


Patient management framework

# Gynaecological tumour stream: ovarian cancer



a guide to  
**consistent**  
cancer care



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## Acknowledgements

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## 1. Introduction

Cancer is the leading cause of death in Victoria, representing 28.9 per cent of all deaths in 2002<sup>24</sup>. Population ageing will significantly increase the number of new cases of cancer over the next ten years, with an estimated 10,000 more cases per annum in Victoria by 2016. In 2003, 310 Victorian women were diagnosed with ovarian cancer and in 2002, 247 deaths were due to ovarian cancer<sup>24</sup>.

Cancer is a complex disease to diagnose and treat, and represents a significant burden to patients and their families, the health system, and the community at large. Victoria's strategic and planned approach to cancer reform includes the establishment of a Ministerial Taskforce for Cancer, and implementation of the *Fighting cancer* policy<sup>2</sup> and *A cancer services framework for Victoria*<sup>25</sup>. Two significant directions of the Cancer Services Framework are the establishment of integrated cancer services in metropolitan and regional Victoria, and the development of service delivery and improvement through a tumour streams model.

Since 2004, eight integrated cancer services have been established in metropolitan and regional Victoria, based on specified geographic populations. The philosophy of an integrated cancer service is that hospitals and primary and community health services develop integrated care and defined referral pathways for the populations they serve. This requires effective collaboration between hospitals and community-based services, including general practitioners. This will promote more effective local coordination of care for cancer patients, and a more rational, evidence-based approach to cancer service planning and delivery. The Cancer Services Framework also recommended that organ or system-specific tumour streams be adopted to support the delivery and improvement of care. The reasoning behind the tumour streams is that a consistent approach to clinical management based on evidence-based practice will reduce unacceptable variations in care across the state.

## 2. Patient management frameworks

The Cancer Services Framework suggested some areas for improvement in the quality of care for cancer patients in Victoria. These included:

- under-treatment of patients with colorectal, lung and prostate cancer<sup>9,21,22</sup>
- inadequate follow-up surveillance of patients with testicular cancer<sup>26</sup>
- a high proportion of cancer patients undergoing surgery with surgeons who performed relatively few operations for colorectal cancer<sup>11,22</sup>
- a high proportion of surgery for ovarian cancer having been undertaken by generalists rather than specialist surgical oncologists<sup>10</sup>.

As a consequence, the Cancer Services Framework recommended that tumour streams be developed to reduce unwanted variation in practice. In response, the Ministerial Taskforce for Cancer recommended that patient management frameworks be developed to provide a consistent statewide approach to care management in each tumour stream. The patient management frameworks are a clear description of the care pathway, identifying the critical points along that pathway and the optimal model of care required. It is important that all patients are assessed and managed appropriately throughout each stage of their journey; however, it should be noted that not all patients will progress through each step of the relevant patient management framework. This is a consequence of many factors, including disease outcomes, management decisions, and patient decisions.

### 2.1 Purpose of the patient management frameworks

The patient management frameworks **are a guide** to the **optimal care management** of patients in each tumour stream. They are intended to improve patient outcomes by facilitating consistent care based on evidence and best practice across the state. They set out the key requirements for the provision of optimal care which need to be considered at each step of the care pathway. In contrast to clinical practice guidelines that guide appropriate practice and decision making, the patient management frameworks provide a guide to the patient journey to ensure patients with cancer and their families receive optimal care and support.

As a guide, the patient management frameworks are to be followed subject to the health professional's independent medical judgment and the patient's preference in each individual case. They are designed to provide information to assist in decision making and organisation of service delivery.

The patient management frameworks **are not rules** and **do not carry a sense of prescription**. The patient management frameworks represent the 'what', rather than seeking to prescribe the 'how'. Recognising that services should be responsive to the needs of different patients at different phases, the patient management frameworks draw on best practice and encourage local solutions. For example, while multidisciplinary care is an essential part of treatment planning, how it is organised depends on the local situation.

In their current format, the patient management frameworks are not designed for accreditation purposes, but may be used to facilitate local benchmarking, service mapping and service development.

The patient management frameworks have been developed in collaboration with a wide range of practitioners, consumers and carers. Wherever possible, the patient management frameworks are based on current best practice, including clinical guidelines, care pathways, standards and research that exist to support optimal care at the critical points. In many cases, however, they are a statement of consensus regarding currently accepted approaches to treatment.

## 2.2 Structure of the patient management frameworks

The patient management frameworks set out seven critical steps of the patient journey. The seven steps provide a consistent structure across the ten tumour streams. While the seven steps appear as a linear model, it is clear that in practice patient care does not always occur in this way but rather depends on the particular cancer, when and how the cancer is diagnosed, prognosis, management decisions, and patient decisions.

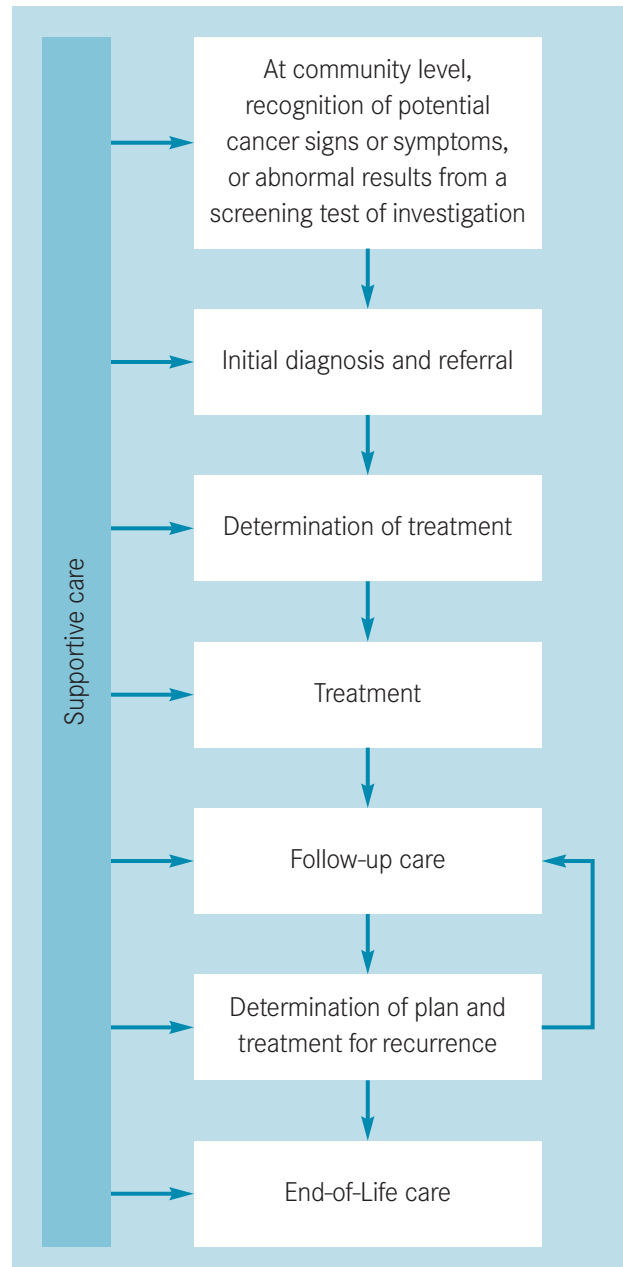
Underpinning the patient management frameworks are key principles that support all seven steps. These are:

**1. patient-centred care.** Patients should be involved as active participants in care planning and decision making, and wherever appropriate so should their partners, families and carers. Ultimately, any treatment decision rests with the patient or designated person. This requires information and discussion in their preferred language and sensitive to their culture

**2. safe and high quality care.** Cancer care is complex, involving a range of clinicians with different expertise. To ensure safe and high quality cancer care, it is important that clinicians have the technical skills and experience to carry out those aspects of cancer care they undertake and that there is institutional capacity to support such care, such as equipment, staffing and skill mix. Further detail is provided in section 3

**3. multidisciplinary care.** The cornerstone of best practice in cancer care is multidisciplinary treatment planning and multidisciplinary care. An effective multidisciplinary approach can result in survival benefit<sup>13</sup>, increased recruitment into clinical trials<sup>16,17</sup>, detection of emotional needs of patients<sup>4</sup>, reduction in service duplication and improved coordination of services<sup>3</sup>. Further detail is provided in section 4

Figure 1: Steps of the patient journey



**4. supportive care.** People with cancer have psychological and social needs that are frequently undetected and unmet<sup>9</sup>. This has the potential to result in long term distress. In the context of cancer, supportive care describes all services that may be required to support people with cancer and their carers to meet their physical, psychological, social, information and spiritual needs. Further detail is provided in section 5

**5. care coordination.** The cancer journey is complex and challenging, and it is not uncommon for patients to be seen by many health professionals within and across multiple health services and across different sectors. A variety of strategies are successful in improving the coordination of care. Some of these include strategies directed at the team, such as multidisciplinary team meetings, clinical protocols and case conferencing; strategies directed at the patient, such as personal patient records, appropriate information provision or case managers; and strategies directed at the health care system, such as electronic medical records, standards, performance indicators and funding models. To ensure patients experience care that is coordinated and integrated over time and settings, services need to consider the range of strategies required to facilitate care coordination.

## 2.3 Development of the patient management frameworks

The patient management frameworks have been developed over a 15-month period in consultation with more than 500 clinicians and consumers through workshops and written submissions. Further information on the development process can be obtained at <http://www.health.vic.gov.au/cancer/tumourstreams.htm>.

Fourteen patient management frameworks have been developed, addressing the following tumour streams and tumour categories:

- breast
- central nervous system (cerebral metastases)
- central nervous system (malignant glioma)
- colorectal (colon and rectal)
- genitourinary (prostate)
- genitourinary (testis)
- gynaecological (ovarian)
- haematological (acute myeloid leukaemia)
- haematological (intermediate grade non-hodgkin's lymphoma)
- head and neck (larynx, pharynx and oral)
- lung (non-small cell)
- skin (melanoma)
- upper gastrointestinal (oesophagogastric)
- upper gastrointestinal (pancreatic).

## 2.4 Future review and development of the patient management frameworks

The 14 patient management frameworks that have been developed will be reviewed in December 2007. Further development of patient management frameworks relevant to the ten major tumour streams will commence in January 2007.

### 3. Credentialling and scope of practice

In 2004, the *National standard for credentialling and defining the scope of clinical practice*<sup>1</sup> was endorsed by the Australian Health Ministers. Developed by the Australian Council for Safety and Quality in Health Care, the standard provides a credentialling framework for all medical practitioners. Credentialling is a formal process for verifying qualifications, competence and performance of individual clinicians as well as defining their scope of practice within a specific health service. The process takes into account the skills and ability of the clinician as well as the capacity of the institution to support the clinician's practice.

This has particular relevance to clinicians working in the area of cancer care. Cancer care is complex for a number of reasons. These include:

- the large number and type of cancers that vary greatly in their pathology and management
- the range of clinicians with different professional expertise (medicine, nursing, allied health) that are involved in care
- the range of specialities for specific treatment modalities, such as breast or colorectal surgeons, radiation and medical oncologists, breast care nurses
- the life-threatening nature of many cancers and the serious complications and side-effects of some treatments
- the advances in technology and research that are changing best practice care at a rapid pace<sup>8</sup>.

In Victoria, the complexity of cancer care poses specific challenges for health professionals working in the area of cancer. The large distances between health services and the relatively low numbers of complex cancers that will be seen at individual health services or by individual health professionals require that innovative approaches to care be developed. These include developing links between health professionals and multidisciplinary teams and initiatives such as the expansion of telemedicine, specific mentoring and upskilling programs.

For patients to have access to safe and high quality services, it is important that professionals working in the area of cancer care ensure:

- they have the necessary skills to carry out those aspects of cancer care they undertake and there is institutional capacity to support such care (for example, equipment, staffing and skill mix)
- they have clear links with a range of specialties or multidisciplinary care team required for cancer care, for the purpose of clinical advice, referral and continuing education
- they follow evidence-based practice or treatment recommendations of a multidisciplinary care team
- they undertake regular review of their performance and contribute to regular audit of their cancer care
- they are actively involved in continuing professional development
- their patients can make an informed choice about their care, including the options of referral to other professionals or specialised centres<sup>8</sup>.

## 4. Multidisciplinary care

### 4.1 Achieving multidisciplinary care

Multidisciplinary care is an approach that includes both treatment planning and ongoing care. The 'gold standard' for multidisciplinary care is a team who meets regularly (whether in person or via teleconferencing) to prospectively plan care and treatment for all patients within a tumour group; however, it is expected that different components of multidisciplinary care will be implemented depending on the setting, the location of the team and the number and type of cancer patients being treated. While it may not always be possible to hold a multidisciplinary team meeting prior to surgery, for instance, it would be expected that some other form of multidisciplinary discussion around treatment planning take place. It is likely that regional multidisciplinary care will look different from metropolitan, while being guided by the principle that interaction between multidisciplinary team members is critical in the determination and effective implementation of the treatment plan. It is also acknowledged that patients move between the private and public sector and multidisciplinary care needs to take this into account.

### 4.2 Principles of multidisciplinary care<sup>18</sup>

#### The team

- There is an established multidisciplinary team comprising all core disciplines, including allied health and psychosocial health practitioners.
- The patient's general practitioner is regarded as a team member and processes to ensure effective communication with general practitioners are implemented.
- Effective communication and referral linkages are made to all core and non-core team members.

#### Communication

- All core disciplines where appropriate and relevant regularly attend multidisciplinary meetings to provide input to diagnostic, treatment, supportive and palliative care planning.

- In instances where not all patients within a tumour group or groups are discussed, team protocols are developed to outline those patients who will be presented at meetings.
- Processes for communicating treatment and care plans for team members who are absent are developed and implemented.

#### Full therapeutic range

- All patients regardless of where they reside will have information about and access to relevant treatments and services.
- Clinical trial involvement is considered for all eligible patients who will be undergoing cancer treatment.

#### Quality

- Decisions, protocols and care pathways are in line with current best practice, including standards, guidelines, research and where these are not available, currently accepted approaches to treatment.
- All relevant diagnostic results, reports and pathology and radiology images are available for multidisciplinary meetings.
- Collaborative links will be formed with smaller and larger referring centres and practitioners. The result will be a network of multidisciplinary teams and practitioners across and between integrated cancer services.
- Professional development activities are supported and held for all team members.

#### Involvement of patient

- Patients are informed of the multidisciplinary team process.
- Patients are informed of the recommendations of the multidisciplinary discussion, provided with information about all aspects of their treatment and participate in the decision making process.
- Patients are routinely given information about and access to supportive care services.

## 5. Supportive care

‘Supportive care is an ‘umbrella’ term for all services, both generalist and specialist, that may be required to support people with cancer and their carers’<sup>20</sup>. It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care<sup>20</sup>.

Supportive care is required throughout the diagnostic, treatment and follow-up phases of care<sup>5</sup>.

In the context of cancer, supportive care needs include:

- physical needs (for example, pain, fatigue)
- psychological needs (for example, anxiety, distress)
- social needs (for example, practical supports, carer needs)
- information needs (for example, regarding diagnosis, prognosis, types of treatment)
- spiritual needs (for example, addressing hopelessness, despair).

### 5.1 Providers of supportive care

Supportive care is provided by generalist and specialist health services as well as community services.

All members of the multidisciplinary team, including general practitioner, surgeon, radiation oncologist, medical oncologist, nurse, social worker and other allied health staff, have a role in the provision of supportive care. In addition, community capacity to support people with cancer makes an important contribution to supportive care. This includes support from family, friends, support groups, volunteers and other community-based organisations.

As a specialist service, palliative care may provide many of the elements of supportive care; however, palliative care also includes specific areas of expertise that may be required, such as unresolved symptoms, and complex psychosocial, end-of-life and bereavement issues<sup>20</sup>.

### 5.2 Achieving supportive care

An important step in the provision of supportive care services is to identify, by routine and systematic questioning of the patient and family, views on issues they require help with for optimal health and quality of life outcomes<sup>7</sup>. Reassessment of their needs is not a ‘once only’ incident because a person’s needs change along the disease trajectory<sup>12</sup>.

A routine and systematic approach to identifying supportive care needs will help to identify people who are at higher risk of psychological or social distress. This identification provides the opportunity for further referral for assessment that is specific to their needs and recognises the individual factors that may place them at increased risk of psychological morbidity. Such factors include characteristics of the individual, such as age and marital status, and characteristics of the disease, such as time of diagnosis or recurrence, stage of disease and prognosis<sup>19</sup>.

A detailed assessment will help to identify those patients who require more specific one-to-one intervention and follow-up.

### 5.3 Establishing a supportive care model

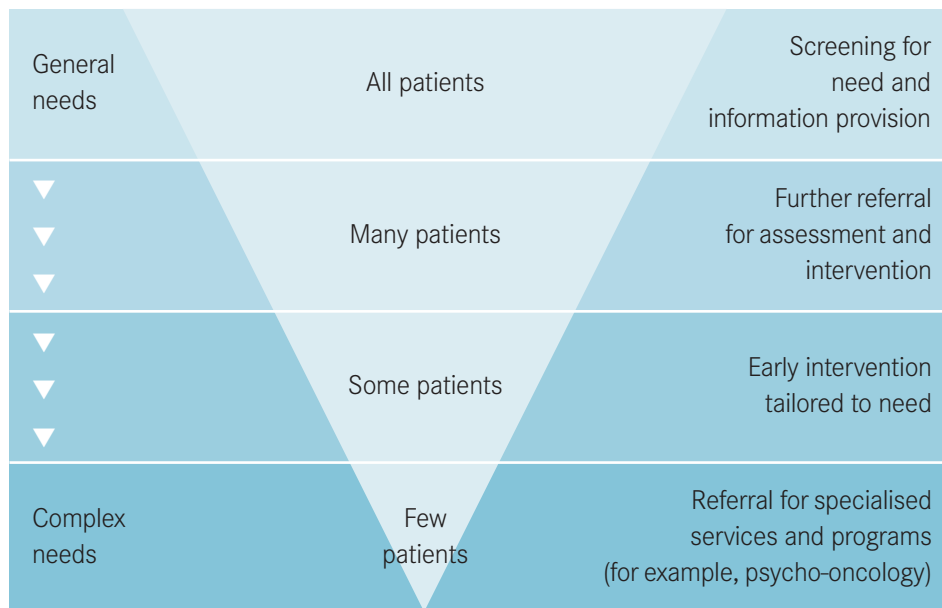
A supportive care model should recognise the variety and the level of intervention required at each phase and be specific to the individual. Such a model (see Figure 2) targets the type and level of intervention required to meet patients' supportive care needs. While there needs to be provision of general information to all patients, only a few patients will require specialised intervention.

As supportive care is provided by a range of services, it is important the following are considered in ensuring cancer patients have access to supportive care:

- processes that assist the identification of patient, family and carer supportive care needs
- clear referral pathways to specialised supportive care services
- adequate staff training in identifying and responding to supportive care needs
- promotion of supportive care as an important element of cancer service delivery.

**Figure 2: Supportive care model**

(Adapted from Fitch<sup>5</sup>. Reproduced with kind permission of Peter MacCallum Cancer Centre).



## 6. Steps in the care of patients with ovarian cancer

This section sets out the steps along the treatment pathway and the optimal care required. Not all patients will follow every step of the pathway. This will depend on the stage of the cancer at diagnosis and the patient's decisions about her care.

### Step 1:

#### At community level, recognition of potential cancer signs or symptoms, or abnormal results from a screening test or investigation

*This step identifies screening programs, the types of women who may be at higher than average risk of developing ovarian cancer, and the types of symptoms that require further investigation by the general practitioner.*

##### 1.1 Screening

- There are no formal screening programs for ovarian cancer.

##### 1.2 Those at higher risk

- Only a small proportion of women develop their cancer as a result of inherited risk.
- Women at potentially higher risk are those with:
  - one first-degree relative diagnosed with epithelial ovarian cancer in a family of Ashkenazi Jewish ancestry
  - two first- or second-degree relatives on the same side of the family diagnosed with breast or ovarian cancer
  - three or more first- or second-degree relatives on the same side of the family diagnosed with any of the cancers associated with hereditary non-polyposis colorectal cancer: colorectal cancer, endometrial cancer, ovarian cancer, gastric cancer, and cancers involving the renal tract
  - a family in which a high risk ovarian cancer mutation has been detected in a gene, such as BRCA 1 and 2, or one of the DNA mismatch repair genes<sup>23</sup>.
- Asymptomatic potentially high risk women should be referred to:
  - a familial cancer centre to ascertain genetic risk
  - a gynaecological oncologist for discussion of appropriate preventative strategies.

##### 1.3 Signs and symptoms that should lead to general practitioner consultation

- Symptoms are vague and non-specific, but persistent symptoms should be investigated, particularly in older women or those with family history. Symptoms may include:
  - abdominal bloating and pain
  - increased abdominal girth
  - abdominal and/or lower pelvic pain.

##### 1.4 Timeframe for general practitioner consultation

- This depends on the severity of symptoms.
- Symptoms that persist for more than four weeks should be investigated. Patients who have symptoms that do not respond to treatment initiated by the general practitioner should return within one to two weeks for review and further investigation.

## Step 2: Initial diagnosis and referral

*This step details the process for establishing the diagnosis and appropriate referral. Management is best undertaken by a certified gynaecological oncologist; however, the types of investigations undertaken by the general practitioner and specialist (gynaecologist, surgeon or certified gynaecological oncologist) depend on many factors, such as the patient's desires, access to particular tests or access to specialists. Decisions on investigations require discussion and agreement between the general practitioner, specialist and patient. If the diagnosis can be confirmed with initial tests, then referral to a certified gynaecological oncologist is optimal. If the diagnosis is suspected, then referral to a specialist for further investigation may occur prior to referral to an appropriate oncologist.*

### 2.1 General practitioner

- General practitioner examinations/investigations should include:
  - a general and pelvic examination
  - trans-vaginal ultrasound by a practitioner experienced in gynaecological ultrasounds
  - CT scan if appropriate.
- Results should be available and the patient reviewed by the general practitioner within one week.

### 2.2 Referral

- Some women need to be referred directly to a certified gynaecological oncologist. Use of a risk of malignancy index in the presence of a pelvic mass is useful in triaging which women would benefit from such referral<sup>23</sup>.
- If referral is to a medical oncologist, surgeon, gynaecologist or other specialist, there should be the opportunity to consult with a certified gynaecological oncologist before commencing treatment<sup>23</sup>.
- Referral should include relevant past history, current history, family history, examination, investigations, social issues, and current medications.
- The appointment should be within one week of suspected diagnosis.
- The specialist should provide timely communication to the general practitioner about the consultation, and should notify the general practitioner if the patient does not attend.

### 2.3 Staging

- Staging is the cornerstone of treatment planning.
- Imaging is used for clinical staging.
- Pathological staging is performed after surgery (step 4). Synoptic reporting by pathologist is encouraged.

## Step 3: Determination of treatment

*This step identifies the members of the multidisciplinary team who need to be involved in initial treatment planning for this type of cancer. While the planning process varies considerably depending on the type of the cancer and the context of the care, the guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.*

### 3.1 Multidisciplinary team

- The multidisciplinary team comprises (in alphabetical order):
  - certified gynaecological oncologist (lead role)
  - general practitioner
  - gynaecologist
  - medical oncologist
  - nurse
  - pathologist with expertise in gynaecological oncology
  - radiation oncologist
  - social worker
- with access to:
  - allied health services where appropriate
  - geneticist and counsellors
  - palliative care services where appropriate
  - pharmacist
  - psycho-oncology services where appropriate (psychologist/psychiatrist).

### 3.2 Multidisciplinary planning

- All women with suspected ovarian cancer should be treated within a setting of a multidisciplinary team.
- For the majority of ovarian cancer cases, diagnosis is made at the time of primary surgery. Pathological diagnosis is not available before surgery.
- Multidisciplinary treatment planning usually occurs at the time of pathology review, but may be required before surgery.
- The primary specialist who makes the referral to the multidisciplinary team is responsible for the patient until care is passed to another practitioner.

### 3.3 Next steps in starting treatment

- The certified gynaecological oncologist is responsible for implementing treatment within the multidisciplinary setting.
- The certified gynaecological oncologist should ensure there is adequate discussion with the patient (and family) of the diagnosis and recommended treatment, including rationale and aim, likely effects, possible outcomes, other treatment options, and psychosocial supports for patient and family.
- There should be timely communication to the general practitioner about the agreed treatment plan.
- Communication to other health professionals (for example, gynaecologist and the general practitioner) should include written documentation of multidisciplinary team recommendations for treatment and management. Communication may include teleconferencing with the general practitioner where practical.
- Progression of care within the multidisciplinary team should be coordinated, ensuring the patient, general practitioner and multidisciplinary team members are clear on their responsibilities for coordination of care.

## Step 4: Treatment

*This step is concerned with the scope of clinical practice to deliver quality and safe practice. Scope of practice reflects both the expertise and experience of the individual as well as the organisational capability for the provision of safe, high quality cancer services<sup>1</sup>.*

### 4A: Surgery

#### 4A.1 Patients who may benefit from surgery

- The majority of patients will be offered surgery during the course of their illness.

#### 4A.2 Training and experience of surgeon

- Certified gynaecological oncologist (FRANZCOG) with adequate training and experience in gynaecological surgery that enables institutional credentialling and agreed scope of practice within this area<sup>1</sup>

#### 4A.3 Hospital or treatment unit characteristics

##### **Staff**

Staffing includes:

- access to gynaecological pathologist, available for frozen section and pathology review
- surgeon as specified in 4A.2.

##### **Facilities**

The following are available:

- anaesthetic services
- high dependency unit
- access within one week to imaging (PET, MRI, CT scan as appropriate)
- access to genetic services
- participation in research and trials.

## 4B: Radiotherapy

### 4B.1 Patients who may benefit from radiotherapy

- Few women with ovarian cancer will have radiotherapy.
- Symptomatic relief and palliation in women with metastatic or recurrent disease can be achieved with radiation therapy<sup>23</sup>.

### 4B.2 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<sup>1</sup>

### 4B.3 Hospital or treatment unit characteristics

#### **Staff**

Staffing includes:

- nurses
- radiation oncologist as specified in 4B.2
- radiation oncology medical physicist
- radiation therapist.

#### **Facilities**

The following are available:

- dual modality LINACS
- CT planning facilities
- treatment planning system
- access to MRI and PET scan where appropriate.

Combined therapy with chemotherapy and radiation therapy needs coordination, especially where facility is not co-located.

## 4C: Drug therapy

### 4C.1 Patients who may benefit from drug therapy

- Adjuvant chemotherapy is recommended for patients with high grade or clear cell histology<sup>23</sup>.
- Chemotherapy may also be of benefit to patients receiving palliation of metastatic disease.

### 4C.2 Training and experience of medical oncologist

- Medical oncologist (FRACP or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice within this area<sup>1</sup>

### 4C.3 Hospital or treatment unit characteristics

#### **Staff**

Staffing includes:

- medical oncologist as specified in 4C.2
- nurses with adequate training in chemotherapy administration, handling and disposal of cytotoxic waste
- If chemotherapy is prepared on site, then a pharmacist with adequate training in chemotherapy medications, including dosing calculations according to protocols, formulations and/or preparation is required.
- Some components of less complex therapies may be delivered in a setting where no medical oncologist is locally available, by another medical practitioner with training and experience that enables credentialling and agreed scope of practice within this area. 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.

#### **Facilities**

- The facility has a clearly defined path to emergency care and advice after hours.
- The facility is able to care for neutropenic patients.
- There is access to haematology testing.
- Cytotoxic drugs are prepared in a pharmacy with appropriate facilities.
- Occupational health and safety guidelines are followed in relation to handling of cytotoxic drugs, including preparation, waste procedures and spill kits<sup>27</sup>.
- Guidelines and protocols, in the case of extravasation of drugs are available and understood.
- Combined therapy with chemotherapy and radiation therapy needs coordination, especially where the facility is not co-located.

## Step 5: Follow-up care

*This step includes monitoring of the status of the disease (including detection of metastatic disease) and management of symptoms that arise following the initial treatment. A clear follow-up plan needs to be established to avoid excessive follow-up by multiple specialists. Follow-up may vary depending on the intent of the initial treatment.*

### 5.1 Plan for follow-up

- The options for follow-up should be discussed at the completion of the primary treatment. No follow-up is also an option<sup>23</sup>.
- A suggested follow-up schedule is:
  - to two years post-treatment: two- to three-monthly
  - to five years post-treatment: four- to six-monthly
  - after five years post-treatment: six- to 12-monthly<sup>23</sup>.
- Investigations should be determined on a case-by-case basis.

### 5.2 Persons involved in follow-up care

- Follow-up care should involve:
  - the multidisciplinary team as appropriate
  - gynaecologist in discussion with the certified gynaecological oncologist
  - general practitioner for routine health checks, co-morbidities and liaison with multidisciplinary team.
- Not all disciplines need to be involved in longer term follow-up. The multidisciplinary team, in consultation with the general practitioner decides on the lead clinician who will coordinate follow-up.
- Responsibility for follow-up investigations needs to be agreed between the designated lead clinician, the general practitioner and the patient, with an agreed plan documented, including notification to the general practitioner or multidisciplinary team member if the patient does not attend.
- Referrals (for example, to genetic counsellors, palliative care, social worker, family counselling) should be on a case-by-case basis.
- The general practitioner has a key role in coordination of follow-up.

## Step 6: Determination of plan and treatment for recurrence

*This step covers treatment for recurrence. The intent is usually disease control and, in some situations, palliative. Clinical evaluation and patient decision making will determine the focus of the treatment.*

### 6.1 Investigative tests

The following investigations may be indicated:

- CA125
- CT scan
- pelvic examination
- chest X-ray
- PET where available and appropriate
- MRI where available and appropriate.

### 6.2 Multidisciplinary team

Management should be discussed by a multidisciplinary team that includes:

- certified gynaecological oncologist
- general practitioner
- medical oncologist
- radiation oncologist
- palliative care service.

General practitioner and palliative care service participation is essential.

### 6.3 Treatments that a patient is most likely to have for recurrence

Treatment will depend on the location and extent of the recurrence and on previous management. Treatment may include surgery (may be needed by a minority of patients (10 per cent), and especially after 12 months), radiotherapy (may be needed by a minority of patients for minimal, isolated disease and palliation), and drug therapy (offered to the majority of patients. Trials and research should be considered.)

## Step 7: End-of-life care

*This step is concerned with quality of life for the patient and her family through care that addresses physical, psychological, emotional and spiritual needs. For the family and carers, this may include bereavement support.*

### 7.1 Multidisciplinary team

- The multidisciplinary team should include (in alphabetical order):
  - allied health staff as appropriate
  - general practitioner
  - medical oncologist
  - nurses
  - palliative care service—relevant team members
  - pastoral care services—relevant team members.

### 7.2 Services that may be required

- Palliative care service: community-based and inpatient
- Home and community care
- Community nursing
- Allied health: dietitian, occupational therapy, pastoral care, physiotherapy

## 7. Specific supportive care needs to consider for patients with ovarian cancer

The supportive care needs of women with ovarian cancer will vary in severity and complexity along the disease trajectory. Identifying and assessing the supportive care needs of women with ovarian cancer involves a general assessment of the physical, psychological, social, information and spiritual needs as detailed in section 5. In addition to these general needs, all members of the multidisciplinary team should be aware of the particular needs related to ovarian cancer detailed below which may require intervention from specific members of the multidisciplinary team.

### Physical needs

- Lower limb lymphoedema, which is common in people with gynaecological cancers who undergo pelvic and/or inguinal lymph node dissection, radiation therapy, or combined vein ligation and inguinal lymphadenectomy<sup>19</sup> can restrict mobility and referral to a physiotherapist or trained lymphoedema massage specialist may be needed.
- Loss of fertility following treatment that involves surgical or radiation therapy to the pelvic organs<sup>23</sup>, or chemotherapy that might induce a premature menopause<sup>19</sup>, require sensitive discussion and possible referral to a social worker, psychologist or psychiatrist.
- Sexual dysfunction, such as vaginal dryness, vaginal bleeding, stenosis, dyspareunia, atrophic vaginitis and pain<sup>19</sup> require sensitive discussion, and referral to a clinician skilled in this area may be appropriate.
- Bowel issues, such as constipation, diarrhoea and cramps, may require support from a continence nurse, stomal therapist or medical specialist<sup>6</sup>.
- Bowel obstruction due to malignancy can occur. Patients need to be alerted to possible symptoms and advised to seek immediate medical assessment<sup>23</sup>.
- Because abdominal ascites may occur<sup>23</sup>, abdominal symptoms need monitoring and assessment.

### Psychological needs

#### Sexuality

- Sexual dysfunction can extend to women clear of active disease for at least two years<sup>23,15</sup>. Clinicians providing follow-up care should continue to assess the possibility of sexual dysfunction. Open discussion about concerns and referral to a social worker, psychologist or psychiatrist with skills in this area may be appropriate.
- Loss of libido or change in sexual activity, such as decreased satisfaction<sup>19</sup>, require sensitive discussion and possible referral to a counsellor with expertise in the area.

#### Body image

- The impact on body image and sexual identity includes an altered sense of self as a social being<sup>22</sup>. Providing patients with tailored, accurate information prior to treatment, facilitating patient decision making about appearance-altering treatment, and meeting others with similar personal experience may assist some people<sup>14</sup>. Support and counselling by a specialist psychologist, psychiatrist or social worker may also be required.

#### Anxiety and depression

- Patients who have had extensive pelvic and abdominal surgery or who receive a multimodality treatment strategy for ovarian cancer are at high risk of depression and heightened anxiety<sup>15</sup>. Regular screening for depression and anxiety specifically for these patients is required. Strategies such as information provision, relaxation techniques, meditation<sup>14</sup> and a referral to a psychologist or psychiatrist as required may be helpful.

## Social/practical needs

- The additional costs of home supports may have a financial impact. Referral to a social worker for further assessment and identification of appropriate funding support may be required.

## Information needs

- Information about avoiding activities that may lead to lymphoedema and identifying early symptoms of lymphoedema should be provided. For further information see a lymphoedema web site, such as <http://www.lymphoedema.org.au/>. If lymphoedema develops, contacts for lymphoedema associations and support groups<sup>19</sup> may be obtained from the Lymphoedema Association of Victoria web site [www.lav.org.au](http://www.lav.org.au).
- Up to 10 per cent of epithelial ovarian cancers are thought to be inherited. Referral to a familial cancer centre if the clinician is unsure of management or the person is at high risk of familial cancer (a family history of cancer in first- and second-degree relatives) may be appropriate<sup>23</sup>.
- Specific information is available from the National Ovarian Cancer Network web site <http://www.ovca.org/>.

## 8. Resource list

### For patients, families and carers

#### 1. The Cancer Council Victoria

1 Rathdowne Street  
Carlton 3053

Telephone: 03 9635 5000  
Facsimile: 03 9635 5270  
Email: [enquiries@cancervic.org.au](mailto:enquiries@cancervic.org.au)  
Web site: <http://www.cancer.org.au>

For information on cancer, its treatment and side effects, support services, medical terminology, and research

#### 2. Cancer Helpline (operated by The Cancer Council Victoria)

Telephone: 13 11 20  
Hours: Monday to Friday, 8.30 am–5.30 pm

For telephone peer support from people who have had cancer experiences or for information on more than 120 cancer support groups across Victoria

#### 3. The Cancer Council Australia

<http://www.cancer.org.au>

##### *Fact sheets:*

Lifestyle: [www.cancer.org.au/lifestyle](http://www.cancer.org.au/lifestyle)  
Early detection: [www.cancer.org.au/earlydetection](http://www.cancer.org.au/earlydetection)  
Post diagnosis: [www.cancer.org.au/diagnosis](http://www.cancer.org.au/diagnosis)

### For health professionals

#### 4. National Health and Medical Research Council

<http://www.nhmrc.gov.au/publications/subjects/cancer.htm>

For downloading clinical practice guidelines for cancer prevention and treatment

#### 5. The Cancer Council Australia

*Fact sheets for health professionals providing advice to patients:*

<http://www.cancer.org.au/factsheets>

One-page fact sheets to help general practitioners and other health professionals advise their patients about cancer prevention, screening and diagnosis. These can also be downloaded from the patient education browser in the latest version (2.86) of the general practice software package, Medical Director.

*Cancer resources for primary health care professionals:*  
[www.cancer.org.au/primarycare](http://www.cancer.org.au/primarycare)

Directory of cancer resources to support general practitioners and other health professionals. Developed by the General Practice Committee of The Cancer Council Australia, the directory provides a single point of access to state, territory and national cancer resources.

#### 6. Clinical trials

A national, online register of clinical trials being undertaken in Australia, the Australian Clinical Trials Registry, is available at <http://www.actr.org.au>. The Australian Clinical Trials Registry includes trials from the full spectrum of therapeutic areas, trials of pharmaceuticals, surgical procedures, preventive measures, lifestyle, devices, treatment and rehabilitation strategies and complementary therapies.

## 9. Abbreviations

BRCA 1 and 2	breast cancer mutations 1 and 2
CA125	cancer antigen 125
CT	computed tomography
FRACP	Fellow of Royal Australasian College of Physicians
FRACS	Fellow of Royal Australasian College of Surgeons
FRANZCR	Fellow of Royal Australian and New Zealand College of Radiologists
LINAC	linear accelerator
MRI	magnetic resonance imaging
PET	positron emission tomography

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