

Managing pain

A guide for people living with a terminal illness and the people close to them



**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 you can manage it.

Everyone's experience of pain is different, and everyone responds to it differently. Pain can also vary according to your illness and treatment. The important thing 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***.



Phil Hrdman/Marie Curie

Contents

What causes pain?	6
How pain may affect you	6
Managing your pain	7
Pain assessment	8
Questions your doctor or nurse might ask	9
Talking about your pain	9
Keeping a pain diary	10
Information for carers: helping someone communicate	11
Types of pain	12
Pain relief medicines	13
Common painkillers	14
Other medicines used to treat pain	16
Side effects	19
Common worries about opioids	19
Drug-free pain relief	20
Emotional and spiritual support	20
TENS machines	20
Acupuncture	21
Heat and cold	21
Complementary therapy	21
Occupational therapy and physiotherapy	21
Information for friends and family: supporting someone in pain	22

Managing medication	22
Getting support	22
Storing medicines	22
Emergency situations	23
Just in case medicines	25
Syringe drivers	26
Why are syringe drivers used?	26
Setting up your syringe driver	26
Using a syringe driver	26
Common worries	27
How Marie Curie can help	28
Useful organisations	29
About this information	31

What causes pain?

Pain is a physical sensation. It happens when damaged areas of your body send signals to your brain.

Many people living with a terminal illness experience pain, but not everyone does. It could be caused by your illness itself, or by a treatment or operation you've had. It could also be caused by a condition you've had for a while, such as arthritis.

Although pain is a physical sensation, we also know that lots of other things can affect how you experience pain. Feeling stressed, anxious, worried, tired, or alone can all make pain worse.

How pain may affect you

Everyone experiences and responds to pain differently.

Pain can affect just about every aspect of your life. It can stop you from moving around doing day-to-day activities. It can also affect your sleep and concentration.

Pain can have a big impact on your emotions, mood and thoughts too. People often tell us that pain affects their confidence, optimism, quality and enjoyment of life, and relationships with other people.



Managing your pain

You do not have to put up with pain. There are lots of treatments available. Tell your doctor or nurse if you're in pain. They 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 cannot be managed. There may also 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, have the best possible quality of life.

Palliative care also helps with a person's psychological, social and spiritual needs. This is because you can manage pain best when have the right emotional, psychological and spiritual support. (see page 20).



Pain assessment

Your doctor or specialist nurse will talk to you about your pain so they can find the right treatment for you. 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. They might do a blood test to help them decide what medicines you can have.

Questions your doctor or nurse might ask

Your doctor or nurse might ask questions about your pain, including:

- 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
 - throbbing.
- Can you rate the pain on a scale of 0 to 10, with 0 being no pain 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?

Talking about your pain

Everyone feels pain in their own way and everyone responds to it differently. This means you are in the best position to say what your pain is like, rather than those around you.

Try to describe any pain you're experiencing to your doctor or nurse. This can be difficult, but it helps them find out what's causing your pain and what the best treatment will be.

Keeping a pain diary

Keeping a pain diary can be helpful. A pain diary is when you write down when you feel pain, what it feels like and what you were doing at the time. You can then use this when you talk to your doctor or nurse so they know what you're feeling.

You can use pen and paper or type it into your smartphone or tablet. There is a pain diary you can use at the back of this booklet.

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

Linda, family member



Information for friends and family: helping someone communicate

If you're caring for someone who has trouble communicating, it can be hard to know if they're in pain or what type of pain they have. 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 cannot communicate at all, you should watch out for signs that they are in pain. There are several signs to look out for, including:

- frowning
- changes in their mood
- changes in their routine such as refusing food
- change in their posture
- agitation or distress
- not being able to concentrate
- becoming withdrawn or not making eye contact
- changes in their breathing.

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



Ben Gold/Marie Curie

Types of pain

There are lots of different types of pain. You might hear your medical team using some of these words to describe pain. It can help to know what they mean:

- **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 it can come and go. It is treated differently to acute pain.
- **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 tummy. The pain comes from the bowel, bladder or gall bladder.

- **Bone pain** can happen if there is damage to bones, including damage from bone 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. The pain 'breaks through' the painkillers. It might be brought on by doing something like eating, moving, sneezing or coughing. This is sometimes called **incident pain**. It may also mean that your painkillers are wearing off.
- **Referred pain** is when you feel pain in one part of your body even though the damage is happening to another part of your body.
- **Total pain** is the term for all the pain you have. It includes physical, emotional and spiritual pain. It also includes any struggles you have with practical issues or worries about coping with your illness.

Pain relief medicines

Your doctors, nurses and other members of your team will work with you to get your pain under control. There are lots of different medicines for treating pain. Some are for different types or severity (amount) of pain.

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's 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 you rub into the painful part 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 cannot be used if you have kidney failure.

Type of medicine and example names	What it's for and how it works	Common side effects
Opioids		
Weak opioids include: • codeine • dihydrocodeine (DF118 Forte®) • tramadol hydrochloride (Zydol®, Tramacet®)	Weak opioids can be used for moderate pain. Strong opioids can be given for many types of moderate and severe pain. Addiction in people with terminal illness is very rare.	All opioids can cause constipation, nausea and vomiting, and drowsiness and sleepiness. Constipation can be eased by taking laxatives regularly (they help you go to the toilet).
Strong opioids include: • morphine • diamorphine • Methadone • oxycodone (OxyNorm® and OxyContin®) • buprenorphine (Transtec® patches, BuTrans® patches) • fentanyl (Durogesic®, Mezolar patches®)	They might be given as tablets, injections, liquids, in a patch on your skin or through a syringe driver (see page 26). Oramorph (oral morphine) is swallowed as a liquid. It is often used to treat breakthrough pain.	Nausea and vomiting usually wear off after a few days. Anti-emetic (anti-sickness) medicines can help with this. If you feel extremely drowsy, have jerking movements or find it hard to breath, contact your doctor or nurse. These are all signs of taking too much opioid.

Other medicines used to treat pain

Type of medicine and example names	What it's for and how it works	Common side effects
Antidepressants		
• Amitriptyline • Nortriptyline • Duloxetine • Mirtazapine	These are usually used to treat depression, but they are also very good at treating nerve (neuropathic) pain.	Side effects are usually mild and improve after a few days. You might get nausea, dizziness or a dry mouth.
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's for and how it works	Common side effects
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Steroids

• Dexamethasone • Prednisolone	These can reduce swellings that are causing pain. For example, a headache due to a brain tumour. They also help with pain caused by pressure around nerves.	They can cause difficulty sleeping and increased appetite. High doses can increase your blood sugar. This will need to be monitored.
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Bisphosphonates

• Pamidronate (Aredia®) • Ibandronic acid or ibandronate (Bondronat®) • Sodium clodronate (Bonefos®, Clasteon®, Loron®) • Zoledronic acid or zoledronate (Zometa®)	These 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 headache, sickness and diarrhoea.
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Ben Gold/Marie Curie

When to take medicines

Some people feel they should wait until the pain is really bad before taking any painkillers. It is better to take painkillers 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.

Other ways to give pain relief

If your pain cannot be controlled by medicines, there are other options. Palliative care doctors work closely with anaesthetists. They are doctors who specialise in treating pain. An anaesthetist might be able to give you a nerve block or medicine into your spine.

Nerve blocks are when pain medicines, steroids or local anaesthetic (numbing medicine) are injected into your nerves. This stops them from detecting pain and sending messages to your brain, meaning you do not feel pain in that part of your body.

Spinal therapy is when medicines are injected into the fluid around your spinal cord. This blocks the pain messages travelling from your spinal cord to your brain.

Both of these treatments are usually provided in hospital by specialist doctors and nurses.

Side effects

All medicines can cause side effects. These are unwanted symptoms caused by the drug. You might experience one, more than one, or none at all. Common side effects for different medicines are listed on pages 14-17. They can cause other side effects too.

If you have side effects, do not stop taking your medicines or change the dose without speaking with your GP or nurse. They may be able to change the dose, try different medicines or help you manage the side effects.

Common worries about opioids

A lot of people worry about taking morphine or other opioids.

Some people worry that having morphine can make them die more quickly. This is not true. Morphine and other opioids are very safe and effective when prescribed and taken correctly. They can make people sleepy, so make sure you understand the side effects.

Some people think that being given opioids means you are near the end of your life. This is not true. Opioids can be given to people who are not terminally ill, but opioids are often used to manage someone's pain when they are at the end of their life too.

You or your friends and family 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

There are ways of relieving pain that do not involve drugs. You can try these on their own, or along with taking medication.

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

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 30 for more information about finding a counsellor or psychotherapist near you.

TENS machines

TENS (transcutaneous electrical nerve stimulation) machines deliver gentle electric pulse that can help relieve pain. You attach electrodes to your body wherever the pain is felt. The pulse might tingle a bit, but it is not painful.

The machine is easy to use and you can try it at home. You can buy them at many pharmacies. If you are interested in trying TENS, talk to your GP who can refer to you a physiotherapist or a pain specialist who can help you to set it up.

Acupuncture

Acupuncture involves having very thin needles inserted into certain parts of your body. It is safe and 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 30) for more information.

Heat and cold

Heat and cold therapies might help with pain relief. Hot water bottles and warm baths can reduce pain, ease stiffness, and increase muscle relaxation and circulation. Using an ice pack on certain parts of your body might help reduce pain and swelling too.

For safety, make sure that you:

- do not use boiling water in a hot water bottle
- wrap a hot water bottle or ice pack in a towel or pillowcase to avoid burns to your skin
- only apply heat or cold therapy to your body for 10 - 15 minutes
- do not go to sleep while using the treatment.

Complementary therapy

Complementary therapies can be used alongside your medical treatment. They might be able to help you relax, sleep and manage your pain. Common therapies include mindfulness, meditation, massage, aromatherapy, reflexology, hypnotherapy, music therapy and reiki.

Some complementary therapies might not be suitable or safe for you, depending on your health condition and treatment. 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.

Information for friends and family: supporting someone in pain

As well as giving medicines, there are other ways you can help the person to manage their pain. People feel less pain when they feel relaxed and supported. They can also be distracted from their pain when they have meaningful activities to do:

You can help them to feel more comfortable by:

- spending time with them
- listening to their worries
- helping them to talk about their feelings
- 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 the 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**

Managing medication

If you are living with a terminal illness, you might have a lot of medicines to take. It can be hard to understand what they are all for and how to take them. Carers, including friends and family, can play a very important role in managing medicines.

If you were given medicines in a hospice or hospital, you should have been told what your medicines are and how to take them. If not, your GP or carer might have been. The labels on the medicines will have instructions on safety and storage, as well as the correct dose.

If you have any medication through a syringe driver (see page 26) this will be set up by your GP, specialist palliative care nurse or district nurse.

Getting support

Many people find managing medicines quite challenging at first. Do not be afraid to ask your nurse, doctor or pharmacist for help.

You might find it difficult to organise your medicines. For example, you might forget if you've taken your medication yet or not. There are things you can do to help with this.

Dosette boxes are special boxes with small compartments that show which pills need to take and when. They help you check if you've taken your medication already. They can also remind you when you should take each medicine.

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 and securely. Nobody else should be able to access your medication unless they are caring for you and helping you to take them. It can be dangerous if other people take them.

You should:

- read the instructions on the label carefully
- check on the label how long they will last once they've been opened
- not 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

All medicines can cause side effects (see page 14–17). It's important not to have extra doses, even if you think you need them. Using planning tools like dosette boxes (see page 23) can help stop you accidentally taking too much.

If you think you've taken too much, call your doctor or emergency services for advice. If there is someone in the house with you, tell them as well.

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

You might be given “just in case” medicines if you are being cared for at home. These are sometimes called anticipatory medicines. These are medicines that you do not need now but might need if you become more ill or in pain. A doctor or specialist nurse can prescribe you these medicines in England, Scotland and Wales. You then keep them at home in case you need them. If you do, a district nurse can be called out to the house to give them to you.

Just in case medicines can be used for:

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

Just in case medicines might include injections. These are sometimes useful if you cannot take your medicines orally (by mouth) anymore. You might also need some equipment if you suddenly become more unwell.

If you're in any doubt about using the medicines or whether the situation is an emergency, contact your nurse or doctor, or call **111** for advice. For emergencies, call **999**.

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

Syringe drivers

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 tube just under the skin.

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

It's common to feel nervous about having a syringe driver, but most people find that they help them manage their symptoms and feel reassured.

Why are syringe drivers used?

A syringe driver might be helpful if you cannot 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 cannot absorb your medicines properly or the medicines are not 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 doctor or nurse will set your syringe driver up for you. They will also change or top up your medicines each day. If your symptoms are not under control quickly, your doctor can change or adjust your medicines.

Using your syringe driver

In general, syringe drivers are safe, reliable and do not need a lot of care. But it's important to:

- keep the syringe driver and the area around the tube dry
- contact your nurse if the skin is sore or irritated
- try not to drop it – if you do, contact your nurse
- 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 is not pulled out.

If it stops working

If the machine stops working, don't panic. 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***.

Common worries

Some people worry that having a syringe driver means they will die very soon. This is not necessarily true. Syringe drivers can be used at any stage of your illness. Some people just use them for a short time to manage their symptoms.

Some people are concerned that having a syringe driver can make them die sooner. There is no evidence this is true. Syringe drivers are often used at the end of life because they are the easiest way to give someone the medicines they need to feel comfortable at that time.

How Marie Curie can help

Marie Curie Support Line

0800 090 2309*

Ask questions and find support. Speak to a trained member of staff or a nurse for free confidential information on all aspects of terminal illness. Open 8am to 6pm Monday to Friday and 11am to 5pm Saturday. Your call may be recorded for training and monitoring purposes.

Marie Curie Online Chat

You can talk to our trained staff and get information and support via our online chat service.

mariecurie.org.uk/support

Marie Curie Community

Share experiences and find support by talking to people in a similar situation.

community.mariecurie.org.uk

Marie Curie Information

We have a range of free information available to view online or as printed booklets.

mariecurie.org.uk/support

Ongoing support from a bereavement volunteer

The Marie Curie Bereavement Service is for people who might want to have ongoing support, from the same person, over the phone.

You can access up to six telephone sessions of 45 minutes. For more information call the Support Line or visit **mariecurie.org.uk/support**

support

Check-in and Chat

If you, or someone close to you, is terminally ill, and looking for regular emotional support our Check-in and Chat service may be for you. Check-in and Chat is our befriending call-back service where you'll be matched with one of our volunteers. They will be able to give ongoing support and be a friendly ear when you need to talk. For more information call the Support Line or visit **mariecurie.org.uk/support**

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. Our hospices also support people who have been bereaved, and some offer support for children.

mariecurie.org.uk/hospices

Marie Curie Nursing Services

Marie Curie Nurses and Healthcare Assistants work 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 Helper Volunteers

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.

Marie Curie

We're here for everyone affected by dying, death and bereavement in the UK. We offer expert care, guidance and support to help people get the most from the time they have left.

Marie Curie Support Line

0800 090 2309*

Got a question? Call our Support Line to speak to someone who can help, including specially trained nurses. To find out more visit **mariecurie.org.uk/support**

Ongoing support

Whatever your situation, you can access regular emotional support over the telephone from our specially trained volunteers through our Check-in and Chat befriending service. You can also visit **community.mariecurie.org.uk** to share experiences and find support by talking to people in a similar situation.

Bereavement support

We offer a Bereavement Service for people who might want to have ongoing support, from the same person, over the phone. To find out more call free on **0800 090 2309** or visit **mariecurie.org.uk/support**

We can't do it without you

Our Information and Support service is entirely funded by your generous donations, so the work we do would not be possible without your help. Thanks to you, we can continue to offer people the free information and support they need, when they need it. **mariecurie.org.uk/donate**



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