

# Managing side-effects - Mood Changes

Some women experience one or more side-effects from taking hormone therapy, others do not. There is no way to predict who will experience side-effects, and who won't.

It's important not to assume that any unwanted effect you might be experiencing after breast cancer is solely due to hormone therapy. There are a range of possible causes, such as other treatments (e.g. chemotherapy) or medicines. The normal ageing process and the menopause can also account for some symptoms women can experience. So stopping hormone therapy would not necessarily mean symptoms would disappear.

Side-effects can vary in level of intensity and this can change over time; a side-effect may become less frequent or intense or disappear altogether as time goes on. Again, it's not possible to predict whether this will happen to you. Rather than looking at all the side effects now, you may find it helpful to come back to this page if and when your side effects change.

The good news is that **there are many things that can help with side-effects.** This section includes information about some of the most common side-effects women can experience, and a range of tips and hints for managing these.

This section includes information on the following topics:

- Why might you have mood changes?
- Is all this emotional stress bad for you?
- Challenging negative thinking
- Tips for managing mood changes and irritability
- When to seek further help
- Further help and support



# **Mood Changes**

We know that hormone therapy can often have a direct (that is, biological) effect on a woman's emotional balance. This is due to changes in the body's hormones (and oestrogen specifically).

Some women describe this experience as 'feeling' more intensely – that both pleasant moments and low moments can become intensified, going higher and lower. Some describe this as 'mood swings'. Some women find that the 'lows' are more prominent, and they feel more unpleasant feelings like sadness, depression, irritation or anxiety

These changes in mood are common in all breast cancer survivors, not just in women who are taking hormone therapy.

This section will help you understand and find ways to manage these mood changes.



This section has been written by Dr Alex King, Consultant Clinical Psychologist in Cancer Care at Imperial College Healthcare NHS Trust. Dr King an expert in the psychological and social aspects of a cancer diagnosis and long-term consequences.

# Why might I have mood changes?

The effects of hormone therapy on mood mix with the very normal psychological impact of a cancer diagnosis and treatment, and the transition to living with and beyond cancer.

This transition is a process, and it takes time - recovering from treatment, reorienting to living, adjusting to a changed body, living with uncertainty, etc. During this time, it is entirely normal to experience strong feelings and mood changes. Many women also say that they miss the support that they had during treatment from their breast cancer team or from their friends and family.

Experiencing these emotional changes because of the hormone therapy may also re-activate past struggles with mood, anxiety, bereavement or traumatic experiences. It's like coming across a smell or taste that brings back the whole memory and experience of a place and time long ago. The feelings now may be



similar to the feelings then, and so they trigger the whole set of memories about that earlier time – even if the situations now and then are not the same and the problems long ago resolved.

So, there can be several 'layers' to a woman's emotional state, at this point:

- hormonal changes affecting emotional balance
- living with side effects of treatment, such as hot flushes/night sweats, fatigue or joint pain
- emotional impact of re-adjusting to life following the end of hospital treatment and
- triggering of past emotional challenges.

Given this, it's not surprising that women can sometimes find their mood is affected by taking hormone therapy, either very up and down or quite low a lot of the time.

#### Is all this emotional stress bad for me?

Of course, emotional stress is not pleasant, and not welcome. We would all very much prefer to put it all behind us, and 'get back to normal'.

However, we need time to recover physically and emotionally. As part of that process of re-adjustment, we should expect (and allow for) stress and emotional upsand-downs.

**Having strong emotions at this time is not bad or dangerous.** Doctors often hear from people who are concerned that having strong emotional reactions (usually the unpleasant ones, like fear, sadness, shock, anger, bitterness) means that:

- they are 'not coping'
- they are causing harm to their recovery
- they are going to get cancer again
- they are letting others down.

There are many reasons why people think this, and it is not surprising. It is common in our culture that we praise people who are calm and 'cope well'. There is also a widespread belief that 'stress causes cancer'. So, it follows that, 'being emotional' means losing control, not coping and causing oneself harm.

None of this is true. There is some evidence that long term chronic stress (such as abuse, poverty, or racism) may affect the body's immune system. However, this is



not true for short term emotional responses to cancer, which are normal, relevant and a healthy part of adjustment.

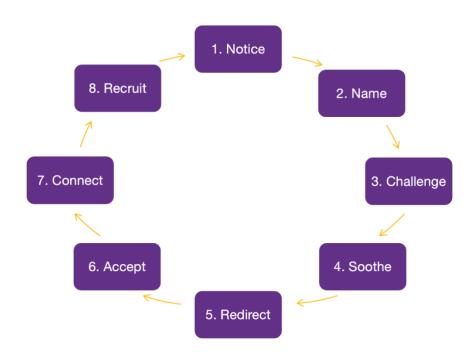
Although stress and emotional changes can be normal parts of adjusting to a breast cancer diagnosis and treatment, this does not mean that we do not support, advise, and guide people in how to deal with this.

In the Healthy Living, Healthy Mind section, we cover some of the main aspects of adjustment after cancer treatment, and offer some guidance to support a positive process of adjustment.

In other parts of this section, we focus specifically on managing the side effects of hormone therapy on emotional changes or 'mood swings'.

## Challenge negative thinking

This section provides some advice from Dr Alex King for how you can manage your mood changes. This advice is suggested as a series of steps that you can work through to try and become aware of your mood, to challenge any negative thinking and to reach a place of acceptance. These steps are based on ideas around acceptance and mindfulness, as well as cognitive behaviour therapy. They have been shown to be effective at improving mood in women with cancer.





#### **Notice**

As soon as you notice a strong emotion or 'mood swing', pause and take notice: What is your body feeling? What is going through your mind? Some people visualise looking from above, or physically take a step back to 'observe'. Even if these are intense and unpleasant emotions, try to approach them with curiosity and an exploring attitude. As you learn and notice patterns, create a mental list so that you can more easily 'tick off' what you notice.

#### Name

Name what you are experiencing. For example, 'Ah, yes, these are the emotions that come with hormone changes'. Some people enjoy giving it a silly name or character – if you can find an edge of humour in this, it can 'break the spell'.

#### Challenge

We all engage in automatic thinking sometimes – these are instantaneous thoughts that we have about situations, often without even realising we have them. Become aware of and challenge any automatic thinking about your mood that is judgemental, catastrophising (assuming the worst will happen), hopeless or self-critical – and give yourself a realistic, supportive, and more balanced response.

Here are some examples of automatic thinking and more self-supportive responses. You may want to try and develop some of these responses for your own automatic thinking

Automatic thinking	Self-supporting response
'I should not be having this.'	'I don't like having this reaction, but it's not unexpected, it's-a completely normal part of cancer treatment and adjusting to life'
'Having this stress is dangerous'	'The hormone therapy actually reduces risk, and these emotions are not dangerous.'
'This will never end'	'This is just an intense moment, it will pass, and I know that with time these settle for most women.'
'I should be doing better'	'I can't do much about having these emotional changes, it's just the cancer and hormone therapy. I am doing my best to accept and work around this'



Notice what kind of thoughts you have about yourself and the way you are coping with hormone therapy, or just coping with life in general. You can use this box to note down any thoughts you notice that are self-critical, negative or judgemental. Now have a go at coming up with some more helpful, positive self-supporting responses. It might help to ask yourself:

- is this thought really accurate?
- what would a close friend/family member say to me?
- what would I say to them if they were struggling in this situation?
- what would a self-supportive alternative be?

You can write these in the boxes below:

Critical, negative thoughts	Supportive, neutral thought	S
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	<b>→</b>	
	<b>→</b>	
	<b>→</b>	

## Soothe

Give yourself the time and care needed to let the feelings settle. Relaxation and paced breathing (slow, deep breathing from your diaphragm/abdomen) can be very useful here, to reduce the intensity of the emotional response. This may take a little while, but don't put too much pressure on yourself. Try to notice any pressure and thoughts like 'get over it, I don't have time for this'. Bring in a self-supportive response like 'I can't rush this, it's not the end of the world – I can allow myself some time after all this.'

Think of it like riding the waves in a storm – no matter how big your boat, you won't control the weather, you have to navigate smoothly and let it pass.



#### Redirect

After a while, and with patience and kindness, shift your attention from your thoughts and bodily reactions towards the outside world. Think about what you could be focusing on instead, that would make this moment brighter, more helpful, creative or constructive. You may want to have a few small projects on the go that you can turn to at times like these. This might be gardening, doing a craft, writing, reading or doing some housework.

## **Accept**

When (inevitably) another wave of emotion comes, welcome it ('ah, here we go again') and ride it out once more. Congratulate yourself for getting wiser and learning to cope with these emotions.

Or sometimes, if you get caught up in the storm, and get swept away before you notice, and it is hours before you wash up on a beach somewhere else: Think to yourself 'okay, it happens'. Don't be too hard on yourself. You will be wiser and more prepared next time. Have a consolation cup of tea.

#### Connect

In parallel to working this out on your own, also consider if you would be open to learning from other women, by joining a forum or group. You may want to be active and ask questions, or just quietly observe and listen — either way, we know that peer groups can help us feel less isolated, help us to learn in a practical way and motivate us to copy useful coping.

You can find some useful links for support groups in the **Further Help and Support** section of this document.

#### Recruit

There will be many people who won't get what you're going through. Hopefully, there are still some people around you who are open, honest and supportive. Consider recruiting them to support you — explain what you're feeling, tell them how you're trying to cope (ask them to read this, perhaps) and ask them to help you by nudging you to remember and keep up your efforts to notice and challenge your thoughts.



# Tips for managing mood changes and irritability

Here you can find some practical tips you can try when you experience low mood, mood changes or irritability. These things should also help to improve your general health and wellbeing

## Improve your mood

Here you can find some practical tips you can try when you experience low mood, mood changes or irritability. These things should also help to improve your general health and wellbeing.

## Talk about how you are feeling

One of the most important things you can do is to talk to others about how you are feeling. This often helps to reduce the tension you may be feeling. Your friends and family might not be aware of what you are going through, and they may be better able to support you once you tell them how you are feeling. Remember that feelings of stress, low mood or anxiety are common and you shouldn't have to hide them from people close to you.

You may also find it helpful to speak to other women with breast cancer. Breast Cancer Now's 'Someone Like Me' service can put you in touch with a volunteer who has finished their breast cancer treatment and has been trained to support other women with breast cancer. For more information, or to speak with a volunteer, complete the webform on their website, type this weblink into your browser: https://breastcancernow.org/information-support/support-you/someone-metelephone-support

You can also speak to other women in support groups or online forums. To find a support group, look at the **Further Help and Support** section within this document.

If you would like to speak to a trained professional, you can contact helplines such as the Breast Cancer Now Helpline on 0808 800 6000. These helplines provide tailored information and specialist support for people affected by breast cancer.

## Be active and exercise regularly

Being active and exercising regularly can help improve mood. When we exercise, our body releases endorphins which can lower our stress hormones and improve mood. Exercising can also provide a sense of satisfaction, pride and self-esteem. Joining a walking group or an exercise class can also provide some social contact for people who are feeling isolated or lonely.



"Group exercise at Maggie's has been a great help both in motivating one and providing social contact where others understand how one feels."

Kiran, Breast Cancer Patient, Age 74

"Was as active as possible all the way through my treatment - surgery, chemo, radiotherapy and hormone therapy. It has been essential for my mood and selfesteem; and I had read that it would help manage all the side effects of treatment and menopause."

Dolly, Breast Cancer Patient, Age 53

You can find more about being active, including useful resources and tips for getting started, in the **Healthy Living**, **Healthy Mind** section of the HT&Me website.

## Take care of your body

**Maintaining a healthy diet can help to improve your mood.** This involves following sensible drinking guidelines and avoiding consuming too much caffeine or sugary foods. Consider stopping smoking if you are currently a smoker. You can read more about diet and smoking, and get tips and advice, in the **Healthy Living, Healthy Mind** section of the HT&Me website.

Making sure you get enough sleep is also likely to improve your mood. You can read more about sleep in the **Sleep Problems** section of the HT&Me website.

#### Make time for yourself

As well as taking care of your body, it's also important to **take care of your mind and be kind to yourself.** Many women find it helpful to engage in hobbies to keep them busy and distract themselves from a low mood. These hobbies can also provide a sense of pride or self-esteem, and often give a social interaction as well.

Some people find it helpful to try and do one positive thing for themselves each day. This might be listening to music, having a bath (if you can tolerate the hot water!), going for a walk or spending time with pets or family. Try to make time for yourself to do these little things that you love, and don't feel guilty for taking care of yourself.

"I would advocate keeping going with hobbies as much as possible especially if you go to weekly classes to give something to aim for, a focus to each week



and probably social interaction e.g. I was back at my weekly piano class 10 days after my op (admittedly a bit groggy!) and have continued ever since."

Patricia, Breast Cancer Patient, Age 76

"I also make sure I get out into the fresh air everyday as I find this helps an awful lot to maintain a reasonable state of mind."

Ruth, Breast Cancer Patient, Age 58

You also may want to **try meditation or mindfulness to help you relax.** These are techniques to help you to notice what is going on in the present moment. they help people to feel more calm and more able to deal with stressful or unhelpful thoughts. The Further Help and Support section in this document contains links to resources on using meditation, mindfulness and relaxation to help your mood.

## Deal with irritability

Tips for coping with irritability:

- **Notice how your body feels.** Try to notice the signals that you are becoming irritable. This may be muscle tension, shallow breathing or sweating.
- Consider what it is that is making you irritable. Sometimes simply knowing
  what is making you feel on edge can reduce the tension. Instead of lashing out
  at those around you, try simply telling them that you are feeling irritable and
  not yourself.
- Take a moment to take a few deep breaths. Use this time to step back and consider the bigger picture. Will you still be annoyed about this in a few days' time?
- Treat yourself with compassion, and allow others around you to be compassionate to you.
- Take a break. If you are feeling like you are snapping at those around you or are becoming frustrated with a task, it is often a good idea to take a break. You may find it helpful to go for a slow peaceful walk or to go for a run to burn off some of the tension. You may also try to listen to some music, have a bath, or do some yoga.
- **Reduce caffeine and alcohol** as both can be triggers for irritability. You may want to try cutting down on these and seeing if it changes how you feel.
- Consider seeking additional help if you feel that your irritability occurs alongside low mood and feelings of hopelessness or helplessness, as this may be a sign of depression.



## When to seek further help

As we discussed above, emotional changes (like mood swings, a sad day, a moment of panic) are common, normal and part of the process of adjustment.

However, it is sometimes possible to dip further than normal, into a state of mind which feels overwhelming and 'stuck'. In this case, a diagnosis of clinical depression (or other mental health disorder) may be relevant.

A period of clinically significant depression can happen to around 1 in 10 women after breast cancer. This is slightly higher than the risk in the general population, so it's important to make you aware that this can happen.

For women who do experience clinical depression, self-help isn't enough, and they will need some external help.

If you notice that most or all of the time, for at least two weeks, you are feeling low in mood, are not finding your usual pleasures or interests in everyday life, are withdrawing or being very irritable, are close to tears and easily overwhelmed or are constantly thinking the worst, we strongly recommend that you tell a healthcare professional that you trust (maybe your GP, cancer nurse specialist or consultant).

If you are worried about speaking to someone about how you feel, you can find some practical suggestions for how to talk to a health professional in the **Help and Support** section which can be accessed from the homepage of the HT&Me website.

Learn more about the treatment of clinical depression in cancer by typing this weblink into your browser: https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/depression



# Further help and support

#### What should I do if these problems are really impacting on my life?

If these hints and tips do not help and your mood becomes very problematic for you and badly impacts on your day-to-day life, it is important to talk to your breast cancer team or GP. They may be able to suggest something which will help.

## Helplines

To access the following helplines, call the following numbers or type the weblinks into your browser:

- For Breast Cancer Now call 0808 800 6000 or type: https://breastcancernow.org/
- For the Macmillan Support Line call 0808 808 0000 or type: https://www.macmillan.org.uk/
- For the Samaritans call 116 123 or type: https://www.samaritans.org/

## Other sources of 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 with problems with mood 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 take a look, type this weblink into your browser: https://forum.breastcancernow.org

Or, if you would prefer something in person, you can find a support group local to you. To take a look, type this weblink into your browser: https://www.macmillan.org.uk/in-your-area/choose-location.html

#### Resources on mindfulness, relaxation and meditation

To take a look on the following resources on mindfulness, relaxation and meditation, type the following weblinks into your browser:



- For tips on relaxation and mindfulness from Mind: https://www.mind.org.uk/information-support/tips-for-everyday-living/relaxation/relaxation-tips/
- For an online programme for Mindfulness-Based Cognitive Therapy: https://www.bemindfulonline.com/
- To download Headspace or browse free online guided meditations and mindfulness exercises: https://www.headspace.com/
- For Kara, a web-app developed to provide range of guided mindfulness meditations designed to support people affected by cancer: https://thisiskara.com/
- For the Oxford Mindfulness Centre: https://www.oxfordmindfulness.org/

If you feel that you have tried everything and the side-effects are still unbearable, do talk to your breast cancer team or GP who will be able to help you decide what to do. Often, they will be able to switch you to another form of hormone therapy or prescribe an additional treatment to help you. If that still doesn't work, the best decision for you might be to stop taking hormone therapy. Ultimately it is a personal decision taking into account the risks and benefits and what is right for you.