

Pancreatic Cancer UK

**The care you should expect
and receive**
Patient Charter



The care you should expect and receive

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How to use the Patient Charter

This booklet explains the standards of care everybody with pancreatic cancer should have while they are being diagnosed and treated for pancreatic cancer. You can use it as a guide to what you should expect. It can also help you talk to your doctors and nurses about the care you should receive.

The National Institute for Health and Care Excellence (NICE) have produced guidelines on the diagnosis and management of pancreatic cancer to improve care. These guidelines are for the most common type of pancreatic cancer, pancreatic ductal adenocarcinoma. They apply in England, Northern Ireland and Wales. Doctors don't have to follow these guidelines in all situations, but they must take them into account. There are also other guidelines for cancer care across the UK.

We have produced a version of the NICE guidelines for people with pancreatic cancer and their families, to help you understand the care you should have and make decisions about your treatment. You can also use this to speak to your doctors if you feel you are not getting the care you should have. Read more about this on page 14.



Find out more in the **NICE guidelines for diagnosing and managing pancreatic cancer** on our website at **pancreaticcancer.org.uk/NICE**

If you have any questions about anything in this booklet, the NICE guidelines, or the care you should expect, talk to your doctor or nurse.



You can also talk to our specialist nurses on our free Support Line on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**



We have a wide range of information about pancreatic cancer, including diagnosis, treatment and managing symptoms. You can find all our information and order publications on our website at **pancreaticcancer.org.uk/informationandsupport**

A diagnosis of pancreatic cancer can be a lot to take in. It can have a huge impact on you and your family and friends. You should be informed and involved in discussions about your care during your diagnosis, treatment, and if necessary, any end of life care.

1 Assessment and treatment by a specialist team of health professionals

Specialist teams and centres

Your case should be reviewed by a specialist pancreatic Multidisciplinary Team (MDT) at a specialist centre. There are specialist centres across the UK. Hospitals in the region work with the specialist centre to make sure people get the best treatment.

The MDT is the team of medical professionals responsible for your treatment and care. They will agree the best treatment and care for you, and should take your wishes into account. You may not need to go to the specialist centre or meet the members of the MDT. You may be treated in your hospital's local cancer unit, but your doctor should tell you what the MDT has decided.

Clinical nurse specialists

You should have access to a named clinical nurse specialist (CNS) or other health professional (sometimes called a keyworker) who will coordinate your care, including care across different hospitals. They will be your main contact and may be the person that you speak to most. You can contact them with any questions.



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

2 A clear explanation of your diagnosis, what it means, and treatment options

Diagnosis

You should be told that you have pancreatic cancer in a sensitive way. The diagnosis should be given in a face to face meeting in a quiet, private room. You should be able to have your family or friends with you at the meeting, if you want them there. You should have enough time to ask any questions you may have.



Read more about diagnosis, including test results, in our fact sheet, **How is pancreatic cancer diagnosed?** or on our website at pancreaticcancer.org.uk/diagnosis



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

Information

You should be given high quality information that you can understand, in a format that meets your needs. This may include written as well as verbal information.

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
- how pancreatic cancer can affect your diet and nutrition, and how this can be managed
- your CNS or keyworker's contact details
- any other support you may need and how to access this.

3 Timely treatment that is individual to you, and proper management of symptoms and side effects

Treatment decisions

You should be fully involved in decisions about your care.

Your medical team should explain your cancer and treatment options in a way that you can understand. The benefits of any treatment should be discussed, as well as the disadvantages. They should involve you in making decisions about your care, and should answer any questions you have. It's up to you whether or not you have the treatment they have recommended.

Speak to your doctor about how your treatment fits with the NICE guidelines. If it doesn't fit with the guidelines, ask why not. The NICE guidelines recommend the best treatment options based on your diagnosis, whether the cancer has spread, and how well you are.



Read our version of the NICE guidelines for people affected by pancreatic cancer on our website at **pancreaticcancer.org.uk/NICE**

Read more about treatment options on our website at **pancreaticcancer.org.uk/treatments** or in our booklet, **Pancreatic cancer: An overview of diagnosis and treatment.**



Speak to our specialist nurses on our Support Line with any questions about treatment and side effects.

Second opinion

You can ask for a second opinion from a different doctor, if you want one. You don't have a legal right to a second opinion, but most doctors will help you get one, if you ask for one. Don't delay your treatment while you get a second opinion, as it can take several weeks.

Treatment as soon as appropriate

You should receive treatment for pancreatic cancer as soon as the doctors have finished tests to work out the stage of your cancer and the best treatment options for you. The stage describes the size of the cancer and whether it has spread. Your first treatment should begin within 31 days of agreeing with your doctor what treatment you will have.

For example, the NICE guidelines recommend that people who can have surgery but have jaundice should be offered surgery, rather than having a procedure to relieve jaundice symptoms first – as long as they are fit enough for surgery.

Holistic needs assessment

You should be offered a holistic needs assessment at key points in your care. During the holistic needs assessment, your nurse or keyworker will discuss a range of things with you, including any physical, emotional, spiritual or practical issues. They should then develop a care plan for you, which should include managing any of these issues.

Diet and nutrition

You should be given advice and support to manage problems with eating and symptoms related to diet and nutrition.

Pancreatic cancer and its treatment can affect how well your pancreas produces the enzymes which help you digest (break down) food. This can cause symptoms which can be treated with pancreatic enzyme supplements. These help to digest food and can make a big difference to how you feel.

Soon after your diagnosis you should be given information about diet and managing any symptoms you have. You should also be given enzyme supplements. You should be told how to take the enzyme supplements properly, so that you are confident doing this.

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



You can speak to our specialist nurses on our free Support Line about any questions about diet and nutrition.



Read more about diet in our booklet, **Diet and pancreatic cancer**, and on our website at pancreaticcancer.org.uk/diet

Pain

Your medical team should help you manage any pain you may have effectively. They may refer you to a specialist palliative or supportive care team, who are experts in managing symptoms, including pain. Palliative care aims to relieve any symptoms you may have, including pain, as well as making sure you get the emotional, physical, practical and spiritual support you need. Supportive care aims to make sure that you get this care from diagnosis and throughout your cancer.

Palliative and supportive care aren't just for people at the end of life, and this care should not affect any treatment you may be having.



Read more about pain and how it is managed in our booklet, **Pain and pancreatic cancer**, or on our website at **pancreaticcancer.org.uk/pain**

Clinical trials

You should be told about any research study such as clinical trials that may be suitable for you to take part in. Speak to your doctor about whether there are any clinical trials that might be suitable for you.



Read more about clinical trials and find pancreatic cancer clinical trials on our website at **pancreaticcancer.org.uk/clinicaltrials**

Follow-up care

Following any treatment, you should have appropriate follow-up care and any side effects should be monitored. You should have check-ups after your treatment to check how well your treatment is working and to manage any side effects. You should be provided with information on what to expect following treatment and how to manage any possible side effects.

Your GP should keep a record of your diagnosis and treatment. Throughout your treatment, your GP should be told about any changes in your condition, treatment, and any possible stays in hospital.

You and your family should be involved in plans for your ongoing care. Your medical team should make arrangements for any support that you need at home. The support offered might include nursing care at home involving Macmillan or district nurses, care packages by health or social care, or special equipment or adaptations.



If you have any questions about your treatment, diet, clinical trials, symptom management and follow-up care, speak to our specialist nurses on our free Support Line.

4 Compassion, dignity and respect, as well as practical and emotional support

Compassionate care

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

Emotional care

Your doctor or nurse should ask how you are coping emotionally, including coping with your diagnosis of pancreatic cancer, any symptoms and any feelings of anxiety or depression.

Support services

You should be offered emotional support. If you are having difficulty coping with pancreatic cancer, you should be given information about, or referred to, specialist support such as counselling. You should also be told about organisations that can support you. This support should be available throughout your care and tailored to your needs.

We can provide information and support to you and your family

You can speak to our specialist nurses on our confidential Support Line. Call the specialist nurses free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

We provide high quality information about every aspect of pancreatic cancer. You can also talk to others affected by pancreatic cancer on our online Forum. And our Living with Pancreatic Cancer Support Days provide local face to face support for people with pancreatic cancer. There are also support groups where you can meet others.



Find out more at

pancreaticcancer.org.uk/informationandsupport

You should be given information about practical support available, such as support with financial issues.



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

5 Information and support for your family

Support for family members

If you wish, your family should be given information about your cancer, treatment options and side effects, and they can be involved in discussions about your treatment and care.

Your family should only be involved in discussions about your care if you want them to be.

Your family should be given access to emotional and practical support. This should include counselling and information about support organisations, such as Carers UK and Carers Trust. Your family may also be eligible for financial support, if caring responsibilities mean they are unable to work or can only work part-time.



We have information for family members in our booklet, **Caring for someone with pancreatic cancer: Information for families and carers** and on our website at [**pancreaticcancer.org.uk/families**](http://pancreaticcancer.org.uk/families)

End of life

It is important that people who are approaching the end of their life receive the right support and management of symptoms.

6 Access to well-coordinated end of life care, if needed

You should receive well-coordinated palliative care. Palliative care aims to relieve any symptoms you may have, including pain, nausea and fatigue, as well as making sure you get the emotional, physical, practical and spiritual support you need.

Your palliative care should be properly coordinated and provided by specialist professionals. Your hospital team or GP can refer you to your local palliative care services, so that you can get a full range of support and services at home. As part of this care, you should be given the opportunity and support needed to develop a care plan based on what matters to you.

Who provides your care after you leave hospital will depend on your needs and local services, but may include your GP, a district nurse, your local hospice or a specialist palliative care team. Any end of life care you have should be properly arranged and coordinated, so that you know what to expect and have the support you need.

You should have access to specialist palliative care advice when you need it. You should be given a key contact you can reach any time you need help or advice. Speak to your doctor or nurse about local palliative care services and how to access them. You may also have access to a hospice helpline.

Your family should also be given information about services where they can access support.



Read more in our booklet, **Pancreatic cancer and end of life care: information for people in the last few months, weeks or days of life**, or on our website at pancreaticcancer.org.uk/end-of-life

What should I do if I have concerns about my care?

NHS care

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



You can speak to our specialist nurses on our free Support Line to guide you through this process.

If talking to the doctor or nurse doesn't improve the situation, you may want to take the issue further.

- In England, you can speak to the Patient Advice and Liaison Service (PALS). Find out more on the NHS Choices website.
- In Scotland, you can speak to the Patient Advice and Support Service. Find out more from Citizens Advice Scotland.
- In Wales, you can speak to the Local Health Board or NHS Trust. Find out more from NHS Direct Wales.
- In Northern Ireland, the Patient and Client Council can help you with your complaint. Find out more from the nidirect website.

If you are not happy with the response you receive, you can contact the Ombudsman. This is an organisation that handles health complaints. These include:

- the Parliamentary and Health Service Ombudsman in England
- the Scottish Public Services Ombudsman
- the Public Services Ombudsman for Wales
- the Northern Ireland Public Services Ombudsman.

Private healthcare

With private healthcare, you should first talk to the doctor or nurse about your concerns. 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.

Further information and support

Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

We're here to support and to listen

Our free and confidential Support Line is a lifeline for thousands of people affected by pancreatic cancer. Our specialist nurses understand the issues you might be facing and their expert help will support you in coping with pancreatic cancer.

Call free on **0808 801 0707** weekdays 10am-4pm, or email **nurse@pancreaticcancer.org.uk**

We're here with the information you need

We have the most up-to-date information on everything you need to know about pancreatic cancer. We can help you every step of the way through diagnosis and treatment options to managing your symptoms and the care you receive.

Go to **pancreaticcancer.org.uk/informationandsupport**

Download or order our free publications at

pancreaticcancer.org.uk/publications or call **0808 801 0707**

We're here so you can share

Our Forum is a supportive place where everyone affected by pancreatic cancer can be there to support each other online, any time of day or night: **forum.pancreaticcancer.org.uk**

Our Living with Pancreatic Cancer Support Days provide local face to face support in an informal setting for people with pancreatic cancer: **pancreaticcancer.org.uk/supportdays**

Local support groups mean you can meet other people to share your experiences: **pancreaticcancer.org.uk/supportgroups**

Useful organisations

Care Quality Commission in England

www.cqc.org.uk

Tel: 03000 616161

The independent regulator of health and adult social care in England. The CQC makes sure services are safe, effective, compassionate and high-quality.

Carers Trust

www.carers.org

Email: info@carers.org

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

Carers UK

www.carersuk.org

Adviceline: 0808 808 7777 (Mon-Tues 10am-4pm)

Information, advice, and support for carers.

Citizens Advice

www.citizensadvice.org.uk

Tel: England 03444 111 444; Wales 03444 77 20 20;

Scotland 0808 800 9060

In person at your local Citizens Advice Bureau.

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

General Medical Council

www.gmc-uk.org

Tel: 0161 923 6602 (Mon-Fri 8am-6pm; Sat 9am-5pm)

The independent regulator for doctors in the UK, working to protect patient safety and improve medical practice.

Healthcare Improvement Scotland
www.healthcareimprovementscotland.org
Tel: 0131 623 4300

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

Healthcare Inspectorate Wales
hiw.org.uk
Tel: 0300 062 8163

The independent inspector and regulator of NHS and independent healthcare in Wales.

National Institute for Health and Care Excellence (NICE)
www.nice.org.uk

NICE provide guidance, advice and information for health professionals. They have produced guidelines for the diagnosis and care of people with pancreatic cancer.

NHS Choices
www.nhs.uk

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

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

Health information in Wales, including local services.

NHS inform
www.nhsinform.scot

Tel: 0800 22 44 88 (Mon-Fri 8am-10pm; Sat-Sun 9am-5pm)
Provides information about different health conditions and living well, and local services in Scotland.

nidirect
www.nidirect.gov.uk

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

Northern Ireland Public Services Ombudsman **nipso.org.uk**

Freephone: 0800 34 34 24

Carries out independent reviews of complaints about public services in Northern Ireland. They will only consider complaints after the public service has already considered the complaint.

Parliamentary and Health Service Ombudsman **www.ombudsman.org.uk**

Helpline: 0345 015 4033 (Mon-Fri 8.30am-5.30pm)

Makes final decisions on complaints that have not been resolved by the NHS in England, and makes recommendations for improvements.

Public Services Ombudsman for Wales **www.ombudsman.wales**

Tel: 0300 790 0203

Looks into complaints about public services and independent care providers in Wales.

Regulation and Quality Improvement Authority **www.rqia.org.uk**

Tel: 028 9536 1111

Monitors and inspects the availability and quality of health and social care services in Northern Ireland, and encourages improvements in the quality of those services.

Scottish Public Services Ombudsman **www.spsso.org.uk**

Freephone: 0800 377 7330

Looks into complaints about public services in Scotland, including the NHS, after the complaint has been through the service's own complaints process.

References to the sources of information used to write this booklet, and a list of health professionals who reviewed it, are available on our website.

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This Patient Charter is endorsed by

