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## Help and support

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**Different women deal with cancer and its treatment at different speeds and that's ok.**

**You can ask for help whenever you need help. It doesn't matter whether you've only just started taking hormone therapy or you are taking it for a while.** Try not to feel like you need to put on a brave face for the benefit of others, or that you need to hide your feelings, as this can feel like an extra burden.

*I don't know whether other women feel that as time goes on in their recovery, they're less forthcoming with reaching out to their breast care team. It took me ages to pluck up the courage to ring my nurse because I just thought to myself, "There are so many ladies just starting their breast cancer journey that need her help and time more urgently than I do," which is why I felt reluctant to ask for help because I just thought, "Come on, Teresa, you finished chemo a year ago now. You've had the all clear. You feel well. You're okay. Pull yourself together and stop feeling like that." But I realised that the time factor is irrelevant. I did speak to my breast care nurse in the end and just had a quick check with her. It was good and she's such an amazing lady. Don't ever feel you shouldn't be needing any help and support now because x amount of time has elapsed. That was massive for me.*

*-Teresa, Breast Cancer Patient, Age 52*

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**There are plenty of ways in which you can get support with your hormone therapy**

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### Support from your breast cancer team

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**It is important that you contact a health professional about any issues or concerns that you may have relating to your hormone therapy.** This section outlines some of the support you can get from your breast cancer team, your pharmacist, and your GP.

The information in this section has been provided by Dr Victoria Harmer, a Consultant Nurse in breast care in Imperial College Healthcare NHS Trust, Professor Adam Todd, a pharmacist and researcher at Newcastle University and Dr Brian Nicholson, a GP and researcher at the University of Oxford.

## Support from your breast cancer team

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You should be able to contact a member of your breast cancer team if you have any concerns about your ongoing treatment. They will be able to support you many things.

Here are some examples:

- **Worries about your hormone therapy.** You can speak to your breast cancer team if you have any questions or concerns about taking your hormone therapy, including concerns about side-effects or long-term impacts on your health. They will be able to advise you on the best way to manage these side effects and can provide information about the medicine. They may also be able to switch you to a different type of hormone therapy.
- **Issues relating to previous cancer treatment.** Your breast cancer team can provide advice and support with issues relating to your previous and ongoing treatment, such as surgery or chemotherapy. This includes things like reconstruction and prostheses, lymphoedema (swelling), bone scans, and fertility.
- **New symptoms.** You can speak to your GP or breast cancer team if you find any new lumps or bumps or if you are concerned about other symptoms such as pain in your bones (e.g. back, hips) that doesn't get better with pain relief, as these may be a sign that your cancer has come back.
- **General support.** Your breast care team are also available to discuss your personal situation and needs, and link you to relevant local support groups and can provide information and support across a range of areas including social, financial, psychological, work or education.

## Support from your pharmacist

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You can talk to your pharmacist at any time without making an appointment; this can be face to face or on the telephone. You can also go into any community pharmacy and get advice – it doesn't necessarily have to be your regular pharmacy. Remember that you can ask to speak to the pharmacist in a private consultation area, so your conversation is not overheard and everything is kept confidential.

The pharmacist will be able to advise you about the following:

- **Ordering your hormone therapy prescriptions.** There are many ways to order your repeat prescription from the GP to ensure your hormone therapy is ready for you to collect at the pharmacy every month. You might be able to

order your prescription directly online; the pharmacy might be able to do it on your behalf; or, in some cases, the GP can provide a batch of prescriptions to your regular pharmacy where you can collect your hormone therapy every month. If you are unsure which approach would be best for you, speak to the pharmacist and ask what options are available for you. Find out more about ordering your prescription online by typing this weblink into your browser: <https://www.nhs.uk/nhs-services/online-services/how-to-order-a-repeat-prescription/>.

- **Side-effects.** Your pharmacist will be able to advise you if any symptoms you are experiencing could be side-effects of the hormone therapy and can advise on how best to manage the symptom (whether or not it is related to hormone therapy).
- **Taking other medicines.** Your pharmacist will be able to tell you whether any additional medicines will interfere with your hormone therapy. They can guide you on medicines you get on prescription from your doctor or the hospital, or ones which you can buy over the counter. Remember, it's always best to check with a pharmacist or GP if it is ok for you to take additional medicine on top of your hormone therapy.
- **Brands of hormone therapy.** Some women find that certain brands of hormone therapy suit them better than others. Speak to your pharmacist to see whether they can get a specific brand in for you. This may also be something you can discuss with your GP.

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### Support from your GP

Your GP can be a source of support and advice to you throughout your ongoing cancer care - GPs are specialists at looking at the whole picture. For example, you may want to talk about your diagnosis and what it means, any symptoms you are experiencing to understand what might be the cause, or your hormone therapy or other medicines you are taking.

There are many ways to ask for advice or information from your GP, including by telephone, video call, or in a face-to-face appointment.

Your GP will be able to advise you on the following:

- **Living with and beyond cancer.** You may want to ask your GP questions about what your cancer diagnosis means and the treatment you have received, or to clarify things that you have discussed in appointments with your specialist. Sometimes a little more time is needed to allow all the information to sink in after an appointment with your breast cancer team at

the hospital before you think of questions to ask, or you might forget questions that you intended to ask. Your GP can help to answer these questions.

- **Current symptoms.** Your GP can help you to understand any symptoms that you may be experiencing. GPs are experts at interpreting symptoms and will be able to guide you if you are unsure of the cause of your symptoms. Your GP could help you to decide what to do if your symptoms are side-effects of your hormone therapy and will guide you through what else might be causing them and if any other investigation or treatment is needed.
- **Taking your hormone therapy.** Your GP could offer advice if at any point you are considering stopping your hormone therapy or your pharmacist has suggested talking to your GP about your medicine. They can revisit the reasons for taking hormone therapy. They can also help your pharmacist to ensure that your prescriptions are organised so that you receive your hormone therapy for long enough.

### **Tips for talking to your breast cancer team about hormone therapy**

If you are struggling with your hormone therapy or if you have concerns about the treatment, it's important to discuss these with your healthcare team.

It's completely normal to have concerns about telling your healthcare team about how you feel. Some women have said they avoid speaking to their doctors because that they don't want to be a nuisance or that they feel their concerns are embarrassing or trivial. However, **if side-effects of hormone therapy (for example) are having a big impact on your day-to-day life, then it's important to get support.**

Remember that health professionals (e.g. any member of your breast cancer team, your GP or practice nurse, pharmacist, physiotherapist) are used to being asked questions about this topic, and expect this. It is part of their role to answer these questions or signpost you to someone else if they are unable to answer. Once they know how you are feeling they are in a much better place to be able to support you.

*"The breast care nurse was always there in case we had any questions, we could ring her anytime"*

*-Annie, Breast Cancer Patient, Age 62*

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Below are some top tips for speaking to your healthcare team and getting the most out of your appointment.

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### Booking the appointment

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- **Think about who you want to talk to.** This will depend on what you need. It may be specific clinical expertise, or it may be about personal 'fit' and a warm, trusting relationship. It's great if you can get both in the same package – but you may have to choose. Is there someone in your healthcare team you feel more comfortable with? Maybe you can request to see a specific GP whom you know well. Maybe there is someone in the team at your doctor's surgery who specialises in breast cancer, or women's health. If you want to speak to a pharmacist, remember you can ask to speak to them in a private consultation area in the pharmacy, so people don't overhear you.

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### Preparing for the appointment

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- **Think about what you really want to get out of this discussion.** Imagine you are walking out of there 10 minutes later, really satisfied - what would you have gotten?
- **Write down the specific questions you want to ask.** It is easy to forget when you are sitting in front of the health professional. If you feel you cannot say it out loud, or read the question out, you could hand your questions to them during the appointment.
- **Rehearse what you want to say** to the health professional before the appointment. This can make you feel more confident and help you get the words out.

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### In the appointment

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- At the start of your appointment, tell the health professional you would like some time to address some issues or questions. Try to explain as well how this would help you - 'I need to ask some questions about my medication, so I can continue to feel safe to take it'.
- To get what you really need out of this conversation, it can help to start by laying out clearly what you feel, or what you think already. Then you can invite the professional to give you their perspective. This makes it much easier for them to meet you 'where you are at'. Without this, they may answer the question 'technically' but miss the feelings or intentions behind it.

- Do not worry about using the right medical words - use words that you understand.
- Try to be upfront about how you feel. Tell them if you are embarrassed or feeling nervous about the consultation. e.g. you can say “This feels embarrassing to talk about but.....” People are likely to respond with more attention and compassion when they see it's sensitive to you.
- Listen careful to the answers and repeat back what you have understood - 'So, let me see I've got this right, you are saying that...'. By doing this, you will avoid misunderstandings and improve your recall.
- Tell the person you are seeing that you would like to record the conversation for yourself, to remember it better. You can use a note recording app on your mobile. You need their permission to record, but most people will be okay with that. We know there is very good evidence that it really helps people manage their health better.
- If something is not clear to you, stop and say so, and ask the health professional to go over it again. ‘Can I check, when you say X, in a previous discussion I heard Y, these seem quite different to me, can you explain?’
- If the reason you are having this discussion is related to side-effects or symptoms, it could really help to focus the conversation if you can show the professional a log or diary your side effects over the past few weeks. If you have been using the HT&Me diary you can show them this so they can see for themselves how frequent, intense or disruptive these symptoms are.
- If the health professional recommends something, ask them to talk through the details – e.g. How long you should try it for? What should you expect to see if it is working? When should you come back to talk about other options if it is not helping? If you sense this is frustrating for them (unfortunately this can happen), explain that you are trying to do your best to make this advice work first time, so you don’t have to come back.
- If your issue is not resolving, you just are not getting the response you were looking for, and there’s no progress in the consultation – it’s good to be upfront and ask if there is anyone else you could talk to again about this, to get a fresh perspective.
- Consider taking someone you trust with you to the appointment. This person can be a second pair of ears for you and may be able to remember things that you’ve missed. Brief them before the discussion, about what you really want to get from it, so they can keep focused on that – even if you get diverted.



## **Talking to your friends and family about hormone therapy**

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Some people find it difficult to talk to others about their feelings. This section provides some simple hints and tips for telling other people how you are feeling.

Remember that **from the outside, to your friends and family it may appear that your treatment is over and that everything is “back to normal” for you**. They may not realise that you are taking hormone therapy or fully understand how this may make you feel. It's important to share this with them, otherwise they may not be able to support you.

**You may also want to involve your family and friends in your ongoing treatment, for example attending medical appointments with you.** This allows them to understand what you have been told first-hand, and gives them an opportunity to ask questions. This should give them greater understanding of what you are going through, and should allow them to better support you. You may also want to share the HT&Me animation or relevant sections of the HT&Me website with people to give them greater understanding.

**Different people are able to provide different types of support, so it is important to think about who you want to speak to about what.** For example, some people can provide practical support – for example, going to the shops for you if side effects are making it challenging for you. Others can offer emotional support - for example, you may talk to them about concerns or fears that you may have. Other people can provide companionship by doing things together (e.g. going to the cinema); this can help restore a sense of normality.

If you don't have people close to you that you can talk to, you can find information on sources of support at the end of this section.

*“I have to say telling you this has helped me, as it feels good to actually say how it is! I have no close friends and a very small family with their own health issues and so keep my problems very much to myself.”*

*-Sarah, Breast Cancer Patient, Age 61*

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### **Hints and tips to make talking to other people easier**

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- **Be clear about your needs.** This could be practical support, such as helping with household or childcare responsibilities, or emotional support, for example just being there to listen. Try not to assume that the person you are

talking to will be able to sense how you're feeling or what you need. The more you can explain to them what you need, the better they will understand and be able to support you.

- If you are, or the person you wish to talk to, is very busy, it can be difficult to find time to talk. **Schedule time to be alone with this person**, allowing time to talk both about your ongoing treatment, but also about everyday things.
- If you want to talk about something sensitive, you may wish to **plan elements of the conversation in advance**. Think about the key things that you want to talk about and perhaps note them down. Then consider whether you would be more comfortable having the conversation face to face or on the phone.
- **Remember people that you choose to speak to may not respond as you would expect**. They may say or do the wrong thing, not because they are unkind or do not care, but simply because they do not know how to respond. For example, they may feel upset or uncomfortable and might be afraid of upsetting you. Try to be patient and try not to take any of this personally. You might also decide to focus on family and friends who can give you the kind of support you need.
- You may find there are certain topics that you do not feel comfortable talking about. You may find it helpful to **plan a response for situations where these topics come up**, so that you can comfortably change the topic or end the conversation. For example, "I feel really tired of talking about cancer. Let's talk about something else." or "You know, usually I am OK talking about things like this, but today I just can't handle it. I'm sure you understand."
- You may find that people tell you to "cheer up" or "just be positive" if you talk to them about your concerns. **It is OK to ask them gently if they'd be willing just to listen without judgement or advice** (unless you ask for it).
- You may want to **share the HT&Me animation about hormone therapy or relevant sections of this website** with people to give them a greater understanding of what you are going through, and how they can help you. You can find this animation in the Taking Hormone Therapy section of this website.

## Support at work

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**This section provides some tips around returning to work and outlines what support is available to you in the workplace.**

As well as helping you pay your bills, returning to work can also have many other benefits, such as:

- restoring a sense of normality and routine



- boosting your confidence by reminding you of what you are capable of
- giving you something else to focus on
- improving your quality of life
- providing you with an important source of social support.

Although positive in many ways, returning to work can be a struggle for some women, especially those who are still dealing with the long-term physical or emotional impact of cancer treatment.

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### When should I go back to work?

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There is no reason why you should not be able to return to work once you feel ready. By the time you read this, you might have started working again (even on a part time basis) or are already planning a return to work.

Some women are unsure about when it is appropriate for them to return to work, and often wait for their GP or breast cancer team to give them the “all clear”. It is important for you to initiate the conversation with your GP as they may not be aware you are thinking about returning to work.

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### Tips for returning to work and getting support in the workplace

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- Try to **keep in touch with your employer in the run up to your return** and maintain open communication. Research shows that those links, relationships and discussions are key to ensuring a smooth return to work. Together you can make a realistic plan for your return to work. If your workplace has a Human Resources (HR) team or officer, you can link with them to plan your return to work.
- **Discuss any concerns with your manager.** Although you do not need to tell your employer about your breast cancer, the more you communicate, the more they will be able to support you. They will most likely want to support you but may not know how best to do this without a little guidance.
- If possible, **consider popping into work and catch up with a few colleagues prior to your return date** to help reassure yourself and calm any nerves. You may find it helpful to talk to a few close colleagues about your experiences. This may seem daunting, but telling them may help them to support you.
- **Be patient with yourself.** You might be out of the routine of working, feel fatigued or have other side-effects of the breast cancer treatment. It may be that you need to return with reduced working hours, with a phased return or work from home more often. These things will all help to ease you back into work.

- You may still find that your memory and concentration are not what they used to be following your cancer treatment. If so, you might want to **use additional tools like alarms to remember key meetings or tasks.**
- Be aware that **people in your workplace might think that everything is “back to normal” with you** because you have returned to work. Your manager and colleagues won’t know any different unless you share with them how you are feeling, or how you are getting on at work.

*“At the time, my work was very supportive but I think later on, they probably considered me “back to normal” but in my mind I was a completely different person and struggling to cope with the new me, I didn't know who I was anymore.”*

*-Suzanne, Breast Cancer Patient, Age 62*

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### **What are my rights at work?**

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Hopefully your return to work will be smooth and you will not experience any issues. However, in case of any problems you may find it helpful to be aware of your rights.

For the purposes of the Equality Act 2010 (previously the Disability Discrimination Act 1995) anyone who has or has had breast cancer is classed as disabled; this includes those whose cancer is in remission. This Act, or law, protects you from being discriminated against because of your breast cancer. This applies to any job you had before the breast cancer, but also continues even if you move to another place of work after your diagnosis. You are protected by this law regardless of how long you were in your job prior to diagnosis. This law also requires your employer to make “reasonable adjustments”, which are changes to support you to return, and continue to, work. You can find out more about reasonable adjustments in the section **What does my employer have to do?**

You can find out more about your employment rights by checking your employer’s policies or speaking to an HR manager. You can also contact Citizen’s Advice or contact a helpline like the Macmillan Cancer Support Line (telephone: 0808 808 0000); you can also email them or talk part in a live online chat. To find out more, type the following weblink into your browser:  
<https://www.macmillan.org.uk/cancer-information-and-support/diagnosis/talking-about-cancer/talking-to-people-at-work>.

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## What does my employer have to do?

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Your employer is required to make 'reasonable adjustments' to help you continue to work, return to work, have time off for medical appointments or for continued treatment and recovery. The term reasonable means that any changes or adaptations must be practical for your employer, in terms of cost and effects on other workers.

### Reasonable adjustments may include:

- a phased return to work, which could help you gradually adjust to your normal working pattern
- shortening your working days so you work fewer hours
- altering your working hours - for example, to start earlier and have a longer lunch break to allow you to rest, or attend appointments, in the middle of the day
- altering your working environment to make your work less tiring in some way - for example locating you next to equipment you need, or providing a trolley to reduce the need to carry heavier items.

If your workplace has Occupational Health team you can ask to speak to them about adjustments that could help support you to work. Before making any reasonable adjustments, your employer may ask for your permission to contact a medical professional to find out how to best support you.

*"When I returned to work, I had guidance from Occupational Health who were great in trying to get me back in gently, work colleagues made sure that I didn't have piles of work on my desk, I started at 11am for a couple of hours a couple of days a week and gradually built up"*

*Maggie, Breast Cancer Patient, Age 62*

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## Additional resources for getting support in the workplace

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- To read Breast Cancer Now information on employment, type this weblink into your browser: <https://breastcancernow.org/information-support/facing-breast-cancer/living-beyond-breast-cancer/life-after-breast-cancer-treatment/work-breast-cancer>
- To find out about the Macmillan Cancer Support work support service, type this weblink into your browser: <https://www.macmillan.org.uk/cancer-information-and-support/get-help/help-with-work/work-support-service>
- To find out about Working With Cancer - a social enterprise providing lots of resources and information around work, type the following weblink into your browser: <https://workingwithcancer.co.uk/>

- To access Citizens Advice, type this weblink into your browser:  
<https://www.citizensadvice.org.uk/>

## Additional sources of support

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Having breast cancer and treatment can be difficult to manage. You do not have to cope alone – there are many other additional sources of support that you may find helpful, depending on your preferences.

*"But it's just the difference it makes, sitting with people who've been through, in some cases, exactly the same, very similar, and talking about it. Because anybody else you speak to about it can sympathise, but they don't understand. So you can just say it as it is, and somebody goes, 'God! Yeah'."*

*-Jane, Breast Cancer Patient, Age 53*

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## Support groups

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You may find it helpful to talk to other women who have had breast cancer. Women in support groups will have been through similar experiences to you and may be able to understand exactly what you are going through and how you are feeling. Support groups are a great place to share your experiences and to learn from other women.

Here are some examples of online support groups:

- **Breast Cancer Now Forum**, where you can ask questions, get support, and connect with other women in a situation similar to you. To access this, type this weblink into your browser: <https://forum.breastcancernow.org/>
- **Macmillan Cancer Support Online Community**, where you can explore options for different support groups depending on whether you are looking to connect with someone who has a similar experience to you, or share tips on how to cope. To take a look, type this weblink into your browser: <https://community.macmillan.org.uk/>

Or if you would prefer something in-person:

- You can search for a support group or event local to you through the Macmillan Cancer Support website. To take a look, type this weblink into your browser: <https://www.macmillan.org.uk/in-your-area/choose-location.html>

- Maggie's Centres also run support groups. To find your nearest Maggie's Centre, type this weblink into your browser: <https://www.maggies.org/our-centres/>
- You could also ask your breast cancer nurse about local support groups. Sometimes they have information about these at the hospital.

## Helplines

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Some women find that speaking to someone on the telephone can be a helpful source of support. There are a range of helplines available to you.

- **Breast Cancer Now Helpline** is a free confidential service (if calling from a UK landline or mobile) available between 9am – 4pm Monday to Friday, and 9am – 1pm Saturday and Sunday. Here you, or anyone else affected by breast cancer (such as your family and friends), can get specialist support and tailored information from a breast care nurse. Call **0808 800 6000** or to find more information, type this weblink into your browser: <https://breastcancernow.org/information-support/support-you/call-our-helpline>.
- **Macmillan Support Line** offers confidential support to anyone living with cancer and their loved ones. They offer support on a range of topics such as emotional and practical information, clinical information, financial guidance, welfare rights and more. Call **0808 808 0000** or to find more information, type this weblink into your browser: <https://www.macmillan.org.uk/cancer-information-and-support/get-help/emotional-help/macmillan-support-line>.
- **Breast Cancer Now: Someone Like Me** telephone support 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. To speak with a volunteer, complete the webform on their website or to just find more information, type this weblink into your browser: <https://breastcancernow.org/information-support/support-you/someone-me-telephone-support>.

## Other websites

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Websites such as Breast Cancer Now, Macmillan Cancer Support and Maggie's contain specialist and tailored information on a range of topics associated with breast cancer and hormone therapy. You can find their websites below:

- Breast Cancer Now: <https://breastcancernow.org/>
- Macmillan: <https://www.macmillan.org.uk/>
- Maggie's: <https://www.maggies.org>