

# Managing side-effects - Fatigue

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:

- What can help with fatigue?
- Changing the way you think and feel about fatigue
- Further help and support

# **Fatigue**

Many women who have had breast cancer feel very fatigued. Fatigue is a feeling of extreme tiredness and exhaustion but is different to just feeling tired because it does not necessarily go away after sleep and rest.

Fatigue can be debilitating and affect many areas of life which can make it challenging to cope with and manage.



Fatigue can be caused by the long-lasting effects of the cancer itself, or other cancer treatments. This can make it **difficult to work out exactly what is causing your fatigue.** For example, if you have had chemotherapy and/or radiotherapy you may experience fatigue that can last weeks or even months after your treatment has finished. Fatigue can also be caused (or made worse) by other things such as your mood, sleep, diet and how active (or inactive) you are. So, stopping taking your hormone therapy may not necessarily improve your fatigue.

# What can help with fatigue?

These are some things that you can do that may help you to manage or cope better with fatigue.

Below are some hints and tips you may find helpful for managing your fatigue. These tips are based on evidence from research studies, and also the experiences of women similar to you who have taken hormone therapy for breast cancer who told us what helped them with their fatigue.

## Keep a diary of your fatigue

Try to keep a record of when you feel most fatigued, and most energetic. You can use My Hormone Therapy Diary on the HT&Me website to do this. You can make notes if there are certain times of the week, or the day, that your fatigue is worse. Are there certain activities that make you feel more exhausted than others? Are there some foods or drink that affect your energy levels? Do you have more energy in the morning compared with the evening? Being aware of this could help you to plan your time most effectively.

If you plan to ask your GP for help or referral to a specialist service, you can share your diary with your GP.

#### Plan ahead

Many women describe how planning days around when you are likely to feel most energised or most fatigued is helpful for managing fatigue in day-to-day life. For example, if you have identified that you have most energy around lunchtime, that may be a good time to schedule in any social events or tasks that need doing.

"I was exhausted all the time. This has eased up to some extent, but I'm not the same as I was. I can basically manage one 'thing' a day; a short walk,



coffee or lunch with a friend, a few hours work at my desk, hoovering one room, a zoom lecture... but then I'm done in for the day."

Tracy, Breast Cancer Patient, Age 60

#### Keep active

It may sound counter-intuitive because the last thing you may feel like doing when you have no energy is to be physically active. However, there is good evidence to suggest that increasing your physical activity can be helpful for reducing physical fatigue, painful joints and muscle aches, as well as boosting your mood and helping with sleep.

"I struggled with fatigue for some time, and my advice would be to try and force yourself to do some exercise because it couldn't very well make you feel that much more tired than you were – and fatigue is different from tiredness!"

Lauren, Breast Cancer Patient, Age 56

"I have found that regular exercise (walking at least 5 days a week) has helped combat any bone and joint pains as I feel none, and has given me energy (no fatigue) and in turn has helped my mental well-being."

Diana, Breast Cancer Patient, Age 48

There are a number of different things you can to do keep active, and it is important to find what works best for you. Even just increasing the amount you are active in your day-to-day life can help. For example, doing housework such as hoovering, gardening or walking around when talking on the telephone can all help you be more active.

"I do think that getting outside in the fresh air helps. I have found gardening a great therapy, walking with friends and of course the dog!"

Annette, Breast Cancer Patient, Age 67

For more information and suggestions for keeping active take a look at **Being Active** in the **Healthy Living, Healthy Mind** section on the HT&Me website.

## Listen to your body

Although keeping active has been shown to help reduce fatigue, it is important that you **listen to your body and rest when you need to.** Over-doing it could make you feel more exhausted later on.



"I do get tired easily, so when my body is telling me it is tired and has had enough, I stop and rest."

Sue, Breast Cancer Patient, Age 62

#### Do things at your own pace

It may be helpful to pace things, and only do as much as you can.

There may be a new norm for doing things and you may need to modify how much you do. Maybe you will be able to do a bit less or slower than before and this is something that you just need to accept.

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# Eat a healthy diet

The food we eat can impact our energy levels and mood, which in turn can both impact upon feelings of fatigue. Trying to follow a healthy, balanced diet can therefore help with fatigue.

You should also try to stay hydrated. When we are dehydrated, we can feel more tired. Try to drink plenty of fluids (6-8 glasses a day).

For more information and suggestions for eating a healthy diet, take a look at **Healthy Eating** in the **Healthy Living**, **Healthy Mind** section on the HT&Me website.

## Get a good night's sleep

When you feel fatigued you may feel like sleeping all the time, however this can make it more difficult to have good quality sleep at night. **Keeping to a regular sleep routine in which you try to go to bed and wake up at the same time each day can help** you to have good quality sleep. This may help with your fatigue and make you feel less like you need to sleep during the day.

For some, taking naps in the day can help with sleeping at night, but for others napping can make it more difficult to fall asleep or stay asleep. You may therefore find it helpful to try to work out how napping affects you.



For more information and suggestions for getting a good night's sleep, take a look at **Sleep Problems** in the **Dealing with side-effects** section on the HT&Me website.

#### Speak to others

**Talking about your fatigue with others** may also help, especially about the emotional consequences of experiencing fatigue. Friends and family may not understand how you feel and how it is impacting upon your life.

For more information and suggestions for speaking to others, take a look at the **Help** and **Support** section of the HT&Me website.

### Manage your mood

You may find that you sometimes feel low or anxious, which can make you feel more fatigued. There are lots of sources of support for helping you to manage your mood. For example, research has shown that **psychological tools and therapies can be effective in helping you to feel more like yourself.** 

For more information and suggestions for managing your mood, take a look at the **Changing the way you think and feel about fatigue** section, **or Mood Changes** in the **Dealing with side-effects** section on the HT&Me website.

If you are continuing to struggle with your mood, you should speak to your breast cancer team or GP who will be able to guide you towards appropriate support.

# Complementary therapies

Some women find that **complementary therapies such as yoga, meditation and acupuncture can be helpful** in helping to manage feelings of fatigue. This is largely based on anecdotal evidence, and more research is needed to show whether these do actually work. However, they shouldn't do you any harm so you might like to try them. In particular, some women suggest that relaxation techniques can be helpful, such as listening to relaxation CDs and practicing mindfulness.

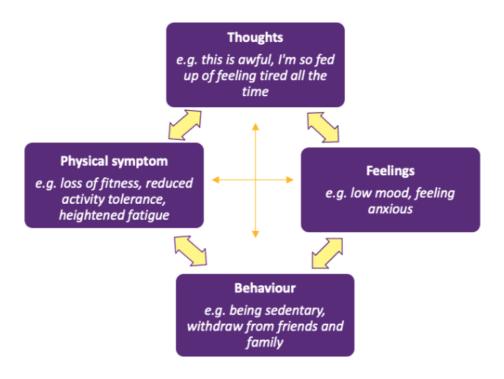
# Changing the way you think and feel about fatigue

You may find that sometimes your fatigue can make you feel anxious or low in mood, which can then make you feel more fatigued. So, changing the way you think, and feel could help to improve your fatigue.



Cognitive (thinking) behaviour therapy (CBT) focuses on the links between physical symptoms, thoughts, feelings, and behaviour. **Cognitive and behavioural strategies,** or tips, can be used to develop a calmer or more accepting view of a situation and help you to feel more in control.

For example, when you are having problems with fatigue, you may experience thoughts like 'this is awful' or 'this is never going to end', or that you will make yourself worse by doing any activity. This may make you feel anxious or affect your mood. You may then feel that you need to rest and withdraw from activities. This inactivity and anxiety can lead to physiological changes which can then make you feel more tired. This is because a lack of activity often leads to unfitness. Inactivity can also lead to a loss of muscle tone or strength, and poor sleep. **Trying to keep a regular routine and engage in consistent activity will help the body to stay fit and reduce feelings of fatigue.** 

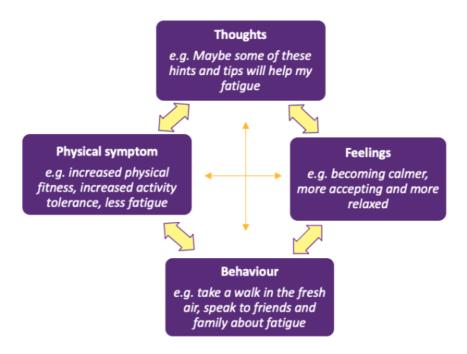


CBT can help you to find ways to reduce these negative feelings about fatigue. Learning calmer more neutral responses may help you to feel more accepting, more in control and more able to cope and do things. This, in turn, might help to improve your fatigue.

For example, instead of worrying that the fatigue is unmanageable or will never end, a more supportive thought may be that the hints and tips here have helped other women with fatigue, so maybe they can help me too. This should lead to feeling calmer, more accepting, and more relaxed, which may lead you to feeling able to

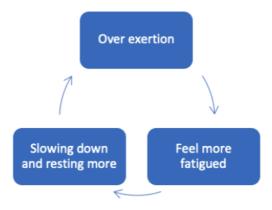


take a walk in the fresh air and speak to your friends and family about how fatigue affects you and how they can help. This should lead to you increasing your physical fitness and strength which over time should lead to you feeling less fatigued.



Behavioural tips for fatigue – avoiding boom and bust

Many women with fatigue understandably try to take advantage of the times when they feel they well, and push themselves too far, and then rest when they feel more fatigued. This is called 'boom and bust'. However, sometimes these **extremes of rest and activity can actually make your fatigue feel worse.** For example, overexerting yourself is likely to make you feel more fatigued, which is then often managed by you feeling the need to slow down or resting completely.



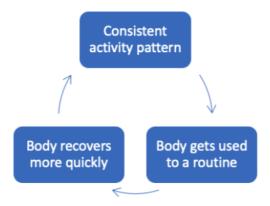
This can become a vicious cycle that is difficult to break because resting too much can lead to:

More tiredness, reduced motivation, poor sleep



- Loss of muscle and strength in your legs. This can mean that when you stand up, less blood goes to your heart which can lead to low blood pressure. This means less blood goes to the brain which can cause you to feel dizzy and fatigued.
- A more unfit cardiovascular system, which can make you feel more fatigued and breathless.

Having a more consistent activity pattern means you will start to gain more control over your fatigue, rather than your fatigue having control over you. Your body will get used to your routine and will start to recover more quickly from activity. This means that over time, you will be less likely to feel as fatigued and might even feel able to do more.



The following tips may help you to develop a more consistent activity pattern:

- Increase your activity gradually. Too much too soon will risk overexertion
- **Be patient and kind to yourself**. These changes will take time to make and so acknowledge the small changes
- Try to plan in a mixture of things you have to get done such as cleaning and caregiving with activities you find relaxing and enjoyable.

For more information and suggestions for keeping active take a look at **the Being Active** section of the HT&Me website, that can be found under **Healthy Living**, **Healthy Mind**.

# Further help and support

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

If these hints and tips do not help and the problems with fatigue become very difficult for you, or get worse as time goes on, and badly impact 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.

#### **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 the following 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 cancer-related fatigue 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/

#### Other websites and resources

Here are links to websites and reading you may find helpful. To take a look type the following weblinks into your browser:

- To go to Breast Cancer Now: The research and care charity: https://breastcancernow.org/information-support/facing-breast-cancer/going-through-breast-cancer-treatment/side-effects/fatigue
- To go to Macmillan Cancer Support: https://www.macmillan.org.uk/cancerinformation-and-support/impacts-of-cancer/tiredness
- To go to Cancer Research UK: https://www.cancerresearchuk.org/about-cancer/coping/physically/fatigue/managing-treating-cancer-fatigue

#### Other resources that may help with fatigue

Although these resources are designed for those with chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME), you may find some of the general tips on managing fatigue to be helpful.

To get NHS patient information booklet about understanding fatigue and an overview of self-management techniques type this weblink into your browser: https://www.torbayandsouthdevon.nhs.uk/uploads/25531.pdf

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.