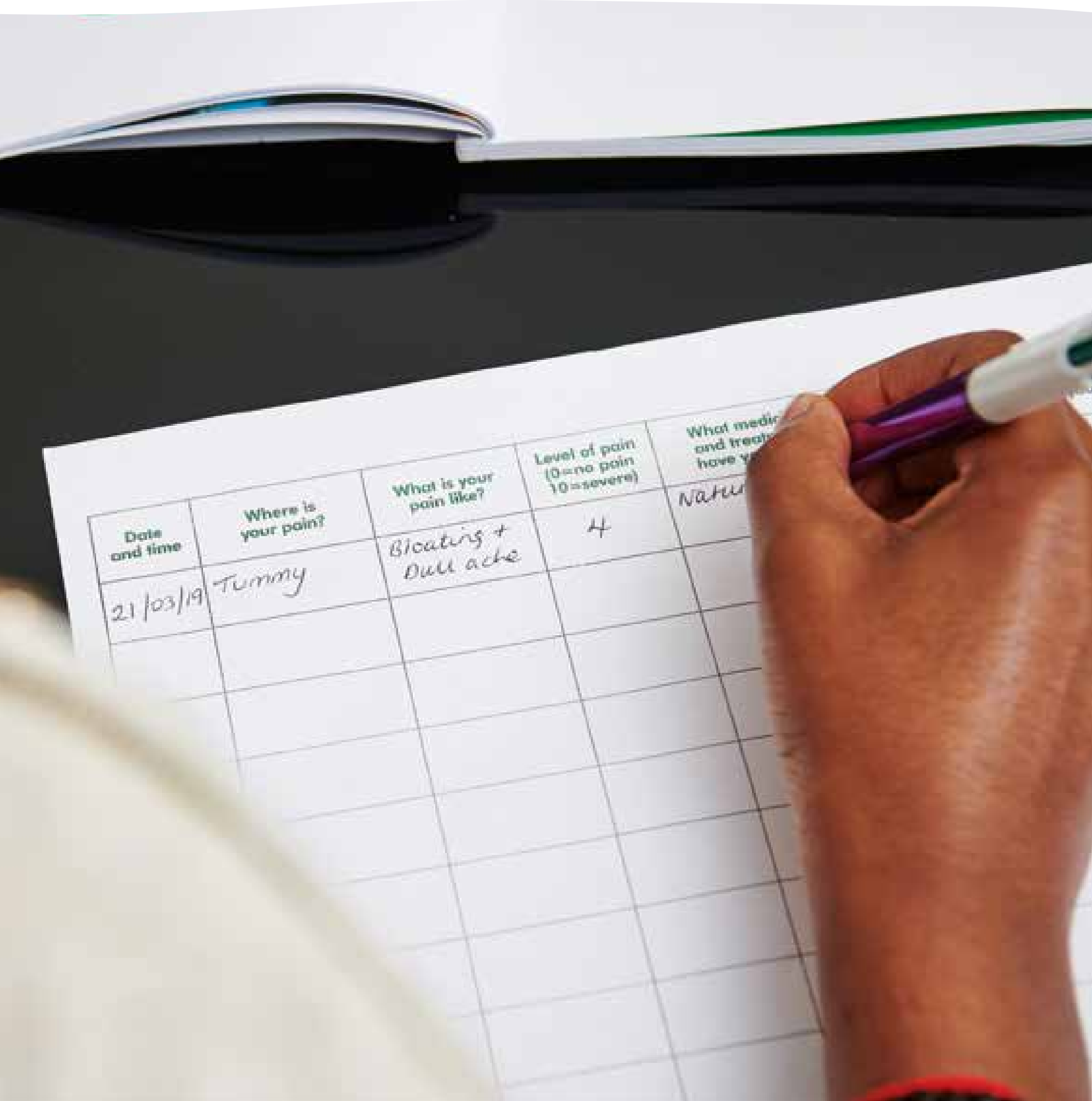
MACMILLAN
CANCER SUPPORT

MANAGING CANCER PAIN



About this booklet

This booklet explains the different ways that cancer pain can be managed. This can be with painkillers and other treatments, including some complementary therapies.

It is for anyone affected by cancer who is experiencing pain. It may also be helpful for carers, family members and friends.

We hope it helps you deal with some of the questions or feelings you may have.

Recording the pain can help to see what makes it better or worse. We have attached a pain diary to page 17 to help you do this. You might want to pull it out and photocopy it, so you can use it a few times.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 84 to 91, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had cancer pain, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

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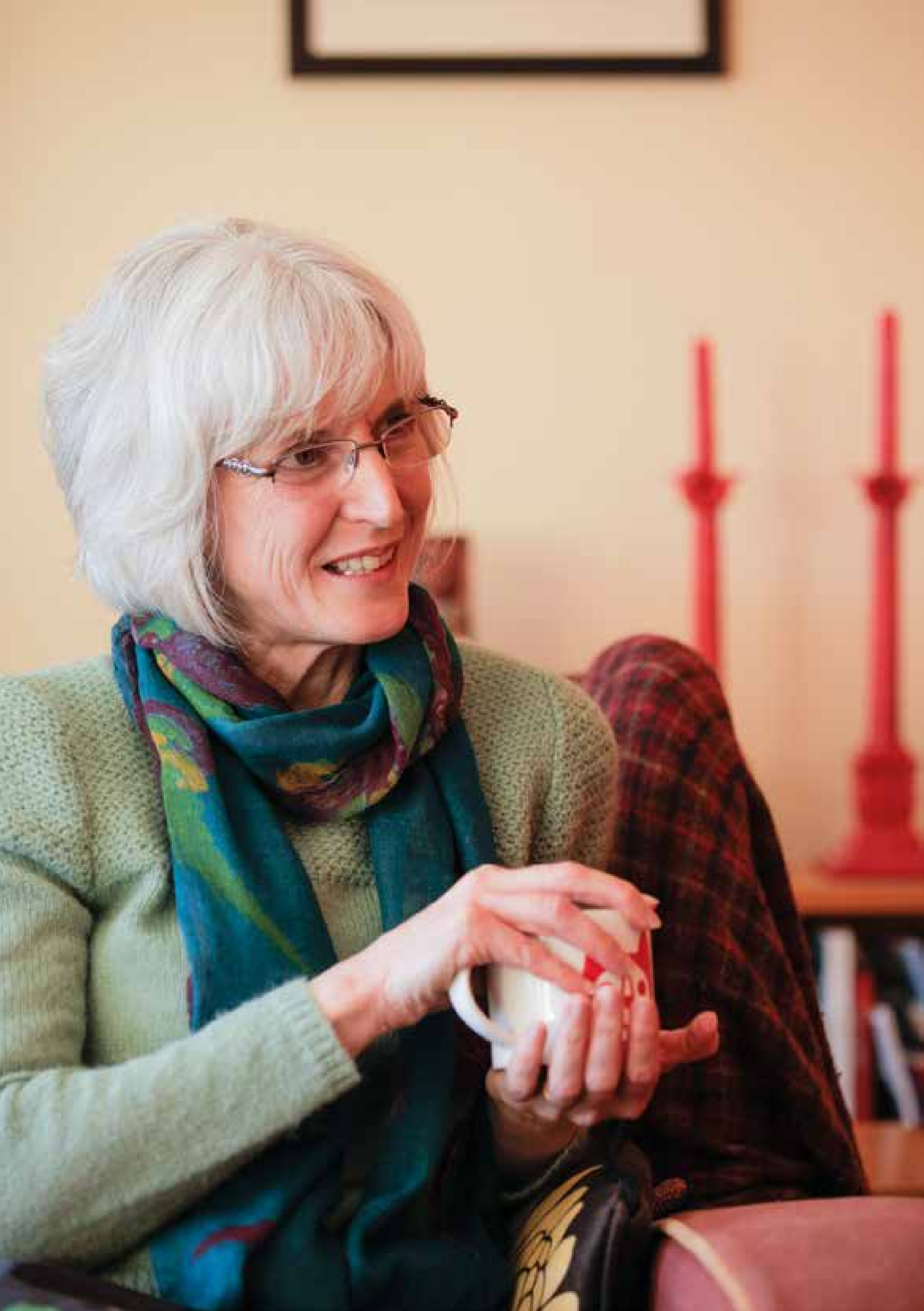


ABOUT PAIN

About cancer pain

Having cancer does not mean you will have pain. But if you have pain there are different medicines and treatments than can help. These include non-drug treatments and things you can do to help relieve pain.

The amount of pain a person has is not related to how advanced a cancer is. Pain does not always get worse as cancer develops. Some people may not experience any pain.

Pain is usually caused by an injury or illness in the body. Nerves in the damaged part of the body send warning signals to the brain. The brain responds by making us feel pain or discomfort.

But pain is also an emotional experience. How we feel can be linked to how we experience pain. Pain can feel worse when we feel anxious and easier to cope with when we feel more relaxed.

When pain is not treated, it is common to feel anxious, irritable, frustrated and depressed. Tiredness and lack of sleep also make pain feel worse and harder to cope with. Your home or work life and the people around you can also have a positive or negative effect on pain.

Different health professionals can help to make sure the pain is well controlled. When pain is controlled, you can keep doing the things in your life that are important to you. You may feel more in control and able to enjoy being with the people close to you.

Everyone's experience with pain is different. The aim is to find the pain relief that suits you and allows you the best possible quality of life. Pain control is more effective when it starts as soon as possible. But it should continue through treatment and your follow-up care if needed.

Causes of pain

People with cancer may have pain for different reasons. Pain may be caused by the cancer, or its treatments, or have another cause.

Pain can affect people with cancer at any stage. But it is more common when cancer is advanced. Having the pain controlled is an important part of your treatment and care.

Some treatment side effects may cause pain, but this often improves in the weeks after treatment.

Always tell your cancer doctor or nurse if side effects do not improve. People who have recovered from cancer may sometimes have pain from late effects of treatment. Late effects are side effects that do not improve after treatment, or start months or years later.

Some possible reasons for pain are:

- the cancer pressing on tissues or nerves, or on bone or an organ nearby
- the cancer blocking a part of the body, for example the bowel, and stopping it working normally
- surgery causing nerve or tissue damage in the area
- radiotherapy damaging the skin or nerves in the treated area
- side effects of anti-cancer drugs, such as a sore mouth, nerve damage (peripheral neuropathy), or muscle or joint stiffness or pain.

If you get a new ache or pain you may worry the cancer has come back, or is getting worse. This is a common worry. But there are different reasons for changes in pain levels.

Always tell your doctor about any new pain or symptom. They can then check what is causing it and treat it.

Some people have pain from other health conditions, for example, arthritis or diabetes. Tell your cancer doctor or nurse about this. Your pain treatment plans should also include other conditions that cause pain. Make sure you keep appointments for these conditions and tell the specialist about any changes.

We have a booklet called **Worrying about cancer coming back** that you may find useful (see page 80).

Other factors

Sometimes, emotional stress such as anxiety, depression and tiredness can make pain feel worse (see page 75). But people may also develop these problems if pain is not controlled. Getting emotional support may help to relieve pain.

Social or work stresses can also affect how you experience pain. For example, not being able to get out and see friends or go to work may make pain feel worse.

Types of pain

Your doctors or nurses may talk about the pain you have in different ways. There are many types of pain. Pain can be described or grouped depending on:

- how long it lasts
- the parts of the body that are affected.

Acute pain

This often starts suddenly and feels ‘sharp’. It usually lasts days or weeks. Acute pain usually stops when the cause of the pain has been treated or tissue in the area has healed.

Acute pain can be caused by things such as:

- an operation
- a broken bone
- an infection.

If acute pain is not relieved, it may become chronic pain. For example, if you have pain after surgery, it may cause you to move the area less. This may mean it takes longer for the area to heal.

Chronic pain

Chronic pain lasts for a longer time, usually for 3 months or more. It may be caused by the cancer or sometimes by long-term effects of cancer treatments (called late effects).

Breakthrough pain

This is a sudden pain that ‘breaks through’. It usually happens when chronic pain is being controlled with regular long-acting painkillers. Breakthrough pain is common.

Sometimes it is not clear why it happens. It may be because:

- the effect of the regular long-acting painkillers has worn off and the dose is not high enough
- the pain is worse at a certain time of day or evening
- of sudden movement or even coughing.

Breakthrough pain can be successfully treated with short-acting painkillers or an increase in the dose of painkillers (see pages 31 to 39). People often take long-acting painkillers and use short-acting painkillers when they need to.

This gives you more control in how you manage pain on a day to day basis. Using a short-acting pain killer can be especially helpful if:

- you plan to do something more energetic
- there is an event you want to go to.

Bone pain

If the cancer has spread to the bones, it can cause pain. If the cancer started in the bones, this can also cause pain, but it is less common. The pain may be a dull ache that does not go away. It is often worse when you move.

Soft tissue pain

This is when there is damage to, or pressure on, your organs or muscles. For example, when the liver is swollen it causes pain and discomfort in the tummy (abdomen).

Nerve pain

This is caused by pressure on the nerves or by nerve damage due to the cancer or its treatments. It can come and go and the area may feel numb or sensitive. You might describe the pain as:

- burning or tingling
- stabbing or shooting
- pins and needles.

Certain anti-nerve pain drugs and other treatments can be used to treat nerve pain.

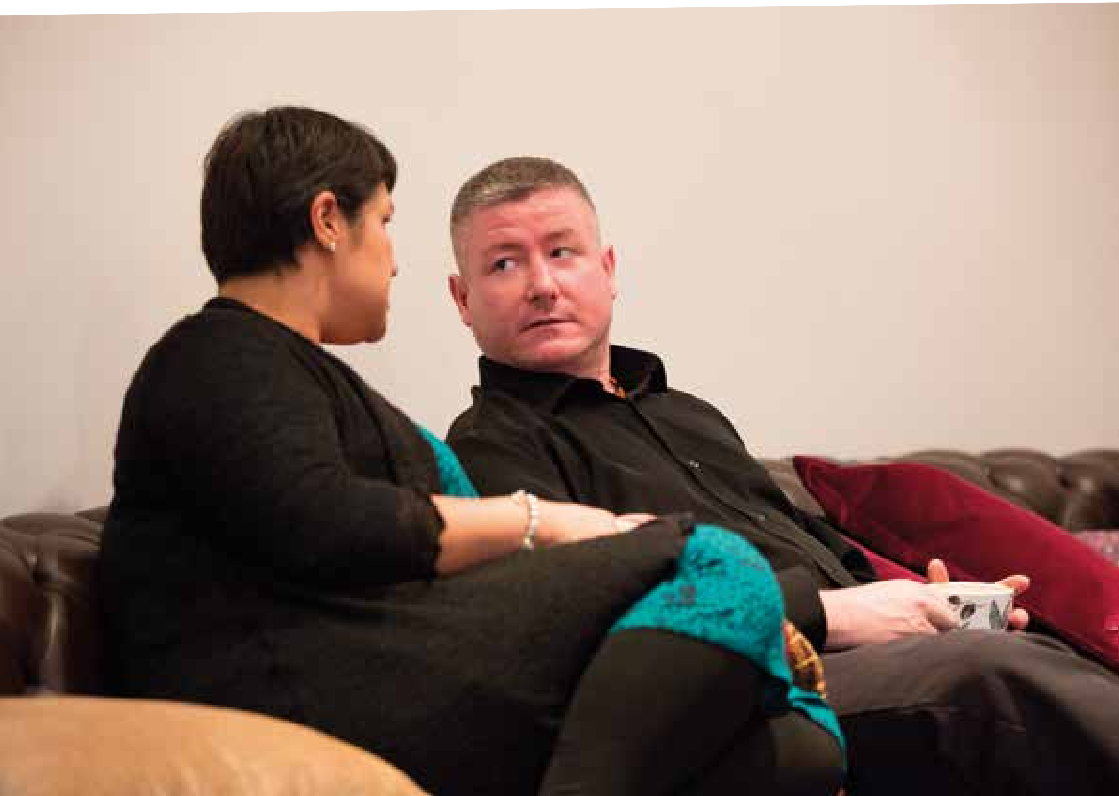
Referred pain

This is when you feel pain in one part of the body in another area that is further away. For example, someone with a swollen liver may feel pain in their right shoulder. This is because pain messages from the liver travel along the same nerves as messages from the skin. The brain confuses them and thinks the pain is coming from a different place.

Phantom pain

This is when you experience pain in a part of the body that has been removed. For example, this could be after having a limb amputated, or sometimes after a breast is removed (mastectomy).

Phantom pain can cause different pain sensations which are very real to the people who experience it. It can improve with time and may eventually go away. It may be complicated to treat and is usually managed by expert doctors at a pain clinic.



Talking about pain

It is important to tell your doctor or nurse if you have pain and how it is affecting you. Relieving pain is an important part of your treatment and care.

Some people may not want to talk about the pain they are having. They may feel they are complaining and should accept having pain. Or they may worry that the pain means the cancer has got worse. But there are many reasons pain happens. Controlling pain is an important part of your care. It will help you do the things you want to do and stay more positive and active.

You can play an active role in managing your pain by:

- being open with your health care team about the pain
- describing the pain, where it is and how it affects your life
- telling them if the pain gets worse or lessens
- talking to them about any worries you have about the pain relief options.

Having a pain assessment

Your doctor or nurse will start by asking you lots of different questions about the pain and how it is affecting you. This is called a pain assessment. A pain assessment is very important. It helps to make sure your doctors give you the best painkillers or treatment for your situation.

They will ask you to describe the pain. If you are keeping a pain diary they will also want to look at this.

Your doctor also usually examines you. If they need to check the cause of the pain, they may arrange some tests for you.

All this information helps your team, you and your family to plan the best way to manage the pain.

Keeping a record of the pain even for a few days may show a pattern. This pattern can be used to improve pain control.

Ways to describe pain

Describing the pain helps your doctors and nurses understand the type of pain you are having. This is important because the right treatment can depend on the type of pain you have.

Sometimes it is hard to put this into words. The questions below will help you describe the pain. We have a list of different words to help describe pain on page 15, and in our pain diary on page 17.

Where is the pain?

Is the pain in one part of your body, or in more than one place? You can use a diagram like the one in our pain diary to mark where the pain is.

What is the pain like?

You might use the following words to describe your pain:

- aching
- tender
- sharp
- shooting
- hot
- burning
- nagging
- intense
- stabbing
- tingling
- dull
- throbbing.

Our pain diary has more words you may find helpful to describe your pain (see page 17).

How bad is the pain?

If you measure your pain on a scale of 0 to 10, how do you rate it? This is where 0 means no pain, and 10 means severe pain.

When are you in pain?

- Are you in pain all the time or does it come and go?
- Is it better or worse at night?
- Does it keep you awake or wake you up?

Does anything make the pain better or worse?

- Do you feel better or worse when you are standing, sitting or lying down?
- Does a heat pad or ice pack help?
- How much do painkillers, such as paracetamol, help the pain and for how long?
- Can you reduce the pain yourself by reading, listening to music, watching TV?
- Has anything else helped the pain in the past?

How does the pain affect your daily life?

- How does the pain affect what you can do in or outside the home?
- How does the pain affect your sleep and your mood?
- Can you sit long enough to eat a meal?
- Does the pain stop you from concentrating?
- Does it affect your social life or your sex life?

It is important your doctor or nurse understands the problems the pain is causing for you. Your input helps your doctor or nurse plan the best way to manage the pain.

> ‘I kept a diary of my painkillers and pain so that I felt I had things under control. Plus, I would know when I could take the next dose of painkiller.’
>
> **Caroline**

Keeping a pain record or diary

Sometimes keeping a record of the pain can be helpful and show a pattern. It helps to include information such as:

- the date and time you experienced the pain and how long it lasted
- where it started and if it was specific to one area or moved to other parts of the body
- anything you were doing that made the pain worse
- anything that helped make the pain better
- the pain relief methods you tried and how well they worked – include anything you tried that your health care team did not prescribe or recommend.

This information can help you talk about the pain with your doctor or nurse. Your hospital may give you a pain chart to use. Or you can use our pain diary. It has a diagram of the body so you can mark where you feel pain. And it gives examples of words that you may find helpful when describing your pain.

Writing it down means you keep a record of the progress you have made and what you have learned.

Who can help you treat and manage pain?

Health and social care professionals

Different health and social care professionals may be involved in managing your pain. It is important that you and your family know who is responsible for managing your pain control. You need to know who to contact if you have problems and what numbers to call.

If you are at home, your GP will usually be your first point of contact. If you are in hospital, it is important to talk to the nurses and doctors looking after you. If you are having cancer treatment, you may have contact numbers for your cancer nurse or doctor. You can contact them directly if you have problems.

You may have a specialist symptom control nurse who visits you at home, or you may attend a pain clinic. It depends on your individual situation. If you are not sure who you should contact, ask your GP.

GP

When you are at home, your GP can talk to you about medicines or treatments to help control the pain. They can prescribe painkillers and check to see how well they are working for you. They can increase the dose of the painkiller or change you to a different drug if needed. Your GP can also contact your cancer doctor or nurse for further advice.

Your GP can arrange for a district nurse to visit. They can also refer you to other health professionals. For example, this could be to a specialist palliative care team or to a pain clinic team.

Cancer doctor or nurse

If you are having treatment or going to clinic regularly, it is important to tell your cancer doctor (oncologist) or nurse about any pain. They can explain what is causing the pain and how to treat or control it. Some people may need tests to find out the cause of the pain.

Your cancer doctor or nurse may ask you to contact them if you have pain, or if it gets worse. It is very important to follow their advice.

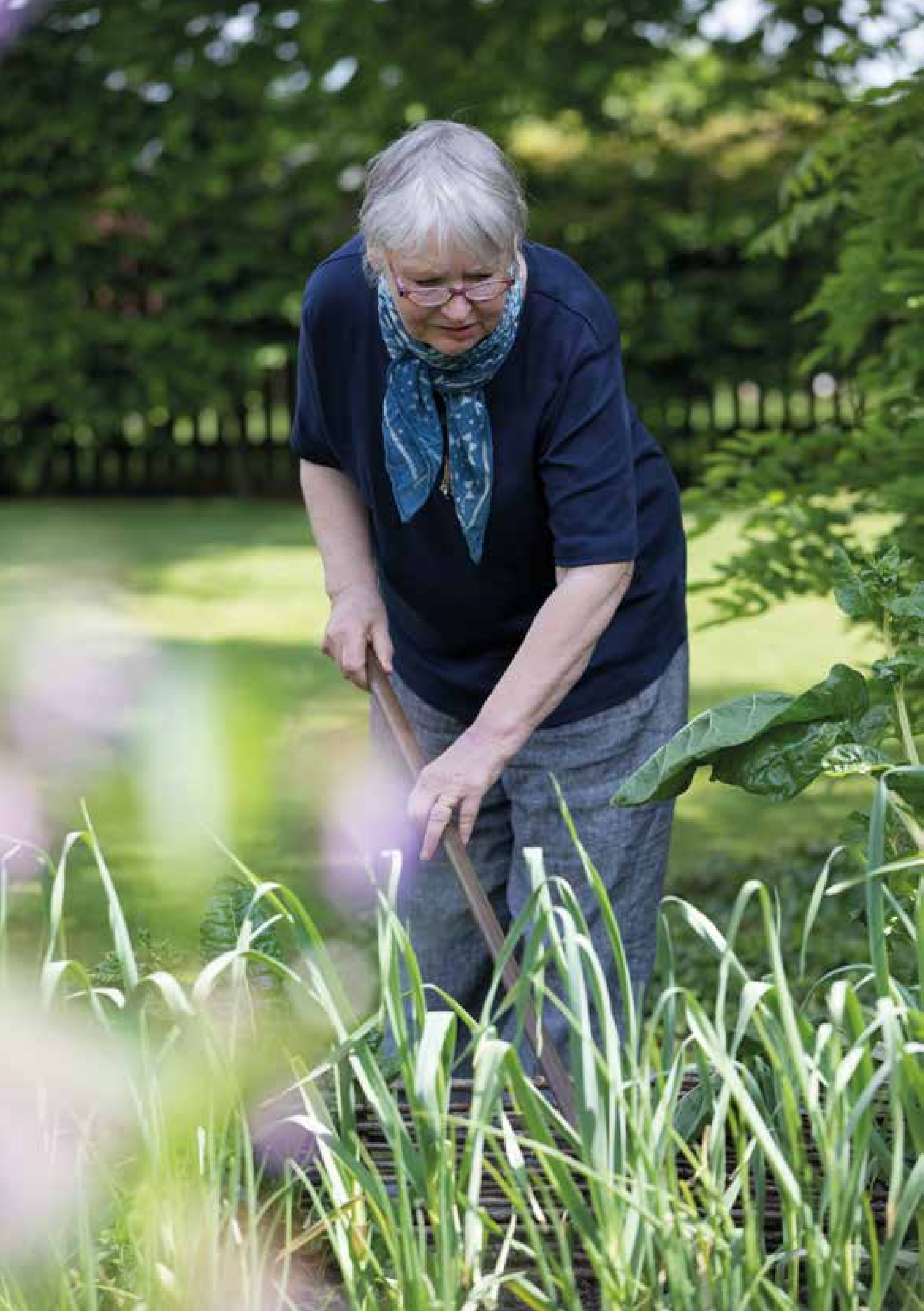
District nurse

A district nurse can visit you at home to help you manage your pain. They can check your pain relief is working and advise you about taking your medicines. They can also advise you about:

- different ways of managing the pain
- getting equipment that helps make you more comfortable.

Physiotherapist

Seeing a physiotherapist can be helpful in certain situations. They may be able to show you different ways of moving to help manage the pain. If the pain is affecting how far you can walk, they can suggest ways to make getting around easier. For example, they can arrange for you to have a wheelchair.



Occupational therapist

An occupational therapist can help provide equipment to make you more comfortable. For example, this could include special cushions or mattresses for when you are sitting or lying down. If you have difficulties moving around, they can arrange handrails and ramps for your home to help you move more easily. They can also suggest ways to improve your energy and be more active.

Pharmacist

A pharmacist will know about any medicines you have been prescribed. They can check your prescription, give you advice about your medicines and explain how they may affect you. Tell your pharmacist if you are buying any over-the-counter medicines. They can tell you whether it is safe to take them with your prescribed painkillers.

Specialist palliative care team

Specialist palliative care doctors and nurses are experts in managing symptoms, such as pain. They also provide emotional support. Specialist palliative care teams work in hospitals, in the community and in hospices. The team may also include a physiotherapist, an occupational therapist, a counsellor or a psychologist.

Hospital teams can help you with your pain control if you are:

- going to an outpatient clinic
- in hospital.

They keep in touch with your GP to make sure they know what is happening. They may also refer you to a community palliative care team to provide ongoing support when you are at home.

Community palliative care teams are usually based in hospices. Community specialist palliative care nurses work closely with your GP, district nurse and other hospital services. They will tell you more about their services, how to contact them and when they are available.

Counsellor or psychologist

Some people find it helpful to see a counsellor or psychologist. This is a person trained to help you manage your emotions. They can help you think about other things that may be causing you pain, or making it worse. They can help you find ways of:

- coping with the pain
- dealing with any worries or emotions that may be making the pain worse.

We have more information you might find helpful in our booklet **How are you feeling? The emotional effects of cancer** (see page 80).

Pain team

Many hospitals have specialist pain teams. The team includes doctors, nurses and usually an anaesthetist. Some teams also have a psychologist.

Your GP, cancer doctor or specialist palliative care team can refer you to a pain team. This can be very useful if your pain is difficult to control or you need a nerve block (see page 61).

Anaesthetist

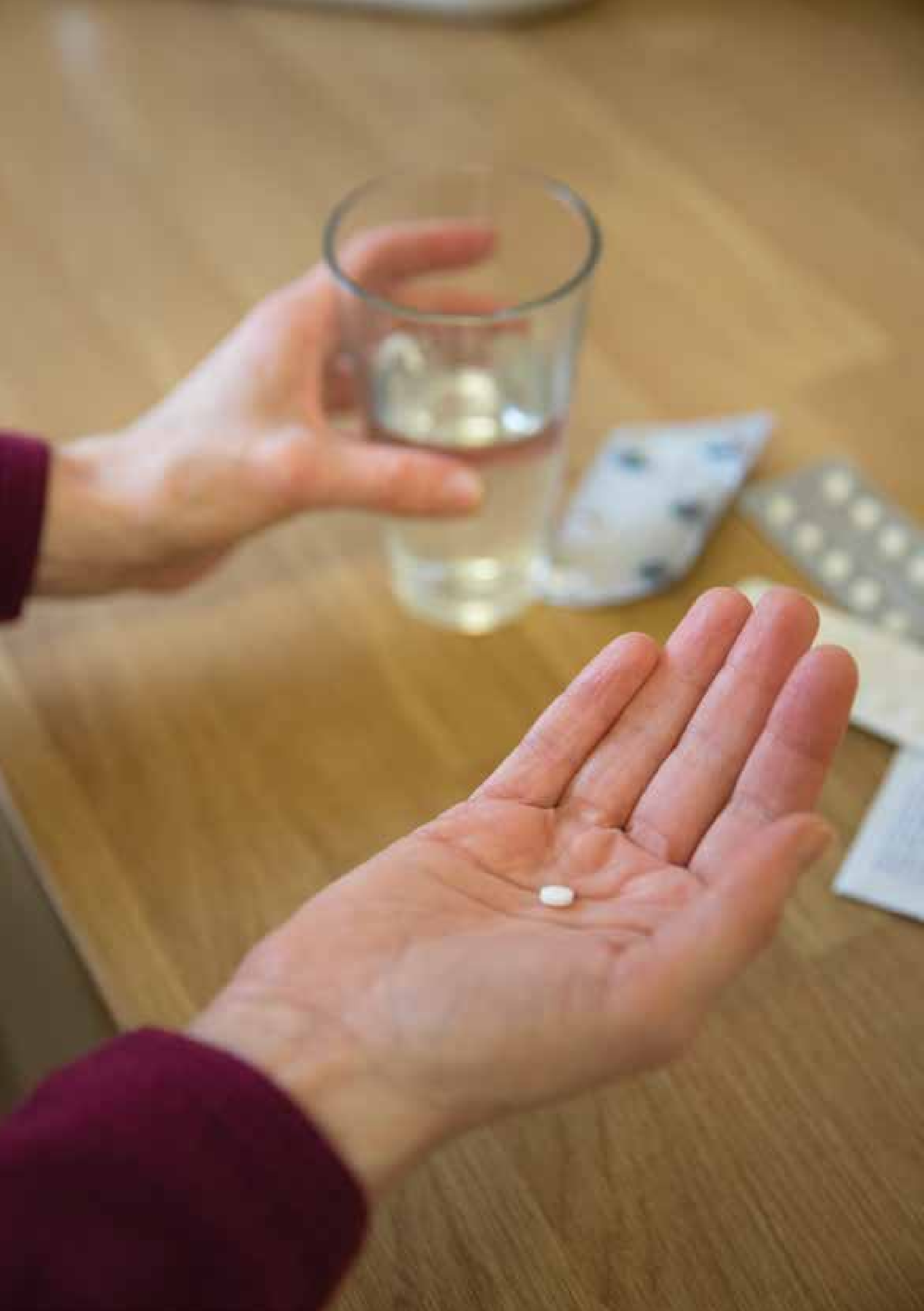
Some anaesthetists are also experts in pain relief and help treat cancer pain. They may be part of a pain team. They can give you specialist treatments, such as a nerve block.

Hospices

Sometimes it can help to spend some time in a hospice having your pain, symptoms and other problems treated. This is often for 1 to 2 weeks. Your community specialist palliative care team or GP can arrange this for you.

In the hospice, the doctors and nurses can adjust the dose of painkillers, or give you new ones. They can often do this more quickly than if you were at home. Once your pain is controlled, you can go home again. At home, your GP and community specialist palliative care team can continue to help you. Your GP will know about community palliative care and hospice services in your area.

> ‘Pain is, I think, one of these situations that is very individual. I’ve had neuropathy and that still continues to cause me pain which is controlled with tablets. I did need physiotherapy to help.’
>
> **Karen**



MANAGING PAIN WITH MEDICINES

Painkillers and ways of taking them

Painkilling drugs are sometimes called analgesics. To make it easier to understand, we use the term painkillers in this content. There are many painkillers available. They can treat different levels and types of pain.

There are other drugs you often have with painkillers to help relieve pain (see page 49 to 51). For example, drugs to treat nerve pain, drugs for bone pain called bisphosphonates, and steroids. Your doctor or nurse will regularly assess the pain to find the right combination of medicines for you.

Taking painkillers regularly

If you have had pain for more than a few months, you usually need to take painkillers regularly to control it. Doctors sometimes call this type of pain chronic or persistent pain.

Always take your painkillers at regular intervals exactly as prescribed by your doctor. This is to make sure they work as well as possible for you. The aim is for pain control to be constant. Putting off taking painkillers can make the pain more severe. It may then take longer to get it under control when you do take them.

If you have been given painkillers for breakthrough pain, do not wait for it to get bad before taking them (see page 10).

It is very important to tell your doctor or nurse if pain gets worse. This means they can treat it before it becomes harder to control. You may need to have your regular dose adjusted, or have a different painkiller. It can sometimes take time to get the right painkiller and dose.

Ways of taking painkillers

Tablets and capsules

You usually take painkillers as tablets or capsules. If you find these hard to swallow, many painkillers come as liquids and some can be dissolved in water.

If you have a feeding tube, some liquid or soluble painkillers can be given through it.

Skin patches

Painkillers can be absorbed through the skin. You put a patch onto the skin, which slowly releases a constant supply of the painkiller over a few days. This can be helpful for people who have difficulty swallowing or remembering to take their painkillers regularly.

Buccal and sublingual medicines

These are painkillers that are absorbed through the lining of your mouth so you do not have to swallow. You put them in the side of your cheek (buccal) or under your tongue (sublingual).

As an injection

You can also have painkillers as an injection:

- under the skin (subcutaneous)
- into a muscle
- directly into a vein (intravenous).

Painkillers through a pump

Painkillers are sometimes delivered continuously over a set time through a pump. There are different ways and reasons for doing this. The painkillers can be given in the following ways:

- Under the skin, through a fine needle connected to a small pump. This is called a syringe pump. It can be used to manage cancer pain in different situations.
- Into a vein through a pump. This is usually done after surgery for short-term pain control.
- Into a fine tube in the back (epidural and intrathecal), which is connected to a pump. This is done by an anaesthetist and used after certain types of surgery. But it can also be used to control cancer pain that is difficult to manage.

Syringe pump

This is a small battery-operated pump. It is used to give a continuous dose of painkillers through a needle under the skin for a set time. Other drugs, such as anti-sickness drugs, can be given at the same time. A syringe pump can be used for different reasons, for example:

- if you are feeling or being sick
- if you are having difficulty swallowing painkillers
- if your symptoms are not being well-controlled with tablets or injections.

A nurse will usually change the syringe every 24 hours. Some people have a syringe pump until their symptoms improve. This could be at home or in hospital.

Having a syringe pump does not stop you moving around as usual. You can carry it in a pocket or bag. You can go out shopping or for a meal wearing the pump.

Suppositories

These are inserted into the back passage (rectum).

Gels or creams you put on skin

If the pain is in one area (local), rubbing a gel or cream onto the skin may help relieve it. For example, non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, are available as gels. There are also gels or plasters that contain local anaesthetics. These are sometimes helpful. Creams containing menthol may help with muscle pain. Another cream called capsaicin may be used to treat nerve pain. Capsaicin is the substance that makes chilli peppers hot. Your doctor needs to prescribe this.

Ask your doctor or nurse for advice first. Do not use any gels or creams on skin that is inflamed or broken. Wash your hands after applying any cream or gel.

Nasal sprays

Some painkillers can be sprayed into the nose.

Gas and air (Entonox®)

This is a painkiller that you breathe in. You sometimes have it before procedures, such as a bone marrow test or a dressing change, to reduce pain. It is only available in some hospitals.

Types of painkiller

Pain is often described as being mild, moderate or severe. Different types of painkillers are effective for different levels of pain. Once your doctors and nurses have assessed your pain, they will prescribe the best painkillers to help control it. There are other drugs that you may have with painkillers to help relieve pain (see pages 49 to 51). These include steroids and muscle relaxants.

To get your pain under control, you usually start by taking a **short-acting painkiller**. This provides quick pain relief that lasts until you take the next dose. The dose can be adjusted until your pain is well controlled. When the doctor knows what dose you need, they may change to a slow release or **long-acting painkiller**.

Treating mild pain

If pain is mild, it can often be controlled with simple painkillers such as:

- paracetamol
- non-steroidal anti-inflammatory drugs (NSAIDs) – for example, ibuprofen.

You can buy either of these drugs from a pharmacy or supermarket. Other medicines you can buy, such as cold and flu remedies, may also contain paracetamol or anti-inflammatory drugs. Be careful that you do not take more than the recommended dose of any painkillers. If you are unsure, check with a pharmacist before buying any over-the-counter medicines.

Paracetamol

Paracetamol can be used for most types of mild pain. It has few side effects, but it is very important not to take more than the recommended dose. Higher doses can damage the liver. Talk to your doctor or nurse as soon as possible if you think you have taken more than the recommended dose.

Anti-inflammatory drugs

Non-steroidal anti-inflammatory drugs (NSAIDs) are often used to relieve pain and reduce inflammation and swelling. They may be taken on their own or with other types of painkillers.

Ibuprofen is a NSAID that has different brand names, including Brufen® and Nurofen®. You can buy these drugs from a supermarket or pharmacy. Check with your doctor or nurse before taking NSAIDs. They do not always work for everyone and there are other medicines they should not be taken with.

Other anti-inflammatory medicines, such as diclofenac and naproxen, need to be prescribed by a doctor.

These drugs can cause indigestion and may irritate the lining of the stomach. It is important to take them with food or a drink of milk. Your doctor may prescribe another medicine to help protect your stomach. If you have had problems with your stomach your doctor may advise taking a different type of painkiller. If you have muscle or joint pain, they may suggest anti-inflammatory skin patches or gel that you rub onto the skin.

When taking these drugs, always check the recommended dose on the packet and never take a higher dose.

Drugs for mild to moderate pain

Doctors usually treat mild to moderate cancer pain with drugs called opioids. These may also be called ‘morphine-type’ medicines. There are different types of opioids and some are stronger than others. Opioid drugs used for mild to moderate pain include:

- codeine phosphate
- dihydrocodeine (DF118 Forte®, DHC Continus®)
- tramadol.

Some people are prescribed these drugs combined with paracetamol in a single tablet. For example, co-codamol is a combination of codeine and paracetamol. There is a limit to the number of these tablets you can take in one day. If the pain is not controlled tell your doctor or nurse so they can give you stronger painkillers. Some doctors prescribe a low dose of a stronger opioid (see below) to treat mild pain.

Drugs for moderate to severe pain

Doctors usually treat moderate to severe pain with stronger opioids. The most commonly used ones are:

- morphine (see page 35)
- fentanyl (see page 37)
- oxycodone (see page 36)
- buprenorphine (see page 38)
- diamorphine (see page 38).

Other opioids that are less commonly used include:

- tapentadol (see page 39)
- methadone (see page 39)
- alfentanil (see page 39).

Your doctor usually prescribes you a low dose of the opioid drug to start with. They gradually increase it until it reaches a dose that controls your pain. If the pain gets worse, they can increase the dose of your painkiller.

It can take a few days to adjust to taking a stronger opioid, or a higher dose. Your doctor may increase or decrease the dose of the painkiller depending on the level of pain.

Stronger painkillers can have more side effects (see pages 40 to 42). If you have side effects, tell your doctor or nurse. They may be able to prescribe a different type of strong painkiller that does not cause the same side effects.

Your doctor may prescribe other drugs, such as paracetamol or ibuprofen, to take regularly along with strong painkillers. It is important to take these as well.

Morphine

You can take morphine as:

- short-acting tablets or syrup
- long-acting tablets, capsules or granules you mix with water to make a drink
- a short-acting injection.

Morphine is known by different brand names, such as Morphgesic SR®, MST Continus®, MXL®, Oramorph®, Sevredol® and Zomorph®.

To begin with, you usually take a short-acting type of morphine every 2 to 4 hours. You take this as a tablet or a liquid. Your doctor or specialist nurse will tell you how often to take it. Liquid morphine has a bitter taste but mixing it with a fruit drink can help.

When the doctor knows how much morphine you need to control the pain, they usually change you to long-acting drugs. These drugs release the dose of morphine slowly over either 12 or 24 hours. You may still need to take short-acting morphine in between if you get breakthrough pain (see page 10).

Taking both types of pain relief helps you to have better control of the pain and manage it as needed. This helps you to do the things you want without too many changes to your daily life.

You can also have morphine as an injection under the skin or through a syringe pump (see pages 28 to 29).

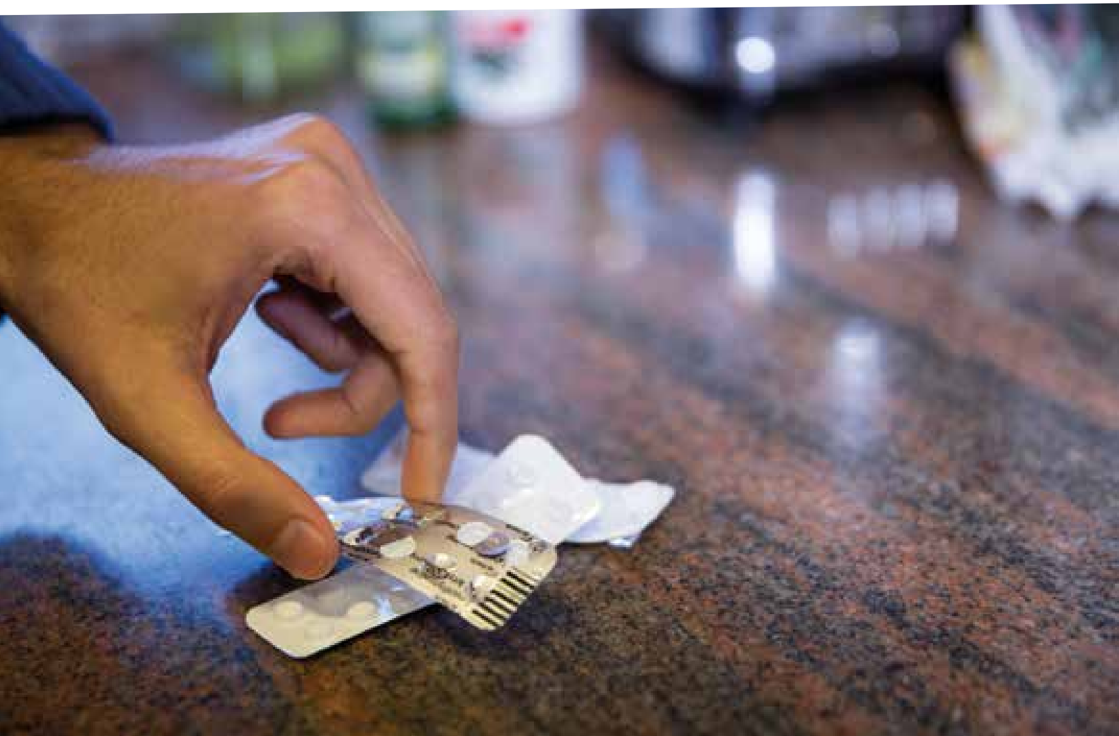
Oxycodone

If you cannot have morphine, or it is not working well for you, your doctor may prescribe oxycodone. Oxycodone can also help if there are problems with how well your kidneys or liver are working.

You can take it by mouth as:

- short-acting capsules or liquid that you take every 4 to 6 hours, such as Lynlor®, OxyNorm®, Shortec®
- long-acting tablets that you take every 12 hours, such as Abtard®, Carexil®, Ixyldone®, Leveraxo® Longtec®, OxyContin®, Reltebon® or Targinact® (Targinact® also contains naloxone to help prevent constipation).

Oxycodone can also be given by injection under the skin. Or it can be give continuously through a syringe pump (see page 29).



Fentanyl

You may have fentanyl once your doctor or nurse has worked out the right dose of opioid for you. You can have it in different ways.

Fentanyl patches

Fentanyl patches look like waterproof plasters you stick onto your skin. They release the drug at a constant rate through your skin. You change the patches every 3 days. You put the new patch on a different area of skin.

When you first use the patch, it takes around 12 to 24 hours for fentanyl to reach its level in the blood. During this time, you usually need to take a short-acting drug, such as morphine, to keep the pain under control. If you are using fentanyl patches:

- Place patches on areas of dry flat skin that have little or no hair.
- Write the date on the patch so you remember when to change it.
- Protect the patch from the sun, hot water, heat pads and hot water bottles, to stop it getting hot.
- Let your doctor or nurse know if you have a temperature. This may affect how the medicine is absorbed through your skin.
- Tell your nurse if the patch causes a skin rash or itching.

Other ways of taking fentanyl

You can also take fentanyl by mouth, by placing it between your cheek and gum, where it is quickly absorbed. There are different types, but the following are all taken in the same way as fentanyl:

- a short-acting lozenge (Actiq® or Cynril®)
- a tablet (Effentora®)
- a dissolvable film (Breakyl®).

You can also take fentanyl as:

- a tablet you put under the tongue (Abstral®)
- a nasal spray (Instanyl®).

The drug is absorbed into the body from these areas and works quickly. It is usually used for breakthrough pain.

Buprenorphine

This may be given as:

- a skin patch you change every 7 days or 3 days
- a tablet you dissolve under the tongue every 6 to 8 hours.

Diamorphine

Diamorphine is a drug that is given as an injection. It is usually given continuously through a small needle under the skin connected to a syringe pump. Diamorphine changes to morphine in the body. You may have diamorphine if you are being sick or if you find it difficult to swallow tablets or liquids.

Tapentadol

Tapentadol (Palexia®) can be given as:

- short-acting tablets
- a short-acting syrup
- long-acting tablets.

Methadone

Methadone (Physeptone®) may be given as:

- a tablet
- a syrup.

Methadone is usually only given under close supervision from a specialist palliative care doctor or pain doctor. It may help reduce nerve pain.

Alfentanil

Alfentanil (Rapifen®) is another strong painkiller that is only given by injection or continuously through a syringe pump. It is more likely to be used if a person's kidneys are not working well.

Side effects of strong painkillers

As with most medicines, some people get side effects from strong painkillers. But they will not affect everyone and most side effects improve after a few days. We have explained some of the common side effects below.

Drowsiness

Strong painkillers may make you feel drowsy when you first start taking them. This usually improves within a few days once you are used to the dose. Talk to your doctor or nurse if it does not. Other drugs you may be taking could also cause drowsiness. Your nurse or doctor can check if this is happening.

Alcohol can make drowsiness worse. It may be better to avoid it or to only drink small amounts. If you feel drowsy, avoid things like driving or operating machinery.

You should not drive if you have recently started taking strong painkillers or if you have increased the dose. They may make you drowsy and slow your reactions.

Tell your doctor or specialist nurse if you get drowsy after you have been taking strong painkillers for a while. This sometimes happens if you have had other treatments to shrink the cancer, which has helped to reduce the pain. You may need a lower dose or a different type of painkiller.

Constipation

Constipation is a common side effect of strong painkillers. Your doctor will need to prescribe you laxatives. There are different types of laxative. Some laxatives soften stools and make them easier to pass. Others stimulate the bowel to push the stools along more quickly. You may need a combination of laxatives to prevent constipation.

Do not take laxatives yourself. Ask your doctor or nurse first.

There are also things you can do, for example:

- try to drink plenty of fluids
- eat more high-fibre foods including whole-grain breads, cereals, fresh fruit, dates, apricots, raisins, prunes, prune juice and nuts
- avoid or reduce foods that make you constipated, such as cheese or eggs
- try to do some light exercise if possible.

Sickness

Some people may feel sick for a few days when they start taking painkillers. Your doctor will prescribe an anti-sickness (anti-emetic) drug for at least the first week of treatment. If it does not improve, tell your doctor. They may need to prescribe you a different painkiller.

Dry mouth

Strong painkillers can make your mouth dry. Tell your doctor or nurse if this happens. There are different things that can help:

- taking regular sips of water – fizzy water may feel more refreshing
- sucking ice cubes or lollies
- having sugar free gum or products containing artificial saliva
- keeping food moist by adding sauces and gravies.

Other side effects

If the dose of a strong painkiller is too high, it may cause other symptoms. It could cause you to:

- feel forgetful or confused
- have vivid dreams and hallucinations (seeing things that are not real)
- feel dizzy or faint or lower your blood pressure
- have slower, deeper breathing.

Let your doctor know straight away if you have any of these side effects.

If your pain is not well controlled, or side effects are a problem, tell your doctor or nurse. They can change your dose of painkiller or give you another type. Some strong painkillers may suit you better than others.

Common questions about painkillers

Some people have concerns or questions about taking painkillers, especially strong ones like morphine. If you feel like this, it may make you less likely to take the drugs as your doctor prescribes them. This can make it harder to control the pain.

Talk to your doctor or nurse about any concerns you have about painkillers, whatever these may be. They are used to talking about these things so it will not be unusual for them. Below are questions and answers that may help with some concerns.

When should I start taking painkillers?

Start taking your painkillers when you have pain. There is no need to delay taking them. Sometimes people think they should delay using painkillers for as long as possible. They may think they should only get help when the pain becomes really bad. Doing this means they are in pain when they do not need to be. It also makes the pain harder to control.

> ‘I’d suggest taking painkillers as soon as you start to feel pain, to keep on top of it. I took co-codamol which took the edge off, but I didn’t start it soon enough.’
>
> **Niamh**

Does taking a strong painkiller mean the cancer is advanced?

Strong painkillers, such as morphine (an opioid), are often used for severe pain. But morphine can also be given in lower doses for moderate or mild pain. Having morphine does not mean the cancer is more serious. The dose can be changed if the pain gets better or worse. If you have a strong painkiller, this does not mean you will always need to take it. For example, if the pain improves, your doctor may change you to a milder painkiller.

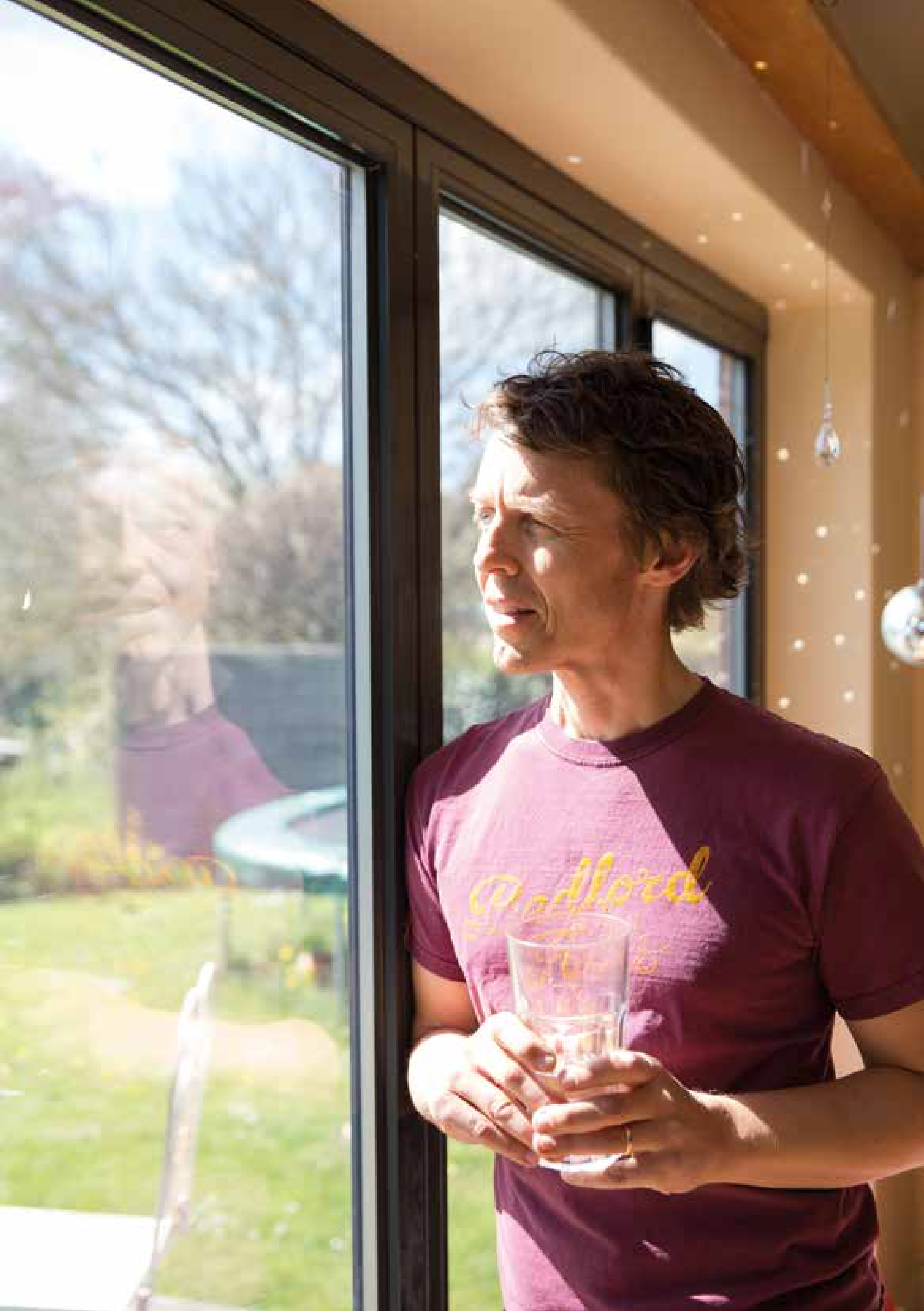
Is there a maximum dose for strong painkillers?

There is no maximum dose for strong painkillers. If you take them as prescribed, you will not overdose. Never increase the dose without talking to your doctor first. Suddenly increasing the dose is dangerous.

Will I become addicted to painkillers?

Some people worry about becoming addicted to strong painkillers. Talk to your doctor or nurse if you feel like this. If the people close to you have the same concerns, you could ask them to come to an appointment with you.

Addiction is usually when people without physical pain do not have control over taking drugs. It means they take drugs to the point where it is harmful to them. This is very different to when a doctor prescribes the right dose of a strong painkiller to treat cancer pain.


Bedford

Can I stop taking a strong painkiller?

If you are taking morphine or another strong painkiller, it is important that you do not suddenly stop taking it. Talk to your doctor first. They will explain if it is a good idea to reduce your dose. They will also tell you how to do this gradually to avoid withdrawal problems.

Signs of withdrawal include:

- diarrhoea
- cramping pains in the stomach and bowel
- sickness
- sweating
- feeling restless or agitated.

Can I drink alcohol if I am taking painkillers?

This depends on the type of painkiller you are taking. It is best to avoid alcohol if you are taking opioid painkillers. Alcohol can increase side effects, such as drowsiness. Some people may also be taking other drugs that cause drowsiness (see pages 49 to 51). Drinking alcohol with milder painkillers is not usually a problem.

The painkillers come with a patient information leaflet. This will have information about alcohol. Ask your doctor, nurse or pharmacist for more information about the painkillers you are taking.

What is the advice about driving and painkillers?

When you first start taking strong painkillers, they may make you feel tired and drowsy. You may not be able to concentrate and your reactions may be slow. If this happens, you should not drive or operate machinery. You may also be taking other drugs for pain control which may also make you drowsy and affect driving (see pages 49 to 51). It is important to follow the advice you are given about any drugs you are taking.

It is a good idea not to drive for a few days:

- when you start taking strong painkillers
- if the dose has been increased.

If you are not drowsy and you feel able to drive after this, you should be okay to drive. Do not drive immediately after taking an extra (breakthrough) dose of a strong painkiller.

Keep your first drive short and easy. Take another driver with you in case you feel drowsy while you are out. Ask your GP for advice if you are worried that you may not be safe to drive.

You do not have to tell the DVLA (or DVA in Northern Ireland) if you are taking strong painkillers. But they may need to know about your illness. Your doctor or specialist nurse can give you more information. Visit **gov.uk/cancer-and-driving** for more information. Or visit **nidirect.gov.uk** for Northern Ireland.

It is a good idea to tell your insurance company if your ability to drive may be affected. Each company is different, but your insurance may not be valid if you do not tell them. Make sure you know what your doctor’s advice is before you phone your insurance company.

The law and strong painkillers

It is an offence to drive with certain drugs above certain limits in your body. This includes some prescription medicines. You will not be breaking the law if the painkillers are not affecting your ability to drive safely and:

- you are taking them exactly as your doctor prescribed them
- you are following the information that came with the painkillers.

If you are not sure whether you are able to drive, you should not drive. The police can stop people driving and do tests to check whether they have taken any drugs. It is a good idea to carry a copy of your prescription and the packaging the painkillers come in.

Your doctor, specialist nurse or pharmacist can give you more information about this .Or you can visit **gov.uk/drug-driving-law**

Other drugs used to control pain

Your doctor or nurse may prescribe other drugs to help control the pain. You may take these with painkillers or on their own. The drugs you have will depend on the type of pain you have. Sometimes it may take some time to find the drug and dose that works best for you.

Your doctor or nurse will tell you which drug is most suitable for you. They will also explain the different side effects and how they may affect you.

Drugs to treat nerve pain

Pain caused by nerve damage can be treated with specific drugs that treat nerve pain. They are taken as tablets or capsules. The dose of the drug may need to be gradually increased. It may take up to a few weeks to feel their full effect. It is important to continue taking the drug your doctor prescribed, even if does not work immediately.

Some of these drugs work as anti-epilepsy drugs. They change the way in which nerves send messages to your brain. These include:

- gabapentin
- pregabalin.

Other drugs that treat nerve pain can also be used to treat depression. Some people worry about taking them because of this. Research shows that in lower doses they work well in targeting and reducing nerve pain. They include:

- duloxetine
- amitriptyline.

Drugs to treat bone pain

Bisphosphonates

People who have pain from cancer that has spread to the bones may be prescribed drugs called bisphosphonates. As well as helping to reduce pain, bisphosphonates also strengthen the affected bones. You have them as a drip into a vein, usually once a month, or as tablets. Commonly used bisphosphonates are:

- sodium clodronate
- ibandronic acid
- disodium pamidronate
- zoledronic acid.

Denosumab

Denosumab is another treatment that can be used to relieve bone pain. You have it as an injection just under the skin, every 4 weeks.

Steroids to reduce swelling

Steroids can reduce swelling and pain caused by a tumour pressing on a part of the body. You usually have steroids as tablets, but they can also be given as an injection. There are different types. People usually have dexamethasone or prednisolone.

We have more information about bisphosphonates, denosumab and steroids on our website. Visit **mamillan.org.uk/treating**

Drugs to relax muscles

If muscle spasms make the pain worse, your doctor may prescribe a short course of a drug to relax the muscles.

Commonly used muscle relaxants are:

- diazepam
- clonazepam
- baclofen (Lioresal®)
- hyoscine butylbromide (Buscopan®), which relaxes muscles in the bowel and helps tummy cramps.

Organising and storing painkillers

Taking medicines can sometimes be confusing. Getting organised helps make sure you store them safely. It may also help you to remember to take them exactly as your doctor prescribed them.

Here are some general tips for storing your painkillers:

- Check the date has not expired.
- Keep them in their original bottle or packet where you can clearly read the label.
- Keep them in a cool, dry place.
- Keep them out of the reach of children. Lock the painkillers away if necessary.
- Return any unused medicines to the pharmacist who provided them so they can dispose of them properly. Do not put them in the bin or down the toilet.

Remembering to take your medicines

To remind yourself to take your medicines:

- make taking your medicines part of your daily routine – maybe by taking them after meals, depending on the instructions
- set an alarm on your mobile phone or computer to remind you
- write a note in a notebook that you keep nearby
- ask your partner, relative or friend to remind you to take them.

Using the pain diary may help you keep track of when to take your drugs (see page 17). It is best to make things as simple as possible. If you find it hard to remember to take medicines several times a day, tell your doctor. Sometimes other types of the same drug can be taken less often.

If you are taking several different drugs, you may find it helpful to write down:

- the drugs you are taking
- what they are for
- their doses
- the time of day you need to take them.

Your doctor or nurse can help you do this. They may give you a chart or medicine planner to write on. You can include notes about what the medicine looks like, when to take it and when to re-order it. You can also use the planner as a reminder for things like inhalers and creams, too.

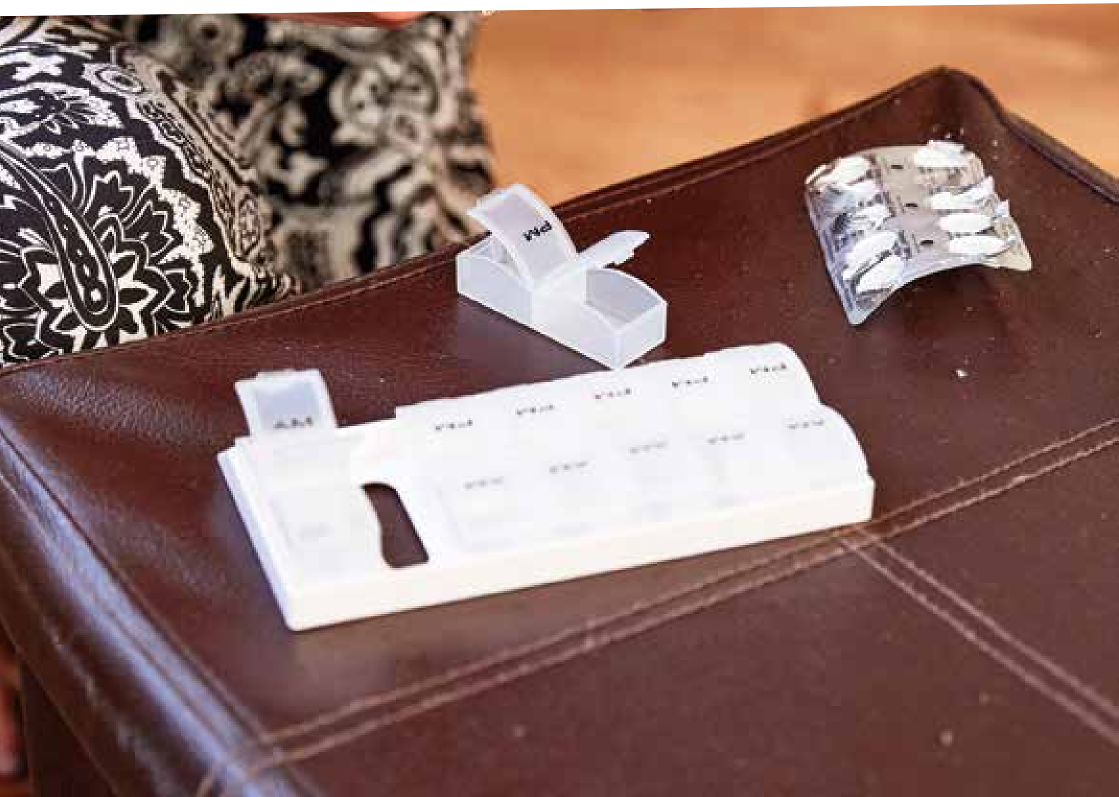
Your local pharmacist can also give you advice about medicines. In some Boots stores, there are specially trained Boots Macmillan Information Pharmacists.

You may find our Macmillan Organiser helpful. There is space inside to record your medication, when you should take it and any side effects (see page 80 and 83).

Pill organisers

You may find it easier to have your drugs arranged in a blister pack or in a dosette box. These have separate compartments which clearly show the day and time when you should take your medicines. Your GP may be able to organise this with your pharmacist. You can also ask your pharmacist for more information if you think these methods could help you.

You can also buy your own medicine container boxes (pill organisers) from most pharmacies. You can fill it with your medicines or ask a family member or friend to help you.



Travelling with your medicines

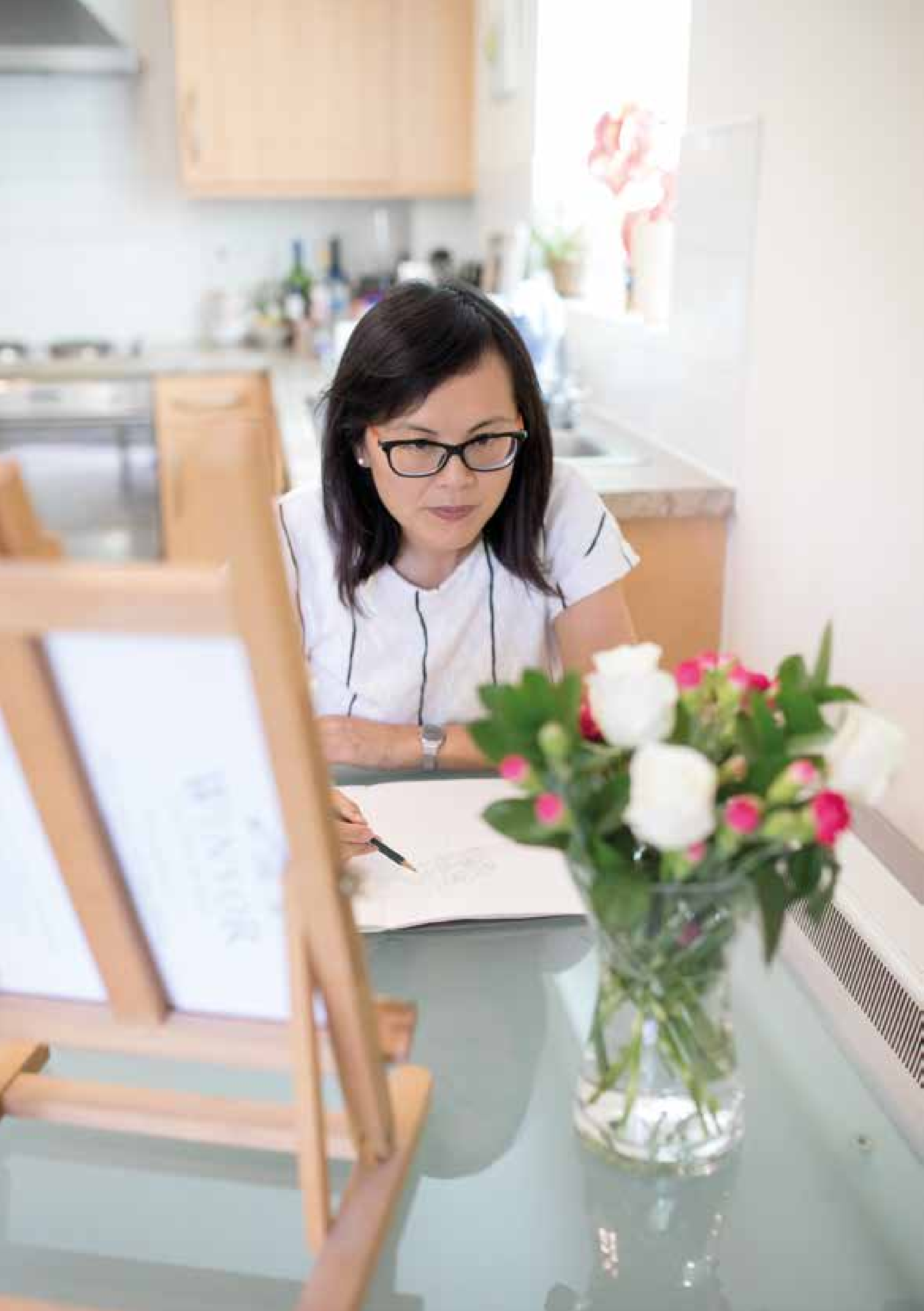
If you are planning to be away from home, make sure you get organised in advance.

Ask your pharmacist if you will need a letter to prove that your medicine is prescribed for you. You need this for ‘controlled drugs’, such as stronger painkillers. If you are going for more than 3 months you will need to get a licence. You can read more about this at **gov.uk/travelling-controlled-drugs**

Here are some tips for travelling with your medicines:

- Check if there are restrictions about taking drugs like morphine into the country you are going to.
- Have enough painkillers and medicines to cover the whole time. Take a few extra with you in case you have any delays.
- If your medicines need to be kept cool, buy small cool bags from your pharmacy to store them.
- Keep all medicines and covering letters in your hand luggage.
- Take a list of your medicines, copies of your prescription and your doctor’s phone number.
- If you are travelling abroad and there is a time difference, gradually change the times you take your medicines to fit in with this.

We have more information about travel and medicines in our booklet **Travel and cancer** (see page 80).



OTHER WAYS TO HELP MANAGE PAIN

Managing pain with treatments

Cancer treatments given along with painkillers can also be used to help manage pain. It may take up to a few weeks for them to work and improve the pain.

Radiotherapy

Radiotherapy uses high energy rays to shrink a cancer and can be used to reduce pain and other symptoms. It is often used to control pain when a cancer has spread to the bones. This is called secondary bone cancer. You usually only need 1 to 5 sessions of radiotherapy.

It usually takes 7 to 10 days to reduce your pain. It may take up to 6 weeks for its full effects. You will need to keep taking your painkillers during this time. Sometimes the pain gets worse for a short time after radiotherapy. You may need to increase your painkillers during that time. If radiotherapy works well for your pain, you may be able to reduce your painkillers.

The dose of radiotherapy used to treat pain is low. The treatment usually has very few side effects, other than tiredness.

We have more information in our booklets **Understanding radiotherapy** and **Understanding secondary cancer in the bone** (see page 80).

Sometimes, a type of radiotherapy called radioisotope therapy may be used to help control bone pain. Radioisotope therapy is the use of radioactive substances to treat cancer. It can be given as a drink or capsule, or injected into a vein. Radioisotope treatment can be used if several bones are affected.

We have more information about radioisotope therapy on our website. Visit **macmillan.org.uk/treating**

Having radiotherapy

Surgery

Sometimes surgery can help with pain control by:

- removing part or all of a tumour to relieve pressure on organs or a nerve
- repairing or strengthening a damaged bone when cancer has spread to the bones.

Anti-cancer drugs

You may be having drug treatments that help to shrink the cancer and reduce pain. These include:

- chemotherapy
- targeted therapy and immunotherapy drugs
- hormonal therapies.

Your doctor can tell you how likely a treatment is to work and what the side effects may be. This will help you decide whether the treatment would be helpful for you.

Our booklet **Understanding chemotherapy** has more information about chemotherapy drug treatments (see page 80).

For more information about targeted therapy, immunotherapy drugs and hormonal therapies, visit our website (see page 80).

Nerve blocks

A nerve block is a treatment that blocks nerves from sending messages to the brain. It is a way of switching off a nerve to stop it causing pain. If you have pain that is difficult to treat, your doctor might suggest a nerve block.

There are different types of nerve blocks. They are usually called by the names of the nerves that are blocked. After having the nerve block, you may be able to reduce your dose of strong painkillers (see pages 33 to 39). This can often be repeated.

Nerve blocks are done by an expert pain specialist. This is usually an anaesthetist. They will talk over the benefits and possible risks with you. Your GP or hospital specialist can refer you to a pain team.

The doctor may block the nerve using drugs, such as:

- local anaesthetics (sometimes given with steroids) – these produce a short-lasting nerve block
- alcohol and phenol – these deliberately damage the nerve and give a long-lasting block but are less commonly used because of the side effects.

Your doctor or nurse will tell you what to expect and talk to you about side effects. Nerve blocks do not usually have many side effects. Some nerve blocks may cause low blood pressure or diarrhoea. But this usually improves after a few days.

Non-drug treatments and complementary therapies to help with pain

Some people find non-drug treatments and complementary therapies helpful in managing pain. They can be used along with painkillers or sometimes on their own.

Certain treatments or talking therapies aim to help you cope with pain. For example, this can be with techniques to relax and de-stress your body and mind. Others use physical therapies to relieve the pain.

Physiotherapy and exercise

Pain can stop you from using the part of your body that hurts. This may lead to muscle or joint stiffness. A physiotherapist may be able to help reduce pain and stiffness with gentle massage and exercise.

A physiotherapist can help you stay active and show you exercises which may help to improve your pain. Exercise helps your body release endorphins. These are natural substances produced in your body that can have a painkilling effect. Ask your doctor or physiotherapist whether it is safe to exercise and what type of activity may help.

TENS (trans-cutaneous electrical nerve stimulation)

TENS is a way of managing pain using a mild electrical current.

The current is delivered from a TENS machine which is a small battery-powered device with wires. The wires attach to sticky pads. You put on these the surface of your skin, usually near the area of pain.

The machine sends a small electrical current into your body that feels like a tingling sensation. It has a dial that allows you to control the strength of the electrical current. Some people find that using a TENS machine has helped ease their pain. Check with your healthcare team before using a TENS machine. They are not suitable for everyone.

Pain teams, physiotherapists or a palliative care team can give you advice about whether TENS may be suitable for you. They can show you how to use the machine. They may also be able to give you one on a short-term loan. If it works well for you, you can hire one or buy one from a pharmacy or online.

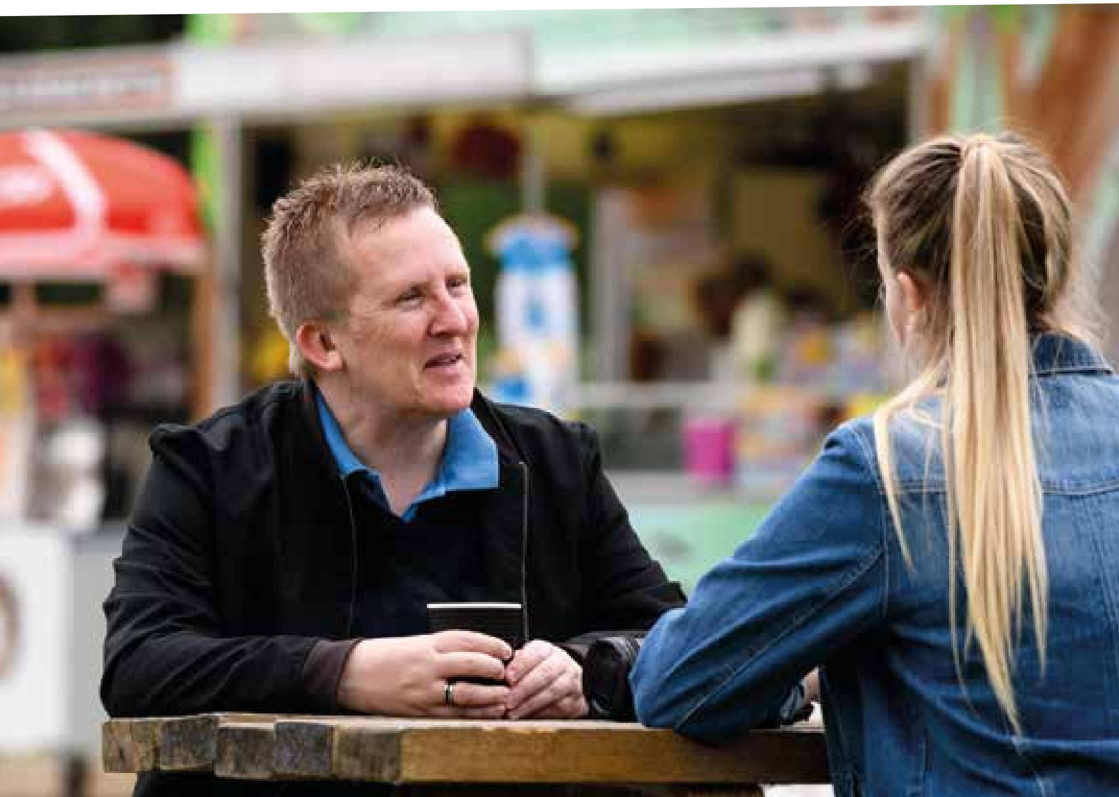
You should always continue to take your prescribed painkillers. A TENS machine alone will not be enough to manage the pain.

Talking therapy (cognitive behavioural therapy)

Cognitive behavioural therapy (CBT) is a talking therapy. It helps people to manage their problems by changing the way they think and behave. It does not make pain go away but may be used to help you to cope with pain.

You can have CBT on a one-to-one basis with a trained therapist, or in group sessions. You will often need a course of sessions over a few months. If you think it may help, ask your doctor or specialist nurse.

CBT is sometimes combined with a type of meditation called mindfulness meditation (see page 67).



Complementary therapies

There are different complementary therapies that may help with pain. Some people find these helpful, but they do not work for everyone.

If you decide to use a complementary therapy, always talk to your doctor first. Complementary therapies should not replace any treatments prescribed by your doctor.

If you use any complementary therapies, always use a qualified therapist. The British Complementary Medicine Association (BCMA) has details of qualified therapists. Your hospital team or local hospice may be able to recommend someone.

We have more information about complementary therapies in our booklet **Complementary therapies** (see page 80).

Acupuncture

Acupuncture uses fine needles inserted just under the skin at certain points on the body. It is not painful as the needles are so tiny.

Acupuncture may help some people with cancer pain. Some doctors think it may work by stimulating the body to produce endorphins (the body's natural painkillers).

Acupuncture is generally safe and side effects or complications are rare. You should not have acupuncture if you are having treatments that could lower your blood counts, such as chemotherapy. If you have lymphoedema, or are at risk of it, do not have acupuncture in the affected area.

Some specialist NHS pain and palliative care teams offer acupuncture. Your GP or cancer specialist can refer you. You may have to pay for this.

Massage therapy

Massage therapy is when someone strokes or applies gentle pressure to your body. It may help you relax and improve your mood. Some people find it reduces pain.

There are different types of massage therapy. Cancer doctors and complementary therapists will usually advise you to try gentle massage and avoid vigorous, deep tissue massage. Your therapist will be able to adjust the pressure for your comfort.

Some people worry that massage could cause cancer cells to spread to other parts of their body. Research has not found any evidence of this. But massage therapists will avoid any areas affected by cancer, such as tumour sites or lymph nodes. Talk to your cancer doctor or nurse if you are worried.

Massage therapists working with people with cancer must be properly trained and qualified. They should have some knowledge of cancer and its treatments. They can sometimes teach relatives or friends how to do basic massages, so they can support you at home.

Meditation

There are different types of meditation but they all aim to calm your mind. Some hospitals or hospices may have people who can help you meditate. Ask your doctor, specialist nurse or palliative care team about it.

To meditate, sit quietly and focus on your breathing without trying to control it. If you have a thought, try to let it go and only concentrate on your breathing. If you prefer, you can put an object in front of you and focus on that instead. For example, this could be a lighted candle or a picture.

If you are having treatment for any mental health problems, check with your doctor before doing meditation.

Mindfulness meditation

There are different types of meditation techniques including mindfulness meditation. The aim is to help people manage problems such as anxiety, stress or chronic pain.
Types of mindfulness include:

- Mindfulness-Based Stress Reduction (MBSR)
- Mindfulness-Based Cognitive Therapy (MBCT)

Mindfulness classes may be available through your hospital, your GP or a cancer support charity.

There are apps and CDs you can use to meditate at home. Some people find it helpful to meditate in a group until they are familiar with the technique.

Hypnotherapy

Hypnosis is a form of deep relaxation. It may help people to focus thoughts and feelings on something other than pain. You can also be taught how to hypnotise yourself. It may make other treatments, like CBT, more effective. If you use hypnosis, it is important to get help from a trained professional. This could be a doctor, nurse or psychologist.

Relaxation

Learning to relax may also help control pain, even if you can only do this for a short time each day. Ask your doctor if there is a healthcare professional who can help you. This might be an occupational therapist, physiotherapist or psychologist.
A technique called progressive muscle relaxation involves learning to tense and relax groups of muscles, individually or together. These could be muscles in the stomach, neck and other areas.

You can also do relaxation exercises to relax your mind. This can be helpful if anxiety is making your pain worse. There are lots of relaxation CDs available to guide you.

To practice relaxation, find a quiet, warm and dimly lit space. Make sure you will not be disturbed, and lie or sit in a well-supported position. These techniques are most helpful if you practise them for 5 to 15 minutes each day.

You may want to try different things until you find the best sort of relaxation exercise for you.

Visualisation

Visualisation is when you bring helpful, relaxing pictures into your mind. Remembering pleasant sounds, sights, tastes or smells may help you feel more relaxed. It may help to distract you from the symptoms of pain and discomfort. Someone who has had special training can help you to practise visualisation. Check with your healthcare team about finding a trained therapist.

Reflexology

Reflexology is a form of foot or hand massage similar to acupressure. Reflexologists believe different areas on the feet or hands represent, and are connected to, different parts of the body. They apply gentle pressure to specific points on the feet or hands. The aim is to help you feel more relaxed.

Reflexology has been used to try to improve symptoms related to cancer or its treatment. These include feeling sick (nausea) and pain. There is no evidence to prove that it is effective when used in this way. But it may help people to feel more relaxed.

Things you can do to help with pain

Sometimes simple things can help to improve pain and make you feel better. These are things you or other people can do to help you feel more comfortable.

Find a comfortable position

The way you sit or lie down can affect your pain, so try to find a comfortable position. If you have difficulty moving, ask a family member or friend to help you change position. What may be comfortable at first may be uncomfortable 15 or 20 minutes later. Changing position will also reduce the risk of your skin becoming sore because of being in one position for a long time.

Other things that can help are:

- v-shaped pillows or supports that help reduce backache and neck pain
- a bed cradle to keep the weight of blankets off your limbs
- a special mattress and cushions
- equipment to help with moving around and sitting.

Your district nurse can help you get these things, or tell you where to get them.

Use heat or cold

Heat pads and warm baths can help relieve aches and pains. They may help relax muscles and reduce joint stiffness. Ice packs can help relieve pain where there is inflammation and swelling. Some people find that alternating heat with cold helps them.

Be careful to protect your skin from burns when using heat pads and ice packs. Cover them up before you put them near the skin. Do not use heat on areas where you have inflammation or swelling.

Use distraction

Finding ways to distract yourself so you think of something else may help. For example:

- watching TV
- reading
- playing computer games
- listening to music
- talking to family or friends and having visitors for a short time
- taking short walks with someone.

Gentle exercise

Some types of gentle exercise, such as walking, may help some people to manage pain. Exercise can help relieve stress, distract you and give you more energy. If you have sore joints, exercise can help ease pain by building muscle strength and improving flexibility. Weight-supported exercises, such as swimming and cycling, can be a good choice as they put less strain on your joints.

We have more information about exercise and cancer in our booklet **Physical activity and cancer** (see page 80).

Music or art therapy

This is using music or art to help with anxiety and to relax you. It may help you to express your feelings in a creative way. You do not have to be musical or artistic. Music or art therapists often run classes at hospitals or hospices. Meeting other people while enjoying an activity may also distract you from pain and help you feel better.

Get practical help

Coping with pain can be harder if you are anxious about:

- treatment
- coping at home or at work
- money worries and finances.

Getting help with these things may help you feel less stressed. This can make pain easier to control.

Having more information about treatments and side effects may help. Talk to your doctors and nurses about concerns you have. You can also talk to one of our cancer support specialists on the Macmillan Support Line (see page 81).

You may worry about pain affecting how you travel to places or how you attend appointments. If this is the case, you may find the Blue Badge scheme useful. It gives parking concessions (allowances) for people with mobility problems. It means you can park close to where you want to go.

A social worker can assess what practical and social help you need. They can visit you at home to do a community care assessment if you need help with things like:

- meals
- personal care, such as washing and dressing
- finances.

The local authority will then decide if they will provide or arrange the services. Each local authority has its own eligibility criteria, so the services will vary from area to area.

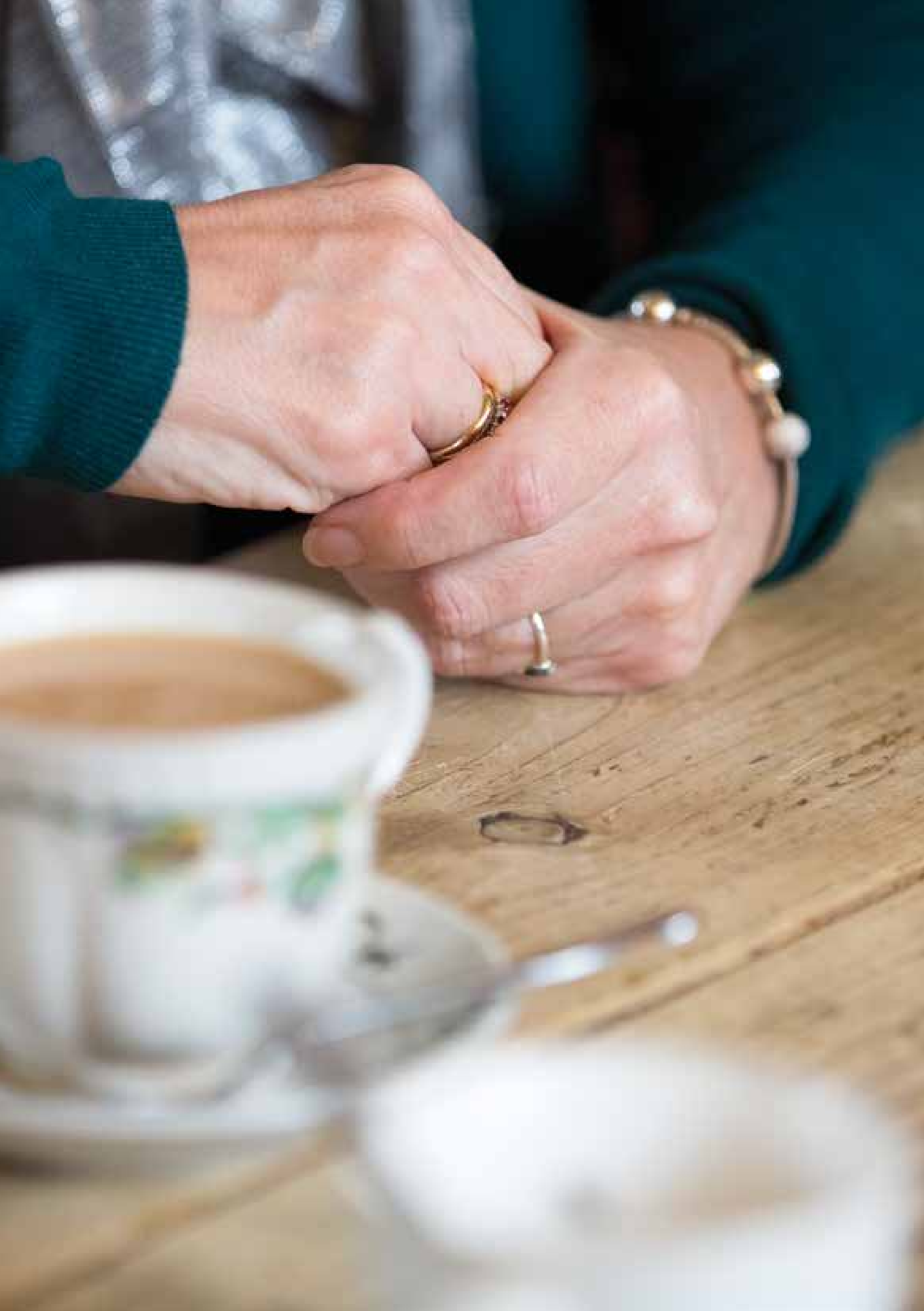
Voluntary and community organisations

There are voluntary and community organisations that may be able to offer support.

The British Red Cross has volunteers who can help you with things like shopping, posting letters or changing library books (see page 88). They may even help with taking you to a hospital appointment. They can also lend equipment like wheelchairs and commodes (portable toilets).

The Disabled Living Foundation (DLF) and Scope give information and advice to disabled people. The DLF also has specialist advisers and occupational therapists who can give advice about mobility aids and specialist equipment (see pages 88 to 89).

Some areas have schemes to help people with things like shopping, meeting other people or transport. These are called good neighbour schemes and are usually run by social services or local community organisations.



Feelings and pain

Being in pain affects not only your body, but also how you think and feel. You may feel angry, frustrated, frightened or isolated.

Controlling the pain will improve the way you feel. It also means you will be able to do the things you enjoy and see other people. Always talk to your doctor if the pain is not controlled. Talking therapies such as CBT may also help you to manage pain (see page 64).

Depression

If pain is not well controlled, you may feel depressed. You may have a low mood most of the time. You may also have difficulty sleeping or no appetite. The pain may feel worse and harder to cope with.

If you think you may be depressed, talk to your GP. They can help you to get the right treatment and support. They may suggest you see a counsellor or psychologist. Your GP may talk to you about taking anti-depressants to improve your mood or reduce anxiety.

Getting emotional support

There are many people and organisations that can help you cope with these feelings. Non-medical treatments may also help. Ask your doctor or specialist palliative care nurse which ones would be best for you.

If you feel okay emotionally, your physical pain may feel better. It can help to talk about your feelings. You could talk to your partner, a close friend or a family member. If you do not talk, they may not realise you are in pain or how the pain is making you feel. They may not understand why you are angry or upset.

You may prefer not to talk to anyone you know about your feelings. If this is the case, you can talk to your GP or specialist palliative care nurse. They can help by putting you in contact with a counsellor. You could also contact the British Association for Counselling and Psychotherapy (see page 87). Or you can speak to our cancer support specialists on **0808 808 00 00**.

Different organisations offer advice, support and information about pain. For example;

- Action on Pain (see page 84)
- Pain Concern (see page 84)
- The British Pain Society (see page 84).

Support groups

It can often help to share how you are feeling with other people who understand what you are going through. Support groups offer a chance to talk to other people who may also be managing pain.

Online support

Many people find support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. These include Macmillan's Online Community (see page 82). You can use these to share your experience, ask questions, get advice, or just read about other people's experiences.

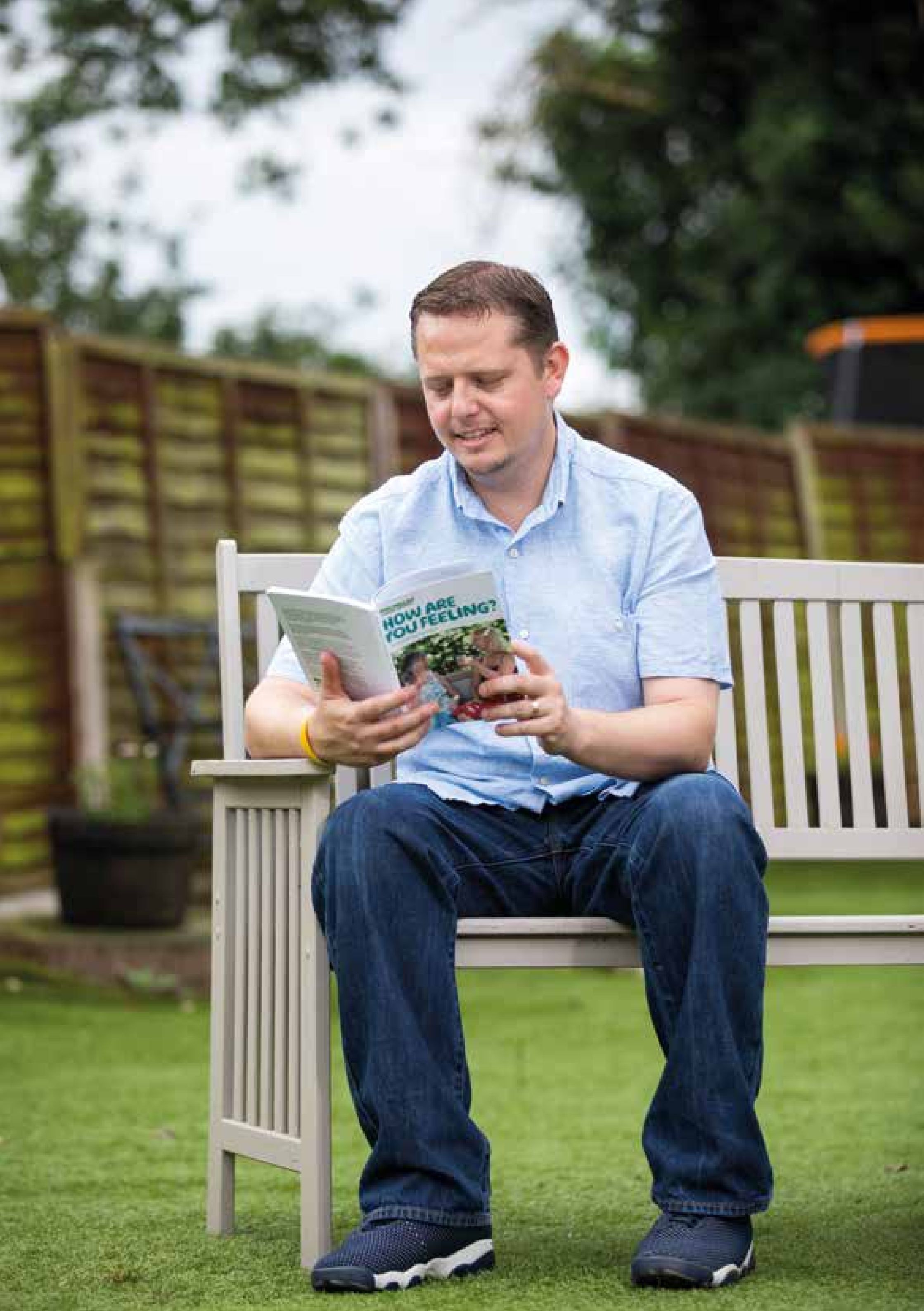
We have more information in our booklet **Talking about cancer** (see page 80)

Spiritual support

A person's spirituality can be an important source of comfort and strength. It may be part of your religious beliefs. Or it may be part of your personal values, beliefs and relationships.

Some people with cancer find their spiritual beliefs are challenged by their situation. They may experience 'spiritual pain' and feel abandoned, or frightened. Sometimes they may withdraw from family and friends.

If you feel like this, it can often help to talk to someone about these feelings. You may find support from other people. For example, you can talk to friends and family, a hospital chaplain or a religious leader. A counsellor or someone from a cancer support organisation may also be able to help (see pages 84 to 91).


HOW ARE YOU FEELING?

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**
If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit **publications.macmillan.org.uk** and search 'book reviews'.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

There are lots of other organisations that can give you information or support.

Pain management and support

Action on Pain

Helpline
(Painline) 0345 603 1593
Email
painline@action-on-pain.co.uk
www.action-on-pain.co.uk
Provides support, advice and help to people affected by chronic pain and those close to them.

British Pain Society

Tel 020 7269 7840
Email
info@britishpainsociety.org
www.britishpainsociety.org
Can provide a list of local pain clinics and self-help groups. Also has booklets and leaflets on managing pain.

Pain Association Scotland

Tel 0800 783 6059
(Mon to Fri, 8am to 4.30pm)
Email
info@painassociation.com
www.painassociation.com
Provides self-management training to help people manage and live with chronic pain. Offers staff-led sessions in coping with pain, and relaxation and movement.

Pain Concern

Helpline 0300 123 0789
(Mon to Fri, 10am to 4pm)
Email
info@painconcern.org.uk
www.painconcern.org.uk
Has free information about managing pain, self-management videos and an online forum for support.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK

Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email
info@cancersupportscotland.org
www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's Centres

Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org

Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline 0303 3000 118
(Mon to Fri, 9.30am to 5pm)
Email
helpline@pennybrohn.org.uk
www.pennybrohn.org.uk
Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum for teenagers going through similar experiences.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

www.hscni.net
Provides information about health and social care services in Northern Ireland.

Healthtalk

Email
info@healthtalk.org
www.healthtalk.org
www.healthtalk.org/young-peoples-experiences (site for young people)
Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Daily, 8am to 10pm)
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind
Helpline 0300 123 3393
Text 86463
Email info@mind.org.uk
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans
Helpline 116 123
Email jo@samaritans.org
www.samaritans.org
Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Equipment and advice on living with a disability

British Red Cross
Tel 0344 871 11 11
Textphone 020 7562 2050
Email information@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disabled Living Foundation (DLF)
Helpline 0300 999 0004
(Mon to Fri, 10am to 4pm)
Email info@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Disability Rights UK

Tel 0207 250 8181
(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)
Email
enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Scope

Helpline 0808 800 3333
(Mon to Fri, 9am to 5pm)
Email helpline@scope.org.uk
www.scope.org.uk
Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for older people

Age UK

Helpline 0800 678 1602
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm, and Sat 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Cancer Caring Coping

www.qub.ac.uk/sites/CancerCaringCoping/
Shares stories and experiences of carers who want to give support, advice and tips on coping in the caring role. Advice for carers on how to look after themselves.

Carers Direct Helpline

Helpline and webchat
0300 123 1053
(Mon to Fri, 9am to 8pm,
Sat to Sun, 11am to 4pm)
www.nhs.uk/carersdirect
Confidential information, advice and support for carers. Offers advice on getting a break from caring, assessments, financial support, going to work.

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline
(England, Scotland, Wales)
0808 808 7777
(Mon to Wed, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 022 2450
(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

Carer's Allowance Unit

Tel 0800 731 0297
Textphone 0800 731 0317
(Mon to Fri, 8am to 6pm)
www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office in the phone book or by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

YOUR NOTES AND QUESTIONS

Disclaimer

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Viv Lucas, Consultant in Palliative Medicine.

With thanks to: Michelle Buono, Macmillan End of Life Education Nurse; Jackie Chipps, Advanced Palliative Care Nurse Practitioner; Dr Paul Farquhar-Smith, Consultant in Anaesthetics and Pain Medicine; and Tina O'Hara, Palliative Care Nurse.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Fallon, Giusti, Aielli et al. Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines. Annals of Oncology. 2018. 29: 166–191.
O'Brien, Christrup, Drewes, et al. European Pain Federation position paper on appropriate opioid use in chronic pain management. European Journal of Pain. 2017. 21: 3-19.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 WAYS
YOU CAN
HELP
SOMEONE
WITH
CANCER

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping.
Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help.
Take part in one of our events or create your own.

Give money
Big or small, every penny helps.
To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don’t let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

FR Registered with FUNDRAISING REGULATOR

If you’d rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about the different ways cancer pain can be treated and managed. It explains the different types of painkillers that are used and other ways of helping to control pain.

There is also information on how to manage side effects and how to cope with some of the feelings you may have.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**.

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

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