

# Optimal cancer care pathway for people with hepatocellular carcinoma





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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.

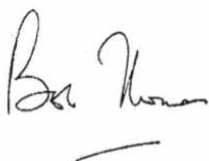
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established 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 and Human Services – Victoria

# 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:** Immunisation for hepatitis B (HBV), monitoring of patients with HBV and hepatitis C (HCV) and use of antiviral drugs can reduce the risk of infection developing into cancer.

Strategies to curb alcohol intake and reduce obesity (and hence type 2 diabetes and non-alcoholic fatty liver disease) will also reduce future hepatocellular carcinoma (HCC) burden.

### Risk factors include:

- chronic HCV infection
- HBV infection
- a family history of HCC
- cirrhosis of the liver of any cause.

**Other risk factors:** male gender, older age, viral co-infection, chronic alcohol consumption, obesity, non-alcoholic fatty liver disease, type 2 diabetes, iron overload, aflatoxin exposure and tobacco smoking.

**Early detection:** Australia does not have a population screening program for HCV, HBV or HCC. Surveillance for HCC should be based on six-monthly abdominal ultrasound in high-risk groups.

## Step 2

### Presentation, initial investigations and referral

**Signs and symptoms:** The following signs and symptoms should be investigated:

- right upper quadrant abdominal pain or discomfort
- a hard lump on the right side of the abdomen
- worsening liver failure (jaundice, ascites, portal hypertension)
- constitutional symptoms
- the presence of multiple signs and symptoms.

### Initial investigations include:

- ultrasound assessment of liver and renal function
- assessment of tumour markers (alpha-fetoprotein (AFP))
- full blood examination
- HBV and HCV serology (HBsAg, anti-HCV antibody).

Tests should be conducted within two to three days of symptom discovery.

**Referral:** Refer all patients with suspected or proven HCC to a specialist linked with a multidisciplinary team within one week. The multidisciplinary team should have a rapid access program/contact person.

### Communication – lead clinician to:<sup>1</sup>

- 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:** The following sequence of investigations is suggested:

- four-phase contrast-enhanced computed tomography (CT) scan
- magnetic resonance imaging (MRI) with contrast in patients who cannot tolerate CT contrast or where diagnostic uncertainty remains
- contrast-enhanced ultrasound, in select cases.

If diagnostic uncertainty still remains, conduct:

- positron emission tomography (PET)
- a liver biopsy (particularly if no surgery is planned).

**Staging:** Staging parameters include imaging (metastases and vascular invasion), Eastern Cooperative Oncology Group (ECOG) status and Child–Pugh score.

**Treatment planning:** All patients with suspected or proven HCC should be discussed by a multidisciplinary team before treatment begins.

**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.

<sup>1</sup> 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 of localised HCC

**Local ablative therapies** are the most common treatment for HCC. They may benefit patients:

- with unresectable disease (due to the size or location of the tumour)
- with a small tumour or tumours (lesions 3 cm or smaller)
- awaiting liver transplant
- with small recurrent tumours.

**Surgery – resection or transplant:** Resection may benefit patients with compensated liver disease and a resectable tumour. Liver transplant may benefit patients with the presence of cirrhosis, including those with decompensation.

**Regional therapies:** Transarterial chemoembolisation (TACE), selective internal radiation therapy (SIRT) or stereotactic therapy may be appropriate.

### Treating advanced HCC

The standard treatment for patients with advanced HCC is either: sorafenib; surveillance and management of the underlying disease; or a combination of surgery and surveillance. Palliation of symptoms may include TACE, surgery, radiation and other therapies.

**Palliative care:** Early referral can improve quality of life and in some cases survival. 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 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.aasld.org/practiceguidelines/pages/default.aspx](http://www.aasld.org/practiceguidelines/pages/default.aspx)

## Step 5

### Care after initial treatment and recovery

#### Management of the underlying liver disease must be carefully managed to help prevent recurrence.

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 general practitioner.

## Step 6

### Managing recurrent, residual and metastatic disease

**Detection:** Most residual or recurrent disease will be detected via routine follow-up or when the patient presents with symptoms.

**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:** Early referral can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

#### 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:** Consider referral to palliative care if not already involved. 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.



# Summary – optimal timeframes

**Timeframes for diagnosis and referral** – Timeframes should be informed by evidence based guidelines where they exist, whilst recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress. The following recommended timeframes are based on expert advice from the Hepatocellular Carcinoma Working Group:

Step in pathway	Care point	Timeframe
Presentation, Initial Investigations and Referral	2.2 Initial investigations by GP	Tests should be conducted within 2-3 days of a patient presenting with symptoms.
	2.3 Specialist appointment	Within one week of finding a suspected HCC the patient should be referred to a specialist multidisciplinary team where possible or specialist (gastroenterologist, hepatologist, oncologist or hepato-pancreato-biliary surgeon). The MDT should have a rapid access program or contact person.
Diagnosis, Staging and Treatment Planning	3.1 Diagnostic workup	Investigations should be completed within 4 weeks of referral.
Treatment	4.2 Treatment	Local ablative therapy should commence within 2 weeks of decision to treat.
	4.2 Treatment	Surgery should commence within 2 weeks of decision to treat.
	4.2 Treatment	Regional therapies should commence within 1-4 weeks depending on modality of decision to treat.

# Intent of the optimal cancer care pathway – key principles

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased 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 (ACQSHC 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.

Services should routinely be collecting relevant minimum datasets to support benchmarking, quality care and service improvement.

## Multidisciplinary care

This is an integrated team approach to healthcare in which medical, nursing 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 2007c).

## 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 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)
- the beginning of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care
- survivorship.

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

Common indicators in patients with hepatocellular carcinoma (HCC) 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 organisation(s) should be considered including:

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

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

## 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 team meetings, supportive care screening/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 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, that initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007b).

## 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 (with their consent).

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, and recordings or written summaries of their consultations. QPL interventions are effective in improving communication, 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 treatment interventions, as well as establishing the role of psychological, supportive 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 the 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 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, regular exercise and maintaining a healthy body weight may help reduce cancer risk. This step outlines recommendations for the prevention and early detection of HCC.

### 1.1 Prevention

There is an increasing burden of HCC in many developed countries, driven by ageing cohorts of people with chronic hepatitis C (HCV) and high levels of immigration of people from endemic hepatitis B (HBV) countries, suboptimal HBV/HCV screening, and continued low levels of antiviral therapy intervention (Dore 2012).

Hepatitis is the leading cause of HCC in Australia, with HCC incidence reported as 6.5 per 1000 among people with HBV (which can be prevented through immunisation), 30 times higher than the rate in the general Australian population (Amin et al 2006). Monitoring of patients with hepatitis and use of antiviral drugs can also reduce the risk of infection developing into cancer.

Strategies to curb alcohol intake and reduce obesity (and hence type 2 diabetes and non-alcoholic fatty liver disease) will also reduce future HCC burden.

### 1.2 Risk factors

A number of factors are associated with the risk of developing HCC. These factors include:

- chronic HCV infection
- HBV infection (particularly for those with an extended period of exposure, childhood-acquired and high viral load)
- a family history of HCC
- cirrhosis of the liver of any cause.

Other risk factors include male gender, older age, viral co-infection, chronic alcohol consumption, obesity, non-alcoholic fatty liver disease, type 2 diabetes, iron overload, aflatoxin exposure and tobacco smoking.

### Further information

Detailed policy information on HBV and HCC is available in the liver cancer chapter of Cancer Council Australia's National cancer prevention policy. See <[www.cancervic.org.au/about/media-releases/2007\\_media\\_releases/october\\_2007/national-cancer-prevention-policy.html](http://www.cancervic.org.au/about/media-releases/2007_media_releases/october_2007/national-cancer-prevention-policy.html)>.

## 1.3 Early detection

### Surveillance screening recommendations

Australia does not have a population screening program for HCV, HBV or HCC. There are surveillance screening programs in some public hospital settings for patients at risk. Patients detected by surveillance have their tumours detected at an earlier stage and therefore better outcomes, including improved survival.

### Further information

Guidelines for screening appropriate populations should be adhered to and are summarised in the National Cancer Institute Liver cancer screening PDQ. See <[www.cancer.gov/cancertopics/pdq/screening/hepatocellular/HealthProfessional/page1/AllPages#Section\\_20](http://www.cancer.gov/cancertopics/pdq/screening/hepatocellular/HealthProfessional/page1/AllPages#Section_20)>.

The most recent guidelines from the American Association for the Study of Liver Diseases recommend that HCC surveillance be based on six-monthly abdominal ultrasound in high-risk groups (Bruix & Sherman 2011).

There is no evidence for increased frequency of ultrasound (less than six months) or for use of other imaging modalities (computed tomography (CT), magnetic resonance imaging (MRI)) as a first-line screening.

Screening with alpha-fetoprotein (AFP) is widely used but not included in current guidelines.



## 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 and medical specialists, and patient preferences.

### 2.1 Signs and symptoms

Many cases of HCC are asymptomatic and will be picked up by screening or as an incidental finding.

The following signs and symptoms should be investigated:

- right upper quadrant abdominal pain or discomfort
- a hard lump on the right side of the abdomen
- worsening liver failure (jaundice, ascites, portal hypertension)
- constitutional symptoms.

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

### 2.2 Assessments by a general or primary medical practitioner

If HCC is suspected, investigations prior to referral should include:

- ultrasound (further imaging to be done in conjunction with specialist referral)
- assessment of liver and renal function
- assessment of tumour markers (AFP)
- full blood examination
- HBV and HCV serology (HBsAg, anti-HCV antibody).

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 expert opinion of the HCC Working Group<sup>1</sup> is for tests to be conducted within two to three days.

### 2.3 Referral

The patient should be referred to a specialist multidisciplinary team where possible (patients treated by multidisciplinary teams have better outcomes). If this is not available, patients should be referred to a gastroenterologist, hepatologist, oncologist or hepato-pancreato-biliary (HPB) surgeon who is affiliated with or has access to a multidisciplinary team and multidisciplinary team meetings.

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<sup>1</sup> The multidisciplinary experts who participated in a clinical workshop to develop content for the HCC optimal care pathway are listed in the acknowledgements list.

Referral for suspected HCC 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 expert opinion of the HCC Working Group is referral to a specialist within one week of finding a suspected HCC. The multidisciplinary team should have a rapid access program or contact person. The supportive and liaison role of the GP 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 supportive care 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:

- treatment for physical symptoms such as pain, fatigue and altered bowel function
- help with the emotional distress of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties
- guidance about financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients and caring arrangements for other family members)
- 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 which specialist(s) they are being referred to, the reason for referral, and expected timeframes for appointments
- support the patient while waiting for the specialist appointment if required.

## 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 multidisciplinary team members should determine the treatment plan.

### 3.1 Diagnostic workup

Diagnosis is primarily by imaging, and biopsy is only required where diagnostic uncertainty remains.

The following sequence of investigations is suggested:

- four-phase contrast-enhanced CT scan according to HCC protocol
- MRI with contrast in patients who cannot tolerate CT contrast or where diagnostic uncertainty remains
- contrast-enhanced ultrasound, which can be a useful modality in select cases.

If diagnostic uncertainty still remains, perform:

- positron emission tomography (PET), but only by credentialed individuals
- a liver biopsy (particularly if no surgery is planned).

### 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 expert opinion of the HCC Working Group is for investigations to be completed within four weeks of referral.

### 3.2 Staging

Staging is a critical element in treatment planning and should utilise validated staging protocols: the Hong Kong Association for the Study of Liver Diseases (HKASLD) or Barcelona Clinic Liver Cancer (BCLC) guidelines. Note that staging of both the liver disease and the tumour are important and independent parameters necessary to inform treatment planning and should be clearly documented in the patient's medical record.

Staging parameters include imaging (metastases and vascular invasion), Eastern Cooperative Oncology Group (ECOG) status and Child–Pugh score.

### 3.3 Treatment planning

#### 3.3.1 Responsibilities of the multidisciplinary team

These 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 all relevant team members, including the general practitioner.

While transplantation is an option for only a small minority of HCC patients, early referral for potential transplant patients should be made to a liver transplant unit, where the specialist multidisciplinary team should determine their suitability for transplant.

### **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 HCC**

The multidisciplinary team should comprise the core disciplines integral to providing good care. Treatment planning for HCC requires hepatobiliary expertise and there are benefits from having separate HCC multidisciplinary teams for these tumour types.

Team membership should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some patients (Department of Health 2007c).

Team members may include a:

- care coordinator (as determined by multidisciplinary team members)\*
- gastroenterologist/hepatologist\*
- hepato-pancreato-biliary surgeon\*
- interventional radiologist\*
- nurse (with appropriate expertise)\*
- medical oncologist\*
- palliative care specialist\*
- pathologist\*
- clinical trials coordinator
- dietician
- general practitioner
- nuclear medicine physician
- occupational therapist
- pharmacist
- physiotherapist
- psychologist
- psychiatrist
- radiation oncologist (palliation)
- social worker.

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

### **3.3.4 The optimal timing for multidisciplinary team planning**

Ideally, all newly diagnosed patients should be discussed at a multidisciplinary team 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 multidisciplinary team discussion. Information about the patient's concerns, preferences and social circumstances should also be presented at the meeting by the care coordinator or lead clinician (Department of Health 2007c).

### **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](http://www.australiancancertrials.gov.au)>.

### **3.5 Prehabilitation, support and communication**

#### **3.5.1 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 prehabilitating newly diagnosed cancer patients prior to starting treatment can be beneficial (particularly for patients suitable for transplant). This may include conducting a physical and psychological assessment to establish a baseline function level, identify impairments and provide 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.

### 3.5.2 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network distress thermometer and problem checklist), 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 common issues identified in the **appendix**, specific needs that may arise at this time include:

- support for alcohol and/or drug addiction (related to hepatitis or underlying liver disease)
- nutritional screening and support
- treatment for physical symptoms such as pain, fatigue and weight loss
- help with psychological and emotional distress while adjusting to the diagnosis, treatment phobias, existential concerns, difficulties making treatment decisions, anxiety/depression, body issues, sexual dysfunction and interpersonal problems
- guidance for financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients and caring arrangements for other family members)
- appropriate information for people from culturally and linguistically diverse backgrounds.

### 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 team meeting
- offer individualised HCC 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 and community and national cancer services and support groups
- use a professionally trained interpreter when communicating with people from culturally or linguistically diverse backgrounds (NICE 2004)
- if the patient is a smoker, provide information about smoking cessation.

### 3.5.4 Communication with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the general practitioner regarding the treatment plan and recommendations from multidisciplinary team meetings and notify the general practitioner if the patient does not attend
- 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 team meetings (consider using video or teleconferencing).

## Step 4: Treatment

Step 4 outlines the treatment options for HCC.

In managing people with HCC, treatment protocols have recently become more complex, with more effective treatments and major surgical programs being offered to patients with potentially curable recurrent cancer; however, therapy may be focused on disease control or palliation, depending on the extent of disease, general health or patient preferences and values.

For detailed information on treatment guidelines refer to the:

- American Association for the Study of Liver Diseases at <[www.aasld.org/practiceguidelines/pages/default.aspx](http://www.aasld.org/practiceguidelines/pages/default.aspx)>
- European Association for the Study of the Liver – European Organisation for Research and Treatment Of Cancer (EASL-EORTC) at <[www.ncbi.nlm.nih.gov/pubmed/22424438](http://www.ncbi.nlm.nih.gov/pubmed/22424438)>
- National Cancer Institute *Liver cancer treatment PDQ* at <[www.cancer.gov/cancertopics/pdq/treatment/adult-primary-liver/HealthProfessional](http://www.cancer.gov/cancertopics/pdq/treatment/adult-primary-liver/HealthProfessional)>.

### 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 commencing treatment.

If appropriate, advance care planning should be initiated with patients at this stage. Advance care planning can offer 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 localised HCC

There is no worldwide agreement on a common treatment strategy for patients with HCC (National Cancer Institute 2014). Several treatments for HCC are available that are associated with long-term survival:

- local ablative therapies
- surgery – resection or transplant
- regional therapies.

### Local ablative therapies

Local ablative therapy is the most common treatment for HCC and may be used in conjunction with surgery. Local ablation may be radiofrequency, microwave or percutaneous alcohol injection, depending on local expertise.

Local ablative therapies may benefit patients:

- with unresectable disease (due to the size or location of the tumour)
- with a small tumour or tumours (lesions 3 cm or smaller)
- awaiting liver transplant
- with small recurrent tumours.

Ablation should be monitored by imaging.

### Timeframe for commencing treatment

Timeframes for starting 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 expert opinion of the HCC Working Group is for treatment to commence within two weeks of decision to treat with local ablative therapy.

### Surgery – resection or transplant

Only a small number of people are suitable for surgery. There are established criteria for surgical intervention, which depend on the severity of liver disease and presence or absence of clinically significant portal hypertension, as well as the size, number and position of the tumours, and residual liver volume.

Resection may benefit patients with compensated liver disease and limited tumour volume.

Liver transplant may benefit patients with the presence of cirrhosis, including those with decompensation, and for patients with a tumour volume within accepted international guidelines (Milan and University of California San Francisco (UCSF) criteria).

### Timeframe for commencing treatment

Timeframes for starting 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 expert opinion of the HCC Working Group is for treatment to commence within two weeks of decision to treat with surgery.



### Training, experience and treatment centre characteristics

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

- Surgeon (Fellow of the Royal Australasian College of Surgeons (FRACS) or equivalent) with adequate training and experience in HPB surgery and institutional cross-credentialling and agreed scope of practice within this area (ACSQHC 2004).
- There is evidence to suggest that surgeons who undertake a high volume of resections have better clinical outcomes for complex cancer surgery (Lu et al. 2014).

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

- a clearly defined path to emergency care and advice after hours
- an intensive care unit
- 24-hour medical staff availability
- 24-hour operating room access
- appropriate molecular pathology access (essential)
- expert and timely interventional radiology
- full support from other surgical specialties including vascular surgery, colorectal surgery, urological surgery and upper gastrointestinal surgery.

There is evidence to suggest that high volume hospitals have better clinical outcomes for complex cancer surgery (Lu et al. 2014). Centres that do not have sufficient caseloads should establish processes to routinely refer surgical cases to a high volume centre.

### Regional therapies

Regional therapies used to treat HCCs are:

- transarterial chemoembolisation (TACE) – a type of chemotherapy that is injected directly into the liver along with a gel or small beads injected into the blood vessels surrounding the tumours; transarterial embolisation (TAE) (as for TACE but without chemotherapy) is a rarely used alternative
- selective internal radiation therapy (SIRT) – a type of radiation and embolisation therapy where radioactive material is injected directly into the blood vessels surrounding the tumours
- stereotactic therapy, which may be appropriate in selected cases.

Regional therapies might have the following benefits:

- as a palliative treatment to slow down the speed at which tumours grow
- for patients awaiting transplant or downsizing of tumour size
- for patients with major vascular invasion (SIRT)
- for selected tumours using chemo-ablation therapy.

### Timeframe for commencing treatment

Timeframes for starting 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 expert opinion of the HCC Working Group is for treatment to commence within one to four weeks of decision to treat with regional therapies, depending on modality.

### Training, experience and treatment centre characteristics

Training and experience required of the appropriate specialist(s):

- interventional radiologist (FRANZCR or equivalent) with adequate training and experience with institutional credentialling and agreed scope of practice in liver cancer as per Interventional Radiology Society of Australasia (IRSA) credentialling guidelines
- SIRT should only be performed by credentialled individuals.

#### 4.2.2 Treating advanced HCC

The standard treatment for patients with advanced HCC is either: sorafenib; surveillance and management of the underlying disease; or a combination of surgery and surveillance. In patients who are intolerant or demonstrate disease progression, participation in clinical trials of potential second-line agents should be considered when available.

Palliation of symptoms may include TACE, surgery, radiation and other therapies.

### 4.3 Palliative care

Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits (Haines 2011; Temel et al. 2010). This is particularly true for poor-prognosis cancers (Temel et al. 2010).

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

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. See <[www.palliativecare.org.au](http://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](http://www.australiancancertrials.gov.au)>.

## 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 multidisciplinary team 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.

Many 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 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 multidisciplinary team who have knowledge of complementary and alternative therapies (such as a clinical pharmacist, dietitian or psychologist) to help them reach an informed decision.

The lead clinician should assure patients who use complementary or alternative therapies that they can still access multidisciplinary team reviews (NBCC & NCCI 2003) and encourage full disclosure about therapies being used (Cancer Australia 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](http://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 identified needs of an individual, their carer and family.

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

- support for alcohol and/or drug addiction (related to hepatitis or underlying liver disease)
- physical symptoms such as pain, weight loss and fatigue
- nutrition screening and support
- decline in mobility and/or functional status as a result of treatment
- 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
- emotional and psychological issues including, but not limited to, body image concerns, coping with stomas, fatigue, quitting smoking, traumatic experiences, 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 (including advance care planning, appointing a power of attorney and 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 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 multidisciplinary team.

## Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completion of 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 multidisciplinary team. 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

In the past two decades, the number of people surviving cancer has increased. 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 follow-up, 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 management of 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)

In HCC management of the underlying liver disease must be carefully managed to help prevent recurrence. This includes consideration of instituting antiviral therapy in patients with chronic viral hepatitis B and C and addressing lifestyle issues (such as alcohol dependence).

## 5.2 Post-treatment care planning

### 5.2.1 Treatment summary

After initial treatment, the patient, carer and general practitioner should receive a treatment summary outlining:

- the diagnostic tests performed and results
- tumour characteristics
- the 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

In patients with cirrhosis, ongoing surveillance is required to detect early or late recurrence.

The underlying liver disease will require specific treatment and/or measures to prevent progressive disease and reduce the risk of recurrence.

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. Not all people will require ongoing tests or clinical review.

Responsibility for follow-up care should be agreed between the lead clinician, the general practitioner, relevant members of the multidisciplinary team and the patient, with an agreed plan documented that outlines:

- 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 cancer treatment
- a process for rapid re-entry to specialist medical services for suspected recurrence.

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

- in the primary care setting
- by other suitably trained staff (i.e. nurse led follow-up)
- 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](http://www.australiancancertrials.gov.au)>.

## 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 families and carers.

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

- support to address alcohol dependence (related to underlying liver disease)
- support to address drug dependence (related to hepatitis)
- nutrition screening and support
- physical symptoms including pain, weight loss and fatigue
- 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 (including advance care planning, appointing a power 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

Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits (Haines 2011; Temel et al. 2010). This is particularly true for poor-prognosis cancers (Cancer Council Australia 2008; Temel et al. 2010).

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on need, not prognosis.

Patients should be encouraged to develop an advance care plan (AHMAC 2011).

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. See <[www.palliativecare.org.au](http://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 about the signs and symptoms of recurrent disease
- provide information about 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 general practitioner regarding:

- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- the patient's progress
- recommendations from the multidisciplinary team
- 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.

All patients with successfully treated HCC should be considered for a surveillance program coordinated by a specialist centre to monitor for recurrence.

### 6.1 Signs and symptoms of recurrent, residual or metastatic disease

Some people will present with symptoms of recurrent disease. Some cases of recurrent disease will be detected by routine follow-up in a patient who is asymptomatic.

### 6.2 Multidisciplinary team

There should be timely referral to the original multidisciplinary team (where possible) for management of recurrent disease.

### 6.3 Treatment

Treatment will depend on the location, extent of recurrent or residual disease, performance status, previous management and patient preferences.

Treatment may include surgery, transplantation, local ablative therapy, radiation therapy and/or drug therapy.

Treatment may also include involvement in a clinical trial.

Discussion of treatment may include advance care planning and referral to other health professionals.

### 6.4 Palliative care

Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits (Haines 2011; Temel et al. 2010). This is particularly true for poor-prognosis cancers (Temel et al. 2010).

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on need, not prognosis.

Patients should be encouraged to develop an advance care plan (AHMAC 2011).

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

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

### Further information

Refer patients and carers to Palliative Care Australia. See <[www.palliativecare.org.au](http://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](http://www.australiancancertrials.gov.au)>.

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

- support to address alcohol dependence (related to underlying liver disease)
- support to address drug dependence (related to hepatitis)
- nutrition screening and support
- physical symptoms including pain, weight loss 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/dying, 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 completing 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 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 and 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, their carer and family.

### 7.1 Multidisciplinary palliative care

If not already involved, referral to palliative care should be considered at this stage (ideally this will include nursing, pastoral care, palliative medicine specialist backup, inpatient palliative care 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 other spiritual advisor
- bereavement counsellor
- therapist (for example, music or art).
- The team might also recommend accessing:
  - home- and community-based care
  - specialist community palliative care workers
  - community nursing.

Consideration of an appropriate place of care and 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. See <[www.palliativecare.org.au](http://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](http://www.australiancancertrials.gov.au)>.

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

- 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.

### 7.3.2 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.

### 7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning and transitioning 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.

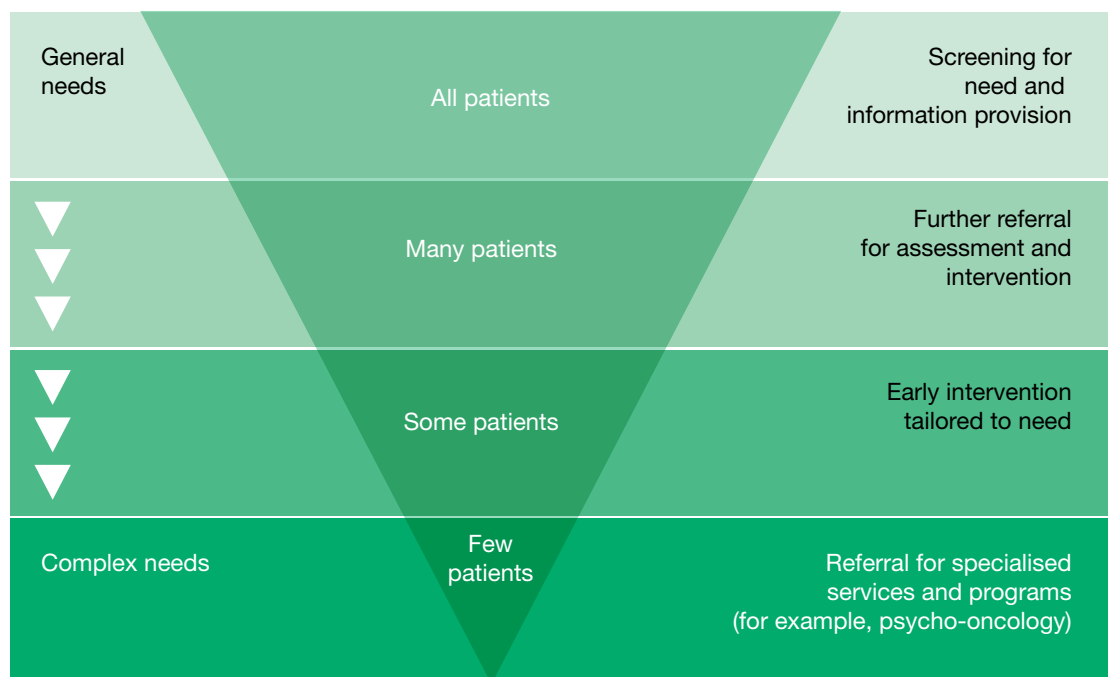
# Appendix: Supportive care

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 their 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, only a few will require specialised intervention. Common indicators in patients with HCC who may require referral to appropriate health professionals and/or organisations include the following:

### **Physical needs**

- Malnutrition can occur as a result of disease or treatment. Validated malnutrition screening tools should be used at the key points in the care pathway to identify patients at risk of malnutrition and refer to a dietitian for nutrition intervention.
- Referral to a pharmacist may be useful for people managing multiple medications.

### **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.
- Patients diagnosed with HCC are reported to have the third highest level of psychosocial distress, when compared across 14 cancer types (Steel et al. 2010). This large number indicates a need for screening patients to identify those at high risk of anxiety or depression.
- For transplant patients, anxiety about transplant outcome, the shortage of organs, the uncertainty of donation and increased understanding that having a transplant may not offer a cure is a large precipitant to psychosocial problems for individuals prior to transplant (Engle 2001).
- 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 psychological 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:
  - having difficulties with quitting smoking or other drug and alcohol use
  - displaying emotional cues such as tearfulness, distress, avoidance or 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 HCC 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 and function
  - struggling with the diagnosis of metastatic or advanced disease
  - 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**

- Many people experience changed relationships, difficulties returning to work or study, and financial impacts. Consider referral to an occupational therapist or social worker for assistance.

### **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 (aged over 70 years)**

Planning and delivering 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**

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 that is 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 modes that are appropriate to the young person
- addressing the needs of all involved, including the young person, 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 discussions of fertility preservation and the late effects of treatment and consider the patient's psychosocial needs
- provide treatment in an AYA-friendly environment.

### **Culturally and linguistically diverse (CALD) communities**

Liver cancer, mainly caused by chronic viral hepatitis, is the fastest increasing cause of cancer death in Australia. A large proportion of the adult population in relevant CALD communities in Australia have chronic HBV infection; however, around half are undiagnosed. The prevalence of chronic hepatitis B among some CALD communities in Australia, based on country of birth, is more than 12 times that of non-Indigenous people born in Australia. In 2011, 38 per cent of people living in Australia diagnosed with chronic hepatitis B were born overseas in the Asia-Pacific region. Australians born in Vietnam, Korea, Indonesia and China are six to 12 times more likely to be diagnosed with liver cancer than other Australians (FECCA 2011). Higher rates of chronic HBV infection are also observed in Australians born in Africa.

Focusing on relevant CALD communities is important for identifying and treating people with an existing infection who are at a significant risk of developing liver cancer if it is not managed. Increased testing would likely uncover people from migrant communities who require treatment.

For people from CALD backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In some 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). Survival also significantly decreases as remoteness increases, unlike the survival 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 2013). 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 2010 it was estimated up to 22,000 (three to four per cent) of Aboriginal and Torres Strait Islander people were living with hepatitis B. The population rate in outer regional Indigenous communities can be up to five times the rate of non-Indigenous Australians. Indigenous Australians are three times as likely to develop, and more than three times as likely to die from, liver cancer and have a lower chance of surviving a further year (21 per cent compared with 33 per cent) than non-Indigenous Australians (AIHW 2013).

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 2013):

- Introduce culturally sensitive HBV treatment programs.
- 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 understanding of care gaps through data monitoring and targeted priority research.

# Resource list

## 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](http://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](http://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](http://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](http://www.cancervic.org.au)>

### Care Search: Palliative Care Knowledge Network

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

- Telephone: (08) 7221 8233
- <[www.caresearch.com.au](http://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](http://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](http://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](http://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](http://www.eviq.org.au)>

### National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment

- <[www.nhmrc.gov.au](http://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 that 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 that is 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 2007c).

**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.

**Prehabilitation** – one or more interventions undertaken with 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 (such as specialist physician, surgeon, oncologist or palliative care specialist). This person will also make referrals for treatment and will be responsible for overseeing 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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# Acknowledgements

Our thanks to the following healthcare professionals, consumer representatives, stakeholders and organisations consulted in the development of this optimal cancer care pathway.

## Expert working group

Dr Ian Kronborg, Head of Gastroenterology, Western Health (Chair)  
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Ballarat Health Services  
Cancer Australia  
Cancer Council Victoria Strategy and Support  
Consumer representatives  
Department of Health, Victoria, Cancer Strategy and Development  
Grampians Integrated Cancer Service  
Monash University  
North Eastern Melbourne Integrated Cancer Service  
Peter MacCallum Cancer Centre  
Royal Hobart Hospital  
Western Health

## Medical colleges and peak organisations invited to provide feedback

Allied Health Professions Australia  
Australian Association of Nuclear Medicine Specialists  
Australian and New Zealand Gastric Oesophageal Surgery Association  
Australian and New Zealand Society of Palliative Care  
Australian Chapter of Palliative Medicine, Royal Australasian College of Physicians  
Australian College of Nursing  
Australian Institute of Radiography  
Australian Medical Association  
Gastroenterological Society of Australia  
Interventional Radiology Society of Australasia  
Medical Oncology Group of Australia  
Royal Australasian College of Physicians  
Royal Australasian College of Surgeons (RACS)  
Royal Australian and New Zealand College of Psychiatrists  
Royal Australian and New Zealand College of Radiologists  
Royal Australian College of General Practitioners

**Other stakeholders consulted to provide feedback including Cancer Action Victoria, a number of health services, and integrated cancer services.**

