**Tackling Cancer Pain**

*You see people looking really ill and when you get the pain better they look so much better. Because they look so ill, you think it’s the disease but you get pain better and they look better. You don’t realise the impact—walking, smiling, interacting, eating. You don’t get that at first.*

Hospice doctor

 **A Toolkit for Patients and Families**

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**Tackling Cancer Pain**

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Hospice doctor

 **A Toolkit for Patients and Families**

**Introduction**

Having cancer does not always mean having pain, but if you do have pain there are many different kinds of medicines, and different ways of taking them, that can help relieve it. There are also a lot of other pain control methods which can help, as well as medicines. You can use these methods on your own, or with some help from family or friends.

* Using a mixture of these different approaches may help you to ‘get on top’ of your pain. You might then be able to sleep and eat better, and be more able to continue with some of your day-to-day activities.

**Tackling Cancer Pain** is designed to help people with cancer, and those close to them, learn about different ways to manage pain and to find what works best for them. The ‘Toolkit’ is in 5 parts. They are not in any particular order and you can choose to use whichever part or parts you think might be helpful.

* **Understanding cancer pain** provides information about what pain is, and what causes cancer pain.
* **Using drugs to control pain** explains the types of painkilling drugs that are used to try and reduce cancer pain.
* **Non-drug approaches to managing pain** looks at how you can use methods like relaxation, distraction or movement.
* **Talking about your pain** considers ways of communicating about your experience of pain with people around you, with health professionals and with others who have cancer.
* **Getting more help** offers guidance on looking for more help if your pain remains unrelieved.

We spoke about experiences of cancer pain to people with cancer, family members and health professionals to help us design **Tackling Cancer Pain.** Every now and then, you’ll see a speech bubble which contains what we hope is a useful comment from one of those people, or from other people who have spoken about their experience of cancer.

“…”

**Tackling Cancer Pain:**

**A Toolkit for Patients and Families**

**Understanding Cancer Pain**

 Here we’ll talk about:

* how to describe pain so that your nurse or doctor can understand how you feel
* what pain is
* what causes pain in people with cancer.

![C:\Users\nhughes\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\OR3NY7SM\MC900104872[1].wmf]() **How can I use this information?**

1. Try to describe your pain using the guidance on pages 2-4.
2. Have a look at the information about pain on pages 5-7 and make a note of anything you don't understand, or want to know more about. You might want to ask a relative or friend to look at it with you.
3. Ask your doctor, nurse or pharmacist if you need to clarify anything which is still unclear.

**Describing Pain**

It’s not always easy to describe pain. Sometimes people don’t even use the word ‘pain.’ But describing the physical sensations in your body as clearly as you can will help your doctors and nurses work out the best way of helping you manage them.

*It’s not a pain. People keep saying to me, ‘How’s your pain?’ It’s not a pain; I wouldn’t describe it as a pain, it’s a rubbing sensation when I move. It’s unpleasant, but it’s not a pain.*

Joan

Here are some of the things you might think about to help you to describe your pain or discomfort.

***Describing where the pain is:*** You can use diagrams (*insert/provide body maps, front and back*) to mark where your pain is. If you have more than one pain you may want to label them (eg A, B)

In your own words:

***Describing how bad your pain is:***

If you measured it on a scale of 0 to 10, how would you rate it (where 0= no pain and 10= the worst pain you've ever had).

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| No pain |  |  |  | x |  |  |  |  |  | Worst pain |

In your own words:

***Describing what the pain is like:*** For example, you may use words such as aching, tender, sharp, hot, burning, nagging, intense, stabbing, tingling, dull or throbbing to describe your pain.

In your own words:

***Describing what makes the pain better or worse:*** For example***,*** standing, sitting or lying down? Does a heat pad or ice pack help? Is it relieved by painkillers such as paracetamol? Do the painkillers stop the pain or just reduce it, and for how long? Can you distract yourself with activities such as reading, listening to music or watching TV?

In your own words:

***Describing how the pain affects your daily life:*** For example, does it stop you from moving around as usual? Can you bend or stretch if you need to? Does it stop you from sitting for very long—for example, can you sit long enough to eat a meal? Does the pain stop you from concentrating or affect your sleep? Does it stop you from walking for short or long distances?

In your own words:

***Describing how the pain makes you feel:*** Does it make you feel anxious, frightened, depressed or hopeless? It can be hard to talk about these things but it might help if you can tell somebody about the way pain makes you feel (see Tackling Cancer Pain: ***Talking about pain***).

In your own words:

**Don't feel that you're being a nuisance or making a fuss by talking about your pain. Describing your pain can help your doctor or nurse plan the best ways to help you manage it.**

**What is pain?**

Pain is an uncomfortable, unpleasant physical sensation that occurs when tissues in the body are damaged. We feel pain because of ‘messages’ that get carried through the nerves in our body to the brain, which is the ‘control centre’ for the whole body. Sometimes the nerves carrying messages to and from the brain become 'sensitised' or 'wound up'. This means that you continue to feel pain even when the cause has gone away.

Pain is a physical experience, with physical causes, but it is also an emotional experience. Emotions such as fear, anxiety and depression can make your pain feel worse. Sometimes pain can be made worse by social- or work-related pressures that cause you stress—for example, not being able to see friends or not being able to work. It's important to find ways of understanding and managing the emotional as well as the physical causes of the pain

**What causes pain in people with cancer?**

Pain is most often **caused by the cancer itself**. For most people, pain comes from the cancer pressing on bones, nerves or other parts of the body. Whether you have pain and the amount you have depends on the type of cancer, its stage (extent) and how much pain your can put with.

**Cancer treatments** can also damage body tissues and cause pain.

* **Surgical** treatment to remove a cancer can cause pain that might last from a few days to a few weeks, depending on the type of surgery.
* Some of the side-effects from **chemotherapy and radiotherapy** treatments can also cause pain. For example, chemotherapy can damage the soft tissues in the mouth and throat, causing soreness that can make it hard to eat, drink and even talk.
	+ Some types of chemotherapy can cause a condition called ‘**peripheral neuropathy’** (PN). This means nerve damage in the body’s ‘edges’ or extremities; that is, your fingers, hands and arms or legs and feet. PN causes pain that feels like burning, stabbing, shooting, tingling, numbness or unusual sensations. It can also cause weakness, clumsiness or difficulty walking.

It’s like spiders crawling all over you

Joe

* **Radiotherapy** treatment can damage the skin around the area being treated, causing soreness and scarring. There can be internal injury from radiation treatment as well, which may cause pain.

Pain caused by these treatments usually goes away once the treatments are completed and the damaged tissues have healed. ‘**Neuropathic pain’** (see below p. ?) from damage to nerves, can sometimes last longer.

**Pain isn't always due to cancer**.

You may also have pain that is nothing to do with your cancer or its treatment. Like anyone, you can get headaches, muscle strains, and other aches and pains. Or you might have other illnesses which cause pain, like arthritis.

* If you develop a new ache or pain, you may understandably worry that this is a sign that the cancer has come back, is getting worse or has spread, but this is not necessarily the case.

It's always best to get any new pain checked out by your doctor or a specialist nurseso you can understand what might be causing the pain and get the right treatment.

*It’s important to try and tease out what the pain really is, so we can get people on the right painkiller. Because they don’t always need morphine.*

Community Palliative Care Specialist Nurse

**Types of pain**

The type of pain you have affects the pain management that you will need. There are a number of different terms that you might hear health professionals use to describe pain:

***Acute pain***

Acute pain can be severe, but usually lasts for a short time. It’s most often a sign that the body has been injured in some way. This pain generally goes away as the injury heals. You might have this kind of pain after surgery.

***Persistent pain***

Persistent pain (sometimes called ‘chronic’ pain) lasts for longer periods of time. With cancer, it's usually caused by the cancer itself, but it can sometimes be caused by cancer treatments. It can disrupt your life if it’s not well managed.

***Breakthrough pain***

Breakthrough pain is a type of pain that is very important in managing persistent cancer pain. It is a flare-up of pain that happens even though you are taking pain medicine regularly. It is different for each person and you can’t always tell when it will happen. In general, it comes on quickly, lasts as long as an hour, and feels much like the persistent pain except that it’s more severe. It may happen many times a day, even when the persistent pain is generally controlled by the regular pain medicine.

Breakthrough pain usually has the same underlying cause as persistent pain. It may be the cancer itself or it may be related to cancer treatment. Some people have breakthrough pain during a certain activity, like walking or dressing. For others, it happens unexpectedly without any clear cause.

(See **Tackling Cancer Pain: *Using drugs to control cancer pain*** for more information on ways to manage breakthrough pain.)

***Neuropathic (nerve) pain***

This is a term that describes pain caused by **nerve damage.** This may be due to tumour growth or cancer treatments. It can also be caused by nerves becoming 'sensitised' or 'wound up’. Neuropathic pain is a type of pain that comes and goes. People describe it using words such as burning, stabbing, shooting, tingling, radiating or spreading. There are specific medicines that can help treat neuropathic pain

* **See Tackling Cancer Pain: *Using drugs to control cancer pain***.

![C:\Users\hcsndh\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\9S40ZTG9\MP900315598[1].jpg]() **Where can I find out more?**

You can find more information about cancer pain in these publications:

* American Cancer Society. 2013. *Pain Control: A Guide for Those with Cancer* *and their Families* <http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/pain/paindiary/index>
* Macmillan Cancer Support. 2011. *Controlling Cancer Pain* (available as booklets from Macmillan Cancer Support, 89 Albert Embankment, London SE1 7UQ Tel: 00808 808 00 00; from local Macmillan Cancer Information Centres or online at [www.macmillan.org.uk](http://www.macmillan.org.uk))

Local contact phone numbers:

**Tackling Cancer Pain:**

**A Toolkit for Patients and Families**

**Using drugs to control cancer pain**

How you manage your pain will depend on a number of things, such as the cause of the pain and how bad it is—as well as what you’ve found from experience works for you. In this part of **Tackling Cancer Pain** we’ll talk about how to manage your pain using painkilling drugs.

The type of drug you might take and the way the drug is given depend on the type and cause of pain. For example, **persistent pain** is best relieved by methods that deliver a steady dose of pain medicine over a long period of time, such as slow-release pills or a patch that releases medicine through the skin gradually.

On the other hand, **breakthrough pain** (see **Tackling Cancer Pain *Understanding cancer pain*)** is best treated with medicines that work fast (quick release), but stay in the body only for a short time.

  Drugs are complicated things and it can sometimes be difficult to get them to work for you in the best possible way. Here, you can learn about:

* Common painkilling drugs used to relieve cancer pain
* How to prevent or manage common side effects of painkilling drugs
* Tips to help you manage your daily drug schedule.

![C:\Users\nhughes\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\OR3NY7SM\MC900104872[1].wmf]() **How can I use this information?**

1. Have a look at the information about the painkilling drugs you are taking on pages xxx and make a note of anything you don't understand, or want to know more about. You might want to ask a relative or friend to go through the information with you. Ask your nurse, doctor or pharmacist if you need a clearer explanation or more information
2. You might find it helpful to watch the DVD *Controlling Your Cancer Pain* to hear expert doctors, nurses and pharmacists talk about the best ways to use strong painkillers.
3. Make a note of these **key things to remember** about getting the most out of your painkillers:
4. Take your pain medicine on a regular schedule (around the clock) to help control persistent pain. Take it when it’s time to take it – even if you are not having pain.
5. Try not to skip doses of your scheduled medicine. The more pain you have, the harder it is to control.
6. If you have breakthrough pain, use your short-acting medicine as instructed. Don’t wait for the pain to get worse – if you do, it can be harder to control.
7. If you think your painkillers aren’t working, if the timing or dose aren’t right for you, or if you’re bothered by side effects, talk to your doctor or nurse
	* See also Tackling Cancer Pain ***Talking about your cancer pain*** and ***Getting more help***.

**Painkillers**

Painkilling drugs are known as **analgesics**, but we’ll stick with ‘painkillers.’ There are many painkillers available to treat different levels and types of pain. Some people with cancer have constant pain, so they need to take painkillers regularly to keep the pain under control. Uncontrolled pain can cause fear, anxiety and difficulty sleeping which can make the pain worse and even more difficult to manage.

There are different types of painkillers that are effective for *mild, moderate* or *severe* pain. Some examples are set out in an ‘analgesic ladder’ (see below).

|  |  |
| --- | --- |
| Severe pain(Step 3) | Strong opioid painkillers eg morphine, oxycodone, fentanyl or diamorphine |
| Moderate pain*(Step 2)* | Weak opioid painkillers eg dihydrocodeine (DF118 Forte®, DHC Continus®), codeine phosphate or tramadol |
| Mild pain*(Step 1)* | Mild painkillers eg paracetamol or anti-inflammatory drugs eg ibuprofen (Brufen®, Nurofen®), diclofenac sodium (Voltarol®) or celecoxib (Celebrex®) |

The idea behind the analgesic ladder is that if a person’s pain is not controlled by the painkillers on one level, or step, their doctor can prescribe a drug from the next level rather than try a different painkiller from the same group.

* For example, if you’re taking a mild painkiller such as paracetamol but are still getting pain, or if your pain gets worse, your doctor can prescribe a weak opioid (moderate) painkiller such as dihydrocodeine, codeine phosphate or tramadol. If the pain still isn’t controlled or if it increases, your doctor could then prescribe a strong opioid painkiller.

You don’t have to start with painkillers from the mild group—if you have moderate or severe pain when you first see your doctor, you can start by taking painkillers from the second or third step of the ladder.

* Often, painkillers from two different groups will be used at the same time, as they work in different ways. For example, a strong painkiller such as morphine can be used at the same time as a mild painkiller such as paracetamol or ibuprofen.

*I’m on MST, slow release morphine. I’m on 500mg paracetamol 4 times a day and diclofenac 3 times a day and then in between that, if I need it, I’ve got liquid morphine which I can take as required to top up.*

Donald

Let’s look in more detail at painkilling drugs commonly used to relieve mild, moderate and severe pain.

**Drugs to relieve mild pain**

Mild pain (0-3 out of 10 on a pain measurement scale) can be treated with **paracetamol** and/oranti-inflammatory drugs, such as **ibuprofen.**

Paracetamol can be used for a variety of mild pains.

* You can buy it, fairly cheaply, from any chemist and from many supermarkets, but you can only buy 32 tablets at once.

* If you’re taking paracetamol regularly, you’ll be able to get a larger quantity if you get it on prescription.

Anti-inflammatory drugs help to reduce inflammation and swelling, and are particularly good at relieving pain in the skin, muscle or bone.

* You can buy ibuprofen without a prescription from pharmacists and from many supermarkets, but, like paracetamol, you can only get a limited quantity without a prescription.
* Other anti-inflammatory drugs need to be prescribed by a doctor, nurse or pharmacist eg diclofenac sodium (Voltarol®) and celecoxib (Celebrex®).

***Side effects of mild painkillers***

It’s important not to take more than the recommended dose of paracetamol to avoid causing damage to your liver.

Anti-inflammatory drugs can cause indigestion and may irritate the lining of the stomach, so it’s important to take them after a meal or snack. Your doctor might prescribe an additional tablet to help protect your stomach. If you’ve had previous problems with stomach ulcers, the doctor might advise you not to take them at all.

**Weak opioid drugs**

Moderate pain (4-7 on the pain scale) is treated with weak opioid drugs such as dihydrocodeine (DF118 Forte®, DHC Continus®), codeine phosphate or tramadol.

These are sometimes combined in a single tablet (eg co-codamol, which contains codeine and paracetamol, or co-dydramol, which contains dihydrocodeine and paracetamol). Combination painkillers have brand names such as Tylex®, Remedeine®, Solpadol®, Kapake® and Tramacet®.

Most of these drugs are only available on prescription. There is a limit to the number of tablets that you should take in one day because of the paracetamol content.

* If your pain isn’t controlled by taking weak opioids, it’s important to let your nurse or doctor know so that you can be switched to stronger painkillers.

**Strong opioid drugs**

Severe pain (8-10 on the pain scale)is treated with strong opioid drugs. Some are more commonly used than others.

|  |  |
| --- | --- |
|  Commonly used \* |  Less commonly used |
| * morphine
* fentanyl
* oxycodone
* buprenorphine
* diamorphine
 | * hydromorphone
* methadone
* alfentanil
* ketamine
 |

\*See Tackling Cancer Pain Fact Sheets on ***Using strong opioids to relieve cancer pain*** for detailed information about these drugs.

With strong opioid painkillers, it’s important for your doctor to find the most effective dose for you. Two people with the same type of cancer may need different doses of a drug, even if they’re at the same stage of their illness.

* It’s common to start at a low dose and build up gradually to a dose that controls your pain. Other painkillers, such as paracetamol or anti-inflammatory drugs, can also be used with a strong opioid painkiller to help keep pain controlled.

If your pain increases or decreases, the dose of your opioid painkiller can be changed. If your pain increases slightly you might only need a small dose increase to get your pain under control again. But if your pain is bad, your doctors may increase the dose by a larger amount—this is more likely to get on top of your pain than a smaller dose increase.

* If your pain decreases you may need a smaller dose of your strong opioid painkiller. It’s important to reduce the dose gradually, with guidance from your doctor, nurse or pharmacist.

***Side effects of opioid drugs***

It can take a few days for your body to get used to strong opioid painkillers – so it is worth persevering with them if you do experience some of the side effects.

* **Constipation** All opioid painkillers cause constipation, which can be painful and distressing*.* Anybody who prescribes a strong opioid for you should also prescribe a laxative and it’s important that you take the laxative regularly for as long as you’re taking strong opioids.
	+ Some laxatives soften stools and make them easier to pass while others stimulate the bowel to push the stools along more quickly. A combination of these two types is often best at preventing constipation.
	+ Eating fruits and vegetables if you can, and drinking water regularly through the day, will also help to prevent constipation. Taking a walk everyday, if you can, will help too.
* **Drowsiness** This usually wears off in a few days once you’re used to the dose. Alcohol may increase drowsiness so if you do drink alcohol, it’s best to cut down when you start taking strong painkillers. You can then gradually increase if drowsiness isn’t a problem.
* If you’re planning to drive, or work with machinery, you should check with the person prescribing your medicines before taking strong opioid painkillers. Don’t drive if you don’t feel fully alert or if your reactions are slowed.
* **Dry mouth** These drugs can make your mouth dry, which can be a nuisance. Drinking plenty of liquids, and chewing gum, can help to reduce this side effect.
* If a dry mouth is really troublesome you can get sprays, or lozenges, of artificial saliva that might help.
* **Sickness** You may feel sick when you first start taking strong opioid painkillers, so you may need to take an anti-sickness (‘anti-emetic’) drug for at least the first week. The sickness will usually wear off, but if it lasts longer than 7 days, tell your doctor.
	+ Changing to a different strong painkiller might stop the sickness.
* **Other effects** If the dose of a strong painkiller is too high, it can cause symptoms such as marked drowsiness, confusion, hallucinations (seeing things that are not real), slow and deep breathing, and low blood pressure which might make you feel dizzy or faint. Tell your doctor straightaway if you experience any of these effects.

**Remember that although all opioid painkillers cause similar side effects, some may suit you better than others. If your pain is not well controlled, or if the side effects are a problem, tell your nurse or doctor so they can change the dose of your strong painkiller or try another type.**

Other drugs can also be used to help control pain. Although they are not painkillers, these drugs can be prescribed along with your painkillers to help relieve specific types of pain. They are referred to as ‘adjuvant’ drugs (this means ‘something additional that helps’) and include anti-depressants, bisphosphonates, steroids, anti-neuropathic drugs and others.

* See Tackling Cancer Pain Fact Sheet *Adjuvant Drugs for Pain Relief*.

**Taking painkillers: your daily drug schedule**

If you are taking several different drugs, you might find it helpful to make a chart that lists:

* The drugs you’re taking
* What they’re for
* The doses you’re taking
* The time of day to take them.

If you don’t feel up to this, ask a relative or friend to help you with it. Or your pharmacist, nurse or doctor may be able to give you a chart to fill in this information. Make sure it has space for you to tick off each dose as you take it.

***Other reminders***

If you sometimes find it difficult to remember when to take your medications, you could try setting up reminder alerts on your computer, or mobile phone:

*It’s there, look. They’re all my tablets and the times I have to take them and the alarm goes off to remind me … and this one goes across telling me I’ve got to have food with my diclofenac.*

Donald

You might find it easier to have your drugs arranged in a container (called a ‘tablet organiser’ or ‘dosette box’) labelled with the times you need to take them. You might be able to get these ready made up from the pharmacy.

*My husband usually manages mine. I manage my little drug box, because they’re already done. But anything extra to that, he will manage because I can’t remember what I’ve taken. So if he’s dishing out the paracetamol liquid and the OxyNorm liquid then at least he knows, because he’s got a very good memory.*

Samantha

*I have a tablet box. I didn’t at first and once or twice I got myself in such a state because I couldn’t remember what I’d taken so I thought, ‘Well, take some more’ just in case I didn’t take it. And that can be dangerous. So we have a tablet box and we work through that week to week. I couldn’t do it on my own. I need my wife to help me do it.*

Mike

The aim is to make things as simple as possible. If you find it difficult to remember to take medicines several times a day, talk this over with your nurse or doctor. There may be other types of the same drug that you can take less often.

**Sometimes you might feel that you need to vary the times that you take your painkilling drugs to fit in with things you want or need to do—avoiding being sleepy at social events, or when you need to drive, for example.**

**You, and those close to you, know best how the drugs are affecting you. If you think the timing or dose of your painkilling drugs aren’t working for you, or the side effects are bothering you, talk to your doctor or nurse and ask them to review your prescription.**

**Keeping a pain diary (*we can provide a sample format, electronic or paper)***

It can help to keep a record of your pain. List how bad it is at different times of the day and note anything that makes it better or worse. This information can help you discuss your pain with the nurses or doctors looking after you. It can also give you a feeling of being a bit more in control of what is happening to you.

* If writing a full diary feels like too much effort, just make a note of times when your pain seems to be worse and if anything helps to relieve it.

**![C:\Users\hcsndh\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\9S40ZTG9\MP900315598[1].jpg]() Where can I find out more?**

* The Tackling Cancer Pain Fact Sheet **‘Facts about drug treatment for cancer pain’** summarises some important information about taking drugs to control cancer pain. You can also get Tackling Cancer Pain Fact Sheets for commonly given strong painkilling drugs.
* American Cancer Society. 2013. *Pain Control: A Guide for Those with Cancer* *and their Families* <http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/pain/paindiary/index>
* Macmillan Cancer Support. 2011. *Controlling Cancer Pain* (available as a booklet from Macmillan Cancer Support, 89 Albert Embankment, London SE1 7UQ Tel: 00808 808 00 00; from local Macmillan Cancer Information Centres or online at [www.macmillan.org.uk](http://www.macmillan.org.uk))

See also:

* Tackling Cancer Pain Fact Sheet Key points about drug treatment for cancer pain.
* Tackling Cancer Pain Fact Sheet Using strong opioids: Morphine
* Tackling Cancer Pain Fact Sheet Using strong opioids: Fentanyl
* Tackling Cancer Pain Fact Sheet Using strong opioids: oxycodone, buprenorphine, diamorphine
* Tackling Cancer Pain Fact Sheet Other helpful drugs for pain relief
* Tackling Cancer Pain Fact Sheet Syringe drivers (to be written)

**Tackling Cancer Pain:**

**A Toolkit for Patients and families**

**Non-drug methods of managing pain**

Non-drug methods such as relaxation are now widely used to help manage cancer pain. Many techniques are used at the same time as pain medicine, though they can also be used alone for mild pain or discomfort.

* Some people find they can take a lower dose of their pain medicine when they also use non-drug methods.
* Sometimes, the simplest ways of making you feel better are overlooked, like making sure you're sitting or lying in a comfortable position.

 In this part of **Tackling Cancer Pain** we’ll talk about:

* Getting comfortable
* Relaxation
* Skin stimulation and massage
* Distraction
* Imagery
* Exercise

![C:\Users\nhughes\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\OR3NY7SM\MC900104872[1].wmf]() **How can I use this informations?**

Here are some general guidelines for managing pain with non-drug methods:-

* Try using a non-drug method along with your regular pain medicines*.*
	+ For example, try a relaxation technique at the same time you take medicine.
* Know yourself and what you can do. Often when people are rested and alert, they can use a method that demands more attention and energy. When tired, you may need to use a method that requires less effort.
	+ Try distraction when you are rested and alert
	+ Use hot and cold packs when you're tired.
* Try different methods to learn which ones work for you. Be open-minded, and keep a record of what makes you feel better and what doesn't help.

Here, we suggest a variety of non-drug methods for you to try. We hope that one or more of them will help reduce or relieve your pain. You may need the help of health professionals – social workers, physiotherapists, psychologists, nurses or others – to learn to use some of these techniques. Family and friends may also be able to help.

* If you have any new pain problems you should report these to the doctor or nurse before trying any medical or non-drug treatments to relieve the pain on your own.

A**re you comfortable?**

The way you sit or lie down can affect your pain. What may feel comfortable at first may be painful 15 or 20 minutes later. Changing your position frequently, asking for help if you need it, may help to relieve your pain.

* Moving about will also reduce the risk of your skin becoming sore as a result of sitting or lying still in one position for a long period of time.

*We do go for the medicines* (for ‘breakthrough’ pain\*) *but we also go for other things like the wheat bags, a comfortable position which can help, like this is comfortable now, with my pillow. So, it’s not a case of, ‘God, I’ve got to get the drugs.’ We do go for other things, not just immediately for drugs.*

Samantha

(\*see Tackling Cancer Pain: *Understanding Cancer Pain*)

If you need to spend a lot of time in bed, your bedding may need to be tidied or changed regularly, too. You may feel a lot better when you get back into a cool bed with fresh bed linen. V-shaped pillows or supports can help reduce backache and neckache, and a bed cradle can keep the weight of blankets or duvets off weak limbs.

* A district nurse may be able to arrange for you to havea special mattress and cushions. Other people from your care team, such as a physiotherapist or occupational therapist, can provide special equipment to help with movement and sitting.

**Relaxation**

Relaxation helps relieve pain, or keep it from getting worse, by reducing muscle tension. It can:-

* help you fall asleep—or, make you less tired and give you more energy
* reduce your anxiety
* help other pain-relief methods work better
	+ some people find that taking pain medicine, or using a hot or cold pack, works faster and better when they relax at the same time.

*I know when I’ve done too much because my pain gets worse. So, I try and relax. I take some of my medication and I relax until it goes away. I just sit down, stop moving until I feel better and then I get up and do whatever it is I want to do.*

Joan

**How to use relaxation**

You can relax sitting up or lying down. Choose a quiet place whenever possible. Close your eyes. Don’t cross your arms and legs because that might cut off circulation and cause numbness or tingling. If you're lying down, be sure you are comfortable. Put a small pillow under your neck and under your knees or use a low stool to support your lower legs.

There are many relaxation methods. We describe the following techniques in more detail in the next few pages:-

1. **Visual concentration and rhythmic massage**
2. **Inhale/tense, exhale/relax**
3. **Slow, rhythmic breathing**
4. **Listening to music**
5. **Progressive relaxation**

**Visual concentration and rhythmic massage**

* Open your eyes and stare at an object, or close your eyes and picture or think of a peaceful, calm scene.
* With the palm of your hand, firmly massage the painful area in a circular movement. Avoid red, raw or swollen areas.
	+ You might want to ask a family member or friend to do this for you if you’re tired or if the pain is in a part of your body that you can’t reach.

**Inhale/tense, exhale/relax**

* Breathe in deeply. At the same time, tense your muscles or a group of muscles.
	+ For example, squeeze your eyes shut or clench your mouth or make a fist. Or you could stiffen your arms and legs, or draw up your arms and legs as tightly as you can.
* Hold your breath and keep your muscles tense for a second or two.
* Let go. Breathe out and let your body go limp.
* Repeat until you feel relaxed.

**Slow, rhythmic breathing**

* Stare at an object or close your eyes and focus on your breathing or on a peaceful scene
* Take a slow, deep breath and, as you breathe in, tense your muscles (such as your arms)
* As you breathe out, relax your muscles and feel the tension draining.
* Now stay relaxed and begin breathing slowly and comfortably. Focus on your breathing, taking about 9-12 breaths a minute.
* To keep a slow, even rhythm as you breathe, you can say silently to yourself, "In, 1,2; Out, 1,2".
	+ It may be helpful at first if someone counts out loud for you. If you ever feel out of breath, take a deep breath and then continue the slow breathing.
* Each time you breathe out, feel yourself relaxing and going limp.
	+ If some muscles, such as your shoulder muscles are not relaxed, tense them as you breathe in and relax them as you breathe out. Do this only once or twice for each muscle group.
* Continue slow, rhythmic breathing for up to 10 minutes, depending how you feel.
* To end your slow, rhythmic breathing, count silently and slowly from 1 to 3. Open your eyes. Say silently to yourself, "I feel alert and relaxed". Begin moving about slowly.

**It might be easier to do this exercise if you ask someone to talk you through the stages until you get used to doing it.**

**Other methods you can add to slow, rhythmic breathing:**

* Listen to a piece of slow, peaceful music that you enjoy

*When I’m suffering, and I’m not sleeping well, I listen to some music for a bit and then I can usually fall asleep for another hour, or an hour and a half. I find that does help. It takes things out of your head because you’re concentrating.*

Patrick

* **Progressive relaxation of body parts.** Once you are breathing slowly and comfortably, you may relax different body parts, starting with your feet and working up to your head.
	+ Think of words such as ‘limp’, ‘heavy’, ‘light’, ‘warm’ or ‘floating’. Each time you breathe out, you can focus on one area of the body and feel it relaxing.
		- Try to imagine that the tension is draining from that area. For example, as you breathe out, feel your feet and ankles relaxing; the next time you breathe out, feel your calves and knees relaxing, and so on up your body to your forehead and scalp.

You can ask your doctor, nurse or a complementary therapist to recommend relaxation CDs for you. These recordings provide step-by-step instructions in relaxation techniques.

**Relaxation: precautions**

Some people who have used relaxation for pain relief have noticed some common problems and have made these suggestions:

* Relaxation may be hard to use when you have severe pain*.* If you have this problem, use quick and easy relaxation methods such as visual concentration with rhythmic massage or breathe in/tense, breathe out/relax.
	+ Or you can wait until your pain medicine starts to help your pain before you start with the relaxation methods.
* Sometimes breathing too deeply for a while can cause you to feel short of breath. If this happens to you, take shallow breaths and/or breathe more slowly.
* You may fall asleep. This can be a good thing if you're ready to go to bed. If you don't want to fall asleep, sit in a hard chair while doing the relaxation exercise or set a timer or alarm.

**If you have trouble using these methods ask your doctor, nurse, social worker or pain specialist to refer you to someone who is experienced in relaxation techniques. Do not keep using any technique that increases your pain, makes you feel uneasy, or causes unpleasant effects.**

**Skin stimulation**

Massage, pressure, warmth or cold can be used to reduce or block the feelings of pain. Sometimes they will reduce pain during the stimulation and for hours after it's finished.

**What you should know before using skin stimulation**

If you're having radiotherapy, check with your doctor or nurse before using these methods. You shouldn't put any ointments or lotions on the treatment area and you shouldn't use heat or extreme cold on treated areas. If you're having chemotherapy, check with your doctor before using hot or cold packs.

**Massage**

By rubbing the painful area, you will help reduce the number of painful messages reaching the brain, and you will also help the muscles relax.

* Using a slow, steady, circular motion, massage over or near the area of pain with just your bare hand or with any substance that feels good, such as talcum powder, warm oil or hand lotion.
* Depending on where your pain is, you can do it yourself or ask a family member, friend or massage therapist to give you a massage. Some people find brushing or stroking lightly more comforting than deep massage. Use whatever works best for you.

**Precautions:** If you're having radiotherapy, avoid massage in the treatment area as well as in any red, raw, tender or swollen areas. Check with your doctor as noted above. You may also need to be careful if you have cancer in the bones, as even gentle rubbing on those areas may make the pain worse.

* If the number of platelets in your blood is low, you will be more likely to bruise. In this case, you may be advised not to have some types of massage until the number of platelets in your blood has increased.

**Pressure**

To use pressure, press on various areas over and near your pain with your entire hand, the heel of your hand, your fingertip or knuckle, the ball of your thumb or by using one or both hands to encircle your arm or leg. You can test this by applying pressure for about 10 seconds to see if it helps.

You can also feel around your pain and outward to see if you can find "trigger points", small areas under the skin that are very sensitive or that cause more pain. Sometimes gradual pressure on the trigger points helps to relieve pain.

* Pressure usually works best if it's applied as firmly as possible without causing more pain.

**Heat and cold**

Heat pads, or packs,and warm baths can relax muscles, reduce joint stiffness and help relieve aches and pains. Ice packs can help relieve pain where there is inflammation and swelling.

* Some people find that alternating heat with cold is more helpful for controlling their pain. As with any of these techniques, you should use what works best for you.

You should always be careful to protect your skin from burns when using heat pads and ice packs. Heat pads should be used with a fleece cover, and ice packs should be wrapped in a towel before putting them on your skin.

* Heat shouldn't be used on body areas that are already inflamed or swollen, as it can make the swelling worse. And, try to keep them away from any pain medication patches, such as fentanyl, that you have on your skin.

**For cold**, try gel packs that are sealed in plastic and stay soft and flexible even when frozen. You can get them at pharmacies*.* They can be stored in a freezer and used again. It's a good idea to wrap the pack in a towel to make it more comfortable. Ice cubes wrapped in a towel, frozen peas or water frozen in a paper cup also work.

**To use heat** for pain relief, you can use gel packs warmed in hot water, hot water bottles, wheat bags, a hot, moist towel, a hot bath or shower.

**Precautions when using heat and cold**

* If you start to shiver when using cold, stop straight away. Do not use cold so intense or for so long that the cold itself causes more pain.
* Do not use heat or cold over any area where your circulation or sensation are poor.
* Do not apply heat or cold for more than 5-10 minutes at a time.
* If you're having chemotherapy, check with your doctor before using a cold pack
* Avoid heat or cold over any area where you're having radiotherapy and for 6 months after treatment has ended.

**Distraction**

Distraction means turning your attention to something other than the pain, so that your awareness of pain is reduced. People use this method without realising it when they watch television or listen to the radio to take their minds off a worry or their pain.

* Distraction may be used alone to manage mild pain or used with medicine to manage brief episodes of severe pain. Distraction is useful when you're waiting for pain medicine to start working. If the pain is mild, you may be able to distract yourself for hours.

*My chap will take me out for a ride in the car, once I’ve got sorted out with the drugs after 20 minutes or half an hour. He’ll take me round the block or down to the local town, which is good for distraction. It takes your mind off pain. And he sits and chats to me. And of course the cats come and annoy me.*

Samantha

**How to use distraction**

Any activity that you must focus on can be used for distraction. Losing yourself in a good book might divert your mind from pain. Watching TV or films, listening to music or playing computer gamesare also good distraction methods. Talking with friends or family can be another useful distraction technique.

*I’ve just realised what I do to escape from the pain. We’ve got film after film after film coming through the letterbox – and what I’ve just realised is that when I watch a film I totally immerse myself in it. My wife has realised this and for that hour and a half we don’t talk about the cancer, we don’t talk about my headaches. I’ve just realised what she’s doing, bless her! So, that’s my release. Even if I’ve got a headache I can sit comfortably, relax and think, ‘For an hour and a half I don’t have to think about anything.’*

Mike

**Distraction techniques**

*I go on my computer or play on my Xbox. I just lose myself in playing the Xbox.*

Chris

*I sometimes read. I can get lost in a book, especially if I’m half way through. If I get comfortable, I’m sorted!*

Samantha

You may find it helpful to listen to rather fast music through a headset or earphones. To help keep your attention on the music, tap out the rhythm. This technique does not require much energy, so it may be very useful when you're tired.

* After using some distraction techniques, some people have said they feel tired, irritable, and in more pain. If this happens to you, try different techniques, and use them only when you have mild pain.

**Imagery/visualisation**

Imagery, sometimes called 'visualisation,' is a way of using your imagination to create mental pictures. The way imagery relieves pain is not fully understood, although it may be simply a combination of relaxation and distraction*.*

* Imagery can be thought of as a deliberate daydream that uses all of your senses – sight, touch, hearing, smell and taste.

Images that are meaningful to you may reduce your pain both during imagery and for hours afterwards*.*  If you must stay in bed or can't leave the house, you may find that imagery helps you feel less closed in – you can imagine and revisit your favourite places in your mind.

* Imagery can help you relax, relieve boredom, decrease anxiety, and help you sleep. It can also give you a feeling of being in control of what is happening to you.

**How to use imagery/visualisation**

Imagery usually works best with your eyes closed. You may want to use one of the relaxation techniques described above before you try imagery.

* The image can be something like a ball of energy moving through your body, or a picture drawn in your mind of yourself as a person without pain—for example, imagine that you're cutting the wires that send pain signals from each part of your body to the brain.
* Or think of a pleasant, safe, relaxing place or activity that has made you happy. Exploring this place or activity in your mind can help you feel calm, and reduce your awareness of pain.

**How to use imagery/visualisation**

Here's an exercise with the ball of energy:-

* Close your eyes. Breathe slowly and feel yourself relax.
* Focus on your breathing. Breathe slowly and comfortably from your abdomen (belly)—as you breathe in push your belly out, as you breathe out pull your belly in.
	+ As you breathe in, say silently and slowly to yourself, "In, 1, 2". As you breathe out, say, "Out, 1, 2". Breathe in this slow rhythm for a few minutes.
* Imagine a ball of energy forming in your lungs or on your chest. It may be like a white light. It can be vague – it doesn't have to be clear or vivid. Imagine this ball forming, taking shape.
* When you are ready, imagine that the air you breathe in blows this ball of energy to the area of your pain. Once there, the ball soothes and relaxes you.
* When you breathe out imagine the air blows the ball away from your body. As it goes, the ball takes your pain with it.
	+ Repeat the last 2 steps each time you breathe in and out.
* You may imagine that the ball gets bigger and bigger as it takes more and more discomfort away from your body.
* To end the imagery, count slowly to 3, breathe in deeply, open your eyes, and say silently to yourself, "I feel alert and relaxed". Begin moving about slowly.

**It might be easier to do this exercise if you ask someone to talk you through the stages until you get used to doing it.**

Problems that might occur with imagery are much like the ones that occur with relaxation.

**Do you need to move around a bit more?**

When we experience acute pain, it makes us rest so that healing can take place. For example, if you sprained your wrist, the pain would stop you using it so that it could heal. However, with persistent pain – a lot of cancer pain is this type of pain – you may feel pain even though there is no injury and no healing.

* Persistent pain can cause you to avoid certain movements and activities, making your muscles and joints stiff. This, in turn, makes the pain worse and so you continue to avoid movement—this is called the ‘pain cycle.’

When you have persistent pain, you may be afraid to do exercise. However, staying active, within realistic limits, can be very beneficial. It can:-

* Loosen up your muscles and joints
* Improve your mobility
* Help your circulation
* Improve your posture
* Help reduce the pain.

Working out just how much exercise you can do may take some thinking about. You might not feel that you have much motivation, or capacity, for ‘exercise’ if that word brings up images of going to the gym or training for a 10k run.

You might prefer to think of it just as ‘movement,’ instead, and try to keep active by taking short walks that don’t tire you too much – or make your pain worse. You could also try gentle bending and stretching.

* As with all the methods we’ve described here, what works best for you is the most important thing.

**![C:\Users\hcsndh\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\9S40ZTG9\MP900315598[1].jpg]() Where can I find out more?**

To find someone who specialises in these techniques or learn more about them:

* Talk with your doctor or nurse
* Contact a local hospice, cancer information/support centre or pain clinic
* Look in your local bookshops or library, if you have them, or on the internet.

**Tackling Cancer Pain**

 **A Toolkit for Patients and Families**

**Talking about pain**

Everybody is different when it comes to talking. For some people it's natural to share their experiences. Others might feel that they don't want to talk about being in pain. You might think, 'How can talking help? Won't it just upset everybody?'

* Some people feel that there's no need to talk, because those around them can see when they're in pain.
* Some people do want to talk, but their partners or children don't want to, or find it difficult.
* How you talk to people about your pain, or about having cancer, will depend very much on your personality and how you usually talk to the people around you.

 In this part of **Tackling Cancer Pain** we’ll focus on:

* How talking can help
* Why talking can sometimes be difficult
* Talking to your partner and family
* Talking to health professionals
* Talking to other people with cancer

![C:\Users\nhughes\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\OR3NY7SM\MC900104872[1].wmf]() **How can I use this information?**

Have a look at the information on pages xx-xx and think about how the way you talk, or don't talk, about your pain is affecting you and those around you. Thinking about what you usually do might lead you to try something different.

* As with all the pain control methods we describe in **Tackling Cancer Pain**, what works best for you is the most important thing.

**What are the benefits of talking about your pain?**

If you talk to somebody close to you about your pain, they may be able to help you find ways to relieve it—they might give you a massage, help you organise your tablet box, or organise something enjoyable that will distract you from the pain.

* Talking might help you to feel closer to your partner or family members—you may be able to tackle the pain together as a ‘team’.

Being able to describe your pain to a doctor or nurse can help them to know what sort of pain you've got so they can work out which drugs might help to relieve it.

Talking to other people with cancer might help you feel that there are other people who really know what you're going through.

**Talking to your partner and family**

It can be hard to disentangle talking about pain from talking about cancer. ‘*We don’t talk about it* (her diagnosis of terminal cancer)’, Joan said, *‘because we don’t need to. He* (her son) *was with me when they told me, he knows the whole story and he’s been with me every step of the way*.’

* Mike and his wife don’t talk about his pain so much, but ‘*there’s no bigger subject in my house*,’ than his brain cancer and the impact it’s having on their lives.

*We talk about it all the time. Because B wants to know what’s going on in my head, what I’m thinking and feeling. And I want to know what she’s thinking and feeling. So we do talk about it. And I find it comforting to know that we think along the same lines. She understands what I want and I understand what she needs.*

Mike

Mike

**It can be hard to talk about cancer and pain**

Sometimes people in pain really don't want to talk about it. There may be many reasons for this:-

* Sometimes, it's because you want to protect people you love from your suffering.
* Some people's upbringing and character make them feel that they should put up with pain and get on with life, without complaining about things or drawing attention to themselves.
* For some people, talking about the pain can make it feel worse.

There isn't always an obvious reason for not wanting to talk.

*I don’t tell my wife and I don’t tell my son. I try not to. I think they’ve got enough on their plate with what I’ve got without knowing I’m suffering as well so I try to hide that from them.*

Donald

 *Can’t always do it, but try my best.*

Donald, throat cancer.

*He never discussed whether he had pain or not, so you could never tell. You never knew if he was suffering pain or not. He didn’t tell me. Basically he kept it to himself.*

Margaret

It can be hard for partners to bring up the subject of pain, because they worry about upsetting the person with cancer:

*You don’t like to approach them, in case they resent it or don’t want to discuss it. Because some people just want to push it to the back.*

Dorothy

People who are close to you can sometimes tell if you are in pain even if you don't talk about it. But others don’t always realise when you have pain and they might be pleased if you did tell them.

*He doesn’t have to tell me he’s in pain, I know when he’s in pain and I just say, ‘Do you want some painkillers?’ He doesn’t tell me he’s in pain, not unless it’s really bad. But I can always tell.*

Andrea

**Talking to other people with cancer**

Sometimes people find it helpful to talk to others with cancer. Sharing experiences can help you feel less alone, and you can get suggestions from other people about practical things that might help—how to get the strong painkillers you need ‘out of hours’, for example.

* You might talk to other people with cancer when you meet them at clinic appointments. Or there may be a support group you could join for people with your type of cancer at your local cancer centre or hospice.

If you use the internet, you might want to join an online support group or chat room. They're easy to join and you can 'talk' to other people in real time. If you prefer you can stay anonymous and just read other people's emails or posts—and you can leave at any time without having to give an explanation.

* It can be helpful to find that other people have similar experiences, thoughts and feelings—and they may also suggest new ways to manage or live with your pain.

There is an online community you could try at Macmillan Cancer Support ([www.macmillan.org.uk/community](http://www.macmillan.org.uk/community)).

****

**Talking to health professionals**

At various points in **Tackling Cancer Pain** we mention talking to doctors, nurses or pharmacists about your pain. This is probably always going to be important, because you may need painkillers which must be prescribed by a health professional.

* It might also be helpful to have professionals answer your questions about your cancer and about the pain control methods you're using, or want to try.

There is a wide range of health professionals you can talk to about your cancer pain, including:-

* Oncologists and others involved in your cancer treatment
* Clinical Nurse Specialist
* GP
* District Nurse
* Community pharmacist
* Hospice doctors and nurses
* Pain specialists

Sometimes it might not be at all clear who you should talk to, how you can get hold of them, or even what you want to say. If this happens, you could try talking to your hospital cancer care team, general practitioner, or community nurse specialist.

* See **Tackling Cancer Pain*: Getting more help***about how to plan for regular review of your pain management and about how to get urgent help if you need it.

Local contact phone numbers:

**![C:\Users\hcsndh\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\9S40ZTG9\MP900315598[1].jpg]() Where can I find out more?**

*Any ideas?*

**Tackling Cancer Pain**

 **A Toolkit for Patients and Families**

**Getting more help**

At various points in **Tackling Cancer Pain** we mention talking to doctors, nurses or pharmacists about your pain. This is probably always going to be important because you may need painkillers which must be prescribed by a health professional. It might also be helpful to have professionals answer your questions about your cancer and about the pain control methods you're using, or want to try.

* If your pain gets out of control, it will be even more important that you talk to a healthcare professional.
* If it’s not clear who you should talk to about managing your pain, or how you can get hold of them, it might be helpful to have a discussion with your hospital cancer care team, or your GP, about how to **plan for regular review** of your pain management.
* You can also ask about how to **get urgent help** if you need it.

 In this part of **Tackling Cancer Pain** we’ll focus on how to talk to healthcare staff in ways that will help them to understand what you want and need.

![C:\Users\nhughes\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\OR3NY7SM\MC900104872[1].wmf]()**How can I use this information?**

If the pain relieving methods you’re using are not working contact your GP, or the hospital department where you received cancer treatment, to talk about what else you can do to manage your pain and reduce the impact it’s having on you.

* It’s helpful if you can describe your pain problems as clearly and accurately as you can. This might not be easy but it will give the nurse or doctor a better understanding of your situation so they can help you in the best way.
* In **Tackling Cancer Pain: *Understanding Cancer Pain*** we give some examples of the language you can use to describe your pain.

**Here are some tips** about how to prepare what you want to say before you see the doctor or nurse, or talk to them on the phone:

* **Write down the most important points** that you want to talk about on a piece of paper that you can take with you to appointments, or have with you at home if you are being visited by a nurse or doctor.
* **Try to think of the most important thing you want to get across before you meet or talk to your doctor or nurse**.
	+ Sometimes there might be a few things that you want help with and you might forget that there is one that is really important. Try to make sure that you mention it, and that you get a response that you’re satisfied with.
* **Have a relative or friend with you when you meet your nurse or doctor**. They can help you remember things the doctor or nurse says, and remind you of questions you may want to ask but forget.
* **Make sure you understand what the doctor or nurse says to you about what can be done differently to try and relieve your pain**. Ask if there’s anything you’re not sure about.
	+ It’s a good idea to summarise their answers—try saying something like, ‘If I’ve got that right, what you’re saying is…’ This makes it clear how much you’ve understood, and can encourage the nurse or doctor to explain things more clearly if necessary.
* **Ask for simple explanations**. If you don’t understand, or if there is a lot to remember, it’s fine to ask the person to explain again and to go through everything point by point.
	+ Some people are happy for you to record the discussion—on a mobile phone, for example—so that you can listen to it later.
	+ Or you might want to ask the doctor or nurse to give you, or family members who are helping you, some written guidance about what you can do to relieve your pain.

Here is an example of **what you might say to a nurse or doctor** if you’re feeling that pain or discomfort is really bothering you:

I’d like to talk to you about my pain. Over the past week, most of the time my pain has been so severe that I haven’t been able to:-

 [ ]  sleep

 [ ]  do the things I normally do at home (or work)

 [ ]  visit my friends.

(*Tick all that apply and add anything else that your pain, or the side-effects of your medications, has interfered with*)*:*

 ---------------------------------------------------------------------------------------

[ ]  I’ve been taking all my prescribed medication (*tell the doctor or nurse which medicines you’ve taken, how much and how often).*

OR

[ ]  I haven’t taken ---------(*name medication*) as prescribed because:

I didn’t like the side effects (*describe*)

I forgot

It didn’t work

Other reason

I’ve been doing other things to try and relieve the pain (eg *relaxation, using a hot or cold pack, trying to distract myself etc*).

I’ve still got pain that is bothering me. Can we talk about what we can do to help me get on top of it?

**Other things to think about. Ask your GP or nurse:-**

* Can I get advice about pain from my local pharmacy?
* Can I get a list of local pharmacies that are open at night and at weekends?
* How will the hospital staff who treated my cancer help me to manage my pain?
* Can I be referred to a doctor/nurse/service that specialises in pain control?
* What should I do if pain becomes unbearable in the middle of the night, or over the weekend?
* What should I do if the syringe driver stops working, or runs out before it’s supposed to?

Local contact phone numbers:-

**Tackling Cancer Pain: Using Drugs to Control Cancer Pain**

**Fact Sheet Key points about drug treatment for cancer pain**

* Cancer pain can almost always be reduced or relieved
* Keeping pain from starting and keeping it from getting worse are the best ways to control it
* Addiction is rarely a problem for people taking strong painkillers for pain relief
* ‘Tolerance’ is not the same as addiction
* Side effects from pain medicines can be managed and often prevented

**Cancer pain can almost always be reduced or relieved**

There are many medicines and methods that can be used to control cancer pain. Doctors and nurses want and need to hear about what works for your pain and what does not. Not everyone feels pain in the same way—and there's no need to 'tough it out' or be 'brave' if you seem to have more pain than other people with the same kind of cancer. In fact, as soon as you have any pain you should speak up.

**Keeping pain from starting and keeping it from getting worse are the best ways to control it**

Pain is best relieved when treated early. You may hear some people refer to this as 'staying on top of the pain.' Do not try to hold off as long as possible between doses. Pain may get worse if you wait. Then it may take longer, or you may need larger doses, for your medicine to give you relief.

The nurses tell us everyday, ‘*Take your medicine regularly!’*

Mike

**Addiction is rarely a problem for people taking strong painkillers for pain relief**

People who are taking strong painkillers are often afraid of becoming addicted to them. Such fear may even keep people from taking the drugs they need. Family members may fear addiction, too, and encourage you to hold off as long as you can between doses.

* Addiction is defined as uncontrollable drug craving, seeking and continued use. When opioids – the strongest painkillers available – are taken for pain, they rarely cause addiction as defined here.

If your pain decreases and you need a lower dose of strong painkiller, the doctor will lower the amount of medicine you're taking over a few days or weeks. Your body will adjust gradually to a lower dose.

* Talk to your doctor, nurse or pharmacist about how to take strong painkillers safely and about any concerns you have about addiction.

 **‘Tolerance’ is not the same thing as addiction**

Pain should be treated early, and stronger painkillers should not be saved for later. It's important to take whatever medicine is needed when it's needed. Your body may get used to the drug you're taking so it may not relieve the pain as well as it once did. This is called *tolerance.*

Tolerance is seldom a problem with cancer pain treatment because your doctor can increase the amount of strong painkiller you're taking or add other drugs that will help. Some people are alarmed by this because they are afraid it means they are addicted, but it's not the same thing. It only means that your body has learned to adjust to the drug in your system over time.

**Side effects from pain medicines can be managed and often prevented**

Some painkillers can cause constipation, confusion, dizziness, drowsiness, itching, or nausea and vomiting. Some of these problems go away after a few days of taking the drug—and many side effects can be managed by changing the drug, the dose, or the times when the drug is taken. Others, like constipation, can often be prevented with stool softeners and other measures.

**Tackling Cancer Pain: Using Drugs to Control Cancer Pain**

**Fact Sheet Using Strong Opioids: Morphine**

Morphine can be taken in various ways:

* short-acting tablets (Sevredol®)
* long-acting tablets and capsules (Morphgesic® SR (slow-release), MST Continus®, MXL®, Zomorph®)
* short-acting syrups (Oramorph®)
* long-acting granules to mix with water (MST Continus®)
* suppositories, which are usually short-acting, inserted into the rectum (‘back passage’)
* a short-acting injection (morphine sulphate)

A short-acting type of morphine is usually taken every four hours to begin with so that the dose can be adjusted until the pain is well controlled. You will usually take it as a tablet or a liquid. Liquid morphine has a bitter taste that can be improved by mixing it with a fruit drink.

* Once the right dose has been worked out, you will be able to take long-acting tablets, capsules or granules to mix with water. These release the morphine dose very slowly over a period of either 12 or 24 hours, depending on which type you are taking.

If you can’t swallow or are vomiting, morphine can be given by injection or as an infusion using a syringe driver (see Fact Sheet on syringe drivers). Occasionally morphine suppositories are used.

**Side effects**

Morphine has the usual side effects of strong painkillers—constipation, drowsiness, dry mouth, sickness.See Tackling Cancer Pain: **Using Drugs to Control Cancer Pain** for information on how to prevent or manage these side effects.

* Some people find that the side effects of morphine can’t be controlled. They may have ongoing drowsiness or sickness that isn’t relieved by the usual medicines. In this case, your doctor would probably switch you to a different strong opioid painkiller such as fentanyl or oxycodone (OxyNorm®).
* Side effects of painkillers vary from person to person and from one drug to another, so it’s usually possible to find another drug that suits you better.

**Tackling Cancer Pain: Using Drugs to Control Cancer Pain**

**Fact Sheet Using Strong Opioids: Fentanyl**

Fentanyl is usually given as a skin patch or a ‘buccal’ medicine (ie dissolved in the mouth).

The **patches** (Durogesic DTrans®) look like waterproof plasters. They are stuck on to the skin and the drug is released slowly through the skin. You usually change the patch every three days and put the new patch on a different area of skin. The patches can be convenient, as you don’t need to remember to take tablets regularly.

* When the patch is first used, it takes around 12-24 hours for the fentanyl to reach its maximum level in the blood. During this time you’ll usually need to take a short-acting strong opioid such as morphine to keep the pain controlled.

There are two **buccal** preparations: a short-acting lozenge (Actiq®) and a buccal tablet (Effentora®). You put the lozenge or tablet in the mouth between the cheek and the gum. They are absorbed from the soft tissues lining the cheek and act quickly to reduce pain. They work best for breakthrough pain.

* Fentanyl can also be taken as a nasal spray or as a tablet that you place under the tongue (‘sublingual’).

**Side effects**

The side effects of fentanyl are the same as for all strong opioid painkillers—constipation, drowsiness, dry mouth, sickness\*. In addition, the patches may also cause a slight skin rash where they are applied. For some people, fentanyl causes less constipation than other types of opioid drugs.

* When using the skin patch, warmth can make the skin absorb the fentanyl more quickly. So, if you have a high temperature it’s important to tell your doctor or nurse straightaway. It’s also important to avoid heating the skin patch, so take care when going out in the sun, bathing, showering or using a heat pad near the patch.

\* See Tackling Cancer Pain: **Using Drugs to Control Cancer Pain** for information on how to prevent or manage these side effects.

**Tackling Cancer Pain: Using Drugs to Control Cancer Pain**

**Fact Sheet Using Strong Opioids: Oxycodone, Buprenorphine, Diamorphine**

**Oxycodone**

Oxycodone is given as short-acting capsules or liquid (OxyNorm®) which you take every 4-6 hours, or long-acting tablets (OxyContin®), which you take every 12 hours. You can use oxycodone if morphine causes too many side effects or doesn’t control the pain well enough.

* Oxycodone can also be given by injection or continuously in a syringe driver (see Tackling Cancer Pain Fact Sheet Using a Syringe Driver)

**Buprenorphine**

Buprenorphine can be given as:

* A patch (Transtec®) that you change every 3-4 days
* A patch (BuTrans®) that you change every 7 days
* A tablet (Temgesic®) that you dissolve under the tongue every 6-8 hours.

**Diamorphine**

Diamorphine can be used for people who can’t swallow and who need to have their painkillers given by injection or continuously by a syringe driver.

Oxycodone, buprenorphine and diamorphine all have the same general side effects as other strong opioid painkillers:

* Constipation
* Drowsiness
* Dry mouth
* Sickness

See Tackling Cancer Pain: **Using Drugs to Control Cancer Pain** for information on how to prevent or manage these side effects.

**Tackling Cancer Pain: Using Drugs to Control Cancer Pain**

**Fact Sheet Other helpful medicines (‘adjuvant’ drugs)**

You may be prescribed other medicines, known as ‘adjuvant’ drugs, to take along with your regular painkillers. ‘Adjuvant’ means ‘something else that helps.’ These drugs include:

* Bisphosphonates
* Steroids
* Antiepileptic drugs
* Antidepressant drugs
* Antibiotics
* Muscle relaxants

**Bisphosphonates**

People who have pain from cancer that has spread to the bones may find drugs called ‘bisphosphonates’ helpful. As well as helping to reduce pain, these drugs can also strengthen the affected bones. They can be given as a drip into a vein, usually once a month, or as tablets.

**Steroids**

When pain is caused by a tumour pressing on or damaging a nerve, steroid drugs may help relieve this pressure and so reduce pain. They may be given alone or with your painkillers. Commonly used steroids are dexamethasone and prednisolone.

*Side effects of steroids*

Steroids generally make you feel better and they may also increase your appetite. They might make you put on weight, and they can increase your risk of getting infections.

* The levels of sugar in your blood may also change temporarily. Tell your doctor or nurse if you become very thirsty and start going to the toilet to pass urine more often, as this may be due to an increase in your blood sugar level.

Some people find that steroids make them feel agitated or irritable because they make the mind more active. They can make it more difficult to sleep, but this is less of a problem if you take them in the morning. The side effects disappear gradually once treatment is over.

* Steroids can also cause indigestion and may irritate the lining of the stomach (sometimes causing bleeding), so it’s important to take them after a meal or snack. Your doctor may prescribe other tablets along with the steroids to help protect your stomach.

**Antiepileptic and antidepressant drugs**

These drugs can help reduce pain caused by nerve damage (neuropathic pain). They work by reducing nerve activity. The dose may need to be gradually increased over a few days or weeks to control the pain, so it’s important to continue taking them even if they don’t work straightaway.

* Antiepileptic drugs used to treat pain include gabapentin, pregabalin and carbamazepine.
* Amitryptiline is an anti-depressant that can help.

Some people find that amitryptiline can make them feel sleepier or slightly ‘hungover’. If this happens to you, tell your nurse or doctor. It’s also a good idea to take the dose at night to so you don’t feel too sleepy during the day.

Some people worry that if they’re started on low doses of antidepressants for nerve pain, it’s because their doctor thinks they’re depressed. But this isn’t the case. Research has shown that low doses of antidepressants are effective for nerve pain, but higher doses are needed to treat depression.

**Muscle relaxants**

If muscle spasms are making your pain worse, you might have a short course of a drug to help relax the muscles—for example, diazepam (Valium®), baclofen (Lioresal®) or clonazepam (Rivotril®).

Fact Sheet Using Syringe Drivers to be written.