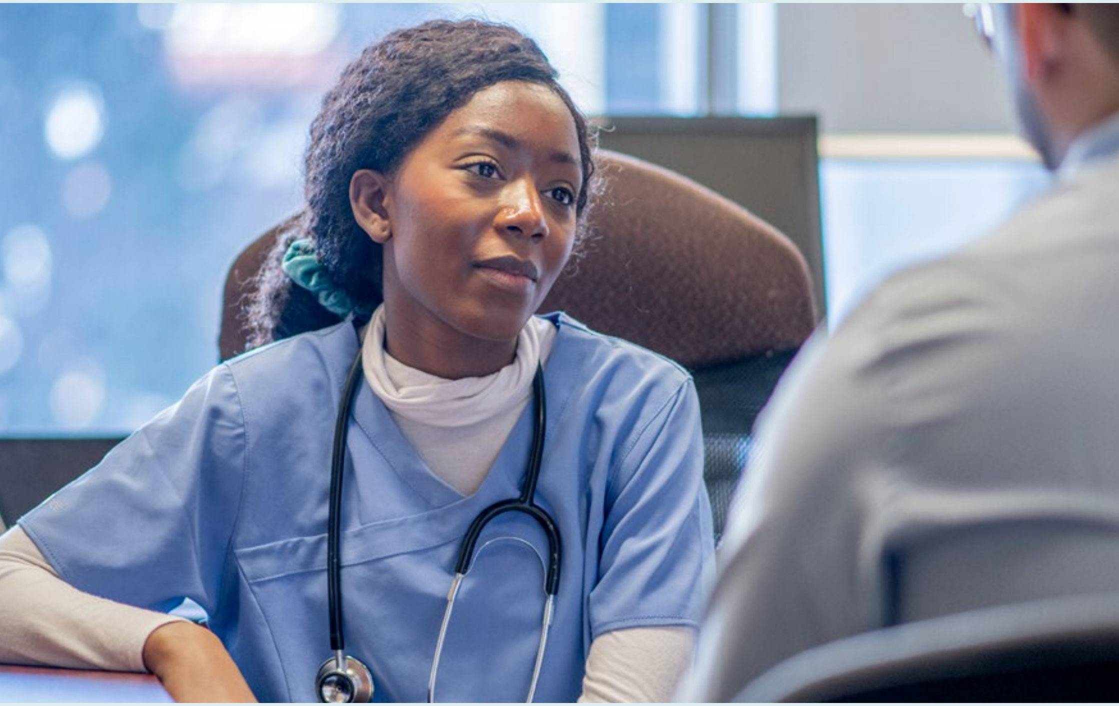
Pancreatic
CANCER UK



What to expect from your care if you have pancreatic cancer

Introduction

Being diagnosed with pancreatic cancer can be a lot to take in. Knowing what to expect can help.

This booklet is a guide to the care people with pancreatic cancer should get from the NHS. Private healthcare may be different. This booklet is based on UK guidelines for managing pancreatic cancer. These include the National Institute for Health and Care Excellence (NICE) guidelines in England, Northern Ireland and Wales, and guidelines for cancer care in Scotland.

Read the guidelines at: **pancreaticcancer.org.uk/NICE**

Contents

How to use this booklet

You don't have to read this booklet all at once. Look at the contents on page 2, read the sections that feel most helpful, and come back to it if you need to know more. There is more information and support on our website. Find out more at: **pancreaticcancer.org.uk**

Use the colours below 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 the doctor or nurse

Things you can do to help

There are contact details of the organisations we mention on page 28.

Key facts about your care

- You should be treated with compassion throughout your care.
- Your medical team should give you information you can understand about your diagnosis and treatment options.
- They should involve you in decisions about your treatment and care. Read more about your medical team on pages 5-6.
- You should have a key contact. This may be a nurse called a clinical nurse specialist (CNS). They can support you and answer your questions.
- You and your family should get information about practical and emotional support that's available (see page 18).
- The care you receive should be well coordinated between the different healthcare teams you may see.
- If you need more support to understand your care, our specialist nurses of our free Support Line can help. Call them on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**
- If you have any concerns about your care, speak to your doctor or nurse first. They can help to sort it out. They can also tell you how to make a complaint if you need to.

Who should manage your care?

Specialist teams and specialist centres

Your diagnosis should be reviewed by a multidisciplinary team (MDT). The MDT is the team of medical professionals responsible for your treatment and care. They will work out the best treatment and care for you, and should take your wishes into account.

The MDT may be based at a specialist centre. A specialist centre is a hospital where there is a team of medical professionals who specialise in pancreatic cancer. There are specialist centres across the UK. Local hospitals work with the specialist centres to make sure people get the best treatment and care.

You may not need to go to the specialist centre or meet all the members of the MDT. You may be treated at your local hospital's cancer unit, but your consultant (senior doctor) or nurse should tell you what the MDT recommends.

A key contact to support you

The hospital should provide a key contact to support you during your treatment and care. They will help coordinate your care if you are having treatment for the cancer.

You should be told who this key contact is early on, and if it changes. It's important that you know how to contact them. If you are not sure, ask any member of the medical team.

The key contact may be a specialist nurse, sometimes called a **clinical nurse specialist or CNS.** They provide expert support, care and advice.

You may also have a patient care coordinator or navigator. These are only available in some hospitals, or may be called something different. They will work with the medical team and CNS to coordinate your care, including across different hospitals.

Your CNS or care coordinator may change if the hospital where you receive care changes.

Compassionate care

You should be treated with compassion, dignity and respect at all times by your medical team. This includes listening to your concerns and taking your wishes into account.

Find out more about specialist centres, the MDT, and the health professionals involved in your care on our website at: **pancreaticcancer.org.uk/care**

> "I know if I've got any kind of worry or something comes up, I can just pick that phone up and ask for my clinical nurse."

Understanding your diagnosis

Getting clear information

Your doctor or nurse should give you high quality information that you can use and understand. This may include written as well as spoken information, or accessible versions like large print.

The information should cover:

- a description of the cancer and your diagnosis
- your treatment options
- the side effects of treatment, and how to manage them
- symptoms you may get from the cancer, and how these can be managed
- information about how pancreatic cancer may affect your digestion and about taking pancreatic enzymes to help with this (see page 15)
- contact details for your medical team
- any other support you may need and how to access this.

The hospital should tell your GP about your diagnosis and treatment.

Understanding your prognosis

Some people want to know whether their cancer can be cured or how long they have left to live. This is called your prognosis. You may not want to know your prognosis, but if you do, speak to your doctor. They won't be able to give you an exact timeframe, as everybody is different. But they should be able to give you an idea of what to expect.

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

What can I do?

- If you are not given information, ask your main contact for it.
- You could show them the list on page 7, to make sure you get the information you need.
- Ask about how pancreatic cancer will affect your digestion, and how this will be managed.
- You might find it helpful to write a list of the questions you want to ask, or bring someone with you to appointments to take notes.

Treatment options

Deciding on your treatment

Treatments for pancreatic cancer include surgery, chemotherapy and radiotherapy. Chemotherapy uses drugs to kill cancer cells, and radiotherapy uses radiation to destroy them. What treatment you can have depends on whether the cancer has spread.

Your medical team should explain your treatment options in a way that you can understand. They should talk to you about the benefits of any treatment, as well as the disadvantages and risks. They should involve you in making decisions about your care, and answer any questions or worries you have. It is up to you whether or not you have the treatment or care they recommend.

Read more about treatment options on our website at: **pancreaticcancer.org.uk/treatments**

If you have any questions about your treatment you can speak to our specialist nurses on our free Support Line. They can talk you through your options and explain what's involved.

Timing of the treatment

Your treatment for the cancer should start within 31 days of agreeing with your medical team what treatment you will have.

If you can't have treatment

Some people may not be able to have treatment for the cancer. But there are still treatments to help with symptoms. Hospital or community teams will care for you.

Community teams may include your GP, district nurses, Macmillan nurses, or a hospice team. They will be able to assess your symptoms and provide treatments to help with these. They can also help you get care and support at home. They may refer you to a specialist palliative care team (see page 13).

If you are told that you can't have any treatment to control your cancer, it can be a shock. If you or your family need support, our specialist nurses on our Support Line can talk for as long as you need.

Clinical trials

Your doctor should tell you about any clinical trials that may be suitable for you to take part in. Clinical trials are carefully controlled medical research studies that involve people. They can be an important treatment option for people with pancreatic cancer.

Most pancreatic cancer trials are looking at new treatments, or different ways of using current treatments. Speak to your doctor about whether there are any clinical trials that might be suitable for you.

Read more about clinical trials and find open trials at: **pancreaticcancer.org.uk/clinicaltrials**

Second opinions

You can ask for a second opinion about what your options are. This means a different doctor, possibly in a different hospital, will review your diagnosis and treatment options.

Ask your hospital doctor or GP to refer you for a second opinion, if you want one. You don't have a legal right to this, but most doctors will help you get one. Don't delay your treatment while you get a second opinion, as it can take several weeks. Keep in mind that the second team's opinion may not be any different.

Second opinion for people getting rapidly worse

Under new rules being introduced from 2024, families can ask for a second opinion if their loved one is rapidly getting worse in hospital. You may hear this called Martha's Rule. This is different from asking for a second opinion on your diagnosis or treatment options.

Read more about getting a second opinion at: **pancreaticcancer.org.uk/secondopinion**

Follow-up care

After treatment for the cancer, your medical team should give you regular check-ups. You may hear this called follow-up care. The aim of follow-up is to check how well your treatment is working and to manage any side effects.

You should be given information on what to expect after treatment. Ask your doctor or nurse what your follow-up care will involve.

Care if your cancer can’t be cured

Palliative and supportive care

If you have cancer that can’t be cured, you may see a specialist palliative or supportive care team. These teams help people to live as well as possible for as long as possible.

Palliative care is not just for people at the end of their life. It is available at any point during your treatment or care. It aims to manage any symptoms you may have, as well as emotional, physical, practical and spiritual support. Supportive care is similar. It aims to make sure that you get this support from a very early stage in your care.

Your healthcare team should tell you what to expect and make sure you have the support you need.

Read more about palliative and supportive care at:
pancreaticcancer.org.uk/palliative

Thinking about your future care

You should be supported to think about how you would like to be cared for in the future, as your health changes. This might include what care you would or wouldn’t want, and where you want to receive any care. This is called **advance care planning**.

You may want to create a written record of your wishes and share this with your family, healthcare team and GP. You can change your wishes at any time.

Read more about planning your future care at:
pancreaticcancer.org.uk/planningcare

If you need end of life care

Accessing end of life care

If you are approaching the end of your life, your care will focus on managing any symptoms you have, as well as supporting you emotionally and practically. It aims to help you live as well and as comfortably as possible.

If you haven't been referred to specialist palliative care services, ask your GP, district nurse or hospital team about whether a referral would be helpful.

Well coordinated care

You should get well coordinated care towards the end of your life. The healthcare team looking after you may include your GP, a district nurse, your local hospice or a specialist palliative care team (see page 13).

Read more about end of life care in our booklet:
Pancreatic cancer and end of life care
Or at: **pancreaticcancer.org.uk/end-of-life**

How will symptoms and side effects be managed?

Support with symptoms

Your medical team should help manage any symptoms you may have. These may be things like pain and fatigue. There are things that can help.

You can speak to our specialist nurses with any questions about managing symptoms.

Read more about dealing with symptoms at:
pancreaticcancer.org.uk/managingsymptoms

Digestion and nutrition

Your medical team should give you advice and support to manage problems with eating and digestion.

The pancreas produces enzymes which help to break down (digest) food. Pancreatic cancer, and surgery to remove the cancer, can affect this. This can cause symptoms like tummy pain, weight loss, wind and changes to your poo.

These symptoms can be managed with **pancreatic enzyme replacement therapy (PERT)**. These are capsules that help you digest food and can make a big difference to how you feel. PERT can also help you cope better with treatments like chemotherapy. Most people with pancreatic cancer will need to take PERT.

Your medical team should tell you how to take PERT properly, so that you are confident doing this.

Who is the dietitian?

You may see a dietitian, ideally a specialist dietitian who is an expert in diet and cancer. They can provide advice tailored for you.

Not all hospitals have a specialist dietitian. Your doctor or nurse may help you with digestion symptoms, or they may refer you to a general dietitian. Ask them about whether PERT might help you.

Read more about digestion and PERT in our booklet:
Diet and pancreatic cancer
And at: **pancreaticcancer.org.uk/diet**

Managing diabetes

Diabetes is where the amount of glucose (a type of sugar) in your blood is too high. Some people with pancreatic cancer develop a type of diabetes called type 3c diabetes. This is different to other types of diabetes and is treated differently. Information and advice about diet for type 1 or type 2 diabetes may not be right for you.

You should be referred to a diabetes nurse, who will explain how to manage your diabetes.

Read more about managing diabetes at:
pancreaticcancer.org.uk/diabetes

Practical and emotional support

Your healthcare team should check how you are doing at key points in your care. This is so they can support you. A member of your healthcare team will talk to you about any physical, emotional, spiritual or practical issues you may have. They may call these checks a needs assessment or holistic needs assessment (HNA), but they may not. They will help you manage any issues you have.

Emotional care

Your doctor or nurse should ask how you are coping emotionally. This includes how you are coping with your diagnosis, any symptoms you have, and any feelings of anxiety or depression. It's common for people with pancreatic cancer to feel worried, sad or to have low mood. But there are ways to get help.

If you are finding it hard to cope, you should be given information about the support that is available. You should also be told about other organisations that can support you. This support should be available throughout your care and tailored to your needs.

> "The nurses were brilliant. When they came to see dad, the nurse saw that mum wasn't coping and spoke to her for an hour. We are very thankful." Nicola

What can I do?

- Speak to your healthcare team at any time if you need support. Don't struggle alone with worries and problems.
- Read our tips and information about dealing with the emotional impact of pancreatic cancer on our website, at: **pancreaticcancer.org.uk/coping**.
- You can speak to our specialist nurses on our confidential Support Line. Call our specialist nurses free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**
- Find out about the other ways we can support you at: **pancreaticcancer.org.uk/support**

Practical support

Cancer can have an impact on everyday life for you and your family. There is practical support available, such as support with financial issues. This may be from charities and other organisations. Ask your healthcare team or GP who you can speak to about what practical support is available.

Find out more about the different kinds of practical support available on our website at: **pancreaticcancer.org.uk/practical**

Support at home

You and your family should be involved in plans for any care you have at home. For example, you may need help from a community nurse. These services can support families as well as the person with cancer.

Planning for when you leave hospital

If you are leaving hospital, your medical team will assess what care and support you may need at home. This is called a needs assessment or discharge planning.

The assessment will be used to create a discharge plan and, if needed, a care plan. These include details such as what treatment and support you will have at home, and who to contact if there is a problem.

What can I do?

- Read about getting the care you need at home at: **pancreaticcancer.org.uk/nursingsupport**
- Talk to your community nurse, GP or specialist nurse at any time about how you are coping at home. They can help you get the right care and support.
- It can sometimes take time to organise care and support at home, so do this as soon as you can.
- Talk to them again if anything changes.

What support is there for families?

Involving those close to you in your care

Your family and friends can be involved in your care, but only if you want them to be. If you wish, you can give your medical team permission to speak to those close to you about your care.

Support for families

Your family should be given information about the emotional and practical support that is available to them. They can ask your medical team or their GP about this.

If you or your family are worried about family history of pancreatic cancer, your medical team can discuss this with you. This isn't common, but sometimes pancreatic cancer can run in families.

Your family may also be able to get financial support, if looking after you means they can't work or can only work part-time. Macmillan Cancer Support and Citizens Advice also provide expert help with managing finances.

We have information for families in our booklet:
Caring for someone with pancreatic cancer
And at: **pancreaticcancer.org.uk/families**

Being told that a family member has pancreatic cancer can be a huge shock. Our specialist nurses on our Support Line speak to lots of families. They are specialists in pancreatic cancer, and can talk and listen for as long as your family need.

> “The support I get from the nurses on the Support Line is incredible! My nephew was able to contact them with questions too. They were just fantastic.”
> Catherine

How to get support

We know that dealing with your care can be tiring and confusing. There is support available if you need it.

How can I get more support?

- Talk to your doctors and nurses. It's ok to ask questions and tell them what you think about your care. They can support you.
- Our specialist nurses are just a call or email away. They are experts in pancreatic cancer. Whether you have a long list of questions or don't know where to start, they will provide practical, honest information to help you.
- Think about asking someone to help you understand and manage your care. This could be a friend or family member, or an independent person who can act on your behalf (see page x).
- We know it can feel lonely dealing with pancreatic cancer, but sharing your experiences could help. Through the Real Life Stories on our website, you can read other people's stories or tell your own.
- Other cancer charities offer support. Examples include Macmillan Cancer Support, Maggie's, Tenovus Cancer Care in Wales, and Cancer Focus Northern Ireland.

> “I reached out to all the help offered to me from Macmillan, Maggie’s, the hospice and Pancreatic Cancer UK. The support has helped both myself and my loved ones to navigate through this and has provided great comfort when we needed it.” Jenny

Getting support if you have concerns about your care

This booklet explains how care should happen. But we know things don’t always go to plan.

Be aware that sometimes you may have to push for things to be done. For example, don’t be afraid to ask a lot of questions, chase appointments, or ask for care and support to be put in place.

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

Support from an advocate

If you need independent support to deal with any problems with your care, there are organisations that can help you. This service is called advocacy. An advocate is someone who helps you have your say and know your rights. They can help you tell healthcare professionals about what you want. They can also help you raise concerns about your care if you need to.

- **In England,** charities such as VoiceAbility offer advocacy services for NHS complaints.
- **In Scotland,** you can use the Scottish Independent Advocacy Alliance to find advocacy services in your area.
- **In Northern Ireland,** the Patient and Client Council can help.
- **In Wales and England,** local councils may provide advocacy. Find out more on the NHS website.

What if I have concerns about NHS care?

If you have concerns about NHS care, talk to your doctor or nurse first. It's important to raise any concerns you have. Don't be worried that this will affect your future treatment and care.

If talking to the doctor or nurse doesn't help, you may want to take the issue further. You need to do this within 12 months of the when the issue happened. There are services you can use to help you do this. See page 28 for contact details of these organisations.

- **In England,** you can speak to the Patient Advice and Liaison Service (PALS).
- **In Scotland,** the Patient Advice and Support Service (PASS) can help.
- **In Wales,** Llais can support you in raising your concerns.
- **In Northern Ireland,** the Patient and Client Council can help you with your complaint.

Concerns about private healthcare?

If you use private healthcare and have concerns, you should first talk to your doctor or nurse. If the situation isn't sorted out, you can speak to the organisation that regulates the service. For example, you can report certain complaints to:

- the Care Quality Commission in **England**
- Healthcare Improvement Scotland or the General Medical Council in **Scotland**
- the Public Services Ombudsman for Wales or the Healthcare Inspectorate in **Wales**
- the Regulation and Quality Improvement Authority in **Northern Ireland**.

Citizens Advice have more information about complaining about private healthcare.

There is more information about giving feedback and making complaints on our website, at: **pancreaticcancer.org.uk/concerns**

Useful organisations

UK wide

Citizens Advice

citizensadvice.org.uk
Provides information and advice on issues including work, benefits, healthcare, and patient rights.

Macmillan Cancer Support

macmillan.org.uk
Support Line: 0808 808 0000 (Every day, 8am-8pm)
Practical, medical and financial support for anyone affected by cancer, including families.

Maggie's Centres

maggies.org
Tel: 0300 123 1801
Centres around the UK and online offering free practical, emotional and social support for anyone affected by cancer.

National Institute for Health and Care Excellence (NICE)

nice.org.uk
NICE have guidelines for health professionals diagnosing and caring for people with pancreatic cancer. Read more at: **nice.org.uk/guidance/ng85**

England

NHS website

nhs.uk

Information about health conditions, living well, care, and local services in England. You can also find your local **patient advice and liaison service (PALS)**. PALS can help people in England raise concerns about care.

VoiceAbility

voiceability.org

Offers advocacy services for issues with NHS care in England.

Northern Ireland

Cancer Focus Northern Ireland

cancerfocusni.org

Nurse line: 0800 783 3339 (Mon, Weds, Fri, 9am-1pm)

Care and support for people affected by cancer and their families in Northern Ireland.

nidirect

nidirect.gov.uk

Information about local services in Northern Ireland, including health services.

The Patient and Client Council

pcc-ni.net

Offers an advocacy service to support people with concerns about Health and Social Care in Northern Ireland.

Scotland

Healthcare Improvement Scotland

healthcareimprovementscotland.org

Works to ensure better quality health and social care in Scotland. They also regulate private hospitals.

NHS inform

nhsinform.scot

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

Patient Advice & Support Service (PASS)

pass-scotland.org.uk

Independent service that works with anyone who has a complaint or feedback about NHS services in Scotland.

Scottish Independent Advocacy Alliance (SIAA)

siaa.org.uk

Supports advocacy in Scotland. It does not offer advocacy, but it has a list of advocacy services on its website.

Wales

Llais

llaiswales.org

Information and support in making a complaint about health and social services in Wales.

NHS 111 Wales

111.wales.nhs.uk

Health information in Wales, including local services.

Tenovus Cancer Care

tenovuscancercare.org.uk
Tel: 0808 808 1010

Advice and support for people affected by cancer in Wales.

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 treatment and care. This information should not replace advice from the medical team – ask them any questions.

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

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

We would like to thank the people who reviewed this:

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Pancreatic Society • of Great Britain and Ireland •