Patient Charter
What you should expect from your care
Patient Charter
What you should expect from your care

1. Your case should be assessed by the relevant health professionals, and you should be treated by a specialist team of health professionals.

2. Your diagnosis and your treatment options should be clearly explained to you.

3. Your treatment should be tailored to your own situation, and any symptoms and side-effects should be properly managed.

4. You should be treated with compassion, dignity and respect, and be given practical and emotional support.

5. Your family should be offered information and support (but patient confidentiality must be respected).

6. If necessary, you should have access to high-quality, well-coordinated palliative care.
How to use the Patient Charter

This Patient Charter explains the standard of care all people with pancreatic cancer should have. You can use it as a guide as to what you can expect.

If you have any concerns about your care, or you think that you are not getting the care that we’ve described here, use the Charter to discuss this with your medical team. If that doesn’t improve things, speak to a patient advice service, such as the Patient Advice and Liaison Service (PALS) in England, the Patient Advice and Support Service (PASS) in Scotland, the Community Health Council in Wales or the Patient and Client Council in Northern Ireland.

For more information call our Support Line. If you are having private healthcare, ask the hospital manager about their complaints procedure.

You can discuss this Patient Charter with our specialist nurses on our free Support Line on: **0808 801 0707**
Or email: **support@pancreaticcancer.org.uk**
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.

The following standards apply throughout your care.

1. **Your case should be assessed by the relevant healthcare professionals, and you should be treated by a specialist team of health professionals.**

**Specialist teams and centres**

**Your case should be reviewed by a pancreatic Multidisciplinary Team (MDT) at a specialist centre.** The MDT is the team of medical professionals responsible for your care. They will make sure you receive suitable treatment and care for your own situation. Your doctor should tell you what the MDT has decided.

Specialist centres have been set up regionally across the UK. Hospitals in the region work with the specialist centre to make sure people get the best care. For pancreatic cancer, these may be called Hepatopancreaticobiliary (HPB) centres, which specialise in pancreatic cancer. You may not need to visit a specialist centre, but your case should be reviewed at one.

**Clinical nurse specialists**

**You should have access to a named clinical nurse specialist (CNS) or other keyworker who will coordinate your care.** You can contact them with any questions. They will be part of the MDT and will update them on how you are getting on.

Find out more about the MDT and health professionals involved in your care on our website at [pancreaticcancer.org.uk/specialistcentres](http://pancreaticcancer.org.uk/specialistcentres)
Your diagnosis and treatment options should be clearly explained to you

Diagnosis

You should be told that you have pancreatic cancer in a sensitive manner. 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.

Information

You should be given high quality information that you can understand. 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 keyworker’s contact details
- the support available.

Second opinion

You should be supported to get a second opinion if you want one. It is good practice for your doctor to help you get a second opinion from a different doctor, if you want one. However, don’t delay your treatment while you get a second opinion.

You can find more information about diagnosis, including test results, on our website at pancreaticcancer.org.uk/diagnosis

If you have any questions about your diagnosis you can call our specialist nurses on our free Support Line
Your treatment should be tailored to your own situation, and any symptoms and side effects should be properly managed.

**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. They should involve you in making decisions about your care, and should answer any questions or concerns you have.

**Holistic needs assessment**

*You should be offered a holistic needs assessment at key points in your care.* A holistic needs assessment will look at whether you need any emotional or practical support, as well as your treatment. The MDT should develop a formal care plan, which should take account of the results of the needs assessment.

You should have an assessment at the beginning and end of your first treatment. You should have regular check-ups, in hospital or in the community, to make sure your symptoms and side effects are being properly managed and you have the support you need.
Diet and nutrition

You should be given advice and support to manage problems with eating and symptoms related to diet and nutrition. You should see a specialist dietitian, who can provide expert advice about diet. Pancreatic cancer and its treatment can affect how well your pancreas produces enzymes. These help to break down food so that your body can absorb the nutrients from it.

At an early stage, your medical team should assess whether you need pancreatic enzyme supplements to help break down food. This is called Pancreatic Enzyme Replacement Therapy (PERT). It can help manage any dietary symptoms you have.

PERT should be explained to you so that you understand how to take the supplements, and are confident in this.

For more information, read our booklet, Diet and pancreatic cancer at pancreaticcancer.org.uk/diet

Clinical trials

You should be told about any pancreatic cancer clinical trial that may be suitable for you, and where you can find out more about trials.

Find more information on our website at pancreaticcancer.org.uk/clinicaltrials

Follow-up care

Following any treatment you should be provided with appropriate follow-up care and monitoring of any side effects. You should have check-ups after your treatment to check how your cancer is responding to treatment, and any side effects or symptoms you have. You should be provided with information on what to expect following treatment and how to manage any side effects.
Your GP should keep a record of your diagnosis and treatment. Your GP should be told about any changes in your condition, treatment, and when you leave hospital.

You and your family should be involved in plans for your care after you leave hospital. Your medical team should make any arrangements for any support that you need at home before you leave hospital. The support offered might include home care, special equipment or adoptions.

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

You should be treated with compassion, dignity and respect, and be given practical and emotional support.

Compassionate care

You should be treated with compassion, dignity and respect. This means having your concerns listened to and your wishes valued.

Support services

You should be given information about local support groups and/or organisations that offer support. For example, we provide information and support for people with pancreatic cancer.

You should be offered practical and emotional support. If you are having difficulty coping with your diagnosis you should be given information about, or referred to, specialist support, such as counselling. You should also be told about organisations, such as Macmillan Cancer Support and Citizens Advice, which can support you with practical or financial issues.
Your family should be offered information and support (but patient confidentiality must be respected).

**Support for family members**

**If you wish, your family should be given information about your cancer, and involved in discussions about your treatment and care.** They should be given information on pancreatic cancer, the treatment options and the side effects. 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 the 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 at pancreaticcancer.org.uk/informationandsupport
End of life

Some people survive pancreatic cancer, but unfortunately this isn’t true for everyone. It is essential that those approaching the end of their life receive good quality care and support. If you are reaching the final stages of life, you should be given care that meets the following standards.

6. You should have access to high quality, well-coordinated palliative care

Palliative care

You should receive high quality palliative care in line with NICE guidelines. Palliative care is aimed at relieving your pain and other symptoms, as well as making sure you get the emotional, physical, practical and spiritual support you need. Whilst palliative care is an important part of end of life care, it is not only for patients approaching the end of their life. Your family should also get any support they 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 service, so that you can get a full range of support and services at home.

Who provides your care after you leave hospital will depend on your needs, but may include your GP, a community 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.

Advice services

You should have access to specialist palliative care advice when you need it, including out of hours. This may include access to a telephone advice service that is open 24 hours a day, seven days a week. Your family should also be given information about services where they can access support.
Pancreatic Cancer UK services

We have a range of services to support you and your family in dealing with pancreatic cancer.

Our Support Line

Our Support Line is a lifeline for thousands of patients, families and friends. Our specialist nurses understand the issues you might be facing. They are there for you, giving you personalised information and support, when you need it.

Call us free on 0808 801 0707 (Monday to Friday from 10am-4pm), or email us at support@pancreaticcancer.org.uk

Our information

We have the most up-to-date information on everything you need to know about pancreatic cancer on our website. We can help you every step of the way, from explaining your diagnosis and treatment options, to managing symptoms, and questions to ask at your appointments.

Go to www.pancreaticcancer.org.uk
Download or order our publications, for free, at www.pancreaticcancer.org.uk/publications

Our online community

Our online community is a supportive place where everyone affected by pancreatic cancer can be there for each other. Find us at forum.pancreaticcancer.org.uk

Support groups

We help set-up local support groups in communities all across the UK. These groups provide the opportunity for sharing personal experiences, understanding and support.

Check to see if there’s a group near you at www.pancreaticcancer.org.uk/supportgroupsmap