Pancreatic
CANCER UK

Pain and pancreatic cancer

Introduction

This booklet is for you if you have pancreatic cancer and have pain. Family and friends may also find it helpful. It describes what causes pain and ways of treating it.

If you have pain, asking for help early on will help you deal with it. If you have any questions or are worried about pain, speak to your medical team. You can also speak to our specialist nurses on our free Support Line.

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**

Contents

What is pain and what causes it? 4

Who can help manage my pain? 11

Painkillers 14

Nerve blocks and other types of pain relief 28

Dealing with pain 38

More information and support 43

How to use this booklet

You don’t have to read this booklet all at once. Look at the contents on page 2, read the sections that feel most helpful, and read other sections later if you need to know more. There is more information available on our website and we provide a lot of support (see page 44). Find out more at **pancreaticcancer.org.uk**

Use the colours below to help you find out where you can get more help.

Call our Support Line free on **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**

Read more on our website at:
pancreaticcancer.org.uk/information

Order or download our free booklets at:
pancreaticcancer.org.uk/publications

Questions to ask your doctor, nurse or dietitian

Things you can do to help yourself

At the end of the booklet you will find:

- A list of common medical words on page 43.
- Contact details for organisations we mention on page 45.

What is pain and what causes it?

Key facts

- Pain is your body's way of telling you that something isn't right.
- Tell your doctor or nurse about any pain as soon as possible. Early treatment can make pain easier to deal with.
- Palliative care and supportive care teams provide specialist care for people with cancer that can't be cured. They manage complex symptoms, including pain. These services aren't only for people at the end of their life.
- The cancer can cause pain or discomfort in different ways. It may affect nerves near the pancreas, or block the bowel. It can also cause a build-up of fluid, which is called ascites.
- The pancreas is involved in digesting food, but pancreatic cancer can affect this. Problems with digestion can cause pain or discomfort.
- Some treatments for cancer can cause pain. For example, if you have surgery, you may have some pain or discomfort while your body heals.
- Your emotions can also affect your pain. Practical and emotional support can help.

Speak to our specialist nurses on our Support Line with any questions or worries.
Call free on **0808 801 0707** or
email **nurse@pancreaticcancer.org.uk**

What is pain?

Many people with pancreatic cancer have pain at some stage. But pain can be managed, so ask for help as early as you can. Read about treatments for pain on page 14.

Everyone experiences pain differently. People sometimes think of pain as something they only feel in their body. But your mind and body work together and influence each other.

This means that your emotions, your relationships with people and your beliefs can affect how you feel and react to pain. For example, your pain may seem worse at times when you have a lot to cope with, or when you don't feel you are getting the support you need. Your pain may also be worse when you are tired.

You can find out more about dealing with pain on page 38.

What does it mean if my pain gets worse?

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 doctor or nurse about your worries. They can help you understand what your pain means, and help you deal with it. The sooner your pain is treated, the better the chances of getting it under control.

Types of pain

You may have different types of pain.

- Nerve (or neuropathic pain) is described by some people as **shooting, stabbing or burning or like pins and needles**. Others describe nerve pain as feeling like a toothache type pain. Nerve pain may also spread like a band around your waist.
- Soft tissue (or visceral) pain may feel **dull, deep, squeezing, aching or cramping**.
- Background pain is **ongoing pain that you can manage with regular pain relief**. If it isn't fully controlled, you may have pain shortly before your next dose of pain relief.
- 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.
- Incident pain is similar to breakthrough pain, but it is **caused by an activity, like moving around**.
- Bone pain is not very common in pancreatic cancer. People describe it as **aching or throbbing, or a gnawing pain** like toothache which some people notice in their back. They may have an area that's tender.

Different types of pain are treated differently. It is important to tell your doctor about any pain, or if your pain changes.

Read more about different types of pain on our website at: **pancreaticcancer.org.uk/types-of-pain**

What causes pain?

The cancer and some treatments can cause pain.

How does the cancer cause pain?

- The cancer can press on a **bundle of nerves called the coeliac plexus**, which is near the pancreas. This causes pain in the tummy or back. Painkillers or a nerve block may help with this.
- The cancer can also cause pain by **blocking the duodenum** (the first part of the small intestine) or causing a **build-up of fluid (ascites)**. If the cancer has spread, it can cause **pain in other parts of the body**.
- The pancreas plays an important role in **digesting food**. Pancreatic cancer can affect this, and cause symptoms including tummy discomfort or pain, cramps, wind and bloating. **Pancreatic enzyme replacement therapy (PERT)** can help manage these symptoms.

How do treatments cause pain?

- Some people may have **surgery** to remove the cancer, or to treat a blocked duodenum or bile duct. The bile duct is a tube that takes bile (a fluid) from the liver to the small intestine. It is normal to have some pain and discomfort for a few weeks after surgery. This is **managed with painkillers** and will improve.
- **A stent** is a small tube that opens a blocked bile duct or duodenum. It is used to treat symptoms such as jaundice or sickness. You may have tummy pain for a few days after the stent is put in. This can be **managed with painkillers** and will improve.

- **Chemotherapy** can sometimes have uncomfortable or painful side effects. These include peripheral neuropathy, which causes pain or tingling in your hands or feet. Chemotherapy can also cause a sore mouth, or joint and muscle pain. **Tell your doctor or nurse about side effects**.
- **Constipation** is when you find it harder to poo. This can be very uncomfortable or painful. Some medicines, including opioid painkillers and anti-sickness medicines can cause constipation. There are ways to manage it, including **medicines called laxatives**.

Read more about these treatments for pancreatic cancer at: **pancreaticcancer.org.uk/treatments**

Read about managing symptoms and side effects at: **pancreaticcancer.org.uk/managingsymptoms**

Metastatic spinal cord compression

Sometimes the cancer can spread to the bones in the spine or tissues around the spinal cord and can press on the spinal cord. This is called **metastatic spinal cord compression (MSCC)**. It is rare but is serious and needs urgent medical attention. Symptoms can include pain in your back or neck or numbness in your arms, legs or around your bottom. It can also cause problems controlling when you poo or pee (incontinence).

It's important that you contact your medical team, GP, or go to A&E straight away if you have these symptoms.

Macmillan Cancer Support has more information about MSCC.

Your feelings and beliefs

Many things can affect the way you feel pain, including:

- how you feel about dealing with pain
- stress and worry
- feeling tired
- depression
- your spiritual or religious beliefs
- your relationships with other people, like your family, friends or medical team.

There are things that can help you deal with the emotional effects of pain and pancreatic cancer. Read more on page 39.

Questions to ask your doctor or nurse

What is causing my pain?

How can it be managed?

Are my treatments likely to cause uncomfortable or painful side effects?

Would pancreatic enzyme replacement therapy (PERT) help with my digestion?

Who can help manage my pain?

The doctors and nurses who can help you manage your pain may include your:

- GP
- district nurse (also called community nurse)
- clinical nurse specialist (CNS)
- or hospital team.

You may also be referred to other services, such as a specialist palliative care team, a supportive care team or a hospice if you have cancer that can't be cured. Seeing these services early on can make it easier to deal with your pain.

What are palliative care and supportive care?

Palliative care teams help people with cancer that can't be cured to live as well as possible for as long as possible. They are not just for people at the end of their life. Some hospitals also have supportive care teams. These aim to see people at a very early stage in their cancer treatment to manage their symptoms.

Working with your medical team, these specialist teams provide care to manage complex symptoms such as pain. Early palliative or supportive care can help manage your symptoms more effectively.

If you haven't seen a palliative care or supportive care team and need more support speak to your GP or medical team about referring 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 I need help with pain out of hours?

Your doctor or nurse should give you a phone number for help at night or at the weekend. If you haven't been given a number, ask them about it. There may also be an out of hours number on your GP's answer phone message.

If you live in England, Wales or Scotland, you can call the NHS on 111 for advice out of hours. In Northern Ireland, there are local out of hours phone numbers on the nidirect website.

Read more about palliative care, supportive care and hospices on our website at: **pancreaticcancer.org.uk/palliative**

> "Get help as soon as possible for your pain, the earlier it's treated the better. There's nothing wrong with asking for help."

What can I do?

- Talk to your doctor or nurse about any pain you have or any other worries.
- Ask who you should contact if your pain gets worse.
- Find out who to contact if you need help at the weekend or at night.
- Speak to your doctor or nurse about whether a specialist palliative or supportive care team could help.

Painkillers

Key facts

- There are different types of painkillers used to treat pancreatic cancer pain.
- Non-opioid painkillers include paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs), like ibuprofen or naproxen.
- Opioid painkillers include morphine and oxycodone.
- There are also other medicines that are usually used to treat other health conditions, but can also be used to relieve pain (see page 30).
- Painkillers come in different forms, including tablets, granules or tablets that dissolve, liquid or a patch on your skin. Or they may be given through a syringe pump (see page 16).
- You are likely to take more than one type of painkiller to help your pain.

In this booklet, we use the general (generic) name of each drug, rather than the brand name.

How are painkillers taken?

Your doctor or nurse will tell you how and when to take your painkillers, and how long the pain relief should last. They should also explain any possible side effects.

It’s important to follow your doctor’s instructions. For example, you may need to take your painkillers at regular times, to stop the pain coming back when the medicine wears off. Pain can be harder to control if you wait until your pain is bad before taking painkillers.

Your doctor and nurse should check your pain regularly to make sure your painkillers are working well. Tell them if your pain gets worse. They will look at your painkillers, and may increase the dose or add different painkillers.

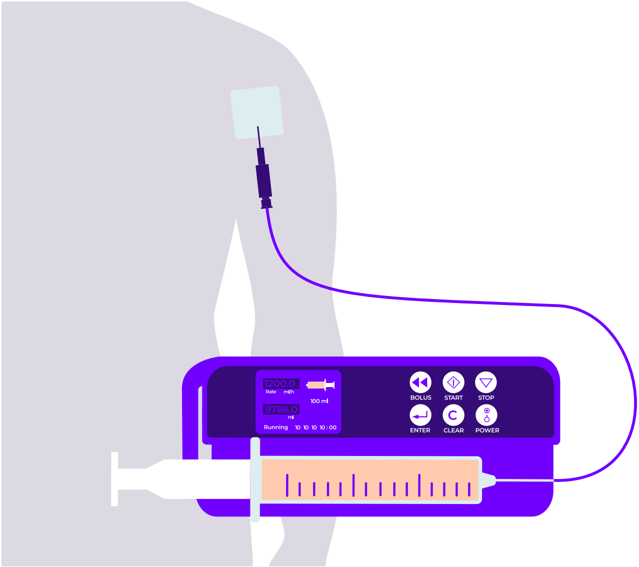
What is a syringe pump?

A syringe pump (also called a syringe driver) provides a steady flow of painkillers. It is a small battery operated machine which is attached to a needle that is put under the skin. This needle is then replaced with a plastic tube. A doctor or nurse will set it up for you.

A syringe pump is used if you can’t swallow medicines, are being sick or your bowel can’t absorb medicines. It’s also used if your drugs can only be given by injection.

A syringe pump can also be used for other medicines, such as anti-sickness medicine. You can move around with a syringe pump, and can use it at home.

Diagram of a syringe pump



What can I do?

- Tell your medical team as soon as you can about any new pain or any pain that has got worse. This will help them manage it as well as possible.
- Keep a record of things like where the pain is, how bad it is on a scale of 0 to 10, how it affects everyday things like sleeping, and whether anything makes it better or worse.
- You could use a pain diary or mobile phone app to record your pain. Ask your doctor or nurse if they can recommend anything.
- If you are taking lots of medicines, you could use a pill box, to help you remember when to take them. Ask your nurse for any other tips.

Side effects

Painkillers can cause side effects. Ask your doctor or nurse about side effects of the painkillers you are taking.

Tell them if you get any side effects. They may prescribe medicine to prevent or treat side effects, or they may change the painkiller. Don't stop taking your painkillers without speaking to your doctor or nurse first.

Tell your doctor or pharmacist about any other medicines you are taking. Medicines can affect each other, causing more side effects or stopping another drug from working. This includes drugs you can buy at your local pharmacy, like ibuprofen and paracetamol, and some herbal remedies.

Non-steroidal anti-inflammatory drugs (NSAIDs) and paracetamol

Non-steroidal anti-inflammatory drugs (NSAIDs) include ibuprofen and naproxen. They can help with some types of pain, such as tummy pain or bone pain. Paracetamol can also help with pancreatic cancer pain, even if the pain is bad.

Paracetamol and NSAIDs can be taken with opioid painkillers (see page 20) or with other types of pain relief (see page 30).

Medicines you buy, like cold and flu medicines, often include paracetamol or NSAIDs. Always check with the pharmacist or your doctor before taking them so that you don't take too much by mistake.

Side effects of NSAIDS

NSAIDs can cause side effects which include stomach problems like indigestion and runny poo (diarrhoea), so you should take them after food. There is also a risk that they could cause stomach ulcers. Your doctor or nurse may give you medicine to prevent stomach ulcers if they think you are at high risk.

Chemotherapy and paracetamol or NSAIDs

Chemotherapy can increase your risk of an infection, which can be serious and needs urgent treatment. Paracetamol or NSAIDs can lower your temperature and hide signs of an infection.

If you are having chemotherapy, always check your temperature before taking paracetamol or NSAIDs. Call the chemotherapy 24 hour emergency number if you have a high temperature, based on the advice of your chemotherapy team. Also call them if you have symptoms of an infection and are taking regular paracetamol.

Read more about chemotherapy and infections in our fact sheet: **Chemotherapy for pancreatic cancer**
Or at: **pancreaticcancer.org.uk/chemotherapy**

Opioid painkillers

There are different types of opioid painkillers, including weaker and stronger opioids. They may be taken in different ways, and have different side effects. You may take them with other types of pain relief (see page 30). The type of painkiller you have will depend on what kind of pain you have, and your general health.

Different types of opioids

Weaker opioids include codeine, dihydrocodeine and tramadol. Stronger opioids include morphine, oxycodone, fentanyl, buprenorphine and methadone.

Some stronger opioids are available in two forms:

- fast acting opioids, which are also called immediate release
- long acting opioids, which are also called slow or modified release.

Fast acting opioids

Fast acting (immediate release) opioids start to work after about 20 minutes and reach full effect after about an hour. This makes them good for treating breakthrough pain (see page 7) or sudden changes in pain.

You may start off with a fast acting opioid.

Long acting opioids

You usually take a **long acting (modified release) opioid** twice a day to control background pain (see page 7). These opioids take longer to have the full effect. So you must take them regularly at the same time of day for them to work properly.

Your doctor or nurse will work out the best dose for you that manages your pain with as few side effects as possible. The dose can be increased, so let your doctor or nurse know if you still have any pain.

> “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 explain 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. Others may last longer.

Speak to your doctor or nurse if you have any side effects. Your doctor may prescribe medicine to treat the side effects or change the dose of your painkillers. Or they may give you a different opioid drug or another type of pain relief.

Do not stop taking opioids without talking to your doctor first. Stopping opioids suddenly can make you very unwell.

Constipation

Opioids can cause constipation, which is when you find it harder to poo.

Your doctor or nurse may give you medicines, called laxatives, to prevent or treat constipation. If you are taking a stronger opioid like morphine, you may need to start taking a laxative straight away. You will need to take laxatives as long as you are using stronger opioids. It can also help to drink plenty of water and try to keep active, if you can.

Speak to your dietitian or nurse for any diet tips that might help with constipation.

> “We found that including things like prune juice or syrup of figs into his diet helped with constipation.”

Sickness and dry mouth

Opioids can make you feel and be sick (nausea and vomiting). This usually gets better after two to five days as your body gets used to your painkillers, but it can last longer for some people. Your doctor or nurse will give you medicine to prevent sickness. They may change the type of painkiller if your sickness continues.

You may also get a dry mouth. Drinking water, sucking ice lollies or chewing gum may help. There are also gels and sprays that can help.

If you have white spots in your mouth or a white coating on your tongue, you may have oral thrush. Your doctor can give you medicine to treat this.

Find out more about feeling and being sick on our website at: **pancreaticcancer.org.uk/sickness**

Find tips for coping with sickness and a dry mouth at: **pancreaticcancer.org.uk/diettips**

Tiredness

Another common side effect of opioids is tiredness. You may also feel dizzy or have trouble concentrating. You may have this when you first start taking a new opioid, or when you change the dose. The tiredness will usually go away within a day or two as you get used to your painkillers.

Drinking alcohol can make tiredness worse. Tiredness and trouble concentrating can affect your driving (see page 26).

Tiredness may not just be caused by your painkillers. The cancer and treatment can cause extreme tiredness (fatigue).

Read more about fatigue in our booklet:
Fatigue and pancreatic cancer
Or at: **pancreaticcancer.org.uk/fatigue**

Other side effects

Other possible side effects include:

- mood changes or feeling confused
- having strange dreams
- itchy skin
- problems emptying your bladder completely
- muscle twitches or jerks.

It’s rare but sometimes people may also sense things that aren’t there (hallucinations). Read more on page 25.

Speak to your doctor or nurse if you have any of these side effects, especially if you have recently changed your painkiller. They may check your medicines, change the dose of your painkiller, or give you a different painkiller.

Ask our specialist nurses on our Support Line any questions about opioids and side effects.

Common concerns about opioid painkillers

Some people worry about taking opioid painkillers. We explain some common concerns here.

Do not stop taking opioids without talking to your doctor first. Stopping opioids suddenly can make you very unwell.

Can I get addicted to opioid painkillers?

Addiction shouldn’t be a problem for people with cancer if they take their painkillers as prescribed by their doctor.

Very occasionally, your body can get used to a painkiller if you take it for a long time. This means that a stronger dose, or a different painkiller is needed to have the same effect on your pain. This is known as drug tolerance, which is very different to drug addiction.

Some people worry there will not be a stronger painkiller available if they need it later. But there are many options, so it is important to take your painkillers or increase the dose when prescribed. Your doctor or nurse will help you manage this.

If you are worried about becoming addicted to opioid painkillers, speak to your doctor or nurse. They can explain how the dose is worked out, and can discuss your concerns.

Is there a risk of an overdose with opioid painkillers?

It is important that you follow your doctor’s instructions when taking your painkillers, and don’t take more than they have prescribed. If the painkillers don’t control your pain properly, speak to your doctor or nurse.

Will opioid painkillers make me confused or hallucinate?

Some opioid painkillers can cause confusion or sensing things that aren’t there (hallucinations). But this is rare. Tell your doctor or nurse straight away if the painkillers cause confusion or hallucinations. They will check to see if there is anything else that might be causing this.

Can I drive if I take opioid painkillers?

Your doctor or nurse should tell you if your painkillers will make you feel sleepy, and if this may affect your driving.

You should not drive if you feel sleepy, if you have just started a new type of pain relief, or if you have recently changed the dose. Your doctor or nurse can tell you how long to avoid driving for.

You are legally allowed to drive if you are taking opioid painkillers as prescribed and they don't affect your ability to drive. You should carry proof that you have been given opioids for a medical condition, for example, a copy of your prescription. The Department for Transport has more information about driving while taking strong painkillers.

Can I drink alcohol while taking opioid painkillers?

Alcohol and other medicines can affect the way your painkillers work, or cause side effects such as tiredness. Speak to your doctor before drinking alcohol while taking opioid painkillers.

> "You don't have to endure pain without help or medication. You don't have to put up with it."

Do stronger painkillers mean my cancer is getting worse?

Taking a strong painkiller does not mean your cancer is growing or spreading. Lots of different things can affect the pain you feel. The strength of your painkiller can be reduced or increased as your pain gets better or worse.

If you are taking strong painkillers, it does not mean you will always have to take them.

What if my pain relief isn’t working?

Don’t wait to ask for help with pain. Tell your doctor or nurse straight away if your pain gets worse or is not being controlled.

Your doctor or nurse may increase the dose of your painkillers or change the way you take them. Or they may suggest switching to a different pain relief (see page 28).

If your pain isn’t under control, it may help to have a specialist palliative care or supportive care review. Your GP or hospital team can refer you for this. Read about palliative care and supportive care on page 11.

Questions to ask your doctor or nurse

Can you explain how and when I should take painkillers?

What side effects might I get?

Should I take anything to prevent side effects?

Will other medicines affect my pain relief?

How will these painkillers affect my daily life?

Can I drive if I’m taking opioid painkillers?

What should I do if the pain doesn’t get better or gets worse?

Nerve blocks and other types of pain relief

Key facts

- As well as painkillers, there are other types of pain relief for pancreatic cancer.
- A nerve block is a treatment that blocks nerves from sending messages to the brain, and so treats pain.
- Drugs that are used to treat other health conditions can also be used to relieve pain. These include drugs usually used for epilepsy or depression.
- Chemotherapy can help to slow down the growth of the cancer. It may also help with symptoms like pain.
- Palliative radiotherapy can help with some types of pain.

You can speak to our specialist nurses on our free Support Line if you have any questions about these different types of pain relief.

What is a nerve block?

A nerve block is a treatment that blocks nerves from sending messages to the brain. It interrupts the pain signal. You may be able to have a nerve block on the nerves in the coeliac plexus. This is a thick bundle of nerves behind the pancreas.

You may have a nerve block if:

- you have nerve pain that isn't controlled or
- you have a lot of side effects from painkillers or
- you need increasing doses of painkillers.

A nerve block may mean you can reduce the amount of painkillers you take. Nerve blocks work well for some people, but they don't work for everyone. You may have a nerve block as a one off, or you may be able to have a longer-term nerve block.

Speak to your doctor or nurse about whether a nerve block might be suitable for you.

What does a nerve block involve?

The doctor will use needles to inject medicine such as anaesthetic, alcohol or steroids into the coeliac plexus nerves and stop them working. This will block the nerves from sending pain messages from the pancreas to the brain. It will stop the pain for some time.

You will have a local anaesthetic so you won't feel anything during the procedure, but you will be awake. You may also have a medicine to relax you.

Doctors can do the procedure in different ways. Your doctor may 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 into your mouth and down your throat. The ultrasound probe will create images of the inside of your body. The doctor will use these images to guide the needles through your upper tummy area.

Sometimes, the doctor may guide the needles through your back.

If you find the nerve block helps but the pain gets worse again, talk to your doctor or nurse about having another nerve block.

You can read more about having an EUS on our website at: **pancreaticcancer.org.uk/tests**

Are there any side effects from having a nerve block?

You may have runny poo (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.

Other types of pain relief

Medicines that are usually used to treat other health conditions can also be used to relieve pain. Taking these drugs does not mean that you have the condition they are usually used to treat.

You can take these drugs with other painkillers, such as opioids. This may mean that the dose of opioids can be reduced. This can help if you have bad side effects from opioids.

It can take up to a week for some drugs to have an effect on your pain. Continue to take the drugs, even if you don't feel a difference straight away.

> "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."

Pregabalin and gabapentin

Pregabalin and gabapentin are usually used to treat epilepsy, but can also be used to treat nerve pain. They are usually taken as tablets.

These drugs can cause side effects, such as feeling sick, dizziness, tiredness or a dry mouth. Speak to your doctor or nurse if you have any side effects.

Amitriptyline or duloxetine

Amitriptyline and duloxetine are usually used to treat depression, but can also be used to relieve nerve pain. You usually take these drugs as tablets or capsules. Amitriptyline also comes as a liquid.

If you get any side effects, tell your doctor or nurse. Amitriptyline can cause constipation, dry mouth, feeling dizzy, feeling tired, problems peeing or headaches. Common side effects of duloxetine include problems sleeping, headaches and feeling dizzy.

Steroids

Steroids to help manage cancer pain include dexamethasone and prednisolone. They can help to manage severe pain that needs treating quickly while other pain relief takes effect.

Steroids can be used on their own, or with opioid painkillers. They are given as tablets which should be taken with food, or as a liquid or an injection.

It is important to take steroids exactly as they are prescribed by your doctor. Do not stop taking them without talking to your doctor.

Side effects of steroids

Steroids should only be used for a short time, usually between two and four weeks. This is because they can cause side effects. These include weak legs, a puffy face, indigestion, changes in your mood, confusion, tummy pain or higher blood sugar levels.

Steroids can also damage the stomach lining, so if you are taking them for more than a few days you will usually be given a drug to protect your stomach. Speak to your doctor or nurse if you have side effects, or if you have diabetes.

Treatment for tummy pain

If you have tummy pain, tell your doctor or nurse. They can check to see what is causing it.

Pancreatic enzyme replacement therapy (PERT)

Tummy pain may be caused by problems with digestion. This can be managed with **pancreatic enzyme replacement therapy (PERT)**. This helps your body break down and digest food properly. Most people with pancreatic cancer will need to take PERT.

If you have not been given PERT, speak to your doctor or nurse.

Antispasmodic medicines

Antispasmodic medicines help relax muscles in your bowel, and can relieve tummy cramps and pain.

These drugs include hyoscine butylbromide (Buscopan®). This can be prescribed by your GP, or you can have it at the hospital.

Hyoscine butylbromide can cause side effects, such as a dry mouth or constipation.

Radiotherapy and chemotherapy

Radiotherapy can help to control some types of pain. It is called palliative radiotherapy when it is used to treat symptoms in people with cancer that can't be cured.

Palliative **chemotherapy** can slow down the growth of the cancer and may help to relieve symptoms, including pain.

Find out more about radiotherapy on our website at:
pancreaticcancer.org.uk/radiotherapy

Read about chemotherapy in our fact sheet:
Chemotherapy for pancreatic cancer
Or at: **pancreaticcancer.org.uk/chemotherapy**

Ketamine

Ketamine is used as an anaesthetic but in low doses it is an effective painkiller. It can be used with opioid painkillers if opioids are not relieving all your pain.

Ketamine is given in low doses, usually as a liquid or by syringe pump (see page 16). The dose can be gradually increased if needed.

We need more research about ketamine and pain. It isn’t used regularly, and should only be used by doctors who have experience using it.

Side effects of ketamine

Ketamine can cause side effects, including sensing things that aren’t there (hallucinations), blurred vision or dizziness. These side effects will be closely monitored by your medical team. Speak to your doctor or nurse if you have any side effects.

Some people worry about becoming addicted to ketamine, but this won’t happen if you take it as prescribed.

Cannabis-based products

Medicines or products containing cannabis can’t be prescribed by the NHS for cancer pain. This is because there isn’t enough evidence to show it works.

Specialist doctors can prescribe cannabis-based products for some specific conditions if there is clear evidence to show it is helpful. But it is not available for pancreatic cancer.

Some products containing cannabis are available online or in shops, such as cannabidiol (CBD) or hemp oil. These may make lots of claims. They tend to have only small amounts of CBD, could be poor quality, and may also be illegal. Cannabis that is smoked, or ‘street cannabis’, is illegal and could be dangerous.

It’s very important that you tell your doctor if you are using cannabis products. They may affect other medicines you are prescribed including your chemotherapy.

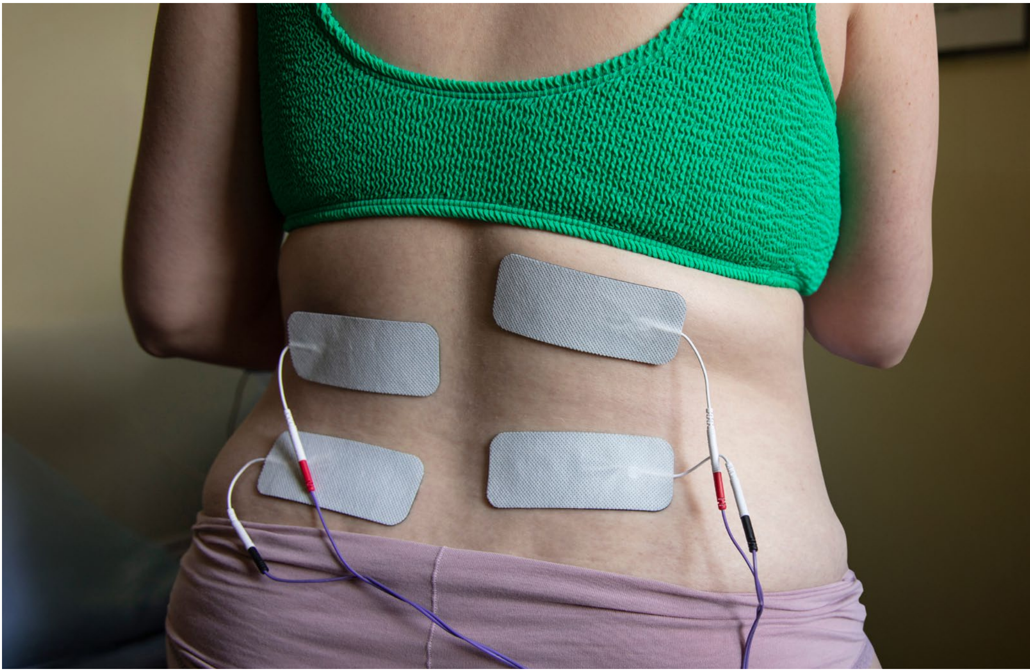
TENS

Transcutaneous electrical nerve stimulation (TENS) uses pulses of small electrical currents to temporarily block the nerves from sending pain messages to the brain. They may also help the body to make its own natural painkillers, called endorphins. This can give short term pain relief.

How do I use a TENS machine?

Sticky pads, attached to a small battery powered machine, are put onto your skin around the painful area. The pads give out pulses of small electrical currents. This can feel tingly, like pins and needles.

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. The NHS website has more information about TENS.



Questions to ask your doctor or nurse

Is a nerve block suitable for me?

How long will the pain relief from a nerve block last?

What else might help with my pain?

Are there any other drugs that would help manage my pain?

Would a TENS machine help?

How can I get a TENS machine?

Dealing with pain

Key facts

- There is support available to help you cope with pain.
- Speak to your doctor or nurse early on about pain. This will mean there is a better chance of getting it under control, and may help you cope better with it.
- Your emotions, relationships and spiritual beliefs can all affect how you feel and react to pain. You are not alone and there is support available.
- Regular physical activity, such as going for a short walk, may help improve your mood.
- Some people find that complementary therapies help them feel more in control of their pain. Always speak to your doctor before trying complementary therapies.

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

> “To deal with pain you have to take it from all angles. Spending time with loved ones, getting out and about and doing something you enjoy can help.”

The emotional impact of pain

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 on other things.

Your mood can also affect your pain. Lack of sleep and feeling anxious, depressed, or worried can make pain feel worse. Your mind and body work together and influence each other, and both may impact your pain.

Talk to your medical team. Being open with them about your feelings will help them support you better. They can answer your questions, find ways to manage the pain, provide emotional support, and help you deal with it.

Talking about it

Talking about your cancer, the pain, and how you are feeling can help you cope. Family and friends may be able to support you. It might help to connect with other people affected by pancreatic cancer. They may really understand how you feel.

Find out how we can connect you with others at:
pancreaticcancer.org.uk/support

Read about dealing with emotions at:
pancreaticcancer.org.uk/coping

> “I found that online support groups really helped. Talking virtually to people who also had a loved one with pancreatic cancer. Hearing their stories, sharing hopes and fears and receiving support and virtual love.”

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 and keep you fit. Speak to your doctor or nurse about what physical activity might be suitable for you.

You can read more about physical activity on our website at: **pancreaticcancer.org.uk/exercise**

Complementary therapies

Some people find that complementary therapies help them deal with pain. These include acupuncture and massage. These therapies work alongside your medical treatments – don’t stop any cancer treatments.

There isn’t much evidence about complementary therapies, and they don’t work for everyone. But they may help you manage your pain. Always speak to you doctor before trying any complementary therapies, as some may affect your cancer treatment. And tell your complementary therapist about your treatment.

> “We used a specialist cancer massage therapist and it really helped, he slept very well after each session. Especially in the early stages.”

Read more about complementary therapies at:
pancreaticcancer.org.uk/complementarytherapies

What can I do?

- Ask for a referral to a physiotherapist or occupational therapist (OT) to talk about physical activity if your mobility is poor, or you are worried about falling.
- You could include something like a short walk in your daily routine.
- Some people find psychological (emotional) support such as counselling or cognitive behavioural therapy (CBT) helpful. CBT is a talking therapy that helps you manage problems by changing how you think and feel about them.
- You might find something you enjoy like a hobby can give you something different to focus on. This may help you deal with the cancer and pain.
- Find out what complementary therapies are available near you. Hospitals, hospices and charities may offer some and there may be private therapists.

Questions to ask your doctor or nurse

What can I do myself to help with pain?

Where can I get support to help me cope?

Would counselling be helpful?

Is there anyone I can speak to about my beliefs, such as a chaplain?

What sort of physical activity might help?

Would any complementary therapies help?

More information and support

Medical words explained

We have explained some of the medical words that you may hear if you have pancreatic cancer pain.

Analgesic: a medicine that relieves pain.

Bile: fluid which is produced by the liver and helps digestion.

Bile ducts: tubes that carry bile from the liver to the small intestine.

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

Dose: the amount of a medicine that is given at one time.

Duodenum: the first part of the small intestine.

Jaundice: can be a symptom of pancreatic cancer. Symptoms include yellow skin and eyes, dark urine, pale poo and itchy skin.

Pancreatic enzyme replacement therapy (PERT): capsules that help digest food when the pancreas isn't producing enough enzymes.

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

We are here for you

If you or someone you care about has pancreatic cancer, we are here to help.

Find out more at: **pancreaticcancer.org.uk/support**

Our specialist nurse Support Line

Our specialist nurses are experts in pancreatic cancer. They can talk for as long as you need, as often as you like. Whether you have a long list of questions or don't know where to start, they will provide practical, honest information to help you make the right choice for you.

Call free on **0808 801 0707** or
email **nurse@pancreaticcancer.org.uk**

Information about pancreatic cancer

Our website, videos and publications can answer your questions. The information can help you understand what you have heard from your medical team, and make decisions about your treatment and care.

Go to: **pancreaticcancer.org.uk/information**
Download or order our free publications at
pancreaticcancer.org.uk/publications or
call **0808 801 0707**

Real life stories

Whether you want to read other people's stories or tell your own, sharing experiences of pancreatic cancer could help.

Go to: **pancreaticcancer.org.uk/stories**

Useful organisations

Cancer Research UK

cancerresearchuk.org
Helpline: 0808 800 4040
Information for anyone affected by cancer.

Department for Transport

gov.uk/drug-driving-law
Information on drugs and driving, including painkillers.

Hospice UK

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

Macmillan Cancer Support

macmillan.org.uk
Support Line: 0808 808 00 00 (Every day 8am-8pm).
Practical, medical and financial support for anyone affected by cancer.

Maggie’s Centres

maggies.org
Centres around the UK and online offer free, comprehensive support for anyone affected by cancer.

Marie Curie

mariecurie.org.uk
Support line: 0800 090 2309
(Mon-Fri 8am-6pm, Sat and Sun 10am-4pm)
Care and support for people living with a terminal illness, and their families, including nurses and hospices.

NHS 111 Wales

111.wales.nhs.uk
Health information in Wales, including local services.

NHS inform

nhsinform.scot
Provides information about different health conditions and living well, and local services in Scotland.

NHS UK

nhs.uk
Information about health conditions, living well, care and local services in England.

nidirect

nidirect.gov.uk
Information about local services in Northern Ireland, including health services.

Pain Association Scotland

painassociation.com
Tel: 0800 783 6059 (Mon-Fri 8.30am-4.30pm).
Provides professionally led pain management to people with long term pain in Scotland.

Pain Concern

painconcern.org.uk
Helpline: 0300 123 0789
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.

We try to make sure that our services provide accurate information about pancreatic cancer. We hope this will add to medical advice and help you make decisions about treatment and care. This information should not replace advice from the medical team – please speak to them about any questions.

Email us at **publications@pancreaticcancer.org.uk** for the sources used to write this booklet. If you have any feedback, email us or write to our Information Manager.

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

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