



# MAKING APPOINTMENTS WORK FOR YOU

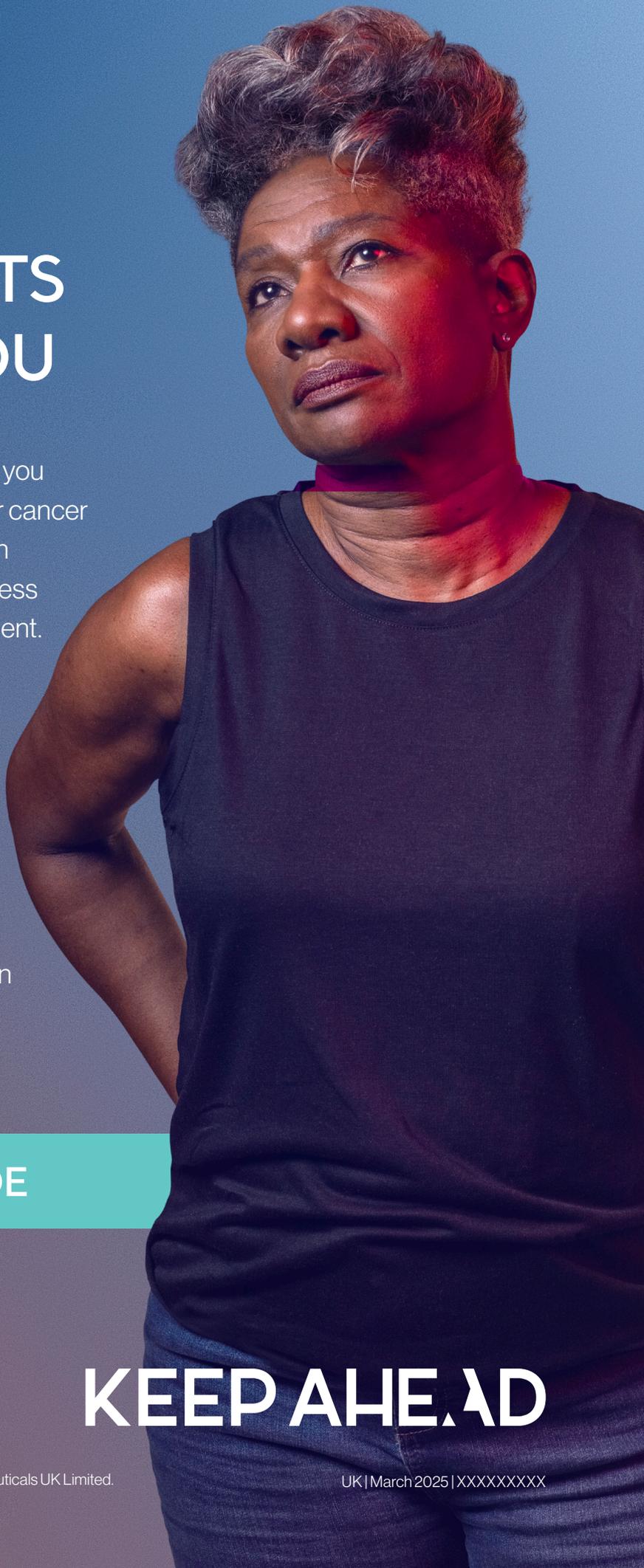
This guide has been created to support you when attending appointments with your cancer care team. Use this as a resource to gain knowledge, speak confidently and express your needs and expectations for treatment.

Towards the back of this guide you can find a useful question guide and a Symptom and Side Effect Tracker to give your healthcare team a clear picture of your unique cancer situation. By recording any changes you experience, they can ensure you are receiving the most appropriate care plan and treatment.

**APPOINTMENT GUIDE**

[www.keep-ahead.co.uk](http://www.keep-ahead.co.uk)

**KEEP AHEAD**



# KEY FACTS

## What is early breast cancer?

Early breast cancer refers to cancer that is confined to the breast or nearby lymph nodes and has not spread to distant parts of the body.<sup>1</sup> Detecting breast cancer at this stage is crucial, as it is often highly treatable with a good prognosis.<sup>2</sup>

## What is recurrence?

- Recurrence is when the cancer becomes active again after surgery and other initial treatments like chemotherapy or radiation.
- It can occur in the same breast, nearby lymph nodes, or another part of the body.
- After surgery and other initial treatments, you may achieve “no evidence of disease” (remission), but a few individual cancer cells may remain in the body and may start to grow again, causing cancer recurrence.<sup>2</sup>

## Understanding your risk of recurrence

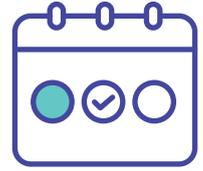
Understanding your risk and the factors that contribute to recurrence is an incredibly important step to reducing your risk of cancer returning.

Your personal risk depends on many factors, including:<sup>3</sup>

- |                                      |                           |
|--------------------------------------|---------------------------|
| ✓ Cancer type                        | ✓ Age at diagnosis        |
| ✓ Cancer stage                       | ✓ Lifestyle factors       |
| ✓ Cancer size                        | – Regular exercise        |
| ✓ Nodal involvement                  | – A balanced diet         |
| ✓ Hormone receptor status            | – Managing stress         |
| ✓ The type of treatment you received | – Quitting smoking        |
|                                      | – Reducing alcohol intake |

Taking an active role with your healthcare team can help you understand your personal risk so you can work together to decide the best adjuvant treatment plan for you.

# BEFORE YOUR APPOINTMENT



## Think about the questions you want to ask ahead of time

Open-ended questions can be especially helpful, as they often lead to more detailed responses beyond a simple 'yes' or 'no.' If you need to, you can always ask your specialist to clarify anything you feel unsure about or do not fully understand.

It can be helpful to write down questions as you think of them as you could forget.



Here are just a few example questions you can ask your doctor:

- What is the goal of my treatment?
- What side effects should I expect?
- How can I manage these side effects?
- Are there ways to prevent or reduce these side effects?
- What other treatment options are available?
- What can I be doing at home to reduce my risk of recurrence?

## Rehearse your appointments

Rehearsing your appointments can help you feel more prepared and confident when speaking with your healthcare team. Practicing what you want to say beforehand, either alone or with the help of a friend or family member, can ensure you cover all the important points and express your concerns clearly. This can also help you feel more comfortable during the appointment, making it easier to get the information you need.

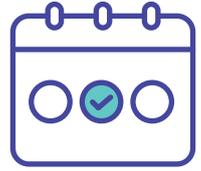
## Use the resources available to you

Consider using the list of questions at the end of this guide and using the **Symptoms and Side Effect Tracker** to note any issues you have been struggling with. Filling these out and bringing them along to your appointments ensures that you get to discuss the important topics you need to.



See the back of this guide for a comprehensive list of questions you can ask covering a variety of topics. >

# DURING YOUR APPOINTMENT



## Take notes or have a friend or loved one help

Taking notes during your appointments can help you remember important details about your condition, treatment options and any next steps you agree on. If possible, consider bringing a friend or family member to take notes for you. This will allow you to focus on listening and engaging in the conversation.

This can be especially helpful when processing complex medical information or discussing difficult topics. If writing notes isn't practical, you might also ask your healthcare provider if you can record the discussion for reference.

## Be as open and honest as possible

Being open and honest with your healthcare team is essential for receiving the best possible care. It can sometimes feel uncomfortable to share personal details with someone you don't know well, but it's important to remember your doctors and nurses are there to help.

If something isn't clear or doesn't feel right, don't hesitate to ask questions or express your thoughts. The more transparent you are, the better your care team can support you in managing your condition.

## Talking about difficult subjects

During your appointments, you may need to discuss topics that feel a little uncomfortable, such as intimacy, menopause, and fertility. These are important conversations, especially when navigating breast cancer, and your healthcare team is there to provide information and support without judgment.

Remember, you are in a safe space where you can speak openly and honestly. Your cancer care team want to help you find ways to cope and improve your quality of life. If you're unsure how to bring up these topics, here are some questions that might help guide the conversation:

- What can you tell me about how my cancer will affect my sex life?
- Can you tell me more about the symptoms associated with menopause?
- Is there anything I can do to alleviate any symptoms of early menopause?
- Is there anybody I can speak to about my intimate life with my partner?

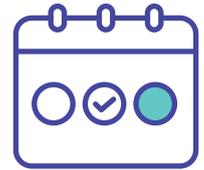


**For more help with questions, please see towards the end of this guide.**





# AFTER YOUR APPOINTMENT



## Review and revisit

Reviewing your notes with a partner or loved one can help reinforce important information and ensure you fully understand what was discussed during your appointment.

Going over key points from the appointment together allows you to clarify any uncertainties and identify any questions you may still have. Your notes can also serve as a starting point for further research, helping you gain a deeper understanding of your condition, available treatment options, your risk of recurrence and ways to manage any side effects you may experience.

## Prepare for your next appointment

If you have another appointment in the diary, it is a good idea to make use of the **Symptoms and Side Effects Tracker** as early as you can before your next appointment. Keeping detailed notes of any changes helps your healthcare team make appropriate adjustments to your care plan.

You can also jot down any questions you think of between appointments. Writing these, and any other thoughts or concerns you have, ensures that you don't forget to ask you care team, as it might be a while until you attend your next appointment.



Going over key points from the appointment together allows you to clarify any uncertainties and identify any questions you may still have.



## Reporting side-effects

If you get side-effects with any medication you are taking, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the information leaflet that comes in the pack. You can report side effects via the Yellow Card Scheme at <https://www.mhra.gov.uk/yellowcard>. By reporting side effects, you can help provide more information on the safety of your medication.

# QUESTIONS TO CONSIDER ASKING AT YOUR APPOINTMENT

This is a list of topics that might be important for you to discuss with your care team over the course of your breast cancer treatment. You can record the answers you acquire here to have all relevant information in one place.

## Treatment

- Q **What factors are considered when developing my treatment plan?**
- Q **What kind of treatments are typically used for my type of cancer?**
- Q **What may be part of my treatment plan?**
  - *What does each treatment aim to achieve?*
  - *What are the differences between these treatments?*
  - *What are the benefits of each treatment?*
  - *What are the possible risks and side effects of each treatment?*
- Q **Who do I see now for my care?**
  - *Who will be involved in my care?*
  - *Who would be my primary point of contact on my healthcare team?*
- Q **What next appointments should I schedule and with whom?**
- Q **What caused my breast cancer?**
- Q **Where can I find more information about breast cancer?**
- Q **How will you know if my treatment is working?**
- Q **Is my cancer curable?**
  - *Does any option offer cure or long-term cancer control?*
- Q **How long do I have to decide about treatment, and is there a social worker or someone who can help me decide?**
- Q **Are there any programs to help pay for treatment?**
- Q **What is neoadjuvant therapy and why do I need it?**
- Q **What are the types of treatment that I may receive?**
- Q **How long is neoadjuvant therapy?**
- Q **What are the possible risks and side effects? How will they be managed?**
- Q **What if I prefer not to have neoadjuvant therapy?**
- Q **When is breast conserving surgery possible?**
- Q **When is mastectomy recommended?**
- Q **What does it mean to have lymph node dissection?**
- Q **What can I do to help in my recovery? Are there any exercises I can do?**
- Q **Will my breast feel different after surgery?**



## Risk of recurrence

- Q What does risk of recurrence mean?**
  - Q Can you please explain my individual risk of recurrence?**
    - *Is it possible to determine my own individual risk of recurrence?*
    - *How and when will this be measured?*
    - *Will you be able to say whether I am at high- or low risk of recurrence?*
  - Q What can I do to decrease my risk of cancer recurrence?**
    - *Are there any lifestyle tips that may help protect against cancer recurrence?*
  - Q Are there any treatment options available to reduce my risk of recurrence?**
    - *When will I know if I need to take this treatment?*
    - *Is this treatment going to be similar to chemotherapy?*
    - *How will I know if this treatment is working to reduce my risk of recurrence?*
  - Q What follow up is needed after I complete my treatment?**
  - Q What happens if my cancer recurs?**
- 



## Possible side effects of treatment

- Q What are the most common side effects that I might experience with this treatment?**
  - Q How likely is it that I will experience these side effects, in your opinion?**
  - Q Do you have suggestions or tips for home management of some of the potential side effects?**
  - Q Are there side effects that, if I experience them, I should call your office?**
  - Q Will treatment affect my fertility?**  
(for pre-menopausal women)
  - Q Will I go into early menopause?**  
(for pre-menopausal women)
  - Q Will I experience similar side effects as during menopause?**  
(for post-menopausal women)
  - Q Could treatment lead to intimacy issues / affect sexual partnerships? What can I do about this?**
- 



## Adherence and monitoring

- Q What do I do if I forget a dose / treatment?**
- Q Do you have any tips to help me remember to take my medication on time?**
- Q What should I do if I experience a serious side effect during the night or on a weekend? When do I know it is time to contact my healthcare team about occurring side effects?**
- Q Will the side effects go away after my treatment is stopped?**
- Q What check-ups are necessary to monitor the therapy?**
- Q Will I need any additional tests along the treatment path?**
  - *If so, when and what are they for?*



# TRACK YOUR SYMPTOMS OR SIDE EFFECTS

## Examples of the symptoms you can record

You can look for changes in your breast where the primary cancer was found, the other breast, the remaining tissue around where your breast has been removed or around the chest wall and skin.

It's important to note any changes you notice and bring it up with your care team as soon as possible. Changes can include:<sup>4</sup>



**Swelling on your chest,** in your armpit or around your collarbone



**A change in shape or size**



**A change in skin texture,** such as puckering or dimpling



**The nipple has become pulled in (inverted)** or looks different, for example changed position or shape



**Liquid (discharge)** that comes from the nipple without squeezing it



**Swelling in the arm or hand**



**Redness or a rash** on the skin, in or around the nipple or in the area of the mastectomy scar line of your treated breast



**A lump or thickening** that feels different (with your treated breast this could be on or away from the scar line)



# TRACK YOUR SYMPTOMS OR SIDE EFFECTS

Date/time	Description of symptom or side effect and any medication taken to help with this	Circle the appropriate rating (if applicable)
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10

Date/time	Description of symptom or side effect and any medication taken to help with this	Circle the appropriate rating (if applicable)
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10
		1 2 3 4 5 6 7 8 9 10

**Reference:**

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3. BreastCancer.Org. Breast cancer recurrence risk. Available at: [www.breastcancer.org/treatment/planning/risk-of-recurrence](http://www.breastcancer.org/treatment/planning/risk-of-recurrence) [Accessed: March 2025]
4. Breast Cancer Now. Breast cancer recurrence symptoms. Available at: [https://breastcancer.org/about-breast-cancer/diagnosis/breast-cancer-recurrence/breast-cancer-recurrence-symptoms/?gad\\_source=1&qclid=CjwKCAiAw5W-BhAhEiwApv4goHaHr3neb7b8YAlpiDKb-9uL2tbKa-dv205b9MwHvjT80wY5lUkoUxoCEk8QAvD\\_BwE](https://breastcancer.org/about-breast-cancer/diagnosis/breast-cancer-recurrence/breast-cancer-recurrence-symptoms/?gad_source=1&qclid=CjwKCAiAw5W-BhAhEiwApv4goHaHr3neb7b8YAlpiDKb-9uL2tbKa-dv205b9MwHvjT80wY5lUkoUxoCEk8QAvD_BwE) [Accessed: March 2025]

