Dying Matters

What Can You Do About Pain?

Pain management for people who want to die at home
1. Are there different types of pain?

Pain can be steady, throbbing, stabbing, aching, pinching, or felt in many other ways. Sometimes, it can be mild, other times it can be physically debilitating, affect our mood and emotional states (chronic pain can cause feelings of anger, hopelessness, sadness and anxiety) and inhibit the way we go about our daily life.

Pain is usually classified as either acute or chronic. Acute pain is usually severe and short-lived, and often happens if your body has been injured. Chronic pain can range from mild to severe, is present for long periods of time, and is often the result of a disease that may require ongoing treatment.

The British Pain Society's website provides additional information about the various types and physical causes of pain.
2. **How can I best identify and describe my different types of pain?**

Pain is different for everyone. Describing your pain clearly will help the people looking after you to find the best treatment for you. Explain to your carer or health care team where the pain is, what it feels like (for example dull, sharp, burning), how bad it is, how often it happens, and if anything has helped to relieve similar pains in the past.

Some people keep a pain diary. This can help you explain your pain to your carer or health care team.

People with dementia can sometimes find it difficult to communicate pain symptoms. [The Pain Assessment in Advance Dementia (PAINAD) Scale](#) can be used to help identify pain for people with this condition. The National Council for Palliative Care's guide *How would I know? What can I do?* may also help with this.

3. **Why should I talk to someone about my pain?**

If you have pain, it can almost always be reduced. It’s very important to let your carer, doctor or nurse know as soon as it starts. The earlier treatment is started, the more effective it will be.

A good time to talk about and plan for your future pain relief can be when you have discussions with your care team about your future care. You should be offered opportunities to discuss your wishes and preferences for your future care as part of developing a personalised care plan for you. This can also include [Advance Care Planning](#), which enables you to tell your health care team what you would want to happen if you weren’t able to decide or speak for yourself due to reduced mental capacity.
4. How can I manage my pain at home and who can help me do this?

There are lots of ways to control your pain either by using medication or by using alternative methods that don’t involve medication. Your experience of your pain is personal to you and different approaches will work for different people. Talk to your health care team about the different options – this could be your General Practitioner (GP), District Nurse, Hospice or Palliative Care Team.

4.1 Controlling pain with drugs

Painkillers

There are many different types of painkillers available.

The most common are paracetamol or ibuprofen which can be used to treat mild pain. You can buy these over the counter from your local pharmacy or supermarket - always read the information provided on the medication’s packaging before taking and check with your GP.

Moderate to severe pain is usually treated with stronger painkillers called opioids. These have to be prescribed by your doctor or nurse – be sure to tell your care team about any painkillers you have already been using.

This progression from weaker to stronger types of pain relief is sometimes called the ‘analgesic ladder’.

There is no evidence to suggest that increasing dosages of pain relief through medication has any effect on life expectancy. However, strong painkillers can cause side effects in some people, including dizziness, nausea, and constipation. If you have any side effects, you should tell your carer and your health care team, as they can be minimised.
Syringe drivers or pumps

Sometimes a small battery operated device called a ‘syringe driver or pump’ is used if you can’t swallow your medications anymore - for example, you may be very weak, have difficulty swallowing or feel nauseous all the time. The purpose of the syringe driver is to ensure you have a continuous amount of medication to control your symptoms (e.g. pain, nausea or vomiting).

The driver/pump releases a dose of painkiller (and any other medications e.g. anti-nausea) continuously 24 hours a day through a needle placed just under the skin. This will usually be set up daily for you by your district nurse or a doctor. Use of syringe drivers or pumps does not speed up dying.

Marie Curie’s website has more details about syringe drivers.

Anticipatory prescribing

Anticipatory prescribing is a way for you and your health care team to plan ahead in case you might need extra painkillers in the future. The medications are usually prescribed by GPs and enable medicines such as painkillers to be prescribed for people before they need them. This ensures that when symptoms do arrive they can be managed effectively and without delay.

As part of anticipatory prescribing, ‘Just in case’ medicines are a selection of medicines that can be prescribed ‘just in case’ by your GP, and stored securely in a readily identifiable place in your home along with needles and syringes. A typical selection might include drugs for agitation, nausea and respiratory secretions as well as pain.

A ‘message in a bottle’ is a small plastic bottle kept at the individual's house that contains basic personal and medical details, in case of an emergency. The bottle is kept in the fridge, where the emergency services will expect to find it in the event of being called to your home. They will know you have a bottle by two labels. One is fixed on the inside of the front door or the main entrance to your home and the other to the door of your fridge.
4.2 Who can help you administer drugs at home?

- GPs can monitor your pain and prescribe you painkillers to use at home. They can also arrange for a community palliative care team including doctors and nurses to come to your home, assess your needs and guide your medications.
- Pharmacists supply you with the drugs that your GP has prescribed and also give advice about how to take the medication and possible side affects.
- If a prescription sheet is used, district nurses can help you with taking the medicines at home. In most areas this service is available out of hours.
- In some areas of England, there are training schemes for carers, allowing family members and carers to be trained to administer drugs at home. If you or your carers would like to do this, then ask your care team about its availability.

4.3 Controlling pain without drugs

There are also various non-drug treatments that can help reduce pain. These range from other medical treatments such as radiotherapy (e.g. for pain in bones caused by cancer), to complementary therapies such as massage. Talk to your team about what is available to you and what might be helpful. Complementary therapies should not replace any treatments prescribed by your doctor.

Examples of complementary therapies might include:

- Aromatherapy
- Acupuncture
- Massage therapy
- Reflexology
You may also find other things that help control your pain, for example:

- Physiotherapy and exercise
- Moving position regularly
- Cognitive behavioural therapy (CBT)
- Meditation
- Heat pads, warm baths or ice packs
- Simple things such as watching TV, reading or listening to music
- Some people also find that anxiety and distress can cause physical pain, so emotional or spiritual support may help.

5. **What can people caring for you do to help?**

- Supporting with administering painkillers
- Supporting to change position
- Applying heat pads/ice packs
- Providing company and distraction
- Listening to concerns people might have about their pain and dying

6. **Further info/support**

- If you or the person you’re caring for has dementia, then [NCPC’s guidance on pain & distress for people with dementia](#) might help
- If you’re dealing with pain caused by cancer, [Macmillan’s website](#) may help you think about treatment and other support
- Both [NHS Choices](#) and [Marie Curie](#) have additional information and support about pain management on their website
Dying Matters’ mission is to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. For further information on any of these topics, visit:

www.dyingmatters.org

help.dyingmatters.org

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