

# Pancreatic Cancer UK

**Caring for someone with  
pancreatic cancer**  
Information for families and carers



# Introduction

This booklet is for family and friends who are looking after someone with pancreatic cancer. When we talk about “family member” in this booklet, we mean anyone who is looking after someone with pancreatic cancer.

You may hear yourself described as their carer, although you may not see yourself as a carer. You may simply see yourself as their partner, family member or friend. But anyone who looks after a family member or friend, unpaid, and provides support that that person couldn't manage without, is a carer. You might not think that you are doing anything unusual. But the care you give them is really important.

Caring for someone with pancreatic cancer can have a big impact on you physically, emotionally and financially. But you may not have much time to find out about or get the support you may need. This booklet should help you find support for yourself and your family member.

Not all the information in this booklet might be relevant to you. It's been designed so that you can dip in to find the information you need, when you need it.

If you have any questions about anything you read here, speak to your family member's doctor or nurse. Or you can speak to our specialist nurses on our free Support Line.



Call the specialist nurses free on **0808 801 0707**,  
or email **[nurse@pancreaticcancer.org.uk](mailto:nurse@pancreaticcancer.org.uk)**

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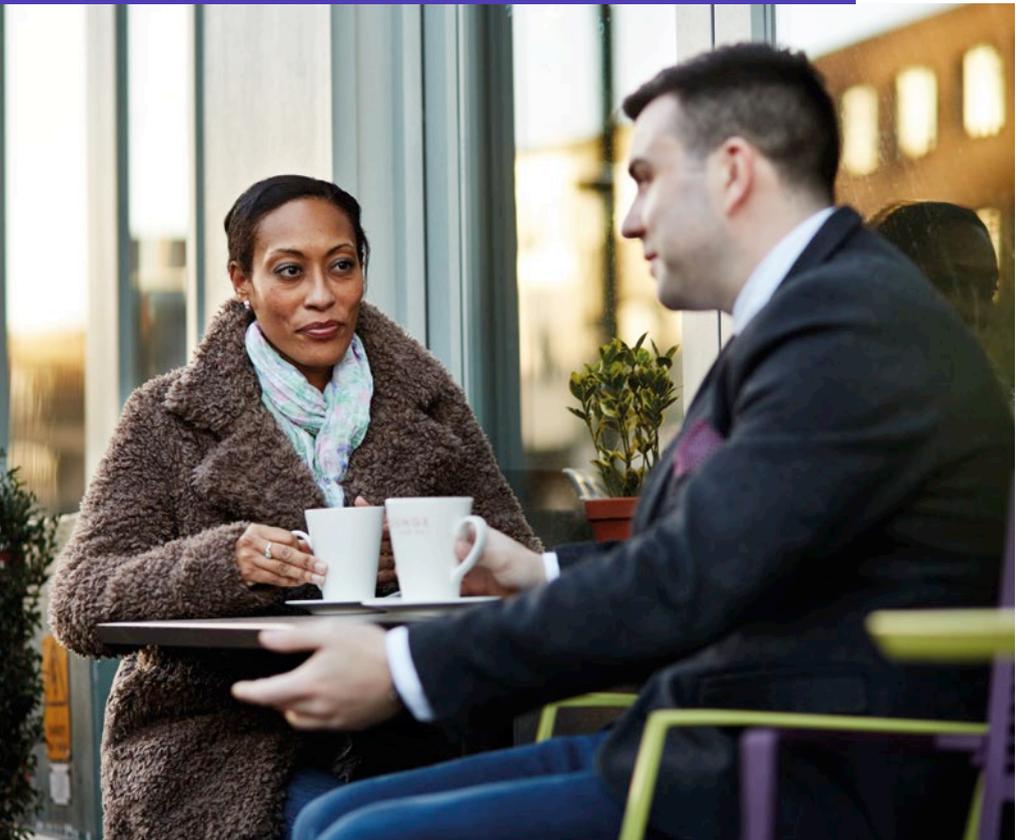
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## Section 1

# Looking after yourself

Many family members are so busy helping the person with cancer, they ignore their own needs – especially the emotional impact of having a family member with cancer. This section has information on sources of emotional support for you.



## How you might be feeling

When someone close to you has been diagnosed with pancreatic cancer you will probably experience a range of emotions at different times. These might include disbelief, anger, fear, confusion and denial. You may feel helpless, that you don't know what to do, and don't know enough about pancreatic cancer to help them. If your family member has been unwell for some time, you may even feel a bit relieved that at least now you know what is wrong with them. There is no 'right' way to feel, and how you react will be very individual to you.

When you are caring for someone with cancer, you might think that your feelings come second to theirs, or you might be too busy to think about how you are feeling. Your family member may be everyone's focus, but that doesn't mean that what you do as their carer is not appreciated.

You may think that you always have to be the strong one who copes with everything. You may find it difficult to talk to your loved one about their cancer. Macmillan Cancer Support have information on talking about cancer (see page 60 for contact details).

People tell us that one of the hardest things can be feeling that you are the only person in this situation. But you aren't alone. Many others are going through similar experiences, and there's support available. Make sure you get support when you need it.

**“ The most helpful advice? Never give up hope and take each day as it comes.”**

**“ Everybody copes differently. I concentrated on the practical things I could do.”**

## Who can you contact for emotional support?

Getting some support for yourself can be helpful, as well as helping you support your family member better. Your family and friends can be great sources of support – just having someone to talk to can be a huge help.

The medical team looking after your family member can also help – especially their keyworker. They will be able to answer your questions and provide you both with emotional support, as well as medical care. See page 13 for more information about the medical team.

### **Who is the keyworker?**

The keyworker is the main point of contact in the medical team for you and your family member. They will usually be a specialist nurse. If your family member hasn't been given details of a keyworker, ask their consultant about this. The consultant's secretary may also be able to put you in touch with the keyworker.

There is also emotional support available from a range of organisations (see pages 7-11).

**“ Support of friends, music, books, poetry, meditation, acupuncture, red wine... all helped me cope with my feelings.”**

“ My sister and I spent a lot of time talking to each other, or having a cry together – we were lucky in that we are close. Dad doesn’t show many emotions, but as time progressed even he mellowed and we all coped together, in our own ways.”

“ I emailed close friends with all the details, which acted like a diary; it helped me cope.”

### **Pancreatic Cancer UK services**

We’re here for everyone affected by pancreatic cancer.

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**

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.



Find out more at **forum.pancreaticcancer.org.uk**

We have the most up-to-date information on everything you need to know about pancreatic cancer through our website and publications.



Go to **[pancreaticcancer.org.uk/informationandsupport](http://pancreaticcancer.org.uk/informationandsupport)**  
Download or order our free publications at  
**[pancreaticcancer.org.uk/publications](http://pancreaticcancer.org.uk/publications)**  
or call **0808 801 0707**

Our Living with Pancreatic Cancer Support Days provide local face to face support in an informal setting for people with pancreatic cancer, and key family members or carers.



Find out more at **[pancreaticcancer.org.uk/supportdays](http://pancreaticcancer.org.uk/supportdays)**

“ What makes it a little easier is the Pancreatic Cancer UK forum – knowing that there are other people out there going through what I am, knowing I am not the only person in the world that this is happening to, because sometimes it feels like I am.”

“ The Pancreatic Cancer UK nurse gave us a lifeline with advice and support. I’m not sure how we would have coped without her.”

“ The things that helped me cope? Being very informed, reading lots of information. The Pancreatic Cancer UK forum. Outstanding doctors and nurses.”

## Support groups

There are cancer support groups around the country. They are often open to family members as well as the person with cancer. At a support group, you can meet other people going through similar experiences.



There are some groups specifically for pancreatic cancer – go to **pancreaticcancer.org.uk/supportgroups**

There are also groups for people caring for someone with cancer. The GP or nurse will know what groups are available locally. Macmillan Cancer Support have information about cancer support groups (see page 60 for contact details).

**“ Try to speak to someone who has experienced the same thing. Only they know how you feel.”**

## Carers' organisations

There are organisations that offer information and support for carers, including emotional support. Carers UK and Carers Trust both provide information and support across the UK. See pages 58-59 for contact details of these organisations.

There are also carers' centres around the UK that provide free support for carers. Carers Trust have more information, or ask your local council if there's a carers' centre in your area.

## Counselling

It can be emotionally draining when someone you're close to has pancreatic cancer. People often find their own ways of coping, but you might find counselling helpful.

Counselling can help you come to terms with your feelings and develop some coping strategies. You may be able to find a counsellor or psychotherapist who specialises in supporting carers through your GP, hospital or hospice. Hospices can support you in a variety of ways (see page 40), and don't just provide care for people at the end of their life. The British Association for Counselling and Psychotherapy has information about counselling, and you can search for a therapist (see page 58 for contact details).

**“ The hospital put me in touch with a hospice for counselling, which helped.”**

**“ I had access to an advice line at work; I spoke with my doctor three times, and joined a support group as soon as I could. I focus my energy into doing positive things which has helped me.”**

## Support for children

You may need support for children or grandchildren as well as yourself.

For most children and teenagers it's best to be honest and talk to them as much as possible about what's going on. There is information and support available to help you talk to children. You can find details of these organisations on pages 60 and 62.

- Macmillan Cancer Support produce a booklet, **Talking to children and teenagers when an adult has cancer.**
- The Fruit Fly Collective produce a range of information and tools to help children with a parent who has cancer.
- Teenagers may find it easier to talk to their friends or another adult outside the family, or find support online. For example **www.riprap.org.uk** is a website for teenagers who have a parent with cancer.
- Winston's Wish provides information and support for children with a parent with a serious illness, or who have been bereaved.

Your family member's keyworker may also be able to give you information and advice about talking to children.

## Section 2

# The medical team and healthcare system

It can be difficult to work out how to get the care and support your family member needs, especially if you've never had to do it before. If you're not sure what to do then the first people to speak to are the specialist nurse, keyworker or consultant in the multidisciplinary team.



## The multidisciplinary team (MDT)

The multidisciplinary team (MDT) is the team of medical professionals responsible for your family member's treatment and care. You probably won't meet all of them, but they will discuss your family member's test results and agree on the best treatment for them. Your family member won't need to be present at this meeting.

The health professionals most likely to be involved are the specialist nurse (also called a clinical nurse specialist or CNS), gastroenterologist, oncologist, surgeon, dietitian, radiologist (who use images to diagnose and treat illnesses), and palliative care nurse. You may meet others at different stages. There's more information about these health professionals and space to write down their details on pages 53-57.

Your family member will be given a main contact, who may be called a keyworker. They will usually be a specialist nurse. They will support your family member and you, and coordinate their care. They will be the person you speak to most. They will also be part of the MDT. If your family member hasn't been given a specialist nurse or keyworker, ask their doctor about this.

As long as the person you're caring for gives their GP and medical team permission to speak to you, you can talk to them about your family member's treatment and care.



If you have any questions or problems getting the care your family member needs, contact our specialist nurses on our free Support Line.



You can find out more about what care your family member should expect in our **Patient charter: What you should expect from your care**

*“ We were well informed and supported. We had a long consultation with the consultant and the specialist nurse, then we saw the dietitian which was really helpful.”*

## Where is pancreatic cancer treated?

In the UK anyone diagnosed with pancreatic cancer should have their case reviewed at a specialist cancer centre where there is a specialist team (the MDT) to assess and treat pancreatic cancer. In particular, surgery should only be carried out in specialist centres. There are specialist centres across the UK.

People with pancreatic cancer may not have to go to the specialist centre. Tests are often done at local hospitals, as is chemotherapy treatment. But wherever someone is treated, the MDT at the specialist centre should always be involved in decisions about their treatment. You can ask the doctors which specialist centre is involved with your family member's care, and about the decisions made by the MDT at the specialist centre.



There is a list of specialist centres on our website – **[pancreaticcancer.org.uk/specialistcentres](http://pancreaticcancer.org.uk/specialistcentres)**

## The care plan

Your family member should be offered an assessment, called a holistic needs assessment. The keyworker should discuss a range of things with your family member, including:

- their physical needs – for example around symptoms or side effects
- any practical issues, such as work or any care they need
- emotional concerns, such as sadness, depression or spiritual questions.

They should have a holistic needs assessment after they've been diagnosed, and if their needs change. The timing of the assessment may depend on how well they're coping with their diagnosis – their keyworker will find the right time to carry it out. Their doctor or nurse should develop a care plan, which includes how to manage anything raised in the assessment. If they haven't been offered a holistic needs assessment, they can ask for one.

**“ When they're going through treatment be there for them, supporting them with your presence, sharing their concerns, worries and fears.”**

### ? Questions to ask

Who are the members of the MDT?

Does the person I'm caring for have a specialist nurse?  
How do we contact them?

How do we access community services if the person I'm caring for leaves hospital?

## **Who do I call out of normal hospital hours or in an emergency?**

You will normally be given a name and contact number if you need to talk to someone out of normal hospital hours. There's space to write it down on page 53.

If your family member is having chemotherapy they will be given an emergency phone number. For example, you should call this number if their temperature goes above 37.5°C or 38°C (depending on the advice you've been given by their chemotherapy team), as this could be a sign of an infection (see page 31).

For any other emergency you should take the person you care for to accident and emergency (A&E), or call 999 and ask for an ambulance.

**“ We had emergency numbers on a card directing us to the appropriate hospital and department.”**

## **How do we get a second opinion?**

If you want to get a second opinion from a different doctor, you can ask for one. This means seeing a different consultant, possibly in a different hospital. For example, sometimes people or their family may be concerned about the diagnosis or recommended treatment and may want a second opinion.

A second opinion is free on the NHS or can be paid for privately. If your family member agrees, you can ask for one on their behalf. You will need to ask their current consultant or GP for a referral for a second opinion. You don't have a legal right to a second opinion, but doctors usually won't refuse.

Asking for a second opinion won't affect someone's care. But it can take time, so it is a good idea to start any treatment while going through the process, rather than delaying treatment.

Think about what getting a second opinion might mean before asking for one. For example, if the two consultants agree it may make you feel more confident. But if a different treatment is offered you might worry about which treatment to choose.

NHS Choices, NHS Direct Wales and Citizens Advice have more information about getting a second opinion, including what to do if you have any problems getting one. If you live in England, the My Cancer Treatment website lists cancer services and the quality of care you can expect. See pages 59-62 for contact details.

**“ You don't have to accept the initial information on diagnosis and treatment as being the only possibility. Don't be left thinking, I wish I'd asked about that, I wish I'd known about that.”**

## **What do we do if we have any concerns about care?**

If you have any concerns about the NHS care your family member is getting, then talk to the consultant, nurse or keyworker first. It's important to raise any concerns you have. Don't be worried that this will affect future treatment and care.

If that doesn't improve the situation you may want to make a complaint.

- In England, you can speak to the Patient Advice and Liaison Service (PALS). Find out more on the NHS Choices website.

- In Scotland, you can speak to the Patient Advice and Support Service. You can find out about them from Citizens Advice Scotland.
- In Wales, you can speak to the Local Health Board or NHS Trust. Find out more from NHS Direct Wales.
- In Northern Ireland, you can speak to the Northern Ireland Commissioner for Complaints. Find out more from the nidirect website.

With private healthcare, you should first talk to the consultant, specialist nurse or keyworker about your concerns. If the situation isn't sorted out you can speak to the professional organisation that regulates the service. Citizens Advice have more information about complaining about private healthcare.

You can find details of all these organisations on pages 59-62.

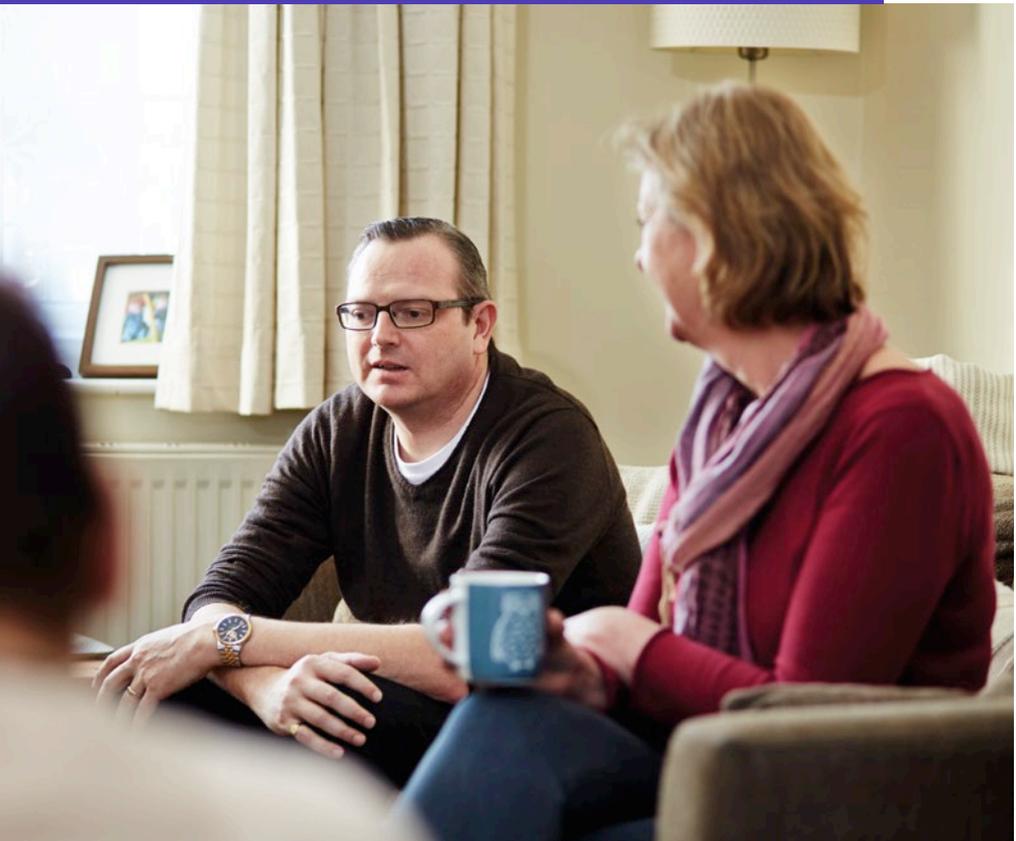
**“ The best thing you can do to help a loved one who is ill and frightened is to push to get help for them when they are too ill to fight themselves. Keep fighting for help, even when you feel nobody is listening and it feels hopeless.”**

**“ I felt very well supported throughout my husband's illness, and felt the care he received was outstanding. The shock and horror of the initial diagnosis wore off and I made a decision to deal only with “definites”, and not worry about things unless they happened.”**

## Section 3

# Managing symptoms and side effects

People will get different symptoms at different stages of their cancer. It can help if you know about the main symptoms, what to do about them and where to get help if you need it.



## What are the key symptoms I need to be aware of?

We have included the most common symptoms and side effects that people with pancreatic cancer get. People may get symptoms caused by the cancer, or side effects from treatments such as chemotherapy. So it can sometimes take a bit of time to work out the exact cause and how best to treat it.

### Pain

Many people with pancreatic cancer have pain at some stage, but not everyone will get pain. Pain can be managed well, so it's important to ask for help as early as you can if your family member has any pain.

There are different ways to manage pain. These include:

- painkillers, including mild painkillers such as paracetamol, and stronger painkillers such as codeine and morphine
- other drugs, such as anti-depressants or anti-convulsants (which are usually used to treat epilepsy), which can work together with painkillers to relieve pain
- a procedure called a nerve block, which blocks nerves from sending pain messages to the brain
- radiotherapy can help to control some types of pain, and chemotherapy can slow down the growth of the cancer and may help to relieve symptoms, including pain.

It's important that you speak to your family member's medical team or GP as early as possible about any pain, if it gets worse, or isn't controlled well. The earlier they get treatment, the better the chance of getting the pain under control. The medical team will look at what is causing the pain, how bad it is and how it is affecting the person you're caring for. This will help them find the

best treatment. If your family member needs further treatment or support to control their pain, they may be referred to specialist services, such as a palliative care team or a pain clinic.

If your family member's pain is very bad at night or at the weekend, contact the emergency number your medical team should have given you. If you haven't been given a number, ask them about this.

Your family member's emotions may affect their pain. For example, their pain may be worse at times when they feel they're not coping. The support you give them, such as emotional support, help in taking medication and managing side effects, or speaking to their medical team, may help to reduce their stress. This may help them cope better with their pain.



If pain is a problem, talk to the specialist nurse, medical team, or GP. You can also speak to our specialist nurses on our free Support Line.



Read more about pancreatic cancer pain in our booklet, **Pain and pancreatic cancer**, or on our website at **[pancreaticcancer.org.uk/pain](https://pancreaticcancer.org.uk/pain)**

## Problems with diet and digestion

The pancreas plays an important role in digesting food, as it produces enzymes that help to break down the food. Nutrients from the food can then be absorbed into the blood and used by the body. Pancreatic cancer can reduce the number of enzymes that your pancreas makes. It can also block the enzymes from getting to the bowel, where they are needed for digestion. This means that food is not properly digested, and the nutrients are not absorbed properly.

This can cause symptoms, including loss of appetite, weight loss, sickness, tummy discomfort and pain, and changes to bowel habits.

Finding ways to manage symptoms related to diet can help your family member feel better generally. One of the most effective ways of controlling these symptoms is pancreatic enzyme supplements. These replace the enzymes that the pancreas would normally produce and help to break down food. This is known as pancreatic enzyme replacement therapy (PERT). Brands include Creon<sup>®</sup>, Pancrease<sup>®</sup>, Nutrizym<sup>®</sup> and Pancrex<sup>®</sup>.

If the person you're caring for hasn't been told about pancreatic enzyme supplements, or is taking enzymes but is having problems, they should speak to their specialist nurse or a dietitian.



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

The multi-disciplinary team (MDT) at the hospital (see page 13) should include a dietitian. They can check any symptoms around diet and offer advice to help manage them. If your family member hasn't seen a dietitian and is having problems, ask their specialist nurse or GP to refer them to one.



If you're shopping or preparing meals for someone, you will find tips to help them deal with different diet symptoms in our booklet, **Diet and pancreatic cancer**, or on our website at **[pancreaticcancer.org.uk/diettips](https://pancreaticcancer.org.uk/diettips)**

There is also information about pancreatic enzyme supplements and how to take them.

**“ It was primarily Pancreatic Cancer UK’s support nurses who told us about the medication available for different symptoms so we went armed with this to the appointments.”**

### **Diabetes and pancreatic cancer**

The pancreas produces a hormone called insulin which helps to control the amount of sugar in the blood (blood sugar level). If the pancreas doesn't produce enough insulin, this can cause diabetes. Diabetes is a condition where the amount of sugar in the blood is too high. This may happen if someone has pancreatic cancer, or has had all or part of their pancreas removed.

If your family member is diagnosed with diabetes, they should see a specialist pancreatic dietitian. They may also see a diabetes nurse for help with managing their diabetes, but the nurse should speak to the pancreatic dietitian before making any changes to their treatment or diet. It's important that they get advice about diabetes that is relevant to them. There are different types of diabetes, and a lot of information available may not be right because of their pancreatic cancer.

If they have lost weight or are struggling to eat, the usual advice about diet and diabetes may not be appropriate. They may need more calories (energy) to help them put weight back on. This may include foods that increase their blood sugar level. Their diabetes will be managed around this. For example, the diabetes medication may be increased if necessary.

If they have sickness or diarrhoea and take tablets for their diabetes, they might not absorb the diabetes medication properly. Speak to their doctor, nurse or dietitian if they have these symptoms.

Managing diabetes and pancreatic cancer can be difficult and confusing. If you have any questions, speak to your family member's specialist nurse, dietitian, doctor or diabetes nurse.



You can also call our specialist nurses on our free Support Line with questions about diabetes.



Read more about diabetes and pancreatic cancer in our booklet, **Diet and pancreatic cancer**, or on our website at [pancreaticcancer.org.uk/diabetes](http://pancreaticcancer.org.uk/diabetes)

## Feeling and being sick

People may feel sick (nausea) or be sick (vomiting) for several different reasons.

Sometimes the cancer can block the duodenum (the first part of the small intestines), stopping food passing out of the stomach into the duodenum. This causes sickness. It can lead to dehydration if the person you are caring for continues being sick (persistent vomiting). See page 26 for more about dehydration, and page 33 for information about persistent vomiting. A stent (a hollow tube) can be put in to open up the blockage. This should stop them being sick, and they should start to feel like eating again.

The cancer can also block the bile duct (the tube that carries a fluid called bile from the liver to the duodenum). This can cause jaundice. Jaundice can cause yellow skin and eyes, and itching. It can also cause sickness and issues with appetite and digestion. A stent can be put into the bile duct to open up the blockage, which should also relieve the symptoms.



Read about having a stent inserted in our fact sheet, **Stents and bypass surgery**, or on our website at **[pancreaticcancer.org.uk/inoperable](http://pancreaticcancer.org.uk/inoperable)**

Feeling and being sick can also be a side effect of chemotherapy or radiotherapy. And other drugs, such as painkillers called opiates (for example, morphine), can also make someone feel sick.

Pancreatic cancer can also cause changes to how well the bowel works. This can stop the stomach emptying properly and

cause sickness. And if the cancer affects the liver, it can affect how well the liver works and cause sickness.

There is a range of anti-sickness medication available, so your family member should talk to their specialist nurse or doctor about their symptoms. They can work out the most suitable type of medication. There are also other things that might help, including ginger, peppermint, and complementary therapies such as acupuncture and meditation.



Read more about ways to manage sickness, including the different anti-sickness medication available, on our website at **[pancreaticcancer.org.uk/nausea](https://pancreaticcancer.org.uk/nausea)**

## **Dehydration**

Dehydration happens when the body loses more water than it takes in. It might happen if someone is sick a lot and can't keep down any fluids, or if they have diarrhoea (runny, watery poo). It is especially a concern when someone has diabetes.

Signs of dehydration include:

- dark coloured urine (pee) and passing less urine
- a headache
- feeling dizzy or light headed
- feeling thirsty.

Read more about being sick on page 25, persistent vomiting on page 33, and diarrhoea on page 27.

## Changes to bowel habits

Many people with pancreatic cancer will notice changes in their bowel habits. This may be constipation (problems emptying the bowels) due to some of the pain relief medications, or diarrhoea (runny, watery poo).

Some people get a symptom called steatorrhoea which is caused by fat in the poo. Poo can be pale, oily, smell horrible, float and be difficult to flush down the toilet. This happens if your body can't digest fat in your food properly – because the pancreas isn't producing enough enzymes. Undigested food passing quickly through the body can also cause diarrhoea. Taking pancreatic enzyme supplements (see page 22) can help to relieve these symptoms.

Diarrhoea can cause dehydration quite quickly, so it's important for your family member to drink plenty of fluids. This can include water, diluted squash, diluted fruit juice or milk. Small, frequent sips can be easier than bigger drinks. When someone is dehydrated they also lose salts and sugars. A sugary drink and salty snack can help. Or try rehydration products which can be bought at the chemist's or prescribed by the GP. Read more about dehydration on page 26.

Contact the medical team if bowel problems don't improve or get worse.

## Fatigue

Fatigue is extreme tiredness. It isn't the same as simply feeling tired. It can be a constant feeling of tiredness or it can come on suddenly for no apparent reason. People may feel weak, unable to concentrate, or have problems sleeping.

Many people with pancreatic cancer will have fatigue at some stage during their cancer and treatment. It may be caused by the cancer itself or treatment such as chemotherapy, or be a result of symptoms. It can get worse during treatment and go on for several months after treatment finishes, sometimes longer.

There are ways to manage fatigue, so it's important to talk to the medical team about it. They may carry out a few simple tests. Once they know what's causing the fatigue they may be able to treat the cause and help with the symptoms.



Read more about fatigue and how to manage it on our website at [pancreaticcancer.org.uk/fatigue](http://pancreaticcancer.org.uk/fatigue)

Macmillan Cancer Support produce a useful booklet called **Coping with fatigue** (see page 60 for contact details).

## Anxiety and depression

When someone has cancer and is facing an uncertain future, feelings of anxiety, fear, anger and worries about what will happen are natural. But these feelings can become overwhelming at times. Anxiety and depression can be common in people with pancreatic cancer. Depression can affect the quality of your family member's daily life, and they may feel less able to cope with treatment such as chemotherapy.

Symptoms of depression include:

- loss of appetite and weight loss
- negative thoughts and feeling hopeless
- loss of any interest or pleasure in daily life
- problems sleeping.

Some of the symptoms of depression can be similar to symptoms of pancreatic cancer. Speak to the medical team or GP if your family member has any of these symptoms. They can find out what's causing them and how best to manage them.

There are ways to deal with depression and anxiety. For example, support in dealing with what might be causing the anxiety might help – such as help with financial issues, or dealing with any symptoms or side effects. Speaking to the medical team or a counsellor may help your family member come to terms with their cancer diagnosis and what that might mean for the future. Hospitals and hospices often have counsellors or psychotherapists who specialise in cancer. Or the British Association for Counselling and Psychotherapy has details of qualified counsellors (see page 58).

Anti-depressant drugs can also help manage anxiety and depression.

It can be difficult for you if your family member is struggling with anxiety or depression. But getting the right support can help them cope with their emotions.

## Are there any symptoms that need urgent medical attention?

Some symptoms need urgent medical help. We've listed some of the main symptoms that need to be treated urgently.

If you think the person you're caring for has any of these symptoms or needs urgent help, then call any emergency contact numbers you've been given by the medical team, the GP, take them to accident and emergency (A&E), or call 999 and ask for an ambulance. Don't worry that you're being a nuisance.

### Blood clot in a vein

If a blood clot forms inside a vein, it can block the vein and reduce or prevent blood flow. It can happen in veins that are deeper in the body – this is known as deep vein thrombosis (DVT). DVT is most common in the lower leg (calf), thigh or pelvis (area below the belly button). A part or all of the blood clot may come free and travel to the lungs. This is called a pulmonary embolism. It isn't common but it can be very serious.

People with pancreatic cancer are at higher risk of a blood clot in a vein – especially people with cancer that has spread to other parts of the body (advanced cancer).

Blood clots in a vein often don't cause any symptoms, although there are some that you can look out for. These include:

- pain, or tenderness in the leg or calf
- swelling in the calf
- warm skin or redness in the affected area.

Symptoms of pulmonary embolism include:

- shortness of breath
- pain in the chest (especially when breathing in)
- coughing up blood.

Most blood clots can be successfully treated with blood thinning drugs (anti-coagulants) such as enoxaparin or warfarin.



Read more about blood clots in a vein at  
**[pancreaticcancer.org.uk/bloodclots](https://pancreaticcancer.org.uk/bloodclots)**

## Neutropenic sepsis

Neutrophils are white blood cells that fight infection. Neutropenic sepsis is an infection that can happen when the neutrophil level drops significantly. This can happen during chemotherapy. It is a medical emergency and needs urgent treatment.

You won't know that the neutrophil level is low unless your family member has had a blood test that picked it up. But signs that they may have an infection include a high temperature, headache, feeling shivery or achy, and generally feeling unwell. You need to check their temperature. If it is 37.5°C or 38°C or above (depending on the advice you've been given by the medical team) you should phone the emergency contact number they will have been given. You should have a digital thermometer to measure their temperature accurately.

If it is out of normal hospital hours and you can't contact any of the team, go to your local A&E or call an ambulance. Tell them that the person you're caring for is having chemotherapy – this is important so that they are not exposed to other sick people in the waiting area who may have infections.



You can read more about neutropenic sepsis in the chemotherapy information on our website – **[pancreaticcancer.org.uk/chemotherapy](http://pancreaticcancer.org.uk/chemotherapy)**

## Stent infection

Hollow tubes called stents are sometimes inserted to relieve symptoms caused by the cancer blocking the bile duct or duodenum. See page 25 for more about stents.

There is a risk that the stent may get infected. This may be caused by the stent getting blocked, or by the bile flowing more slowly through a stent in the bile duct.

Signs of an infection can include:

- feeling unwell
- being sick (vomiting)
- loss of appetite
- pain
- fever, shivering or feeling cold
- yellow eyes (a sign of jaundice).

If your family member does have an infection, they will usually be admitted to hospital and treated with intravenous antibiotics (into a vein). The stent might also be replaced.



You can read more about stents in our fact sheet, **Stents and bypass surgery**, or on our website at **[pancreaticcancer.org.uk/inoperable](http://pancreaticcancer.org.uk/inoperable)**

## Persistent vomiting

Being sick a lot with no improvement (persistent vomiting) is a clear sign that something is wrong, though it can have a variety of causes. If someone has been vomiting for half a day or longer and can't keep down any food or fluid, there's a risk of dehydration (see page 26).

Your family member will probably need to be admitted to hospital for intravenous fluids (into a vein) and to find out the cause of the vomiting.

## Gastric outlet obstruction

The cancer can block the opening of the stomach into the duodenum. This is called gastric outlet obstruction. If this happens, food can build up in the stomach as it can't pass into the duodenum. This can cause persistent vomiting (see above).

The vomiting can cause dehydration (see page 26). If your family member has been vomiting for half a day or longer this needs medical attention.

They may need to be admitted to hospital for fluids into a vein (intravenously). They may also need to have a hollow tube called a stent inserted to open up the duodenum. See page 25 for more about stents.



Read more about stents in our fact sheet, **Stents and bypass surgery**, or on our website at **[pancreaticcancer.org.uk/inoperable](https://pancreaticcancer.org.uk/inoperable)**

## Will there be different symptoms at different stages?

Every person with pancreatic cancer is different. They react differently to their cancer and respond differently to treatment. Different types of pancreatic cancer also behave differently. So it's difficult to know what symptoms they will get, and at what stage.

Some people want to know what to expect – but not everyone will. If you or your family member do, speak to the doctor or nurse. They will be able to talk to you about your loved one's situation.

Most symptoms can be relieved, so make sure you speak to the GP, medical team or nurse about any new or worsening symptoms.



You can also contact our specialist nurses on our free Support Line. You can talk through any concerns you have with them.

**“ We didn't really know what to expect in terms of symptoms at different stages. It seems the nature and progression of symptoms like pain varies with every patient.”**

## How can I help with managing symptoms and side effects?

One of the best ways you can help is by knowing a bit about symptoms, and what to do or who to ask for help.

- Talk to the GP or nurse – either the district, Macmillan or specialist nurse (see page 38), depending on who your family member sees. It can be helpful to keep a note of any problems or concerns so that you can ask about these.
- Read more detailed information about pancreatic cancer symptoms and side effects on our website – **pancreaticcancer.org.uk/informationandsupport**
- Contact our specialist nurses on our free Support Line. They can answer questions, talk through concerns and help you work out what to do or who else to talk to. Call **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**
- Make sure you can quickly find any emergency or out of hours contact numbers you have been given – you can make a note of them on page 53.

You can read about the support available from health professionals and social services on pages 37-43.

**“ We live in Scotland and the most helpful sources of support were the family medical centre nurses – also the Macmillan nurses.”**

**“ Nothing about any of my daughter’s symptoms was too much trouble for me – I just didn’t want her to suffer.”**

## Section 4

# Help and support locally

Many people live a long way from their local hospital so it's important to be aware of local services that can support you and the person you're caring for. This section explains the services that are mainly based locally in the community rather than in hospital, and the range of practical support available.



## Community health services

If you are caring for someone with pancreatic cancer at home, you will probably want to access community health services at some stage. Most community services support people at home. For example you might need help from a community nurse at home. These services support families as well as people who are ill, so make sure you ask for support if you need it.

These community services also frequently offer access to practical support, such as equipment. There is detailed information on the practical help that's available on page 44.

It can sometimes take a while to get services organised, so try to find out what's available in your area before you need it. If you're not sure where to start, speak to the GP.

## What happens when someone leaves hospital?

Before someone with pancreatic cancer leaves hospital, they should be given advice and information about any care they might be offered at home, which may be called a care package. The support offered will depend on things like the person's age, how unwell they are, and support from the family, as well as the stage of their cancer.

It's a good idea to ask about this well before they are discharged, if it hasn't already been discussed. The nurse in charge of the ward may be able to arrange it. The first stage is usually an assessment by the community nursing service (see page 38) or the occupational therapy team in the hospital (see page 46). The GP should also be aware of the care package.

## Community nursing service

If your family member needs nursing support at home, this is most likely to come from the community nursing service. Community nurses provide nursing care such as giving medicines, carrying out examinations, dressing wounds, and providing emotional support. They work closely with GPs, social services, and other services to coordinate care.

Depending on how services are organised where you live, nursing support may be given by district nurses, community matrons and/or palliative care or Macmillan nurses.

### **What is palliative care?**

You may hear the term palliative care. Palliative care aims to relieve pain and other symptoms. It also provides people with emotional, physical, practical and spiritual support to help them deal with pancreatic cancer that can't be cured. And it supports family members. Palliative care isn't just for people in the final stages of life.

Nurses will usually visit during the day, but there will be a team on duty in the evenings and at night, so it should be a 24-hour service. Make sure you know the number to contact the team out of normal hours – you can make a note of it on page 53.

People should be given advice about the community nursing service before they leave hospital (see page 37). If your family member is at home and needs nursing support, ask the GP to organise an assessment by the community nursing team, or to give you the phone number so you can contact them.

“ Once the district nurses were assigned they were really good at coming and checking dad.”

“ Don’t be afraid to ask the community nurses what equipment is available and how to get it. Be persistent if you need to. Get equipment as soon as it’s needed to make life more comfortable. Having the equipment at home definitely helped us care for Nicola in the environment she wanted to be in.”

### Specialist nursing support

Ideally, everyone with cancer should have access to a specialist nurse once they are discharged from hospital. These nurses help people with cancer and their families with all aspects of living with cancer, from providing pain and symptom relief and discussing problems and feelings, to coordinating with other members of the care team. Depending on where you live, these nurses may be palliative care nurses, hospice nurses or Macmillan nurses – whatever their title, they all work in a similar way.

These nurses are different to the clinical nurse specialist who your family member will have seen at the hospital (see page 13). But you will still be able to contact the clinical nurse specialist – for example, with questions about treatment or side effects.

It’s a good idea to ask to be put in touch with a nurse in your area early on, as they can be a great help. The GP or keyworker should be able to refer your family member to a specialist nurse. The nurse will usually do an initial assessment, then further visits depending on the individual situation.

Marie Curie nurses have a different role. They provide nursing care at home for people with cancer who are nearing the end of their lives. For example, they may come in overnight so that a carer can get some sleep. Contact the GP or district or community nurse to be put in touch with a Marie Curie nurse.

## Hospices

Hospices aim to improve the lives of people with an illness that can't be cured (a terminal or life-limiting illness). They provide support for their physical needs, such as dealing with pain or symptoms. They also provide emotional, social and spiritual support. Hospices also support carers and families. A hospice care team may include nurses, doctors, social workers, counsellors, complementary therapists and more.

Hospice care isn't just for someone at the end of their life. Services are free and will vary depending on the hospice, but they may include:

- **pain and symptom control**
- **emotional and social support**
- **complementary therapies**, such as massage and aromatherapy, to help deal with symptoms
- **day care** – spending time in the hospice without being admitted
- **respite care** – staying at the hospice for a few days to give family and carers a break.

Hospice care is provided in different places.

- **In hospices** – which can offer services such as day care, respite care, a massage or just a cup of tea and a chat. People may also stay at the hospice for a short time, for example to get symptoms such as pain under control.

- **In people's homes** – by 'Hospice at Home' services, Marie Curie or hospice nurses, and community palliative care teams.
- **In hospitals** – by hospital-based palliative care teams.

Most people are referred for hospice care by their GP, district nurse or Macmillan or palliative care nurse. Ask them what hospice services are available locally. Hospice UK has details of hospice services in your area (see page 60). Or you can call your local hospice to ask about their services.

*" I was told about the local hospice straight away. I saw them in the early days about supporting our children, to find out what they could offer. I was offered support, groups and complementary therapy – I declined, but knew it was there if needed."*

*" We received great support from the local hospice. If we had any concerns we only had to phone Nicola's community hospice nurse and she visited. This prevented us having any more stress and concern than necessary."*

## **Social care and homecare**

Social care and homecare are the terms used for support provided to someone in their home by care workers, to help them with daily living. There may be times when you need extra support for your family member, or for you. For example, they may need help with washing or getting dressed, or cooking, cleaning or the shopping. Services can be organised through your council's social services department or privately. They may depend partly on your financial circumstances.

## Social services

The person you're caring for may be eligible for support from your local council's social services department. Social services may provide services such as:

- care at home from care workers
- respite care or day centre care to give you a break from looking after your family member
- equipment or adaptations to the home (see page 46)
- help with daily household tasks, such as laundry.

Social services must do an assessment to work out what care your family member needs. If you are spending a lot of your time caring for your relative, social services must also carry out a carer's assessment to find out what support you need. They have a legal duty to do these assessments.

Getting services can take time and persistence so it's a good idea to start the assessment process as soon as possible – contact the social services department at your local council. Carers UK have more information about getting support from social services. You can find details of your local council on the gov.uk website (see page 60 for contact details).

Once the assessments are done, the council will decide whether they will provide any care. They will look at whether your needs and your family member's needs meet the criteria for getting support. If you do meet the criteria, social services will draw up a plan to meet your needs.

Services may be provided:

- directly by the **council**
- by **independent organisations** (such as homecare agencies) on the council's behalf
- by a **direct payment** so that you can choose how you organise the support you or your family member is entitled to.

You may have to pay for some of the care. This will depend on what the service is and your financial circumstances. Social services will do a financial assessment to work this out.

If you do need to contribute and money is tight, there are sometimes grants available from local charities – ask social services for details of any in your area. For example, the Elizabeth Coteman Fund makes small grants to people with pancreatic cancer (see page 59 for contact details).

If your needs don't meet the criteria for getting support, the council should still give you information and advice about support that is available.

### **Private care**

Your family member may not be eligible for support from social services, or may prefer to arrange and pay for additional support themselves.

The social services department should give you information about finding local support services and care providers. For lists of care organisations and reports on their services, have a look at the Carers UK website (see page 59).

**“ Don’t be afraid to ask – be very confident and assertive about your needs.”**

**“ Source services early and use them. It’s a very difficult disease to contend with. Everyone needs strength to deal with it and you need support to maintain this strength.”**

## **Practical support**

There is a wide range of practical support available – for you as a carer, as well as for the person you care for. Practical support might include equipment to help you care for someone at home, or benefits and financial help.

If you’ve got family or friends who want to help, ask for specific things – such as a lift to hospital, help with shopping or cooking, or spending time with the person you care for to give you a break.

## **Blue Badge scheme**

If your family member can’t walk or finds walking very difficult – and this is a permanent problem – they may be able to apply for a parking permit under the Blue Badge scheme. The permit can be used in any vehicle they are travelling in, as a passenger or driver. It allows parking without a time limit or charge in restricted parking areas, disabled public parking bays, or yellow lines. Private car parks aren’t covered by the scheme, but they may have their own disabled parking spaces.

You can apply for a Blue Badge on behalf of the person you care for and they don’t have to be the driver to qualify. The Blue Badge scheme is run by your local council.

You can apply from your local council, or online at:

- **gov.uk** if you live in England or Wales
- **mygov.scot** if you live in Scotland
- **nidirect** if you live in Northern Ireland.

See pages 60-62 for contact details. Don't apply for a Blue Badge from anywhere else, as it may not be legitimate.

If your family member's cancer can't be cured, it's best to ask for a paper form from your council, or from the Blue Badge Unit if you live in Northern Ireland. Tell them that the person you care for has terminal cancer. This may make the application process easier. If you do apply online, make it clear that they are terminally ill.

### **Hospital parking and discounts**

Many hospitals charge for parking. However, some people should be able to get free or reduced parking charges, including:

- people who often have to go to hospital as an outpatient
- family members of people who are in hospital for a longer period of time
- people with relatives who are very ill.

Check what the situation is at your hospital. Find more information about hospital parking on the gov.uk website (see page 60).

**“ I noticed on the hospital website that anyone with cancer or visiting someone having cancer treatment could get reduced parking but I wasn't told this by a member of the hospital staff.”**

## **Travel to hospital**

If you find it tiring driving your family member to hospital regularly, see if you can share this with other friends or relatives. If your family member relies on public transport or lifts from other people, they may be able to arrange their appointments to suit, although this isn't always possible. Some hospitals provide transport, as do the British Red Cross, local charities and support groups. Ask what is available locally.

If you are finding that frequent travel to hospital is expensive, you may be able to get financial help. Ask the hospital staff for information on grants that might be available. Or get in touch with Macmillan Cancer Support for information about any financial support. You can find contact details of the organisations mentioned here on pages 58 and 60.

## **Equipment and adaptations**

Getting the right equipment to help you manage at home can make a huge difference. This might include ways to raise a seat to make getting up easier, grab rails to help someone get out of the bath, a wheelchair or a hospital-style bed.

An occupational therapist is a professional who can help your family member find ways to carry out everyday tasks that might be difficult. This might include recommending specific equipment or adaptations at home. They will carry out an assessment to work out what is needed and help you access it. Ask the GP, specialist nurse or another health or social care professional to refer your family member to an occupational therapist. You can also contact your council, or pay to see a private occupational therapist.

You may need to pay towards the cost of the equipment or installing it. This will depend on your local council. You may be

able to apply for a grant to help with the cost. Many hospices provide similar assessments and access to equipment.

If you are thinking of buying any equipment yourself, the Disabled Living Foundation can provide information and advice about what's available. See page 59 for contact details.

If the person you're caring for only needs special equipment for a short time, such as while recovering from surgery, then the hospital or district nurse will usually supply equipment for as long as it's needed. This may depend on your local services. Charities such as the British Red Cross (see page 58) lend equipment such as wheelchairs or raised toilet seats.

**“ Approach everyone who you feel could help, especially Pancreatic Cancer UK, who will point you in the right direction. Don't be afraid to phone charities like the Red Cross who have many practical items they will loan you.”**

**“ The most helpful practical support was equipment – mattress, bath seat, wheelchair. We never had any issues in obtaining any of this. The community nurses were excellent in giving us information and very proactive in obtaining the equipment.”**

### **Financial support**

Financial issues probably won't have been the first things you thought about when your family member was diagnosed with pancreatic cancer. But looking after someone with cancer can have an unexpected impact on your finances.

For example, caring for your family member may mean you can't work, or can only work part time, so money may become an issue, even if this is only temporary. And if the person you're caring for has to stop work, pay for travel to treatment sessions, or needs a special diet, it can affect the household budget.

Dealing with your financial situation is important so that it doesn't become something you worry about. If you can, try to sort things out before they become a problem.

There is lots of help available. Macmillan Cancer Support, Carers UK, Carers Trust, Citizens Advice and Turn2Us can all give expert information and advice on work-related issues, benefits and financial matters. See page pages 58-62 for contact details.

These are some things that might help.

- You may be able to claim for benefits such as Carer's Allowance, which is the main benefit for carers. Your family member may also be able to claim benefits.
- If you or your family member are working, speak to your employer about your options.
- Prescriptions in Scotland, Wales and Northern Ireland are free. In England, the person you are caring for is entitled to free prescriptions if they are having treatment for cancer, including symptoms or side effects. They will need to apply for a medical exemption certificate – ask your doctor for a FP92A form, which they will need to sign.
- You may be able to apply for a grant from a charity or fund, for example to help with bills, or buy equipment. The Elizabeth Coteman Fund (see page 59) provides grants to people with pancreatic cancer and their families.

“ Money was a very big worry for my dad. One call to a Macmillan benefits adviser helped sort things out for him. It’s no longer a worry.”

“ I was informed about benefits (such as emergency benefits for terminal cancer patients) by the specialist nurse from the hospice, but was not informed about wheelchairs or Blue Badges, both of which would have been so helpful.”

## Thinking about the future

If the person you are caring for has advanced cancer, you may want to think about what will happen if their cancer gets worse in the future. For example, they may want to think about what care they would or wouldn’t want. This is called advance care planning. Or they could make a Lasting Power of Attorney (Enduring Power of Attorney in Northern Ireland), which allows someone to make decisions about their health and welfare, or their property and financial affairs, on their behalf.

Planning for the future may be difficult, but it can help you both feel more in control. It may make it easier for you to follow their wishes. And they may feel comforted that plans have been put in place.

NHS Choices has more information about planning care on their website (see page 61 for contact details).

## Is there other support for carers?

When social services carry out a carer’s assessment (see page 42) they should consider the impact the care and support you provide is having on your health and your life.

Carers are often so busy looking after their family member that they forget about their own health. There are various examples of support that may help, such as:

- short breaks or respite care
- the right to request flexible working from your employer
- counselling for emotional support
- an emergency plan in case you are no longer able to provide care.

You should be able to talk to someone at your local council about different types of support that may be available for you as a carer. You can speak to the GP or other members of your loved one's medical team with any questions about their care.



You can also speak to our specialist nurses on our free Support Line.

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

**“The most helpful support was the visits from dad’s friends, which allowed us time to do practical jobs such as washing.”**

## Section 5

# Further information and support

In this section, we explain some key medical words, and provide information about organisations that can support you. There's also space to record the contact details of the medical team.



## Glossary

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

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

**Bilirubin:** a yellow substance found in bile. It is the waste product of the normal break down of old red blood cells. Jaundice develops when there is a build-up of bilirubin in the blood.

**Duodenum:** the first part of the small intestines.

**Hepatobiliary:** this term covers the liver, gall bladder and bile ducts. These are very close to the pancreas, and hepatobiliary doctors and nurses may specialise in treating pancreatic diseases as well.

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

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

**Steatorrhoea:** caused by fat in poo. Symptoms include large, pale stools, which can look oily, smell horrible, float and are difficult to flush down the toilet.

**Stools:** poo. Also called faeces or bowel motions.



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

## Important names and numbers

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

## Out of hours or emergency contact

**Name:**

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**Telephone:**

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**Notes:**

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## Keyworker

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

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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### **Specialist nurse**

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

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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### **Gastroenterologist**

A doctor who treats diseases of the digestive system, including the pancreas.

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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### **Oncologist**

A doctor who treats cancer with treatments such as chemotherapy or radiotherapy.

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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## Surgeon

A doctor who carries out surgery.

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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## Dietitian

A professional who provides expert advice about diet and nutrition, including managing the symptoms of pancreatic cancer related to diet.

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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## General practitioner (GP)

The GP will be able to help manage your family member's cancer. For example, they may help manage some symptoms, and can refer them for other medical services.

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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## Community nursing service

There are different nurses who can provide support and care locally in the community.

- **Community or district nurse** – provide nursing care in people’s homes, including giving medication and pain control.
- **Palliative care nurse** – nurses who specialise in managing pain and other symptoms.
- **Macmillan nurse** – nurses who specialise in an area of cancer care. For example, Macmillan chemotherapy nurses give chemotherapy. Some Macmillan nurses are palliative care nurses – but not all.
- **Hospice nurse** – provide palliative care and support at a hospice. They may also visit you at home.
- **Marie Curie nurse** – nurses who provide nursing care in your home, often overnight.

### Nurse

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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### Social services contact

Your council may be able to provide support through social services. This might include practical and financial support.

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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### Occupational therapist

A professional who can help find ways to carry out everyday tasks that might be difficult, for example by recommending specific equipment or adaptations at home.

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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### Other

**Name:**

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**Telephone:**

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**Email:**

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**Notes:**

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## Useful organisations

### **British Association of Counselling and Psychotherapy**

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

**Tel: 01455 883 300** (Mon-Fri 9am-5pm)

Information about counselling and a database of registered therapists.

### **British Red Cross**

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

**Tel: 0344 871 1111**

Provides a range of support including lending medical equipment, support at home and help with transport.

### **Cancer Research UK**

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

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

Information for anyone affected by cancer.

### **Carers Direct**

**Helpline: 0300 123 1053**

(Mon-Fri 9am-8pm, weekends 11am-4pm)

Advisors provide information for carers living in England, including information about assessments, benefits, and national or local sources of help.

### **Carers Trust**

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

**Email: [info@carers.org](mailto:info@carers.org)**

Information and support for carers, and a directory of local care services.

## **Carers UK**

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

**Adviceline: 0808 808 7777** (Mon-Fri 10am-4pm)

Information, advice, and support for carers, including benefits checks, and advice on financial and practical issues.

## **Citizens Advice**

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

**Tel: England 03444 111 444; Wales 03444 77 20 20;**

**Scotland 0808 800 9060**

In person at your local Citizens Advice Bureau. Provide information and advice on a range of issues including work, benefits, healthcare, patient rights and information for carers.

## **Diabetes UK**

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

**Helpline: 0345 123 2399** (Mon-Fri 9am-6pm)

Information on managing different types of diabetes.

## **Disabled Living Foundation**

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

**Helpline: 0300 999 0004** (Mon-Fri 10am-4pm)

Provide free and impartial information and advice about equipment to help with daily living.

## **Elizabeth Coteman Fund**

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

**Tel: 01223 782171**

Provide grants for expenses to take part in a clinical trial, and grants for people with pancreatic cancer who are struggling financially, for equipment and respite. Provide support and friendship to those affected by pancreatic cancer.

## **Fruit Fly Collective**

**[www.fruitflycollective.com](http://www.fruitflycollective.com)**

Provide information and support for families affected by cancer.

## **GOV.UK**

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

Provides information about government services, including information about benefits, transport, money and guidelines for hospital parking.

## **Health in Wales**

**[www.wales.nhs.uk](http://www.wales.nhs.uk)**

Information about the NHS in Wales, and a directory of local services.

## **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** (Mon-Fri 9am-8pm)

Provides practical, medical and financial support for anyone affected by cancer, including family members.

## **Maggie's Centres**

[www.maggiescentres.org](http://www.maggiescentres.org)

**Tel: 0300 123 1801**

Centres around the UK and online offer free practical, emotional and social 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)

Provides care and support to people with a terminal illness and their families, including nurses and hospices.

## **My Cancer Treatment**

[www.mycancertreatment.nhs.uk](http://www.mycancertreatment.nhs.uk)

Directory of cancer services in England. Allows you to find and compare cancer services in your area.

## **mygov.scot**

[www.mygov.scot](http://www.mygov.scot)

Information about public services in Scotland, including health and social care services.

## **NHS inform**

[www.nhsinform.scot](http://www.nhsinform.scot)

**Tel: 0800 22 44 88**

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

## **NHS Choices**

[www.nhs.uk](http://www.nhs.uk)

Provides information about health conditions, living well, care, and local services in England.

## **NHS Direct Wales**

[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

**Tel: 0845 46 47**

Health information in Wales, including local services.

## **NICan (Northern Ireland Cancer Network)**

[survivorship.cancerni.net](http://survivorship.cancerni.net)

Information about services in Northern Ireland to support people with cancer and their families.

## **nidirect**

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

Information about local services in Northern Ireland, including health services and information and support for carers.

## **rirap**

[www.rirap.org.uk](http://www.rirap.org.uk)

Website for teenagers with a parent with cancer. It provides information about cancer, real life stories, and support.

## **Turn2Us**

[www.turn2us.org.uk](http://www.turn2us.org.uk)

**Helpline: 0808 802 2000** (Mon-Fri 9am-8pm)

Provides information to people in financial hardship about benefits, charitable grants and support services.

## **Winston's Wish**

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

**Freephone Helpline: 08088 020 021** (Mon-Fri, 9am-5pm)

Provide support to children with a close family member who has a serious illness, and children who have been bereaved.

This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK. It has been reviewed by health professionals and people affected by pancreatic cancer.

References to the sources of information used to write this booklet, and a list of health professionals who reviewed it, are available on our website – **[pancreaticcancer.org.uk](http://pancreaticcancer.org.uk)**

Pancreatic Cancer UK makes every effort to make sure that its 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](mailto:publications@pancreaticcancer.org.uk)** or write to the Information Manager at the address on the back cover.

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

# Pancreatic Cancer UK

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