<sup>12</sup> but it's important to reach out to family or friends and let your GP or healthcare team know if you are feeling this way. They may refer you to a counsellor, psychologist, or psychiatrist for further support.

## Keeping in touch with your healthcare team

Regular healthcare appointments during treatment can be encouraging – it's reassuring to know that you have the experience and support of your healthcare team behind you! Coming to the end of your hospital-based early breast cancer treatment often means you will have less contact with your healthcare team, which might leave you feeling less supported. Also, after having so much of your time taken up with treatment over the past few months, the sudden change in rhythm may initially seem disorientating.

AS YOUR HOSPITAL-BASED TREATMENT COMES TO AN END, IT CAN BE REASSURING TO FIND OUT FROM YOUR BREAST CARE TEAM HOW YOU WILL BE FOLLOWED UP IN THE FUTURE. MAKE SURE YOU HAVE A CLEAR OUTLINE OF YOUR FOLLOW-UP CARE PLAN AND A CALENDAR OF NEXT VISITS – THIS CAN HELP YOU FEEL LESS UNCERTAIN ABOUT WHAT THE FUTURE HOLDS!

It's also useful to find out who to contact if you have any questions or concerns and write down their names and contact details. There is space at the end of this booklet to record this information.

Remember, if you have any worries or concerns you can always get in touch with your healthcare team. You may also find it valuable to access support through patient associations, peer support forums and support groups.



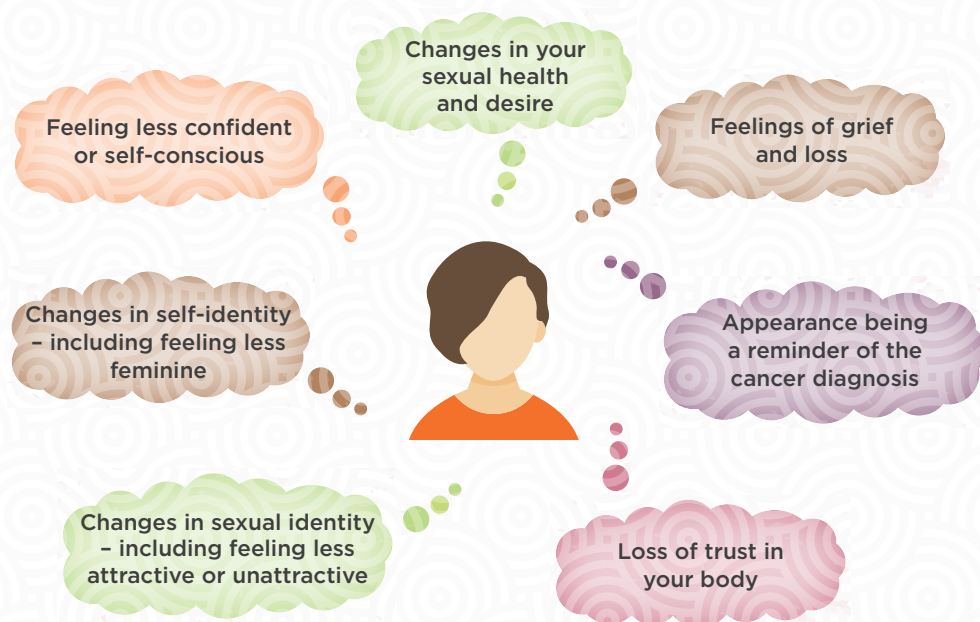
## Learning to accept changes to your body and your life

You may have noticed some changes in your confidence, self-esteem, and the way you view your body since your breast cancer diagnosis.

There are lots of different ways that treatment can impact your body; some of the physical impacts are covered later in this booklet (page 20). Treatment for breast cancer can also affect the way you look; for example, if you've had surgery you may have had your breast or breast tissue removed and be left with scars, or you may have lost your hair if you've had chemotherapy, or your hair may be weaker than normal. Treatment can also cause you to gain or lose weight, affect your skin and bone health, or cause you to start the menopause early.<sup>13</sup>

Lots of people find accepting changes to their appearance difficult to cope with.


**Common concerns include:**<sup>13,14</sup>





All of these changes can be difficult to adjust to, but there are some things you can do that might help you start to rebuild your confidence:

- 🌀 **Get familiar with your scars:** It can be helpful to look at and touch your scars (or breast reconstruction) so that you get used to how it looks and feels. Your scars may also be improved by self-massage once the skin has healed
- 🌀 **Look into reconstruction:** If you're unhappy with the way your breast looks after surgery, reconstructive surgery may be an option for you. This is when you have surgery to rebuild the shape of the breast. Some women find that it helps to restore their confidence
- 🌀 **Look into getting a prosthesis** (an artificial breast form): Other women find that wearing a prosthesis to restore the shape of the breast can help them to feel more comfortable. A prosthesis can also prevent orthopaedic damage if you had a one-sided mastectomy
- 🌀 **Make some changes:** Lifestyle changes, such as exercising, may help if you are feeling conscious about side effects of treatment, such as weight gain
- 🌀 **Spend quality time with loved ones:** Spending time with people who make you feel positive about yourself can help remind you that people value you for many reasons. Also, try and avoid being around people who make you feel negative or sad



 **Avoid comparing yourself to others:** Try not to compare yourself to others – pictures on social media, TV and magazines are often unrealistic and don't reflect real life

 **Update your wardrobe:** Finding bras and clothing that you feel comfortable in may help you to feel better in yourself

 **Don't be afraid to get some support:** Talking openly with a partner, trusted friend or family member, or accessing professional support may also help you to adjust to the way you feel about your body

 **Talk to people that have had a similar experience:**

Talking to other people affected by breast cancer through support groups or patient organisations may help you to feel less alone. It might be helpful to find out how other people have rebuilt their confidence after breast cancer treatment



YOU CAN ALSO FIND MORE INFORMATION  
ON CHANGES TO YOUR SEXUAL RELATIONSHIPS  
ON PAGE 54.



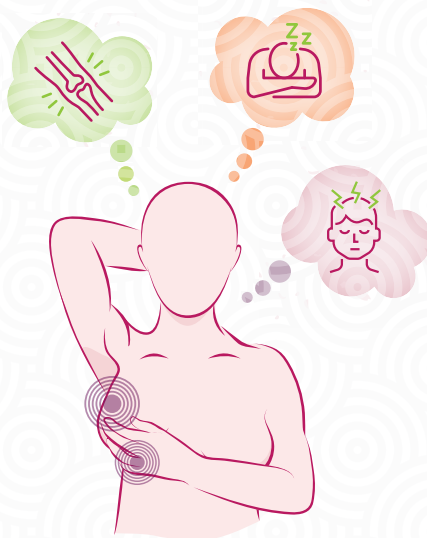
# ENDING HOSPITAL-BASED TREATMENT FOR EARLY BREAST CANCER: MANAGING THE IMPACT ON YOUR BODY

Treatment for early breast cancer can cause lots of changes to your body and you may find it difficult to adapt to the 'new normal' for your body and to start trusting it again.

This section will explain how to check for changes to your body and what you need to look out for. It also covers some of the lifestyle changes that might help you look after your health and wellbeing as you move on from hospital-based treatment.

## Checking for changes

Although you will have follow-up appointments with your healthcare team, it's still important that you regularly check for changes to your breast and body, so that you know what's normal for you after your treatment. This will help you detect if you have any symptoms that are unusual for you and may need further investigation by your healthcare team.



IT CAN FEEL OVERWHELMING OR SCARY TO CHECK FOR CHANGES AT FIRST. IF YOU'RE ONLY JUST STARTING TO MOVE ON AFTER YOUR TREATMENT, YOUR BODY PROBABLY FEELS VERY DIFFERENT - IT MIGHT BE HARD TO KNOW WHAT'S NORMAL ANYMORE!



Make some time to look and feel for any changes. You can check by scanning your breasts, armpit and collarbone with your fingers and looking in the mirror for any changes. Some people say that including their checks as part of their normal self-care routine, for example, when they're showering or getting dressed in the morning, makes it a little less overwhelming. Try and make it part of your routine as soon as you can, so that you have a good idea of what is normal for you as soon as possible. You may also want to keep a journal to record any changes you notice to help track which come and go, and which you should raise with your healthcare team. Checking once a month is enough. Try not to get overanxious about your health – remember that your treatment and follow-up appointments have been tailored to your needs and your risk of recurrence.<sup>4</sup>



## Signs and symptoms of a recurrence

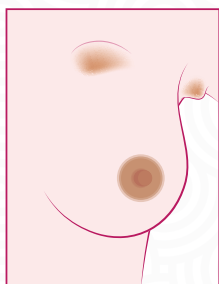
Signs and symptoms of a breast cancer recurrence can happen in the breast area and in other parts of the body. This is because there are different types of breast cancer recurrence.

**Local recurrence** is when the breast cancer comes back in, or near, the same place it was found in before. If you've had a lumpectomy the cancer might come back in the nearby breast tissue and if you've had a mastectomy it might come back in the scar line. In some rare cases, cancer might come back in the breast on the other side of the body.<sup>15</sup>

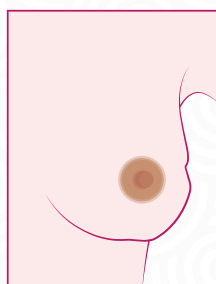
**Regional recurrence** is when the breast cancer comes back and spreads to the chest wall or skin of the breast, or the lymph nodes around the chest, neck and under the breastbone.<sup>15,16</sup>

**Metastatic recurrence** is when breast cancer comes back and spreads to other parts of the body, such as the bones, liver or lungs.<sup>15,16</sup>

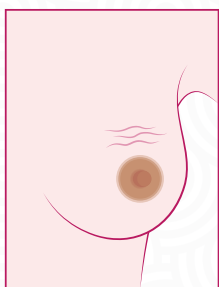
## Symptoms in the breast area may include:<sup>4,16</sup>



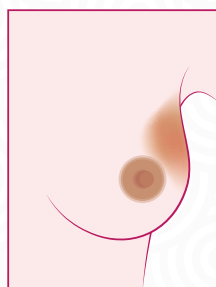
**Swelling on your chest,**  
in your armpit or  
around your collarbone



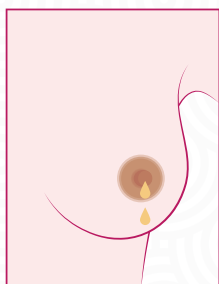
A change in  
the **breast**  
**shape or**  
**size**



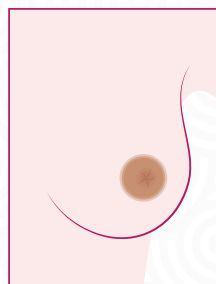
A change in  
**skin texture**,  
such as  
puckering  
or dimpling



**Redness or**  
**a rash** on or  
around the  
nipple or on  
the skin



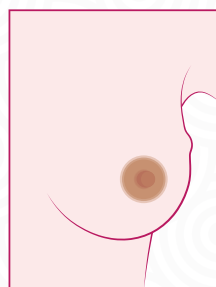
**Liquid**  
(discharge)  
that comes  
from the  
nipple



The **nipple**  
becoming  
**inverted**  
(pulled in)  
or **looking**  
**different**



**Swelling in**  
**the arm or**  
**hand**



A **lump or**  
**thickening**  
that feels  
**different** (this  
could be on  
or away from  
the scar line)

**Metastatic breast cancer can cause symptoms in other parts of the body, which can include:<sup>4,17</sup>**



Pain or aches in your bones that's worse at night and doesn't get better with pain medication



Weight loss or loss of appetite, for no apparent reason



Bad, ongoing headaches



Changes to your vision or speech



Weakness in your limbs and losing your balance



An ongoing cough or feeling breathless

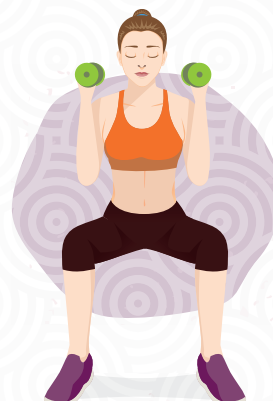


Feeling tired all the time

THESE SYMPTOMS CAN BE LINKED TO MANY OTHER HEALTH CONDITIONS. FOR EXAMPLE, ACHES AND PAINS CAN BE CAUSED BY DOING EXERCISE, AGEING OR SIDE EFFECTS FROM YOUR MEDICATION. MOST BREAST CANCERS DON'T COME BACK AFTER TREATMENT, BUT IT'S IMPORTANT THAT YOU TELL A HEALTHCARE PROFESSIONAL IF YOU NOTICE A CHANGE THAT IS UNUSUAL FOR YOU, OR IF YOU HAVE ANY SYMPTOMS THAT PERSIST OR ARE WORRYING YOU.<sup>4</sup>

## Adapting your lifestyle to improve your health and wellbeing

You might decide to make health and wellbeing a priority after your hospital-based treatment. You might also have included some beneficial activities during your treatment and you may be wondering how to best incorporate them into your new routine. There are lots of ways of looking after your health and wellbeing, such as exercising regularly, eating a balanced diet, reducing the amount of alcohol you drink, stopping smoking and accessing complementary therapies to support relaxation.



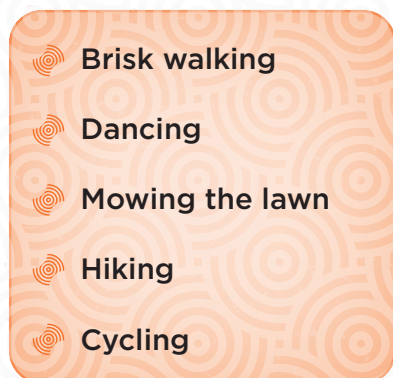
Taking care of your health and focusing on something positive can be a valuable part of moving forward after early breast cancer treatment and making these changes may even lower the risk of your cancer returning.

THIS SECTION INCLUDES SOME TIPS FOR A HEALTHY LIFESTYLE. THEY ARE JUST SUGGESTIONS AND IF YOU DON'T FOLLOW THEM IT'S DOESN'T MEAN THAT YOUR CANCER WILL COME BACK. MAKING LIFESTYLE CHANGES CAN BE HARD AND YOU MAY FEEL THAT YOU DON'T WANT THE PRESSURE OF MAKING THESE CHANGES AS YOU START TO GET USED TO LIFE AFTER HOSPITAL-BASED TREATMENT.

### Exercise and keeping active

Regular exercise may be linked to a lower risk of breast cancer coming back. Just 2.5 hours of moderate intensity exercise per week (about 20 minutes each day) can help lower the risk of the cancer returning and help you live longer. It's important to note that these are standard recommendations.<sup>7</sup> You can get started by identifying the best time in your day to practice gentle exercise and then build up slowly. It's better to begin small, for example, once a week, and increase frequency and duration step by step.

Moderate intensity exercise is exercise that raises your heart rate, makes you breathe faster and feel warmer, such as:<sup>18</sup>



Regular exercise can also improve your mental wellbeing by reducing anxiety, depression and low mood and increasing self-esteem.<sup>19</sup> After hospital-based treatment for early breast cancer, exercise may also help reduce some of the side effects of treatment including fatigue, joint pain, weight gain and osteoporosis.<sup>20</sup> More detail on these side effects can be found on page 28.

If you're thinking about starting to exercise, or increasing the amount that you already do, it's best to start slowly and gradually build up your fitness levels over time.<sup>20</sup> Talk to your doctor if you have any questions about how much exercise they would recommend for you. Too much exercise might make side effects such as fatigue worse, so it's important to find the right balance.<sup>20</sup> Your healthcare centre or a patient association may also be able to help you adapt physical activity to your needs.



You might be told to avoid certain exercises if you have had your lymph nodes removed and you have lymphoedema, or you are at risk of developing it.<sup>21</sup> There is more information about lymphoedema on page 40 of this booklet.



## Eating well and maintaining a healthy weight

Eating a balanced and healthy diet is important for everyone. After undergoing cancer treatment you may be thinking about your diet more, and what you can do to improve it.

As for everyone else, your diet should be high in vegetables, fruits, whole grains, and lean protein, such as chicken, fish, or lentils and beans, especially if you don't eat animal products. A well-balanced diet is important to ensure that you get enough vitamins and minerals (e.g. iron).

Keeping a record of foods that increase your wellbeing or seem more difficult to digest can be valuable for helping you plan your meals.

Being overweight, or very overweight, can increase the risk of breast cancer coming back.<sup>10</sup> Eating a balanced, healthy diet and exercising regularly can help you maintain a healthy weight. Making sure that family members also understand the importance of this can encourage them to support you in making changes to your diet.

If you're overweight, reaching a healthy weight is not always easy! There are some resources that may help you on page 60 of this booklet.



## Smoking

If you already have a family history of breast cancer, smoking may increase your risk of developing breast cancer and the risk is higher if you started smoking before the age of 17.<sup>8</sup>

There are many benefits of stopping smoking, but it is often a difficult habit to break – your doctor or pharmacist will be able to support you to stop smoking. There are plenty of resources out there to support you at home too; you can find some useful organisations on page 60 of this booklet.





## Alcohol

Drinking alcohol, even in small amounts, is also linked to an increased risk of developing breast cancer.<sup>9</sup>

Drinking alcohol may be a big part of your social life, or the way you currently relax and unwind. It can be difficult to lower the amount you are drinking if it is part of your everyday routine. For further support with reducing the amount of alcohol you drink, the organisations on page 60 of this booklet may be of help.



## Psychological wellbeing

Stress and traumatic events might increase the risk of a breast cancer recurrence.<sup>22,23</sup> Breast cancer is also a stressful experience in itself, so it's especially important to take time to look after your psychological wellbeing during and after your treatment. Different people relax in different ways; however, mind-body-based complementary therapies, such as mindfulness, meditation, yoga, Tai Chi and Qigong, may help you reduce stress levels and improve your emotional wellbeing.<sup>24</sup>



## Sticking to your treatment plan

After standard treatment has ended, people with certain types of breast cancer may be offered further treatment, based on specific characteristics of their own tumours. Not everyone with a breast cancer diagnosis will have these specific characteristics, meaning that they would not benefit from the treatments targeting them. Any further treatment your healthcare team will offer will be based on evidence that shows it adds value.

If you are offered additional treatment, then it's important that you are clear about the added value of the treatment and take it as it's prescribed, especially in the case of oral therapies that you take at home, as missing doses may make treatment less effective and increase your risk of recurrence.<sup>25</sup>











## Managing the side effects of treatment

Treatment for breast cancer can be challenging. You very likely experienced a range of side effects as you were going through treatment. Some of them were probably easier to manage than others. Even as treatment is coming to an end, or has finished, you may well continue to experience side effects. It can take your body and mind some time to get over them. This can be frustrating when you are trying to move on and put treatment behind you, or when family and friends expect you to be happy that treatment is over. You may feel very different about it and may also wonder if these side effects are normal and if you're meant to be feeling this way!

If you're offered further treatment, you may experience side effects, just like with your previous treatments, but your healthcare team will be able to help you manage these.

Side (or late) effects are very individual and will depend on the type of treatment you've had – some people don't experience any effects at all, while others may find them really challenging. There are often ways of managing treatment side/late effects and it is important to seek help if they are affecting your quality of life.

**Common side effects include:**<sup>26,27</sup>

-  **Menopausal symptoms**
-  **Joint pain and body stiffness**
-  **Sleep disorders**
-  **Long-term fatigue**
-  **Changes in memory and concentration**
-  **Neuropathic pain**
-  **Fertility issues**
-  **Lymphoedema**
-  **Osteoporosis**
-  **Urinary problems**
-  **Gastrointestinal (GI) symptoms**




This section describes some of the side effects or physical changes you might experience, what they might feel like and how you can best manage them.

## Menopausal symptoms

Some breast cancer treatments can affect hormones and cause an early menopause; in some cases, treatments can even cause menopausal symptoms in women who have already been through the menopause.<sup>28</sup>



### Menopausal symptoms can include:<sup>28</sup>

-  **Hot flushes and sweats:** Hot flushes can make you feel extremely hot all of a sudden. They're normally felt on your upper body or face, can cause sweating and are sometimes worse at night. They can be really overwhelming, but usually only last a few minutes!<sup>29</sup> You may find that learning to manage stress and relaxation exercises can help reduce the frequency and intensity of hot flushes<sup>30</sup>
-  **Anxiety, depression, or mood changes:** You may find that you are more irritable or anxious than usual or feel unexpectedly low. This may be due to the changes in your hormone levels
-  **Changes in memory and concentration:** You may notice that you become more forgetful and can't concentrate for very long



**Urinary problems, such as infections or incontinence:**

You may find that it becomes more difficult to hold on to your urine, or that you start getting urine infections more frequently



**A low sex drive (libido):** This can be caused by the changes in your hormones; sometimes coping with other menopausal symptoms, such as hot flushes and low mood, can also mean that you become less interested in sex<sup>26</sup>



**Dry skin:** You might notice that hormonal changes make your skin and hair feel dryer and thinner



**Vaginal dryness:** The tissue in this area might become drier or thinner, which may be uncomfortable on a daily basis and during sex<sup>31</sup>



**Bone thinning (osteoporosis):** You may experience bone thinning. This doesn't usually cause any symptoms in itself, so you may be regularly screened by your doctor if you're at risk of osteoporosis<sup>32</sup>



**Sleep problems:** You may have problems falling asleep or staying asleep during the night



**Weight changes:** You may notice that you start gaining weight, especially around your middle. You may also find that it becomes harder to build or maintain muscle<sup>33</sup>

These symptoms can be very difficult to cope with. You are unlikely to experience all of them at once, but even experiencing a couple of them can have a big impact on your quality of life! It is important to talk to your healthcare team about your symptoms. You may sometimes find this embarrassing, but keep in mind that your healthcare team will be very used to talking about these issues and will be able to suggest approaches to help you manage your symptoms.

## Joint pain and body stiffness

You may experience joint pain, aches and stiffness after treatment for breast cancer, which can impact quality of life in many ways. Joint pain is more common in women who have been treated for breast cancer than in those who haven't, and may be linked to treatment with hormone therapies, chemotherapy, and targeted therapies.<sup>34</sup>

Joint pain may improve over time, as your body gets used to your treatment. Ask your healthcare team for advice on using pain killers to try and manage the pain.<sup>26</sup>

**Your healthcare team may also offer additional support in a number of ways, including:**<sup>35,36</sup>



**Medication:** Your doctor may change the medication causing your joint pain or prescribe medication to help you manage the pain such as stronger pain killers.



**Physiotherapy:** Your doctor may refer you to a physiotherapist for treatment and advice, or an occupational therapist who will be able to support you to manage everyday tasks with joint pain.



**Complementary therapies:** You may find that complementary therapies, such as acupuncture, relaxation techniques or massage can help you control the pain.





## Sleep disorders






You may find that you have trouble falling asleep, or staying asleep, after your treatment for breast cancer.<sup>37</sup> This is also called insomnia and is more common in women affected by breast cancer; this might be because side effects of treatment such as hot flushes, anxiety and depression make it harder to sleep.<sup>26</sup> You may even find that an urge to move forward after treatment by leading a busy, active life can make it more difficult for you to get the rest and sleep that you need. Sleep plays a big role in our general health and wellbeing and if you aren't sleeping well you might be left feeling extremely tired, irritable, struggling to concentrate, or feeling low. Sleep issues can be really frustrating and the more you worry about it, the more difficult it might become to fall asleep!



**There are some things you can do that may help improve the quality of your sleep.<sup>38,39</sup>**

-  **Keeping a good sleep routine:** Try to go to bed and wake up at a similar time every day – creating a routine helps the body to expect to sleep at a certain time each day
-  **Avoiding your phone and other screens before bed:** The light from your phone screen can prevent you from switching off and falling asleep. Staying up and checking emails, playing games, and surfing the internet also keeps your mind active when it should be resting<sup>39,40</sup>



-  **Exercise (but not too close to bedtime):** Exercising regularly can help you to get a better night's sleep, but you might not feel the effects of exercise for weeks or even months. Try to avoid exercising just before bed, as it can stimulate your body and stop you from falling asleep
-  **Making sure you have good sleeping conditions:** The right temperature, a comfortable bed, and a dark and quiet room help to create a relaxing environment, which may make it easier to wind down before bed and help you fall and stay asleep more easily
-  **Avoiding caffeine and alcohol:** Alcohol and caffeine can stop you from falling asleep or disrupt your sleep throughout the night
-  **Avoiding naps or sleeping in the day:** Napping in the day can disrupt sleep at night – if you do need to nap, try to nap for no longer than 30 minutes
-  **Relaxation techniques:** Worry and stress can prevent us from falling asleep – taking some time to calm your mind and body before bed might help you to switch off

If problems with your sleep don't get better, or start to affect your quality of life, then you may want to talk to your doctor.

If your insomnia is caused by worry, then you may want to talk to someone such as a psychologist or a counsellor, who will be able to recommend approaches you may find helpful. For example, cognitive behavioural therapy, a type of talking therapy that aims to change the way you think and behave,<sup>41</sup> has shown success in improving sleep in people that have been affected by breast cancer.<sup>42</sup>


## Long-term fatigue


You may find yourself feeling extremely tired and lacking energy after your breast cancer treatment.<sup>43,44</sup> Fatigue includes physical and psychological elements and is different to normal tiredness or sleepiness; it doesn't get better with rest or sleep, and it can have a major impact on your everyday life.<sup>45</sup>


IF YOU'RE LIVING WITH FATIGUE YOU MIGHT FIND THAT YOU STRUGGLE TO CARRY OUT EVERYDAY TASKS, LIKE GETTING READY IN THE MORNING OR PREPARING MEALS. FATIGUE CAN ALSO AFFECT YOUR CONCENTRATION LEVELS AND MOTIVATION.<sup>43</sup>





Fatigue can be really frustrating – you may feel like it's holding you back from doing the things you want to do, like socialising, working, hobbies and family life. But there are some steps you can take to manage fatigue:

 **Keep active:** Exercising can help to ease the symptoms of fatigue.<sup>44</sup> Exercising with fatigue can be hard – it’s probably the last thing you feel like doing when you are low on energy! The key is to start gently and build gradually; for example, you might do a short, gentle walk and gradually increase the duration of your walk over time.<sup>45</sup> Try various activities to find out which you enjoy the most and are happy to practice regularly

 **Try complementary therapies, such as massage or acupuncture:** It’s still not fully known how effective these are at improving fatigue, but around 50% of people affected by cancer reportedly start using complementary therapies after their diagnosis.<sup>46</sup> They may also help you feel calmer and more relaxed. Complementary therapies should be discussed with your healthcare team

 **Manage your energy levels:** Use the times when you feel more energetic to be productive and make sure you listen to your body and allow yourself to rest when you need to!<sup>45</sup> Resting can become an important part of your daily routine

 **Keep a fatigue diary:** You may find that recording when you feel most tired and logging your activities each day can help you identify the points in the day when you need to rest and the types of activities that make you especially tired. Writing down which activities help you gain energy and when they are most effective may also allow you to cope better with fatigue<sup>44,45</sup>

 **Try to keep a normal sleep routine:** Cancer-related fatigue may be linked to problems sleeping.<sup>43</sup> Keeping to a routine might help you get better quality sleep – even if you feel tired in the day, following your normal routine might help you sleep better that night!<sup>45</sup> Recording which activities make going to sleep easier for you may also help you improve your sleep patterns

If the effects of fatigue become difficult to cope with, it's important that you talk to your doctor, who may be able to offer advice, or in some cases may refer you to an occupational therapist. An occupational therapist is a health worker who supports you with finding ways of doing everyday tasks if you are struggling.<sup>47</sup>

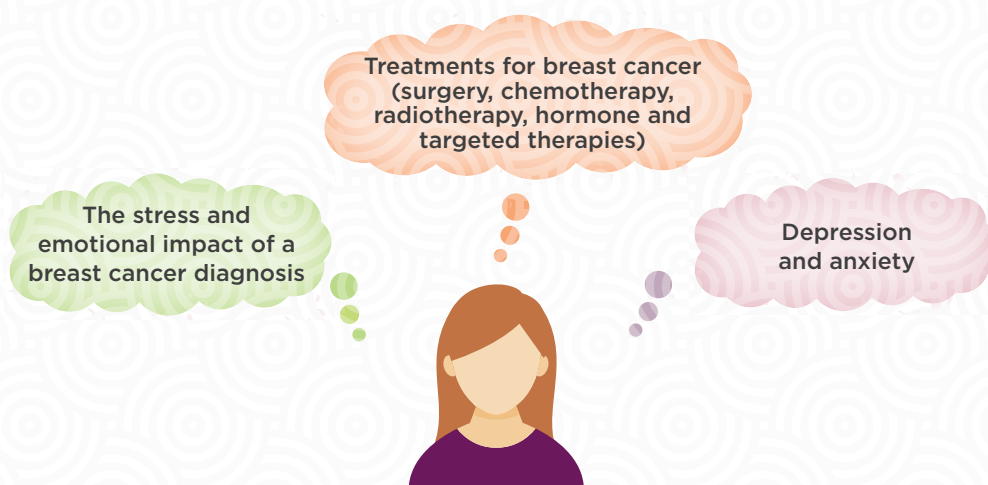


## Changes in memory and concentration

It's common to experience changes in memory and concentration following treatment for breast cancer. Up to 75% of people diagnosed with breast cancer report experiencing changes to their memory and concentration levels. For some, the effects are very mild, but for others they are very challenging. If you are affected, you are likely to recover after a year or so, but in some cases the changes can last much longer.<sup>48,49</sup>








**Memory and concentration changes might be caused by:**<sup>48,49</sup>



You may find that these changes make it more difficult to cope at work, to focus on tasks and to remember names, birthdays and anniversaries of friends and loved ones. It can leave you feeling embarrassed, annoyed with yourself or even guilty, but remember that this is a normal side effect of treatment and it's not your fault!

**There are ways that can help you manage changes to memory and concentration, including:<sup>50,51</sup>**

-  **Talking:** Talking to the people in your life may help them to understand and support you if you are more forgetful and distracted than usual
-  **Writing things down:** Making notes and keeping a list of important dates, names and numbers can be a helpful way to remember things
-  **Exercising:** This may help you to destress and feel more awake and alert
-  **Mind puzzles:** You may find that exercises such as puzzles, crosswords and sudokus, or learning a new language also help to keep your mind active. Some healthcare centres may offer dedicated cognitive exercise workshops (For details on resources, see page 60)
-  **Talking to your doctor:** If your memory and concentration are severely impacting your daily life, it's important you speak to your doctor, who may refer you to a specialist for further support



## Neuropathic pain

Some breast cancer treatments, including certain types of chemotherapy and surgery, can cause damage to nerves. You may notice burning or shooting pain, numbness in hands and feet, loss of balance, pins and needles, difficulty doing fiddly tasks such as fastening buttons, or increased sensitivity to touch or temperature. Symptoms usually improve with time, but in some cases they may take months or years to get better.<sup>52,53</sup>

### Your healthcare team may:



Prescribe medication to relieve nerve pain<sup>54</sup>



Suggest alternative ways of trying to manage symptoms, such as physiotherapy or acupuncture<sup>52</sup>



Refer you to an occupational therapist for additional support<sup>52</sup>

### Other things you can do include:



Avoiding injury - e.g. wear slippers and well-fitting shoes and use oven gloves when cooking to protect your feet and hands. If your balance is affected, avoid trip hazards<sup>52</sup>



Keeping your hands and feet warm by wearing socks and gloves<sup>52</sup>



For pain in the breast, wearing a supportive bra or a soft, adjustable bra may help you be more comfortable<sup>54</sup>



## Fertility issues

Some treatments for breast cancer can cause fertility issues. Sometimes, these are temporary and make it harder for you to get pregnant for a while. In other cases, they are permanent and mean that you will no longer be able to get pregnant naturally.<sup>55</sup>



You may have discussed fertility with your doctor before you started treatment; however, as you come to the end of your hospital-based treatment and start to focus on the future, you may start thinking about your fertility more. It can be very difficult to know that you may have fertility issues. Even if you are unsure whether you would like to have children in the future, you may want to know that you have the option.





You might find it helpful to discuss your fertility concerns with your healthcare team who will be able to refer you for fertility treatment or provide support and advice if you decide to try for a baby.

No matter how you feel, you do not have to cope alone! There are lots of organisations that provide support to people going through fertility issues (for details, see page 60 of this booklet). It can be a difficult and lonely time and sometimes it helps to talk to someone who understands and is having a similar experience.

## Lymphoedema

Breast cancer treatments, such as surgery to remove the lymph nodes, can cause a long-term condition called lymphoedema. The main symptom of lymphoedema after breast cancer surgery is swelling of the arm on the side the lymph nodes were removed.<sup>56</sup> This is because removing lymph nodes can affect the fluid drainage channels of the lymphatic system. Fluid then doesn't drain in the normal way, so the area swells.<sup>56,57</sup> The amount of swelling (also called oedema) varies from person to person. You might experience slight swelling or severe swelling. Sometimes the affected arm is several inches larger than the other arm.<sup>57</sup>

Lymphoedema can last months or even years after treatment and at the moment there isn't a cure for it, but there are steps you can take to ease the symptoms.<sup>56</sup> The recommended treatment for lymphoedema is called decongestive lymphatic therapy. It includes:<sup>58,59</sup>

-  **Keeping a skin care routine** to help keep the skin in good condition and reduce the chances of getting an infection in the arm
-  **Arm exercises** that use the muscles in the affected arm to help improve fluid drainage. Your doctor will be able to show the right exercise for you
-  **Compression bandages** to move fluid out of the affected arm and reduce a further build-up of fluid
-  **Specialized massage techniques** known as manual lymphatic drainage to help stimulate the flow of fluid in the lymphatic system and reduce swelling

If lymphoedema is left untreated it can get worse. Getting treatment right away can lower your risk of infections and complications so it's important you tell your doctor about any new swelling.<sup>57</sup>




## Osteoporosis

Breast cancer treatments such as chemotherapy and hormone therapy can lower bone density and increase the risk of developing osteoporosis, a condition where the bones become less dense and are more likely to fracture.<sup>28</sup>

Osteoporosis doesn't usually cause any symptoms so you may not even be aware that you have it! If you've had treatment that can increase your risk of osteoporosis, you should be offered a scan to measure your bone density at the start of treatment and regularly throughout your treatment period.<sup>32</sup>



You may feel worried if you have been told that you're at risk of developing osteoporosis, but there are a few things you can do to support your bone health, including:

-  **Exercising regularly:** Weight-bearing exercise (such as walking, yoga or tennis) and muscle strengthening exercise (such as using resistance bands and weights) help maintain bone strength which will help prevent fractures in the future<sup>60</sup>
-  **Making sure you get enough vitamin D:** Vitamin D helps your body absorb calcium – you can get it from exposure to sunlight (around 10 minutes in the sun once or twice a day), food (such as eggs and oily fish) and supplements<sup>61</sup>
-  **Getting enough calcium in your diet:** Calcium can help strengthen your bones – you can find it in foods such as dairy products and dark leafy vegetables. Some breads, cereals and dairy-free alternatives to milk also have added calcium. Most adults need around 700 mg of calcium a day<sup>62</sup>

Your doctor will be able to give you further advice about preventing osteoporosis and will also be able to measure your vitamin D levels using a simple blood test.

## Urinary problems

Breast cancer treatments that lower hormone levels in the body can lead to incontinence or urine leakage.<sup>63</sup> These symptoms can be difficult to cope with; you may feel embarrassed by them and be concerned about them happening when you're out and about.

It's important not to keep urinary problems to yourself. Urinary issues are common after breast cancer, and your healthcare team will have experience in recommending ways to manage your symptoms, including:<sup>63</sup>



### **Pelvic floor exercises**

that strengthen your pelvic floor muscles



### **Vaginal creams or pessaries**

that contain oestrogen and may help reduce incontinence. Be aware, however, that at the moment there is not enough evidence to show they're safe in people with hormone-dependent breast cancers



**Medications** that are not hormone-based may also be available to reduce incontinence



**Surgery** might be considered depending on the type of incontinence you have. Your doctor will be able to discuss if surgery is the best option for you



## Gastrointestinal (GI) symptoms

You may experience GI symptoms, such as tummy pain, bloating and diarrhoea, that can be caused by some breast cancer treatments. In many cases, you will be able to manage these symptoms at home, but if they are severe, are getting worse or last longer than 24 hours it's important that you let your doctor know.<sup>64</sup>

It is very natural to feel embarrassed by GI symptoms; you may worry about what other people will think or be concerned about leaving the house. Reassuringly, GI symptoms often don't last long and start to get better as you get used to your treatment.

**In the meantime, you may be able to prevent and manage your symptoms by:**<sup>65,27</sup>



Taking medicines to reduce diarrhoea



Drinking plenty of fluids  
(diarrhoea can cause dehydration)



Avoiding caffeine and alcohol (try herbal teas or water as alternatives)



Avoiding foods that are high in fibre. Generally, foods that are high in fibre are very good for us so this should only be a short-term change



Being prepared when you are out and about – make sure you know where the nearest toilet is, avoid long journeys and take spare underwear out with you, just in case



Making sure you rest during and after an episode of diarrhoea - these can be very tiring and leave your body feeling exhausted

## MANAGING RELATIONSHIPS AND EVERYDAY LIFE

As you start to move forward and find your 'new normal' after breast cancer treatment, you may find yourself looking back on your life before cancer. Breast cancer can cause a lot of changes, and it can affect not just you but also the people around you. You may worry about how breast cancer and its treatment has affected your relationships – this doesn't just mean a relationship with a partner, but with friends, family members, and colleagues as well!

It's very common to experience changes, and sometimes problems, in your relationships following a diagnosis of breast cancer – even very close couples, families and friendships can be affected. You may also be concerned about the people that are not yet in your life, for example, if you're thinking about starting a new relationship.

Every relationship is different – you may experience different issues with different people. This section deals with common concerns in relationships following treatment for breast cancer and offers some support and advice in managing them.





## Changing your priorities

You might find that your outlook on life and priorities have changed following your breast cancer treatment.<sup>66</sup> Some people decide that they want to appreciate the small things in life going forward and live at a slower pace, others might decide that they want to live at a faster pace and fit in as much as possible. You might also re-evaluate relationships and friendships and feel like you want to put yourself first for the first time in a while!<sup>66</sup>

Sometimes this is described as one of the positives that can come out of a breast cancer diagnosis. Many people report having a new zest for life and want to make the most of it (although not everyone will feel this way). Sometimes having a change in priorities can cause friction with the people around you, especially if your priorities are different to theirs. It can be helpful to talk to them about how you're feeling and why this new way of living is important to you – talking it through might help you find a compromise that works for the both of you.



## Changes to your relationships with family and friends








The way people react to you during or after your treatment for breast cancer can be really unexpected. Sometimes the people that you are closest to, who you imagined would support you through anything, are the ones that are not there for you, whereas other people may surprise you by being a real source of comfort or support.



Some people don't know how to deal with cancer at all – it may have been a reminder to them that it can happen to anyone, or they might feel concerned that they will say or do the wrong thing.

It can be very difficult when you feel let down or hurt by a loved one! You may want to talk to them to let them know how you feel, especially if you want to improve your relationship with them.

Even if your friends and family have been supportive during hospital-based treatment, they might not realise that you may continue to need support afterwards. It might help to let them know what you need from them now that treatment has ended so that you're on the same page. Your needs might change over time, so keep them updated when they do – you could let them know:<sup>67</sup>

-  If you've missed or appreciated their support during your treatment
-  If you want to be invited to social events, even if you can't always go
-  If you'd prefer to talk in person, on the phone or over text or email
-  If you'd prefer to socialise at home instead of going out
-  If you want to talk about breast cancer or not
-  If you want advice or for them to just listen to you
-  If you need help with carrying out everyday tasks, like shopping or childcare

## Changes to your relationships at work

When you were first diagnosed and started treatment for breast cancer, you may have taken some time off work. Depending on your employer, you may have felt well supported or you may have faced some challenges at work. As you come to the end of your hospital-based treatment, expectations around work may be changing yet again. Treatment for breast cancer may have affected the way you feel about work, and you may have worries about.<sup>66,68</sup>



- 🌀 Feeling unsupported by your employer
- 🌀 Financial issues
- 🌀 Difficulty managing the late effects of treatment in the workplace
- 🌀 Difficulty managing your mental wellbeing in the workplace
- 🌀 Guilt about taking time off
- 🌀 Fear of not meeting expectations
- 🌀 Feeling out of the loop or like things have changed a lot since you went on leave
- 🌀 What your colleagues might think, or how they will react
- 🌀 Questioning the type of job you want to do altogether

You may find it helpful to talk to your employer. Decide on what types of information you would like to share with Human Resources, your manager and your colleagues – these might be quite different!

You may find it useful to agree on a plan with your employer's Human Resources team – this could include flexible working, reduced hours, or an agreement to allow you some extra breaks and support whilst you are managing the late effects of treatment.

If you have been away from work for some time, it might also be a good idea to reach out to your colleagues to arrange a catch-up – this could be lunch or even just a phone call. This can offer a chance for you to help them understand what you have been through, which may mean they will be better able to offer support when you return.



If you don't feel fit to work at all, it might be a good idea to search for some legal advice about possible social security benefits or pensions.

## Putting yourself first

You might find yourself feeling guilty after your breast cancer treatment, for example, you might feel guilty about the stress your family and friends have been under or feel like you've been a burden on them.<sup>69</sup> You might feel guilty about not working for a while and may find that there is little space for the concept



of 'recovery time' after going through exhausting treatments. You might even feel guilty for developing breast cancer in the first place! This is a really normal reaction to a cancer diagnosis but remember that it is not your fault. You did not cause your breast cancer – it is a complex disease caused by lots of different factors.

It can be helpful to talk your feelings through with the people around you – they might be able to provide you with some reassurance and support! It might also be helpful to talk it through with a professional, like a councillor, psychologist, or a support group of people that have had a similar experience to you.

It's not always easy having these types of conversations, but there are some tips for having open conversations on page 58 of this booklet.

If you have children, you might also worry that that they will be affected by breast cancer in the future. This may also leave you feeling guilty. Talk to your doctor if you're concerned about your family history of cancer. They might refer you and your family for testing if they think they might have an increased risk of developing breast cancer in the future.



## Talking to children

It's normal to worry about the children in your life when you're diagnosed with breast cancer. You might've tried to protect them from feeling worried or scared for you during your treatment, and if you're not feeling yourself after treatment, you might still be trying to protect them!

Children can often sense when the adults in their life are worried or stressed. Not really knowing what is causing the stress might lead them to think that the situation is worse than it really is.

It is better to have open communication with children about breast cancer. If the information is delivered in a sensitive way and at the right level for their age group, it can help them to feel less overwhelmed and understand what's going on.<sup>70</sup>

### You might want to talk to them about:



Sometimes children might not be open to talking at first and some children are better at opening up than others. Try to be patient and let them know that you're ready to talk when they are.

There is a list of organisations that can support you with talking to children about cancer on page 60.



## Living with your partner

Breast cancer can put a lot of pressure on a relationship. Both of you have been thrown into a situation you weren't expecting and didn't want to be in. It's likely that you've both experienced a lot of strong feelings such as fear, worry, hopelessness and sadness since the diagnosis.



Different couples manage the pressures of breast cancer in different ways. For some the pressure brings them closer together, for others the pressures might create new issues in the relationship or highlight issues that were already there, such as:



**Changing roles:** During your hospital-based treatment the roles you played in your relationship might have changed. Maybe your partner started taking on more responsibilities during your treatment, when usually you're always the one to take the lead. You might feel that the changes are welcome and be happy with the new way your relationship is working; in other cases, you may wish for things to go back to how they were before your treatment



**Pressure to go back to normal:** As your treatment ends, you may find that your partner wants everything to get back to how it was before your diagnosis. It can be difficult to cope with this pressure when you are still adjusting to life after breast cancer. You may feel like cancer has changed many things for you and if your partner doesn't understand this, it can feel quite lonely or isolating



**Feeling unsure about where you stand:** Some couples find that a breast cancer diagnosis can create a distance in their relationship. It might have been hard for you both to say exactly how you were feeling to one another during treatment. Maybe you couldn't put how you were feeling into words, or you were concerned about worrying or overwhelming each other. After treatment, you might feel like you need some reassurance that everything is ok and that you both still feel the same way about each other - your partner might also need some reassurance too

Talking to your partner can help them know how you're feeling, and it can also give you a chance to find out how they feel too! Talking will give you the opportunity to work out what you both want from your relationship going forward - page 58 has some tips for having open conversations.






If you still feel like you're not getting anywhere, you could look into getting some counselling together.

## Changes to your sexual or intimate relationships

You may experience changes in your sexual relationships following treatment for breast cancer.<sup>71</sup> You might be concerned about changes to your sex life with your current partner, or you may be worried about starting a new sexual relationship with someone in the future.

Common concerns include:<sup>26</sup>



-  **Side effects of treatment:** Fatigue, pain and the many menopausal symptoms, including vaginal dryness, hot flushes, and lack of sexual desire, might mean that sex becomes painful, uncomfortable or less important to you
-  **Changes to your breast:** If your breasts have always been a big part of your sex life, losing a breast or breast changes due to treatment can impact how you feel about yourself and your sex life
-  **Self-confidence:** Changes to the way you look can also affect your confidence and how you feel about yourself and your femininity
-  **Depression:** Feeling depressed or low following treatment can also cause you to lose interest in sex
-  **Stress and anxiety:** Feeling worried or anxious in general can make it harder to relax and enjoy sex. If you're worrying about sex or your relationship you might be adding more pressure on yourself for everything to be okay<sup>71</sup>



Different people will be affected in different ways – and some people will not be affected at all!

It's often helpful to talk to your partner about how you are feeling – for some people this can feel embarrassing or uncomfortable but being open with your partner may help them to understand how you feel and what you need from them. Your partner may have also been thinking about the changes to your sex life and may have avoided talking to you about it for fear of upsetting you or making you feel awkward.





## Starting a new relationship


If you are starting a new relationship, it can sometimes be difficult to find the right time to talk about your breast cancer treatment. There is no right time to tell someone about your experience and it is very normal to feel worried about it. Different people will react in different ways – some people may be unsure of what to say and may need a little time to process the news. Talking openly will help you to both understand how the other is feeling and may also help make things easier if you decide to start a sexual relationship together.





WHATEVER STAGE YOUR RELATIONSHIP IS  
AT, THERE ARE SOME THINGS THAT YOU CAN  
DO THAT MIGHT IMPROVE THE WAY YOU  
FEEL ABOUT SEX, INCLUDING:

 **Find your 'new normal':** Try not to compare your sex life to before your treatment for breast cancer. It might be quite different at first and it might take you some time to adjust and feel comfortable again

 **Take it slowly:** Don't feel like you have to rush back in to sex. Intimacy can take many forms, such as hugging, kissing or holding hands and it can help to start with a level of intimacy you feel comfortable with and gradually build up

 **Don't be afraid to talk:** Talk to your doctor about any issues you are having, they may be able to help! For example, they might prescribe lubricants or moisturisers if you're suffering with vaginal dryness or refer you for emotional support if you are struggling with anxiety or depression

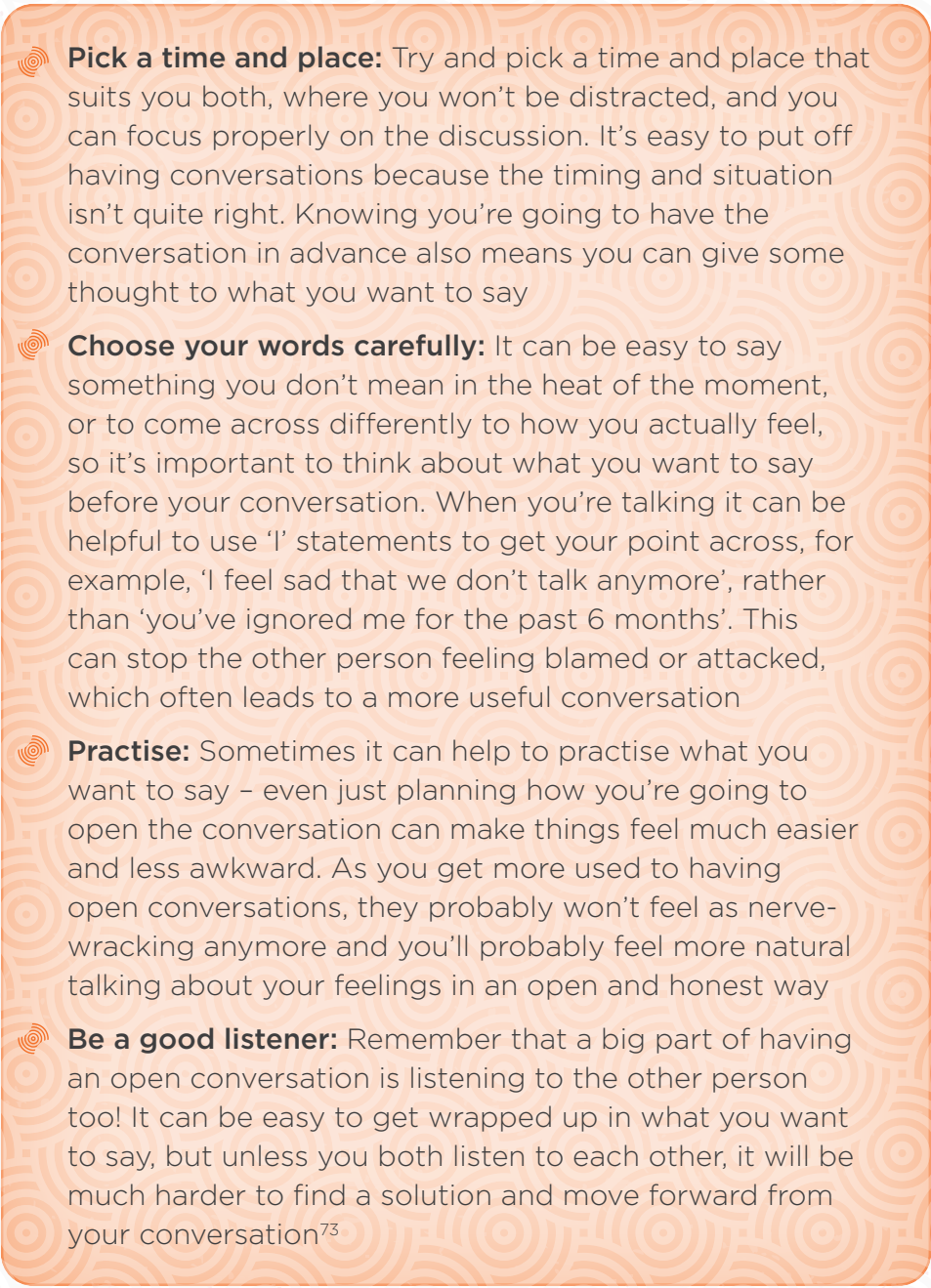
 **Make sure you're comfortable:** Make sure you feel relaxed and you're wearing something you feel comfortable in, for example, some women prefer to wear a bra and prostheses or nightwear to bed if they're not comfortable taking their clothes off


 **Get to know your body again:** It can be helpful to get to know your body again by looking in the mirror and touching yourself. This can help you know what feels good and what might be painful or uncomfortable for you after your treatment<sup>72</sup>


## Talking about your feelings


Lots of the issues in relationships can be improved by open communication and letting the other person know how you really feel. This sounds simple enough, but it can be really hard – especially when you're talking about something that's difficult to put into words and means a lot to you both. However, there are some things you can do to make having conversations a bit easier and more comfortable for both of you, including:






 **Pick a time and place:** Try and pick a time and place that suits you both, where you won't be distracted, and you can focus properly on the discussion. It's easy to put off having conversations because the timing and situation isn't quite right. Knowing you're going to have the conversation in advance also means you can give some thought to what you want to say

 **Choose your words carefully:** It can be easy to say something you don't mean in the heat of the moment, or to come across differently to how you actually feel, so it's important to think about what you want to say before your conversation. When you're talking it can be helpful to use 'I' statements to get your point across, for example, 'I feel sad that we don't talk anymore', rather than 'you've ignored me for the past 6 months'. This can stop the other person feeling blamed or attacked, which often leads to a more useful conversation

 **Practise:** Sometimes it can help to practise what you want to say – even just planning how you're going to open the conversation can make things feel much easier and less awkward. As you get more used to having open conversations, they probably won't feel as nerve-racking anymore and you'll probably feel more natural talking about your feelings in an open and honest way

 **Be a good listener:** Remember that a big part of having an open conversation is listening to the other person too! It can be easy to get wrapped up in what you want to say, but unless you both listen to each other, it will be much harder to find a solution and move forward from your conversation<sup>73</sup>

## WHERE TO FIND FURTHER SUPPORT?

If you have been affected by any of the issues covered in this booklet, remember that you don't have to cope with them on your own! It's important to talk to your healthcare team and taking this booklet to your next appointment might help you to bring up the challenges you are dealing with.

There are also organisations that offer specialist support, and they might even be able to put you in contact with people going through similar experiences. These include:



-  **ESMO Guide for Patients with Breast cancer**  
<https://www.esmo.org/for-patients/patient-guides/breast-cancer>
-  **ASCO's patient information website:**  
<https://www.cancer.net/>
-  **World Health Organization - Breast cancer**  
<https://www.who.int/news-room/fact-sheets/detail/breast-cancer>
-  **European Breast Cancer Coalition**  
<https://www.europadonna.org/>
-  **Think Pink Europe:**  
<https://www.thinkpinkeurope.org/>



# NOTES

This section is for you to write notes.



**Your disease history so far:**



**Your treatment history so far:**

# NOTES

This section is for you to write notes.

 **Your healthcare team:**

Healthcare professional	Name	Telephone number	Notes

# NOTES

This section is for you to write notes.



## Your future follow-up plans:

Appointments with your healthcare team

Appointments with your GP

Tests and scans

Treatment and side effects

# NOTES

This section is for you to write notes.



**Questions to ask your healthcare team:**

# NOTES

This section is for you to write notes.



**General notes:**

# NOTES

This section is for you to write notes.



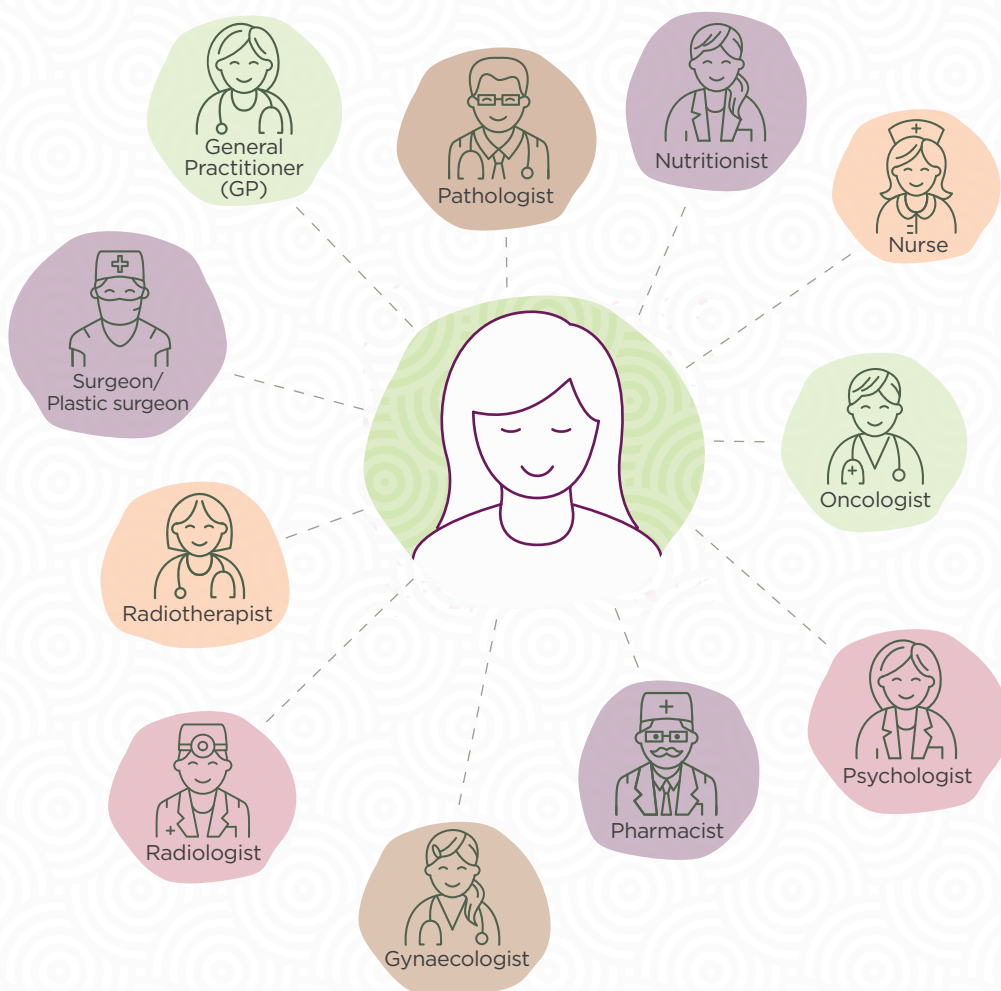
## **Journal:**

(How are you feeling? What makes you feel better? e.g. a walk, meditation, a creative activity etc)



# THE HEALTHCARE TEAM

There are a number of healthcare professionals from different disciplines who will support you throughout your treatment, referred to as a multidisciplinary team. You play an important role in discussing your treatment with your team to help ensure the right decisions are made for you and with you.<sup>74</sup>



*Note: the healthcare team can vary depending on country and/or hospital as well as on the individual patient case. Also, most members of the healthcare team may be connected, but not all.*

# GLOSSARY

Chemotherapy:	A treatment used to kill fast-growing cells in the body, such as cancer cells
Chest wall:	The muscle, bones and joints in the chest area
Cognitive Behavioural Therapy:	A type of talking therapy that aims to change the way you think and behave
Complementary therapy:	Therapies that can be used alongside medical treatments, such as massage, acupuncture, hypnotherapy etc.
Early breast cancer:	Breast cancer that hasn't spread beyond the breast or the lymph nodes under the arm
Grade:	The appearance of cancer cells compared to normal cells. A lower grade looks more like normal cells and isn't growing quickly
Hormone therapy:	Drugs that block the effect of hormones on cancer cells
Hormones:	Chemical messengers produced by the body to control growth and reproduction
Local recurrence:	Breast cancer that has come back in the same place, or near, where the cancer was found before
Lymph nodes:	A small bean-shaped structure that is part of the body's immune system. Sometimes called lymph glands
Lymphoedema:	Swelling caused by a build-up of lymph fluid in the surface tissues of the body. It can occur if there is damage to the lymphatic system, for example, because of surgery or radiotherapy

# GLOSSARY

**Metastatic recurrence:**

When cancer has come back and spread to other parts of the body such as the bones, lungs, liver or brain

**Occupational therapist:**

Healthcare worker who helps people who have difficulties carrying out day-to-day activities because of a disability, illness, trauma, ageing, and a range of long-term conditions

**Osteoporosis:**

Health condition that causes bones to become weak and brittle

**Prosthesis:**

Artificial form that takes the shape of the breast

**Quality of life:**

General wellbeing of people and how their life is being impacted by a condition

**Reconstruction:**

Surgery to rebuild the shape of the breast

**Recurrence:**

When cancer comes back. There are different types of recurrence

**Regional recurrence:**

Breast cancer that has come back and has spread to the chest wall or skin of the breast, or the lymph nodes around the chest, neck and under the breastbone

**Risk factor:**

Something that increases your chance of developing a disease

**Side effect:**

An unwanted effect of a medication or therapy

**Stage:**

The size of the cancer and how far it has spread

**Tumour:**

Overgrowth of cells that forms a lump (can be cancerous or non-cancerous)

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