



South Australian
Gynaecological
Cancer Care Pathway
Optimising Outcomes
for Women with
Gynaecological
Cancer

October 2011



Government
of South Australia

SA Health



Australian Government

Cancer Australia

Developed by the Gynaecological Oncology Working Party
of the Statewide Cancer Clinical Network February 2010

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EXECUTIVE SUMMARY

The South Australian (SA) Gynaecological Cancer Care Pathway was created under the auspices of the SA Cancer Clinical Network. It provides recommendations based on current evidence for best practice in the management of women with gynaecological cancer.

The SA Gynaecological Cancer Care Pathway has been developed through a collaborative effort involving a wide range of health professionals involved in the gynaecological cancer journey. It is a statement of consensus based on current best practice, evidence and accepted approaches to the management of women throughout their cancer journey. Recommendations should be followed subject to the health professional's independent medical judgment and the woman's choice in each individual case. The pathway adopts a multidisciplinary approach with involvement of all relevant health professionals.

In South Australia gynaecological cancers contribute to approximately 3.73% of all cancer deaths. From 1999 to 2008, 33,243 women died from cancer of which 1,240 had a gynaecological malignancy. Optimal cancer management is achieved through a coordinated service provision between public and private hospitals, general practitioners (GPs), Aboriginal Health Services and Palliative care services. It is essential to expedite treatment and access to supportive care with the aim to maximize quality of life.

Recommendations

Stage in Cancer Journey	Pathway Recommendations	System Recommendation
All stages of the cancer journey	Psychosocial support to be available for women at all stages of the cancer journey in public and private care.	A suitable location to be provided for psychosocial counselling. Increased and ongoing education and training for all staff regarding the role of psychosocial support. Increased access to specialised psychosocial support services by the multi-disciplinary team.
Genetic risk assessment	Genetic counsellors are available and accessible for all women seen at high risk clinics.	An increase in the number of counsellors is required to support the need of all women seen at high risk clinics.
	The recording of family history should be done routinely for recognition of women with genetic risk.	A checklist to be developed to assist clinicians with the recording of family history for cancer.
Early detection and screening	Education for women should be commenced as teenagers.	Gynaecological cancer education should be part of sexual education at school
	Best practise referral systems and timely access to screening.	Ongoing information of GPs regarding available services and referral methods
	Women should have access to information about screening and cancer related risk factors.	Information should be easily accessible from both websites and primary health care clinics.

	Cervical screening should be offered by all primary healthcare facilities.	Training for midwives and nurses is supported and provided by SHine SA. (http://www.shinesa.org.au)
Diagnosis and Treatment	All women with a diagnosis of a gynaecological cancer have to be discussed at a Gynaecological Oncology Multidisciplinary Team Meeting (MDT).	Any woman who is diagnosed with a gynaecological malignancy by a GP or specialist must be referred to a Gynaecological Oncology MDT for discussion and recommendation.
	The information about women with a gynaecological cancer has to be collected and processed for discussion at the MDT in a timely fashion.	A position of a MDT coordinator needs to be created.
	Electronic MDT clinical summary tool.	Training, education and access available to all staff for access to MDT discussion and recommendations.
	Rural GPs and specialists are encouraged to refer a woman to the Gynaecological Oncology MDT if needing advice.	Case is discussed by a multidisciplinary team and treatment recommendations sent back to referring clinician.
	All GPs and specialists seeing a woman with a suspected gynaecological malignancy should consult the best practise referral pathway.	All women should be encouraged to follow the advice from their treating practitioner regarding the referral pathway
Treatment	Women needing surgery for gynaecological cancer should be operated by a specialist Gynaecological Oncologist	GPs and specialists have to be informed about how best to access Gynaecological Oncologists
End of life / Palliative Care	Specialist palliative care services can improve outcomes in relation to women's satisfaction, being cared for in their place of choice, control of physical and emotional symptoms.	Early referral is often helpful. The involvement of palliative care services does not preclude, and will frequently support, the commencement or continuation of active treatment
	Access to specialist palliative care is limited in rural and remote areas; point of care tools and resources such as eviQ (www.eviq.org.au) should therefore be promoted and used.	GPs and clinics in rural and remote areas should be given increased support to provide palliative care.

1. INTRODUCTION

1.1. Gynaecological Oncology Pathway Development

The four most common gynaecological cancers are:

- Cervical cancer
- Ovarian cancer
- Endometrial cancer
- Vulvar cancer

Over 4,000 women are diagnosed with gynaecological cancer and over 1,500 women die from this disease in Australia each year.

Overall cancer survival is lower in people living in regional Australia. Aboriginal and Torres Strait Islander women have an increased incidence of cervical cancer and are more likely to die of their disease.

Care principles of women with a gynaecological cancer include:

- Timely access to services to avoid unnecessary delays in diagnosis and treatment
- Optimal multidisciplinary management according to best practice guidelines
- Access to a 'safe' physical, emotional and cultural environment
- Well co-ordinated care
- Access to optimal supportive care including:
 - Information provision and decision-making tailored to women's needs
 - Assessment and management of short and long-term physical side effects
 - Provision of psychosocial care including assessing and responding to emotional, psychological, spiritual, social and familial requirements
 - Provision of practical support including access to financial, transport and accommodation needs
 - Support and information to assist with psychosexual and fertility issues
 - Issues related to survivorship and end of life care
 - Particular attention needs to be paid to the specific needs of women from regional and remote Australia, Aboriginal and Torres Strait Islander women and women from culturally and linguistically diverse backgrounds

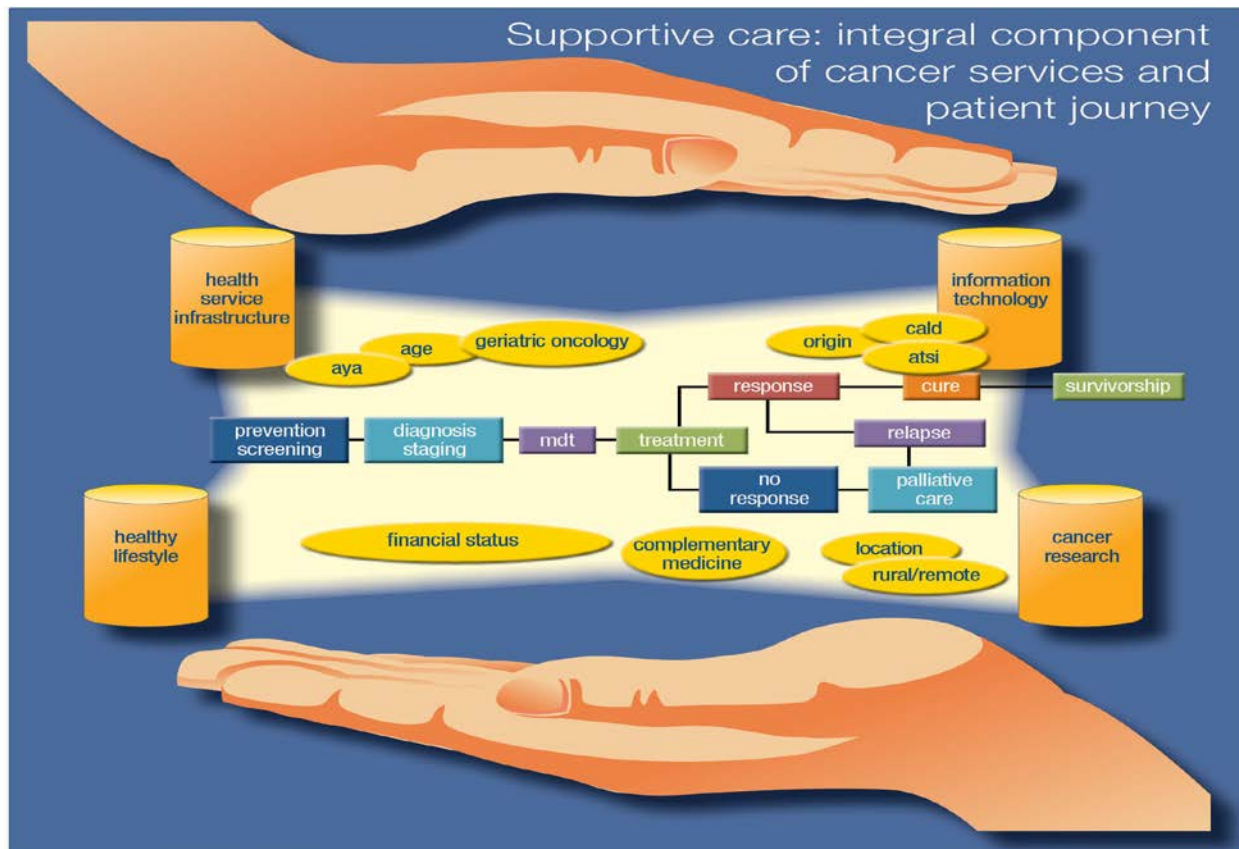
The Gynaecological Oncology working party focused on the following key areas:

- Prevention and Early Detection
- Multidisciplinary care
- Diagnosis and staging
- Treatment
- Follow-up
- Survivorship needs / End of life care

The pathways are designed around the patient journey – described in the Cancer Pathway Model. ([Figure 1](#)).

Each working party of the SA Cancer Clinical Network utilised the common cancer pathway model as a basis for individual pathway development to ensure consistency with the concept.

Figure 1 - Cancer Pathway Model¹



Explanatory notes

- Pillars represent the key requirements that provide support for cancer services.
- Central cancer pathway illustrates the clinical aspects of the cancer journey.
- Hands represent supportive care, which is integral to clinical care.
- Circles or 'pods' surrounding the pathway highlight the key issues that require due consideration in planning all cancer clinical and supportive care.

1.2. SA Health Aboriginal Health Impact Statement and Checklist

An Aboriginal and Torres Strait Islander Companion Document to the Statewide Cancer Control Plan (2011 – 2015) and Cancer Care Pathway has been developed by The Aboriginal and Torres Strait Islander Committee of the SA Cancer Clinical Network. This document serves as a guide outlining the range of issues facing Aboriginal and Torres Strait Islander cancer patients and their families. These issues impact on all stages of a patient's experience from diagnosis, treatment and support, to palliative and bereavement care and survivorship. The document gives some clear direction on ways to improve the outcomes for Aboriginal South Australians with a cancer diagnosis. For full details please go to the following website: <http://www.sahealth.sa.gov.au>

2. GYNAECOLOGICAL CANCER REFERRALS

Gynae-oncology services are currently provided in three public hospitals.

Women can be referred to a Gynaecological Oncology Multidisciplinary team meeting (MDT) at either the Royal Adelaide Hospital or Flinders Medical Centre.

To make a referral please call the following hospitals.

2.1. Gynaecological Oncology Services in Public Hospitals

ROYAL ADELAIDE HOSPITAL

Location is in the Central Business District

Department of Gynaecological Oncology

Royal Adelaide Hospital

North Terrace

ADELAIDE SA 5000

Phone: (08) 82224816 – Secretary

Fax: (08) 82225952

Phone: (08) 82225917 – Women's Health Centre

Email: GynaeOnc.RAH@health.sa.gov.au

Switchboard phone: (08) 8222 4000 ask for Gynaecological Oncology Registrar or Gynaecological Oncology Nurse Specialist

FLINDERS MEDICAL CENTRE

Location is 14 kilometres south of the Adelaide Central Business District

Department of Obstetrics and Gynaecology

Flinders Medical Centre

Flinders Drive

BEDFORD PARK SA 5042

Gynaecological Oncology consultant can be contacted through FMC switchboard on his mobile (08) 8204 4346

0884042151-Flinders Cancer clinic

Switchboard phone: (08) 8204 5511 ask for Gynaecological Oncology Registrar/Fellow or Gynaecological Oncology Nurse Specialist Pager 38374

QUEEN ELIZABETH HOSPITAL

Location is 9.5 kilometres west of the Adelaide Central Business District

Queen Elizabeth Hospital

28 Woodville Road

WOODVILLE SOUTH SA 5011

Switchboard phone:

(08) 8222 6000 ask for Gynaecological Oncology Registrar or Gynaecological Oncology Nurse Specialist

2.2. Private Gynaecological Oncologists

There are four Gynaecological Oncologists who work across the public and private health sectors in SA.

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3. INCIDENCE OF GYNAECOLOGICAL ONCOLOGY

In order to accurately meet the population needs for targeted prevention and specific cancer therapies, the incidence of cancer according cancer type and region are being monitored.

Table 1 and Graph 1 shows the incidence of gynaecological cancers in SA between 1999 and 2009, according to the type of cancer. The total incidence of gynaecological cancers in SA across this period demonstrates a clear gradual increase. Uterine cancer is the main contributor to this trend, followed by a slight increase in ovarian cancer incidence for this period. The numbers of cervical, vulvar, vaginal and other unspecified female genitalia cancer types, however, are fairly stable.

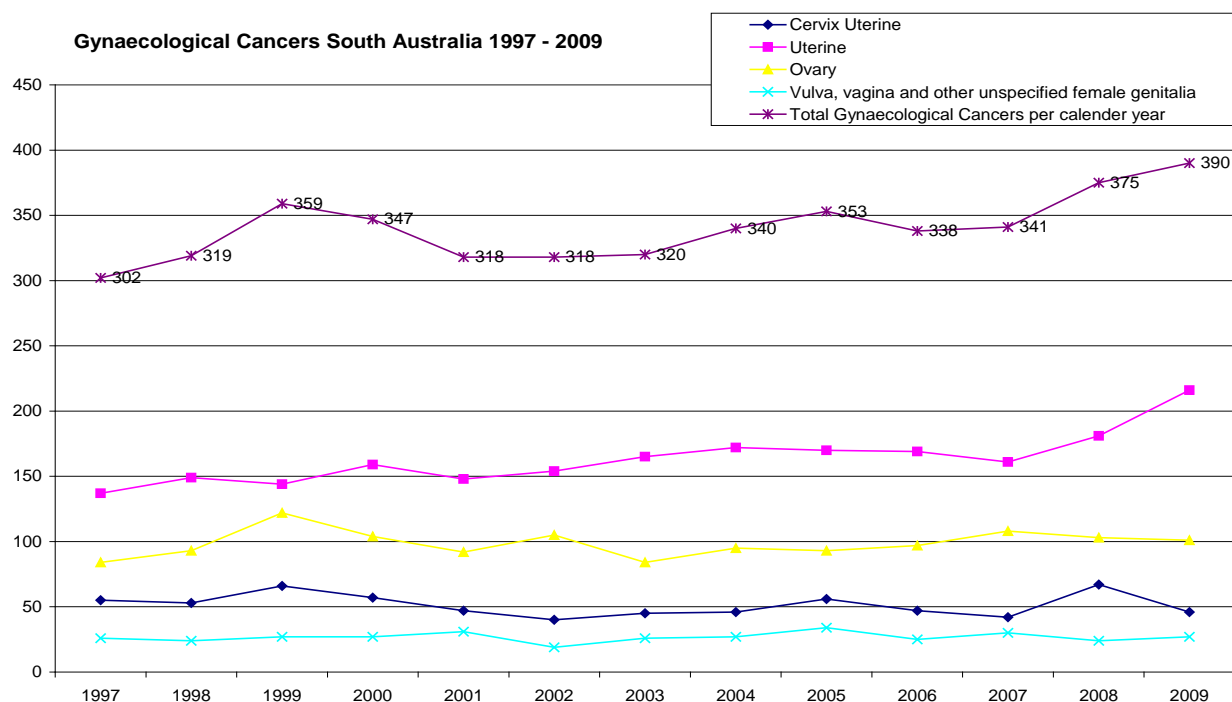
Table 2 shows the incidence of gynaecological cancers in SA between 1999 and 2009, according to regional statistical division. The Adelaide statistical division accounts for about three quarters of all gynaecological cancer incidences in SA, followed by Outer Adelaide at about 8%. While gynaecological cancer incidence for Adelaide is clearly trending upwards in line with the total population incidence, the other statistical divisions do not have a large enough sample size to clearly demonstrate trends in incidence.

Table 1 - SA Gynaecological Cancer Incidence – whole State

Year	Cervix Uterine	Uterine	Ovary	Vulva, vagina and other unspecified female genitalia	Total
1999	66	144	122	27	359
2000	57	159	104	27	347
2001	47	148	92	31	318
2002	40	154	105	19	318
2003	45	165	84	26	320
2004	46	172	95	27	340
2005	56	170	93	34	353
2006	47	169	97	25	338
2007	42	161	108	30	341
2008	67	181	103	24	375
2009	46	216	101	27	390
Total	667	2125	1076	347	4420

Source: SA Health Cancer Registry. Last updated by Epidemiology Branch, SA Health – 24 March 2011

Graph 1 - SA Gynaecological Cancer Incidence – whole State



Source: SA Health Cancer Registry. Last updated by Epidemiology Branch, SA Health – 24 March 2011

Table 2 - SA Gynaecological Cancer Incidence – by Region

STATISTICAL DIVISION								
Year	Adelaide	Outer Adelaide	Yorke and Lower North	Murray Lands	South East	Eyre	Northern	Total
1999	267	24	16	13	11	9	19	359
2000	266	18	13	14	14	5	17	347
2001	234	20	8	19	11	11	15	321
2002	228	21	14	10	12	12	21	318
2003	230	33	11	9	15	7	15	320
2004	260	16	14	13	11	6	19	339
2005	261	24	14	13	18	11	12	354
2006	250	23	17	13	16	9	10	339
2007	256	32	7	10	12	9	15	341
2008	272	23	14	17	22	4	23	375
2009	295	32	16	11	20	5	11	390
Total	3272	310	171	172	186	98	210	4420

Source: SA Health Cancer Registry. Last updated by Epidemiology Branch, SA Health – 24 March 2011

4. REFERRAL PATHWAYS FOR GYNAECOLOGICAL CANCER

There are several ways to refer a woman to the Gynaecological Cancer Service in South Australia. To ensure that a woman is treated in a timely manner certain clinical information should be available prior to referral and discussion by a MDT. The required clinical information is dependent on the type of suspected or diagnosed cancer.

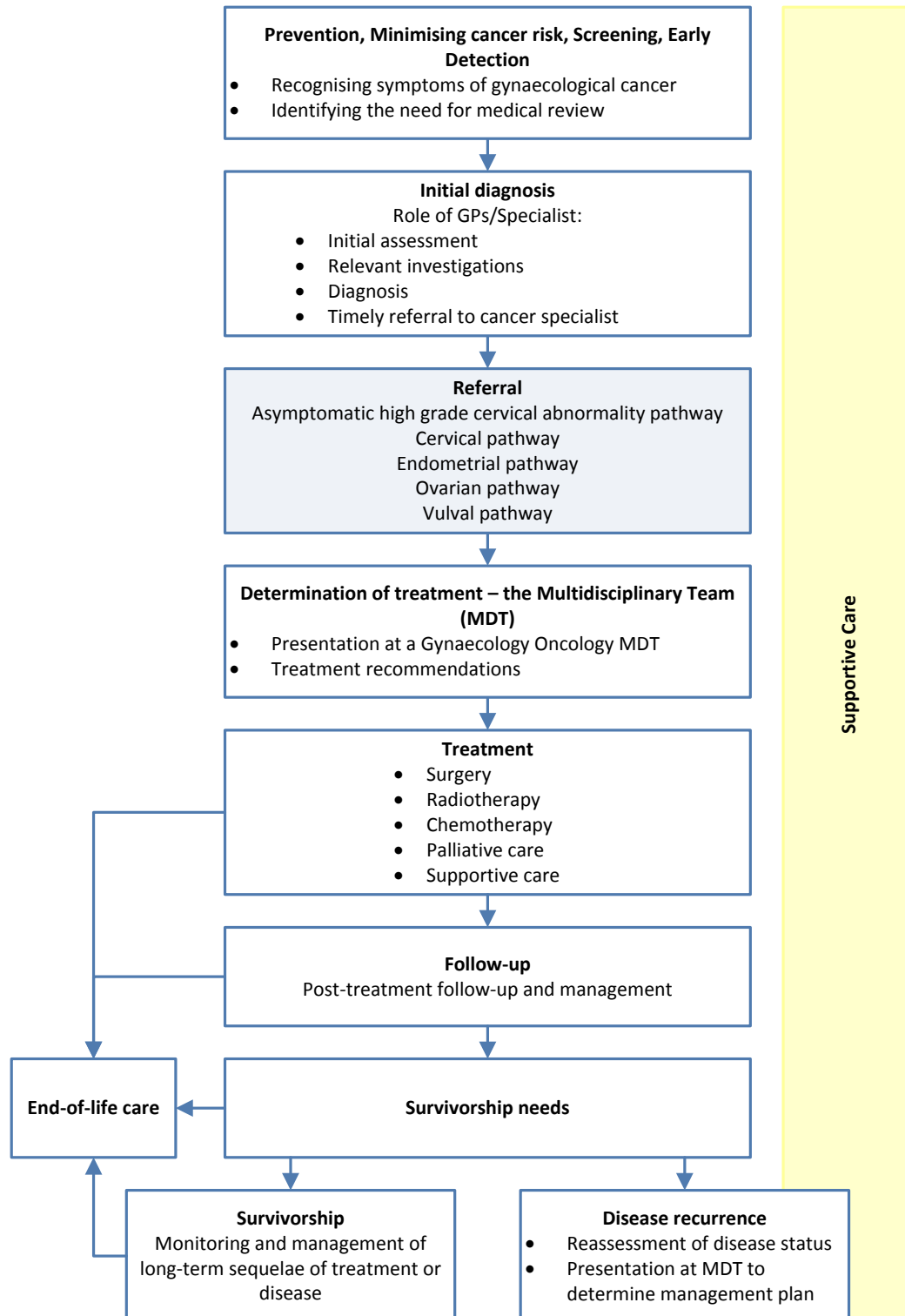
Please refer to the individual referral pathways for information and guidance.

- [Asymptomatic high grade cervical abnormality pathway](#)
- [Cervical cancer pathway](#)
- [Endometrial cancer pathway](#)
- [Ovarian cancer pathway](#)
- [Vulvar cancer pathway](#)

Please refer to the Gynaecological Oncology Service Directory in [Chapter 2](#) for details of available treatment centres.

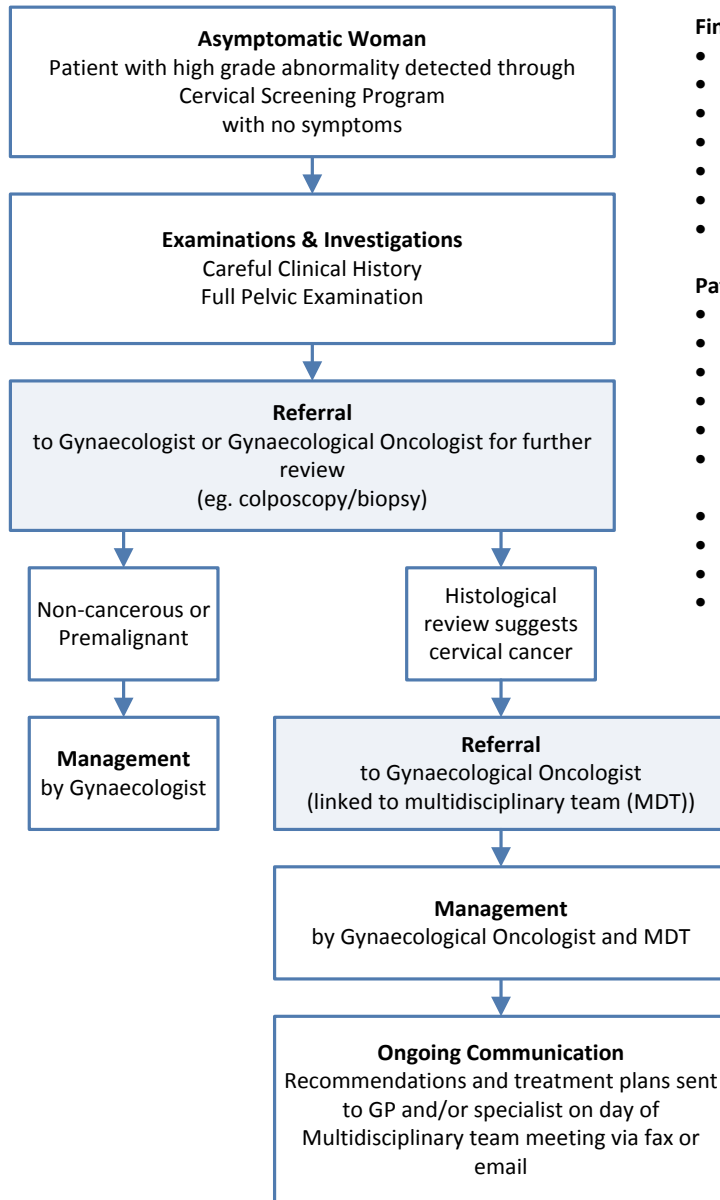
4.1. Generic Gynaecological Cancer Pathway

Generic Gynaecology Oncology Cancer Pathway



4.2. Asymptomatic High Grade Cervical Abnormality Pathway

Asymptomatic High Grade Cervical Abnormality Pathway



Findings to note

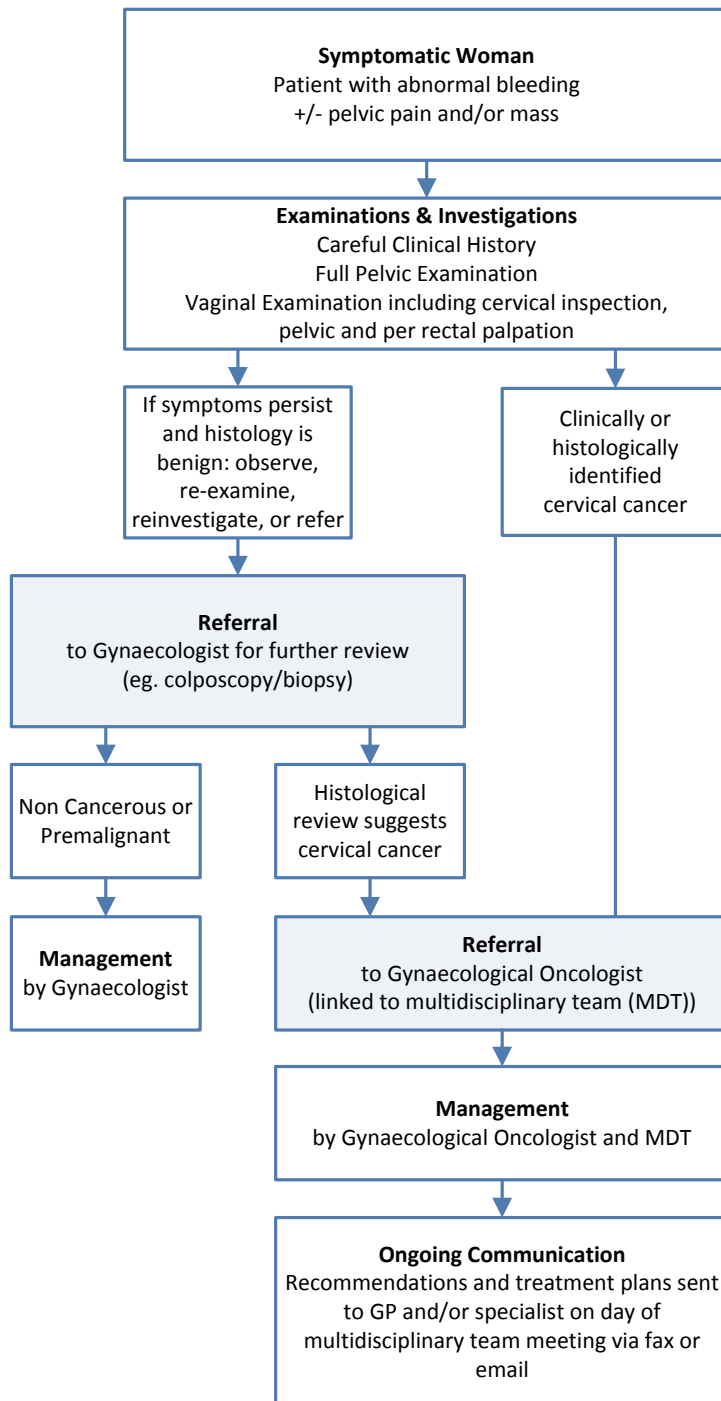
- Abnormal looking/feeling ectocervix
- Signs of vaginal discharge
- Contact bleeding from the cervix
- Cervical tenderness
- Friability of tissue, ulceration or cervical polyp
- Other possible sites of bleeding
- Thickening or mass on palpation

Patient History

- Age
- Sexual history
- Obstetric History
- Hormonal therapy and contraceptive history
- Smoking status
- Pap testing history - incl. last test and previous abnormal results
- Past history of bleeding
- Previous investigations
- History of STIs
- Past gynaecological history (incl. investigations, treatments, surgeries etc.)

4.3. Cervical Cancer Pathway

Cervical Cancer Pathway



Checklist for assessing symptoms

Types of symptoms

- Intermenstrual bleeding (IMB)
- Postcoital bleeding (PCB)
- Postmenopausal bleeding (PMB)
- Pelvic discomfort
- Deep pelvic pain
- Vaginal discharge
- Dyspareunia
- Unilateral leg oedema
- Sciatica

Findings to note

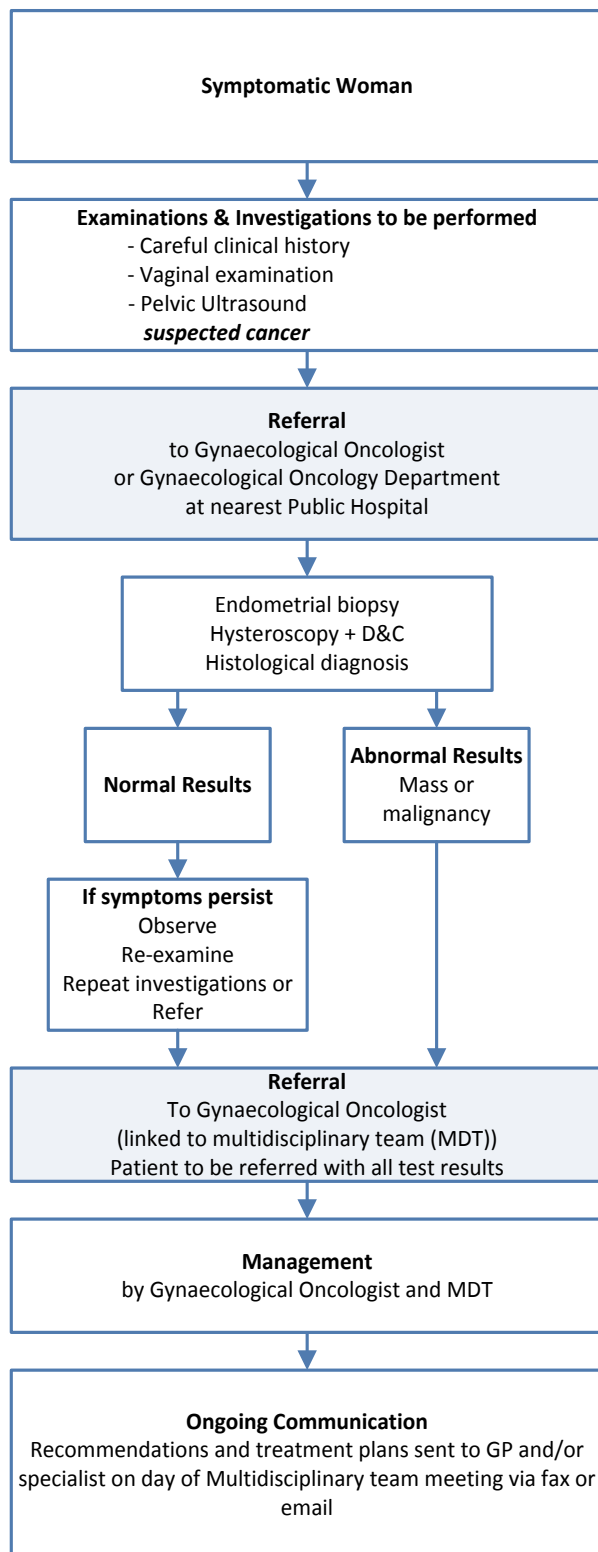
- Abnormal looking/feeling ectocervix
- Vaginal discharge
- Contact bleeding from the cervix
- Cervical tenderness
- Cervix with friable tissue, ulceration or abnormal polyp
- Other possible sites of bleeding
- Cervical mass on palpation

Patient History

- Age
- Sexual history
- Obstetric History
- Hormonal therapy and contraceptive history
- Smoking status
- Pap testing history - incl. last test and previous abnormal results
- Past history of bleeding
- Previous investigations
- History of STIs
- Past gynae history (incl. investigations, treatments, surgeries etc.)

4.4. Endometrial Cancer Pathway

Endometrial Cancer Pathway



Types of symptoms and findings

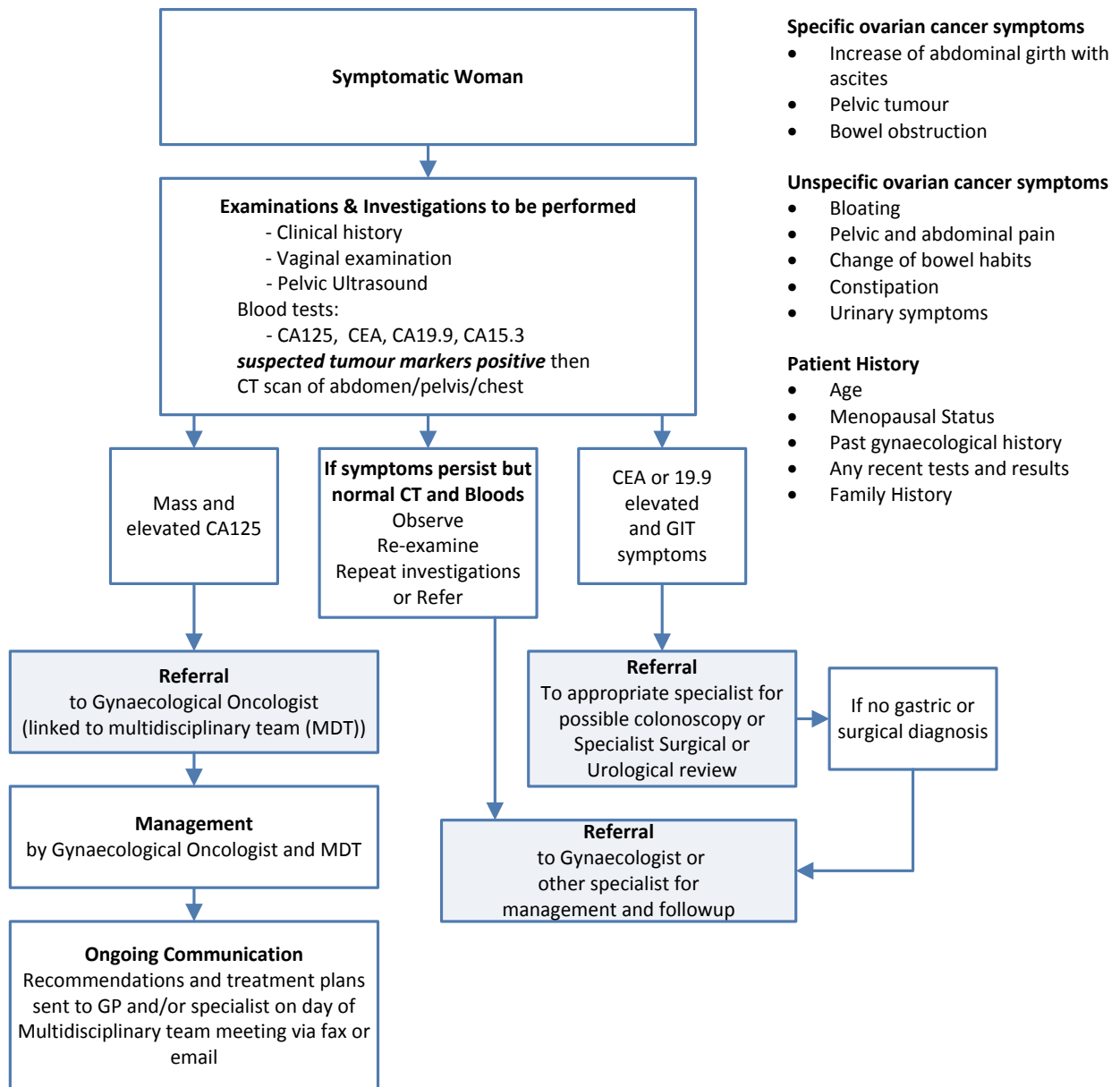
- Postmenopausal bleeding
- Postcoital bleeding
- Prolonged periods or bleeding between periods
- An abnormal vaginal discharge
- Abdominal or pelvic pain
- Abnormally thickened endometrium on ultrasound

Patient History

- Age (higher risk after menopause)
- Obstetric History
- BMI (increased risk with obesity)
- Unopposed oestrogen
- HRT
- Menopausal Status
- Past gynae history (incl. investigations, treatments, surgeries etc.)
- History of Tamoxifen use or similar

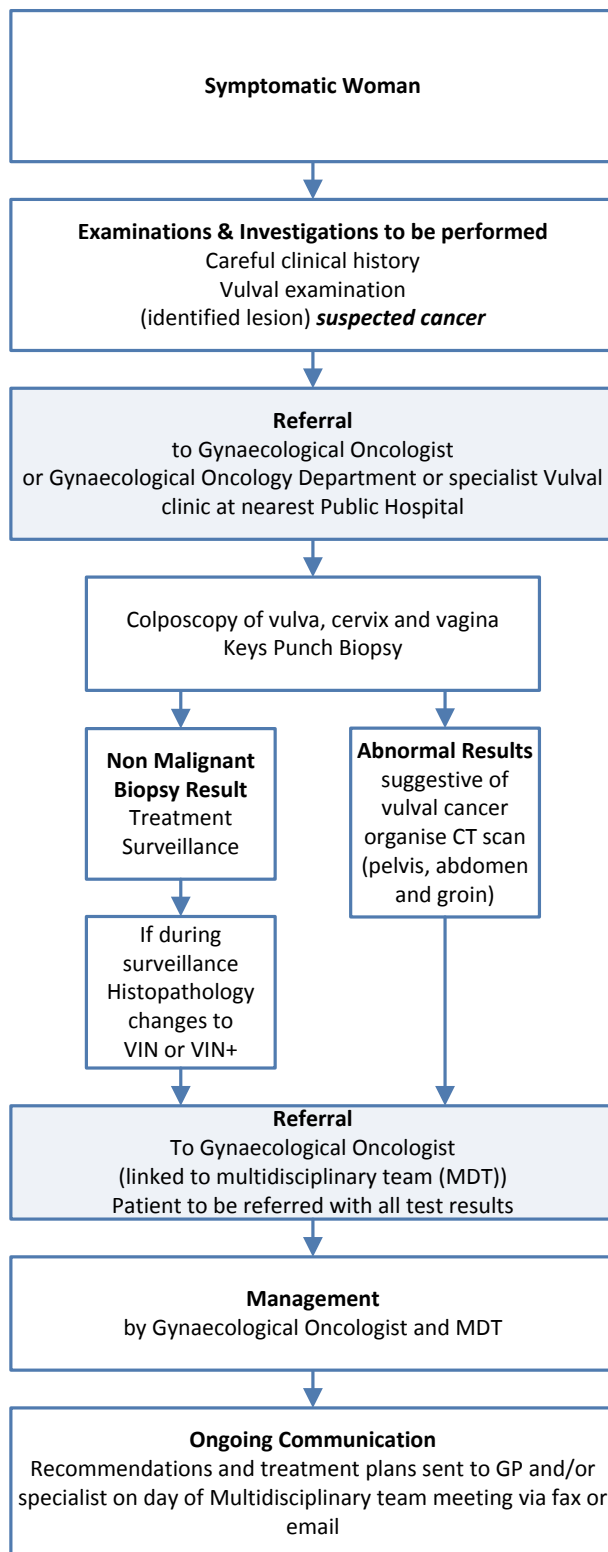
4.5. Ovarian Cancer Pathway

Ovarian Cancer Pathway



4.6. Vulvar Cancer Pathway

Vulvar Cancer Pathway



Types of symptoms

- Vulval itching, burning and pain
- a lump, swelling or wart-like growth
- thickened, raised, red, white or dark patches on the skin of the vulva
- Bleeding or a blood stained vaginal discharge
- Burning pain when passing urine
- Vulval sore or ulceration
- A mole on the vulva that changes shape or colour

Patient History

- Age
- Menopausal Status
- Smoking status
- History of vulval intraepithelial neoplasia (VIN)
- Prolonged skin conditions e.g. lichen sclerosus
- Past gynaecological history (incl. investigations, treatments, surgeries etc.)
- Any recent tests and results

5. DETERMINATION OF TREATMENT – THE MULTIDISCIPLINARY TEAM (MDT)

5.1. Gynaecological Oncology MDTs in South Australia

Gynaecological oncology multidisciplinary team meetings are held at the Royal Adelaide Hospital and Flinders Medical Centre each week. Referral to a MDT is via the hospital registrar, gynaecological oncology nurse specialist, multidisciplinary meeting coordinator or departmental secretary (please refer to [Chapter 2](#), Gynaecological Cancer Referrals).

5.2. Terms of reference:

Please refer to [Appendix A](#) for the Gynaecological Cancer Multidisciplinary Team Terms of Reference

Typical members of the Gynaecological Oncology Multidisciplinary Team

- Gynaecological Oncologists
- Medical Oncologists
- Radiation Oncologists
- Palliative Care Specialists
- Radiologists
- Pathologists
- Geneticists
- Psychologists
- Gynaecological Oncology Nurses
- Social workers
- Clinical trials coordinators

Specialist Gynaecological Oncology Multidisciplinary team care is an approach to health care that is critical to treatment planning and ongoing management of gynaecological cancer. It is provided by a team who meet regularly either face to face or via tele/videoconferencing to plan the care and treatment for women with gynaecological cancer. This approach is essential for women with gynaecological cancer regardless of being in the public or private healthcare setting.²

5.3. Principles of MDT meetings

The following principles highlight multidisciplinary team care

A team approach³

- There is an established multidisciplinary team that comprises relevant core disciplines, including allied health and psychosocial health specialists.
- Effective communication processes between the multidisciplinary team and GPs are established.
- Effective communication processes exist with access and referral links between all core and non-core team members.

Communication among team members

- All core team members regularly attend the MDT to provide input into diagnosis, treatment as well as supportive and palliative care planning.
- Referring practitioners are welcome to attend the meeting.
- Processes are in place for electronic communication regarding treatment recommendations and care plans between core team members and hospital based members of the treating team via the Oacis clinical summary system.

Provision of care according to agreed standards and pathways

- Informed decision making is guided by best practise principles.
- All relevant diagnostic results, pathology reports and radiological imaging are available for MDT.
- Professional development activities for all MDT members are offered and supported.

Involvement of women in decisions about their care

- Informed consent is obtained from all women prior to a MDT.
- Women are informed of the MDT including the billing process through Medicare
- Women are informed about the MDT recommendations
- Women are provided with information about access to supportive care services
- All women regardless of where they live should have access to relevant services
- Clinical trial involvement is considered for all eligible women who undergo cancer treatment.

6. SUPPORTIVE CARE

6.1. Supportive care principles of Gynaecological Oncology

The impact of gynaecological cancer on a woman and her family will be similar to that experienced by all people diagnosed with cancer, with feelings of anxiety, distress and grief commonly experienced. The specific and intimate nature of gynaecological cancer involving the reproductive and sexual organs means there are often specific issues for women, related to their fertility, sexuality, self-image, body image and sexual function. In the literature about 30% of women treated for gynaecological cancer are reported to develop sexual dysfunction.⁴

All members of the MDT have a role in the provision of supportive care. In addition the woman may have support from family, friends, support groups, volunteers and other community-based organizations. Supportive care clinicians include Allied Health providers (psychologists, social workers, dieticians, occupational therapists, physiotherapists, and pastoral care providers) and medical specialists (psychiatrists, specialist palliative care providers and fertility and menopause specialist).

Supportive care is a core component of cancer service delivery and is defined as care that

...helps the woman and their family to cope with cancer diagnosis and treatment – from diagnosis and treatment to cure, continuing illness or death and into bereavement. It helps the woman to maximise the benefit of treatment and to live as well as possible with the effects of the disease.⁵

Referrals to supportive care can be made by all members of the treating team. There is comprehensive evidence that early supportive care can have major benefits for women (and their family/carers) at all points of the health care continuum from diagnosis, during treatment, through palliative care and also for survivors.

Increased distress is common in the cancer population with prevalence estimates from large-scale studies typically exceeding 30%.⁶ Distress in response to cancer diagnosis can vary in severity ranging from 'expected' distress as a normal response to a more significant level, consistent with a psychological or psychiatric disorder. It is important that the needs of people are met in a timely fashion. Addressing women's needs in a prompt fashion from the time of diagnosis can address barriers to treatment and completion of treatment, prevent psychological morbidity and enhance quality of life.

The needs of women diagnosed with cancer include:

- Information about their condition according to their wishes. This includes written information with a proposed plan for treatment and follow-up care after completion of treatment as well as information regarding the common emotional responses to diagnosis and treatment. In addition, the opportunity to discuss and ask questions of the treating team and receive assistance with decision-making should be provided.
- Management of physical symptoms and side effects across the cancer continuum.
- Practical, financial and employment assistance, particularly for people from rural and remote areas.
- Social, emotional, familiar and spiritual needs.
- Cultural and linguistic needs (Refer to [Chapter 13](#): Needs of Specific Populations)
- Psychological and psychosexual needs.

A NSW study looking at supportive care needs of long term survivors with gynaecological cancer found a large percentage (87%) of women reporting a need for supportive care services with nearly one third having clinical levels of anxiety mainly around fear of disease recurrence.⁷

The type and level of intervention required to meet the supportive care needs of women and their carers will vary. The needs of many women will be met through the provision of general information, while others will require specialised intervention. Although the psychosocial needs should be identified for all women and support services made available, many women will report that they receive adequate support from their doctor and family and so do not require specialised psychosocial care.

6.2. Management of psychosocial care needs:

Identification, assessment and regular screening of supportive care needs

The International Psycho-Oncology Society (IPOS) has endorsed the concept that distress be named the sixth vital sign in oncology and that screening for distress at critical points along the continuum of care provides a practical way of identifying those most vulnerable, in order to develop a comprehensive management plan to address needs.

Supportive care includes the identification and assessment of specific needs of women and their family/carers. This is achieved through regular discussion and systematic review of patients. Regular reassessment is essential, as individual needs frequently change throughout the cancer journey.

The NHMRC Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (2003)⁸ can assist clinicians in identifying those at risk of developing psychosocial problems in order to refer for psychosocial care. Risk factors encompass both personal and disease related factors which include:

- History of mental health issues
- Lack of social support, younger age at time of diagnosis
- Prior cancer history
- Advanced stage of disease at time of diagnosis
- Increased physical symptoms of functional impairment
- Progressive disease.

For further information, please refer to the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer: <http://www.nhmrc.gov.au/files/nhmrc/file/publications/synopses/cp90.pdf>

6.3. Referral to specialised psychosocial supportive care services

It is important to screen women for increased distress and emotional concerns at every medical appointment, but particularly at times of increased vulnerability like at time of diagnosis, at commencement or end of treatment, at discharge from hospital, during follow up appointments and at recurrence / progression of disease.

Due to the difficulty in consistently identifying supportive care needs, including psychosocial issues, routine screening of distress to identify those of highest need has been recommended by the NHMRC Clinical Practice Guidelines and NCCN (United States National Comprehensive Cancer Network) .⁹ The SA Gynaecological Oncology Working Party supports screening with a validated screening tool for all women diagnosed with gynaecological cancer.

It is common for people who are experiencing increased distress to have difficulty recalling and remembering information. To assist in reducing anticipatory anxiety, it is important that women understand their disease and treatment options. Women should be provided with educational material and made aware that times of transition can be associated with increased vulnerability and distress.

Supportive care issues that will impact on treatment should be integrated into multidisciplinary treatment planning. This should address psychosocial supportive care needs of most women by the treating clinicians. However some women may require referral to specialised psychosocial supportive care services. These services may be provided by psychologists, social workers and psychiatrists. Guidelines for referring to specialised psychosocial services can be found in [Appendix C](#).

Challenges to providing best practice supportive care

A major challenge involves addressing the current inequity of access to supportive care for women with gynaecological cancer both in metropolitan and rural services as well as across the public and private sectors. Key issues include:

- Implementing a screening programme to identify those women exhibiting high levels of distress and at risk of developing psychological morbidity to enable supportive care needs to be addressed promptly.

- The literature increasingly supports the use of risk screening tools to identify people at greater risk of developing psychological distress; however there have been practical difficulties in implementation. The “distress thermometer” (DT) screening tool has been recommended by the NCCN and has been validated in various other countries including Australia.^{10, 11, 12, 13, 14, 15, 16, 17, 18 19} The value of the DT lies in the 5 domains of needs: physical, practical, financial, emotional/ family and spiritual. In addition, this screening tool is quick and easy to use.
- Using a risk screening tool facilitates the engagement of women and their carers/families on supportive care issues, particularly psychosocial issues where the literature has pointed to some reluctance by patients to accept referral to psychosocial support services.
- Addressing workforce inadequacies: Australian investment in the allied health workforce (in particular social workers and psychologists) has not kept up with the incidence of cancer. This has a dramatic impact on supportive and psychosocial care of women with cancer. Screening data offers the opportunity to quantify workforce needs and to determine any changes over time.
- Up-skilling of the supportive care workforce, particularly in the area of sexual health.
- Improving knowledge about existing psychosocial support resources available
- Improving continuity of supportive care from diagnosis, through the treatment phase and through follow up. It is well reported that once active cancer treatment is completed, women have few opportunities to access support to deal with survivorship issues, which in some cases can persist for a significant period of time.

Supportive Needs of Specific Populations

A gynaecological cancer diagnosis for an Aboriginal and Torres Strait Islander woman is considered “women’s business”. For admission to hospital the following needs to be considered:

- Nursing and Medical staff should be culturally aware and have attended Aboriginal Cultural Awareness training. If possible admission under a female doctor would be preferred.
- Specific requirements for admission are:
- Family must be considered as part of the support network and provision for them to stay at the hospital if required
- Location of room – preferably not closed in
- A bible should be made available
- Referral to the following must be offered:
- Interpreter must be offered as English could be 3rd or 4th language – please note: Aboriginal women may just say “yes” when asked if they understand, however, they may have limited understanding of what has been discussed
- Allocation of an Aboriginal Health Worker is essential – please note that the women may choose not to use an Aboriginal Health Worker however this must be offered
- A referral to a minister of religion for visits and support should be offered
- A therapist to provide art equipment and music therapy if available.

7. FAMILIAL CANCER, EARLY DETECTION AND SCREENING

7.1. Familial screening

SA Clinical Genetics Service – Familial Cancer Unit

The two most common familial cancer syndromes associated with gynaecological malignancies are Hereditary non-polyposis colon cancer syndrome (HNPCC, Lynch syndrome) (endometrial, ovarian, colorectal and other gastrointestinal cancers), and breast and ovarian cancer syndrome (BOC) (underlying BRCA mutations). Other familial gynaecological cancer syndromes are much rarer.

The SA Familial Cancer Service provides genetic counselling and testing for individuals and families at increased genetic risk of developing cancer. The service aims to both decrease the incidence of cancer and increase its detection in our community.

What is familial cancer?

Familial cancer accounts for approximately 5% of all cancers.

The following features are suggestive of a hereditary predisposition to develop cancer:

- Early age of onset of cancer in affected family member(s)
- Multiple cancers in affected family member(s)
- Several family members affected with the same or associated cancers.

Patients with those features should be referred to the Familial Cancer Unit for assessment and advice.

What does the Familial Cancer Unit do?

Clinical geneticists and genetic counsellors of the Familial Cancer Unit assess the level of genetic risk of developing cancer, inform about cancer prevention and offer surveillance strategies. They also advise about communicating cancer risk information in a family, and in selected cases, initiate genetic testing to clarify the genetic risk of developing cancer.

These services are available for people with hereditary gynaecological cancer and for unaffected people at increased genetic risk of developing cancer. The provision of such services may extend over many years as the cancer risk for a person changes with age.

How to access the Service

The Familial Cancer Unit operates as a medical specialty service and accepts referrals from GPs and medical specialists. Referrals should be faxed to the Unit on 08-8161 7984.

The following information should be included in the referral:

- Patient contact detail
- Issue of concern as seen by the referring health care provider.

On receipt of the referral, the woman will be asked to provide details on the family history. This information will be reviewed by the clinical geneticist. Preliminary written advice may be provided to the referring practitioner and patient, or an appointment will be arranged with a clinical geneticist and/or genetic counsellor. After the appointment, the result of the assessment is summarized in writing for the patient and referring doctor.

7.2. Cervical screening

The National Cervical Screening Program aims to reduce morbidity and deaths from cervical cancer in a cost-effective manner through an organised approach to cervical screening. The program encourages women in the target population to have regular Pap smears. It promotes routine screening with Pap smears every two years for women between the ages of 18 (or two years after first sexual intercourse, whichever is earlier) and 69 years.

The Screening Program implements and monitors the adherence to the nationally agreed screening policy and the establishment of Pap test registers in each state and territory.

The screening pathway involves the following steps:

- Encouraging all eligible women to enter and remain in the screening program
- Ensuring optimal quality of Pap smears by adequate training of Pap smear takers
- Ensuring optimal quality of Pap smear reading through a quality assurance program for laboratories
- Ensuring appropriate follow up of abnormal Pap smears through management guidelines
- Providing an efficient system for notifying women of their results by Pap smear providers
- Providing recall and reminder systems to ensure adequate follow up of women with screen-detected abnormalities
- Maintaining the participation of women in the program by encouraging providers to set up reminder systems, and developing cervical cytology registers and national cancer data.

In SA, Pap smears are primarily done by gynaecologists, GPs and practise nurses. The SA database is currently managed by the Well Women's Screening Program. The Well Women's Screening Program is responsible for managing the data storage and retrieval regarding the Pap smear results. They also manage the reminders for women when to have their next smear and act as link between the laboratories and GPs. Well Women's staff travel into the community to educate GPs and practise nurses about how to take a Pap smear.

Sexual Health Information Networking and Education SA (SHine SA), in conjunction with SA Cervix Screening Program, has developed a Pap Smear Provider Course. This course is supported by South Australian Division of General Practice and ensures that the nurse is appropriately qualified and trained to take a Pap smear in a general practise setting. For more information go to <http://www.shinesa.org.au>²⁰

Human papilloma virus (HPV) infection is a necessary cause of cervical cancer. A free HPV vaccination (Gardasil) is currently provided through the School Immunisation Program in SA. Females between 12 and 13 years of age can receive the vaccine which is given as a series of three injections within a six month period. However, the HPV vaccine protects only against about 70% of HPV-related cervical cancers. Therefore women still need to have a Pap smear regardless of vaccination status.

School girls and young women require information regarding gynaecological examinations and prevention of gynaecological disease including cancers. This information should be included in education curricula, particularly as part of sexual education at school and in the Public Health and Nursing/Midwifery courses at University.

Following up of abnormal smear tests

The management of asymptomatic women with screen detected abnormalities to assist medical practitioners in taking appropriate action on receipt of Pap smear reports is described in the following table.²¹

Table 3 – Abnormal Pap smear report management responses

Pap smear report	Management
Negative smear within normal limits	Repeat Pap smear in 2 years
Negative smear within normal limits and no endocervical cells present	Repeat Pap smear in 2 years
Negative smear with inflammation	Repeat Pap smear in 2 years
Unsatisfactory	Repeat Pap smear in 6-12 weeks after appropriate treatment where indicated
Possible low grade squamous intraepithelial lesion or Low grade squamous intraepithelial lesion	Repeat Pap smear at 12 months. If the woman is 30+ years, and has no negative cytology in previous 2-3 years, repeat Pap smear in 6 months or immediate colposcopy.
Possible high grade squamous intraepithelial lesion or High grade squamous intraepithelial lesion	Refer for colposcopy
Glandular abnormalities including adenocarcinoma in situ	Refer for colposcopy which should be performed by a gynaecologist with expertise in cervical dysplasia or by a gynaecological oncologist
Invasive squamous cell carcinoma (SCC) or adenocarcinoma	Refer to gynaecological oncologist

For any additional referral information please refer to [Section 4.1.2](#), “Asymptomatic high grade abnormality referral pathway”.

Contact SA Cervix Screening Program

Postal address: PO Box 287, Rundle Mall, Adelaide, SA 5000
 Telephone: (08) 8226 8181
 Fax: (08) 8226 8190
 Country callers telephone: 13 15 56
 Email: cervixscreening@health.sa.gov.au
 Website: SA Cervix Screening Program

Backup Record System Reminder Service

For women to change details or for general reminder enquiries please contact on:

Telephone: (08) 8226 8731 - ask to speak to a Reminder Officer
 Free call: 13 15 56 - ask to speak to a Reminder Officer
 Fax: (08) 8226 8190
 Postal address: PO Box 287, Rundle Mall, Adelaide, SA 5000
 Email: PapSmearReminders@health.sa.gov.au

8. TREATMENT & FOLLOW-UP²²

8.1. Cervical cancer

Cervical cancer is a malignant neoplasm of the uterine cervix. In many cases it is detected through a Pap smear, which is the only established early detection test for this disease. There are no specific early signs of cervical cancer and many women presenting with typical symptoms like bleeding are already suffering from advanced stage disease. Treatment for cervical cancer usually consists of surgery in early stage disease and combined chemo-radiotherapy when the disease is more advanced.

Treatment principles

Treatment is dependent on the stage of the cervical cancer and the woman's general condition.

Surgery

Typically, surgery for cervical cancer consists of a radical hysterectomy and pelvic lymph node dissection. The operation should be performed by a specialist gynaecological oncologist.

Chemo-radiotherapy

In cases where the disease is more advanced or a patient is not suitable for surgery due to medical reasons, combined chemo-radiotherapy is the treatment of choice. Chemotherapy is given in combination with radiation therapy to sensitize the cancer cells to the radiation and to increase the effectiveness of the treatment. Chemotherapy sometimes may also be used as single treatment modality in certain patients with advanced disease.

8.2. Endometrial cancer

Endometrial cancer (EC) is the most common uterine cancer. It originates from the inner lining of the uterus called endometrium. Most endometrial cancers are adenocarcinomas (cancers that begin in glands).²³

There is no screening test for endometrial cancer. 98% of all women with this disease will present with abnormal uterine bleeding. The majority of women with endometrial cancer are diagnosed at an early stage and therefore will have an excellent prognosis with high likelihood of cure by surgery .

Each year in South Australia, 100 -120 women will be diagnosed with EC. The majority of these women are postmenopausal, but about 10% are less than 50 years old.

Statistically women who develop endometrial or uterine cancer:

- Had only few or no pregnancies
- May have had irregular menses, or other period problems
- Very frequently are overweight, have blood pressure or diabetes problems.²⁴

There are also uterine cancers arising from the muscular wall of the uterus. These types of cancers are called uterine sarcomas.²⁵

Treatment principles

Treatment is dependent on the stage of the cancer and the general condition of the woman.

Surgery

In most cases, a hysterectomy performed by a gynaecological oncologist is the treatment of choice. The ovaries are almost always removed at the same time to ensure that there is no cancer spread. Furthermore, the ovaries produce oestrogen which may stimulate the growth of endometrial cancer cells. The pelvic lymph nodes have to be removed in some cases to exclude cancer spread.

Lymphadenectomy

EC cancer spreads either by growth through the uterine wall, down into the cervix, into the lymphatic system, and/or via the blood stream. Therefore the pelvic lymph nodes have to be removed in most cases to exclude cancer spread. Histopathology examines the spread of disease and other features indicating a high risk of recurrence to determine if further treatment is needed.

Radiation therapy

External beam radiation therapy will be given to women where spread of disease out of the uterine cavity has been confirmed by pathology or when the risk is increased. Internal radiation (brachytherapy) is offered in cases where there is an increased risk that a recurrence may occur at the top of the vagina. In some cases when surgery is not possible, radiation therapy alone or use of a “Mirena” intrauterine device may be a treatment option.

Hormone therapy

Occasionally hormone therapy will be indicated. The female hormone progesterone can suppress the growth of endometrial cancer cells. Progestogens given as tablets are used occasionally in endometrial cancer for:

- Prophylaxis – in women where the clinician is concerned that there is a high risk that the disease might recur
- Primary therapy.

Chemotherapy

Chemotherapy may be used in cases of uterine cancer after surgery when the risk of recurrence is very high or when the disease has spread. It is also given frequently when the disease recurs.

8.3. Ovarian cancer

Over 100 women are diagnosed with ovarian cancer in SA each year. As symptoms are usually vague, and therefore difficult to recognise, many women have advanced disease when it is diagnosed. There is no early detection test for ovarian cancer.

Treatment principles

Treatment is dependent on the stage of the cancer and the general condition of the woman. It usually consists of a combination of surgery followed by chemotherapy or vice versa.

Surgery

Surgery is commonly the first treatment; both to make the diagnosis, by sampling of cancer tissue, and also to treat the disease by removing as much of it as possible. This will include removing both ovaries, the uterus, as well as the omentum (a fatty apron which is attached to the large bowel and can be involved if the cancer has spread.) The lymph nodes might also have to be removed .

If the disease is confined to the ovary it is sometimes possible to limit the surgery to the removal of the diseased ovary. This will preserve fertility and hormonal function in young women

Chemotherapy

Cytotoxic therapy is an essential part of ovarian cancer treatment, except for patients with very early disease. It will usually be given after surgery but can also be given before. Chemotherapy is also used if the disease comes back.

Radiation Therapy

Radiotherapy is usually not part of ovarian cancer treatment and is given only to selected patients.

8.4. Vulvar cancer

There are about 20 women who are diagnosed with vulvar cancer in South Australia each year. The majority will be older women well beyond menopause but young women are also occasionally affected.

Treatment Principles

Treatment is dependant on the stage of the cancer and the general condition of the woman.

Surgery

a) Vulvectomy

A vulvectomy involves the surgical removal of parts of the vulva. The extent of the surgery depends on the size, location and extent of the cancer and should be performed by a gynaecological oncologist. In some cases a plastic surgeon will be involved to help with vulvar reconstruction.

The aim of a vulvectomy is to remove the cancer and tissue with possible spread, for example the groin lymph nodes. The surgery will in many cases change the appearance of the vulva and vagina and women should see pictures of vulvar changes after surgery to get psychologically prepared. Patients will continue to be able to conduct a normal life including sexual intercourse after surgery.

b) Removal of groin lymph nodes

Vulvar cancers tend to spread to the groin lymph nodes which therefore have to be removed as part of the cancer surgery in most cases. Lymph node removal from the groins can be associated with long-term side effects such as leg lymphoedema and cellulitis.

Radiation therapy

Radiotherapy is used to shrink down vulvar cancers to be able to remove them by surgery. It is also given when the groin lymph nodes are found to contain cancer after surgery to prevent further spread and recurrence of disease.

Chemotherapy

Chemotherapy is usually not used alone as vulvar cancer treatment. It is commonly combined with radiation therapy or when the vulvar cancer has spread to distant organs.

9. ADJUVANT TREATMENTS

9.1. Radiation therapy

Radiation therapy is an established and highly effective method in the treatment of cancer. It can be given alone or in combination with surgery and/or chemotherapy. There are several different methods by which radiotherapy is delivered.

Radiation can be given externally as “external beam radiotherapy” and internally as “brachytherapy”. External beam radiotherapy is given as outpatient treatment on a daily basis over a number of weeks depending on the total dose of radiation to be delivered. Brachytherapy is given either as an inpatient or an outpatient treatment depending on the circumstances.

Radiation treatment can be given with the aim of eradicating the cancer. This is called curative treatment and usually involves a prolonged course of high dose radiation therapy over several weeks. Radiotherapy can also be given with the aim to control symptoms for incurable disease. This is called palliative treatment and usually involves a shorter course and lower dose of radiation.

The overall process of destroying all cancer cells with radiation can take some time and it is usually some months after treatment before the final effects of the radiation are evaluated.

External beam radiotherapy

This radiotherapy is delivered in a specially insulated room where the radiation therapy machine is located. Generally this treatment takes only 10-15 minutes to deliver and involves no sensation to the body. There is no impression of heat or burning and there is no radiation within the body which presents any danger to any other person. Radiation therapists administer the treatment. It is given as an outpatient, daily from Monday to Friday, usually over several weeks.

Vaginal brachytherapy

This treatment differs from external beam radiation therapy in that the radioactive source is placed close to the tumour. This provides an extra boost of radiation to the tumour, but less to the skin and other healthy tissues nearby.

a) Low dose rate brachytherapy

Low dose brachytherapy is given as an inpatient, and takes several days to complete. This treatment is done in a specially insulated room in the hospital. An anaesthetic is administered prior to the device being placed. A urinary catheter is also inserted for 2-3 days.

b) High dose rate radiotherapy

High Dose Rate (HDR) brachytherapy requires a short time for treatment, as a high dose is given each time. It is given as an outpatient, usually 3 times a week.

For vaginal brachytherapy, a smooth plastic cylinder is placed in the vagina. The cylinder is then connected to the machine which holds the radioactive sources. During treatment patients will be alone in the treatment room, but will be monitored by a TV screen, and staff can speak to them via an intercom.

After a brachytherapy session a small amount of pink vaginal discharge, burning on urination or loose bowel motions for 24 – 48 hrs may occur.

Side effects of radiotherapy

Radiation treatment can have an effect on both cancerous and normal tissues within the treated area. The effects of radiation treatment on normal tissues may produce side effects. Early side effects occur during treatment and are very common. Late side effects can occur months to years after treatment, and only affect a small proportion of women.

Early side effects

a) Fatigue

Fatigue is common towards the end of treatment and it can take some weeks before energy levels return. Limiting demanding activities and a rest during the day for 60 – 90 minutes is recommended during treatment.

b) Skin Problems

The risk of skin problems depends on the treated area.

Radiation therapy nursing staff are able to advise about skin care during treatment. It includes:

- Shower or bathe in warm water, pat skin dry, do not rub.
- Avoid overheating the skin with hot packs, electric blankets, infra red lamps etc
- Do not sunbathe. Swimming is possible as long as an alcohol-free sunblock is used.
- Use loose fitting cotton or silk material in contact with the skin
- Ointments and petroleum-based products should be avoided.
- Aloe vera products may be used to keep the skin moist.
- There may be a loss of pubic hair.
- If there is any itch, redness or pain in the treatment area medical advice must be sought.

c) Bowel side effects

Women may experience bowel looseness during treatment.

d) Bladder problems

Urinary irritation is common and is usually managed with “Citralite” sachets which help reduce the acidic content in the urine. These early side effects are limited to the duration of the treatment and settle down within a number of weeks after treatment.

Late side effects

Late side effects can occur months to years after treatment but only affect a small proportion of women. Treatment plans are designed to minimise the risk of late side effects.

a) Menopausal symptoms

Radiation of the pelvis induces an early menopause in most cases. Hormone replacement therapy (HRT) might then be indicated.

b) Bowel effects

A proportion of people notice a change in their bowel habit long term. These changes can include:

- Loose stools or diarrhoea
- Frequency of bowel motion
- Bleeding from the bowel
- Leakage from the bowel
- Feeling that the bowel has not emptied properly
- Too much wind
- Bowel pain
- Difficulty emptying the bowels
- Greasy and pale stools²⁶

c) Bladder effects

The risk of significant long term effects on the bladder is small and may include frequent urination and in a few cases passing of blood.

d) Lymphoedema

Leg swelling can occur in a small percentage of women if groin and/or pelvic irradiation is given. It is not always possible to prevent lymphoedema.

Symptoms include:

- Increased size of legs and thighs
- Changes to the look or feel of the skin
- Feelings of heaviness
- Swelling

Preventative measures include:

- Walking daily – at least 30 minutes
- Activities such as cycling, swimming, or aerobics
- Moisturising skin on the feet and legs.
- Care when shaving, clipping toenails and general foot care
- Always treat tinea, nail infections and wounds on feet and legs
- Elevation of feet when sitting
- Use of flight socks when flying or on long car trips

e) Vaginal function

Surgery and radiation can both reduce the length and capacity of the vagina. Radiation may also make it drier and less elastic due to scarring, particularly at the upper part of the vagina. These changes are called vaginal stenosis.

Regular sexual intercourse can reduce the severity of vaginal stenosis. Sexual intercourse may be resumed as soon as it is comfortable after completing treatment. The use of a vaginal dilator will be necessary if vaginal intercourse cannot occur at least twice a week. The dilator is a smooth plastic cylinder, which is inserted into the vagina to keep it open. It helps the doctor examine the treated area inside the vagina and makes vaginal examinations more comfortable.

Dilators should be used frequently for a reasonable time each week and for several years after radiation treatment has finished. Although the use of the dilator might cause some discomfort initially, it is important to try to get used to it. A learning resource is available for health care professionals at the following site: <http://modules.cancerlearning.gov.au/psgc/>

9.2. Chemotherapy

Chemotherapy involves intravenous or oral drugs which prevent or slow cancer growth. Cancer cells divide more often than normal cells and are thus more sensitive to damage by chemotherapy. Intraperitoneal (IP) chemotherapy is also used in selected women with ovarian cancer.

Side Effects of Chemotherapy

Whilst directed at cancer cells, chemotherapy also affects 'normal' dividing cells like hair follicles, the inner lining of the bowel and bone marrow. Most chemotherapy treatments, also called chemotherapy cycles, last only one day and are repeated every 1 to 4 weeks.

Different drugs will have different side effects and these will be considered when planning treatment.

Side effects of Chemotherapy can include:

- Nausea/Vomiting – referral to a hospital must take place if the woman cannot keep any food or fluids down.
- Change in appetite
- Mouth ulcers
- Fatigue
- Skin effects – the skin may be more sensitive to the sun, women must minimise exposure to the sun to avoid possible burning or rashes.
- Hair loss – if treated in a public hospital, women may be entitled to financial assistance to buy a wig. For private patients some health funds may cover the cost of a wig if hair loss is part of the disease or its treatment. Women will need a referral letter from their GP to make a private claim.
- Effects on the blood:
 - Red Blood Cells – women may become anaemic, presenting with tiredness and/or shortness of breath. Referral to the treating oncologist is recommended as a blood transfusion may be required.
 - White Blood Cells – women may be at a greater risk of infection due to a drop in their white blood cell count.
 - Platelets – bruising and unusual bleeding may occur due to low platelet count. Referral to the treating medical oncologist is recommended as a platelet transfusion may be required.

Febrile Neutropenia

- Some women with very low white cells may develop a temperature of greater than or equal to 38°C. If not treated immediately they may develop septic shock.
- Women must be admitted to a hospital immediately for treatment if they have high fever.
- Hospitals have specific protocols for dealing with this serious condition.

General information whilst being treated with chemotherapy

a) Sexuality

There can be a variety of problems with sexuality including loss of libido and/or vaginal dryness which can make intercourse uncomfortable. Vaginal lubricants can be used if dryness is a problem.

Referral to any member of the treating team including the specialist gynaecological oncology nursing staff at one of the 3 public hospitals or to a rural specialist should be made if this is a problem. Please see service directory for details.

b) Fertility

The ability to have a child is likely to be severely affected or even made impossible by chemotherapy treatment. Furthermore, it is important not to become pregnant during treatment because of the risk of damage to the foetus. Oral contraceptives can be unreliable during chemotherapy and other methods of contraception such as barrier methods must be used.

9.3. Clinical trials

Research studies are vital to establish new cancer treatments and provide one of the most important means of improving both survival and quality of life.

The Royal Adelaide Hospital and Flinders Medical Centre are actively taking part in international research studies and enable South Australian patients to participate and to benefit from latest innovations.

Trials of new therapies involve 3 phases:

Phase 1 – establishes the correct dosage and any potential harmful side effects.

Phase 2 – examines the effectiveness in a given cancer type.

Phase 3 – compares the new treatment against the best existing treatment.

Phase 3 studies are usually randomized controlled trials. Women are randomly allocated to either the existing or the new treatment. There is no obligation to take part in clinical trials, however the majority of women are encouraged and supported to participate, both for benefits they may receive personally and to help others.

Cancer research / Clinical trials website: <http://www.australiancancertrials.gov.au/>

10. OTHER THERAPIES

10.1. Complementary therapies

The term 'complementary therapies' encompasses a range of approaches to health care aimed at enhancing quality of life and improving well-being. They may be used alongside standard evidence-based medical (conventional) cancer treatments, such as surgery, radiotherapy, chemotherapy, hormonal and biological therapies. Complementary therapies that have been shown to be helpful in the management of the symptoms of cancer and its treatment include: counselling, meditation and relaxation, support groups, art and music therapy, spiritual practices, massage, aromatherapy, reflexology, acupuncture, yoga and physical activity, tai chi, qi gong, some herbal medicine and nutritional advice.²⁷

Although the term "Complementary and Alternative Medicine (CAM)" is frequently used, it is important to distinguish between complementary and alternative therapies. Alternative therapies are used instead of standard evidence-based medical cancer treatments. There is no evidence to support the use of alternative therapies in the treatment of cancer.

It is important that the primary treatment team are aware of complementary therapies, recognise the potential for impact of such therapies in the clinical setting and promote open discussion about these therapies with their patients.

How complementary therapies may help cancer patients

Complementary therapies are intended to support the well-being of women and are not considered treatment for cancer.²⁸ Although large-scale clinical trials are pending, there have been many studies of complementary therapies involving woman with cancer. Scientific data is not available that shows an effect on survival, however several studies suggest therapeutic benefits of complementary therapies for management of both the symptoms of cancer and the side effects associated with conventional cancer treatment

Beneficial effects reported for some complementary therapies include:

- reducing pain or use of analgesia
- reducing chemotherapy-related fatigue
- reducing menopausal symptoms such as hot flushes
- reducing acute nausea
- promoting relaxation
- improving sleep
- improving the sense of well-being
- reducing stress, anxiety and depression
- improving overall coping capacity
- promoting a feeling of self worth

However, some complementary therapies can interact with conventional cancer treatments and make them less effective. Others may actually be harmful if taken in combination with conventional cancer treatments.²⁹

Discussing complementary therapies with women and/or caregivers

Based on current guidelines it is recommended that oncology health professionals provide an opportunity for women to talk openly about complementary therapies in the context of the overall health care plan^{30,31}. The multidisciplinary team should identify which member of the clinical team should be best placed to conduct this discussion.

- All women with cancer should be asked specifically about their use of CAM at multiple time points in the treatment pathway
- Communication about CAM should be conducted in an open, evidence-based and woman-centred manner by the cancer-specialist.
- Detailed enquiries by the woman and family / carers about those complementary therapies deemed suitable in their particular case should be directed to the complementary therapist / prescriber.
- Responses to questions about CAM use should be documented in the case notes.
- In order to ensure that those women considering CAM are well informed, they should be offered the Understanding Complementary Therapies booklet³² and/or the Cancer Council SA Helpline number (13 11 20) both of which provide balanced, evidence-based information about the advantages and limitations, including contraindications, of complementary therapies. A brochure providing guidance to identifying qualified complementary therapists should also be offered.³³

Information for women and caregivers

The Cancer Council Australia urges people with cancer to remain in the care of qualified doctors who use proven methods of treatment and participate in clinical trials of promising new treatments. If you are using or considering a complementary or alternative treatment, it is important to discuss it with your doctor or call the Cancer Helpline for advice.

Furthermore, if patients are thinking about using any other method instead of conventional medical treatment, they should carefully consider and investigate the claims made and any evidence for those claims, the credentials of the people or organisation promoting the treatment, the costs and the potential risks of delaying conventional therapies.

The American Cancer Society (ACS)³⁴ recommends the following checklist to flag approaches or therapies that might be open to question and advises that if the answer to any of these questions is 'yes', people should carefully consider whether the proposed treatment is of any value.

- Is the treatment based on an unproven theory?
- Does the treatment promise a cure for all cancers?
- Are you told not to use conventional medical treatment?
- Is the treatment or drug a 'secret' that only certain providers can give?
- Does the treatment require you to travel to another country?
- Do the promoters attack the medical/scientific establishment?

Further information resources

- Cancer Council resources on complementary care are available online or by phoning the Cancer Helpline (13 11 20)
- Cancer Council Victoria brochure: 'Complementary and alternative cancer therapies – for people with cancer, their family and friends'.
www.cancervic.org.au/downloads/brochures/CISS_brochures/Complimentary_Altern_therapies1.pdf

10.2. Alternative Therapy

Alternative therapies are treatments which are used instead of conventional medical therapies. Some examples are:

- Chinese medicines and megavitamin therapy
- Shark cartilage supplementation
- Oxygen therapy
- Laetrile and radio wave cancer treatment

Women using these therapies should discuss them with the doctor managing their care. These therapies are often promoted as “cancer cures”, however most are unproven and have not undergone rigorous scientific testing.

11. SURVIVORSHIP NEEDS

11.1. Life after cancer treatment

The change from being a patient, where decisions are mostly out of your hands, to being in control of daily life can take much longer than expected. Many people will have significant problems in readjustment when cancer treatment has been completed and they return to their normal life. Loss of confidence is expected and can often be long lasting but also physical symptoms such as fatigue can be a major problem.

Women may experience feelings of anger, sadness or tiredness after the treatment, although most of these feelings will settle over a period of time. However, for a small number of women these emotional symptoms may become a long term problem affecting their daily activity. They might then require psychological support.

The Cancer Council of South Australia runs a program called "Living with Cancer". It covers a wide range of topics to assist women. For more information phone the Cancer Council of South Australia on 13 11 20.

11.2. Follow up care for Gynaecological Cancers

Follow-up care after primary treatment should be conducted and coordinated by the treating gynaecological oncologist.

A common strategy involves follow-up visits every three months within the first two years, followed by six monthly examinations from year 3 to 5. The gynaecological oncologist may then refer the woman back to the GP or gynaecologist for yearly assessment.

If the woman develops any symptoms suggesting a recurrence she should be referred back to the gynaecological oncologist. Symptoms may include:

- Abdominal or back pain
- Bleeding from vagina, bladder or bowel
- Weight loss
- Change in bowel or bladder habits

A physical examination should attempt to identify the reason for the symptoms. It should always include a speculum, pelvic and rectal examination. It should also include a vaginal or cervical Pap smear when indicated.

11.3. Disease recurrence

For disease recurrence individual management is required. Referral of the woman should be back to specialist care and MDT discussion for treatment planning.

12. END-OF-LIFE CARE

12.1. Palliative Care

General Information about Palliative Care Services

Palliative care is specialist care and support provided for patients whose disease cannot be cured with the aim to control symptoms and to improve quality of life.

It may provide many elements of supportive care and specific expertise such as management of refractory symptoms of cancer and/or its treatment, complex psychosocial issues and end of life and bereavement issues. (Ref: National Institute for Clinical Excellence. Guidance on Cancer Services – Improving Supportive and Palliative Care for Adults with Cancer: The Manual, National Health Service, London, 20)

Care for complex cases can involve:

- Pain management
- Wound care

Activities of daily living assessment and management

End of life care:

- At home
- Admission to Palliative Care Unit
- Admission to Hospice

Referrals into Palliative care:

- Can be generated by Allied Health, GP's or Specialist's.
- Are assessed for need of this service.

Palliative care will access the needs with the following criteria:

- Community care
- Symptom control
- End of life care

One of the major problems for the palliative care team are patients under their care who present to an emergency department with an expectation of survival. GPs referring a woman into an emergency department need to precisely identify that the woman is under the care of palliative care, however is expected to survive and not be treated as a terminal case.

Palliative care is a consultative service with inpatient beds in hospices. The service does not have bed cards to admit women into general hospitals hence consultation and shared care services are incorporated for woman treatment. Patients will be transferred if truly palliative. If a woman is transferred to a hospice they will not be resuscitated.

In South Australia referral to Palliative Care can be made by contacting the services as listed in [Appendix D](#).

13. NEEDS OF SPECIFIC POPULATIONS

13.1. Patients living in rural and remote locations

Within South Australia all tertiary cancer treatment centres are located in metropolitan Adelaide. Studies have shown that survival is best at centres with a critical minimum caseload and tumour expertise.³⁵ Country GPs are likely to see extremely small numbers of cancer patients in the gynaecological cancer group throughout their career. It is therefore critical that all cases of suspected gynaecological cancer are referred to a centre of expertise for diagnosis and staging.

As most women with gynaecological cancer from rural areas need to relocate to Adelaide during treatment, it is essential that they are provided with adequate accommodation and support. Relocation often means separation from family members for a period of time. It is highly likely that family members or the patient's partner will need to remain in the rural or remote area for employment or family commitments.

13.2. Aboriginal and Torres Strait Islander Peoples

Australia's Indigenous population is comprised of Aboriginal and Torres Strait Islander people. One in four Aboriginal and Torres Strait Islander people live in rural and remote regions of Australia. Aboriginal and Torres Strait Islander people are more likely to present with advanced illnesses and may have multiple co-morbid illnesses in addition to cancer.³⁶

The concept of health and wellbeing for Aboriginal and Torres Strait Islander people is a holistic one, encompassing all aspects of physical, emotional, social, spiritual and cultural wellbeing and a specific kinship with family.^{37,38} Many Aboriginal and Torres Strait Islander people believe that wellbeing is determined socially, rather than biologically or pathologically.^{39,40} Given the powerful role of traditional beliefs about illness and health, it is important when managing the health care of Aboriginal and Torres Strait Islander people to include the input of those who are familiar with their culture⁴¹ and language and to incorporate specific understandings of the needs of those residing in rural and remote areas.

Staff with specific expertise in the management and support of Aboriginal and Torres Strait Islander patients are located in the larger metropolitan public hospitals. Aboriginal health nurses and Aboriginal hospital liaison workers are available to provide assistance following patient referral by the multidisciplinary team and to provide advice on culturally safe and respectful care. For more information and resources see [Appendix B](#).

13.3. Culturally and linguistically diverse communities

Australia has one of the most culturally diverse communities in the world. In 2004, one in four Australians was born outside Australia.⁴² It is therefore essential to consider the culturally and linguistically diverse needs of all people in relation to diagnosis, treatment and management of cancer.⁴³

All patients are individuals and require a person-focused approach to care. Health professionals should engage in respectful enquiry about preferences that intersect with health care, including religious or spiritual values, cultural values, gender preferences and dietary requirements. These aspects are connected to a successful health care experience and outcomes⁴⁴

Within the culturally and linguistically diverse community, language barriers and lack of knowledge of the South Australian health care system limit access to health information and health care services.⁴⁵

Cultural perspectives or preferences may include:⁴⁶

- patient preference to see a medical professional of their own sex
- myths and misconceptions about cancer diagnosis
- cancer may be a taboo subject or cause discrimination, contamination, shame, or retribution

- religion may play a fundamental role in the person's attitude towards their disease and treatment
- patients may have perceptions attributed to pain and suffering.
- family (including extended family) have a central role in many cultures with family members often sharing the rights and responsibilities for decision-making, which may influence the choice of treatment.

Attitudes to caring and support may vary between and within cultures. It is important for health professionals not to make assumptions or stereotype individual patients. Patients should be encouraged to seek support from family and friends, and from community, ethnic and religious organisations, if appropriate. Regardless of cultural background, wherever possible, patients should be offered the opportunity to bring a family member or friend with them to consultations and treatment. People may not be accustomed to the concept of support from external agencies, so this requires a sensitive and respectful approach.

Further information

[Appendix B](#) lists key sources of information for South Australian people with cancer including services available for Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities.

Statewide Clinical Networks

Gynaecological Cancer MDT Terms of Reference

1. Definition of Multidisciplinary Care

Multidisciplinary care (MDC) is an integrated team approach to health care in which medical, nursing, and allied health care professionals consider all relevant treatment options and develop collaboratively an individual treatment plan for each patient¹

2. Aim

The overall aim of the multidisciplinary cancer meeting is to enable a formal mechanism for multidisciplinary input into treatment planning and ongoing management and care of patients with cancer.

The multidisciplinary team provides advice to the referring clinician. Treatment decisions are the responsibility of the primary clinician responsible for the patient.

3. Objectives of the MTD meeting are:

- to ensure evidence-based treatment recommendations are being made with respect to patient management as clinical circumstances dictate
- to facilitate the referral, presentation and discussion of 100% of new cases of a gynaecological cancer diagnosed in South Australia at the Multidisciplinary Team meeting.
- to maintain documentation of treatment recommendations for each patient, and communicate these to relevant team members including the referring physician, primary physician, and patient's medical chart
- to provide an opportunity to discuss: enrolment of particular patients in clinical trials and research activities (including clinical audit)
- to obtain data documenting time from initial patient presentation to diagnosis to treatment for each patient
- to provide an educational environment for multidisciplinary team members, fellows, registrars and interns and visiting clinicians
- to contribute to a complete database of gynaecological cancers diagnosed in South Australia

4. Operational Guidelines

4.1 Membership

Membership of the multidisciplinary cancer meeting comprises medical staff, nursing, allied health, pharmacy, psychosocial professionals, other supportive care services providing clinical services in relation to gynaecological cancer throughout South Australia.

¹ NBOCC Multidisciplinary meetings for cancer care, A guide for Health Service Providers, National Breast Centre 2005.

MDT Attendees:

The following categories of attendee have been ratified by the Cancer Clinical Network Steering Committee:

Core clinical members:

Medical consultants, medical registrars, RMOs, nurses and allied health clinicians for whom involvement/attendance at the MDT is a core part of their duties.

Support staff:

Staff members who may be required to assist with meeting implementation, for example administrative assistants.

Invitees

Visitors: clinicians such as GPs who are invited to attend the discussion of a particular patient.

Observers: such persons are included under the general patient agreement to be in attendance but are non-contributory to the final decision. These include:

relevant health care profession students

a clinician who is not a usual attendee and/or without direct connections with the hospital/service/MDT whose attendance is approved by the MDT Chair

NB: All MDT attendees are required to sign the attendance register and ensure the Chair is aware who is attending at remote sites.

Refer to Appendix B for a sample MDT meeting register.

Credentialing Requirements:

All core medical MDT members are required to be credentialed and scope of practice recognised in the health service where the MDT is located or centrally located in the instance where multiple sites are involved. This includes public and private medical staff. Core members who are primarily private practitioners, must, like public employees, be credentialed by a public hospital and have relevant scope of practice to attend the site at which the meeting is held.

It is the prospective/current MDT medical member's responsibility to obtain health service credentials/mutual recognition of scope of practice to provide evidence to the MDT Chair for noting.

The Chair is responsible for ensuring core medical attendees are credentialed. The Chair may use discretion to allow that medical attendee to remain for the meeting.

Other non medical health professionals currently do not require credentialing for attendance at cancer MDT's. Non-medical health professionals from the private sector are required to provide the Chair with evidence of professional registration for noting.

Example of MDT Membership:

Disciplines required for a Gynaecological MDT include:

- Gynaecological Oncologist
- Medical Oncologist
- Radiation Oncologist
- Palliative Care Physician
- Radiologist
- Pathologist
- Nurse specialist(s)
- Allied Health staff according to tumour type and patient need: eg
 - Social Work
 - Psychologist
 - Other Supportive Care staff as required

Relevant fellows / registrars / RMOs attached to a specialty will be members of the MDT team for the duration of their attachment.

Additional disciplines recommended for contributory involvement include:

- General Practitioner

Refer to Appendix A for a directory of team members for the Gynaecological Cancer MDT.

Those team members who are presenting a patient at the MDT are to arrange a proxy in the event that they are unable to attend the meeting.

When specific clinical needs have been identified by the referrers which require specific skills and targeted input the chairperson will invite the appropriate staff member(s) to attend that particular meeting.

4.2 Patients to be discussed

- All newly diagnosed patients
- Review patients either at relapse or with newly identified symptoms
- As requested by referring clinician in consultation with Chair

The referring clinician must send all referral details to the Chair/MDT Co-ordinator or Administrative Assistant (as agreed) no later than [3 days] prior to the meeting. This is to facilitate prioritisation of presentations and to ensure adequate time for investigation results to be prepared for the meeting.

The referring clinician must ensure radiology is made available for the meeting, particularly private films. The administrative MDT support may be able to facilitate this when provided with relevant information to source radiology images/pathology.

Consent

All patients must be made aware that their case will be presented at the multidisciplinary team meeting for discussion and consent to this process. Consent may be either verbal or written and it must be noted in the patient's clinical health record and/or on the multidisciplinary meeting referral form.

(Patient information brochure on multidisciplinary team meetings is available)

4.3 Chair

Good leadership and facilitation are key factors in the success of multidisciplinary team meetings.

Role of the Chair²

- Keeping meetings to the agenda
- Ensuring all visiting members are appropriate to the meeting and where required exclude attendees
- Ensuring there is appropriate representation in the meeting to enable a comprehensive recommendation to be made
- Commencing and facilitating discussions
- Prompting the full range of input into discussions if it is not forthcoming
- Summarising the discussion and inviting further input before moving to the next case
- Negotiating resolution of conflict
- Promoting mutual professional respect among all team members.

² NBOCC Multidisciplinary meetings for cancer care, A guide for Health Service Providers, National Breast Centre 2005.

The Chair and Deputy Chair positions will be appointed annually. If the Chair or Deputy Chair is unable to attend, the Chair will arrange a proxy to chair the meeting.

4.4 Meeting Time & Venue

Meetings should be held at the same time and place. The duration and frequency of meetings will be determined by each MDT meeting based upon size of site/number of cases requiring discussion.¹

The day and time of meetings should be convenient for core members who should also be asked to submit best times to ensure a mutually beneficial time for all attendees and due consideration for off site members including rural.¹

It is appropriate to limit the meetings to 45 – 90 minutes. Any time not used for case discussion may be used for educational purposes or discussion of other relevant issues.¹

Meeting room facility must meet the requirements of the MDT (i.e. access and display of radiology images, pathology slides, videoconferencing etc)

4.5 Meeting Agenda

Case presentation will be determined and prioritised by the Chair upon review of referrals and/or discussion with referee.

The Chair will determine closing day/time to receive referrals. All late referrals must be discussed with the Chair. (It is suggested at least 3 days prior to the meeting to be the closing day of referrals to enable MDT coordinator/administrative support to ensure required patient information is available at the meeting)

The Agenda will include:

- Meeting Particulars
- Information required for patient presentation:
 - patients name, DOB, UR no.
 - referring Clinician
 - comprehensive clinical summary
 - test results
 - Education topic
 - Other business

The referring clinician must provide the MDT Chair with the appropriate clinical summary and investigation/diagnostic test results prior to the MDT Meeting.

Late inclusions to the agenda are acceptable. In this instance it is the responsibility of the presenting clinician to ensure all appropriate clinical results are available to the meeting.

The Agenda will be circulated 2 days prior to the meeting. Hard copies may be provided at the meeting.

The MDT Chair will provide the team with a summary of outcomes from the previous meeting.

In the absence of adequate numbers of patients to discuss the MDT Chair or delegate will arrange an education session for the team.

4.6 Case Discussion

Unless otherwise arranged with the Chair, only patients whose referring clinician (or their delegate) is present at the meeting will be discussed.

The referring clinician is responsible to ensure that all necessary patient clinical information is available for the meeting.

Case presentation and discussion will include the patient's clinical condition and any relevant psychosocial aspects impacting on clinical management.

The Chair will summarise the recommendations made from the discussion before moving to the next case.

The Chair will provide a summary for all cases discussed during the MDT. Copies will be distributed to the referring clinician, other relevant MDT members, and the (original copy will be filed into the patient's medical record.)

4.7 Confidentiality

All patient information presented remains confidential and only to be used for the purpose of clinical management.

All health care professionals are subject to confidentiality agreements through their regular employment

4.8 Education

Multidisciplinary team meetings provide opportunities for sharing of expertise, enhancing understanding of the diversity of provider roles and dissemination of information to enhance best practice in provision of cancer care.

This can be achieved by:

- Multidisciplinary case presentations and care planning
- Participation by all providers
- Scheduling of regular presentations by team participants as a forum for
- providing feedback from conferences,
- disseminating current information relevant to specific tumour cancer care
- education specific to provider specialities.

4.9 Meeting Documentation

Referral documentation records will be kept by the Chair/MDT coordinator/MDT administrative support. A record of the referral is required to be filed into the patient clinical health record.

Treatment and management recommendations from the meeting discussion will be documented on the MDT recommendation proforma which must be made available to the referring clinician and inserted in the patients' clinical health record. The Chair signature is required.

The referring clinician or delegate is responsible for discussing the meeting recommendations with the patient/family/carer within 7 days and developing the treatment plan which takes into account the patient preferences. This plan is to be made available to relevant team members, the GP and noted in the patient's clinical health record.

The MDT Chair will maintain one copy of the agenda and all attendance records.

4.10 Performance monitoring

MDT Key performance indicators should be regularly reviewed. These may include:

- Number of patients discussed
- Number of patients reviewed
- Service origin of patients discussed
- Number of attendees
- Differentiation of providers attending
- Number of education sessions

It is recommended that the MDT database is used to aid standardised data collection and to aid running of reports for review by the team.

An ongoing review of satisfaction and effectiveness will be conducted informally 6 monthly.

Formal evaluation will be conducted annually and results communicated to the MDT members for action as required.

Adoption of Terms of Reference

- All members of the MDT will be provided with the terms of reference.
- The MDT Chair is responsible for ensuring members adhere to the MDT terms of reference.
- MDT members are responsible for adhering to the terms of reference.
- The terms of reference require annual review and when/if core member's change.

Subsequent revision dates:

No.	Date	Nature of Change(s)
1	7 th May 2010	Endorsed by Cancer Clinical Network Steering Committee
2		Reviewed
3		

Appendix A: Example template

Directory of [Gynaecological Cancer] MDT Team Members**

MDT Membership	Identified team members	Contact details
Chair		
Deputy Chair		
Specialist Surgeon		
Medical Oncologist / Haematologist		
Radiation Oncologist		
Palliative Care Physician		
Radiologist		
Pathologist		
Cancer Clinical Pharmacist		
General Practitioner		
Other medical disciplines** according to the tumour type and patient need:		
Gastroenterologist		
Endocrinologist		

Nuclear Medicine		
Respiratory Physician		
Gynaecological Oncologist		
Other:		
Specialist Nurse(s): e.g. Cancer nurse practitioner		
Cancer Specialist Nurse (eg Breast Care Nurse) / Cancer Care Coordinator		
Cancer trained nurse		
Allied Health**: According to the tumour type and patient need:		
Dietitian		
Physiotherapist		
Social Worker		
Occupational Therapist		
Speech Pathologist		
Stomal Therapist		
Aboriginal Health Workers		
Psychologist		
Pastoral Care		
Other supportive care		
Clinical Trial Coordinator		
Data Manager		
MDT Coordinator / Pathway Project Officer		
Administrative Officer		

**remove those disciplines which will never be required for this Team

Appendix B: Sample MDT Attendance Registers

Multidisciplinary Team Meeting Attendance Register for [cancer type]

Location: local site/regional/statewide

Chair: _____

Meeting Date: _____ Time: _____

SA Health and ----- Region Health Service are committed to safeguarding the privacy of patient information and have implemented measures to comply with its obligations under the SA Government’s Information Privacy Principles Instruction.³

All staff are bound by law and ethical practice to keep patient information confidential. Patient information will only be disclosed for purposes directly related to patient treatment and in ways the patient would reasonably expect for their current and future care. Patient health information will be shared with staff involved in their care in order to determine best treatment for them and to assist in the management of the health services provided to them.⁴

Team Members:

Name	Discipline	Title / position (consultant, registrar, RMO, student)	Participation method (in-person, tele/video conf)	Signature
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Visitors:

Name	Discipline	Organisation	Signature
_____	_____	_____	_____
_____	_____	_____	_____

³ http://www.premcab.sa.gov.au/pdf/circulars/pc12_privacy.pdf

⁴ North Coast Area Health Service, NSW Health, Palliative Care Multidisciplinary meetings Terms of Reference

APPENDIX B – Useful Websites

SOME USEFUL WEBSITES & SERVICES FOR TREATING CLINICIANS OR WOMEN WITH A GYNAECOLOGICAL CANCER

Cancer Learning

<http://www.cancerlearning.gov.au/>

This website is designed to help health professionals and consumers understand more about cancer care through education and development.

Cancer research / Clinical trials

<http://www.australiancancertrials.gov.au/>

This website is designed to help people with cancer to learn about types of cancers and treatments and find out what cancer clinical trials are currently available in Australia.

SA Cervix Screening Program

www.cervixscreening.sa.gov.au

The Cancer Council South Australia

www.cancersa.org.au

This website provides information sheets and on-line services including:

- Free counselling for people affected by cancer
- Cancer connect – a service that connects women with a cancer survivor
- Living Healthy after cancer
- Look good feel better.
- Legal and Financial Planning Referral Services including:
 - Getting affairs in order – making a will, powers of attorney and advance care planning.
 - Financial issues, including early access to superannuation, insurance, debt management, consumer credit law and Centrelink
- Employment issues for women and carers

The “Look Good, Feel Better” Program

This program offers a free workshop to women undergoing chemotherapy and/or radiotherapy for cancer. The aim is to improve self image, self esteem and confidence through providing the knowledge, techniques and encouragement to help with your appearance.

For more information: Freecall 1800 650 960

The Cancer Council Australia

www.cancer.org.au

This website provides information on research, woman support and advocacy on behalf of cancer patients for improved treatment and access to services.

Cancer Helpline: Phone 13 11 20

National Breast and Ovarian Cancer Centre (NBOCC)

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

This website provides information about all stages of an Ovarian cancer journey

National Association of Grief and Loss

www.grieflink.asn.au

This website provides information, strategies and referrals to services for women and family members with a cancer diagnosis

Palliative Care Council of South Australia

www.pallcare.asn.au

This website is a Palliative Care resource and information service representing services and hospices in South Australia. The site contains consumer and professional information including multicultural information in twenty languages.

Palliative Care Council of South Australia: Phone 8291 4137

Women's' Services

Department of Veteran's Affairs

www.dva.gov.au

This website provides information about Veteran's Affairs services.

DVA provides aids, equipment, counselling, pensions and benefits. The Veteran's Affairs Network provides information and referral services to veterans and war widows.

Phone 13 32 54

Royal District Nursing Association of SA Inc (RDNS)

www.rdns.net.au

This website provides information about the Royal District Nursing Service.

District nurses can provide nursing care according to assessed needs. RDNS provides a 24hr home visiting nursing service. This service can also provide advice and support for carers and families.

Phone 1300 364 264

Meals on Wheels (SA)

www.mealsonwheelssa.org.au

This website provides information about Meals on Wheels Services.

Meals can be provided for frail aged, chronically ill or disabled people for either short or long-term assistance. Also available is a library service of large print books.

Phone 8271 8700

Migrant Health Services

People from non-English speaking backgrounds are eligible for services provided by bilingual nurse, doctors and counsellors.

21 Market Street, Adelaide

Phone 8237 3900

Multicultural Communities Council of SA (MCC)

www.mccsa.org.au

This website provides information about non-English speaking services.

Information and referral to appropriate services for people of non-English speaking background.

113 Gilbert St, Adelaide

Phone 8410 0300

Seniors Information Service (SIS)

www.seniors.asn.au

This website provides information for seniors.

Provides information to older people, their relatives and friends, carers and service providers.

Phone 18 00 636 368

APPENDIX C – Psychosocial referral pathway

Before referring for psychosocial care please consider the following:

<p>Is the woman and/or her family member experiencing an acute exacerbation of distress following a period of increased vulnerability? Is her distress directly related to: Sadness associated with loss of usual good health Preoccupation with thoughts about illness and treatment Worries about future? Worries about the impact the illness is having on their family? Relationship or family issues?</p> <p>Are there significant practical concerns? (e.g. financial stress, transport issues, power of attorney, end of life decisions, etc)</p>	<p>Is the person experiencing chronic elevated distress that is impacting on pain or symptom control, normal functioning, and/or her ability to complete cancer treatment?</p> <p>Does she have a past history of mental health concerns or history of trauma (i.e. PTSD)?</p> <p>Is she experiencing severe anxiety related to her medical condition (eg is hyper-vigilant, experiencing panic attacks, highly irritable)?</p> <p>Does she appear to be depressed or reporting suicidal thoughts?</p> <p>Is she describing illness specific fears and phobias (i.e. needle phobia, hypochondriasis)?</p> <p>Is she reporting issues with body image or sexuality?</p> <p>Is she concerned by chronic disruption of sleep, appetite and/or concentration?</p>	<p>Is the person's primary presentation psychiatric in nature?</p> <p>Are there imminent risk issues? (e.g. suicidal plan/intent or aggression)</p> <p>Does the person have a previous psychiatric history or does she currently receive psychiatric treatment?</p> <p>Is there evidence of a thought disorder or psychosis?</p> <p>Is the person non-compliant with treatment?</p> <p>Are there signs or symptoms of suspected delirium?</p>
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Consider consultation or referral to the following disciplines:

<p>Social Work Interventions may include: Supportive counselling for women and their families Links with external psycho-social supports Support groups and/or individual counselling Family meetings Grief counselling</p>	<p>Clinical Psychology Psychological intervention may include a combination of formal assessment, cognitive behavioural therapy, hypnotherapy, management suggestions, and other relevant therapeutic interventions.</p>	<p>Psychiatric Referral Formal Psychiatric Assessment and Review</p>
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Adapted from: Bond, M. & Collins, K. (2010). Cancer Centre Clinical Psychology Referral Pathway, Royal Adelaide Hospital.

APPENDIX D – Palliative Care Services

Central Adelaide Palliative Care Service

Mary Potter Hospice
89 Strangways Terrace
NORTH ADELAIDE SA 5006
(08) 8239 9144
(Calvary switchboard 08 8239 9100)
Royal Adelaide Hospital
North Terrace
ADELAIDE SA 5000
(08) 8222 2021
(RAH switchboard 08 8222 4000)

Lyell McEwin Palliative Care Service

Lyell McEwin Health Service
Haydown Rd,
ELIZABETH VALE SA 5112
(08) 8182 9208
(Switchboard - 08 8182 9000)

Modbury Palliative Care Service

Modbury Hospital
Smart Rd,
MODBURY SA 5092
(08) 8161 2351
(Switchboard - 08 8161 2000)

Southern Adelaide Palliative Services

Daw House,
700 Goodwood Rd,
DAW PARK SA 5041
(08) 8275 1732
(Daw House Hospice Desk -08 8275 1714)

Western Adelaide Palliative Care Service

Queen Elizabeth Hospital
28 Woodville Rd,
WOODVILLE SA 5011
(08) 8222 6825
(Switchboard - 08 8222 6000)

Women's and Children's Hospital

72 King William Rd,
NORTH ADELAIDE 5006
(08) 8161 7994
(Switchboard - 08 8161 7000)

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- 1 Developed by DM Keefe and K Linke on behalf of the SA Cancer Clinical Network Steering Committee, 2007.
 - 2 National Breast Cancer Centre, 2005, Multidisciplinary meetings for cancer care: a guide for health providers, National Breast Cancer Centre, Campredown, NSW, Australia.
 - 3 National Breast Cancer Centre, 2005, Multidisciplinary meetings for cancer care: a guide for health providers, National Breast Cancer Centre, Campredown, NSW, Australia.
 - 4 Andersen,BL et al Controlled Prospective Longitudinal Study of Women With Cancer: 1. Sexual functioning Outcomes Journal of Consulting and Clinical Psychology.1989 ,vol 57,no 6, 683-691
 - 5 National Institute of Clinical Excellence. 2004. Improving supportive care and palliative care for adults with cancer. National Institute of Clinical Excellence, London.
 - 6 Zabora, J Brintzenhofe Szoc K, Curbow B, etal: The Prevalence of distress by cancer site. Psychooncology 10:19-28,2001
 - 7 Hodgkinson,K,Butow,P,et al Long Term survival from gynaecological cancer; Psychosocial outcomes, supportive care needs and positive outcomes Gynaecological Oncology 104 (2007) 381-389
 - 8 National Health and Medical Research Council. April 2003. Clinical practice guidelines for the psychosocial care of adults with cancer.
 - 9 National Comprehensive Cancer Network (NCCN) 2008. Distress Management. Fort Washington.
 - 8 Jacobsen PB,Donovan KA, Trask PC et al Screening for psychological distress in ambulatory cancer women: a multicentre evaluation of the Distress Thermometer, Cancer 2005;103:1494-1502
 - 11 Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher HI, Holland Rapid screening for psychological distress in men with prostate cancer. Cancer 1998;82 :1904-1908,
 - 12 Ransom S, Jacobsen PB, Booth Jones M. Validation of the Distress Thermometer with bone marrow transplant women. Psycho-Oncology 2006 15:604-612.
 - 13 Hoffman BM, Zevon MA, D'Arrigo MC, Cecchini TB. Screening for distress in cancer women: the NCCN rapid screening measure. Psycho oncology 2004; 13:792-799.
 - 14 Patrick-Miller LJ, Broccoli TL, Much JK, Levine E. Validation of the Distress Thermometer: a single screen to detect clinically significant psychological distress in ambulatory oncology women, J Clin Oncol (2004 ASCO Annual Meeting Proceedings) 2004;22,14S:6024
 - 15 Trask PC, Paterson A, Riba M et al. Assessment of psychological distress in prospective bone marrow transplant women. Bone Marrow Transplant 2002;29:917-925
 - 16 Akizuki N, Akechi T, Nakanishi T et al. Development of a brief screening interview for adjustment disorders and major depression in women with cancer. Cancer 2003;97:2605-2613
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