

Access to cancer treatment

This information is for people who feel they would benefit from a treatment or drug that isn't routinely funded by their local health body.

Key to acronyms

Throughout this section the following acronyms appear:

IFR – Individual Funding Requests

IPTR – Individual Patient Treatment Requests

NHS – National Health Service

NICE – National Institute for Health and Clinical Excellence

PCT – Primary Care Trust

SHA – Strategic Health Authority

SMC – Scottish Medicines Consortium

Each nation has a different name for local health bodies. In England, they are called primary care trusts (**PCTs**), in Scotland and Wales they are called **health boards**, and in Northern Ireland they are called **health and social care trusts**.

If you want to apply to your local health body for a drug or treatment, you'll need to follow the procedures they set out. These may differ from region to region. Some have leaflets or information on their websites explaining what you should do. Your cancer specialist will also explain the local process to you.

Some people may consider other options, such as paying for drugs or treatments that they can't get on the NHS.

It can be very difficult when you feel that a drug or treatment that could benefit you isn't readily available. You may feel angry, frustrated and let down. Dealing with this as well as your cancer can feel overwhelming.

We hope this information answers your questions. If you have any more questions, you can ask your doctor or nurse or speak to one of our cancer support specialists.

The cancer drugs fund

The UK government's £200 million cancer drugs fund for England came into effect on 1 April, 2011. The fund aims to help people who are trying to access cancer drugs which aren't available on the NHS. For more information see our section on the Cancer Drugs Fund.

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Home > Cancer information > Cancer treatment > Getting treatment > Access to treatment > How drugs and treatments are made available in the NHS

How drugs and treatments are made available in the NHS

All medicines in the UK are subject to a system of licensing laid down by European and UK law.

Before a drug is licensed, it will have been through years of research and development. After this, the developer will apply for a licence for the drug. This is when the safety of the drug is looked at, as well as how it compares to drugs currently in use.

Most new cancer drugs must be licensed by the European Medicines Evaluation Agency. The organisation that regulates medicines in the UK is the Medicines and Healthcare Products Regulatory Agency. Until a new drug is licensed, it can't be widely prescribed within the NHS.

When a drug is licensed, it's usually for a specific use. For example, a drug that is licensed to treat breast cancer should not be prescribed to treat any other type of cancer. If new trials show that the drug is also helpful in treating another type of cancer, the makers will have to apply for an additional licence.

Non-drug treatments - for example, new ways of giving radiotherapy - become available when there's good evidence from studies that they work well.

Organisations that give advice to the NHS

The National Institute for Health and Clinical Excellence (NICE) is an independent organisation. It gives advice on which new and existing drugs and treatments should be available on the NHS, and on how particular illnesses like cancer should be treated. NICE advises the NHS in England and Wales. In Wales, the All Wales Medicines Strategy Group advises on the use of treatments that haven't yet been evaluated by NICE.

In Scotland, guidance about treatment is developed by the Scottish Intercollegiate Guidelines Network. The Scottish Medicines Consortium (SMC) advises Scottish NHS Boards on the use of new drugs. Sometimes, the NHS in Scotland will choose to adopt NICE guidance on certain treatments.

In Northern Ireland, the Department of Health, Social Services and Public Safety reviews guidance produced by NICE. If it decides the guidance can be applied to Northern Ireland, it will endorse it for use by health and social care trusts.

NICE and the SMC look at how a new drug or treatment compares to the treatment already available and whether it's good value for money. When all the information has been reviewed, a decision is made about the new drug or treatment and guidance is then issued.

NICE and the SMC don't make decisions about all drugs or treatments used in the NHS. If they haven't issued guidance, local health bodies can use other information to decide whether to provide a drug or treatment.

A lack of NICE or SMC guidance is not a reason for not providing a treatment. Your doctor can prescribe a drug for you before NICE guidance is available, but your local health body needs to agree to this. However, if NICE approves a medicine, this replaces any previous local decisions. If NICE does not approve a particular drug, it may still be accessible through exceptional funding or the Cancer Drugs Fund.

Local health bodies must make arrangements to fund the drug within three months. However, guidance for a non-drug treatment is not enforced in the same way, so differences in regions can happen.

Despite these procedures and any guidance, it's still up to the doctor to decide whether to use a treatment or prescribe a drug. Doctors may wish to treat a patient with an unlicensed drug. In this situation, the local health body will assess how useful it is. They may then allow it to be prescribed on an individual basis.

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Home > Cancer information > Cancer treatment > Getting treatment > Access to treatment > Why some drugs or treatments are difficult to access

Why some drugs or treatments are difficult to access

Local health bodies need to make sure the drugs and treatments they fund are of clear benefit to the people in their area. They also need to make sure they are spending their money wisely.

This means that they may decide some drugs and treatments, which aren't approved by NICE or the SMC, won't be readily available. Usually, local health bodies keep a list of drugs or treatments that are not automatically funded.

Cancer drugs or treatments may not be automatically funded if the local health body decides they haven't been proven to be more effective than other treatments, or if they aren't good value for money.

The effectiveness of a drug or treatment may be decided after trials have been done and when decisions are made by NICE or the SMC.

Whether or not a drug or treatment is funded in individual cases will be decided by the local health body. Each local health body must have a process in place to make these decisions.

We have more information on how treatments are made available, which you may find helpful.

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Home > Cancer information > Cancer treatment > Getting treatment > Access to treatment > What your doctor can do for you

What you and your doctor can do if a particular drug isn't readily available

To begin with, it's important to talk to your cancer specialist. You can then both decide whether it really is the best treatment for you.

Choosing the best treatment will depend on a number of factors, such as:

- the type and stage of cancer you have
- any other treatments you've had
- whether there are any other treatments that might be suitable
- what the side effects of this particular treatment are likely to be.

If you decide to apply to your local health body for a drug or treatment, you'll need to follow the procedures they set out. Please click on your region below for more information.

Find information for where you live



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Home > Cancer information > Cancer treatment > Getting treatment > Access to treatment > What your doctor can do for you > What you can do if you live in England and treatment isn't available

What you can do if you live in England and treatment isn't available

If you and your doctor feel you would benefit from a particular drug or treatment, you can apply to your Primary Care Trust (PCT), asking for it to be made available to you as an exception from their usual rules.

On this page

- Applying to your PCT
- What happens next?
- Making an appeal

In England, PCTs usually call these applications **individual funding requests (IFRs)**.

PCTs will be replaced by **Clinical Commissioning Groups** in April 2013. These groups will have similar responsibilities to the PCTs they are replacing.

Applying to your PCT

Usually you would ask your cancer specialist or GP to apply on your behalf. IFRs need to be made by someone who knows your medical situation well and believes that the drug or treatment will help control your cancer. They should make a written request to the PCT. Many PCTs have specific forms for these requests. If you're too ill to be actively involved in the application, you can ask someone else to act on your behalf.

The PCT will consider different factors to help them make its decision. It's important to read about these before making an application. You can ask the PCT for this information.

The request form should tell you who it should be sent to. If this isn't clear, the PCT can provide this information.

Your application should include:

- your relevant medical history
- details of the medical need for which the exceptional funding is requested
- the expected benefits of the drug or treatment
- supporting information and a summary of why the drug or treatment should be granted
- details of any research or trial that supports the use of the drug or treatment in cases like yours.

Some forms may ask for details of your personal circumstances. Ask your doctor for a copy of the request. It's a good idea to keep a written record of all contact with the PCT.

What happens next?

You'll be sent a letter confirming that your application has been received. Your PCT should have all the relevant information at this point, so make sure you've included everything needed for your application.

The decision about whether you'll be able to have the treatment will be made by a panel of PCT board

members. You can ask whether you can attend their meeting. It's likely this will include an opportunity for you (or your representative) and your doctor to present your case or answer questions from the panel.

The PCT will make a decision within a set period of time. This is usually between 4–8 weeks, but it can vary around the country. When the PCT acknowledges your application, it may tell you when it will make its decision.

If your request is approved, your doctor can usually prescribe the drug or treatment shortly afterwards.

Making an appeal

If the request is denied, the reasons for this will be explained and you'll be told how you can appeal against the decision. There will be a time limit within which an appeal must be made (usually 28 days). At this point, you and your doctor can also ask for further explanation of the decision.

If you want to appeal, either you or your representative must notify the PCT in writing that you intend to do this. Some people have been able to get original decisions changed through appeal.

The appeal can include a letter of support from your doctor. You should also explain in your letter whether your circumstances have changed since the original application.

Each PCT will have a timescale for hearing the appeal and informing you of their decision.

If your appeal is unsuccessful, you can't appeal again to the PCT, but you can use the NHS complaints procedure or write to the Parliamentary and Health Service Ombudsman. You can also seek legal advice.

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Home > Cancer information > Cancer treatment > Getting treatment > Access to treatment > What your doctor can do for you > What you can do if you live in Scotland and treatment isn't available

What you can do if you live in Scotland and treatment isn't available

If you and your doctor think that you would benefit from a particular drug or treatment that has not been recommended by the SMC, you can apply to your health board asking for it to be made available to you as an exception from its usual rules.

On this page

- What happens next?
- Making an appeal

In Scotland, these applications are called **Individual Patient Treatment Requests (IPTRs)**.

Each health board is required to provide information to you if you ask for it. It should explain how the IPTR process works in your area.

You need to ask your cancer specialist or GP to make the request on your behalf. An IPTR needs to be made by someone who knows your medical situation well and believes that the drug or treatment will help control your cancer. They must show why you are more likely to benefit from a medicine than would normally be expected.

You can only apply for a drug that has been licensed for your particular condition. If you're too ill to be actively involved in the application, you can ask someone else to act on your behalf.

The health board will consider different factors to help them make a decision. It's important to read about these before making an application, and you can request this information from the health board.

Your application should include:

- your relevant medical history
- details of the medical need for which the exceptional funding is requested
- the expected benefits of the drug or treatment
- supporting information and a summary of why the drug or treatment should be granted
- details of any research or trial that supports the use of the drug or treatment in cases like yours.

Some forms may ask for details about your personal circumstances. Ask your doctor for a copy of the request. It's a good idea to keep a written record of all contact with the health board.

When you are going through the request process, you should be given the name of someone who can give you information, advice and support.

What happens next?

The decision about whether you'll be able to have the treatment will be made by a specially formed panel. The membership of the panel will depend on the medicine being requested, and your health board should inform you who is on the panel.

The panel will make a decision within a set period of time, which will be set out in the health board's written policy on IPTRs. The decision will be given to your doctor, who will discuss it with you.

If your request is approved, your doctor can usually prescribe the drug or treatment shortly afterwards.

Making an appeal

If the request is denied, the reasons for this will be explained, and you will be told how you can appeal against the decision. Some people have been able to get original decisions changed through appeal. At this point you and your doctor can also ask for further explanation of the decision.

You can appeal if you think the panel's decision was not justified or if the proper process was not followed. You can only appeal if your doctor supports your decision.

Each health board must have a process in place for IPTR appeals. There will be a time limit within which an appeal must be made.

If your appeal is unsuccessful, you can't appeal again, but you can use the NHS complaints procedure or write to the Public Service Ombudsman. You can also seek legal advice.

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Home > Cancer information > Cancer treatment > Getting treatment > Access to treatment > What your doctor can do for you > What you can do if you live in Wales and treatment isn't available

What you can do if you live in Wales and treatment isn't available

If you and your doctor think that you would benefit from a particular drug or treatment that has not been recommended for use on the NHS in Wales, your GP or cancer specialist can apply to your local health board asking for it to be made available to you as an exception from its usual rules.

On this page

- Applying to your local health board
- What happens next?
- Making an appeal

Your GP or cancer specialist will usually complete the application form for you and submit it to the health board along with any supporting information. This application is called an **Individual Patient Funding Request (IPFR)**.

Applying to your local health board

When making the application, your GP or cancer specialist will need to demonstrate why they feel that your request has exceptional clinical circumstances.

Your application should include:

- your relevant medical history
- details of the medical need for which the exceptional funding is requested
- the expected benefits of the drug or treatment
- supporting information and a summary of why the drug or treatment should be granted
- details of any research or trial that supports the use of the drug or treatment in cases like yours.

There is an All Wales Individual Patient Funding Request Policy that outlines how decisions are made and the process for making them. A patient leaflet explaining how to make an Individual Patient Funding Request (IPFR) is also available. You can download it from the website of your health board, and it should also be available in local libraries and GP surgeries. Each health board should have an IPFR coordinator, whose contact details will be available on the health board website and on the patient information leaflet.

What happens next?

The health board will reply to you, normally within 10 working days of receiving your request, to let you know what will happen next.

Your request will be considered by a special panel called the IPFR panel. It meets every month and consists of a mix of clinically qualified people, as well as a lay (non-clinical) member who does not work for the health board. All panel members have the expertise to assess the information and evidence that your doctor has provided.

Each request is considered on an individual basis, and all the information is treated confidentially. The panel does not see any information that will identify who you are. They follow a checklist when making their decisions and they do not consider the social circumstances of patients when deciding whether or not to

approve a request.

The doctor who made the request on your behalf will usually be informed of the panel's decision within five working days of the meeting. They will contact you to explain the decision and discuss what it means for your care.

If your request is approved, your doctor can usually prescribe the drug or treatment shortly afterwards.

Making an appeal

If your request is denied and you and your doctor would like the decision of the panel to be reviewed, you should notify the health board within 25 working days of the date you receive the decision letter. Your doctor will have a copy of the review request form that you will need to complete together and send to the health board.

You can ask for a review of a decision if you feel that the panel did not take into account all relevant factors, or if you think the correct process was not followed. You can only request a review if your doctor supports your decision.

All reviews are heard by a separate review panel. If the review panel upholds the grounds for review, your request will be referred back to the IPFR panel to be reconsidered.

If you remain unhappy after your review decision, you can refer the matter to the Public Services Ombudsman for Wales, or you can use the NHS complaints procedure. You can also seek legal advice.

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[Home](#) > [Cancer information](#) > [Cancer treatment](#) > [Getting treatment](#) > [Access to treatment](#) > [What your doctor can do for you](#) > [What you can do if you live in Northern Ireland and treatment isn't available](#)

What you can do if you live in Northern Ireland and treatment isn't available

The criteria for accessing new cancer drugs in Northern Ireland is currently under review. Your cancer specialist should be aware of what drugs are available and funded.

Cancer drugs may be available under different circumstances, including:

- if the drug is approved by NICE
- if NICE has not published a recommendation, but a health and social care trust has agreed funding based on a case being made for its funding and availability.

If NICE has recommended that a drug should not be used within the NHS, it is unlikely to be funded in Northern Ireland. In exceptional circumstances, drugs may be funded on an individual basis where it has been agreed by the trust. Patients who feel they have exceptional circumstances should discuss this with their cancer specialist.

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Home > Cancer information > Cancer treatment > Getting treatment > Access to treatment > Other things you can do if a treatment isn't available

Other things you can do if a treatment isn't available

There might be other things you can do if treatment isn't available.

On this page

- Contact your local member of parliament
- Paying for your own drugs or treatment
- Co-payment (or top-up payments)
- Useful organisations

Contact your local member of parliament

Some people find it helpful to contact their local MP (Member of Parliament), MSP (Member of the Scottish Parliament), or AM (Assembly Member) for a letter to support their request.

There may be a national organisation for your type of cancer that is campaigning for a particular treatment to become routinely available. It may be able to give you further advice or put you in touch with other people who've been through this process, who can share their experiences with you and offer their support.

Paying for your own drugs or treatment

You may choose to pay for your treatment yourself. This usually includes the cost of treatment, drugs and all the care you receive.

Cancer treatments can cost thousands of pounds, so this would be a serious decision and one to discuss with your doctor, family and friends. Your doctor still needs to agree to prescribe the medicine or treatment.

Agreeing to pay for your treatment privately only applies to one medical condition. If you have private cancer treatment and then develop a totally different condition, you could have it treated either on the NHS or privately.

Private health insurance is also an option, but only if you have a pre-existing policy. Some policies don't include certain treatments for cancer, or may not fund more than one course of this type of treatment. Your insurer will be able to give you more detailed information based on your individual situation.

Co-payment (or top-up payments)

Co-payment is when a patient having NHS treatment pays privately to have a drug that isn't available to them on the NHS. People can do this by paying for it themselves or through an existing insurance policy. Some insurance companies have policies to fund drugs that are given alongside another treatment but aren't available on the NHS.

Current guidance in England, Scotland and Northern Ireland says that patients can pay to have drugs not available on the NHS while continuing with their NHS treatment. The NHS care and the privately funded care must be given separately. Wales is expected to adopt similar guidance.

As well as paying for the cost of the drugs given outside the NHS, you'll also have to pay for the costs related to giving these drugs. This includes staff time and any tests and scans associated with the extra care.

It is recommended that people using co-payment are given the drug or treatment in a different area to where NHS treatment is given. This could be at another hospital or in a private area in a ward or clinic at their usual hospital.

Co-payment should only be used when other means of getting a drug on the NHS have been looked at.

There may be variations on how co-payment is dealt with across the UK. Talk to your cancer specialist to find out how co-payment is dealt with in your local health body.

Useful organisations

Board of Community Health Councils in Wales

Provides help if you have a problem or complaint with NHS services in Wales.

Health Rights Information Scotland

Produces information for patients about their rights and how to use NHS services in Scotland.

Parliamentary and Health Service Ombudsman

Considers complaints about government departments and agencies in the UK and the NHS in England.

Patient Advice and Liaison Services (PALS)

Provides information, advice and local support to help patients, families and their carers in England.

Public Services Ombudsman for Wales

Scottish Public Services Ombudsman

Northern Ireland Ombudsman

The Patients Association

Advises patients on their rights and access to health services.

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Home > Cancer information > Cancer treatment > Getting treatment > Access to treatment > References for the access to treatment section and thanks

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This information has been compiled using information from a number of reliable sources, including:

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Reviewing information is just one of the ways you could help when you join our Cancer Voices network.

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