WA Cancer & Palliative Care Network

Gynaecologic Cancer Model of Care

6 November 2008

Government of **Western Australia**
Department of **Health**

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1. Introduction

Cancer is the leading cause of death in Western Australia, representing 30.6 per cent of all deaths in 2006.

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 Western Australia by 2016. In 2006, 400 Western Australians were diagnosed with Gynaecologic cancer and there were 147 deaths due to this type of cancer in 2006.[6]

Model of Care

The WA CPCN Model of Care for Cancer 2008. (http://www.healthnetworks.health.wa.gov.au/modelsofcare/docs/Cancer_Model_of_Care.pdf) provides the basis for this tumour site specific model of care.

This document describes how Gynaecologic Cancer care should be delivered in WA.

The eight steps in figure 1 describe the patient centred journey that provides safe, quality, evidence based, and multidisciplinary care resulting in optimum outcomes.

Underpinning this journey is the integration of primary care, supportive care, psycho-oncology and palliative care. Associated Models of Care can be accessed at http://www.healthnetworks.health.wa.gov.au/modelsofcare/.

2. Comments from the Senate Inquiry into Gynaecologic Cancer in Australia

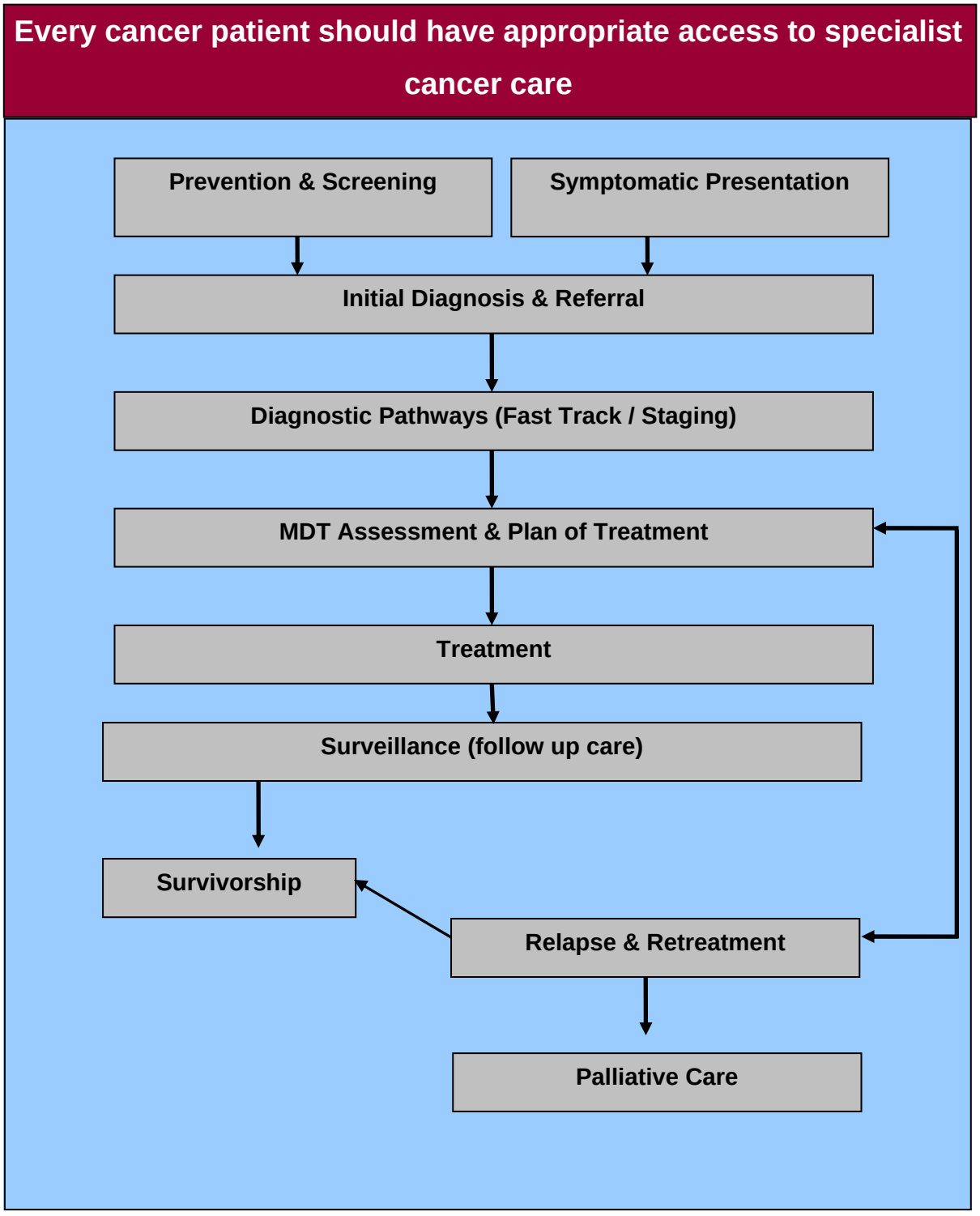
Following the Senate Community Affairs Reference Committee Inquiry into Gynaecological Cancer in Australia, a report was released in February 2007 titled, "Commonwealth Government Response to the Committee's Report: Breaking the silence: a national voice for gynaecological cancers." [1]

Several Commonwealth Government Agencies and Non-Government Organisations are specifically mentioned in this report (Cancer Australia, National Breast Cancer Centre, and NHMRC) and in particular, a key recommendation is for the establishment of a Centre for Gynaecological Cancers within the auspices of Cancer Australia.

The Centre for Gynaecological Cancers will provide a national focus to gynaecological cancer issues. The Centre will also make optimal use of communications and information technologies to support information sharing on gynaecological cancer issues.

In the proposed model of care for the management of gynaecologic cancers in Western Australia there will be references to the Centre for Gynaecological Cancers setting and the recommendations from the Senate Inquiry and these will be detailed in reference section.

Figure 1.


Every cancer patient should have appropriate access to specialist cancer care
Prevention & Screening
Symptomatic Presentation
Initial Diagnosis & Referral
Diagnostic Pathways (Fast Track / Staging)
MDT Assessment & Plan of Treatment
Treatment
Surveillance (follow up care)
Survivorship
Relapse & Retreatment
Palliative Care

3. Screening & Prevention

3.1 Screening

Of all the gynaecologic cancers, only cervical cancer is suitable for a screening program aimed at identifying the disease at a pre-invasive phase. The National Cervical Screening Program is described at the following website:

http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/cervical-1lp

The Pap smear screening program is mature and widely accepted. The establishment of Cervical Cytology Registries (www.kemh.health.wa.gov.au/services/cervical_cancer/, www.vccr.org), have been highly successful in obtaining important data and ensuring high participation rate for Pap smears in the target population. [1]

At an organisational level, Pap smears are taken by general practitioners and authorised health workers. Public awareness campaigns through the various forms of media have ensured that at an individual level, patients are periodically reminded of the need to have regular Pap smears. Members of the Western Australian Gynaecologic Cancer Service (WAGCS) have been supportive of these educational campaigns.

A woman who has an abnormality detected on the Pap smear is then managed according to the NHMRC endorsed guidelines. It is the responsibility of the practitioner taking the Pap smear to contact the patient with the result of the Pap smear. As a failsafe mechanism, the Cervical Cytology Registries will contact practitioner if no follow-up information becomes available after a predetermined time. Where clinically indicated, the woman with an abnormal result is referred for a colposcopic examination. The guidelines are available on the following website:

http://www.nhmrc.gov.au/publications/synopses/wh39syn.htm

The colposcopic assessment of women with a screen detected abnormality should be undertaken in the community by appropriately credentialed gynaecologists. In special circumstances such as in remote areas where there are no specialist services, a general practitioner with a special interest in women's health may be specifically trained in colposcopy to triage women who need treatment. This should not be necessary in the metropolitan area or where specialist services are readily available as this may result in two separate colposcopic assessments on the one patient.

The services at King Edward Memorial Hospital (KEMH) should be maintained for the purposes of teaching specialist trainees and for the assessment and management of more complex cases. Routine low risk colposcopy should be referred back to the community gynaecologist. Following treatment of a screen detected abnormality, the patient should be referred back to her referring doctor or general practitioner in accordance with the 2006 NHMRC guidelines.

3.2 Surveillance for High Risk Subjects

Certain groups in our community have been identified as being at particularly high risk of developing gynaecological cancers. In the case of cervical cancer, high risk subjects are those who are of indigenous background or are immunosuppressed. Models of care for these subjects are discussed in more detail below. In the case of endometrial cancer, high risk subjects are those who are on Tamoxifen or who carry an HNPCC mutation. Practitioners looking after women with these risks should maintain a high index of suspicion. Referral of appropriate patients for genetic counselling would be ideal to ensure the woman is fully aware of the risks and her options. In the case of ovarian cancer, high risk subjects are those who carry a genetic mutation such as BRCA and Hereditary Non-Polyposis Colon Cancer (HNPCC). A strong family history of related cancers is invariably present and ideally these women should be offered referral for genetic counselling.

3.3 Screening in Indigenous Women

At a policy level, the Commonwealth Government is committed to improving the screening rate for indigenous women. [2]

3.4 Surveillance of women with a hereditary cancer risk

Surveillance of high risk subjects should include women who have a hereditary risk for a gynaecologic cancer. Women who carry a BRCA mutation or HNPCC mutation should have access to the State-wide Genetic Services of Western Australia. This service should be provided in a multidisciplinary setting. Women who are identified at high risk should have expert counseling regarding their risk, and provided non-directive options with regard to the management of their risk. Access to expert imaging should also be available. Where a surgical option is selected, the woman should be referred to an appropriate specialist who is able to provide comprehensive counseling as well as perform additional surgery where an occult cancer is discovered at the time of surgery.

3.5 Prevention

With the advent of the HPV vaccine, 70% of cervical cancers are potentially preventable. It is still necessary for vaccinated women to have a regular pap smear and it is important to ensure that the health providers and the public do not become complacent in regard to the National Cervical Screening Program.[3]

4. Initial Diagnosis and Referral

4.1 Symptoms and Signs

As gynaecologic cancers constitute a diverse group of cancers with different symptoms and signs, the cancers are discussed separately. Other health authorities have established templates to assist referring doctors with the workup of patients with suspected or proven gynaecologic cancers and these are appended at the end of this section.[4]

a. Vulvar, vaginal and cervical cancers may present with pruritis vulvae, a visible, palpable or ulcerated lower genital tract lesion, abnormal per vaginal discharge or bleeding, or lower genital tract pain. Locally advanced lesions may present with palpable groin nodes, bladder or bowel dysfunction including fistula formation. Should these symptoms or signs be elicited, a thorough examination of the lower genital tract should be undertaken, including performing a Pap or vulvar smear. Referral for specialist assessment with or without colposcopy should be organised if there is high index of suspicion or confirmation of a cancer. If the appearance of the vulva, vagina or the cervix is abnormal referral is appropriate even if the lower genital tract cytology is negative.

b. Endometrial cancers may present with abnormal vaginal bleeding, discharge or abdominal pain. Locally advanced cases may present with bowel or bladder dysfunction including fistula formation. Should these symptoms or signs be elicited, a thorough examination of the lower genital tract should be undertaken, including taking a Pap smear. A pelvic ultrasound may help in the investigation of women presenting with post-menopausal bleeding. Referral for specialist assessment with or without colposcopy should be organised if there is high index of suspicion or confirmation of a cancer. The Scottish Intercollegiate Guidelines Network has developed guidelines for the assessment of post-menopausal bleeding. [4]

c. Ovarian cancer often presents at a late stage due to the non-specific symptoms and signs associated with this disease. The NHMRC have developed guidelines to assist primary physicians with the assessment of women with persistent non-specific symptoms. [5]

4.2 Timeframe to See a Specialist

Referral of a patient with a suspected gynaecologic cancer diagnosis to a Certified gynaecologic oncologist is important for their management. Patients who have their primary cancer care undertaken by a gynaecologic oncologist have a better outcome than those patients managed by another specialist.

Patients with suspected gynaecological cancer should have their initial outpatient assessment within four weeks of referral. If the patient is symptomatically distressed then more urgent assessment may be needed.

It is important that the gynaecological cancer workforce be sufficient to provide timely assessment and treatment. [7]

4.3 Type of specialist

A woman with a confirmed diagnosis of a gynaecologic cancer should be referred to a Certified Gynaecologic Oncologist (CGO) or a RANZCOG recognised Gynaecologic Oncology Service with access to a multidisciplinary team (WAGCS).

A woman with a differential diagnosis that includes a high probability of a gynaecologic cancer should either be referred directly to a CGO or the patient should be discussed with a CGO and referred as appropriate.

Patient and General Practitioner education is required to facilitate appropriate referral patterns and this is supported by the Commonwealth Government initiatives. [8]

The WAGCS provides a Statewide 24 hour telephone consultation service for medical practitioners who require advice on the management of a patient with a suspected or confirmed gynaecologic malignancy. Continuing education of practitioners and medical students on the utilisation of the risk of malignancy index for ovarian cancer is provided. When the risk of malignancy has been assessed to be high, advice is given regarding any further investigations and arrangements are made for a timely consultation.

The appropriateness of some referrals to the WAGCS is currently under review. This review is undertaken in collaboration with the Gynaecology Service at KEMH.

Referrals to the WAGCS are by telephone call followed by a written referral, or a written referral that is posted and/or faxed to KEMH. The referral is then triaged by a consultant to an appropriate clinic. If the patient is from a rural area, all efforts are made to involve the rural Cancer Nurse Coordinator to help facilitate the transport, pre-consultation investigations and to shorten the referral/consultation/treatment process to minimise the disruption to the patient and her family.

5. Diagnostic Pathways

This step deals with the investigations that may be required to confirm the diagnosis of cancer and assess the extent (staging) of the cancer.

This may involve complex tests in different departments/locations and wherever possible should be coordinated to improve patient convenience and well being. Fast track, coordinated diagnostic pathways should be implemented at a system level.

5.1 CAT Scan

CAT scan of the chest abdomen and pelvis is a useful imaging study to determine the presence of locoregional and distant metastasis. This should be available in both the public and private community setting, and in both metro and regional areas. It is appropriate for GPs or specialists to organise a CAT scan in a private radiology community setting as this will expedite this investigation. Discussion with the specialist at the time of referral may lead to this investigation being performed so that it is available at the time of initial specialist consultation. Timely access to CAT scanning should be available in metro and regional centres.

There is no on-site CT scanning service at King Edward Memorial Hospital and therefore women who require CT scans are referred to other hospitals. Doctors are encouraged to obtain this investigation prior to assessment.

5.2 Magnetic Resonance Imaging (MRI)

MRI is used in the assessment of cervical cancer to determine the local extent of disease and operability. The need for this investigation is usually determined by the gynaecologic oncologist and the MDT as part of the comprehensive assessment prior to determining the type of treatment. When required, decision planning is dependant on the result, otherwise treatment is delayed. It is expected that MRI will be available in a timely fashion so that treatment delay does not occur.

There are no on-site MRI scanning services at King Edward Memorial Hospital and, therefore women who require MRI scans are referred to other hospitals.

5.3 Positron Emission Tomography (PET)

PET may be useful in the assessment of metastatic disease and disease recurrence after treatment, in all gynaecological cancers but especially in ovarian cancer. Access to PET scan services in Western Australia has become more difficult with only one PET scanner servicing the State.

5.4 Pathology

Assessment of tissue specimens by appropriately qualified histopathologists is critical to the diagnostic process. Fine Needle Aspiration specimens for cytology may be obtained from sites of potential metastasis and expert cytopathologists are required to assess this material. Timely provision of these services will usually be carried out by the state pathology service, PathWest or by private pathology

providers. Specialist gynaecological histopathology assessment is often required intraoperatively during surgical treatment.

6. MDT Assessment and Plan of Treatment

All patients should have access to a MDT to plan the management of their cancer. It is essential that a cancer specialist lead the MDT approach and that this be available to all patients no matter where they live. It is expected that patients in rural and remote areas will have access to this care and that this will be co-ordinated by their GP, local specialist or cancer nurse coordinator using video-conferencing or assisted travel where appropriate.

6.1 Multidisciplinary Team

Women with gynaecological cancers should be managed by a specialist multidisciplinary gynaecological oncology team ideally based at a Cancer Centre, such as WAGCS. This team should liaise closely with designated gynaecologists at a Cancer Unit Level.

All members of the MDT should have a special interest in gynaecological cancer. One member should take managerial responsibility for the service as a whole.

MDT members

- Gynaecological oncologists
- Radiation Oncologist
- Medical Oncologist
- Palliative Care Physician
- Gynaecologic histopathologist/cytologists
- Radiologist
- Social Work
- Cancer Nurse Coordinator/Oncology Liaison Nurse

With access to:

- Allied health services including physiotherapy, dietician, where appropriate
- Palliative care service for patients with locally advanced cancers and metastatic disease.
- Psycho-oncology services as required (psychologist/psychiatrist)
- Anaesthetic and Physician consultation perioperatively.
- Cancer genetics specialist
- Gynaecologists and pathologists at the Cancer Unit
- GP/primary health care provider

The specialist gynaecological oncology team meet weekly at a multidisciplinary Tumour Board (case conference) to review, discuss and determine the management of newly diagnosed patients, and those presenting with a recurrence.

6.2 MDT Treatment Care Plan

Treatment will be planned after all relevant investigations have been reviewed and discussed at the weekly Tumour Board.

In general, all patients, private and public, with gynaecological cancer are (and should be) discussed at the Tumour Board in an MDT setting where there is expertise in gynaecological cancer management. Discussion will usually take place before initial treatment, but in some circumstances will occur after surgery has occurred and a cancer has been discovered.

The primary specialist who makes the referral to the MDT is responsible for the patient until care is passed to another practitioner.

The MDT must be adequately resourced to undertake the following responsibilities and should:

- Specify and document who will be the primary treating specialist
- Fully document the agreed care plan
- Circulate the agreed care plan to all relevant members of the team
- The progression of care within the MDT should be coordinated ensuring that the patient and all care givers understand their responsibilities for delivering this care.
- The GP should be informed of the planned treatment and their role in this plan

The patient and their family should be centrally involved in arriving at the preferred treatment plan but it is not necessary for the patient to be present at the Tumour Board discussion

6.3 Referral Pathways for Allied Health Services

It is recognised that gynaecologic cancer patients will need to access Allied Health Services, such as physiotherapy, psychological services, social work and dietitians. Specific problems may be encountered by patients with treatment related lymphoedema of the lower limbs who are in need of compression garments. There is currently an inequity for access such that private patients may find it difficult to access these services without significant cost implications. [10]

Psychosexual and psychosocial assessment of patients with gynaecologic cancer is important and integral to the WAGCS. It is recommended that a clinical psychologist be available to participate in the assessment of all new and selective follow-up patients.

7. Treatment

This step is concerned with the type of treatment that will be delivered, who will provide it and where it should be provided to ensure safe, high quality and effective care

Treatment should be delivered according to best practice and evidence based guidelines, where available, WA Guidelines are available and are based on National and International best practice.[12]

Surgical treatment should be performed by certified gynaecological oncologists, or trainees under their supervision, and such specialists should be associated with a multidisciplinary gynaecological cancer centre/unit.[13]

7.1 Surgery

All women with gynaecologic cancers should have their cases discussed at a multidisciplinary clinico-pathological meeting. If surgery is required, then the surgery should be performed by a CGO or under the CGOs supervision. This is important for several reasons:

- Surgery is performed by an appropriately trained subspecialist who can provided comprehensive surgical care at a single surgical event
- Surgery performed by a CGO will generally be in one of three hospitals where there is ready access to tertiary level intraoperative histopathological assessment, which will determine the scope of surgical treatment.
- Surgery performed by a CGO or under the supervision of a CGO will maintain the standards of skills for the CGO and the trainee CGOs. With an annual caseload of approximately 400 cases, of which 75 – 80% may require primary surgery, dilution of this caseload may result in the deskilling of the subspecialist.
- Patients benefit from having concentration of skilled practitioners (medical and allied health) with higher experience in dealing with the small numbers of these types of cancers.
- Recruitment of patients with gynaecologic cancers into clinical and other trials is logistically easier if the service is centralised.

7.2 Radiation Treatment

- For gynaecologic cancer, primary radiation therapy, adjuvant pre-operative or post-operative radiation treatment may be prescribed. The radiation therapy may be in the form of brachytherapy, external beam or interstitial therapy.
- Radiation treatment should be given by a radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialing and agreed scope of practice within this area.
    - Radiation treatment should be performed in accredited institutions with experience in complex treatment planning

Radiation therapy is not available at KEMH and is currently provided at Royal Perth Hospital and Perth Radiation Oncology.

In specific cases, combined chemotherapy and radiation therapy may be required and needs effective coordination, especially where the facilities are not co-located. This is currently the situation for women with gynaecologic cancers who may require combined radiation therapy and chemotherapy. This is not ideal for the patient for practical reasons.

7.3 Drug Therapy

- Drug therapy including chemotherapy is usually given to patients who are at high risk of relapse and who may benefit from adjuvant therapy
- Drug therapy may be given to those patients with locally advanced or metastatic disease
- Drug therapy is usually given by a Medical Oncologist (FRACP or equivalent) with adequate training and experience that enables institutional credentialing and agreed scope of practice within this area
- Drug therapy is usually given in an institution with the following characteristics:
  - Staff including a medical oncologist, nurses with adequate training in chemotherapy administration, handling and disposal of cytotoxic waste, pharmacist with adequate training in chemotherapy medications and preparation
  - Less complex therapies may be given in secondary, regional or primary care settings (where no medical oncologist is locally available) by another medical practitioner or nurse chemotherapy provider with training and experience that enables credentialling and agreed scope of practice. This should be in accordance with a detailed treatment plan arising from a MDT setting, and should be under the supervision of a medical oncologist with communication as required.
  - Facilities for safe administration of drug therapy include:
    - Emergency care and advice after hours
    - Care for neutropenic patients
    - Access to haematology testing
    - Cytotoxic drugs are prepared in a pharmacy with appropriate facilities, including provision and transport of such drugs from a tertiary or secondary institution
    - Guidelines and protocols for the safe administration of drugs including management of extravasation
    - Intensive care/high dependency unit availability (not sure this is necessary)

Currently patients do receive chemotherapy in regional settings, including Bunbury, Geraldton, Albany and Kalgoorlie. Visiting Medical Oncology Services are available from WAGCS to Geraldton and Bunbury, with other services providing care to the other sites.

8. Surveillance (Follow-Up Care)

This step concerns the monitoring of the patient following initial treatment. The aim is the early detection of disease relapse and /or the management of symptoms arising from treatment or the disease. It also provides reassurance to patients who appear to be free of disease. A clear documented plan of surveillance should be established and be available to the patient. This should avoid multiple visits to multiple specialists.

8.1 What Follow-up Care is Needed:

- Patients who are medically fit should undergo regular surveillance as they are at increased risk of second primary cancers and recurrent disease.
- Patients who are medically fit , who are at moderate to high risk of metastatic or recurrent disease, should undergo surveillance to identify potentially treatable disease.
- A surveillance/follow up plan should be agreed by the patient and the coordinating MDT clinician and clearly documented in the patient record
- The surveillance plan must be communicated to the patient's general practitioner
- The surveillance plan should be individualised according to risk of recurrence and patient needs
- Clinical examination and investigations such as colposcopy, CT scan, Chest x-ray and Tumour markers should be available in tertiary, secondary and primary care settings as recommended in established clinical practice guidelines
- The exact location of follow up will be decided in consultation with the patient, GP and lead clinician

8.2 Who Should Provide the Follow-up Care:

- The MDT team in consultation with the GP will decide who should lead the follow up care
- Responsibility for follow up investigations (colposcopy, tumour markers, CT scan) should be agreed by the lead clinician, GP and patient and should be documented
- Patient failure to attend for follow up should be notified to the responsible clinicians
- Every effort must be made to reduce multiple visits to different treatment disciplines
- Patient specific follow up may require involvement of occupational therapists, physiotherapists, dietitians, stomal therapists, social work, psycho-oncology support and nurses

8.3 Where Should Follow-up be Provided:

- Follow up should be provided in public hospitals (tertiary and secondary), private hospitals, private specialist consulting rooms and general practitioner rooms

- Imaging studies can be provided by any appropriately credentialed facility as long as results are delivered to the appropriate responsible clinician.
- Regional centres should be encouraged to provide coordinated follow up according to protocol, with input from the lead clinician as required, if necessary by videoconference.
- The General practitioner has a key role in the coordination of follow up.

Timing of follow-up appointments have been developed for the WAGCS, as detailed in Appendix 2.

9. Survivorship

The transition from active to post treatment care is critical to long term health. Care should be planned and coordinated. Survivors should have knowledge of their increased risk of second/ recurrent cancers or treatment related morbidities. This encourages them to actively participate in their continuing post treatment care. This approach is essential so that routine follow up visits become opportunities to promote a healthy life style, check for cancer recurrence and manage lasting effects of the cancer experience.

Survivorship may be medically led, particularly through primary care, nurse-led or patient-led. Cancer councils across Australia are developing and evaluating approaches that are patient centred.

Survivorship is described in the literature as either:

- Having no disease after diagnosis or completion of treatment
- The process of living with, through and beyond cancer. By this definition cancer survivorship begins at diagnosis

The nature of gynaecological cancer tells us that the WAGCS - will always be caring for the complete spectrum those patients that are cured with surgery and require no adjuvant treatment and those who continue to live with their cancer all the while accessing treatment.

The key areas to be aware of when considering the care needs of survivors with cancer are easily identified using a quality of life model.[14] In relation to gynaecological cancers this means: (Appendix 3)

- Management of Lymphoedema
- Management of Recurrent Bowel Obstruction
- Management of Early menopause
- Management of Fertility Issues –
- Management of Psychosexual Issues
- Employment Issues
- Fear of Recurrence
- Screening for second cancers and osteoporosis

10. Relapse and Retreatment

This step concerns the diagnosis and management of patients who have recurrence of the disease (local or metastatic) and who need assessment regarding further treatment. This assessment may be made by the GP initially with subsequent involvement of the specialist and the MDT. Clinical evaluation and patient discussion will determine the most appropriate treatment which may be curative or palliative in intent.

Patients who relapse require expert opinion as to the best plan of management and this will usually be provided by the MDT. Treatment for relapse may require drug therapy, radiation therapy or surgery.

10.1 What Should be Provided:

- The diagnosis of relapse will usually be made by the patient who develops symptoms, GP or the specialist surgeon/physician coordinating follow up
- Timely referral for full assessment and discussion by the MDT is recommended
- Timely access to appropriate investigations is important including
  - Blood tests
  - Chest X ray
  - Ultrasound
  - CT scan
  - MRI pelvis where appropriate
  - PET where appropriate
  - Colposcopy

10.2 Management Should Be Discussed By:

- The lead clinician in liaison with the GP and with involvement of one or more relevant members of the multidisciplinary team with input from other specialists if necessary
- The management plan should be decided in consultation with the patient and fully documented in the patient record
- Participation by the GP and palliative care team is essential

10.3 Where Should Assessment and Retreatment Occur:

- Following diagnosis and confirmation of relapse, assessment should occur in a setting that involves the lead clinician and the MDT, often in a tertiary cancer centre but could be in a secondary or regional centre with input by the relevant clinician/oncologist and the MDT. Telehealth may be of assistance in some cases
- Surgical treatment for relapse often involves complex therapy and is usually carried out in a tertiary cancer centre. Patients receiving palliative chemotherapy could be treated public tertiary or secondary hospitals or large private hospital with appropriate infrastructure.

- The extent of disease and the patient's health may lead to a process of disease control or palliation rather than a curative approach.

11. Palliative Care

The WA Palliative Care model defines the appropriate approach to symptom management and end of life care.

It is important that patients and their families receive optimal palliative care and early referral for assessment and advice is recommended.

It is also important to recognise that a major component of palliative care involves symptom relief and this may require surgical intervention, radiation therapy or chemotherapy.

(related Models of Care available at www.healthnetworks.health.wa.gov.au/modelsofcare).

Women with gynaecological cancers are considered a special needs group because of the known high incidence of symptoms (compared to patients with most other malignancies.) The WA Palliative Care Model of Care promotes the need for tertiary services to have the capacity and resources to provide leadership, outreach advice, episodic care and consultancy to secondary and primary care services in both metropolitan and rural locations.

By its nature, WAGCS (KEMH) provides a specialist service, but does not warrant full-time appointments of Palliative Care specialist medical and nursing staff. Nevertheless it is required to offer the same services as a tertiary Palliative Care service, but on a smaller scale. At present part-time palliative care medical appointments are in place at WAGCS and it is possible that in the future a formal relationship can be established with a tertiary care Specialist Palliative Care Service, as defined in the Palliative Care Model of Care document.

Clinical Guidelines

Gynaecological Oncology Palliative Care Guidelines have recently been drawn up by the Gynaecological Oncology Palliative Care Advisory Group of the NSW Greater Metropolitan Clinical Taskforce Gynaecological Oncology Committee. These guidelines are currently being reviewed and are likely to be adopted or adapted for use in Western Australia. They are based on the premise that "women with gynaecological malignancies are at risk of numerous symptoms, and palliative care may be beneficial for those who are carrying a symptom burden that interferes with their ability to live well."

Palliative Care at WAGCS

This is integrated at outpatient assessment clinics, follow-up clinics and inpatient services. This is detailed in Appendix 4.

12. Recommendations

1. The centralised model of care for the management of women with a gynaecologic cancer must be maintained.
2. All patients with a diagnosed gynaecologic cancer or have a high risk of a gynaecologic cancer should either be referred to a Certified Gynaecologic Oncologist or at the very least have their case discussed with a Certified Gynaecologic Oncologist
3. It is a matter of urgency that the inequity in access to allied health services be addressed so that no patient with a gynaecologic cancer should have her care potentially compromised on the basis of health insurance status.
4. The ideal model of care for the WAGCS would include recurrent funding for a full time clinical trials nurse/data manager.
5. The ideal model of care for the WAGCS would include a fully funded hospital based Cancer Nurse Specialist or Case manager working in liaison with the Tumour Collaborative Gynaecologic Cancer Nurse Coordinator and the Rural Cancer Nurse Coordinator.
6. Medical students should be exposed to the concept of multidisciplinary team care and the subspecialty of gynaecological oncology in their curriculum.
7. Trainee general practitioners should be exposed to the concept of multidisciplinary care and the sub-specialty of gynaecological oncology in their training.
8. It is recommended that chemotherapy and radiation treatment be available at a single collocated site.
9. It is recommended that the recommendations of the Senate Inquiry into gynaecological cancer be adopted wherever possible.

References

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11. Management Guidelines for Gynaecological Cancer: WA Gynaecology Cancer Services, May 2003
12. Commonwealth Government Response to the Senate Community Affairs References Committee Inquiry into Gynaecological Cancer in Australia "*Breaking the silence: a national voice for gynaecological cancers*": **Recommendation 24**
13. Commonwealth Government Response to the Senate Community Affairs References Committee Inquiry into Gynaecological Cancer in Australia "*Breaking the silence: a national voice for gynaecological cancers*": **Recommendation 25**
14. http://www.cityofhope.org/Pages/default.aspx

Appendices

Appendix 1

ONCOLOGY REFERRAL

ALL doctors referring patients to Oncology MUST fax referral to 9340 1016.
URGENT referrals telephone 9340 1383 or 9340 1128 during office hours
0800 – 1600 hours, Monday to Friday.

WESTERN ASUTRALIAN GYNAECOLOGICAL CANCER REFERRAL GUIDELINES

- Gynaecologic cancer that has been confirmed
- Gynaecologic cancer that is highly likely (eg., clinical cancer of the vulva, vagina or cervix, severe atypical endometrial hyperplasia, elevated Ovarian Risk of Malignancy Score* (ROM score), ovarian mass with ascites)
- Risk reduction counselling and surgery
- Complex pelvic surgery service is also offered but will have lower priority

SPECIFIC REFERRAL GUIDELINES

- Refer to Colposcopy Clinic if not obviously clinical cancer of vulva, vagina or cervix
- Refer to Outpatient Hysteroscopy Clinic if history of postmenopausal bleeding or endometrial thickening without tissue diagnosis.

VULVA/ VAGINA	CERVIX	UTERUS / ENDOMETRIUM	OVARY
Biopsy with histology results ❑ Clinical cancer ❑	Biopsy with histology results ❑ Clinical cancer ❑	Biopsy with histology results ❑	CA 125 result (provide normal range)
Clinical findings	Colposcopy findings	Hysteroscopy findings	Pelvic ultrasound findings Results attached ❑
CT abdomen/pelvis CXR results Results attached ❑	CT abdomen/pelvis CXR results Results attached ❑	CT abdomen/pelvis CXR results Results attached ❑	CT abdomen/pelvis CXR results Results attached ❑
BMI	BMI	BMI	BMI

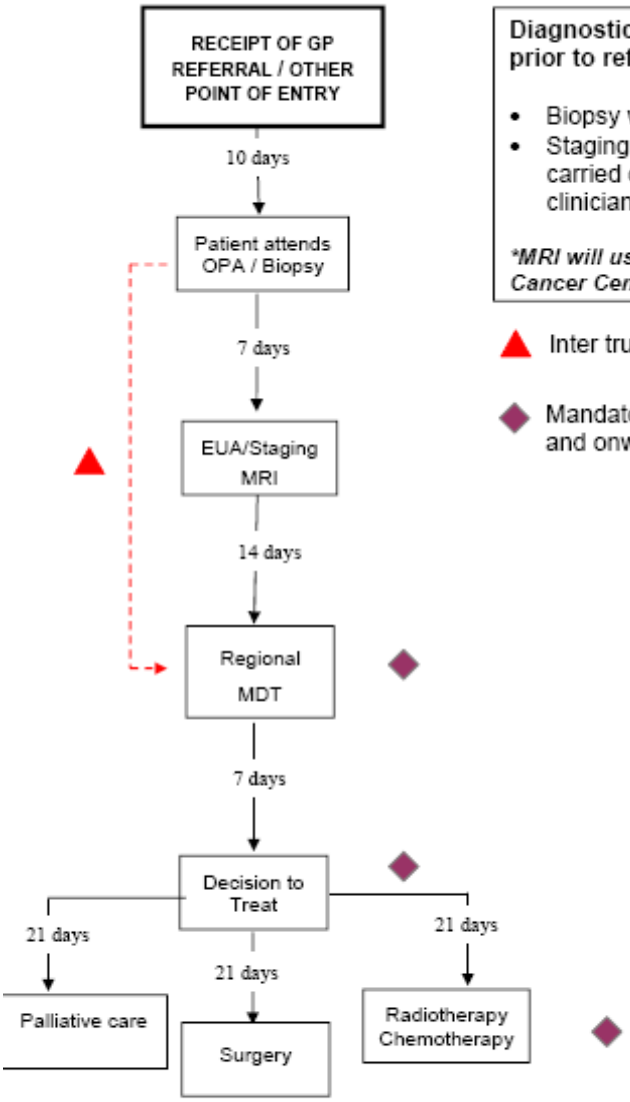
*ROM Score = multiplication of the following factors:

Menopausal status (pre = 1; post = 3) x **USS features** (simple = 1; complex = 3) x **absolute CA 125 level**
Refer if >200 (if CA 125 NR <35)
>120 (if CA 125 NR <21)

FIGURE 1. INVESTIGATIONS TO BE COMPLETED AT CANCER UNIT TO BE FORWARDED WITH TERTIARY REFERRAL

Cervical	Vulval	Endometrial	Ovarian
• Biopsy with histology review. • Staging procedure - this may be carried out by a special interest clinician at a Cancer Unit. ***MRI will usually be carried out at the Cancer Centre.***	• Biopsy with histology results. • Anaesthetic assessment as appropriate • CT Scan of Pelvis/Abdomen/Chest - may be done at Cancer Unit or at Centre. • MRI of pelvis if suspicion of pelvic node involvement – may be completed at Unit (following appropriate protocols) or at Centre.	• Hysteroscopy/ biopsy with histology results. • MRI (following appropriate protocols). • Anaesthetic Assessment as appropriate	• Abdominal Ultrasound & CA125 - use these to calculate the Risk of Malignancy Index (RMI) • CEA, C19.9 • CT of Pelvis / Abdomen / Chest • Peritoneal/Pleural tap or Core Biopsy with histology results - may be required where there is doubt regarding the primary origin of the tumour (special histological stains may be sought also). *To be completed at Unit where facility is available* • Anaesthetic fitness assessment as appropriate

CARE PATHWAY CERVICAL CANCER



Diagnostics to be completed at Unit prior to referral to tertiary centre

- Biopsy with histology review
- Staging procedure - this may be carried out by a special interest clinician at a Cancer Unit.

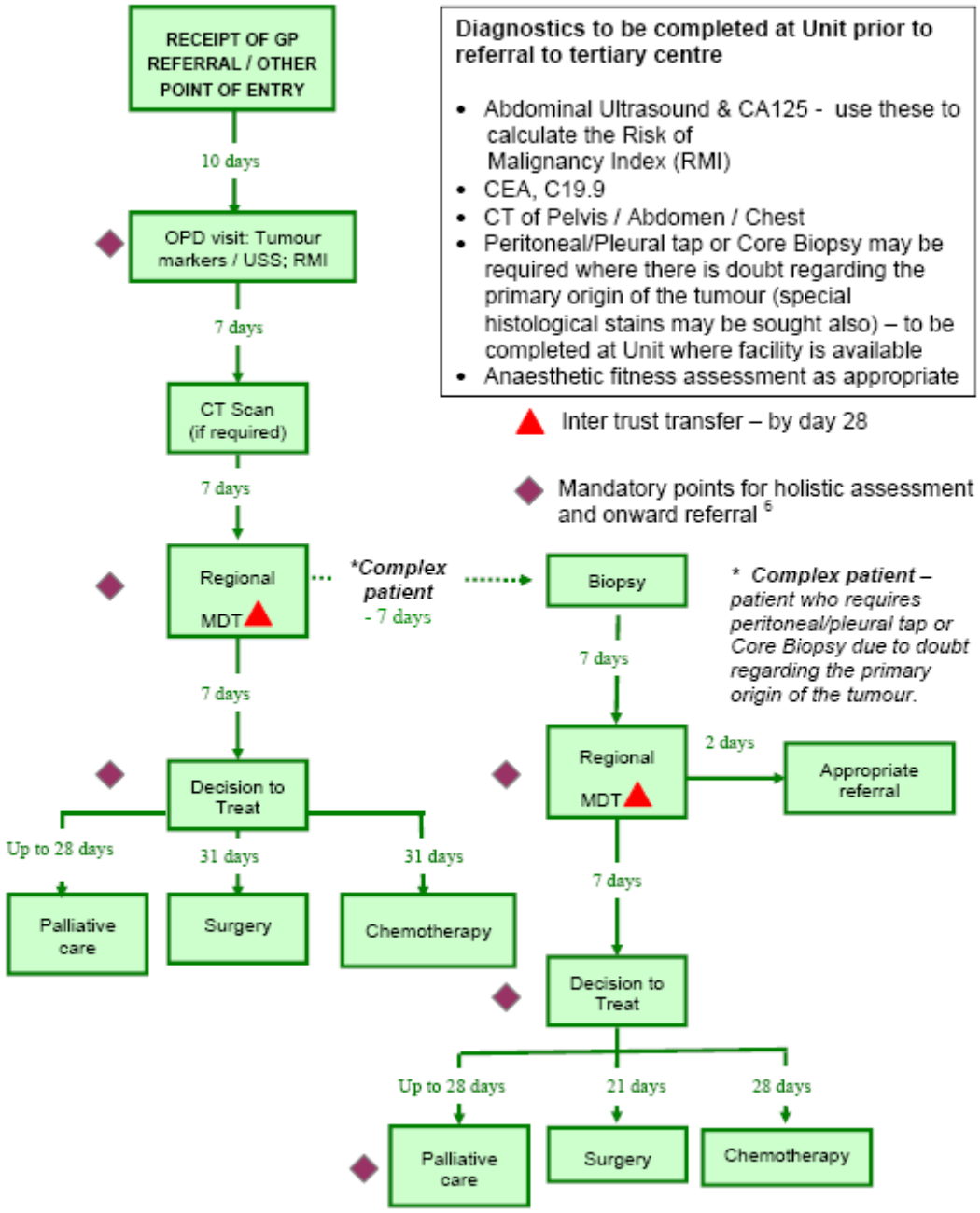
MRI will usually be carried out at the Cancer Centre.

▲ Inter trust transfer – by day 28*

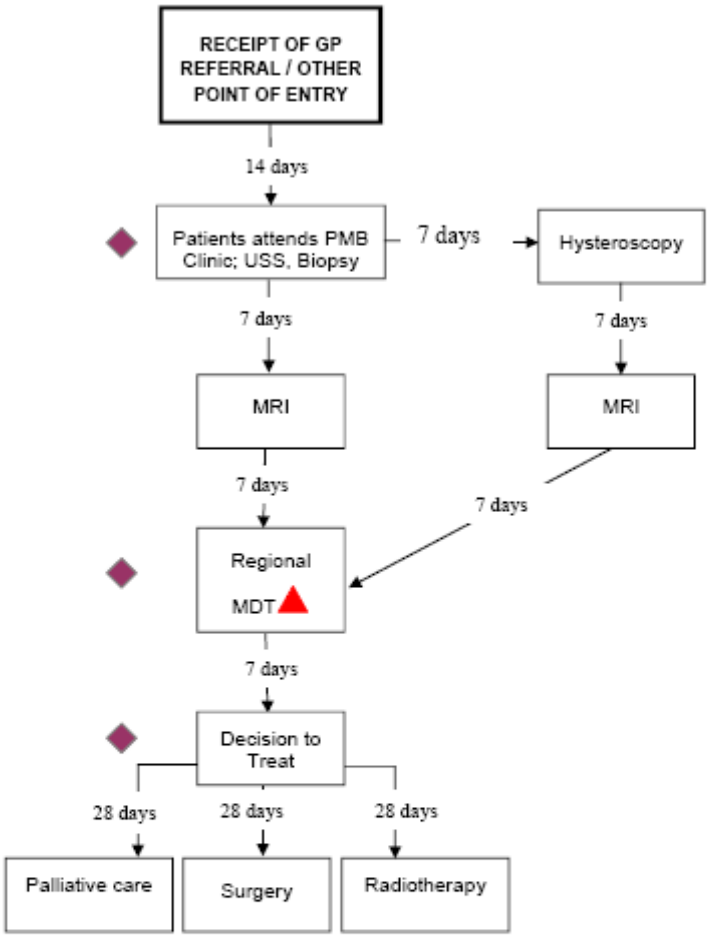
◆ Mandatory points for holistic assessment and onward referral [6]

** Referral to centre is not dependent upon completion of other investigations*

CARE PATHWAY OVARIAN CANCER



CARE PATHWAY ENDOMETRIAL CANCER



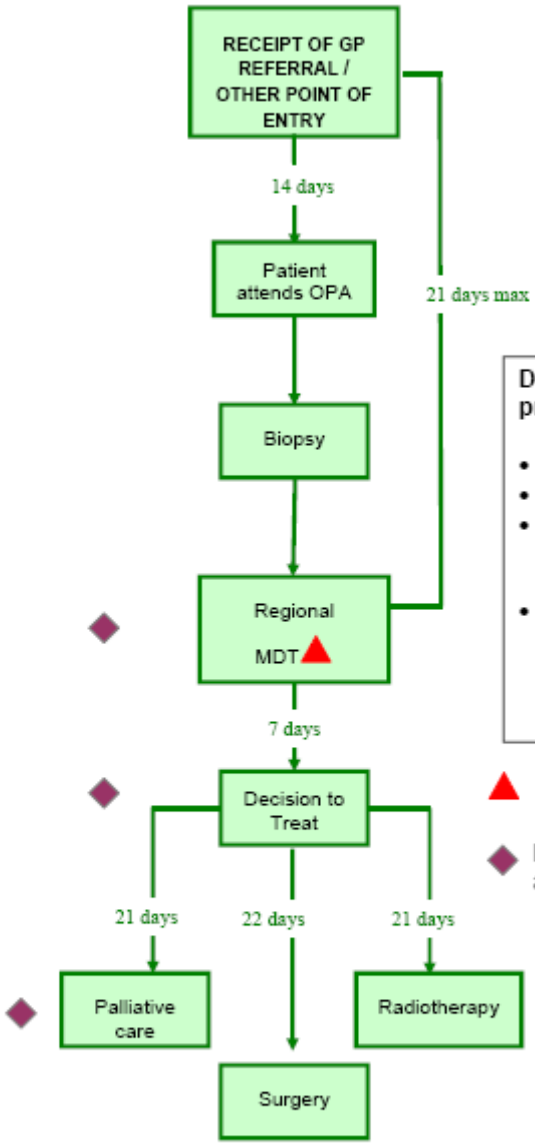
Diagnostics to be completed at Unit prior to referral to tertiary centre

- Hysteroscopy/ biopsy
- MRI (following appropriate protocols).
- Anaesthetic Assessment as appropriate

▲ Inter trust transfer – by day 28

◆ Mandatory points for holistic assessment and onward referral [6]

CARE PATHWAY VULVAL CANCER



Diagnostics to be completed at Unit prior to referral to tertiary centre

- Biopsy with histology results
- Anaesthetic assessment as appropriate
- CT Scan of Pelvis/Abdomen/Chest - may be done at Cancer Unit or at Centre.
- MRI of pelvis if suspicion of pelvic node involvement – may be completed at Unit (following appropriate protocols) or at Centre.

▲ Inter trust transfer – by day 28

◆ Mandatory points for holistic assessment and onward referral [6]

For women with Gynaecological Cancer treated at Western Australia Gynaecological Cancer Service

Cancer Type	Initial Visit	YEAR 1 - 2	YEAR 3 - 5	AFTER 5 YEARS	PROTOCOL	EXCEPTIONS
VULVA						
All stages Vulvar Cancer except advanced	6-8 Weeks	6 monthly	Yearly	GP Yearly	Examine Vulva and Groins Yearly Pap if Cervix present	1. Vulvoscopy as indicated
	Fellow Clinic					
Advanced Vulvar Cancer requiring Chemo-rads	*Rad Onc Clinic*			*Tailored to Patient*		
CERVIX					1. Ask re: symptoms especially bleeding 2. Physical, Speculum, PV/PR exam	
1. Surgery Only	6-8 Weeks	6 monthly	Yearly	GP Yearly	1. & 2. above + Vault Cytology	1. Lymphoedema: Referral to physiotherapy 2. If there is any concern of recurrence: Referral to Thursday clinic
	Registrar Clinic					
2. Surgery + Rads	6-8 Weeks	6 monthly	Yearly	GP Yearly	1. & 2. above + Vault Cytology	
3. Chemo-rads or Rads	3 months	4 monthly	6 monthly	GP Yearly	1. & 2. above + Cx/Vault Cytology	
	First 2 yrs Thurs, then Registrar Clinic					
4. Advanced/ Metastatic Disease at Presentation	*Thursday Clinic*				Individualised care usually involving Radiation Oncology and PCS	
UTERUS						
All Stages Endometrial Cancer: 1. Without Rads	6-8 Weeks	6 monthly	Yearly	GP Yearly	1. Ask re: symptoms especially bleeding 2. Physical, Speculum, PV/PR exam NO need for PAP unless suspicious lesion	1. Metastatic Disease at initial presentation 2. Recurrent Disease Above groups will require consultation with Medical Oncology and PCS 3. If low risk, consider share care
	Registrar Clinic					
2. With Rads	6-8 Weeks	6 monthly	Yearly			
	Thursday Rad Onc Clinic		*Registrar*			
OVARY						
1. Surgery only	6-8 Weeks	6 monthly	6 monthly	GP Yearly	1. & 2. above + Ca 125	1. Liase wit Medical Oncology at SCGH to avoid double booking patient appointments 2. Imaging studies not routinely booked 3. Consider involvement of PCS
	Registrar Clinic					
2. Surgery + Chemo On Trial Protocol	6-8 Weeks	6 monthly	6 monthly	GP Yearly	1. & 2. above + Ca 125	
Off Trial Protocol	6-8 Weeks	4 monthly	6 monthly	GP Yearly	1. & 2. above + Ca 125	
	Thursday or Fellow Clinic					
3. Non-epithelial Granulosa Cell Malignant Germ Cell	6-8 Weeks	6 monthly	6 monthly	KEMH Yearly	1. & 2. above + GRANULOSA CELL: Inhibin GERM CELL: Relevant Marker	Individualised Care for many of these tumours
4. Borderline Tumours Stage 1 & 2: TAHBSO	6-8 Weeks	6 monthly	Yearly	GP Yearly	1. & 2. above + Ca 125 2. Scan if abnormality	
Stage 3: TAHBSO	6-8 Weeks	6 monthly	Yearly	GP Yearly		
Staged with Remaining Ovary	6-8 Weeks	6 monthly	6 monthly	GP Yearly	1. & 2. above + Ca 125 2. TVUS of remaining ovary at each visit.	Consider Pelvic Clearance once close to menopause or childbearing is complete
	Registrar Clinic					

Appendix 3

Management of Lymphoedema

Free lifelong access to appropriate compression garments for public patients. A minimum of two garments to be supplied.

A life long access to affordable Lymphoedema Management with at least 5 free treatments per year.

Promotion of Education programs for Lymphoedema management to increase the number of providers available. (This could create the opportunity for the Gynae-Oncology tumour collaborative to form a partnership with universities with undergraduate physiotherapy students)

Management of Recurrent Bowel Obstruction

Women have clear information about the symptoms of bowel obstruction and clear plan of management plan -

Management of Early menopause

Access to Menopause After Cancer clinic (MSAC)

Management of Fertility Issues –

Access to counselling prior to surgery or treatment and a priority pathway back to discuss options post treatment

Management of Psychosexual Issues

Ongoing access to counselling as the impact of change of body image and sexual issues as these issues may change across the life span. (Impacts on our younger women who may not be in relationships at the time of treatment or women or meet new partners)

Employment

Women who have been treated for Gynae-oncology cancer may need assistance to negotiate with employers their work environment. Some may not be able to return to work full time but may have capacity to work part time.

Fear of Recurrence

This is the most predominant concern for survivors. On discharge from KEMH a clear Survivorship Care Plan would assist with reducing anxiety.

The literature supports the development of a Cancer survivor Care Plan as per Cancer Patient to Cancer Survivor: Lost in Translation 2006.

http://www.iom.edu/Object.File/Master/30/879/fact%20sheet%20-%20care%20planning.pdf

Key components of the care plan being:

- Prevention

- Surveillance
- Intervention
- Co-ordination between the specialist - KEMH and primary care provider - GP

Research

Promotion of local research into the issues for survivors of gynaeoncology cancer in Australia

References

2006 Cancer patient to Cancer survivor: Lost in Translation Institute of Medicine

Screening for second cancers and osteoporosis

Increased 5-year relative survival rates means that a significant and increasing cohort of women are becoming long term survivors of gynaecological cancers. “Women with a personal history of breast, ovarian or endometrial cancer are at an increased risk for developing a second primary breast cancer in the unaffected breast, endometrial cancer, ovarian cancer or colorectal cancer.” “Premenopausal women who have been successfully treated for these cancers are often subjected to a premature menopause.” “These women are not usually candidates for HRT and one of the consequences of long-term oestrogen deficiency is an increased risk for bone loss, osteoporosis and fractures.” (*Cancer Practice* Vol. 8 No 6 American Cancer Society 2000)

In spite of statistical evidence from the United States that survivors have an increased risk for second cancers, osteoporosis and fractures specific patient education initiatives and screening guidelines that differ from those applicable to the general population have not been published.

Consideration needs to be given to the routine inclusion of education and advice on relative risks and recommendations for screening to both patients and their primary care physicians.

Appendix 4

Organisation at KEMH

The current model of Palliative Care physicians being integrated into the weekly outpatient clinic works very well, with patients often being seen on the same day by Gynaecological Oncologists, Allied Health staff and a Palliative Care physician.

It is highly desirable that all patients undergo routine review of physical symptoms and psychological distress on each and every occasion of service at all WA Gynaecological Cancer Services, and that those identified as suffering or potentially suffering receive a timely cross-referral to specialist Palliative Care staff. This may be achieved by the development of a brief inventory of symptoms which could be completed by patients in the waiting room and handed to the CGO or other practitioner they are attending on the day.

That many patients with gynaecological malignancies will be afflicted with a disproportionately high incidence of bowel obstruction or bowel dysfunction should be recognised and strategies employed to minimise the development of symptoms.

Patients with cancer, including those with gynaecological cancers have a significant incidence of (often unrecognized) humoral hypercalcaemia of malignancy which responds to both targeted cancer therapy and bisphosphonates. If bisphosphonates are to be employed, review and correction of poor dental health in the workup for cancer treatment is needed to minimize the incidence of osteo-necrosis of the jaw. Thus access to dental health services is an important emerging preventative health strategy relevant to gynaecological cancer services.

Palliative Care staff should be employed at the KEMH to gain experience in the particular symptom complexes most associated with gynaecological cancers. They will also act as a resource and support for symptom identification and management of patients who choose to receive their Palliative Care in the community, particularly those who wish to return to regional centres or rural areas for end-of-life care. The use of telehealth technologies to review palliative care patients who have returned to rural and other centres should be embraced wherever possible.

KEMH should aim to be recognized as a centre of excellence in the Palliative Care of women with gynaecological malignancies and liaise with the Royal Australasian College of Physicians to be accredited for sessional training for Palliative Care Registrars training at a major tertiary care hospital.

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