



MAKING APPOINTMENTS WORK FOR YOU

This guide has been created to support you when attending appointments with your cancer care team and in between. Use this as a resource to track results, take note of any questions or observations you may have and capture them in one place.

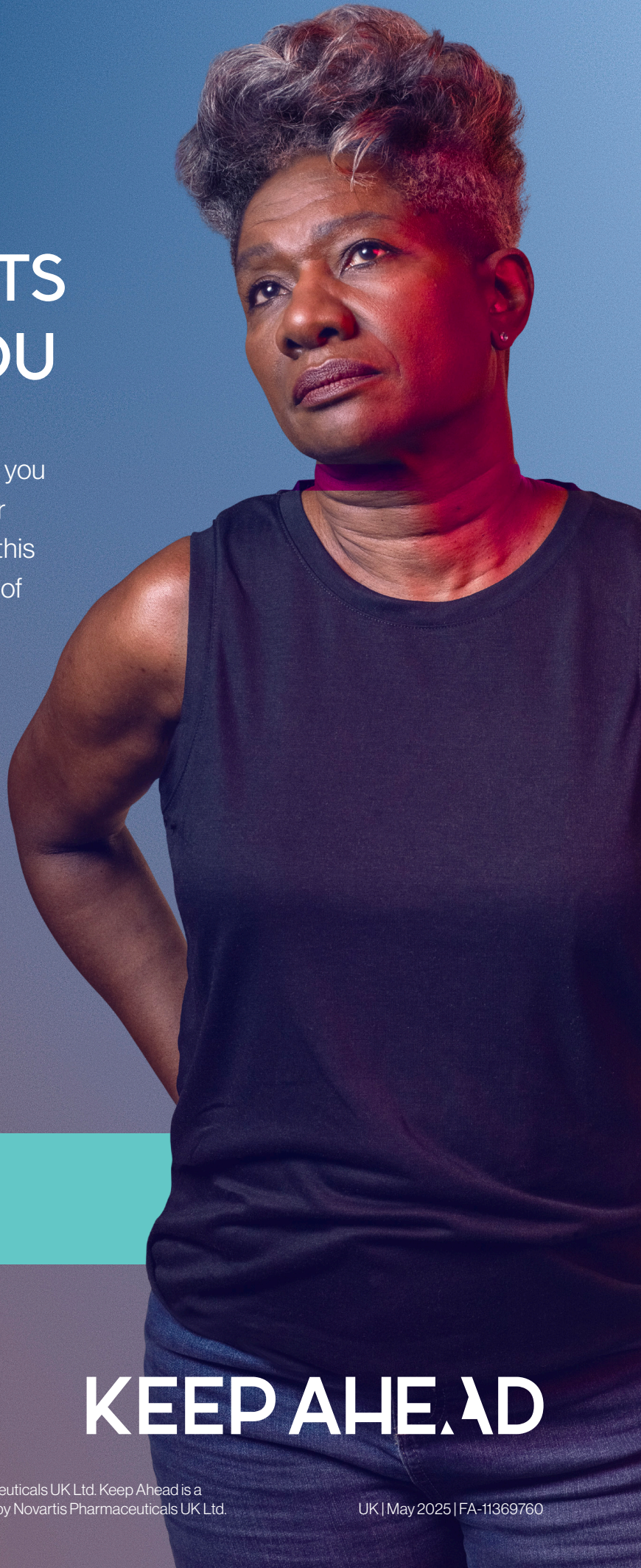
APPOINTMENT AND
BEYOND GUIDE

www.keep-ahead.co.uk

KEEP AHEAD

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BEFORE YOUR APPOINTMENT



Make your goals clear

Determine what you want to achieve from your appointment. Do you need clarity about your treatment plan, emotional support or help with managing symptoms?

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.

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 ask or share 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.

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. You can also check the keepahead.co.uk website or the resources created by UK patient groups, such as Breast Cancer Now.

Breast Cancer Now:

Visit www.breastcancernow.org

Macmillan UK: Visit www.macmillan.org.uk

Maggie's: Visit www.maggies.org

Cancer Research UK:

Visit www.cancerresearchuk.org

Future Dreams House:

Visit www.futuredreams.org.uk

Alike UK: Visit www.alike.org.uk/mission



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

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

Cancer Research UK - <https://www.cancerresearchuk.org/>
Future Dreams House - <https://www.futuredreams.org.uk/>
Alike UK - <https://www.alike.org.uk/mission>

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 and help process complex medical information. You can also ask your healthcare provider to record the discussion.

Communicate in a way that works for you

Not everyone feels comfortable discussing sensitive topics face-to-face. If you find it more manageable you could try writing down your thoughts or sending questions in by email.

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.

Talking about difficult subjects

During your appointments, you may need to discuss topics that can 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 are unsure how to bring up these topics, you may find questions to help guide the conversation later in the guide on page 6 of this guide.



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



AFTER YOUR APPOINTMENT



Be patient with yourself

Appointments can be emotionally taxing. If you feel overwhelmed, didn't get all the answers you need or perhaps received some news you weren't expecting, it's okay to take a moment to process and follow up later. Give yourself time to recover and revisit the conversation when you feel ready.

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.

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

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. It is also a good idea to jot down any questions you can think of between appointments.



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.



Understanding your Diagnosis

- Q What is my breast cancer stage and what does it mean?
- Q What is my breast cancer subtype and what does it mean?
- Q How common is my type of cancer and what is my prognosis?
- Q Is my cancer curable?
- Q What tests or procedures will I have?
- Q Do I need a biopsy or tissue testing?
- Q Is genetic testing recommended for me, and how does it impact my treatment plan?



Treatment Planning

- Q What are the treatment options for my type of cancer?
- Q What are the differences between these treatments?
- Q What are the benefits of each treatment?
- Q What are the possible risks and side effects of each treatment?
- Q How will you know if my treatment is working?
- Q Who will be involved in my care and what are their roles?
- Q Who would be my primary point of contact on my healthcare team?



Neoadjuvant Therapy

- Q What is neoadjuvant therapy and why do I need it?
- Q How long is neoadjuvant therapy?
- Q What are the possible risks and side effects? How will they be managed?



Local Therapy – Surgery

- Q Why do I need to have surgery?
- Q When is breast conserving surgery possible?
- Q Will my breast feel different after surgery?
- Q What does it mean to have lymph node dissection?
- Q What can I do to help in my recovery and are there any activities that I should avoid after surgery?
- Q Will I be able to breastfeed after surgery?
- Q Will surgery be able to remove all my cancer? Or are there further treatments needed?



Local therapy – Radiation

- Q When is radiation therapy needed?
- Q What should I expect during radiation therapy?
- Q How many times will I have radiation?
- Q Does radiation therapy require a hospital stay? If so, for how long?
- Q How will the rest of my body be protected from radiation?



Adjuvant Therapy

- Q What is adjuvant therapy?
- Q What is the goal of adjuvant therapy?
- Q What medications will be given to me?
- Q How long will I have to take the medications?
- Q Why do I have to complete the duration of therapy? What will happen if I stop?
- Q Where can I learn more about adjuvant therapy? Any materials or digital applications that you recommend?



Potential Side Effects

- 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 (if pre-menopausal) Will treatment affect my fertility? Will I go into early menopause?
- Q How can I manage menopausal symptoms?
- 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?
- Q When do I know it is time to contact my healthcare team about occurring side effects?
- Q What check-ups are necessary to monitor the therapy?



Risk of Recurrence

- Q What does risk of recurrence mean?
- Q Can you help me determine my own individual risk of recurrence?
- Q 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?
- Q 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?
- Q 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?



Patient Support & Holistic Management

- Q What supportive care and services are available to me and my caregivers?
- Q Are there specific organizations, support groups or programs in my area that you recommend?
- Q What is the best way to contact you or my point of contact if I have questions or concerns?
- Q Who can support me in overcoming difficult emotions?
- Q Should I be aware of any precautions related to pregnancy or fertility during and after treatment (for pre-menopausal women)?
- Q Can I take herbal supplements and complementary medicines while on my treatment plan?

TRACK YOUR SYMPTOMS

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. It's important to keep vigilant. Changes can include:¹



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



A change in shape or size of your breast



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



Ongoing general feeling of being unwell e.g. tiredness, nausea, headaches, dizziness, unexplained weight loss



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)



Unexplained body pain, swelling or fluid retention



Unexplained speech, vision and/or memory problems



Breathlessness and/or persistent cough





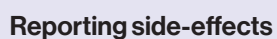
TRACK YOUR SYMPTOMS OR SIDE EFFECTS

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

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		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:
1. Breast Cancer Now. Breast cancer recurrence symptoms. Available at: https://breastcancernow.org/about-breast-cancer/diagnosis/breast-cancer-recurrence/breast-cancer-recurrence-symptoms/?gad_source=1&qclid=CjwKCAiAw5W-BhAhEiwApv4goHaHr3neb7b8YAtpiDKb-9uL2tbKa-dv205b9MwHvIT80wY5lUkoUxoCEk8QAvD_BwE [Accessed: April 2025]

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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 **www.mhra.gov.uk/yellowcard**. By reporting side effects, you can help provide more information on the safety of your medication.

KEEP AHEAD

