Shared follow-up and survivorship care model for women with low-risk endometrial cancer

Guidance toolkit
Endometrial cancer is cancer affecting the lining of the uterus (called the endometrium). It is the most common type of cancer of the uterus and the most common gynaecological cancer diagnosed amongst Australian women. Follow-up and survivorship care is recommended for women who have completed their active treatment for low-risk endometrial cancer. Follow-up and survivorship care allows for:

- early detection of recurrence
- identification, monitoring and management of side-effects and co-morbidities
- screening and management of supportive care needs
- support for living well.

Within Australia, shared follow-up care has been successfully and safely implemented across a range of health settings and conditions including diabetes, paediatric oncology and obstetric care. It involves active participation from both the primary care and specialist teams to help plan and manage patient care.

The definition of ‘low-risk endometrial cancer’ may vary from one specialist gynaecological cancer service to another. Suitability of a woman with endometrial cancer to participate in shared follow-up care should be determined by the treating multidisciplinary team.

The International Federation of Gynaecology and Obstetrics (FIGO) endometrial cancer stage according to 2009 definitions can be found here: https://meteor.aihw.gov.au/content/index.phtml/itemId/424206.
Snapshot

Endometrial cancer is cancer that arises from the lining of the uterus (called the endometrium). 1

Endometrial cancer is the most common type of uterine cancer, which is the most common gynaecological cancer diagnosed in Australian women. 2, 3

Incidence rates of gynaecological cancers in 2019. 3-5

Gynaecological cancer include cancers of the uterus (endometrium), ovary, cervix, vulva, fallopian tubes, placenta and vagina

Uterine cancer (48.3% of gynaecological cancers) 3 include cancers of the uterus lining (endometrium) and muscle tissue (myometrium)

Endometrial cancer (95% of uterine cancers) 4, 5 affects the uterus lining (endometrium).

In 2019, uterine cancer is estimated to account for 48.3% of gynaecological cancers 5 and endometrial cancer accounts for approximately 95% of uterine cancer cases. 4, 5

Incidence rates of uterine cancer in Australia are increasing. Indigenous Australian women experience higher rates of mortality than non-Indigenous Australian women for uterine cancer. Mortality rates for uterine cancer in Australia are expected to remain stable.

90% of women diagnosed with uterine cancer are over the age of 50 years. In 2011–2015, the 5-year relative survival rate for uterine cancer was 83.3%. In 2014, there were 10,454 women living who had been diagnosed with uterine cancer in the previous five years.

It is currently estimated that the risk of a woman being diagnosed with uterine cancer by her 85th birthday will be 1 in 40.
## Risk of recurrence for low-risk endometrial cancer

Women who have been treated for **low-risk endometrial cancer** are at risk of local, regional or distant recurrence. The risk of recurrence for low-risk endometrial cancer is:

<table>
<thead>
<tr>
<th>Less than 5%, usually occurring within the first two to three years after diagnosis</th>
<th>Minimal for women who have been asymptomatic for more than five years</th>
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Recurrences usually occur locally, are symptomatic, and are usually treatable.

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Co-morbidities and treatment-related side effects

Many women with low-risk endometrial cancer experience a range of co-morbidities, including:

- obesity-related issues
- hypertension
- diabetes
- cardiovascular disease *

These conditions are often associated with modifiable risk factors such as weight gain, obesity, physical activity and diet. Addressing underlying risk factors for these conditions may have the greatest potential to improve outcomes of women affected by endometrial cancer. 

*Evidence suggests that cardiovascular disease is the leading cause of death among women with endometrial cancer.*

Psychosocial and psychosexual wellbeing of women may be affected during treatment for low-risk endometrial cancer. A holistic approach to identifying, monitoring and managing treatment-related side effects is required to address supportive care needs.

Follow-up and survivorship care is recommended after completion of active treatment for low-risk endometrial cancer and may be undertaken by the specialist team or primary care team. Given the increased risk of recurrence within the first two to three years after treatment, more frequent follow-up is recommended within this time period.

### Care teams

Follow-up and survivorship care is recommended after completion of active treatment for low-risk endometrial cancer and may be undertaken by the **specialist team** or **primary care team**. Given the increased risk of recurrence within the first two to three years after treatment, more frequent follow-up is recommended within this time period.

#### The specialist team may include:
- gynaecological oncologist(s)
- specialist nurse(s)
- allied health professional(s)
- gynaecologist(s)

#### The primary care team may include:
- the General Practitioner (GP)
- primary health care nurse(s)
What is the purpose of follow-up and survivorship care?

- **Early detection of local, regional or distant recurrence**
- **Reviewing and updating family history information** relating to endometrial cancer and co-morbidities
- **Identification, monitoring and management** of treatment-related side effects, co-morbidities (such as overweight/obesity, hypertension and diabetes) and secondary prevention
- **Providing holistic care** including treatments for co-morbidities
- **Screening, assessment and management** of supportive care needs (such as psychosocial distress, anxiety or depression and impact on sexual wellbeing)
- **Exploring and managing the woman’s expectations** and supporting her to openly discuss the care, support and information she needs
What is shared follow-up and survivorship care?

In Australia, follow-up and survivorship care are predominantly carried out in tertiary settings by specialist clinicians. In the context of growing numbers of cancer survivors and limited resources, some of these approaches may be unsustainable.

A new approach to follow-up care for women with low-risk endometrial cancer is required which delivers safe, effective, person-centred care, optimising available resources.¹

Shared follow-up and survivorship care is the joint participation of primary and specialist teams in the planned delivery of patient care.² Shared care has been successfully and safely implemented across a range of health settings and conditions including diabetes, paediatric oncology and obstetric care.

Principles

Shared follow-up and survivorship care for low-risk endometrial cancer by multidisciplinary teams should be guided by the following principles:

- **Person-centred care**
- **Care delivered according to best practice**
- **Coordination of care**
- **Support for living well**
- **Support for primary care providers**
- **Support for specialist treatment team**
- **Care is informed and improved by data**
What are the benefits of shared follow-up and survivorship care?

Shared follow-up and survivorship care provides patients the benefits of care by a specialist team combined with continuity of care and ongoing management from primary care team.

Shared follow-up and survivorship care has the potential to provide a safe and effective service delivery model while helping to address equity of access issues for women with low-risk endometrial cancer in Australia.¹

Potential benefits of a shared follow-up and survivorship care model for low-risk endometrial cancer may include:²

- **improved access** to holistic and accessible care (including management of comorbidities and supportive care needs)
- **increased capacity** for specialist teams to manage and support high-risk patients
- **strengthened care coordination** between specialist and primary care teams
- **improvements** in patient choice and shared decision-making.

Overview

Key strategies and practical resources to guide implementation of best practice shared follow-up and survivorship care for low-risk endometrial cancer include:

<table>
<thead>
<tr>
<th>Adherence to clinical best practice</th>
<th>Multidisciplinary treatment planning and care management</th>
<th>Agreed roles and responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deliver shared follow-up and survivorship care in accordance with best practice</td>
<td>Joint participation between specialist and primary care teams, with access to shared information</td>
<td>Agree on shared follow-up and survivorship care arrangements by specialist and primary care teams that are clearly communicated to the woman</td>
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<th>Timely and effective communication</th>
<th>Rapid access to specialist services</th>
<th>Supportive care</th>
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<tr>
<td>Between specialist and primary care teams and the woman to support coordination of care and shared decision-making</td>
<td>Establish clear referral systems for rapid access to specialist teams for primary care teams</td>
<td>Deliver supportive care through routine screening, assessment and management of the woman’s needs</td>
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</table>
Adherence to clinical best practice

Deliver shared follow-up and survivorship care in accordance with best practice

The transition from active treatment to post-treatment care is a critical stage to long-term health. Best practice suggests the following care during follow-up visits.

<table>
<thead>
<tr>
<th>Method</th>
<th>Years 1-2</th>
<th>Year 3</th>
<th>Years 4-5</th>
</tr>
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<tbody>
<tr>
<td>History and physical examination</td>
<td>Every 3–6 months</td>
<td>Every 6–12 months</td>
<td>Every 12 months</td>
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References:
Multidisciplinary treatment planning and care management

Joint participation between the specialist and primary care teams in follow-up and survivorship care, with access to shared information

Multidisciplinary care is considered best practice when planning treatment and care for patients with cancer. Multidisciplinary care is an integrated team approach to healthcare in which healthcare providers consider all relevant treatment options and follow-up care requirements, and collaboratively develop an individual treatment and care plan for each woman.

A Shared Care Plan should be developed and agreed between the specialist and primary care teams and the woman to support multidisciplinary follow-up and survivorship care approaches.

For further information on multidisciplinary cancer care visit: canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care

Who is involved in multidisciplinary care?

Core disciplines integral to the provision of good care should be part of the multidisciplinary team. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care and the woman’s primary care team.

A multidisciplinary team for women with low-risk endometrial cancer may include:
- gynaecological oncologist(s)
- gynaecologist(s)
- radiation oncologist(s)
- specialist nurses
- general practitioner(s)
- primary health care nurse(s)
- allied health professionals (including social workers, psychologists, physiotherapists and dietitians)
- counsellors in sexual health and/or genetics
- an expert in providing culturally appropriate care to Aboriginal and Torres Strait Islander people.*

A Shared Care Plan

A Shared Care Plan is an individualised care plan that contains the key follow-up elements and schedule required to provide ongoing comprehensive care to a woman who has received treatment for low-risk endometrial cancer. A Shared Care Plan enables the specialist and primary care teams to manage follow-up care together.

*A culturally appropriate healthcare professional may be an Aboriginal and Torres Strait Islander Health Worker, Health Practitioner, or Hospital Liaison Officer.
Agreed roles and responsibilities

Agree on shared follow-up and survivorship care arrangements by specialist and primary care teams that are clearly communicated to the woman.

Discuss and agree on the roles and responsibilities of each member of the multidisciplinary team prior to commencing shared follow-up care.

Document these responsibilities in the Shared Care Plan and share with the woman.

The Medicare Benefits Schedule (MBS) includes Chronic Disease Management (CDM) items to financially support and enable the primary care team to plan and coordinate multidisciplinary care of patients with chronic or terminal medical conditions.

Agreed roles and responsibilities

**Case conference**

The primary care and specialist teams may hold a case conference at the commencement of shared follow-up and survivorship care to discuss the joint approach. This case conference provides an opportunity to:

- agree on the roles and responsibilities
- discuss the woman's individual Shared Care Plan
- agree on methods of communication between the multidisciplinary team throughout the woman's care, in particular, when follow-up raises a clinical issue that requires rapid access to specialist consultation.
Timely and effective communication

Timely, effective communication between specialist and primary care teams and the woman to support coordination of care and shared decision-making

Establishing an effective relationship and communication pathway among all multidisciplinary team members is essential in providing a comprehensive approach to care coordination, and achieving continuity of care.

Care coordination and delivery should include:

- Multidisciplinary team meetings and shared care planning
- Supportive care screening/assessment
- Development of shared care/communication protocols
- Referral practices and rapid access
- Data collection
- Information provision and individual clinical treatment
Timely and effective communication

Each woman with cancer has different communication needs, including cultural and language differences. Ensure these communication needs are met throughout follow-up and survivorship care.

After completion of initial treatment, provide the woman with a treatment summary and Shared Care Plan including a comprehensive list of individual care needs identified by all members of the multidisciplinary team.

Further information and resources

- Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer
- Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer – Quick reference guide
- What to expect – Endometrial cancer
- Cancer – What to expect – Information for Aboriginal and Torres Strait Islander people who have cancer
- Checking for cancer – what to expect - Information for Aboriginal and Torres Strait Islander people who might have cancer
Timely and effective communication

Communication roles and responsibilities for shared follow-up and survivorship care

- The specialist team should ensure there is adequate discussion with the woman about the recommended follow-up care, including the intent of shared follow-up and survivorship care, and supportive care options available.

- The primary care team and the woman should have open discussions during the provision of follow-up and survivorship care about signs and symptoms of recurrence, effects of treatment, management of comorbidities, information on healthy lifestyles and the woman's psychosocial needs.

- The specialist team, primary care team and the woman should discuss and agree on the Shared Care Plan, establish clear roles and responsibilities for shared follow-up and survivorship care, including shared care/communication protocols and referral practices according to the woman's needs.

- The relevant multidisciplinary team member should record follow-up care visits and results, provided by either the primary care team or specialist team, and should communicate the outcomes to the other team members. Rapid access to specialist advice and consultation should also be available to the primary care team if any clinical issues arise.

Further information and resources

- Roles and responsibilities for the delivery of care
- Rapid Access Request
- A guide for women on shared follow-up care
Rapid access to specialist service

Establish clear referral systems for rapid access to specialist teams for primary care teams

Access to urgent specialist consultation is an integral part of shared follow-up and survivorship care. This helps ensure that primary care teams and the woman are able to raise urgent clinical issues that require advice or consultation from specialist teams.

Agree on the rapid access process between the primary care and specialist team, and document the process that facilitates communication and referral.

Further information and resources

- Roles and responsibilities for the delivery of care
- Rapid Access Request
- A guide for women on shared follow-up care
Supportive care

Deliver supportive care through routine screening, assessment and management of the woman’s needs

A diagnosis of cancer can affect a person’s physical, emotional, psychological, spiritual and social wellbeing. Some of these effects will resolve over time due to personal coping resources and social and professional support, and some needs may emerge later or increase over time.1

Women surviving gynaecological cancer experience a number of specific needs which if left unmet, may impact on their quality of life. In addition to the many common experiences of people with a cancer diagnosis (such as pain, fatigue, anxiety, financial stress and managing treatment regimens), women who have received treatment for low-risk endometrial cancer may face more specific problems associated with:1

- surgically or chemically induced menopause
- sexual health needs, sexual dysfunction, including vaginal dryness, bleeding and stenosis, and pain during intercourse
- emotional and psychological issues including body image, relationship and sexuality concerns
- bowel or bladder dysfunction (which may have been present prior to treatment or be exacerbated by treatment)
- loss of fertility
- lower leg lymphoedema, which can affect mobility (unlikely following treatment for low-risk endometrial cancer)

Further information and resources

Screening, Assessment and Management of Supportive Care Needs of Women
Supporting Self-management and Living Well
The NCCN Distress Thermometer and Problem List for Patients

Supportive care

Deliver supportive care through routine screening, assessment and management of the woman’s needs

Assist women to self-manage and implement wellbeing strategies by providing high-quality information and support. Manage co-morbidities and modifiable lifestyle factors (if any) which may include weight gain, obesity, physical activity and diet.1

All members of the multidisciplinary team are responsible to help manage supportive care needs. During key points along the care pathway (including follow-up and survivorship care) identify the issues that the woman may require assistance with to optimise their health and quality of life outcomes.1 This may be done by routine and systematic screening and assessment of the woman, their carer and family.1


Further information and resources

- Screening, Assessment and Management of Supportive Care Needs of Women
- Supporting Self-management and Living Well
- The NCCN Distress Thermometer and Problem List for Patients
Resource list for specialist and primary care teams

- **Optimal Care Pathway for women with endometrial cancer** and **Optimal Care Pathway for women with endometrial cancer - Quick reference guide**
  outlines best practice cancer care for women with endometrial cancer. The pathway is designed to promote a full understanding of the patient journey in order to foster quality cancer care from diagnosis.

- **National Framework for Gynaecological Cancer Control**
  outlines future directions in national gynaecological cancer control to improve outcomes for women affected by gynaecological cancers.

- **Follow-up care for women with low-risk endometrial cancer: A guide for General Practitioners**
  provides guidance for GPs in managing aspects of follow-up and survivorship care for women following completion of active treatment for low-risk endometrial cancer.

- **Roles and responsibilities for the delivery of care**
  outlines key roles and responsibilities of specialist and primary care teams in the delivery of shared follow-up and survivorship care for low-risk endometrial cancer.

- **Shared Care Plan**
  provides a template for contribution by the specialist and primary care teams and the women to produce an agreed individualised follow-up care plan.

- **Rapid Access Request**
  provides the primary care team with a process to communicate when rapid access to specialist consultation is required.

- **Screening, assessment and management of supportive care needs of women with low-risk endometrial cancer**
  provides guidance to assist multidisciplinary teams in managing supportive care needs of women affected by low-risk endometrial cancer and their carers and families.

- **Principles of shared follow-up care for low-risk endometrial cancer**
  provides a list of principles that should guide multidisciplinary teams when treating women with low risk endometrial cancer.

- **NCCN Distress Thermometer and Problem List for Patients**
  measures distress and allows women to inform their doctor if they are having concerns in areas such as practical, family, emotional, spiritual and physical problems.

- **Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer** and **Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer - Quick reference guide**
  outlines the aspects of the cancer care pathway that need to be responsive to the needs of Aboriginal and Torres Strait Islander people with cancer. The pathway complements the best practice information provided in the tumour-specific pathways to facilitate the delivery of culturally safe and competent care.
Resource list for women, their carers and families

- **A guide for Women on Shared Follow-up Care** provides information on what to expect during shared follow-up care.

- **Supporting Self-management and Living Well** provides guidance to women promoting health and wellbeing, self-management and living well.

- **Follow-up of survivors of endometrial cancer** is for women who have completed treatment for endometrial cancer. It explains why follow-up appointments with your health care team are important.

- **What to expect – Endometrial cancer** explains to women what to expect during each stage of treatment and beyond.

- **Cancer – what to expect - Information for Aboriginal and Torres Strait Islander people who have cancer** explains what to expect before, during and after your cancer treatment, and tells you about the care you should be offered. Carers, family and community might also find this information helpful.

- **Checking for cancer – what to expect - Information for Aboriginal and Torres Strait Islander people who might have cancer** explains what to expect while you’re getting checked out. Carers, family and community might also find this information helpful.
References


Glossary

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