

Controlling pain

A guide for people living with a terminal illness and their carers



**Marie
Curie**

Care and support
through terminal illness

If you're living with a terminal illness, or caring for someone who is, you may be worried about pain. This booklet is to help you understand how pain can be effectively managed and treated.

Everyone's experience of pain is different, and pain can vary according to the illness, the individual and the treatment. The main thing to know is that most pain can be controlled, and sometimes people experience none at all.



You can find more information about managing pain and related topics at mariecurie.org.uk/help or call the Marie Curie Support Line on **0800 090 2309***.



Kieran Dodds/Marie Curie

* Calls from landlines are free, but there may be a charge if you're calling from a mobile. Check with your mobile provider for details. Calls from any type of phone will be free from 1 July 2015.

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What causes pain?

Pain can affect the muscles, bones, organs, skin, joints and tissues of the body. It can be caused by an illness, an operation or treatment you might be having. It can also occur because of a condition you may have had for a while, like arthritis. When the nerve endings in the body are damaged, for example by a disease, they send a message to the brain, which makes you feel pain or discomfort.

How pain may affect you

Everyone's tolerance for pain is different and some people can cope with more discomfort than others. Pain can affect just about every aspect of your life. It can affect your movement, your ability to take part in activities, sleep patterns and concentration. It may have a big impact on your emotions, mood and thoughts, too.

We often hear from the people we care for that it can affect their confidence, optimism, quality and enjoyment of life, and relationships with other people. It can make everyday activities stressful and irritating, leaving you drained emotionally and feeling unable to cope.



We have more information about coping with fatigue, anxiety and loneliness on our website at mariecurie.org.uk/help

Managing your pain

Managing pain is an important part of **palliative care**. Palliative care aims to help people living with a terminal illness, and their friends and relatives, achieve the best quality of life. As well as managing pain and other physical symptoms, it will also help with any psychological, social or spiritual needs. This is because we know



Chris Renton/Marie Curie

that pain can be made worse by how you're feeling mentally and emotionally, as well as from fatigue, anxiety, stress and loneliness. However, this doesn't mean the pain is all in the mind.

Pain management is about controlling your pain so you aren't suffering unnecessarily. However, managing pain doesn't always mean that you'll be completely free from pain. Some people find they prefer to have some discomfort rather than have high doses of painkillers, in case they become sleepy and unable to communicate.

If you're worried about side effects

Some people worry about experiencing unpleasant side effects when they're taking pain medications, like loss of control. They can be particularly worried about morphine or other strong painkillers. In fact, morphine is a very safe drug when it's prescribed and taken correctly. Morphine and other strong pain killers may even be taken for a long time, gradually increased to higher doses. Being given morphine doesn't mean someone is approaching the end of their life.

You or your carer might also be worried about the risk of addiction, particularly if you're receiving medication through a syringe driver (see page 19) or regularly taking other strong painkillers. This isn't something to worry about as it's rarely an issue for people needing pain relief for terminal illness. Syringe drivers can be the best way of making someone comfortable and managing pain. You can still move around while wearing one, too. See pages 19-20 for more information about syringe drivers and pages 16-17 for information about side effects.

Talking to your doctor about what you're feeling and what you want from your treatment will help them make the right medication plan for you.

Talking about your pain

Everyone feels pain in their own way and how someone responds to pain is personal. This means the person in pain is in the best position to say what the pain is like, rather than those around them.

Try to describe any pain you're experiencing to your doctor or nurse. This can be difficult, but it helps them decide what medication you might need.

Questions your nurse or doctor might ask

- Where is the pain in your body?
- Where does the pain travel to?
- What kind of pain is it – does it come and go, is it sharp, is it throbbing or tingling, is it a dull ache, does the area feel as if it's burning, or is it tender to touch?
- Can you rate your pain on a scale of 0 to 10, with 10 being the worst pain and 0 free from pain?



Kieran Dodds/Marie Curie

- How often and when do you get the pain – after meals, early in the morning, at night?
- What makes the pain worse – movement, eating, deep breathing?
- What helps the pain – medication, resting?
- How is it affecting your life?

Information for carers: helping someone communicate

If you're caring for someone who has trouble communicating, ask the nurse or doctor for other ways to tell if they're in pain. They might suggest a visual chart or picture cards if the person can't speak. If they can't communicate at all, there are several signs to look out for, including:

- high pulse
- changes in breathing
- changes in mood
- agitation or increased temper
- lack of concentration
- withdrawal or refusal to make eye contact

If you notice any of these things or are worried that your friend or relative is in pain, speak to a member of the healthcare team.

How pain may be described

Doctors and nurses may describe your pain as acute, chronic, neuropathic, somatic, visceral or breakthrough pain.

- **Acute pain** usually happens suddenly. It can happen regularly or when you do something in particular, like move in a certain way. It can be sudden and come in spasms or waves.
- **Chronic pain** is pain that lasts a long time. It can be constant or go away and come back again.
- **Neuropathic or nerve pain** may be experienced in a variety of ways, for example, as stabbing, burning, sharp pain or tingling. It's caused by damaged nerve endings or a trapped/irritated nerve. You might get it in a part of the body where you don't usually feel anything, so it can feel a bit strange.
- **Somatic pain** is pain that occurs in the muscles or bones. It's caused by inflammation and causes tenderness.

- **Visceral pain** occurs when internal organs are damaged or inflamed. It includes colic.
- **Breakthrough pain** is when pain happens even though you're taking painkillers. It may happen when you do something in particular – such as eat, move, sneeze or cough. It may also mean that a dose of a drug is wearing off.

What help can you get?

Good pain management will involve health professionals, such as doctors, nurses and physiotherapists, working with you to find the best way to help you.

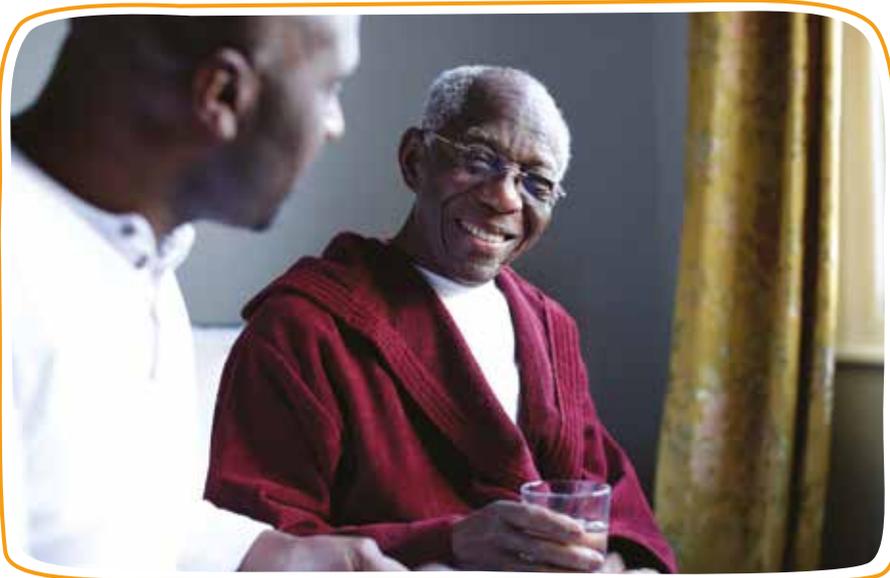
This may involve you checking your own pain regularly, because you know best what your pain feels like, how it's affecting your quality of life, and how much pain relief you need. You can talk to your doctor or nurse about the options for pain relief.

You should be able to decide on the level and type of pain management you need or want. Sometimes people prefer not to take too many drugs, and may want to try other methods of pain relief.

Your local pharmacist can give you information about when and how to take any medication you've been prescribed. They may also deliver medication to your home.

You don't have to live with pain

Always tell your district nurse, doctor or Marie Curie Nurse about your pain, especially if it's keeping you awake at night. You won't be bothering them. They're here to help you and may not know you're in pain. There are many medications that can help you to cope with pain.



Layton Thompson/Marie Curie

Pain relief

There is a range of different medicines that may help. These may be aimed at relieving pain or to help ease other symptoms. Tell your doctor or nurse if you're taking any over-the-counter or herbal medications not prescribed by a doctor.

The next few pages list some medications used for pain relief. Some can be given at home while others can only be given in a hospital or hospice by a medical professional. Sometimes medications may be combined, for example, codeine and paracetamol might be used together to provide the right kind of pain relief. Radiotherapy is sometimes used to treat bone pain, for those fit enough to have it.

We had lots of conversations with the doctor about pain relief, and what to try, and we understood what was going on.

Linda, family member

Common types of pain medication

Medication type and example names

What the medication is for and how it works

Non-opioid analgesics

- Paracetamol
- NSAIDs (non-steroidal anti-inflammatory drugs) like aspirin, naproxen, ibuprofen (Nurofen®, Brufen®)
- Initially, if the pain is not too intense, you can use these analgesics. They are all available on prescription or over the counter.
- Sometimes paracetamol is combined with aspirin, according to your needs and type of pain.
- NSAIDs are also used to relieve bone pain.

Weak opioids

- Codeine
- Dihydrocodeine (DF118 Forte®)
- Tramadol hydrochloride (Zydol®, Tramacet®)
- These provide the next level of pain control, as they are stronger than paracetamol.

Strong opioids

- Morphine
- Diamorphine
- Methadone
- Oxycodone (OxyNorm® and OxyContin®)
- Buprenorphine (Transtec® patches, BuTrans® patches, Temgesic®)
- Fentanyl (Durogesic®, Mezolar patches®)
- These are safe and effective pain killers.
- Morphine can be given as tablets or as a liquid by mouth. If you often feel sick or vomit, it's more likely to be given as an injection through a syringe driver (see page 19). This enables a steady flow of the drug to be absorbed into the blood stream.

Strong opioids (continued)

- Sometimes more than one type of painkiller is prescribed. For example, long acting drugs are used to manage underlying (background) pain and short acting drugs are used for breakthrough pain.

Other types of pain medication

Medication type and example names

What the medication is for and how it works

Anti-convulsant or anti-seizure drugs

- | | |
|--|--|
| <ul style="list-style-type: none"> • Sodium valproate (Epilim[®], Episenta[®]) • Gabapentin (Neurontin[®]) • Pregabalin (Lyrica[®]) | <ul style="list-style-type: none"> • These may be prescribed to relieve nerve (neuropathic) pain. |
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Anti-spasmodic

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|---|--|
| <ul style="list-style-type: none"> • Hyoscine butylbromide (Buscopan[®]) • Hyoscine hydrobromide • Mebeverine (Colofac[®]) | <ul style="list-style-type: none"> • These can control colicky and crampy pains in the bowel. • They work by relaxing the bowel. They're not usually given if the bowel is obstructed. Your doctor can give you more information about this. |
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Anti-depressant medications

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| <ul style="list-style-type: none"> • Amitriptyline • Nortriptyline • Duloxetine | <ul style="list-style-type: none"> • These act on nerve pain and are often used for pain relief, even if the person isn't depressed. |
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Stress relieving drugs

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| <ul style="list-style-type: none"> • Midazolam (Hypnovel[®]) • Diazepam • Lorazepam | <ul style="list-style-type: none"> • These can help with agitation. |
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Steroids

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|---|---|
| <ul style="list-style-type: none"> • Dexamethasone • Prednisone | <ul style="list-style-type: none"> • These may be prescribed to reduce swellings that are causing pain, for example, a headache due to a brain tumour, and pain caused by pressure around nerves. • They may also be used to strengthen the effects of anti-emetic (anti-sickness) drugs. |
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Bisphosphonates

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| <ul style="list-style-type: none"> • Disodium pamidronate (Aredia[®]) • Ibandronic acid or ibandronate (Bondronat[®]) • Sodium clodronate (Bonefos[®], Clasteon[®], Loron[®]) • Zoledronic acid or zoledronate (Zometa[®]) | <ul style="list-style-type: none"> • These work on the tissue of the bone to relieve bone pain. |
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Anaesthetics

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| <ul style="list-style-type: none"> • Ketamine (Ketalar[®]) | <ul style="list-style-type: none"> • Taken in low doses, ketamine can relieve neurological or nerve pain by blocking specific pain receptors. It's not commonly used. |
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Spinal anaesthetics and nerve blocks

- Spinal anaesthetics are injected into the fluid around the spinal cord.

Spinal anaesthetics and nerve blocks (continued)

- Nerve blocks are procedures where nerves are injected with painkillers to modify and block pain.
- Both of these treatments are generally provided in hospital.



We have more information about managing common symptoms on our website at mariecurie.org.uk/symptoms

Side effects of medication

Tell your healthcare assistant, doctor, district nurse or Marie Curie Nurse if you have any change in symptoms after taking a new drug. If the symptoms are severe, you might need different medication.

Steroids

These can cause:

- increased appetite, leading to weight gain
- difficulty sleeping
- indigestion

Anti-inflammatory drugs

These can cause irritation of the stomach or bowel, ulcers and bleeding from the stomach. Medication can be prescribed to protect the stomach lining.

Anti-spasmodics

Hyoscine butylbromide (Buscopan®) can cause a dry mouth.

Bisphosphonates

This group of medications can cause:

- headache
- sickness
- diarrhoea
- a flu-like reaction within 48 hours of taking a dose

Opioids

It's helpful to be aware of the side effects of strong painkillers like morphine. These can include:

- **Constipation** – this is the most common side effect of morphine and can be eased by laxatives (which help someone go to the toilet).
- **Nausea and vomiting** – anti-emetic (anti-sickness) medication can be prescribed.
- **Depressed breathing** – if breathing is laboured and slow, it might be necessary to reduce the dose of morphine gradually. This is very unusual if morphine has been prescribed correctly. Speak to your doctor or nurse urgently about this because you may also be given an antidote to morphine called naloxone, which works very quickly.
- **Drowsiness and sleepiness** – if someone is so tired that they can barely communicate, the dose may need to be lowered.
- **Jerking** – these motions may be the result of too high a dose of morphine.

Always tell the healthcare assistant, nurse or doctor about these problems, and ask for changes to be made to medication.

Drug-free pain relief

TENS machines

TENS (transcutaneous electrical nerve stimulation) machines are small devices that are attached to the body with electrodes placed wherever the pain is felt. They deliver gentle electric pulsing to the area, which can tingle, but isn't painful. These electrical pulses can help relieve pain. The machine is easy to use and you can try it at home.

Acupuncture

Acupuncture is widely used to relieve pain, particularly in pain clinics within hospitals. It is safe and effective in treating chronic pain. It may be available in hospices, in your local hospital, occasionally through your GP practice, or through a private practitioner. Contact the British Acupuncture Council on **020 8735 0400** or **acupuncture.org.uk** for more information.

Holistic care

It's natural for people with a terminal illness to feel emotionally or spiritually distressed, whether they're religious or not. Your state of mind can affect the amount of pain and discomfort you feel. Talking to a professional who isn't emotionally involved can help. This could be a:

- counsellor
- psychotherapist
- spiritual adviser or faith leader



AlexRaiths/Thinkstock

See page 25 for information about finding a counsellor or psychotherapist near you.



We have more information about coping with spiritual and emotional pain on our website, at **mariecurie.org.uk/help**

Complementary therapies

Complementary therapies are often available to people with a terminal illness. They can help calm the mind and body, help you to sleep and reduce pain. Common therapies include: meditation, massage, aromatherapy and reiki.

Music therapy has been found to be beneficial in easing pain. Studies have also shown that reiki, combined with massage, can help to reduce pain and anxiety.

I've [also] got arthritis which makes it difficult to put my arms into my shirt sleeves and get dressed. But the massage (at the hospice) has really helped.
Willie, living with a terminal illness

Your Marie Curie Nurse, healthcare assistant or district nurse can help you find out what local free services there are.



We have more information about complementary therapies at **mariecurie.org.uk/complementarytherapies**

Syringe drivers

You might have been given a device called a syringe driver, to help control pain, sickness, agitation or fits. A syringe driver helps reduce symptoms by delivering a steady flow of injected medication continuously under the skin. It's sometimes called a continuous subcutaneous infusion.

Syringe drivers are a very reliable way to control symptoms. In general, they don't need a lot of care, but it's important to:

- avoid dropping the syringe driver
- keep the syringe driver and area around the needle dry
- look out for signs of redness or discomfort where the needle meets the skin
- keep the syringe driver dry when washing or bathing – if you drop it into water contact your nurse or doctor



Chris Renton/Marie Curie

If the device stops working

If the device stops working, don't worry as the effect of the medication will last for a while. Call your Marie Curie Nurse, district nurse or doctor as soon as possible.

If the alarm goes off

Let your nurse know if the syringe driver alarm goes off as this may mean there is a problem, or it may just need a new battery. Your nurse will give you batteries and you should be left with a spare.



There is more information about syringe drivers, including a film guide for carers, on the Marie Curie website at mariecurie.org.uk/syringedrivers

Managing medications

It's essential for you or your carer (if you have one) to learn how to manage, give and/or take medication.

Carers will need to know what the medications are for, how often they need to be taken, how to store them and how to administer them.

If you've been discharged from hospital or a hospice, full instructions on how to manage and take medications will be given to you, your doctor and carer. The labels on the medication also carry full instructions on safety and storage, and the required dose.

If any medication is going to be given through a syringe driver, this will be set up by your Marie Curie Nurse or district nurse. They will check the syringe driver each day.

Storing medicines

There are several important things to note when storing medicines:

- Read the instructions carefully. If the print is too small, ask someone else to read them and note down the details.
- Check on the label to see how long they will last once opened.
- Keep them out of the reach or sight of children.
- Store in a cool, dry place, away from direct heat and light.
- Some medication should be stored in the fridge once opened. Put it on a top shelf – especially when children are nearby.
- Don't use the medication if it's out of date.

Emergency situations

Nobody else should be allowed access to your medication as it can be dangerous in the wrong hands. It's also essential that the dose isn't exceeded, even if you believe it's needed. If you suspect that the dose has been accidentally exceeded, call the doctor or emergency services immediately.

If someone (especially a child) accidentally takes some medication, you should contact emergency services or take them to A&E (accident and emergency) at a local hospital. If it's a young child you may not be able to find out whether they've definitely taken it, but it's best to seek medical advice just in case.

Multiple medications

You may find that you're managing many different medications and feel confused about what to take when. Ask your pharmacist, doctor or nurse about what planning tools are available. You could also try a medication planning app for your smartphone, which will alert you when it's time for the next dose. Some of these have a free trial.

If there are any changes in your condition or behaviour after new medication has been introduced, speak to the doctor or nurse as soon as possible.

If you need help, it's vital that you ask your district nurse or Marie Curie Nurse, pharmacist, or doctor.

Just In Case boxes

The NHS issues Just In Case boxes in England, Scotland and Wales for people who are ill and being cared for at home. These include medications and equipment for use in emergency situations.

The box includes medication for:

- breathlessness
- agitation
- breakthrough pain

If you're in any doubt about using the medication or whether the situation is an emergency, contact your healthcare assistant or nurse, or ring emergency services on 999.

For emergency medical supplies in Northern Ireland, speak to your district nurse or pharmacist.

How we can help

We help everyone affected by a terminal illness get the information and support they need, whether you have an illness yourself or you're a family member or friend.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support. Open 9am to 5pm Monday to Friday. (Your call may be recorded for training and monitoring purposes.)

*Calls from landlines are free, but there may be a charge if you're calling from a mobile. Check with your mobile provider for details. Calls from any type of phone will be free from 1 July 2015.

Marie Curie Community **community.mariecurie.org.uk**

For anyone affected by terminal illness to share experiences and support each other. Available 24 hours a day.

More information and further support

We also have an extensive range of information materials available to view online or in print. Visit **mariecurie.org.uk/help** where you can also find film guides, information about our services, and links to further support.

Marie Curie Nurses

Marie Curie Nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. If you're living with a terminal illness, they can help you stay surrounded by the people you care about most, in the place where you're most comfortable.

mariecurie.org.uk/nurses

Marie Curie Hospices

Our hospices offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether you're staying in the hospice, or just coming in for the day.

mariecurie.org.uk/hospices

Marie Curie Helper

We know the little things can make a big difference when you're living with a terminal illness. That's where our trained Helper volunteers come in. They can visit you regularly to have a chat to over a cup of tea, help you get to an appointment or just listen when you need a friendly ear.

mariecurie.org.uk/helper

Useful organisations

British Association for Counselling and Psychotherapy

01455 88 33 00

bacp.co.uk

Find detailed information about different types of therapy and counselling. You can also search for a therapist near you on the It's Good To Talk portal, which can be found on the website homepage.

Carers UK

0808 808 7777 (England, Wales and Scotland)

028 9043 9843 (Northern Ireland)

carersuk.org

Provides expert advice, information and support to carers. There are links to its national services from the website homepage.

Complementary and Natural Healthcare Council

020 7653 1971

cnhc.org.uk

An accredited voluntary regulator for complementary therapists in the UK. Find a therapist near you or read about the different therapies available on its website.

Pain Concern

painconcern.org.uk

0300 123 0789

A charity which provides support and information about pain and pain management. Features a forum and podcasts with real-life stories.

Patient.co.uk

patient.co.uk

A free health site which contains over 4,000 health information leaflets, a wellbeing centre, a free health check, and discussion forums.

Marie Curie – what we're here for

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support. Open 9am to 5pm Monday to Friday. (Your call may be recorded for training and monitoring purposes.)

mariecurie.org.uk/help

You can also visit **community.mariecurie.org.uk** to share experiences and find support by talking to people in a similar situation.

* Calls from landlines are free, but there may be a charge if you're calling from a mobile. Check with your mobile provider for details. Calls from any type of phone will be free from 1 July 2015.



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through terminal illness**