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. Different people have different levels of pain. If you do have pain, asking for help early on will help you deal with it.

This booklet describes what causes pain (see page 9) and different types of pain (see page 17). It has information on how to describe pain to your medical team (see page 21), and ways of treating it. This might include painkillers such as opioids (see page 31), nerve blocks (see page 43) and other types of pain relief (see page 45). Some people also find that complementary therapies can help them deal with pain (see page 51).

If you can have surgery to remove your cancer, such as a Whipple’s operation, it is normal to have pain and discomfort for a few weeks after the surgery. This is usually controlled with painkillers. There is more information about pain and surgery on page 12. There may be parts of this booklet that are not relevant to you.

If you have any questions or are worried about pain, speak to your GP, or the doctors and nurses treating your cancer and pain. You can also speak to our specialist nurses on our confidential Support Line.

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

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

What is pain and who can help manage it?

Different people feel pain in different ways. This means that how you feel and cope with pain will be very personal to you.
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 treated, so ask for help as early as you can. You can read about treatments for pain on pages 26 and 42.

People sometimes think of pain as something they only feel in their body. But it is not only about what is going on in your body. 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 55.

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 you get treatment for your pain, the better chance of getting it under control.

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. You can record it on page 64. There will also be a number for the out of hours doctor on your GP’s answer phone message.
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 Macmillan nurse
- or your hospital team.

Macmillan nurses work in hospitals and the community. They specialise in caring for and supporting people with cancer. Your hospital team may include a specialist nurse and an oncologist (cancer doctor).

If your cancer can’t be removed by surgery, 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.

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. Supportive care teams provide similar services and are available in some hospitals. The service you are referred to may vary, depending on what is available in your area.

These services aren’t just for people at the end of their life. Palliative care and supportive care teams 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. They also provide people with practical and spiritual support, and provide support to family members.
**Where can I receive this care?**

Your GP or district nurse will provide some palliative care, and will arrange support from the specialist palliative care team if you need this. There are specialist palliative care teams based in the community who may be able to visit you at home. Sometimes these teams may be based at a local hospice.

Different hospices provide different services, but these may include:

- inpatient care, where you stay at the hospice for a short time – for example, to get your pain under control
- outpatient care, where you go to the hospice for an appointment and then go home after treatment
- ‘hospice at home’ services, which provide nursing care at home – this service is usually available at night.

Not all services may be available everywhere. If you need more support speak to your GP.

Palliative care can also be provided in hospitals by hospital-based palliative care teams.

Some hospitals offer supportive care. Supportive care is similar to palliative care. It aims to see people at a very early stage in their cancer treatment to manage their symptoms. In some areas, supportive care teams can also provide this care to people who have finished their treatment, but are still dealing with symptoms such as pain.

You may also be offered care through a pain clinic. Pain clinics offer specialist pain management and support. Your doctor or nurse may work with a pain clinic at the hospital, or you may be referred to a pain clinic in your local area.
If you haven’t already been referred to a specialist palliative care team or supportive care team, speak to your doctor or nurse about being referred.

Our specialist nurses on our free Support Line can explain how to access support.

Read more about local nursing support at pancreaticcancer.org.uk/nursingsupport

Questions to ask your doctor or nurse

Who can help manage my pain?

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

Who should I contact for help at night or at the weekend?
Section 2

What causes pain?

There are lots of things that can cause pancreatic cancer pain. These may include the cancer itself, problems with digestion, cancer treatments or constipation.
The cancer

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

Pancreatic cancer can affect the nerves or organs near the pancreas. This can cause pain in the tummy area (abdomen) or the back. Read more about nerve pain on page 19.

Pancreatic cancer can sometimes block the duodenum (the first part of the small intestine), which means that food can’t easily flow out of the stomach. This can cause pain and discomfort, as well as making you feel full and be sick. A tube called a stent can be put into the duodenum to treat these symptoms.

Read more about stents in our fact sheet Stents and bypass surgery, or on our website at pancreaticcancer.org.uk/stents

If the cancer has spread to the liver, it can make the liver grow larger, and cause pain.

Sometimes, pancreatic cancer can cause fluid to build up in the tummy area. This is called ascites and it can cause pain and discomfort. A small drain may be put into your tummy to drain the fluid. This can help you feel more comfortable.

Speak to our specialist nurses on our Support Line for more information on ascites.
Problems with digestion and diet

The pancreas plays an important role in digesting food, as it produces enzymes that help to break down the food (see glossary on page 60 for more about enzymes and digestion). Pancreatic cancer can affect this, which means that food is not properly digested. This can cause lots of symptoms, including tummy discomfort or pain such as cramps, lots of wind, and bloating.

Pancreatic enzyme supplements can help manage problems with digesting food, including pain and discomfort. They replace the enzymes that your pancreas would normally produce and break down food. Brands include Creon®, Pancrease®, Nutrizym® and Pancrex®.

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

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

Speak to our specialist nurses on our Support Line for more information about diet.
**Cancer treatment**

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

**Surgery**

You may have surgery, depending on your cancer.

- If there are no signs that the cancer has spread outside of the pancreas, you may be able to have surgery, such as the Whipple’s operation, to remove your cancer.
- Some people with cancer that can’t be removed by surgery may have bypass surgery, to treat a blocked bile duct or a blocked duodenum. 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. For the first few days, painkillers can be given through an epidural (a drip in your spine), or through patient controlled analgesia (PCA). With a PCA, painkillers are given to you through a drip in your arm. If you have pain, you press a button to control the PCA, which will give you the pain relief.

Once your pain has reduced, you can take painkillers as tablets. There is more information about painkillers on page 26.

It is important to speak to your hospital team if you have any problems with pain when you get home after your surgery. If you get sudden tummy pain or your pain gets worse, call your surgical team.
You may have some pain and discomfort for a few months after your operation. This is normal. You may have tingling or occasional sharp pains in your tummy as your muscles heal and your nerves regrow. This may be a sign that your tummy is starting to repair. It can also be a sign that you are doing too much lifting and bending, and your body needs more time to heal.

**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 infected or move out of place. This can cause sudden 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.

**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 cause discomfort and pain. This may depend on the type of chemotherapy drug you are having.
Chemotherapy can sometimes damage the nerves in your arms, hands or feet. This can cause pain and tingling or numbness in these areas. This is called peripheral neuropathy, and you may need painkillers to help with 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 and the side effects in our fact sheet, Chemotherapy for pancreatic cancer, or on our website at pancreaticcancer.org.uk/chemotherapy

**Constipation**

Constipation is when you have problems emptying your bowels. This can be very uncomfortable and cause discomfort or pain. You may also feel bloated or feel sick.
There are a few causes of constipation. You may be more likely to get constipation if you are not moving around much, or if the cancer has affected your digestion (see page 11). Some chemotherapy drugs or opioid painkillers, such as morphine, 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 (see page 35).

**Your feelings and beliefs**

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

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

Your doctor or nurse should regularly check the emotional impact of the symptoms of pancreatic cancer, including pain. This is to check that you are getting the treatment and support you need. Make sure you speak to your doctor or nurse about how you are feeling, especially if you are struggling at all.

There are things that can help you cope with the emotional effects of pancreatic cancer. Your medical team can offer emotional as well as medical support. And you may also be able to have counselling. Some people find that complementary therapies such as massage can help manage pain and the emotional impact. Read more about coping with pain on page 55.
Getting help early on can help you feel more in control of your pain. Don’t try to cope alone. Speak to your doctor or nurse, or ask a family member or friend to speak to them for you.

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.

There is more information about coping with pancreatic cancer on our website at pancreaticcancer.org.uk/coping

“Get help as soon as possible for your pain, the earlier it’s treated the better. There’s nothing wrong with asking for help.”
Section 3

Types of pain

This section describes the main types of pain that people with pancreatic cancer may have. Some people have more than one of these, or have different types of pain at different times.
There are a few types of pain, including nerve pain, soft tissue pain and bone pain. Pain can last some time, or it can come and go quickly in short bursts, with or without warning. Tell your doctor about any pain you have, or if your pain changes.

**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. You may not know when you’re going to get breakthrough pain.

Treatment for breakthrough pain includes some opioid painkillers, such as morphine or oxycodone (see page 33).

Tell your doctor or nurse as much as you can about your pain. This will help them give you the right treatment. If you are getting a lot of breakthrough pain, you may need a different dose or type of pain relief. It can help to keep a diary of your pain to share with your doctor or nurse – read more about this on page 23.
**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 32.

**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 damage the coeliac plexus, causing pain.

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

Nerve pain can be treated with opioid painkillers (see page 31), and other drugs that help manage pain (see page 45).

A nerve block (see page 43) is a treatment that blocks nerves from sending messages to the brain, and so treats pain. This may be used if painkillers aren’t controlling nerve pain, or if the side effects of painkillers are hard to deal with.

**Soft tissue pain**

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

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

Treatments for soft tissue pain can include painkillers and nerve blocks (see pages 26 and 43). Drugs called anti-spasmodic drugs are sometimes used to help with tummy cramps and pain (see page 46).

“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 26 and 48.

*Questions to ask your doctor or nurse*

What type of pain do I have?

How is this type of pain managed?
Section 4

Talking about pain

It’s important that you speak to your doctor or nurse as early as you can about any pain.
Tell your doctor, nurse or GP about any new pain or any pain that has got worse as soon as you can. Don’t try to cope with it yourself. The earlier you get treatment, the better the chance of getting the pain under control.

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

**Describing pain**

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

Your doctor or nurse will look at what is causing your pain, what type of pain you have, how bad it is and how it is affecting you. This will help them find the best treatment for you. They will ask you about your pain and will examine you.

They may ask you how the pain is affecting the following things.

- Your body – where is the pain, does it spread to other parts of your body, what brings it on or helps to improve it, and how does it feel?
- Your daily life – does it get in the way of everyday activities, like eating, resting and sleeping?
- Your feelings – how does it affect your mood and how you feel?
- Your relationships – how does it affect your relationships with your family and friends?
• Your sex life – how does it affect the way you feel about your body and your relationship with your partner, if you have one?
• Your spiritual feelings – how do you feel about yourself, your beliefs and your future?

**Pain scales**

Pain scales help you describe how bad your pain is. Your doctor or nurse may ask you to rate your pain on a scale from 0 to 10, where 0 means no pain and 10 means the worst pain you can imagine. They may also ask you if your pain is mild, moderate or severe (very bad).

There are no right or wrong answers to these questions – only you know how bad your pain is. Tell your medical team if you have any pain, even if the pain feels better than it was before. This will help you and your medical team keep track of changes in your pain and how well your treatment is working.

**Pain diaries**

Keeping a diary can help you remember details of your pain and help you describe it to your medical team.

Try thinking about the following questions when you are writing about your pain.

• Where is the pain?
• Do you have pain in more than one area?
• How bad is the pain on a scale from 0 to 10?
• Does the pain spread to other parts of your body?
• When do you get pain?
• How long does the pain last?
• Does anything make the pain better or worse?
• Is the pain worse at a certain time of day or in the night?
• What do you think is causing the pain?
• What pain relief have you had?
• Has the pain relief helped with the pain, partly helped or not helped at all?
• Have you had any side effects from the pain relief?
• How do you feel about your pain and the pain relief you have had?

Take your diary to your appointments and show it to your doctor or nurse. You should talk to your medical team regularly about your pain. This will help to make sure your pain is managed as well as possible and that you are getting the support you need.

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

You can speak to our specialist nurses on our free Support Line if you have any questions about how to talk about your pain.
“You have to trust the professionals and ask for advice – that is their job so encourage the person to speak up about any aches and pains, and describe all symptoms.”

“As a carer, you notice changes in the person you’re caring for, and can speak to the professionals on their behalf.”

Questions to ask your doctor or nurse

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

I’m worried that my pain is getting worse. What does this mean?

Do you have a pain diary I can use?

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

Painkillers

This section explains the painkillers used to treat pancreatic cancer pain.
There are two main types of painkillers – non-opioids and opioids. Non-opioid painkillers include paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs), like ibuprofen or naproxen. Read more about these painkillers on page 29. Opioid painkillers include morphine and oxycodone (see page 31).

In this booklet, we use the general (generic) name of each drug, rather than the brand name. You may take more than one type of painkiller to help your pain. Or you may take painkillers with other drugs (see page 45) that can help to manage pain.

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 their instructions when taking painkillers. 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 very bad before taking painkillers.

Don’t stop taking your painkillers without speaking to your doctor or nurse first, even if you don’t think they are helping your pain. If you are worried about side effects, speak to them before changing anything.

Use our **Pain Medicines Record Card** on page 62 to help you remember when to take your pain relief. Your doctor or nurse and your local pharmacy can also give you advice about how to remember to take your painkillers at certain times.

Your doctor and nurse should continue to check your pain during your care. This is to make sure that your painkillers are working properly, and that you have the information and support you need.
“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.”

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

**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 driver (see below), or have painkillers by injection.
- Some painkillers, such as fentanyl and buprenorphine (see page 33), can be given through a patch that is put on your skin.

**Syringe Driver**

A syringe driver (sometimes called a syringe pump) provides a steady flow of painkillers, which means that you get your pain relief continuously. It is a small battery operated machine which is attached to a needle that is inserted under the skin.
A syringe driver can also be used to provide other medications, such as anti-sickness medicine. You can move around while using a syringe driver, and can use it while at home or out of the house.

**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 31) or with other types of pain relief (see page 45).

Paracetamol is normally taken as a tablet. It is also available as a liquid or can be given by injection if you have problems swallowing tablets.

Follow your doctor’s instructions when taking paracetamol or NSAIDs. Don’t take more than the dose they give you. For example, too much paracetamol can damage the liver.

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 from the pharmacy or supermarket, 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

If you are having chemotherapy, your doctor may tell you not to take paracetamol or NSAIDs. Or they may tell you to always check your temperature before you take them. This is because chemotherapy can make you more at risk of an infection. If you have an infection, paracetamol or NSAIDs can hide this by lowering your temperature and making you feel better, but they won’t cure the infection.

If your temperature is normal, it’s safe to take them. If it’s high, don’t take them and contact your chemotherapy team – they should have given you a phone number to call. If you are having chemotherapy, a high temperature is 37.5°C or 38°C, depending on the advice of your chemotherapy team.

If you’re not sure what to do, talk to your chemotherapy team. An infection is a medical emergency if you are having chemotherapy, and needs treating straight away.

Read more about chemotherapy and infections in our fact sheet, Chemotherapy for pancreatic cancer, or on our website at pancreaticcancer.org.uk/chemotherapy
Opioid painkillers

Opioid painkillers, like morphine or oxycodone, are used to treat pancreatic cancer pain. You may take them with other types of pain relief (see page 45).

There are different types of opioid painkillers, including weaker and stronger opioids. They may be taken in different ways, and have different side effects. The type of painkiller you have will depend on what kind of pain you have, and your general health.

If your pain gets worse tell your doctor or nurse. They will look at your painkillers again. It’s normal for doctors to change the dose of painkillers. For example, they may increase the dose of your painkiller or add different drugs. If you have bad side effects, they may offer you a different painkiller.

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, including non-opioid painkillers. If this pain relief is not helping tell your doctor or nurse so that they can increase the dose, or give you a different or stronger painkiller.
**Stronger opioids**

If weaker opioids do not control your pain, you may have a stronger opioid. 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.

Your doctor or nurse will work out the best dose for you that manages your pain, without causing bad side effects.

Some stronger opioids are available in two forms:

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

**Immediate release opioids**

Immediate release opioids start to work after about 20 minutes and reach full effect after about an hour. This makes them good for treating breakthrough pain or sudden changes in pain (see page 18).

You may start off with an immediate release opioid while your doctor or nurse works out the best dose of a modified release opioid for you.

It can be useful to keep a record of when you take your painkillers so you know when to take your next dose. You can use the **Pain Medicines Record Card** on page 62 for this.

**Modified release opioids**

You usually take a modified release opioid twice a day to control background pain (see page 18). These opioids take a longer amount of time to have their full effect. So you must take them regularly at the same time of day for them to work properly.
Types of stronger opioid

**Morphine**
Morphine is usually the strong opioid that people start with. There are two types – immediate release morphine and modified release morphine.

You usually take morphine by mouth, as a tablet or liquid. But you can have it as an injection if you are being sick or have trouble swallowing. Morphine can also be given by a syringe driver (see page 28).

**Oxycodone**
This drug works in a similar way to morphine and comes in immediate release and modified release forms. You may have oxycodone if morphine causes side effects.

You usually take oxycodone by mouth as a tablet, capsule or liquid. You can also have it as an injection, or by a syringe driver.

**Fentanyl**
This type of opioid painkiller can be a good choice for people who find it hard to swallow tablets, or who can’t take morphine. There are a few types of fentanyl, including injections and skin patches.

Fentanyl patches are used for controlling stable background pain (see page 18) and are usually changed every three days. The patches don’t control unstable or short-term pain.

Fentanyl also comes as tablets which dissolve under your tongue, lozenges that you suck, and nose sprays. These can treat breakthrough pain, and may be used with other painkillers.
Buprenorphine
This is another option for people who have stable pain and who find it difficult to swallow tablets. Buprenorphine is available as a skin patch, or as a tablet that you dissolve under your tongue.

Methadone
Methadone can be taken by mouth as a liquid, tablet or capsule. You can also have it as an injection.

Methadone works for different lengths of time in different people, so the dose will be specific to you. It may only be offered by doctors who have a lot of experience in using it.

Tapentadol
Tapentadol is a tablet that you take by mouth. It is available in immediate release and modified release forms. You normally take tapentadol between two and four times a day.

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

Speak to your 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 or lower 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 problems emptying your bowels. Fentanyl may be less likely to cause constipation than morphine.

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 lots 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 can give you medicine to prevent sickness. They may change the type of painkiller you are using if your sickness continues.

You may also get a dry mouth. Some people find that drinking plenty of water, sucking ice cubes or chewing gum helps.

“"We found pineapple juice and frozen pineapple were good to help a dry mouth, and ice lollies helped with a fresher taste.”"
Other side effects
Other possible side effects of opioid painkillers 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 pain medicine. They may change the dose of your painkiller, or give you a different painkiller.

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. 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 drugs work and how the dose is worked out, and can discuss any concerns you have.
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 31).

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. They will check any side effects and change the dose or the type of painkiller to help with these side effects. If you are worried about any side effects, speak to your doctor or nurse.
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 of your pain relief.

You are legally allowed to drive when you are taking opioid painkillers, as long as the drug doesn’t affect your ability to drive. You should carry proof that you’ve been given opioids for a medical condition. This might be a copy of your prescription, or the information leaflet that comes with the medicine. The Department for Transport has more information about driving while taking strong painkillers (see page 69 for contact details).

Can I drink alcohol while taking strong painkillers?
Alcohol and other medication 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?

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

Your doctor or nurse may increase the dose of your painkillers or change the way you take them. For example, 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 45).

If your pain isn’t under control, it may help to have a specialist palliative care or supportive care review (see page 6). Your GP or hospital team can refer you for this. It may include having an appointment with the palliative care team, or going into a hospital or a hospice for a short time to treat your pain and other symptoms. Once your pain is back under control, you can go home again.

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

“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.”
Questions to ask your doctor or nurse

What type of painkiller should I take?

Can you explain how and when I should take painkillers?

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

What side effects might I get?

Should I take anything to prevent side effects?

How will these painkillers affect my daily life?

Will I be able to drive?

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

Are there any instructions on how to store my painkillers?

If my medicine is changed, what should I do with the painkillers I no longer need?
Section 6

Nerves blocks and other types of pain relief

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.
Nerve blocks

A nerve block is a treatment that blocks nerves from sending messages to the brain, and so treats pain. You may be able to have a nerve block on the nerves in the coeliac plexus. The coeliac plexus is a thick bundle of nerves behind the pancreas. Pancreatic cancer can damage these nerves, causing pain. See page 19 for more about nerve pain.

You may have a nerve block if:

- you have nerve pain that isn’t controlled
- 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.

If your doctor thinks a nerve block might help, you will see a team that specialises in using nerve blocks. You will continue to have other pain relief while you wait to have the nerve block.

What does a nerve block involve?

You will have a local anaesthetic so you won’t feel anything during the procedure. You may also have a medicine to relax you.

The doctor will use needles to inject alcohol into the coeliac plexus nerves. This will block the nerves from sending pain messages from the pancreas to the brain.
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 a picture of the inside of your body. You will lie on your back, and the doctor will pass the needles through your upper tummy area.

Sometimes, your doctor may ask you to lie on your front, and pass the needles through your back.

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.

Questions to ask your doctor or nurse
Is a nerve block suitable for me?
What are the advantages of a nerve block?
If I have a nerve block, where and when will I have it?
Other types of pain relief

Your doctor or nurse may suggest drugs that are usually used to treat other health conditions, but 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 one of these other drugs may mean that the dose of painkillers such as 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, which comes on suddenly (see page 18). Continue to take the drugs, even if you don’t feel a difference straight away.

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

Amitriptyline is usually used to treat depression, but may be used to relieve nerve pain. It can also help if you are struggling to sleep.

You usually take amitriptyline as tablets. You will start on a low dose, which can be slowly increased every few days if needed.
This drug can cause side effects, such as feeling tired, problems passing urine, changes to your vision or a dry mouth. If you get any side effects, tell your doctor or nurse.

**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 19). They can help to control short bursts of pain, or severe pain that needs treating quickly.

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.

They should only be used for a short period of time, usually up to two weeks. This is because steroids can cause side effects. These include indigestion, changes in your mood, confusion, tummy pain or increased blood sugar levels. Speak to your doctor or nurse if you have any side effects, or if you have diabetes.

**Drugs for tummy cramps**

These drugs are known as antispasmodic drugs. They help relax the muscles in your bowel, and can relieve tummy cramps, discomfort 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 driver (see page 28).
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 can be used to help control nerve pain. It can be used with opioid painkillers if opioids are not relieving all your pain.

Ketamine is given in low doses, as a tablet, an injection or by a syringe driver (see page 28). The dose can be gradually increased to help control your pain better.

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 a lot of experience using it.

**Cannabis-based products**

Specialist doctors can prescribe certain medicines containing cannabis, or products based on cannabis for some specific symptoms. But this is only if there is clear research to show it is helpful, and when there are no other medicines that could help.

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 products 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 cannabidoil (CBD) or hemp oil, but these may also be poor quality. Cannabis that is smoked, or ‘street cannabis’, is illegal and could be dangerous.

If you are thinking about trying any cannabis products, speak to your doctor or nurse first.

**Radiotherapy and chemotherapy**

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

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

Ask your doctor or nurse about these treatments to see if they may be suitable for you.

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

Find out more about chemotherapy in our fact sheet, *Chemotherapy for pancreatic cancer*, or on our website at [pancreaticcancer.org.uk/chemotherapy](http://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 provides more information about TENS.

Questions to ask your doctor or nurse

What else might help with my pain?

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

Would a TENS machine help?
Section 7

Other things that can help

Some people find that other things help them deal with pain. These include physical activity and complementary therapies, such as acupuncture or massage.
Physical activity

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

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

“"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.”""

You can read more about physical activity in our booklet, Diet and pancreatic cancer, and on our website at pancreaticcancer.org.uk/exercise

Complementary therapies

Some people find that complementary therapies, such as acupuncture and massage, help them deal with pain. 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 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.
Your medical team can tell you what complementary therapies are available in your area. Hospitals, hospices and local charities may offer some complementary therapies for free, but this can often be limited. The Complementary & Natural Healthcare Council (see page 68 for contact details) have a list of registered therapists.

We describe some common complementary therapies in this section. Find out as much as possible about the complementary therapy before you try it. Macmillan Cancer Support and the NHS website have more information about complementary therapies, including things to consider if you are thinking about using them.

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

**Acupuncture**

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

There is limited evidence that acupuncture helps with cancer pain. It may help when used alongside prescribed painkillers. Needles placed in the ear may also help people with nerve pain (see page 19), but we need more research into this.

The British Acupuncture Council have more information and a list of qualified acupuncturists. See page 68 for contact details.
Massage
Some people find massage calming and relaxing. It may help to reduce pain and anxiety, and help you feel better generally. Many TENS machines (see page 49) have a massage setting.

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

Reiki is a gentler type of massage where the therapist’s hands gently brush over the body, or a few inches above the body. This may be useful for people who can’t have regular massage.

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

Aromatherapy uses essential oils, such as lavender oil, to massage the body.

“ When my partner started to get referred pain into his shoulder, what he said helped was me massaging his shoulder. He would often fall asleep straight after as the pain subsided for a while.”

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

Relaxation therapies, such as meditation, mindfulness or hypnotherapy, may help you to cope with pain.

**Meditation** involves concentrating to calm your mind and relax your body. It can help you manage your thoughts and cope with your feelings. Your medical team can give you details of local teachers.

**Mindfulness** uses breathing and meditation to change the way you think and feel about a situation. Ask your doctor or nurse if they know of any books, websites or mobile phone apps that can help you try mindfulness.

**Hypnotherapy** is a type of deep relaxation that can help you change the way you think about pain. It can also help you feel more able to cope with pain. You can get details of hypnotherapists from the British Society of Clinical Hypnosis (see page 68 for contact details).

Questions to ask your doctor or nurse

What sort of physical activity might help with my pain?

Are there any complementary therapies that might help?

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

Coping with pain

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

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

Your doctor or nurse should regularly check the emotional impact of the symptoms of pancreatic cancer, including pain, during your care. They should offer you information and support to help you cope with pancreatic cancer.

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

**How can I help myself?**

There are things you can do at home to distract yourself from pain or help you feel more able to deal with it. For example, you could try a hobby, reading a book, watching television or listening to music. Chatting to family and friends may also help. And you could try some of the complementary therapies on page 51.

“*My husband had upper abdominal pain, radiating to his back. The only relief from the pain was having a hot bath.*”
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. It might help to talk to them about ways that they can help you.

You can also talk to your doctor or nurse. You should have a main contact, who will often be a nurse. They can provide emotional support as well as medical care.

Some people find counselling helpful. This involves talking to a trained counsellor, who can help you talk about and deal with your feelings. If you’re interested in counselling, speak to your medical team – they may be able to refer you. You can find more information about counselling from the British Association of Counselling and Psychotherapy (see page 68 for contact details).

You may also find it helps to talk to others affected by pancreatic cancer, who can understand what you’re going through. We have an online discussion forum where you can speak to other people affected by pancreatic cancer. We also hold Living with Pancreatic Cancer Support Days which provide face to face support in an informal setting. There are talks about dealing with pancreatic cancer, and you can meet others with it.

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.

You can also speak to our specialist nurses on our free Support Line. They have time to listen to your concerns and answer your questions.
“I found that online support groups really helped. Talking virtually to people all over the world who also had a loved one with pancreatic cancer. Hearing their stories, sharing hopes and fears and receiving support and virtual love.”

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

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

We have information about pancreatic cancer on our website at pancreaticcancer.org.uk/informationandsupport

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?
Is there any local support I can get?
Would counselling be helpful?
Is there anyone I can speak to about my beliefs, such as a spiritual leader?
Section 9

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 provide information about our services and other organisations that can support you.
Glossary

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.

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

**Dose:** the amount of drug that is given at one time.

**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 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.

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

You could take the record card with you to your appointments and if you go into hospital or a hospice.

Speak to your doctor if you are having trouble remembering when to take your medicines, as there are other things that can help you remember.
Record of when to take pain medicines

Week beginning

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Dose</th>
<th>Time</th>
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<tbody>
<tr>
<td><strong>Pregabalin First dose</strong></td>
<td>150mg (3 tablets)</td>
<td>9am</td>
</tr>
<tr>
<td><strong>Pregabalin Second dose</strong></td>
<td>As above</td>
<td>6pm</td>
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Write down the times you take your medicines.
## Tick when taken

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</tbody>
</table>

Write down the times you take your medicines and tick when taken.
**Multidisciplinary team (MDT) members**

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

**Out of hours or emergency contact**

**Name:**

**Telephone:**

**Notes:**

**General practitioner (GP)**

The GP will help manage your cancer. They can refer you for other medical services to help manage symptoms, including pain.

**Name:**

**Telephone:**

**Email:**

**Notes:**

**Clinical nurse specialist**

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

**Name:**

**Telephone:**

**Email:**

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

**Name:**

**Telephone:**

**Email:**

**Notes:**

**Consultant surgeon**
A doctor who carries out surgery.

**Name:**

**Telephone:**

**Email:**

**Notes:**

**District nurse**
A nurse who visits and treats people in their own home.

**Name:**

**Telephone:**

**Email:**

**Notes:**
Hospital palliative care team
A team of professionals at hospital who can help you manage your pain and other symptoms, and help you to live as well as possible. The team may include doctors, specialist nurses, physiotherapists, occupational therapists and counsellors.

Name:

Telephone:

Email:

Notes:

Community palliative care team
Similar to the hospital palliative care team, but they may visit you at home to help you manage your pain. Some teams are based at hospices.

Name:

Telephone:

Email:

Notes:
Pancreatic Cancer UK services
We are here for everyone affected by pancreatic cancer.

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

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

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

Go to pancreaticcancer.org.uk/informationandsupport

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

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

Our Living with Pancreatic Cancer Support Days provide local face to face support in an informal setting for people diagnosed with pancreatic cancer: pancreaticcancer.org.uk/supportdays

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

British Acupuncture Council  
www.acupuncture.org.uk  
Tel: 020 8735 0400  
The UK’s regulatory body for acupuncture therapists. Provide information on acupuncture and a list of qualified acupuncturists.

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

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

Cancer Research UK  
www.cancerresearchuk.org  
Helpline: 0808 800 4040 (Mon-Fri 9am-5pm)  
Information for anyone affected by cancer.

Complementary & Natural Healthcare Council  
www.cnhc.org.uk  
Tel: 020 3668 0406 (Mon-Fri 9.30am-5.30pm)  
Information about complementary therapies and a register of therapists.
Department for Transport  
www.gov.uk/drug-driving-law  
Information on drugs and driving, including medicines for pain relief.

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

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

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

Maggie’s Centres  
www.maggiescentres.org  
Centres around the UK and online offer free, comprehensive support for anyone affected by cancer.

Marie Curie  
www.mariecurie.org.uk  
Support line: 0800 090 2309 (Mon-Fri 8am-6pm, Sat 11am-5pm)  
Provides care and support for people living with a terminal illness, and their families.
The NHS website
www.nhs.uk
Provides information about health conditions, living well, care, and local services in England.

NHS Direct Wales
www.nhsdirect.wales.nhs.uk
Health information in Wales, including local services.

NHS inform
www.nhsinform.scot
Tel: 0800 22 44 88 (Mon-Fri 8am-10pm; Sat-Sun 9am-5pm)
Provides information about health conditions, living well, and local services in Scotland.

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

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

Email us at publications@pancreaticcancer.org.uk for references to the sources of information used to write this fact sheet. Details of the health professionals who reviewed this fact sheet are available on our website – pancreaticcancer.org.uk

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

**Give us your feedback**
We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions. Email us at publications@pancreaticcancer.org.uk or write to our Information Manager at the address on the back cover.

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