

Getting the Most Out of Your Appointments



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You know you best



Nobody knows you better than yourself; not even your healthcare team. This means you will need to express how you are feeling to them clearly. Only you have an idea of how particular symptoms are affecting you, the impact they have on your day to day life and how you feel when they are at their best and worst. This is personal knowledge that you will need to express to your healthcare team when you have appointments.

We have put together some tips on how you can get the most from your appointments.

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The Moments That Count campaign has been developed and funded by Novartis Pharmaceuticals UK Limited. It has been created in collaboration with secondary breast cancer patients whose knowledge and insights have informed the content and direction for the campaign.

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Tip 1

Write a list

This can be useful in helping you remember what you would like to discuss with your healthcare team and it may also help you optimise the time allocated for your appointment.

You can write a list of questions, symptoms that have been affecting you particularly badly or even more general questions to better help you understand the condition.

You may find asking open ended questions helpful as you may receive more detailed answers that are not simply a 'yes' or a 'no'.

Example questions to ask your doctor:

- Can you talk me through my scan and explain the results to me?
- Can you tell me more about my tumours? Where are they located?
- What is the aim of my treatment?
- What side effects can I expect from my treatment?
- What can I do to help manage these side effects?
- Can these side effects be prevented or reduced? If so how?
- What other treatment options are available?

Remember you can always ask your specialist to go over anything you feel uncomfortable with or do not understand.



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Write your list here:

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Tip 2

Be as specific as possible

Think about which symptoms have been affecting you the most and try to keep track over a week or so. It is a good idea to keep note of which symptoms you are experiencing on a regular basis and how they have changed over time, to give your healthcare team a clear indication of their progression.

Examples of symptoms for you to record

Feel free to record any symptoms that you feel are important for example:



Pain

It is useful for your doctor if you record your pain on a scale of 1 (no pain) to 10 (worst pain you've ever had). You can record where you are feeling the pain, what type of pain it is (dull ache, stabbing pain, intense, nagging etc.)



Fatigue

You can also rate how tired you are feeling from 1-10. 10 would be when you are experiencing extreme fatigue, for example when you are constantly tired, sleeping or resting throughout most of the day.

Recording your symptoms and when you are experiencing them may show you a pattern and reveal a possible trigger for these symptoms.

It is a good idea to list every symptom you experience in preparation for an appointment.

These symptoms can include:

- Breathlessness
- Change in bowel habits
- Nausea or vomiting
- Poor appetite
- Problems sleeping
- Menopausal problems (hot flushes)
- Unintended weight loss or gain
- Pain
- Fatigue

| 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 |
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| | | 1 2 3 4 5 6 7 8 9 10 |



Tip 3

Rehearse your appointments

It can be a good idea to practise what you would like to say at your appointment beforehand. If you can, request help from a friend or family member. This can help you ensure you cover and practice everything you want to discuss.



Tip 4

Be as open and honest as possible

We know it is difficult to be completely forthcoming with somebody you are not close with, but it is very important to be completely honest about your symptoms and how they are affecting you. You don't need to feel embarrassed when discussing anything with your healthcare team. If you don't understand or you disagree with something they have said, do not be afraid to say so.

The more honest you are, the quicker your treatment and care can be tailored to your needs.



Tip 5

Talking about difficult subjects

During your appointments, you might find yourself feeling uncomfortable speaking about particular subjects, like intimacy, menopause or fertility. You should remember that your doctor is there to provide information and that they will take an objective view of such subjects, which means they will not judge you for speaking openly about any worries you may have.

Below are some examples of questions that you could ask your doctor to help steer the conversation gently towards these potentially uncomfortable topics:

- 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?



Tip 6

Bring a family member or friend along

This is entirely up to you! However, it can be helpful having two sets of ears listening, especially if one or both of you are taking notes. This way, it is less likely any information received will be lost or forgotten about.

If you have spoken to them about any concerns beforehand, they can prompt you to make sure you don't forget to mention it to your healthcare team.



Tip 7

Summarise what has been discussed

During the appointment, you may find it helpful to summarise to your healthcare professional your understanding of what has been discussed. This gives them an idea of your understanding and it is an opportunity for them to fill in any missing gaps.



Tip 8

Discussing in-depth, clinical topics

After your appointment it is always good to have a little think about what has been discussed and what your possible next steps are. How do you feel? What has been decided with your healthcare team? What can you do to prepare for any next appointments?

We recommend going back to Tip 1 and creating another list of the subjects you would like to discuss. Write all your thoughts and feelings down for your next appointment and your healthcare team will be happy to discuss these with you.

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