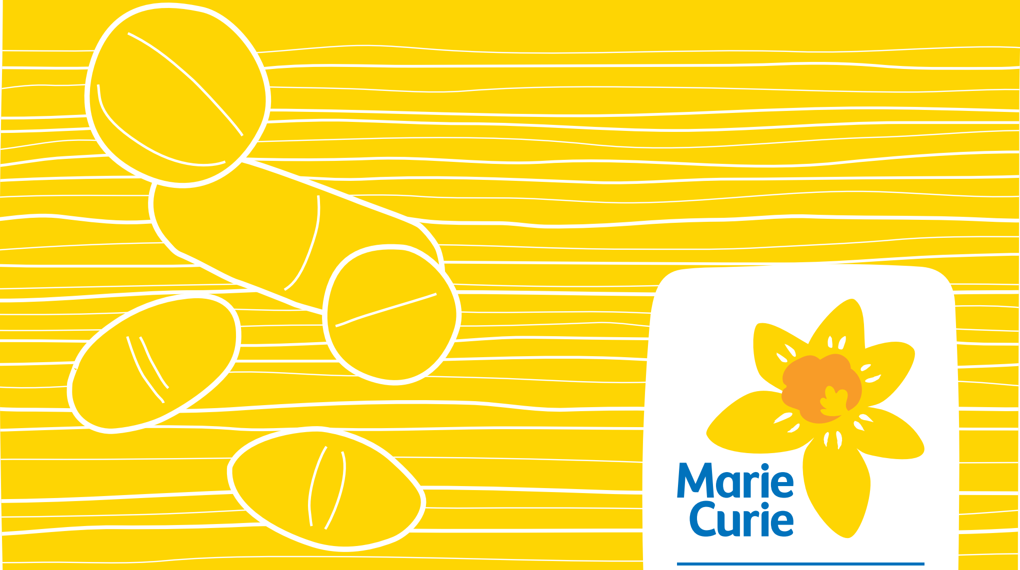
Managing pain

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



Marie Curie

Care and support through terminal illness

*Calls to the Marie Curie Support Line are free from landlines and mobiles. Your call may be recorded for quality and training purposes.

If you're living with a terminal illness, or caring for someone who is, you may be worried about pain. This booklet explains what causes pain and how it can be effectively managed.

Everyone's experience of pain is different, and pain can vary according to your illness and treatment. The main thing to know is that with the right treatment and support, pain can usually be managed.

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

Kieran Dodds/Marie Curie

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What causes pain?

Pain can be caused by your illness itself or treatment for an illness, such as an operation. It might also be caused by a condition you've had for a while, such as arthritis.

Pain is transmitted from damaged areas of the body through nerves. These send messages to the brain which make you feel pain or discomfort.

We often think of pain as being a physical sensation. But we also know that lots of other things can affect how you experience pain. Feeling stressed, anxious, worried, tired, or alone can all make the pain feel worse.

How pain may affect you

Many people living with a terminal illness experience pain, but not everyone does. Everyone's experience of pain is different. If your pain isn't managed, it can affect just about every aspect of your life. It can affect how able you are to move around, your ability to take part in activities, your sleep and concentration. It may have a big impact on your emotions, mood and thoughts too.

We often hear from people we care for that it can affect their confidence, optimism, quality and enjoyment of life, and relationships with other people.

Chris Renton/Marie Curie

Managing your pain

You don't have to put up with pain. Tell your doctor or nurse if you're in pain. There are lots of different treatments available and there may be things you can do yourself to help manage the 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.

Your GP and palliative care team will work with you to find the best treatments for you. Pain can usually be managed with the right treatment and support. In fact, it's rare that someone has pain that can't be managed. We know that pain is managed best when you feel you have enough emotional, psychological and spiritual support (see page 19).

Ben Gold/Marie Curie

Pain assessment

Your doctor or specialist nurse will carry out a pain assessment. This might involve asking you questions about your pain and doing a physical examination. Sometimes they might need to arrange tests to find out what's causing the pain, or do a blood test to help make a decision about the types of medicines you can have.

Talking about your pain

Everyone feels pain in their own way and how someone responds to pain is personal. This means the person with 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's causing your pain and what treatment or medicines you might need.

> 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

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 to help the person express what their pain is like. If they can't communicate at all, there are several signs to look out for, including:

- frowning
- changes in mood
- changes in their routine such as refusing food
- change in posture
- agitation or distress
- lack of concentration
- withdrawal or refusal to make eye contact
- changes in breathing.

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

Questions your doctor or nurse might ask

- Where is the pain in your body?
- Does the pain travel to other parts of your body?
- What does the pain feel like? For example, tingling, burning, aching, tender to touch, dull, sharp, shooting, or throbbing.
- Can you rate the pain on a scale of 0-10, with 0 being pain-free and 10 being the worst pain you can imagine?
- How often do you get the pain?
- Does anything make the pain better, such as resting or pain medicines?
- Does anything make the pain worse, such as moving, eating, or taking a deep breath?
- How is the pain affecting your life?

They may ask you to keep a pain diary – keeping a note of when you feel pain and what it feels like.

Different types of pain

You might hear your medical team using some of these terms to describe pain:

- **Acute pain** is pain that lasts for a short time – normally less than six months. It often comes on suddenly and is usually caused by damage to your body such as an injury or a tumour.
- **Chronic pain** is pain that lasts a long time. It can be constant or intermittent (on and off).
- **Neuropathic or nerve pain** is pain caused by damage to the nerves themselves. It often feels like stabbing, burning, sharp pain, or tingling.
- **Visceral pain** occurs when the internal organs are damaged or inflamed (swollen). This includes **colic**, which feels like waves of squeezing pain in your abdomen (tummy). The pain comes from the bowel, bladder or gallbladder.

- **Bone pain** can happen if there is damage to the bone, including damage from cancer. It often feels like an intense aching pain. Bone pain is sometimes worse at night.
- **Breakthrough pain** is when you have pain even though you're taking regular painkillers. It might be brought on by a particular activity such as eating or moving, or involuntary movements like sneezing or coughing. This is sometimes called **incident pain**. It may also mean that a dose of a painkiller is wearing off.
- **Referred pain** is when you feel pain in one part of your body even though the damage is in another part of your body.
- **Total pain** is the term for all the pain you have. It includes any physical pain, emotional and spiritual distress, struggles you have with practical issues, and worries about coping with your illness.

Pain relief medicines

Your doctors, nurses and other members of your team will work with you to find the best ways to get your pain under control.

There are lots of different types of pain medicines. Some are for different types of pain.

Some people feel they should wait until the pain is really bad before taking any painkillers, but this is not a good way to manage pain. It is better to take painkillers on time, and as often as your doctor prescribed, even if you're not experiencing pain at the time. This helps to keep the pain under control between doses.

It can take a while to find the medicines that work best for you. Tell your doctor or nurse if your pain gets worse or feels different, and they can increase your dose or try a new medicine or drug-free technique.

Common painkillers

The three main types of painkillers are:

- simple painkillers for mild pain
- weak opioids for moderate pain
- strong opioids for severe pain.

It's common to take simple painkillers alongside opioids for moderate or severe pain.

Type of medicine and example names	What it is for and how it works	Common side effects
Simple painkillers		
Paracetamol	Paracetamol can be used for most types of mild pain.	Paracetamol rarely causes side effects.
NSAIDs (non-steroidal anti-inflammatory drugs) such as: • Aspirin • Naproxen • Ibuprofen (Nurofen®, Brufen®)	NSAIDs can come as tablets or in a gel that's rubbed into the painful area of your body. NSAIDs work well for pain caused by inflammation, including cancer pain. NSAIDs are also used to relieve bone pain.	NSAIDs can cause irritation of the stomach or bowel, ulcers and bleeding from the stomach and bowel. Medicines can be prescribed to protect the stomach lining. NSAIDs can't be used if you have kidney failure.

Type of medicine and example names	What it is for and how it works	Common side effects
Opioids		
Weak opioids include: • Codeine • Dihydrocodeine (DF118 Forte®) • Tramadol hydrochloride (Zydol®, Tramacet®) Strong opioids include: • Morphine • Diamorphine • Methadone • Oxycodone (OxyNorm® and OxyContin®) • Buprenorphine (Transtec® patches, BuTrans® patches) • Fentanyl (Durogesic®, Mezolar patches®)	Weak opioids can be used for moderate pain. Strong opioids can be given for many types of moderate and severe pain. When used correctly, opioids do not cause addiction. They might be given as tablets, injections, liquids, in a patch on your skin, or through a syringe driver (see page 22). Oramorph (oral morphine) is swallowed as a liquid. It is often used to treat breakthrough pain.	All opioids can cause constipation, nausea and vomiting, and drowsiness and sleepiness. Constipation can be eased by taking laxatives regularly (this helps you go to the toilet). Nausea and vomiting usually wear off after a few days. Antiemetic (anti-sickness) medicines can help with this. Extreme drowsiness, jerking movements and difficulty breathing are all signs of having too much opioid. If any of these happen you should contact your doctor or nurse.

Other medicines used to treat pain

Type of medicine and example names	What it is for and how it works	Common side effects
Antidepressants		
• Amitriptyline • Nortriptyline • Duloxetine • Mirtazapine	Although these are usually used to treat depression, they are also very effective at treating nerve (neuropathic) pain.	You might get nausea, dizziness or a dry mouth. Side effects are usually mild and improve after a few days.
Anticonvulsants (anti-seizure)		
• Gabapentin (Neurontin®) • Pregabalin (Lyrica®)	These are usually used to prevent seizures (fits) but they can also relieve nerve (neuropathic) pain.	They can sometimes cause weakness, tiredness and blurred vision.
Antispasmodics		
• Hyoscine butylbromide (Buscopan®) • Hyoscine hydrobromide • Mebeverine (Colofac®)	These can relieve colic (crampy pains in the tummy). They work by relaxing the bowel.	Hyoscine butylbromide (Buscopan®) and hyoscine hydrobromide commonly cause a dry mouth. Drinking water and sucking boiled sweets can help.

Type of medicine and example names	What it is for and how it works	Common side effects
Steroids		
• Dexamethasone • Prednisolone	These can reduce swellings that are causing pain, for example a headache due to a brain tumour, and pain caused by pressure around nerves.	They can cause difficulty sleeping and increased appetite. If high doses are used they can increase your blood sugar and this will need to be monitored.
Bisphosphonates		
• Pamidronate (Aredia®) • Ibandronic acid or ibandronate (Bondronat®) • Sodium clodronate (Bonefos®, Clasteon®, Loron®) • Zoledronic acid or zoledronate (Zometa®)	Bisphosphonates are sometimes used for bone problems such as osteoporosis. They relieve bone pain by working directly on the tissue of the bones.	They can cause headaches, sickness and diarrhoea.

Kieran Dodds/Marie Curie

Other ways to give medicines

Palliative care doctors work closely with pain specialists (anaesthetists). If your pain is not controlled, you might have the option to have a nerve block or medicine into your spine.

- Nerve blocks are procedures where nerves are injected with pain medicines, steroids or local anaesthetic (numbing medicine). This stops the nerves from detecting pain and sending messages to your brain.
- Spinal therapy is when medicines are injected into the fluid around the spinal cord. Morphine and other medicines are used. This blocks the pain messages travelling from your spinal cord to your brain.

These treatments are usually provided in hospital.

Layton Thompson/Marie Curie

Side effects

All medicines have the potential to cause side effects, so it's important to make sure you understand the side effects you might get.

You might experience one or more side effects, or you might not have any at all. We've listed some of the common side effects for each medicine (pages 12-16). They can cause other side effects as well. Ask your doctor or pharmacist about specific side effects for your medicines.

If you have side effects, talk to your doctor or nurse. Don't stop taking your medicines suddenly or change the dose without talking to them. They may be able to change the dose, try different medicines or help you to manage side effects.

Ben Gold/Marie Curie

Common worries

Some people worry that having morphine or a syringe driver (see page 22) can make someone die more quickly. Morphine and other opioids are very safe and effective painkillers when prescribed and taken correctly. They can make people more sleepy, so make sure you understand the side effects.

Being given opioids doesn’t necessarily mean someone is approaching the end of their life, but opioids are often used to manage pain at this stage.

You or your carer might also be worried about the risk of addiction. This is rarely an issue for people needing pain relief for a terminal illness.

Drug-free pain relief

Emotional and spiritual support

It's normal 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. You may find that it helps to talk to a professional. This could be a:

- counsellor
- psychotherapist
- spiritual adviser or faith leader.

Speak to your doctor or nurse about getting this kind of support. Or see page 28 for more information about finding a counsellor or psychotherapist near you.

TENS machines

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

Acupuncture

Acupuncture is safe and is sometimes effective in treating chronic pain. Check with your doctor if it might be suitable for you. It may be available in your local hospice, hospital, through your GP practice, or through a private practitioner. Contact the British Acupuncture Council (see page 28) for more information.

Heat and cold

You might feel relief from pain by using heat and cold therapies. Hot water bottles and warm baths can ease pain. Using an ice pack on certain areas of your body might help too.

Complementary therapy

Complementary therapies can be used alongside your medical treatment. They might be able to help you relax, sleep and reduce pain. Common therapies include acupuncture, aromatherapy and massage.

Some complementary therapies might not be suitable or safe for you, depending on your health condition and treatment. So you should speak to your doctor or nurse before you have any. They can also help you find out what free services there are in your area.

Occupational therapy and physiotherapy

Occupational therapists (OTs) and physiotherapists can help you adjust your home and daily activities to manage your pain. Mobility aids can make moving around less painful. Changing positions regularly or using special cushions can help ease pain too.

> I’ve also got arthritis which makes it difficult to get dressed. But the massage at the hospice has really helped.
>
> Willie, living with a terminal illness

Information for carers: supporting someone in pain

Carers, including friends and family members, play a very important role in providing care for their loved ones.

As well as giving medicines, there are other ways that you can help your loved one to manage their pain. People feel less pain when they feel relaxed and supported. They can also feel distracted from their pain when they have meaningful activities to do. So you can help them to feel more comfortable by:

- spending time with them
- listening to their worries
- encouraging them to express their emotions
- helping them to relax by playing music, or reading to them
- helping them to do their favourite activities such as reading or seeing friends.

Ask your nurse if there is a carers support group in your local area where you can get more support with this.

We have tips and support for carers on our website at **mariecurie.org.uk/carers**

Syringe drivers

You might have a syringe driver for medicines that help manage symptoms such as pain, sickness, seizures (fits), agitation and breathing problems.

A syringe driver is a small, battery-powered pump that delivers medication at a constant rate throughout the day and night. The medication is delivered through a very fine needle, inserted just under the skin.

Chris Renton/Marie Curie

It's common to feel nervous about having a syringe driver but most people find that they are very helpful for managing symptoms and give a feeling of reassurance.

Why are syringe drivers used?

A syringe driver might be helpful if you can't take your medicines orally (by mouth), for example if you have difficulty swallowing or are being sick. They may also be used if your body can't absorb your medicines properly or the medicines aren't working.

Syringe drivers are often used in the last few weeks and days of life but they can be useful for managing symptoms at any stage.

Setting up a syringe driver

Your syringe driver will be set up for you by your doctor or nurse, who will change or top up your medicines each day. If your symptoms aren't under control quickly, your doctor can change or adjust your medicines.

Taking care when using a syringe driver

In general, syringe drivers are safe, reliable and don't need a lot of care, but it's important to:

- keep the syringe driver and area around the needle dry
- contact your nurse if the skin is sore or looks irritated
- avoid dropping it
- keep the syringe driver dry when washing – if you drop it into water contact your nurse or doctor
- take extra care when washing and dressing to make sure the tube isn't pulled out.

If it stops working

If the machine stops working, don't worry as the effect of the medicines will continue for a while. Call your doctor or nurse as soon as possible.

If the alarm goes off

The alarm will go off if there is a problem with the syringe driver, such as a low battery, leak or blockage in the tube. Let your nurse know so they can come and check it.

You can find out more about syringe drivers at **mariecurie.org.uk/syringe-drivers** or call the Marie Curie Support Line on **0800 090 2309***.

Managing medication

People living with a terminal illness often have a lot of different medicines to take and it can be challenging to learn how to manage them all. Carers, including friends and family members, can also play a very important role in managing medicines.

If you started having medicines in a hospice or hospital, full instructions on how to manage and take your medicines will be given to you, your GP and your carer, if you have one. The labels on the medicines also carry full instructions on safety and storage, as well as the correct dose.

If you have any medication through a syringe driver (see page 22) this will be set up by GP, specialist palliative care nurse or district nurse.

Getting support

Many people, and their carers, find managing medicines quite challenging at first. Don't be afraid to ask your nurse, doctor or pharmacist for help. If you are finding it difficult to organise the medicines, ask if any planning tools are available such as blister packs, or dosette boxes for pills. These are special boxes with small compartments that show clearly which pills need to be taken at what time of day. You could also try a medication planning app if you have a smartphone or tablet, which will alert you when it's time for the next dose. Many of these are free to download.

Storing medicines

It’s important to store medicines safely. Make sure you:

- read the instructions on the label carefully
- check the label to see how long they will last once they’ve been opened
- don’t use medicines if they are out of date
- keep them out of the reach or sight of children
- store in a cool, dry place, away from direct heat and light
- store them in the fridge if needed.

Ask your doctor, nurse or pharmacist if you are unsure about anything.

Emergency situations

Nobody else should be allowed access to your medication as it can be dangerous if other people take it. All medicines have the potential to cause side effects (see page 17).

It’s important not to have extra doses, even if you believe they’re needed. If you think that you’ve taken too much medicine, call your doctor or emergency services for advice. Using planning tools like dosette boxes (see page 24) can help stop you accidentally taking a wrong dose.

If you become unwell after accidentally taking some medicine, you should contact emergency services or go to A&E (accident and emergency).

Just in case medicines

A doctor or specialist nurse can prescribe 'just in case' medicines in England, Scotland and Wales for people who are ill and being cared for at home. These include medications for injection and equipment in case someone becomes suddenly more unwell. They are also useful if someone suddenly can't take their usual medicines orally (by mouth) anymore. These medicines are usually given by a district nurse who can be called out to the house.

The just in case medicines are used for:

- vomiting and nausea
- breathlessness
- agitation
- breakthrough pain
- respiratory secretions (too much fluid in the lungs, or throat).

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

For emergency medical supplies in Northern Ireland, speak to your doctor, 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 8am to 6pm
Monday to Friday, 11am to 5pm Saturday.
*Your call may be recorded for training and monitoring purposes.

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 have an extensive range of information materials available to view online or in print. Visit **mariecurie.org.uk/support** where you can also find practical videos, 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, to 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 Service
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 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 Acupuncture Council
020 8735 0400
acupuncture.org.uk
Find an accredited private (paid-for) acupuncturist near you in the UK.

British Association for Counselling and Psychotherapy
01455 883300
bacp.co.uk
Find detailed information about different types of therapy and counselling. You can also search for a therapist near you.

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 3668 0406
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
0300 123 0789
painconcern.org.uk
A charity which provides support and information about pain and pain management. Features a forum and podcasts with real-life stories.

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

About this information

This booklet was produced by Marie Curie's Information and Support team. It has been reviewed by health and social care professionals and people affected by terminal illness.

If you would like to provide feedback about this booklet or would like the list of sources used to create this information, please email **review@mariecurie.org.uk** or call the Marie Curie Support Line on **0800 090 2309***.

Notice

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

*Calls to the Marie Curie Support Line are free from landlines and mobiles. Your call may be recorded for quality and training purposes.

Notes

Notes

Tell us what you think about this booklet

We'd like to hear what you think about this information. Your comments will help us make sure we're providing useful and accessible information. We won't share any responses that could identify you outside of Marie Curie. Read more at **mariecurie.org.uk/privacy**

We'd be very grateful if you could complete this form and email it to **review@mariecurie.org.uk** or post it to:

Information and Support Content team
Marie Curie
89 Albert Embankment
London
SE1 7TP

Which sentence best describes your situation?

☐ I have a terminal illness
☐ I am a carer, family member or friend of someone with a terminal illness
☐ I was a carer, family member or friend of someone who has died
☐ I am a health or social care professional using this resource to support someone affected by a terminal illness
☐ Other (please specify) ....

Where did you get this booklet from?

☐ Ordered through the Marie Curie website
☐ Ordered through the Marie Curie website after calling the Support Line
☐ Downloaded from the Marie Curie website
☐ A Marie Curie Nurse, volunteer or hospice staff member
☐ Healthcare professional (eg GP, district nurse)
☐ Other (please specify) ....

How likely are you to recommend this information to friends and family if they were in a similar situation to you?

☐ Extremely likely ☐ Likely ☐ Neither likely nor unlikely
☐ Unlikely ☐ Extremely unlikely ☐ Don't know / not applicable

Please tell us the main reason for the answer you've given.

....

....

....

....

Was there any information you couldn't find that would have been helpful for you?

....

....

How easy or difficult to understand was the information?

☐ Very easy ☐ Quite easy ☐ Neither easy nor difficult
☐ Quite difficult ☐ Very difficult ☐ Don't know / not applicable

Please tell us why.

....

....

How did you feel about the amount of information?

☐ Too much ☐ The right amount ☐ Too little ☐ Don't know / not applicable

Please tell us why.

....

....

Would you have preferred to access this information in another format?

☐ Audio ☐ Braille ☐ Large print
☐ Another language (please specify) ....
☐ Other (please specify) ....
☐ Don't know / not applicable

Do you have any other comments?

....

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We're looking for volunteers to join our Readers' Panel and help us improve our information for people affected by terminal illness.

We're also looking for volunteers to share their experiences publicly about how our information has helped them.

If you would like to help, please email us at **review@mariecurie.org.uk** and we'll tell you more about these volunteering opportunities.

Marie Curie – who we're here for

We're here for people living with any terminal illness, and their families and friends. 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 8am to 6pm Monday to Friday, 11am to 5pm Saturday. **mariecurie.org.uk/support**

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

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Health & care information you can trust
The Information Standard
Certified Member

Marie Curie
Care and support through terminal illness