

The Support Guide for Anyone on a Suspected Cancer Pathway

Your guide to key questions to ask when you are referred for tests to investigate for cancer, or if you have already been diagnosed with cancer.



Welcome to your Cancer Pathway Support Guide

A suspected cancer referral can be an overwhelming experience. This guide has been developed to support you in making the right decisions for you and your needs. It provides key questions to ask during your appointments and consultations. It also allows you to make notes as you go along, print sections as you need and signposts you to relevant information.

There are 2 ways to access and use the guide - this document, or online via the website. Both online and paper options contain the same questions. Your healthcare professionals will be able to support you, to get the most out of using them.



For some readers, the guide may be hard to understand and use. If you usually need a family member, friend, carer or support worker to help you when you see your doctor or go to hospital, then please ask them to assist you.



You are referred urgently for tests by your GP (or other healthcare professional) on a two week wait referral to rule out cancer

GP or other healthcare professional refers onto a suspected cancer pathway: In the UK, suspected cancer referrals are treated as high priority. This means when cancer is suspected, then there is a faster route to get further tests and specialist advice. The suspected cancer referrals are also known as 2 week waits or target referrals.

What is an urgent cancer referral?

When cancer is suspected there is a fast route within the NHS to get further tests and specialist advice to rule out cancer. These are called 2 week wait referrals and you should be seen within 2 weeks of being referred. More and more people are getting diagnosed with cancer and the earlier we catch it the better the chances are of survival and quality of life. Most people who are referred by their GP on this route will NOT have cancer (9/10) and it is important that if your GP has referred you for this urgent pathway that you do make arrangements to attend.

cancerresearchuk.org/cancer-symptoms/what-is-an-urgent-referral

When will my appointment take place?

You should receive your appointment to rule out suspected cancer, 2 weeks from the date that you were referred.

Where will my appointment be?

You can discuss which hospital you want to be referred to with your GP. Please note that some hospitals have more than one site where your appointment might take place. You will find this information on your appointment letter when you get it.

How will the appointment take place?

You may be sent directly for tests, or you might speak to a specialist first. Most appointments will be face to face at the hospital depending on the investigations you may need. Sometimes, you may also have a telephone or video call. The hospital will let you know when communicating with you.

Section One - Investigation for your symptoms

Will I have my appointment before any tests are done?

Sometimes the hospital will decide it is faster for you to get a test done before having a consultation with a doctor/nurse (this can be called a 'straight to test' appointment).

What can I do to prepare for this appointment?

The hospital will let you know what you should do to prepare for your appointment. You may wish to consider if you want to bring someone with you and make plans for your travel to and from the hospital on the day.

Is there support to get to the hospital, if its needed?

Check your hospitals website for patient transport information and request further guidance.

www.nhs.uk/nhs-services/hospitals/going-into-hospital/how-to-organise-transport-to-and-from-hospital/

What should I do, if my symptoms get worse, change or if new symptoms develop before my appointment?

Contact your GP surgery as soon as possible and request to be seen urgently by your GP so that you can get further advice. If out of hours you will should contact 111 or seek urgent medical attention.

What can I do if I feel worried after being referred?

It is okay and normal to feel worried after being referred for suspected cancer investigations. It may help if you are concerned and have any questions, to ask for a follow up call with your GP before your cancer referral appointment. There are also a number of support services you may wish to consult if relevant to you.

www.macmillan.org.uk/cancer-information-and-support/get-help/emotional-help/macmillan-support-line



You enter the cancer pathway through another route

What are these other routes?

You may get urgent cancer investigations after attending A&E, seeing your specialist at hospital or through the National Cancer Screening Programmes. The programmes consist of the bowel cancer screening using the poo sampling test kit (known as FIT), cervical cancer screening, and breast cancer screening.

Additionally you may be contacted for a lung health check.

What do I need to do after being referred for an urgent appointment even though it was not by my GP?

Your appointment and the referral process will be the same as someone who is referred directly by a GP or a dentist. You should receive your letter and your appointment date within two weeks of being seen for your symptoms.

If you have not got an appointment by then, you must contact the referring team or your GP.

Will my GP know that I have been referred for an urgent cancer investigations appointment?

Most surgeries will get a notification by electronic mail and sometimes there can be a delay in sending or receiving this. You are welcome to share any information you receive with your GP practice, if you think they have not got this information.

Attending my FIRST appointment after being referred (usually with a healthcare professional, such as a doctor or nurse)

Usually this will be with a healthcare professional, for example doctor or nurse.

What will happen at my appointment?

You will be seen by a doctor or a nurse who will carry out a further consultation about your overall health and symptoms to identify the tests that will be required.

Section One - Investigation for your symptoms

What should I do if I need support to understand what is happening at my consultation?

If you need a translator or advocate, ask what services are available to help you to get the most from your consultation.

What can you tell me about the symptoms I have?

For example you may wish to ask what could be causing your symptoms or what actions you can take while you wait for tests.

What tests will I need to have?

The tests will depend on your individual symptoms. The doctor or nurse that you see will advise which test/s and how to prepare for them as well as how long they will take.

Will I need more than one appointment?

There may be a series of appointments depending on the number of tests and the requirements for each test. It is a good idea to prepare so you can attend all of these, for example to arrange time if you are employed or have care responsibilities.

How do I contact the cancer team if I need to?

Ask if a named person or department number and/or email is available.

Can I see my health records online?

Ask your cancer team if you can access to your records online. If not, you can also request this information as a printed copy from your GP surgery.

<https://digital.nhs.uk/services/nhs-login/>

Where can I get information about hospital parking or support with travel costs?

The hospital website will have helpful information on how to get there via public transport and tell you what parking arrangements are available. Information on support with travel costs can also be found on this website.

www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs/



If my first appointment is a 'Straight to Test'

What does straight to test mean? Why did this happen?

Some people may be referred to have tests straight away, before being seen by a doctor. This could be to have a colonoscopy or an endoscopy.

This is because it makes it faster to get to a result and let you know it. The hospital will inform you of the test result.

How long will my appointment take?

The length of the appointment for the test can vary, depending on the test you are having. All of the information about details of the test and the time it will take will be in your hospital appointment letter.

How do I get my test results?

A face to face consultation, a telephone call or a letter are the usual ways. If you haven't received your test results in the specified time you can call the number given in your hospital letter.

www.macmillan.org.uk/cancer-information-and-support/diagnosis/waiting-for-results



Section One - Investigation for your symptoms

My tests

Do I need to prepare for the test?

Lots of tests will require some sort of preparation from you. Please read any supporting information sent to you with your appointment letter. If you are not sure of anything, please call the phone number provided in the letter to get more information.

Will I be able to travel home alone after my tests?

If this information hasn't been provided, you should ask the hospital team.

How will I find out my results? When will I get them?

A face to face consultation, a telephone call or a letter are the usual ways. Ask the clinical team how long you will have to wait for your results. You can ask for a telephone number or email so that you can follow up.

How long does it take to do the tests?

The length of a test can vary, depending on the test you are having. It's helpful to make sure you know what you are having and how much time to plan to have this done. You may have one or more tests over a day or days.

How do I let the hospital know if I can't make the appointment and need to rearrange it?

The contact information for rearranging appointments will be in the hospital letter you receive.

Can I see my health records and test results online?

Ask if your hospital gives you access to your records online.

<https://digital.nhs.uk/services/nhs-login/>



Section One - Investigation for your symptoms

I will need further tests

Why are more tests needed?

Sometimes test results can be unclear or more information is required to help your medical team make a diagnosis.

Section Two - Your Diagnosis

I do not have a cancer diagnosis and I have not been given any diagnosis for symptoms

I don't have cancer but I still have symptoms what should I do?

Contact your GP to talk to them more about your ongoing symptoms or issues.

Will my GP be notified that I don't have cancer?

Yes, your GP will receive a letter from the hospital.

Is there any advice you can give me to reduce my chances of getting cancer in the future?

Taking part in the national cancer screening programmes (like the FIT bowel cancer testing) and having a healthy lifestyle are just some things you may wish to consider. Check the hyperlink for more information.

www.cancerresearchuk.org/about-cancer/causes-of-cancer/can-cancer-be-prevented-0



I do not have cancer. I have another condition that is causing my symptoms

I don't have cancer but I have received another diagnosis, what does that mean for me?

The hospital team will be able to offer further information about your diagnosis, you can also seek support from your GP if you have any concerns.

Who will I see for my new diagnosis?

You may be referred on to another specialist. Contact your GP as they will be able to provide information about any referrals made.

I have a diagnosis of cancer

What does this mean for me?

The diagnosis of cancer can be overwhelming and you and your family may be experiencing lots of emotions and have many questions. It may be helpful to think about these questions, write them down and talk through with your GP or cancer team. www.macmillan.org.uk/diagnosed-with-cancer



Section Two - Your Diagnosis

What is a cancer nurse specialist (CNS)?

They are a key person in your clinical care. They will be your main point of contact as you progress through your pathway. Your CNS will help you understand every stage of the pathway and your treatment options. They will provide support, updates, information and coordinate things on your behalf.

Can I choose to have appointments in person or virtually - by phone or video?

Yes, please talk with your cancer team about your options. Some appointments may need to be in person as physical examination may be required.



What treatment options do I have?

The treatment options will depend on the type of cancer and if it has progressed to other areas. Your doctor will explain the ones relevant for you and will give you written information about these.

www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions

How do I make the best treatment decision for me?

You can talk through your options with your cancer team and also ask for more information to help you understand your choices better.

Section Two - Your Diagnosis

What happens next?

Your clinical team will talk you through the next steps. Improving your physical health (physical activity and nutrition) before you undertake treatment has been shown to be of benefit, so ask for advice about being as active and well as possible.

www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/prehabilitation/what-is-prehabilitation

Where will my treatment take place?

Your treatment may take place at one or more hospital sites. Discuss this with your cancer team and get further details.

I am feeling emotional. Who can I talk to about this?

You may wish to talk about your feelings with your clinical team or ask them to signpost you to a local service that provides emotional support. There may also be people in your own support network who you may find it helpful to speak to.

www.macmillan.org.uk/cancer-information-and-support/get-help/emotional-help/macmillan-support-line / www.cancerresearchuk.org/about-cancer/coping

I am a carer for a family member with cancer, can I access support?

This guide provides more details and links to specific charities that can help depending on what you need. Alternatively you may ask your family member's clinical nurse specialist for advice, or you can access the Macmillan Information and Support Service at the hospital.

<https://patient.info/news-and-features/what-health-support-is-available-for-carers>



Section Two - Your Diagnosis

I have a family history of cancer - will others in my family get cancer?

It's important you discuss any family history of cancer you know of with your clinician. They will be able to advise on any potential risks for your family members in getting cancer, and next steps.

How do I know that I am receiving the best care and support for me?

Your cancer care will be personalised for you to make sure you receive the best care and support for the things that matter most to you.

You should be offered a Holistic Needs Assessment, Treatment Summary and Health and Wellbeing Information and Support. Information on these is available in the link. And you can ask any member of your cancer team about when/how to receive these. <https://cancerwellbeinglondon.nhs.uk/health-and-wellbeing-information/affected-by-cancer/>

How do I tell my family and others that I have cancer?

Explaining a diagnosis of cancer to loved ones can be challenging. There are lots of resources that are available to help you with this. You can also speak to your clinical nurse specialist for further support and advice.

www.macmillan.org.uk/cancer-information-and-support/diagnosis/talking-about-cancer/how-to-tell-people-you-have-cancer, www.macmillan.org.uk/cancer-information-and-support/diagnosis/talking-about-cancer/talking-to-children-and-teenagers



My MDT (multidisciplinary team) will be discussing my cancer management plan

What is an MDT? How does it help me?

A multidisciplinary team (MDT) is a group of health professionals who will work together to recommend the best treatment options to explore with you. By having different health professionals working together this will make your experience and management of your condition much better.

A member of the MDT will outline the options discussed and work with you to decide which treatment(s) will be best for you.

www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/your-multidisciplinary-team-mdt

Deciding on the best cancer treatment for me

Is the cancer I have curable?

'Cure' means the cancer will go away with treatment and is not expected to come back. Your medical team will be able to tell you about the aims of the treatment you will be receiving - to cure your cancer or to slow the progression of the disease and help manage symptoms. www.cancer.org/treatment/understanding-your-diagnosis/cancer-be-cured.html

What are my treatment options?

There are many different types of cancer treatment. From surgery, chemotherapy, radiotherapy to newer ones like targeted treatment. Your clinical team will go through the best options for you. www.macmillan.org.uk/cancer-information-and-support/treatment/types-of-treatment



Section Three - Your Treatment and Care

How do I know what is best for me?

There are a number of patient support tools that have been developed to help you make your choice. www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions

What will treatment involve? How much time do I need to commit?

This will depend on the treatment you receive. For example surgery may mean you have to stay in hospital for a period of time.

Chemotherapy may require a number of visits and tests. Details about the treatment you will receive will be given to you by your cancer team. www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/questions-to-ask-your-healthcare-team

What are the side effects and how long will I have them for?

Your cancer treatment will likely have some side effects and these can be short term (during treatment) or longer term (occur at a later stage after treatment).

Ask your clinical team for information about the effects of treatment - they will have written information or will be able to explain these to you in person (or over the phone if you prefer).

Will the treatments offered affect my ability to work or do my usual daily activities?

You may have concerns around ability to drive, work or do exercise and you can discuss these with your cancer team.

Section Three - Your Treatment and Care

How may this all affect any existing health conditions I have or interact with any medication I take already?

Make sure your cancer team are aware of any other health conditions that you may have. These will be taken into account in planning of your treatment.

They will also talk with you about any implications of cancer treatment on these existing conditions.

I have heard about cancer clinical research trials. Would I be able to join a clinical trial for my cancer?

Ask your clinical team if there are any clinical trials that would be relevant for you to join. www.cancer.gov/about-cancer/treatment/clinical-trials

I may need more practical support around finances, benefits and work. Who can I ask?

These are important questions to ask. Have a look at the links included here.

Also ask your clinical nurse specialist for a holistic needs assessment to be conducted with you. This will help identify the issues that you might be experiencing. A care plan can be drawn up to signpost/refer you to local services that will be able to help you.

www.citizensadvice.org.uk/benefits/

www.macmillan.org.uk/cancer-information-and-support/get-help/practical-help

www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/holistic-needs-assessment



Section Three - Your Treatment and Care

How can I make sure I can be as physically fit as I can for upcoming treatment?

Improving your physical health before you undertake treatment has been shown to be of benefit.

You can ask if there is a local physical activity programme for people with cancer that you can take part in. www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/prehabilitation/what-is-prehabilitation



I am going through my cancer treatment

Where will I have my treatment and can I choose?

Your treatment, depending on what it is, may be offered at one or more hospitals. Discuss your options for choosing the location for your treatment with your clinical team.

If I experience side effects what can do I do and who can I speak to ?

Your specialist team will advise you on who to contact or sources of information depending on your symptoms.

I am being referred to another hospital as part of my treatment plan

Why am I being transferred?

Some parts of your treatment is better managed at a hospital which has expertise in this area.

Where I am being referred to?

Your team will let you know and will give you plenty of notice about any referrals to different hospitals.

Will they have information about me?

Your team will be share your relevant clinical records with the hospital.

How can I find out more?

Ask your team for more information on the hospital - including arrangements about how to travel there.



Section Three - Your Treatment and Care

I am returning to my original hospital, to continue my care

Will they have information about what happened at the specialist trust?

The hospital will share clinical information about your care back to the hospital you started at. You can always ask to have this information shared with you too.



My treatment review

Has my cancer been cured?

Your doctor will update you on how your cancer has responded to the treatment you have received.

Will there be more treatment?

Your cancer team will give you this information once they have received any relevant test results.

Section Three - Your Treatment and Care

Do I need ongoing cancer monitoring or checks?

Your cancer team will make you aware of this.

Ask to receive a Treatment Summary. This document is completed by your multidisciplinary team and will have information about any upcoming or ongoing cancer surveillance tests you will receive.

What signs and symptoms should I be looking out for?

If needed, you will be told to look out for specific symptoms or signs, and who to contact if this occurs. This information will also be available in the Treatment Summary that will be sent to you and your GP.

If you have not received your Treatment Summary, please ask your cancer team to send this to you.

I have ongoing symptoms related to my treatment, what can I do?

You should discuss these with your clinical team and GP for further advice.

Is there an easy to read summary of my treatment so far?

Your team will produce a Treatment Summary for you and your GP. This document covers what treatment you have had and highlights the key long term effects to be aware of. www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/personalised-care



I am going to be discharged from hospital care soon

How long do I stay under the hospital care?

Everyone will have an individual plan for what their ongoing hospital care looks like. People can have ongoing check-ins at hospital, in the community (e.g. GP) or as and when they feel they need it. These plans are personalised cancer follow up plans.

<https://canceralliance.wyhpartnership.co.uk/our-work/living-with-and-beyond-cancer/personalised-care/personal-stratified-follow-and-supported-self-management>

Do I need ongoing cancer monitoring or checks?

Some cancers will require ongoing monitoring. Your clinical team and GP will be told what that means for you.

What support is available to help me move forward with or after cancer?

Cancer can have a significant impact on our lives. Health and Wellbeing Events (HWBEs) are education and support sessions that provide individuals living with or beyond cancer with information to live as healthily and actively as possible during or after cancer treatment. <https://cancerwellbeinglondon.nhs.uk/health-and-wellbeing-events/>



Section Three - Your Treatment and Care

How will I continue to get support once I am discharged?

Your GP practice will be able to offer support - they can carry out cancer care reviews once you are ready. Contact them if you do not hear anything.

www.youtube.com/watch?v=WwxIreE3pVU

How do I get help if I have further questions?

The hospital team and GP team, as well as many of the cancer charities, can provide a lot of advice depending on need.

www.cancerresearchuk.org/about-us/contact-us/talk-to-our-nurses

What information do I need to have about my treatment so far?

You will have had a holistic needs assessment (HNA) at various points of your care.

Your team will also be producing a summary document of your treatment to date. This document should highlight the main long term effects to be aware of. This is an important document to share with your GP.

www.macmillan.org.uk/cancer-information-and-support/treatment/coping-with-treatment/holistic-needs-assessment-hna

www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/personalised-care



Section Three - Your Treatment and Care

What should I do if I am worried my cancer is back after discharge?

Contact your GP for any new concerns you may have. It's helpful to flag if you have a history of cancer when booking your appointment so the administrative team can help to give you priority.

You can also call the Cancer Research Helpline and speak to a Nurse Tel: 0808 800 4040 www.cancerresearchuk.org/about-us/contact-us/talk-to-our-nurses

What can I do about long term effects of my cancer treatment?

This will depend on what the effects are. You should talk to your doctor for further advice. www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/chemotherapy/side-effects/late-effects

I need support to help me living with or after cancer

Coping with having cancer can be difficult. There are a number resources for help and support - from coping with emotions to daily practical support.

You may also find it useful to visit the Macmillan Information and Support Centre at your hospital and ask what ongoing support is available for you.

www.cancerresearchuk.org/about-cancer/coping



Section Three - Your Treatment and Care

Can I give feedback about my care?

The NHS has a number of patient surveys, which give insightful feedback to healthcare providers so they can improve their service. In cancer care, the Quality of Life Survey has been introduced for those who have been living with cancer for the last 18 months. You may wish to take part when you are asked.

www.cancerqol.england.nhs.uk/about_the_survey/index.html



Disclaimer

This checklist has been co-created with residents, patients and carers from the five north central London boroughs of Barnet, Camden, Enfield, Haringey and Islington, as well as healthcare professionals. The checklist gives an overall picture of the main steps in the cancer pathway but recognises there will be variation for many people. The signposted third party resources have been carefully selected and verified. We endeavour to ensure they are current and active but cannot guarantee this.



The cancer pathway support guide is provided by the The North Central London Cancer Alliance. An NHS organisation that brings together patients, hospital trusts, GPs, health service commissioners, local authorities, charities and community organisations to improve cancer outcomes and care. The guide is not geographically specific and can be used by any healthcare professional or user in NHS England.

We welcome your feedback and experiences in using this guide. Please email us at: uclh.nclcanceralliance@nhs.net