Pain and pancreatic cancer
Introduction

This booklet is for you if you have been diagnosed with pancreatic cancer and have pain, or if your cancer has come back after treatment. Family and friends may also find it helpful.

Pancreatic cancer can cause pain, but it’s important to remember that not everyone with pancreatic cancer will get pain. If you do have pain, asking for help early on will help you manage it.

This booklet describes the different types of pain that pancreatic cancer can cause. It has information on how to describe pain to your medical team, and ways of keeping it under control, including painkillers. Not all the information here may be relevant to you. The booklet has been designed so that you can dip in and out to get the information you need.

If you have any questions or worries about pain, speak to your GP, medical team or palliative care team (find out more about palliative care on page 21). You can also speak to our specialist nurses on our confidential Support Line.

Call the specialist nurses free on 0808 801 0707 or email support@pancreaticcancer.org.uk

Pain can be a symptom of pancreatic cancer before it is diagnosed – you can read about this on our website at pancreaticcancer.org.uk/symptoms
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Section 1

What is pain?

Different people feel pain in different ways. This means that your pain is very individual to you.
Pain is often a sign of damage to your body – it’s your body’s way of telling you that things aren’t right. Many people with pancreatic cancer have pain at some stage. But pain can be treated, so ask for help as early as you can. You can read about treatments on page 19.

People sometimes think of pain as something they only feel in their body. But it is more than just a physical feeling. Your emotions, your relationships with people (like your medical team) and your spiritual beliefs can all affect how you feel and react to pain. For example, your pain may be worse at times when you feel you’re not coping, or when you don’t feel you’re getting the support you need. You may have less pain at times when you feel confident about dealing with your pain. You can find out more about coping with pain on page 43.

**Who can help manage pain?**

Your GP, oncology team, surgical team, or hospital or community palliative care team can help you manage your pain. Read more about palliative care on page 21. These professionals are part of your multidisciplinary team (MDT). In this booklet, we describe them as your medical team. You can write down their contact details on page 56.

To begin with, your GP or oncology team may help you manage your pain. If you need further treatment or support to control your pain, they may refer you to other specialist services, such as a palliative care team or a pain clinic. The service you are referred to may vary, depending on what is available in your area. Read more about palliative care services on page 20.
Section 2

What causes pain?

Pancreatic cancer pain is complex, with many possible causes. These may include the cancer itself, problems with digestion, cancer treatments, constipation, and your emotions and beliefs.
**The cancer**

You may get pain from the cancer in the pancreas, or from pancreatic cancer that has spread to other parts of the body (advanced or metastatic cancer).

Pancreatic cancer can affect the nerves or organs near the pancreas. This can cause pain in the tummy area (abdomen) or the back.

Cancer that has spread to the liver can make the liver grow larger, which can cause pain. If the cancer has spread to the liver or the thin layer of tissue that lines the abdomen (peritoneum), it can cause a build-up of fluid. This is called ascites, and it can cause pain and discomfort. Macmillan Cancer Support have more information on ascites.

Less commonly, pancreatic cancer can spread to the bones and cause pain (see page 14).

**Problems with digestion and diet**

The pancreas plays an important role in digesting food, as it produces enzymes that help to break down the food (see glossary on page 54 for more about enzymes and digestion). Pancreatic cancer can affect this, which means that food is not properly digested. This can cause a variety of different symptoms, including tummy discomfort or pain, and bloating.

Pancreatic enzyme supplements can help you manage problems with digesting food. These replace the enzymes that your pancreas would normally produce. This is known as pancreatic enzyme replacement therapy (PERT). A common brand is Creon®, but there are others available. The supplements help
to break down food, and can help you manage symptoms, including discomfort and pain. Pancreatic enzyme supplements can make a big difference to how you feel.

If you are having any problems with your diet and eating, or haven’t been told about enzyme supplements, speak to your nurse or dietitian.

You can also call our specialist nurses on our free Support Line.

Read more about managing your diet in our booklet, *Diet and pancreatic cancer*, or on our website at *pancreaticcancer.org.uk/diet*

**Cancer treatment**

Some cancer treatments can cause short-term or long-term pain.

**Surgery**

You may have surgery such as the Whipple’s operation to remove your cancer. Or you may have surgery to relieve symptoms of your cancer, such as having a small tube called a stent inserted to relieve sickness or jaundice.

You may have pain and discomfort for a few weeks after your operation, and you should be given painkillers to manage this. Speak to your medical team if you have any problems with pain after your surgery.
Chemotherapy

Chemotherapy can cause different types of discomfort and pain, depending on the type of chemotherapy drug you are having. These can include:

- a sore mouth and mouth ulcers
- sore palms of your hands and soles of your feet
- joint or muscle pains
- bloating and discomfort in your tummy.

Tell your doctor or nurse if you have any of these side effects – or any others – while having chemotherapy. They can help you manage side effects.

If you are having chemotherapy and have any chest pain or tightness in your chest, or any pain or swelling in your arms or legs, contact your medical team straight away.

Although chemotherapy can cause some uncomfortable side effects, it can also help to treat pain by shrinking the cancer.

You can read more about these treatments and the side effects in our treatment fact sheets and on our website at pancreaticcancer.org.uk/treatments

Constipation

Constipation is when you can’t empty your bowels as often as usual, or you find it difficult to completely empty your bowels. This can cause discomfort or pain. Some painkillers that treat moderate to severe pain (opioid painkillers) can cause constipation. Read more about this on page 32.
Emotions and beliefs

Many things can affect the way you feel pain, including:
• how you feel about dealing with pain
• stress and worry – about the pain, cancer, or other things
• depression
• your spiritual and religious beliefs
• your relationships with other people, like your family or medical team.

Getting help early on can help you feel more in control of your pain. Don’t try to cope alone. Speak to your medical team, or ask a family member or friend to speak to them for you.

You can also speak to our specialist nurses on our free Support Line with any questions or concerns about your pain.

Questions to ask

What is causing my pain?
How can my pain be managed?
Who can help with managing my pain?
Section 3

Types of pain

This section describes the main types of pain that affect people with pancreatic cancer. Some people have more than one of these, with each needing a different treatment. Read more about treatments for pain on page 19.
There are several different types of pain, including nerve pain, soft tissue pain and bone pain. Pain can last some time, or it can come on quickly, with or without warning.

If your pain suddenly gets bad, contact your GP or medical team as soon as possible, even during the night. Your medical team should give you details of who to contact out of normal hospital hours. You can record these on page 56.

**Background pain**

Background pain is ongoing pain that you can manage with regular pain relief. If it isn’t fully under control, you may have pain shortly before your next dose of pain relief is due. If this happens, you may need a different dose or type of pain relief.

**Breakthrough pain**

Sometimes, you might get short bursts of severe pain that come on quickly and last for a few minutes or a few hours. This is called breakthrough pain, as it “breaks through” your regular pain relief. You may not know when you’re going to get breakthrough pain.

Treatment for breakthrough pain includes some opioid painkillers, like fast acting morphine or oxycodone – see page 29.

If you have breakthrough pain, tell your medical team as much as you can about it. This will help them give you the right treatment. If you are getting a lot of breakthrough pain, you may need a different dose or type of pain relief.
Incident pain

Incident pain is similar to breakthrough pain but it is caused by an activity, like moving around. If you know what is likely to cause pain, you may be able to prevent it by taking painkillers 20 to 30 minutes before doing that activity.

Nerve (neuropathic) pain

Many people with pancreatic cancer have some nerve pain (neuropathic pain).

The nerves from the pancreas form a thick bundle, called the coeliac plexus, behind the pancreas. These nerves send messages from the pancreas to the brain. Pancreatic cancer can damage the coeliac plexus, causing pain.

Nerve pain can come and go and can be difficult to describe. Some people say it feels like a burning, shooting, tingling or stabbing pain or like pins and needles.

Treatment for nerve pain includes non-opioid or opioid painkillers (see page 23) together with other drugs, such as tricyclic antidepressants and anti-convulsant drugs for epilepsy. Don’t worry about taking these other drugs. Even though their main use is treating depression and epilepsy, they also control nerve pain when used with painkillers (see page 35). Nerve blocks are another option if painkillers aren’t controlling the pain or if the side effects are hard to deal with (see page 35).

Some pancreatic cancer chemotherapy drugs can also damage other nerves. This can cause numbness and pins and needles in your arms or legs. This is called peripheral neuropathy. Tell your medical team if you have any numbness or tingling.
**Soft tissue pain**

If pancreatic cancer spreads to nearby organs like the liver, it can cause a type of pain called soft tissue (visceral) pain. The pain may feel deep, squeezing, aching or cramping. You may find it difficult to say exactly where the pain is coming from.

Soft tissue pain can sometimes cause pain in another part of the body. For example, you may feel pain in your neck or shoulder. This is called **referred pain**.

Treatment options for soft tissue pain include opioid painkillers and nerve blocks (see pages 27 and 35).

“My husband had pain in his shoulder. Now you wouldn’t think about pain in the shoulder, with pancreatic cancer in the stomach area. You think all the pain’s going to be where the problem is.”

**Bone pain**

In a small number of people, pancreatic cancer can spread to the bone, causing pain. People sometimes describe the pain as aching, gnawing, throbbing, or cramping. You may have one particular area of bone that feels tender to touch.

Treatments include non-opioid and opioid painkillers, drugs called bisphosphonates, and radiotherapy. See pages 23 and 34.

:**Questions to ask**

What type of pain do I have?  
How can my pain be treated?
Section 4

Talking about pain

It’s important that you speak to your medical team as early as possible about any pain. Don’t try to cope with it yourself. The earlier you get treatment, the better the chance of getting the pain under control.
Tell your GP or medical team about any new pain or any pain that’s got worse as soon as you can. If your pain is very bad at night or at the weekend, contact the emergency number your medical team should have given you. If you haven’t been given a number, ask them about it. You can record it on page 56.

If you get any new pain or your pain gets worse, you may be worried that this means the cancer is growing. But this isn’t always the case. Talk to your medical team about your concerns. They can help you understand what your pain means. They can also explain the different ways of managing pain.

“Don’t be ashamed to ask for help. Doctors and medical professionals understand the difficulty and will do everything they can to provide support.”

**Describing pain**

Only you know how your pain feels and how it affects your life. You may find it hard to describe your pain but there are some tools that can help, such as pain scales and pain diaries.

Your medical team will ask you about your pain and will examine you. They may ask you how the pain is affecting the following things.

- Your body – where is the pain, does it spread, what brings it on and how does it feel?
- Your daily life – does it get in the way of everyday activities, can you rest and sleep?
- Your emotions – how does it affect your mood and how you feel?
• Your relationships – how does it affect your relationships with your family and friends?
• Your sex life – how does it affect the way you feel about your body and your relationship with your partner, if you have one?
• Your spiritual feelings – how do you feel about yourself, your beliefs and about your future?

**Pain scales**

Pain scales help you describe how bad your pain is. Your medical team may ask you to rate your pain on a scale from 0 to 10, where 0 means no pain and 10 means the worst pain you can imagine.

There are no right or wrong answers to this question – only you know how bad your pain is. This will help you and your medical team keep track of changes in your pain and how well your treatment is working.

**Pain diaries**

Keeping a diary can help you remember details of your pain and help you describe it to your medical team. Try thinking about the following questions when you’re writing about your pain.

• Where is the pain?
• How many areas of pain do you have?
• How bad is the pain on a scale from 0 to 10?
• Does the pain spread to other areas of your body?
• When do you get pain?
• How long does the pain last?
• Does anything make the pain better or worse?
• What do you think is causing the pain?
• What pain relief have you had?
• Has the pain relief helped with the pain, partly helped or not helped at all?
• Have you had any side effects from the pain relief?
• How do you feel about your pain and the pain relief you’ve had?

Take your diary with you when you have a medical appointment.

Your medical team may give you a diary to fill in, or you can get one from Macmillan Cancer Support’s booklet, **Controlling cancer pain.** There are also some mobile phone apps that help you keep a record of your pain. If you think this would be helpful, ask your medical team if they know of any good apps.

You can speak to our specialist nurses on our free Support Line if you have any questions about how to describe your pain.

❓ **Questions to ask**

Who should I contact for help at night or the weekend?

Do you have a pain diary I can use?

Can you recommend any mobile phone apps for keeping a record of pain?
Section 5

Ways of managing pain

Your medical team will look at what is causing your pain, what type of pain you have, how bad it is and how it is affecting you. This will help them find the best treatment for you.
Your medical team will help you manage your pain effectively. It’s important that you follow their instructions when taking pain relief. For example, if you’re taking painkillers, you will need to take these regularly to control the pain. Don’t stop taking your pain relief without speaking to your medical team. If you’re worried about side effects, speak to them before changing how you take your pain relief.

Your medical team may work with a pain clinic to help you manage your pain. They may refer you to a clinic if there is one available in your area.

Different types of pain relief work in different ways and have different side effects. The type of pain relief you have will depend on what kind of pain you have and your overall health. We have described the main treatment options. You can read about painkillers on page 23 and other treatments on page 34. Speak to your medical team about which ones may help you.

“Our palliative care nurse was great and explained what the pain relief drugs were and how long they would take to work.”

What if my pain relief isn’t working?
Tell your medical team straight away if your pain gets worse or is not being kept under control. Don’t wait to ask for help with pain. Your medical team will want to know about it.

Your medical team may increase the dose of your painkillers, change the way you take them or change the type of pain relief. For example, they may suggest switching to a different painkiller.
If your pain isn’t under control, it may be helpful to have a palliative care review. Your medical team can refer you for this. It may include going into a hospital or a hospice for a short time to treat your pain and other symptoms. Once your pain is back under control, you can go home again. Hospices also provide care in people’s homes.

If you haven’t already seen a palliative care or pain specialist, ask your doctor or nurse to refer you to one.

**What is palliative care?**
Palliative care aims to improve the lives of people with an illness that can’t be cured. It provides support for people’s physical needs, such as dealing with pain or side effects. It also provides emotional, social and spiritual support, and supports families. Hospices provide palliative care, but there are also palliative care specialists in hospitals and the community. Hospices and palliative care are not just for people in the final stages of life.

Read more about hospices on our website at [pancreaticcancer.org.uk/nursingsupport](https://pancreaticcancer.org.uk/nursingsupport), or in our booklet, *Caring for someone with pancreatic cancer: Information for families and carers.*
What else can help?
Some people find that complementary therapies, like acupuncture and massage, can help them deal with pain (see page 39).

You could also ask your medical team if you can join any clinical trials for cancer pain. Clinical trials are medical research studies involving people, which test new treatments. Cancer Research UK have details of trials for pain in cancer.

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You can read more about clinical trials and search for pancreatic cancer trials in the UK on our website at pancreaticcancer.org.uk/clinicaltrials
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“I think people sometimes think they are on the highest dose they can be when they’re given something like morphine and that’s not always true. Often the pain can be due to other things and there are other things that can be done.”

What if I’m concerned about my care?
If you have any concerns about your care, speak to your doctor or nurse first. If you are still unhappy, there are other people you can ask for help. This won’t affect your future care.

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Read more about what to do if you have concerns about your care on our website at pancreaticcancer.org.uk/concerns or in our booklet, Caring for someone with pancreatic cancer: Information for families and carers.
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Section 6

Painkillers

Painkillers are also called analgesics. In this booklet, we use the general (generic) name of each drug, rather than the brand name.
Painkillers can successfully control your pain if you take them regularly, ‘by the clock’. Your doctor will explain how much to take and how often. It’s important to follow their advice to make sure the painkillers work effectively.

There are two main types of painkillers – non-opioids and opioids. There is more information about these on pages 26-27.

Your painkillers will come with an information leaflet explaining how to take them and describing possible side effects. You can also find these leaflets on the Electronic Medicines Compendium website.

Some people worry about getting addicted to painkillers like morphine. You can take the full dose that your doctor has given you without worrying about taking too much (overdosing) or getting addicted. Addiction shouldn’t be a problem for people with cancer if they take their painkillers as prescribed by their doctor.

If you plan to travel abroad, you may need to take a letter from your GP to say which medicines you’re taking. Read more in Macmillan Cancer Support’s booklet, *Travel and cancer*.

**The pain ladder**

The type of painkiller you have will depend on how bad your pain is. Your medical team will use a ‘pain ladder’ to work out which type of drug to start with. The pain ladder shows which types of painkillers treat different levels of pain.
You will start at whichever step is right for you. For example, if you have moderate pain, you would start at step two of the ladder. If your pain gets worse, you will move up the pain ladder to the next type of painkiller.

You can take non-opioids together with opioids at steps two and three. You may also take other drugs, like anti-depressants, at the same time to help control your pain (see page 35). It may take some time to find the right drug and dose to control your pain.

**The pain ladder**

**Mild pain**
- Non-opioid painkillers
- With or without other pain relief

**Moderate pain**
- Weaker opioids
- With or without non-opioid painkillers
- With or without other pain relief

**Moderate to severe pain**
- Stronger opioids
- With or without non-opioid painkillers
- With or without other pain relief

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**Step 1**

**Step 2**

**Step 3**
Non-opioid painkillers

Non-opioid drugs treat mild pain. You can also take them together with opioid drugs to treat stronger pain. Examples of non-opioids include paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen.

It’s important to follow your doctor’s instructions when taking non-opioid painkillers. Don’t take more than the recommended dose. For example, too much paracetamol can damage the liver.

NSAIDs can help relieve pain in the tummy area and in bone. Possible side effects include stomach problems, like loose and runny stools (diarrhoea), so you should take them after food. There is also a risk that they could cause stomach ulcers. Your doctor may give you a medicine to prevent this if they think you’re at high risk.

Medicines you buy from the chemist or supermarket, like cold and flu medicines, often include paracetamol or NSAIDs. Always check with the pharmacist or your medical team before taking them.

If you’re having chemotherapy, your doctor may tell you not to take paracetamol or ibuprofen. Or they may tell you to always check your temperature before you take them. This is because chemotherapy can make you more at risk of an infection. If you have an infection, paracetamol or ibuprofen can hide this by lowering your temperature and making you feel better, but they won’t cure the infection.
If your temperature is normal, it’s safe to take them. If it’s high, you should avoid taking them and contact your chemotherapy team – they should have given you a phone number to call. If you’re having chemotherapy, a high temperature is 37.5°C or 38°C, depending on the advice of your chemotherapy team.

If you’re not sure what to do, talk to your chemotherapy team. An infection is a medical emergency if you’re on chemotherapy and needs urgent treatment.

Read more about chemotherapy and infections in our fact sheet, **Chemotherapy for pancreatic cancer**, or on our website at [pancreaticcancer.org.uk/chemotherapy](http://pancreaticcancer.org.uk/chemotherapy)

**Opioid painkillers**

Opioid drugs treat moderate and severe pain. They are used at steps two and three of the pain ladder (see page 25). You may take them together with a non-opioid or other drugs. You can read more about other drugs on page 35.

You usually take opioid painkillers by mouth, as tablets, capsules or as a liquid. If you are having trouble swallowing or you have sickness (vomiting), you may have a tablet or film that dissolves in your mouth, a skin patch, an injection or an infusion into a vein. Another option is a syringe driver, which is a small, battery-operated machine that delivers a steady flow
Other medicines and alcohol can affect the way your painkillers work or cause side effects, such as sleepiness. Check with your doctor before taking any medicines you’ve bought from the chemist.

Weaker opioids
The drugs codeine, dihydrocodeine and tramadol are weaker opioids. They treat mild to moderate pain at step two of the pain ladder. You may have a weaker opioid or a low dose of a stronger opioid, with or without a non-opioid drug.

Stronger opioids
Stronger opioids treat moderate to severe pain, at step three of the pain ladder.

Some stronger opioids are available in two forms – immediate release opioids and modified release opioids.
Immediate release opioids
Immediate release opioids start to work after about 20 minutes and reach full effect after about an hour. This makes them good for treating very bad pain or breakthrough pain (see page 12). You may also start off with an immediate release opioid while your medical team works out the best dose for you. In this case, you will take it every four hours before you switch to a modified release opioid.

Modified release opioids
Modified release opioids take longer to reach their full effect when you first start taking them. You may take a modified release opioid once or twice a day to control stable background pain (see page 12). You must take them regularly for them to work.

Types of stronger opioid
Morphine
Morphine controls pain well for most people and is usually the first strong opioid that people start with. There are two types – immediate release morphine and modified release morphine.

You usually take morphine by mouth. But you can have an injection or infusion under the skin or into a vein if you are being sick or have trouble swallowing.

Oxycodone
This drug works in a similar way to morphine and comes in immediate release and modified release forms. You usually take it by mouth as tablets, capsules or a liquid. You can also have it as an injection or infusion under the skin or into a vein if you are being sick or have trouble swallowing.
You may have oxycodone if morphine does not suit you or causes side effects.

**Hydromorphone**
This drug is available in capsules that you take by mouth. Hydromorphone is similar to morphine and comes in immediate release and modified release forms.

If you find it difficult to swallow capsules, you may be able to open the capsules and sprinkle the contents onto a spoonful of cold, soft food. Check with your doctor before doing this as it may affect how the drug works.

**Fentanyl**
This type of opioid painkiller can be a good choice for people who find it difficult to swallow or who can’t take morphine.

Fentanyl comes in several forms for treating different types of pain. Fentanyl skin patches are used for controlling stable background pain. The patches can’t control unstable or short term pain. Fentanyl also comes as tablets, lozenges, films and nasal sprays for treating breakthrough pain.

**Buprenorphine**
This is another option for people whose pain is stable and who can’t take drugs by mouth. It is available as a skin patch and as a tablet that you dissolve under your tongue.

**Methadone**
Methadone can be taken by mouth as a liquid, tablet or capsule. You can also take it as an injection. Sometimes, doctors give it as a suppository into the back passage (rectum).
Methadone works for different lengths of time in different people. For this reason, it may only be offered by doctors who have a lot of experience in using it.

**Tapentadol**

Tapentadol is a tablet that you take by mouth, normally twice a day. This is a fairly new painkiller and we need more research to show how well it works. But it looks like it works as well as morphine.

"Take painkillers as soon as you experience any pain. Don’t feel you have to suffer in silence or that it’s better not to take them. Dealing with pain quickly and effectively will improve the quality of your life."

**Side effects of opioids**

Like all medicines, opioids can cause side effects. We describe the most common side effects here but you may not get all or any of these. Some side effects settle down within a few days of starting a new drug. Other side effects may last longer.

Speak to your medical team if you have any side effects. It may not always be clear what is causing your side effects because the cancer can sometimes cause similar symptoms. Your medical team may lower the dose of your painkillers. Or they may give you a different opioid drug or another type of pain relief, like a nerve block or radiotherapy (see pages 35 and 37).

You can also ask our specialist nurses on our free Support Line any questions you have about side effects of opioids.
Constipation

Opioids can cause constipation (problems opening your bowels) in some people. Fentanyl and tapentadol may be less likely to cause constipation than morphine.

Your doctor may give you medicines, called laxatives, to prevent or treat constipation. If you are taking morphine, you should start taking a laxative straight away.

Tiredness

Another common side effect of opioids is sleepiness. You may have this when you first start taking a new opioid, or when you change the dose. Drinking alcohol can make this worse.

You should not drive if you feel sleepy, if you have just started a new opioid painkiller or if you have recently changed the dose. You are legally allowed to drive when you are taking opioids as long as the drug doesn’t affect your ability to drive. You should carry proof that you’ve been given opioids for a medical condition – for example a copy of your prescription, or the information leaflet that comes with the medicine. The Department for Transport has more information about this (see page 61 for contact details).

Sickness and dry mouth

Opioids can make you feel and be sick (nausea and vomiting). This usually gets better after five to ten days as your body gets used to your painkillers, but it can last longer for some people. Your doctor may give you a medicine to prevent sickness.

You may also get a dry mouth. Some people find that drinking plenty of water, sucking ice cubes or chewing gum helps.
Other side effects
Other possible side effects of opioid painkillers include:
- problems sleeping
- mood changes
- sensing things that aren’t there (hallucinations)
- itchy skin
- muscle twitches or jerks.

Speak to your medical team if you have any of these.

Questions to ask

What type of painkiller should I take?

Can you give me written information on how and when I should take painkillers or other drugs?

What pain relief should I take for breakthrough pain, and how should I use it?

What side effects might I get?

Should I take anything to prevent side effects?

What should I do if the pain doesn’t get better?
Section 7

Other types of pain relief

As well as painkillers, there are other types of pain relief for pancreatic cancer. These include other drugs, nerve blocks, radiotherapy, chemotherapy, transcutaneous electrical nerve stimulation (TENS), cognitive behavioural therapy and complementary therapies.
**Other drugs**

Your medical team may offer you drugs that are usually used to treat other health problems but that work together with painkillers to relieve pain. These are called adjuvant drugs.

Tricyclic anti-depressants or anti-convulsant drugs are usually used to treat depression and epilepsy. They are also used to treat some types of pain. They can be used together with opioid and non-opioid painkillers to control nerve pain (see page 13). It can take a few days for these drugs to have an effect on your pain. Taking these drugs does not mean that you are depressed or have epilepsy.

Anti-depressant drugs that may be used include amitriptyline and imipramine. Anti-convulsant drugs used include gabapentin, pregabalin, carbamazepine and phenytoin.

If the cancer has spread to your bones, you may take drugs called bisphosphonates, which treat the pain and make the bone stronger. Macmillan Cancer Support have more information about bisphosphonates.

**Nerve blocks**

A nerve block is a treatment that blocks nerves from sending messages to the brain, and so treats pain. You may be able to have a nerve block on the nerves in the coeliac plexus (see page 13).

You may have a nerve block if you have nerve pain or soft tissue pain and you need more pain relief, alongside your opioid painkillers. After having the nerve block, you may be able to reduce your dose of opioid painkillers.
Nerve blocks can work well for some people but they don’t work for everyone. They may be less likely to work if the cancer has spread to the lymph nodes near the pancreas. Lymph nodes are tiny oval structures throughout the body that are part of the immune system.

If you decide to have a nerve block, you will see a team that specialises in managing pain. They will explain what will happen and answer your questions. You will continue to have other pain relief while you wait to have the nerve block.

You will have a local anaesthetic so you won’t feel any pain during the procedure. You may also have a medicine to relax you. The doctor will then use needles to inject alcohol into the nerves. They can do the procedure in different ways. The most common way is for you to lie on your front and the needles are passed through your back.

Sometimes, doctors use an endoscopic ultrasound scan (EUS) to guide the needles into the right place. An endoscope is a long, thin tube with an ultrasound probe at the end. The doctor passes the endoscope through your mouth and down your throat. The probe uses sound waves to create a picture of the inside of your body. You will lie on your back, and the doctor will pass the needles through your upper tummy area. Using an EUS to guide the needles may cause fewer side effects and give pain relief for longer, but we need more research into this.

Read more about having an EUS in our fact sheet, How is pancreatic cancer diagnosed? and on our website at pancreaticcancer.org.uk/tests
You may get loose and runny stools (diarrhoea) or low blood pressure for a few days after having a nerve block. Very occasionally, nerve blocks can cause temporary weakness in the legs. In rare cases, this weakness can be permanent.

A less common way of blocking pain signals involves cutting the nerves during surgery. This is called thoracoscopic splanchnicectomy.

Speak to your medical team about whether you may benefit from a nerve block if your pain isn’t well controlled.

Questions to ask

- Is a nerve block suitable for me?
- What are the risks and benefits of a nerve block?
- What type of nerve block can I have?
- If I have a nerve block, where and when will I have it?

Radiotherapy and chemotherapy

Radiotherapy can help to control some types of pain, for example bone pain. This is called palliative radiotherapy. Radiotherapy can also shrink the cancer, which may help to relieve pain.

Palliative chemotherapy can slow down the growth of the cancer and may help to relieve your symptoms, including pain.
Ask your medical team about these treatments early on to see if they may be suitable for you. Getting help early will help you get the most out of the treatment.

Find out more in our factsheets, Radiotherapy for pancreatic cancer and Chemotherapy for pancreatic cancer, or on our website at pancreaticcancer.org.uk/treatments

TENS
Transcutaneous electrical nerve stimulation (TENS) involves using a small, battery-powered machine that you can carry around. You place sticky pads onto your skin, which give out pulses of small electrical currents. This feels tingly on your skin.

The currents temporarily block nerves from sending pain messages to the brain. They may also stimulate the body to produce its own natural painkillers, called endorphins.

We need more research to show how well TENS machines work for people with cancer pain. But they are easy to use and rarely cause any side effects.

Cognitive behavioural therapy
Cognitive behavioural therapy (CBT) can reduce pain, improve your daily life and help with depression. It works by teaching you how to change the way you think or act when you feel pain, which can help you cope with it. For example, you can learn how to replace negative thoughts with planned phrases like, ‘I have pain now but it will get better soon.’
Your GP can give you details of NHS and private CBT therapists.

**Physical activity**

Regular physical activity, such as going for a short walk, may help improve your mood and how you feel. It may also help you cope better with your pain, but we need more research to show that it helps people with pancreatic cancer pain. Speak to your medical team before starting any exercise plan.

You can read more about physical activity in our booklet, *Diet and pancreatic cancer*, and on our website at [pancreaticcancer.org.uk](http://pancreaticcancer.org.uk)

**Complementary therapies**

Some people find that complementary therapies help them deal with pain. Complementary therapies work alongside your medical treatments. Don’t stop any cancer treatments without speaking to your doctor first.

Complementary therapies don’t work for everyone, and there isn’t much evidence to show that they work. But they may help you feel in control of your pain, which may mean you feel less pain.

Hospitals, hospices and local charities may offer some complementary therapies. Physiotherapists may use massage, heat and cold, acupuncture and other physical therapies.

Always tell your medical team before you start a complementary therapy, as some may affect your cancer treatment. And tell your complementary therapist about your cancer treatments. The Complementary & Natural Healthcare Council have a list of
registered therapists. We describe some of the most common complementary therapies here. Macmillan Cancer Support’s booklet, *Cancer and complementary therapies*, has more information.

“Complementary therapy made my days and pain more bearable. It gave me a positive focus amidst a day packed with tests and observations.”

**Acupuncture**

Acupuncture uses fine needles which are inserted just under the skin, in specific places in the body. Acupuncture needles are so fine that they shouldn’t hurt, although you may feel a tingle or dull ache as they go in.

There is limited evidence that acupuncture may help with cancer pain. Needles placed in the ear may help people with nerve pain but we need more research into this.

**Massage**

Some people find massage calming and relaxing. It may help to reduce pain and help you feel better generally.

You should not have massage in the area of your cancer or near enlarged lymph nodes. So avoid the tummy area and upper back. People with advanced cancer who have problems with bleeding should avoid deep tissue massage.

“When my partner started to get referred pain into his shoulder, what he said helped was me massaging his shoulder. He would often fall asleep straight after as the pain subsided for a while.”
Reiki is a gentler type of massage where the therapist’s hands gently brush over the body. This may be useful for people who can’t have regular massage.

Reflexology is a type of massage that involves putting pressure on parts of the hands or feet. This may help to relieve pain in other parts of the body.

“One of the things my daughter absolutely loved was having her feet massaged with lavender oil and lovely smelling creams. This really seemed to help relax her and I think helped with easing pain and discomfort.”

**Relaxation therapies**

Relaxation therapies like meditation and hypnotherapy may help you to cope with pain.

Meditation involves concentrating to calm your mind and relax your body. Mindfulness is a type of meditation where you focus on what is happening at that moment in time. It helps you to manage your thoughts and cope with your feelings. Some members of your medical team may be able to teach meditation and mindfulness, or they can give you details of local teachers. The Be Mindful website has more information and contact details of teachers.

Hypnotherapy is a type of deep relaxation that can help you change the way you think about pain. It can also help you feel better able to cope with pain. You can get details of hypnotherapists from the British Society of Clinical Hypnosis.
Visualisation

Visualisation or imagery can help to distract you from pain. A therapist will help you use your imagination to think of, or remember, pleasant or positive situations. For example, you may remember the sights and smells of a favourite place. Or you may imagine yourself feeling stronger. A therapist can also teach you how to practice visualisation yourself at home.

Art and music therapies

Art therapy allows you to express your emotions through art, such as painting or drawing. It can help you cope with pain and improve your daily life by helping you to express your emotions. Talking to an art therapist about your art can help you to start talking about how you feel and may help you feel more in control.

Music therapy involves using musical instruments or recorded music to express yourself. There isn’t much evidence to show that it works but it may reduce pain and anxiety and help to improve your daily life.

Questions to ask

What else might help with my pain?

Are there any complementary therapies available that might help?

Can you give me details of any local therapists?
Section 8

Coping with pain

There is support available to help you cope with pain. There are also some things you can do yourself.
Getting help for pain early on can help you to cope better. Pain can affect your mood. For example, you may feel worried about being in pain, have trouble eating or sleeping, or find it hard to concentrate.

The amount of pain you have may not be linked to how advanced your cancer is and doesn’t always mean that the cancer is growing. It’s really important to tell your medical team about any changes to your pain, so they can make sure you have the right dose of pain relief (see page 20).

People with pancreatic cancer may be more likely to have depression. Symptoms of depression include feeling very down, low, hopeless, or losing interest in things that used to give you pleasure. It is normal to feel this way when you are first diagnosed, but these feelings should start to improve over time. If these feelings are stronger than normal or if they don’t get better, speak to your medical team. Getting depression diagnosed and treated may help you cope with pain by helping you to feel more in control and better able to ask for help.

You can read more about depression on our website at pancreaticcancer.org.uk/coping

If you are struggling at all, speak to your medical team. They can answer your questions, find ways to manage the pain and help you deal with it. Don’t stop taking your pain relief or change your dose without speaking to your medical team first.
How can I help myself?

There are things you can do at home to distract yourself from pain or help you feel better about yourself. You could try reading a book, watching television or listening to music. Chatting to family and friends may also help. And you could try some of the complementary therapies on page 39.

“My daughter was my focus. On bad days the pain would be so severe but she gave me something to smile for and it helped immensely.”

“My husband had upper abdominal pain, radiating to his back. The only relief from the pain was having a hot bath.”

“If I didn’t prepare for the days I was in a lot of pain, my daughter wouldn’t have been fed or gone to preschool.”

Finding out more

Some people feel more in control of their pain when they find out more about their cancer, their pain, and how it can be managed. Even if you don’t want to know everything about pancreatic cancer, make sure you speak to your medical team, ask them questions, and understand your treatment options.

We have information about pancreatic cancer on our website at pancreaticcancer.org.uk/informationandsupport
You can also call our specialist nurses on our free Support Line. They have time to listen to your concerns and answer questions about any aspect of pancreatic cancer. The Support Line is open Monday-Friday, 10am-4pm. Call free on 0808 801 0707, or email support@pancreaticcancer.org.uk

**Talking about it**

Talking about your cancer, the pain, and how you are feeling can help you cope with pain. Family and friends can be a fantastic support. It might help to talk to them about ways that they can help you.

Some people prefer not to talk to family or friends – for example because they don’t want to worry them. You can also talk to your medical team. You should have a main contact, or keyworker, who will usually be a specialist nurse. They can provide emotional support as well as medical care.

You may find it helps to talk to others affected by pancreatic cancer, who can understand what you are going through. We have an online discussion forum for anyone affected by pancreatic cancer. And there are support groups around the country where you can meet others.

“I found that online support groups really helped. Talking virtually to people all over the world who also had a loved one with pancreatic cancer. Hearing their stories, sharing hopes and fears and receiving support and virtual love.”
Some people find counselling helpful. This involves talking to a trained counsellor, who can help you talk about and deal with your feelings. If you’re interested in counselling, speak to your GP or nurse – they may be able to refer you. Cancer centres and Maggie’s centres sometimes have counsellors. You can find more information about counselling from the British Association of Counselling and Psychotherapy.

**Spiritual beliefs**

Having cancer can make some people think more about their spiritual and religious beliefs. They may start to question their beliefs, or they may begin to think about what their beliefs are. Support with talking about your spiritual beliefs can help you cope with your cancer and pain. You can speak to others who are in the same situation, health professionals, family and friends or religious or spiritual leaders.

**Questions to ask**

- What can I do myself to help with pain?
- Where can I get support to help me cope?
- Are there any local support groups I could join?
- Would counselling be helpful for me?
Section 9

Information for family, friends and carers

Family and friends often provide vital emotional and practical help to people with pancreatic cancer. But you may also need support yourself, to help you both cope.
It can be difficult seeing someone you love in pain. Supporting or caring for someone with pain can affect you physically, emotionally and financially. But you may be providing a huge amount of support to them.

For example, you may have taken on some caring responsibilities for them. You may help them with their medication and make sure supplies aren’t running low, particularly at weekends. Or you may need to act on their behalf if they’re not able to speak to the medical team, for example by describing the pain they’re having and reporting any side effects of the pain relief.

There is support available for you – read more in our booklet, *Caring for someone with pancreatic cancer: Information for families and carers.*

You can also speak to our specialist nurses on our free Support Line about any questions or concerns.

“It really helped having good friends to listen to me and other members of my family to talk to.”

“I remember keeping flowers very visible in my daughter’s room so that she was always able to see them and I moved them whenever I turned her so she always had something lovely to look at. I think these quite small details were extremely important for both myself and my daughter.”
Section 10

Further information and support

In this section, we provide a place for you to record your pain relief, explain some key medical words, and provide information about our services and other organisations that can support you.
My pain relief

You can ask your pharmacist for a list of all your medicines and when you need to take them. Or you can record the details here to help you remember the pain medicines you are taking, and when to take them.

The list on page 52 has space for you to record the details of each medicine.

The list on page 53 is for you to write down the time when you take each dose. Remember to include any top-up doses you take. You’ll need a new list each week.

You might want to photocopy these pages, or you can download more copies from our website at pancreaticcancer.org.uk/pain

You could take these lists with you to your appointments and if you go into hospital or a hospice. Speak to your doctor if you are having trouble remembering when to take your medicines.
### Pain medicines I’m taking

<table>
<thead>
<tr>
<th>Name of medicine</th>
<th>Description</th>
<th>Dose</th>
<th>How often I take it</th>
<th>What I take it for</th>
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## Record of when to take pain medicines

Week beginning ____________________________

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<th>Medicine</th>
<th>Time</th>
<th>Tick when taken</th>
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### Top-up doses taken

<table>
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<th>Date</th>
<th>Time</th>
<th>Medicine and dose</th>
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Glossary

We have explained some of the medical words that you may hear when you are finding out about, and being treated for, pancreatic cancer pain.

You can find more medical words in our Useful medical words on our website at pancreaticcancer.org.uk/medicalwords

Acute pain: short-term pain that comes on quickly.

Adjuvant: treatment given alongside or after the main treatment.

Analgesic: a medicine that relieves pain.

Background pain: ongoing pain that you can manage with regular pain relief.

Breakthrough pain: short bursts of severe pain that come on quickly and last for a few minutes or a few hours. It “breaks through” your regular pain relief.

Chronic pain: long term pain.

Digestion: digestion is what your body does to break down your food to get the nutrients from it.

Enzymes: substances produced by different glands in the body, including the pancreas. Different types of enzymes have different roles in the body. Pancreatic enzymes help to break down our food and drink.
Hospice: a place where you can get medical care for an illness that can’t be cured. Many also offer complementary therapies and spiritual and social support. Hospices are smaller and quieter than hospitals. You can visit a hospice during the day, or you can stay for short visits or for longer periods of time.

Jaundice: a symptom of pancreatic cancer. It develops when there is a build-up of a substance called bilirubin in the blood. Symptoms include yellow skin and eyes, and itching.

Neuropathic pain: pain caused by damage to nerves or pressure being put on nerves. It can feel like a burning, shooting, tingling or stabbing pain.

Palliative care: a range of care for people with an illness that can’t be cured. It aims to provide physical, emotional, spiritual and social support to help improve people’s daily life. It’s not just for people at the end of their life.

Refractory pain: pain that is difficult to manage or is no longer controlled by pain relief.

Visceral pain: pain caused by damage to organs or soft tissue in the body. It can feel like a deep, squeezing or sharp pain.
Multidisciplinary team (MDT) members

Use this space to record the names and numbers of the key professionals involved in your treatment and care.

Out of hours or emergency contact

Name:

Telephone:

Notes:

Keyworker
The keyworker is your main point of contact. They will often be a specialist nurse.

Name:

Telephone:

Email:

Notes:

Specialist Nurse
A nurse who provides expert care and advice about a condition, such as pancreatic cancer. The specialist nurse may be your main contact or keyworker.

Name:

Telephone:

Email:

Notes:
Consultant oncologist
A doctor who treats cancer with treatments such as chemotherapy or radiotherapy.

Name:

Telephone:

Email:

Notes:

Consultant surgeon
A doctor who carries out surgery.

Name:

Telephone:

Email:

Notes:

Hospital palliative care team
A team of professionals who can help you manage your pain and other symptoms at hospital. The team may include doctors, specialist nurses, physiotherapists, occupational therapists, psychologists and counsellors.

Name:

Telephone:

Email:

Notes:
**Community palliative care team**
Similar to the hospital palliative care team, but they may visit you at home or arrange an outpatient appointment to help you manage your pain. Some teams are based at hospices.

**Name:**

**Telephone:**

**Email:**

**Notes:**

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**Pain specialist**
A doctor or nurse who helps manage pain.

**Name:**

**Telephone:**

**Email:**

**Notes:**
Pancreatic Cancer UK services

We are here for everyone affected by the pancreatic cancer.

We’re here to support and to listen

Our free and confidential Support Line is a lifeline for thousands of people affected by pancreatic cancer. Our specialist nurses understand the issues you might be facing and their expert help will support you in coping with pancreatic cancer.

Call free on 0808 801 0707 weekdays 10am-4pm, or email support@pancreaticcancer.org.uk

We’re here with the information you need

We have the most up-to-date information on everything you need to know about pancreatic cancer. We can help you every step of the way through diagnosis and treatment options, to managing your symptoms and the care you receive.

Go to pancreaticcancer.org.uk/informationandsupport

Download or order our free publications at pancreaticcancer.org.uk/publications or call 0808 801 0707

We’re here so you can share

Our Forum is a supportive place where everyone affected by pancreatic cancer can be there for each other online, any time of day or night: forum.pancreaticcancer.org.uk

Local support groups mean you can meet other people to share your experiences: pancreaticcancer.org.uk/supportgroups

Our Living with Pancreatic Cancer Information Days provide local face to face support in an informal setting for people with pancreatic cancer: support@pancreaticcancer.org.uk
Useful organisations

Be Mindful
www.bemindful.co.uk
A website from the Mental Health Foundation, offering an online mindfulness course and details of teachers.

British Association of Counselling and Psychotherapy
www.itsgoodtotalk.org.uk
Tel: 01455 883 300 (Mon-Fri 9am-5pm)
Information about counselling and a database of registered therapists.

British Pain Society
www.britishpainsociety.org
Information on pain clinics, pain management programmes and other ways of managing pain.

British Society of Clinical Hypnosis
www.bsch.org.uk
Tel: 01262 403 103
Information about choosing a hypnotherapist and a database of registered therapists.

Cancer Research UK
www.cancerresearchuk.org
Helpline: 0808 800 4040 (Mon-Fri 9am-5pm)
Information for anyone affected by cancer.
Complementary & Natural Healthcare Council  
www.cnhc.org.uk  
Tel: 020 3668 0406 (Mon-Fri 9.30am-5.30pm)  
Information about complementary therapies and a register of therapists.

Department for Transport  
www.gov.uk/drug-driving-law  
Information on drugs and driving, including medicines for pain relief.

Electronic Medicines Compendium  
www.medicines.org.uk/emc  
Patient information leaflets for all licensed medicines.

Healthtalk  
www.healthtalk.org  
Personal experiences presented in written, audio and video formats, including people talking about pancreatic cancer.

Hospice UK  
www.hospiceuk.org  
Tel: 020 7520 8200  
Information about hospices, and a database of hospices in the UK.

Macmillan Cancer Support  
www.macmillan.org.uk  
Support Line: 0808 808 00 00 (Mon-Fri 9am-8pm)  
Provides practical, medical and financial support for anyone affected by cancer.
Maggie’s Centres
www.maggiescentres.org
Centres around the UK and online offer free, comprehensive support for anyone affected by cancer.

Marie Curie
www.mariecurie.org.uk
Support line: 0800 090 2309
(Mon-Fri 8am-6pm, Sat 11am-5pm)
Provides care and support for people living with a terminal illness, and their families.

Pain Association Scotland
www.painassociation.com
Tel: 0800 783 6059 (Mon-Fri 8am-4.30pm)
Provides professionally led pain management to people with long-term pain.

Pain Concern
www.painconcern.org.uk
Helpline: 0300 123 0789 (Mon & Fri 1-4 pm, Wed 10 am-1 pm)
Information and support for people with pain, and their families.
This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK. It has been reviewed by health professionals and people affected by pancreatic cancer.

References to the sources of information used to write this booklet, and a list of health professionals who reviewed it, are available on our website – pancreaticcancer.org.uk

Pancreatic Cancer UK makes every effort to make sure that our services provide up-to-date, unbiased and accurate information about pancreatic cancer. We hope that this information will add to the medical advice you have received, and help you make decisions about your treatment and care. This information should not replace information and advice from your medical team – please speak to your doctor, nurse or other members of your medical team about any questions or concerns.

Give us your feedback
We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions.

Email us at publications@pancreaticcancer.org.uk or write to the Information Manager at the address on the back cover.

The photographs in this booklet are of people affected by pancreatic cancer, including family members, as well as people who haven’t been affected by pancreatic cancer.