CARING FOR SOMEONE WITH PANCREATIC CANCER

INFORMATION FOR FAMILIES AND CARERS

PANCREATIC CANCER UK
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INTRODUCTION

This booklet is for family members of someone with pancreatic cancer that can’t be cured. This includes people with cancer that has spread from the pancreas to other parts of the body (advanced or metastatic cancer). It also includes people with cancer that has spread to structures around the pancreas, such as blood vessels (locally advanced cancer), who can’t have surgery to remove the cancer.

You may hear yourself described as their carer. You may not see yourself as a carer. You may simply see yourself as their husband or wife, partner, daughter or son, or friend. But anyone who looks after a family member or friend, unpaid, and provides support that that person couldn’t manage without, is a carer. You might not think that you are doing anything out of the ordinary. But the care you give them is really important, from doing the shopping, taking them to hospital appointments, or just being there when they need to talk.

Supporting or caring for someone in this situation can have a big impact on you – physically, emotionally and financially. But because there’s so much going on, you may not have much time to find out about or get the support you may need. This booklet aims to help you to find support, for yourself and your family member.

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

If you have any questions about anything you read here or about the treatment and support available, you can speak to our specialist nurses on our free Support Line.

📞 Call the specialist nurses free on 0808 801 0707, or email support@pancreaticcancer.org.uk
LOOKING AFTER YOURSELF

Many family members are so busy helping or looking after the person with cancer, that they ignore their own needs – especially the emotional impact of having a family member with a life-limiting illness. This section has information on sources of emotional support.

HOW YOU MIGHT BE FEELING

When someone close to you has been diagnosed with pancreatic cancer you’re bound to experience a range of emotions at different times, from disbelief and anger to fear and confusion. You may also feel helpless, that you don’t know what to say or do and don’t know enough about pancreatic cancer to help them. And when you’re also caring for that person you might think that your feelings come second to theirs, or you might not even have time to think about how you’re feeling.

You may think that you always have to be the strong one, the one who copes with everything. People often tell us that one of the worst things can be thinking that you are the only person in this situation. It’s important to remember that you aren’t alone – many others are going through similar experiences – and there’s support available.

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

“Everybody copes differently. I concentrated on the practical things I could do – it was no good sitting in the corner crying.”
WHO CAN YOU CONTACT FOR EMOTIONAL SUPPORT?

Getting some support for yourself can be helpful, and can help you support your family member better. Your family and friends can be great sources of support – just having someone to talk things through with can help enormously.

The medical team looking after your family member can also help – especially their key worker. They will be able to answer your questions and provide you both with emotional support, as well as medical care. See page 33 for more information about the medical team.

Who is the keyworker?
The keyworker is the main point of contact in the medical team for you and your family member. They will usually be a specialist nurse.

There is also a huge variety of emotional support from a range of organisations and individuals.

PANCREATIC CANCER UK SERVICES

We run a confidential Support Line for anyone affected by pancreatic cancer. We are here for families and carers as well as for patients. Our experienced specialist nurses have time to listen to your concerns, answer your questions and provide information on any aspect of pancreatic cancer.

The service is available Monday-Friday, 10am-4pm. Call free on 0808 801 0707 or email support@pancreaticcancer.org.uk
We also run an online discussion forum. Members include carers and families as well as people with pancreatic cancer. This is an opportunity for you to get in touch with other people in similar situations. You can share experiences, information, inspiration and hope.

Find out more and register on our website at www.pancreaticcancer.org.uk

We provide information about pancreatic cancer, treatments, side effects and living with pancreatic cancer. All our information is based on the latest evidence, and reviewed by health professionals and people affected by pancreatic cancer.

Go to www.pancreaticcancer.org.uk. Download and order publications at www.pancreaticcancer.org/publications

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

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

“The things that helped me cope? Being very informed, reading lots of information. Reading the Pancreatic Cancer UK forum, and ultimately posting, so knowing I wasn’t alone. An outstanding consultant, specialist nurse and oncology team, and a great GP.”
SUPPORT GROUPS

There are cancer support groups around the country. They are often open to family members as well as the person with cancer. At a support group, you can meet other people going through similar experiences to share support and friendship. Taking part in a group may help you come to terms with what is happening to the person you care for, as well as giving you ideas on how best to help and how to take care of yourself.

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

You may still find a general group helpful and there are also groups specifically for people caring for someone with cancer.

The GP, specialist nurse or Macmillan nurse (see page 56) will know what groups are available locally. Macmillan Cancer Support have information about cancer support groups.

“Try to speak to someone who has experienced the same thing. Only they know how you feel. There are no right or wrong feelings.”

CARERS’ ORGANISATIONS

There are organisations that offer information and support specifically for carers, including emotional support. As well as these national organisations there are many carers’ centres around the UK that are run by charities and provide free support for carers. You can search online, on the Carers Trust website, or ask your local council if there’s a carers’ centre in your area. See page 59 for details of carers’ organisations.
**COUNSELLING**

It can be emotionally draining when someone you’re close to has pancreatic cancer. People often find their own ways of coping, from talking to a close friend or getting some exercise. But if you need some extra support you may find counselling helpful.

Counselling gives you a safe place to come to terms with your feelings and perhaps develop some coping strategies. You may be able to find a counsellor or psychotherapist who specialises in supporting carers through your GP, hospital or hospice. Hospices can support you in a variety of ways, and don’t just provide care for people at the end of their life (see page 42). Or try the Counselling Directory (see page 60 for details).

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

**SUPPORT FOR CHILDREN**

You may be in the position of needing support for children or grandchildren as well as yourself.

For most children and teenagers the best thing is to be honest and talk to them as much as possible about what’s going on. Many people find that telling children that a parent or grandparent has cancer is easier than they expected it to be. You may find Macmillan Cancer Support’s booklet, Talking to children and teenagers when an adult has cancer, helpful (see contact details on page 60).
Storybooks about someone being ill may be helpful for younger children – your local library might be able to help. Teenagers may find it easier to talk to their friends or another adult outside the family, or find support online. For example www.riprap.org.uk is a dedicated website for teenagers who have a parent with cancer.

Again, there is professional support available, such as specialist palliative care nurses (see page 41) or local charities, so don’t be afraid to ask for help.

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

“I was in shock the whole time. Numb, not ready to lose my mother. I remained cheerful when I was with her, suggesting things we could do or watch on TV. I collapsed in tears when I turned the first corner home. I have no other family so I had to do it alone.”

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

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

This section outlines what pancreatic cancer is, gives an overview of how it is treated and where, and signposts to our more detailed information. It also explains what to do if you have any concerns about someone’s care.

WHAT IS THE PANCREAS?

The pancreas is a large tadpole-shaped gland (about 15cm long) that lies behind the stomach in the back of the abdomen, surrounded by several large and important organs and blood vessels.

Pancreas with surrounding organs
The pancreas makes enzymes that help break down food so the body can absorb nutrients. It also makes hormones including insulin, which helps to control the amount of sugar in the blood.

**WHAT IS PANCREATIC CANCER?**

Normal healthy cells grow in a carefully controlled way. Pancreatic cancer happens when cells in the pancreas grow out of control, forming a tumour.

Pancreatic cancers are divided into two main groups.

- Exocrine tumours start in the enzyme producing cells. More than nine out of ten pancreatic cancers (95%) are exocrine tumours. About nine out of ten (90%) of these are called pancreatic ductal adenocarcinomas (PDAC).
• Endocrine tumours (also called neuroendocrine tumours) start in the hormone producing cells in the pancreas. Only about five out of one hundred (5%) of all pancreatic cancers are endocrine cancers.

Within these two groups there are many different types of pancreatic cancer that behave differently, produce different symptoms and are treated differently.

Read more about the different types of pancreatic cancer on our website at www.pancreaticcancer.org.uk/types

HOW IS PANCREATIC CANCER TREATED?

Treatment for pancreatic cancer depends on the specific type of pancreatic cancer, whether it has spread and how far, and where it is in the pancreas. It will also depend on the person’s age, general health and fitness.

Treatment may not cure the cancer, but it can slow down the growth of the cancer, and help manage symptoms and improve the quality of people’s daily life.

Treatment options may include:

• surgery – to remove the cancer if the tumour is small, or surgical procedures to help manage symptoms

• chemotherapy – one of the most common treatments for pancreatic cancer, it won’t cure the cancer but may help slow down its growth and help relieve symptoms
- **radiotherapy** – for people with locally advanced cancer, it may be given together with chemotherapy (chemoradiotherapy) to help control the cancer and slow its growth. It may also be used for pancreatic cancer that has spread to other parts of the body to control symptoms.

You can read more about the different treatments on our website at [www.pancreaticcancer.org.uk/treatments](http://www.pancreaticcancer.org.uk/treatments)

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**FINDING OUT MORE**

You can read more detailed information about pancreatic cancer diagnosis, treatment and care on our website at [www.pancreaticcancer.org.uk](http://www.pancreaticcancer.org.uk)

You may also want to download or order our booklet for people who have recently been diagnosed – Pancreatic cancer: an overview of diagnosis and treatment.

You can also call our Support Line free – our specialist nurses can answer your questions and send you information by post.

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

> “After the initial shock it was time to get on with the business of caring for my daughter, so there was a sense of being on auto pilot and staying very practical. My feelings constantly fluctuated from flickers of hope to total despair.”
MANAGING SYMPTOMS AND SIDE EFFECTS

Every person with pancreatic cancer is an individual. The symptoms they get will be different and will occur at different stages of their cancer. It can help if you know about the key symptoms people get, what to do about them and where to turn if you need help.

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

WHAT ARE THE KEY SYMPTOMS I NEED TO BE AWARE OF?

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

PAIN

Abdominal pain is a symptom in about 70% of pancreatic cancer cases. It often starts as general discomfort or pain in the abdomen
(tummy) which can spread to the back. It can be worse after eating or when lying down. Sitting forward can sometimes relieve the pain. The pain is often worse at night, interfering with sleep and leading to tiredness. At first the pain may come and go, but over time it may become more constant. The abdomen (tummy) may also be tender to touch, which may be because some of the organs (pancreas, liver or gall bladder) in the abdomen are inflamed or enlarged.

Pain may be caused by the cancer affecting nerves or organs near the pancreas. It can also be due to the tumour causing a blockage in the stomach or duodenum (top part of the small intestines).

Pain in the upper back (not the lower back) can occur due to the pressure of the tumour on the nerves around the pancreas. Pain caused by problems with nerves is called neuropathic pain. Neuropathic pain can come and go and can be difficult to describe. People use words like burning, shooting, tingling, stabbing or pins and needles to explain how it feels.

Sometimes people think that pain is a part of having cancer and that they just have to put up with it, but this isn’t the case. Most types of pain can be well controlled with different types of painkillers as long as they’re taken properly.

Where pain is caused by large tumours pressing on other organs or structures such as nerves or the spine, radiotherapy is particularly good at controlling and relieving pain. The radiotherapy can shrink the cancer, relieving the pain. Sometimes a procedure called a nerve block (coeliac plexus nerve block) may be used to relieve pain by destroying the nerves that supply the pancreas.

We have information about radiotherapy and nerve blocks on our website at www.pancreaticcancer.org.uk
If pain is a concern, talk to your specialist nurse or palliative care team who are experts in pain relief (see page 41). You can also call our specialist nurses on our free Support Line.

**DIETARY-RELATED SYMPTOMS**

It’s common for people with pancreatic cancer to have symptoms that cause problems with eating and digesting food. These can include loss of appetite, weight loss, sickness, and changes to bowel habits. Some people may also develop diabetes.

Finding ways to manage dietary-related symptoms can help your family member feel better generally. One of the most effective ways of controlling these symptoms is pancreatic enzyme supplements that help to break down food. This is known as pancreatic enzyme replacement therapy (PERT).

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

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

The MDT team at the hospital should include a dietitian. They can check any dietary-related symptoms and offer advice to help manage them. They will give nutritional advice and tips on boosting calorie and protein intake. If your family member hasn’t seen a dietitian and is having problems, ask their specialist nurse or GP to refer them to one.

If you’re shopping or preparing meals for someone with these symptoms, tips to help them enjoy eating might include serving small snacks rather than big meals if they have a poor appetite.
Or adding cream or cheese to foods if they need more calories because they’ve lost weight.

You’ll find plenty of information on common dietary-related symptoms, the use of pancreatic enzyme supplements, nutritional supplements and diet in our Diet and pancreatic cancer booklet, which is available on our website, www.pancreaticcancer.org.uk/publications

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

NAUSEA AND SICKNESS

Nausea (feeling sick) and vomiting (being sick) can occur for several different reasons.

If a tumour blocks the bile duct, this can cause inflammation of the pancreas and possibly jaundice, resulting in nausea and issues with appetite and digestion. A stent (a hollow tube) may be inserted into the bile duct to relieve the blockage, which should also relieve the symptoms. Symptoms of jaundice, such as yellow skin and eyes, and itching, should also improve.

Sometimes a tumour can press on the duodenum (the first part of the small intestines), stopping food passing out of the stomach into the bowel. This usually causes vomiting, which can lead to dehydration and an imbalance of minerals and salts in your body if it carries on (see page 28 for information about persistent vomiting). A stent can be inserted to open up the blockage, allowing the stomach contents to empty into the bowel. The vomiting should settle down.
Nausea and vomiting can also be a side effect of chemotherapy or radiotherapy treatment.

There is a range of anti-sickness medication available, so your family member should talk to their specialist nurse or doctor about their symptoms, so they can work out the most suitable type.

Other things that might help include:

- **ginger** – such as fizzy ginger ale, fresh ginger grated in hot water or crystallised stem ginger
- **peppermint** – such as mints or tea made with fresh mint or peppermint teabags
- **sucking sweets or sipping fizzy drinks** – make sure they are sugar-free to avoid problems with teeth and gums
- **acupressure bracelets such as Sea-Bands** – these apply pressure to specific points on the inside of the wrist, which can help to relieve nausea
- **eating something** – nausea is usually worse on an empty stomach.

**CHANGES TO BOWEL HABITS**

Many people with pancreatic cancer will notice changes in their bowel habits. This may be either constipation (problems opening the bowels), due to some of the pain relief medications, or sometimes loose stools or even diarrhoea (loose watery stools).

Some people experience a symptom called steatorrhoea (stools that are large, pale, oily, floating and smelly). This happens because the cancer affects the production of the enzymes needed to digest food, particularly high fat food. Undigested food passing quickly through
the body can also cause diarrhoea and result in weight loss. Taking pancreatic enzyme supplements (see page 19) can help to relieve these symptoms.

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

**FATIGUE**

Fatigue is the term given to extreme tiredness. It may be caused by the cancer itself, be a result of symptoms caused by the cancer, or be a side effect of treatment such as chemotherapy. People can feel tired or exhausted for much of the time.

You might want to keep a fatigue diary, so you can see for example when your family member has more energy to do things. This may be important if they are having chemotherapy so you can change activities around the days when they are feeling better, and allow them to rest on days when they are more tired than normal.

Keep a note of how it affects your life too – it can be useful to take to appointments to discuss how it can be managed best.

Macmillan Cancer Support produce a useful booklet called Coping with fatigue. You can download or order it for free from their website (see page 60 for contact details).
When someone has cancer and is facing an uncertain future, feelings of anxiety can become overwhelming and can trigger depression. It can be hard to separate how someone is feeling from the effects of their illness, but if your family member feels low for most of the day, lacks energy and has problems sleeping at night, they may be depressed.

Depression can be managed successfully with anti-depressant drugs or through counselling. Counselling can provide a safe place for people to come to terms with their feelings and develop some coping strategies. Hospitals and hospices often have counsellors or psychotherapists who specialise in cancer. Or the Counselling Directory provides details of qualified counsellors (see page 60).

If you think your family member may be depressed then you may want to encourage them to talk to their GP, specialist nurse or Macmillan nurse about getting some help.
ARE THERE ANY SYMPTOMS THAT NEED URGENT MEDICAL ATTENTION?

Some symptoms do need urgent medical help. We've listed some of the main symptoms that need to be treated urgently. If you think the person you're caring for needs urgent help, call any emergency contact numbers you've been given, take them to A&E, or call 999 and ask for an ambulance – don’t worry that you’re being a nuisance.

BLOOD CLOT IN A VEIN (DEEP VEIN THROMBOSIS OR DVT)

If a blood clot forms inside a vein, it can block the vein and reduce or prevent blood flow. It often occurs in deep veins, and this is known as deep vein thrombosis (DVT). DVT is most common in the lower leg (calf), thigh or pelvis. A part or all of the blood clot may come free and travel to the lungs. This is called a pulmonary embolism (PE). It isn’t common but it can be very serious.

People with pancreatic cancer, especially those with advanced or metastatic cancer (cancer that has spread beyond the pancreas to other parts of the body), are at higher risk of DVT.

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

• pain, swelling or tenderness in the leg (or calf)
• warm skin or redness in the affected area
• heavy ache in the affected area.

Symptoms of pulmonary embolism include:

• shortness of breath
• pain in the chest (especially when breathing in)
• coughing up blood.
Most blood clots can be successfully treated so it is important to contact the medical team or GP urgently, or go straight to A&E.

Read more about blood clots at [www.pancreaticcancer.org.uk/dvtrisk](http://www.pancreaticcancer.org.uk/dvtrisk)

**NEUTROPENIC SEPSIS**

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

Signs of infection include a high temperature, headache, lethargy and generally feeling unwell. You need to check the temperature of the person you’re caring for. If it is 37.5°C or 38°C or above (depending on the advice you’ve been given) you should phone the emergency contact number they will have been given.

If this is out of normal hospital hours and you can’t contact any of the team on the emergency number, go to your local A&E. Tell the receptionist that the person you’re caring for is having chemotherapy – this is important so that they aren’t exposed to other sick patients in the waiting area who may have infections.

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

Hollow plastic or metal tubes called stents are sometimes inserted to relieve a blockage in the bile duct caused by the cancer.

The bile flows more slowly through the stent and this can encourage bacteria to travel up the stent from the bowel and cause an infection. This might be an infection of the bile duct (acute cholangitis) or an infection in the blood (septicaemia).

Signs of an infection can include:

- feeling unwell
- lethargy
- vomiting
- pain
- fever
- shivering
- yellowing of the eyes (a sign of jaundice).

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

If the person you’re caring for has signs of an infection take them to A&E or call an ambulance. If they are on chemotherapy they will have an emergency number to call, which can help avoid delays.
PERSISTENT VOMITING

Persistent vomiting is a clear sign that something is wrong, though it can have a variety of causes. If someone has been vomiting for half a day or longer and can’t keep down any food or fluid, there's a risk of dehydration. This is especially a concern when someone is diabetic.

Your family member will probably need to be admitted to hospital for intravenous fluids (into a vein) and to find out the cause of the vomiting. Take them to A&E or call an ambulance. If they are on chemotherapy they will have an emergency number to call, which can help avoid delays.

GASTRIC OUTLET OBSTRUCTION

Gastric outlet obstruction happens if the tumour is pressing on the pylorus, which is the opening of the stomach into the duodenum (first part of the small intestine). It causes vomiting because food builds up in the stomach as it can’t pass into the duodenum.

The vomiting can result in dehydration, and is of particular concern when someone is diabetic. They may need to be admitted to hospital for intravenous fluids into a vein. They may also need to have a hollow tube called a duodenal stent inserted to open up the duodenum.

If your family member has been vomiting for half a day or longer this needs attention. Call their GP or specialist nurse, or the chemotherapy emergency number (if they are on chemotherapy). If you can’t access any support or advice, take them to A&E or call an ambulance.
SHOULD I EXPECT DIFFERENT SYMPTOMS AT DIFFERENT STAGES?

Every person with pancreatic cancer is different. They react differently to their illness and respond differently to treatment. Different types of pancreatic cancer also behave very differently. So it’s almost impossible to know what symptoms to expect, and at what stage to expect them.

When you see someone all the time, it can be difficult to notice new or different symptoms, as changes can happen gradually. The person you’re caring for may just say that they don’t feel well or that something isn’t quite right, rather than anything more obvious. They might be feeling nauseous, a bit more tired, or just a bit down. So don’t be surprised if someone else picks up something that you haven’t necessarily noticed. It might just be that they haven’t visited for a while.

The most important thing is to know that most symptoms can be relieved – for example nobody should have to put up with pain. So if you have any concerns about symptoms, talk to the GP, medical team, district nurse or Macmillan nurse.

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

“We didn’t really know what to expect in terms of symptoms at different stages. It seems the nature and progression of symptoms like pain varies with every patient.”
How can I help with managing symptoms and side effects?

One of the best ways you can help is by knowing what symptoms your family member might get, and what to do or who to ask for help.

- Read and download more detailed information about pancreatic cancer symptoms and side effects on our website – [www.pancreaticcancer.org.uk](http://www.pancreaticcancer.org.uk)

- 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. Email [support@pancreaticcancer.org.uk](mailto:support@pancreaticcancer.org.uk) or call on 0808 801 0707.

- Talk to the GP or nurse – either the district, Macmillan or specialist nurse (see page 40), depending on who your family member sees. It can be helpful to keep a note of any problems or concerns when they happen so that you can ask about them later.

- Make sure you can quickly find any emergency or out of hours contact numbers you've been given (for example, you can make a note of them on page 58).

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

“Nothing about any of my daughter’s symptoms was too much trouble for me – I just didn’t want her to suffer.”
THE MEDICAL TEAM AND HEALTHCARE SYSTEM

It can be difficult to work out how to get the care and support your family member needs, especially if you’ve never had to do it before. If you’re not sure what to do then your first port of call is the specialist nurse, keyworker or consultant in the multidisciplinary team responsible for your family member (see page 33).

If you don’t have any contact details or aren’t sure who to call, then phone our specialist nurses, as they can guide you.

It’s useful to know that as long as the person you’re caring for gives their GP and healthcare team permission, either verbally or in writing, you can talk to them about their treatment and care.

WHERE IS PANCREATIC CANCER TREATED?

In the UK anyone diagnosed with pancreatic cancer should have their case reviewed at a cancer centre where there is a specialist team to assess and treat pancreatic cancer. This is called a multidisciplinary team (MDT) – see page 33. In particular, surgery should only be carried out in specialist centres as research has shown that this gives patients the best outcomes. There are specialist centres across the UK.

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

There is a list of hospitals with specialist pancreatic teams on our website – [www.pancreaticcancer.org.uk/specialistcentres](http://www.pancreaticcancer.org.uk/specialistcentres)

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**THE MULTIDISCIPLINARY TEAM (MDT)**

The multidisciplinary team (MDT) is the team of medical professionals responsible for your family member’s treatment and care. You probably won’t meet most of them, but they will meet to discuss the cancer and treatment options. The MDT will use their expert knowledge, together with national guidelines for pancreatic cancer treatment, to agree on the best treatment. They should also take the patient’s wishes into account.

The health professionals most likely to be involved are the gastroenterologist and oncologist. But others, such as a dietitian, will be involved if necessary. See page 55 for more information about these health professionals.

Your family member will be given a main contact, who will usually be a specialist nurse (either a hepatobiliary or upper gastrointestinal nurse specialist). They will support your family member and you, and will be the person you speak to most. They will also be a part of the MDT, and will let the MDT know how your family member is getting on.

There is space on page 54 to note down the names and contact details of the health professionals you have most contact with.
If you have any problems getting the care your family member needs, or questions about who to speak to, call our specialist nurses on our free Support Line.

“We were well informed and supported. We had a long consultation with the consultant and the specialist nurse, then we saw the dietitian which was really helpful. This was in the regional unit. We were then seen by the oncologist and specialist nurse at our local hospital, and referred to the hospice for support.”

QUESTIONS TO ASK

- Who are the members of the MDT for the person I’m caring for?
- Does the person I’m caring for have a specialist nurse? How do we contact them?
- How do we access community services if the person I’m caring for leaves hospital?
WHO DO I CALL OUT OF NORMAL HOSPITAL HOURS OR IN AN EMERGENCY?

You will normally be given a name and contact number if you need to talk to someone out of normal hospital hours (there’s space to make a note of it on page 58).

If your family member is having chemotherapy they will have been given an emergency contact number to phone. For example, you should call if their temperature goes above 37.5°C or 38°C (depending on the advice you’ve been given by your chemotherapy team), which could be a sign of an infection (see page 26).

In the case of any other emergency you should take the person you care for to A&E, or call 999 and ask for an ambulance.

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

HOW DO WE GET A SECOND OPINION?

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

A second opinion is free on the NHS or can be paid for privately. Asking for a second opinion won’t affect someone’s care. But it can take time, so it is a good idea for people to start any treatment offered while going through the process, rather than delaying treatment.
Think about what getting a second opinion might mean before asking for one. For example, if the two consultants agree it may make you feel more confident. But if a different treatment is offered you might worry about which treatment to choose.

If your family member agrees, you can request a second opinion on their behalf. You will need to ask their current consultant for a referral for a second opinion – most will be happy to do this if it will be helpful. If you have any difficulty in getting the person you’re caring for referred, you can try talking to the Patient Advice and Liaison Service (PALS) at your local hospital. (See page 37 for more information about PALS.)

NHS Choices has more information about getting a second opinion. You can also look at the cancer services directory on the My Cancer Treatment website to find cancer services near you and the quality of care you can expect. These might be useful if your family member wants to be treated somewhere else. See page 61 for contact details.

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

**WHAT DO WE DO IF WE HAVE ANY CONCERNS ABOUT CARE?**

If you have any concerns about the NHS care being given to your family member, then talk to the consultant, specialist nurse or keyworker first. It’s important to raise any concerns you have. Don’t be worried that speaking up will affect future treatment and care.
If that doesn’t improve the situation you may want to talk to someone from PALS – the Patient Advice and Liaison Service. Their advice and support is confidential. You can contact them at your local hospital. Find information about PALS on the NHS Choices website (see page 61).

With private healthcare, again you should talk first to the consultant, specialist nurse or key worker about your concerns. If the situation isn’t sorted out you will need to ask the hospital manager about their complaints procedure.

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

“I felt very well supported throughout my husband’s illness, and felt the care he received was outstanding. The shock and horror of the initial diagnosis wore off and I made a decision to deal only with “definites”, and not worry about things like possible side effects unless they happened.”
HELP AND SUPPORT IN THE COMMUNITY

Many people live a long way from their local hospital so it’s important to be aware of local services that can support you and the person you’re caring for. In this section you’ll find information on the health and care services that are mostly based locally in the community rather than in hospital, together with details of the range of practical support available.

COMMUNITY-BASED SUPPORT

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

These community-based services also frequently offer access to practical support, such as equipment. There is detailed information on the practical help that’s available on page 46.

It can sometimes take a while to get services organised, so try to find out what’s available in your area before you need it. The information here should give you some guidance on what sort of support is available and how to access it. If you’re not sure where to start then your GP might be the best person to talk to first.
WHAT HAPPENS WHEN SOMEONE IS DISCHARGED FROM HOSPITAL?

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

It’s a good idea to ask about this well before they are discharged, if it hasn’t already been discussed. The first stage is usually an assessment by the community nursing service (see below) or the occupational therapy team in the hospital.

COMMUNITY NURSING SERVICE

If your family member needs nursing support at home, this is most likely to come from the community nursing service. Community nursing teams include different specialist staff, but the ones you are most likely to see are:

- **district nurses** – who deliver nursing care in people’s homes, including giving medication and pain control.

- **community matrons** – senior nurses who work with patients with serious or complex conditions.

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

Nurses will generally visit during the day, but there will be a team on duty in the evenings and at night, so it should be a 24-hour service. Make sure you know the number to contact the team out of normal hours – you can make a note of it on page 58.
People should be given advice about the community nursing service before they are discharged from hospital (see page 40). If your family member is at home and needs nursing support, ask the GP to organise an assessment by the community nursing team, or to give you the phone number so you can contact the team directly.

“Once the district nurses were assigned they were really good at coming and checking dad. They dressed the bed sores he’d come out of hospital with.”

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

**SPECIALIST NURSING SUPPORT**

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

It’s a good idea to ask to be put in touch with a nurse early on, as they can be a great help. For example, if you or your family member want to discuss how to manage a particular symptom, or how to go about getting extra help at home. The simplest thing to do is ask the
GP or keyworker to refer your family member. The nurse will usually do an initial assessment, then follow-up visits depending on the individual situation.

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

**HOSPICES**

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

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

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

- **In hospices** – which can offer services such as day care, respite care, a massage or just a cup of tea and a chat. People may also stay as inpatients for 7-10 days, for example to control symptoms such as pain, nausea or vomiting.

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

- **In hospitals** – by hospital-based palliative care teams.

Most people are referred for hospice care by their GP, district nurse or Macmillan or palliative care nurse. Ask them what hospice services are available locally.

Hospice UK has details of hospice services in your area (see page 60 for contact details). Or call your local hospice to ask about their services.

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

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

**SOCIAL CARE AND HOMECARE**

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

**SOCIAL SERVICES**

Your family member may be eligible for support from your local council’s social services department. The first thing social services must do is work out what their care needs are by doing a community care assessment. If you are doing a lot of caring for your family member, social services must also carry out a carer’s assessment to find out what your needs are. They have a legal duty to do these assessments. Getting services can take time and persistence so it’s a good idea to start the assessment process as soon as possible – contact the social services department at your local council.

Once the assessments are done, the council will decide whether or not they will provide any community care services. They will look at whether your needs and your family member’s meets the criteria for getting support.

If you do meet the criteria, social services may provide services such as:

- **care at home** – for example, help from care workers, aids and equipment
- **care away from home** – for example, respite care or day centre care to give you a break from looking after your family member
- **housing** – for example, adaptations or disabled parking bays.

Services may be provided:

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

You or your family member may have to pay something towards the care. This will depend on what the service is and your financial circumstances. Social services will do a financial assessment to work this out. If you do need to contribute and money is tight then grants are sometimes available from local charities – ask social services for details of any in your area.

PRIVATE CARE

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

The social services department should give you information about finding local support services and care providers. Or you may be able to get a recommendation from someone you know locally.

Homecare providers are regulated throughout the UK, although the regulators are different in England, Scotland and Wales. For lists of care organisations and reports on their services, have a look at the Carers UK website (see page 59 for details).

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

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

There is a wide range of practical support available – for you as a carer, as well as for the person you care for. Practical support might include equipment to help you care for someone at home, or benefits and financial support. You can find details of organisations that provide information and advice to help you get services and any financial help or benefits you may be entitled to on page 59.

If you’ve got family or friends who want to help, don’t hesitate to ask for specific things – such as a lift to hospital, shopping or cooking, or spending time with the person you care for to give you a break.

BLUE BADGE SCHEME

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

You can apply for a Blue Badge on behalf of the person you care for and they don’t have to be the driver to qualify. The Blue Badge scheme is run by your local council. You can apply online at GOV.UK (see page 60).
HOSPITAL PARKING AND DISCOUNTS

Most hospitals charge for parking, which can become expensive if you often need to take your family member to hospital, such as for daily radiotherapy treatment.

However, the government published guidance in August 2014 advising hospitals to offer parking concessions, including free or reduced charges for some people, including:

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

So ask what the situation is at your hospital – you may even want to refer to the guideline. It’s available on the GOV.UK website (see page 60 for details).

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

TRAVEL TO HOSPITAL

If you drive your family member to hospital, you may find it becomes tiring – for example, if they’re having daily radiotherapy. You might be able to share this with other friends or relatives.

If your family member is relying on public transport or lifts from other people, they may be able to arrange their appointments to suit, though this isn’t always possible. Some hospitals provide transport,
as do local charities and support groups, so if they need help ask what is available locally.

If you are finding the cost of frequent travel to hospital very high, you may be able to get financial help. Ask the hospital staff for information on grants that might be available. Or get in touch with Macmillan Cancer Support (see page 60) for information about any financial support that may be available.

**EQUIPMENT AND ADAPTATIONS**

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

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

If you would like the council to supply the equipment they will do a financial assessment to see if you need to pay for the equipment or installing it. See page 44 for more information about social services. Many hospices have therapy departments that provide similar assessments and access to equipment.

If the person you’re caring for only needs special equipment for a short time, such as while recovering from surgery, then the hospital or district nurse will usually supply equipment for as long as it’s necessary. Often, voluntary organisations or charities like the Red
Cross will lend equipment such as wheelchairs or commodes (a portable toilet so that your family member doesn’t have to go to the bathroom if they have trouble moving around).

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

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

**FINANCIAL SUPPORT**

Financial issues probably won’t have been the first things you thought about when your family member was diagnosed with pancreatic cancer. But looking after someone with cancer can have a big impact on your finances – which you may not have expected.

For example, looking after your family member may mean you can’t work, or can only work part time, so money may become an issue, even if this is only temporary. And if the person you’re caring for has to stop work, pay for travel to and from treatment sessions, or needs a special diet, the effect on the household budget can be considerable.

You may be eligible for Carer's Allowance, which is the main benefit for carers. To qualify you need to meet all the criteria:

- you must be 16 years old or over
• you must care for someone for at least 35 hours a week
• the person you care for must receive a qualifying disability benefit, such as Disability Living Allowance (DLA)
• if you work, you must not earn over £102 a week (after tax and care costs while you’re at work)
• you must not get certain other benefits, such as the state pension
• you must have been in England, Scotland or Wales for at least two of the last three years
• you must normally live in England, Scotland or Wales, unless you’re a member of the armed forces
• you must not be a full-time student.

Even if you don’t qualify for Carer’s Allowance, it may still be worth applying because if you are on a low income it can give you access to other benefits, such as Housing Benefit to help with rent.

Dealing with your financial situation is important so it doesn’t become a source of stress. If you can, try to sort things out before they become a problem. There’s lots of help available. Carers UK, Carers Trust, Citizens Advice and Macmillan Cancer Support can all give expert information and advice on work-related issues, benefits and financial matters – contact details are on page 59.

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

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

When social services carry out a carer’s assessment (see page 44) they should consider the impact the care and support you provide is having on your health and your life.

Carers are often so busy with their caring role that they forget about their own health. There are various examples of support that may help:

• short breaks or respite care
• the right to request flexible working from your employer
• counselling for emotional support
• an emergency plan in the event of you not being able to provide care.

Your local council should have somebody with responsibility for carers who you can talk to about different types of support that may be available for you as a carer.

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

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

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

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

**Diarrhoea:** passing loose watery stools (poo).

**Dehydration:** this happens when your body loses more fluid than you take in. It might happen if someone has persistent vomiting or diarrhoea.

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

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

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

**Pancreatic enzyme replacement therapy (PERT):** pancreatic enzyme supplements that can be taken to help break down food.

**Steatorrhoea:** stools (poo) that are large, pale, oily, floating and smelly. This can be a symptom of pancreatic cancer. It happens because the cancer affects the production of the enzymes needed to digest food, particularly high fat food.

You can find more medical words in our Medical A-Z fact sheet on our website – [www.pancreaticcancer.org.uk/publications](http://www.pancreaticcancer.org.uk/publications)
USEFUL INFORMATION

IMPORTANT NAMES AND NUMBERS

Use this space to record the names and numbers of the key professionals involved.

MULTIDISCIPLINARY TEAM (MDT) MEMBERS

The MDT is the team of medical professionals responsible for your family member’s treatment and care (see page 33).

Keyworker

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

Name:
Telephone:
Email:
Notes:

Specialist Nurse

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

Name:
Telephone:
Email:
Notes:
**Gastroenterologist**  
A doctor who treats diseases of the digestive system, including the pancreas.

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

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**Surgeon**  
A doctor who carries out surgery.

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**Dietitian**

A professional who provides expert advice about diet, including how to manage the dietary symptoms of pancreatic cancer.

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**COMMUNITY TEAM**

**NURSES**

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

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

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## Nurse

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## Social services contact

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

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

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**Out of hours/emergency contact**

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USEFUL ORGANISATIONS

British Red Cross
www.redcross.org.uk
Telephone: 0844 871 1111
Provides a range of support including lending medical equipment, support at home and help with transport.

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

Carers Direct
Helpline: 0300 123 1053 (Mon-Fri 9am-8pm, weekends 11am-4pm)
Confidential information and advice for carers from the NHS. Interpreted calls available in 170 different languages.

Carers Trust
www.carers.org
Email: support@carers.org
Information, advice and practical support for carers.

Carers UK
www.carersuk.org
Adviceline: 0808 808 7777 (Mon-Fri 10am-4pm)
Expert advice, information and support for carers, including benefits checks, carers employment rights, services available for carers and any financial and practical matters related to caring. Also provide access to information about care organisations.
Citizens Advice
www.citizensadvice.org.uk
Telephone: England 03444 111 444; Wales 03444 77 20 20;
Scotland 0808 800 9060
In person at your local Citizens Advice Bureau.
Provide information and advice on a range of issues including work,
benefits, NHS healthcare and patient rights.

Counselling Directory
www.counselling-directory.org.uk
Telephone: 0844 8030 240 (Mon-Fri 9am-5pm)
Information about counselling, and a list qualified counsellors.

GOV.UK
www.gov.uk
Provides information about government services, including
information about benefits, transport, money and guidelines for
hospital parking.

Healthtalkonline
www.healthtalk.org
Personal experiences presented in written, audio and video formats.

Hospice UK
www.hospiceuk.org
Telephone: 020 7520 8200
Information about hospices, and a directory of hospices in your area.

Macmillan Cancer Support
www.macmillan.org.uk
Support Line: 0808 808 00 00 (Mon-Fri 9am-8pm)
Provides practical, medical and financial support for anyone affected
by cancer, including family members.
Maggie’s Centres
www.maggiescentres.org
Centres around the UK, and online. Offer free, comprehensive support for anyone affected by cancer.

Marie Curie
www.mariecurie.org.uk
Support Line: 0800 090 2309 (Mon-Fri 9am-5pm)
Provide care and support to people with a terminal illness and their families, including nurses and hospices.

My Cancer Treatment
www.mycancertreatment.nhs.uk
Directory of cancer services in England. Allows you to find and compare cancer services in your area.

NET Patient Foundation
www.netpatientfoundation.org
Call free on 0800 434 6476
Information and support for people with neuroendocrine tumours (NETs).

NHS 24
www.nhs24.com
Telephone: 111
Out of hours service for Scotland. Provides health information and advice, and you can search for local services.

NHS Choices
www.nhs.uk
Provides information about different health conditions, living well and care and support, and allows you to find services in your area.
**NHS Direct Wales**
www.nhsdirect.wales.nhs.uk
Telephone: 0845 4647
Health information in Wales, including local services.

**NICan (Northern Ireland Cancer Network)**
survivorship.cancerni.net
Information about services in Northern Ireland to support people with cancer and their families.

**nidirect**
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
Website for teenagers with a parent with cancer. It provides information about cancer, real life stories, and support.
This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK. It has been reviewed by healthcare professionals and people affected by pancreatic cancer.

References to the sources of information used to write this booklet and an acknowledgement of the health professionals who reviewed the booklet are available on our website – www.pancreaticcancer.org.uk

Pancreatic Cancer UK makes every effort to make sure that its services provide up-to-date, unbiased and accurate information about pancreatic cancer. We hope that this information will add to the medical advice you have received and help you to take part in decisions related to treatment and care. Please do continue to talk to the doctor, specialist nurse or other members of the care team if you are worried about any medical issues.

Give us your feedback We hope you have found this information helpful. If you have any comments or suggestions about this booklet or any of our other publications you can email us at publications@pancreaticcancer.org.uk or write to the Information Manager at the address on the back cover.

The photographs in this booklet are of people affected by pancreatic cancer, including family members.