

Pancreatic cancer

Your guide to best cancer care



About this guide

Being told you have pancreatic cancer or could have pancreatic cancer can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help to guide you and your family and friends through this experience.

Information and support

Cancer Council: For information and support, call Cancer Council on **13 11 20** to talk to an experienced healthcare professional or visit www.cancer.org.au.

For more information about pancreatic cancer, look for Cancer Council's Understanding Pancreatic Cancer booklet on your local Cancer Council website.

PanKind: For patient and carer information, call **(02) 7207 6970** or visit www.pankind.org.au.

Pancare Australia: For information or to talk to a cancer nurse, call **1300 881 698** or visit www.pancare.org.au.

Translating and Interpreting Service (TIS): If you need a translator, call TIS on **13 14 50** or visit www.tisnational.gov.au.

Initial tests and referral

Symptoms

Your general practitioner (GP) should do a check-up to see if they can find what is making you feel unwell. They will ask you about any symptoms you might be having such as losing weight for no reason, strong pain in your stomach area or abdomen, or your skin turning yellow or urine becoming darker.

Initial tests you may have

Blood test to assess liver function and tumour markers.

A sample of your blood will be taken and tested to see if your liver is working well (liver function test) and to see if you have tumour markers.

Computed tomography (CT) scan. Computers and x-rays are used to make a detailed picture of the pancreas.

Ultrasound. Soundwaves are used to make a picture of the pancreas.

Referrals

If your GP has concerns, you will be referred to a pancreatic cancer specialist at a public hospital or in private practice for more tests. Pancreatic cancer specialists are doctors who are highly trained in pancreatic cancer.



You can bring a family member or friend with you to your appointments.



Timeframes

Your specialist appointment should happen **within one week** of referral.

If you can't get an appointment within this time, follow up with your GP.



Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- Can I choose the specialist I see?
- How much will appointments cost me?

Diagnosis and staging

The specialist will do more tests to see if you have pancreatic cancer. This process of working out if you have a medical problem is called making a **diagnosis**. You might have one test or a mix of tests:

Computed tomography (CT) scan. If you haven't already had one.

Magnetic resonance imaging (MRI). A scan where a powerful magnet and radio waves are used to make a detailed picture of the body.

Positron emission tomography (PET). A small amount of radioactive material is injected and your whole body is scanned to show where the cancer is.

Endoscopic ultrasound (EUS). A flexible tube with a camera on it (called an 'endoscope') is put inside your throat to reach your stomach. It uses soundwaves to make a picture of the pancreas.

Laparoscopy. Small cuts are made on your abdomen or stomach area. The specialist puts a small tube with a camera on the end, through the cut, into your abdominal cavity to look at your pancreas and other organs. This is a laparoscope. This is done under general anaesthetic (you will be put to sleep).

Biopsy. A small sample of your pancreas is taken to check under a microscope. The biopsy can be taken at the time of the EUS or laparoscopy.

These tests will give the specialist more information about the cancer such as where exactly it is, if it is growing, if it has spread and at what stage it is. This is called **staging**.

Staging helps to work out the best treatment for you.



Timeframes

Results should be available **within one week** from when you have the tests.



Questions you might want to ask

- What is pancreatic cancer?
- What tests will I have?
- How much will tests/appointments cost?
- Where should I be treated? Do I have a choice?
- What stage is my cancer?
- What support services are available to me?

Treatment

There are several ways to treat pancreatic cancer. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You might have one treatment or a mix of treatments:

Surgery is where the cancer is cut out.

Radiation therapy uses x-rays to kill cancer cells and stop the cancer growing. Radiation therapy may be used with chemotherapy.

Chemotherapy uses drugs to kill cancer cells and stop the cancer growing.

Targeted therapy uses drugs to attack specific features of cancer cells and stop the cancer growing. It may be used if surgery is not an option or the cancer has spread.

For more information visit www.cancer.org.au/cancer-information/treatment.

Palliative care

Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with cancer. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

Additional supportive care (treatment or services that support you through a cancer experience) are also available.



Timeframes

Treatment should start **within four weeks** of your diagnosis, depending on how urgent your treatment is needed and the type of treatment.



You can ask your GP for a referral to another specialist for a second opinion.

Clinical trials

You may be offered to take part in a clinical trial. Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit www.australiancancertrials.gov.au.

Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.



Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?



Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be.

If you have concerns about costs talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation during treatment
- the possible financial impact of your treatment.

You can call Cancer Council on **13 11 20** to speak to a healthcare professional about financial support.

For more information about costs, visit www.cancer.org.au/support-and-services/practical-and-financial-assistance and www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment.

Recovery

Cancer treatment can cause physical and emotional changes.

Follow-up care plan

Your healthcare team will work with you to make a plan for you and your GP. This plan will explain:

- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- understanding and dealing with side effects of treatment
- how to get help quickly if you think the cancer has returned or is worse.

Many people worry that the cancer will return. Your specialist and healthcare team will talk with you about your needs and can refer you to other healthcare professionals and community support services.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

For more information visit www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment.



Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

Living with advanced cancer

If cancer returns

Sometimes cancer can return after treatment. It can come back in the same place or can appear somewhere different in your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

Treatment will depend on how far the cancer has spread, how fast-growing it might be and the symptoms you are experiencing.



Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit www.advancecareplanning.org.au.

Palliative care

If you're living with cancer or your cancer returns, your specialist may refer you to palliative care services.

Speak to your GP or specialist or visit www.palliativecare.org.au.

Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer. For more information visit www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment.



Questions you might want to ask

- What can you do to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?

Disclaimer: Always consult your doctor about matters that affect your health. This guide is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided above.

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This resource is based on information from the optimal care pathway for people with pancreatic cancer, (2nd edition), available at www.cancer.org.au/OCP.