The Winston Churchill Memorial Trust Of Australia

Sally Goss
RN, Grad Dip Nursing (Ind Pract), MA
2009 Churchill Fellow

Psychosocial Support for Women with Gynaecological Cancers

Difficulties mastered are opportunities won!
Churchill

I understand that the Churchill Trust may publish this Report, either in hard copy or on the internet or both, and consent to such publication.

I indemnify the Churchill trust against any loss, costs or damage it may suffer arising out of any claim or proceedings made against the Trust in respect of, or arising out of the publication of any Report submitted to the Trust and which the Trust places on a website for access over the internet.

I also warrant that my Final Report is original and does not infringe the copyright of any person, or contain anything which is, or the incorporation of which into the Final Report is, actionable for defamation, a breach of any privacy law or obligation, breach of confidence, contempt of court, passing-off or contravention of any other private right or of any law.

Signed:                                      Dated:
INDEX

INTRODUCTION 3

EXECUTIVE SUMMARY 4

PROGRAM 6

BACKGROUND 9
Acute Care facilities 11
Cancer Support Centres 26
Cancer Institutes/Agenices 31
Gynaecological Cancer Organisations 34
E-Health Initiatives 37
IPOS Conference, Quebec 38

KEY HIGHLIGHTS 39

CONCLUSION 40

RECOMMENDATIONS 42

IMPLEMENTATION & DISSEMINATION 43

REFERENCES 44
**INTRODUCTION**

Currently in Australia, the number of people diagnosed with cancer is increasing as our population grows and ages. The impact of the diagnosis has been likened to riding an emotional roller coaster with feelings such as shock, fear, panic, denial, anger, guilt, and uncertainty. Distress was identified at the International Psychosocial Oncology Society (IPOS) in 2009 as the sixth vital sign to monitor in effective cancer management. It was intended that in endorsing distress as an essential component of the whole patient experience, that there would be a ‘call to action’ for care providers and the health care system as a whole.

While a young trainee nurse, I first became aware of the myriad of psychological, emotional and spiritual challenges facing the person with a diagnosis of cancer. The memory stayed with me and was further compounded by observing the cancer experiences of close family members and friends over the years.

After a career in women’s health, in 2008, I was offered a Cancer Australia funded project looking at the support needs of people with the late diagnosed gynaecological and lung cancers. My findings of this small sample concurred with much larger studies showing that the provision of adequate support and appropriate information play an essential role in facilitating adjustment and a sense of control with a diagnosis of cancer.

While the clinical facilities and outcomes in Australia have continued to improve for the person diagnosed with cancer, sources of support and accessible information continue to be variable. Although there is a growing body of evidence regarding successful models of cancer support, experience has shown that it is particularly difficult to both establish and sustain support activities or groups for women with gynaecological cancers due in part to late diagnosis, poor prognosis and lesser numbers.

When encouraged to apply for a Churchill fellowship, I realised this was an excellent opportunity to visit centres of excellence in Canada, USA and UK to investigate how others deal with the challenges and more effectively meet the supportive and information needs of the cancer patient in general and the women with gynaecological cancer in particular.

I will be forever grateful to the Winston Churchill Trust for the wonderful opportunity the fellowship has given me to pursue this mission. I would also like to express my thanks and appreciation for the support and assistance I received from the many generous people in Canada, USA and UK who gave up their valuable time to arrange meetings and presentations to ensure I had all the information they could possibly provide. I would also like to thank my referees and colleagues, Margaret Adams, Kim Pearce and Kathryn Nattress who encouraged and supported me every step of the way. I would like to acknowledge Timothy Hogan, the CEO from the Chris O’Brien Lifehouse at RPA, Kendra Sundquist and Gillian Batt from the Cancer Council NSW, Karen Livingstone from Ovarian Cancer Australia and Lisa Purser from the San Gynae Group, for letters of recommendation and introductions.

A huge thank you to the members of the San Gynae Group who were the “wind beneath my wings”. This special group of women continue to demonstrate the true strength and integrity of the human spirit as they make their own journeys with resourcefulness, resilience, grace and courage.
EXECUTIVE SUMMARY

Sally Goss, RN, Grad Dip Nurs (Ind Pract) MA
1/10 Holdsworth Street, Neutral Bay 2089 NSW, Australia. Telephone 0411 224 585
Cancer Support Consultant

Objective of the Fellowship
To explore referral processes and sustainability for support activities/groups for women with late diagnosed/poor prognosis gynaecological cancers – Canada, USA, UK

Key Highlights
✓ The range of innovative, flexible programs provided at inviting, well promoted, cancer support centres in each country
✓ The “person centred” model of supportive care with implementation processes to embed it into the culture of the institution.
✓ The patient symptom assessment & management tool
✓ Eye catching, accessible staffed information centres in hospitals
✓ E-tools giving the patient access to their complete medical history and information on psychosocial support activities and how to access them
✓ The site specific, trained holistic nurse practitioner model operating in the survivors follow up clinic
✓ Attending the IPOS Conference in Quebec
✓ The inspirational nursing leaders and the passion, dedication and generosity of all the people I met.

Recommendations
While acknowledging programs already in place in Australia, I make these recommendations: that major cancer hospitals/centres develop and implement a supportive care model similar to the Canadian model; that cancer centres develop a patient symptom assessment and management tool with a view to expanding it to sub centres; that the nurse navigator model already in use be modified for expanded use in smaller hospitals and rural areas; implementation of highly visible staffed cancer information booths in hospitals; that Cancer Australia and major centres investigate the use of the e-tools to greatly assist patients right along the cancer journey; and that private hospitals investigate models of supportive care. I emphasise though, frameworks are not enough and it was the Canadian model of effective implementation that was so impressive.

For stand alone cancer support centres, I recommend they: maintain collaborative relationships with hospital staff in oncology, nursing, social work, psychology and dietetics - to ensure the research and development of programs and the facilitation of groups while enhancing the credibility of the centre; a Steering Committee comprising health professionals from appropriate disciplines, representatives from community, marketing and fundraising; flexible frameworks to ensure comprehensive volunteer training and support; fundraising and marketing programs to raise both funds and awareness; collaborative research relationships with universities; and the provision of accessible, diverse and flexible programs to meet the needs of their communities particularly where support groups for site specific cancers are not possible to sustain.

I also fully endorse the achievements of our cancer agencies and encourage further the taking the resources to the people, such as: the Macmillan model of highly visible staffed hospital information booths. Also, for the more isolated in our communities, to continue to develop and provide a range of support initiatives, such as: mobile services; online and telephone support groups, book groups and chat rooms; and video link workshops.
Conclusion
In visiting these leading hospitals and centres in Canada, USA and UK, I was able to observe some very innovative models in operation and to find many challenges in common. What I discovered was that there was no single tool to aid referral to support services by health professionals. Closest to ‘best practice’ in a sustainable model for gynae cancer support groups, was the acute care centres with the gynae-oncology multidisciplinary team referring and encouraging patients to attend ‘in house’ support activities and programs. However, many such centres had still shared the experience of the group folding when the majority of the group succumbed to cancer.

My original hunch proved correct! If we establish an innovative and flexible model of acute care service delivery that provides access to information and support right along the cancer continuum, besides providing the opportunity for the patient to make informed choices, there will be multiple points for health professional referral to other services as required. Thus, with a cancer site specific multidisciplinary team, a “person centred” supportive care model, a nurse navigator position and such tools as: patient symptom assessment and management program; accessible information booths; and the e-tool, the patient has access to information and support every step of the way! A real safety net! While the challenges in implementing and embedding this comprehensive supportive care model are acknowledged, the rewards have been demonstrated to be significant for patients, their families and for health professionals. Evidence has shown an economic benefit in terms of diminished use of medical services when this level of support was provided. Importantly, staff satisfaction levels were higher resulting in lower staff turnover.

With more patients accessing support centres for information and support, some degree of sustainability for these services is ensured. Taking into account the challenges of maintaining site specific cancer support groups, the preferred model may be to offer a range of services to ensure there is a group or activity of interest to all. Some individuals may prefer to attend regularly for a skills program such as yoga, relaxation or meditation, others perhaps writing or music therapy. Again informed choice and a range of flexible services is the key! Joining women with breast and gynae cancer in sub groups such as the Younger Women’s Cancer Group and the Women’s Metastatic Cancer Group has proved successful at some centres due to sufficient similarity of concerns. Alternately peer support programs or online or telephone support groups may meet the needs of other women wanting to communicate with someone “in the same boat”.

While there are differing models for the ‘in house’ support services, autonomous support centres located adjacent to hospitals or even community groups, all play an essential role. For all centres, providing a regular and very well advertised Living Well after Cancer Treatment Program is perhaps the single most important strategy to assist cancer survivors on the next stage of their journey and to inform them of the programs and resources available to them at their local centre. All individuals with cancer can benefit from access to a choice of support services that help preserve dignity and autonomy, optimise well being and improve quality of life!

Implementation and Dissemination
• Circulate report to National Centre for Gynaecological Cancers, state governments departments, cancer hospitals and cancer agencies
• Present findings to colleagues working in psychosocial cancer care.
• Present findings at the Clinical Oncology Society Conference 2010
• Help establish a steering committee at Sydney Adventist Support Centre
• Work with gynae oncology staff at (Chris O’Brien Lifehouse Centre) RPA
PROGRAM

May 12 to 14, 2010

Vancouver, Canada

BC Cancer Agency (BCCA)
- Gina Mackenzie, Practice Leader, Patient & Family Services
- Sydney Foran, SW and Gynae Group Leader
- Inservice by Video, Cannabis Use in Oncology
- Staff Meeting
- Karen Flood, SW Clinical Counsellor, Stress Reduction Program
- Ann Syme & Natalie Ferguson, SAMS Symptom Assessment & Management System
- Mary McCullum, Hereditary Cancer Program
  Ovarian Cancer Canada (OCC)
- Tracey Kolwich, Regional Manager BC/Yukon

May 16 to 21, 2010

Toronto, Canada

Ovarian Cancer Survivorship Program (OCC)
- Clinical Trials & Therapies, Dr Hal Hirte
- Complementary Therapies, Tracey Truant, CAMEO, BC Cancer Agency
- Workshop: Picking Up the Pieces, Ardythe Taylor, Breast Cancer Supportive Care Foundation, Calgary
- Caring Voices, Sara Urowitz, Cancer Survivorship Centre, Toronto Hospital

Canadian Cancer Society
- Heather Sinardo, National Manager
- Maggie De Bruyne, Provincial Coordinator
- Janet Canavan, Peer Support Manager
- Helen Taylor, Manager, Professional & Community Partnerships

Cancer Care Ontario
- Esther Green, Provincial Head, Nursing & Psychosocial Oncology

Princess Margaret Hospital
- Sara Urowitz, Manager, Educational Informatics, ELLICSR
- Janet Papadokos, Manager, Patient Education & Survivorship
- Scott Secord, Manager Breast & Gynae Survivorship Program
- Aleksandra Chafranskaia, Aftercare Program Leader

Odette Cancer Centre, Sunnybrook Hospital
- Support Care Program, Margaret Fitch, Head Oncology Nursing, Leader Patient and Family Support Group
- Patient & Family Support Program, M Fitch, J Myers, P Brown
- Symptom Management, Tracey Das Gupta, APN Gynae Oncology
- Patient Education, Andrea Lombardi
- Care Across the Continuum, Gynae, Care delivery model, Palliative Care
- Family Experience Study
- Sexual Health & Rehab Clinic (SHARE), Lauran Adams
Wellspring, Sunnybrook Centre, Cancer Support Centre
- Dawn Waslow, Manager and Barb Riley, Program Coordinator
Ovarian Cancer Canada
- Elisabeth Ross, CEO

May 25/26
Boston USA
Dana Farber Cancer Centre
- Anne Elperin, CNS Nursing & Patient Care, Education Practice & Quality
- Karen Schultz, Nursing & Research, Policy & Procedures
- Patricia Reid Ponte, Senior VP, Patient Care Services, Chief Nurse
- Donna Barry, ESRA, Patient Symptom Management
- Susan Anastas, Clinical Business Information, ELMAR, Patient Gateway
- Nate Lamkin, Social Work Manager, Dept Care Coordination

May 26 to 28
Quebec City, Canada
- World Congress of Psycho-Oncology, IPOS Conference

June 1
New York City, USA
Memorial Sloane Kettering Cancer Centre
- Dr Barrie Cassileth, Chief, Integrative Medicine Centre
- Nancy Houlihan, NP, Clinical Program Manager, Survivorship Program
- Karen Popkin, Music Therapist, Integrative Medicine Service
- Rachel Zinaman, Project manager, Evelyn Lauder Breast Centre

June 2 to 8, 2010
London UK
St Mary’s Hospital, Paddington
Macmillan Cancer Support
- Kim Diprose, Information & Support Manager
- Helene Buijs, Information Centre, Northwick Park Hospital
Royal Marsden Hospital
- Shelley Dolan, Chief Nurse
Hammersmith Hospital, cancelled
Cancer Research UK, Martin Ledwick
Ovacombe UK, Louise Bayne
Breast Cancer Haven, Tina Glynn
Jo’s Trust, Cervical Cancer, Robert Music
Maggies Cancer Caring Centres Kristine Roberts, Operations Manager
Florence Nightingale School of Nursing
- Isabelle White, Macmillan Clinical Research Fellow in Cancer Rehabilitation
June 9 to 15, 2010

Scotland
Maggie’s Centre, Edinburgh
  - Andrew Anderson, Manager
Edinburgh Cancer Centre, Western General Hospital
  - Camille Busby-Earle, Gynae Oncologist
  - Claire Forrester, CNS, Gynae Clinic
  - Fiona Taylor, Ward Charge Nurse
  - Shelley Marie O’Hare, Chemotherapy
  - Kathryn Brechin, Clinical Nurse Manager Cancer and Palliative Care Services
  - Melanie McKean, Gynae Oncologist
  - Jane McCafferty, CNS Fife
Fort William
  - Macmillans Library Display
Inverness, Maggie’s Centre
  - Linda MacKay, Information & Support
Aberdeen, CLAN Cancer Support Centre
  - Kathryn Fraser
**BACKGROUND**

The aim of this Churchill project was to explore best practice models in the maintenance and sustainability of support groups and initiatives for women with gynaecological cancers. Currently in Australia, 70% of these women will have their ovarian cancer diagnosed at an advanced stage and the majority of this group will not survive five years. In spite of the literature showing a strong need for information and support, support groups for women with gynaecological (gynae) cancers have been shown to be difficult to establish and sustain. Groups tend to be established and flourish until the majority of members succumb to their cancer. The sustainability of support groups is dependent on newly diagnosed women hearing about the services available. Newly diagnosed women may sometimes feel very confronted by the number of women with progressive cancer attending the group.

The secondary aim of the project was to explore recruitment initiatives and to investigate tools to improve referral rates by oncologists and all health professionals to ensure all patients are provided with relevant information regarding access to support and information activities.

We are currently well placed in Australia with the National Centre for Gynaecological Cancers providing leadership in the area and working closely with key stakeholders. In addition the funding grants to build new “state of the art” comprehensive cancer centres at Peter MacCallum Hospital in Melbourne and the Chris O’Brien Lifehouse at RPA, provide Australia with a unique opportunity to develop cutting edge services.

In perspective, mine was therefore a very small niche area, where, recognising the reality of the women’s experiences and the research, I could delve deeper and learn more about support groups and initiatives in practice. What works and what have been the lessons learned? I recognised that while the major focus of the project was on initiatives for women with gynaecological cancers, much of the information learned would be applicable for many cancer groups.

The cancer journey is a very challenging one for women with gynaecological cancers. So many of these women find themselves thrust onto the treadmill of extensive surgery and intensive chemotherapy regimes or invasive radiotherapy while grappling with the reality of a poor prognosis. Emotional or psychosocial distress is a natural phenomena and an expected response to a diagnosis of a life threatening illness. People who are not able to find a way to meet their own needs in this confronting situation are likely to experience ongoing and escalating emotional distress. This distress can in turn escalate “to significant levels where it can compromise adherence to therapy, increase utilisation of other health services, and elevated costs for care”.

---

**References**

1. [Source 1](#)
2. [Source 2](#)
Why support cancer groups? A 2005 Report to the Department of Health and Ageing, *Building Effective Cancer Support Groups* reported that peer support groups and initiatives are successful not only “on the premise that shared experience is a valuable coping resource” but also they improved peoples ability to cope and adapt, reducing anxiety and depression and enhancing self esteem. In their studies participants reported benefits such as hope, encouragement and reassurance, access to knowledge about their cancers, a sense of belonging and a normalising of their experience. Concurring with this study, the women participating in the research project at the Sydney Adventist Hospital (San) in 2009 reported greater quality of life and access to support and information due to attending the group. They expressed the following major benefits: the opportunity to meet others “in the same boat”, diminishing the feeling of being alone; access to quality information; a safe environment where feelings can be fully discussed, the opportunity to really say it as it is; and the support of others who are understanding, compassionate and caring.

However only a small percentage of individuals with cancer attend these groups and we acknowledge that in terms of psychosocial support and access to information there is no one size fits all. First, individuals need to know what support and information services are available to them and then will access these services “how, when, where and why” they want them. The impact of peer support, of meeting others taking a similar journey is significant for many people. Some individuals may prefer to use a telephone support group, others an online support service, some like to come together regularly to learn a lifestyle skill such as meditation, yoga, stress management while others will enjoy art or music therapy classes. Information workshops are the choice of many in today's rapidly changing world, wanting to know more about their cancer, the treatment and side effects, the research and healthy lifestyle topics. Ideally there needs to be a range of choices available and we need to ensure the people living with cancer are fully informed of what is available for them. Car parking is essential!

The other issue commonly discussed with colleagues in the cancer support area, was the perception of “need”. Anecdotally there has been discussion regarding health professionals’ only referring patients to support services who they perceived as “needy”. The reality for many of those who facilitate gynaecological groups is that the participants tend to be a resourceful group of women who, having been dealt a tough hand, want to leave no stone unturned in their quest for an improved quality of life and as much time as possible. What about all the other women? The Canadian supportive care model in which I was interested, demonstrates that *all* patients require some assessment of their supportive care needs on an ongoing basis “with provision of relevant information, basic emotional support, good communication and astute symptom management”. As stated earlier for this reason I therefore needed to visit acute care facilities to observe what initiatives were in place from point of diagnosis. My theory was that if access to psychosocial support and appropriate and accessible information was provided right along the cancer continuum, people living with cancer would not feel so isolated and lacking in understanding about their treatment and the journey they were taking. Information of local support services available to them would enable them to make informed choices!
Consequently the report will be undertaken under the following headings and information will be related to the aims of the project:

1. Acute Care and the “big picture” - cancer hospitals and institutions.
2. Cancer support centres, groups and initiatives.
3. Cancer agencies and their role. Research, information, phone and IT initiatives
4. Gynaecological Cancer Organisations
5. E-health initiatives
6. IPOS World Congress of Psycho-Oncology

I should state at the outset, this report is in no way intended to be an academic paper but rather a reflective account of my personal experiences. I have endeavoured to write in a style most likely to be meaningful to health professional and community members alike. There are obviously many important variables in the hospitals and centres visited, not least, the healthcare system of the particular country, budgetary issues and issues relating to public versus private care. Although these issues impact on how the healthcare system operates they will not be covered in this report. Comparatively, more space will be given to new initiatives currently being implemented in Canada as greater time was spent there and the information learnt was then highlighted at the IPOS Conference in Quebec. It should be noted that the hospitals visited in USA and UK are international leaders in the cancer field and already have many of these Canadian initiatives so they will not be discussed further. It should also be pointed out that at each hospital visited, staff from perhaps different areas or levels were interviewed resulting in very valuable but non comparable information.

**Acute Care Facilities**

Hospitals and institutes visited which offered clinical services included:

- BC Cancer Agency, Vancouver
- Princess Margaret Hospital, Toronto
- Odette Cancer Centre, Sunnybrook Hospital, Toronto
- Dana Farber Hospital, Boston
- Memorial Sloane Kettering Hospital, New York City
- Royal Marsden Hospital, London
- Western General Hospital, Edinburgh

**CANADA**

**BC Cancer Agency**

The BC Cancer Agency (BCCA) in Vancouver is the hub for a province wide, population based cancer control program, which includes assessment and diagnostic services, chemotherapy, radiation therapy, and supportive care. Over 15,500 new patients are treated at the centre annually.
The evidence based supportive care services include: patient and family counseling, support and information activities, a hereditary cancer program, nutritional assistance, pain management, symptom control, and palliative care. Research and clinical trials are also based here and an integral part of the “one stop shop” service.

**Patient Assessment**

On the first visit, patients attending the centre are asked to complete psychological screening form. Patients then identified at risk are referred to appropriate health professionals within the centre. A new project of assessment is in implementation stages and combines the use of Symptom Management Guidelines with a newly developed Interactive graded Symptom Assessment and Collection system. A change management project manager has been working closely with health professionals in the province to understand their work practices and challenges. She has then been able to develop a comprehensive and flexible training package and a feasible timetable to ensure the new system is fully implemented and embedded into practice. The new system and technology empowers the patient through having a tool to effectively communicate their symptoms. Likewise it assists health professionals to manage symptom distress through the provision of a consistent, systematic and evidence based approach. In this Edmonton Symptom Assessment System, patients are asked to rate the following on a scale of 1 to 10 (worst possible).

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible pain</td>
</tr>
<tr>
<td>Not tired</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible tiredness</td>
</tr>
<tr>
<td>Not nauseated</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible nausea</td>
</tr>
<tr>
<td>Not depressed</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible depression</td>
</tr>
<tr>
<td>Not anxious</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible anxiety</td>
</tr>
<tr>
<td>Not drowsy</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible drowsiness</td>
</tr>
<tr>
<td>Best appetite</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible appetite</td>
</tr>
<tr>
<td>Best sense of wellbeing</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst sense of wellbeing</td>
</tr>
<tr>
<td>No shortness of breath</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible shortness of breath</td>
</tr>
</tbody>
</table>

**Patient information**

Following completion of the screening, patients not requiring further professional intervention are made aware of available resources at the centre and on the very informative website. The BCCA website is comprehensive for both patients and health professionals. On the excellent *Coping with Cancer* page, is listed further comprehensive information under the headings of: emotional support, support groups, cancer in my family, nutritional support, practical support (financial, work related, home support), managing symptoms and side effects, palliative support and pamphlets.

The BCCA has a very accessible "walk-in" library on the ground floor where library staff assist patients, members of the public, and health-care professionals to find information, using a wide variety of resources including electronic information sources and internet searches.
People from “out of town” can utilise the Contact us link to request resources and the Recommended Websites on cancer and health are compiled and evaluated by BC Cancer Agency Librarians and BC Cancer Agency experts. When I visited the library, a small friendly dog was in residence in between his visits to the treatment centres where he provides a welcome diversion to those waiting!

A range of support initiatives were available including education programs:

- Nutritional Workshops
- Cancer Transitions Program (after treatment)
- Coping with Cancer
- Look Good Feel Better
- Stress reduction
- Mindfulness Meditation etc

Support groups meet on a regular basis

- Site specific support groups, ovarian, lung, brain, prostate, colorectal, breast, lymphoma
- Specific groups for: younger women; women with metastatic cancer; lesbian & bisexual women; Chinese support group: children’s’ club
- Relaxation and mindfulness sessions weekly

In response to increasing questions about specific alternative therapies, in 2008, BC Cancer Agency and the UBC School of Nursing started a research project - the Complementary Medicine Education and Outcomes (CAMEO) Program which has been well utilized by both patients and health professionals.

Weekly online support and discussion groups are also proving to be another very successful support tool. Some people actually prefer the slightly more anonymous nature of the service while others embrace them due to their inability to access regular services due to distance or perhaps physical limitations. Health professionals in the team facilitate the groups.

“One stop shop” Cancer hub

| Province wide, pop based cancer program |
| Person centred care model |
| Patient symptom assessment tool, implementation |
| Cancer site specific teams |
| Psychosocial team & activities |
| Information/library facilities, very accessible |
| www.bccancer.bc.ca |
| Gynae Support Group |
| Referral, effective |
| Highlights, all the above points, such an integrated model |
TORONTO
Toronto (pop > 2.5 million) is the largest city in the province of Ontario (pop > 12 million) and has two major comprehensive cancer centres. Princess Margaret Hospital is fifth largest and the Odette Cancer Centre sixth largest in the world. Both centres are justifiably proud of their very broad based innovative clinical research and supportive care initiatives.

Odette Cancer Centre (OCC), Sunnybrook Hospital, Toronto.
The OCC, on the campus of Sunnybrook Hospital sees over 11,000 new patients annually in the beautiful atrium like “state of the art” building.

I was very fortunate to spend time with Dr Margaret Fitch RN, Head, Oncology Nursing and Lead, Patient and Family Support Group, and her team who gave a presentation of the innovative work being done in this area. Margaret’s long term interest and work in “patient centred” care over sixteen years has been instrumental in the Supportive Care Framework not only used in Canada but many centres worldwide. As this model of supportive care impacts so effectively on the psychosocial needs of the woman with gynae cancer and this project, further details will be provided at this point.

Supportive care, a framework for patient-centred care
Supportive Care is the provision of the necessary services for those living with or affected by cancer to meet their physical, psychosocial, informational and spiritual needs during the diagnostic, treatment and follow-up phases, encompassing issues of survivorship, palliation and bereavement. The OCTRF (Ontario Cancer Trials &Research Foundation) Statement on Supportive Care 1996, defined the basic standards for Supportive care as follows:

- All individuals receive ongoing supportive care assessment (see Figure 1 for an example)
- All individuals have the opportunity to be referred to an appropriate supportive care resource
- All individuals have the opportunity of self referral to supportive care resources
- All individuals have access to understandable, relevant information regarding the medical, practical and emotional aspects of their cancer and its treatment
- All individuals receive supportive care that is relevant to their needs and sensitive to their age, gender, language, culture, sexual preferences, religion and economic status
Providing Supportive Care Services

Cancer Patients Entering the Cancer System

100%

All patients require assessment of supportive care needs on an ongoing basis. With provision of relevant information, basic emotional support, good communication, and astute symptom management.

Many will need additional information, education, and encouragement to seek additional help & engage in peer support groups.

Some will require expert professional intervention for symptom management/psychosocial distress.

A few may need intensive & complex care.

20% will only require this level of service

30% will also require this level of service

35%-40% will also require this level of service

10%-15% will also require this level of service

Figure 1, Service provision based on proportion of patients requiring assistance
The supportive care model recognises the patient as “front and centre” and the patient and family as defined by the patient as the central focus. Supportive care needs to be flexible with a wide variety of services and interventions as no one size fits all. For the person living with cancer it is a 24/7 experience with changing needs. Consequently supportive care must be available, accessible and visible to all those living with cancer and their family members. It seeks to improve and preserve quality of life, autonomy and dignity of those living with cancer and to optimise their well being. To further progress this model the Odette Cancer Centre (OCC) successfully amalgamated departments providing: psychosocial oncology, social work, psychiatry and psychology, drug reimbursement, physiotherapy, occupational therapy, nutrition, speech language pathology, spiritual care and palliative care, to form the Patient and Family Support Program.

Patient Education
An essential component of the person centred care model is accessibility to appropriate information and education each step of the way. To facilitate this a Patient Education and Research Learning (PEARL) centre was established. The major highly visible centre is located in close proximity to registration and is staffed by trained volunteers. The centre provides a lending library, cancer site packages, touch screen computer/internet stations for learning, relaxation, small group discussions and organised programming. Related services include:

- Satellite patient education lounges with patient education virtual centre
- Database and catalogue of literature
- Literature ordering system and tailored information packages
- Training – patient portal, internet etc
- Mobile roaming cart of resources including cancer relevant materials, CDs, DVDs, general reading material, news, games and puzzles. Provided by trained volunteers for patients, families and visitors
- Patient Education Skills course for health professionals, interactive teaching
- Virtual chemotherapy and radiotherapy online module for new patients

Gynaecological Cancer Initiatives
OCC cares for one of the largest groups of gynae cancer patients in Canada and in 2000 undertook research to investigate Understanding Supportive Care Needs of Patients with Gynae Cancer. This comprehensive study was undertaken across Canada and the results now underpin the service provided within the Gynae Oncology unit. The research identified frequently unmet sexual needs in women following treatment for gynae cancers, consequently a unique SHARE (Sexual Health Clinic) was established offering sexual health and sexuality support for all patients. Very positive evaluation of services to date!
**Odette Cancer Centre, Sunnybrook Hospital**

<table>
<thead>
<tr>
<th>Feature</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person Centred Care Model</td>
<td>✔️ ✔️ ✔️</td>
</tr>
<tr>
<td>All staff trained in the model</td>
<td>✔️</td>
</tr>
<tr>
<td>Patient Symptom Assessment &amp; Mgt Procedure with tracking and alert system</td>
<td>✔️ ✔️</td>
</tr>
<tr>
<td>Patient Information Facilities, accessible</td>
<td>✔️ ✔️</td>
</tr>
<tr>
<td>PEARL</td>
<td>Well displayed</td>
</tr>
<tr>
<td>Patient &amp; Family Support Initiative</td>
<td>✔️ ✔️ ✔️</td>
</tr>
<tr>
<td>Embedded into practice</td>
<td>✔️</td>
</tr>
<tr>
<td>Gynae Cancer Inter Disciplinary Team</td>
<td>✔️</td>
</tr>
<tr>
<td>Web</td>
<td><a href="http://www.sunnybrook.ca">www.sunnybrook.ca</a></td>
</tr>
<tr>
<td>New patient information</td>
<td>✔️</td>
</tr>
<tr>
<td>Gynae Cancer Support Group</td>
<td>No</td>
</tr>
<tr>
<td>Pts referred to activities at Wellspring Support Centre or to online services</td>
<td>✔️</td>
</tr>
<tr>
<td>Referral to p/social support services, effective</td>
<td>✔️ ✔️</td>
</tr>
</tbody>
</table>

**Highlights**

- Patient centred care, embedded into practice. All components accessible and user friendly
- The Patient Education and Research Learning (PEARL) Centre
- A passionate multidisciplinary team dedicated to the provision of best practice for the patients.
- A progressive, creative work environment, skilled and inspirational leadership,
- New electronic symptom assessment, screening and intervention tool currently being implemented
- Sexual health clinic

**Princess Margaret Hospital, Toronto**

Princess Margaret Hospital, a major teaching hospital of the University of Toronto, is devoted exclusively to cancer research, treatment and education. Another hospital with a great emphasis on a person centred care model developed by their own team.

**Patient Assessment &Support**

Patients are seen in site specific areas and I met with the Breast Cancer Survivorship Program team which has recently merged with Gynaecological cancers. Prior to surgery, all patients attending this unit see a team member (social worker or psychologist) who uses an in house standardized screening tool to work with the patient to develop a survivorship care plan. The plan will ultimately cover the three phases of diagnosis, treatment and long term survivorship. An excellent software system [www.infowall](http://www.infowall) can be utilised for the patient to enter their care plan, track their journey with the capacity for access to information, results, doctors visits etc. Patients identified as requiring further services are referred to appropriate team specialists or departments.
A specialist lymphoedema clinic staffed by highly trained physiotherapists, nurses and massage therapists provide lymphoedema assessment and care. Healthy lifestyle choices are also covered, embracing weight management, diet and exercise.

**Patient Education**
Besides a wonderfully visible, staffed and well equipped *Patient Education Program* at point of entry on the ground floor, there was a smaller specialist information centre within the breast and gynae centre, with the full range of specialist resources for these women – CDs, DVDs, books, brochures, packages and touch screen computers.

**Survivorship Centre**
Funded by an Ontario Innovative Grants Scheme, ELLICSR, a Collaborative Centre for Health, Wellness & Cancer Survivorship opened in June 2010. This amazing basement centre has “state of the art” IT facilities, cooking demonstration kitchens, specialty meeting rooms with videoconferencing, exercise and activities rooms, counselling and meditation facilities, and information centres. Patients are invited to attend the centre to learn important life skills around diet and exercise, proven approaches to improve side effects of treatment as well as overall health and quality of life. A research team will work on site to investigate strategies to improve the cancer experience.

**Support Activities**
A comprehensive program of events is offered with the Patient Education & Survivorship Program. These include workshops on topics ranging from Head Wrap Workshop, Look Good feel Better through to Chemo Questions, Managing your Cancer Journey, and Medical Information I Need to Know. Healthy lifestyle topics include: Healthy eating; balancing your life; healthy steps, relaxation and managing cancer related fatigue and more. The monthly program lists not only in house activities but other activities available at cancer support centres in the Toronto area.

A wonderful online program for cancer survivors, [www.caringvoices](http://www.caringvoices) is available to assist women to build relationships with other survivors and to provide support for each other. It is managed by the dedicated psychosocial support team (mainly nurses and social workers) at the hospital to ensure ongoing quality and reliability. The site contains: a resource library; people matching per diagnosis; chats and forums; online events with topics such as – cancer is a word not a sentence, radiation /chemo therapy questions, parenting while coping with cancer, clinical trials, open chat for care givers and more!
Princess Margaret Hospital
Person Centred Care Model
All staff trained in the model
Patient Symptom Assessment Procedure
Preliminary appt pre surgery for ALL
Patient Information Facilities
Also in Breast/Gynaec unit
Patient & Family Support Initiative
Gynae Cancer Inter Disciplinary Team
Patient Navigator Process
Indirect
Web /www.uhn.ca/applications/PMH
www.infowall.ca www.caringvoices.ca
Gynae Cancer Support Group
Highlights
• Comprehensive “person centred” care model of best practice with all essential activities right along cancer continuum
• Very professional and innovative team
• New patient assessment procedure, symptom assessment tool
• Integrated on site support groups/initiatives
• Multiple patient information facilities
• ELLICSR Survivorship Centre & programs
• Lymphoedema service
• IT facilities, and Caring Voices support
• Excellent fundraising facilitating further resources

USA, BOSTON
Dana Farber Cancer Institute
Dana-Farber Cancer Institute (DFCI) is one of the world’s premier cancer centres combining treatment and research. TheYawkey Centre, a new, state-of-the-art building for patient care and clinical research, is due for completion in 2011 and will retain Dana-Farber’s trademark compassionate, family-centered, and innovative care model. The hospital prides itself on a culture of support with all staff from the car parking valet, the catering staff and health professionals receiving appropriate training during orientation. Besides continuing with the patient centred model incorporating a patient symptom screening tool and patient navigators, accessible patient information booths, multidisciplinary teams will operate per specific cancer site.

The services at the DFCI are fully electronic with not only full medical records, treatments regimens, research trial information for health professional staff but also an e-tool - patients gateway system which allows the patient to access records, test results, further information across a raft of topics and contact with health professionals. This system is empowering for the patients as besides enabling them to access further information it provides relevant information on comprehensive support services and how to access them.
The DFCI Nursing and Patient Care Services team delivers expert, compassionate care in an environment that fosters hope and inspiration. They are justifiably proud of their nursing research and mentoring program which is educating and progressing the next generation of nurses. In recognition of their achievements they were given a Magnet award – the highest honor a hospital can receive for nursing excellence!

**Survivorship**
The Perini Family Survivors’ Center at Dana-Farber Cancer Institute helps cancer survivors access post-treatment follow-up care, including counseling and monitoring of long-term side effects of treatment. The centre offers tailored care for survivors of both adult and childhood cancers with information about the issues that survivors of cancer face today, including emotional and physical symptom management; legal rights concerning health care and employment; finding support groups; maintaining, repairing, or enhancing personal relationships; and pursuing appropriate follow-up care.

In recognition that cancer is often now seen as a longer term chronic disease, programs have been implemented to provide training in patient education, patient and family support and survivorship for family physicians (general practitioners) to enable them to undertake a greater role in patient care.

**Support Activities** Dana-Farber/Brigham and Women's Cancer Center has a well established Patient and Family Supportive Care team coordinated by a social worker. A psychosocial care multidisciplinary team operates per specific cancer site. The centre offers a variety of educational seminars and support groups to help patients and their families find the tools they need to regain a sense of control over their lives. Presented in small-group settings to encourage questions and in-depth discussion, the seminars allow patients to: explore the role of spirituality in illness; discover ways to eat better; practice relaxation techniques; and to learn to integrate exercise into treatment and follow-up care.

There are currently nineteen support groups, which are geared to specific cancers and methods of treatment, allowing patients to meet with one another and share information and moral support.

| Person Centred Care Model                           | ✔✔✔  |
| All staff trained in the model                     | ✔    |
| Patient Symptom Assessment Procedure              | ✔    |
| with tracking and alert system                     |      |
| Patient Information Facilities                     | ✔    |
| Patient & Family Support Initiative                | ✔✔✔  |
| Gynae Cancer Inter Disciplinary Team               | ✔    |
| Patient Navigator Process                          | ✔    |
| Survivorship Program                               | ✔    |
| Web www.dana-farber.org                            | ✔    |
| E-tool, www.patient gateway                        | ✔✔✔  |
| Gynae Cancer Support Group                         | ✔    |
Dana Farber Cancer Institute Highlights

- Comprehensive “person centred” care model of best practice with all essential activities right along cancer continuum
- Committed award winning nursing team
- Integrated on site support groups/initiatives
- Collaborative research base
- E-tool, Patient Gateway
- Fully electronic systems

NEW YORK CITY
Memorial Sloane Kettering Cancer Centre

The Memorial Sloan-Kettering Cancer Center (MSKCC) is the world’s oldest and largest private cancer centre. Annually, more than 22,000 patients are admitted to MSKCC with 466,000 outpatient visits at its Manhattan and regional sites combined. Due to the size and complexity of MSKCC, this visit only covered: the Integrative Medicine Centre, the Survivorship Program and the Evelyn H Lauder Breast Centre.

The MSKCC Integrative Medicine Centre, located in an old bank, provided a very harmonious, relaxed ambience in the heart of New York City. The centre reflects a strong research background as it continues to investigate initiatives to assist the person along the cancer pathway. Free inpatient services are available even for patients in the intensive care unit and include: music therapy, massage therapy, reflexology, in bed yoga, chair aerobics and more. Qualified volunteers provide hair and nail services for inpatients where appropriate. With an emphasis on empowering the patient and family members, initiatives are available such as: reflexology workshops to teach family members; self hypnosis CDs and more. Many clinics and workshops are offered for outpatients and comprehensive complementary therapies information is available electronically and in hard copy. I was very fortunate to accompany a music therapist on her rounds in the hospital. She visited a boy of eleven with a complex cancer which resulted in him spending long periods in hospital for treatment. It was very moving to watch this sensitive young woman communicate gently with him to investigate his interest in music and from her large cache of instrument (both professional and home made improvisations) what he might like to play with. By the end of the hour his eyes were alight with the delight of the experience and he invited her to return soon!

Nurse Practitioner Role in Survivorship care

MSKCC piloted a new model to address needs of cancer survivors returning over many years for (often five minute) annual check ups. Cancer advocates were recommending a new way of looking at the broad based needs of the cancer survivor. Again it was not only the physical needs but the psychological, emotional, social and spiritual needs.
As the clinical workforce was shrinking, the number of cancer survivors was increasing, it was evident that a large part of an oncologist's day may be used up seeing patients for routine check-ups while the waiting list for new patients requiring immediate care lengthened. Economically it was certainly not the best use of resources.

A multidisciplinary steering group was formed and utilising the available evidence, a program was developed using nurse practitioners (NP). To be employed in this role the nurses needed considerable oncology nursing experience and appropriate postgraduate qualifications. However it was stressed that they also needed to have the right personal skills - empathy, enthusiasm and good communication skills. A three month training course and guidelines were developed as well as ongoing professional development modules. The NPs conduct the follow up surveillance visits and address the needs of the patients, arranging access to appropriate services to address ongoing issues as required. They provide counseling on preventative health care and strategies for healthy lifestyle. Survivorship nurse practitioners now see over 50% of the surveillance appointments amounting to over 7000 annually. More nurse practitioners now work in acute care since recent legislation was passed limiting the number of hours physicians in training may work.

**Person Centred Care Model**

- **Patient Symptom Assessment Procedure**
- **Patient Information Facilities**
- **Patient & Family Support Initiative**
- **Gynae Cancer Inter Disciplinary Team**
- All electronic services, [www.mskcc.org](http://www.mskcc.org)
- Gynae Cancer Support Group
- Referral to Gilda’s Club and online support groups

**Highlights**

- Integrative Cancer Unit
- Inpatient support services
- Nurse practitioner model

*Insufficient time at MSKCC to comment further*

**UNITED KINGDOM**

**Royal Marsden Hospital, London**

The Royal Marsden (RMH) is the largest comprehensive cancer institute in Europe, combining acute care with cutting edge research. More than 30,000 patients from UK and abroad are treated there annually. Over 500 clinical trials may be in progress at any given time and over 30% of patients are participating in a trial. The hospital's mission is to continually improve the science of cancer, the treatment of cancer, the experience of living with cancer, and the full range of related issues such as support initiatives, complementary therapies and survivorship issues. The ethos at RMH is to never accept there is nothing further can be done for a patient but rather that symptoms can always be managed and the highest level of comfort and support ensured.
With regard to comfort, great attention is paid to items such as the best quality bed linen and twenty four hour availability of nutritious appetising food, well presented. No styrene cups!

A unique practice at the RMH is that all staff from porters and catering staff to health professionals learn about current research at the hospital. This ensures all staff are aware of the positive aspects of the research for the patients.

There is a highly skilled and dedicated nursing workforce of 800 which includes 10 Nurse Consultants, 56 Clinical Nurse Specialists and 15 Nurse Practitioners, all with Masters or PhD qualifications. Shelley Dolan, the Chief Nurse describes the nurses as "the glue in the system". She says they work happily in partnership with their patients, identifying each patient’s specific needs, supporting each step of the way and bridging the gaps. Shelley herself rolls up her sleeves to work a shift in a different ward every three weeks.

Recognising that caring for people with cancer can be quite demanding, donated money is used to employ two fulltime staff counsellors. The counsellors support staff one-on-one, in the wards, at staff meetings and may lead active group work where morale is down (e.g. after a recent fire). In a recent UK survey, staff at the Royal Marsden rated their job satisfaction in the top 10%.

Person Centred Care Model
All staff trained in the model. Specific training to be sensitive and be aware of patients needs.
Patient Symptom Assessment Procedure
with tracking and alert system

Patient Information Facilities
Patient & Family Support Initiative
Gynae Cancer Multi Disciplinary Team
Patient Navigator Process
Web www.royalmarsden.nhs.uk
Excellent Patients Guide
Gynae Cancer Support Group

Highlights
• Highly committed professional workforce
• Patient Centred Care +++, best practice
• Inspired nursing team
• Leading research facility
• Facilities for CALD translations
• Award winning food (flexible)
• Radio Marsden
• Staff Counsellors
St Marys Hospital, Paddington
At St Mary’s Hospital, I had a short meeting with Christine Norton, Professor of Nursing Innovation. Christine's major clinical work and research has been regarding the impact of surgery, radiotherapy and chemotherapy on the bowel. As treatment has become more radical, and patients surviving for a longer time, the impact and side effects of these treatments are greater. Patients constantly feel humiliated and embarrassed at their symptoms. Many report a significantly reduced quality of life and some are even housebound. Patients often report feeling they cannot complain, as they are still alive so perhaps they just have to put up with the debilitating symptoms. Discussion surrounded the impact of radical treatment on women with ovarian cancer resulting in problems with bowel function, obstruction and fistulas. These issues impact on dignity, quality of life, the woman's sense of femininity and body image. Where a patient symptom assessment tool is being used in conjunction with a nurse navigator, the patient can be assisted and supported through the earlier stage of treatment and referred for professional assistance as required. However, further research is needed in this area.

Florence Nightingale School of Nursing, London
Here I met with Isabelle White, Macmillan Clinical Research Fellow. Isabelle’s specialty area is the psychosexual issues for people adversely affected by cancer treatment. This is a concern for many women treated for gynaecological cancers but a particular issue for younger women for whom there may be fertility issues as well as the physical discomfort, body image and psychological and relationship issues experienced by others. The potential stigma experienced by some women with cervical cancer was discussed. Isabelle reported a real lack of services for these women with many health professionals not comfortable in asking questions regarding sexual relations. Isabelle believed that psychosexual specific services tend to be ad hoc, generally established by an interested person rather than fully integrated into the person centred care model. More work needs to be done in this area too!
SCOTLAND
Western General Hospital, Edinburgh
The Western General Hospital (WGH) is one of two major cancer centres in Scotland and as such services rural and remote areas. With the Royal Edinburgh Infirmary (where a good deal of cancer surgery is undertaken) the WGH is part of the NHS Lothian Healthcare system.

At WGH, I was fortunate to attend a weekly multidisciplinary gynae-oncology meeting with 22 very committed health professionals physically in attendance and rural members attending by video link. All cases were presented very efficiently with history, test and MRI or scan results. Following discussion specific recommendations were made.

The WGH has a comprehensive staffed Macmillan’s information booth at a highly visible and accessible point within the hospital as well as the original Maggie’s Support Centre on campus. Two excellent sources of information and support!

Nurses on this enthusiastic and innovative unit were well supported with a four day orientation, staff development programs and regular staff issues meetings. Recognising the needs of staff working with cancer patients, the issue of support for all health professionals was high on the agenda after a recent workshop. Debriefing systems and better access to counselling were under discussion.

In the chemotherapy unit, each nurse has a specified caseload resulting in an individual patient being cared for at every visit by the same nurse. The patient is able to telephone her specific nurse at the unit for information or with any problems. A great source of support!

| Person Centred Care Model                             | ✔️ ✔️ ✔️ |
| Patient Symptom Assessment Procedure                  | ✔️    |
| Patient Information Facilities                        | ✔️    |
| Highly visible Macmillan’s staffed information booth   | ✔️ ✔️ |
| Patient & Family Support Initiative                   | ✔️    |
| Gynae Cancer Multi Disciplinary Team                  | ✔️ ✔️ |
| Patient Navigator Process                             | ✔️    |
| Web www.nhslothian.scot.nhs.uk/hospitals/wgh.asp      | ✔️    |
| Gynae Cancer Support Group                            | ✔️    |
| Referred to Maggie’s Centre on WGH campus             | ✔️ ✔️ |

Highlights
- Professional, innovative & compassionate team, strong focus on research
- Excellent rural and remote services
- Individual chemotherapy nurse service
- Excellent information & support with McMillan’s booth accessible within hospital and Maggie’s Centre on campus
**Cancer Support Centres**

Cancer Support Centres visited included:
- Wellspring Centre, Toronto
- Maggies Centre, London
- Breast Cancer Haven, London
- Maggies Centre, Edinburgh
- Maggies Centre, Inverness
- Cancer Link Aberdeen & North (CLAN), Aberdeen

**Wellspring Centre, Toronto**

Wellspring is an innovative network of nine centres providing high-quality cancer support, education and coping skills to a growing number of individuals, family members and professional caregivers in Canada. The Wellspring network fosters new program development, research and evaluation, quality control, expansion and outreach to underserved communities. It also improves healthcare system effectiveness through training and education for healthcare professionals, and assists many other community agencies through model sharing, advice, volunteer training and partnership. All group leaders and workshop facilitators are fully paid.

The Wellspring Centre on the Sunnybrook campus seeks to help as many people affected by cancer as possible and aims to reduce barriers related to culture, geography, age, socio-economic circumstances, disability and other factors. Services offered include:
- One-to-one peer support and counseling
- *The Healing Journey*, a regular multi-level support and coping program
- Group programs per cancer site; children & parents groups; carers; lesbian & partners group; gay men’s group
- Workshops: relaxation; meditation; qi gong; tai chi; yoga; cancer exercise; art therapy; drumming; quilting; spiritual growth; returning to work
- Specialised support programs to healthcare professionals to address the many challenges and demands of their profession.

<table>
<thead>
<tr>
<th>On hospital campus, Sunnybrook Hospital</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff (non clinical)</td>
<td>✓</td>
</tr>
<tr>
<td>1FT Manager, 1FT Program Coordinator</td>
<td>✓</td>
</tr>
<tr>
<td>Accountant 1 day</td>
<td>✓</td>
</tr>
<tr>
<td>Strong links with hospital clinical staff who coordinate many groups. Wellspring staff on OCC committees</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>Volunteers 40, front desk &amp; peer support</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>Volunteer selection/training – some experience of ca</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>Interview, 2 day training</td>
<td>✓</td>
</tr>
<tr>
<td>Volunteer support/ meetings</td>
<td>✓ ✓</td>
</tr>
<tr>
<td>Fundraising, very strong &amp; innovative</td>
<td>✓ ✓</td>
</tr>
<tr>
<td>Web <a href="http://www.wellspring.ca/odette">www.wellspring.ca/odette</a></td>
<td>✓</td>
</tr>
<tr>
<td>Board/ Steering committee</td>
<td>✓</td>
</tr>
<tr>
<td>Good representation</td>
<td>✓</td>
</tr>
</tbody>
</table>

**Psychosocial Support for Women with Gynaecological Cancers**
Wellspring Centre Highlights

- Integration with hospital, two way cross fertilisation
- Warm, welcoming, homely atmosphere
- Free services/programs
- Staff experienced and excellent management qualifications
- Peer support very strong
- Volunteers, very proud service
  - monthly training update
  - Awards lunch June
- Innovative fundraising

Hope and Cope, Montreal

While this centre on the campus of the Jewish General Hospital in Montreal, was not visited, time was spent at the IPOS Conference speaking with centre staff and hearing presentations about the work of this very progressive service. The staff of Hope and Cope, along with over 400 volunteers, provide a comprehensive range of services which include: one-on-one support; hospital visits; support groups; fully stocked library & resource centre; patient education lectures; wigs, scarves, turbans, Look Good .... Feel Better; palliative care and bereavement support; program for young adults with cancer.

The freestanding Wellness Centre is a separate facility offering a nutrition program, a fully equipped exercise room and physical activities program, and complementary therapies such as yoga, relaxation training, art and choir. The staff and volunteers at Hope and Cope work closely with the health care professionals at the Segal Cancer Centre, including the nurse navigators who coordinate the care of patients. Volunteers provide support and guidance at the oncology clinic, radiation oncology and the palliative care unit. In addition, Hope and Cope staff have a presence at medical rounds and hematology-oncology rounds. Through their Research Director, Hope and Cope works collaboratively with McGill University, particularly in the fields of Social Work, Oncology and Physical and Occupational Therapy. www.jgh.ca/en/hopeandcope

Breast Cancer Haven, London

The London Breast Cancer Haven is one of three in the UK offering free support, information and complementary therapies to anyone affected by breast cancer. Participants are offered the expertise of specialist nurses and therapists and also peer support from meeting others going through a similar experience. The centre is committed to furthering the research evidence base of complementary therapies and integrated healthcare through a program of research and audit.

The Breast Cancer Haven offers: introduction sessions demonstrating available therapies and programs; individual consultation with a senior therapist for a personalised program; individual complementary therapy sessions to alleviate the side effects of medical treatment; over twenty different therapies; a range of
seminars and groups; a multi-media package is available for email/mailing.
Breast Cancer Haven
On hospital campus no
Staff; 8: Manager RN, MSC Complementary Therapies
2 admin staff, research staff
Trusts, marketing, & events managers
Volunteer selection/training
Volunteer support/ meetings Fundraising
Link www.breastcancerhaven.org.uk
Strong research function
Board: 6 trustees
Advisory & Scientific Committee: 17, including 10 professors
Highlights
• Very warm welcoming ambience in an old church
• Dedicated, professional staff
• Excellent range of therapies
• Ongoing research
• Very effective marketing and fundraising
• Comprehensive volunteer recruitment and training
• Accessible/affordable parking

Maggie’s Centre, London
The Maggie Keswick Jencks Cancer Caring Centres Trust was founded by Maggie Keswick Jencks in 1995 to provide support for people affected by cancer, their families, carers and friends, to empower people to live with, through and beyond cancer.

Following her own experience with cancer, Maggie was convinced that everybody would feel better as she did, if they felt able to take some active role in what was happening to them. In order not to be a ‘cancer victim’, she believed you needed help with information, that would allow you to be an informed participant in your medical treatment, help with stress reducing strategies, psychological support and the opportunity to meet up and share with other people in similar circumstances in a relaxed domestic atmosphere. She talked to her medical team at the Western General Hospital in Edinburgh about a place to help their patients with the very real problems of living with cancer. She wanted people to be able to access help with information, benefits advice, psychological support both individually and in groups, courses and stress reducing strategies all under one roof.
Maggie's unique model of psychosocial support transforms the way that people live with cancer. It is a model that enables anyone who is affected by cancer to have access to high quality, evidence based psychological, emotional and informational support. The organization has worked to create a network of over twelve centres across the UK and has recently assisted communities in Hong Kong and Barcelona to open Maggie's Centres.

Maggie wanted the centres to be there for anybody to use in the way they want to. There wasn’t a one size fits all recipe for how you live with cancer. She believed everyone needs to find his or her own way. Her theory was:

Above all, what matters is not to lose the joy of living in the fear of dying

### Maggie’s London

On hospital campus, Charing Cross Hospital, opened 2008  
Purpose built, beautiful, architect designed building  
Accessible, welcoming and uplifting  
Staff 6FT  
Centre Head CNS, Onc nurse, Benefits Advisor, Psychologist, Fundraising and admin staff  
Sessional therapists  
Maggies UK, 8 executive directors  
Volunteers admin, assist with fundraising events

**Fundraising**

Programs include: Transitions, Nutrition Workshop, Tai Chi, Talking Heads, Living with Cancer, Yoga, Relaxation, Stress Reduction, Expressive art, What now, Gardening Group and more!

Web: www.Maggiescentres.org  
Maggies Online Centre  
Facebook  
Online weekly support group  
Tai Chi podcast  
Maggies UK Board 8

**Highlights**

- Oncology nurse managers
- Free, all welcome, people find their own way or level
- Sense of ownership local community. Work together
- Beautiful space, architect designed to Maggie's wishes. Homely, enlightening, uplifting, empowering
- Happy to share model, assist communities to establish own Maggie's Centre
Maggie’s Centre, Edinburgh
On hospital campus, Western General Hospital
Purpose built beautiful architect designed building
Accessible, welcoming and uplifting

<table>
<thead>
<tr>
<th>Staff</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>Similar staff ratio to London</td>
<td>✓</td>
</tr>
<tr>
<td>Volunteers 2</td>
<td>✓</td>
</tr>
<tr>
<td>Fundraising</td>
<td>✓ ✓</td>
</tr>
<tr>
<td>Programs</td>
<td>✓ ✓</td>
</tr>
<tr>
<td>Board/ Steering committee</td>
<td>✓</td>
</tr>
</tbody>
</table>

“Maggie’s has shown me how to regain hope and determination whilst still allowing for the emotional reality of it all”
Robert, during treatment for prostate cancer

“We have good doctors...but Maggie’s is the jewel in the crown of what we do here”
Mike Dixon, Surgeon, Western General Hospital

Maggie’s Centre, Inverness
On hospital campus, Raigmore Hospital
Purpose built beautiful architect designed building
Accessible and welcoming

<table>
<thead>
<tr>
<th>Staff</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>Similar model</td>
<td>✓</td>
</tr>
<tr>
<td>Volunteers 1</td>
<td>✓</td>
</tr>
<tr>
<td>Fundraising</td>
<td>✓ ✓</td>
</tr>
<tr>
<td>Programs</td>
<td>✓ ✓</td>
</tr>
<tr>
<td>Board/ Steering committee</td>
<td>✓</td>
</tr>
</tbody>
</table>

Cancer Link Aberdeen & North (CLAN), Aberdeen
CLAN is an independent charity for anyone affected by cancer. Based at CLAN House in Aberdeen, it provides outreach services for the whole of Grampian, Orkney and Shetland and includes accommodation in Aberdeen for people from out of town receiving treatment. A range of services include: one-to-one peer support and counseling, health and well being therapies, group programs per cancer site, skills workshops, benefits advice, information services and library and social activities.

Support Volunteers attend a compulsory COSCA (Scotland's professional body for counseling and psychotherapy) in-house training over four weekends. The training involves assessment and not all trainees who complete the course will be asked to become support volunteers.
CLAN Aberdeen, not on hospital campus

Staff, Manager, Volunteer Coordinator, administrative and fundraising ✓
Charity Shops 4
Volunteer selection/training ✓
Volunteer support/meetings ✓
Telephone Support Line 24 hour ✓
Fundraising ✓ ✓ ✓
Web www.clanhouse.org
Board/Steering committee ✓

Cancer Institutes/Agencies

Agencies and institutes visited included:
- Cancer Care Ontario, Toronto
- The Canadian Cancer Society, Toronto, Ontario
- Macmillan Cancer Support UK
- Cancer Research UK

Cancer Care Ontario, Toronto

Cancer Care Ontario is the provincial agency responsible for continually improving cancer services. As the government’s cancer advisor, Cancer Care Ontario works to reduce the number of people diagnosed with cancer, and make sure patients receive better care every step of the way. Eight health professions were involved in developing the Psychosocial Oncology Program which takes a whole-person approach to cancer care, addressing the social, psychological, emotional, spiritual and functional aspects of the patient journey. Staff within the unit work collaboratively with providers, research agencies, cancer agencies and support services to prevent duplication, to support research and to show leadership across the cancer continuum.

Their focus is on quality, performance and innovation as they work across the preventative care, screening and treatment streams to palliative care. My visit was focused on their strong leadership role in the implementation of person centred care in the province; the employment of change management consultants to assist with the current roll out of the Patient Symptom Management tool and the Patient Navigator Project being piloted in seven locations.

The Canadian Cancer Society, Toronto, Ontario

The Canadian Cancer Society (CCS) is a private non-profit organization, funded by donations from the public and money raised through fundraising activities. Its mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer and the three main roles include: funding research; offering comprehensive and credible information on cancer, risk reduction and treatment; and providing support for people living with cancer, family members and friends.
Cancer agencies such as the CCS are playing an increasingly important role in the ever changing cancer arena as the improvements in cancer treatment mean there are greater numbers than ever receiving treatment and far greater numbers of survivors. Their major initiatives included:

- Cancer support – nurses helpline, telephone support groups, online support groups and peer support programs
- Information services – internet, resources, brochures, CDs and DVDs, information booths at hospitals
- Community services – working with key stakeholders in regional, rural and remote communities
- Practical support – transport, accommodation, financial assistance

They also play a very collaborative role working with other agencies to provide information and training for nursing and medical students and working with pharmacists, nurses and general practitioners.

<table>
<thead>
<tr>
<th>Major Research initiatives</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Helpline</td>
<td>✓</td>
</tr>
<tr>
<td>Cancer Connect</td>
<td>✓</td>
</tr>
<tr>
<td>Community cancer support initiatives</td>
<td>✓</td>
</tr>
<tr>
<td>Links with acute care providers</td>
<td>✓</td>
</tr>
<tr>
<td>Peer Support initiatives</td>
<td>✓</td>
</tr>
<tr>
<td>Resource development</td>
<td>✓</td>
</tr>
<tr>
<td>Information booths, displays</td>
<td>✓</td>
</tr>
<tr>
<td>Web <a href="http://www.cancer.ca/Ontario">www.cancer.ca/Ontario</a></td>
<td>✓</td>
</tr>
</tbody>
</table>

**Macmillan Cancer Support UK**

Macmillan Cancer Support has grown to become the largest cancer care and support charity in the UK. Providing not only information and support but helping with all the diverse things that people affected by cancer and their families and carers want and need. This includes an excellent website and printed resources, library booths, health lines, financial and practical assistance. All services are very “hands on”, working very closely with the people requiring them. Macmillan also funds a specialised nursing service and builds cancer care centres. There are currently 2400 site specific Macmillan funded nurses. They are registered nurses with at least five years’ experience, including two or more years in cancer or palliative care. They also complete specialist courses in managing pain and other symptoms, and in psychological support. Macmillan nurses are usually employed by the NHS and their posts are funded by Macmillan for a set time, commonly the first three years. After that time, the long-term funding is taken up by the NHS or other partner organisations. The nurses work in NHS hospitals and the community, but are not usually associated with private health care.

I was fortunate to visit a Macmillan’s on site cancer information booth at a Northwick Park Hospital. Staffed by an experienced oncology nurse, it was strategically located where all patients attending appointments, radiotherapy or chemotherapy could easily access it.
Besides a library and hard copy resources there were touch screen PCs and a small private area for counseling. I also visited a Macmillan’s library booth at Fort William in Scotland, very effectively bringing accessible resources to the isolated community.

Major Research initiatives

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Helpline</td>
<td>✔️</td>
</tr>
<tr>
<td>Cancer Connect/Online communities</td>
<td>✔️  ✔️</td>
</tr>
<tr>
<td>Volunteers</td>
<td>✔️  ✔️</td>
</tr>
<tr>
<td>Fundraising</td>
<td>✔️  ✔️</td>
</tr>
<tr>
<td>Community cancer support initiatives</td>
<td>✔️  ✔️</td>
</tr>
<tr>
<td>Courses for people/families living with cancer</td>
<td>✔️  ✔️</td>
</tr>
<tr>
<td>Community awareness programs</td>
<td>✔️  ✔️</td>
</tr>
</tbody>
</table>

Links with acute care providers/tertiary institutions.

Peers Support initiatives

Training & support for support group facilitators

Resource development

Information booths, displays

Web www.macmillan.org.uk

Highlights

- “Best practice” organisation in cancer support
- Creative, innovative and “hands on”
- Adapting to the needs of the community
- Macmillan’s Nurses
- Practical assistance
- Advocacy
- Information booths with Macmillan’s nurses
- Library advisory service and booths
- Macmillan QEM, quality tool
- Mobile vans
- Young peoples programs
- Start up funding for support groups

Cancer Research UK

Cancer Research UK is the world’s leading charity dedicated to beating cancer through research. Grants are provided to scientists and doctors working in universities, hospitals and their own institutes and centres.

Besides playing such a leading role in research, other major initiatives include:

- CancerHelp UK, award-winning website
- Cancer information nurse helpline
- Health awareness campaigns and publications
- Cancer information for health professionals – including cancer statistics and overviews for a wide range of cancers.
- Informing the political debate and campaigning for change. Cancer Research UK scientists and researchers advise the national parliament on health and scientific policy and charity regulation.
Besides a raft of fundraising events and initiatives, Cancer Research UK has nearly 600 charity shops across the UK. These shops are a staple of many high streets and help raise valuable funds for research into cancer. A shop online facility is also available.

<table>
<thead>
<tr>
<th>Major Research initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Helpline, experienced oncology nurses (3 lines), email enquiries</td>
</tr>
<tr>
<td>Patient Forum, highly moderated</td>
</tr>
<tr>
<td>Open Forum</td>
</tr>
<tr>
<td>Community cancer support initiatives</td>
</tr>
<tr>
<td>Links with acute care providers</td>
</tr>
<tr>
<td>Resource development</td>
</tr>
<tr>
<td>Web <a href="http://www.cancerresearchuk.org">www.cancerresearchuk.org</a></td>
</tr>
<tr>
<td>All resources in PDF</td>
</tr>
<tr>
<td>Database of clinical treatments</td>
</tr>
<tr>
<td>10,000 enquiries annually</td>
</tr>
</tbody>
</table>

**Gynaecological Cancer Organisations**

Centres visited included:
- Ovarian Cancer Canada, Vancouver & Toronto
- Ovacome, the Ovarian Cancer Network UK
- Jo’s Cervical Cancer Trust UK

**Ovarian Cancer Canada, Vancouver & Toronto**

Ovarian Cancer Canada is a very innovative organization which has achieved a great deal in raising awareness both in the community and with health professionals. It is a registered Canadian charitable organisation whose mission is to overcome ovarian cancer, providing leadership by:

- Supporting women living with the disease and their families
- Raising awareness in the general public and with health care professionals
- Funding research to develop early detection techniques, improved treatment and, ultimately, a cure

Support initiatives include:

- [You are Not Alone](#), resource for newly diagnosed women
- Information line/Email, information and support. Non medical
- Clinical trial information
- Support group information, where to find one in your area
- Online support group
- Telephone education, past recordings on YouTube

Awareness Programs include:

- *Listen to the Whispers*, a very successful 60-minute education and ovarian cancer awareness program created specifically for women – in the workplace, the community, church or groups
• Survivors teaching students, in which ovarian cancer survivors share their experiences with medical students, nursing students and other health professional students. In addition to the psychosocial aspects of coping with a serious disease, students learn about the signs and symptoms of ovarian cancer and the experience of the treatment and post-treatment trajectory.

• Ovarian cancer Information Project, resources

Ovarian Cancer Canada has supported research in
• Early detection
• Effective diagnosis
• Better treatment
• Enhanced quality of life such as supportive care and communication

Ovarian Cancer Canada, worked with McMaster University and Memorial University to deliver an online accredited course in ovarian cancer for family physicians (GPs).

I was so very fortunate to be in Toronto to participate in the Ovarian Cancer Survivorship Workshop arranged by Ovarian Cancer Canada. It included:

*Clinical Trials and Emerging Therapies* 9:15 am – 10:15 am Dr. Hal Hirte, MD.(Toronto), FRCP, ABIM Associate Professor, McMaster University Chief of Oncology, Juravinski Cancer Centre, Hamilton ON.

What is new in ovarian cancer treatment? What is under development and what is the latest news in emerging therapies? A review of insights into the optimal treatment of ovarian cancer from recently completed clinical trials, ongoing clinical trials and exciting new treatments that will be studied in trials in the near future.

*Complementary Therapy* 10:30 – 11:30 pm
Tracy Truant, RN, MSN, Regional Professional Practice Leader, Nursing Co-Investigator, CAMEO Complementary Medicine Education & Outcomes, BCCC
Up to 80% of people with cancer use some form of it, yet most people make decisions about Complementary Medicine (CAM) without the assistance or knowledge of their conventional health care provider. Trying to sort though the complex maze of CAM decisions alone, while dealing with a cancer diagnosis and treatment can lead to feelings of frustration, distress, and being overwhelmed with information. The worst case scenario is that patients either use a CAM therapy that makes their treatment side effects worse, or reduces the effectiveness of their chemotherapy or radiation. Missing out on effective CAM therapies is also a part of that worst case scenario when making CAM decisions in isolation from your conventional oncology health care provider.

*Picking Up the Pieces: Moving Forward After Surviving Cancer* 11:30 – 12:30
Dr. Ardythe Taylor, Breast Cancer Supportive Care Foundation, Calgary AB.
Many survivors speak of feeling fragmented and needing to pick up the pieces of their lives once cancer treatment is over.
Exhausted, anxious, managing side effects, and trying to make sense of what they have been through, survivors feel as if they have been dropped into a void. While the focus of treatment is on eliminating the disease, the recovery phase is centred upon healing the whole person. Dr. Ardythe Taylor, who runs support programs for cancer survivors at Wellspring, Calgary uses the *Picking Up the Pieces* model developed by the authors Sherri Magee and Kathy Scalzo.

*Caring Voices presentation*
Sara Urowitz, MA, MSW, PhD, Manager, Educational Informatics
ELLICSR – Cancer Survivorship Centre, Toronto General Hospital

*Picking Up the Pieces Workshop* 2 – 4:30 pm
An in-depth experience of *Picking Up the Pieces*.

This workshop gave me the opportunity to speak with the participants many of whom had travelled vast distances to attend. The day evaluated very well and the women were so enthusiastic at the opportunity they had to meet with others a similar journey. Not surprisingly they discussed similar needs to groups back in Australia: access to credible information, a forum where they could talk openly, the opportunity to meet others “in the same boat”. I discovered there was no Ovarian Cancer (nor Gynae Cancer) Support Group currently operating in Toronto and these women were very eager to get one started. Their contact details were taken and Ovarian Cancer Canada informed them they would work with the Wellspring Centre at the Sunnybrook Hospital or the Gilda’s Support Centre to establish a group.

**Ovarian Cancer Canada**
Research initiatives
Relationship with acute care providers
On line & phone support and information

<table>
<thead>
<tr>
<th>Community initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Listen to the Whispers</em></td>
</tr>
<tr>
<td>Resource development</td>
</tr>
<tr>
<td>Advocacy</td>
</tr>
<tr>
<td>Health professional education</td>
</tr>
<tr>
<td>Fundraising extensive, corporate sponsors</td>
</tr>
<tr>
<td>Board/advisory group</td>
</tr>
<tr>
<td>Ovarian Cancer Survivorship Program</td>
</tr>
<tr>
<td>Web <a href="http://www.ovariancanada.org">www.ovariancanada.org</a></td>
</tr>
</tbody>
</table>

**Ovacome, the Ovarian Cancer Network. UK**
Ovacome is a registered charity established in 1996 with over 5,000 members that provides support and information for women affected by ovarian cancer, their families and friends.
Psychosocial Support for Women with Gynaecological Cancers

### Research initiatives
- On line & phone support and information (nurses)
- Phone friends, peer support
- Information available support groups

### Community initiatives
- Newsletter 3/year
- Ovarian Cancer Information day, annual

### Resource development
- 15 factsheets

### Advocacy

### Health professional liaison & education

### Fundraising extensive, corporate sponsors

### Board/advisory group

### Web www.ovarian.org.uk

---

**Jo’s Cervical Cancer Trust UK**

Jo’s Cervical Cancer Trust (Jo’s Trust) is the only UK charity dedicated to women and their families affected by cervical cancer and cervical abnormalities. Their aim is to offer information, support and friendship to women of all ages, to help them to understand the importance of cervical screening, and to provide support for women with abnormal results or those diagnosed with cancer. Services include: comprehensive, easy to understand information, on line support and social events.

### Research initiatives

### On line support

### Advocacy

### Community cancer support initiatives
- Resource development
- Fundraising extensive, corporate sponsors
- Board/advisory group
- Web www.jostrust.org.uk

---

**E-health Initiatives**

Today, increasing numbers of individuals and decision makers consider e-health applications as critical components of health systems and person-centred care. An e-health tool, the Oncology Interactive Navigator TM (OIN) was observed at the IPOS conference and had been successfully trialed at several centres in Canada and the US. OIN is an evidence based, clinically integrated web-based cancer support intervention designed to complement providers’ efforts to support individuals with cancer. A carefully structured, efficient, and comprehensive web-based cancer information and supportive tool for patients – the OIN is a person-centred intervention, customised to the individual centre, integrated in the clinical environment, bridging gaps from the point of diagnosis through treatments and survivorship. It is designed to serve as a complement to professional and peer navigation initiatives by providing comprehensive cancer and health information. In addition to offering information about the pathophysiology of cancer, the OIN offers assistance in treatment decision-making and guides health care services navigation. A “one stop” shop!
In addition, the OIN highlights cancer survivorship issues through the provision of a personalised survivorship care plan. It also features hospital and community support resources, including printable help sheets and resources to assist patients in finding many kinds of support to help cope with the disease in their day-to-day lives. A repository of ongoing clinical trials integrated within the OIN is designed to deliver quick and easy matches, so that patients can choose to be part of the most relevant ones.

Other very effective e-tools in place included the www.infowall at Princess Margaret Hospital and the www.patientgateway at the Dana Farber Institute.

**IPOS World Congress of Psycho-Oncology, Quebec**

I was enormously privileged to attend the 12th Annual IPOS Congress, which provides the medical and scientific communities with the opportunity to benefit from the expertise of numerous researchers and practitioners bringing together the research and practice. Psychologists, psychiatrists, oncologists, nurses, social workers and other health professional attended to hear a multidisciplinary perspective highlighting the conference theme “Hope, Meaning, and Science for Quality of Care in Psycho-Oncology and Palliative care”.

Of particular interest for me was the opportunity to hear staff from centres already visited present both formally and in workshops. I attended the following:

- A Patient Centred Care Vision for Canada
- Person Centred Care, making the vision a reality
- The Truth of It: Talking about cancer
- Healthy Hope versus False Hopelessness
- Body image and sexuality after cancer
- Why Psychosocial Care is Difficult to Integrate into Routine Cancer Care: Stigma is the Elephant in the Room
- Fatigue and Exercise
- Addressing Nurses Knowledge and Skills Needs in Providing Emotional Care to patients
- Research, Training and Practice in Professionally led Online Support Groups
- Screening for Distress, the 6th Vital Sign
- Hope, Meaning and Coping
- Cancer Navigation in Canada: Models, Framework, Competencies and Tools
- Patient Navigation using e-tools
KEY HIGHLIGHTS

✓ The range of innovative, flexible programs provided at inviting, well promoted cancer support centres
✓ The “person centred” model of supportive care and implementation processes to embed it into the culture of the institution. Empowering for the patient and health professional alike!
✓ The patient symptom assessment tool ensuring a universal language among care providers. Excellent guidelines essential for management and follow up.
✓ Nurse navigators, flexible models ensuring ongoing access to information and support for the patient.
✓ The benefits of support programs and activities provided within acute care cancer institutions, facilitated and evaluated by dedicated health professionals. Effective referral processes.
✓ Eye catching, accessible staffed information centres/libraries located where patients are attending for appointments or treatment.
✓ User friendly websites where individuals can access in depth credible information about all aspects of their cancer, the treatments, the research, support and information activities, the full range of healthy lifestyle activities etc.
✓ E-tools such as Oncology Interactive Navigator empowering the person on their cancer journey by having access to their complete medical journey and very importantly to evidence based information on a full range of psychosocial support activities and how to access them.
✓ Participating in the Ovarian Cancer Survivorship Workshop in Toronto.
✓ Attendance at the IPOS World Congress of Psychosocial Oncology at Quebec.
✓ The range of fundraising activities undertaken by all cancer support centres, the spin off being greatly raised community awareness regarding services available.
✓ The site specific, trained nurse practitioner operating in the survivors follow up clinic. A holistic model ensuring access to information and referral to other multidisciplinary team members as required.
✓ The employment of very experienced oncology trained nurses to manage the Maggie’s centres and to staff Macmillan’s information booths and cancer agency help lines.
✓ The inspirational nursing leaders and the passion, dedication and generosity of all the people I met.
CONCLUSION

In visiting these leading hospitals and centres in Canada, USA and UK, I was able to observe some very innovative models in operation and to find many challenges in common. What I discovered was that there was no one single tool to aid referral to support services by health professionals. Closest to ‘best practice’ in a sustainable model for gynaec cancer support groups, was the acute care centres with the gynae-oncology multidisciplinary team referring and encouraging patients to attend ‘in house’ support activities and programs. However, many such centres had still shared the experience of the group folding when the majority of the group succumbed to cancer.

My original hunch proved correct! If we establish an innovative and flexible model of acute care service delivery that provides access to information and support right along the cancer continuum, besides providing the opportunity for the patient to make informed choices, there will be multiple points for health professional referral to other services as required. Thus, with a cancer site specific multidisciplinary team, a “person centred” supportive care model, a nurse navigator position and such tools as: patient symptom assessment and management program; accessible information booths; and the e-tool, the patient has access to information and support every step of the way! A real safety net! While the challenges in implementing and embedding this comprehensive supportive care model are acknowledged, the rewards have been demonstrated to be significant for patients, their families and for health professionals. Evidence has shown an economic benefit in terms of diminished use of medical services when this level of support was provided. Importantly, staff satisfaction levels were higher resulting in lower staff turnover.

With more patients accessing support centres for information and support, some degree of sustainability for these services is ensured. Taking into account the challenges of maintaining site specific cancer support groups, the preferred model may be to offer a range of services to ensure there is a group or activity of interest to all. Some individuals may prefer to attend regularly for a skills program such as yoga, relaxation or mediation, others perhaps writing or music therapy. Again informed choice and a range of flexible services is the key! Joining women with breast and gynaec cancer in sub groups such as the Younger Women’s Cancer Group and the Women’s Metastatic Cancer Group has proved successful at some centres due to sufficient similarity of concerns. Alternately peer support programs or online or telephone support groups may meet the needs of other women wanting to communicate with someone “in the same boat”.

While there are differing models for the ‘in house’ support services, autonomous support centres located adjacent to hospitals or even community groups, all play an essential role. For all centres, providing a regular and very well advertised Living Well after Cancer Treatment Program is perhaps the single most important strategy to assist cancer survivors on the next stage of their journey and to inform them of the programs and resources available to them at their local centre.
Finally, as a higher percentage of the people with cancer utilise the internet daily to not only access information but to participate in support activities and blog sites, it is imperative these sites are very user friendly, well maintained and professionally managed. In conjunction with the well designed e-tool, this is the way of the future. All individuals with cancer can benefit from access to a choice of support services that help preserve dignity and autonomy, optimise well being and improve quality of life!
**RECOMMENDATIONS**

Taking into account the many initiatives already in place in Australia, I make these recommendations:

**Acute Care Centres**

- That major cancer hospitals/centres develop and implement evidence based supportive care models which incorporate: the site-specific multidisciplinary team; the patient symptom assessment tool and process; and a nurse navigator role.
- That major centres implement user friendly websites for patients and work towards incorporating an e-tool to link patients to the broadest range of information and support services.
- That smaller cancer centres and private hospitals work towards an appropriate supportive care model, incorporating a patient symptom assessment and management tool and a more flexible nurse navigator model to work across cancer sites as required.
- That accessible, highly visible staffed information booths be established in hospitals/institutions providing cancer treatments. Besides paper resources, they will have touch screen computers with access to in depth information, research and all local support activities.
- That major cancer centres investigate models to provide some level of psycho sexual support for all women with gynaecological cancers.
- That Cancer Australia investigate e-tools such as Oncology Interactive Navigator (OIN) with a view to implementation.
- That all centres investigate the provision of therapeutic support services for in patients.

I emphasise though, frameworks on their own are not enough and it was the Canadian model of effective implementation that was so impressive.

**Cancer Support Centres**

- That centres establish and maintain close collaborative relationships with hospital staff in oncology, nursing, social work, psychology, dietetics and physiotherapy departments to ensure the development and ongoing research of supportive programs and the facilitation of groups and workshops. These activities also enhance the credibility of the centre.
- That centres have a vigorous Steering Committee comprising health professionals from appropriate disciplines, representatives from community, business, marketing and fundraising.
- That centres introduce flexible organisational frameworks to ensure best practice in the use of volunteer services and policies for the recruitment, comprehensive training and ongoing professional support of volunteers.
- That centres have their own marketing and fundraising programs, to ensure not only funding for free services but also to raise awareness of the centre and its services within the community.
- To establish collaborative relationships with universities to ensure ongoing research into services and programs.
- To investigate combination support services: Younger Women’s Support Group, Breast and Gynae Cancers; Progressive Cancer Group, Breast & Gynae cancers.
• That centres ensure accessible, affordable car parking!
**Supportive Care Programs** and initiatives offered in the acute care centres, at stand alone centres or in the community, continue to provide a wide range of evidence based programs, activities and support groups to specifically meet the needs of their community. To ensure access for the greater number of patients, I recommend the following strategies to provide a continuum for the patient and a direct entrée into the facility where further information and support activities can be accessed as appropriate to the individual:

- Regular, well advertised and promoted *Living Well after My Cancer Treatment Workshops* (or similar), providing participants with the skills, information and support for the next phase of their lives. These should be held at times to best suit the participants and full day Saturday programs are working best in many countries visited.
- Regular (annual, biannual) well advertised and promoted patient information sessions per cancer site with specialist speakers discussing current cancer management, latest research and the cancer experience (or similar).

**Cancer Agencies**

- A continuing awareness of the changing needs of the person with cancer and a “hands on” approach, taking the resources to the people, such as: the Macmillan model of highly visible staffed information booths within hospitals; Macmillan Nurses; Macmillan library program.
- To continue to investigate and implement strategies to bring a greater range of support initiatives to women living in rural and remote communities, such as: mobile services; online and telephone support groups and chat rooms; online book groups; video link information workshops; resources available at libraries etc.

**Implementation & Dissemination**

- To share my report with National Centre for Gynaecological Cancers at Cancer Australia, state government departments, acute care cancer hospitals and cancer agencies.
- To discuss experiences and make presentations for colleagues and interested parties working in psychosocial cancer care.
- To present findings at Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting in Melbourne November 2010.
- To work closely with staff at the Sydney Adventist Hospital in establishing a Steering Committee for their ‘stand alone’ Cancer Support Centre.
- To liaise with gynae- oncology staff at Royal Prince Alfred Hospital (Chris O’Brien Lifehouse at RPA).
- To work with Ovarian Cancer Australia, to discuss opportunities to increase activities and presence outside Victoria.
REFERENCES


ii Holland, 1999; Browne et al., 1990; Zabora et al., 2001, cited in Fitch, M.I. et al. 2009, Supportive Care Framework. 18


iv Report to Cancer Australia, Lung and Gynaecological Cancer Support Groups Project, May 2009


vi Fitch, M.I. et al 2009, Supportive Care Framework, p.22

vii as above. P.24

viii as above

ix as above

x Fitch MI et al, 2000 Understanding Supportive Care Needs of Patients with Gynaecological Cancer