

# **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. In this booklet, when we talk about your 'family member' we mean the person with pancreatic cancer who you are looking after.

You may hear yourself described as their carer. You may not see yourself as a carer, you may simply see yourself as their partner, family member or friend. But a carer is anyone who looks after a family member or friend, unpaid, and provides help that person couldn't manage without.

Caring for someone with pancreatic cancer can have a big impact. This booklet should help you find support for both yourself and your family member.

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# How to use this booklet

You don't have to read this booklet all at once. Look at the contents on page 2, read the sections that feel most helpful, and read other sections later if you need to know more. There is more information available on our website and we provide a lot of support (see page 6). Find out more at: **[pancreaticcancer.org.uk](http://pancreaticcancer.org.uk)**

Use the symbols to help you find out where and when you can get more help.



Call our Support Line free on **0808 801 0707**  
or email **[nurse@pancreaticcancer.org.uk](mailto:nurse@pancreaticcancer.org.uk)**



Read more on our website at:  
**[pancreaticcancer.org.uk/information](http://pancreaticcancer.org.uk/information)**  
Order or download our free booklets at:  
**[pancreaticcancer.org.uk/publications](http://pancreaticcancer.org.uk/publications)**



Questions to ask the doctor or nurse



Things you can do to help

## **At the end of the booklet there is:**

- A list of common medical words on page 57.
- Contact details of the organisations we mention on page 59.

# Emotional support

## Key facts

- When someone close to you has pancreatic cancer, you may have lots of different emotions.
- It can be hard to find time to look after yourself, including having space to think and talk about your feelings.
- You are not alone and there is emotional and practical support available.
- Family and friends can be a great source of help and comfort.
- The medical team can also provide support and help you access services elsewhere.
- We provide support by telephone and email, online support sessions and our online forum. Our free information can help you understand pancreatic cancer.
- Other organisations may offer groups or services local to you.



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

## How you might be feeling

When someone close to you has been diagnosed with pancreatic cancer you will probably have different feelings at different times. You may feel shocked, upset, numb, scared, confused or worried about the future. It can be hard to know what you feel, or how to explain your feelings to others.

If your family member has been unwell for some time, you may even feel a bit relieved that you finally know what is wrong with them. Or you may feel frustrated or angry at not getting a diagnosis sooner. If someone was quite well before being diagnosed it can be a big shock, and you may find it hard to believe.

There is no 'right' way to feel.

When you are caring for someone, it can be hard to think about what you need, or find time to take a break. But it's important to find ways to take care of yourself too.

At times you may feel very alone and isolated. But there are ways to connect with others who are going through the same thing. There is also support there for you if you need it.

**“I first felt bad for asking for so much help, but I realised I needed it for my Mum, for my family and for myself. There is no shame in needing help and asking for it. I had help from Macmillan, Pancreatic Cancer UK and Marie Curie.”**

## Who can you contact for emotional support?

Getting some support for yourself can help you cope. It can also help you look after your family member better. Find someone that you can talk to, whether it's through family or friends, social media, or an online forum.

The medical team looking after your family member can also help you. This might be the specialist nurse, GP or community nurse. They can answer your questions as well as providing emotional support and medical care. Read more about the medical team on page 14.

## How we can help

We are here for everyone affected by pancreatic cancer. Our specialist nurses on our confidential Support Line speak to lots of families and friends, and understand the issues and worries you might have. They can provide emotional support to you and your family, as well as answering any questions about pancreatic cancer. Their expert help will support you in coping with pancreatic cancer.



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

As well as our Support Line, our range of services are here when you need them most.

**Expert information:** Our free information covers everything about pancreatic cancer to help you and your family member understand their diagnosis, ask questions, make decisions and live as well as possible.

**Living with Pancreatic Cancer Online Support Sessions:** Our online support sessions are hosted by our specialist nurses and will give you and your family member the chance to connect with others who are affected by pancreatic cancer.

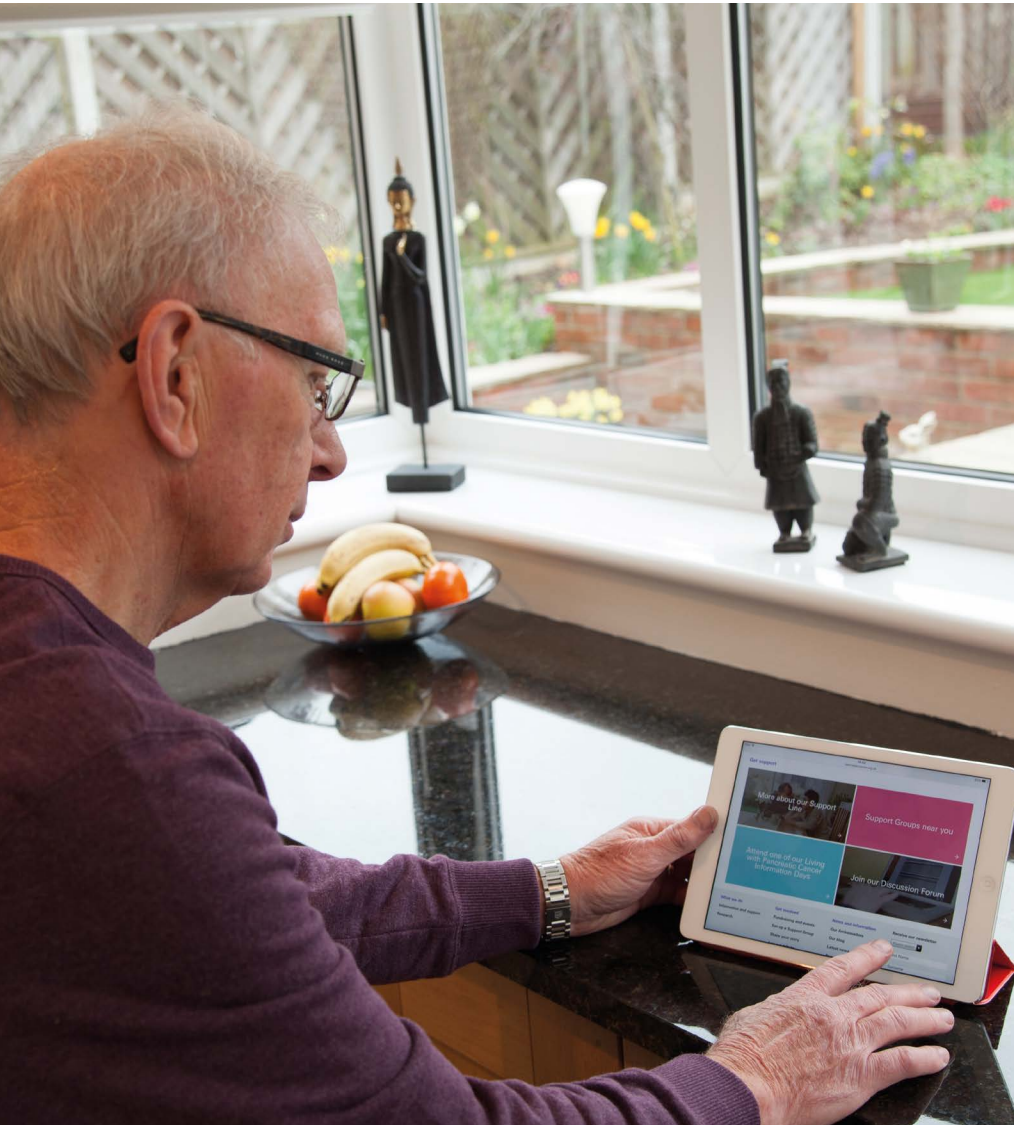
**Online forum:** The forum is a supportive online space where everyone affected by pancreatic cancer can be there for one another at any time.

**Real life stories:** Read other people's experiences of pancreatic cancer on our website to find out how they coped with their diagnosis and treatment, and their tips on looking after themselves.



Find out more about how we can support you at: [pancreaticcancer.org.uk/support](https://pancreaticcancer.org.uk/support)

*“I called Pancreatic Cancer UK and talked to a specialist nurse. I was given advice to help care for my mum better and deal with my own feelings. I felt like I had a place to go to vent, to cry, to laugh, and to really digest what was happening.”*



“What makes it a little easier is the Pancreatic Cancer UK forum – knowing I am not the only person in the world that this is happening to.”



## Counselling

**Counselling** or **'talking therapy'** involves talking to a trained professional about your thoughts and feelings. It may help you work through your feelings and find ways of coming to terms with things. There are different ways to get counselling.

- Ask your GP to refer you.
- Some organisations for carers offer counselling. You can search for local services on the Carers Trust website.
- Check whether your local hospital, Macmillan cancer support centre or Maggie's centre have specialist counsellors.
- Check the British Association for Counselling and Psychotherapy for a counsellor who has experience of working with people affected by cancer.
- Counselling and other types of psychological emotional support can be accessed directly through the NHS England Improving Access to Psychological Therapies (IAPT) services. You need to be registered with a GP in England, but you can refer yourself through the NHS website.

**"The hospital put me in touch with counselling, which helped."**

## Support groups

There are cancer support groups around the country where you can meet other people going through similar experiences. They are often open to families as well as the person with cancer.



Find groups specifically for pancreatic cancer on our website: [pancreaticcancer.org.uk/supportgroups](https://pancreaticcancer.org.uk/supportgroups)

There are also support groups for people caring for someone with cancer. We have suggested some organisations you can contact below. Your family member's nurse may know what groups are available in your local area.

### **Organisations supporting carers**

There are organisations that offer information and help for carers across the UK. These include:

- Carers UK
- Carers Trust
- Macmillan Cancer Support

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.

Carers can also get emotional support from a local cancer support centre, for example, a Maggie's Centre or a Macmillan information and support centre. In Northern Ireland, an organisation called Cancer Focus Northern Ireland can also provide information and support.

### **Communicating with your family member**

Whatever your relationship, a cancer diagnosis will mean some things change and that can be hard. Finding ways to communicate will make things easier for you both and can even bring you closer.

It's a good idea to have an open conversation about what support your family member would like from you and what you can offer. Try not to guess what they think and feel, or what they expect from you. Listen to what is important to them.

Being open with each other can help to avoid confusion or arguments over everyday issues.

Make time and space for conversations, so there are chances to talk about how you are both feeling. But keep in mind that sometimes your family member may not want to talk about their feelings, or may not have the energy for a deep conversation. There will be times when one or both of you is feeling upset or stressed and communication may be more difficult. It can help to get support for yourself if this is happening (see page 6).

You might find that focusing on practical things and agreeing how some situations should be handled can help. For example, you could ask if it's useful for you to remind your family member to take their medicines, or if there is anything they would prefer you don't do. It's a good idea to have these conversations more than once, to check whether anything has changed.

## Support for children

If you or the person you are caring for has children or grandchildren, you may need support for them as well.

- Macmillan Cancer Support have a booklet, **Talking to children and teenagers when an adult has cancer**.
- Maggie's Centres offer support to help you talk to children about cancer, and provide specialist services for families.
- 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. RipRap is a website for teenagers who have a parent with cancer.

- Winston's Wish provide information and support for children with a parent who has a serious illness, or who have been bereaved.
- Your family member's nurse may also be able to give you information and advice about talking to children.

You can find more details of these organisations on page 59.

For most children and teenagers, it is best to be honest and talk to them as much as possible about what is going on. Depending on the age of the child, use language they will understand. Check they have understood by asking them to tell you what they think is happening in their own words.

Some children and teenagers behave differently, or become quiet and withdrawn when someone they know is affected by cancer. It can help to let their school know what is happening so they can get any support they need from staff at the school.



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

- Talk to family and friends about how you are feeling. Sometimes just talking can help you make sense of things.
- Write down how you are feeling. This can help you deal with difficult feelings.
- Ask for practical help from family and friends with tasks like shopping, cleaning, or looking after children. This can be a big help.

- If you have questions about how best to care for your family member, talk to their medical team. You can also talk to our specialist nurses on our Support Line.
- It's important to take breaks from caring to look after yourself.
- Join a support group, either with your family member or by yourself.

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



### Questions to ask the doctor or nurse

What kind of support can the medical team offer?

What other emotional and practical support is available to me, as a carer?

Are there local organisations that offer support and services to families?

Is there support available for my children or my family member's children?

# The medical team and healthcare system

## Key facts

- A team of medical professionals should review the information about your family member's diagnosis. The team is called a multidisciplinary team (MDT).
- Your family member should be given the details of a nurse (called a clinical nurse specialist). They can support you and your family member and answer your questions.
- The medical team or specialist nurse should regularly check how your family member is coping with any symptoms or side effects.
- If you are caring for your family member at home, you should be told who to call if you need help.
- If you have any questions at all, ask the medical team or nurse.

**“If you don't understand something don't be afraid to say you don't. Don't be afraid to ask questions. I know I needed many questions answering as they would just race through my mind and I wouldn't settle.”**

## What is the multidisciplinary team (MDT)?

The multidisciplinary team (MDT) is the team of health professionals responsible for your family member's treatment and care. They will agree on the best treatment and care for them, and should involve your family member in these decisions. Your family member might not meet everyone in the MDT, but their doctor or nurse should tell them what the MDT have decided.

The team should include a specialist nurse (sometimes called a clinical nurse specialist or CNS). They are your family member's main contact. They will provide expert care and advice and will coordinate their care. They will also help support your family member and you, and will be the person you speak to most. If your family member hasn't been given a specialist nurse or a main contact, ask their doctor about this.

Some teams include cancer care coordinators, sometimes known as navigators, who will support you and your family member. They can provide information and guidance on any concerns you have and act as a link with the medical team.

As long as the person you are 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.



Find out more about the MDT, and the health professionals involved in pancreatic cancer care on our website at: [pancreaticcancer.org.uk/care](https://pancreaticcancer.org.uk/care)



There are guidelines for cancer care across the UK. Find out more in our booklet: **The care you should expect and receive: Patient Charter.**

The National Institute for Health and Care Excellence (NICE) have produced guidelines for health professionals diagnosing and caring for people with pancreatic cancer in England, Wales and Northern Ireland. Read more about these in our fact sheet: **Explaining the NICE guidelines for diagnosing and managing pancreatic cancer.**

## Where is pancreatic cancer treated?

Anyone diagnosed with pancreatic cancer should have their case reviewed at a specialist cancer centre where there is a specialist pancreatic cancer team (the MDT). Your family member may not need to go to the specialist centre in person as the specialist team will report back to your local hospital.

Your family member may have tests and some treatments – such as chemotherapy and radiotherapy – at their local hospital. If they are having surgery to remove their cancer (such as the Whipple's operation), this should be done at a specialist centre.





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

## Supportive care or palliative care

If your family member has been told their cancer can't be cured, they may see a specialist palliative care team or supportive care team. These teams help people to live as well as possible for as long as possible, and they provide support to family members too.

These services aren't just for people at the end of their life, they are available at any point during treatment or care. They provide specialist care to manage complex symptoms such as pain and emotional symptoms, like depression and anxiety. They also provide people with practical support.

Specialist palliative care teams may be based in the hospital, at a hospice, or in the community where nurses visit your family member at home. Supportive care teams provide similar services and are available in some hospitals. They aim to see people at a very early stage in their cancer treatment to manage their symptoms. In some areas, district nurses provide this type of care.

If your family member has cancer that can't be cured, speak to the doctor or nurse about referring them to a specialist palliative or supportive care team.



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

## Support needs

The doctors and nurses should regularly check how your family member is coping with any symptoms, such as problems with digestion, tiredness and pain. Read more about managing symptoms on page 24.

They should talk to your family member about how they are feeling emotionally, and ask about practical issues like finances, or help at home. Read more about local help and support on page 43.

If the medical team don't talk to your family member about these concerns, or you are worried about anything, speak to their nurse about this.

Some medical teams may offer a Holistic Needs Assessment (HNA) to your family member. This is an opportunity for them to talk about any concerns your family member has, and to agree the best ways to manage them. These may include symptoms and treatment, but also emotional, practical or other concerns.

**“I managed to get an email for the oncologist secretary – before he had his oncology appointment, we were able to email the secretary in advance with our questions and they could answer them in the appointment.”**

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

Your hospital team will tell you who to call if your family member's symptoms get bad at night, or at the weekend. If you are caring for your family member at home and need help, you will need to contact their GP or community nurse – this may be the district or palliative care nurse (see page 44). If you haven't been given a number to use out of hours, ask their hospital team or GP about this. You may not get through to the right person straight away, but they should call you back.

If your family member is having chemotherapy, they should be given a 24 hour emergency phone number. Call this if they are unwell or need information about side effects. If your family member hasn't been given an emergency number, ask their nurse about this.

If you live in England, Wales or Scotland, you can call the NHS on 111 for advice out of hours. In Northern Ireland, there are local out of hours phone numbers for each region, which you can find on the NI Direct website. Your GP answer phone message will also have an out of hours number for you to call. If it is an emergency, you should take the person you care for to A&E, or call 999 and ask for an ambulance.

**“ It's really important to have easy access to out of hours contact numbers. Keep them on the fridge or somewhere handy.”**



## What can I do?

- Find out as much as you want to know about pancreatic cancer – we have lots more information on our website. Our information for people recently diagnosed is a good place to start: **[pancreaticcancer.org.uk/justdiagnosed](http://pancreaticcancer.org.uk/justdiagnosed)**
- Support your family member by helping to prepare questions before they speak to their doctor or nurse.
- If your family member is happy for you to join them at their appointments, you can make notes of what is said.
- Ask about the best way to contact the nurse with any questions.
- Keep a note of important numbers, such as who to call out of hours.

## Getting a second opinion

Your family member can ask for a second opinion, if they want one, and it won't affect their care. This means seeing a different doctor, possibly in a different hospital. For example, some people may want a second opinion if they are concerned about the diagnosis or recommended treatment.

Your family member shouldn't delay treatment while they get a second opinion, as it can take several weeks. Keep in mind that the second team's opinion may not be any different.

Your family member can start treatment while they are going through the process.

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 hospital doctor 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.

Citizens Advice and Macmillan Cancer Support have more information about getting a second opinion.

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

### **NHS care**

If you have concerns about the NHS care your family member is getting, then talk to their doctor or nurse first. It is important for you and your family member to raise any concerns you have. Don't be worried that this will affect future treatment and care. If talking to the doctor or nurse doesn't help things, you may want to take the issue further.

- In England, you can speak to the Patient Advice and Liaison Service (PALS). Find out more on the NHS website. Your local Healthwatch service can also help if you want to make a complaint.
- In Scotland, you can speak to the Patient Advice and Support Service. Find out about them from Citizens Advice Scotland.
- In Wales, each Local Health Board or NHS Trust has its own concerns team. Find out more from NHS 111 Wales.
- In Northern Ireland, the Patient and Client Council can help you with your complaint. Find out more from the nidirect website.

## Private healthcare

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



Read more about what to do if you have concerns about your family member's care on our website at: [pancreaticcancer.org.uk/concerns](https://pancreaticcancer.org.uk/concerns)



If you have any concerns about your family member's care, you can speak to our specialist nurses on our free Support Line for information.



### Questions to ask the doctor or nurse

What treatment does the MDT recommend?

Does my family member have a specialist nurse or main contact? How do we contact them?

What are the best contact details to use out of hours or in an emergency?

Where will my family member have their treatment?

# Dealing with symptoms and side effects

## Key facts

- Not everyone will have the same symptoms of pancreatic cancer or the same side effects from treatments.
- There are ways to manage most symptoms and improve your family member's daily life.
- If your family member has any symptoms or side effects, speak to their doctor or nurse for help managing them.
- Taking capsules called pancreatic enzymes with food can help problems with digestion.
- Your family member should see a dietitian for help with problems with digestion and eating.
- Ask the doctor or nurse for help with pain as soon as possible – there are treatments that can help.
- Pancreatic cancer may cause diabetes. This can be treated with tablets or insulin injections.
- Extreme tiredness (fatigue) is a common symptom. There are things that can help, like balancing rest with activities.

This section explains some common symptoms of pancreatic cancer and side effects of treatment. It's important to talk to the medical team about any symptoms as they can help manage them.



## **Problems with digesting food**

The pancreas plays an important role in digesting food, as it makes enzymes that help to break down food (part of digestion). The body then absorbs nutrients from the food. Pancreatic cancer can affect this process, which means that food isn't properly digested and your family member may not get the nutrients they need.

Problems with digestion can cause symptoms, including losing their appetite and losing weight, feeling and being sick, runny poo (diarrhoea), pale oily floating poo (steatorrhoea), tummy discomfort or pain, and needing to poo urgently, especially after eating.

It can be worrying if your family member is struggling to eat or has lost weight. When someone's appetite changes it can have an impact on everyday life and socialising. Problems with eating can also be a daily reminder of their illness, which can be upsetting.

It is important that problems with digestion are managed. This can make a big difference to how they feel. It can also help them cope better with treatments.

## **Getting support with digestion problems**

If possible, your family member should see a dietitian to help manage problems with digestion. Specialist pancreatic or oncology dietitians are experts in diet and cancer. If your family member hasn't been referred to a specialist dietitian, ask their nurse or GP about this.

Not all hospitals have a specialist dietitian. Your family member's doctor or nurse may help with their diet and symptoms. Or they may refer them to a general dietitian at the hospital.

## Pancreatic enzyme replacement therapy (PERT)

Pancreatic enzymes replace the enzymes the pancreas would normally make. They are capsules that your family member can take when they eat. They help to break down food, and can help to manage the symptoms on page 25. They can really improve how someone feels.

Your family member's dietitian, nurse or doctor can prescribe enzymes. In the UK, brands include Creon®, Nutrizym® or Pancrex®. If your family member has any of the symptoms on page 25, ask their doctor, nurse or dietitian about enzymes.



Read more about how to take PERT and how to deal with digestion problems in our booklet:

**Diet and pancreatic cancer**

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



Contact our specialist nurses on our free Support Line for more information on diet and taking pancreatic enzyme supplements.

*“If it wasn't for me pushing the doctors to give my dad PERT we would have lost him a few weeks earlier. Not many people know about enzyme replacement therapy and I think it's essential more people know about this.”*



## What can I do?

Try not to put pressure on your family member to eat. It can be hard for them, and frustrating for you if they don't eat what you've prepared. Instead ask them what would help. Some of these tips may also help.

- If your family member hasn't been told about PERT or is having problems taking it, talk to their dietitian or nurse.
- If they are having any problems getting PERT speak to our specialist nurses on our free Support Line for information.
- If you prepare meals for them, ask them what they would like you to cook.
- They may find it easier to eat smaller amounts often, so regular snacks can help.
- Support your family member to eat what they can, when they can, but don't try to make them eat when they don't want to. They may not have much appetite.
- Keep a note of any problems so that you can ask about these. Keeping a food diary can also help to monitor symptoms. You can find a food and enzymes diary on our website: **[pancreaticcancer.org.uk/diet](https://pancreaticcancer.org.uk/diet)**
- Read more tips for dealing with digestion problems at: **[pancreaticcancer.org.uk/diettips](https://pancreaticcancer.org.uk/diettips)**



“ It was hard at first getting to grips with enzyme supplements, but once it was sorted it was a noticeable difference with my Mum.”

## Pain

Some people with pancreatic cancer may have pain at some point. You may find this worrying, but there are ways to manage pain, for example with painkillers.

It is important that you tell the doctor or nurse about any pain – the sooner it's treated, the better the chance of getting it under control.



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



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

## Extreme tiredness

Fatigue is extreme tiredness. It isn't the same as just feeling tired. Your family member might feel drained or exhausted. Fatigue is a common symptom of pancreatic cancer.

Talk to the medical team if your family member has fatigue. They can look at what is causing it, how to manage it and how to get your family member the support they need.



## What can help?

- Physical activity, like a short walk or some light gardening, can help with fatigue and increase energy levels. Physical activity is unlikely to make their fatigue worse, but it's also important that they rest when they need to.
- Our fatigue diary can help you keep track of their fatigue, and plan how much activity they can manage. Download it at: **[pancreaticcancer.org.uk/managing-fatigue](https://pancreaticcancer.org.uk/managing-fatigue)**
- If you can help with things like household chores or organising medical appointments, this can help your family member to save their energy for things they enjoy. Talk to them about what help they would like.
- Friends and family often want to visit more often when someone is ill. While this can be nice, it may also be tiring for your family member. Ask them when and how often they want to see people.



Read more about fatigue and how to manage it in our booklet: **Fatigue and pancreatic cancer**  
Or on our website at:  
**[pancreaticcancer.org.uk/fatigue](https://pancreaticcancer.org.uk/fatigue)**

## Diabetes and pancreatic cancer

The pancreas produces hormones, including insulin, which control sugar levels in the blood. Pancreatic cancer can reduce the amount of hormones the pancreas makes. This can cause diabetes, which is a condition where the amount of sugar in the blood is too high. Surgery to remove the cancer can also cause diabetes.

There are different types of diabetes. The usual information about diet and diabetes may not be right for your family member because of the cancer. They may need to eat a normal diet, or they may need more calories in their diet to help them put weight on. The diabetes will need to be managed around this. If your family member already had diabetes before being diagnosed with pancreatic cancer, the cancer may mean that their diabetes now needs to be treated differently.

Speak to the dietitian, clinical nurse specialist or diabetes nurse about how to manage your family member's diabetes.



Speak to our specialist nurses on our free Support Line with questions about diabetes.



We have information about managing diabetes on our website at:  
**[pancreaticcancer.org.uk/diabetes](http://pancreaticcancer.org.uk/diabetes)**

## Anxiety and depression

When someone has cancer and is facing an uncertain future, it is natural for them to go through a range of emotions including distress, fear, sadness and anger. Sometimes these feelings can become overwhelming. It's common for people with pancreatic cancer to have anxiety and depression.

There are things that can help. For example, support in dealing with anything that may be worrying your family member, such as their symptoms or financial issues. It can also help to find things they enjoy doing, and to try relaxation techniques, like breathing exercises, meditation, or gentle physical activity.

Speaking to a counsellor may help your family member. Taking medicine called antidepressants may also be helpful for some people.



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

## Feeling and being sick

Sickness can be caused by the cancer itself, and treatments such as chemotherapy. Speak to the GP, specialist nurse or palliative care team for help.

There are treatments for sickness, including anti-sickness medicine.



If your family member is being sick a lot and is struggling to keep food or water down, this can be a sign that something is wrong. It can also lead to dehydration (see below).

Contact their medical team, GP or district nurse if they have been vomiting for half a day or longer and can't keep down any food or fluid, or have symptoms of dehydration.



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

## What is 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 food or water, or if they have diarrhoea (runny poo).

Signs of dehydration include dark or strong smelling urine (pee) and passing less urine. It can also cause headaches, feeling thirsty and feeling dizzy or light headed.

If your family member has any signs of dehydration, tell their doctor or nurse as soon as possible. Dehydration needs to be treated to make sure it doesn't become a serious problem. Dehydration may be more serious if someone has diabetes.

## **Bowel problems**

Many people with pancreatic cancer notice changes to their poo, including diarrhoea and constipation. Speak to your family member's doctor or nurse, so they can work out what is causing these problems, and find ways to manage them.

### **Constipation**

Constipation (when you find it hard to poo) can be a side effect of some treatments. For example, opioid painkillers like morphine can cause constipation. Not moving around much, not eating much, and dehydration, may also make constipation more likely. Constipation can be very uncomfortable, and can cause bloating and sickness.

Laxatives are medicines used to treat and prevent constipation. If your family member is taking opioid painkillers, they should be given laxatives to prevent this.

### **Steatorrhoea**

Some people get a symptom called steatorrhoea, which is pale poo that floats and smells horrible. This happens if the body can't digest the fat in food properly. Taking pancreatic enzymes (see page 26) can help with steatorrhoea.

### **Diarrhoea**

Diarrhoea (runny poo) can be caused by problems digesting food, an infection or some types of chemotherapy. If the diarrhoea is caused by problems digesting food, taking pancreatic enzymes can help.

Some people have ongoing diarrhoea that isn't helped by enzymes. If your family member has diarrhoea that isn't getting better, they may have bile acid diarrhoea – which can happen if there is too much bile (see page 57) in the intestine. Or they may have small intestinal bacterial overgrowth (SIBO), which is caused by having too much bacteria in the intestines.

Speak to the doctor, nurse or GP if your family member's diarrhoea isn't getting better. They may need to see a gastroenterology team, who are experts in problems with the stomach and intestines. There are tests that can be done to check for bile acid diarrhoea and SIBO, and medicines to treat them.



Read more about bowel problems on our website at: **[pancreaticcancer.org.uk/bowelhabits](https://pancreaticcancer.org.uk/bowelhabits)**

Find tips for managing diarrhoea at: **[pancreaticcancer.org.uk/diettips](https://pancreaticcancer.org.uk/diettips)**



Speak to our specialist nurses on our Support Line if you have any questions about bowel problems.

## Jaundice

If your family member has jaundice, their eyes and skin may turn yellow. It can also make them feel itchy and cause pale poo and dark urine. Blood tests may also show if they have jaundice.

Pancreatic cancer can cause jaundice by blocking the bile duct. The bile duct is the tube that takes a fluid called bile from the liver to the duodenum. We explain these words on pages 57–58.



There is information about treatments for jaundice on our website. Read more at: **[pancreaticcancer.org.uk/jaundice](http://pancreaticcancer.org.uk/jaundice)**

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

Some symptoms need to be treated straight away. If you think your family member needs urgent help, call any emergency contact number you have been given, take them to A&E, or call 999.

It is important to tell the person you speak to that your family member has pancreatic cancer. Don't worry about being a nuisance – these symptoms need to be treated as they are an emergency.

### Infection during chemotherapy

Chemotherapy can increase the risk of getting an infection.

**If your family member is having chemotherapy, an infection is an emergency and needs treating straight away.**

The chemotherapy team should have given you a number to call for urgent advice. You can also go to A&E or phone 999. Tell them your family member is having chemotherapy.

Signs of an infection include:

- a high temperature, which is 37.5°C, 38°C or higher (depending on the advice of the chemotherapy team)
- feeling shivery or cold
- headaches and sore muscles
- a cough or sore throat
- pain or burning when they pee
- generally feeling unwell.



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

## Stent infection

If your family member has had a stent put in there is a risk it could get infected. This is normally caused by the stent getting blocked.

Signs of a stent infection include:

- tummy pain
- sore muscles
- a high temperature, fever, shivering or feeling cold
- being sick or loss of appetite
- signs of jaundice (see page 35).

They will usually need antibiotics to treat the infection, and the stent can be replaced.



Read more about stents in our fact sheet: **Stents to treat jaundice caused by a blocked bile duct**  
On our website at: [pancreaticcancer.org.uk/stents](https://pancreaticcancer.org.uk/stents)

## Blood clot in a vein

People with pancreatic cancer may be more at risk of a blood clot forming in a vein. Having surgery and some chemotherapy drugs can increase the risk of a blood clot.

A blood clot in a vein is serious, and needs to be treated straight away. It often happens in the lower leg (calf), thigh, pelvis (area below the tummy button) or arm. It can block the normal flow of blood through the veins. This is known as deep vein thrombosis (DVT). Symptoms include pain, tenderness and swelling in one leg, and warm or red skin in the affected area.

Part of a clot can also break off and travel in the blood to the lungs. This is called a pulmonary embolism. This isn't common, but it can be very serious. Symptoms include feeling short of breath, sudden chest pain, and coughing. This is usually a dry cough but can include coughing up blood.

If your family member gets any of these symptoms, tell the doctor straight away, call any emergency number you have, or go to A&E.



Read more about blood clots, including the symptoms, at: [pancreaticcancer.org.uk/bloodclots](https://pancreaticcancer.org.uk/bloodclots)

## Symptoms towards the end of life

If your family member is approaching the end of their life, their care will focus on managing their symptoms and supporting them to be as comfortable as possible.

When someone is in the last few months or weeks of their life, their symptoms may change, or they may get new symptoms. 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, let you know what symptoms to expect and how they can be managed.



Read about caring for someone at the end of their life in our booklet: **Pancreatic cancer and end of life care: Information for people in the last few months, weeks or days of life.**

Or at: [pancreaticcancer.org.uk/end-of-life](http://pancreaticcancer.org.uk/end-of-life)



You can also contact our specialist nurses on our free Support Line, and talk through any worries you have.



“ 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.



### What can I do?

- Ask the doctor or nurse about any symptoms, problems or anything that you are worried about.
- Make sure you can quickly find any contact numbers, including emergency or out of hours numbers. For example, you might find it helpful to keep a list by the phone.
- Read more about symptoms and side effects at: **[pancreaticcancer.org.uk/managingsymptoms](https://pancreaticcancer.org.uk/managingsymptoms)**
- 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**

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



### Questions to ask the doctor or nurse

What can help with my family member's symptoms?

What can I do to help manage their symptoms?

How can I support them to eat well?

Who do we contact if we need to speak to someone in an emergency, or out of normal hospital hours?

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

# Help and support locally

## Key facts

- Local community support can include help from a nurse at home and practical support such as equipment.
- If your family member needs nursing support at home, this is most likely to come from the community nursing service.
- Hospices provide free palliative care for people with an illness that can't be cured. This includes managing symptoms. Hospice care isn't just for someone at the end of their life.
- Ask the GP or nursing team who to contact if you need help in the evenings, at night or over the weekend.
- Respite care may help when you need a short break from caring for your family member (see page 46).
- Your local council's social services department may also provide support. You can request an assessment from them to work out what care your family member needs.
- Getting the right practical and financial support can make a huge difference.

## **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. For example, you might need help from a community nurse at home. These services support families as well as people who are ill.

It can sometimes take time to organise care and support at home, so try to find out what is available before you need it. The GP can help you with this.

### **What happens when someone leaves hospital?**

Before someone leaves hospital, their medical team should give them advice about the care they may need at home. The medical team will write to your family member's GP and they should also let them know who to contact if they have any concerns or need more support. This may be called a care package.

It's a good idea to ask about this support well before your family member leaves hospital. The nurse in charge of the ward may be able to arrange it. Your family member will normally have an assessment by a community nurse (see below) or an occupational therapist at the hospital (see page 53).

The GP should also be aware of the care package. If your family member's needs change while they are at home, ask for another assessment.

### **Nurses in the community**

If your family member needs nursing support at home, this is most likely to come from the community nursing service.

Your family member's GP or main contact at the hospital should be able to refer them to nurses in the community. The community nurse will normally do an assessment. They will then make further visits depending on what support your family member needs.

Nurses will normally visit during the day, but there will be a team available in the evenings. In most areas, nurses will also be available at night, so it should be a 24 hour service. Ask the GP or the nursing team about how to get help during the night.

Depending on how services are organised where you live, nursing support may be given by different nurses who provide different types of care.

- District nurses give nursing care and work closely with GPs and other services to coordinate care.
- Specialist nurses (palliative care nurses, hospice nurses or Macmillan nurses) work alongside the district nurses to help people manage their symptoms, and give practical support.

Specialist nurses in the community are different to the clinical nurse specialist your family member sees at the hospital (see page 15). The clinical nurse specialist will be able to help with treatment or side effects, but won't visit you at home.

If your family member is having palliative care at home, the main contact will be the district nurse or palliative care nurse, rather than the clinical nurse specialist. If you don't know who to contact about your family member's care, ask their GP or main contact at the hospital.

Marie Curie nurses have a different role. They provide nursing care at home for people who are nearing the end of their lives. For example, they may come in overnight so that a carer can get some sleep. The GP or district nurse can put you in touch with a Marie Curie nurse. Other organisations might also provide this service – for example, Sue Ryder, the local hospice or private companies.



**Our specialist nurses on our Support Line can explain how to get support at home.**

## **What is respite care?**

Sometimes, you may need a short break from caring for your family member. This can help you rest and may help you cope better. Respite care involves someone else looking after your family member for a short time. This may be somebody coming in to sit with them for a few hours, day care, or a stay in a care home. Ask the GP or district nurse about respite care.

**“ During the last weeks of mum’s life we had Marie Curie come out and night sit with mum, so me and dad could sleep. This took the pressure off us.”**

## Hospice care

Hospices provide palliative care (see page 18). A hospice care team may include nurses, doctors, social workers, counsellors, and more. A hospice isn't just for someone at the end of their life.

Hospice care is free. Services can vary between hospices, so not all hospices provide all the services mentioned here.

Services may include:

- managing symptoms such as pain
- inpatient care, where your family member stays at the hospice for a short time – for example, to get symptoms under control
- outpatient care, where your family member goes to the hospice for an appointment and then comes home after treatment
- day care, where your family member spends the day in the hospice but doesn't need to be admitted or stay overnight
- Hospice at Home services, which provide nursing care at home
- emotional, spiritual and social support
- support for families
- practical and financial advice
- complementary therapies.

Most people are referred for hospice care by their GP, district nurse, clinical nurse specialist or palliative care nurse. Ask them what hospice services are available. Hospice UK has details of hospices in your area. 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. I was offered support groups and complementary therapies.”



## Social care and homecare

There may be times when you need extra support for your family member, or for you. Social care and homecare include support provided to someone in their home by care workers. Care workers can help with everyday care, including washing, dressing, or housework such as cooking, cleaning or shopping.

### Social services

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

- care at home from care workers
- respite care (see page 46) or day centre care to give you a break
- equipment or adaptations to the home (see page 53)
- help with daily household tasks, such as laundry.

Social services must do a needs assessment to work out what care your family member needs. A needs assessment is free, and anyone can ask for one. Getting services can take time, so it's a good idea to start the assessment process as soon as possible. The GP or hospice can help you organise this care.

If you are spending a lot of your time caring for your family member, social services must also do a carer's assessment to find out what support you need. They should look at the impact the care you provide has on your health and your life. If you live in Scotland this may be called a Carers Support Plan.

If you or your family member have not had an assessment, contact the social services department at your local council. They have a legal duty to do these assessments. Carers UK have more information on needs assessments.

Based on the assessments, the council will decide whether your family member meets the criteria for care. If they do, social services will draw up a care and support plan to meet their needs.

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 (means test) to work this out. If your family member's needs don't meet the criteria for getting support, the council should still provide information and advice about support that is available.

If your family member's needs change and they need more or different care, speak to their GP or nurse about this.

If you do need to pay 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 gives small grants to people with pancreatic cancer.

### **Private care**

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

The social services department should give you information about finding local services and care providers. The Carers UK website has lists of care organisations and reports on their services.

**“ 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.

### Blue Badge scheme

If your family member can't walk or finds walking very difficult, 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 for free in restricted parking areas, disabled public parking bays, or yellow lines.

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. You can apply for a Blue Badge 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.

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:

- anyone with a Blue Badge
- people who often have to go to hospital for treatment, but do not need to stay overnight (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.

**“ The hospital my Mum was being treated at gave free passes for parking for those being treated for cancer or their carers, so it is worth checking.”**

## Travel to hospital

If you find it tiring driving your family member to hospital regularly or you don't drive, ask if friends or relatives can help. If your family member relies on public transport or lifts from other people, they may be able to arrange their appointments around this, although this isn't always possible.

Some hospitals provide transport, as do the British Red Cross, local charities and support groups. Ask the nurse what help is available in your area.

If you are finding that travelling to hospital is expensive, you may be able to get financial help or claim some of the costs back. Ask the hospital staff for information on benefits and grants that might be available. Or get in touch with Macmillan Cancer Support for information about any financial support.

## Equipment

An occupational therapist (OT) is a professional who provides advice and equipment to help people stay independent and carry on doing the things they want to do. Your family member's GP or medical team can refer them to an OT. They will do an assessment to work out what equipment is needed and help you get it. This might include ways to raise a seat to make getting up easier, or grab rails to get out of the bath.

Some equipment may be free. This will depend on your local council. Your family member's local hospice may also provide some equipment.

If you are thinking of buying any equipment yourself, the Disabled Living Foundation can provide information. You may be able to claim benefits or apply for a grant to help with the cost.

If the person you are caring for only needs equipment for a short time, such as after surgery, the hospital or district nurse may supply this. Charities such as the British Red Cross also lend equipment.



Read more at:

**[pancreaticcancer.org.uk/equipment](https://pancreaticcancer.org.uk/equipment)**

**“ Incontinence pads were provided by the NHS and were invaluable.”**

**“ Get equipment as soon as it is needed to make life more comfortable. Having the equipment at home definitely helped us.”**

## Financial support

Looking after someone with cancer can impact your finances. For example, you may not be able to work as much as before.

Get support with financial issues and find out about benefits and grants as soon as possible. Macmillan Cancer Support, Carers UK, Carers Trust and Citizens Advice can provide expert information and advice about this.



We also have tips that might help at:  
**[pancreaticcancer.org.uk/money](https://pancreaticcancer.org.uk/money)**

**“ 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.”**

## Help from family and friends

If you have family or friends who want to help, ask for specific things. For example, they could update other friends and family about recent hospital visits or test results.

Family or friends may also be able to help with driving your family member to hospital appointments, shopping or cooking, or spending time with them to give you a break.



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

- Talk to the GP about what local support may be available, ideally before you need it.
- If your family member is in hospital, talk to the staff about the care package for when they come home.
- Keep track of the dates of appointments and what was said.
- Ask for a social services assessment if social care support would be helpful.
- Let friends and family know if there are specific things they can do to help, such as shopping, driving or cooking.

## **Thinking about the future**

If the person you are caring for has advanced cancer (cancer that has spread to other parts of the body), they may want to think about what will happen if their cancer gets worse. They might want to think about what care they would or wouldn't want, before they need it. This is called advance care planning.

Your family member could also make a Lasting Power of Attorney. This is a legal document, which allows someone to make decisions about their health and welfare on their behalf. They can make a Lasting Power of Attorney for their property and financial affairs as well.



Read more about planning care, including the different ways of making decisions and recording them, on our website at: [pancreaticcancer.org.uk/planningcare](https://pancreaticcancer.org.uk/planningcare)

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 are in place.



### Questions to ask the doctor or nurse

What support are we entitled to?

How do we get support and care at home?

What support can social services provide?

Can we get help with hospital parking or travel to hospital?

Where can I get financial advice and support?



# Further information and support



Our **easy read** booklets use pictures and simple words to help people who might struggle with written information understand pancreatic cancer. Download or order on our website, call **0808 801 0707**, or email **publications@pancreaticcancer.org.uk**

## Medical words explained

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

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

**Complementary therapies:** therapies that work alongside medical treatments – don't stop any cancer treatments. They include acupuncture and massage. They help some people cope with anxiety and some symptoms and side effects. Always speak to the doctor or nurse before trying a complementary therapy.

**Constipation:** when you find it harder to poo. Read more on page 34.

**Diarrhoea:** loose, runny poo. Read more on page 34.

**Digestion:** what your body does to break down your food to get the nutrients out of it. The pancreas plays an important role in digestion.

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

**Enzymes:** substances produced by different glands in the body, including the pancreas. Different types of enzymes have different roles in the body. Pancreatic enzymes help break down food and drink.

**Hepato-pancreato-biliary (HPB):** this term covers the liver, pancreas and bile ducts. HPB doctors and nurses specialise in treating pancreatic diseases.

**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. Read more on page 35.

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

**Steatorrhoea:** caused by fat in poo. Poo may be pale, look oily, smell horrible, and be difficult to flush down the toilet. Read more on page 34.

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



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

## Useful organisations

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

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

**Tel: 01455 883 300** (Mon-Fri 9am-4pm)

Information about counselling and a database of registered therapists.

### **British Red Cross**

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

**Tel: 0344 871 11 11**

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

### **Cancer Focus Northern Ireland**

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

**Nurse line: 0800 783 3339**

Care and support for people affected by cancer and their families in Northern Ireland, through one-to-one and group support services. They also provide support to children who have a family member with cancer.

### **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 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)

**Advice line: 0808 808 7777** (Mon-Fri 9am-6pm)

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)

Information and advice on a range of issues including work, benefits, healthcare, patient rights and information for carers.

## **DLF (Disabled Living Foundation)**

[livingmadeeasy.org.uk](http://livingmadeeasy.org.uk)

**Helpline: 0300 999 0004** (Mon-Fri 9am-5pm)

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

## **Elizabeth Coteman Fund**

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

**Telephone: 01223 782171**

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. Support and friendship to those affected by pancreatic cancer.

## **Fruit Fly Collective**

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

Information and support for families affected by cancer.

## **GOV.UK**

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

Information about government services, including information about benefits, transport, money and hospital parking.

## **Healthtalk.org**

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

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

## **Healthwatch**

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

Supports people in England to provide feedback about health and care services.

## **Hospice UK**

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

**Telephone: 020 7520 8200**

Information about hospices, and a database of hospices in the UK.

## **Macmillan Cancer Support**

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

**Support Line: 0808 808 00 00** (Every day, 8am-8pm)

Practical, medical and financial support for anyone affected by cancer, including families.

## **Maggie's Centres**

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

**Telephone: 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)

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

**mygov.scot**

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

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

**NHS 111 Wales**

**[www.111.wales.nhs.uk](http://www.111.wales.nhs.uk)**

Health information in Wales, including local services.

**NHS inform**

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

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

**NHS website**

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

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

**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.

**riprap**

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

Website for teenagers with a parent with cancer. Information about cancer, real life stories, and support.

**Winston's Wish**

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

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

Support for 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.

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

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

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

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

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

# Pancreatic Cancer UK

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