

The best cancer
information
for everyone
from Cancerbackup
and Macmillan
Cancer Support

Getting the best from your cancer services

Questions to help you
get the best care and information

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 cancerbackup

Introduction

These questions have been designed to help people with cancer and their families get the best care and information from cancer services.

You can ask these questions of your GP, community nurse, consultant, specialist cancer nurse or any other health professional involved in your cancer treatment and care.

The questions have been divided into three sections:

- **Diagnosis**
- **Treatment and care**
- **Palliative care**

After each question there is a description of what should happen in a good cancer service. This is to help you understand the care and information you should receive at each stage of your cancer treatment.

Good care and information are described in a large study of cancer services, carried out by the Commission for Health Improvement (CHI) and the Audit Commission: *NHS Cancer Care in England and Wales*. It was published in March 2002. The work of CHI is now done by the Healthcare Commission, the independent watchdog for health care in England. The National Audit Office has also reported on cancer services in England.

If you would like more information about any aspect of cancer, see the contact details at the back of this booklet.

Diagnosis

Why are you referring me to a specialist?

What should happen: Your GP will use the National Cancer Referral Guidelines to decide whether your symptoms mean that you need to see a specialist within two weeks or as a routine referral. There are National Guidelines for GPs in England, Scotland and Wales.

How quickly will I be seen? Are you referring me as urgent or non urgent?

What should happen: If your GP suspects you may have cancer you will be referred to be seen urgently. You should get your first hospital appointment within two weeks (currently in Northern Ireland, the two-week guideline applies only to breast cancer).

How long will it be before I have all the tests? Where will they be carried out? Will I need to go to several hospital departments?

What should happen: Your hospital should organise your tests as quickly as possible. The people looking after you should tell you where the tests will be carried out and what

you need to do to prepare for the tests.

What are the tests for? How many will I need? Who will give me the results and when?

What should happen: You should be told why you are having the tests and what they will involve, when you will receive the results and who will give them to you.

Will the person doing the test look after me while it is being done? Will they tell me what to expect?

What should happen: Although tests can be uncomfortable, you should be supported by the staff and any discomfort should be kept to a minimum. You should be given full, understandable information about the tests. Let your doctor or nurse know if you are not sure why a particular test is needed.

What times are available for me to have my tests? For instance, could they be done in the evening?

What should happen: As far as possible, your tests should be organised at a time to suit you.

Diagnosis

Is the doctor I will be seeing a recognised cancer specialist?

What should happen: You should be referred to the specialist who is most appropriate for you. This may be a surgeon, a cancer specialist or other specialist depending on your situation. You can ask the doctor about their area of experience.

Will the doctor have all my test results? Will the meeting be for diagnosis or treatment?

What should happen: Your test results should be passed quickly to the specialist who will be seeing you. The first meeting is normally to give you the diagnosis and discuss what happens next.

Can I bring someone with me to discuss my diagnosis and treatment?

What should happen: You should feel welcome to bring someone with you when your diagnosis and treatment options are being discussed.

Will the consultant understand my concerns and give me time to ask questions? Will a specialist nurse be there to help me?

What should happen: The consultant discussing the diagnosis with you should be trained in communication skills. They should use understandable language and give you enough time to ask questions. You can also ask for a specialist nurse to be there to talk to you and help you.

Who can I telephone when I think of questions later? Can I make another appointment to see someone in person? Can I ask for a second opinion?

What should happen: Someone should be available after your initial interview, to discuss your diagnosis and how it may affect you. You can contact them either by telephone or during another visit. You can ask for a second opinion, and most doctors are happy to grant this.

Will someone tell my GP the diagnosis and what is planned? How quickly will this happen?

What should happen: Your GP should be told quickly about your diagnosis and proposed treatment.

Treatment and care

How quickly will the treatment start?

What should happen: Hospital staff should tell you when your treatment will start.

Will my treatment be discussed by a multidisciplinary team?

What should happen: Your treatment plan should be discussed by a multidisciplinary team. This team is made up of all the healthcare staff involved in your care. It includes cancer nurses and all the main consultants.

What will the treatment be like and how long will it take? Will there be side effects and what can I do about them?

What should happen: Your doctor or nurse should describe the treatment, how it is given and how it will affect you.

Is my surgeon a specialist in my form of cancer? Is this important for my type of cancer?

What should happen: If you have the kind of cancer where evidence shows that it is important, your surgery should be performed by a specialist surgeon. You can ask your consultant whether this applies to you.

Who prescribes the chemotherapy? Who will give the chemotherapy?

What should happen: Chemotherapy is the use of drugs to kill cancer cells or prevent or slow their growth. It should be prescribed by a doctor who specialises in treating cancer (an oncologist). Chemotherapy is given by nurses who have had specific training in giving chemotherapy.

Can I have the chemotherapy in my local hospital?

What should happen: Some chemotherapy can be given in local cancer units, while some needs to be given at a specialist cancer hospital.

Can I have my surgery, radiotherapy or chemotherapy more quickly if I have them outside normal office hours?

What should happen: Your treatment should be carried out efficiently to avoid delays.

Treatment and care

Will all the hospitals I attend know about my diagnosis and treatment?

What should happen: If you attend more than one hospital, your complete hospital records should be available in each place.

Who should I contact if I'm worried about my diagnosis, treatment or prognosis? What help is available for my family? What patient support groups are there in my area?

What should happen: Good supportive care should be available throughout your treatment. The healthcare staff looking after you should tell you how to get more help and information.

Please see last page of this leaflet for further contacts.

Will I need special equipment or support when I go home? Will I get this? Does my GP know I am being discharged?

What should happen: Your healthcare staff should make detailed plans to meet your needs at home after you have been discharged from hospital. Your GP should be told quickly when you have been discharged.

Who should I contact if I have questions or concerns, once my treatment has finished?

What should happen: The people looking after you should tell you who is responsible for your follow-up care and they should give you contact details.

What are the treatment guidelines and standards for my treatment and care? Can I see them?

What should happen: A cancer network is the group of cancer organisations in a particular area that provide treatment and care. Your cancer network should have agreed treatment guidelines and standards. You can ask the healthcare staff to show you these. The guidelines and standards are based on national guidance provided by the National Institute for Health and Clinical Excellence (NICE) in England and Wales, Scottish Intercollegiate Guidelines Network (SIGN) in Scotland and Northern Ireland Cancer Network (NICaN) in Northern Ireland.

Palliative care

Who will take responsibility for identifying any new care needs I may have? Will someone also offer support to me and my family?

What should happen: A designated nurse or doctor should take responsibility for making sure that all your needs for palliative care are recognised and met. If you feel that you have any needs for palliative care, you should ask someone, such as your GP or district nurse, about this.

Will I be able to talk to a palliative care consultant or a specialist palliative care nurse?

What should happen: You should be put in touch with specialist staff for palliative care.

What if I need help overnight or at a weekend?

What should happen: Good arrangements should be in place for you to contact palliative care staff outside normal office hours. You should be told about these arrangements.

Who do I go to first if I need help or have questions?

What should happen: Your ongoing care should be

Palliative care is care which reduces or gets rid of symptoms (for example, pain or tiredness), but is not designed to bring about a cure.

coordinated by a designated person. The staff looking after you should tell you who this person is and how to contact them.

**Who else can I talk to about how I am feeling?
What support is available for my family?**

What should happen: You and your family should have good practical and emotional support whenever you or they need it. You can ask for support from your GP or from the hospital.

If I die, will I be able to die where I want?

What should happen: Whenever possible you should be able to die where you and your relatives choose. If you want to die at home you should be offered support services.

If I die, who will offer my family support?

What should happen: The people looking after you should make sure that bereavement care is offered to your family.

These questions and service guidelines have been taken from *NHS Cancer Care in England and Wales (March 2002)*, a report published by the Commission for Health Improvement and the Audit Commission.

The full report can be downloaded free from:

www.audit-commission.gov.uk

or ordered from:

Audit Commission Publications on 0800 50 20 30.

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This leaflet is based on the Commission for Health Information and Audit Commission booklet *Questions for Patients to Ask* published in 2001. It has been produced in accordance with the *NHS Cancer Referral Guidelines for Adults and Children*. NICE. 2005.

Although every effort has been made to ensure accuracy, Macmillan and its advisers cannot accept any liability in relation to the information in this booklet. It is not a substitute for professional medical advice. Readers are strongly advised to discuss the information provided and seek personalised advice from their doctor or specialist cancer nurse.

For more information

Phone 0808 800 1234 for a free copy of this leaflet or to speak to a cancer information nurse specialist who can answer questions on any aspect of cancer.

Interpretation is available for people whose first language is not English.

Our information is also available on the internet at www.cancerbackup.org.uk

We can also send you a leaflet *Ask About Your Cancer Medicines*, which contains questions to ask to help you get the best from your chemotherapy and cancer medicines.

Ask About Medicines website:
www.askaboutmedicines.org



The best cancer information for everyone

Cancerbackup has merged with Macmillan Cancer Support. We will be providing the same high-quality, expertly developed information about cancer, and now we can make it available to everyone who needs it.

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.

Get support or get involved at www.macmillan.org.uk

For further copies, call us on 0800 500 800
or visit www.be.macmillan.org.uk

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