

Understanding NICE guidance

Information for people who use NHS services

Drug treatments for neuropathic pain

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of people with neuropathic pain in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with neuropathic pain but it may also be useful for their families or carers or for anyone with an interest in the condition.

This booklet gives details about the drugs (medication) that may be offered to people to help them manage their neuropathic pain. It describes the care that people can expect from their GP or as part of general hospital care. Pain clinics or other specialist clinics may offer other treatments that are not described here.

The booklet is to help you understand the care and treatment options that should be available in the NHS. It does not describe neuropathic pain or the tests or treatments for it in detail. Your doctor should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisation listed on page 11.

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The advice in the NICE guideline covers:

- adults with neuropathic pain.

It does not specifically look at:

- adults with neuropathic pain who are being treated in pain clinics
- other (non-drug) treatments for neuropathic pain.

Your care

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm). All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your treatment and care with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should explain neuropathic pain and the possible treatments for it. They should cover possible benefits and risks related to your personal circumstances. You should be given relevant information that is suitable for you and reflects any religious, ethnic, or cultural needs you have. It should also take into account whether you have any physical or learning disability, sight or hearing problem or language difficulties. You should have access to an interpreter or advocate (someone who helps you put your views across) if needed.

Your family and carers should be given their own information and support. If you agree, they should also have the chance to be involved in decisions about your care.

You should be able to discuss or review your care as your treatment progresses, or your circumstances change. This may include changing your mind about your treatment or care. If you have made an 'advance directive' (have already given instructions) about any treatments that you do not wish to have, your healthcare professionals have a legal obligation to take this into account.

All treatment and care should be given with your informed consent. If, during the course of your illness, you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family or carers unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/consent) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.publicguardian.gov.uk. In Wales healthcare professionals should follow advice on consent from the Welsh Assembly Government (www.wales.nhs.uk/consent).

Neuropathic pain

Neuropathic pain is a type of pain that is caused by damage or changes to nerves which mean that they don't work properly. This is different from pain caused by damaged or inflamed tissue that gets better after a process of healing. Neuropathic pain can be present at the same time as pain caused by damaged tissues.

People with neuropathic pain sometimes describe the pain using words like shooting, stabbing, an electric shock, burning, tingling, tight, numb, prickling, itching or a sensation of pins and needles. The pain can come and go, or be there all the time.

Neuropathic pain is associated with a number of conditions. Examples include diabetic neuropathy (which is caused by damaged nerves in some people with diabetes), post-herpetic neuralgia (pain that some people have after recovering from shingles) and trigeminal neuralgia (which affects the face). A common cause of neuropathic pain is a trapped nerve, for example in the back or neck. Neuropathic pain can also occur after a stroke, after amputation of an arm or a leg, and in people with cancer, multiple sclerosis and some other conditions.

Painkillers such as paracetamol, anti-inflammatory drugs (like aspirin and ibuprofen) and codeine may not be effective in easing neuropathic pain, but other drugs are available that can help a person to manage their pain.

Questions you might like to ask your healthcare team

- Please tell me more about neuropathic pain.
- What might be the cause of the pain?
- Are there any support organisations for people with neuropathic pain?
- Can you provide any information for my family/carers?

Choosing medication to help with neuropathic pain

When you talk with your doctor (or other healthcare professional) about medication to help with your neuropathic pain, they should tell you about the benefits and possible side effects of the different drugs, and explain why a particular drug is being offered. They should advise you about ways of managing both the pain and any side effects of treatment. They should also explain that other (non-drug) treatments are available for neuropathic pain.

Your doctor should ask you about your preferences, and about anything else that might influence the choice of medication. This could include your day-to-day work and leisure activities, any physical or mental health problems you may have, and any other medication you are taking.

If you are already having treatment for neuropathic pain and this is helping you, you should be able to continue with that treatment.

If your neuropathic pain is severe or is having a significant effect on your daily life, or the health problem that has caused your pain has got worse, your doctor may offer you an appointment at a pain clinic and/or another specialist clinic. Healthcare teams in pain clinics have a lot of experience in helping people to manage this sort of pain.

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

First treatments

To begin with, your doctor should usually offer you a drug called amitriptyline or one called pregabalin. Both of these drugs are taken orally (as tablets or syrup).

But if you have painful diabetic neuropathy, you should usually be offered a drug called duloxetine rather than amitriptyline or pregabalin. If you can't take duloxetine for medical reasons (for example, if you have liver disease or severe kidney disease, or you are taking certain other drugs), you should be offered amitriptyline instead.

Whichever drug you take, you should usually be started on a low dose, which is then increased gradually over time. This means that it might be some weeks before you get the full benefit. The dose should be increased until there isn't any further improvement. Some people find that the dose can't be increased any more because they get unpleasant side effects that don't get any better. Your doctor should explain the reasons for the gradual increase in dose, and give you written information about doses if possible.

Is the treatment working?

Soon after you start treatment with a new drug, your doctor should check whether it is suitable for you. They should ask you whether you are having any side effects. They may consider offering you a different dose, or changing the treatment.

You should see your doctor regularly for as long as you are taking medication for neuropathic pain. At each visit your doctor should ask you whether, and by how much, your pain has improved. They should also talk with you about your mood, whether you are sleeping well and how you are feeling generally. This includes whether you have been able to get back to something like your normal life and start doing things again that you had to stop because of the pain (such as jobs around the house, work, driving and social activities). You should also talk about any problems you have had, such as side effects of the medication. Your doctor may suggest that you keep a diary to remind you about how you have felt.

If you are taking amitriptyline and it is helping with the pain but the side effects are a problem, your doctor may offer you nortriptyline or imipramine tablets instead. These drugs work in a similar way to amitriptyline but have different side effects that may be less of a problem for some people.

If the drug you are taking is helping you, and side effects aren't a significant problem, you should continue with the treatment. After a while your doctor might suggest a trial to see whether you can manage with a lower dose, because this can help with any side effects. The dose will be reduced gradually to make it less likely that you will be affected by symptoms that can occur when a drug is stopped suddenly (these are sometimes called 'discontinuation' or 'withdrawal' symptoms). Sometimes neuropathic pain can improve enough for drug treatment to be stopped altogether.

Amitriptyline, duloxetine, imipramine and nortriptyline can be used to treat depression (they are sometimes called antidepressants). Pregabalin is an anti-epileptic (anticonvulsant) drug that is sometimes used to treat epilepsy. These drugs can also help people with neuropathic pain (or other types of pain) to manage their pain. This effect is separate from their action in treating depression or epilepsy.

Questions about medication

- What are the possible benefits and risks of taking this particular drug?
- What sort of improvements might I expect in my symptoms and everyday life?
- When should I take my medication?
- When should I start to feel better, and what should I do if I don't start to feel better by then?
- What are the possible side effects, and what should I do if I get any of these?
- Why are you offering me an antidepressant (or an anti-epileptic drug) for my neuropathic pain?
- Why is the dose being increased (or decreased)?
- How long will I need to take the medication for?
- Might I have problems when I stop taking the medication?

What if my pain doesn't improve?

You may find that your neuropathic pain is still causing you problems even though the dose of the first drug has been increased as much as it can be. Your doctor may offer you a different drug after discussing the options with you. They should also talk with you about whether to carry on taking the first drug if you start taking a new one. They may suggest that you take the new drug as well as the first one to begin with, and then gradually reduce the amount of the first drug. This can help to control your pain when you are changing treatments.

If you want to try a different drug your doctor may offer you the following:

- If you have been taking amitriptyline, nortriptyline or imipramine, you should be offered pregabalin.
- If you have been taking pregabalin, you should be offered amitriptyline. (If amitriptyline helps you but side effects are a problem, nortriptyline and imipramine are possible alternatives – see page 7.)
- If you have been taking duloxetine and are going to stop taking it, you should be offered either amitriptyline or pregabalin instead.
- If you are going to carry on with duloxetine and start taking a second drug as well, this should be pregabalin.

If at any stage your pain has got worse despite treatment, your doctor may offer you an appointment at a pain clinic and/or another specialist clinic.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team in the first instance.

If you have talked to your healthcare team, and you think that a treatment is suitable for you but it is not available, you can contact your local patient advice and liaison service ('PALS') or NHS Direct Wales.

Further treatments

Some people find that their pain still causes them significant problems even after trying the treatments described in this booklet. If this happens to you, you should be offered an appointment at a pain clinic and/or another specialist clinic.

While you are waiting for your appointment, you may be offered a drug called tramadol (a type of opioid – see the box below) instead of, or as well as, the other medication you are taking.

If you are unable to take oral medication (tablets or syrup) for medical reasons or because you have a disability, your doctor may offer you a treatment called lidocaine. Lidocaine is a local anaesthetic, which is applied to the skin on a patch (like a plaster) and works on the area where it is placed.

You should not be offered other opioids (such as morphine or oxycodone) for your neuropathic pain unless you have been assessed in a specialist clinic. But drug treatments that have been started by doctors in a specialist clinic can continue to be prescribed by your GP. You should have a written 'care plan' that gives details of the treatments you are having and who is providing them. Your GP should keep a careful eye on any side effects.

Tramadol, morphine and oxycodone are drugs called opioids. Opioids are commonly used to treat pain, and vary in strength. As with many drugs, people may experience side effects when taking opioids. Also, some people who need to take opioids for a long time are seen by a specialist because these drugs can be habit-forming. You should talk to your doctor about any concerns you might have. But some people find that opioids suit them and help to make their pain more manageable.

More information

The organisation below can provide more information and support for people with neuropathic pain. NICE is not responsible for the quality or accuracy of any information or advice provided by this organisation.

- Pain Concern, helpline: 0844 499 4676
www.painconcern.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of the guideline aimed at healthcare professionals are available at www.nice.org.uk/guidance/CG96

*You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2116). The NICE website has a screen reader service called *Browsealoud*, which allows you to listen to our guidance. Click on the *Browsealoud* logo on the NICE website to use this service.*

We encourage NHS and voluntary organisations to use text from this booklet in their own information about neuropathic pain.