

your thoughts matter

This appointment matters to us. Spend some time before your visit thinking about your questions and what matters most to you. Bring this leaflet with you and give it to your care team.

What matters to you?

People often have questions and concerns when they come to their appointment. Your care team is keen to answer your questions. **Thinking about your questions and concerns before your visit will help with your appointment.** This leaflet will help you identify and prioritize the most important questions and concerns you have right now.

Common questions and concerns for appointments are listed below; these may or may not be important to you.

Get ready for your visit

Some people find it helpful to talk with family and friends about their appointment. **Write down all your questions and think about which ones are the most important.** Bring this leaflet with you and give it to your care team.

If this is not your first visit, please look back at your previous notes

Let's partner in your care

Many people have questions during their visit

Here are some common things people have questions about:

My illness

What I think has caused my illness.
How serious it is.
How common it is.
Can I pass it on to somebody else in my family?
Can it be cured?
Might it get better by itself?

My tests

What are the results of the tests I've had?
What other tests are possible?
What are the reasons for and against each test?

My treatment

What treatments are available *(including clinical trials)*?
What are the reasons for and against each treatment?
What are the side effects of each treatment?
How helpful can I expect treatment to be?
What would happen if I decide not to have any treatment?
What are the costs for each treatment?

My care

When should I come back to see you or my GP?
Who else could I see who might be able to help?
What other services and supports are available?
Where can I read more?
How can I look after myself?
Who can I talk to for support?
Who can my family or friends talk to?

Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

Is there any sign of where the cancer might have started?

What tests do you recommend and why? How invasive will they be? What information will these tests show?

What happens if you can't find where the cancer started? How will this affect my treatment?

Can you explain the results of the tests to me?

If you find out where the primary cancer is, will my treatment change?

What treatment do you recommend and why?

What will treatment involve? When will it start? How long will it last?

How much will treatment cost?

Who will be coordinating my treatment?

What are the likely side effects of treatment?

What can I do to help prevent or reduce the side effects I may have from treatment?

What will happen if I don't have treatment?

Are there any clinical trials available to me?

Are there any complementary therapies that might help me?

My Questions

Use this space to note down your questions

Work

Will I be able to continue working?
How much time will I need to take off work?
Where can I get support with work-related issues?
Who can I speak to about going back to work once treatment finishes?

Help with money worries

Will there be any financial costs to me?
Where can I get money advice?
How do I get free prescriptions for my cancer treatment?
Can I get help with travel or hospital parking costs?

Family

What help is available for my family?
Will I still be able to care for my children?
How do I tell my children?
Who can support my children?
Can I still go on holiday?
How can I find travel insurance providers that can cover me?

How can I get help with how I am feeling?

Are there any support groups in my area?
Is there any psychological support or counselling available?

Things I need to remember

Write important details from your visit here.

Next steps for me

Note any follow-up steps or actions recommended by your care team.

Notes about my visit

Write down anything else that stood out during your appointment.

Tips to help you form questions and concerns

If you're unsure how to phrase your questions, these prompts may help:

I wonder...
What if...
I feel...
Should I...
I don't understand...
Can I...
I am worried that...
I sometimes think that...
I am scared about...

Additional Resources

World Cancer of Unknown Primary Alliance
worldcupawareness.org

Macmillan Cancer Support Booklet
cupfoundjo.org/wp-content/uploads/2023/04/ Macmillan-booklet-2023.pdf

Missie Tumor Onbekend
missietumoronbekend.nl

Sarah Jennifer Knott Foundation
sjkfoundation.org

Peter Mac
Peter MacCallum Cancer Centre
Victoria Australia

This booklet has been adapted from the original "your thoughts matter" created by the Peter MacCallum Cancer Centre and Deakin University (Melbourne, Australia)



worldcupawareness.org