Optimal care pathway for women with endometrial cancer

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Contents

Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple healthcare providers and covers a range of institutions, both public and private. The optimal are 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.

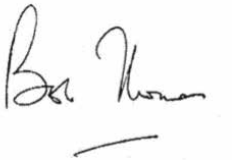
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established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



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Summary

Please note that not all women 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

Risk factors for endometrial cancer:

- obesity (including hypertension and diabetes)
- polycystic ovarian syndrome
- Lynch syndrome (40–60 per cent lifetime risk of endometrial cancer)
- a family history of endometrial cancer in a first-degree relative
- unopposed postmenopausal oestrogen therapy
- endometrial hyperplasia
- nulliparity
- anovulation
- early menarche and late menopause
- tamoxifen use.

Prevention: Maintaining a healthy weight and taking birth control pills (especially over a long period) can lower risk.

All women with an intact uterus using hormone replacement therapy should have progesterone therapy as part of their regimen to reduce the risk of developing endometrial cancer.

Preventative surgery: For women with a hereditable risk factor, surgery to remove the uterus (hysterectomy) or treatment with hormones (progesterone) may prevent endometrial hyperplasia from developing into endometrial cancer.

All women considering risk-reducing surgery should have a thorough family history taken, and consider referral to a familial cancer clinic to try to define the actual risk, not only for the woman herself, but also for other family members.

Step 2

Presentation, initial investigations and referral

Signs and symptoms include:

- vaginal bleeding after menopause
- bleeding between periods
- abnormal, watery or blood-tinged vaginal discharge
- pelvic pain or pain during intercourse
- unexplained weight loss.

General/primary practitioner investigations:

- a general and pelvic examination (including a speculum and Pap smear)
- referral for a transvaginal pelvic ultrasound by an experienced gynaecological ultrasonographer.

Results should be available and the woman reviewed by the general practitioner within four weeks.

Referral: If the diagnosis is suspected, then referral to a specialist gynaecologist for further investigation is required. If the diagnosis is confirmed with initial tests, then referral to or consultation with a gynaecological oncologist or service is required.

Communication – lead clinician to:[1]

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

Step 3

Diagnosis, staging and treatment planning

Diagnosis: The following sequence of preoperative investigations should be considered:

- transvaginal pelvic ultrasound (if not already done)
- routine blood tests
- other imaging as indicated by clinical assessment.

Investigations should be completed within two weeks of specialist review.

Staging: Staging is generally pathological following surgery.

Treatment planning: All newly diagnosed women should be discussed in a gynaeoncology multidisciplinary team meeting before definitive treatment.

Special considerations that need to be addressed at this stage may include issues around obesity, diabetes, early menopause and hormonal changes.

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

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the woman/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.

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

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 options

Surgery: For early-stage endometrial cancer hysterectomy and bilateral salpingo-oophorectomy with or without lymph node dissection. Lymphadenectomy may be considered in select patients.

Radiation therapy: For women with higher risk factors, adjuvant radiation may be offered. In selected cases radiation therapy may also be considered as part of primary treatment or for symptomatic relief and palliation of metastatic disease.

Chemotherapy and other systemic therapy: Chemotherapy may be considered after further discussion at a multidisciplinary team meeting:

- following surgery in women at high risk , usually in conjunction with radiation therapy
- as primary treatment for metastatic disease where the patient is not suitable for surgery
- where there is residual disease at the completion of surgery or the disease has spread.

Hormonal therapy: May be appropriate for young women who wish to retain fertility or for symptom management.

Refer to the endometrial optimal care pathway for recommendations for screening for Lynch syndrome

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 woman/carer including the intent of treatment and expected outcomes
- discuss advance care planning with the woman/carer where appropriate
- discuss the treatment plan with the woman's general practitioner.

For detailed information see <http://wiki.cancer.org.au/australia/Guidelines:Endometrial_cancer/Treatment/Early_stage>.

Step 5

Care after initial treatment and recovery

For premenopausal women, ongoing assessment of the effects of surgical menopause is required after surgery.

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

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

- medical follow-up required (tests, surveillance)
- care plans for managing late effects
- 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 woman/carer
- inform the woman/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 of recurrent disease: Some cases of recurrent disease will be detected by routine follow-up in a woman who is asymptomatic.

Treatment: Where possible, refer the woman to the original multidisciplinary team. Treatment will depend on the location, the extent of recurrence, previous management and patient 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 woman/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 woman/carer
- establish transition plans to ensure the woman's needs and goals are addressed in the appropriate environment.

Summary – optimal timeframes

Optimal timeframes: Timeframes 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 Endometrial Cancer Working Group.

Step in pathway	Care point	Timeframe
Presentation, Initial Investigations and Referral	2.1 GP investigations	Results should be available and the woman reviewed by her general practitioner within four weeks.
	2.3 Specialist appointment	If any investigations cannot be provided in the local setting then referral to enable appropriate investigation and diagnosis should occur within four weeks.
Diagnosis, Staging and Treatment Planning	3.1 Diagnosis 3.2 Staging	Diagnostic/investigations should be completed within two weeks of specialist review.
	3.3 Multidisciplinary meeting	All newly diagnosed women should be discussed in a multidisciplinary team meeting so that a treatment plan can be recommended.
Treatment	4.2 Treatment – surgery	Treatment within four weeks of diagnosis.
	4.2 Treatment – radiation therapy	Primary treatment in two to four weeks of a decision to treat with radiation therapy. Adjuvant treatment in four to eight weeks of a decision to treat with radiation therapy (if appropriate).
	4.2 Treatment – chemotherapy	Primary treatment in two to four weeks of a decision to treat with chemotherapy. Adjuvant treatment in four to eight weeks of a decision to treat with chemotherapy.

Intent of the optimal cancer care pathway

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased care for women 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-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 credentialled 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 a woman's 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 woman. 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 access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007b).

Supportive care

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

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

All members of the multidisciplinary team 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 woman 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 woman and carer and a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

Common indicators in women with endometrial cancer that may require referral for support include:

- malnutrition including obesity (as identified using a validated malnutrition screening tool or presenting with weight loss)
- pain
- difficulty managing fatigue
- difficulty sleeping
- psychosexual issues
- 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 woman, 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
- a dietitian
- an exercise physiologist
- nurse practitioner and/or specialist nurse
- an occupational therapist
- a physiotherapist
- peer support groups
- a social worker
- specialist palliative care
- a speech therapist.

See the **appendix** for more information on supportive care and the specific needs of women with endometrial 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 woman 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 wholeof-system response – that is, that initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007c).

Communication

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

- individualised
- truthful and transparent, though handled with sensitivity
- 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 woman, their carer and family
- use professionally trained interpreters when communicating with patients from culturally and linguistically diverse backgrounds
- ensure the woman and/or their carer and family have the opportunity to ask questions
- ensure the woman 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 woman
- respond to questions in a way the woman understands
- enable all communication to be two-way.

Healthcare providers should also consider offering the woman 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 care and palliative care interventions (Sjoquist & Zalcberg 2013).

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

There are around 2,000 cases of endometrial cancer diagnosed in Australia each year, with more than 60 per cent of cases diagnosed in postmenopausal females over 60 years of age (AIHW & Cancer Australia 2012).

The pathway describes the optimal cancer care that should be provided at each step for people with endometrial cancer.

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 endometrial cancer.

1.1 Screening

There is no standard or routine population screening for endometrial cancer.

1.2 Risk factors

Risk factors for endometrial cancer include:

- obesity (including hypertension and diabetes)
- polycystic ovarian syndrome
- Lynch syndrome (40–60 per cent lifetime risk of endometrial cancer)
- a family history of endometrial cancer in a first-degree relative
- unopposed postmenopausal oestrogen therapy
- endometrial hyperplasia
- nulliparity
- anovulation
- early menarche and late menopause
- tamoxifen use (ESMO 2013, NCI 2015).

1.3 Prevention

Maintaining a healthy weight (weight loss if overweight, avoiding obesity) and taking birth control pills (especially over a long period) can lower the risk of endometrial cancer.

All women with an intact uterus using hormone replacement therapy (HRT) should have progesterone therapy as part of their regimen to reduce the risk of developing endometrial cancer.

1.3.1 Preventative surgery

Linkage studies show a hereditable risk factor in some cases of endometrial cancer and identification of mismatch repair (MMR) gene abnormalities in Lynch syndrome. Surgery to remove the uterus (hysterectomy) or treatment with hormones (progesterone) may prevent endometrial hyperplasia from developing into endometrial cancer (Cancer Australia 2014; Schmeler et al. 2006).

All women considering risk-reducing surgery should have a thorough family history taken, which includes male relatives, and consider referral to a familial cancer clinic (FCC) to try to define the actual risk, not only for the woman herself, but also for other family members.

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 women's preferences.

2.1 Signs and symptoms

Symptoms of endometrial cancer may include:

- vaginal bleeding after menopause
- bleeding between periods
- abnormal, watery or blood-tinged vaginal discharge
- pelvic pain
- pain during intercourse
- unexplained weight loss.

See the NICE guidelines on suspected cancer recognition and referral (NICE 2015) at <https://www.nice.org.uk/guidance/ng12>.

Timeframe for general practitioner consultation

- Any bleeding or abnormal vaginal discharge after menopause (more than 12 months since the last period) should be investigated without delay.
- Any new, persistent or progressive symptoms in women over the age of 40 should raise suspicion and should be investigated.
- Symptoms that do not respond to treatment initiated by the woman's general practitioner (the pill or progesterone) should be re-evaluated within three months.

2.2 Assessments by the general or primary medical practitioner

General practitioner examinations/investigations should include:

- a general and pelvic examination (including a speculum and Pap smear)
- referral for a transvaginal pelvic ultrasound by an experienced gynaecological ultrasonographer.

To aid in determining menopausal status and key considerations for pre-, peri- and post-menopausal women, refer to the *Toolkit for managing the menopause* available under the 'menopause' section at: <http://www.ranzcog.edu.au/college-statements-guidelines.html>.

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 women's distress.

The following recommended timeframes are based on expert advice from the Endometrial Cancer Working Group[1]: Results should be available and the woman reviewed by her general practitioner within four weeks.

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

2.3 Initial referral

If the diagnosis is suspected, then referral to a specialist gynaecologist for further investigation is required.

If the diagnosis is confirmed with initial tests, then referral to or consultation with a gynaecological oncologist or service is required.

Referral should include relevant past history, current history, family history, examination, investigations, social issues and current medications.

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 women's distress.

The following recommended timeframes are based on expert advice from the Endometrial Cancer Working Group: If any of the above cannot be provided in the local setting then referral to enable appropriate investigation and diagnosis should occur within four weeks.

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

2.4 Support and communication

2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified needs of a woman and her family/carer(s). 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 and fatigue
- help with the emotional distress of dealing with a potential cancer diagnosis, anxiety and depression (particularly about potential loss of fertility), interpersonal problems, stress and adjustment difficulties
- guidance about financial and employment issues (such as loss of income, travel and accommodation requirements for rural women 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 woman and her carer(s) 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 medical practitioner who made the referral is responsible for the woman 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 woman and her family.

The general or primary practitioner should:

- provide the woman with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
- support the woman 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 Specialist diagnostic workup

After a thorough medical history and examination, the following sequence of preoperative investigations should be considered:

- transvaginal pelvic ultrasound if not already done
- routine blood tests
- other imaging as indicated by clinical assessment.

Abdomino-pelvic–chest computed tomography (CT) scan may be considered where there are symptoms, clinical signs or other investigations suggestive of metastatic disease.

Magnetic resonance imaging (MRI) may be considered in some circumstances (for example, where surgery is contraindicated because of wishes to retain fertility or advanced pelvic malignancy where primary site is unknown).

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 women's distress.

The following recommended timeframes are based on expert advice from the Endometrial Cancer Working Group: Diagnostic investigations should be completed within two weeks of specialist review.

3.2 Staging

Staging is the cornerstone of treatment planning and prognosis. Staging for endometrial cancer is generally pathological following surgery and is staged according to the International Federation of Gynaecology and Obstetrics (FIGO) system (Pecorelli 2009), which involves hysterectomy with bilateral salpingo-oophorectomy (BSO). Pelvic plus or minus aortic lymph node dissection may be appropriate in selected cases based on careful perioperative assessment by a multidisciplinary team.

The benefits, limitations and morbidity of lymphadenectomy in the absence of compelling evidence of a survival advantage related to full surgical staging, particularly for patients at low risk of nodal metastases, should be considered (Cancer Council Australia 2014).

Synoptic reporting by a pathologist should be undertaken.

3.3 Treatment planning

3.3.1 The optimal timing for multidisciplinary team planning

All newly diagnosed women should be discussed in a gynaeoncology multidisciplinary team meeting before definitive treatment so that a treatment plan can be recommended. The level of discussion may vary depending on both the clinical and psychosocial factors.

Results of all relevant tests and imaging should be available for the multidisciplinary team discussion. Information about the woman's concerns, preferences and social circumstances should also be available.

3.3.2 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 team meeting
- circulate the agreed treatment plan to relevant team members, including the woman's general practitioner.

3.3.3 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 woman and her 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 a clinician responsible for overseeing the activity of the team and for implementing treatment within the multidisciplinary setting.

3.3.4 Members of the multidisciplinary team

The multidisciplinary team for endometrial cancer should comprise the core disciplines integral to providing good care. Team membership should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some women (Department of Health 2007b).

Team members may include a(n):

- care coordinator (as determined by multidisciplinary team members)*
- gynaecological oncologist*
- radiation oncologist*
- oncology/gynaecology nurse*
- medical oncologist*
- pathologist with expertise in gynaecological oncology*
- radiologist*
- clinical trials coordinator
- dietitian
- general practitioner
- geneticist and genetic counsellors
- geriatrician
- gynaecologist
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- psychologist
- psychiatrist
- social worker.

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

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 Special considerations

Special considerations that need to be addressed at this stage may include issues around obesity, diabetes, early menopause and hormonal changes. This may require appropriate referral for management of these issues.

Referral to a dietitian, endocrinologist or bariatric service may be appropriate.

The option of fertility preservation may need to be discussed prior to treatment starting. There should be a planned approach for fertility-preserving therapy. Referral to a fertility service for counselling and evaluation of options may be appropriate.

Referral for psychological services or to a women's health or sexual and reproductive health practitioner may be appropriate regarding loss of hormonal function and impact on sexual function.

3.6 Prehabilitation, support and communication

3.6.1 Prehabilitation

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

Referral to a dietitian or nutritional service may be required preoperatively for women who are obese.

Evidence indicates that, for newly diagnosed cancer patients, prehabilitation 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 woman'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.

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

- treatment for physical symptoms such as fatigue and pain
- nutrition:
  - malnutrition/undernutrition as identified using a validated malnutrition screening tool or presenting with unintentional weight loss
  - obesity: note that many patients with a high BMI may be malnourished (Chaves et al. 2010)
- help with psychological and emotional distress while adjusting to the diagnosis, treatment phobias, existential concerns, stress, difficulties making treatment decisions, anxiety/depression, psychosexual issues such as potential loss of fertility and premature menopause, history of sexual abuse, and interpersonal problems
- guidance for financial and employment issues (such as loss of income, travel and accommodation requirements for rural women and caring arrangements for other family members)
- appropriate information for people from culturally and linguistically diverse backgrounds.

3.6.3 Communication with the patient

The lead clinician should:

- establish if the woman has a regular or preferred general practitioner
- discuss a timeframe for diagnosis and treatment with the woman and carer
- discuss the benefits of multidisciplinary care and make the woman aware that her health information will be available to the team for the discussion at the multidisciplinary team meeting
- offer individualised endometrial cancer information that meets the needs of the woman 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 woman is a smoker, provide information about smoking cessation.

3.6.4 Communication with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the woman's general practitioner regarding the treatment plan and recommendations from multidisciplinary team meetings and should notify the general practitioner if the woman does not attend appointments
- gather information from the general practitioner, including their perspective on the woman (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 endometrial cancer. For detailed information on treatment options refer to:

- Cancer Council Australia 2014, Clinical practice guidelines for the treatment and management of endometrial cancer (see <http://wiki.cancer.org.au/australia/Guidelines:Endometrial_cancer/Treatment/Early_stage>)
- European Society of Medical Oncology 2013, ESMO clinical practice guidelines for diagnosis, treatment and follow-up (see <https://annonc.oxfordjournals.org/content/24/suppl_6/vi33.full.pdf+html>).

4.1 Treatment intent

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

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

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

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

If appropriate, advance care planning should be initiated with women 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 Screening for Lynch syndrome

According to the best current evidence women diagnosed with endometrial cancer before age 60, as well as those diagnosed with endometrial cancer at any age whose personal or family history of cancer meet the Revised Bethesda criteria for Lynch syndrome (Umar et al. 2004) should have immunohistochemistry (IHC) for mismatch repair (MMR) proteins performed on their tumour specimens (Buchanan et al. 2014).

IHC for MMR should be routinely requested by pathologists on endometrial cancer resection specimens in women under 60 years of age. Where a resection specimen is inadequately fixed or not available for that patient the curette specimen should be tested.

Where the IHC is abnormal the report should raise the possibility of Lynch syndrome and suggest referral to an FCC.

4.3 Treatment options

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

Most women with early-stage endometrial cancer will not require adjuvant treatment with radiation therapy or chemotherapy as they are at low risk of recurrence with good prognosis (Obermair 2012).

There is no agreement on the standard treatment for advanced endometrial cancer, but typically a combination of surgery, radiation therapy and/or chemotherapy is employed (ESMO 2013).

4.3.1 Surgery for primary disease

Surgery is the primary treatment for endometrial cancer. The type of surgery offered will depend on a number of factors: the stage of the disease; the age and performance status of the woman; and the desire to retain fertility.

For early-stage endometrial cancer confined to the uterus, hysterectomy and BSO with or without lymph node dissection is the standard surgical approach (ESMO 2013; Obermair 2012) unless the woman is interested in, and a candidate for, fertility sparing options (NCCN 2015).

Total abdominal hysterectomy (laparotomy) is used less frequently today in favour of laparoscopy, a minimally invasive option providing equivalent results with fewer complications (Cancer Council Australia 2014; ESMO 2013).

Lymphadenectomy may be considered in select patients (Cancer Council Australia 2014).

For premenopausal women, ongoing assessment of the effects of surgical menopause is required after surgery.

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

Gynaecological oncologist (FRANZCOG) with adequate training and experience in gynaecological cancer surgery (ACSQHC 2004). All patients must be assessed in a gynaeoncology multidisciplinary team meeting for treatment planning. There may be occasions where it is appropriate for a specialist gynaecologist to perform the surgery.

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 women's distress.

The following recommended timeframes are based on expert advice from the Endometrial Cancer Working Group: Surgery should be within four weeks of diagnosis.

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

- appropriate nursing and theatre resources to manage complex surgery
- 24-hour medical staff availability
- 24-hour operating room access
- specialist pathology
- in-house access to radiology
- an intensive care unit.

4.3.2 Radiation therapy

Most women with early-stage endometrial cancer will not require adjuvant treatment with radiation therapy as they are at low risk of recurrence with good prognosis (Obermair 2012). For women with higher risk factors, adjuvant radiation (external beam or brachytherapy) may be offered to improve local control (Cancer Council Australia 2014).

In selected cases radiation therapy may also be considered as part of primary treatment following multidisciplinary team meeting discussion. When surgery is not feasible, pelvic radiation therapy is an option to consider (ESMO 2013).

Some women may benefit from radiation therapy for symptomatic relief and palliation of metastatic or recurrent disease (NBCC & NCCI 2003), following discussion at a multidisciplinary team meeting.

For detailed information on postoperative radiation therapy refer to:

- *Postoperative radiation therapy for endometrial cancer: American Society for Radiation Oncology evidence-based guideline* (ASTRO 2014) available at <http://jco.ascopubs.org/content/early/2015/07/02/JCO.2015.62.5459.full>
- *ESMO-ESGO-ESTRO Consensus Conference on Endometrial Cancer* (Colombo et al. 2015) available at <http://www.esmo.org/Guidelines/Gynaecological-Cancers/ESMO-ESGO-ESTRO-Consensus-Conference-on-Endometrial-Cancer>.

Training, experience and treatment centre characteristics

Training and experience of radiation oncologist:

- Radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice within this area (ACSQHC 2004) and who is also a core member of a gynaecological oncology multidisciplinary team.

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

- trained radiation therapists, physicists and therapists
- access to CT/MRI scanning for simulation and planning
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where the facility is not collocated
- access to allied health, especially nutrition health and advice.

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 women's distress.

The following recommended timeframes are based on expert advice from the Endometrial Cancer Working Group:

- Primary treatment within a maximum of four weeks of the decision to treat with radiation therapy.
- Adjuvant treatment within a maximum of eight weeks of the decision to treat with radiation therapy (if appropriate).

4.3.3 Chemotherapy

Chemotherapy may be considered after further discussion at a multidisciplinary team meeting:

- following surgery to reduce the risk of recurrence in women at high risk, usually in conjunction with radiation therapy
- as primary treatment for metastatic disease where the patient is not suitable for surgery
- where there is residual disease at the completion of surgery or the disease has spread (Cancer Council Australia 2014; SA Health 2011).

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 women's distress.

The following recommended timeframes are based on expert advice from the Endometrial Cancer Working Group:

- Primary treatment within a maximum of four weeks of the decision to treat with chemotherapy.
- Adjuvant treatment within a maximum of eight weeks of the decision to treat with chemotherapy.

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:

- access to allied health, especially nutrition health and advice
- 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 available to deliver treatment safely (including dealing with extravasation of drugs).

4.3.4 Hormonal therapy

Hormonal therapy may be appropriate for:

Fertility preservation: For young women who wish to retain fertility, a hormonal approach using intrauterine progestins is being used in well-differentiated early-stage endometrial cancer (Obermair 2012). This is considered experimental and should be recommended only following discussion at a multidisciplinary team meeting.

Symptom management: Postoperative oestrogen replacement therapy (ERT) may be recommended after discussion of its risks and benefits if quality of life is affected or applied topically for vaginal symptoms (Obermair 2012).

Recurrent/metastatic disease: Patients with progesterone-receptor-positive recurrence may benefit from high-dose oral progesterone (Obermair 2012).

4.4 Palliative care

Early referral to palliative care for patients with advanced or recurrent endometrial cancer can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). Communication about the value of palliative care in improving symptom management and quality of life should be emphasised to women and their carers.

The lead clinician should ensure women 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).

Further information

Refer patients and carers to Palliative Care Australia via <www.palliativecare.org.au>.

4.5 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>.

4.6 Complementary or alternative therapies

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

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

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

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

If the woman 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 her reach an informed decision.

The lead clinician should assure women 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>.

4.7 Support and communication

4.7.1 Supportive care

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

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

- loss of fertility or other symptoms associated with treatment and surgically or chemically induced menopause, which require sensitive discussion and possible referral to a clinician skilled in this area (NBCC & NCCI 2003)
- sexual dysfunction, such as vaginal dryness, vaginal bleeding, stenosis, dyspareunia, atrophic vaginitis and pain, which require sensitive discussion (referral to a clinician skilled in this area may be appropriate)
- nutrition:
  - malnutrition/undernutrition as identified using a validated malnutrition screening tool or presenting with unintentional weight loss
  - obesity: note that many patients with a high BMI may be malnourished (Chaves et al. 2010)
- coping with hair loss and changes in physical appearance (refer to *Look Good, Feel Better* – see resource list)
- decline in mobility and/or functional status as a result of treatment (a referral to physiotherapy and occupational therapy may be needed)
- physical symptoms such as pain and fatigue, which may benefit from regular gentle exercise
- lower limb lymphoedema after lymphadenectomy, which is a common side effect in women with gynaecological cancers (NBCC & NCCI 2003) (this can restrict mobility and referral to a physiotherapist or trained lymphoedema massage specialist may be needed)
- bowel dysfunction, gastrointestinal or abdominal symptoms, which may need monitoring and assessment
- assistance with managing complex medication regimens, multiple medications and 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, fatigue, existential anxiety, treatment phobias, anxiety/depression, relationship or interpersonal problems and sexuality concerns (referral to a psychological support service may be needed)
- potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment (referral to a social work service may be needed)
- financial issues related to loss of income and additional expenses as a result of illness and/or treatment
- legal issues (including accessing superannuation, 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.

4.7.2 Communication with the patient, carer and family

The lead clinician should:

- discuss the treatment plan with the woman and carer, including the intent of treatment and expected outcomes – provide a written plan
- provide the woman and carer with information on the possible side effects of treatment, self-management strategies and emergency contacts
- initiate a discussion regarding advance care planning with the woman and involve her family/carers if she wishes.

4.7.3 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 woman'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, women 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, women will require ongoing, hospital-based care.

5.1 Survivorship

In the past two decades, the number of women 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 women having active treatment for cancer.

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

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

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

Ongoing coordination of care between providers should also address any comorbidities, particularly ongoing complex and life-threatening comorbid conditions such as obesity, hypertension and diabetes.

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

5.2 Post-treatment care planning

5.2.1 Treatment summary

Upon completion of initial treatment, the woman, the woman's nominated 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

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

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

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

- in the primary care setting
- by other suitably trained staff (nurse-led follow-up)
- in a non-face-to-face setting (for example, by telehealth).

The options for follow-up should be discussed at the initiation and completion of the primary treatment. Patient education about symptoms of recurrence is critical for optimal aftercare as two-thirds of patients will have abnormal bleeding or pain as symptoms of recurrence and should contact their general practitioner early (Obermair 2012).

Patients with a low risk of recurrence (3 per cent or less) may not need to be reviewed on a regular basis unless they develop symptoms (Obermair 2012). For all other patients, suggested frequency for follow-up is every three to six months with physical and gynaecological examination, which includes a pelvic examination for the first two years, then within a six- to 12-month interval until five years. Pap smears are not routinely recommended in women who have been treated for endometrial cancer.

It is important that a clear and mutually agreed care plan be offered to women who have been treated for endometrial cancer.

Access to a range of health professions may be required including physiotherapy, occupational therapy, nursing, social work, dietetics, genetic counselling, 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 Special considerations

Special considerations that need to be addressed at this stage may include loss of hormonal function following treatment that involves surgical or radiation therapy to the pelvic organs or chemotherapy that might induce premature menopause (NBCC & NCCI 2003); these require sensitive discussion. Symptoms associated with surgically induced menopause may be more severe than for women who go through natural menopause. Referral to a physician with a special interest in menopause, social worker, psychologist or psychiatrist may be appropriate (NBCC & NCCI 2003).

Issues regarding obesity may require referral to a dietitian, endocrinologist or bariatric service.

5.5 Support and communication

5.5.1 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 women, their families and carers.

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

- loss of fertility or other symptoms associated with treatment and surgically or chemically induced menopause, which require sensitive discussion and possible referral to a clinician skilled in this area (NBCC & NCCI 2003)
- sexual dysfunction, such as vaginal dryness, vaginal bleeding, stenosis, dyspareunia, atrophic vaginitis and pain (NBCC & NCCI 2003), which require sensitive discussion and possible referral to a clinician skilled in this area
- nutrition:
  - malnutrition/undernutrition as identified using a validated malnutrition screening tool or presenting with unintentional weight loss
  - obesity: note that many patients with a high BMI may be malnourished (Chaves et al. 2010)
- coping with hair loss and changes in physical appearance (refer to *Look Good, Feel Better* – see resource list)
- decline in mobility and/or functional status as a result of treatment (a referral to physiotherapy and occupational therapy may be needed)
- physical symptoms such as pain and fatigue, which may benefit from regular gentle exercise
- lower limb lymphoedema after lymphadenectomy, which is a common side effect in women with gynaecological cancers (NBCC & NCCI 2003) and can restrict mobility (referral to a physiotherapist or trained lymphoedema massage specialist may be needed)
- bowel dysfunction and gastrointestinal or abdominal symptoms, which may need monitoring and assessment
- emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, relationship or interpersonal problems and sexuality concerns
- potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- 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.

5.5.2 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.

5.5.3 Palliative care

Early referral to palliative care for patients with advanced or recurrent endometrial cancer can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). Communication about the value of palliative care in improving symptom management and quality of life should be emphasised to women and their carers.

The lead clinician should ensure women receive a 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 woman should be encouraged to develop an advance care plan and involve her family/carer if she wishes (AHMAC 2011).

Further information

Refer patients and carers to Palliative Care Australia via <www.palliativecare.org.au>.

5.5.4 Communication with the patient, carer and family

The lead clinician should:

- discuss the management of any of the issues identified in 5.5.1
- 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.
- provide clear information about the role and benefits of palliative care.

5.5.5 Communication with the general practitioner

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

- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- the woman's progress
- recommendations from the multidisciplinary team
- any shared care arrangements
- a process for rapid re-entry to medical services for women 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 women will present with symptoms of recurrent disease. Some cases of recurrent disease will be detected by routine follow-up in a woman who is asymptomatic.

6.2 Multidisciplinary team

There should be a timely referral to the original multidisciplinary team (where possible), with referral on to a specialist centre with specific expertise in endometrial cancer for recurrent disease as appropriate.

6.3 Treatment

The extent of endometrial cancer recurrence should be determined using a CT of the pelvis, abdomen and chest (Obermair 2012). Further investigation such as a biopsy or positron emission tomography (PET) scan may be a useful adjunct and should be considered based on a multidisciplinary team discussion.

Treatment will depend on the location and extent of the recurrence and on previous management and patient preferences. Treatment should aim to control symptoms but may have some curative potential in selected cases. Treatment may include surgery, radiation therapy or systemic therapy, which might involve endocrine therapy or chemotherapy.

6.4 Palliative care

Early referral to palliative care for patients with advanced or recurrent endometrial cancer does improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). Communication about the value of palliative care in improving symptom management and quality of life should be emphasised to women and their carers.

The multidisciplinary team should ensure women receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

The woman should be encouraged to develop an advance care plan and involve her family/carer if she wishes (AHMAC 2011).

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

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

Further information

Refer patients and carers to Palliative Care Australia via <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 the common issues outlined in the **appendix**, specific issues that may arise include:

- emotional and psychological distress resulting from fear of death/dying, existential concerns, anticipatory grief, communicating wishes to loved ones, interpersonal problems and sexuality concerns
- 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
- cognitive changes as a result of treatment and disease progression (such as altered memory, attention and concentration)
- 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)
- nutrition:
  - malnutrition/undernutrition as identified using a validated malnutrition screening tool or presenting with unintentional weight loss
  - obesity: note that many patients with a high BMI may be malnourished (Chaves et al. 2010)
- decline in mobility and/or functional status as a result of recurrent disease and treatments (a referral to physiotherapy and occupational therapy may be needed)
- physical symptoms such as pain and fatigue, which may benefit from regular gentle exercise
- coping with hair loss and changes in physical appearance (refer to *Look Good, Feel Better* – see resource list)
- lower limb lymphoedema after lymphadenectomy, which is a common side effect in women with gynaecological cancers (NBCC & NCCI 2003) and can restrict mobility (referral to a physiotherapist or trained lymphoedema massage specialist may be needed)
- bowel dysfunction, gastrointestinal or abdominal symptoms, which may need monitoring and assessment
- bowel obstruction due to malignancy (women need to be alerted to possible symptoms and advised to seek immediate medical assessment) (Fitch et al. 2000; NBCC & NCCI 2003)
- abdominal ascites, which may need to be actively managed
- loss of fertility, sexual dysfunction or other symptoms associated with treatment and surgically or chemically induced menopause, which require sensitive discussion and possible referral to a clinician skilled in this area (NBCC & NCCI 2003)
- potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment
- 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 woman, carer and family

The lead clinician should ensure there is adequate discussion with the woman 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 woman's symptoms are increasing and functional status is declining. Step 7 is concerned with maintaining the woman's quality of life and addressing her health and supportive care needs as she approaches the end of life, as well as the needs of her 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 woman and her family.

7.1 Multidisciplinary palliative care

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

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

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

- pain service
- 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 via <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 the common issues identified in the **appendix**, specific issues that may arise at this time include:

- emotional and psychological distress from anticipatory grief, fear of death/dying, anxiety/depression, interpersonal problems and anticipatory bereavement support for the woman as well as her family/carers
- physical symptoms including pain and fatigue and bowel management
- changes in physical appearance
- increasing dependence on others
- decline in mobility and/or functional status impacting on discharge destination (a referral to physiotherapy and occupational therapy may be needed)
- practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the woman
- 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 women 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 woman, 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 woman's needs and goals are addressed in the appropriate environment. The woman's general practitioner should be kept fully informed and involved in major developments in the woman's illness trajectory.

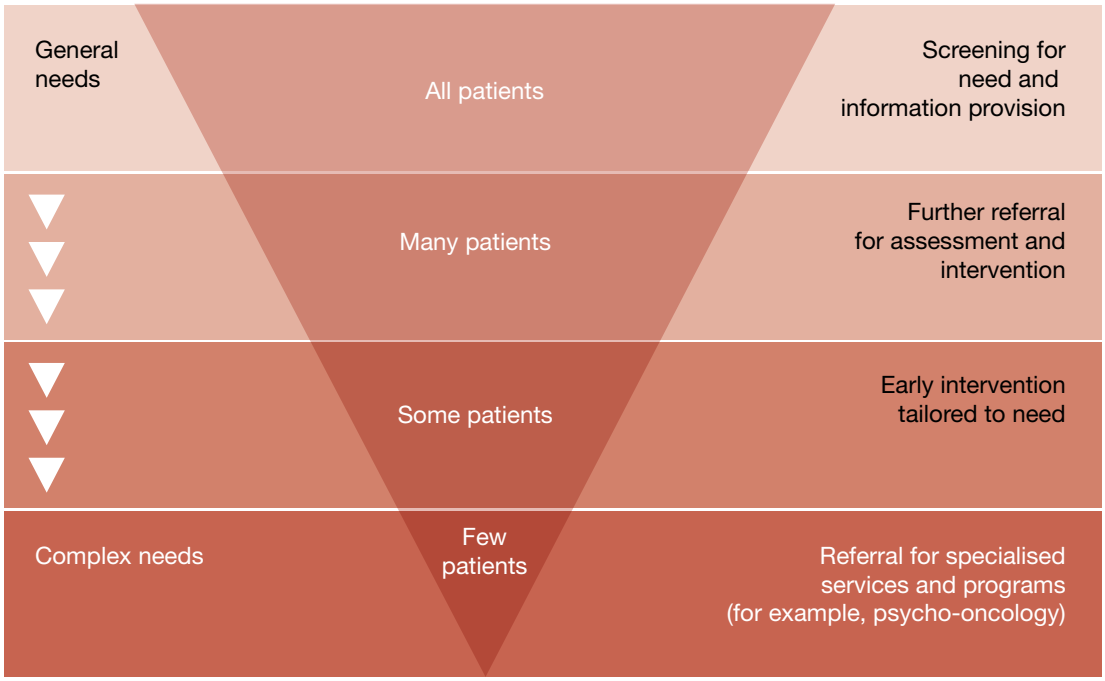
Appendix: Supportive care

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 women's supportive care needs.

Figure 1: The tiered approach



While all women require general information, only a few will require specialised intervention. Common indicators in women with endometrial cancer who may require referral to appropriate health professionals and/or organisations include the following:

Physical needs

- Nutrition can be a significant issue for women and may require referral to a dietitian before, during and after treatment:
  - malnutrition/undernutrition as identified using a validated malnutrition screening tool or presenting with unintentional weight loss
  - obesity: note that many patients with a high BMI may be malnourished (Chaves et al. 2010)
- Loss of fertility or other symptoms associated with treatment and surgically or chemically induced menopause require sensitive discussion and possible referral to a clinician skilled in this area (NBCC & NCCI 2003).
- Sexual dysfunction, such as vaginal dryness, vaginal bleeding, stenosis, dyspareunia, atrophic vaginitis and pain (NBCC & NCCI 2003) require sensitive discussion, and referral to a clinician skilled in this area may be appropriate.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy often requires strategies such as maintaining written notes or a diary and repetition of information.
- Referral to a pharmacist may be useful for women managing multiple medications.
- Although treatments have improved, nausea and vomiting are still serious side effects of cancer therapy. Some women 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 and bowel obstruction 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.

Psychological needs

- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, transgender and intersex communities) an endometrial cancer diagnosis can come with additional psychosocial complexities. Uncertainty about discrimination may also make these groups less inclined to seek regular medical and gynaecological care. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Women who have had extensive pelvic and abdominal surgery or who receive a multimodality treatment strategy for endometrial cancer are at high risk of depression and heightened anxiety (Le et al. 2003). Regular screening for depression and anxiety specifically for these women is required. Strategies such as information provision, relaxation techniques, meditation (Kearney & Richardson 2006) and a referral to a psychologist or psychiatrist may be helpful.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some women may have disabling symptoms and may benefit from referral to psychology services.
- Distress and depression can be just as common in carers and family members including children.
- Consider a referral to a psychologist, psychiatrist or social worker if the woman is:
  - 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 or the changed goals of their treatment
  - worried about loss associated with her daily function, dependence on others and loss of dignity
  - becoming isolated from family and friends and withdrawing from company and activities that she previously enjoyed
  - feeling hopeless and helpless about the impact that endometrial cancer is having on her life and the disruption to her life plans
  - struggling with communicating to family and loved ones about the implications of her 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 drug and alcohol use
  - having difficulties transitioning to palliative care.

Body image

- Support and counselling from a psychologist, psychiatrist, occupational therapist or social worker may be required.

Fertility preservation

- The option of fertility preservation needs to be discussed prior to treatment starting. Referral to a fertility service for counselling and evaluation of options may be appropriate.

Social/practical needs

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

Spiritual needs

- Women 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 women with cancer (aged over 70 years)

Planning and delivering appropriate cancer care for elderly women 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 the 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 women 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.

Guided intervention using aged care services is appropriate.

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.

Culturally and linguistically diverse communities

For women from culturally and linguistically diverse backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In many languages there is not a direct translation of the word ‘cancer’, which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis.

In addition to different cultural beliefs, when English language skills are limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for women. 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 women (Department of Health 2009).

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>

beyondblue

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

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

Cancer Australia

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

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

Cancer Council (operated by Cancer Council Victoria)

A confidential telephone support service for people affected by cancer providing 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>

CanTeen

Australian organisation for young people living with cancer that offers support, information, resources and flexible services including phone, email and online counselling

- Telephone: 1800 226 833
- <www.canteen.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>

Look Good, Feel Better

A non-medical, free community service program dedicated to teaching women how to manage the appearance-related side effects caused by cancer treatment

- Telephone: 1800 650 960 (Monday to Thursday 9.00am – 5.00pm)
- <www.lgfb.org.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>

Australasian Lymphology Association

Professional organisation promoting best practice in lymphedema management, research and education; provides a public register of lymphoedema practitioners in Australia and New Zealand

- <www.lymphoedema.org.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>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment

- <www.nhmrc.gov.au>

Glossary

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

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

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

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

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

General/primary medical practitioner – the practitioner to whom the woman 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 woman (Department of Health 2007b).

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

Optimal 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 frameworks – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal care pathways are updated versions of these models.

Prehabilitation – one or more interventions performed in a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the woman 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 woman to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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Grampians Integrated Cancer Service
Monash University
North Eastern Melbourne Integrated Cancer Service
Peter MacCallum Cancer Centre
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Australian and New Zealand Gynaecological Oncology Group
Australian and New Zealand Society of Palliative Care
Australian College of Nursing
Australian Institute of Radiography
Australian Medical Association
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