Accessing NHS funding for treatments that are not routinely offered

In certain circumstances your doctor may recommend a treatment that is not routinely offered on the NHS. This is more likely to happen if you have a rare form of migraine or other treatments have proved inappropriate or ineffective for you.

The NHS may not routinely offer a treatment if:

- it is new and not yet approved by NICE* or the SMC**
- it is requested to treat a condition that is not its normal use
- it is licensed but not approved by NICE* or the SMC**
- it is for very rare conditions/symptoms

* The National Institute for Health and Care Excellence (NICE) is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. NICE determines which drugs and treatments are available for patients on the NHS in England and Wales based on the evidence available regarding its’ effectiveness, safety and cost effectiveness. In Northern Ireland, the Department for Health, Social Services and Public Safety reviews NICE recommendations before applying them locally.

** The Scottish Medicines Consortium (SMC) analyses information supplied by the medicine manufacturer on the health benefits of the medicine and justification of its price. It issues guidance and accepts for use those newly licensed medicines that clearly represent good value for money to NHS Scotland.

Individual Funding Requests

Your doctor can request that your local Clinical Commissioning Group (CCG)/Health Board fund/Health and Social Care Trust the treatment for you even if it is not routinely offered. He/She will make the request on your behalf if they think that this treatment will benefit you. This process has a different name depending on where you live in the UK:

England and Wales: Individual Funding Request

Scotland: Individual Patient Treatment Request***

Northern Ireland: Individual Funding Request

The process will be outlined in your local CCG/Health Board/Health and Social Care Trust’s procedures, typically found on their website. It will normally require an application form or a letter from your consultant. It is important that the best possible case is made in support of your application on medical grounds. Your consultant will need to present information about the treatment including clinical data and evidence of its’ effectiveness. They will also need to explain the nature of your condition and why
the treatment is necessary for you, ensuring that they meet the criteria outlined in the policy. Although personal information and lifestyle impact may be useful to demonstrate the effect of your migraine the decision about whether to fund the treatment will be based on the medical and cost benefits against the CCG/Health Board/Health and Social Care Trust’s budget. Your consultant will need to submit all supporting evidence with the request. This may include your medical records, details of any other specialists or second opinions.

**A new Peer Approved Clinical System (PACS) is currently being piloted in some areas of Scotland to replace the Individual Patient Treatment Request.**

**Proving exceptionality**
Your doctor will make the request if they think you meet the “clinical exceptionality” requirement. This means that you are different to other patients with the same condition or might benefit from the treatment in a different way to other patients. ‘Exceptional’ does not mean ‘unique’. You are not expected to prove that you are the only person requiring this treatment. Your CCG/Health Board/Health and Social Care Trust will define what they deem as ‘exceptional’ in their policy. Your doctor is unlikely to submit a request unless they think you have a strong case and they will discuss this with you.

You can request for your GP/neurologist to copy you into all correspondence with the PCT to ensure that you are fully informed at all stages of your application.

**Receiving a decision**
Your application will be considered by a panel and the evidence submitted will be assessed. In some circumstances your consultant may be invited to the meeting if deemed necessary although often CCGs/Health Board/Health and Social Care Trusts do not allow individuals to attend.

You and your consultant will be informed of the decision.

**Submitting an appeal**
If your request is refused you and your consultant are able to appeal the decision. Your CCG/Health Board/Health and Social Care Trust will have an appeals policy and you can request this if it has not already been provided.

You must initially write to the CCG/Health Board/Health and Social Care Trust appealing the decision. Details of who to address this to should be available in the policy. The CCG/Health Board/Health and Social Care Trust will then consider whether you have grounds for appeal and if so will refer your case on to an appeal panel.

Your letter must evidence reasons why the original decision was unsound. This may be because the panel did not properly adhere to the special/exceptional funding policy or failed to appropriately consider the available information and evidence. It is not enough to appeal on the basis that you disagree with the decision. You must be able
to justify your argument for the CCG/Health Board/Health and Social Care Trust to review the refusal.

It is important to have a copy of the funding refusal letter so that you can appeal directly against the reasons outlined for the refusal; this must be addressed clearly in the appeal letter. New evidence can normally be submitted at an appeal (updated clinical evidence may be an example of this) and you are able to appeal against the CCG/Health Board/Health and Social Care Trust’s procedure in handling your case as well as the rationality of their decision on the basis of the information/evidence provided. You can also appeal if you feel that the CCG/Health Board/Health and Social Care Trust has acted unlawfully.

**Supporting an appeal**

It is important to submit as much information as possible in support of an appeal from you and your consultant. Consider carefully if the following steps can strengthen your appeal:

**Contact The Migraine Trust Advocacy Service**

Submitting an appeal can be an overwhelming process. Our Advocacy Service can support you throughout the process. Get in touch via the Contact Us form for an in-depth discussion about your individual circumstances. You can also download our Open Letter of Support to include with your appeal.

**Contact your MP, MSP or Assembly member**

Contact your locally elected representative by letter, telephone, email or by attending their local surgery to discuss your issues around funding for migraine treatment. They may be able to act on your behalf by writing to your CCG/Health Board/Health and Social Care Trust or by raising the issue with the relevant minister. You can find out contact details for your locally elected representative here.

**Submit a Subject Access Request under The Data Protection Act 1998**

Under the data Protection Act 1998 you are entitled to request information and data stored about you. Reviewing information about your original funding request allows you to raise any issues that you feel were unfair or overlooked with the appeal panel. You may want to request:

- The original application the CCG/Health Board/Health and Social Care Trust received from your consultant
- All documentation received by the panel in relation to your request for funding
- Full minutes of the meeting(s) to consider your request, including the date.
- Details of the professionals sat on the panel, including information about their relevant qualifications, professional knowledge and experience of migraine.
- Details of which professionals will sit on the appeal panel and whether a neurologist with experience of treating migraine will be present
You must request this in writing (by post, fax or email). The act allows the organisation to charge you a maximum of £10 or £50 if you are requesting to see paper based health records. Each organisation will have individual rules about charging. They have 40 days to respond to you with the information from receipt of the request and fee. In certain circumstances a request can be lawfully denied. We have created a template Subject Access Request letter to get you started.

Submit an Information Request under the Freedom of Information Act 2000
Under the Freedom of Information Act 2000 you can request information held by your CCG/Health Board/Health and Social Care Trust if you are not able to find it elsewhere. To assess whether your request was handled fairly and if you may have grounds for appeal it may be helpful to view:

- The local Prescribing and Managing Medicines Strategy
- Individual/Special/Exceptional cases funding policy (name will vary)
- Data regarding the population base for the CCG/Health Board/Health and Social Care Trust area.
- Information documents about the treatment/drug that you are requesting funding which was used to inform the original decision.
- Data on the number of requests for funding of this treatment made (with dates)
- Data on the number of requests for this treatment which were accepted and denied (with dates)

Before requesting information try to find out if this is already available e.g. on the website. The CCG/Health Board/Health and Social Care Trust has to reply to a written information request within 20 days of receipt. In certain circumstances a request for information from a public authority can be lawfully denied. We have created a template Information Request letter to get you started.

What happens next?
The appeal panel will review your case. If you have grounds for appeal they will either:

- Decide to overturn the original decision and award funding.
- Allow a hearing to be made to a fresh appeal panel.

Each CCG/Health Board/Health and Social Care Trust’s policy will vary. In some instances you or your consultant may be able to attend an appeal hearing in person. The CCG/Health Board/Health and Social Care Trust will write to you and your consultant regarding their decision.
What to do if your appeal is unsuccessful
If your appeal is unsuccessful you do not have to stop there. You, or your neurologist, may be able to submit a further appeal with new evidence to support your case. Or, if new evidence about the treatment/medication has been published since your initial request, you may choose to submit a new application.

Making a Complaint
If you feel that the process has been unjust you can consider submitting a formal complaint to the Chief Executive of the CCG/Health Board who may review the information and circumstances of your hearings to make a final judgement. The Patient Advice and Liaison Service (PALS) can provide information and support around making a complaint. Keep your local MP informed throughout this process.

Contact the media
Sharing your story with the media can help to put pressure and raise the spotlight on migraine treatment and your local CCG/Health Board’s funding policies. This will likely be a last resort once you have taken all other steps. Journalist may want to print identifiable information about you to be able to write a story. If you are considering this route we would be happy to speak to you about this first. We can help you to prepare and even involve our press team to contact the media. Get in touch via the Contact Us form to find out more.

Contact the Ombudsman
If you have submitted a complaint but are unhappy with the outcome you can take the case to the Ombudsman. The Ombudsman is independent of the NHS and Government and can investigate complaints that the CCG/Health Board/Health and Social Care Trust has not acted fairly.

Parliamentary and Health Service Ombudsman England
Public Services Ombudsman for Wales
Scottish Public Services Ombudsman
NI Ombudsman

Judicial Review
You may have grounds to take a case against your CCG/Health Board/Health and Social Care Trust to a judicial review. A judicial review is a court in which a judge reviews whether a public body has acted lawfully. They are able to consider whether the actions and procedures that have been followed are unlawful but are not there to decide whether the decision not to fund your treatment was right or wrong. Therefore this may not be appropriate action in all cases. If you are considering taking a case to judicial review you need to seek legal advice.

More Information
For more information and to discuss your circumstances in more details please contact our Advocacy Service.