

A practical guide to tests  
and treatments

# GETTING THE BEST FROM YOUR CANCER SERVICES

**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 and your family get the best from your cancer services.

It suggests questions you can ask *any* health or social care professional you're seen by, including your GP, nurses and consultants (cancer specialists).

This leaflet is divided into the following sections:

- **Diagnosis**
- **Treatment and care**
- **Palliative care**
- **When your healthcare is not as good as it should be**
- **Support for each other**
- **Further information.**

We hope the questions in this leaflet will give you a better understanding of what to expect at every stage of your treatment and care. **Each question is followed by a description of what should happen, according to the recommendations laid out by official national guidelines.**

The questions and service guidelines in this leaflet were originally taken from *NHS cancer care in England and Wales (March 2002)*, a report published by the Commission for Health Improvement/Audit Commission. The content of this leaflet has since been revised using updated reports and guidelines.

Good care and information are discussed in a large study of cancer services carried out by the Department of Health: *National cancer patient experience survey programme – 2010 national survey report*. You can download this report from the Department of Health website – see **dh.gov.uk**

In Scotland, these areas are discussed in a 2008 report by the Scottish Government (**scotland.gov.uk**) called *Better cancer care, an action plan*.

In Northern Ireland, the Department of Health, Social Services and Public Safety (**dhsspsni.gov.uk**) have a report called *Service framework for cancer prevention, treatment and care*. This report looks at the standards of care and treatment that people with cancer should be able to expect from the healthcare professionals they see.

If you would like more information about any aspect of cancer, please see the contact details at the back of this leaflet. You can also get information and support – and ask many of the questions contained in this leaflet – in person at your nearest Macmillan cancer information and support centre or mobile Macmillan cancer information centre. To find out where these are, please visit **macmillan.org.uk/informationcentres**

## Diagnosis **Why are you referring me to a specialist?**

Your GP should explain that they are unsure what is causing your symptoms, and they are referring you to a specialist for further tests. To help the GP decide which symptoms could be caused by a cancer and need further investigation, they will have used national cancer referral guidelines. There are national guidelines for GPs in England and Wales, in Scotland and in Northern Ireland. The three guidelines are essentially very similar, but there are some differences in what they say.

### **When will I be seen? Are you referring me as urgent or non-urgent?**

Depending on your situation, you will be referred to the hospital in one of three ways: as immediate, urgent or non-urgent. An **immediate** referral means you should be seen by a cancer specialist within a few hours. An **urgent** referral means you should have to wait a maximum of two weeks (although in Northern Ireland the two-week guideline currently only applies to breast cancer). A **non-urgent** referral is treated as a routine hospital referral and may take longer. To find out more about referral times in England and Wales, you can visit the National Institute for Health and Clinical Excellence (NICE) website at [nice.org.uk](https://www.nice.org.uk) and search for 'cancer referral guidelines'.

**Your hospital will try to organise any tests you need as soon as possible.**

If you live in Scotland, you can visit the Scottish Government website at **scotland.gov.uk** and search for 'cancer referral'. If you live in Northern Ireland you can visit the Northern Ireland Cancer Network website at **cancerni.net**

### **When will I be tested?**

Your hospital should organise your tests as quickly as possible. The people looking after you should explain where the tests will be carried out and how you can prepare for them.

### **What are the tests for and what will they involve?**

You should be told why you are having the tests, what they will involve, when you will receive the results, and who will give them to you. The type of test(s) or scan(s) you have will depend on the type of cancer that is suspected. You should be told how many tests you will need.

### **Who will give me the results and when?**

The cancer specialist should tell you how long it will take before the results are known, and will usually give you the results during an appointment that will be made for you. They should also tell you about any information and support available to help you while you wait for the results.



**Knowing what to expect can help you feel more in control.**

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

Although tests can be uncomfortable, you should be supported by staff and any discomfort should be kept to a minimum. You should be given full, understandable information about the tests. Let your cancer specialist or nurse know if you aren't sure why a particular test is needed.

**What times are available for me to have my tests?**

You should be told that, as far as possible, your tests can be organised at a time that suits you. However, there will be lots of people having tests for different reasons, so it may not always be possible for the tests to happen at a convenient time.

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

You should be referred to the specialist who is most appropriate for you. This may be a surgeon, cancer specialist (oncologist) 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?**

Your test results should be passed quickly to the specialist who will be seeing you. The first meeting after your results have come through is normally to give you the diagnosis and discuss what happens next.

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

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

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

Your cancer specialist should be trained in communication skills. They should use clear 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 if I think of  
questions later? Can I see someone  
in person?**

Someone (usually a nurse) should be available after your initial appointment to

**You may like to  
take a relative  
or friend with  
you when your  
diagnosis is  
being discussed.**

**You will be told who to contact if you think of questions you want to ask after your initial appointment.**

discuss your diagnosis and how it may affect you. You will be told who to contact and will be able to contact this person by telephone or during another visit. If you think of questions later, you may also find it helpful to speak to someone at your nearest Macmillan cancer information and support centre or mobile Macmillan cancer information centre (see **macmillan.org.uk/informationcentres** to find out where this is).

### **Can I ask for a second opinion?**

Your GP or cancer specialist should be willing to refer you to another specialist for a second opinion if you feel it would be helpful. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it would give you useful information.

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

If you are diagnosed with cancer, your GP should be told about this by the end of the next working day (according to the *Manual for cancer services 2004* guidance from the Department of Health).

# Treatment and care

**Support is available if you have to choose between different treatments.**

## What are my treatment options?

Your cancer specialist should tell you about all of the treatment options available to you. They will discuss the benefits and disadvantages of the treatments and how they might affect you. Your cancer specialist may also discuss participating in clinical research trials for new treatments. You may find our booklets *Understanding cancer research trials (clinical trials)* and *Making treatment decisions* useful. We can send you copies of these booklets free.

## When will the treatment start?

After diagnosis, your cancer specialist will usually want to carry out further tests and investigations to learn more about your cancer. They will be able to tell you how long these tests will take. If you're diagnosed with cancer and doctors decide that you need treatment, then there should be a maximum wait of 31 days between this decision and the start of treatment. This is according to targets in place across the UK.

## Who will oversee my treatment?

Your treatment will be discussed and planned by a group of specialists called a multidisciplinary team (MDT). This team will be made up of all the healthcare staff involved in your care. It will include cancer nurses, your cancer specialist and other

relevant specialists, such as a dietitian or physiotherapist. You should be put in contact with a nominated 'key worker', who will keep you in touch with the MDT.

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

Your cancer specialist or nurse should describe the treatment and how it is given. They will discuss the possible side effects of the treatment and what can be done to help relieve them. They will answer any questions you have and may also give you some written information about the treatment that you can take home.

**You will be told about the side effects of your treatment, as well as how to help relieve them.**

**If I need surgery, will it be performed by a specialist in my type of cancer?**

Some types of cancer need more specialist surgery than others, which should be performed by a specialist surgeon. You can ask your cancer specialist whether this applies to you.

**If I have chemotherapy, who will prescribe it? Who will give me the chemotherapy?**

Chemotherapy – often called 'chemo' for short – is the use of anti-cancer drugs to destroy 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?**

Some types of chemotherapy can be given in cancer units within local hospitals, while other types need to be given at a specialist cancer hospital.

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

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?**

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

### **Are there patient support groups in my area?**

You should be given information about support groups in your area. You can find out about people affected by cancer who meet in your area to support each other by calling us on **0808 808 00 00** or visiting

**You may find it helpful to speak to other people affected by cancer.**

**Our booklet  
Lost for words  
is written for  
the relatives  
and friends of  
people with  
cancer. We can  
send you a  
copy free.**

**[macmillan.org.uk/selfhelpandsupport](https://macmillan.org.uk/selfhelpandsupport)**  
You can also share your experiences and  
discuss your feelings at **[macmillan.org.  
org.uk/community](https://macmillan.org.org.uk/community)**

### **What help is available for my family?**

Your healthcare team should direct you  
towards support groups for families  
affected by cancer.

### **Will I need special equipment or support when I go home? Will I get this?**

Your healthcare team should make detailed  
plans to meet your needs at home after you  
have been discharged from hospital.

### **Does my GP know I'm being discharged?**

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? Will I have any follow-up care?**

The people looking after you should tell you  
who is responsible for your follow-up care,  
and they should give you their contact  
details. Your follow-up care will usually  
depend on the type of cancer and  
treatment you've had. You'll usually have  
a check-up about 6–8 weeks after the end  
of your treatment. Your doctor will examine

you and ask questions about your health and how you've been feeling. You may also have blood tests.

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

**Our leaflet *Ask about your cancer treatment* has questions you can ask your doctors and nurses about your treatment.**

You can ask the healthcare team to show you the guidelines and standards. These are based on national guidance provided by the National Institute for Health and Clinical Excellence (NICE) in England and Wales, the Scottish Intercollegiate Guidelines Network (SIGN) in Scotland, and the Northern Ireland Cancer Network (NICaN) in Northern Ireland.



## **Palliative care**

Palliative care is care that reduces symptoms (eg pain or tiredness) but is not designed to bring about a cure. Palliative care is not only aimed at helping with physical problems, but with psychological and spiritual ones too.

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

Your key worker will be your first point of contact. They can help you get help and support from other healthcare professionals involved in your care, such as your GP or district nurse. Your key worker should also take responsibility for making sure that all the palliative care needs that you and your family have are recognised and met.

**Will I be able to talk to a palliative care professional, such as a consultant or specialist nurse?**

You should be able to talk to a nurse and doctor who understand your condition. If you need more support than you're getting from the healthcare professionals you're already seeing, you can be put in touch with specialist staff for palliative care.

**You and your family should have good practical and emotional support whenever you need it.**

### **What if I need help overnight or at the weekend?**

Arrangements should be in place for you to contact your district nurse, who can tell you about the care available during the night or at weekends. If you need more specialist input, they can refer you to a specialist palliative care professional. You should be told about these arrangements.

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

Your care should be overseen by a designated key worker. 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?**

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 where you had your treatment. You can also call the Macmillan Support Line on **0808 808 00 00** to speak to one of our cancer support specialists about how you're feeling.

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

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 to help make this possible.

### **If I die, who will offer my family support?**

The people looking after you should make sure that bereavement care is offered to your family. There are many organisations that run groups for people who are grieving, such as Cruse Bereavement Care – see [cruse.org.uk](http://cruse.org.uk)

**Call us on 0808 808 0000 (Mon–Fri, 9am–8pm) for support and more information about all aspects of cancer.**

## When your healthcare is not as good as it should be

Most of the time, treatment and care within the NHS goes well. However, it doesn't always work out that way and sometimes things go wrong. If you're unhappy with the care you have received, you may want to complain. Complaints can also be made by a carer who is acting on your behalf.

All hospitals and GP practices will have a member of staff who is responsible for dealing with complaints, called the complaints manager. Your local hospital or trust will have their own complaints procedure and can give you a copy.

A good place to get free advice about making a complaint is your local Citizens Advice (see page 21 for details).

In England, you can also talk to a Patient Advice and Liaison Service (PALS). All hospitals in England have access to a PALS, and they are there to help with any queries or issues you have about your healthcare. You can contact your local PALS by telephoning the hospital where you were treated. The PALS can usually help solve problems, or they can put you in contact with the Independent Complaints and Advocacy Service (ICAS), who can offer you advice.

Help and advice about making a complaint is available in Northern Ireland from the Patient and Client Council – visit [patientclientcouncil.hscni.net](http://patientclientcouncil.hscni.net)

In Scotland, you can get advice from your local NHS Board. Visit [scotland.gov.uk/Topics/Health/NHS-Scotland/Boards](https://scotland.gov.uk/Topics/Health/NHS-Scotland/Boards) to find contact details for your local board.

In Wales, help and advice is available from your Community Health Council (go to [wales.nhs.uk](https://wales.nhs.uk) to find your local council).

You can find out more about making a complaint by visiting [macmillan.org.uk/Makingacomplaint](https://macmillan.org.uk/Makingacomplaint) We also have a fact sheet that you can order free of charge by calling one of our cancer support specialists on **0808 808 00 00**.

## Support for each other

No one knows more about the impact cancer has on a person's life than those who have been affected by the disease themselves. That's why we help to bring people with cancer and carers together online and in their communities.

You can find out about people affected by cancer who meet in your area to support each other by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://macmillan.org.uk/selfhelpandsupport) You can also share your experiences, ask questions and get support from others by heading to our online community at [macmillan.org.uk/community](https://macmillan.org.uk/community)

## Further information

We have more information about cancer types, tests, treatment 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:

To order any of our booklets, visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call us on 0808 808 00 00.

### 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)

Alternatively, visit [macmillan.org.uk](http://macmillan.org.uk)

**Hard of hearing?** Use textphone 0808 808 0121, or Text Relay.

**Non-English speaker?** Interpreters available.

## Useful websites

### [www.macmillan.org.uk](http://www.macmillan.org.uk)

Find out more about living with the practical, emotional and financial effects of cancer.

### [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

#### (Citizens Advice)

Get free advice if you wish to make a complaint about the care you've received.

### [www.dh.gov.uk/cancer](http://www.dh.gov.uk/cancer)

#### (Department of Health)

Provides cancer guidelines for England and Wales.

<http://guidance.nice.org.uk/topic/cancer>

**(National Institute for Health and Clinical Excellence)**

Provides cancer service guidelines for England and Wales.

[www.cancerni.net](http://www.cancerni.net)

**(Northern Ireland Cancer Network)**

Provides referral guidelines for suspected cancer in Northern Ireland.

[www.sign.ac.uk](http://www.sign.ac.uk)

**(Scottish Intercollegiate Guidelines Network)**

Provides cancer guidelines for Scotland.

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

**(NHS Direct Online)**

Health information site for England, covering all aspects of health, illness and treatments.

[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

**(NHS Direct Wales)**

Provides health information and contact details for Community Health Councils.

[www.nhs24.com](http://www.nhs24.com)

**(NHS 24 in Scotland)**

Health information site for Scotland.

[www.n-i.nhs.uk](http://www.n-i.nhs.uk)

**(Health and Social Care in Northern Ireland)**

The official gateway to health and social care services in Northern Ireland.

## 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.

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Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community supporting you online, any time. The fundraisers who make it all possible.

You don't have to face cancer alone. We can give you the strength to get through it. We are Macmillan Cancer Support.

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

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

 <p><b>The Information Standard</b> Certified member</p>	<p>This organisation has been certified as a producer of reliable health and social care information. <a href="http://www.theinformationstandard.org">www.theinformationstandard.org</a></p>
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