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 your 'family member' we mean the person with pancreatic cancer.

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 on both you and your family member. This booklet should help you understand what to expect, and how to find support for both yourself and your family member.

Contents

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 come back to it if you need to know more. There is more information and support on our website. Find out more at: **pancreaticcancer.org.uk**

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

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

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

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

Questions to ask 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 61
- contact details of the organisations we mention on page 63.

Emotional support

Key facts

- When someone close to you has pancreatic cancer, you may have lots of different emotions.
- Making time to look after yourself is important. It may help you cope better with caring for your family member.
- There can be lots of information to take in and practical things to think about, which can feel overwhelming.
- Finding ways to communicate with your family member will make things easier for you both.
- It's important to talk to children and be as honest as possible. There are organisations that can support you with this.
- The medical team can provide support and help you access local services.
- We provide support by telephone, email and online. Our free information can help you understand pancreatic cancer and what to expect.

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 may feel shocked, overwhelmed, upset, scared or worried about the future. It can be hard to know what you feel, or how to explain your feelings.

If your family member has been unwell for some time, you may even feel a bit relieved that you finally have some answers. Or you may feel frustrated or angry if it took a while to get a diagnosis. There is no ‘right’ way to feel.

Looking after yourself

When you are caring for someone, it can be hard to think about what you need or find time to take a break. Caring for family members can be an expected part of life in some cultures. You may feel embarrassed or ashamed to ask for support. But it’s important to take care of yourself too.

Caring for someone can lead to anxiety and depression. Feeling stressed for a long time can also make you feel exhausted or ‘burnt out’. This can make it harder to care for your loved one.

> “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.”

Looking after yourself and getting any support you need can help you cope better. How you do this will be different for everybody. But you may find the following tips useful.

What can I do?

- Have a space where you can let your emotions out. Shout, scream or cry if you need to.
- Try keeping a journal to help process your feelings.
- Think about what you can and can't control.
- Organise support to help with your family member's care. This can give you a break and allow you to get some rest. Read more on page 51.
- Try to maintain a routine and look after your own health. Eat well and try to be as active as you can.
- Be kind to yourself. Try to find time to continue doing things you enjoy.
- Connect with other carers through discussion forums or support groups. This can help with feelings of isolation.
- Try using an app to boost your mental wellbeing. There are apps available that focus on relaxation and mindfulness techniques.

Where to find emotional support

Getting support for yourself can help you cope. Just having someone to talk to can make things easier. That could be family or friends, or connections made through support groups or social media.

The medical team looking after your family member can also help provide emotional support for you. Read more about the medical team on page 18. If you have care workers looking after for your family member at home, they often provide emotional support to everyone in the home.

We have more information about how caring may affect you emotionally and getting support on our website at: **pancreaticcancer.org.uk/emotions**

We can help you

Our **specialist nurses on our confidential Support Line** speak to lots of families and friends. They understand the issues and worries you might have, can provide expert support, and can help you work out what you need to know.

Contact our specialist nurses with any questions or worries. Call **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**

> “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.”

Our **free information** can help you understand your family member’s diagnosis, ask questions, make decisions and support them to live as well as possible. If your family member has just been diagnosed, you can also sign up to our information and support emails to get key information.

Through our online support, we can **connect you with others** affected by pancreatic cancer, including other families. You can also **read other people’s experiences** of pancreatic cancer.

Find out more about how we can support you at:
pancreaticcancer.org.uk/support

> “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 find ways of coming to terms with things.

There are different ways to get counselling.

- Ask your GP or the cancer nurse to refer you, or for details on how to refer yourself.
- Search for local services offering counselling for carers on the Carers Trust website.
- Check what is offered through your local hospital, hospice, Macmillan cancer support centre or Maggie's centre.
- If you are working, you might be able to access counselling through an employee support programme.
- If you live in England, you may be able to refer yourself for counselling and other types of emotional support through the NHS website.
- In Scotland, you can access support from a therapist through Living Life – a free phone service from NHS 24.
- In Northern Ireland, you can access counselling through Cancer Focus Northern Ireland and Action Cancer.

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

Bear in mind that there are often waiting lists for counselling services. It might be worth looking into a few different options. Depending on where you live, you may also be able to access online self-help services for free. These include SilverCloud wellbeing programmes in Scotland and Wales.

Organisations supporting carers

The following organisations provide support for carers.

- **Carers organisations.** These specialise in offering information, advice and emotional support for carers. They often provide other services too. Examples include Carers UK and Carers Trust.
- **Local cancer support centres.** Examples include Maggie’s Centres (in England, Scotland and Wales) and Macmillan Cancer Support centres (across the UK).
- **Cancer support groups.** These are often open to families and carers. There are often support groups for particular communities too. Your family member’s nurse may know what’s available in your local area.
- **Other cancer charities.** These often offer support and advice for carers. Examples include Macmillan Cancer Support, Tenovus Cancer Care in Wales, and Cancer Focus NI and Action Cancer in Northern Ireland.

We have a full list of organisations, including contact details, on page 63.

Find groups specifically for pancreatic cancer on our website: **pancreaticcancer.org.uk/supportgroups**

Communicating with your family member

It can be hard to know how to talk about cancer with someone close to you. Both you as a carer and the person with cancer may struggle to talk about it. All families communicate differently, and for some, there can be a stigma around discussing cancer.

But finding ways to communicate with your family member will make things easier for you both. It can help you both feel better emotionally, and can even bring you closer.

Tips to help you communicate

- Try to have an open conversation about what support they need and what you can offer. This can help to avoid confusion or disagreements and assist with making plans.
- Focus on practical things and try to agree how some situations should be handled. This may include deciding how to tell or update other family or friends.
- Try to keep talking to each other, as things may change.
- Make time and space for conversations, so there are chances to talk about how you are both feeling.
- Keep in mind that your family member may not always want or feel able to talk. They may also hide their own concerns or feelings to try and protect you or others.
- If one or both of you are feeling upset or stressed, it can make communication more difficult. Getting support for yourself can help (see page 7).

When someone doesn’t want to talk

Some people may not want to talk about their cancer at all. This is a natural reaction and may be their way of coping with it. Try to show that you are ready and open to talking yourself. This may encourage your family member to open up.

There are things you can do to help

- Do not pressure them. Allow them to talk whenever they feel ready.
- Show them that you are open to listening, giving plenty of opportunities for them to talk. When they do talk, don’t interrupt or judge them. They may not need you to give advice or solutions, just show that you are listening.
- Do things you enjoy together and talk about things other than the cancer. It can help to ease any tension and may help them to open up in time.
- Support them to be the person they were before they had cancer, whether that’s your parent, partner or friend. It can help to maintain their sense of identity.
- If they find it hard talking to you, ask them whether they would prefer to talk to someone else. This might be another family member or friend, their nurse or a counsellor.

Macmillan Cancer Support have more information on talking about cancer.

Relationships with partners

If your partner has cancer, it can have a big impact on your relationship, both physically and emotionally. Coping with difficult feelings and changes in your roles can add stress to your relationship. But some people find they grow closer going through something like cancer together.

Intimate relationships

The stress of dealing with cancer, as well as symptoms and side effects of treatment may make an intimate relationship difficult. Try to discuss things openly with your partner. You may find you are experiencing similar emotions. You can try different ways of spending time together, or of having a physical connection.

Your partner’s medical team can explain how treatments may impact on sex and intimacy. Don’t be afraid to ask them if you have any questions.

Support for children

If you or the person you are caring for has children or grandchildren, you may need support for them as well. Your family member’s nurse may be able to give you information and advice about talking to children.

For most children and teenagers, it is best to be honest and talk to them as much as possible about what is going on. A good starting point can be to ask them what they think is happening. Depending on the age of the child, you can then respond and explain things in simple language they will understand.

Answer any questions as honestly as you can and check they have understood. If appropriate, try to involve them in family decisions.

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 at school.

Where can I get help supporting children?

There are several organisations that provide support for children who have a parent with cancer, including the following.

- The Fruit Fly Collective produce a range of helpful information and resources.
- Riprap is a UK website aimed at teenagers.
- The Osborne Trust offer emotional and practical support to children and young people.

You can find more details of these organisations on page 63.

We have a full list of organisations supporting children on our website:
pancreaticcancer.org.uk/supportforchildren

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.
- Make time and space for open conversations with your family member.
- 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 health professionals will be responsible for your family member's care. This is called a multidisciplinary team (MDT).
- Your family member should be given the details of a key contact. This may be a clinical nurse specialist (CNS). They can provide support and answer your questions.
- If you haven't been given a key contact, ask the doctor who to contact if you have any questions.
- The medical team or specialist nurse should regularly check how your family member is coping with symptoms or side effects from treatment. But ask if you need advice.
- 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. It is important you understand what is happening and how to support your family member.
- You can ask for a second opinion about the diagnosis or treatment if you wish.

The healthcare system can be confusing. This section provides key information about what to expect and the health professionals you may see.

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 decisions. Your family member might not meet everyone in the MDT, but their doctor or nurse should tell them what they recommend.

Who is our main contact?

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 support, care and advice and will coordinate their care. They will also support you. If your family member has not been given a specialist nurse or 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 questions you have and act as a link with the MDT.

Can I speak to the medical team?

If they wish, the person you are caring for can give their GP and medical team permission to speak to you. This means you can talk to them about your family member's care.

Find out more about the MDT and the health professionals involved at: **pancreaticcancer.org.uk/care**

There are guidelines for cancer care across the UK. Find out more on our website at: **pancreaticcancer.org.uk/patientcharter**

The National Institute for Health and Care Excellence (NICE) have produced guidelines for health professionals caring for people with pancreatic cancer in England, Wales and Northern Ireland. Read more about these at **pancreaticcancer.org.uk/nice**

The information in this booklet explains how care should happen. But we know things don't always go according to plan. Be aware that sometimes you may have to push for things to be done. For example, don't be afraid to ask questions, chase appointments, or ask for care and support to be put in place.

We know this can be frustrating and exhausting. If you need information and support, you can always contact our specialist nurses on our free Support Line.

"If you don't understand something don't be afraid to say so. 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."

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. Your family member may not need to go to the specialist centre in person. The specialist team will report back to their local hospital.

Your family member may have tests and some treatments at their local hospital. These might include chemotherapy and radiotherapy. If they are having surgery to remove their cancer, 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.”

Specialist palliative or supportive care

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

These services are not 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 practical support, and can support with making decisions about future care.

Specialist palliative care teams may be based in the hospital or at a hospice. Palliative care nurses can also visit your family member at home.

Supportive care teams are available in some hospitals and in the community. They can sometimes be called different things. In some areas, this supportive care is provided by the GP and local district nurses. It may also include your cancer nurse in hospital.

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. You can ask how long this would normally take.

Read more about specialist centres, palliative care and supportive care on our website at: **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 29.

They should also talk to your family member about any concerns they have, and the best way to deal with them. This may include how they are feeling emotionally, and practical issues like finances or help at home. Read more about local help and support on page 46.

Some medical teams may discuss these issues as part of something called a Holistic Needs Assessment (HNA). Not all hospitals offer an HNA. But if you have any concerns or would like your family member to have an HNA, speak to their nurse or a member of their team.

> “I managed to get an email address for the oncologist’s 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?

It's important to know who to contact at night or at the weekend.

- The hospital team will tell you who to call if symptoms are bad out of hours.
- If you are caring for your relative at home, their GP, community nurse or palliative care team should explain what to do if you need help at night or the weekend.
- If you live in England, Wales or Scotland, you can call NHS 111 or use NHS 111 online for advice out of hours.
- In Northern Ireland, you can find local out of hours phone numbers for each region on the nidirect website.
- Your GP answer phone message may also have an out of hours number.

The doctor or nurse should tell you what to do in an emergency. If they haven't, ask them. If your family member has made an advance care plan (see page 60), this might record the treatment they would or wouldn't want in an emergency.

> "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 can about pancreatic cancer so you can understand what's happening.
- We have lots more information on our website. Our information for people recently diagnosed is a good place to start: **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 how long your family member should expect to wait for any tests, test results and treatments. You can also ask who to contact if they have not heard anything within this time.
- 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.

> "We had emergency numbers on a card directing us to the appropriate hospital and department."

Getting a second opinion

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

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.

Your family member should not 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.

A second opinion is free on the NHS or can be paid for privately. Your family member doesn't have a legal right to a second opinion, but doctors usually won't refuse.

Second opinion for people getting rapidly worse

Under new rules being introduced from 2024, families and carers can also ask for a second opinion if their loved one is rapidly getting worse in hospital. This is different from requesting a second opinion on their diagnosis or treatment options. We have more information on our website.

Read more about getting a second opinion on our website at: **pancreaticcancer.org.uk/secondopinion**

Macmillan Cancer Support also 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 NHS care, talk to the doctor or nurse first. If this does not help things, you may want to take the issue further.

More information and support

These organisations offer free advice and support in making a complaint if you decide to.

- 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 you make a complaint.
- In Scotland, you can speak to the Patient Advice and Support Service (PASS). You can access them through Citizens Advice Scotland.
- In Wales, you can speak to Llais for support raising your concerns. Find out more from the Llais website.
- In Northern Ireland, the Patient and Client Council can help you with your complaint. Find out more from nidirect.

Private healthcare

With private healthcare, you can make a complaint directly with the clinic or hospital. If the situation isn't sorted out you can contact the Independent Sector Complaints Adjudication Service (ISCAS) or the Care Quality Commission. Citizens Advice have more information.

Read more about what to do if you have concerns about your family member's care on our website at: **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?

When will my family member start the recommended treatment?

Where will my family member have their treatment?

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?

What happens next?

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.
- Common symptoms include problems with digestion and eating, pain, diabetes, fatigue and bowel problems like constipation and diarrhoea.
- 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.
- Ask the doctor or nurse who to call if you are worried about any symptoms.
- Taking capsules containing pancreatic enzymes when eating can help problems with digestion.
- There are some symptoms that need urgent attention. It's important to be aware of these.

This section explains some common symptoms of pancreatic cancer and side effects of treatment. You can help your family member by knowing about symptoms, how to manage them and who to ask for help.

Your can speak to our specialist nurses on our Support Line for information and support managing symptoms.

Problems with digesting food

Pancreatic cancer can affect how your body digests (breaks down) food. This means your family member may not get the nutrients they need. Problems with digestion can cause symptoms such as weight loss, appetite loss, tummy discomfort and changes to their poo.

If possible, your family member should see a specialist pancreatic or oncology dietitian. Ask their nurse or GP about this. If the hospital doesn't have a specialist dietitian, their doctor or nurse may be able to help. Or they may refer them to a general dietitian.

Pancreatic enzyme replacement therapy (PERT)

Ask about getting a prescription for pancreatic enzyme replacement therapy (PERT). PERT are capsules that your family member can take when they eat to help break down food. This can help with symptoms and can make a big difference to how they feel. PERT can also help them cope better with treatments.

In the UK, brands include Creon®, Nutrizym® or Pancrex®. If your family member is having any problems getting PERT, speak to our specialist nurses on our free Support Line.

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**

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

What can I do?

These tips may help if your family member is having digestion problems.

- Encourage them 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.
- They may find it easier to eat smaller amounts more often, so regular snacks can help.
- If you prepare meals for your family member, ask them what they would like. There aren't any foods that they need to avoid because of the cancer.
- Use smaller plates so meals feel easier to manage. Try presenting the food to make it more tempting.
- If they have lost weight, you could add cheese, butter, cream or mayonnaise to dishes to get more calories and protein into their food. Read more tips at: **pancreaticcancer.org.uk/diettips**
- Keep a note of any problems, so you can ask about these. You can find a food diary to monitor symptoms at: **pancreaticcancer.org.uk/diet**

"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 do."

Pain

Many people with pancreatic cancer have pain at some point. This can be caused by the cancer itself or due to problems with digestion, or side effects of treatment. There are lots of ways to manage pain. These include different types of painkillers and other pain relief.

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.

Read more about managing pain in our booklet: **Pain and pancreatic cancer**

Or on our website at: **pancreaticcancer.org.uk/pain**

> "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."

Fatigue (extreme tiredness)

Fatigue is extreme tiredness. It isn't the same as just feeling tired. Your family member might feel both mentally drained and physically 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 help get your family member the support they need.

What can help with fatigue?

- Gentle activity, like a short walk or some light gardening, can help with fatigue and increase energy levels.
- Physical activity is unlikely to make fatigue worse, but it’s also important your family member rests 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**
- Ask whether you could help with things like household chores or organising medical appointments. This can help your family member save their energy for things they enjoy.
- Friends and family may want to visit more, but this can 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**

Diabetes and pancreatic cancer

The pancreas produces hormones, including insulin, which control sugar levels in the blood. Someone with pancreatic cancer may not produce enough insulin. This can cause a type of diabetes called type 3c diabetes, where sugar levels in the blood become too high. Surgery to remove the cancer can also cause diabetes.

Type 3c diabetes is different to other types of diabetes. A lot of the information available about diabetes, such as changing what you eat, may not be right for your family member. Speak to the dietitian, specialist nurse or diabetes nurse about how to manage your family member's diabetes.

We have more information about managing diabetes on our website at: **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. But for many people with pancreatic cancer, feelings of fear and sadness can become overwhelming, leading to anxiety and depression.

What can help?

Try to support your family member with anything that may be worrying them. It can also help to find things they enjoy doing to take their mind off things. They could try some relaxation techniques, like breathing exercises, meditation, or gentle physical activity.

Speaking to a counsellor may help your family member to work through their feelings. Read more about counselling on page 8. Their medical team may also prescribe medicines for depression or anxiety.

Find more information and tips for dealing with the emotional impact of pancreatic cancer at: **pancreaticcancer.org.uk/coping**

Feeling and being sick

Sickness can be caused by the cancer itself, or by treatments such as chemotherapy. Speak to the GP, specialist nurse or palliative care team if your family member needs help with this. There are treatments for sickness, including anti-sickness medicine.

Contact the medical team, GP or district nurse if your family member is sick for more than half a day and can't keep down food or fluid. They may need to go to hospital, where they will work out the cause of the vomiting.

You should also get urgent help if your family member is vomiting blood, or if they have symptoms of dehydration.

What is dehydration?

Dehydration is when the body loses more water than it takes in. It can happen after sickness or diarrhoea. Signs can include needing to pee less often than normal and dark or strong-smelling pee. Your family member may also have headaches and feel thirsty.

Dehydration needs to be treated to prevent serious problems. It may be more serious if someone has diabetes.

Read more about treating sickness at:
pancreaticcancer.org.uk/sickness

Bowel problems

Many people with pancreatic cancer notice changes to their poo. Speak to your family member's doctor or nurse about this. They can work out what is causing these problems and find ways to manage them. Common bowel problems include the following things.

- **Constipation (when you find it hard to poo).** Taking opioid painkillers, not moving around or eating much, and dehydration may make constipation more likely. Medicine called laxatives can treat constipation. Encouraging your family member to drink fluids and to move around as much as they can, may help.
- **Steatorrhoea.** This is pale, oily poo that smells worse than normal and is difficult to flush. It's caused by fat in the poo that hasn't been digested properly. Taking pancreatic enzymes (see page 30) can help with steatorrhoea.
- **Diarrhoea (runny poo).** This can be caused by problems digesting food, an infection or chemotherapy. Encourage your family member to drink as much as they can manage to prevent dehydration. If it is caused by problems digesting food, pancreatic enzymes can help. If it doesn't get better, your family member may need tests to check for other causes.

Read more about bowel problems on our website at:
pancreaticcancer.org.uk/bowelhabits

Find tips for managing diarrhoea at:
pancreaticcancer.org.uk/diettips

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.

Jaundice

Pancreatic cancer can cause jaundice by blocking the bile duct. This is a tube that takes a fluid called bile from the liver to the duodenum, to help with digestion. We explain these words on page 61.

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. Jaundice is serious, but it can be treated. Speak to your family member's doctor or nurse urgently if they have symptoms.

There is information about treatments for jaundice on our website. Read more at:
pancreaticcancer.org.uk/jaundice

Stent infection

If your family member has jaundice, they may have a stent put in to open their bile duct. This may get infected if it becomes blocked.

Signs of a stent infection include:

- tummy pain
- aching muscles
- a high temperature or shivering
- signs of jaundice (see page 39).

Your family member 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**

Or on our website at:
pancreaticcancer.org.uk/biliarystent

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 give you a 24-hour emergency number to call for urgent advice. Phone this number if your family member has any of the signs of infection listed on page 41, or suddenly feels unwell.

Signs of an infection include:

- a high temperature – the chemotherapy team will tell you what this is
- feeling shivery or cold
- headaches
- 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**

Blood clot in a vein

People with pancreatic cancer are at higher risk of a blood clot in a vein. Having surgery and some chemotherapy drugs can increase the risk of a blood clot.

A blood clot is serious and needs to be treated straight away. It often happens in the lower leg (calf), upper leg (thigh) or arm. This is known as deep vein thrombosis (DVT). Symptoms include pain, tenderness and swelling in your arm or leg. The skin may also be warm and look red or a different colour to normal.

Part of a clot can also break off and travel in the blood to the lungs. This is called a pulmonary embolism. This is serious and needs medical attention straight away. Symptoms include feeling short of breath, sudden chest pain, and a dry cough or 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**

High and low blood sugar levels

If your family member has diabetes, their diabetes team will explain how to manage their blood sugar levels. The aim is to avoid them becoming too high or too low.

Ask your family member's doctor or nurse what the ideal range for their blood sugar level is, and when you should seek help.

Very high blood sugar levels

An illness or infection can sometimes cause conditions called diabetic ketoacidosis (DKA) or hyperosmolar hyperglycaemic state (HHS). These happen when blood sugar levels become very high. The diabetes team should explain what to do if your family member has diabetes and is unwell.

DKA and HHS are both serious conditions that need treating urgently. Symptoms include feeling drowsy or confused, and passing out. It can also cause sweet or fruity-smelling breath (like nail varnish or pear drop sweets).

Take your family member to A&E immediately if you think they have DKA or HHS.

Low blood sugar levels

A low blood sugar level is known as hypoglycaemia or a 'hypo'. You can read more about this on our website.

Read more about managing diabetes and blood sugar levels on our website at:
pancreaticcancer.org.uk/diabetes

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?

Are there treatments, like pancreatic enzyme replacement therapy, that would help their symptoms?

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

Are there other specialists who can help manage their symptoms? For example, a dietitian or palliative care specialist?

Read more symptoms and side effects and how to manage them on our website: **pancreaticcancer.org.uk/managingsymptoms**

Contact our specialist nurses on our free Support Line if you have any questions or concerns about symptoms. Call **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**

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 let you know what symptoms to expect and how you can get support in managing them.

Read about caring for someone at the end of their life in our booklet: **Pancreatic cancer and end of life care**

Or at: **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.”

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 care and support after leaving hospital, this should be included in a care plan.
- It can sometimes take time to organise care and support at home. The GP or specialist nurse can help you with this.
- 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.
- If your family member is eligible for NHS continuing healthcare, the NHS will arrange and pay for their care.
- Social services may also provide support for you and your family member. Request an assessment from your local council to find out what you are entitled to.
- Pancreatic cancer can have a huge impact on your and your family's life. There is practical and financial support available.

Community health services

If you are caring for someone with pancreatic cancer at home, you should have support from community health services. This might include community nurses, physiotherapists for mobility problems, and occupational therapists to advise on equipment and adaptations.

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 or specialist nurse can help you with this.

What happens when someone leaves hospital?

Before your family member leaves hospital, their medical team will assess what care and support they may need at home. This is called a needs assessment or discharge planning.

The assessment will be used to create a discharge plan and if needed, a care plan. These include details such as:

- what treatment and support will be provided at home
- who to contact if there is a problem
- if they need palliative care (see page 21), who will provide this.

Read more about needs assessments on page 53.

The medical team should write to your family member's GP to explain why they were in hospital and any care they will need when they go home.

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 their local community or district nursing service. Their GP or main contact at the hospital can refer them. Ask how long this is likely to take.

Nurses will normally visit during the day, but in most areas, nurses will also be available at night. Ask the GP or the nursing team how to get help during the night.

Which nurses can help at home?

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

- **District nurses** give nursing care and work closely with GPs and other services to coordinate care.
- **Specialist nurses** include palliative care nurses, hospice nurses and Macmillan nurses. They work with district nurses to help manage symptoms and give practical support.

Specialist nurses in the community are different to the clinical nurse specialist (CNS) at the hospital (see page 19). The CNS will help with treatment, side effects and managing symptoms, but won't visit you at home.

Marie Curie nurses have a different role. They provide nursing care at home for people nearing the end of their lives. They may provide care overnight so you can get some sleep. The GP or district nurse can refer you.

Other organisations might also provide this service. Examples include the charity Sue Ryder, your local hospice or private companies.

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

Respite care

Respite care involves someone else looking after your family member for a short time. This can give you a break from caring, help you rest and may help you cope better.

Respite care may involve somebody coming in to sit with them for a few hours, day care, or a short stay in a nursing or care home. Ask the GP or district nurse about respite care.

Hospice care

Hospices provide care for people with cancer that can't be cured. They can care for people at any point during their illness, not just at the end of their life.

Hospices may provide palliative care (see page 21) in your family member's home. Or they may go to a hospice as a day patient, or for a short stay to get symptoms under control. A hospice care team may include nurses, doctors, social workers and counsellors.

Hospice care is free. Services may include:

- managing symptoms, such as pain
- physiotherapy and occupational therapy
- emotional, spiritual and social support
- support for families
- practical and financial advice
- complementary therapies, such as massage.

Services can vary between hospices.

Most people are referred for hospice care by their GP, district nurse, clinical nurse specialist or palliative care nurse. Ask your family member's main contact what hospice services are available in your area. You can also find details from Hospice UK, or contact your local hospice directly 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."

Support and help at home

There may be times when you need extra support in your family member's day-to-day care. Care workers can help with everyday care, including washing and dressing, or tasks such as cooking, cleaning or shopping. You may be able to access this support through NHS continuing healthcare, social services, or private care.

NHS continuing healthcare

If you live in England, Wales or Northern Ireland, your family member may be eligible to have all their care arranged and paid for by the NHS. This is known as continuing healthcare.

It covers care provided in any setting, including their home or a care home. They may be eligible if they are assessed as having long-term, complex health needs, which they need help to manage. It's important to find out if they qualify.

Your family member's nurse, doctor or social worker will need to assess them to see whether they might be eligible. This can take time. If your family member's health is getting worse quickly, they may be able to have a fast-track assessment. Ask the medical team if this is an option.

You can find out more about NHS continuing healthcare from Carers UK, Marie Curie and in England, Beacon.

In Scotland, this type of care is only funded by the NHS for people in hospital. It's called Hospital Based Complex Clinical Care. Citizens Advice Scotland have more information about this. Outside of hospital, you can apply for support through social services.

Social services support

If your family member does not qualify for NHS continuing healthcare, they may still be eligible for support from social services through their local council. As a carer, you may be eligible for support too.

Social services may provide support such as:

- care for your family member at home from care workers
- respite care (see page 50) to give you a break
- equipment or adaptations to the home (see page 56)
- practical help with household tasks, such as laundry.

How can we get this support?

To get social services support, you will need to contact your or your family member's local council. The GP or hospice may be able to help you organise this.

There are two types of assessment they can do.

- A **needs assessment** is for the person you are looking after. It will work out what care and support they need. You can request one on their behalf.
- A **carers assessment** will look at what support you need. In Scotland this may be called an adult carer support plan. In Wales, it may be called a carer's needs assessment.

You can have the assessments done at the same time, or separately. You are entitled to have a carer's assessment if you are providing regular, unpaid care. You can have this even if your family member has not had a needs assessment.

There is more information on the NHS website about care and these assessments. Carers UK also have more information on getting support from social services.

Based on the assessments, the council will decide whether you or your family member are eligible for any support. If so, they will do a financial assessment (means test) to see whether they can offer any funding.

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

Private care

Your family member may need to pay for their care if they are not eligible for support from social services. Or they may prefer to arrange and pay for it themselves.

You can arrange for paid carers through a homecare agency, or by employing a carer directly.

The council's social services department should be able to tell you about local services and care providers, even if they are not funding this. Ask if they have not provided this information. Carers UK also have lists of care organisations on their website.

Sometimes, local charities may provide grants. For example, the Elizabeth Coteman Fund gives small grants to people with pancreatic cancer.

> "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.

How can we get a Blue Badge?

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.

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.gov.uk if you live in Northern Ireland.

Do not apply for a Blue Badge from anywhere else, as it may not be legitimate.

If your family member’s cancer can’t be cured, the council is usually able to fast-track the application. It’s best to ask for a paper form from your council, or from the Blue Badge Unit if you live in Northern Ireland.

Hospital parking and discounts

Many hospitals charge for parking. But free or reduced parking charges may be available to people who:

- have a Blue Badge
- have regular outpatient appointments – at least three times a month, for at least three months
- have family members in hospital for a long period of time
- are visiting relatives who are very ill.

Ask at the hospital’s main reception about this.

> “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

You may find your family member has a lot of hospital appointments. This can be tiring, expensive, and difficult if you don't drive. There may be support available.

- Ask friends and family to help drive them. People are often happy to help in this way, and it gives you a break.
- Some hospitals provide transport for certain patients. Ask the GP, nurse or hospital staff to see if this is available.
- Organisations including the British Red Cross, local charities and support groups may help with transport.
- If your family member receives certain benefits, you may be able to claim some travel costs back. Ask a member of the healthcare team or at the hospital reception.

Equipment

An occupational therapist (OT) can assess your family member, and provide advice and equipment to help with everyday tasks they may find difficult. This can help them to stay independent. Examples include chair raisers to help with getting up, or grab rails for the bath.

Bear in mind that this can take time to organise. Ask your family member's GP or medical team to do an OT referral as soon as you think it may be needed.

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

There are different ways to get equipment or adaptations to your home.

- Your local council may fund some adaptations to the home.
- Your family member's local hospice may provide some equipment.
- If equipment is only needed for a short time, the hospital or district nurse may supply this.
- If you have to buy equipment yourself, you may be able to claim benefits or apply for a grant to help with the cost.
- You can hire some equipment from charities such as the British Red Cross.

The organisation Living Made Easy can provide information on equipment to help with daily living.

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

> “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 family or friends offer 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 give practical support. For example, they can help with driving your family member to hospital appointments, shopping, housework or cooking. They may be able to spend time with them too, to give you a break.

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?

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.
- Talk to the doctor or nurse about options for respite and hospice care, if your family member might need these.
- Ask the medical team whether your family member might be eligible for NHS continuing healthcare.
- Ask for a social services assessment for both you and your family member, if social care support would be helpful.
- Look into what benefits and financial help you and your family member might be entitled to.
- 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 your family member has cancer that can't be cured, they may want to think about their future care, before they need it. This might include what care they would or wouldn't want, and where they want to receive any care. This is called advance care planning.

Your family member may want to create a written record of their wishes and share this with you, their medical team and GP. They don't need to decide anything they are not comfortable with. They can change their wishes at any time.

Read more about planning care at:
pancreaticcancer.org.uk/planningcare

Making a will

Your family member may also want to think about making a will, if they do not already have one. We can help them write their will for free, either online or through a solicitor. They don't need to leave a gift to us if they use this service.

Read about our free Will writing services at:
pancreaticcancer.org.uk/free-will-writing-service

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.

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 contains a substance called bilirubin. It is produced by the liver and stored in the gallbladder.

Bile duct: tube that carries bile from the liver to the small intestine.

Complementary therapies: therapies including acupuncture and massage, that work alongside medical treatments to help with symptoms and side effects. Always speak to the doctor or nurse before trying these and do not stop any cancer treatments.

Constipation: when you find it harder to poo. Read more on page 38.

Diarrhoea: runny poo. Read more on page 38.

Digestion: how your body breaks down food to get nutrients. 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, that do different things. Pancreatic enzymes help break down food and drink.

Hepato-pancreato-biliary (HPB): a term that 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 39.

Pancreatic enzyme replacement therapy (PERT): capsules containing pancreatic enzymes to help break down food. Used if the pancreas isn't producing enough enzymes. Examples include Creon®, Nutrizym® and Pancrex®. Read more on page 30.

Steatorrhoea: caused by fat in poo. Poo may be pale, look oily, smell worse than normal, and be difficult to flush down the toilet. Read more on page 38.

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

Useful organisations

Action Cancer

actioncancer.org

Tel: 028 9080 3344

Support for people with cancer in Northern Ireland.

Beacon

beaconchc.co.uk

Tel: 0345 548 0300

Provide support and information to people and families having the NHS Continuing Healthcare assessment.

British Red Cross

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

cancerfocusni.org

Nurse line: 0800 783 3339 (Mon, Weds, Fri, 9am-1pm)

Care and support for people affected by cancer and their families in Northern Ireland.

Carers Trust

carers.org

Tel: 0300 772 9600 (Mon–Fri 9am–5pm)

Support for carers, and a directory of local care services.

Carers UK

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

citizensadvice.org.uk

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

Elizabeth Coteman Fund

ecfund.org

Tel: 01223 782171

Provides grants for equipment and respite, for people with pancreatic cancer who are struggling financially.

Fruit Fly Collective

fruitflycollective.com

Information and support for children affected by cancer.

Healthwatch

healthwatch.co.uk

Advice and support for people using health services in England, including help with making a complaint.

Hospice UK

hospiceuk.org

Tel: 020 7520 8200

Information and a database of hospices in the UK.

Independent Sector Complaints Adjudication Service

iscas.cedr.com

Tel: 020 7536 6091 (Mon-Fri 9am-5pm)

Provides independent decisions about complaints for the private healthcare sector.

Llais

llaiswales.org

Information and support in making a complaint about health and social services in Wales.

Living Made Easy

livingmadeeasy.org.uk
Free advice about equipment to help with daily living.

Macmillan Cancer Support

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

Maggie's Centres

maggies.org
Tel: 0300 123 1801
Centres around the UK and online offering free practical, emotional and social support for anyone affected by cancer.

Marie Curie

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.

NHS 111

111.nhs.uk
Information on what to do if you need medical help now.

NHS 24

nhs24.scot
Living Life Tel: 0800 328 9655 (Mon-Fri, 9am-9pm)
Digital health and care services in Scotland.

NHS website

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

nidirect

nidirect.gov.uk
Information about local services in Northern Ireland including health services, and information for carers.

riprap

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

Sue Ryder

sueryder.org
Tel: 0808 164 4572 (Mon-Fri, 9am-5pm)
Support for people approaching the end of life or living with grief.

Tenovus Cancer Care

tenovuscancercare.org.uk
Tel: 0808 808 1010
Advice and support for everyone affected by cancer in Wales.

The Osborne Trust

theosbornetrust.com
Tel: 07712 089 273
Emotional and practical support for children and young people who have a parent with cancer, across the UK.

You can find more sources of information and support at: **pancreaticcancer.org.uk/organisations**

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.

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