

Healthy Living, Healthy Mind- Dealing with the emotional impact of cancer

Hormone therapy is the most effective way to reduce the chance of the breast cancer coming back. Being active and having a healthy diet can help too! Why not try to **combine hormone therapy with a healthy lifestyle** to reduce your risk of breast cancer coming back.

In this section you can find suggestions, hints and tips for making changes to your lifestyle or looking after your physical and mental health. These are based on research and conversations with women taking hormone therapy. They may also help with some of the side-effects of hormone therapy that you might experience.

Why should I combine hormone therapy with a healthy lifestyle?

Some people don't like the idea of taking medicines. They may have heard that other methods can be used to manage cancer risk, like special diets, herbal or other alternative treatments, or simply maintaining a healthy lifestyle and positive attitude. It's true that anything you do to maintain a healthy lifestyle - like healthy eating and staying active - can only help. However, in terms of reducing the risk of breast cancer coming back the evidence is strongest for hormone therapy, and it is best if you are able to combine taking HT with a healthy lifestyle. Research shows that hormone therapy works and combining it with a healthy lifestyle is the best way to reduce your risk of breast cancer coming back.

This section includes information on the following topics:

- Living well after cancer
- Living well in the social world
- Living well in your internal world
- Living well for the future
- Mood & anxiety disorders, and recognising when you need additional help
- Further help and support



Dealing with the emotional impact of cancer



This section has been written by Dr Alex King, Consultant Clinical Psychologist in Cancer Care at Imperial College Healthcare NHS Trust. Alex is an expert in the psychological care of people living with and beyond cancer.

Living Well after cancer

We often hear from women that breast cancer is a 'wake-up call', causing them to reflect on their lives and make changes. This may include changes in day-to-day things like diet, exercise, alcohol consumption and smoking, or thinking about making bigger "life changes", for example around work-life balance or relationships. This reflection can also bring up a lot of emotions.

"I mean I'm generally an incredibly positive person, I'm never glass half empty, never. It just doesn't work for me, but you do have a little cloud that hangs over your head and follows you around. I would say that little cloud becomes less important as time goes on but in those first few months when you start your treatment, when you've finished your hospital treatment and you're on your own and it's quite an emotional and difficult and challenging time because all of a sudden you're on your own."

Annie, Breast Cancer Patient, Age 59

It's completely normal to go through many different emotions as you adjust to life after cancer. You and your body have been through a lot and it may take some time to fully process this. You can use this section as a space to reflect and consider how best to take care of yourself.

This section will look at three broad areas of wellbeing.



Living well in the social world

There is no doubt that the experience of cancer will bring some changes to your relationships with others. Women often have questions about whom they should, or could, talk to and how best to do that.

Who to talk to about what?

After hospital treatment, when starting to return to a more usual pattern of social life, women often describe a dilemma around how they want to be seen. On one hand, you may want to be seen and treated by others exactly the same as you were before, and yet on the other hand, you may want to be treated with some particular care and consideration.

You may want to think about what it is exactly that you need from different people in your life.

- If you do want a particular relationship to feel like it did before it's ok to talk less about cancer and focus more on doing stuff together like before.
- If you do want people to acknowledge your cancer, then take the lead and explain what they can do to help you. Try to be specific. Most people will not have a clue what you will need, and may even assume it's all fine if you've 'finished' your hospital treatment. Remember that most people don't know that hormone therapy treatment for breast cancer can continue for many years.

Communicating with your partner

The people you are in a committed, close and intimate relationship with will have seen up close how the cancer 'journey' affected you.

They will have tried to cope with that from their side – maybe being very practical, sensitive and caring, or maybe distanced and uncommunicative. It's likely that they will also have been affected by this experience and may have their own needs and concerns.

Having good communication is really important, especially at this stage, as recovery and survivorship can come with new challenges.

Lead the way by creating the time and space to talk openly with one another (at a good time, not a stressful or busy time, or within another argument). You can share what you are grateful for and also ask what you would like to be done differently. Be open to listening to their requests as well.

You may want to discuss together how you will continue to talk about cancer in your extended family and social life – your preferences are important, but the other



person has a stake in this too. That said, the strain of cancer can often bring up and worsen previous tensions, problems or arguments. Relationship counselling or family therapy, if accepted by all sides, could help address these.

Talking to children

Younger & adult children will also have a part in the cancer 'journey'. You may be worried about burdening or worrying your children, and keeping your role as a parent as much as possible unchanged. Hopefully you can reject any passing thoughts about 'being responsible' for bringing this trouble to your children – we don't bring cancer, it happens to 1-in-3 of us.

It could be valuable for your children if they can learn from you now about how to support each-other and how to cope with difficult circumstances. Marking anniversaries (e.g. the year since diagnosis) together can create an opportunity to listen and talk about difficult times as well as look ahead with hope, and appreciate what good there is

You can read more about talking to others in the Help and Support section (which also includes some practical tips) and there are some useful links at the end of this section.

Living well in your internal world

Almost all women report feeling some kind of psychological impact from their cancer experience. Women talk about a complex mix of shock, sadness, worry and positive change.

"You are never the same person. I don't mean that in a negative way either. I mean that in a positive way...I spent so many years holding on to negative things, negative people, I don't really need that in my life anymore. So that helped me come to terms with that fact and what time I have got left on this planet I intend to use it very wisely and in a kind way and embrace all the positivity that is around. So that's all about the mindfulness and mental health side I'm trying to get at there."

Karen, Breast Cancer Patient, Age 54

In the next part, we will touch on understanding this psychological impact, making space for thinking about what has happened to you, and responding to your thoughts and feelings with compassion and skill. This is all part of the process of "psychological adjustment" following a significant life experience, like cancer.



What do we mean by psychological adjustment?

The term 'psychological adjustment' refers to the process of coming to terms with a significant life event like cancer. We often say we want to 'go back to normal' or to what life was like before the cancer. However, it is very unlikely that anyone will be left unchanged by this experience.

Adjustment is about the changes that follow the cancer and how you come to terms with them and feel ok about them.

It is normal for the process of adjustment to have many ups and downs. The main thing is to be patient and accept these changes as they come.

There are often some unwanted changes – for example, changes in appearance or energy levels. There may be lots of learning and changes in the way you see yourselves. For example, you may see changes in your hopes, your values, your relationships with others and your sense of independence.

And some of these changes may be welcome changes – for example, a sense of being stronger, wiser, more selective in friendships, more compassionate or more self-assured.

Making space to reflect

After all the pressures of being on treatment, at the beck-and-call of hospitals, it is often a good idea to allow time to recover emotionally as well as physically.

As much as 'getting on with normal life' can be welcome and necessary, or perhaps a sense of 'catching up for lost time' feels urgent, consider if you can invest some time in recharging first.

It may be less visible from the outside, but remember that important stuff is going on inside. You may take this time to reflect and talk to loved ones about how you are feeling. Some women prefer doing a relaxing activity like swimming, hiking, running or doing a craft. You may also find it useful to write down some of your thoughts in a journal or a diary. A change of scenery and travel, if possible, can stimulate a reflective state of mind.

You may find it helpful to read the article 'After Treatment Finishes' by Consultant Clinical Psychologist Peter Harvey. You can take a look by typing this weblink into your browser: https://www.workingwithcancer.co.uk/wp-content/uploads/2013/03/After-the-treatment-finishes-then-what.pdf

Dealing with thoughts & feelings

Having (or taking) time to reflect can make you more aware of your thoughts and feelings. It may be that some of the impact of what you have been through is only



just hitting you now. You may also feel there is an empty space where advice and guidance from healthcare staff used to be.

It's completely normal to have all kinds of thoughts rushing around your mind. These may be questions, worries, hopes or frustrations. But remember, you do not actually have to find perfect solutions or plans for all these thoughts and concerns. It is often helpful to take a step back, take a breath, and consider – is this an actual solvable thing? Is your mind actually being useful and practical, or is it just whizzing around? Is more thinking going to crack the problem?

If it is a solvable problem – then find a good time (but not the middle of the night!), to break the problem down into steps and make a plan for what you are going to do.

If not – accept that you may have these thoughts, but that you don't need to follow them. Instead, visualise putting them aside – on a mental shelf – and turn your attention back to the current moment: how will you make the day today a little bit better? Turn your focus from the inside of your head to the outside world – try some exercise, relaxation, creativity, or socialising. You can find some useful resources at the end of this section.

If you are finding worry, tension and fear to be intense, persistent and troubling, this may need specific clinical attention. See the next section below on mood and anxiety disorders for some tips on getting support.

Self-compassion

Most people would agree that we should be kind to ourselves, especially when going through a tough time like cancer. However, you may find that being kind to yourself doesn't come easy.

This may come from growing up in difficult circumstances, or if other people have not treated you with kindness. You may feel that being kind means letting your guard down or accepting defeat.

It's important to try and be kind, gentle and forgiving to yourself, even when accepting that you may feel moments of fear or doubt. You can develop self-compassion by talking to yourself in the same way that you might speak to someone else that you care about. Instead of judging yourself for how you are thinking, you can stop and tell yourself how difficult this situation is and think about how you can best comfort yourself.



Living well for the future

While undergoing treatment, it's normal to feel like you want to get it over and get back to living. Then – one day you get there, and hospital treatment finishes. How do you live – and can you live well – after this?

As we mentioned before, it is unusual that life goes back to exactly what it was. Not only is the present very different, but our sense of the future is also different. Women often describe mixed feelings, with hopes, goals and fears all up in the air.

Worrying about the cancer coming back

We know very well that, for most people, the fear of cancer coming back is vivid and hard to shift, even when they know the statistics are very positive.

As you move forward you may find that these feelings are particularly heightened around your follow up appointments or hospital visits. For example, you may find having a mammogram stressful, and it may be on your mind a lot in the weeks before.

Even in the months or years between hospital visits, cancer thoughts can be triggered – by a story, an anniversary, a random word or image. At its most intense, some people report daily preoccupation, persistent stress, not wanting to make plans, and constantly expecting the worst.

Here are some ideas that may help you to manage these feelings:

- Remember that these thoughts and feelings about cancer returning won't always be as strong as they are in the beginning. For most people, they will subside with time (over months and years, though, not weeks). As the years roll by, and all remains well, the worst fears don't come true and you gradually regain trust in your body. 'It will pass' can be a very soothing thing to say to yourself.
- How you speak to yourself about your cancer outlook can also help. Try and frame things in a more balanced way. For example, instead of saying to yourself 'I don't know if the cancer will come back', you can say 'I had all the treatment, it's been clear so far and for most people it doesn't come back there is a good chance it won't bother me again'. Noticing your thoughts and actively stepping in to balance them can be very helpful.
- While you cannot control having worried thoughts pop up in your mind –
 there will be lots of triggers you can choose not to continue thinking about 'what-if' scary future scenarios. It is the difference between having a thought,



and following a thought. Put effort into noticing the worry, and develop your ability to not engage with it – 'not doing this now, not useful' – instead, focus on something real and relevant in the present moment. Remember, you are not trying to stop or control all your thinking – you are choosing where it is useful to focus your attention.

- If you find that despite your best efforts, the worry and fear is constant, very hard to manage, and has a direct impact on how you function every day (e.g. You cannot concentrate because of worry) or live your life (e.g. you cannot make any plans) then please do seek clinical help. It may be that with some more careful and clear explanations of the clinical outlook by your doctors you will feel more reassured and steady. If you realise that no matter how much you are told, the fear does not shift, you may benefit from a psychological approach to help you to adjust.
- You may also find it helpful to read Breast Cancer Now's information on symptoms of recurrence. To read this, type this weblink into your browser: https://breastcancernow.org/information-support/facing-breast-cancer/living-beyond-breast-cancer/life-after-breast-cancer-treatment/coping-emotionally/breast-cancer-recurrence-symptoms

Mood & anxiety disorders and recognising when you need additional help

As we discussed, it is very common to experience distressing thoughts and feelings in response to cancer. Most of these concerns can resolve with advice, information, support and self-help.

But sometimes these feelings can become too intense, persistent, unmanageable and overwhelming, to the point of getting in the way of recovery. In other words, they are not just a normal part of the process of adjusting, but a mental health problem.

Studies show that roughly 1 in 10 women (or 10%) could be diagnosed with clinical depression after cancer, which is more than woman of similar age without cancer (1 in 20, or 5%).

In this section, we will talk about recognising signs and symptoms of psychological difficulties that need clinical assessment from healthcare professionals.

You may not be sure where the tipping point is between 'normal' stress and a clinical disorder. As a general rule, if you are troubled, not your usual self, it's getting worse or not changing for a substantial time, and affecting your work or relationships: talk to your GP or breast cancer team. They will help you take stock and refer you for specialist assessment if this is required.



Women who have had past psychological difficulties and mental health disorders (such as traumatic stress disorder, panic disorder, generalised anxiety or depression), are particularly advised to monitor their wellbeing during the stresses of cancer treatment and recovery.

Anxiety

Look out for: persistent thoughts and feelings of: tension, agitation, stress, being on edge, fearing and imagining the worst, being irritable, unusually disturbed sleep (over and above night sweats), persistent bad dreams, physical sensations like pain becoming filled with panic & extra anxiety, going to great lengths to avoid something.

You can find out more about anxiety disorders by typing this weblink into your browser: https://www.nhs.uk/mental-health/conditions/anxiety/

Mood

Look out for: gradually slipping into feeling flat or 'slowed down', persistently feeling bleak, detached and uninterested, withdrawing and preferring to be alone, irritable and unusually intolerant, unable to think clearly or concentrate, welling up in tears much more easily or unpredictably, feeling there's little point in planning or looking forward.

You can find out more about mood disorders by typing this weblink into your browser: https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/feelings-and-symptoms/low-mood-sadness-depression/

While it's not unusual for these reactions to settle with time, support and self-care, it's very much recommended to seek clinical advice. There are therapies (different types of medication and psychological therapies) and many sources of support that can ease or resolve these difficulties, for most people. Start somewhere, with speaking to your breast cancer team or your GP.

You can find some practical tips about how to speak to a health professional in the **Help and Support** section



Further help and support

Support from Breast Cancer Now Nurses

You may find it helpful to use the confidential 'Ask our nurses' email service on the Breast Cancer Now website, especially if you find it difficult to talk to someone in person. To access this, type this weblink into your browser:

https://breastcancernow.org/information-support/support-you/email-our-nurses

Where can I speak to other women?

You do not have to cope on your own. You may find it helpful to join online forums and support groups to talk to other women who are in a similar situation to you. One example of this is the Breast Cancer Now online forum, to access this, type this weblink into your browser: https://forum.breastcancernow.org/

Other websites and resources

To take a look at the following resources, type the weblinks into your browser:

- To read tips from Maggie's on managing anxiety around follow up appointments: https://www.maggies.org/cancer-support/managingemotions/fear-cancer-returning/
- To read tips from Maggie's on talking to others: https://www.maggies.org/cancer-support/managing-socially/talking-people/
- To read the Macmillan booklet on worrying about cancer coming back: https://be.macmillan.org.uk/Downloads/CancerInformation/TestsAndTreatments/MAC14215WorryingaboutcancercomingbackE01lowrespdf20131023.pdf
- To read Cancer Research UK resources for relationship counselling: https://www.cancerresearchuk.org/about-cancer/coping/emotionally/talking-about-cancer/counselling/counselling-organisations

Resources on mindfulness, relaxation and meditation

More information on coping with worries - The Worry Tree. To access this, type this weblink into your browser: https://www.getselfhelp.co.uk/docs/worrytree.pdf

You may also find the book 'Mindfulness Living with the Enemy: Coping with the stress of chronic illness using CBT, mindfulness and acceptance' by Ray Owen helpful. This is available online or in bookshops.



General resources to help with the psychological/emotional impact of cancer

Breast Cancer Now Moving Forwards Course: This is currently run online and is open to anyone who has finished their hospital-based treatment within the last two years. You can connect with others and get tips for managing physical or emotional changes and improving wellbeing. To register online, type this weblink into your browser: https://breastcancernow.org/information-support/support-you/moving-forward-online-course

You can also download the Breast Cancer Now Moving Forward Book or Becca app which also provide lots of information and support for moving forwards and living well after treatment.

- The Breast Cancer Now Moving Forward book: https://breastcancernow.org/information-support/publication/moving-forward-people-living-beyond-breast-cancer-bcc197
- Becca app: https://breastcancernow.org/information-support/support-you/becca

The Complete Guide to Breast Cancer: How to Feel Empowered and Take Control by Professor Trisha Greenhalgh and Dr Liz O'Riordan. This book is written by two doctors who have experienced breast cancer first-hand. It covers topics such as coping with the emotional burden of breast cancer, staying healthy after treatment and dealing with fear of recurrence.

Resources for self-care and self-compassion

- To read Breast Cancer Now's tips for self-care, type this weblink into your browser: https://breastcancernow.org/information-support/facing-breast-cancer/living-beyond-breast-cancer/your-self-care-toolkit
- To read Breast Cancer Now's 10 tips to boost self-esteem, type this weblink into your browser: https://breastcancernow.org/about-us/news-personalstories/10-tips-boost-self-esteem