

Optimal care pathway for people with colorectal cancer



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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.

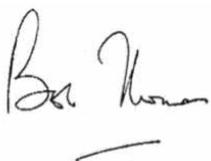
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established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

- eating a healthy diet, including plenty of vegetables, fruit and whole grains while minimising intake of red meat and processed meat
- maintaining a healthy body weight
- exercising regularly
- avoiding or limiting alcohol intake
- not smoking.

Early detection:

- Average risk
- No personal history of colorectal cancer, adenoma or chronic inflammatory bowel disease, or
- No more than one close relative diagnosed at age 55 or older.

Screening recommendations:

- If over 50 years, screen every two years using a faecal occult blood test (FOBT)
- Participation in the National Bowel Cancer Screening Program recommended if eligible.

Increased or high risk – refer to the colorectal optimal care pathway for screening recommendations.

Step 2

Presentation, initial investigations and referral

The following signs and symptoms should be investigated:

- positive FOBT
- passage of blood with or without mucus in the faeces
- unexplained iron deficiency anaemia
- change in bowel habit (loose stools or constipation)
- undiagnosed abdominal pain
- unexplained rectal or abdominal mass
- unexplained weight loss
- the presence of multiple signs and symptoms.

Positive screening test: All patients with a positive FOBT should be referred for a colonoscopy within four weeks.

Initial investigations include:

- physical examination
- digital rectal examination
- blood tests including iron studies.

Test results should be provided to the patient within one week.

Referral: If symptoms suggest cancer, the patient should be referred for a colonoscopy within four weeks.

Communication – lead clinician to:¹

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

Step 3

Diagnosis, staging and treatment planning

Diagnosis and staging:

- For colon cancer
 - Computed tomography (CT) scan of the chest, abdomen and pelvis
 - Whole-body fluoro-deoxyglucose positron emission tomography (FDG PET) (if suspected limited metastatic disease)
- For rectal cancer:
 - CT scan of chest, abdomen and pelvis
 - Local staging with magnetic resonance imaging (MRI) and/or endoscopic rectal ultrasound

Treatment planning: All newly diagnosed patients should be discussed by a multidisciplinary team. Patients with rectal cancer should be discussed prior to surgery.

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.

Surgery:

- Surgery is frequently recommended for patients with colorectal cancer.
- Surgeons should have adequate qualifications and expertise, especially those undertaking rectal surgery.

Radiation therapy may benefit people with:

- high-risk rectal cancer for whom adjuvant preoperative (or less commonly post-operative) radiation therapy is recommended
- symptomatic non-resectable locally advanced cancer who may benefit from radiation with palliative intent.

Chemotherapy or drug therapy may benefit people with:

- a high risk of relapse
- locally advanced rectal cancer, treated with neoadjuvant chemo-radiation
- non-resectable locally advanced or metastatic disease.

Palliative care: Early referral to palliative care 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 <http://www.nhmrc.gov.au/guidelines/publications/cp106>

Step 5

Care after initial treatment and recovery

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

Treatment summary (provided 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.

Follow-up care plan (provide a copy to 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: Most residual or recurrent disease will be detected via routine follow-up or by the patient presenting 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 patient preferences.

Palliative care: Early referral to palliative care 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
- 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 Colorectal Cancer Working Group.

Step in pathway	Care point	Timeframe
Presentation, Initial Investigations and Referral	2.2 Initial investigations by GP	Test results should be provided to the patient within one week of testing. If symptoms are suggestive of colorectal cancer, patients should be referred for colonoscopy within 4 weeks.
	2.3 Specialist appointment	Patients should be seen by a surgeon within 2 weeks of GP referral.
Diagnosis, Staging and Treatment Planning	3.1 Diagnostic workup	Investigations should be completed within 2 weeks. 10-15% of colorectal cancers will present as an emergency. This necessitates appropriate acute care followed by management from a multidisciplinary team.
Treatment	4.2 Treatment	Neoadjuvant radiation therapy should commence within 3 weeks of the management plan.
	4.2 Treatment	Neoadjuvant chemotherapy should commence within 3 weeks of the management plan. Adjuvant chemotherapy should commence within 8 weeks of surgery.

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 (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.

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 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
- 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, and a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

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

- malnutrition (as identified using a validated malnutrition screening tool or presenting with weight loss)
- 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 clinical psychologist or psychiatrist
- a genetic counsellor
- community-based support services (such as Cancer Council Australia)
- 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 colorectal 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 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.

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 provider's 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). The provision of 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

This step outlines recommendations for the prevention and early detection of colorectal cancer.

1.1 Prevention

Modifiable dietary and lifestyle factors have been estimated to account for 70 per cent of the attributable risk for colorectal cancer in Western populations (Giovannucci 2002).

Recommendations for preventing colorectal cancer include:

- eating a healthy diet, including plenty of vegetables, fruit and whole grains while minimising intake of red meat and processed meat
- maintaining a healthy body weight
- exercising regularly
- avoiding or limiting alcohol intake
- not smoking.

There is evidence that low doses of aspirin can prevent new adenomas (bowel polyps) developing in people with a history of prior adenomas (ACN 2005) and daily aspirin for at least five years reduces colorectal cancer incidence and mortality (Rothwell et al. 2011).

1.2 Early detection and risk factors

Based on family history, people can be placed into one of the three categories of relative risk of developing colorectal cancer. Age is an independent risk factor for colorectal cancer, with the incidence increasing significantly after the age of 50 years. These categories were developed by the National Health and Medical Research Council (NHMRC).

General practitioners and primary care nurses should educate patients and encourage them to participate in the screening appropriate to the individual's level of risk.

1.2.1 Those at slightly above average risk

People fit into this category if there is:

- no personal history of colorectal cancer, colorectal adenomas or chronic inflammatory bowel disease and no confirmed close family history of colorectal cancer
- one first-degree relative (parent, sibling, child) or second-degree relative (aunt, uncle, niece, nephew, grandparent, grandchild) with colorectal cancer diagnosed at age 55 or older, or
- two relatives diagnosed with bowel cancer at age 55 or older but on different sides of the family.

Screening guidelines

- Screening using an FOBT is recommended every two years for all people over the age of 50.
- Timely and full examination of the large bowel by colonoscopy is recommended for people who have a positive FOBT.
- If eligible, participation in the National Bowel Cancer Screening Program is recommended.

Further information

- Visit the National Bowel Screening Program website at <www.cancerscreening.gov.au/bowel>.

1.2.2 Those at moderately increased risk

People fit into this category if there is:

- one first-degree relative with colorectal cancer diagnosed before the age of 55 (without potentially high-risk features as in 1.2.3), or
- two first- or one first- and second-degree relative(s) on the same side of the family diagnosed with colorectal cancer at any age (without potentially high-risk features as in 1.2.3).

Screening guidelines

- Offer colonoscopy every five years starting at 50 years. Alternatively, offer it at an age 10 years younger than the age of first diagnosis of colorectal cancer in the family, whichever comes first.
- Consider offering an FOBT in the intervening years. People should be informed that a positive test will require further investigation (NHMRC 2005).

1.2.3 Those at potentially high risk

People fit into this category if there is:

- three or more first-degree relatives or a combination of first- and second-degree relatives on the same side of the family with colorectal cancer
- two or more first- or second-degree relatives on the same side of the family diagnosed with colorectal cancer plus any of the following high-risk features
 - multiple colorectal cancers in a family member
 - colorectal cancer before the age of 50 years
 - a hereditary non-polyposis colorectal cancer (HNPCC)-related cancer
- at least one first-degree or second-degree relative with a large number of adenomas throughout the large bowel (suspected familial adenomatous polyposis (FAP)), or
- being a member of a family in which a gene mutation that confers a high risk of bowel cancer has been identified.

Screening guidelines

- Consider referral to a familial cancer service for further risk assessment and possible genetic testing.
- Refer to a bowel cancer specialist to plan appropriate surveillance and management.

1.2.4 Communication with the patient, carer and family

- The lead clinician should advise first-degree relatives of people with colorectal cancer who fall into the NHMRC moderate risk group (where a relative is diagnosed under 55 years of age or where there are multiple first-degree relatives with colorectal cancer) to see their general practitioner with a view to referral for colonoscopy if appropriate.
- All other relatives should be advised to follow the average risk guidelines, including participation in the National Bowel Cancer Screening Program.

Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral. The types of investigations 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

The following signs and symptoms should be investigated:

- positive FOBT
- passage of blood with or without mucus in faeces
- unexplained iron deficiency anaemia
- change in bowel habit, especially a recent one (loose stools or constipation)
- undiagnosed abdominal pain
- unexplained rectal or abdominal mass
- unexplained weight loss (ACN 2005).

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

2.2 Assessments by the general or primary medical practitioner

Investigations prior to referral should include:

- physical examination
- digital rectal examination
- full blood examination including iron studies (ACN 2005).

Note: a negative result from an FOBT does not exclude cancer.

A detailed family history should be obtained from patients presenting with colorectal cancer symptoms.

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 Colorectal Cancer Working Group¹ is to provide test results to the patient within one week.

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

2.3 Referral

All patients referred for colonoscopy should be seen by a clinician or surgeon accredited in colonoscopy by the Conjoint Committee of the Royal Australasian College of Surgeons, Royal Australasian College of Physicians or Gastroenterological Society of Australia.

Referral for suspected colorectal 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.

If a pathological (or endoscopic) diagnosis has been made, the patient should be referred to a general or colorectal surgeon affiliated with (or with access to) a multidisciplinary team (and multidisciplinary team meeting). Some early cancers can be managed by endoscopy alone without surgical consultation but should also be considered by a multidisciplinary team.

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 expert advice from the Colorectal Cancer Working Group:

- Patients should be referred for colonoscopy within four weeks if symptoms are suggestive of colorectal cancer.
- The patient should be seen by the surgeon within two weeks of referral. The patient should bring a copy of the colonoscopy report and other relevant medical and psychosocial history.

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 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
- pre-surgical education with a stomal therapist wherever a diversion of permanent stoma is possible
- pre-surgical referral to a psycho-oncologist for support over body image expectations associated with surgical treatment
- 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 expected timeframes for specialist 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 multidisciplinary team members should determine the treatment plan.

3.1 Diagnostic workup

People thought to have resectable or potentially curable disease should have routine blood tests (full blood count (FBC), urea and electrolytes (U&E), liver function tests (LFT), carcinoembryonic antigen (CEA)), a complete colonic assessment by colonoscopy, plus:

For colon cancer:

- Computed tomography (CT) scan of the chest, abdomen and pelvis
- Whole-body fluoro-deoxyglucose positron emission tomography (FDG PET) (if limited metastatic disease is suspected). PET should only be performed by credentialled health professionals

For rectal cancer:

- CT scan of chest, abdomen and pelvis
- Local staging with magnetic resonance imaging (MRI) and/or endoscopic rectal ultrasound. MRI should be performed by a radiologist (FRANZCR or equivalent) with adequate training and experience and with MRI-specific accreditation
- Accurate assessment of tumour location by the treating surgeon

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 Colorectal Cancer Working Group is for investigations to be completed within two weeks.

Between 10 and 15 per cent of colorectal cancers will present as an emergency. This necessitates appropriate acute care followed by management from a multidisciplinary team.

3.2 Staging

Staging is an essential element in treatment planning and should be clearly documented in the patient's medical record.

Preoperative staging including the above investigations is used to define the extent of tumour spread.

Clinical pathological staging will occur after surgery and is needed to inform post-treatment care. Synoptic reporting is encouraged.

Screening for loss of expression of mismatch repair protein in patients younger than 50 years of age who have had a tumour resection is recommended.

3.3 Treatment planning

3.3.1 Responsibilities of the multidisciplinary team

The responsibilities of the multidisciplinary team 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.

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 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 colorectal cancer

The multidisciplinary team 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 2007c).

Team members may include a:

- care coordinator (as determined by multidisciplinary team members)*
- gastroenterologist with colorectal expertise*
- general and/or colorectal surgeon*
- medical oncologist*
- nurse (with appropriate expertise)*
- pathologist*
- radiation oncologist*
- radiologist with expertise in MRI*
- clinical psychologist
- clinical trials coordinator
- dietitian
- general practitioner
- geneticist
- hepato-pancreatobiliary surgeon
- nuclear medicine physician with FDG-PET expertise
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- psychiatrist
- social worker
- stomal therapist.

* 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. The level of discussion may vary depending on both the clinical and psychosocial factors.

Multidisciplinary discussion for patients with rectal cancer should take place before surgery because multimodality neoadjuvant therapy is often considered optimal care.

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>.

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. 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).

Using an enhanced recovery after surgery (ERAS) protocol is likely to improve outcomes. For more information visit <www.erassociety.org>.

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:

- treatment for physical symptoms such as pain, fatigue, weight loss and altered bowel function
- 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
- pre-surgical education with a stomal therapist wherever a diversion of permanent stoma is possible
- pre-surgical referral to a psycho-oncologist for support over body image expectations associated with surgical treatment
- 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 colorectal 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 to communicate with people from culturally or linguistically diverse backgrounds.
- 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 should 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 colorectal cancer. For detailed information on treatment options refer to the NHMRC's clinical practice guidelines (2005) at <www.nhmrc.gov.au/guidelines/publications/subject/Cancer>.

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 as there can be 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 Surgery

Surgery is recommended for many patients diagnosed with colorectal cancer.

Training, experience and treatment centre characteristics

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

- surgeon (FRACS or equivalent) with adequate training and experience and institutional cross-credentialing and agreed scope of practice within this area (ACSQHC 2004)
- specifically for rectal surgery, surgeons must be sub-specialists with an appropriate level of training and experience and treat an appropriate caseload annually.

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
- pathology
- a diagnostic imaging facility
- stomal therapy support.

4.2.2 Radiation therapy

Patients who may benefit from radiation therapy include:

- people with high-risk rectal cancer for whom neoadjuvant (or less commonly post-operative adjuvant) radiation therapy is recommended
- those with symptomatic, non-resectable locally advanced cancer who may benefit from radiation therapy with or without concurrent chemotherapy given with palliative intent.

For people with colon cancer, radiation therapy has a limited role in radical treatment and is confined to patients with tumour penetration to a fixed structure but it does play a role in palliative care (Department of Health, Western Australia 2008).

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 Colorectal Cancer Working Group is for neoadjuvant treatment to commence within three weeks of the management plan.

Training, experience and treatment centre characteristics

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

- radiation oncologist (FRANZCR) with adequate training and experience with institutional credentialing and agreed scope of practice in colorectal cancer (ACSQHC 2004).

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

- access to PET and electronic transfer of PET data for planning
- access to allied health, especially nutrition health and advice
- access to CT scanning for simulation and planning
- trained radiation therapy nurses, physicists and therapists.

4.2.3 Chemotherapy or drug therapy

Patients who may benefit from chemotherapy or drug therapy include:

- those at high risk of relapse and who may benefit from adjuvant therapy
- those with locally advanced (high-risk) rectal cancer, treated with neoadjuvant chemo-radiation
- those with non-resectable locally advanced or metastatic disease.

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 Colorectal Cancer Working Group is that:

- neoadjuvant chemotherapy should commence within three weeks of the management plan
- adjuvant chemotherapy should commence within eight weeks of surgery.

Training, experience and treatment centre characteristics

The following training and experience is required of the appropriate specialist(s):

- Medical oncologists (RACP 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 prepared by a pharmacist with adequate training in chemotherapy medication, including 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 are available to deliver treatment safely (including dealing with extravasation of drugs)
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not co-located
- appropriate molecular pathology access (such as Kras molecular testing).

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. 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 <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>.

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>.

4.6 Support and communication

4.6.1 Supportive care

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

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

- physical symptoms such as pain, weight loss, fatigue and altered bowel function
- gastrointestinal symptoms (such as nausea, vomiting, mucositis and 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, 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 – a written plan should be provided
- 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, Greenfield & Stovall 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).

5.2 Post-treatment care planning

5.2.1 Treatment summary

After initial treatment, the patient, carer (as appropriate) 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

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 (oncology, stomal), 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>.

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:

- malnutrition post-treatment due to ongoing treatment side effects (such as weight loss or reduced oral intake) – this requires monitoring and nutrition intervention where indicated
- altered bowel function and incontinence
- stoma management
- 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

Evidence suggests that referral to palliative care is associated with better outcomes in terms of quality of life, survival and aggressiveness of care at the end of life (Haines 2011; 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).

Further information

Refer patients and carers to Palliative Care Australia <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.

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), with referral on to a specialist centre for recurrent disease as appropriate.

6.3 Treatment

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

In managing people with colorectal cancer, treatment programs have recently become more complex, with more effective chemotherapy and major surgical programs being offered to patients with potentially curable recurrent cancer; however, therapy may be focused on disease control or palliation, based on the extent of disease and the patient's general health, preferences and values. Treatment may include surgery, radiation therapy and/or drug therapy.

Treatment may also include involvement in a clinical trial and/or invitation to participate in research.

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

6.4 Palliative care

Evidence suggests that referral to palliative care is associated with better outcomes in terms of quality of life, survival and aggressiveness of care at the end of life (Haines 2011; 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 about 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>.

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>.

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:

- altered bowel function and incontinence
- stoma management
- 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 (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.

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 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 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 palliative care team may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or 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 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 <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>.

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:

- altered bowel function and incontinence
- stoma management
- 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.

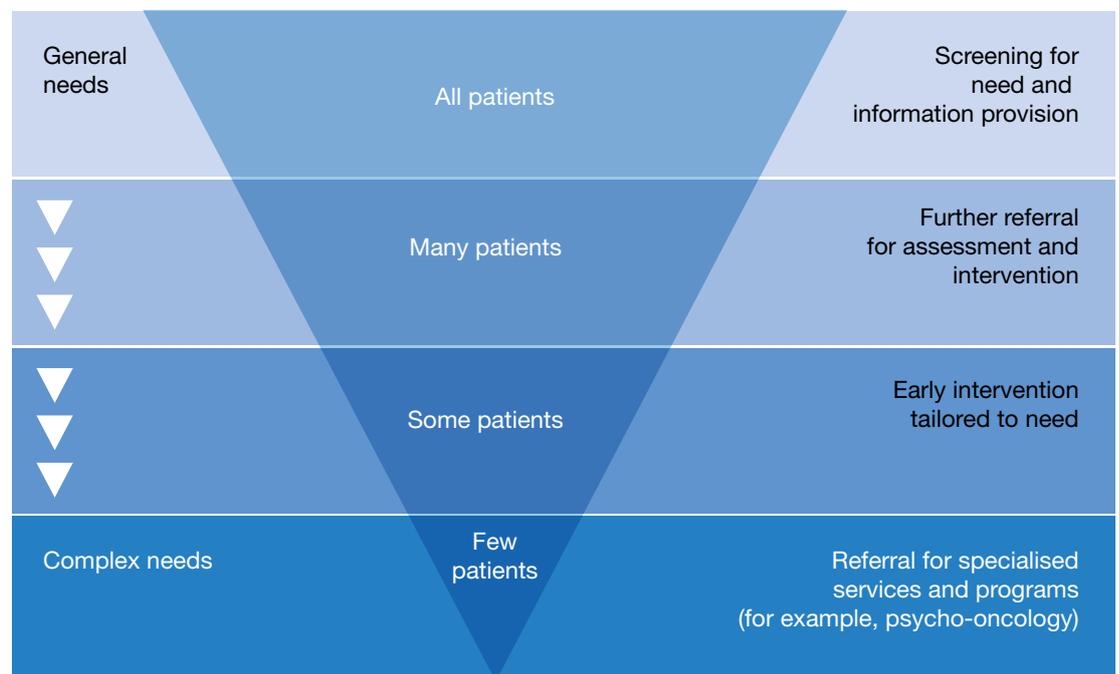
Appendix: Supportive care

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 colorectal cancer who may require referral to appropriate health professionals and/or organisations include the following:

Physical needs

- Weight loss, change in taste and decrease in appetite can be a significant issue for patients and may require referral to a dietitian before, during and after treatment.
- 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.
- Increased bowel movements and/or diarrhoea or constipation are important issues. Patients may be helped by talking about the management of these symptoms with specialist nurses, such as a stomal therapist or continence nurse (NBCC & NCCI 2003).
- Treatment for rectal cancer may result in urinary incontinence in some patients. Referral to continence nurses should be considered.
- Odours and flatus may arise from stomas, faecal or urinary fistulae. Referral to continence nurses or stomal therapist nurses may be useful.
- Reduced sexual interest and sexual dysfunction – particularly in stoma patients compared with patients with intact sphincters (Yan & Sellick 2004) – may require referral to medical specialists. Sensitive discussion and referral to a clinician skilled in this area may be appropriate.
- Erectile dysfunction and ejaculation dysfunction require sensitive discussion; referral to a clinician skilled in this area may be appropriate (NBCC & NCCI 2003).
- 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 psycho-social complexities. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Between 25 and 50 per cent of patients report psychosocial distress, depression or anxiety following a diagnosis of colorectal cancer and patients with stomas are at higher risk (ACN 2005). This large number indicates a need for screening patients to identify those at high risk of anxiety or depression at each visit.
- Consider strategies such as information provision, relaxation techniques, meditation and referral to a psychologist, psychiatrist or social worker (Kearney & Richardson 2006).
- 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 a psychology service.
- Post-traumatic distress disorder among women with colorectal disease is associated with perceived intensity of cancer treatment and problems with clinicians. Consider assessment for post-traumatic stress, particularly in women, and referral to a psychologist or psychiatrist for specific treatment (NBCC & NCCI 2003).
- 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 colorectal 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 and function
 - struggling with the diagnosis of metastatic or advanced disease
 - having difficulties with quitting smoking or other drug and alcohol use
 - having difficulties transitioning to palliative care.

Body image

- Low self-esteem and disturbed body image are reported and are more prevalent in stoma patients than in non-stoma patients. Provide patients with tailored and accurate information before treatment, and facilitate patient decision making about appearance-altering treatment and meeting others with a similar personal experience (Kearney & Richardson 2006).
- Support and counselling from a psychologist, psychiatrist, occupational therapist or social worker may be required.

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.
- There may be significant social restrictions due to altered bowel habits. Consider referral to a social worker or occupational therapist.

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.

Adolescents 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, 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 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 discussions about 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

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 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):

- 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 focussed on the post-treatment survivorship phase

- Telephone: +61 3 9656 5207
- <www.petermac.org/cancersurvivorship>

Beyond Blue

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

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

Bowel Cancer Australia

Information about bowel cancer prevention, diagnosis and treatment

- <www.bowelcanceraustralia.org/bca>

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

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

- Telephone: 13 11 20
(Monday to Friday, 8.30am – 5.30pm)
- <www.cancerciv.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>

National Bowel Cancer Screening Program

Information about the national screening program

- <www.cancerscreening.gov.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 a 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, 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 care pathway.

Expert working group

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Ballarat Health Services

Cancer Australia

Cancer Council Victoria Strategy and Support

Consumer representatives

Department of Health 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

Allied Health Professions Australia

Australian Association of Nuclear Medicine Specialists

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

Medical Oncology Group of Australia

Royal Australasian College of Physicians

Royal Australasian College of Surgeons

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.

