

Managing pain with strong opioids in people with advanced, progressive disease

Information for the public

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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice about managing pain with strong opioids in people with advanced, progressive disease that is set out in NICE clinical guideline 140.

Does this information apply to me?

Yes, if you are an adult (18 years and older) with advanced, progressive disease who needs strong opioids for pain control.

No, if you are an adult who has not yet had a pain assessment to check whether you need

strong opioids to manage your pain.

Your care

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

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/en/DH_132961). 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 or discuss with you the use of strong opioids for people with advanced, progressive disease. 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 decision' (known as a 'living will' in the past) in which you 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/en/DH_103643) and the code of practice for the Mental Capacity

Act. Information about the Act and consent issues is available from www.nhs.uk/CarersDirect/moneyandlegal/legal. In Wales healthcare professionals should follow advice on consent from the Welsh Government (www.wales.nhs.uk/consent).

Managing pain with strong opioids

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

People who are living with advanced, progressive diseases (such as advanced cancer, heart disease, liver disease, lung disease, kidney disease, HIV and some diseases of the nervous system) may need strong medication to alleviate their pain when other types of pain relief do not help. Strong opioids, such as morphine, may be used to treat pain in these circumstances.

If you have an advanced, progressive disease and you experience pain that is not controlled with usual painkillers, you may be offered strong opioids as part of your palliative care. Palliative care means alleviating pain and discomfort to improve a person's quality of life when it is not possible to cure their disease.

Information about taking strong opioids

If you are offered strong opioids, your healthcare professional should discuss them fully with you (and, as appropriate, your family and/or carer) and should give you some written information about them. They should explain:

- when and why strong opioids are used to treat pain
- how effective they are likely to be at relieving your pain
- about taking strong opioids for 'background pain' (pain that is constant and continuous) and 'breakthrough pain' (sudden, intense pain in addition to background pain), including how, when and how often to take them, and how long pain relief should last
- possible side effects, and signs to watch out for that might mean there is too much of the medication in your system

- how to store strong opioids safely
- how the pain control and any side effects will be monitored, and how and when you will get your next prescription
- who you can contact outside of surgery hours if you have any problems, particularly when you first start treatment.

Discussing your concerns

Some people worry that they will become addicted to strong opioids or that there will be unpleasant side effects. Your healthcare professional should reassure you that addiction to opioids is very unlikely and that you will be monitored carefully for side effects. They should also reassure you that being offered strong opioids can happen at different stages in the course of a disease, and it does not necessarily mean you are close to the end of your life.

Starting treatment with strong opioids

There are many types of strong opioids that can be given in different ways. The first opioid treatment you should be offered is morphine. It should be offered in a form that you can take by mouth, such as tablets, capsules, liquid or powder. You should be offered one of two types of morphine, depending on your condition and which you prefer: this should either be a short-acting type that you will need to take several times a day (called immediate-release), or a slow-release type that can be taken less frequently (called sustained-release, because it is absorbed slowly by the body over several hours).

If you are taking sustained-release morphine you should also be offered a supply of immediate-release morphine which you can take as well to help you to manage any breakthrough pain.

There is no standard dose of strong opioid: the amount needed to control pain varies from person to person. Over the first few days the amount of morphine you are taking should be frequently monitored and adjusted to find the lowest dose that controls your pain with the fewest side effects.

If you have trouble swallowing

If you cannot take opioids by mouth and your pain is fairly stable (that is, it remains steady and does not fluctuate), you should be offered an opioid patch that releases the medication through the skin. If your pain is fluctuating, injections may be considered instead.

Reviewing your pain control

When you start taking strong opioids you should be offered regular reviews of your pain control and any side effects. This should happen throughout your treatment but is particularly important at the beginning when your dose may need to be adjusted.

Continuing treatment for your pain

After a dose of opioid has been found that controls your pain, you should be offered a sustained-release form of morphine that you can take by mouth to continue your treatment. You may have already started your treatment with a sustained-release form of morphine, in which case this will be continued.

You should not usually be offered an opioid patch for your continuing treatment if you are able to take your morphine by mouth.

If your pain is not well controlled, even after the dose has been adjusted several times, your healthcare professional should review your pain relief plan and may ask for advice from a specialist.

Treating breakthrough pain as part of continuing treatment

As part of your continuing treatment, your healthcare professional should offer you a supply of immediate-release morphine to take by mouth in case you have breakthrough pain. If your breakthrough pain is not controlled, even after the dose has been adjusted, your healthcare professional may ask for advice from a specialist.

Managing side effects

Constipation

Constipation (when passing stools becomes difficult or painful, or you pass stools less often) affects nearly everyone who takes strong opioids. If you start taking strong opioids you should also be offered laxatives to relieve constipation. Laxatives work by making the stools looser or stimulating the bowels to work. They can take time to work so it is important to continue taking them as your healthcare professional advises. If constipation becomes severe, it may be necessary to change the type of opioid you are taking. However, your healthcare professional should make sure you are taking the most effective type and dosage of laxative before this is considered.

Nausea

You may experience nausea (feeling sick) when starting strong opioids or when the dose is increased, but it is likely to last only a short time. However, if it persists, you should be offered anti-sickness medication to relieve your symptoms. Your healthcare professional should make sure you are taking the most effective type and dosage of anti-sickness medication before they consider changing the opioid you are taking.

Drowsiness

You may experience mild drowsiness or problems with concentration when starting strong opioids or when the dose is increased, but it is likely to last only a short time. Your healthcare professional should warn you that having problems concentrating might affect your ability to carry out manual tasks such as driving.

If you have more severe or long-lasting problems with drowsiness or loss of concentration and your pain is under control, your healthcare professional may discuss with you the possibility of reducing the dose of opioid you are taking. If, however, your pain is not being well controlled, your healthcare professional may consider changing the opioid you are taking. If the problems you are having are not relieved by these changes, your healthcare professional may seek specialist advice.

Questions you might like to ask your healthcare professional

- Please tell me more about strong opioids for pain relief.
- Can you tell me more about the side effects or risks associated with taking strong opioids?
- Will I become addicted to strong opioids?
- How long will it take for this medication to work?
- What do I do if I am still in pain after taking strong opioids?
- What are my options for taking some other type of pain relief?
- Can you give me some written material (a leaflet) about strong opioid treatment?

More information

The organisations below can provide more information and support for people with advanced, progressive disease. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- CancerHelp UK (the patient information website of Cancer Research UK), 0808 800 4040 www.cancerhelp.org.uk
- Macmillan Cancer Support, 0808 808 0000 www.macmillan.org.uk
- The British Pain Society, www.britishpainsociety.org (click on 'For Patients' drop-down menu)

You can also go to NHS Choices (www.nhs.uk) for more information.

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Accreditation

