

## 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. Pancreatic cancer can cause pain, but not everyone will get pain. This booklet describes what causes pain and ways of treating it.

Different people have different levels of pain and everyone's experience with pain is different. If you do 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 confidential 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](http://pancreaticcancer.org.uk/symptoms)

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# 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 60). Find out more at: **pancreaticcancer.org.uk**

Use the symbols to help you find out where and when 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 or nurse



Things you can do to help yourself

## At the end of the booklet there is:

- A list of common medical words on pages 55-56.
- Contact details of the organisations we mention on pages 61-62.

# What is pain and who can help manage it?

## Key facts

- Pain is your body's way of telling you that something isn't right.
- There are ways to manage pain.
- It's important to tell your doctor or nurse about any pain early on, so it can be more effectively treated.
- Managing pain may involve your GP, district nurse, hospital doctor or palliative care team.
- Palliative care and supportive care teams provide specialist care to manage complex symptoms, including pain. These services aren't only for people at the end of their life.
- Practical and emotional support can also help – your pain may seem worse at times when you don't feel supported.
- Different people feel pain in different ways. This means that how you feel and cope with pain will be very personal to you.



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

## What is pain?

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 managed, so ask for help as early as you can. You can read about treatments for pain on page 23.

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 spiritual beliefs can all 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. You can find out more about coping with pain on page 48.

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.

## Who can help manage my pain?

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

- GP
- district nurse
- palliative care nurse
- or your hospital team.



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

You may also be referred to other services, such as a specialist palliative care team, a supportive care team or a hospice. Seeing these services early on can make it easier to deal with your pain.

Your hospital team should give you an emergency number to contact if your pain suddenly changes and gets very bad at night or at the weekend. If you haven't been given a number, ask them about it. There will also be a number for the out of hours doctor 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 for each region, which you can find on the nidirect website.



Read more about local nursing support at:  
**[pancreaticcancer.org.uk/nursingsupport](https://pancreaticcancer.org.uk/nursingsupport)**

## **What are palliative care and supportive care?**

Palliative care teams help people who have cancer that can't be cured to live as well as possible for as long as possible. They work together with your medical team. Supportive care teams provide similar services and are available in some hospitals. They aim to see people at a very early stage in their cancer treatment to manage their symptoms. Hospices also provide specialist palliative care. The service you are referred to may vary, depending on what is available in your area.

These services aren't only for people at the end of their life. They are available at any point during your treatment or care. They provide specialist care which aims to prevent and

manage complex symptoms, including pain and emotional (psychological) symptoms, such as depression and anxiety. Their services may include occupational therapy, which provides advice and equipment to support you to carry out your daily activities. They also provide people with practical and spiritual support, and support families.

Not all services are available everywhere. If you haven't seen a palliative care or supportive care team and need more support speak to your GP about referring you.



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



### **What can I do?**

- Talk to your doctor or nurse about any pain you have or any other concerns.
- Ask who you should contact if your pain gets worse.
- Find out who to contact if you need to talk to someone at the weekend or at night.
- If you haven't already been referred to a specialist palliative care team or supportive care team, speak to your doctor or nurse about whether this would help.





Our specialist nurses on our free Support Line can explain how to access support, and answer your questions about pain.



### Questions to ask your doctor or nurse

Who can help manage my pain?

How often will my pain be checked by my medical team?

Would it help for me to see a specialist palliative care team?

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

# What causes pain?

## Key facts

- The cancer can cause pain or discomfort by affecting nerves, or causing bowel or bile blockages, or a build-up of fluid.
- The pancreas is involved in digesting food but pancreatic cancer can affect this. Problems with digestion can cause pain or discomfort. Pancreatic enzyme replacement therapy (PERT) can help manage problems with digestion.
- Some treatments for cancer can cause pain. For example, if you have surgery, you may have some pain or discomfort while your body heals. This should improve.
- It is important to speak to your doctor or nurse about any pain so they can treat it.
- How you feel can also affect the way you feel pain. Getting emotional support can be important too.



**Our specialist nurses on our free Support Line can provide emotional support, and have time to listen to your worries and answer your questions about pancreatic cancer and pain.**

## 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 nerves near the pancreas, causing pain in the tummy or back.
- The cancer can sometimes block the duodenum (first part of the small intestine), which can cause discomfort and sickness. A tube called a stent may be put in to treat this.
- Sometimes the cancer can cause fluid to build up in the tummy area. This is called ascites. It can cause pain and discomfort. A small drain may be put in to drain the fluid.
- If the cancer spreads to the liver, it can make the liver larger, which can cause pain.



Read more about stents for the duodenum at:  
**[pancreaticcancer.org.uk/duodenalstent](https://pancreaticcancer.org.uk/duodenalstent)**

Read more about ascites at:  
**[pancreaticcancer.org.uk/ascites](https://pancreaticcancer.org.uk/ascites)**

## Problems with digestion

The pancreas plays an important role in digesting food, as it produces enzymes that help to break down the food. We explain these medical words on page 55. Pancreatic cancer can affect this, and cause lots of symptoms. These include tummy discomfort or pain, cramps, lots of wind, and bloating.

Pancreatic enzyme replacement therapy (PERT) can help manage problems digesting food and these symptoms. They replace the enzymes that your pancreas would normally produce. Brands include Creon®, Nutrizym® and Pancrex®.

If you have any of these symptoms, or haven't been told about enzymes, speak to your doctor, nurse or dietitian.



Read about digestion in our booklet:  
**Diet and pancreatic cancer**

Or at: [pancreaticcancer.org.uk/diet](https://pancreaticcancer.org.uk/diet)



You can also speak to our specialist nurses on our free Support Line about diet and digestion.

## Cancer treatment

Some cancer treatments can cause pain or discomfort.

### Surgery

Some people with pancreatic cancer have surgery.

- If there are no signs that the cancer has spread outside of the pancreas, you may be able to have surgery to remove your cancer.
- Some people with cancer that can't be removed by surgery may have bypass surgery, to treat a blocked duodenum or a blocked bile duct. This can help deal with symptoms such as sickness or jaundice.

It is normal to have some pain and discomfort for a few weeks after surgery. This is usually controlled with painkillers, and will improve.



Read about surgery to remove pancreatic cancer in our fact sheet:

**Surgery to remove pancreatic cancer**

Or at: [pancreaticcancer.org.uk/surgery](https://pancreaticcancer.org.uk/surgery)

Read more about bypass surgery at:  
[pancreaticcancer.org.uk/bypass](https://pancreaticcancer.org.uk/bypass)

## Stents

A stent is a small tube that is used to open a blocked bile duct or a blocked duodenum. This can help treat symptoms such as jaundice or sickness.

There is a risk that your stent can get blocked, infected or move out of place. This can cause tummy pain. Tell your doctor or nurse about any pain straight away. They can give you painkillers to help manage your pain, or antibiotics to treat any infections. The stent may need to be replaced.



Read more about stents:

- in our fact sheet: **Stents to treat jaundice caused by a blocked bile duct**
- or at: [pancreaticcancer.org.uk/duodenalstent](https://pancreaticcancer.org.uk/duodenalstent)



“ Get help as soon as possible for your pain, the earlier it’s treated the better. There’s nothing wrong with asking for help.”

## Side effects of chemotherapy

Chemotherapy is one of the main treatments for pancreatic cancer. It can help to control the cancer and manage symptoms, but it can sometimes have side effects that can be uncomfortable or painful. These may depend on the chemotherapy drug you are having.

Chemotherapy can sometimes damage the nerves in your hands or feet. This can cause pain, tingling or numbness in these areas. This is called peripheral neuropathy, and you may need painkillers for it.

Chemotherapy can also cause:

- a sore mouth and mouth ulcers
- sore palms of your hands and soles of your feet
- joint or muscle pains
- diarrhoea or constipation which can be uncomfortable
- bloating and discomfort in your tummy.

Tell your doctor or nurse if you have any of these or any other side effects while having chemotherapy.

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



You can read more about chemotherapy in our fact sheet: **Chemotherapy for pancreatic cancer**  
Or at: **[pancreaticcancer.org.uk/chemotherapy](http://pancreaticcancer.org.uk/chemotherapy)**

## Constipation

Constipation is when you find it harder to poo. This can be very uncomfortable and cause discomfort or pain.

If you aren't moving around much or drinking enough, you may be more likely to get constipation. Some opioid painkillers such as morphine, or chemotherapy drugs can also cause constipation.

There are ways to deal with constipation. For example, you should be given medicines called laxatives to take with opioid painkillers to prevent constipation. Read more on page 31.

## Your feelings and beliefs

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

- how you feel about dealing with pain
- stress and worry, for example about the pain, cancer, or other things
- depression
- your spiritual or religious beliefs
- your relationships with other people, like your family or medical team.

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

There are things that can help you deal with the emotional effects of pain and pancreatic cancer. Read more on page 49.





### **What can I do?**

- Talk to your doctor or nurse about any pain or discomfort you have. The earlier you get treatment for pain, the better the chances of getting it under control.
- If you have any problems with digestion, or haven't been told about pancreatic enzymes (PERT), speak to your doctor or nurse or ask to be referred to a dietitian.
- If you are feeling stressed or worried about something, try to find ways to sort this out and help reduce your worries.
- Having good support can help. Talk to your medical team, friends and family about how you feel and how they can help.



### **Questions to ask your doctor or nurse**

What is causing my pain?

How can it be managed?

Would pancreatic enzymes help with my digestion?

What other support is available to me locally?

# Types of pain

## Key facts

- There are different types of pain that people with pancreatic cancer may have.
- These include nerve pain and soft tissue pain.
- Some people have more than one type of pain, or different types at different times.
- Pain can last some time or it can come and go in short bursts.
- It is important to tell your doctor about any pain you have, or if your pain changes.
- There are ways to manage the different types of pain.



**Speak to our specialist nurses on our free Support Line with any questions or worries.**

## **Background pain**

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 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.

Treatment for breakthrough pain includes some fast acting (immediate release) opioid painkillers (see page 29). 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 fast acting (immediate release) painkillers 20 to 30 minutes before doing that activity, or by changing the activity. Read more on page 29.

## **Nerve (neuropathic) pain**

Many people with pancreatic cancer have some nerve pain. This is also called neuropathic pain.

There is a bundle of nerves, called the coeliac plexus, behind the pancreas. These nerves send messages from the pancreas to the brain. Pancreatic cancer can press on the coeliac plexus or damage it, causing pain in the tummy area and back.

Nerve pain can come and go and can be difficult to describe. Some people say it feels like a burning, shooting or stabbing pain, or like pins and needles. Opioid painkillers (see page 28) help treat nerve pain for some people, and other drugs such as amitriptyline and pregabalin are also used (see page 43).

A nerve block is a treatment that can sometimes be used for nerve pain. Read more about this on page 40.

## Soft tissue (visceral) pain

If pancreatic cancer spreads to nearby organs, like the liver or bowel, it can cause a type of pain called soft tissue or 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**. It is common and can be managed.

Treatments for soft tissue pain can include painkillers and nerve blocks (see pages 23 and 40). Drugs called antispasmodic drugs are sometimes used to help with tummy cramps and pain (see page 44).



“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

For some people, pancreatic cancer can spread to the bone, causing pain. But this is not very common. Some chemotherapy drugs can also cause bone pain. People describe bone pain as aching, throbbing, or cramping. You may have an area that feels tender to touch.

Treatments for bone pain include painkillers and radiotherapy. Read more on pages 23 and 46.



### What can I do?

- Tell your doctor or nurse as much as you can about your pain. This will help them give you the right treatment.
- It can help to keep a diary of your pain to share with your doctor or nurse.
- Take your pain relief as advised by your doctor. This will help to make sure it works as well as possible.
- Speak to our specialist nurses on our free Support Line with any worries.



### Questions to ask your doctor or nurse

What type of pain do I have?

How is this type of pain managed?

# 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 41).
- Painkillers come in different forms, including tablets or a patch on your skin. Or they may be given through a syringe pump (see page 26).
- You are likely to take more than one type of painkiller to help your pain.
- Painkillers can cause side effects. Ask your doctor or nurse about any side effects, and tell them if you have any side effects.
- Do not stop taking opioids without talking to your doctor first. Stopping opioids suddenly can make you feel very unwell.

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

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. Pain can be harder to control if you wait until your pain is bad before taking painkillers.

Tell your doctor or pharmacist about any other medicines you are taking. Medicines can affect each other, causing extra 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.

Don't stop taking your painkillers without speaking to your doctor or nurse first. If you are worried about side effects, speak to them before changing anything.

Your doctor and nurse should check your pain regularly. This is to make sure that your painkillers are working properly. Tell them if your pain gets worse. They will look at your painkillers again. They may increase the dose or add different painkillers. If you have bad side effects, you may be offered a different painkiller.



### **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 our **Pain Medicines Record Card** on page 58, or a pill box, to help you remember when to take them. Ask your nurse for any other tips.

## How are painkillers taken?

Different types of painkillers can be taken in different ways.

- You will normally take them as a tablet, capsule or liquid that you swallow.
- Some painkillers are also available as granules that you dissolve in water to drink.
- If you find it hard to swallow or you are being sick, you may be able to have a tablet or film that dissolves in your mouth.
- You may also be able to have a syringe pump (see page 26), or have painkillers by injection.
- Some painkillers, such as fentanyl and buprenorphine (see page 29), can be given through a patch that is put on your skin.

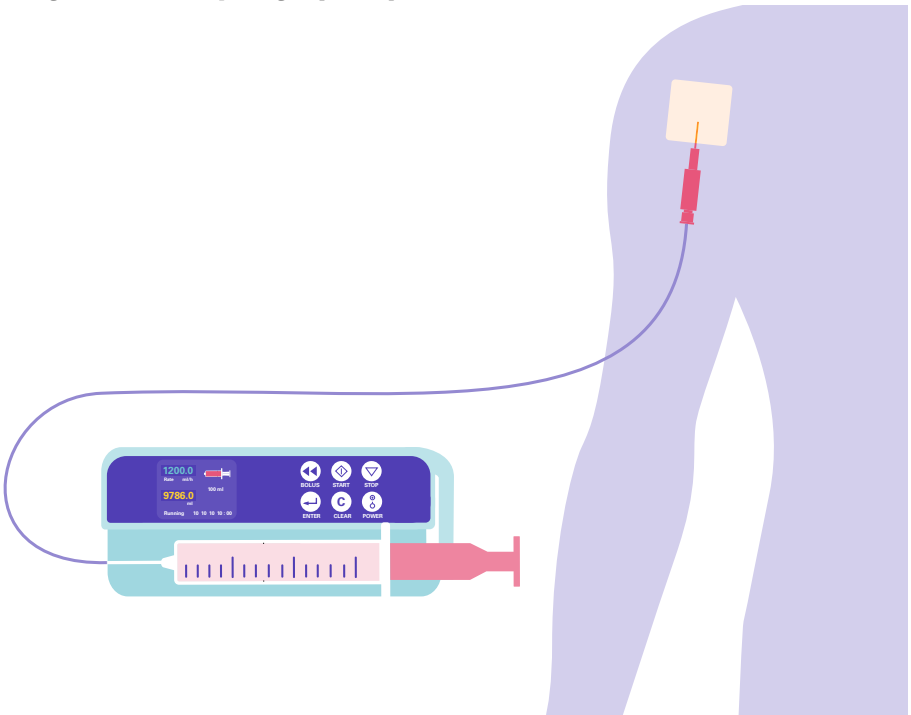
## What is a syringe pump?

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 inserted under the skin. 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 the medicines. It's also used if the drugs you need can only be given by injection.

A syringe pump can also be used to provide other medicines, such as anti-sickness medicine. You can move around while using a syringe pump, and can use it at home or out of the house.

## Diagram of a syringe pump



## **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 28) or with other types of pain relief (see page 41).

NSAIDs can cause side effects which include stomach problems 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.

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.

## **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 emergency number if you have a high temperature, based on the advice of your chemotherapy team.



Read more about chemotherapy and infections in our fact sheet: **Chemotherapy for pancreatic cancer**

Or at: [pancreaticcancer.org.uk/chemotherapy](https://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 41). The type of painkiller you have will depend on what kind of pain you have, and your general health.

If you have been taking opioids for a long time, you must not stop taking them suddenly. This can cause severe symptoms like stomach pains, sickness and feeling worried or restless. Your doctor or nurse will help you to slowly reduce the dose so that you don't get these symptoms.

### Weaker opioids

Weaker opioids include codeine, dihydrocodeine and tramadol. You may have a weaker opioid if your pain isn't controlled by paracetamol or NSAIDs.

You may take a weaker opioid on its own, or with other drugs. If you still have pain, tell your doctor or nurse so that they can change the dose or painkiller.

## Stronger opioids

If weaker opioids do not control your pain, you may have a stronger opioid. Your doctor or nurse will work out the best dose for you that manages your pain, without causing bad side effects. You will usually start on a lower dose of a stronger opioid. The dose can be increased, so let your doctor or nurse know if you still have any pain.

Stronger opioids include morphine, oxycodone, fentanyl, buprenorphine, methadone and tapentadol.

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 opioids (immediate release)** 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 19) or sudden changes in pain.

You may start off with a fast acting opioid.

### Long acting opioids

You usually take a **long acting opioid (modified release)** twice a day to control background pain (see page 19). 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. Sometimes you may take a fast acting dose and a long acting dose at the same time. This will give you pain relief straight away, followed by the effect of the long acting medicine.



“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. Ask your doctor or nurse about possible side effects. 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. It may not always be clear what is causing them because the cancer can sometimes cause similar symptoms. Your doctor may change the dose of your painkillers. Or they may give you a different opioid drug or another type of pain relief.

### 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 – your doctor can advise you about this. It can also help to drink plenty of water and try to keep active, if possible.

**“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. Some people find that drinking water, sucking ice cubes or chewing gum helps and there are also artificial saliva gels and sprays. If you have white spots in your mouth or a white coating on your tongue, you may have an oral thrush infection. 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](https://pancreaticcancer.org.uk/sickness)**

Find tips for coping with sickness and a dry mouth at: **[pancreaticcancer.org.uk/diettips](https://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 36).

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. How to deal with tiredness](#)**

Or at: **[pancreaticcancer.org.uk/fatigue](https://pancreaticcancer.org.uk/fatigue)**



## Other side effects

Other possible side effects include:

- mood changes or feeling confused
- sensing things that aren't there (hallucinations)
- itchy skin
- problems emptying your bladder completely
- muscle twitches or jerks.

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



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



### What can I do?

- Talk to your doctor or nurse about your pain, or side effects from painkillers.
- If you haven't seen a palliative or supportive care specialist, ask to be referred.
- Keep a note of any problems or anything you are worried about, so that you can ask about these.
- Tell your doctor, nurse or pharmacist about any other medicines you are taking.

## **Common concerns about opioid painkillers**

People have often heard stories about opioid painkillers, which may make them worry about taking them. We explain some common concerns here.

### **Can I get addicted to opioid painkillers?**

Some people worry about getting 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 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 on opioid painkillers?**

You can take the full dose of the painkiller your doctor has given you without worrying about taking too much (an overdose). 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 so that they can look at your pain relief.

Do not stop taking your opioids without discussing this with your doctor first. Stopping your opioids suddenly can make you feel very unwell (see page 28).



“Keep persisting until you receive all the advice and support you need. There’s no such thing as a silly question and sometimes if you don’t ask you don’t get.”

### **Will opioid painkillers make me confused or hallucinate?**

Some opioid painkillers can cause confusion or sensing things that aren't there (hallucinations). But if you follow your doctor's instructions when taking your painkillers, these side effects are unlikely.

Your medical team will regularly check your pain and the painkillers you are taking. Tell them about any side effects so they can help you to manage them.

### **Can I drive if I take opioid painkillers?**

Your doctor will tell you whether 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 when you are taking prescribed opioid painkillers, as long as they don't affect your ability to drive and you are taking them as instructed. 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 strong painkillers?**

Alcohol and other medicines can affect the way your painkillers work, or cause side effects such as tiredness. If you want to have some alcohol, ask your doctor as this is usually possible.

## **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 painkiller. If your painkillers are not controlling your pain, there are other types of pain relief and other ways of managing your pain (see page 39).

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 7.

**“You don't have to endure pain without help or medication. You don't have to put up with it.”**



You can speak to our specialist nurses on our free Support Line if you have any questions about painkillers.



### 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 medicines?

How will these painkillers affect my daily life?

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

Can you recommend a pain diary or any mobile phone apps to keep a record of pain?

# Nerve blocks and other types of pain relief

## Key facts

- As well as painkillers, there are other types of pain relief for pancreatic cancer. These can be used with your painkillers, or if your painkillers aren't working well.
- 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, such as 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 nerve blocks and pain relief.

## Nerve blocks

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. See page 19 for more about nerve pain.

You may have a nerve block if:

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

A nerve block may mean you can reduce the amount of opioid painkillers you take. Nerve blocks work well for some people, but they don't work for everyone. Speak to your doctor or nurse about whether a nerve block might be suitable for you if your pain isn't well controlled.

### What does a nerve block involve?

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

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, and stop the pain.

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.



You can read more about having an EUS on our website at: [pancreaticcancer.org.uk/tests](https://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. These drugs can be taken with other painkillers, such as opioids. Taking these drugs does not mean that you have the condition they are usually used to treat.

Taking these drugs 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, so they are not used to treat breakthrough pain (see page 19). 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, gabapentin or carbamazepine**

Pregabalin, gabapentin and carbamazepine are usually used to treat epilepsy, but can also be used to treat nerve pain (see page 19). They can also help if you are struggling to sleep. 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.

If you get any side effects, tell your doctor or nurse.

Amitriptyline can cause constipation, dry mouth, feeling dizzy, feeling tired, problems passing urine (peeing) or headaches. Common side effects of duloxetine include problems sleeping, headaches and feeling dizzy.

## **Steroids**

Steroids used to help manage cancer pain include dexamethasone and prednisolone. They can be used to treat nerve pain, soft tissue pain or bone pain (see page 18). 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. Steroids can damage

the stomach lining, so you will usually also be given a drug to protect your stomach.

Steroids should only be used for a short time, usually up to two 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. Speak to your doctor or nurse if you have side effects, or if you have diabetes.

### **Drugs for tummy cramps**

These drugs are known as antispasmodic drugs. They 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. It is given by an injection, or by a syringe pump (see page 26). Tablets are available but they don't work as well.

Hyoscine butylbromide can cause side effects, such as a dry mouth or constipation. Speak to your doctor or nurse about taking antispasmodic drugs if you have tummy cramps.

### **Ketamine**

Ketamine is used as an anaesthetic but in low doses it is an effective painkiller. You won't become addicted to ketamine if you take it as prescribed. 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 26). The dose can be gradually increased if needed.

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.

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

## **Cannabis-based products**

Specialist doctors can prescribe cannabis-based products for some specific conditions. But only if there is clear evidence to show it is helpful, and there are no better medicines.

Medicines or products containing cannabis **can't** be prescribed for cancer pain. This is because there isn't strong enough evidence to show how well it works, and we need more research into this.

Some products containing cannabis are available online. These may make lots of claims, but may not work and could be poor quality. They may also be illegal and could be dangerous. Health food shops may also sell products containing cannabis, such as cannabidiol (CBD) or hemp oil, but these may also be poor quality. 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.

## Radiotherapy and chemotherapy

Radiotherapy can help to control some types of pain. It is called palliative radiotherapy when it is used to treat symptoms.

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



Find out more about radiotherapy on our website at: **[pancreaticcancer.org.uk/radiotherapy](https://pancreaticcancer.org.uk/radiotherapy)**

Read about chemotherapy in our fact sheet: **Chemotherapy for pancreatic cancer**

Or at: **[pancreaticcancer.org.uk/chemotherapy](https://pancreaticcancer.org.uk/chemotherapy)**

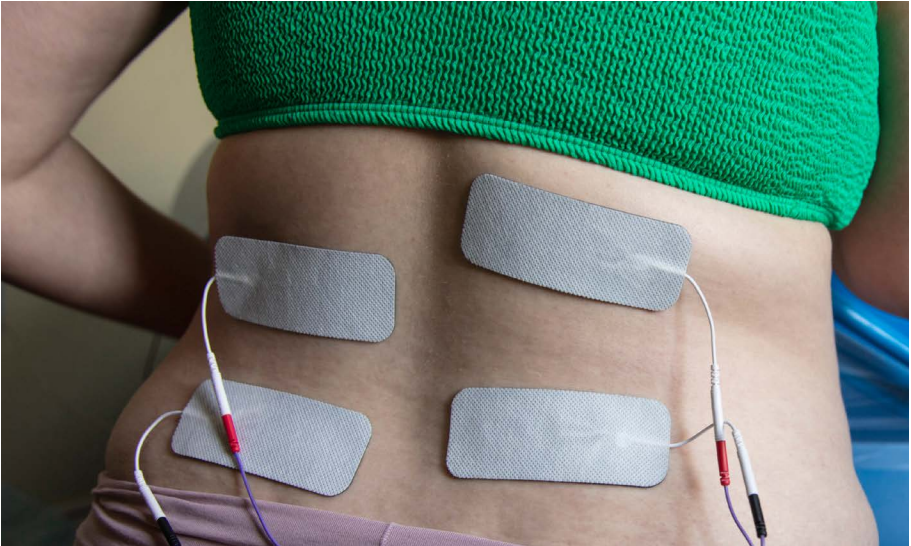
## TENS

Transcutaneous electrical nerve stimulation (TENS) involves using a small, battery powered machine that you can carry around. You place sticky pads onto your skin around the painful area. The pads give out pulses of small electrical currents. This feels tingly on your skin, and can feel like pins and needles.

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. This produces short term pain relief.

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.

## Picture of someone using a TENS machine



### 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.
- As well as your doctor and nurse, the supportive or palliative care team can provide support.
- 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.
- Keep talking to your doctor or nurse about any pain and any other concerns you have. They can help.
- 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.
- There are things you can do yourself. For example, distracting yourself from pain with something you enjoy, or talking to family and friends may help.
- 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.



## **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 need help to manage your pain.

Getting help for pain early on can help you deal with it better. Talk to your nurse about how you are feeling. Being open with them will help them support you better. They can answer your questions, find ways to manage the pain and help you deal with it. Your doctor or nurse should regularly check how the symptoms of pancreatic cancer, including pain, are affecting you emotionally. They should offer you information and support to help you deal with pancreatic cancer.

It's really important to tell your doctor or nurse about any changes to your pain, so that they can make sure you have the right pain relief. Don't stop taking your pain relief or change your dose without speaking to your medical team first.

Palliative care or supportive care teams (see page 7) are experts at supporting people with cancer. They can help manage pain and other physical symptoms. They can also support you with emotional symptoms, such as depression and anxiety.

### **Distracting yourself**

You could try finding things that distract you from pain. For example, you could try a hobby, reading a book, watching television or listening to music. Talking to family and friends may also help.

Finding ways to relax can help with managing pain. You could try relaxation techniques, like meditation and mindfulness, or some of the complementary therapies on page 52.

### **Talking about it**

Talking about your cancer, the pain, and how you are feeling can help you cope. Family and friends can be a fantastic support. You can also talk to your doctor or nurse. You should have a main contact who will often be a specialist nurse. They can provide emotional support as well as medical care.

Some people find counselling or other forms of psychological (emotional) support such as cognitive behavioural therapy (CBT) helpful. Counselling involves talking to a trained professional about your thoughts and feelings. CBT is a talking therapy that can help you manage problems by changing the way you think and behave. Your medical team may be able to refer you for support. You can find out more from the British Association for Counselling and Psychotherapy (see page 61 for contact details).

You may also find it helps to talk to others affected by pancreatic cancer, who can understand what you are going through. Our Living with Pancreatic Cancer online support sessions give you the chance to connect with others. They cover a range of topics including managing symptoms. We also have an online discussion forum where you can speak to others.

Having cancer can make some people think more about their spiritual and religious beliefs. You may find it helps to speak to a religious or spiritual leader.



Read more about dealing with the emotional impact of pancreatic cancer on our website at: [pancreaticcancer.org.uk/coping](https://pancreaticcancer.org.uk/coping)

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

“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.”

### **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 ask your medical team any questions you have.

### **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 maintain your physical fitness, but we need more research to show that it helps people with pancreatic cancer pain.

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



You can read more about physical activity on our website at: [pancreaticcancer.org.uk/exercise](https://pancreaticcancer.org.uk/exercise)

## Complementary therapies

Some people find that complementary therapies help them deal with pain. These include acupuncture and massage, as well as relaxation techniques like meditation and mindfulness. Other options that might be available to you are guided visualisation, art and music therapies, pet therapy or using virtual reality headsets. Complementary 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 be useful in helping you manage your pain, alongside your other treatments. They can help you feel more in control of your pain, which may mean you have less pain.

Always speak to your doctor before trying any complementary therapies, as some may affect your cancer treatment. And tell your complementary therapist about your cancer treatment.



Read about complementary therapies at: [pancreaticcancer.org.uk/complementarytherapies](https://pancreaticcancer.org.uk/complementarytherapies)



### **What can I do?**

- Talk to your doctor or nurse. They can help with pain relief and support you emotionally.
- Ask your nurse about what physical activity you could do. You could include something like a short walk in your daily routine.
- Try different hobbies to see if they help distract you from the pain.
- Find someone you can talk to about how you feel. It might be a relative, friend, or someone on our online forum.
- Find out about what complementary therapies are available near you – hospitals, hospices and local charities may offer some.



### **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 spiritual leader?

What sort of physical activity might help?

Would any complementary therapies help?



“ 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.”

# Further information and support

In this section, there's space for you to record your pain relief. We also explain some key medical words, and our services and other organisations that can support you.



Our **easy read** booklets use pictures and simple words to help people who find reading hard. Download or order on our website, call **0808 801 0707**, or email **publications@pancreaticcancer.org.uk**

## Medical words explained

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

**Adjuvant:** a treatment given alongside or after the main treatment.

**Analgesic:** a medicine that relieves pain.

**Bile:** fluid which helps digestion. It is produced by the liver and stored in the gallbladder.

**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.

**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:** provides care and support for people with an illness that can't be cured, and for their families. For example, they can manage symptoms such as pain. They may also offer complementary therapies and emotional, spiritual and social support. You can visit a hospice during the day, or you can stay for short visits to treat symptoms or for longer periods of time.

**Jaundice:** can be 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, dark urine and itchy skin.

**Pancreatic enzyme replacement therapy (PERT):** used if the pancreas isn't producing enough enzymes. It involves taking pancreatic enzymes to replace the enzymes the pancreas would normally make, to help break down food.



You can find more medical words on our website at: [pancreaticcancer.org.uk/medicalwords](https://pancreaticcancer.org.uk/medicalwords)



## Pain medicines record card

You can record the details of your pain medicines on the next page to help you remember what you are taking, and when to take them. You can ask your nurse for a list of all your medicines and when you need to take them.

Write down your medicines and the time when you take each dose. Then tick when you have taken them.



You will need a new list each week. You can download more copies from our website at: **[pancreaticcancer.org.uk/pain](https://pancreaticcancer.org.uk/pain)**

We can also send you printed copies. Contact our Support Line on **0808 801 0707** or email **[publications@pancreaticcancer.org.uk](mailto:publications@pancreaticcancer.org.uk)**

# Record of when to take pain medicines

Week beginning \_\_\_\_\_

Medicine	Dose	Time Write down the times you take your medicines
<i>Pregabalin First dose</i>	<i>150mg (3 tablets)</i>	<i>9am</i>
<i>Pregabalin Second dose</i>	<i>As above</i>	<i>6pm</i>

	Tick when taken						
	Mon	Tues	Wed	Thur	Fri	Sat	Sun
	✓	✓	✓				
	✓	✓					

## Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

### Our specialist nurses are here to talk now

We can answer your questions, recommend practical steps, and provide emotional support when you need it most.

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

### Expert information

Our free information can help you understand your care, ask questions, make decisions and live as well as you can.

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

### Our online forum

The forum is a supportive online space where everyone affected by pancreatic cancer can be there for each other.

Go to: **forum.pancreaticcancer.org.uk**

### Living with Pancreatic Cancer Online Support Sessions

Our online support sessions are hosted by our specialist nurses and will give you the chance to connect with others.

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

### Real life stories

Read other people's experiences of pancreatic cancer.

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

## Useful organisations

### **British Association for Counselling and Psychotherapy**

**[www.bacp.co.uk](http://www.bacp.co.uk)**

**Tel: 01455 883 300** (Mon-Fri 10am-4pm)

Information about counselling and a database of registered therapists.

### **Cancer Research UK**

**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

**Helpline: 0808 800 4040** (Mon-Fri 9am-5pm)

Information for anyone affected by cancer.

### **Department for Transport**

**[www.gov.uk/drug-driving-law](http://www.gov.uk/drug-driving-law)**

Information on drugs and driving, including medicines for pain relief.

### **Healthtalk.org**

**[www.healthtalk.org](http://www.healthtalk.org)**

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

### **Hospice UK**

**[www.hospiceuk.org](http://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](http://www.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**

**[www.maggies.org](http://www.maggies.org)**

**Telephone: 0300 123 1801**

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

## **Marie Curie**

**[www.mariecurie.org.uk](http://www.mariecurie.org.uk)**

**Support line: 0800 090 2309** (Mon-Fri 8am-6pm, Sat 11am-5pm)

Care and support for people living with a terminal illness, and their families, including nurses and hospices.

## **nidirect**

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

Information about local services in Northern Ireland, including health services.

## **Pain Association Scotland**

**[www.painassociation.com](http://www.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**

**[www.painconcern.org.uk](http://www.painconcern.org.uk)**

**Helpline: 0300 123 0789** (Mon 2-4pm & Weds 6-8pm)

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 we provide accurate information about pancreatic cancer. We hope this will add to the medical advice and help you make decisions about treatment and care. This information should not replace advice from the medical team – please speak to the medical team 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.

We would like to thank the people who reviewed this information.

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- Pancreatic Cancer UK Lay Information Reviewers
- Pancreatic Cancer UK Specialist Nurses

# Pancreatic Cancer UK

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