



Pancreatic cancer and end of life care

Information for people in the last few
months of life

Introduction

This booklet is for people with pancreatic cancer in the last few months of life. It may also be helpful for your family.

It explains the symptoms you may get and how to manage these. There is also information about accessing care, planning future care and making plans for after you die.

We also have a booklet for family and friends of people who are dying of pancreatic cancer:
**What to expect in the final weeks and days of life.
When someone close to you has pancreatic cancer.**

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How to use this booklet

You may find some of this information upsetting or difficult to read. You don't have to read this booklet all at once. Read the sections that feel most helpful, and come back to it if you need to know more.

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

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

Read more on our website at:

pancreaticcancer.org.uk/information

Order or download our free booklets at:

pancreaticcancer.org.uk/publications

Questions to ask your healthcare team

Things you can do to help yourself

At the end of the booklet there is:

- a list of common medical words on page 55.
- contact details of the organisations we mention on page 57.

Coping when you are approaching the end of your life

Key facts

- If you have been told you are approaching the end of your life you may have a huge range of emotions.
- You are not alone. There are people who can support you.
- Our specialist nurses on our free Support Line can provide emotional support and answer any questions you have.
- Hospices and local cancer centres can also provide free emotional support.
- Counselling can help you talk about your feelings in a safe space.
- You can speak to someone about your beliefs and spirituality, such as a chaplain.
- If you have financial worries, you can get advice and support from a range of charities including Citizens Advice.
- The support we mention in this section is also available for your family.



It is natural to find it hard to deal with the news that you are approaching the end of your life. You may have lots of different emotions.

This section explains how to get emotional support for you and your family if you need it.

Who can support me?

It is ok to ask for help. You don't have to face this alone.

Your healthcare team may be able to provide emotional support as well as medical care. You may see a palliative care team, who can provide emotional support to you and your family. Read more about palliative care on page 15.

You can talk to someone about your beliefs or spirituality.

Some people find it helps to speak to a chaplain. They have links to all faith groups, either religious or non-religious. Most hospitals and hospices have a chaplain. Or you may wish to speak to your local faith leader.

Hospices, charities and local cancer centres, like Maggie's, can provide emotional support. For example, they may run group sessions where you can meet other people with cancer. Some, like Marie Curie, can also offer emotional support at home. Ask your GP or nurse about any local services. Read more about hospices on page 20.

You can talk through your worries and questions with our specialist nurses on our Support Line.

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

Counselling

Counselling gives you a safe place to come to terms with your feelings and find ways to cope. It's confidential, so you can be honest about how you feel.

Speak to your GP or nurse about what counselling is available. If you think counselling would help, try to get a referral as soon as possible as there may be a waiting list. Your local hospice may offer counselling.

What about financial help?

Finances can be a worry for people near their end of life.

Macmillan Cancer Support and Citizens Advice provide expert advice and help with claiming for financial support. Some hospices and palliative care teams have welfare rights advisors who can give advice about benefits.

We also have tips that might help at:

pancreaticcancer.org.uk/money



Questions to ask your medical team

What support is there to help me cope?

How can a counsellor help? Can you refer me?

What local services can help?

Talking about dying

Key facts

- It can be hard to know how to start conversations about dying.
- Talking openly about your feelings and wishes can help your family and medical team support and care for you.
- If you have young children or teenagers in the family, be honest and explain what is happening.
- Speak to your healthcare team about any questions or worries you may have.
- Writing down your questions before your appointment can help with these conversations.
- Talk to those close to you about how you would like them to support you.

“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.”

How can I talk to my family and friends?

It can be difficult talking to those close to you about dying. 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.

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.

If you find that you are having to tell lots of people about what's happening, you could ask one person to update the rest of your family and friends for you.

Talking to children

For most children and teenagers, it's best to be honest and explain what's going on. You may feel you want to protect them, but even very young children often sense when something is wrong.

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. You may worry about getting upset in front of children, but this can help them understand that it's okay for them to be upset too. Don't worry if they listen to what you tell them but don't seem to react. This is normal and doesn't mean they haven't understood.

Getting support for children

It can help to speak to their school, as school staff can provide support. They may also find it helpful to be aware of what's going on at home, for example in planning schoolwork, or if the child's behaviour changes. Students can talk to their college or university, who can provide support and help them with their workload.

Winston's Wish provide support to help you talk to children about serious illness. Many hospices and palliative care teams have counsellors who can help you talk to children.

We have a list of organisations that can help support children and teenagers on our website, at: pancreaticcancer.org.uk/supportforchildren

Making memories

Making memories can be a positive experience for everyone. If you are well enough, this might be going on a trip or doing activities with family or friends. Or you might want to make a memory box, write messages for your loved ones, or simply spend time together looking at photos and talking about things you've done together. You could also try making video or voice recordings.



“Mum was diagnosed and immediately referred for palliative care. Our focus was very much on making memories and we especially wanted to fulfil her last wish to go to the seaside. The journey took 4 hours with having to stop for mum to be sick, but we made it. We surprised her with a beach hut we had booked out and had the BEST time together. Fish & chips by the sea, ice creams, looking at the little shops and mum sitting by the sea enjoying the sun and salty air. We made her wish come true, and we’re left with such special memories of that day.”

Laura and Amy

Talking to health professionals

You may want to know how long you have left to live and what will happen over the coming months. Your doctors and nurses will be able to support you and answer questions.

What can help with talking to health professionals?

If you find talking to your doctor or nurse hard, these things may help.

- Think about how much you want to know.
- If you wish, you can give your doctors and nurses permission to speak to your family and answer their questions without you being there.
- Write a list of questions to ask your doctor or nurse.
- You might find it helpful to have someone with you for support and to take notes.
- If you want to know how long you might have left to live, ask your doctor direct questions. They may find it difficult to give a clear answer, but they should be able to give you information based on your situation.
- Some people prefer not to know how long they may have left and live each day as it comes. The doctors and nurses will respect this decision.
- Tell your doctor or nurse what you hope will happen in the future. But think about what you want if things don't go to plan, for example if you can't be cared for where you would like. Read more about planning your care on page 22.



Questions to ask your healthcare team

How long do I have left to live?

What symptoms might I get in the coming weeks?

How do I record my wishes for my future care?

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

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

What support is there for my family?



Your care

Key facts

- As you approach the end of your life, your care will focus on managing any symptoms you have, as well as supporting you emotionally and practically.
- Your care will aim to help you carry on doing things you enjoy, and to live as comfortably as possible.
- You may get this care from a specialist palliative care team. They are experts in managing complex symptoms like pain that's difficult to control, and can provide emotional and psychological support.
- Hospices provide specialist palliative care for people with an illness that can't be cured. They are not just for those at the very end of their life. Hospices may also offer complementary therapies, spiritual care and support for your family.
- GPs, district and community nurses can provide palliative care at home.
- Where you are cared for will depend on your needs and preferences.
- It can be useful to think early on about your future care. For example, where you would like to be cared for and any treatments you do not want to have.
- Talk to your doctor about your future care as early as you like. You do not have to wait for them to speak to you.

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

If you need information and support, you can always contact our specialist nurses on our Support Line.

What is palliative care?

Palliative care teams help people with cancer that can't be cured to live as well as possible for as long as possible. They provide specialist care to manage symptoms such as pain, and emotional symptoms like depression and anxiety. They provide support to family members too.

Early palliative care can help manage your symptoms more effectively. It's a good idea to ask your medical team or GP about a referral to palliative care early on.

Palliative care may be provided in:

- your home – see page 17
- hospices – see page 20
- hospitals – see page 21
- care homes – see page 21.

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.

They provide specialist care for people who may need more complex palliative care. For example, they can help if pain is hard to control.

Not everyone will need specialist palliative care services. Many people will have palliative care that is provided by the GP and district nurse (see page 17). They may also arrange support from the specialist palliative care team if you need this.

Choosing where to receive care

You can speak to your doctor or nurse about where you would like to be cared for. It's a good idea to do this as early as you can because it can take time to get some things in place. You may also want to think about where you would like to die and discuss this with them. This can be recorded in any plans you make about your care (see page 22).

Your doctor or nurse will try to arrange support and care so that you can be cared for where you wish. But 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.

Let your doctor or nurse know if your wishes about where you want to be cared for and die change.

Care at home

You may want to be cared for and die at home. Your GP, district nurse or community palliative care nurse will organise your care at home and will be your main contact.

It can take some time to arrange care and equipment (see page 19) at home, so try to organise this as early as possible. Ask your GP or nurse to help you with this.

There are different nurses that can help you at home, and they provide different types of care. Your GP can refer you to the nursing teams in your area.

- **District nurses** (also called community nurses) may provide a lot of your palliative care, including nursing care and emotional support. They will work closely with GPs, social services, and other services to arrange your care.
- **Specialist nurses** (palliative care nurses, hospice nurses or Macmillan nurses) help people living with cancer and their families. This might include managing pain and other symptoms, giving practical advice, and emotional support. They work alongside the district nurses and GP.
- **Marie Curie nurses** or **Hospice at Home nurses** give nursing and personal care at the end of life. This is often at night so your family can rest.
- **Marie Curie** has information about their nurses and hospices on their website.

If you need help in an emergency, contact the GP or district nurse. Read about out of hours services on page 30.

Can I get personal care at home?

Care workers can help you with everyday care such as washing, dressing and eating. You can have long-term help or short periods of care, for example, to give your family a rest.

Ask your GP, district nurse, or community palliative care team to help arrange care workers at home. The hospice or hospital can also help with this if they are involved in your care. It can take some time to organise care workers. You might need to contact different teams and agencies.

Funding for personal care

In England, Wales and Northern Ireland you may be eligible to have your care arranged and paid for by the NHS. This is called **continuing healthcare**. Your doctor or nurse will assess you to see if you are eligible. If your health is getting worse quickly, you may be able to have your assessment fast-tracked. Ask your medical team about this.

In Scotland, you need to ask your council's social care team to carry out an assessment to work out what you need. Tell the social care team if you need the assessment urgently.

Read more about organising care at home at:
pancreaticcancer.org.uk/socialcare

“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 and so on.”

Equipment at home

You may need equipment to help you manage at home, such as a commode (portable toilet) or hospital bed. The district nurse or an occupational therapist will see what equipment you need and help you to get it. An occupational therapist is a professional who helps people be as independent as possible.

If you are being treated in hospital, the occupational therapy team may assess you before you go home and order any equipment you might need.

Your local hospice or charities such as the British Red Cross may also be able to lend some equipment.

Read more about how to access support at home at:
pancreaticcancer.org.uk/care

When it's not possible to stay at home

It's not always possible to stay at home, as it can sometimes be difficult to get the care that you need.

If you need treatment to manage your symptoms, you may go into hospital or a hospice for a short time. If you need longer-term care for weeks or months, you may go into a care home (see page 21).

Care at a hospice

Hospices provide specialist palliative care. You can go to the hospice for an appointment or for the day to use their services before returning home. Or you may stay at the hospice for a period of time, for example to get symptoms under control. Some hospices also have 'Hospice at Home' services, which provide nursing care at home (see page 17).

What services do hospices offer?

Hospices are free. The services each hospice offers can vary and not all will provide the services mentioned below.

Hospice services may include:

- support from specialist palliative care doctors and nurses
- managing symptoms, such as pain
- physiotherapy or occupational therapy
- emotional and social support
- spiritual support, such as speaking to a chaplain
- support for your family, including for children, and bereavement support
- practical and financial advice
- complementary therapies, such as massage and aromatherapy, to help deal with symptoms.

Your nurse or doctor can refer you to a hospice. Contact your local hospice or go to their website to find out about their services. Hospice UK has details of hospices in the UK.

“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.”

Care in hospital

You may need to go to hospital, for example, in an emergency. Hospitals have their own palliative care teams. If you are not seen by the palliative care team, you should ask to be referred.

Being cared for in a care home

You may be able to stay in a care home for a short time or long-term if you can't manage at home. Some care homes offer nursing care and palliative care. Others will just offer personal care, such as helping with washing, dressing and eating. If the care home does not offer palliative care, the community palliative care team should still be able to see you.

You may be able to get funding to stay at a care home. Ask your GP, nursing team, hospital or hospice to help you with this. You may need to have an assessment to see what support you need. If you do need to pay for a care home, ask your healthcare team what funding may be available.



Questions to ask your healthcare team

Can you refer me to the palliative care team?

What palliative care services are there locally?

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

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

Can you help me plan my future care?

Planning your care

Thinking about the care you want in the future makes it easier for your family and medical team to plan your care and follow your wishes. As you become less well, you may be less able to make decisions or tell your family or medical team what you want. Talk to the medical team if there's anything you are worried about, so they can support you. It can be difficult to think about your future care, but it can help you feel more in control.

Planning your care is called **advance care planning**. There are different ways to make decisions about your care and record them. Ask your medical team to help you with this, or you can make your own record. You may also wish to talk to people close to about your decisions about your care.

Your wishes may change, and you can change your care plan at any time. If you have given your plan to your healthcare team, remember to tell them if your wishes change.

Advance statement (also called advance care plan, future care plan or preferred priorities for care)

An advance statement is a written record of your wishes for your future care. This means there is a guide if you become too ill to make decisions for yourself. You can ask someone from your medical or palliative care team to help you write it.

You can include anything that is important to you, such as:

- where you would like to be cared for
- treatment you would or wouldn't want in an emergency
- religious or spiritual beliefs that you would like to be reflected in your care
- cultural practices that are important to you, before and after death
- for LGBT+ people, ensuring that your partner is fully recognised in care and funeral decisions
- for transgender people, access to trans healthcare at the end of your life, and respect for your identity
- where you would like to die
- who you want to be with you when you die.

Keep a copy of your advance statement. Give copies to your medical teams, GP and people important to you, so they all know your wishes.

An advance statement is not legally binding. Although everyone will do their best to follow your wishes, this is not always possible. So do think about what you want to happen if your preferred choices are not possible.

You can write your own advance statement or use a template. Compassion in Dying has a template on their website.



Advance decision to refuse treatment

This is sometimes called a living will. In Scotland, it is called an **advance directive**. It allows you to record **treatments you do not want to receive** if you can't make or communicate a decision about your care in the future. For example, you may not want treatment to extend your life once your cancer advances to a certain stage.

You can't use an advance decision to ask for a specific treatment, only to say you do not want a treatment. You can update an advance decision at any time.

An advance decision is legally binding in England, Wales and Northern Ireland. In Scotland the decision is not legally binding but should be taken into account by your doctors. Compassion in Dying has an online template for an advance decision.

Deciding about resuscitation

As part of the advance decision to refuse treatment, your healthcare team may talk to you or your family about a ReSPECT or DNR (do not resuscitate) form. These forms are used to record a person's decision not to be resuscitated. Resuscitation is the treatment given if your heart stops beating, or you stop breathing.

This can be a difficult decision to make, and your healthcare team will talk you through it in detail. You may want to talk to those close to you about this decision.

It's important to make sure that your GP is also aware of your wishes to refuse treatment.

Lasting Power of Attorney

A Lasting Power of Attorney is a legal document. You can name one or more adults you trust to make decisions on your behalf if you are not able to yourself.

Types of Lasting Power of Attorney

In England, Wales and Scotland, there are two types of Lasting Power of Attorney. One allows someone to make decisions about your health and welfare. The other type is for your property and finances.

You will need to register the Power of Attorney, which will involve paying a fee. It can take up to 20 weeks to register, so it is best to think about this as early as you can. You can find out more at GOV.UK. You may also want to get advice from a solicitor, or from Citizens Advice.

In Northern Ireland, there is an Enduring Power of Attorney for your property and finances, but there isn't one for health and welfare. If you are no longer able to make decisions about your care, your healthcare team should speak to the people close to you. But they don't legally have to follow their wishes.

Tell the person you have appointed as Power of Attorney if you have an advance statement or advance decision to refuse treatment.

“We decided to transfer my husband’s car into my name, which gave us one less complication to worry about or sort out when it came to financial matters”

Symptoms towards the end of life

Key facts

- Symptoms can include pain, fatigue (extreme tiredness), sickness, weight loss and bowel problems.
- Your symptoms may change in the last months or weeks of life, and you may get new symptoms.
- You may become less mobile, feel weak and be less able to do your everyday activities. This is normal.
- There are ways to manage most symptoms. Speak to your doctor or nurse about any symptoms you have.
- Ask who to contact if you get new or worse symptoms.
- Ask your GP or nurse for an out of hours number for help with symptoms at night or the weekend.
- Tell your doctor or nurse straight away about any pain. The sooner you get treatment, the better the chance of getting the pain under control (see page 31).
- Taking pancreatic enzyme replacement therapy (PERT) when you eat can help with problems with digestion.

This section explains symptoms and how they can be managed. Not everyone will get all the symptoms here.



What can I do?

Speak to your doctor or nurse about any symptoms, including new symptoms or if any symptoms get worse. It's important to tell them about:

- any new pain, including back or neck pain
- numbness in your arms, legs or around your bottom
- problems controlling when you poo or pee (incontinence)
- breathlessness
- swelling and pain in your leg
- swelling in your tummy
- jaundice
- feeling more thirsty than usual, and weeing more
- being sick.

Ask them to review your symptoms. They will work out the best way to manage your symptoms and make you as comfortable as possible.

If you have any questions about symptoms you can talk to our specialist nurses on our free Support Line.

What if I need help with symptoms out of hours?

Your GP, community nurse or palliative care team should explain what to do if you need help with symptoms at night, or at the weekend. You should have a phone number for out of hours services. If you haven't been given one, ask the palliative care team or GP.

If you live in England, Wales or Scotland, you can call the NHS on 111 or use NHS 111 online for advice out of hours. In Northern Ireland, there are local out of hours phone numbers on the nidirect website. Your GP answer phone message may also have an out of hours number.

“Don't hold back on asking for help or pain relief because it is the night time or you don't want to bother anyone. It is important to call and get the medicines before the pain gets worse.”

Just in case medicines

As your health changes, your medical 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**. 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.

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 about any new pain or if your pain gets worse. The sooner you get treatment, the better the chance of getting the pain under control.

You can read more about 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 give you a steady flow of painkillers. This means that you get your pain relief continuously.

A syringe driver is a small machine which is attached to a needle that is put in under the skin. It can also be used for other medicines, such as anti-sickness medicines. Or it can be used if you can't swallow tablets, or you are being sick.

You can move around while using a syringe driver, and can use it at home as well as in hospital or a hospice.

Extreme tiredness (fatigue)

Fatigue is common for people approaching the end of their life. Fatigue isn't the same as just feeling tired. You might feel drained or exhausted. You may sleep more than usual and feel less able to do everyday things. You may also have problems concentrating and remembering things.

What can I do?

- Tell your doctor or nurse if you have fatigue. They can look at the cause and how to manage it.
- Physical activity may help if you feel up to it. You could try a short walk or using the stairs.
- Don't try to do everything on a good day, as it might make you more tired for the next few days.
- Ask to see an occupational therapist. They can help you with ways to save your energy.
- Try to have a time when you nap each day. But try to avoid sleeping too much during the day, as this can upset your sleep at night.

Find more tips for fatigue, in our booklet:

Fatigue and pancreatic cancer

Or 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 digesting food

Pancreatic cancer can cause problems digesting food. This can cause symptoms such as discomfort after eating, bloating, appetite loss, weight loss, and changes to your poo.

Pancreatic enzyme replacement therapy (PERT) helps to break down your food, and can help manage these symptoms. There are different brands of pancreatic enzymes, which include Creon®, Nutrizym® and Pancrex®. You should take pancreatic enzymes with food for as long as you are still eating.

If you are still eating but have not been given PERT, speak to your medical team about it. If you are no longer able to eat you do not need to take pancreatic enzymes.

Taking PERT if you are in hospital or a hospice

If you go into a hospice or hospital and are taking PERT, tell the staff about this. Healthcare professionals who are not specialised in pancreatic cancer may not know about it. Explain that you need to take it with food, milky drinks or nutritional supplements, to help digest these. It may help to keep the capsules by your bed.

Hospices or hospitals sometimes look at all your medicines and stop any that are no longer needed. Tell them why you still need to take PERT. It's very important that you take it if you are eating or taking nutritional supplements, to help you digest your food.

Read more about PERT in our booklet:

Diet and pancreatic cancer

Or at: pancreaticcancer.org.uk/pancreaticenzymes

If you have any questions about digestion or PERT, speak to our specialist nurses on our Support Line.

Weight loss and reduced appetite

In the last few months and weeks of life you may gradually feel less like eating. This is normal. As your body slows down, it needs less food. The cancer can also reduce your appetite, and symptoms such as sickness, pain or fatigue may put you off eating.

People in their last months of life can develop cachexia. This is extreme loss of muscle and fat. You may lose a lot of weight, which may mean you look different. Eating more won't help you put on weight. People with cachexia can also feel very tired and weak. Talk to your doctor or nurse if you want more information about cachexia.

Eating less and losing a lot of weight can be upsetting for both you and your family. It can be difficult if you don't feel like eating and you are losing weight. But remember that this is normal. Try not to worry about how much you are eating or about putting weight back on.

What can I do?

- Speak to your doctor, nurse or dietitian for help with weight loss. Tell them about anything that is stopping you eating such as pain or sickness.
- It's fine to eat and drink what you feel like, even if that's only small amounts.
- Try having small meals or snacks. Soft food such as soup, yoghurt or ice cream may be easier to eat.
- You might find it easier to have drinks like milkshakes, smoothies or nutritional supplements.
- Try to keep having meals together as a family, as the social part of eating together can help.
- You should keep taking PERT (see page 33) while you are eating. But you can reduce the amount you take if you are eating less.
- Gentle physical activity can help increase your appetite, and maintain your strength and fitness.

Your doctor or nurse may refer you to a dietitian for help with eating. They may suggest changes to your diet to increase the amount of energy and protein in your diet, or suggest nutritional supplements. This can help you feel better and have more energy.

Find examples of high calorie foods at:

pancreaticcancer.org.uk/diettips

Diabetes

If you have diabetes, the way your diabetes is managed may change as you approach the end of your life. For example, you may not need to monitor your blood sugar levels as much, and higher blood sugar levels may not be a problem if you are feeling well.

Speak to your doctor or diabetes nurse for advice about how to manage your diabetes. They may talk to you about changing the dose or type of diabetes medicine you take if, for example, you are eating less or have problems swallowing. They can also give you advice about how to manage diabetes alongside your other medicines, such as PERT (see page 33).

You can read more about managing diabetes at:

pancreaticcancer.org.uk/diabetes

Feeling and being sick

Pancreatic cancer can make you feel and be sick (nausea and vomiting). This is unpleasant and distressing. If you are sick, you may not absorb medicines, such as pain relief.

Speak to your doctor or nurse if you are being sick. They may give you anti-sickness medicines. These may be tablets or injections, or you may have them through a syringe driver (see page 31).



If you have been vomiting for a day or more, contact your GP, district nurse, or your GP out of hours service. 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). Read more about dehydration on page 43.

What can I do to help with sickness?

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

- Try eating small meals. You may feel worse if you have an empty stomach, so try to eat something – even some toast might help.
- Eating foods that are high in calories and easy to digest may be helpful – speak to your doctor, nurse or dietitian about this.
- Sit up after eating. If you feel up to it, you could try to move around after meals.
- Drink small amounts regularly during the day.
- Some people find eating a biscuit or cracker, grated ginger in hot water, ginger biscuits, peppermint tea or sucking sugar-free sweets helps.

If the cancer is blocking the duodenum

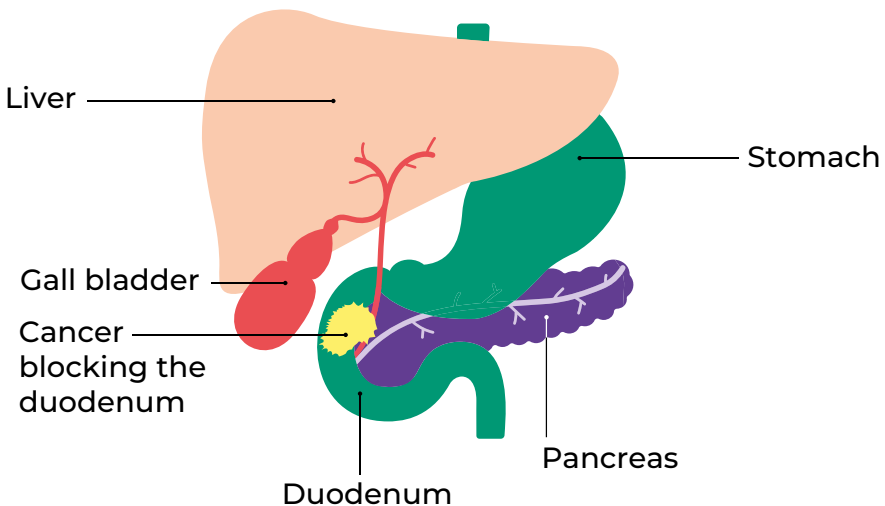
If the cancer blocks the duodenum (the first part of the small intestine), this can cause sickness and make you feel full. This is because food can't pass out of the stomach.

It can also cause indigestion and reflux. Reflux is when some of the contents from your stomach, including stomach acid, move from the stomach into the throat.

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. You may also lose your appetite, lose weight and have pain, cramping and bloating in your tummy.

Your doctor will give you medicine to manage the sickness as well as any other symptoms, such as pain.

Diagram showing the cancer blocking the duodenum



How is a blocked duodenum treated?

Some people with a blocked duodenum may be able to have a tube called a duodenal stent put in. This opens the blockage so that food can pass through. This should stop you feeling sick and you should find it easier to eat.

A duodenal stent won't be suitable for everyone. You will need to be fit enough to have the procedure.

Some people may have their stomach drained to stop them being sick. This may be done with a nasogastric tube, which is a tube that passes up your nose and down into your stomach. Fluid and air from your stomach are drained back through the tube. This may help you feel better.

Read more about a duodenal stent on our website at:
pancreaticcancer.org.uk/duodenalstent

Read about diet after having a stent put in at:
pancreaticcancer.org.uk/stentdiet

If the stomach is emptying slowly

Pancreatic cancer can affect the nerves and hormones that control the stomach. If this happens, food passes through the stomach more slowly, making you feel sick, feel full quickly, and feel bloated. This is called delayed gastric emptying or gastroparesis.

Your doctor or nurse may give you medicines to help the stomach empty. They can also give you medicine to help with symptoms, such as anti-sickness medicines. Sometimes it may be possible to drain your stomach using a nasogastric tube (see page 40).

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

Bowel problems

Pancreatic cancer and treatments can cause bowel problems, such as:

- **finding it hard to poo** (constipation)
- **runny poo** (diarrhoea)
- **pale, oily poo** that floats, smells horrible and is difficult to flush down the toilet (steatorrhoea).

Speak to your doctor or nurse if you have any bowel problems. They can work out what is causing it and find ways to help manage it.

Constipation

Constipation can be very uncomfortable. It can cause bloating, pain and make you feel or be sick. Speak to your doctor or nurse if you have constipation.

You may be more likely to get constipation if you are not moving around or eating much, or are dehydrated (see page 43). It can help to drink plenty of fluids, if you can.

You may get constipation if you are taking strong painkillers called opioids, such as morphine. You should be given medicines called laxatives to take with opioids. These prevent constipation.

Take the laxatives regularly. If you struggle to take laxatives, it is important to continue taking the opioid painkillers, and speak to your medical team. They may be able to help you find a way to deal with the constipation.

You can read more about painkillers and constipation in our booklet: **Pain and pancreatic cancer**
Or at: **pancreaticcancer.org.uk/opioid**

Diarrhoea

Diarrhoea can be caused by different things, such as the cancer, some medicines, or an infection.

If your diarrhoea doesn't get better, or you have diarrhoea several times a day, tell your GP or nurse.

If you have diarrhoea, try to keep your bottom clean using wipes or damp cotton wool. Wash the area using gentle soap and water, and pat dry. Wear cotton underwear and loose fitting clothes. If your bottom is sore, your nurse may recommend a cream to use.

Try to drink plenty of fluids so you don't get dehydrated (see page 43). It can be easier to have small, frequent sips.

What is dehydration?

Dehydration is where your body loses more water than it takes in. It may be more likely if you have diarrhoea or are being sick.

If you are dehydrated you might have dark pee, headaches, feel thirsty, dizzy or light headed. Speak to your doctor or nurse if you have diarrhoea or are vomiting and have any of these signs. They may be able to treat the dehydration, or help you get more fluids if you are not drinking as much as you normally would.

Overflow diarrhoea

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, you may be taking laxatives to prevent constipation. If you think you have diarrhoea, don't stop taking the laxatives and don't take any medicines to stop diarrhoea. It may be overflow diarrhoea. Speak to your nurse about what to do. They can work out what is causing it and how to manage it.

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. You may also find it difficult to get comfortable when lying down, or on your side. Use pillows to prop yourself up when you sleep.

How is ascites managed?

If you have any of these symptoms, tell your doctor or nurse. Depending on how well you are, the fluid may be drained off to make you more comfortable.

The fluid can build up again and you may need to have it drained more than once. Some people may have a permanent drain put in so the fluid can be regularly drained by the district nurse at home. This will not be suitable for everyone.

If the fluid can't be drained off, your medical team may use a medicine called a diuretic and painkillers to help manage your symptoms. Diuretics may help reduce the fluid, although it doesn't always make a big difference.

What is oedema?

Fluid can also build up in other parts of your body, such as your arms, legs, feet and genitals. This can cause swelling, and is called oedema. Oedema can be uncomfortable, painful and make it harder for you to move around.

How is oedema managed?

Tell your doctor or nurse if you have any swelling. They may suggest pressure stockings to help control the swelling, and exercises to help the fluid drain away. Putting your feet up when you are sitting down can help. Try to have your feet higher than your hips if possible.

It is also important to look after your skin by moisturising the swollen areas. Ask your nurse what moisturiser to use. Tell them if you get any cracks in your skin in these areas.

Sometimes you may be offered medicine 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 by the cancer. The bile duct carries a fluid called bile (which helps with digestion) 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 have darker pee and paler poo.

If you get jaundice, your doctor or nurse will decide whether you need a biliary drain or a stent.

- **A biliary drain** is a small tube that is put through your skin into the bile duct, and drains the bile into a bag.
- **A biliary stent** is a small tube that is put into the bile duct to open up the blockage.

Your doctor or nurse will treat any symptoms you get. They may give you medicine to help with any sickness or itching. They may also suggest a cream for the itching. Wearing loose clothing, keeping the area cool, and drying yourself by patting with a soft towel can all help the itching.

Read more about biliary stents on our website at:
pancreaticcancer.org.uk/biliarystent

Bedsores

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

Bedsore 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 a chair. They can be painful, and if they aren't treated they can become infected. Your nurse should check whether you are at risk of bedsore.

Signs of a bedsore are red skin or skin that doesn't turn white if you press it. The area of skin may also feel warm or hard. If you notice this, tell your nurse so they can check it.

How can bedsores be prevented?

- The best way to prevent bedsores is to change position. Your doctor or nurse may suggest you change position every few hours and show you how to do this. If you are not able to move yourself, you will need help from your family or healthcare team.
- Your doctor or nurse can arrange special equipment to help, such as pressure cushions for your chair and a mattress for your bed.
- If your skin is wet or inflamed, the nurse may give you a cream which can help prevent bedsores.

Tell your nurse if you have any sore areas of skin. Ask them how to prevent bedsores.

If you develop a bedsore, your nurse should check it regularly. You should be given a pressure relieving mattress or pressure cushions. Your nurse will discuss any other treatments with you. For example, you might have a dressing put on a bedsore to protect it and help it heal.

“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. It can also make it harder to chew or swallow food. You may need more time to talk, or to take sips of fluid more often when you are talking.

What can help?

- Try to keep your mouth clean by brushing your teeth regularly and using mouthwash.
- Try chewing gum, taking regular sips of drinks and sucking ice cubes or ice lollies. Eating refrigerated pineapple cubes can help too.
- Use a small spray bottle to mist your mouth with water.
- You can also get products from the pharmacy.
- Use a lip balm to stop your lips getting dry.

Read more about how to deal with a dry mouth in our booklet: **Diet and pancreatic cancer**
Or 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 your daily life and you may feel less able to cope with other symptoms. Symptoms of depression include difficulty sleeping, extreme tiredness, loss of appetite and feeling hopeless.

What can help with anxiety and depression?

Support in dealing with the cause of anxiety or depression might help. This might include managing any symptoms, planning your future care (see page 22), 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 also help.

You can speak to your GP, nurse or specialist palliative care team for support with anxiety and depression. Read more about getting emotional support on page 4.



Questions to ask your healthcare team

How can my symptoms be managed?

Who can I talk to about my anxiety and depression?

How will my medicines change as I become less well?

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

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



Can complementary therapies help?

Some people find that complementary therapies can help them to relax and feel better. Complementary therapies can't treat the cancer. But they can be something pleasant to look forward to.

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

- Acupuncture is a treatment that involves putting very fine needles into different parts of the body. Some people find it can help with symptoms like pain and sickness.
- Massage may help you relax. Check with your doctor or nurse if it is safe for you to have a 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.

Some hospices, hospitals and charities offer complementary therapies. Ask your nurse what is available in your area.

Read more about complementary therapies at:
pancreaticcancer.org.uk/complementarytherapies

Making plans for after you die

Some people feel comforted to know that they have made plans for what should happen after they die. This might include making a will, planning a funeral, or making sure your family and pets are looked after.

Making your will

A will is a way to take control of what happens to your money and property when you die. It is a good idea to do this early on, so that it's one less thing to worry about.

Look at GOV.UK for more information about making a will.

We can also help you make a will through our **Free Will Service**. Depending on where you live, you can make or update your will at home, online or with a solicitor. There is no charge. Find out more at: pancreaticcancer.org.uk/freewill

Planning your funeral

Some people want to plan their own funeral. Others don't want to be involved at all. And some people don't want a funeral.

Thinking about what you would like can be difficult. But letting your loved ones know what you want can take the pressure off them and give them peace of mind. You may want to talk to those close to you about your wishes, or you may find it easier to write them down. Or you could use the The Farewell Guide online funeral planning tool to record your wishes.

You might find these things useful to think about.

- Do you want the ceremony to be religious or non-religious?
- Would you like to be buried or cremated?
- Are there any readings you would like, or certain music played?
- Do you want to choose a charity for donations in your memory?

There are different ways to pay for a funeral, including pre-paid funeral plans, insurance plans or savings. If you or your family need help paying for the funeral, the government has a Funeral Expenses Payment. Marie Curie has information about funeral costs.

“She planned her funeral and had a lovely white wicker basket for a coffin, and she had the songs ‘Somewhere Over the Rainbow’ and ‘Never Enough’. She loved The Greatest Showman.” Dan

What's a living funeral?

A living funeral is a way for a person who is dying to celebrate their life with the people they love before they die. A living funeral can be tailored to whatever the person wants. It could include a celebrant who leads it in a structured way. Or it could be more informal, perhaps with friends sharing stories and playing or listening to music.

Other things to think about

There are some other things you might want to plan before you die.

- What do you want to happen with your social media accounts? Cruse has information about managing social media when someone dies.
- Make sure someone you trust has access to your online accounts, email and subscriptions.
- Who will look after your pet? There are charities that can help such as Blue Cross.
- Would you like to leave videos, letters or other items for your loved ones?

More information and support

Medical words explained

Ascites: build-up of fluid in the tummy that may cause swelling (see page 44).

Bile: fluid which helps digestion. The bile duct carries bile from the liver to the duodenum.

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

Duodenum: the first part of the small intestine.

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

Oedema: swelling caused by a build up of fluid in parts of your body (see page 45).

Pancreatic enzyme replacement therapy (PERT): capsules that help digest food when the pancreas isn't producing enough digestive enzymes.

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

We are here for you

If you or someone you care about has pancreatic cancer, we are here to help.

Find out more at: pancreaticcancer.org.uk/support

Our specialist nurse Support Line

Our specialist nurses are experts in pancreatic cancer. They can talk for as long as you need, as often as you like. Whether you have a long list of questions or don't know where to start, they will provide practical, honest information to help you make the right choice for you.

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

Information about pancreatic cancer

Our website, videos and publications can answer your questions. The information can help you understand what you have heard from your medical team, and make decisions about your treatment and care.

Go to: pancreaticcancer.org.uk/information

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

Real life stories

Whether you want to read other people's stories or tell your own, sharing experiences of pancreatic cancer could help.

Go to: pancreaticcancer.org.uk/stories

Useful organisations

Blue Cross

bluecross.org.uk

Their Pet Peace of Mind service rehomes pets after someone dies.

Citizens Advice

citizensadvice.org.uk

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

Compassion in Dying

compassionindying.org.uk

Information line: 0800 999 2434 (Mon-Fri 11am-3pm)

Information on how to plan ahead for the end of life. Their website **mydecisions.org.uk** helps you plan your future treatment and care.

Cruse Bereavement Support

cruse.org.uk

Helpline: 0808 808 1677 (Monday, Wednesday, Thursday, Friday 9.30am-5pm and Tuesday 1pm – 8pm)

Support and information to people who have been bereaved.

GOV.UK

gov.uk

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

Hospice UK

hospiceuk.org

Tel: 020 7520 8200

Information and a database of hospices in the UK.

Macmillan Cancer Support

macmillan.org.uk

Support Line: 0808 808 00 00 (Everyday, 8am-8pm)

Support for anyone affected by cancer.

Maggie's

maggies.org

Centres around the UK and online offering free, expert care and support for anyone affected by cancer.

Marie Curie

mariecurie.org.uk

Support Line: 0800 090 2309

(Mon-Fri 8am-6pm, Sat 11am-5pm)

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

NHS 111 online

111.nhs.uk

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

nidirect

nidirect.gov.uk

Information about local services in Northern Ireland, including health services and registering a death.

The Farewell Guide

thefarewellguide.co.uk

An online service to make funeral planning simple.

Winston's Wish

winstonswish.org

Helpline: 08088 020 021 (Mon-Fri 8am-8pm)

Provide support to children and young people who have been bereaved and those who care for them.

This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK.

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

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

- Samantha Arter, Community Palliative Care/Nutrition Support Dietitian, Ealing Community Partners
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- Pancreatic Cancer UK Specialist Nurses

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

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