Optimal care pathway for people with pancreatic cancer

Quick reference guide

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

The optimal care pathways describe the standard of care that should be available to all cancer patients treated in Australia. The pathways support patients and carers, health systems, health professionals and services, and encourage consistent optimal treatment and supportive care at each stage of a patient's journey. Seven key principles underpin the guidance provided in the pathways: patient-centred care; safe and quality care; multidisciplinary care; supportive care; care coordination; communication; and research and clinical trials.

This quick reference guide provides a summary of the *Optimal care pathway for people with pancreatic cancer.*

Please note that not all patients will follow every step of the pathway.

Step 1: Prevention and early detection

Prevention

The two most effective prevention strategies are avoiding tobacco smoking and maintaining a normal body weight.

Risk factors

- Tobacco smoking (most established risk factor; risk increases significantly with greater intensity and duration)
- Cystic lesions of the pancreas
- Obesity
- Increased consumption of red meat and processed meat
- Family history of pancreatic cancer
- Older age
- Chronic pancreatitis
- Longstanding type 2 diabetes mellitus
- Male gender
- Asian or Pacific Islander ethnicity
- Chronic alcohol consumption
- Liver cirrhosis
- Stomach infections
- Heavy occupational exposure to certain pesticides, dyes and chemicals used in metal refining
- Certain hereditary conditions

Early detection

People with a strong family history of pancreatic cancer and related hereditary conditions should be referred to a familial cancer service, geneticist or oncologist for possible genetic testing.

Potential monitoring for pancreatic cancer in high-risk populations includes endoscopic ultrasound for small pancreatic head tumours and blood tests (CA 19-9, carcinoembryonic antigen and liver biochemistry).

Screening

Population screening is not recommended for pancreatic cancer in Australia.

Checklist

- ❑ Recent weight changes discussed and the patient's weight recorded
- ❑ Alcohol intake discussed and recorded and support for reducing alcohol consumption offered if appropriate
- ❑ Smoking status discussed and recorded and brief smoking cessation advice offered to smokers
- ❑ Physical activity recorded
- ❑ Referral to a dietitian considered
- ❑ Referral to a physiotherapist or exercise physiologist considered
- ❑ Education on being sun smart considered

Step 2: Presentation, initial investigations and referral

Signs and symptoms included in the tables below are based on best available evidence on how patients may present to their general practitioner (GP) with pancreatic cancer.

Signs and symptoms

Patients presenting to their GP with the following signs and symptoms should be investigated. Signs and symptoms have been categorised by highest, higher, moderate and lower risk, underpinned by primary care evidence. See referral and safety netting section for more detail on appropriate next steps.

Checklist

- ❑ Signs and symptoms recorded
- ❑ Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required

SECOND EDITION

Australian Government
Cancer Australia

Cancer Council

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Step 2: Presentation, initial investigations and referral continued

Highest-risk symptoms About 6 out of 100 people with this symptom are likely to have pancreatic cancer	Jaundice (may be accompanied with dark urine, light-coloured/greasy stools and itchy skin)
Higher-risk symptoms About 3-5 out of 100 people with a higher-risk symptom are likely to have pancreatic cancer	N/A*
Moderate-risk symptoms About 1-2 out of 100 people with a moderate-risk symptom is likely to have pancreatic cancer	N/A*
Lower-risk symptoms Less than one person out of 100 with one of these symptoms is likely to have pancreatic cancer	Abdominal pain, bloating or distention Abnormal liver function tests Appetite loss Constipation Diarrhoea Dyspepsia Dysphagia Low haemoglobin Malaise/fatigue Nausea/vomiting New onset diabetes Raised inflammatory markers Unexplained weight loss

*N/A: There is no evidence of specific symptoms which place patients at a higher or moderate risk of having pancreatic cancer.

Signs, symptoms and symptom combinations of pancreatic cancer

Presenting to general practice with a combination of signs and symptoms may increase a patient's risk of having pancreatic cancer. This table demonstrates the single symptoms associated with pancreatic cancer, and how the risk changes when presenting with more than one symptom. Signs and symptoms have been categorised by highest, higher, moderate and lower risk, underpinned by primary care evidence.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 2: Presentation initial investigations and referral continued

	Single symptoms	Symptom combinations
Highest-risk symptoms About 6 out of 100 people with jaundice alone are likely to have pancreatic cancer About 9-22 out of 100 people with jaundice and an additional symptom are likely to have pancreatic cancer	Jaundice	• Jaundice with any of the following: – abdominal pain – back pain – constipation – diarrhoea – malaise – nausea and/or vomiting – new onset diabetes – unexplained weight loss
Higher-risk symptoms About 3-5 out of 100 people with this symptom or combination are likely to have pancreatic cancer	N/A	• Abdominal bloating with raised aspartate aminotransferase (AST)*
Moderate-risk symptoms About 1-2 out of 100 people with these symptoms or symptom combinations is likely to have pancreatic cancer	N/A	• Abdominal pain with any of the following: – constipation – nausea and/or vomiting – raised alkaline phosphatase (ALP) – raised bilirubin – raised cancer antigen (CA) 125 – raised ferritin – or repeat presentations of abdominal pain • Abdominal bloating with either: – low albumin – raised ALP • Unexplained weight loss with any of the following: – abdominal pain – back pain – constipation – diarrhoea – nausea and/or vomiting – new onset diabetes
Lower-risk symptoms Less than one person out of 100 with one of these symptoms is likely to have pancreatic cancer	Abdominal pain, bloating or distention Abnormal liver function tests Appetite loss Constipation Diarrhoea Dyspepsia Dysphagia Low haemoglobin Malaise/fatigue Nausea/vomiting New onset diabetes Raised inflammatory markers Unexplained weight loss	

* Abdominal bloating with raised AST occurs in both women and men; however in the primary care evidence, only men with this symptom combination reach the 'higher-risk' threshold.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 2: Presentation, initial investigations and referral continued

These recommendations are generated from evidence in populations primarily aged >40 years. The risk of an undiagnosed cancer increases with age for all signs and symptoms.

Underlying risk factors outlined in Step 1 (e.g., family history of pancreatic cancer, hereditary conditions such as Lynch syndrome and BRCA-related breast and ovarian cancer syndrome, and chronic pancreatitis) should be considered in the presence of signs and symptoms of pancreatic cancer and could be used to lower the threshold for initial investigation.

Initial investigations include

- liver function tests
- serum CA 19-9
- abdominal computed tomography (CT) scan with pancreatic protocol.

Where jaundice is present, the following should be performed urgently:

- liver function tests
- abdominal ultrasound
- abdominal CT.

Safety netting

For patients with low-to-moderate-risk symptoms, further investigation to identify an underlying cause is appropriate. All patients should be provided with safety-netting advice, including a planned timeframe for follow-up that is agreed with the patient, and the need for patient-initiated follow-up if new symptoms develop, if symptoms persist or worsen, or if the patient has further concerns.

Referral options

At the referral stage, the patient's GP or other referring doctor should, where possible, advise the patient about their options for referral, waiting periods, expertise, if there are likely to be out-of-pocket costs and the range of services available. This will enable patients to make an informed choice of specialist and health service.

Communication

The GP's responsibilities include:

- explaining to the patient and/or carer who they are being referred to and why
- supporting the patient and/or carer while waiting for specialist appointments
- informing the patient and/ or carer that they can contact Cancer Council on 13 11 20 for additional support.

Checklist continued

- ❑ Patient notified of support services such as Cancer Council 13 11 20
- ❑ Referral options discussed with the patient and/or carer including cost implications

Timeframe

Patients who present with jaundice should be referred for tests **within 48 hours** and followed up rapidly. Other symptoms require review **within 2 weeks**. Patients with suspected or proven pancreatic cancer should be seen by a gastroenterologist, oncologist or hepatopancreaticobiliary surgeon with expertise in pancreatic cancer management and linked to a multidisciplinary team **within 1 week** of referral to the specialist.

Step 3: Diagnosis, staging and treatment planning

Diagnosis and staging

Most diagnostic procedures should be completed before the MDM. Biopsy is only required where there is diagnostic uncertainty, or tissue is required for further management or clinical trials. A contrast-enhanced CT scan should be completed first if not already performed. Additional tests may also be requested by the multidisciplinary team. If diagnostic uncertainty still remains, conduct:

- endoscopic ultrasound with or without biopsy
- contrast-enhanced MRI of the pancreas or magnetic resonance cholangiopancreatography (MRCP) in patients who cannot tolerate contrast or where diagnostic uncertainty remains
- diagnostic laparoscopy with or without laparoscopic ultrasound when resection is planned.

Staging pancreatic cancer may include the following investigations:

- CT scan of the chest/abdomen/pelvis and PET scan
- MRI pancreatic and/or liver
- laparoscopy plus or minus laparoscopic ultrasound for high-risk patients.

Genetic testing

Five to 10 per cent of pancreatic cancers arise due to a genetic predisposition. A referral to a familial cancer service should be considered for all patients newly diagnosed with pancreatic cancer, particularly if any of the following features are noted:

- a family history of pancreatic cancer
- young age of diagnosis (< 60 years)
- a personal and/or family history of melanoma, breast, ovarian, stomach or colorectal cancer
- a family history of chronic pancreatitis
- Ashkenazi Jewish ancestry.

Checklist

- ❑ Diagnosis confirmed
- ❑ Full histology obtained
- ❑ Performance status and comorbidities measured and recorded
- ❑ Patient discussed at an MDM and decisions provided to the patient and/or carer
- ❑ Clinical trial enrolment considered
- ❑ Supportive care needs assessment completed and recorded and referrals to allied health services actioned as required
- ❑ Patient referred to support services (such as Cancer Council) as required
- ❑ Treatment costs discussed with the patient and/or carer

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 3: Diagnosis, staging and treatment planning continued

Treatment planning

The patient's case must be discussed **within 1 week** of completing the diagnostic and staging investigations and a management plan should be finalised.

Research and clinical trials

Consider enrolment where available and appropriate. Search for a trial <www.australiancancertrials.gov.au>.

Communication

The lead clinician's[1] responsibilities include:

- discussing a timeframe for diagnosis and treatment options with the patient and/or carer
- explaining the role of the multidisciplinary team in treatment planning and ongoing care
- encouraging discussion about the diagnosis, prognosis, advance care planning and palliative care while clarifying the patient's wishes, needs, beliefs and expectations, and their ability to comprehend the communication
- providing appropriate information and referral to support services as required
- communicating with the patient's GP about the diagnosis, treatment plan and recommendations from multidisciplinary meetings (MDMs).

Timeframe

Diagnostic and staging investigations should be completed **within 2 weeks** of referral.

Step 4: Treatment

Establish intent of treatment

- Curative
- Anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- Symptom palliation

Treatment for resectable pancreatic cancer: The potential for curative surgery depends on the staging of the tumour, and only 10–20 per cent of patients have clearly resectable disease after careful pretherapeutic staging. This potential is assessed by the multidisciplinary team.

Curative surgery includes Whipple procedure, distal or total pancreatectomy, with or without chemotherapy (adjuvant or neoadjuvant chemotherapy or neoadjuvant chemoradiation).

Treatment for unresectable pancreatic cancer: If unresectable, any other treatment is almost certainly palliative because pancreatic cancer is unlikely to be cured by chemotherapy or radiation therapy. The most commonly used therapies include:

- endoscopic or radiological intervention
- surgical interventions
- chemotherapy with or without chemoradiation
- coeliac plexus or intrapleural block.

Palliative care: In general, all patients with pancreatic cancer, given the poor prognosis, should be offered a referral for a palliative care assessment as an integrated aspect of their overall oncology care. For more, visit the Palliative Care Australia website <www.palliativecare.org.au>.

Communication

The lead clinician and team's responsibilities include:

- discussing treatment options with the patient and/or carer including the intent of treatment as well as risks and benefits
- discussing advance care planning with the patient and/or carer where appropriate
- communicating the treatment plan to the patient's GP
- helping patients to find appropriate support for exercise programs where appropriate to improve treatment outcomes.

Checklist

- ❑ Intent of treatment established
- ❑ Risks and benefits of treatments discussed with the patient and/or carer
- ❑ Treatment plan discussed with the patient and/or carer
- ❑ Treatment plan provided to the patient's GP
- ❑ Treating specialist has adequate qualifications, experience and expertise
- ❑ Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- ❑ Early referral to palliative care considered
- ❑ Advance care planning discussed with the patient and/or carer

Timeframe

Treatment should begin **within 4 weeks** of the initial diagnosis, depending on urgency and modality.

Postoperative adjuvant chemotherapy should begin **within 12 weeks** of surgery.

1 Lead clinician – the clinician who is responsible for managing patient care.
The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

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Step 5: Care after initial treatment and recovery

Most patients with pancreatic cancer are palliated. If a patient is thought to have been cured after their treatment, then care in the post-treatment phase is driven by predicted risks, as well as individual clinical and supportive care needs.

Provide a treatment and follow-up summary to the patient, carer and GP outlining:

- the diagnosis, including tests performed and results
- tumour characteristics
- treatment received (types and date)
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health professionals
- potential long-term and late effects of treatment and care of these
- supportive care services provided
- a follow-up schedule, including tests required and timing
- contact information for key healthcare providers who can offer support for lifestyle modification
- a process for rapid re-entry to medical services for suspected recurrence.

Communication

The lead clinician's responsibilities include:

- explaining the treatment summary and follow-up care plan to the patient and/or carer
- informing the patient and/or carer about secondary prevention and healthy living
- discussing the follow-up care plan with the patient's GP.

Checklist

- ❑ Treatment and follow-up summary provided to the patient and/or carer and the patient's GP
- ❑ Supportive care needs assessment completed and recorded and referrals to allied health services actioned as required
- ❑ Patient-reported outcome measures recorded

Step 6: Managing recurrent, residual or metastatic disease

Detection

It is likely that the patient's current symptoms will progressively worsen. This should be managed following discussion by a multidisciplinary team in consultation with palliative care specialists.

Treatment

Evaluate each patient for whether referral to the original multidisciplinary team is appropriate. Treatment will depend on the location and extent of disease, previous management and the patient's preferences.

Advance care planning

Advance care planning is important for all patients but especially those with advanced disease. It allows them to plan for their future health and personal care by thinking about their values and preferences. This can guide future treatment if the patient is unable to speak for themselves.

Survivorship and palliative care

Specialist palliative care is recommended for all patients with pancreatic cancer. Survivorship and palliative care should be addressed and offered early. Early referral to palliative care can improve quality of life.

Communication

The lead clinician and team's responsibilities include:

- explaining the treatment intent, likely outcomes and side effects to the patient and/or carer and the patient's GP.

Checklist

- ❑ Treatment intent, likely outcomes and side effects explained to the patient and/or carer and the patient's GP
- ❑ Supportive care needs assessment completed and recorded and referrals to allied health services actioned as required
- ❑ Advance care planning discussed with the patient and/or carer
- ❑ Patient referred to palliative care if appropriate
- ❑ Routine follow-up visits scheduled

Step 7: End-of-life care

Palliative care

Consider a referral to palliative care. Ensure an advance care directive is in place.

Communication

The lead clinician's responsibilities include:

- being open about the prognosis and discussing palliative care options with the patient
- establishing transition plans to ensure the patient's needs and goals are considered in the appropriate environment.

Checklist

- ❑ Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- ❑ Patient referred to palliative care
- ❑ Advance care directive in place

Visit our guides to best cancer care webpage <www.cancercareguides.org.au> for consumer guides. Visit our OCP webpage <www.cancer.org.au/OCP> for the optimal care pathway and instructions on how to import these guides into your GP software.

Published in June 2021 and amended in June 2026 to enhance guidance on initial investigations and referral in Step 2.