Pancreatic
Cancer
UK

Pancreatic cancer and end of life care:

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

Introduction

This booklet is for people with pancreatic cancer, and your family, friends and carers. When we talk about family, friends or carers, we mean anyone who is close to you or helping to care for you.

This booklet explains what may happen in the last few months of life. It has information about the symptoms people with pancreatic cancer may get towards the end of their life and how to manage these. There is information about how to get the care and support you might need, how to deal with the emotional impact of dying, and information for families.

Contents

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 if you need to know more. There is more information available on our website and we provide a lot of support. Find out more at **pancreaticcancer.org.uk**

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

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

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

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

? Questions to ask 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 66.
- Contact details of the organisations we mention on page 69.

Coping with the news that you are dying

Key facts

- It can come as a huge shock to be told that you are approaching the last few months or weeks of your life.
- You are not alone. There are people who can support you.
- Your medical team can support you emotionally.
- Our specialist nurses on our free Support Line can provide emotional support and answer any questions you have.
- Hospices, local cancer centres and Maggie's 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.
- 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 dying. This section explains how to get emotional support for you and your family if you need it.

You may have lots of different emotions. Pancreatic cancer can grow and spread quickly. So you may feel you haven't had much time, if any, to come to terms with being diagnosed before being told you are approaching the end of your life.

You may want to know how long you have left to live, or what will happen over the coming months and weeks. If you do want to know more, speak to your doctor or nurse. It can be difficult for doctors to give you a clear timescale, but they may be able to give you some information about your situation. Some people prefer not to know and to live each day as it comes. The doctors and nurses will respect this decision.

You may want to discuss things with your family as they might want different information from you. If you wish, you can give your doctors and nurses permission to speak to your family and answer their questions without you being there.

Getting support

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

Talking to family and friends about how you are feeling can be comforting (see page 10). These can be difficult conversations, and some people find it easier to talk to people outside their family or friends.

You can talk to a member of your healthcare team, who will 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 17.

You can talk to someone about your beliefs or spirituality. Some people find it helpful to speak to a chaplain who will have links to all faith groups, or a spiritual advisor, either religious or non-religious. Most hospitals and hospices will have a chaplain.

Hospices and local cancer centres may provide free emotional support. For example, they may run group support sessions where you can meet other people with cancer. Your GP, nurse or medical team should know about any services that are available locally. You can read more about hospices on page 19.

Counselling

Some people find it helpful to talk to a counsellor. 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.

Your local hospice or hospital may offer counselling, and some hospices have counsellors who can visit you at home. Speak to your GP or nurse about what counselling is available. You can also search for counsellors on the British Association for Counselling and Psychotherapy website, including counsellors who specialise in cancer.

How can we support you?

You don't have to face pancreatic cancer alone. Our specialist nurses on our free Support Line provide emotional support, and you can talk about your worries with them.

Our free online support sessions give you the chance to meet others and share experiences. You can also speak to others in a similar situation on our online discussion forum. Read more about our support on page 68.

☎ Call our Support Line free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk** with any questions you have, and to get support.

Support from other charities

Macmillan Cancer Support, Marie Curie and Maggie's Centres all provide free support to people with cancer and their families.

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

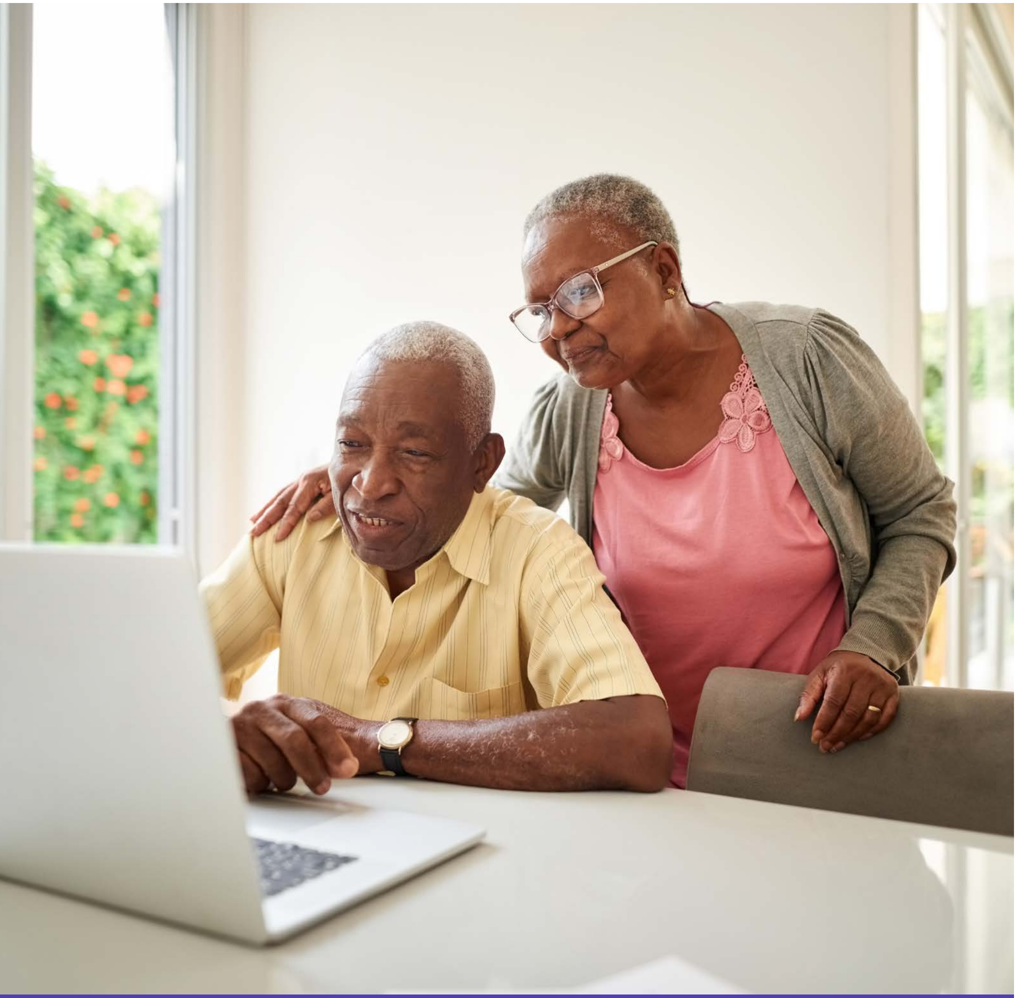
Questions to ask your healthcare team

Who can I talk to about my worries?

What support is there to help me cope emotionally?

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

What local services can help?



> “I found the Pancreatic Cancer UK website. I later found the discussion forum and Support Line. I cannot stress how valuable I found these. It definitely helped both of us to know that we weren’t the only people going through this.”

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 healthcare team support you and care for you.
- If you have young children or teenagers in the family, be honest and explain to them what is happening.
- Ask your healthcare team any questions you may have, and talk to them about anything that is worrying you.
- Writing down your questions before your appointment can help with these conversations.

Talking to family and friends

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

These can be difficult conversations. But being open and honest about your feelings and wishes can be comforting to you and your family. For example, you may feel less worried about the future if your family know how and where you would like to be cared for. The organisation Dying Matters has information on how to talk about dying.

Some people worry about being a burden to their family, or losing their independence. Talk to those close to you about how you would like them to support you. If there's anything you would rather they didn't do, let them know this as well.

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.

> "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."

Talking to children

If you have young children or teenagers in the family, you may worry about how to talk to them and how much you should tell them. For most children and teenagers, it's best to be honest and explain to them 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.

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

Winston's Wish provide information and support to help you talk to children about serious illness. RipRap is a website with information for teenagers who have a parent with cancer. 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**

Talking to health professionals

Your doctors and nurses can answer any questions you or your family have about your cancer. They can also help you think about what care you will want in the future (see page 16). Ask them any questions you may have, and talk to them about anything that is worrying you.

What can help?

If you find talking to your doctor or nurse hard, these things may make it a bit easier.

- Think about how much you want to know. It is up to you how much or how little you want them to tell you.
- Tell your doctor or nurse that you want them to be fully honest with you, if that is what you want.
- Let your healthcare team know if you'd like a relative or friend there with you during conversations.
- You could write a list of questions before speaking to your doctor or nurse. There are some suggested questions at the end of each section in this booklet.
- Write down their answers or ask a family member or friend to write notes and help you remember what was said.

- Tell your doctor or nurse what is important to you and what you hope will happen in the future. But also think about what you want to happen if things don’t go to plan, for example if you can’t be cared for where you would like to be. Read more about planning your care on page 16.

Questions to ask your healthcare team

How long do I have to live?

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 the things you enjoy, and to live as well and as comfortably as possible.
- You can speak to your healthcare team about where you would like to be cared for in the future. This may be at home, in a hospice, at hospital or in a care home.
- You can make decisions about your future care as early as you like. You don’t have to wait for a doctor or nurse to speak to you about this.
- You may see a specialist palliative care team, who can help manage your symptoms and provide emotional support.
- Hospices also provide specialist palliative care.

Planning your care

It can be useful to think early on about how you want to be cared for in the future. This is because as you become less well, you may be less able to make decisions about your care or tell your family or healthcare team what you want. The earlier you think about what you would like, the easier it is for them to plan your care and follow your wishes. It can be difficult to think about your future care, but it can help you feel more in control.

Planning your care is known as **advance care planning.** There are different ways to make decisions about your care and record them. Your healthcare team can help you with this or you can make your own record. Think about what's important to you. You may want to plan what treatment and support you would like, and where you would like to be cared for (see page 20).

You can talk to your healthcare team at any time about how you would like to be cared for. You don't have to wait for them to speak to you about this. Your wishes may change over time, and you can make changes to your care plan at any time.

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

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

What is palliative care?

You may hear the term palliative care. The aim of palliative care is to help you live as well as possible for as long as possible. It helps to manage symptoms such as pain. And it provides emotional, physical, practical and spiritual support to help you deal with pancreatic cancer that can't be cured. It also supports family members.

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. Your GP or district nurse (see page 21) may provide some palliative care. They will also arrange support from the specialist palliative care team if you need this.

Palliative care may be provided in:

- your home – see page 20
- hospices – see page 19
- hospitals – see page 24
- care homes – see page 25.

Not all palliative care services may be available everywhere. Speak to your GP if you need more support.

If you haven't seen the palliative care team, ask your GP or district nurse to refer you, as they can provide a lot of support.

☎ You can also call our specialist nurses on our free Support Line, who can explain how to get support.

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

What is a hospice?

Hospices provide specialist palliative care. You may visit the hospice for an appointment (outpatient care), or for the full day to use their services before returning home. Or you may stay at the hospice for a short time, for example to get symptoms under control (inpatient care). Some hospices also have ‘Hospice at Home’ services, which provide nursing care at home (see page 21).

Hospices are free, but the services each hospice offers can vary. Not all hospices may provide the services mentioned below. Check with your GP or district nurse what services are available locally, and if they can refer you to these. You can also contact your local hospice or go to their website to find out about their services. Hospice UK has details of hospices across the country.

Hospice services may include:

- managing symptoms, such as pain
- physiotherapy or occupational therapy to help you manage day to day, and get any equipment or support you need at home
- emotional and social support
- spiritual support, such as speaking to a chaplain
- support for your family, including support for children and bereavement support
- practical support and financial advice
- complementary therapies, such as massage and aromatherapy, to help deal with symptoms.

Choosing where to receive care

You can speak to your doctor or nurse about where you would like to be cared for and where you would like to die. This can be recorded in any plans you make about your care (see page 16). They can try to arrange support and care so that you can be cared for where you wish. But be aware that this may not always be possible – for example, if there isn't a bed available at the local hospice. Speak to your family as well so that they are aware of your wishes.

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

Care at home

Many people want to be cared for and die at home, where they are in familiar surroundings and have family and friends close by. Your GP, district nurse or community palliative care nurse will organise your care at home and will be your main point of contact. They will work with other health professionals to support you and your family so that you can stay at home.

It can take some time to arrange care, support and equipment (see page 22) at home, so it is best to organise this as early as possible – your GP or nurse can 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) give general nursing care, medicines and pain relief. They 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 and their families with living with cancer. 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 care at the end of life. This is often at night so your family can rest.

If you need help in an emergency, contact the GP or district nurse. If it is out of usual working hours, the GP answer phone should have the out of hours number to call. Some hospices also have a helpline you can call. Ask your GP or nurse for the best number to use in an emergency.

Marie Curie have practical information about how to care for someone at home. They also have information about Marie Curie nurses and hospices.

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

Personal care at home

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

Your GP, district nurse, or community palliative care team can help arrange care workers at home. The hospice or hospital can also help with this if they are involved in your care. Care is free for people approaching the last few months of life, but you will need to have an assessment to see what care you need.

We have more information 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, help her with the commode 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 carry out everyday activities, for example by using equipment or adaptations to the home. They support people to live as well as possible. If you are being treated in hospital, the occupational therapy team may assess you before you go home so the equipment is ready.

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

There is more information about support if you are cared for at home and how to access it at:
pancreaticcancer.org.uk/nursingsupport

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 or equipment that you need. You may need to go into a hospice, hospital or care home.

If you need treatment to manage your symptoms, you may go into hospital or a hospice for a short time. You will be able to go home once your symptoms are under control. But if you need longer-term care for weeks or months, you may go into a care home (see page 25). Your GP or nurse can answer any questions you may have about this.

Some people would rather not die at home. If you are at home, your family will be your main carers, which can be stressful. It may also sometimes take longer for the GP and nurses to come, especially at night or at the weekend. Some people may not want their families to link the home with medical equipment or any upsetting memories.

Care at a hospice

If you need help managing pain or other symptoms you may go to a hospice for a short time. Read more about the care hospices provide on page 19.

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

If you are thinking about spending time in a hospice, you may want to visit one beforehand so you know what to expect. You can search for hospices near you on the Hospice UK website.

> " 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 or if you can't get care at home or in a hospice. Hospitals have their own palliative care teams who will provide care and support to you and your family.

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, but others will just offer daily personal care – such as helping with washing, dressing and eating.

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 stay in a care home, ask your healthcare team what funding may be available.

Macmillan Cancer Support and Marie Curie both have information about planning and arranging care.

Questions to ask your doctor or nurse

Can you refer me to the palliative care team?

What palliative care services are available 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?

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

Symptoms towards the end of life

Key facts

- Symptoms towards the end of life 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.
- There are ways to manage most symptoms. Speak to your doctor or nurse about any symptoms you have.
- 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.
- Pancreatic cancer can cause problems with digestion. Taking capsules called pancreatic enzymes when you eat can help.
- As you approach the end of life you may feel less like eating, and lose weight. This is normal.
- If you need help with symptoms at night or over the weekend, you should have an out of hours number to use. Ask your GP or nurse how best to contact them out of hours.

We explain common symptoms and how they can be managed on pages 28-49. We explain symptoms people may get in the last few days on pages 59-61.

Not everyone will get all of the symptoms we've included here. There are ways to manage most symptoms to help you feel better, and to make sure you are as comfortable as possible.

Some symptoms can develop quite quickly. Speak to your doctor or nurse about any symptoms, including any new symptoms or any that get worse. Your doctor or nurse will work out the best way to manage your symptoms. This will depend on your own situation and what is best for you.

If you need help with symptoms at night or over the weekend, your district nurse or palliative care team may have an out of hours number. The GP's answer-phone will also give you the number of the out of hours GP. Your local hospice may have a 24 hour advice line, usually run by nurses, who will be able to help or tell you where to get help. Ask your healthcare team how best to contact them out of hours.

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

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

Pain

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

There are different ways to treat pain. These include:

- painkillers, including paracetamol and ibuprofen, and stronger painkillers called opioids, such as morphine
- some medicines that are usually used to treat other health problems can also be used to treat pain – these include some antidepressants, steroids or drugs that are used to treat epilepsy
- a nerve block, which is a procedure that blocks the nerves around the pancreas from sending pain messages to the brain. This treatment isn't suitable for everyone. It may be done at a specialist centre, and you will need to be well enough to have the procedure.

There are also other things that can help you deal with pain, such as complementary therapies (see page 50). Getting emotional support may also help.

You can read more about pain in our booklet:
Pain and pancreatic cancer.
Or 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 while at home as well as in hospital or a hospice.

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

Extreme tiredness (fatigue)

Fatigue is common for people with pancreatic cancer. Fatigue isn't the same as just feeling tired. You might feel drained or exhausted. It can be constant or it can come on suddenly. 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 about any fatigue you have, or if your fatigue is getting worse. They can look at what is causing it 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 the next few days.
- Talk to the occupational therapist or nursing team about what may help. They can suggest some exercises that are suitable for you, and help get you equipment at home to make daily tasks easier (see page 22).
- Use your energy to do the things that are important to you, and rest in between.
- You could keep a diary of your fatigue to help you see what helps and how to plan your time when you may have more energy.

Read more about fatigue, including tips to help manage it, in our booklet: **Fatigue and pancreatic cancer: How to deal with tiredness.** Or at: **pancreaticcancer.org.uk/fatigue**

Download our fatigue diary at: **pancreaticcancer.org.uk/managing-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 with digesting food. This can cause symptoms such as discomfort after eating, wind, bloating, appetite loss, weight loss, and changes to your bowel habits, such as diarrhoea (runny poo).

Most people with these symptoms will have been given pancreatic enzymes (pancreatic enzyme replacement therapy), which help to break down your food. They can help manage these symptoms, and make a big difference to how you feel. There are different brands of pancreatic enzymes, which include Creon®, Nutrizym® and Pancrex®.

Pancreatic enzymes are taken as capsules with food. If you find it difficult to swallow capsules, you can open the capsule and mix the granules inside with a teaspoon of cold, soft, acidic food – such as apple sauce, apricot jam or yoghurt. Swallow the food straight away and wash it down with a cool drink. Don't chew the granules – if they get stuck between your teeth, they can cause mouth ulcers.

You should take pancreatic enzymes with food for as long as you are still eating. If you haven't been given pancreatic enzymes but you are still eating and have these symptoms, speak to your doctor, nurse or dietitian to see if the enzymes would help. If you are no longer able to eat you don't need to take pancreatic enzymes.

A dietitian is an expert in diet and nutrition. If you haven't seen a dietitian, ask your doctor or nurse to refer you to one. They can help manage your symptoms and help you eat as well as possible.

If you go into a hospice or hospital and are taking pancreatic enzymes, tell the staff about these. Explain that you need to take them with anything you eat to help digest your food, including with meals, snacks and milky drinks. 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. This is to reduce the number of pills you need to take. But it's important that you still take pancreatic enzymes if you are eating.

Read more about pancreatic enzymes in our booklet: **Diet and pancreatic cancer.**
Or at: **pancreaticcancer.org.uk/pancreaticenzymes**

If you have any questions about pancreatic enzymes, you can speak to our specialist nurses on our free Support Line.

Weight loss and reduced appetite

Many people with pancreatic cancer lose weight. In the last few 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.

Losing a lot of weight can be upsetting for both you and your family. Try not to worry about how much you are eating or about putting weight back on. There are things that can help manage appetite and weight loss.

What can I do?

- Speak to your doctor, nurse or dietitian about weight loss and how they can help.
- It’s fine to eat and drink what you feel like, even if that’s only small amounts.
- If you feel sick or very full, have a break and try to eat some more an hour or so later.
- Try having small meals or snacks. You may find soft food such as soup, yoghurt or ice cream easier to eat.
- You should keep taking pancreatic enzymes (see page 32) while you are eating, but you can reduce the amount you take if you are eating less.
- It is important that you speak to your doctor or nurse for help with any problems that are stopping you eating, such as pain or sickness.
- Gentle physical activity can help to increase your appetite and help you 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 or nutritional supplements, which are drinks or powders. These help to increase the amount of energy (calories) and protein in your diet. This can help you feel better and have more energy.

You can also find examples of high calorie foods in our booklet: **Diet and pancreatic cancer.**
Or at: **pancreaticcancer.org.uk/diettips**

If you have symptoms that make eating or drinking difficult, you may have treatment to give you nutrients and fluids called artificial nutrition and hydration. Some people have a tube put in through their nose, or some people have this treatment through a drip into a vein. Artificial nutrition and hydration can help some people feel better, but it isn't suitable for everyone, and can be difficult to manage. Your doctor, nurse or dietitian can talk to you about artificial nutrition, and whether it might help you.

Information for families – helping with eating

It can be difficult if your family member doesn't feel like eating and is losing weight. But remember that this is normal. Don't try to make them eat if they don't want to. Support them by asking what they fancy and preparing food for them. And try not to be upset if they don't eat much of it. Try to keep having meals together as a family, as the social part of eating together can help.

Diabetes

If you have diabetes, the way it is managed or monitored may change as you approach the end of 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.

Your blood sugar levels may be affected if you are being sick or have diarrhoea (runny poo). Some treatments can also affect diabetes, such as nutritional supplements or steroids.

Speak to your doctor, diabetes nurse or pancreatic dietitian for advice about how to manage 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 pancreatic enzymes (see page 32).

You can read more about managing diabetes at:
pancreaticcancer.org.uk/diabetes

Feeling and being sick

Pancreatic cancer and its treatment can make you feel and be sick (nausea and vomiting). This is unpleasant and distressing. It may also mean that you aren't properly absorbing the medicines you take, such as pain relief.

Feeling and being sick can be caused by:

- the cancer blocking the duodenum (see page 39)
- the stomach not emptying, or emptying slowly (see page 40)
- jaundice, when the liver is not working properly (see page 45)
- constipation (when you find it hard to poo)
- a thrush infection in your mouth or throat
- some medicines
- anxiety.

Speak to your doctor or nurse if you are being sick. They will work out what is causing your sickness, and give you treatment. They may give you anti-sickness medicines. These may be tablets, liquids, or injections. You can also have some anti-sickness medicines through a syringe driver (see page 29).

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?

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

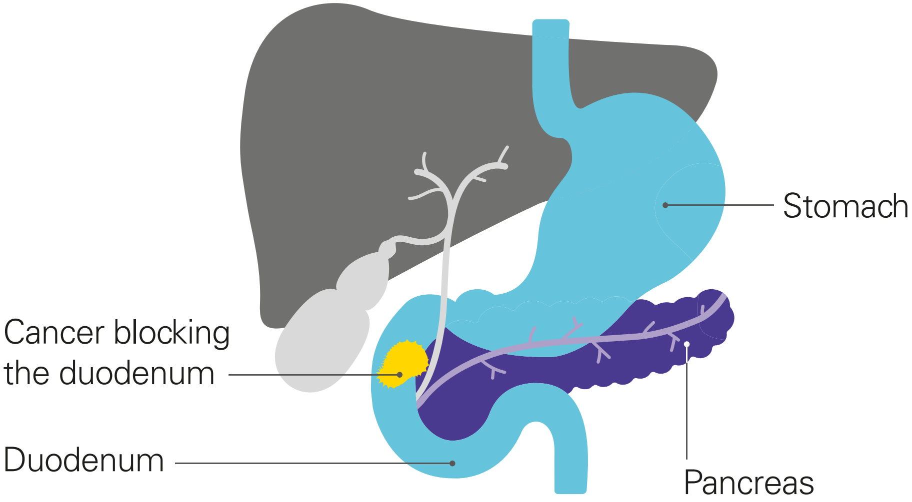
- You could try eating small meals. You may feel worse if you have an empty stomach – even some dry toast can help.
- Eating foods that are high in energy (calories) and easy to digest may be helpful – speak to your doctor, nurse or dietitian about this.
- Sit up after eating. If you feel up to it, you could try to move around after meals.
- Drink small amounts of fluid regularly throughout the day.
- If the smell of cooking makes you feel sick, ask someone to cook for you. Try cold food which smells less than cooked food.
- Some people find eating a dry biscuit or cracker, grated ginger in hot water, ginger biscuits, peppermint tea or sucking sugar-free sweets helps.
- Using travel sickness wrist bands, such as Sea Bands®, can also help.
- It's important to keep your mouth clean if you are being sick. This helps to keep your mouth healthy and get rid of the unpleasant taste. Try using a mouthwash to rinse your mouth after you have been sick.

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.

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 the tummy area.

Diagram showing the cancer blocking the duodenum



If you have a blocked duodenum, you may be able to have a hollow tube called a duodenal stent put in. This will open the part of the duodenum that is blocked so that food can pass through. This should stop you feeling sick and you should find it easier to eat.

Sometimes stents can become blocked. To stop this happening, try having small meals often, and have soft foods like porridge, minced meat and mashed potato. If the stent does get blocked, it can make you feel sick again, and the stent may need to be replaced.

A duodenal stent won't be suitable for everyone. You will need to be fit enough to have a sedative (to make you sleepy) to have the procedure. If a stent isn't suitable for you, your doctor will give you medicine to manage the sickness as well as any other symptoms, such as pain.

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**

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

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 above).

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.

There are different things that can cause constipation. You may be more likely to get it if you aren't moving around or eating much, or are dehydrated (see page 43). It can help to drink plenty of fluids, if you can.

You may also 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. If you are able to, take the laxatives regularly. If you aren't able to take laxatives, it is important to continue taking the opioid painkillers as your medical team recommend.

As you approach the end of life, your doctors and nurses may focus more on managing constipation to help you feel comfortable, and less on treating the cause. Speak to your doctor or nurse if you have constipation.

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

Diarrhoea

Diarrhoea can mean you need to rush to the toilet, and can cause stomach cramps. It can be unpleasant. There are different things that can cause it, such as the cancer, some medicines, or an infection.

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

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 doctor or nurse may be able to recommend a cream to use.

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

Dehydration

If you are dehydrated you might have dark coloured pee, headaches, feel thirsty, and feel dizzy or light headed. Speak to your doctor or nurse if you think you might be dehydrated, or if you have diarrhoea 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.

Steatorrhoea

Steatorrhoea is caused by fat in your poo. Your poo may be pale, oily, smell horrible and be difficult to flush down the toilet. You may get it if your body can't digest the fat in your food properly. Pancreatic enzymes can help with steatorrhoea (see page 32).

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. If you have any of these symptoms, tell your doctor or nurse.

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

The fluid may be drained off to make you more comfortable. To do this, you will have a local anaesthetic in your tummy so that it's numb and you don't feel anything. A needle is used to put a thin tube into your tummy to drain the fluid. The tube connects to a drainage bag which will collect the fluid.

The fluid can build up again and you may need to have it drained more than once. You may have a permanent drain put in so that the fluid can be regularly drained off by the district nurse at home. You can ask your doctor or nurse about this.

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

Macmillan Cancer Support has more information about treatments for ascites.

What is oedema?

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

Tell your doctor or nurse if you have any swelling. They may recommend pressure stockings to help control the swelling, and suggest exercises you can do 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. Sometimes you may be offered medicine called a diuretic to treat the oedema, although this may not make a big difference.

Marie Curie has more information about treatments for ascites and oedema.

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 lose weight, and feel tired and thirsty.

If you develop 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. The cancer can grow to block the stent, causing the jaundice to come back. If this happens the stent may need replacing.

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 recommend a cream to help with 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/stents

Bedsores

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

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

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

What can help prevent bedsores?

- 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.
- If your skin is wet or inflamed, the nurse may give you a cream which can help prevent bedsores.

If you are worried about getting a bedsore, have any sore areas of skin, or want to know more about how to prevent bedsores, speak to your nurse.

Marie Curie and the NHS website have more information about bed sores.

If you develop a bedsore, your nurse should check it regularly. You should be given a pressure relieving mattress or pressure cushions, and your doctor or 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.

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. A dry mouth can be caused by the cancer itself, treatments such as opioid painkillers, or being generally run down.

What can help?

- Try to keep your mouth clean by brushing your teeth regularly and using mouthwash.
- You could try chewing gum, taking regular sips of drinks and sucking ice cubes or ice lollies. Eating refrigerated pineapple cubes can help too.
- You can also get products and gels from the pharmacy that may help.
- 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. You may not have any interest in things that you used to enjoy. The cancer itself can cause similar symptoms, so speak to your GP or nurse to find out what's causing them.

Support in dealing with the cause of anxiety or depression might help. This might include dealing with any symptoms or side effects, planning your future care (see page 16), or help with financial issues. Your doctor can also give you medicines, such as anti-depressants. These can help, although they can take a few weeks to have an effect.

Talking about your worries and fears may help you manage your situation. You can speak to your GP, nurse or specialist palliative care team. They can refer you for emotional help such as counselling, if needed. Read more about counselling and getting emotional support on page 6.

Questions to ask your healthcare team

How can my symptoms be managed?

What support is there for dealing with symptoms?

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

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

Complementary therapies

Some people find that complementary therapies can help with symptoms. These therapies can help you to relax and feel better, although they can't treat the cancer.

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.

- **Massage** may help you relax. It may help to reduce pain and help you feel better generally. Check with your doctor or nurse if it is safe for you to have a massage. You shouldn't have a massage on any areas where you have any broken skin, or if the massage is making your pain any worse. If you have problems with bleeding you should avoid deep tissue massage.

- **Reiki** is a gentler type of massage where the therapist's hands gently brush over the body, or a few inches above the body. This may be useful for people who can't have normal massage.
- **Reflexology** is a type of massage that involves putting pressure on parts of the hands or feet. This may help to relieve pain in other parts of the body.
- **Relaxation** therapies like meditation, aromatherapy and hypnotherapy may help relieve symptoms such as pain.
- Other therapies that you may find helpful include art therapy, music therapy and pet therapy.

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

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

Information for family, friends and carers

Key facts

- Looking after someone who is nearing the end of their life can feel overwhelming. Make sure you get support if you need it.
- Asking the doctors and nurses what to expect can help you to feel more prepared.
- You can speak to the healthcare team without your family member being there, if they have given their permission.
- Ask the doctor or nurse for details of who to call if you need help or advice, especially at night or at weekends.
- Ask friends and family to help with anything you need. People are often happy to help out.
- Think about anything you want to talk to your family member about, or how you would like to make the most of your time together.
- People may have different symptoms in the last few days, and there may be signs that the end of life is near (see page 59).
- There is support available to help you cope with grief and loss after someone dies.

Support for you

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

You may want lots of information about what is happening, or you may just be focusing on caring for them. The doctors and nurses can tell you what to expect, which may help you to feel more in control.

The information on pages 26-49 explains some of the symptoms people with pancreatic cancer get in the last few months and how these are managed. And the information on page 59 explains symptoms they may get towards the end.

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

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

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

You may find counselling helpful (see page 6) or speaking to your own GP about how you are feeling.

If you feel you need a break, you may be able to get temporary care for your family member. This may help you to cope better. Temporary care may be somebody coming in to sit with them for a few hours, day care in a hospice, or a stay in a hospice or a care home. You may hear this called respite care. Speak to your GP or the district nurse about this care.

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

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

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

Caring for your loved one

The demands on you can increase quite quickly in the last few weeks or days, especially if you are looking after someone at home. You may need to do more for them, including washing and personal care, giving medicines, making sure they are comfortable and helping them with eating and drinking. There is more information about getting medical and practical support when you are caring for someone at home on pages 20-23.

Ask friends or family to help with things such as the shopping, cooking or looking after children so you have less to worry about. Marie Curie have more information and tips on helping you plan your time and feel more in control.

When to get medical help

Contact the GP or nurse if:

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

And contact them if your family member:

- is finding it difficult to swallow medication
- has any new symptoms or symptoms are getting worse
- seems uncomfortable
- isn't emptying their bladder or bowels
- has fallen.

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

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

Spending time together

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

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

There may be things you’d like to say to your family member while they are still well enough. You might want to talk about their hopes and wishes, or share memories. You may want to talk about practical things like financial issues, their will, or what they want to happen after they die.

You may just want some quiet time together to say goodbye. Sometimes, people can put things off or feel that it’s too late to start these conversations. But it can be helpful and reassuring for everyone to talk about these things early on. There’s more information about talking about dying on page 9.

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

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

Questions to ask the doctor or nurse

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

What help can I get with caring for my relative?

Who should I contact for help or advice?

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

Signs that the end of life may be near

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

Withdrawing and speaking less

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

Sleepiness

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

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

Eating and drinking less

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

Breathing changes

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

Confusion, restlessness or agitation

Sometimes a person may become confused, restless or agitated. They may not know where they are or who is with them. Or they may fidget, or want to move about even if they're not able to. You may want to reassure them by reminding them of who you are and what is going on around them.

They may describe speaking to someone who has died or they may see things that aren't there. If they're not upset, it's fine to talk to them about what they can see or hear. Some people may be frightened – staying near them, gently touching them and reassuring them may help. A calm room with quiet music and familiar items like photos nearby can also help.

It can be upsetting for you if your family member is confused or agitated. There could be different reasons for why it is happening, so speak to the doctor or nurse. They will look for anything that is causing it, like pain, problems with their bladder or bowels, or issues with their medicines. They may recommend giving medicine to relax and calm them. Or they may suggest putting in a catheter (a tube into the bladder to drain urine). This will stop the bladder getting full and causing discomfort. If you are worried that your family member may be in pain, the doctor or nurse can help with this.

> " My partner became very confused towards the end of his life. For me that was possibly one of the most upsetting things, seeing someone who had been so strong and capable being so vulnerable. The healthcare team were great though."

Changes to their skin and feeling cold

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

Bleeding

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

Changing the medications

In the last few days, the doctor may talk to you about stopping medicines that are no longer needed or that aren't helping to control symptoms. They may also suggest giving medicines in a different way – for example, by injection or a syringe driver (see page 29) if your family member can no longer swallow medicines.

What happens when someone dies

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

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

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

After someone dies

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

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

- Ask the GP or hospital doctor for a medical certificate so you can register the death.
- Register the death within five days in England, Wales and Northern Ireland, and within eight days in Scotland. You will need to do this before a funeral.
- Arrange the funeral – you may want to check if your family member had made any plans for their funeral. You can arrange the funeral yourself or use a funeral director.

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

- **GOV.UK** website in England and Wales
- **National Records of Scotland** or the **Scottish Government** website
- **nidirect** website in Northern Ireland.

If your family member died at home, they can stay there for as long as you wish before the funeral. When you are ready, the funeral director will move them to a funeral home if that is what you want. You can visit them at the funeral home if you wish.

If they died in a hospital, hospice or care home, ask if you can go to visit them in a private room if you want to.

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

Coping with loss

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

What can help?

- **It can be helpful to talk to family and friends about how you are feeling, but there are also organisations that can provide support.**
- **Your GP may have details of local bereavement counsellors that you can speak to.**
- **If your family member was cared for at a hospice, the hospice may offer support and counselling to you and your family, including children. Contact the hospice to see what services they offer.**

- There are online communities where you can talk to others who have been bereaved. You can use our online forum, and Marie Curie and Sue Ryder also have online communities.
- Marie Curie and Macmillan Cancer Support have more information about grief and how to cope after someone dies.

Read more about coping with loss, and the details of organisations that provide bereavement support at: **pancreaticcancer.org.uk/bereavement**

You can also speak to our specialist nurses on our free Support Line if you need support after someone has died from pancreatic cancer. They have the time to listen, and can help you talk through your feelings.

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

More information and support

Medical words explained

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

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

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

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

Bilirubin: a yellow substance found in bile. It is the waste product of the normal break down of old red blood cells.

Constipation: when you find it harder to poo. Poo may be hard and dry.

Diarrhoea: runny poo.

Dietitian: a professional who provides expert advice about diet and nutrition, including how to manage symptoms caused by problems with digestion.

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.

Jaundice: develops when there is a build-up of bilirubin in the blood. It causes yellow skin and eyes, and itching. Read more on page 45.

Oedema: swelling caused by a build up of fluid in parts of your body such as your arms, legs, feet and genitals (see page 45).

Pancreatic enzyme replacement therapy (PERT): capsules that help digest food when the pancreas isn't producing enough digestive enzymes. Read more on page 32.

Steatorrhoea: caused by fat in poo. Poo may be pale, look oily, smell horrible, and be difficult to flush down the toilet. Read more on page 43.

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

Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

Our specialist nurses are here to talk now

We can answer your questions, recommend practical steps, and provide emotional support when you need it most.

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

Expert information

Our free information can help you understand your care, ask questions, make decisions and live as well as you can.

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

Our online forum

The forum is a supportive online space where everyone affected by pancreatic cancer can be there for each other.

Go to: **forum.pancreaticcancer.org.uk**

Living with Pancreatic Cancer Online Support Sessions

Our online support sessions are hosted by our specialist nurses and will give you the chance to connect with others.
Go to: **pancreaticcancer.org.uk/supportsessions**

Real life stories

Read other people’s experiences of pancreatic cancer.
Go to: **pancreaticcancer.org.uk/stories**

Useful organisations

British Association of Counselling and Psychotherapy

www.bacp.co.uk
Tel: 01455 883 300 (Mon-Fri 10am-4pm)

Provides information about counselling and a database of registered therapists.

Carers Trust

www.carers.org

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

Carers UK

www.carersuk.org
Helpline: 0808 808 7777 (Mon-Fri 9am–6pm)

Information and support for carers, including information about financial and practical issues.

Citizens Advice

www.citizensadvice.org.uk

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

Compassion in Dying

www.compassionindying.org.uk
Information line: 0800 999 2434 (Mon-Fri 11am-3pm)

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

Complementary and Natural Healthcare Council
www.cnhc.org.uk
Tel: 020 3668 0406

Information about complementary therapies and a register of therapists.

Cruse Bereavement Care
www.cruse.org.uk
Helpline: 0808 808 1677 (Mon, Fri 9.30am-5pm, Tues-Thurs 9.30am-8pm, weekends 10am-2pm)

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

Dying Matters
www.dyingmatters.org

Help people talk more openly about dying and bereavement, and to make plans for the end of life.

Fruit Fly Collective
fruitflycollective.com

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

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

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

GOV.UK
www.gov.uk

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

Healthtalk.org
www.healthtalk.org
Personal and patient experiences presented in written, audio and video formats, including people talking about pancreatic cancer and looking after someone at the end of life.

Hospice UK
www.hospiceuk.org
Tel: 020 7520 8200
Information about hospices, and a database of hospices in the UK.

Macmillan Cancer Support
www.macmillan.org.uk
Support Line: 0808 808 00 00 (Everyday, 8am-8pm)
Provides practical, medical and financial support for anyone affected by cancer, including information about support at the end of life.

Maggie's Centres
www.maggiescentres.org
Tel: 0300 123 1801
Centres around the UK and online offer free, practical, emotional and social support for anyone affected by cancer.

Marie Curie
www.mariecurie.org.uk
Helpline: 0800 090 2309
(Mon-Fri 8am-6pm, Sat 11am-5pm)

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

National Records of Scotland
www.nrscotland.gov.uk

Information on how to register a death.

NHS Direct Wales
www.111.wales.nhs.uk

Health information in Wales, including local services.

NHS Inform
www.nhsinform.scot

Information about different health conditions and local services in Scotland.

NHS website
www.nhs.uk

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

nidirect
www.nidirect.gov.uk

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

riprap
www.riprap.org.uk

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

Winston's Wish
www.winstonswish.org.uk
Helpline: 08088 020 021 (Mon-Fri 9am-5pm)

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

Samaritans
www.samaritans.org
Freephone: 116 123 (All day, everyday)

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

Sue Ryder
www.sueryder.org
Tel: 0808 164 4572

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

The Compassionate Friends
www.tcf.org.uk
Helpline: 0345 123 2304 (everyday 10am–4pm and 7pm-10pm);

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

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

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.

Email us at **publications@pancreaticcancer.org.uk** for references to the sources of information used to write this booklet.

Give us your feedback

We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions. Email us at **publications@pancreaticcancer.org.uk** or write to our Information Manager at the address on the back cover.

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