



# What to expect in the final weeks and days of life

When someone close to you has  
pancreatic cancer

# Introduction

This booklet is for the families and friends of people who are dying of pancreatic cancer. It explains what may happen in the last few weeks or days of life including how to access care and get support. There is also information about what to do when someone dies, and bereavement support if you need it.

We also have information about care, symptoms and support in the last few months.

Read more in our booklet: **Pancreatic cancer and end of life care. Information for people in the last few months of life**

Or at: [pancreaticcancer.org.uk/end-of-life](http://pancreaticcancer.org.uk/end-of-life)

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# How to use this booklet

We know some of the information in this booklet may be hard to read or upsetting. 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.

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

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

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

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

**Questions to ask** your healthcare team

**Things you can do** to help yourself

Contact details for the organisations we mention in this booklet are on page 29.

# Key facts

- Looking after someone who is nearing the end of their life can feel overwhelming. Make sure you get emotional support if you need it.
- As someone approaches the end of their life, their care is focused on managing symptoms and emotional support.
- People can be cared for in their home, in hospital, a care home or at a hospice.
- If you are caring for your loved one at home, there can be a lot to do and think about. Ask the doctor or nurse for details of who to call if you need help or advice, especially at night or at weekends.
- If your loved one is in hospital, a care home or at a hospice, find out about visiting arrangements. Your family member may want relatives to stay overnight or might want their pet to visit.
- Ask friends and family to help with anything you need. People are often happy to help out but struggle to know what they can do unless you tell them.
- 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.
- There is support available to help you cope with grief and loss after someone dies.

# Emotional 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 everything.

## Where can I get emotional support?

The doctors and nurses can tell you what to expect, which may help you to feel more in control. But you might also need emotional support. Looking after yourself and getting any support you need can help you cope better.

Emotional support may come from friends, family or health professionals. But it's not always easy to share your feelings with people you are close to. It can also help to speak to someone you don't know.

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

Call free on **0808 801 0707** or email  
**[nurse@pancreaticcancer.org.uk](mailto:nurse@pancreaticcancer.org.uk)**

Local cancer centres, including Maggie's, and hospices offer emotional support for people caring for someone with cancer. Hospices provide care and support for people with an illness that can't be cured, and for their families.

Read more about hospices at:  
[pancreaticcancer.org.uk/palliative](https://pancreaticcancer.org.uk/palliative)

Counselling or ‘talking therapy’ involves talking to a trained professional about your thoughts and feelings. It may help you find ways of coming to terms with things. Ask your GP about counselling services in your area.

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

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

## **What is anticipatory grief?**

Sometimes people start to grieve for the loss of the person with cancer before they die. This is called anticipatory grief. It is normal, but these feelings can be very difficult and may feel as intense as grief after a death.

You may be able to get support from your local hospice or organisations such as Maggie’s or Cruse. This can help you prepare for loss and for what the future might hold.

“As soon as mum had her terminal diagnosis, I started to picture my life without her and think about all the experiences we were going to miss. It was really hard. I didn’t really understand my feelings then, but I know now that it was anticipatory grief.” Debra

Read more about dealing with the emotional impact of caring for someone with pancreatic cancer at: [pancreaticcancer.org.uk/emotions](https://pancreaticcancer.org.uk/emotions)



## **Questions to ask your doctor or nurse**

I am struggling with lots of emotions, what support can I get?

How can counselling help me?

Where can I get free counselling?





# Caring for your loved one

Our information explains how things should happen. Be aware that sometimes you may have to push for things to be done. For example, don't be afraid to ask questions, or ask for care and support to be put in place. If you need information and support, you can always contact our specialist nurses on our free Support Line.

## Caring for your loved one at home

If you are looking after your loved one at home, there will be support from different healthcare professionals including your GP and district nurses. Read more on page 10.

You may find the demands on you can increase quite quickly in the last few weeks or days. You might need to do more for your loved one, including:

- washing and personal care
- making sure they are comfortable
- helping with eating and drinking
- talking to healthcare professionals
- ordering repeat prescriptions
- giving medicines.

It can be overwhelming and tiring but some people take comfort from being able to provide this care.

Try not to worry about things that don't matter too much, like housework. If friends or family offer practical help, accept it. This will give you time to focus on supporting your family member, and to have some rest.

Marie Curie have lots of practical information about how to help your family member.

### **What support can we get at home?**

Palliative care teams provide specialist care for people with cancer that can't be cured. They manage symptoms such as pain, emotional symptoms, and support families. End of life care is a type of palliative care, which focuses on managing your loved one's symptoms and giving emotional support.

The GP, district nurse or palliative care nurse will work together to provide end of life care in the home. They will also be your main contacts.

Hospice at Home is a service offering specialist palliative care at home. Marie Curie nurses or Hospice at Home nurses provide nursing care. This sometimes includes at night so you can get a rest.

Your family member might need adaptations to the home or equipment, for example a hospital bed or portable toilet (commode). An occupational therapist (OT) or district nurse can help you get what they need.

Speak to the GP, district nurse or palliative care nurse about referrals to these services.

## Can I get help with personal care for my loved one?

When someone is dying, they can also get support with personal care like washing, dressing and eating. This care is provided by carers, and they come in several times a day. Depending on where you live and your financial circumstances you may be able to get this care for free. Ask the GP, district nurse, or palliative care team for information.

Read about support for people at home in our booklet: **Pancreatic cancer and end of life care**

And at:

**[pancreaticcancer.org.uk/where-to-receive-care](http://pancreaticcancer.org.uk/where-to-receive-care)**

“My dad declined quickly. It was a bit overwhelming knowing what to do and where to go for information. I had great support from the hospice and from the Pancreatic Cancer UK nurses.” Taran

## What if I need help out of hours?

It's important you know who to contact if you need support over the weekend or at night. You can ask the GP, district nurse or palliative care team about this. The GP answer phone should also have an out of hours number to call.

If you live in England, Wales or Scotland, you can also call the NHS on 111 or use NHS 111 online for advice. In Northern Ireland, there are local out of hours phone numbers for each region, which you can find on the nidirect website.

## **‘Just in case’ medicines**

The GP or nurse may give your family member medicines to keep at home for symptoms they may get. These are sometimes called **pre-emptive, anticipatory** or **just in case medicines**. A nurse will be able to give them if your loved one needs them. This can be helpful if they need treatment at night or at the weekend.

“Our local hospice had a 24 hour support line which was invaluable – really practical and amazing service.”

## **Getting a break from caring**

It’s normal for families to need a break. Some people feel guilty about this. But it’s important that you take some time for yourself. It’s easy for your own needs to get pushed to the bottom of the list. But research has found that if you take time to take care of yourself, you may find it easier to care for the person with cancer and to cope.

## **Respite care**

If you need a break, you may be able to get temporary care for your family member. You may hear this called respite care. It might include somebody coming in to sit with them for a few hours, day care, or a short stay in a care home. Speak to your GP or the district nurse about this care.

## Help from family and friends

Ask friends or family to help and be clear with them about what help you need. Support with practical things such as the shopping, cooking or looking after children means you have less to worry about. You could also ask them to sit with your loved one to give you a break.

“We had fantastic nurses coming every day to care for him. However, the 24/7 care took its toll on me physically and mentally. The last two nights our best friends stayed with him so that I could sleep.” Joanne



### Questions to ask your doctor or nurse

Who will be providing care to my loved one?

Will we need any special equipment (like a hospital bed) in the house?

How do I get help out of hours?

What happens if my loved one is in pain?

How is respite care organised?

Our specialist nurses on our free Support Line can answer questions about accessing care at home.

## What if my loved one is in hospital, a hospice or care home?

If your loved one is in a hospice they will get specialist palliative care. If they are in hospital and are not already seeing the palliative care team, ask their medical team for a referral.

Your loved one may be in a care home for a short time or long-term if they are not able to manage at home. They may still be seen by the community palliative care team. But ask the care home team about this as arrangements may vary from place to place.

Read more about where to receive end of life care at:  
[pancreaticcancer.org.uk/where-to-receive-care](https://pancreaticcancer.org.uk/where-to-receive-care)

## Can I help with their care?

Some people like to help with the care of their loved one. For example keeping their mouth and lips clean and moist or looking after their appearance. Speak to the nurses about how you can help.

## Spending time together

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

If your family member would like some time alone with their partner, they could ask their nurses if this is possible. Many people want time to be close and intimate in private and the healthcare team will try to help with this.

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



## **Questions to ask your doctor or nurse**

How will my family member’s symptoms be managed?

Will they see the palliative care team in the hospital or care home?

Can visitors stay overnight?

What are the visiting hours?

Can I bring a pet to visit my loved one?

“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.”

# Saying goodbye

There may be things you would like to say to your loved one while they are still well enough. You might want to talk about their wishes, or share memories. You may want to talk about practical things like financial issues or what they want to happen after they die. Or you may just want some quiet time together to say goodbye.

There may be conflicts or challenges that you or your family member would like to resolve. For some people approaching the end of life, forgiving or being forgiven can help with a more peaceful death. Sometimes, people can put things off or feel that it's too late to start these conversations. But it can be helpful and reassuring to talk about your feelings and wishes early on.

You could ask the hospital or hospice chaplain to help you with these conversations if you are not sure where to start.

Read more about talking about dying at:  
[pancreaticcancer.org.uk/talking-about-dying](https://pancreaticcancer.org.uk/talking-about-dying)

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



# 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.

Ask the doctor or nurse what signs to look out for when your family member is close to the end of their life. They can 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. You can keep talking to your loved one. It can be reassuring for you both.

## Sleepiness

Another sign that someone is in the last few days of life is sleepiness. They 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.

“We played music for my dad at the end. He loved music, even wrote a few songs himself when he was younger. So we played him these, and a couple of Beatles songs he told me a week prior would be his picks for Desert Island Discs. He couldn’t talk or open his eyes, but I remember how he murmured and tried to sway his head when we played them. He died an hour later, but he died in full song, just as he lived.” Taran

## **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, ice lollies or small pieces of ice to suck, to keep their mouth moist.

Ask the doctor or nurse if you can have a mouth hydrator. This small plastic tube releases tiny drops of water or other drink. It helps moisten their mouth.

If they are not awake, the GP or nurse may give you a small, soft brush 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 or less regular in the last few days. Fluid in the throat or chest may make their breathing noisy, or there may be a rattling sound. This is sometimes called a death rattle.

This isn't usually uncomfortable, and they may not be aware of it, 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. This is sometimes known as terminal agitation. They may not know where they are or who is with them. They may make strange or disturbing noises. Or they may fidget or want to move about even if they're not able to.

### **Can anything help with terminal agitation?**

You can 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 are 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 or holding their hand and reassuring them may help. A calm room with quiet music and familiar items like photos nearby can also help.

It can be upsetting if your loved one 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.

The doctor may recommend medicine to relax 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, speak to the doctor or nurse.

## **Changes to their skin and feeling cold**

Towards the end, your family member's skin may become blue, grey or pale. They 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 not common but it can be upsetting and frightening. There may be bleeding internally from the stomach or around the pancreas. This can sometimes cause people to vomit blood or have blood in their poo. If there's blood in their poo it may look very dark or black.

If bleeding happens at home, contact the GP, nurse or hospice team or call the out of hours number. 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 medicines

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

Read more about syringe drivers at:  
[pancreaticcancer.org.uk/syringedriver](https://pancreaticcancer.org.uk/syringedriver)

## How will I know when to get medical help?

### Get help 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.

### Contact them if your family member:

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



## Questions to ask your doctor or nurse

What can I do to support my family member?

Who should I contact for help or advice?

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



# 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. Their skin may change colour or look pale.

“We made the most of every day, watching Mum's favourite ghost programmes and reading ghost stories by candlelight. We can take comfort in the fact that our mum died peacefully at home with her family all together one last time including DeeDee, Mum's cat, who didn't leave her side.” Jen

## After someone dies

If your loved one dies in hospital, a hospice or a care home, the healthcare team will explain what happens next. Ask if you can visit your loved one in a private room if you want to.

If they die at home and no health professionals are there, you will need to contact their GP or district nurse 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. The GP or nurse should give you information about what you need to do next.

## Things 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 if this is what your family member wanted. You may want to check if they had made any plans for it. You can arrange the funeral yourself or use a funeral director.

You can 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.

“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.”





# Coping with loss

It is natural to feel a range of emotions after someone dies. You may have lots of feelings, like sadness, anger, guilt or you may feel numb. You may be relieved that your loved one is no longer suffering. If everything happened very quickly, you might not have felt prepared.

Grief is different for everyone, and you may react differently or cope in different ways to others.

It is common for people to have physical symptoms when they are grieving. You may lose your appetite, have trouble sleeping, or you might feel very tired. If you are feeling anxious you may also feel breathless or have tightness in your chest. Talk to your GP for support.

Marie Curie and Cruse Bereavement Support have more information about grief.

## What can help?

- It can be helpful to talk to family and friends.
- Ask your GP about bereavement counsellors.
- If your family member was cared for at a hospice, the hospice may offer support and counselling to you and your family, including children.
- Faith organisations or community groups may be able to give you emotional or spiritual support.
- Talk online to others who have been bereaved. Marie Curie and Sue Ryder have online communities.

Read about coping with loss and organisations that provide support at:

[pancreaticcancer.org.uk/bereavement](https://pancreaticcancer.org.uk/bereavement)

“The grief of losing my mum was overwhelming, but as time passed, I found solace in our cherished memories. I can now look back and remember her laughter, her warmth and her unconditional love. She was an extraordinary woman whose legacy lives on through my memories.” Kevin

“My daughter found a bereavement group on Facebook for me. I thought about it for six months and eventually joined. I’m glad I did. It was good to hear from people in the same boat.” Anne

# More information and support

## We are here for you

Find out more about how we can support you at:  
[pancreaticcancer.org.uk/support](https://pancreaticcancer.org.uk/support)

## Our specialist nurse Support Line

Our specialist nurses are experts in pancreatic cancer. They can talk for as long as you need, as often as you like.

Call free on **0808 801 0707** or  
email [nurse@pancreaticcancer.org.uk](mailto:nurse@pancreaticcancer.org.uk)

## Information about pancreatic cancer

Our website, videos and publications can answer your questions.

Go to: [pancreaticcancer.org.uk/information](https://pancreaticcancer.org.uk/information)

Download or order our free publications at  
[pancreaticcancer.org.uk/publications](https://pancreaticcancer.org.uk/publications)  
or call **0808 801 0707**

## Real life stories

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

Go to: [pancreaticcancer.org.uk/stories](https://pancreaticcancer.org.uk/stories)

## Useful organisations

### Cruse Bereavement Support

**cruse.org.uk**

**Helpline: 0808 808 1677** (Mon, Wed, Thurs and Fri 9.30am-5pm and Tues 1-8pm)

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

### GOV.UK

**gov.uk**

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

### Hospice UK

**hospiceuk.org**

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

### Macmillan Cancer Support

**macmillan.org.uk**

**Support Line: 0808 808 00** (Every day, 8am-8pm)

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

### Maggie's

**maggies.org**

**Tel: 0300 123 1801**

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

## **Marie Curie**

**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.

## **NHS Inform**

**nhsinform.scot**

Health information for people living in or visiting Scotland.

## **NHS UK**

**nhs.uk**

Health and wellbeing advice and information about services in England.

## **NHS 111 Wales**

**111.wales.nhs.uk**

Health information and advice for people living in Wales.

## **National Records of Scotland**

**nrscotland.gov.uk**

Information on how to register a death.

## **nidirect**

**nidirect.gov.uk**

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

## **Sue Ryder**

**sueryder.org**

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

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

We try to make sure that our services provide accurate information about pancreatic cancer. We hope this will add to the medical advice and help you make decisions about your care. This information should not replace advice from the medical team – please speak to the medical team with questions.

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

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