

Pancreatic Cancer UK

Pancreatic cancer and end of life care

Information for people in the
last few months, weeks or
days of life



Introduction

This booklet is for people with pancreatic cancer, their family, friends and carers who want to know more about what may happen in the last few months of life. It includes information about the symptoms people with pancreatic cancer may get towards the end of their life and how to manage these. There is also information about how to get the care and support you might need, dealing with the emotional impact of dying from pancreatic cancer, and specific information for family members.

You may find some of this information upsetting or difficult to read. Not all of it may be relevant to you at the moment and you may want to come back to it later. The booklet has been designed so that you can get the relevant information when you need it.

People with pancreatic cancer may have a group of people around them who support them, such as a partner, family members and friends. When we talk about family, friends or carers in this booklet, we mean anyone who is close to you or helping to care for you (who is not a professional).

If you have any questions about anything you read in this booklet, speak to your doctor or nurse. You can also speak to our specialist nurses on our confidential Support Line. This can be a very difficult time and they can answer your questions and talk through any worries you may have. They can also support families and carers.



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

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Section 1

Coping with the news that you are dying

It can come as a huge shock to be told that your cancer can no longer be treated and that you are approaching the last few months or weeks of your life. It is natural to find it difficult to deal with what this means for you and your family and friends. This section has information about how to get emotional support if you need it.



Pancreatic cancer can grow and spread quickly. You may feel you haven't had much time, if any, to come to terms with being diagnosed with pancreatic cancer before being told that you may only have a few months or weeks to live. There's no right way to feel, and you may have a range of emotions. You may also be worrying about what will happen to you over the coming months and weeks and how you and your family will cope.

You may want to know how long you have left to live, or what will happen as you approach the end of your life. If you do want to know more, speak to your doctor. It's often difficult for doctors to give you a clear timescale, but they may be able to give you some information about your situation. Or you may prefer not to know and live each day as it comes. The doctors will respect this decision. You may want to discuss things with your family as they might want different information from you. If you wish, you can give the doctors permission to speak to your family and answer their questions without you being present.

There are people who can support you if you're struggling to cope with your feelings. It can be difficult to make sense of what is happening, and it is ok to ask for help. Your family may also need help dealing with how they are feeling, and the support described here is also available for them.

Getting support

You may find it comforting to talk to family or friends about how you are feeling. But these can be difficult conversations, and some people find it easier to talk to people outside their family or friends. For example, some people find it helpful to speak to a spiritual leader, either religious or non-religious. Or you could talk to a member of your healthcare team – they will be able to provide emotional as well as medical support. They should also know about any services locally that can help. Read more about the health professionals who may be involved in your care on page 15.



Our specialist nurses on our free Support Line also provide emotional support, and you can discuss your worries with them. The Support Line is open Monday-Friday, 10am-4pm.

Call free on **0808 801 0707**,
or email **nurse@pancreaticcancer.org.uk**

Some people find it helpful to talk to a counsellor. Counselling can help you find ways to cope with how you are feeling. It is confidential so you can be honest about how you feel without worrying that you may upset other people. Your local hospice or hospital may offer counselling, and some hospices have counsellors who can visit you at home. Speak to your GP or nurse about what counselling is available.

Hospices and local cancer centres may also provide free emotional support. For example, they may run support groups, where you can meet other people with cancer that can't be cured. Read more about hospices on page 16. Speak to your GP or nurse about what's available locally.

You could also join our online discussion forum to talk to others in a similar situation.



Find out more about our online forum and other services that can support you and your family at **pancreaticcancer.org.uk/getsupport**

? Questions to ask

Who can I talk to about my worries?

What support is there to help me cope emotionally?

How can a counsellor help? Can you refer me to one?

What services locally can help?

How long do I have to live?

How will I know when I only have a few weeks or days to live?

“My partner was diagnosed just before Christmas so there was a period of limbo where we really felt we had no one to talk to. This is when I found the Pancreatic Cancer UK website. Later I found the discussion forum and the Support Line. I cannot stress too much how valuable I found both of these. My partner preferred not to use these resources himself but always wanted to know what information I’d got from them. It definitely helped both of us to know that we weren’t the only people going through this.”

“My partner and I didn’t talk much about his feelings about the future, as we preferred to live in the here and now. But he found talking to a counsellor a huge help.”

More information and support

Macmillan Cancer Support and Marie Curie both offer a range of support and information for people at the end of life, including emotional support. They have produced a booklet together, called **End of life: a guide**, which describes some of the things you may need to deal with in the last year of life and provides information about practical and emotional support.

Maggie's Centres provide free emotional and practical support to people with cancer. You can drop into one of their centres, or visit their online centre.

The British Association for Counselling and Psychotherapy explains what counselling is, and you can search for counsellors, including counsellors who specialise in cancer.

The Samaritans offer a safe place for you to talk at any time about anything that's worrying you. You don't have to feel suicidal to contact them.

Healthtalk.org shares people's experiences as stories or videos. They have experiences of pancreatic cancer, including from people who have advanced pancreatic cancer and their families.

You can find details of these and other organisations that can offer information, support or counselling to you and your family on page 66.

Section 2

Talking about dying

It can be hard to know how to start conversations about dying. But talking openly about your feelings or wishes can help your family and healthcare team support and care for you.



Talking to family and friends

Everyone deals with difficult news in different ways. You may not want to talk to family and friends about dying at all. Or you may worry that your family will find talking about it too upsetting.

These can be difficult conversations. But being open and honest about your feelings and wishes can be comforting to you and your family. For example, you may feel less worried about the future if your family know how and where you would like to be cared for. Some people worry about being a burden to their family, or losing their independence. Talk to those close to you about how you would like them to support you. If there's anything you would rather they didn't do, let them know this as well.

Talking to children

If you have young children or teenagers in the family, you may worry about how to talk to them and how much you should tell them. For most children and teenagers it's best to be honest and talk to them as much as possible about what's going on. You may feel you want to protect them. But even very young children often sense when something is wrong and they may get more worried if they are not told what is happening.

Depending on the age of the child, use language they will understand. Check they have understood by asking them to tell you what is happening in their own words. Be prepared to answer their questions and be honest if you don't know the answer. Some people worry about getting upset in front of children, but this can help children understand that it's okay for them to be upset too.

It can help to speak to their school, as schools can access support for children. Schools also find it helpful to be aware of what's going on at home, for example in planning school work, or if the child's behaviour changes at all.

Many hospices and palliative care teams have counsellors who can help you talk to children. Some of the organisations listed on page 12 provide information about talking to children. Some of these also provide information and support directly to children and teenagers.

Talking to health professionals

Your doctor and nurses can answer any questions you or your family have about your cancer. They can also help you think about what care you will want in the future (see page 14).

Even though they are professionals, you may find it difficult talking to your doctor or nurse about the end of your life. These suggestions can help make talking to them a bit easier.

- Think about how much you want to know. It is up to you how much or how little you want them to tell you.
- Tell your doctor or nurse that you want them to be fully honest with you, if that is what you want.
- Write down a list of questions you want to ask and have it with you when you talk to your doctor or nurse.
- Write down their answers or ask a family member or friend to come with you to help you remember what was said.
- Take time to think about what they have told you, before going back with more questions.
- Tell your doctor or nurse what is important to you and what you hope will happen in the future. But also think about what you want to happen if things don't go to plan, for example if you can't be cared for where you would like to be. Read more about planning your care on page 14.

Let your healthcare team know if you'd like a relative or friend there with you during conversations. Ask any questions you may have, and talk to them about anything that is worrying you. There are some suggested questions in each section of this booklet.

? Questions to ask

Is there support to help me talk to my children or grandchildren?

What support is there for my family?

“Some people want to talk about end of life and they want loads of information, other people don't want to talk about it. My mum didn't. She didn't talk about her end of life at all really.”

More information

Macmillan Cancer Support have a range of booklets on talking about cancer with different people, including information about talking to children.

Dying Matters has information on how to talk about dying.

Winston's Wish and The Fruit Fly collective both provide information and support to help you talk to children about serious illness.

The website Riprap has information for teenagers who have a parent with cancer.

You can find details of these organisations on page 66.

Section 3

Your care

As you approach the end of your life, your care will focus on managing any symptoms, as well as supporting you emotionally and practically. It will aim to maintain the quality of your daily life, and help you carry on doing the things you enjoy for as long as possible.



Planning your care

It can be useful to think early on about how you want to be cared for in the future. This is because as you become less well, you may be less able to make decisions about your care or tell your doctors or nurses what you want. It can be difficult to think about your future care, but it can help you feel more in control. It also makes it easier for the people around you to follow your wishes.

Planning your care is known as advance care planning. There are different ways to make decisions about your care and record them. Your healthcare team can help you with this, or you can make your own record. Your wishes may change, and you can change your plans about your care at any time.

You can talk to your healthcare team at any time about how you would like to be cared for in the last weeks and days of your life. You don't have to wait for them to speak to you about this. The earlier you think about what you would like from your care, the easier it is for your doctors or nurses to plan your care.



We have more detailed information about planning your care, including the different ways of making decisions and recording them, on our website at **pancreaticcancer.org.uk/planningcare**

What is palliative care?

You may hear the term palliative care. The aim of palliative care is to help you live as well as possible for as long as possible. It includes managing complex symptoms, including pain and psychological (emotional) symptoms such as depression and anxiety. It provides people with emotional, physical, practical and spiritual support to help them deal with pancreatic cancer that can't be cured. It also supports family members.

Palliative care may be provided in:

- people's homes – by Hospice at Home services (see page 16), palliative care doctors and nurses, or Marie Curie nurses
- hospices – see page 16
- hospitals – by hospital-based palliative care teams
- care homes – see page 21.

Your GP and district nurse will provide some palliative care, and will arrange support from the specialist palliative care team when you need this. If you haven't already been referred to the specialist palliative care team, ask your GP or district nurse to refer you, as they can provide a lot of support.

What is a specialist palliative care team?

Specialist palliative care teams vary, but may include palliative care doctors and nurses, physiotherapists, occupational therapists, dietitians and social workers. You can write contact details of the different professionals you may see on page 58.

There are specialist palliative care teams based in the community who can visit you at home. Sometimes these teams may be based at the local hospice. If you are in hospital, the hospital will also have a palliative care team.

Not all services may be available everywhere. If you need more support speak to your GP. You can also call our specialist nurses on our free Support Line, who can explain how to access support.

“When we were finally given a palliative care nurse I was amazed at how much support she was able to give us, both as a couple and individually.”

What is a hospice?

Hospices provide specialist palliative care for patients and families. Services are free and vary between hospices, so not all hospices may provide all the services mentioned here. Services may include:

- managing symptoms
- inpatient care, where you stay at the hospice for a short time – for example, to get symptoms under control
- outpatient care, where you go to the hospice for an appointment and then go home after treatment
- Hospice at Home services, which provide hands on nursing care at home
- emotional, spiritual and social support
- support for families
- practical and financial advice
- complementary therapies, such as massage and aromatherapy, to help deal with symptoms.

You can ask your GP or district nurse what hospice services are available locally. You can also contact your local hospice to ask about their services. Hospice UK has details of hospices across the country (see page 68).

Choosing where to receive care

You can speak to your doctor or nurse about where you would like to be cared for and where you would like to die. This can be recorded in any plans you make about your care (see page 14). They can try to arrange support and care so that you can be cared for where you wish. But be aware that this may not always be possible – for example, if there isn't a bed available at the local hospice. Speak to your family as well so that they are aware of your wishes.

Your wishes about where you want to be cared for and die may change. For example, if you get a lot of symptoms, you may want to be in a hospice where there are palliative care specialists available, rather than at home. If your wishes do change, let your doctor or nurse know.

At home

Many people want to be cared for and die at home, where they're in familiar surroundings and have family and friends close by. It can take some time to organise care, support and equipment at home – your GP can help you with this.

Your GP, district nurse and community palliative care nurse will organise your care and will be your main point of contact. They will work with other health professionals to support you and your family so that you can stay at home. Your GP can refer you to the district nurse and palliative care team.

If you need help in an emergency, contact the GP. If it is out of usual working hours, the GP answer-phone should have the out of hours number to call. Some hospices also have a helpline you can call.

It's not always possible to stay at home, as it can sometimes be difficult to get the necessary care or equipment. If this is the

case, you may need to go into a hospice, hospital or care home. If you need treatment for symptoms, you may go into hospital or a hospice for a short time and then return home once your symptoms are under control. But if you need longer-term care for weeks or months, you may go into a care home. Your GP or nurse can answer any questions you may have about this.

Some people would rather not die at home. Your family will be your main carers, which can be stressful, and it may take longer for the GP and nurses to come to help you at times, especially at night or at the weekend. (Read more about nursing support at home on page 19.) Some people may not want their families to link the home with their death.

“The home became very medicalised. Mum’s bedroom was almost unrecognisable with a hospital bed, hospital table, commode, and shelves of drugs.”

“We received great support from the GP and community nurses. Equipment was provided, the GP provided daily visits, the nurses multiple visits. All of which enabled us to care as effectively as possible for our daughter and allow her to stay at home, which was her wish.”

Personal care

Care workers can help you with everyday care and support, including washing, dressing, shopping and housework. You can have long-term help or short periods of care, for example, to give a family member a rest.

Your GP, hospice or hospital (if they are involved in your care) can

help organise care workers at home. Care is free for people in the last year of their life.

“About two weeks before Mum died, we qualified for carers who came in four times a day to wash her, change her nightie and sheets, help her with the commode and so on.”

Nursing support at home

Nurses can help with medical care at home. They will usually visit you at home during the day. Ask your GP or the nursing team about how to get help during the night and at weekends if you need it. There are different nurses, providing different types of care.

- District nurses (also called community nurses) give general nursing care, medicines and pain relief. They work closely with GPs, social services, and other services to coordinate care.
- Specialist nurses (palliative care nurses, hospice nurses or Macmillan nurses) help people and their families with everything to do with living with cancer, working alongside the district nurses and GP. This might include managing pain and other symptoms, giving practical advice and emotional support.
- Marie Curie nurses or Hospice at Home nurses give hands-on nursing care at the end of life, often at night so your family can rest and sleep.

You can ask your GP to refer you to the nursing teams in your area.

Equipment

You may need equipment to help you manage at home, such as a commode (portable toilet) or hospital-style bed. You will need to be assessed for this by the district nurse or occupational

therapist. Occupational therapists are professionals who help people carry out everyday activities, for example by using equipment, or adaptations to the home.

Your local hospice may also offer some equipment on loan. If you are being treated in hospital, the occupational therapy team may assess you before you go home so the equipment is ready.



There is more information about the support that's available if you are cared for at home and how to access it on our website at [**pancreaticcancer.org.uk/practical**](http://pancreaticcancer.org.uk/practical)

At a hospice

If you need help with managing pain or other symptoms you may be admitted to a hospice for a short time. Most hospices only let people stay for about two weeks. Read more about the support hospices can provide on page 16.

You may want to spend your last days in a hospice, if a bed is available. There are sometimes waiting lists for hospice places so you may want to think about where you would like to be cared for if a hospice bed isn't available.

If you are thinking about spending time in a hospice, you may want to visit one beforehand so you know what to expect.

“We received great support from the local Hospice. My daughter was an inpatient for a week and we continued to receive excellent community support from them. If we had any concerns we only had to phone her community hospice nurse and she visited.”

In hospital

You may need to go to hospital, for example, in an emergency or if you can't get care at home or in a hospice. Hospitals have their own palliative care teams who will provide care and support to you and your family. Ask to be referred to the palliative care team.

In a care home

You may be able to stay in a care home for a short time or long-term if you are no longer able to manage at home. Some care homes offer nursing care but others just offer daily personal care. You may be able to get funding from your council to stay at a care home – otherwise you will need to pay for your care. Ask your healthcare team what funding may be available.

? Questions to ask

Can you refer me to the specialist palliative care team?

What support is there for me to be cared for at home? How do I access this?

What palliative care services are available locally?

Who should I contact in an emergency, at night or at the weekend?

Where is the local hospice and what services do they provide?

Can you help me plan my future care?

Can I choose where I die and who is with me?

More information

Compassion in Dying provide information about planning your care. Their website **mydecisions.org.uk** can help you record your decisions about your care.

NHS Choices and NHS Inform have more information about care at the end of life, including planning your care.

Marie Curie have information for people at the end of life and their families, including information about how to care for someone at home, and information about Marie Curie nurses and hospices.

Hospice UK explain what hospice care is, and you can search for hospices near you.

Macmillan Cancer Support and Marie Curie both have information about planning and arranging care, and sorting out your affairs and financial issues.

Healthtalk.org shares people's experiences as stories or videos. They have experiences of pancreatic cancer, including from people who have advanced pancreatic cancer talking about their care and planning for the end of life.

You can find details of these organisations on page 66.

Section 4

Symptoms towards the end of life

Advanced pancreatic cancer (cancer that has spread to other parts of the body) can cause some common symptoms, such as pain, weight loss and bowel problems. Your symptoms may change in the last months or weeks, and you may get new symptoms.



The information on pages 25-41 explains some of the common symptoms people with pancreatic cancer get in the last few months and how these can be managed. Pages 49-52 explain symptoms they may get in the last few days.

Not everyone will get all of the symptoms we've included here. There are ways to manage most symptoms and improve the quality of your life for as long as possible. Some symptoms can develop quite quickly. Speak to your doctor or nurse about any symptoms, including any that get worse, or any new symptoms.

Your doctor or nurse will assess your symptoms and work out the best way to manage them. How symptoms are managed may be quite individual and will depend on your own situation and what is best for you.

If you need help with symptoms at night or over the weekend, your GP's answer-phone will give you the number of the out of hours GP. Your local hospice may also have a 24 hour advice line, usually run by nurses, who will be able to help or tell you where to get help.

In the last few weeks of your life, your healthcare team may give you medicines to keep at home for symptoms you may get in the future. These are sometimes called pre-emptive, anticipatory or just in case medicines. They are kept separately in a box or bag marked 'just in case', along with instructions for giving the medicines. If you need these medicines urgently, your nurse can give them to you. This can be helpful if you need treatment at night or at the weekend.



If you have any questions about symptoms you can discuss these with our specialist nurses on our free Support Line.

Pain

Many people worry about having pain towards the end of life. You may not get pain but if you do, there are ways to manage it. Tell your doctor or nurse straight away if you have any new pain or your pain gets worse. The sooner you get treatment, the better the chance of getting the pain under control.

There are a variety of drugs to treat pancreatic cancer pain. These include:

- non-opioid painkillers such as paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen
- opioid painkillers – there are several different opioids, including morphine
- drugs usually used for depression but which also treat pain, including amitriptyline and imipramine
- drugs usually used for epilepsy but which also treat nerve pain, including gabapentin and pregabalin.

Another option for a few people if painkillers are not controlling the pain well is a procedure called a nerve block. This blocks nerves from sending pain messages to the brain, and so treats pain. Whether this is suitable for you will depend on your own situation, and whether you are well enough to have the procedure.

There are also other things that can help you deal with pain, such as complementary therapies (see page 42).



You can read more about pancreatic cancer pain and how it's managed in our booklet, **Pain and pancreatic cancer**, or on our website at **pancreaticcancer.org.uk/pain**

What is a syringe driver?

Your doctor or nurse may suggest a syringe driver (sometimes called a syringe pump) to provide your pain relief and other medication such as anti-sickness medication. A syringe driver is a small, battery-operated machine which is used if you can't swallow tablets, or are being sick. It provides a steady flow of medication, which means that you get your medication continuously. It can be used at home as well as in hospital or a hospice.

A needle is inserted under the skin and attached to the machine using a thin tube. Your doctor or nurse will set it up and top up the medication – usually once a day.

Marie Curie has more information about syringe drivers on their website.

Extreme tiredness (fatigue)

Pancreatic cancer and its treatment can cause extreme tiredness (fatigue). This is common in people with cancer. It is different to normal tiredness because it isn't helped by resting or sleeping. Fatigue can build up over time, making you feel physically and mentally tired. You may sleep more than usual and feel less able to do everyday things.

Lots of things can cause fatigue, including some drugs, and some symptoms of the cancer such as pain, depression, and anaemia (low red blood cell levels).

There are things that can help with fatigue. Tell your doctor or nurse about any fatigue. They can assess what is causing it and ways to manage it. Being active, if you feel up to it, may also help with fatigue.



You can read more about coping with fatigue, including some tips to help manage it, on our website at pancreaticcancer.org.uk/fatigue

“She had days when she felt good and on those days she did what she could, and when she was particularly fatigued, she wouldn’t.”

Problems with diet and digestion

Pancreatic cancer can cause problems with digesting food. This can cause symptoms such as discomfort after eating, wind and bloating, appetite and weight loss, and bowel problems, including diarrhoea (loose, runny poo) and steatorrhoea (pale, oily poo that floats, smells horrible and is difficult to flush down the toilet – see page 37).

Most people will have been given pancreatic enzyme supplements to help them digest their food and manage these symptoms. Brands include Creon[®], Pancrease[®], Nutrizym[®] and Pancrex[®]. Continue taking the enzyme supplements with food for as long as you are still eating. If you haven’t been given enzyme supplements but are still eating and have these symptoms, speak to your doctor about being prescribed these supplements.

The enzyme supplements are capsules. If you find it difficult to swallow capsules, you can open them up and mix the granules inside with a teaspoon of soft, acidic food – such as apple sauce, fruit puree, apricot jam or yoghurt. Swallow the food straight away and wash it down with a cool drink to rinse your mouth. Don’t chew the granules. If the granules aren’t swallowed quickly, or they get stuck between your teeth, they can cause mouth ulcers.

If you go into a hospice or hospital and are taking enzyme supplements, tell the staff about these. Explain that you need to take them with anything you eat, including both meals and snacks, to help digest your food. Hospices or hospitals sometimes review your medication and stop any that's no longer necessary, to reduce the number of pills you need to take. But it's important that you continue to take enzyme supplements if you are eating.

If you are no longer able to eat you don't need to take the pancreatic enzyme supplements.

Diabetes

If you have diabetes, speak to your doctor, diabetes nurse or pancreatic dietitian for advice about how to manage it. They may advise you to change the dose or type of your diabetes medication if, for example, you are eating less or have problems swallowing.

Your blood sugar levels may be affected if you are being sick or have diarrhoea (runny poo). Some treatments can also affect diabetes, such as nutritional supplements and steroids. Your doctor or diabetes nurse can give you advice about how to manage this.



You can read more about pancreatic enzyme supplements and how to take them, and about diabetes, in our booklet, **Diet and pancreatic cancer**, or on our website at pancreaticcancer.org.uk/diet

Weight loss and reduced appetite

Many people with pancreatic cancer lose their appetite and lose weight. People in the last few weeks of life will gradually feel less like eating, and will eat less. This is normal. The cancer can reduce your appetite, and symptoms, such as sickness, pain or fatigue, may put you off eating. And as your body slows down, it needs less food.

Losing a lot of weight can be upsetting for both you and your family. But try not to worry about how much you are eating or about putting weight back on, as you probably won't be able to put on weight. But there are things that can help manage appetite and weight loss.

- It's fine to eat and drink what you feel like, even if that's only small amounts.
- Try having small meals or snacks of things that you fancy. You may find soft food such as soup, yoghurt or ice cream easier to eat.
- You should continue to take pancreatic enzyme supplements while you are eating, but you can reduce the amount you take if you are eating less.
- It is important to treat any problems that are stopping you eating, such as pain, sickness or tiredness.
- Gentle physical activity can help to increase your appetite and help you maintain or improve your strength and fitness.

Your doctor or nurse can refer you to a dietitian for help with eating. They may suggest nutritional supplements to increase the amount of energy (calories) and protein in your diet.

Information for family members – helping with eating

It can be difficult if your loved one doesn't feel like eating and is losing weight. But remember that this is normal. Don't try to make them eat if they don't want to. Support them by asking what they fancy and preparing food for them. And try not to be upset if they don't eat much of it.

Feeling and being sick

Pancreatic cancer and its treatment can make you feel and be sick (nausea and vomiting). Possible causes include:

- cancer blocking the duodenum (see page 32)
- the stomach emptying slowly (see page 34)
- the liver not working properly (see page 38)
- constipation (problems emptying your bowels)
- some medicines
- anxiety.

Feeling and being sick is unpleasant and distressing. It may also mean that you aren't properly absorbing medication that you take as tablets. If you are being sick a lot, there is a risk that you could become dehydrated (where your body loses more water than it takes in).

Speak to your doctor or nurse if you are being sick. If you have been vomiting for a day or more, contact your GP, district nurse, or your GP out of hours service. They will work out what is causing your sickness, and give you treatment. For example, they may give you anti-sickness drugs. There are different drugs available, depending on what is causing your sickness. These may be tablets, liquids, or injections. You can also have some anti-sickness drugs through a syringe driver (see page 26).

There are some things you can try yourself to help with sickness.

- You could try eating small meals or asking someone to cook for you so that you can avoid the smell of cooking.
- Some people find eating a dry biscuit or cracker, grated ginger in hot water, ginger biscuits, peppermint tea or sucking sugar-free sweets helps.
- Using travel sickness wrist bands, such as Sea Bands[®], can also help.
- It's also important to keep your mouth clean if you are being sick. This helps to keep your mouth healthy and get rid of the unpleasant taste. Try using a mouthwash to rinse your mouth after you have been sick.



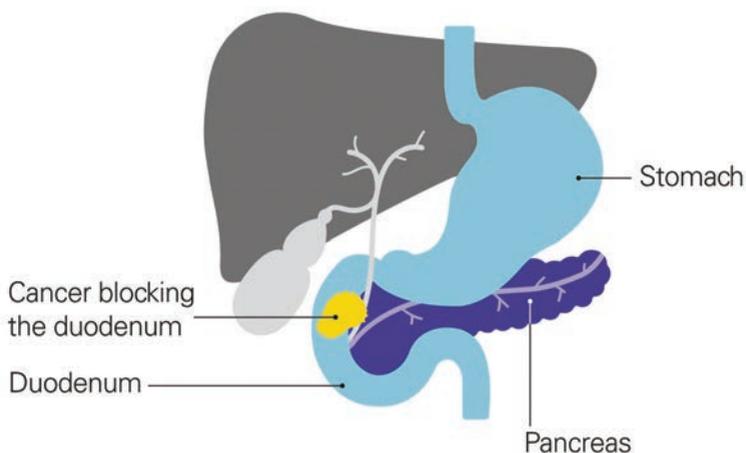
Read more about treatments for sickness on our website at pancreaticcancer.org.uk/nausea

Blocked duodenum

Pancreatic cancer can block the duodenum (the first part of the small intestines), which will mean that food can't flow out of the stomach.

If this happens, food can build up in your stomach, making you feel full and be sick. You may find you are sick more in the evenings or at night, and you may vomit large amounts. You may feel better for a while afterwards but then start to feel sick again. A blocked duodenum may also cause pain, cramping and bloating in the tummy area, loss of appetite and weight loss.

Diagram showing the cancer blocking the duodenum



A duodenal stent to treat a blocked duodenum

Some people may be able to have a duodenal stent inserted to treat a blocked duodenum. This is a tube that will open the part of the duodenum that is blocked. You should find that your symptoms start to improve afterwards.

If you have already had a stent put in, it can get blocked, making you feel sick. If this happens, the stent may need to be replaced.

To avoid the stent getting blocked, eat small, frequent meals and choose soft foods like porridge, minced meat and mashed potato.

A duodenal stent won't be suitable for everyone. You will need to be fit enough to have a sedative (to make you sleepy) or an anaesthetic (so that you are asleep) to have the procedure.



Read more about a duodenal stent in our fact sheet, **Stents and bypass surgery**, or on our website at pancreaticcancer.org.uk/inoperable

Read about eating when you have a duodenal stent in our booklet, **Diet and pancreatic cancer**, or on our website at pancreaticcancer.org.uk/diet-inoperable

If you can't have a duodenal stent

If a stent isn't suitable or if you are not fit enough to have a stent put in, your doctor will give you medication to manage the sickness as well as any other symptoms, such as pain relief.

Some people may be able to have their stomach drained to stop them being sick. This may be done with a nasogastric tube, which is a thin tube that passes up your nose and down into your stomach. Or occasionally a tube called a venting gastrostomy tube can be inserted through the skin into the stomach. This won't be suitable for everyone, and may not be used that often.

Stomach emptying slowly

Pancreatic cancer sometimes affects the nerves and hormones that control the stomach. If this happens, food passes through the stomach more slowly. This is called delayed gastric emptying or gastroparesis. Other possible causes of the stomach emptying slowly include abdominal surgery and diabetes.

Symptoms that your stomach is emptying slowly include:

- feeling and being sick
- bloating
- feeling full quickly.

Other things can cause similar symptoms, so your doctor or nurse will work out what is causing your symptoms, and the best treatment for you. They may give you medicines to help improve your symptoms, such as anti-sickness drugs including metoclopramide and domperidone.

Sometimes it may be possible to drain your stomach using a nasogastric tube or occasionally a venting gastrostomy tube (see page 33). These may not be suitable for everyone, and may not be used that often.

You can help to manage your symptoms by eating small meals that are high in calories (energy) and easy to digest – speak to your dietitian about this. Drink small amounts of fluid regularly throughout the day and sit up after eating, if you can. If you feel up to it, try to move around after meals.



You can find examples of high calorie foods in our booklet, **Diet and pancreatic cancer** or on our website at pancreaticcancer.org.uk/diettips

Bowel problems

Pancreatic cancer and treatments can cause bowel problems including:

- problems emptying your bowels (constipation)
- loose and runny poo (diarrhoea)
- pale, oily poo that floats, smells horrible and is difficult to flush down the toilet (steatorrhoea).

Constipation

Constipation (problems emptying your bowels) can be very uncomfortable, and can cause bloating, pain, nausea and vomiting.

There are several possible causes. You may get constipation if you are taking opioid painkillers, such as morphine. You should always be given medicines called laxatives to take with opioids. These prevent constipation. It's important to take the laxatives regularly, as prescribed.

You may also be more likely to get constipation if you are not moving around much, aren't eating much, or are dehydrated.

Speak to your doctor or nurse if you do have constipation. They can change the dose or type of laxative if necessary. It can also help to drink plenty of fluids, if you can. Try having small, frequent sips.



You can read more about painkillers and constipation in our booklet **Pain and pancreatic cancer** or on our website at **pancreaticcancer.org.uk/pain**

Diarrhoea

Diarrhoea (loose runny poo) can mean you need to rush to the toilet, and can cause stomach cramps. It can be unpleasant and embarrassing. There can be several causes, including the cancer, some medicines, or an infection.

Sometimes if you have constipation, some watery poo which looks like diarrhoea can leak out. This is called overflow diarrhoea. If you are taking opioid painkillers and think you have diarrhoea, keep taking the laxatives you will have been given to prevent constipation (see page 35), and speak to your nurse. They can work out what is causing it and how to manage it. Don't stop taking the laxatives and don't take any medication to prevent diarrhoea without speaking to your nurse.

If your diarrhoea doesn't get better, tell your GP or nurse. They should work out what's causing it, and may give you medicine to stop it.

If you have diarrhoea, try to keep your bottom clean using damp toilet paper or cotton wool. Wash the area using gentle soap and water, and pat dry. Wear cotton underwear and loose fitting clothes.

Diarrhoea can cause dehydration, where your body loses too much water. If you have diarrhoea, try to drink plenty of fluids to prevent this. It can be easier to have small, frequent sips than bigger drinks. Signs of dehydration include dark urine, feeling dizzy or tired, a headache, dry mouth, and feeling thirsty. Speak to your nurse if you have diarrhoea and think you might be dehydrated.

Steatorrhoea

Steatorrhoea (pale, oily poo that floats, smells horrible and is difficult to flush down the toilet) is caused by fat in your poo. You may get it if your body can't digest the fat in your food properly. This happens because the cancer causes problems with digestion. Pancreatic enzyme supplements can help with steatorrhoea (see page 27).



Read more about steatorrhoea in our booklet, **Diet and pancreatic cancer**, and on our website at pancreaticcancer.org.uk/diet

Swelling (ascites and oedema)

What is ascites?

Pancreatic cancer can sometimes cause fluid to build up in the tummy area (abdomen). This is called ascites, and it can cause pain and discomfort. You may have swelling in your tummy and you may feel full quickly when you eat. You might find it harder to move around and may get breathless, even when you are lying down. You may find it difficult to get comfortable when lying down, and find it uncomfortable to lie on your side. If you have any of these symptoms, tell your doctor or nurse.

The fluid may be drained off to make you more comfortable. To do this, you will have a local anaesthetic in your tummy so that it's numb. A small cut is made, and a thin tube is inserted to drain the fluid. The fluid can build up again and you may need to have it drained more than once. The first time it is drained, you will need to go to hospital, but after that, your local hospice may be able to do it. You may also be able to have a permanent drain put in so that the fluid can be regularly drained off by the district nurse at home. You can ask your doctor or nurse about this.

Sometimes ascites may also be treated with medication called a diuretic. This may help reduce the fluid, although it doesn't always make a big difference.

Macmillan Cancer Support has more information about treatments for ascites.

What is oedema?

Fluid may also build up in your legs and feet, causing swelling. This is called oedema. People sometimes also get oedema in their genitals. Oedema can be uncomfortable and painful and can make it harder for you to move around.

Tell your doctor or nurse if you have any swelling. They may recommend pressure stockings to help control the swelling, and suggest some exercises you can do to help the fluid drain away. Putting your feet up, for example on a foot stool, can help. It is also important to look after your skin by moisturising the swollen areas – ask your nurse what moisturiser to use.

Sometimes you may be offered medication called a diuretic to treat the oedema – although this may not make a big difference.

Jaundice

You may get jaundice if your liver isn't working properly, or if your bile duct becomes blocked, stopping the bile draining. Bile is a fluid produced by the liver to help digestion. The bile duct carries bile from the liver to the duodenum.

If you have jaundice, your eyes and skin may turn yellow, and you may feel itchy. You may also feel sick, lose your appetite and lose weight, and feel tired and thirsty. If you have already had a tube called a stent put into your bile duct to treat jaundice, the cancer may have grown to block the stent, causing the jaundice to come back.

If you develop jaundice, your doctor or nurse will assess whether you need a biliary stent or drain. A biliary stent is a small tube that is inserted into the bile duct to relieve the blockage. A biliary drain is a small tube that is inserted through your skin into the bile duct, and drains the bile into a bag.

The doctor or nurse will also treat any symptoms you get. For example, they may give you medication to control any sickness or itching.



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

Bedsores

Bedsores (also called pressure sores or pressure ulcers) are damage to the skin and the layer of tissue below the skin. They are caused by pressure on the same area of skin for a period of time.

Bedsores usually affect the bony parts of the body, such as the heels, elbows, hips, and the base of the spine. They affect people who can't move around much and spend a lot of time in bed or sitting in a chair. They can be painful, and if they aren't treated they can become very serious. Your nurse should assess whether you are at risk of developing bedsore.

The best way to prevent bedsore is to change position – your doctor or nurse may suggest you do this every few hours and show you how. If you are not able to move yourself, you will need help from your family, carers or healthcare team.

If you are at risk of bedsores, the district nurse may arrange special equipment such as pressure cushions. Or you may be able to have a hospital style bed with a pressure relieving mattress. These can help prevent bedsores developing. If your skin is wet or inflamed, the nurse may offer you a cream to help prevent bedsores.

Signs of a bedsore include red or discoloured skin that doesn't turn white if pressed. If you notice this, tell your nurse so that they can check it.

If you develop a bedsore, your nurse should check it regularly. You should be given a pressure relieving mattress, and your doctor or nurse will discuss any other treatments with you.

If you are worried about getting a bedsore, have any sore areas of skin, or want to know more about how to prevent bedsores, speak to your nurse. Marie Curie and NHS Choices have more information about bed sores.

“Mum had bedsores on her shoulder blades, knees, heels and elbows which needed daily management by the District Nurses.”

Dry mouth

Some people get a dry mouth, which can be uncomfortable. This could be caused by the cancer itself, treatments such as opioid painkillers, or being generally run down.

Try to keep your mouth clean by brushing your teeth regularly and using mouthwashes. You could try chewing gum, taking regular sips of drinks and sucking ice cubes or ice lollies. Refrigerated pineapple cubes can also help. You can also get artificial saliva products and gel from the pharmacy that may help. Use a lip balm to stop your lips getting dry.



You can read more about how to deal with a dry mouth in our booklet, **Diet and pancreatic cancer** and on our website at **pancreaticcancer.org.uk/diettips**

Anxiety and depression

It is natural to feel anxious, frightened or angry when you are approaching the end of your life. But you may feel overwhelmed by these feelings at times. Anxiety and depression can be common in people with pancreatic cancer. Getting the right support can help you deal with your emotions.

Depression can affect the quality of your daily life and you may feel less able to cope with other symptoms. Symptoms of depression may include difficulty sleeping, extreme tiredness, loss of appetite, weight loss and a feeling of hopelessness. You may not have any interest in things that you used to enjoy. The cancer itself can cause similar symptoms so speak to your GP or nurse to find out what is causing them.

Support in dealing with the cause of anxiety or depression might help – such as dealing with any symptoms or side effects, planning your future care, or help with financial issues. Your doctor can also give you medicines, such as anti-depressants. These can help, although they can take a few weeks to have an effect.

Talking about your worries and fears may help you come to terms with your situation. You can speak to your GP, nurse or specialist palliative care team. They can refer you for specialist psychological (emotional) help such as counselling, if needed. Read more about counselling on page 6. Some people also find it helpful to talk to a spiritual leader.

Complementary therapies to help deal with symptoms

Some people find that complementary therapies can help with symptoms. These therapies can help you to relax and feel better emotionally and physically, although they can't treat the cancer. We have included a few common complementary therapies, although there are lots available.

- Massage may help you relax. It may help to reduce pain and help you feel better generally. Avoid massage in the area of your cancer or near enlarged lymph nodes – such as the tummy area (abdomen) and upper back. People with advanced cancer who have problems with bleeding should avoid deep tissue massage.
- Reiki is a gentler type of massage where the therapist's hands gently brush over the body. This may be useful for people who can't have normal massage.
- Reflexology is a type of massage that involves putting pressure on parts of the hands or feet. This may help to relieve pain in other parts of the body.
- Relaxation therapies like meditation, aromatherapy and hypnotherapy may help relieve symptoms such as pain.
- Other therapies that you may find helpful include visualisation, art therapy, music therapy and pet therapy.

Always tell your healthcare team before starting a complementary therapy, as some may affect your treatment. And tell your complementary therapist about any treatments you are having.

Some hospices, hospitals and charities offer complementary therapies. Your doctor or nurse can tell you what is available in your area. The Complementary and Natural Healthcare Council has a list of registered complementary therapists.



Read more about complementary therapies on our website at pancreaticcancer.org.uk/complementarytherapies



Questions to ask

How will my symptoms be managed?

What support is there for dealing with symptoms?

What can be done if my symptoms don't improve, or get worse?

What should we do if my symptoms get worse at night or at the weekend?

More information

Macmillan Cancer Support and Marie Curie's booklet, **End of life: a guide**, has information on general symptoms that people with cancer may get towards the end of their life.

Marie Curie have a series of booklets for people who are dying, including information about managing symptoms and living with a terminal illness.

Find details of these organisations, and other organisations that offer support at the end of life, on page 66.

Section 5

Information for family, friends and carers

Looking after someone who is nearing the end of their life can feel overwhelming. Knowing where to get help and information can take some of the pressure off and can help you make the most of the time you have left with your loved one.



Support for you

Being told that your family member is nearing the end of their life is distressing and it's normal to feel a range of emotions. You may take comfort from being able to care for them. Or you may be struggling to come to terms with this new situation. You may not live with your family member, or may be juggling their care with other responsibilities, such as work or children.

You may want lots of information about what is happening, or you may just be focusing on caring for them. Finding out what to expect can help you to feel more in control. You can speak to the doctors and nurses, either with or without your family member present, with their permission.

The information on pages 23-41 explains some of the common symptoms people with pancreatic cancer get in the last few months and how these are managed. And the information on pages 49-52 explain symptoms they may get towards the end.



Our specialist nurses on our free Support Line support families and carers as well as people with pancreatic cancer. You can ask them any questions you have, as well as talking through your worries.



We have more information for families, including how to access emotional, medical and practical support, in our booklet, **Caring for someone with pancreatic cancer: Information for families and carers**, and on our website at **pancreaticcancer.org.uk/families**

Read about the support we can offer you and your family at **pancreaticcancer.org.uk/getsupport**

You may find counselling helpful. Some carers whose family members have died have said that, looking back, they think that starting counselling earlier would have helped them cope with their grief. Read more about counselling on page 6.

If you feel you need a break, you may be able to get some respite care. This is temporary care to give families and carers a break. Carers Trust has information about how to access respite care.

Carers UK and Carers Trust both provide information and support for carers.

“I was offered free counselling. This was an excellent service and has really helped me.”

“We had our daughter, my parents, our son and his partner all living together before our daughter died. This served as a great support network for each other. It also meant we had the flexibility of someone always being with our daughter and for the others to get some time out.”

Caring for your loved one

The demands on you can increase quite quickly in the last few weeks or days, especially if you are looking after someone at home. You may need to do more and more for them, including washing and personal care, giving medicines, making sure they are comfortable and helping them with eating and drinking. There is more information about getting medical and practical support when you are caring for someone at home on pages 17-20.

Ask the doctor or nurse for details of who to call if you need help or advice, including at night or at weekends. Keep these somewhere you can get to them quickly – there's space on page 58.

When to get medical help

Contact the GP or nurse if:

- treatment is no longer keeping symptoms under control
- you are finding it hard to give medicines to your family member
- there's anything you are unsure or concerned about
- you are struggling and finding it difficult to cope.

And contact them if your family member:

- is finding it difficult to swallow medication
- has any new or worsening symptoms
- seems uncomfortable
- isn't emptying their bladder or bowel
- has fallen.

“Keep a list of medication and other important information for out of hours GP visits, as it means this is close to hand when needed.”

Spending time together

The person you are caring for may want relatives, children or pets to be with them in the last weeks of their life. This can be comforting for everyone. If your family member is staying in a hospital or hospice, you can ask whether relatives can stay overnight or if pets are allowed to visit.

If your family member would like some time alone with their partner, they could ask their nurses if this is possible, especially if they are in a hospice or hospital. Many people want time to be close and intimate in private and the healthcare team will do all they can to help.

There may be things you'd like to say to your family member while they are still well enough. You might want to talk about their hopes and wishes, or share memories. You may want to talk about practical things like financial issues, their will, or what they want to happen after they die. Or you may just want some quiet time together to say goodbye. Sometimes, people can put things off or feel that it's too late to start these conversations. But it can be helpful and reassuring for everyone to talk about these things early on. There's more information about talking about dying on page 9.

“The hospice where my mother was staying allowed pets. There were often dogs around that had gone in to visit.”

“I had no idea how to express my feelings to my dad. I was too busy staying positive and telling him all sorts of happy things we had done together rather than expressing to him how lost I would be without him.”

“My friend regretted not having sat down with her dad and gone through what he wanted to do with things like accounts and paperwork when he was well enough.”

? Questions to ask

What can I do to support my family member or friend?

What help can I get with caring for my relative?

Will someone tell me when the person I'm caring for is close to dying?

Signs that the end of life may be near

People often ask how they will know that someone is in the last few days of their life. People with pancreatic cancer can become ill very quickly over a few days, and you may not get much warning that the end is near. It can be hard to cope with this uncertainty but the doctor or nurse can tell you if they think your family member is close to the end of their life. They can explain what signs to look out for and answer any questions you have.

Withdrawing and speaking less

In the final few weeks, you may notice your family member starts to gradually withdraw from the world. They may speak less than usual, be more tired and sleep more and, in the final few days, they may stop speaking. Although this doesn't mean they won't speak again.

Changes in eating and drinking

It is natural for people to stop eating and drinking in the last days of life. You can help your family member stay comfortable by giving them sips of water or small pieces of ice to suck, just to keep their mouth moist. If they're not awake, the GP or nurse can give you swabs to keep their mouth and lips clean and comfortable. Lip balm can help stop their lips getting dry.

Breathing changes

Your family member's breathing may become slower, shallower or less regular in the last few days. Fluid in the throat or chest may cause breathing to become noisy. This isn't usually uncomfortable and they may not be aware that it is happening, but it can be upsetting for family or friends. If it is distressing your loved one, the doctor or nurse may try moving them into a different position or they can use medicines to help reduce it.

Sleepiness

Another sign that someone is in the last few days of life is drowsiness. The person may spend lots of time sleeping or they may slip in and out of consciousness. Even if they are unconscious, they may still be able to hear you speaking to them. It can be comforting to both of you to keep talking to them.

“A friend of mine had a brainwave and appeared at the hospice with a CD player and some of my partner's favourite CDs. So we all listened to the Beatles as he died. I'm sure he could hear too and would have approved.”

Confusion, restlessness or agitation

Sometimes a person may become confused, restless or agitated. Your loved one may not know where they are or who is with them. You may want to reassure them by reminding them of who you are and what is going on around them. They may describe speaking to someone who has died or they may see things that aren't there. If they're not upset, it's fine to talk to them about what they can see or hear. Some people may be frightened – staying near them, gently touching them and reassuring them may help. A calm room and quiet music can also help.

It can be upsetting for you if your family member is confused or agitated. There could be several reasons for why it happens, so speak to the doctor or nurse. They will look for any physical causes, like pain, problems with their bladder or bowels, or issues with their medication. They may recommend giving your relative medicine to relax and calm them. They may also suggest putting in a catheter (a tube into the bladder to drain urine). This will prevent the bladder getting full and causing discomfort. If you are worried that your family member may be in pain, the doctor or nurse can review their pain relief.

“My partner became very confused towards the end of his life. For me that was possibly one of the most upsetting things, seeing someone who had been so strong and capable being so vulnerable. The healthcare team were great though. The doctors, his nurse and the paramedics were kind and patient with him.”

Changes to their skin

Towards the end, your family member's skin may become blue, grey or pale. Their hands, feet, arms and legs may feel cold. Layers of clothes or bedding can help keep them comfortable.

Bleeding

There is a small risk of bleeding towards the end of life. This is rare but it can be upsetting and frightening, so you may want to be aware that it can happen in a very small number of people. In pancreatic cancer, there may be bleeding internally from the stomach or around the pancreas, and people can sometimes vomit blood. If this happens at home, contact your GP, specialist nurse or hospice team or call the out of hours number you have been given. Stay with your family member and try to reassure them. Using dark towels and sheets may help to make it look less frightening.

Changing the medications

In the last few days, the doctor may talk to you about stopping medicines that are no longer needed or that aren't helping to control symptoms. They may also suggest giving medicines in a different way – for example, by injection or a syringe driver if your family member can no longer swallow medicines. See page 26 for more about syringe drivers.

When someone dies

Dying is different for each person. It is a natural process, but you may feel frightened or worried about what will happen. Ask the doctor or nurse about anything that is worrying you, either with or without your family member there. Dying is often very peaceful at the end.

It's not always easy to know when someone has died. Their breathing will slow and become irregular. Sometimes they may take one or two last breaths after they seemed to have stopped breathing. They may seem to relax and may look pale.

“My mother’s death taught me not to be afraid of being with someone when they die. The hospice staff and chaplains were excellent at supporting me.”

After someone dies

If your family member died in hospital, a hospice or a care home, the healthcare team will explain what happens next. If they died at home and no health professionals were there, you will need to contact their GP to come and confirm that they have died. In some areas, you can contact the district nurse. If it's outside working hours, the GP answer-phone message will give you the number of the out of hours doctor.

Marie Curie have more information on their website about what happens when someone dies, including caring for the body and religious customs.

There are some things you need to do soon after someone dies.

- Ask the GP or hospital doctor for a medical certificate so you can register the death.
- Register the death at your local register office within five days of the death in England, Wales and Northern Ireland and within eight days in Scotland.
- Arrange the funeral.

The GP or nurse should give you information about what you need to do. You can also find details of how to register a death, your local register office, and what else to do after someone dies on the:

- GOV.UK website in England and Wales
- National Records of Scotland website
- nidirect website in Northern Ireland.

If your family member died at home, they can stay there for as long as you wish before the funeral. When you are ready, the funeral director will move them to a funeral home if that is what you want. If they died in a hospital, hospice or care home, you can usually go to visit them in a private room if you want to.

Coping with loss

It is natural to feel a range of emotions after your relative or friend has died. You may feel numb, exhausted or worried. You may be relieved that they are no longer suffering. You may have trouble sleeping or keep going over what happened in your mind. If everything happened very quickly, you might not have felt prepared or you might question why you didn't have more time with your loved one.

There is support available to help you deal with your emotions after your family member has died. You can find contact details for these organisations on page 66.

- Hospices may offer support and counselling to you and your family, including young children.
- Your GP may have details of local bereavement counsellors.
- Maggie's Centres and Cruse Bereavement Care offer bereavement support.

- Cruse Bereavement Care's website, **hopeagain.org.uk**, provides information and support for young people who have been bereaved.
- Winston's Wish can provide support and information for bereaved children.
- Riprap provides support for teenagers with a parent who has cancer.
- The Compassionate Friends offers support to people who have lost a child of any age.



You can also speak to our specialist nurses on our free Support Line if you need support after someone has died from pancreatic cancer.

“My young daughter used our local hospice’s child bereavement service and I cannot praise them enough. Their expertise in a delicate matter was fantastic.”

“I saw a bereavement counsellor once before he died then again afterwards. Those two sessions were the most valuable as I felt I could ‘indulge’ myself and not feel I needed to be ‘strong’. I could cry and not worry that I might be worrying someone else.”

More information for families

Healthtalk have videos of people talking about their experiences of looking after someone at the end of life in the **Pancreatic cancer: End of life and professional care** section of their website.

Carers UK has information on getting care and support. This includes information on planning emergency care, in case you are not able to care for your family member for any reason.

Macmillan Cancer Support and Marie Curie's booklet, **End of life: a guide**, has information on what to expect in the last few weeks and days of life.

Marie Curie's booklet, **When someone dies**, has information on what to do after someone has died, coping with grief, registering the death, arranging a funeral and wills.

Macmillan Cancer Support has information on emotional support in their booklet, **After someone dies: coping with bereavement**.

You can find details of these organisations on page 66.

Section 6

Further information and support

In this section, we provide space for you to record contact details for your healthcare team, explain some key medical words, and provide information about our services and other organisations that can support you.



Healthcare team members

You can use this space to record the names and numbers of the key professionals involved in your treatment and care. You may not see all of the professionals listed here.

Out of hours or emergency contact

Name:

Telephone:

Notes:

General practitioner (GP)

The GP will help manage your cancer. For example, they may help manage some symptoms, and can refer you for other medical services. They may be your main contact if you are being cared for at home.

Name:

Telephone:

Email:

Notes:

Community nursing service

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

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

Nurse

Name:

Telephone:

Email:

Notes:

Name:

Telephone:

Email:

Notes:

Hospital palliative care team

A team of professionals who can help manage your symptoms and provide emotional support at hospital – either when you are staying there as an inpatient, or as an outpatient, where you don't stay overnight. The team may include doctors, nurses, physiotherapists, occupational therapists, psychologists and counsellors.

Name:

Telephone:

Email:

Notes:

Community palliative care team

Similar to the hospital palliative care team, but they may visit you at home or arrange an outpatient appointment to help you manage your symptoms. Some teams are based at hospices.

Name:

Telephone:

Email:

Notes:

Hospice

Hospices provide palliative care and services to support people with an illness that can't be cured. Read more on page 16.

Name:

Telephone:

Email:

Notes:

Occupational therapist

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

Name:

Telephone:

Email:

Notes:

Physiotherapist

A health professional who helps people cope with illness and manage symptoms through movement and exercise.

Name:

Telephone:

Email:

Notes:

Social services contact

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

Name:

Telephone:

Email:

Notes:

Carer or care agency

A person or company who help you with everyday tasks like washing, dressing and shopping.

Name:

Telephone:

Email:

Notes:

Other

Name:

Telephone:

Email:

Notes:

Glossary

We have explained some of the medical words that you may hear when you have pancreatic cancer.

Ascites: build-up of fluid in the tummy that may cause swelling (see page 37).

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

Bile duct: a tube that carries bile from the liver to the duodenum.

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

Cachexia: loss of fat and muscle in people with long term illnesses, such as cancer.

Constipation: problems emptying your bowels. Poo may be hard, dry and difficult to pass. Read more on page 35.

Diarrhoea: passing loose watery poo. Read more on page 36.

Dietitian: a professional who provides expert advice about diet and nutrition, including how to manage the dietary symptoms of pancreatic cancer.

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

Duodenum: the first part of the small intestines. It absorbs nutrients and water from food passing out of the stomach.

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

Jaundice: a symptom of pancreatic cancer. It develops when there is a build-up of bilirubin in the blood. It causes yellow skin and eyes, and itching. Read more on page 38.

Pancreatic enzyme supplements: capsules that help digest food when the pancreas isn't producing enough digestive enzymes.

Steatorrhoea: caused by fat in poo. Poo may be pale, look oily, smell horrible, and be difficult to flush down the toilet. It can be a symptom of pancreatic cancer. Read more on page 37.



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

Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

We're here to support and to listen

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

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

We're here with the information you need

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

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

We're here so you can share

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

Local support groups mean you can meet other people to share your experiences:

pancreaticcancer.org.uk/supportgroups

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

Useful organisations

British Association for Counselling and Psychotherapy

www.bacp.co.uk

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

Provides information about counselling and a database of registered therapists.

Cancer Research UK

www.cancerresearchuk.org

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

Information for anyone affected by cancer.

Carers Trust

www.carers.org

Email: info@carers.org

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

Carers UK

www.carersuk.org

Adviceline: 0808 808 7777

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

Citizens Advice

www.citizensadvice.org.uk

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

Scotland 0808 800 9060

In person at your local Citizens Advice Bureau.

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

Compassion in Dying

www.compassionindying.org.uk

Information line: 0800 999 2434 (Mon-Fri 9am-5pm)

Provides information on how to plan ahead for the end of life.

Their website **mydecisions.org.uk** helps you plan ahead for your future treatment and care.

Complementary & Natural Healthcare Council

www.cnhc.org.uk

Tel: 020 3668 0406 (Mon-Fri 9am-5:30pm)

Information about complementary therapies and a register of therapists.

Cruse Bereavement Care

www.cruse.org.uk

Helpline: 0808 808 1677

(Mon, Fri 9.30am-5pm, Tues-Thurs 9.30am-8pm)

Offers support, advice and information to people who have been bereaved.

Dying Matters

www.dyingmatters.org

Help people talk more openly about dying and bereavement, and to make plans for the end of life. They also have a list of services for people in the last years of life and their families.

Elizabeth Coteman Fund

www.ecfund.org

Tel: 01223 782171

Provide grants for people with pancreatic cancer who are struggling financially, for equipment and respite. Provide support and friendship to those affected by pancreatic cancer.

Fruit Fly Collective
fruitflycollective.com

Provide information and support to help families talk to children about cancer.

Good Life, Good Death, Good Grief
www.goodlifedeathgrief.org.uk
Tel: 0131 272 2735

Provide links to information and resources in Scotland to support people at the end of life, and their families.

GOV.UK
www.gov.uk

Provides information about government services, including benefits, transport, money and what to do when someone dies.

Healthtalk.org
www.healthtalk.org

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

Hospice UK
www.hospiceuk.org
Tel: 020 7520 8200

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

Macmillan Cancer Support
www.macmillan.org.uk
Support Line: 0808 808 00 00 (Mon-Fri 9am-8pm)

Provides practical, medical and financial support for anyone affected by cancer, including information about support at the end of life.

Maggie's Centres
www.maggiescentres.org
Tel: 0300 123 1801

Centres around the UK and online offer free, comprehensive support for anyone affected by cancer.

Marie Curie
www.mariecurie.org.uk
Support line: 0800 090 2309 (Mon-Fri 8am-6pm, Sat 11am-5pm)
Provides care and support for people living with a terminal illness and their families, including nurses and hospices.

National Records of Scotland
www.nrscotland.gov.uk
Provides information on how to register a death.

NHS Choices
www.nhs.uk
Provides information about health conditions, living well, care, and local services in England.

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

nidirect
www.nidirect.gov.uk
Information about local services in Northern Ireland, including health services, registering a death, and information and support for carers.

NHS inform

www.nhsinform.scot

Helpline: 0800 22 44 88 (Mon-Fri 8am-10pm, Sat-Sun 9am-5pm)

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

riprap

www.riprap.org.uk

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

Winston's Wish

www.winstonswish.org.uk

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

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

Samaritans

www.samaritans.org

Freephone: 116 123

Offer a safe place for you to talk any time you like, in your own way, about whatever's worrying you. You don't have to be suicidal to contact them.

Sue Ryder

www.sueryder.org

Tel: 0808 164 4572

Provides hospice and medical care as well as practical and emotional support and information.

The Compassionate Friends

www.tcf.org.uk

Helpline: 0345 123 2304 (everyday 10am-4pm and 7pm-10pm);

Northern Ireland 0288 77 88 016 (10am-4pm and 7pm-9.30pm)

Support for people whose child has died at any age and from any cause.

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

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

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

Give us your feedback

We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions.

Email us at **publications@pancreaticcancer.org.uk** or write to the Information Manager at the address on the back cover.

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

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