Supportive and End of Life Care for Pancreatic Cancer

Palliative care and life with advanced pancreatic cancer.

Understanding pancreatic cancer booklet 6

In this booklet you will find information about living with a diagnosis of advanced pancreatic cancer. It will help you to understand what palliative care is, support available to you and how to prepare for the end of life.

Understanding Pancreatic Cancer – Patient Information Booklets

Receiving a diagnosis of pancreatic cancer can be an upsetting, stressful and confusing time. We have listened to patients, relatives and carers to understand what information is useful. Our patient information booklets are easy to understand and beneficial to have at hand to answer any questions or concerns you may have.

All of these publications are produced under the Information Standard certified scheme and are reviewed by medical professionals and patients/carers who have been affected by pancreatic cancer.

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Introduction

What is pancreatic cancer?

Pancreatic cancer occurs when a malignant tumour forms in the pancreas.

Worldwide there are around 496,000 new cases each year; in Europe that figure is more than 104,000. In the UK, approximately 10,500 people are newly diagnosed each year.

Pancreatic cancer affects men and women equally with incidence increasing from the age of 45. The average age at diagnosis is 72.

There are two main types of pancreatic cancer:

Exocrine tumours

These make up the vast majority of all pancreatic cancers (around 95%) and come from the cells that line the ducts in the pancreas which carry digestive juices into the intestine.

These are called pancreatic ductal adenocarcinomas.

Other exocrine tumours of the pancreas are rarer, and include adenosquamous carcinomas and undifferentiated carcinomas.

Endocrine tumours

These are also known as neuroendocrine tumours, (NETS) and are less common. The neuroendocrine tumours we discuss here are found in the pancreas and are called pancreatic neuroendocrine tumours (pNETS).

These are tumours that develop in our endocrine glands that release hormones (which regulate some processes in our bodies), these are then circulated around the body.

Other rare tumours that can affect the pancreas include pancreatic lymphoma, a cancer that arises from the lymphatic tissue in the pancreas; various cystic tumours and pancreatic sarcomas, which develop in the tissue that holds cells in the pancreas together.

Tumours that arise from tissues close to the pancreas, such as the bile duct (cholangiocarcinoma), Ampulla of Vater (ampullary adenocarcinoma), or duodenum (duodenal adenocarcinoma), may cause similar symptoms to pancreatic cancer but have different treatments and outcomes.

You will have undergone various tests such as ultrasound scans, CT scans and possibly had an endoscopy to determine that you have pancreatic cancer. These tests are important as they will inform the doctors about the size and position of the tumour and whether it's possible to have it surgically removed (resected).

What is the aim of pancreatic cancer treatment?

Treatment for pancreatic cancer will depend on the tumour type, where it is and at what stage it is diagnosed. Stages for pancreatic cancer are described in the table below:

Stage	Tumour
I	The cancer is confined to the pancreas and has not spread anywhere else. This is known as early-stage disease
2	A tumour confined to the pancreas and local lymph nodes (small bean like glands near the pancreas) or tissues around the pancreas like the bile duct
3	The tumour has started to involve large blood vessels near the pancreas, this makes it inoperable. In some cases, the tumour may be able to be shrunk away from the blood vessels using chemotherapy and/or chemoradiotherapy which may make it operable.
4	The tumour has spread to other organs such as the liver or lungs. This is known as metastatic disease. These tumours are non-operable as surgery would not improve the outcome.

Introduction

Treatment varies depending on whether your cancer is operable or not.

If your tumour is operable, Pancreatic Cancer Action produces a separate booklet that you may find helpful - "Surgery for Operable Pancreatic Cancer."

Often, pancreatic cancer is detected when the tumour is no longer operable. Treatments will aim to prevent the tumour growing further and the focus will be on quality of life and making sure that you are as involved in treatment decisions as possible.

This booklet focuses on pancreatic adenocarcinomas, (the most common type of pancreatic cancer). Different tumour types such as pancreatic neuroendocrine tumours (pNETs) may be treated differently and are not covered by this booklet.

You should always discuss your treatment options with your medical team.

What is advanced pancreatic cancer?

If your cancer cannot be operated on, you may have been told that you have advanced cancer. This will likely require further conversations around end of life care with your multi-disciplinary team, family and/or friends.

It is important to realise that this does not necessarily mean that you are dying immediately. It means instead that treatment will focus on your quality of life and managing your symptoms.

Often, because the symptoms of pancreatic cancer can be vague, the disease is difficult to diagnose. Therefore, your tumour may have spread to nearby organs and blood vessels (locally advanced) or to distant organs (metastatic) and it is not possible to operate and remove the disease.

This booklet will provide you with information about the progression of your disease, making plans to have the best quality of life possible and making your wishes and needs known regarding your death.

It can be difficult to face this news and you may wish to read through this information with a friend or family member. Pancreatic cancer action also produces a carers booklet to help the people who care about you most understand what is happening to you.

Who will be involved in my treatment and care?

It is possible that you will have already encountered the phrase "multi-disciplinary team" (MDT). This is a group of health care professionals who are involved in diagnosing and treating your condition. There may be several different people and professionals involved in your care and this is likely to change as your condition changes.

There will be oncologists (cancer treatment doctors) and specialist nurses in the MDT. There may be physiotherapists and occupational therapists who can assist in helping you maintain independence. There may also be dietitians who can give you advice on nutrition.

You might also hear about specialist doctors and nurses from the palliative care team. Some people worry that palliative care involves hospice visits and that they are dying quickly. In fact, palliative care teams can help you in any location to keep as independent and symptom free as possible. They are there to help you and your loved ones with all aspects of your diagnosis including your physical, emotional and social needs.

You may also encounter social workers and other professionals based in and out of hospital to help you cope with your diagnosis and maintain your quality of life. You can approach any of these professionals for help and advice.

Introduction

What is palliative care?

It is likely that you have heard the term palliative care in relation to your treatment. Palliative care is different to end of life care. It is providing the treatment you need to manage your symptoms and give you the best possible quality of life. Palliative care acknowledges that death is a part of life and a natural process. It does not aim to speed up or slow down your death, instead it acts to support you and the people who care about you throughout your disease.

Palliative care can be provided wherever you are and by a number of different professionals. Some doctors and nurses specialise in palliative care, whereas for people like your GP or any carers you may have it is part of their everyday job.

You can have palliative care alongside other treatments and with your current medical team. Palliative care aims to support you with any physical, emotional, social and relationship issues that arise over the course of your illness.

What is end of life care?

End of life care is palliative care for when someone is approaching the end of their life. It focuses specifically on making sure this time is comfortable and meets your wishes.

Palliative and end of life care can help you make decisions about the level of treatment you receive, the places where you receive treatment and what your priorities are for your care.

The idea of being at or moving towards the end of your life can be a frightening and lonely time. Some people want to know as much as possible about what to expect and some people prefer to leave things be. It depends on who you are and what your beliefs are, but this booklet can help you to understand what to expect from palliative and end of life care. It also exists to reassure you that you are not alone, there are many people and services available with the right experience to help.

On our website we have patient stories which may help you to understand what to expect throughout your journey.

Emotional impact of pancreatic cancer

A diagnosis of pancreatic cancer is difficult for both you and the people around you. It will affect every aspect of your life and it can feel as though your world has been turned upside down. People who you would expect to be supportive may become distant, others may be more involved and helpful.

You may feel a sense of disbelief or that you need to be strong for others. You may feel as though you need to pull away from others for a time, to be alone and introspective. Or, you may feel as though you want to have friends and family around you all the time and are afraid of being alone. You may experience a mix of these emotions. There is no right or wrong way to react to what is happening to you. If you respect your feelings then you are doing the right thing.

Being open and honest with friends and family about how you are feeling is the best way to support them and yourself. Remember that they may need time and space occasionally as well.

Fear

Fear is common when people think about dying. It may help to try and find out the cause of your fear. Is it the idea of being alone? Is it the thought of being in pain? Or what happens after you die to yourself and the people you care about? It may be a mixture of these things. Once you can turn your fear into questions you know who you have to go to and what you have to do to answer them.

Anger

You may feel angry that this is happening to you. That is understandable and expected, your life may be ending sooner and taking a different path to the one that you imagined for yourself. It can be difficult to know what to do with your anger, to try and find a way to make it something productive. Directing your feelings, the right way can help you make sure that you prioritise the things you want in life and get the care that you want in the place you want it.

Regret

Sometimes you may view things that have happened in your life with regret. Some people blame themselves for not going to the doctors sooner or look back at their past with regret. Try and remember that this diagnosis is not your fault. Making memories and strengthening your relationships in the here and now may help to build bridges.

Grief

You may feel a sense of grief or loss at what is happening to you. Talking to loved ones may help you share those feelings. Feeling sad and grieving is normal, if you feel a sense of hopelessness or you take no pleasure from things you used to enjoy for a long period of time this may be depression. The link between pancreatic cancer and depression is complicated. Rates of depression are high in people with pancreatic cancer, but it is not a normal part of the end of life process. If you are worried about depression it is important that you speak to your medical team.

Loneliness

You may feel as though you are isolated and alone following your diagnosis. It can feel as though you are the only person in the world who can understand how you are feeling. It may feel as though you cannot talk to other people, either because they cannot relate, or you will upset them. There are people who can support you through this time, family, friends and health care professionals. There is no right or wrong person to talk to or way of dealing with loneliness, as long as you talk to someone.

Our charity provides a range of support, including grief counselling. You can find this under the support section of our website, or by contacting info@griefchat.co.uk

Emotional impact of pancreatic cancer

Difficulty sleeping

Difficulty sleeping is called insomnia. Many people with cancer struggle to sleep at various times. It may be due to medication side effects, poorly managed symptoms or anxiety. Not sleeping well can make you feel worse and make any anxiety or worries greater.

Tips for better sleep include;

- Having a regular bedtime routine
- Being as active as possible
- Avoiding caffeine and alcohol
- Avoiding screen time such as smartphones or computer screens in the hour before bed
- Meditation or mindfulness

If you are still unable to sleep well then discuss it with your GP. You may need a short-term prescription or adjustments in your medication to help you sleep.

Relationships

Your diagnosis is likely to impact your relationships with friends and family. Coping with your emotions can be difficult and relationships can suffer especially if partners or close family and friends do not behave the way you are expecting or want. Being open and talking to people about exactly how you are feeling will encourage them to do the same and mean that you can work through the good and the bad days together.

Sexual intimacy and pancreatic cancer

Pancreatic cancer can change how you feel about your body. Body image can be affected by aspects of the disease such as weight loss that makes people feel less attractive. If your symptoms are poorly controlled, then you may not feel like having sex or being intimate with your partner. Or you may just feel as though you don't have the energy. You may be worried about the effect this may have on your partner. Speak to them about how you feel, being as open as possible. Consider the ways that you can still be intimate with your partner, whether that's curling up on the sofa, or just being in each other's company.

Where do I want to be?

Where do I want to be?

Home

Most people say when asked that they want to die at home where they feel the most comfortable. Dying at home can be peaceful and allow you to be surrounded by friends and family members, however, it can be difficult as you become unwell. However, help with tasks of daily living (washing, dressing), managing symptoms (pain, sickness) and providing equipment (hospital bed, toileting aids) is available. There are many organisations who can assist with this. Social services can aid with assessing the financial burden of caring and can provide care packages to assist throughout the day. District nurses and hospice at home can assist with giving pain relief and controlling symptoms. Palliative or hospice care teams include physio and occupational therapists who can assist with equipment needs as well as specialists in palliative care to answer your questions.

Hospice

Hospice care can be accessed from the moment you are given a terminal diagnosis and is not just for people at the very end of their lives. Hospice care is not just the building itself and can be provided in your own home, in a care home, as a day or short-term hospice patient or in hospitals. Hospice teams can help provide much of the care that you and your loved ones need. They can help with emotional wellbeing throughout your illness and their bereavement. Hospice care is free, they offer short term breaks called respite care as well as longer stays. Some people have a number of hospice visits depending on their symptoms and how they want to manage their care. Entering a hospice does not always mean that you are entering the last days of life. Many hospices will show you around and answer any questions you have.

Care home

If you live in a residential or care home, then the staff working there will be alongside palliative care teams in managing your end of life care with you. You can create care plans together to make sure that your priorities are met. In a residential or care home you can receive care from staff twenty-four hours a day and have support with washing, dressing, toileting and meals. Your friends and family are still able to support you with these tasks if they want to. It is important to communicate with staff so that you, your loved ones and staff all know what is important to you as you move towards the end of your life.

Hospital

Many people are admitted to hospital and stay there at the end of their life. Sometimes people who say that they want to die at home change their mind towards the end of their lives due to symptom control or fear of how they and the people they care about will cope at home. Many hospitals have in house palliative care teams. You will have access to nurses and doctors day and night if need be to ensure that they are comfortable, and pain free and chaplain services are also available for spiritual guidance. Many people find the idea of dying in hospital distressing and it can be difficult to have the same level of privacy as other settings. You or your loved ones can communicate with ward staff about visiting and bringing in comforts from home. Staff will want to make you as comfortable as possible and some people find the knowledge that they are there to be very reassuring.

Support for loved ones

Many people worry about the impact of their illness on their loved ones. Talking about this can be difficult as your friends and family may not want to upset you by explaining how they are feeling. Pancreatic Cancer Action produces a carers booklet to help guide your loved ones through the course of your cancer. Carers UK and Carers Trust are two organisations across the UK who can offer information and support to carers. MacMillan Cancer support offer information on support groups and Cancer Research UK provides information and support to patients as well as families. People find their own ways of coping but sometimes talking to someone outside of the situation like a counsellor can be helpful.

Planning ahead with advanced pancreatic cancer

What are my priorities for my life?

When you are diagnosed with pancreatic cancer and told that your disease is terminal, you probably have a lot of questions. You may be thinking about your plans for the end of your life. It can be difficult to know where to start and how best to make these decisions. It may help to start with a list of questions that you can use as a starting point for how you document and tell your friends, family and medical team about what your priorities are at the end of your life.

It can be easier to break your questions down into who, what, where, when and how? Questions like;

- Who do I want to be providing my care? Who do I want to be there in the last days of my life?
- What level of care do I need? What type of care is available in different places?
- Where do I want to die? Where do I want to spend most of my time?
- When should I make decisions about my treatments? When should I think about stopping some of my treatments?
- How do I make sure my wishes are known by the right people? How will my decisions be funded?

Answering these questions can help you decide how you need to record your wishes, what your priorities are and who you need to talk to make sure this happens. There are lots of ways to plan for the end of your life, you can look through a number of options to make sure that you find the right ways to work for you. These decisions may feel very difficult and like something you would rather avoid but they will give you and your loved ones piece of mind if ever you become unwell and cannot communicate what you want.

Planning ahead

Planning ahead can feel daunting. There are many ways of documenting your wishes, which can feel overwhelming and full of terminology which is hard to understand. Listed below are some of the ways you can make plans for your care and record your wishes. Formally documenting your wishes this way makes it clear and simple for your loved ones and those involved in your care to make decisions if you can no longer. These documents can be overridden by yourself if you have the capacity to do so.

Capacity

Capacity refers to having the mental ability to make decisions. Capacity is specific to the time of the decision and what the decision is. Therefore, some people fluctuate in their capacity so that it is there on some days and not on others, especially if they have an illness which may contribute to them becoming confused, for example a urine infection. Some people have the capacity to make some decisions, but not others. For example, they may have capacity to decide when they would like to get up and dressed in the morning, but not about where they can safely live. Capacity must be assumed; people who lack capacity have to be assessed by a trained medical professional as unable to do one of the following things;

- Understand the information needed to make the decision
- Retain that information long enough to use it in their decision
- Weigh up the information, the pros and cons of the decision
- Communicate their decision effectively

If there is a situation where you lack capacity or are very unwell and unable to communicate your decisions, then the documents you use to record your wishes will be used.

Planning ahead with advanced pancreatic cancer

Advanced care plan/ advance statement

This can be made with your medical team and is used to record your wishes around treatments and care. You can include a range of information such as where you want to be cared for at the end of your life, who you want to be there, religious and cultural beliefs, diet and daily routine. You can have an advanced care plan alongside other documents like a lasting power of attorney. You should make sure that it is easily accessible for medical teams looking after you. It can be written with a doctor or nurse, someone you trust or by yourself. There is no official documentation for an advanced care plan but “dying matters” produces a template to follow. The record you create in an advanced care plan is not legally binding but will be considered by the medical team looking after you.

Advance decision (living will)

This differs from an advanced care plan as it can be used to refuse medical treatments, including lifesaving medicines. You can refuse cardiopulmonary resuscitation (CPR), air way support (ventilation), artificial feeding or antibiotics delivered using a drip. You cannot decline basic nursing care such as washing, and dressing and you must be clear about the situations to which your decision applies. A doctor can help explain treatments to you and make sure your decisions are recorded correctly. There is no official template for this. As long as the decisions are recorded clearly and signed by yourself and a witness, the document becomes legally binding and will be followed by your medical team. Therefore, it is important to make sure that those involved in your care and close family and friends have a copy. You can visit mydecisions.org.uk to generate an advance decision. If you are using the decision to refuse treatment, it will need to be signed at witnessed. The paperwork can be downloaded and printed or filled out online.

Lasting power of attorney

You (the donor) can give lasting power of attorney to allow one or more recipients (attorneys) on health and wellbeing, property and financial affairs or both. This is a legal document which gives attorney’s permission to make decisions on your behalf when you are unable (lack capacity) to do so. Lasting power of attorney can be used alongside an advance decision and if there is any disagreement the most recent document is the one used. Lasting power of attorney can make any decision regarding your health and welfare. As a legal document the lasting power of attorney needs to involve you as the donor, attorney(s), a certificate provider (to demonstrate that you are not being pressured into your choice) and up to five people to be notified when the document is registered. It does not require a solicitor but must be registered with the Office of the Public Guardian which involves a fee. The decision can take 8-10 weeks to be implemented.

Preferred priorities for care document

MacMillan cancer care provide a free template for you document your understanding of your disease and priorities of care. This is not a legal document but would be taken into account by a medical team. It is a space to document preferences and future end of life care, especially where you want to be cared for. This can be shared with people you trust such as family and friends, your GP or a hospital medical team. You can find out more about Macmillan at: Macmillan.org.uk

DNAR forms and CPR decisions

CPR or cardio-pulmonary resuscitation are the measures taken when your heart or breathing stops. Sometimes these measures can be successful, if you choke for example. Sometimes it will not be successful, if you are at the natural end of your life. It can be traumatic, and sometimes if it is successful, you may not recover and spend a lot of time somewhere like intensive care which can be upsetting for your loved ones. If you do not have a DNAR or DNACPR order (do not attempt resuscitation) then medical staff will have to attempt to resuscitate you. The order can be made after a discussion between you and your doctor, they will sign the paperwork and you will need to keep a copy at home with you, it would leave hospital with you if you were discharged for example and would need to be bought in with you. You must have a DNAR decision discussed with you and your family before it is in place and signed by a doctor, therefore it is good to have this discussion early on.

You can find out more information about RESPECT formsrespectprocess.org.uk

Planning ahead with advanced pancreatic cancer

Differences in Scotland

Advance decisions in Scotland are referred to advance directives. This document differs in that it is not legally binding but will be taken into account by your medical team as a document of your wishes.

Power of attorney differs in Scotland as well. Health and welfare is known simply as a welfare attorney. In Scotland you need to provide a written document with the names and addresses of your attorney(s) and any powers you would like them to have. You must make a clear statement that you understand the powers of welfare and that you have considered capacity. Your signature must be witnessed, and that witness must then sign the document themselves. Power of attorney comes into force if you lack capacity.

A separate document regarding capacity must also be submitted. This is certificate that needs to be signed by a solicitor who is registered to practise law in Scotland or by a practising doctor in the UK to state that they are satisfied you understand the purpose of welfare power of attorney. That you understand the powers the attorney(s) would have and that you are not being pressured into giving them these powers.

The final documents together must be submitted to the Scottish courts and tribunal services which involves a fee.

Differences in Northern Ireland

In Northern Ireland, there is no Power of Attorney for matters of health and welfare, only finance and property. Therefore, there is no leaglly binding way of documenting your wishes in relation to you health and welfare. However, efforts will still be made to carry out your wishes, ensuring comfort and peace of mind.

Who to discuss these decisions with

Some of the documents listed above can only be signed into action or made by a doctor and therefore your GP or consultant involved in your care will need to be actively involved in the decision-making process. Medical professionals can help to answer any questions you may have and ensure that your thoughts meet the criteria to become legal or are clear to any medical staff who will encounter them. GPs, consultants, district and specialist nurses are all well placed to help. Involving friends and family will also make sure that the people close to you are aware of your decisions and may be able to act as witnesses.

Planning ahead with advanced pancreatic cancer

Organ or tissue donation

There may be limitations to the organs that you can donate when you have cancer. Speak to your doctor if you are interested in organ donation and they can help explain what you may or may not be able to donate. Many people can donate corneas if they cannot donate their organs, this could restore sight in someone and is a valuable donation.

Some people are interested in donating their bodies to science after their deaths to further research into their disease. Your local medical school can answer questions about this and provide consent forms. This cannot be decided by someone else after your death and the decision needs to be in writing and witnessed.

Making a will

A will lets you leave a record of what you want to happen to your money, property and possessions after you have died. It should explain who you want to benefit and in what way, who should look after children under the age of 18 and what happens if the people listed in the will die before you do. You need to decide who will be executor of the will, the person who will carry out of these wishes on your behalf. You can write a will yourself, but many people get advice about this. A will needs to be witnessed and signed to make it valid and then kept somewhere safe like your bank, with a solicitor or a company who stores wills. Changes to an existing will are called a codicil and you can make as many as you want to, but major changes should be made in a new will which would override the old one. Marie Curie provide detailed information on the steps taken to write a will and ensure that it is valid.

Funeral planning

People often don't think about their own funeral and some people don't like to at all. If you do want to make some plans for what happens after you have died you could consider if you would like to be buried or cremated and where you would like this to take place. Some people like to think about what people will wear, what will be read and what music will be playing. You can include your decisions in an advance care plan or in your will. You can keep decisions documented for family and friends in whatever way you feel is best, "dying matters" produces a leaflet where you can record key decisions. Funerals can be expensive, and you may want to consider having the costs come out of your estate. Marie Curie has more detailed information and links to further information about funeral planning on their website.

How will people know I have made these decisions?

Making sure that all of the teams involved in your medical care, emergency contacts or trusted friends and family have a copy of your documents is a good way of making sure that wherever you are and whatever happens to you, your wishes are known and respected.

Discussions about dying

Starting conversations with loved ones about dying and what you want to happen towards the end of your life can be difficult. You may feel as though you don't want to upset friends and family anymore than they already are. You may be concerned that they will think you are being morbid or thinking about these decisions too soon. However, many people find making their wishes known can be empowering and feel like a release.

If you start the conversation early, it can make things easier later. Give people time and warn them that you want to have the discussion with them. They may feel relieved that you have mentioned the topic first and time to prepare may be less of a shock. Thinking about where and when to have the conversation makes sure it is a time that you won't be interrupted, but also there's no pressure. A long car journey, walking the dog or over dinner are often good times to talk.

Symptoms as the end of life approaches

Symptom management

You may have experienced a number of different symptoms over the course of your disease. Everyone is unique and their experience of pancreatic cancer is different. Pancreatic Cancer Action produces a booklet "symptom management for pancreatic cancer" that discusses pancreatic cancer symptoms and side effects of treatments.

What happens towards the end of life?

It is natural to worry about what will happen at the end of life. You may be worried about making sure you are in the place you want to be, peaceful and pain free. Recording your wishes and making sure that the people who are important to you have a copy of your wishes can help to make sure you get the care and treatment you want. The doctor in charge of your care can prescribe any medications you may need at the end of your life prior to the last days. This may reassure you that any symptoms you may develop at the end of life are taken care of. Your regular medications may be stopped, unless they are important to keep you pain free and comfortable.

At the end of life, people begin to disengage from the world. You will become increasingly tired and rest more. You may feel as though you no longer want to want or need to eat or drink anything. There is no pressure to eat or drink. You may prefer to take sips of fluid or keep your mouth and lips clean and moist. You can be helped to do this by family, friends or medical professionals. Some people worry about not being able to drink anything. There is no clear evidence about whether withdrawing fluid speeds up the dying process and if giving fluids through an IV drip slows it down. You may be given fluids through a drip if your medical team are concerned that you are showing symptoms of becoming dehydrated or if this is something that you are worried about.

Pain

You may have experienced pain throughout your disease. This does not necessarily get worse at the end of life, but you may not be able to take medication orally, if you are too sleepy for example. Medication can be given via a number of routes and if you require regular pain relief, you may be given a constant dose of medication using a syringe driver (a small needle under the skin, giving a constant level of one or more medications through a pump for twenty four hours). If you are too sleepy to explain whether or not you are in pain, medical professionals can use a pain score to assess if you need medication and your pain will be regularly assessed.

Nausea and vomiting

Some people can feel or be sick during the last days of their lives. There are a number of reasons for this including medication side effects, constipation and the tumour itself. This can be treated using medications and relieving any medical cause for the problem such as the use of laxatives.

Symptoms as the end of life approaches

Diabetes

Not everyone who has pancreatic cancer also has diabetes, but there is a link between the two diseases. A tumour in your pancreas may damage it and affect its ability to produce insulin, the hormone that controls blood sugar levels in the body. If you are diabetic, then managing this alongside your diagnosis can be difficult.

Speaking to your GP, diabetic nurse and cancer nurse specialist may be useful as well as a dietitian's input. You may need to take medication for your diabetes if you didn't before. Monitoring your blood sugars and keeping them stable may affect the kind of treatments you can have and how you cope with them.

Jaundice

Jaundice is where the bile duct becomes blocked and yellow pigment builds up. This can be itchy and irritating and can also make the skin feel hot and uncomfortable. This itching is called pruritis. Jaundice can also cause nausea and vomiting as well as digestive problems and tiredness.

There are many ways of treating jaundice and your medical team will help you decide which is the right one for you. Surgery is an option and you could be fitted with a stent to remove the blockage and keep the bile duct open. Another option is a surgical procedure called pancreatic biliary bypass. The surgeon will bypass the blockage and allow bile to flow from your stomach to the small intestine which should solve the jaundice. Surgical procedures for jaundice are discussed in more detail in the following pages.

Jaundice can be eased using medications if these surgical approaches are not appropriate to help drain your bile duct. Antihistamines and skin care are also important to relieve the itching. Keeping skin cool and using moisturising creams to stop it drying out can help relieve the symptoms.

Ascites

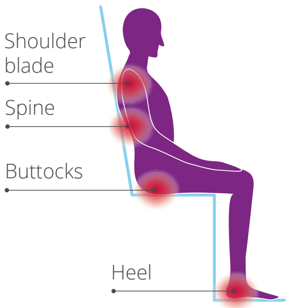
Ascites is a build up of fluid in the peritoneum, layers that line the inside of your abdomen (tummy). This may happen in pancreatic cancer patients if your liver function becomes poor or due to the effects of the tumour or fluid (exudate) it produces. Ascites can cause pain or shortness of breath as your abdomen swells. It can be drained in hospital using a tube that can be either temporary, and removed once the fluid has drained, or permanent.

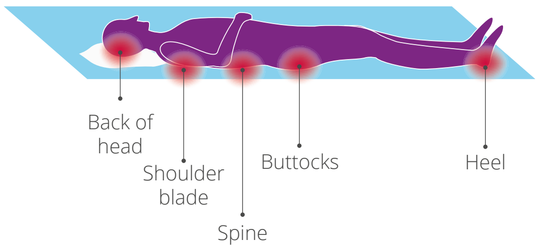
Symptoms as the end of life approaches

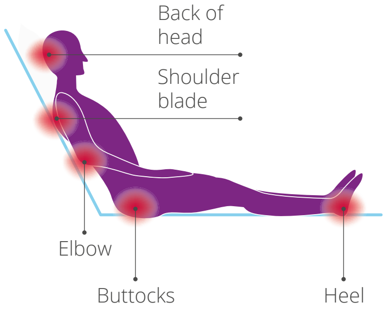
Symptoms as end of life approaches

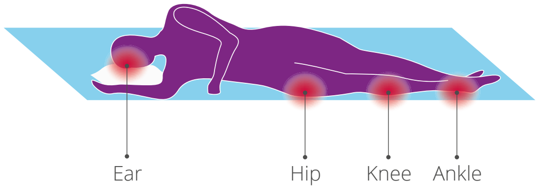
Pressure ulcers

Pressure ulcers, also known as pressure sores or bed sores are an injury of the skin and/or the tissue underneath. They normally occur at a bony prominence such as your heels, ankle or sacrum. If you become unwell and have lost weight in combination with moving around less, you can become at risk of pressure ulcers. Anyone can get a pressure ulcer, but the chances increase if you are unwell with pancreatic cancer.









Pressure ulcers are caused by pressure (and sometimes friction) on the skin. Pressure ulcers can develop slowly over time or quite quickly. If possible, check your skin for areas that appear discoloured and report any areas of pain to your medical or nursing team.

Equipment can be put into place to lower your chances of a pressure ulcer; occupational therapists can help to arrange this. They may offer you a pressure relieving mattress if you are in bed for much of the time or a chair cushion. You can help to manage your own risk by using pillows to remove the pressure under areas such as your heels and changing your position (with help if you need it) as much as possible.

Pressure ulcers are not always preventable, and it may not be the fault of you or anyone else if you do get one. Nurses can help to manage wounds and keep them clean with dressings. If you have a pressure ulcer, the most important thing is that it does not cause you any pain or distress.

Bladder and bowel incontinence

As people near the end of life their muscles relax. Some medications also have the effect of relaxing your muscles and this can cause incontinence of both urine and faeces. It is natural to feel embarrassed about the idea of this happening to you and lots of people don't want to think too hard about this. However, continence aids can be used to make the situation easier. If you have nurses or carers around you, they will be understanding and can reassure you that it is natural. If you are being looked after by family and friends, it may be important to consider if they are able to manage this and if you would want them to.

Some people also have issues passing urine and hold their urine (retention). Then it may be appropriate to fit a catheter to make sure that you are passing urine and to prevent any pain or discomfort.

Symptoms as the end of life approaches

Feeling too hot or too cold

As the body struggles to regulate its own temperature you may feel very warm or cold. This can be relieved through interventions family can do such as opening windows or closing them, taking blankets on and off or using a fan in the room. Some medications such as paracetamol can also help to lower your temperature.

Eating and drinking

Towards the end of life people often feel unable to eat and drink. You may lose your appetite entirely, this normal. If you do not feel hungry and thirsty or uncomfortable you do not need any artificial food and fluids. If you don't fancy eating and drinking anything but are getting a dry mouth then you may be able to use mouthwash, take sips of fluids or use a sponge to freshen your mouth. Sucking on boiled sweets may also help. Vaseline or Chapstick can help prevent your lips from drying out, especially if you are breathing through your mouth. Family and friends can also help with this if you feel as though you are finding it difficult.

Breathlessness

This is common in many people who are approaching the end of their life regardless of the reason why. Breathlessness can be frightening but there are a number of ways of helping you to breathe easier and feel better.

Sitting as upright as possible in bed or chair (with assistance if you need it), using a fan on your face, keeping rooms well ventilated (windows open) and using communication aids such as pen and paper or whiteboard so that you don't have to talk too much in one go can be helpful. Sometimes you can be prescribed medication to help your breathing depending on the cause and a physiotherapist may be able to give you some exercises.

Noisy breathing and secretions

Some peoples breathing may become laboured and make a rattling sound in the last few days of their lives. This is because you are not able to clear secretions in the lungs as well as before. The sound is not the cause of anything dangerous and does not cause pain or discomfort. However, patients and family can find the noise upsetting in which case, medication can be given to help clear up the secretions.

Agitation

Some people may appear very calm and serene towards the end of their life. Some people however can become quite agitated and restless. People may have hallucinations, which may or may not be pleasant for them. Medical professionals need to identify the cause of any agitation and treat it. It may be the side effect of a medication or other problems such as constipation or being unable to pass urine. Medication can be given to resolve the problem and relieve any hallucinations. If the anxiety is caused by a spiritual concern, religious or spiritual figures may visit. Any anxiety may also be relieved by having any questions about the end of life answered or spending more time with friends and family.

What happens at the end of life?

Many of the symptoms above occur throughout illness and towards the end of life. This does not mean that you will experience all of these symptoms and that when you do, end of life is approaching. For most people the end of their life is a very peaceful time. They become increasingly sleepy, have their symptoms under control and are very comfortable.

Finances and palliative care

How will my care be funded?

There are multiple ways to have your care needs funded depending on your level of need and assets. Your care needs will fall into one of two categories, either health or social. If you need support due to a primary care need such as pancreatic cancer you may be eligible for your care to be funded by the NHS under continuing healthcare. This takes place in your preferred place, after an assessment. Social care is means tested and you may have to pay towards your care or for all of it. Social services and hospital discharge teams can assess your care needs and what support you may be entitled to. Social services can complete financial assessments with you to explain how this is calculated.

Needs assessment

If you are needing help to cope day-to-day, a needs assessment can be carried out by social workers from your local council. This aims to assess the level of support that you need and any equipment you may need to allow that to happen. This can be face to face or over the phone and involve questions or functional assessments such as washing and dressing, cooking, walking, getting in and out of bed or a chair. You may want to spend some time before the assessment thinking about the things that you find harder to do and creating a list. It may also help to have someone with you who knows you well. Which? Has created a checklist you can look at to help you prepare. The assessment is free, and you can ask for one at any time, though it is unlikely to take place immediately after you ask. Sometimes assessments take place in hospital if you have been admitted and diagnosed there.

The findings of a needs assessment are transferred into a care and support plan detailing the type of care you need, how this will be given and what level of financial support you will receive. This is designed to help you be independent and have control rather than to restrict you, so it is important that you agree with and understand what is in your care and support plan.

Financial assessment

Once you have had an assessment of your needs, you can have a free financial assessment from social workers in your local authority (or hospital if that is where you are). This looks at the amount of money you have to determine how much you would have to pay towards the cost of your care. The amount of financial support you will receive for your care depends upon your assets and savings. However, if you are assessed as needing nursing or personal care in Scotland, this is free. The cost you pay is towards any residential living costs. You may be asked about earnings, pensions, benefits, savings and UK property. The assessment may ask about things you used to own and therefore giving money or property in the form of gifts in the months and years prior to your assessment will still be taken into account. If you have a paid carer coming into your home, the value of your house will not be taken into the financial assessment. If you are moving into a care home, the value of your house will be taken into account unless you have a spouse or partner still living in it.

Macmillan may also offer a service to help look through benefits - to make sure you are claiming the right things etc.

Financial assistance/ local authority funded package of care

If you qualify for financial help for your care then the money you receive is called a personal budget and can only be spent on social care. This can be managed by social services, an organisation such as a charity or a direct payment to yourself or someone of your choosing to manage. If social services help to manage your personal budget, then they can assist in finding a care agency or care home to suit you. If you chose to manage your budget yourself you can use the money to hire a carer, however this gives you the responsibility of an employer, something you do not have using an agency.

Finances and palliative care

Private care/ self-funding

As a self-funder you can arrange and pay for your care yourself without involving your local authority at all. Some councils may assist in helping you to find care or pay for your care and then bill you, though they may charge a fee for this. It can be expensive and difficult to budget for your care. You can hire a personal assistant or private carer but there are some legal consequences to becoming an employer. Which? And the NHS website have advice to help with making this decision. Financial help is available through PayingForCare, a free information service for older people. A deferred payment scheme can be applied for if your money is in a property that has not yet been sold but you needed to enter a care home for example. Your local authority can provide information and advice on how your care needs can be best managed.

Continuing health care (CHC)

Your needs are funded according to which type of care you need. Healthcare or social care. If you have a what is called a primary healthcare need rather than needing social care you may be eligible for NHS continuing healthcare, meaning that the NHS funds your care in your preferred place. This means that your funding is not means tested and you will not be expected to pay for any of your care. The assessment for this type of funding is based on the intensity, nature, complexity and unpredictability of the persons health and social care requirements. The process involves a few stages. Funding is applied for, a decision to support tool is completed which is like a checklist to see if you would be eligible for a full assessment which can then take place.

Continuing healthcare is designed for people whose needs cannot be met under normal care circumstances. You may have a high level of need but if these can be safely and reasonably met by nursing or care staff you do not qualify for continuing healthcare and therefore while it can be a useful service it is not always appropriate. The checklist and assessment can be carried out with you or your families input but will also need to involve health and social care professionals and someone who can complete and send off the tool, for example in a hospital this may be a member of the discharge team. These decisions are evidence based, so keeping any healthcare communications such as GP letters can be helpful. Once approved the care you need, should be in place within 28 days. If it takes any longer, any costs you pay towards your care after the 28th day will be refunded.

Fast track continuing health care (CHC)

People with rapidly deteriorating conditions who may be approaching the end of their life can be eligible for this process to be fast tracked. This involves a suitable doctor or nurse reviewing your condition and deciding that you meet the criteria for fast track funding without an extensive assessment. The idea is to ensure that you are in your preferred place of care as quickly as possible, within 48 hours according to national guidance.

Finances and palliative care

Financial support

Having an illness like cancer can lead to lots of unexpected costs, an inability to work and this can lead to financial difficulties. This can cause worry on top of what you are already experiencing. Financial help is available and there are different benefits depending on your circumstances. Seeking help can feel quite daunting. Macmillan offer a service to help navigate the benefits system for people with cancer and their carers.

- Personal independence payment (PIP) or disability living allowance (DLA) if you are under the age of 65. DLA is only applicable for people living in Northern Ireland.
- Attendance allowance if you are over the age of 65.

These benefits are not means tested and can be accessed quickly if you have been told that you have six months or less to live. Your doctor will be able to complete the paperwork. You will also be paid the highest rate if this is the case.

You may also be able to access grants from energy companies or charities. Macmillan cancer support has more information on grants and gives out some of its own. Prescriptions are also free for cancer patients if you pay for them currently.

Financial advisors may also be able to give out advice about bank accounts, pensions and any insurance that you have taken out. If a loved one is caring for you they may also be entitled to benefits, Carers UK provides advice and guidance as does Citizens Advice.

If you are self-employed, then speaking to a financial advisor can help you to make decisions about managing your business and your income whilst you are unable to work or need to have reduced hours.

If you are making important decisions regarding your business and finances, it is best to make these when you are calm and when you have had the best advice possible.

Top tips from patients and carers

We spoke to people with direct experience of pancreatic cancer and asked them for tips regarding aspects of their care.

- ✓ Write notes of what has been said during appointments or healthcare interactions.
- ✓ Keep a diary of this to keep track of what is happening.
- ✓ Bring someone with you to all appointments if possible.

Further Information

What to ask your doctor

You may find the following list helpful when thinking about the questions you want to ask your doctor about your illness and treatment. If you don’t understand any of the answers you are given, you can ask for it to be explained again. Sometimes it is useful to bring your partner, another family member or friend with you when you meet with your doctor to help remember what has been said:

☐ What type of pancreatic cancer do I have?
☐ What treatments do you advise and why?
☐ What are the risks and possible side effects of each treatment?
☐ Will I have to stay in hospital, or will I be treated as an outpatient?
☐ How long will the treatment take?
☐ Will I have pain from the cancer of the treatment? What will be done about this?
☐ Will the treatment affect me physically or sexually?
☐ Are there any other treatment choices for me? If not, why not?
☐ What will happen if I don’t have treatment?
☐ Are there any clinical trials that I should know about?
☐ How often will I have check-ups and what will they involve?

Other questions may be answered by information in our patient information booklets or on our website. Visitpancreaticanceraction.org

Further Information

Pancreatic Cancer Action

For further information and advice about pancreatic cancer.
Tel: 03030401770
panact.org

Clinical trials information

For further information about clinical trial types, pros and cons and how to find and take part in a trial.
panact.org/pancreatic-cancer/treatment/pancreatic-cancer-clinical-trials

Compassion in Dying

Resources and information for planning your care and making treatment and end of life decisions.
Tel: 08009992434
compassionindying.org.uk

EUROPAC (European Registry of Hereditary Pancreatitis and Familial Pancreatic Cancer)

Coordinating centre for secondary screening for pancreatic Cancer in the UK
europan-org.eu

Macmillan Cancer Support

Resources and information designed to provide physical, financial and emotional support to cancer patients and their families.
Helpline: 0808 808 0000
macmillan.org.uk

Further information

Maggie's Centres

Maggie's centres provide free practical, emotional and social support to people with cancer and their family and friends. They are often built next to NHS cancer hospitals.

maggiescentres.org

Marie Cure

Marie Curie provide information and support to anyone affected by terminal illness.

Helpline: 0800 090 2309
mariecure.org.uk

Age UK and the Malnutrition Task Force

Have teamed up to provide information on having difficult conversations about what you might want to happen to you at the end of life.
This booklet can be ordered or downloaded for free and is available at:
malnutritiontaskforce.org.uk/resources/letstalk/

Glossary

abdomen
The part of the body between the chest and the hips, which includes the stomach, pancreas, liver, bowel, kidneys and bladder.

adenocarcinoma
This is cancer of the exocrine (enzyme producing) cells that line the pancreatic ducts. The majority of pancreatic cancers are of this type.

adenosquamous carcinoma
A very rare and aggressive form of pancreatic cancer. Two types of cells are affected, gland like cells and squamous cells (thin, flat cells that line some organs including the pancreas).

advance care plan
A document containing your wishes and advice on what treatment you would like to help inform those caring for you.

ampullary adenocarcinoma
Cancer that develops in the Ampulla of Vater (where pancreatic ducts and bile ducts merge).

Ampulla of Vater
The widened portion of the duct through which the bile and pancreatic juices enter the intestine.

anaemia
A condition caused by too few red blood cells or low haemoglobin in each red blood cell.

antihistamines
A type of medication to treat allergies or symptoms associated with allergies such as itchy skin.

anxiety
A feeling of unease, such as worry or fear. This can be either mild or severe. Someone with anxiety find this feeling difficult to control and the feeling is constant.

artery
A blood vessel which delivers oxygen rich blood from the heart to the body.

ascites
Abnormal build-up of fluid in the abdomen under the perineum. Causes swelling of the abdomen which can make breathing feel difficult.

asthma
Common long-term disease in the airways of the lungs. Inflammation, wheezing, coughing, shortness of breath and tightness are symptoms.

Glossary

bile

A fluid made in the liver and stored in the gallbladder that helps with the digestion of fats.

bile duct

The passage leading from the liver and gallbladder to the duodenum. Bile travels through the bile duct.

bilirubin

A yellow pigment formed in the liver by the breakdown of haemoglobin from red blood cells and excreted in bile.

cells

Cells are the basic building blocks of all living things. The human body is composed of trillions of cells. They provide structure for the body, take in nutrients from food, convert those nutrients into energy and carry out specialised functions. Cells also contain the body's hereditary materials and can make copies of themselves.

chaplain

A leader of any faith normally based in a healthcare environment.

clinical trials

Medical studies to test a new treatment or intervention on people. May involve screening, prevention, diagnosis or treatment.

corneas

The eyes outer layer, helps to focus your vision.

CT scan

Computed tomography scan is a machine like a tunnel that produces x-rays to get a detailed 3D view of structures inside the body. Sometimes a dye may be drank or injected beforehand to highlight certain structures.

cystic tumours

Tumours that cause fluid filled sacs in the pancreas, most are benign.

diabetes

A chronic disease in which sugars from food are not properly converted into energy in the body because the pancreas does not produce enough of the necessary hormone (insulin). Diabetes may be a risk factor for pancreatic cancer or develop as a result of it.

diagnosis

The identification and naming of a person's disease.

enzymes

Proteins that are essential for the normal functioning and performance of the body. Enzymes aid in digestion.

glands

Specialised organs or groups of cells that make various fluids that are used in the body or excreted.

hallucination

A sight, sound, smell, touch or taste that the person perceives to be real but which is not.

immune system

The network of cells, organs and substances that help the body fight infections and disease.

incontinence

Involuntary lack of control over urine and/or bowels.

insomnia

Short of long term inability to get to sleep or stay asleep.

insulin

A chemical messenger (hormone) secreted by the pancreas to regulate the amount of sugar (glucose) in the blood. If the body does not produce enough insulin, diabetes will develop.

jaundice

A condition caused by increased levels of bile (specifically bilirubin) in the blood. This causes the skin and whites of the eyes to turn yellow, tiredness, loss of appetite and itchy skin.

malignant

Malignant cancer cells can spread (metastasise) and can eventually cause death if they are not or cannot be treated.

obstruction

A blockage, often caused by a tumour in pancreatic cancer, in some part of the body such as the bile duct.

oral nutritional supplements (ONS)

Macro and micronutrients that are taken orally for people who are unable to meet their nutritional needs. Include powders, liquids and puddings.

palliative care

Care that focuses on symptom management without curing a disease.

Glossary

pancreas
An organ in the digestive system. The pancreas produces insulin and enzymes that help to digest food.

pancreatic lymphoma
Very rare form of pancreatic cancer. Pancreatic lymphoma or primary pancreatic lymphoma (PPL) is a cancer of the lymphatic system of the body that originates as a pancreatic mass.

pancreatic sarcomas
Tumours that form in the connective tissue that holds together the pancreatic cells. This is very rare.

red blood cells
A type of blood cell that contains haemoglobin, the protein which carries oxygen around the body.

symptom management
Aims to prevent or treat the symptoms of a disease as well as side effects caused by other treatments. A key part of palliative care.

tissue
A collection of cells that make up a part of the body.

tumour
A new or abnormal growth of tissue on or within the body. A tumour may be benign or malignant.

undifferentiated carcinoma
A group of cancers that are rare and hard to identify. In this case occurring in the pancreas.

Notes

10

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The Pancreatic Cancer Action lay review panel.
For sources and references used in the compilation of this booklet, please contact us at the address overleaf.

Pancreatic Cancer Action

This booklet has been funded through the generosity of supporters of Pancreatic Cancer Action, a UK charity founded by a pancreatic cancer survivor, Ali Stunt, who was diagnosed with pancreatic ductal adenocarcinoma in 2007. With a focus on early diagnosis, it is Pancreatic Cancer Action's mission to improve survival rates by raising awareness of pancreatic cancer and its symptoms among the public, medical education, improved information and by funding research specifically to improve early diagnosis of the disease.

If you would like to support us or find out more, please contact us at:
enquiries@panact.org or visit panact.org

If you are unsure of anything at any time please consult your own doctor, dietitian or Cancer Nurse Specialist (CNS)

If you would like to help us by either holding an awareness event or by fundraising, please **email enquiries@panact.org** or call **0303 040 1770**. For more information or to donate directly please visit **panact.org**

☎ 0303 040 1770

✉ enquiries@panact.org

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