A practical guide to tests and treatments

ASK ABOUT YOUR CANCER TREATMENT

WE ARE MACMILLAN. CANCER SUPPORT

Macmillan and Cancerbackup have merged. Together we provide free, high quality information for all.
This leaflet aims to help you get the most from your cancer treatment. It suggests questions you may want to ask your doctors and nurses at different times after your cancer diagnosis.

This leaflet suggests what questions you can ask when:

• thinking about your treatment
• choosing your treatment
• you’re having your treatment.
You’ll likely have a lot of questions about your treatment, but perhaps you aren’t sure where to start when it comes to asking them.

You don’t have to ask all of your questions at once. There will be other opportunities to speak to your medical team if you have further questions or if you need to ask the same question again.

You can always make another appointment or speak to them by telephone if you want to discuss things further. Some doctors and nurses can be contacted by email, so you may find it easier to email your questions to them.

To help you remember what you are told, you may want to take notes or have a relative or friend with you when you’re talking to your doctor or nurse.

You can use the notes page on page 13 to help you remember what you want to ask.
This section contains questions you can ask before you make any decisions about your cancer treatment.

Questions like these may be on your mind immediately after your diagnosis:

• What does my diagnosis mean?
• How advanced is my cancer?
• What will happen to me?
• What happens next?
• What treatment can I have?
• How much choice will I have when it comes to my treatment?
• What will my treatment involve?
• How successful will the treatment be?
• Will the treatment cure my cancer?

Questions about practical issues can feel awkward or embarrassing to ask, but the healthcare and social care professionals you speak to will understand. Questions include:

• Will there be any financial costs to me?
• Will my prescriptions be free?
• Do I need more tests before treatment?
• Do I have to have the treatment offered to me?
• What will happen if I don’t have the treatment?
• Can I get a second opinion?

Learning what terms like these mean can help you understand your diagnosis:

• What do you mean by cancer stages?
• What do you mean by the grade of a cancer?
• What is a primary cancer?
• What is a secondary cancer?
• What are survival rates?
• What do you mean by X per cent improvement in survival?
• What is a remission?
• What is adjuvant treatment?
• What is palliative treatment?

Knowing where to get more information about your cancer and how it’s treated can help you feel more in control.

You can see national guidelines for your cancer, its treatment and care by visiting nice.org.uk (National Institute for Health and Clinical Excellence) and dh.gov.uk (Department of Health). In Scotland you can visit sign.ac.uk (Scottish Intercollegiate Guidelines Network).
Choosing your treatment

This section contains questions you can ask to help you choose the cancer treatment that's best for you.

Finding out what your options are can help you make the right decision about your treatment. Your doctor, nurse or pharmacist will be able to guide you, but you may want to ask:

- What treatment do you recommend for me?
- Are there any other kinds of treatment that might be equally effective?
- What are the benefits of each treatment option?
- What are the risks and side effects of each treatment option?
- How can I make a choice between the treatments you have offered me?
- Will I see a cancer specialist throughout my treatment?
- Can I change my mind after I’ve started my treatment?

You may find our booklet Making treatment decisions helpful. We can send you a free copy.

It’s important to tell your medical team about any other medicines, remedies or supplements you’re taking before you start any cancer treatment.
Once you’ve decided on a particular treatment, questions like these can help you understand what will happen next:

• How will the treatment work?
• Will I have tablets? Injections? Drips?
• How soon will the treatment start?
• How long will the treatment last?
• How many courses of treatment will I need?
• How experienced are you and your team with giving this kind of treatment?
• How will I be monitored during the treatment?
• How likely is it that I will have side effects from this treatment?
• Can the side effects be permanent or will they eventually go away?

Our booklet *Understanding cancer research trials (clinical trials)* has more information.

You may want to ask about participating in clinical trials.

• What does it mean to take part in a clinical trial?
• I’ve been offered a trial – do I have to go on it?
Asking practical questions like these may help you organise your life and make things as easy as possible before you start your treatment:

- Will I have all my treatment at this hospital or will I have to travel?
- How long will I need to stay in hospital?
- Can I have my treatment at home?
- Is there any help or support I can have at home?
- What effect will the treatment have on my daily life?
- Will I be able to continue working?
- Is any financial help available?
- Can I still go on holiday?
- Will I still be able to care for my children?
- Will the treatment affect my fertility or my sex life?

Your specialist nurse can help you find financial support or help at home.

You may find our booklet Help with the cost of cancer useful. You can also see this information on our website at macmillan.org.uk
During your treatment

This section suggests questions you can ask when your treatment starts.

If you’d like to know how your treatment works and how to take it safely, you can ask:

• What does this treatment do?
• How long will I be on this treatment?
• Do I need to change my lifestyle while having this treatment?
• Can I drink alcohol?
• Do I need to change what I eat?
• Can I exercise regularly?

Questions like these can help you clear up any uncertainties about treatment:

• How will I know if the treatment worked?
• How will the doctors know if the treatment is working?
• Will I need to have any more tests?
• If my treatment is delayed, will this make a difference?

Knowing what to expect from your treatment can also help you cope, so you might like to ask:

• How can any side effects I have be controlled?
• What should I do if I have side effects?
• If I am having lots of side effects, can I temporarily reduce or completely stop my treatment?
• Are there any complementary therapies that might help?
• What happens when treatment finishes?

Questions like these can help you find out who can help if you have any problems during your treatment:
• Who will be looking after me while I have my treatment?
• Who should I contact in an emergency/out of hours?
• Does my GP know about my diagnosis and treatment?
• Who should I contact with any problems?
• How long should I wait before contacting someone?

Call us on 0808 808 00 00 (Mon–Fri, 9am–8pm) for more information on all aspects of cancer.
Notes

You can use this page to remind yourself of the questions you want to ask your healthcare team and to write down the answers you receive.

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Ask about your cancer treatment 13
We have more information on cancer types, tests, treatments and living with and after cancer. We also have details of other helpful organisations and support groups in your area. You can contact us using the following details:

Macmillan Cancer Support
89 Albert Embankment, London SE1 7UQ
General enquiries 020 7840 7840
Questions about cancer? Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm)
Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available. Alternatively, visit macmillan.org.uk

www.cancerhelp.org.uk (Cancer Research UK)
Contains patient information on all types of cancer and has a clinical trials database.

www.nhsdirect.nhs.uk (NHS Direct Online)
NHS information site for England – covers all aspects of health, illness and treatments.

www.nhsdirect.wales.nhs.uk (NHS Direct Wales)

www.nhs24.com (NHS 24 in Scotland)

www.patient.co.uk (Patient UK)
Provides information about health and illnesses.
Disclaimer

We make every effort to ensure that the information we provide is accurate, but it should not be relied upon to reflect the current state of medical research, which is constantly changing. If you are concerned about your health, you should consult a doctor. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third-party information such as information on websites to which we link. We feature real-life stories in all of our articles. Some photographs are of models.

Thanks

This leaflet has been written, revised and edited by Macmillan Cancer Support’s information development nurses and editorial team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

With thanks to: Christine Clarke, Macmillan Lead Pharmacist; Dr Chris Gallagher, Consultant Medical Oncologist; Dr Jacky Turner, Macmillan Principal Pharmacist; and the people affected by cancer who reviewed this edition.

Sources

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care.

One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

Questions about living with cancer?
Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm)
Alternatively, visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.

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