A practical guide to tests and treatments

GETTING THE BEST FROM YOUR CANCER SERVICES

WE ARE MACMILLAN.
CANCER SUPPORT

This leaflet aims to help you and your family know what you should expect from your cancer services.

It suggests questions you can ask healthcare professionals to help you get the best from your care. This includes your GP, nurses and cancer specialist (oncologist).

It includes questions about:

- diagnosis
- treatment and care
- palliative care.

Each question is followed by a description of what should ideally happen. These descriptions are based on official national guidelines in England and Wales, in Scotland and in Northern Ireland. You'll find more information about these guidelines on pages 30–31. These guidelines are in place to make sure cancer services across the UK are of a high standard at every possible stage. If you find your services are not of a high standard, and are unhappy with any care you receive, the information on pages 33–34 should help.

In this leaflet we've included questions you can ask about being tested for and diagnosed with cancer. We've also included questions you may have during your treatment. These sections might not all be relevant to your situation.

You might have other questions, want more tips on how to speak to your healthcare professional, or just want to speak to someone. You can call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8am. If you're hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

You can also get information and support – and ask many of the questions in this leaflet – at your nearest Macmillan cancer information and support centre. To find one in your area, visit **macmillan.org.uk/informationcentres**

Throughout this leaflet we've included quotes from people affected by cancer, which you might find helpful. These are from the website **healthtalkonline.org** Some names have been changed.

If you find this leaflet helpful, you could pass it on to your family and friends. They may also want to ask questions about how they can support you.

Your healthcare team

Depending on the type of cancer you have and how it's treated, you may be seen by some or all of these professionals:

- a **clinical nurse specialist** – an expert nurse who specialises in a particular area of health, such as cancer, or in a specific cancer type
- an **oncologist** – a doctor who specialises in cancer care and treatment
- a **surgeon** – a doctor who gives operations and specialises in your type of cancer
- a **radiologist** – a specialist in x-rays and scans
- a **therapy radiographer** – an expert in planning and giving radiotherapy
- a **pathologist** – a doctor who studies body tissues
- **palliative care doctors and nurses** – specialists in easing or relieving the symptoms of cancer
- a **haematologist** – a doctor who specialises in diagnosing and treating blood disorders, including some cancers.

You may also be seen by other healthcare professionals, such as a physiotherapist, dietitian, counsellor, psychologist or social worker.

There will also be others involved in your treatment and care, such as your GP (family doctor) and practice nurse.

Ideally, your treatment will be handled by a **multidisciplinary team**. This is a range of different professionals who work together to manage your treatment and care.

You can ask the questions in this leaflet to any member of your healthcare team. If one member of the team can't answer your question, they should be able to refer you to someone else who can help.

You should be told about having a **key worker**. This is often your clinical nurse specialist. Your key worker is the person you're encouraged to speak to as your main point of contact. They'll either be able to answer your questions or point you in the right direction for help or advice. Their name and contact details should be on the record of the first consultation when you're told about having cancer. Your key worker may change during your cancer journey.

‘Communicating with the doctor was very easy. He was very easy to approach.’

Patrick

Questions about diagnosis

Questions you can ask after being referred for tests for cancer

Why are you referring me to a specialist?

Your GP should explain that they're unsure what's causing your symptoms, and that they're referring you to a specialist for further tests. To help your GP decide which symptoms could be caused by cancer and need further investigation, they'll use national cancer referral guidelines. GPs in England, Northern Ireland and Wales currently use a different guideline document to those in Scotland. The guidelines are 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:

- An immediate referral means you should be seen by a cancer specialist within a few hours.
- An urgent referral means you should be seen within two weeks.
- A non-urgent referral is treated as a routine hospital referral and may take longer.

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 done and how you can prepare for them.

What are the tests for and what will they involve?

You should be told:

- why you're having the tests
- what they'll involve
- who will give you the tests
- when you'll get the results
- who will give you the results.

The type(s) of tests or scans you have will depend on the type of cancer that's suspected.

Questions about having tests and getting the results

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.

Will the person doing the test look after me while it’s 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 information about the tests that’s easy to understand and explains everything you want to know. Let your cancer specialist or nurse know if you aren’t sure why a particular test is needed.

Who will give me the results and when?

The cancer specialist should tell you how long it will take before the results are available. You'll usually be given an appointment, and your cancer specialist will give you the results then. They should also tell you about any information and support available to help you while you wait for the results.

Will the specialist have all my test results? Will the appointment be for diagnosis or treatment?

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

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, although there isn't always a specialist nurse for every situation.

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

Your GP should refer you to the specialist who is most appropriate for your situation. This may be a surgeon, an oncologist or another type of specialist, such as a doctor specialising in blood conditions (haematologist). You can ask the specialist about their area of experience.

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

Yes, you can bring someone with you when your diagnosis and treatment options are being discussed.

> **'I would always advise people to take somebody along with them to get another viewpoint.'**
>
> **Alice**

Questions you can ask after getting test results

Who can I phone if I think of questions later? Can I see someone in person?

Someone (usually a nurse) should be available after your initial appointment to discuss your diagnosis and how it may affect you. You'll be told who to contact and you'll be able to contact this person by phone or arrange an appointment to meet them in person.

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 (see **macmillan.org.uk/informationcentres** to find out where this is). You can also call the Macmillan Support Line on **0808 808 00 00**.

‘It's not until some time after that you think, “Well, I wonder what that meant,” or, “I wish I'd asked that”.’

Sonja

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

If you’re diagnosed with cancer, your GP should be told about this promptly by staff at the hospital where you’ve been seen.

Can I ask for a second opinion about my diagnosis or the plan for my treatment?

Your GP or cancer specialist should be willing to refer you to another specialist for a second opinion about your diagnosis or treatment 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.

You can watch a video about getting a second opinion at **macmillan.org.uk/secondopinion**

Who can I talk to about how I'm feeling?

Your GP, cancer specialist or specialist nurse will be able to tell you about how to get any emotional support you need. You can call the Macmillan Support Line on **0808 808 00 00** Monday–Friday, 9am–8pm, whether you have questions or just want to talk about how you feel.

Questions about your treatment and care

Questions you can ask before your treatment starts

> **‘If you don't feel comfortable, ask why they feel that is the appropriate treatment. Don't be afraid to ask questions. This is what the doctors are there for.’**
>
> **Alice**

What are my treatment options?

Your cancer specialist should tell you about all 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 *Making treatment decisions* and *Understanding cancer research trials (clinical trials)* useful. We can send you copies of these booklets.

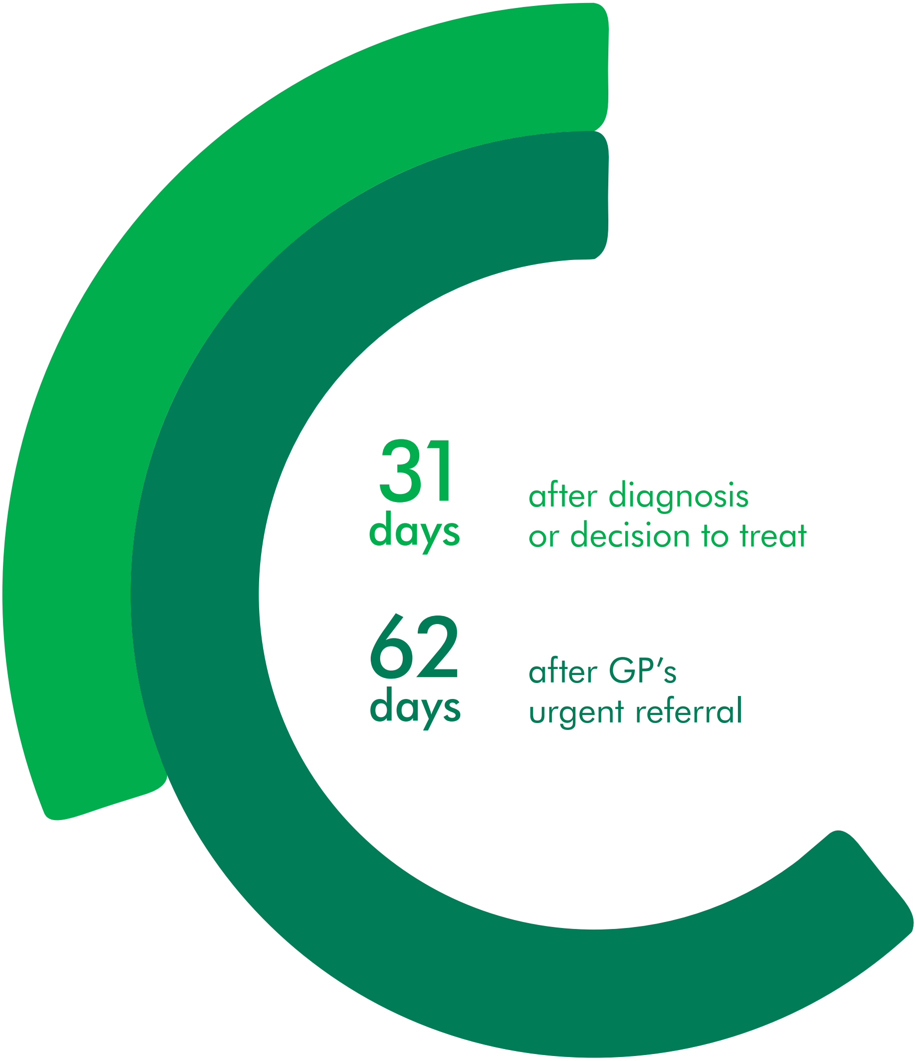
Will any religious or spiritual wishes I have be met?

Your healthcare team should be sensitive about any religious or spiritual beliefs you’ve shared with them. For example, this could mean providing you with information about complementary therapies that could improve your spiritual well-being, such as meditation.

When will the treatment start?

After diagnosis, your cancer specialist will usually want to do further tests and investigations to learn more about your cancer. This will help them plan the best treatment for you. They will be able to tell you how long these tests will take.

If you're diagnosed with cancer and doctors decide you need treatment, then there should be a maximum wait of 31 days between this decision and the start of treatment. If your GP referred you to a specialist as an urgent referral (see page 7), then the total time between this referral and the start of your treatment should not be longer than 62 days. These times come from national targets in place across the UK.



31 days after diagnosis or decision to treat

62 days after GP’s urgent referral

Maximum waiting times before starting treatment

Who will oversee my treatment?

Your treatment should ideally be discussed and planned by a group of specialists called a multidisciplinary team (see page 5). This team will include 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 multidisciplinary team.

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's given. They will discuss the possible side effects of the treatment and what can be done to help relieve them. They'll answer any questions you have. They may also give you some written information about the treatment that you can take home.

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

You can ask your key worker, or any member of the healthcare team, to show you the guidelines and standards. See pages 30–31 for more information about guidelines across the UK.

Questions you can ask about particular treatment types

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

Some types of cancer need more specialist surgery than others, which should be done 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 uses 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 in 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.

Questions you can ask about getting support

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 also find out about local groups by calling us on **0808 808 00 00** or visiting **macmillan.org.uk/selfhelpandsupport** You can also share your experiences and discuss your feelings with other people in your situation on our online community. Visit **macmillan.org.org.uk/community**

What help is available for my family and friends?

Your healthcare team should be able to tell you about support groups for your family and friends.

Questions you can ask about being discharged from hospital and life after treatment

Will I need special equipment or support when I go home?

Your healthcare team should make detailed plans to meet your needs at home after you've been discharged from hospital. As you come to the end of your treatment, someone from the hospital should talk to you about how you're feeling, any concerns you might want to discuss and issues you might face over the next few months. This is sometimes called a **holistic needs assessment** or an **end-of-treatment assessment**.

The healthcare professional may create a care plan with you, based on this discussion. The plan will show how you can get any care or support that might be helpful to you, and what you should do if you have any concerns about your health in the future.

For more information, see our leaflets *What to do after cancer treatment ends: 10 top tips* and *Assessment and care planning for people with cancer.*

Will I have any follow-up care?

‘I got my husband to read everything, so that he could point out things to me that perhaps had gone over my head, or I wasn't taking in.’

Carol

At the end of treatment you may be offered a **treatment summary**. This is a letter from the hospital to your GP and you, which has details of the treatment you’ve had. It also includes information about any follow-up care you may need, such as outpatient appointments and tests to monitor your health. Your follow-up care will usually depend on the type of cancer and treatment you’ve had and your particular needs.

To find out more about getting a treatment summary, you should speak to your key worker, cancer specialist or specialist nurse.

The treatment summary will help when you see your GP, as they’ll know more about the treatment you’ve had and any other issues you’re facing. Your GP may ask you to arrange an appointment with them, to see how you are. This is sometimes called a **cancer care review**. If not, you may still want to make an appointment to see them.

To help you adjust to life after cancer treatment and keep as well as possible, you may be encouraged to become more involved in your own health. Your key worker should be able to give you details of services to help you, such as local health and well-being clinics, support groups, self-management courses and workshops. You can also call the Macmillan Support Line on **0808 808 00 00** to find out more.

Health and well-being clinics, holistic needs assessments and the treatment summary are all parts of something called a **recovery package**. This was developed by the National Cancer Survivorship Initiative (NCSI), which is a partnership between Macmillan and NHS England.

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

Your hospital team should give you the contact details of who to get in touch with if you have any worries or concerns about your health or the possible side effects of treatment. This person can become your new **main contact** or **key worker**.

Does my GP know I'm being discharged?

Your GP should be told quickly when you've been discharged. Your GP will be sent copies of your treatment summary and care plan, so they should know about any important information or follow-up care you need.

How should I expect to feel after treatment?

People often expect to feel positive once treatment has finished, and for life to return to how it was before treatment began. But the reality can be different. People may experience a range of emotions when their treatment is over. This can come as a surprise to both the person having treatment and those around them. We can send you our booklet *Your feelings after cancer treatment*, which you may find helpful. Your GP should be able to put you in touch with support groups and services that can help. You can also contact us for support and information about services.

After having cancer treatment, leading a healthy lifestyle can help speed up recovery and keep you well. It can also help you avoid any late consequences of cancer treatment. Leading a healthy lifestyle includes staying physically active, eating a well-balanced diet, reducing the amount of alcohol you drink and giving up smoking.

We have further information we can send you. We have a *Move more* pack, which has more information about physical activity. We also have booklets about eating well and stopping smoking. All our information is available for free by calling the Macmillan Support Line or by visiting **macmillan.org.uk/movemore**

Many people have concerns about how their work life might change both during and after they finish treatment. Our booklet *Work and cancer* can help you deal with workplace issues. It looks at working during treatment, returning to work, talking to your manager and colleagues, and making decisions about work. It also looks at what you can do if you decide not to go back to work. We also have a leaflet called *Work it out: essential questions to ask about work and cancer*, which you may find useful.

Questions about palliative care

You may reach a stage where your doctors tell you there are no more treatments available to control the cancer. It can be very upsetting and shocking to be told that your illness can't be cured, and you may need help and support to cope with this news.

Although this can be a particularly difficult time, there's a lot that can be done to maintain your quality of life for as long as possible, and control any symptoms you have.

Palliative care is care that reduces symptoms (for example pain or tiredness) towards the end of life, 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.

Questions you can ask about who will support you

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

Your key worker, who is usually your specialist nurse, 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 all the palliative care needs you and your family have are recognised and met. These needs could be physical, psychological, emotional or spiritual.

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

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.

What if I need help overnight or at the weekend?

You should be able to contact your district nurse, who can tell you about the care available during the night or at weekends. If you need more specialist support, the district nurse 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.

Questions you can ask about your feelings and choices

Who else can I talk to about how I'm 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.

Will I be involved in decisions about which types of treatment and care I receive at this stage?

You should be involved in these decisions as much as possible. Your palliative care doctor should ask your views early on so they can influence their plans. Your palliative care doctor should also give you good information and evidence about all the choices available.

There are ways that you can plan ahead and make choices about your future care, for example by writing down your wishes for how you'd like to be cared for. The ways people can plan ahead vary across the four nations of the UK (England, Scotland, Wales and Northern Ireland). We can send you information about advance care planning that's relevant to where you live.

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 bereavement care is offered to your family. There are many organisations that run groups for people who are grieving, such as Cruse Bereavement Care – visit **cruse.org.uk**

Call us on **0808 808 00 00** (Monday–Friday, 9am–8pm) for support and more information about the support available to your family.

National guidelines and standards

There are national guidelines and standards in place across the UK about cancer treatment and care. You can ask your healthcare team to show you these documents if you'd like to read them. You can also find them online. Some of the guidelines and standards used are different across the UK.

England and Wales

- Good cancer treatment and care are outlined in the 2011 Department of Health report *Improving outcomes: a strategy for cancer.* This is available online at **gov.uk**
- The National Institute for Health and Care Excellence (NICE) document *Referral guidelines for suspected cancer* gives recommendations for GPs about referring someone to a specialist when they have symptoms that might be cancer. There's also a version of this document aimed at helping the general public understand the guidelines. Both versions are available from **nice.org.uk** There are also other NICE guidance documents relating to specific treatments and cancers.
- *Living with and beyond cancer: taking action to improve outcomes* is a 2013 Department of Health report that gives guidance about supporting people after cancer treatment.

Scotland

- Guidelines and plans for improving cancer treatment were set out in the 2008 Scottish Government report *Better cancer care: an action plan*. This is available at **scotland.gov.uk** The Scottish Intercollegiate Guidelines Network (SIGN) also produces guidelines about specific cancer types and management of particular conditions. Visit **sign.ac.uk**
- NHS Scotland and the Scottish Government produce the document *Scottish referral guidelines for suspected cancer*. A quick reference version of this guidance is also available. Both versions are available at **scotland.gov.uk**

Northern Ireland

- Standards for treatment and care were set out by the 2011 Department of Health, Social Services and Public Safety report Service framework for cancer prevention, treatment and care. This is available at **dhsspsni.gov.uk**
- The National Institute for Health and Care Excellence (NICE) document *Referral guidelines for suspected cancer* gives recommendations for GPs about referring someone to a specialist when they have symptoms that could be cancer. There’s also a version of this document aimed at helping the general public understand the guidelines. Both versions are available from **nice.org.uk** There's also NICE guidance relating to specific treatments and cancers.

When your healthcare is not as good as it should be

Most of the time, treatment and care goes well. However, it doesn't always work out that way, and sometimes things go wrong. Discussing this with the healthcare professionals involved or another person on the team can often resolve the issue. It's a good idea to raise any concerns you have at the time you notice them, so they can be addressed quickly. However, if this doesn't work, or if you feel that talking about the issue with the people involved won't help, you may want to complain. Complaints can also be made by a carer who's acting on your behalf.

All hospitals and GP practices have a member of staff who's 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.

Support with making a complaint

A good place to get free advice about making a complaint is your local Citizens Advice – visit **adviceguide.org.uk**

In England, you can also talk to a Patient Advice and Liaison Service (PALS). All hospitals in England have access to a PALS. They're there to help with any queries or issues you have about your healthcare. You can contact your local PALS by phoning the hospital where you were treated. The PALS can usually help solve problems, or it can put you in contact with the Independent

Complaints and Advocacy Service (ICAS), who can offer you advice.

In Scotland, you can get advice from your local NHS Board. Visit **scotland.gov.uk/topics/health** to find contact details for your local board. You can also get advice and support in Scotland from the Patient Advice and Support Service (provided by Citizens Advice Scotland) – visit **cas.org.uk/patientadvice**

In Wales, help and advice is available from your Community Health Council. To find your local council online, visit **wales.nhs.uk**

In Northern Ireland, help and advice about making a complaint is available from the Patient and Client Council – visit **patientclientcouncil.hscni.net**

You can find out more about making a complaint by visiting **macmillan.org.uk/makingacomplaint** We also have a fact sheet you can order for free by calling one of our cancer support specialists on **0808 808 00 00**.

Further information

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**

To order any of our booklets, visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Useful websites

American Cancer Society
www.cancer.org
Nationwide community-based health organisation dedicated to eliminating cancer. It aims to do this through research, education and advocacy.

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

Health and Social Care in Northern Ireland
www.hscni.net
The official gateway to health and social care services in Northern Ireland.

Healthtalkonline
www.healthtalkonline.org
www.youthhealthtalk.org
Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

National Cancer Institute – National Institute of Health – USA
www.cancer.gov
Has information about cancer and treatments.

NHS Choices
www.nhs.uk
The online 'front door' to the NHS. It's the country's biggest health website and gives all the information you need to make decisions about your health.

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

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date, but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it.

Thanks

This leaflet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

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More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

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 there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way,
call Macmillan on 0808 808 00 00
(Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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The Information Standard
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This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

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