

# Managing side-effects — Joint aches and pains

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:

- General hints and tips for reducing joint aches and pains
- Keep active to manage your joint pain
- Acupuncture
- Using a diary to track your joint aches and pain
- Further help and support

# Joint aches and pains

Around 50% of women who take hormone therapy for their breast cancer experience aches or pains in the joints (also known as arthralgia) or muscles (myalgia). They are more common in those taking aromatase inhibitors (such as anastrozole, letrozole and exemestane), and are thought to be caused by the body's oestrogen levels



dropping. Who does and doesn't get joint aches and pains is likely down to your genetic make-up. But that doesn't mean you shouldn't try things to help with them.

#### What are aches and pains?

Aches or pains in the joints or muscles are often mild and only last for a short period of time after starting hormone therapy, but for some women can be more severe and may last for longer.

"The first few weeks of taking anastrozole I experienced aching legs, but on occasions prior to the treatment, I used to get aching legs anyway, so it is difficult to categorically state that this symptom was a result of taking the tablet. However, I did find that if I went out for a walk, it helped, and I now only get pains every now and again. At 67 years old, it is probably arthritis.

This is not a problem."

Lily, Breast Cancer Patient, Age 67

Women on hormone therapy tend to experience the aches and pains shortly after they start taking the tablets. The aches are most common in the hands and feet, but can also happen in the knees, hips, lower back and shoulders. They may be there all the time or may come and go. Some women notice that their joints are stiffer in the morning, when they first get up, then the aches ease up during the day.

Women who experience this have described as suddenly feeling much older than they are.

"I can clearly remember my early reaction to the drug because i described it to several people, and also wrote it down: 'It makes me feel 100 years old'. It was the strangest thing, like suddenly being fast-forwarded into extreme old age. My bones ached constantly, and I felt very, very physically tired all the time. But I reminded myself that I wasn't actually in pain and that, as with all cancer treatments, it was better than being dead. And so I persevered, because I was terrified of the cancer coming back. The good news was that after a while — I don't remember exactly how long, those physical symptoms gradually died away."

Sue, Breast Cancer Patient, Age 64

"Achy joints, I used to joke about how old I felt when I got up each morning as I felt like I was over 100! But as the day wore one, the aches in my joints would ease to a more acceptable level."



Many women with mild aches and pains can keep going with their everyday activities. But others may not feel able to.

If the aches and pains make it difficult for you to do everyday tasks – you may find our hints and tips helpful. These tips are based on research studies and experiences of women similar to you who've taken hormone therapy.

## General hints & tips for reducing joint aches and pains

Here are some hints and tips that can help you with joint aches and pain:

- Ask a pharmacist for over the counter pain relief such as paracetamol or ibuprofen. You could try some creams and gels that you apply to your skin. You could also ask a doctor or a pharmacist about glucosamine a medicine that sometimes is used for arthritis. You can also ask your GP to prescribe you something else if over the counter medicine doesn't help you.
- Take the hormone therapy tablets at a different time of day, for example, before going to bed rather than first thing in the morning, as this may change the onset of the symptoms and make them easier to cope with.
- Use either warm compresses (such as wheat packs that you can heat in the microwave, or hot water bottles) or cold packs (such as a bag of frozen peas), or a combination of the two to help ease pain in the sore part of your body. Heat can help reduce muscle cramps and cold can help reduce inflammation (swelling and redness).

"It is definitely worse in the morning and takes a while to get joints moving, and I guess as hard as it is, I just have to adjust... funny but the only time I haven't felt stiff and uncomfortable was when I spent 10 days in the sun abroad at the beginning of the year. So, on that basis I find heat packs do personally work for me. Either that or invest in a hot tub!"

Esther, Breast Cancer Patient, Age 48

- **Take warm baths** (if you can tolerate them) to soothe all-over muscle pain. Remember that for some women warm baths can increase hot flushes.
- **Eat a healthy diet** that includes enough calcium and vitamin D to keep your bones as strong as they can be.



## Keep active to manage your joint pain

Some women find that being active can really help with their joint and muscle aches and pain. Having strong muscles around your joints can help to keep them flexible and reduce pain. If you worry about having weak bones and exercising, you can check with your GP for advice.

#### What activities can help with my joint pain?

# To help you with your joint aches and pains you could start being more active every day.

You can try walking, gardening, jogging, swimming, cycling, walking, Zumba or tennis.

Activities to strengthen your muscles such as walking, jogging or dancing will help to protect the joints in your legs. These will also help strengthen your bones and reduce the risk of osteoporosis (bone thinning).

Activities to build muscle strength and improve flexibility, for example yoga and Pilates, can help stretch and strengthen muscles.

You might even find creative ways to keep yourself moving. For example, if you experience pain or stiffness in your fingers, knitting may be a good way to keep your fingers moving and relieve the pain.

It is best to find an activity that you'll enjoy.

#### What should I do if I have joint pain during or after exercise?

At first, you may feel some pain during or after doing some activities. But this is fine, it means that your body is working. It may take 6 to 8 weeks for your muscles and joints to get used to your new activity level. But sticking to being active can help you feel less pain in the long-term.

Here are some tips to help you manage pain during and after physical activity:

- Start slowly and gradually build up how much you do.
- Try a different type of exercise that puts less pressure on the joints—for example, switch from walking to water aerobics.
- Do proper warm-up and cool-down before and after exercise.
- Be active at a slow pace see if you can carry on a conversation while exercising.



- Make sure you have good fitting, comfortable shoes.
- If you take a class (e.g., yoga, Pilates) ask your instructor which positions to avoid if you have pain while exercising.

You can find more information about being active with joint aches and pains by clicking on the links below:

https://www.cdc.gov/arthritis/basics/physical-activity-overview.html https://www.versusarthritis.org/about-arthritis/exercising-with-arthritis/exercises-for-healthy-joints/

# What have other women with breast cancer who have taken hormone therapy said about how being active helped with their joint pain?

"I do find that I sometimes have aching hands and can be generally stiff and slow to get moving in the morning. I am a keen exerciser and generally feel much better as I get moving and as the day goes on. I don't have any pain that stops me doing anything I want to do!"

Tracy, Breast Cancer Patient, Age 48

"I found it quite hard to deal with at first and almost resented the fact I was uncomfortable and that my mobility was affected (it wasn't badly affected but it was enough for me to notice and to make me think twice about doing certain things). I found the thing that helped most was exercise. It felt counter intuitive to start with - when it hurts to get up, sitting on the sofa all day seems like the most sensible idea! But I found that a bit of regular, gentle exercise really helped. I'm not really a big fan of exercise and wasn't a regular gym goer before treatment but I've started swimming a couple of times a week and it's really helped so I would recommend giving it a go."

Brenda, Breast Cancer Patient, Age 43

"I find mild joint pain and stiffness (particularly in the hip area) is managed by yoga."

Michelle, Breast Cancer Patient, Age 54

"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 and in turn has helped my mental wellbeing."

Angela, Breast Cancer Patient, Age 48



"Creaking joints - that's how I describe it. You're also getting older so that's a factor, but exercise has a very positive impact on mental health as well as physical health... the positive impact on your state of mind is immeasurable and it keeps all your joints moving. Exercise doesn't have to be running or weights or even strenuous, it just has to be to keep the body moving. It has such a positive impact on the whole body (digestion, immune system) not only the joints."

Fran, Breast Cancer Patient, Age 58

To help you with your joint aches and pains try to make being active part of your daily routine. It may help to think of being active as another important part of your overall treatment plan that helps you recover and stay healthy.

In the **Being Active** section, you can find more information about the health benefits of being active, find answers to some questions you may have about being active, see examples of different activities you could try and set some activity goals for the next week. This section will support you in being more active every day.

#### **Acupuncture**

Acupuncture is a treatment that comes from ancient Chinese medicine. Fine needles are inserted at certain sites in the body to treat conditions or help relieve symptoms.

Research suggests that acupuncture can reduce pain from joint symptoms, as well as improve well-being. In one study women who were taking aromatase inhibitors for breast cancer and who were experiencing pain either received true acupuncture, fake (sham) acupuncture (when needles are inserted at non-acupuncture points and at a shallow depth) or no treatment at all. Women who received true acupuncture had less joint pain, and reduced joint stiffness, compared with those in the fake (sham) and no treatment groups.

In May 2018, the American Society of Clinical Oncology – a large and influential organisation of cancer doctors and researchers in America – supported the use of acupuncture for managing symptoms and side effects of cancer and cancer treatment.

Acupuncture does not have any serious side effects and, when done by a trained professional, is generally safe. It's sometimes available on the NHS via your GP or a pain clinic. However, where not available on the NHS, it can be an expensive treatment to pay for yourself.



In the UK, the practice of acupuncture, Chinese herbal medicine, and Chinese therapeutic massage is regulated by The Association of Traditional Chinese Medicine and Acupuncture UK (ATCM). When looking for an acupuncture practitioner, it would be a good idea to check that anyone offering this service is endorsed by the ATCM.

## Use a diary to track your joint aches and pains

You may find it helpful to record the aches and pain you experience in a diary You can make notes if there are certain times that the pain is worse, and what you find helps to reduce it.

Keeping a record can be helpful. If you plan to ask your GP for help or referral to a specialist service – you can share the diary with your GP, such as the one available in this HT&Me website. You can find this by going to **My Hormone Therapy Diary**.

# 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 the problems with joint aches and pains 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.

#### How can my breast cancer team or GP help me?

For example, you could be referred to a rheumatologist (a doctor who has a special interest in joint and muscle pain), physiotherapist (who might be able to suggest exercises that could help) or a pain management clinic.

You can also ask to be referred to an occupational therapist if you are having difficulty doing daily tasks or working as a result of the aches and pains. They will be able to assess your needs and suggest aids and equipment to help you. You can often get referred via the NHS so ask your GP about this. If NHS services are not available, you can see a rheumatologist, physiotherapist or occupational therapist privately but this will have a cost.

For some women, their GP or cancer care team may suggest changing either the brand or type of hormone therapy that they are on. For example, it may be possible for you to switch to another aromatase inhibitor to see if your pain improves, or you might be offered the drug tamoxifen as an alternative. Tamoxifen is less likely to cause joint and muscle aches and pains. However, as with all medication, it can cause other side effects.



#### **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 joint aches and pains 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 the following weblink into your browser: https://forum.breastcancernow.org/

#### Other websites and resources

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

- Breast Cancer Now: The research and care charity. To get answers to 5 commonly asked questions about joint pain: https://breastcancernow.org/about-us/news-personal-stories/5-commonly-asked-questions-about-hormone-therapy-joint-pain
- To read about letrazole side-effects: https://breastcancernow.org/information-support/facing-breast-cancer/going-through-breast-cancer-treatment/side-effects-letrozole-femara#joint
- To read about anastrazole side-effects: https://breastcancernow.org/information-support/facing-breast-cancer/going-through-breast-cancer-treatment/side-effects-anastrozole-arimidex#joint
- To read about exemestane side-effects: https://breastcancernow.org/information-support/facing-breast-cancer/going-through-breast-cancer-treatment/side-effects-exemestane-aromasin#joints
- To go to Macmillan Cancer Support: https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/pain-when-taking-hormone-therapy-for-breast-cancer

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.