

Optimal care pathway for people with pancreatic cancer



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Cancer Australia



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Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple health care providers and covers a range of institutions, both public and private. The Optimal Cancer Care Pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

The optimal care pathways are based on a revision of the original patient management frameworks (Department of Health 2007a) which had, for the first time, attempted to map the cancer pathway in an easily understandable form.

The purpose of this work is to improve patient outcomes by facilitating consistent cancer care based on a standardised pathway of care. The pathways are applicable to care whether it is provided in a public or private service. The principles and the expected standards of good cancer care are not expected to differ, even though treatment regimens may vary from patient to patient for a whole variety of reasons.

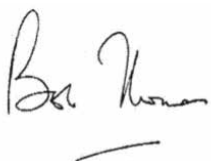
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments (COAG) in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care.

The NCERG has subsequently endorsed these new Optimal Cancer Care Pathways which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

A wide range of clinicians, peak health organisations, consumers and carers were consulted and/or participated in their development and I want to thank all concerned for their generous contributions.

I am sure that those providing cancer care will find the specific pathways useful in deciding how best to organise service delivery to achieve the best outcomes for those we care for.

Importantly, readers should note that these care pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.



Professor Robert Thomas OAM
Chief Advisor Cancer, Department of Health & Human Services

Summary

Please note that not all patients will follow every step of this pathway:

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

Step 1 Prevention and early detection

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

Risk factors: Tobacco smoking is the most established risk factor (increasing significantly with greater intensity and duration). Other risk factors include cystic lesions of the pancreas, obesity, a family history, older age, chronic pancreatitis, longstanding type 2 diabetes mellitus, male gender, Asian/Pacific Islander ethnicity, chronic alcohol

consumption, heavy occupational exposure to certain pesticides, dyes and chemicals used in metal refining.

Having certain hereditary conditions also increases a person's risk of pancreatic cancer.

Early detection: People with a strong family history of pancreatic cancer and related hereditary conditions

should be referred to a genetic counsellor, geneticist or oncologist for possible genetic testing.

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

Step 2 Presentation, initial investigations and referral

Signs and symptoms: Many cases present with non-specific symptoms or are asymptomatic until advanced stages of the disease process.

Symptoms for cancer of the head and neck of the pancreas include jaundice that is progressive, together with unexplained weight loss and abdominal pain that may radiate to the back. Symptoms for cancer of the pancreas include pain that is often severe, unrelenting, of a short duration, and associated unexplained weight loss.

General/primary practitioner investigations: Consider an abdominal CT scan; early referral is indicated, usually prior to a definitive diagnosis being made.

Where jaundice is present, the following should be ordered within 48 hours and followed up as rapidly as possible:

- liver function tests
- abdominal ultrasound
- CT where appropriate.

Referral: Refer all patients with suspected or proven pancreatic cancer to a specialist linked with a multidisciplinary team within one week. The multidisciplinary team should have a rapid access program.

Communication – lead clinician to:¹

- explain to the patient/carer who they are being referred to and why
- support the patient and carer while waiting for specialist appointments.

Step 3 Diagnosis, staging and treatment planning

Diagnosis and staging: Diagnosis of a mass is primarily by imaging. Contrast-enhanced multidetector computed tomography scan (MDCT) according to suggested pancreatic protocol is suggested.

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.

Diagnostic and staging investigations should be completed within one week.

Treatment planning: Immediate treatment is often required before a full multidisciplinary meeting ratifies details of the management plan (which should include full details of the response assessment).

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

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.

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:

Only eight to 12 per cent of patients have disease amenable to surgical resection at the time of presentation as the majority present with metastatic or locally advanced disease (Speer et al. 2012).

Surgery with or without chemotherapy (adjuvant or neoadjuvant chemotherapy, or adjuvant chemoradiation may be appropriate).

Treatment for unresectable pancreatic cancer:

If unresectable, any other treatment is palliative as pancreatic cancer is unlikely to be cured by chemotherapy and radiation therapy. The most commonly used therapies include:

- endoscopic or radiological intervention
- palliative surgical interventions
- chemotherapy with or without chemoradiation

- coeliac plexus or intrapleural block.

Palliative care: Specialist palliative care is recommended for the majority of patients with pancreatic cancer. Early referral can improve quality of life. Referral should be based on need, not prognosis.

Communication – lead clinician to:

- discuss treatment options with the patient/carer including the intent of treatment as well as the risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

For detailed information see www.nhmrc.gov.au/guidelines/publications/subject/Cancer.

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.

Cancer survivors should be provided with the following to guide care after initial treatment.

Treatment summary (provide a copy to the patient/carer and general practitioner) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

Follow-up care plan (provide a copy to the patient/carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the patient/carer
- inform the patient/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the patient's general practitioner.

Step 6

Managing recurrent, residual and metastatic disease

Detection: It is likely that their current symptoms will worsen progressively. This should be managed following discussion at a multidisciplinary clinic in consultation with palliative care specialists.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, previous management and the patient's preferences.

Palliative care: Specialist palliative care is recommended for the majority of patients with pancreatic cancer. Referral should be based on need, not prognosis. Early referral can improve quality of life.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Ensure that an advance care plan is in place.

Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the patient/carer
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Intent of the optimal cancer care pathway

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidence-based care for people with cancer.

The pathway aligns with key service improvement priorities, including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The optimal cancer care pathway can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality improvement initiatives across all aspects of the care pathway. The pathway can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

The following key principles of care underpin the optimal cancer care pathway.

Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Patient or consumer-centred care is increasingly being recognised as a dimension of high-quality healthcare in its own right, and there is strong evidence that a patient-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness as well as patient, family and staff satisfaction (ACSQHC 2013).

Safe and quality care

This is provided by appropriately trained and credentialed clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care. It incorporates collecting and evaluating treatment and outcome data to improve the patient experience of care as well as mechanisms for ongoing service evaluation and development to ensure practice remains current and informed by evidence.

Multidisciplinary care

This is an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient. There is increasing evidence that multidisciplinary care improves patient outcomes.

The benefits of adopting a multidisciplinary approach include:

- improving patient care through developing an agreed treatment plan
- providing best practice through adopting evidence-based guidelines
- improving patient satisfaction with treatment
- improving the mental wellbeing of patients
- improving access to possible clinical trials of new therapies
- increasing the timeliness of appropriate consultations and surgery and a shorter timeframe from diagnosis to treatment
- increasing the access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007b).

Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes. Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

All members of the multidisciplinary team (MDT) have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool) of the patient and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key points along the care pathway, particularly at times of increased vulnerability including:

- initial presentation or diagnosis (first three months)
- commencement of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- survivorship
- recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care.

Following each assessment, potential interventions need to be discussed with the patient and carer, with a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

Common indicators in patients with pancreatic cancer that may require referral for support include:

- malnutrition (as identified using a validated malnutrition screening tool or presenting with weight loss)
- breathlessness
- pain
- difficulty managing fatigue
- difficulty sleeping
- distress, depression or fear
- poor performance status
- living alone or being socially isolated
- having caring responsibilities for others
- cumulative stressful life events
- existing mental health issues
- Aboriginal or Torres Strait Islander status
- being from a culturally and linguistically diverse background.

Depending on the needs of the patient, referral to an appropriate health professional(s) and/or organisations should be considered including:

- psychologist or psychiatrist
- genetic counsellor
- community-based support services (such as Cancer Council Victoria)
- dietitian
- exercise physiologist
- nurse practitioner and/or specialist nurse
- occupational therapist
- physiotherapist
- peer support groups (contact the Cancer Council on 13 11 20 for more information)
- social worker
- specialist palliative care
- speech therapist.

See the **appendix** for more information on supportive care and the specific needs of people with pancreatic cancer.

Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure that care is delivered in a logical, connected and timely manner so the medical and personal needs of the patient are met.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including multidisciplinary meetings, supportive care screening and assessment, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of individual patients and should therefore be considered in their practice. Enhancing continuity of care across the health sector requires a whole-of-system response, that is, initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007c).

Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families and carers are met. Every person with cancer will have different communication needs, including cultural and language differences. Communication with patients should be:

- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families.

In communicating with patients, healthcare providers should:

- listen to patients and act on the information provided by them
- encourage expression of individual concerns, needs and emotional states
- tailor information to meet the needs of the patient, their carer and family
- use professionally trained interpreters when communicating with people from culturally and linguistically diverse backgrounds
- ensure the patient and/or their carer and family have the opportunity to ask questions
- ensure the patient is not the conduit of information between areas of care (it is the providers' and healthcare system's responsibility to transfer information between areas of care)
- take responsibility for communication with the patient
- respond to questions in a way the patient understands
- enable all communication to be two-way.

Healthcare providers should also consider offering the patient a Question Prompt List (QPL) in advance of their consultation, as well as recordings or written summaries of their consultations. QPL interventions are effective in improving communication and the psychological and cognitive outcomes of cancer patients (Brandes et al. 2014). Providing recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway. Research and clinical trials play an important role in establishing efficacy and safety for a range of interventions in treatment of cancer, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcberg 2013).

While individual patients may or may not receive a personal benefit from the intervention, there is evidence that outcomes for participants in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation in research and clinical trials will contribute to care of cancer patients in the future (Peppercorn et al. 2004).

Optimal cancer care pathway

The optimal cancer care pathway outlines seven critical steps in the patient journey. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management and patient decisions, and physiological response to treatment).

The pathway covers pancreatic adenocarcinoma. Pancreatic neuroendocrine tumours (PNETs) are not included in this pathway given the differences in the risk factors and management of these tumours.

Special considerations

Pancreatic cancer has a very poor prognosis and five-year survival rates are extremely low. Median survival from diagnosis is about five months (Speer et al. 2012). In Australia over the last three decades the five-year survival rate has increased slightly from four per cent in 1982–1986 to six per cent in 2007–2011 (AIHW 2014), making it the lowest survival rate among all types of cancer with a death-to-incidence ratio approaching one (Chang et al. 2008). Even if there are good initial treatment outcomes, the recurrence rate is very high. Given the poor prognosis of this cancer at present, for the majority of patients, treatment is often given with palliative rather than curative intent. Early specialist palliative care will be required for patients with pancreatic cancer.

The pathway describes the optimal cancer care that should be provided at each step.

Step 1: Prevention and early detection

Eating a healthy diet, avoiding or limiting alcohol intake, taking regular exercise and maintaining a healthy body weight may help reduce cancer risk. This step outlines recommendations for the prevention and early detection of pancreatic cancer.

1.1 Prevention

In Australia the incidence of pancreatic cancer has remained stable over the past three decades, with 10 cases per 100,000 people in 1982 and 11 cases per 100,000 people in 2010. The average age at diagnosis is 70.9 years (Cancer Australia 2013a). Although the aetiology of pancreatic cancer is unknown, the current prevention strategies involve reducing risk factors. The two most effective prevention strategies include avoiding tobacco smoking and maintaining a normal body weight (American Cancer Society 2013).

Some studies suggest a change in diet may decrease the risk of pancreatic cancer by decreasing soft drink and sugar consumption and increasing consumption of whole grains and vegetables (Pericleous et al. 2014).

1.2 Risk factors

There are a number of factors associated with the risk of developing pancreatic cancer. These factors include:

- tobacco smoking (most established risk factor, risk increases significantly with greater intensity and duration) (Lynch et al. 2009)
- cystic lesions of the pancreas
- obesity
- a family history of pancreatic cancer
- older age
- chronic pancreatitis
- longstanding diabetes mellitus (type 2)
- male gender
- Asian/Pacific Islander ethnicity
- chronic alcohol consumption
- heavy occupational exposure to certain pesticides, dyes and chemicals used in metal refining.

Having certain hereditary conditions also increase a person's risk of pancreatic cancer:

- hereditary pancreatitis syndrome
- hereditary nonpolyposis colon cancer (HNPCC – Lynch syndrome)
- Peutz-Jeghers syndrome
- hereditary BRACA2-related breast and ovarian cancer syndrome
- familial atypical mole melanoma (FAMMM) syndrome.

1.3 Early detection

Screening recommendations

There is no recommended population screening program for pancreatic cancer in Australia.

The cancer antigen 19-9 (CA19-9) tumour marker is not recommended as a population screening tool for pancreatic cancer due to the low sensitivity and specificity of the test, but rather it should be used as a marker of response to treatment (National Cancer Institute 2015).

For people with a strong family history of pancreatic cancer and related hereditary conditions it is recommended that they are referred to a genetic counsellor, geneticist or oncologist for consideration of genetic testing. Families at high risk of pancreatic cancer may undergo more specialised surveillance involving imaging and blood tests.

Potential imaging for the surveillance of pancreatic cancer in high-risk populations includes a range of imaging modalities; however, endoscopic ultrasound is generally accepted as the most sensitive imaging test for small pancreatic head tumours.

Potential blood tests for screening of high-risk groups include:

- CA 19-9 and carcinoembryonic antigen (CEA)
- liver biochemistry.

These are based on the family and past history of the patient. They should not be ordered in general practice but from specialist referral source.

Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral. The types of investigation undertaken by the general or primary practitioner depend on many factors, including access to diagnostic tests, medical specialists and patient preferences.

2.1 Signs and symptoms

Many cases present with non-specific symptoms or are asymptomatic until advanced stages of the disease process. Persistent symptoms require further investigation.

Symptoms for cancer of the pancreas include jaundice that is progressive, together with unexplained weight loss and abdominal pain that may radiate to the back. Symptoms for cancer of the body of the pancreas include pain which is often severe, unrelenting, of a short duration and often associated unexplained weight loss.

The presence of multiple signs and symptoms, particularly in combination with other underlying risk factors, indicates an increased risk of pancreatic cancer.

2.2 Assessments by the general or primary medical practitioner

Primary investigations prior to referral depends upon the presenting symptoms and risk factors.

Where there is suspicion of pancreatic cancer:

- consider an abdominal CT scan with pancreatic protocol
- early referral is indicated, usually prior to a definitive diagnosis being made.

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

- liver function tests
- abdominal ultrasound
- CT where appropriate

An abnormal result should be discussed face to face with the patient and information provided.

Timeframe for completing investigations

Timeframes for completing investigations should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Pancreatic Cancer Working Group:¹

- Where a patient presents with jaundice, tests should be ordered within 48 hours and followed up as rapidly as possible.

Other symptoms require review within two weeks (NICE 2005).

¹ The multidisciplinary experts group who participated in a clinical workshop to develop content for the pancreatic cancer optimal care pathway are listed in the acknowledgements list.

2.3 Referral

If pancreatic cancer is suspected, then the patient should be referred to a gastroenterologist, oncologist or hepatopancreaticobiliary (HPB) surgeon with professional expertise in pancreatic cancer management and access to an MDT. If resectability needs to be determined, referral should be to an HPB surgeon.

The specialist should provide timely communication to the general practitioner about the consultation and notify them if the patient does not attend appointments.

The MDT should have a rapid access program or contact person.

Referral for suspected pancreatic cancer should incorporate appropriate documentation sent with the patient including:

- a letter that includes important psychosocial history and relevant past history, family history, current medications and allergies
- results of current clinical investigations (imaging and pathology reports)
- results of all prior relevant investigations
- notification if an interpreter service is required.

If access is via online referral, a lack of a hard copy (of results) should not delay referral.

Timeframe for referral to a specialist

Timeframes for referral should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Pancreatic Cancer Working Group:

- Where there is a confirmed diagnosis or high level of suspicion, the patient should be seen by a specialist within one week.

The supportive and liaison role of the patient's general practitioner and practice team in this process is critical.

2.4 Support and communication

2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified needs of an individual, their carer and family; referral should be as required.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- physical symptoms such as chronic pain and fatigue
- the emotional distress of dealing with a potential cancer diagnosis, anxiety and depression, interpersonal problems, stress and adjustment difficulties
- financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients, caring arrangements for other family members)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

2.4.2 Communication with the patient, carer and family

Effective communication is essential at every step of the care pathway. Effective communication with the patient and carer is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults) (ACSQHC 2013).

The general or primary practitioner should:

- provide the patient with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
- support the patient while waiting for the specialist appointment.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer, and planning subsequent treatment. The guiding principle is that interaction between appropriate MDT members should determine the treatment plan.

3.1 Diagnostic workup

Diagnosis of a mass is primarily by imaging. This should be performed after discussion with the MDT. Biopsy is only required where there is diagnostic uncertainty or tissue is required for further management or clinical trials. Contrary to the situation with most cancers, definitive tissue diagnosis prior to multidisciplinary planning is not recommended.

The following investigation is suggested (if not already performed):

- contrast-enhanced multidetector computed tomography scan (MDCT) according to suggested pancreatic protocol).

If diagnostic uncertainty still remains the following investigations are recommended:

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

Timeframe for completing diagnostic investigations

Timeframes for completing investigations should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Pancreatic Cancer Working Group: within one week of referral.

3.2 Staging

Staging is the cornerstone of treatment planning and prognosis and synoptic reporting is encouraged where operative resection has occurred and pathological staging is available. The most widely used staging tools for pancreatic cancer are the American Joint Committee on Cancer (AJCC) TNM staging system and stage grouping. The imaging modalities used for diagnosis also allow for simultaneous staging of cancer; however, it is recommended that investigations are only carried out once the diagnosed pancreatic cancer can be defined as resectable, borderline resectable, locally advanced (unresectable) or metastatic as this is the main staging factor that will influence treatment.

Comprehensive staging should include CT chest/abdominal/pelvis and positron emission tomography (PET). Laparoscopy plus or minus laparoscopic ultrasound should be considered for high-risk patients.

Timeframe for commencing staging investigations

Timeframes for commencing investigations should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Pancreatic cancer Working Group: within one week of referral.

3.3 Treatment planning

Immediate treatment is often required before a full multidisciplinary meeting ratifies details of the management plan (which should include full details of the response assessment).

3.3.1 Responsibilities of the multidisciplinary team

The responsibilities of the MDT are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided)
- nominate a team member to coordinate patient care
- develop and document an agreed treatment plan at the multidisciplinary meeting
- circulate the agreed treatment plan to relevant team members, including the patient's general practitioner.

3.3.2 Responsibilities of individual team members

The general or primary medical practitioner who made the referral is responsible for the patient until care is passed to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment, coordination and continuity of care, as well as providing information and support to the patient and their family.

The care coordinator is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The care coordinator may change over the course of the pathway.

The lead clinician is responsible for overseeing the activity of the team.

3.3.3 Members of the multidisciplinary team for pancreatic cancer

The MDT should comprise the core disciplines integral to providing good care. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some patients (Department of Health 2007b).

Team members may include a:

- care coordinator (as determined by MDT members)*
- dietitian*
- gastroenterologist (with expertise in endoscopic retrograde cholangiopancreatography (ERCP) and/or endoscopic ultrasound)*
- hepato-pancreato biliary surgeon*
- interventional/ hepato-pancreato biliary radiologist*
- nurse (with appropriate expertise)*
- medical/radiation oncologist*
- palliative care specialist*
- pathologist*
- clinical trials coordinator
- nuclear medicine physician
- general practitioner
- occupational therapist
- pharmacist
- physiotherapist
- psychiatrist
- psychologist
- social worker.

* Core members of the MDT are expected to attend most multidisciplinary meetings either in person or remotely.

3.3.4 The optimal timing for multidisciplinary team planning

Ideally, all newly diagnosed patients should be discussed in a multidisciplinary meeting before beginning treatment. The level of discussion may vary depending on both the clinical and psychosocial factors.

There may also need to be a review of existing treatment plans for patients who have been discussed previously.

Results of all relevant tests and imaging should be available for the MDT discussion. At the meeting, the care coordinator or treating clinician should also present information about the patient's concerns, preferences and social circumstances (Department of Health 2007b).

3.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit www.australiancancertrials.gov.au.

3.5 Support and communication

3.5.1 Supportive care

Screening with a validated screening tool (for example, the National Comprehensive Cancer Network distress thermometer), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific needs that may arise at this time include:

- nutritional assessment and support (including enzyme support therapy)
- physical symptoms such as chronic pain
- psychological and emotional distress while adjusting to the diagnosis, treatment phobias, existential concerns, stress, difficulties making treatment decisions, anxiety and depression, and interpersonal problems
- financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients, caring arrangements for other family members)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

3.5.2 Prehabilitation

Cancer prehabilitation uses a multidisciplinary approach combining exercise, nutrition and psychological strategies to prepare patients for the challenges of cancer treatment, such as surgery, chemotherapy, immunotherapy and radiation therapy.

Evidence indicates that prehabilitation of newly diagnosed cancer patients prior to starting treatment can be beneficial. This may include conducting a physical and psychological assessment to establish a baseline function level, identifying impairments and providing targeted interventions to improve the patient's health, thereby reducing the incidence and severity of current and future impairments related to cancer and its treatment (Silver & Baima 2013).

Medications should be reviewed at this point to ensure optimisation and to improve adherence to medicines used for comorbid conditions.

3.5.3 Communication with the patient

The lead clinician should:

- establish if the patient has a regular or preferred general practitioner
- discuss a timeframe for diagnosis and treatment with the patient and carer
- discuss benefits of multidisciplinary care and make the patient aware their health information will be available to the team for the discussion at the multidisciplinary meeting
- offer individualised pancreatic cancer information that meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information and support from websites, community and national cancer services and support groups
- utilise a professionally trained interpreter when communicating with people from culturally and linguistically diverse backgrounds (NICE 2004).

3.5.4 Communication with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the patient's general practitioner regarding the treatment plan and recommendations from multidisciplinary meetings and notify the general practitioner if the patient does not attend appointments
- ensure regular and timely (within a week) communication with the general practitioner regarding the treatment plan and recommendations from multidisciplinary meetings
- gather information from the general practitioner, including their perspective on the patient (psychological issues, social issues and comorbidities) and locally available support services
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss management of shared care
- invite the general practitioner to participate in multidisciplinary meetings (consider using video or teleconferencing).

Step 4: Treatment

Step 4 outlines the treatment options for pancreatic cancer. For detailed information on treatment options refer to the National Health and Medical Research Council's clinical practice guidelines (2005) at www.nhmrc.gov.au/guidelines/publications/subject/Cancer.

For detailed information on treatment guidelines refer to:

- National Cancer Institute Treatment option overview for pancreatic cancer available from <http://www.cancer.gov/cancertopics/pdq/treatment/pancreatic/HealthProfessional/page4>
- British guidelines for managing pancreatic cancer available from http://gut.bmj.com/content/54/suppl_5/v1.full.pdf+html.

For European Society for Medical Oncology guidelines refer to: http://annonc.oxfordjournals.org/content/21/suppl_5/v55.full.pdf+html.

4.1 Treatment intent

The intent of treatment can be defined as one of the following:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

The morbidity and risks of treatment need to be balanced against the potential benefits.

The lead clinician should discuss treatment intent and prognosis with the patient and carer prior to beginning treatment.

If appropriate, advance care planning should be initiated with patients at this stage. Advance care planning can produce multiple benefits such as ensuring a person's preferences are known and respected after the loss of decision-making capacity (AHMAC 2011).

4.2 Treatment options

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the patient.

4.2.1 Treatment of resectable pancreatic cancer

Surgery

The potential for curative surgery is dependent upon the staging of the tumour. This potential is assessed by the MDT.

Patients who undergo surgical resection for localised pancreatic cancer have a five-year survival rate of eight to 21 per cent and a median survival of 12–22 months (Chang et al. 2008). Unfortunately, only eight to 12 per cent of patients have disease amenable to surgical resection at the time of presentation as the majority present with metastatic or locally advanced disease (Speer et al. 2012).

Curative surgery includes the following options:

- Whipple procedure (pancreaticoduodenal resection)
- distal pancreatectomy
- total pancreatectomy.

The training and experience required of the surgeon are as follows:

- Surgeon (FRACS or equivalent) with adequate training and experience in HPB surgery with institutional credentialing and agreed scope of practice within this area.

There is strong evidence to suggest that surgeons who undertake a high volume of resections have better clinical outcomes for complex cancer surgery such as pancreatic resections (De Wilde 2012; Sutton et al. 2014).

Hospital or treatment unit characteristics for providing safe and quality care include:

- an intensive care unit
- appropriate ward staff, nursing and theatre resources to manage complex surgery
- 24-hour medical staff availability
- 24-hour operating room access
- pathology
- ERCP
- 24-hour access to interventional radiology or ERCP
- fully supported by other surgical specialties.

There is strong evidence to suggest that high-volume hospitals have better clinical outcomes for complex cancer surgery such as pancreatic resections (De Wilde 2012; Sutton et al. 2014).

Chemotherapy

Even if the surgery is deemed surgically curable the following should be considered (National Cancer Institute 2015):

- adjuvant chemotherapy
- neoadjuvant chemotherapy
- adjuvant chemoradiation therapy.

Training, experience and treatment centre characteristics:

- Medical oncologists (FRACP or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).
- Nurses must have adequate training in chemotherapy administration and handling and disposal of cytotoxic waste.
- Chemotherapy should be reviewed by a pharmacist with cancer services expertise, including adequate training in cytotoxic chemotherapy medication, dosing calculations according to protocols, formulations and/or preparation.
- In a setting where no medical oncologist is locally available, some components of less complex therapies may be delivered by a medical practitioner and/or nurse with training and experience with credentialling and agreed scope of practice within this area, under the guidance of a medical oncologist. This should be in accordance with a detailed treatment plan or agreed protocol and with communication as agreed with the medical oncologist or as clinically required.

Hospital or treatment unit characteristics for providing safe and quality care include:

- a clearly defined path to emergency care and advice after hours
- access to basic haematology and biochemistry testing
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including safe prescribing, preparation, dispensing, supplying, administering, storing, manufacturing, compounding and monitoring the effects of medicines (ACSQHC 2011)
- guidelines and protocols for delivering treatment safely (including dealing with extravasation of drugs)
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not collocated.

4.2.2 Treatment of unresectable pancreatic cancer

If the cancer is deemed unresectable, any other treatment is almost certainly palliative as pancreatic cancer is unlikely to be cured by chemotherapy and radiation therapy. Palliative therapy may be indicated for:

- nutritional assessment and support (including enzyme support therapy)
- surgical or radiologic biliary decompression
- relief of gastric outlet obstruction
- pain control
- psychological care to address the potentially disabling psychological events associated with the diagnosis and treatment of pancreatic cancer.

The most commonly used therapies in unresectable pancreatic cancer include:

- endoscopic or radiological intervention
- surgical interventions – endoscopic biliary stent placement, percutaneous radiologic biliary stent placement, palliative surgical biliary and/or gastric bypass
- chemotherapy
- chemotherapy followed by chemoradiation therapy for those without metastatic disease
- chemoradiation therapy followed by chemotherapy
- coeliac plexus or intrapleural block.

Endoscopic stenting is recommended as initial palliation for biliary obstruction. Percutaneous tranhepatic biliary stenting may be required for failed endoscopic stenting. For patients with gastric outlet obstruction, either surgical bypass or endoscopic stenting would be appropriate.

It is important to weigh up the risks versus benefits of any palliative therapy as the patient's prognosis is not changed with implementation.

Timeframe for commencing treatment

Timeframes for commencing treatment should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Pancreatic Cancer Working Group:

- within four weeks of initial diagnosis depending on urgency and modality.

4.3 Palliative care

Given the poor prognosis of this cancer at present, for the majority of patients, treatment is often given with palliative rather than curative intent. Specialist palliative care will be required for patients with pancreatic cancer.

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

- Patients may be referred to palliative care at initial diagnosis.
- Patients should be referred to palliative care at first recurrence or progression.
- Carer needs may prompt referral.

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for poor prognosis cancers (Temel et al. 2010). Furthermore, palliative care has been associated with the improved wellbeing of carers (Higginson & Evans 2010; Hudson et al. 2015).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

Further information

Refer patients and carers to Palliative Care Australia at www.palliativecare.org.au.

4.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- For more information visit www.australiancancertrials.gov.au (Australia).

4.5 Complementary or alternative therapies

The lead clinician should discuss the patient's use (or intended use) of complementary or alternative therapies not prescribed by the MDT to discuss safety and efficacy and to identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the patient's reason for using these therapies and the evidence base.

Most alternative therapies and some complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective.

Some complementary therapies may assist in some cases and the treating team should be open to discussing the potential benefits for the individual.

If the patient expresses an interest in using complementary therapies, the lead clinician should consider referring them to health professionals within the MDT who have a knowledge of complementary and alternative therapies (for example, a clinical pharmacist, dietitian or psychologist) to assist them to reach an informed decision.

The lead clinician should assure patients who use complementary or alternative therapies that they can still access MDT reviews and encourage full disclosure about therapies being used (ACN & NBCC 2010).

Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <http://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>.
- See the Clinical Oncology Society of Australia's position statement at www.cosa.org.au/publications/position-statements.aspx.

4.6 Support and communication

4.6.1 Supportive care

Screening with a validated screening tool, assessment and referral to appropriate health professionals and/or organisations is required to meet the needs of individual patients, their families and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- nutrition assessment and support
- physical symptoms such as chronic pain and fatigue
- gastrointestinal symptoms (such as nausea, vomiting, mucositis, loss of appetite) as a result of chemotherapy treatment, requiring optimal symptom control with medication and referral to a dietitian if dietary intake is affected
- assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications (referral to a pharmacist may be required)
- decline in mobility and/or functional status as a result of treatment
- emotional and psychological issues including, but not limited to, body image concerns, fatigue, existential anxiety, treatment phobias, anxiety/depression, interpersonal problems and sexuality concerns
- potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment
- financial issues related to loss of income and additional expenses as a result of illness and/or treatment
- legal issues (such as advance care planning, appointing medical and financial powers of attorney, completing a will)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

4.6.2 Communication with the patient, carer and family

The lead clinician should:

- discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes – provide a written plan
- provide the patient and carer with information on the possible side effects of treatment, self-management strategies and emergency contacts
- initiate a discussion regarding advance care planning with the patient and carer.

4.6.3 Communication with the general practitioner

The lead clinician should:

- discuss with the general practitioner their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding:
 - the treatment plan, including intent and potential side effects
 - supportive and palliative care requirements
 - the patient's prognosis and their understanding of this
 - enrolment in research and/or clinical trials
 - changes in treatment or medications
 - recommendations from the MDT.

Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completing their initial treatment, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the MDT. Transition from acute to primary or community care will vary depending on the type and stage of cancer and needs to be planned. In some cases, people will require ongoing, hospital-based care.

5.1 Survivorship

Pancreatic cancer has a very poor prognosis and five-year survival rates are extremely low. In Australia over the last three decades the five-year survival rate has increased slightly from four per cent in 1982–1986 to six per cent in 2007–2011 (AIHW 2014). Even if patients survive five years, the recurrence rate is very high. International research shows there is an important need to focus on helping cancer survivors cope with life beyond their acute treatment. Cancer survivors experience particular issues, often different from people having active treatment for cancer.

Many cancer survivors experience persisting side effects at the end of treatment. Emotional and psychological issues include distress, anxiety, depression, cognitive changes and fear of cancer recurrence. Late effects may occur months or years later and are dependent on the type of cancer treatment. Survivors may experience altered relationships and may encounter practical issues, including difficulties with return to work or study, and financial hardship.

Survivors generally need to see a doctor for regular followup, often for five or more years after cancer treatment finishes. The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes four essential components of survivorship care (Hewitt et al. 2006):

- the prevention of recurrent and new cancers, as well as late effects
- surveillance for cancer spread, recurrence or second cancers, and screening and assessment for medical and psychosocial late effects
- interventions to deal with the consequences of cancer and cancer treatments (including managing symptoms, distress and practical issues)
- coordination of care between all providers to ensure the patient's needs are met.

All patients should be educated in managing their own health needs (NCSI 2015).

5.2 Post-treatment care planning

5.2.1 Treatment summary

Upon completion of initial treatment, the patient, carer and general practitioner should receive a treatment summary outlining:

- the diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

5.2.2 Follow-up care

As most patients with pancreatic cancer are palliated, they should already have a palliative care physician/team that will oversee their palliation. If a patient is thought to have been cured after their treatment, then care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is evidence-based and consistent with guidelines.

There is no established protocol for postoperative surveillance.

Follow-up care over the first two years should include:

- for patients at high risk of a new pancreatic cancer: six-monthly tumour markers and radiological imaging
- for the remaining patients, six-monthly tumour markers and annual radiological imaging.

Symptoms suggestive of recurrence include weight loss, jaundice and abdominal pain. These require investigation and/or referral back to the specialist treating team.

Responsibility for follow-up care should be agreed between the lead clinician, the general practitioner, relevant members of the MDT and the patient, with an agreed plan outlining:

- what medical follow-up is required (surveillance for cancer spread, recurrence or secondary cancers, screening and assessment for medical and psychosocial effects)
- care plans from other health professionals to manage the consequences of cancer and treatment
- a process for rapid re-entry to specialist medical services for suspected recurrence
- whether the lead clinician role should be transferred to the general practitioner or specialist palliative care.

In particular circumstances, follow-up care can safely and effectively be provided:

- in the primary care setting
- by non-medical staff
- in a non-face-to-face setting (for example, by telehealth).

Access to a range of health professions may be required including physiotherapy, occupational therapy, nursing social work, dietetics, clinical psychology and palliative care.

5.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- For more information visit www.australiancancertrials.gov.au (Australia).

5.4 Support and communication

5.4.1 Supportive care

Screening using a validated screening tool, assessment and referral to appropriate health professionals and community-based support services is required to meet the needs of individual patients, their family and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- nutritional assessment and support (including post-surgical enzyme support therapy)
- physical symptoms including pain and fatigue
- malnutrition post-treatment due to ongoing treatment side effects (such as weight loss, reduced oral intake); this requires monitoring and nutrition intervention where indicated
- decline in mobility and/or functional status as a result of treatment
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns
- a need for increased community supports as patients recover from treatment
- financial and employment issues (such as loss of income and assistance with returning to work, and the cost of treatment, travel and accommodation)
- legal issues (such as advance care planning, appointing medical and financial powers of attorney and completing a will)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

5.4.3 Palliative care

Given the poor prognosis of this cancer at present, for the majority of patients, treatment is often given with palliative rather than curative intent. Specialist palliative care is required for patients with pancreatic cancer.

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

- Patients may be referred to palliative care at initial diagnosis.
- Patients should be referred to palliative care at first recurrence or progression.
- Carer needs may prompt referral.

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for poor prognosis cancers (Temel et al. 2010). Furthermore, palliative care has been associated with the improved wellbeing of carers (Higginson & Evans 2010; Hudson et al. 2015).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

Further information

Refer patients and carers to Palliative Care Australia at www.palliativecare.org.au.

5.4.4 Communication with the patient, carer and family

The lead clinician should:

- explain the treatment summary and follow-up care plan
- provide information on the signs and symptoms of recurrent disease
- provide information on secondary prevention and healthy living.

5.4.5 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the patient's general practitioner regarding:

- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- the patient's progress
- recommendations from the MDT
- any shared care arrangements
- a process for rapid re-entry to medical services for patients with suspected recurrence.

Step 6: Managing recurrent, residual or metastatic disease

Step 6 is concerned with managing recurrent or residual local and metastatic disease. If pancreatic cancer recurrence is detected, the patient should be discussed at the multidisciplinary meeting to explore the possibility of further management.

6.1 Signs and symptoms of recurrent, residual or metastatic disease

With the low rates of curable pancreatic cancer and the majority of patients palliated, it is likely that their current symptoms will worsen progressively, and this should be managed following discussion at a multidisciplinary clinic in consultation with palliative care specialists.

6.2 Multidisciplinary team

There should be timely referral to the original MDT (where possible), with referral on to a specialist centre for recurrent disease as appropriate.

6.3 Treatment

If pancreatic cancer recurrence is detected, the patient should be restaged and discussed at the MDT to explore the possibility of further management.

Potential therapies include surgery, stenting, chemotherapy or radiation therapy and include advance care planning. These therapies may also include involvement in a clinical trial.

Treatment will depend on the location and extent of disease, previous management and the patient's preferences.

6.4 Palliative care

Given the poor prognosis of this cancer at present, for the majority of patients, treatment is often given with palliative rather than curative intent. Specialist palliative care is required for patients with pancreatic cancer.

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

- Patients may be referred to palliative care at initial diagnosis.
- Patients should be referred to palliative care at first recurrence or progression.
- Carer needs may prompt referral.

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for poor prognosis cancers (Temel et al. 2010). Furthermore, palliative care has been associated with the improved wellbeing of carers (Higginson & Evans 2010; Hudson et al. 2015).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

Begin discussions with the patient and carer about preferred place of death.

Further information

- Refer patients and carers to Palliative Care Australia at www.palliativecare.org.au.

6.5 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- For more information visit www.australiancancertrials.gov.au (Australia).

6.6 Support and communication

6.6.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- nutritional assessment and support (including enzyme support therapy)
- physical symptoms including pain and fatigue
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- decline in mobility and/or functional status as a result of recurrent disease and treatments
- increased practical and emotional support needs for families and carers, including help with family communication, teamwork and care coordination where these prove difficult for families
- emotional and psychological distress resulting from fear of death or dying, complications of chemotherapy, existential concerns, anticipatory grief, communicating wishes to loved ones, interpersonal problems and sexuality concerns
- financial issues as a result of disease recurrence (such as early access to superannuation and insurance)
- legal issues (such as advance care planning, appointing medical and financial powers of attorney and developing a will)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

6.6.2 Rehabilitation

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care. Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

6.6.3 Communication with the patient, carer and family

The lead clinician should ensure there is adequate discussion with the patient and carer about the diagnosis and recommended treatment, including the intent of treatment and possible outcomes, likely adverse effects and supportive care options available.

Step 7: End-of-life care

End-of-life care is appropriate when the patient's symptoms are increasing and their functional status is declining. Step 7 is concerned with maintaining the patient's quality of life and addressing their health and supportive care needs as they approach the end of life, as well as the needs of their family or carer. Consideration of appropriate venues of care is essential. The principles of a palliative approach to care need to be shared by the team when making decisions with the patient and their family.

7.1 Multidisciplinary palliative care

If not already involved, referral to palliative care should be considered at this stage (including nursing, pastoral care, palliative medicine specialist backup, inpatient palliative bed access as required, social work and bereavement counselling) with general practitioner engagement.

If not already in place, the patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

The multidisciplinary palliative care team may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or spiritual advisor
- bereavement counsellor
- therapist (for example, music, art).

The team might also recommend accessing:

- home- and community-based care
- specialist community palliative care workers
- community nursing.

Consideration of the appropriate place of care and the patient's preferred place of death is essential.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Further information

Refer patients and carers to Palliative Care Australia at www.palliativecare.org.au.

7.2 Research and clinical trials

Participation in research and clinical trials should be encouraged where available and appropriate.

For more information visit www.australiancancertrials.gov.au (Australia).

7.3 Support and communication

7.3.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues identified in the **appendix**, specific issues that may arise at this time include:

- nutritional assessment and support (including enzyme support therapy)
- physical symptoms including pain and fatigue
- decline in mobility and/or functional status impacting on discharge destination
- emotional and psychological distress from anticipatory grief, fear of death/dying, anxiety/depression, interpersonal problems and anticipatory bereavement support for the patient as well as their carer and family
- practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the patient
- legal issues relevant to people with advanced disease such as accessing superannuation early, advance care planning, powers of attorney and completing a will
- information for patients and families about arranging a funeral
- specific spiritual needs that may benefit from the involvement of pastoral care
- bereavement support for family and friends
- specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs.

Communication with the patient, carer and family

The lead clinician should:

- be open to and encourage discussion about the expected disease course, with due consideration to personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the patient and carer with the contact details of a palliative care service.

7.3.2 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning and transition planning to ensure the patient's needs and goals are addressed in the appropriate environment. The patient's general practitioner should be kept fully informed and involved in major developments in the patient's illness trajectory.

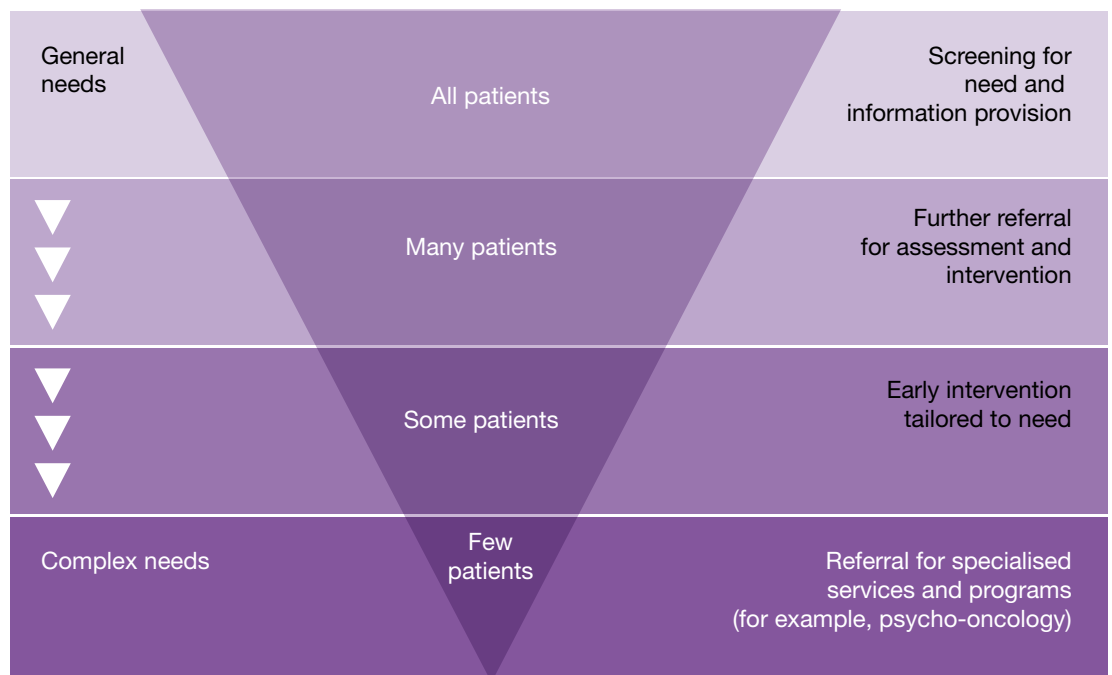
Appendix: Supportive care

Supportive care in cancer refers to the following five domains:

- physical domain, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation (NBCC & NCCI 2003)
- psychological domain, which includes a range of issues related to the person's mental health and personal relationships (NBCC & NCCI 2003)
- social domain, which includes a range of social and practical issues that will impact on the individual and family such as the need for emotional support, maintaining social networks and financial concerns (NICE 2004)
- information domain, which includes access to information about cancer and its treatment, support services and the health system overall (NBCC & NCCI 2003)
- spiritual domain, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns (NICE 2004).

Fitch's (2000) model of supportive care (Figure 1) recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual. The model targets the type and level of intervention required to meet patients' supportive care needs.

Figure 1: The tiered approach



While all patients require general information, some will require specialised intervention. Common indicators in patients with pancreatic cancer that may require referral to appropriate health professionals and/or organisations include the following:

Physical needs

- Nutritional assessment and support (including enzyme support therapy) is required.
- As the majority of people with pancreatic cancer are elderly, the rapid deterioration of their self-care is likely and this may require early consideration of hospice care placement.
- Weight loss and decrease in appetite can be a significant issue for patients and may require referral to a dietitian before, during and after treatment. Validated malnutrition screening tools should be used at the key points in the care pathway to identify patients at risk of malnutrition.
- Reduced sexual interest and sexual dysfunction may require referral to medical specialists. Sensitive discussion and referral to a clinician skilled in this area may be appropriate.
- Alteration of cognitive functioning in patients treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information.
- Referral to a pharmacist may be useful for people managing multiple medications.
- Although treatments have improved, nausea and vomiting are still serious side effects of cancer therapy. Some patients are bothered more by nausea than by vomiting. Managing both is important for improving quality of life.

Psychological needs

- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, gay, bisexual, transgender, and intersex (LGBTI) communities) a cancer diagnosis can come with additional psychosocial complexities. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some people may have disabling symptoms and may benefit from referral to psychology services.
- Distress and depression can be just as common in carers and family members including children.
- Consider a referral to a psychologist, psychiatrist or social worker if the patient is:
 - displaying emotional cues such as tearfulness, distress, avoidance and withdrawal
 - preoccupied with or dwelling on thoughts about cancer and death
 - displaying fears about the treatment process and/or the changed goals of their treatment
 - worried about loss associated with their daily function, dependence on others and loss of dignity
 - becoming isolated from family and friends and withdrawing from company and activities that they previously enjoyed
 - feeling hopeless and helpless about the impact that pancreatic cancer is having on their life and the disruption to their life plans
 - struggling with communicating to family and loved ones about the implications of their cancer diagnosis and treatment
 - experiencing changes in sexual intimacy, libido or function
 - struggling with the diagnosis of metastatic or advanced disease
 - having difficulties with quitting drug and alcohol use
 - having difficulties transitioning to palliative care.

Fertility preservation

- Consider the need for sperm storage or egg banking before treatment. Referral to fertility counselling may be appropriate.

Social/practical needs

- A diagnosis of pancreatic cancer can have significant financial, social and practical impacts on patients, carers and families as outlined above.
- Consider referral to a peer support group.
- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.

Spiritual needs

- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.
- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.

Populations with special needs

Elderly people with cancer

Given the average age at diagnosis of pancreatic cancer is 70.9, the majority of people with pancreatic cancer are elderly and may therefore experience a rapid deterioration. Their ability to self-care means it is likely that they may require early consideration of hospice care placement.

Planning and delivery of appropriate cancer care for elderly people presents a number of challenges. Improved communication between the fields of oncology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as implications of cognitive impairment on suitability of treatment and consent (Steer et al. 2009).

A national interdisciplinary workshop convened by the Clinical Oncology Society of Australia recommended that people over the age of 70 undergo some form of geriatric assessment, in line with international guidelines (COSA 2013). Assessment can be used to determine life expectancy and treatment tolerance as well as identifying conditions that might interfere with treatment including:

- function
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional status
- social supports.

Adolescent and young adults

Malignant pancreatic tumours are rare in children and adolescents with an incidence of 0.46 cases per one million (younger than 30 years) (National Cancer Institute 2015). Recent years have seen the emergence of adolescent and young adult (AYA) oncology as a distinct field due to lack of progress in survival and quality-of-life outcomes (Ferrari et al. 2010; NCI & USDHHS 2006; Smith et al. 2013). The significant developmental change that occurs during this life stage complicates a diagnosis of cancer during the AYA years, often leading to unique physical, social and emotional impacts for young people at the time of diagnosis and throughout the cancer journey (Smith et al. 2012).

In caring for young people with cancer, careful attention to the promotion of normal development is required (COSA 2011). This requires personalised assessments and management involving a multidisciplinary, disease-specific, developmentally targeted approach informed by:

- understanding the developmental stages of adolescence and supporting normal adolescent health and development alongside cancer management
- understanding and supporting the rights of young people
- communication skills and information delivery that are appropriate to the young person
- addressing the needs of all involved, including the young person, their family and/or carer(s)
- working with educational institutions and workplaces
- addressing survivorship and palliative care needs.

An oncology team caring for a young person with cancer must:

- ensure access to expert AYA health professionals who possess knowledge specific to the biomedical and psychosocial needs of the population
- understand the biology and current management of the disease in the AYA age group
- consider clinical trials accessibility and recruitment for each patient
- engage in proactive discussion and management of fertility preservation, late effects of treatment and psychosocial needs
- provide treatment in an AYA-friendly environment.

Culturally and linguistically diverse communities

For people from culturally and linguistically diverse backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In many languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis. In addition to different cultural beliefs, when English language skills are limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for patients. A professionally trained interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those born overseas and particular attention should be paid to supporting these patients (Department of Health 2009).

Aboriginal and Torres Strait Islander communities

The burden of cancer is higher in the Australian Indigenous population (AIHW 2014). Survivorship also significantly decreases as remoteness increases, unlike the survivorship rates of non-Indigenous Australians. Aboriginal and Torres Strait Islander people in Australia have high rates of certain lifestyle risk factors including tobacco smoking, higher alcohol consumption, poor diet and low levels of physical activity (Cancer Australia 2013b). The high prevalence of these risk factors is believed to be a significant contributing factor to the patterns of cancer incidence and mortality rates in this population group (Robotin et al. 2008).

In caring for Aboriginal and Torres Strait Islander people diagnosed with cancer, the current gap in survivorship is a significant issue. The following approaches are recommended to improve survivorship outcomes (Cancer Australia 2013b):

- Raise awareness of risk factors and deliver key cancer messages.
- Develop evidence-based information and resources for community and health professionals.
- Provide training for Aboriginal and Torres Strait Islander health workers and develop training resources.
- Increase understanding of barriers to care and support.
- Encourage and fund research.
- Improve knowledge within the community to act on cancer risk and symptoms.
- Improve the capacity of Aboriginal and Torres Strait Islander health workers to provide cancer care and support to their communities.
- Improve system responsiveness to cultural needs.
- Improve our knowledge through targeted priority research.
- Improve our understanding of gaps through data monitoring.

Resources

For patients, families and carers

Australian Cancer Survivorship Centre

Has general and tumour-specific information, primarily focused on the post-treatment survivorship phase

- Telephone: (03) 9656 5207
- www.petermac.org/cancersurvivorship

beyondblue

Information on depression, anxiety and related disorders, available treatment and support services

- Telephone: 1300 22 4636
- www.beyondblue.org.au

Cancer Australia

Information on cancer prevention, screening, diagnosis, treatment and supportive care for Australians affected by cancer, and their families and carers

- Telephone: 1800 624 973
- www.canceraustralia.gov.au

Cancer Council (operated by Cancer Council Victoria)

A confidential telephone support service for people affected by cancer that provides information on treatment, cancer support groups and other community resources

- Telephone: 13 11 20 (Monday to Friday, 8.30 am – 5.30 pm)
- www.cancervic.org.au

Care Search: Palliative Care Knowledge Network

Information for patients and carers on living with illness, practical advice on how to care, and finding services

- Telephone: (08) 7221 8233
- www.caresearch.com.au

For health professionals

Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are recruiting new participants

- www.australiancancertrials.gov.au

Cancer Australia

Information for health professionals including guidelines, cancer guides, reports, fact sheets, DVDs, posters and pamphlets

- www.canceraustralia.gov.au

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority

- www.cancer.org.au

EviQ

Clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment

- www.eviq.org.au

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment

- www.nhmrc.gov.au

Glossary

Advance care planning – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

Alternative therapies – treatments that are used in place of conventional medical treatment, often in the hope they will provide a cure.

Care coordinator – the health professional nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and where care is primarily located.

Complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life, and help people deal with the side effects of cancer.

End-of-life care – a distinct phase of palliative care, appropriate when a patient's symptoms are increasing and functional status is declining despite anti-cancer therapy.

General/primary medical practitioner – the practitioner to whom the patient first presents with symptoms; this may be the general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

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.

Multidisciplinary care – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each patient (Department of Health 2007b).

Multidisciplinary team – comprises the core disciplines integral to providing good care. The team is flexible in approach, reflects the patient's clinical and psychosocial needs and has processes to facilitate good communication.

Optimal cancer care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.

Palliative care – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

Patient management framework – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal cancer care pathways are updated versions of these models, being developed by the Victorian Government from 2013.

Prehabilitation – one or more interventions performed in a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the patient undergoes treatment and beyond.

Primary specialist – the person who makes the referral to the multidisciplinary team (for example, specialist physician, surgeon, oncologist, palliative care specialist). This person will also make referrals for treatment and will be responsible for oversight of follow-up care.

Rehabilitation – comprises multidisciplinary efforts to allow the patient to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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