



# Woman to Woman

EXECUTIVE SUMMARY &  
RECOMMENDATIONS

**A research report  
on the experience of  
rural women with  
breast cancer and  
implications for the  
provision of health services**



This research was conducted as a collaborative partnership between the Department of Human Services (DHS - Hume region), Women's Health Goulburn North East (WHGNE) and Breast Services Enhancement Program (BSEP - Hume region).

The Department of Human Services, Hume region is a key human services agency with responsibility for the portfolio areas of health, housing, aged care and community services. It leads the delivery of the government's goal of high quality, accessible health and community services, and contributes to the building of cohesive communities and reducing inequalities across the region.

The Hume Breast Services Enhancement Program (BSEP) commenced in late 1999 and was funded by BreastCare Victoria, Department of Human Services (DHS) until June 2004. This program was one of nine quality improvement programs across the State and aimed to establish a model of breast care services in line with established best practice. Key priority areas for the program included increasing access to multidisciplinary care, Breast Care Nurses and Information, Communication and Support.

Women's Health Goulburn North East (WHGNE) was established in July 2000. Previously known as NEWomen, WHGNE is the government funded specialist women's health service for the Goulburn Valley and North-East Victoria. The vision is to lead the Hume region in creating opportunities for women to experience a positive sense of self, health, safety and wellbeing.

Contact DHS Hume region

PO Box 460, Wangaratta, 3677

Phone: 03 57 220 555

Fax: 03 57 220 577

Webpage – [www.dhs.vic.gov.au](http://www.dhs.vic.gov.au)

Contact WHGNE

PO Box 853, Wangaratta, Victoria, 3677

Phone: 03 5722 3009

Fax: 03 5722 3020

Email: [whealth@whealth.com.au](mailto:whealth@whealth.com.au)

Webpage: [www.whealth.com.au](http://www.whealth.com.au)

The information contained in this publication is copyright. When copying or reproducing any part of this document, please acknowledge the partnership of DHS – Hume Region, BSEP – Hume Region and WHGNE as the source and include the title, year and page number.

This report has been written by Angela Verde, Kate Cuss and Debra Parkinson.

© State of Victoria, 2004.



## **Executive summary**

'Woman to Woman' is qualitative participatory research designed to explore the effects of breast cancer and breast cancer treatment on rural women. It documents the experiences of 20 women in the Hume region of Victoria who have been diagnosed and treated for breast cancer in the previous three years. The women were asked to reflect on the effect of breast cancer on their lives generally and on the nature and quality of the services they received. They spoke about what was helpful to them and gave their views on how services may be further enhanced.

The researcher conducting the interviews is herself a breast cancer survivor who disclosed her own experience of breast cancer to the women being interviewed.

The women interviewed ranged in age from 34 to 70 years. All of the women resided within Hume region, in major regional centres, smaller towns and rural settings.

This participatory research was conducted as a collaborative partnership between the Department of Human Services (DHS - Hume region), Women's Health Goulburn North East (WHGNE) and Breast Services Enhancement Program (BSEP - Hume region). A partnership agreement and work plan were developed as a basis for this collaboration, and guidance was provided by a Project Reference Group. This research report has a companion volume of excerpts from the 20 interviews, entitled, 'Woman to Woman: insights from rural women with breast cancer'.

## **Context of the project**

The diagnosis of breast cancer is usually a traumatic event in a woman's life, and the impact of breast cancer and its demands can be significant. Breast cancer is the leading cause of cancer death in Australian women. Over 11,300 Australian women are diagnosed with breast cancer each year and 1 in 11 will be diagnosed with the disease by the age of 74.

Up to 30% of Australian women diagnosed with breast cancer live in rural or remote areas of Australia and have been recognised as having special needs and limited treatment options. High levels of unmet supportive care needs among women diagnosed with breast cancer have been reported, yet there is a paucity of qualitative research examining the needs and experiences of breast cancer patients within the rural Victorian setting.

## **Medical interventions – diagnosis and treatment**

The women interviewed reported undergoing various treatment types in different locations, including within the Hume region, Albury and Melbourne.

Women experienced a range of side effects at each phase of the cancer treatments. Some were temporary and some are now a permanent affliction for the women affected.

It appears that there is a difference in the availability of reconstructive surgery in rural areas compared to Melbourne, with Hume region women rarely having the option of reconstruction at the same time as mastectomy. In fact, the women reported that there was very little discussion of reconstruction at all at the time of diagnosis. In retrospect, this was a concern to them.

## **Health system and financial issues**

Just over half of the women chose to use their private health cover for a particular aspect of their treatment. Women treated in the private system were generally very satisfied with

the treatment they received, although a number commented on having marked difficulty accessing services post discharge from a private hospital.

While some of the women were eligible for different forms of financial support, depending on where they lived, where they had their surgery and whether they had private health insurance, there was clearly a significant financial burden that came along with the diagnosis and treatment of breast cancer. They had no choice but to cope with this as yet another stressor.

### **Women's perceptions of their experience of health services**

Many women interviewed felt that it had been important for them to actively participate in decisions regarding their health at the time of diagnosis and throughout subsequent treatment. Women had to be assertive to have a voice in treatment decisions. They had to advocate for their right to an opinion, or to state a preference, or to have treatment that *they* chose based on comprehensive information.

Women commented on the need to ask questions, research topics and actively seek additional information. Some women found themselves having to argue strongly and convincingly for a particular course of action.

There were mixed responses from the women about their experience of communication with professionals and access to information. Some women experienced great difficulty and reported that their views were dismissed and procedures were not adequately explained. Other women were very satisfied with the communication between themselves and professionals, and felt great confidence in their specialist treatment.

Communication between disciplines was also regarded with mixed views. Some women found this to be satisfactory whilst others reported enormous problems. Some stated they received quite conflicting information from various clinicians.

Women's perceptions regarding the manner in which they were treated were mixed. While many highly praised the specialists, the support personnel and the facilities associated with their treatment, many others were highly critical of various aspects of their care. Some women expressed dissatisfaction with the disrespectful attitude of staff involved in their care and felt a lack of trust in the competence of particular professionals. Some were unhappy with the physical environments where treatments were received.

Women appreciated the service they received from Breast Care Nurses (BCNs) in the region and were clear about needing increased access to the care, support and information offered by BCNs. The part-time nature of the BCN employment means that currently access to BCNs is limited.

Timely information and good communication with health professionals are both critical to women with breast cancer. Women are coping with physical and emotional assaults on their being and struggle with confusion and fear of the unknown.

### **Effects and issues of breast cancer**

The diagnosis of breast cancer brought with it great challenges for each woman. Most poignant was the effect on family. Support from family and friends was essential to the women as a source of great comfort and assistance, and for those who did not receive it as expected, as a source of great disappointment. The women spoke about fear and grief, and loss of friends who did not know how to offer support and so withdrew. Yet, along with all of this, came a greater appreciation of life and a new way of experiencing each day.

Women described concern for their children of all ages as paramount. Caring for their babies and toddlers was clearly a major issue for young women. Young children and

adolescent family members often felt traumatised by the change to their family life and the risk to their mother. They feared for their family's future. There is a clear need for emotional support for them, and, at the same time, a lack of accessible counselling options.

Women with partners were very concerned about the effect of their breast cancer diagnosis on their partner. Men were frequently described as not coping well and finding it very difficult to express their feelings.

There were times when support from other family members was not forthcoming, and it was hurtful and disappointing to the women.

It is not surprising that the absence of hair (albeit temporary) and a breast or breasts would have an impact on women's self image. Some women confessed to feeling very self conscious about their appearance despite being aided by wigs, breast prostheses and reconstructive surgery. Some women experienced a loss of confidence and associated feelings of fragility and insecurity as a result of their breast cancer.

Whilst undergoing treatment, women commonly felt extremely unwell. They needed help with daily tasks and frequently had to ask for assistance. As a result, many felt that they were a burden to others.

The need to take time off work throughout treatment for breast cancer was something women dealt with differently. Some women discontinued work for extended periods. Others felt that they were able to cope with working part time.

### **The impact of rurality on Hume region women with breast cancer**

The stereotypes of rural life appear to be true, as women spoke of the calm atmosphere of the country and friendliness and stoicism of country people.

They appreciated the greater support from small communities, where people know each other and you're treated as a person and not just a number; where the breast care nurse and the district nurse call in to offer advice and support.

The flipside is that, where everyone knows each other, it is impossible to keep things private. As a result, some women felt forced to tell their children and family of their breast cancer before they were ready, and felt branded by their illness.

The women's experiences of accessing treatment and support services differed according to whether they lived in one of the four larger provincial towns, in smaller country towns, in tiny hamlets, or on farms in rural and remote areas. Those who felt best served were the women living in or close to Albury-Wodonga which has radiation and chemotherapy treatment centres. It is the only centre in Hume region to offer both.

For most of these Hume region women, treatment for breast cancer involved extensive travel and the occasional need for accommodation. For women living in rural areas some distance from a provincial centre, travel to and from appointments depended on having a car and, perhaps, a friend to drive them, as public transport was either not available or very limited in the times it was offered. Women spoke of having to set aside half a day or a whole day to attend appointments. When the appointments were for radiation, for some women, they were scheduled on each weekday for six weeks.

### **Strategies**

There were many strategies which women indicated had helped them along their journey with breast cancer. They ranged from changes in lifestyle and attitude - the way they viewed life, its trials and tribulations - through to accessing assistance via information sources, counselling, support for themselves and family members, and practical strategies to alleviate physical discomfort. A key strategy was a determination to live life to the fullest.

Counselling was seen as a very effective strategy to deal with the emotional trauma associated with the disease for the woman and her family. Access to and affordability of counselling services was again underscored as an issue in rural areas.

## Conclusion

This research sought to gain an insight into the experiences of women in Hume region living with breast cancer and their experience of health services in its treatment. The purpose of the research was to improve health services to rural women. This report is for health professionals to read and consider. It is for the funding bodies of health services to inform their decisions. It is for the women who informed this research; for women living with breast cancer; and for those who will be diagnosed in future months.

The experiences of the 20 women who informed this research identified clear avenues for improved services. Implementation of the recommendations in this report will go some way to delivering improved experiences of health service provision for rural women with breast cancer.

## Discussion and recommendations

### ⊕ Accessible treatment for BC

The key recommendation is that women in Hume region have access to best practice care for breast cancer. Crucially, women in rural areas should not have to leave the support and comfort of their families and communities for this to happen. They should not have to travel long distances for treatment or have the added financial burden of travel and accommodation costs. Support services and information should be available to them as to their city counterparts.

Whilst acknowledging workforce issues and the infrastructure costs involved in providing this level of care to women in rural areas, investigation of the feasibility of a second radiotherapy facility in Hume region would be welcome.

The experiences of the 20 women who informed this research identified clear avenues for improved services. Implementation of the following recommendations will indeed go some way to delivering improved experiences of health service provision for rural women with breast cancer.

Tables 8 to 11 on the following pages provide a quick checklist for health professionals, government policy makers, health administrators or executive, and for peak bodies, as recommendations relating specifically to each field are grouped together. The last column in these tables indicate the source of evidence for each recommendation.

Table 8: Recommendations relevant to *healthcare professionals*, and evidence source

Health care professionals	No.	Evidence supporting the recommendation
		<p>1.1 Strongly supported by this research data and the literature</p> <p>1.2 Supported by the literature</p> <p>2.1 Supported by this research data; strongly supported by the literature and professional experience</p> <p>3.1 Strongly supported by professional experience</p> <p>3.2 Strongly supported by professional experience</p> <p>4.1 Strongly supported by the literature and professional experience</p> <p>4.2 Strongly supported by professional experience and the literature</p> <p>5.1 Supported by this research data, the literature and professional experience</p> <p>5.2 Supported by the literature and professional experience</p> <p>5.3 Supported by this research and professional experience</p> <p>6.1 Strongly supported by professional experience and supported by the literature</p> <p>6.3 Supported by the literature and professional experience</p> <p>7.1 Supported by professional experience and this research</p> <p>8.1 Strongly supported by this research, the literature and professional experience</p> <p>9.1 Strongly supported by this research, the literature and professional experience</p> <p>9.2 Strongly supported by the literature and professional experience</p> <p>9.3 Supported by the literature and professional experience</p> <p>10.1 Supported by the literature and professional experience</p> <p>12.1 Strongly supported by this research, professional experience and the literature</p> <p>12.2 Supported by professional experience and strongly supported by this research</p> <p>12.3 Supported by this research</p> <p>12.4 Strongly supported by the literature and professional experience</p> <p>12.5 Strongly supported by the literature and professional experience</p>

**Table 9: Recommendations relevant to *policy makers*, and evidence source**

Government policy makers	No.	Evidence supporting the recommendation
	2.1	Supported by this research data; strongly supported by the literature and professional experience
	5.3	Supported by this research and professional experience
	6.3	Supported by the literature and professional experience
	7.2	Supported by this research and professional experience
	8.1	Strongly supported by this research, the literature and professional experience
	9.1	Strongly supported by this research, the literature and professional experience
	10.1	Supported by the literature and professional experience
	10.2	Supported by the literature and professional experience
	11.1	Strongly supported this research and by professional experience
	12.1	Strongly supported by this research, professional experience and the literature
	12.2	Supported by professional experience and strongly supported by this research
	12.3	Supported by this research

**Table 10: Recommendations relevant to *peak bodies* (e.g. NBCC, CCV, BCNA), and evidence source**

Peak bodies	No.	Evidence supporting the recommendation
	1.1	Strongly supported by this research data and the literature
	1.2	Supported by the literature
	4.2	Strongly supported by professional experience and the literature
	5.2	Supported by the literature and professional experience
	6.2	Supported by the literature and professional experience
	12.2	Supported by professional experience and strongly supported by this research
	12.5	Strongly supported by the literature and professional experience

Table 11: Recommendations relevant to health administrators or executive, and evidence source

Health administrators or exec	No.	Evidence supporting the recommendation
	1.1	Strongly supported by this research data and the literature
	1.2	Supported by the literature
	2.1	Supported by this research data; strongly supported by the literature and professional experience
	3.1	Strongly supported by professional experience
	3.2	Strongly supported by professional experience
	5.2	Supported by the literature and professional experience
	5.3	Supported by this research and professional experience
	6.3	Supported by the literature and professional experience
	7.1	Supported by professional experience and this research
	8.1	Strongly supported by this research, in the literature and professional experience
	9.1	Strongly supported by this research, the literature and professional experience
	9.3	Supported by the literature and professional experience
	10.1	Supported by literature and professional experience
	10.2	Supported by the literature and professional experience
	12.1	Strongly supported by this research, professional experience and the literature
	12.3	Supported by this research
	12.4	Strongly supported by literature and professional experience
	12.5	Strongly supported by the literature and professional experience

## 1 Communication

Communication between consumers and health care professionals is a significant dimension of health care, with evidence suggesting it can affect patient outcomes and behaviours. For cancer patients, better communication of information and improved consumer-clinician relationships, particularly shared decision-making, are noted as some of the most important facets of their treatment.

In clinical practice however, women have reported that communication between themselves and their health care professionals can be problematic. Despite health care professionals often being the preferred information provider for women with breast cancer, many individuals were dissatisfied with the communication and information they received from them.

It would appear that women who had a positive communication environment with their health care professionals experienced reduced emotional distress, anxiety and depression. Sound two-way communication between clinicians and women can lead to women feeling more satisfied with their overall breast cancer care.

There is a clear need to improve the communication skills of nurses and doctors. This includes refining expertise in the processes of communication to complement and strengthen, not replace, expertise in the content communicated.

*It is recommended ...*

- 1.1 That health professionals be trained in effective communication techniques between themselves and women and families; and between each other as health professionals
- 1.2 That health professionals be required to update their communication skills on an ongoing basis

## 2 Integrated care

A team approach to treatment (known as multidisciplinary care) leads to better outcomes for women with breast cancer, both emotionally and physically. The way in which services and health care professionals communicate with each other in the multidisciplinary care of a woman may affect the quality of discussion and the level of collaboration among team members in treatment decisions. The establishment of protocols, referral pathways and communication strategies for continuity of care is to be encouraged, as are multidisciplinary breast team meetings.

Health care professionals must be able to integrate a range of different supports (both formal and informal) for patients and their families so that their difficulties during treatment are minimised. Health care professionals need to be aware of, and develop linkages with, various support services and mechanisms (such as breast care nurses, financial and transport assistance through to support groups) in their particular communities. Integrating multiple supports can result in a more coordinated system of support, reducing the time and distress a woman and her family has to endure when trying to access these services.

Referrals made between health care professionals indicate a level of professional respect and acknowledgement of the expertise that each discipline makes to holistic care of the patient. Further strengthening referral linkages may provide improved care to consumers in terms of treatment options. These referrals occur both within communities and between Melbourne and the local community, when women who have received treatment in the city return home.

*It is recommended ...*

- 2.1 That a team approach to multidisciplinary care should be available for all women diagnosed with breast cancer, to enhance continuity of care

### 3 Shared decision making

Women experienced resistance to their requests for a second opinion and had to be assertive to be given referrals, or to express a chosen treatment option. Women have a role to play in decision making about their own health care. At a time when they are already feeling vulnerable, women felt pressure to accept the opinion of various clinicians, without adequate information, time to absorb the information and other professional opinions.

- 3.1 That a culture of upholding the rights and desires of women regarding their treatment be created
- 3.2 That the right of anyone to a second opinion is accepted by health professionals and facilitated by them

### 4 Information

With few exceptions, women wanted more information than they tended to receive, and on a broader range of topics than simply disease and treatment options. Information provision is a fundamental component in the effectiveness of partnerships between consumers and their health care providers. For people to feel

enabled to participate in decisions about their health care, they must be adequately informed. Health care professionals arguably have a responsibility to provide patients and their families with the specific type of information necessary for informed decision making to take place. Providing adequate information to women with breast cancer is of particular importance as a choice of treatment exists in many cases.

Many women reported that they wanted more information from the point of diagnosis onwards, and that surgeons provided inadequate information for their needs. The fact that not enough information was provided at the time of diagnosis was compounded by the part-time nature of breast care nurse employment in the region, so that contact was delayed until sometime later in many cases. During these critical early weeks, then, some women felt they suffered from a lack of information.

The benefits to consumers of written information to complement and support that received by other means, such as verbally, has been widely acknowledged. Written information leads to increased understanding and gives the opportunity to refer to this written information as required by the woman and her family. While women expressed the desire for professional support around breast cancer information provision, many of them pursued multiple strategies to inform themselves, including the Internet, information seminars, Cancer Council Helpline, and the use of personal and professional networks.

Although many health care professionals believe they are providing adequate information to their patients, this study and others conclude that most women with a breast cancer diagnosis are not receiving the amount or type of information they require, at the time they need it.

Ongoing information about side effects of treatments and strategies and services to alleviate suffering is vital to women as they cope with many months of radiotherapy, chemotherapy and/ or surgeries.

The pressures of life and income don't stop with a breast cancer diagnosis or its treatment. The pressure of the illness is compounded for most women by financial concerns. It is critical that women be advised of entitlements they may have to financial assistance for travel, accommodation, prostheses, home help and other support services.

- 4.1 That a range of timely information be made available to women regarding their specific treatment options; side-effects; available services; and entitlements through health professionals as primary conduit for information. Local resources should also be promoted such as the Albury-Wodonga Resource Kit, the Wangaratta Chemotherapy Packs and the Hume Breast services website.

- 4.2 That general information about cancer diagnoses; treatment options; side-effects; advantages and disadvantages of particular choices; available services; and entitlements be easily accessible to women through government funded and other agencies including Breast Cancer Network Australia, Cancer Council Helpline and BreaCan. The methods could include hard copy information for fax and post; email and website information; and by telephone or personal contact.

## 5 Reconstruction

Women who have had a reconstruction generally find it leads to improved body image and helps them to recover emotionally following a mastectomy. Information offered about reconstruction appears to be either inadequate to allow women to make informed choices, or is non-existent. Women compared the availability of reconstructive surgery in Melbourne with the lack of options in rural areas. For Hume region women, opting for reconstruction usually means treatment must be taken in Melbourne. Early advice about options is therefore critical to decisions about reconstruction. While reconstruction is not for everyone, women should be informed that it is an option available to them.

*It is recommended ...*

- 5.1 That information about options for reconstruction be provided by health professionals to women at the time of diagnosis and at each consultation where treatment options are discussed
- 5.2 That information about reconstruction be generally available to women
- 5.3 That reconstructive surgery be available at regional centres within the Hume region, for example, through visiting specialist surgeons

## 6 Lymphoedema information

Awareness amongst clinicians and the general public about lymphoedema is still variable. Not all women have access to information, education and treatment.

- 6.1 That information about lymphoedema and risk minimisation strategies be provided by health professionals to women throughout their cancer treatment
- 6.2 That information about lymphoedema and risk minimisation strategies be generally available to women

- 6.3 That women have greater access to lymphoedema education and treatment through:
- (a) supporting physiotherapists and nurses to become specialist trained lymphoedema therapists
  - (b) increased hours for publicly funded lymphoedema services

## 7 Health system information

The health system is confusing for many women in this research. There were unexpected bills to pay and surprise at non-eligibility for post-acute care services such as home-help. The *gap* payments required by specialists and health professionals quickly added up to substantial amounts. The *Safety Net* was misunderstood. Our enquiries found that it applies only to out of hospital care. Some women could access needed drugs and others couldn't – depending on their health insurance coverage.

*It is recommended ...*

- 7.1 That information about public and private health systems and the Pharmaceutical Benefits Scheme be given to women at the time of diagnosis and hospital admissions
- 7.2 That the State and Federal Governments produce short, plain-English pamphlets with key points, and provide a 'one-stop' phone contact for follow up information

## 8 Support for special needs

The concerns and specific needs of young women with breast cancer, and women with advanced breast cancer, have been apparent in this research. Women with advanced breast cancer wanted local support groups specific to their particular needs.

Isolation and a sense of being alone were expressed by the younger women, in addition to concerns about fertility, treatment induced menopause, raising family, finances, work body image, sexuality and self-esteem. There was a perception amongst the younger women that general breast cancer support groups did not cater to their needs due to the different issues related to a breast cancer diagnosis at their young age.

Suggestions that more supportive care should be directed to these younger patients to reduce psychological stress have seen the establishment of two sub-regional support groups specifically for younger women, one in Albury-Wodonga and one in Wangaratta, with a third planned in the Goulburn Valley area.

*It is recommended ...*

- 8.1 That funds and in-kind support be sought from government and philanthropic trusts to increase support provided locally for younger women with breast cancer and for women with advanced breast cancer, through a range of measures including:
  - 8.1.1 the further support and development of existing and newly created support groups in Hume region
  - 8.1.2 the establishment of such support groups in localities across the Hume region
  - 8.1.3 teleconference linkage to existing city-based support groups for younger women and women with advanced breast cancer
  - 8.1.4 additional support for women caring for a young family, such as in-home child care and home help

## 9 Supportive care

There is growing evidence that providing supportive care for those with breast cancer leads to better outcomes, both psychologically and physically. Navigating the multitude of services and agencies, which a woman with breast symptoms or disease may have to deal with, can be a harrowing experience, and the support and knowledge of a breast care nurse can be invaluable.

Women want increased access to breast care nurses and supportive care services, every weekday at a minimum, and some after hour's access. Increasing the paid hours of breast care nurses across the region, and having other options available when a breast care nurse is unavailable, are key strategies. This supportive care could encompass assistance from oncology nurses, counsellors, and telephone helplines and be more available to women at the time they need the service.

The women interviewed have expressed the importance of the advocacy role that breast care nurses play in a journey with breast cancer. Many cited examples of the practical and emotional ways that breast care nurses have assisted them. Their involvement as members of the multidisciplinary team is critical as breast care nurses can advocate on behalf of a woman, particularly where the consumer has expressed their desired treatment choices or in cases where there are psychosocial issues of which other team members may not be aware. As equal members of the multidisciplinary care team, BCNs can enhance continuity of care for the women.

Breast care nurses have the potential to free up the time of medical specialists while providing expert and timely care and support to women. There is much scope to increase the profile of services available from breast care nurses in Hume

region - those based in the major regional hospitals as well as those in community health, district nursing or palliative care. An increased profile would lead to more referrals from clinicians and other health care professionals to breast care nurses.

Many of the learnings and models of breast care nursing are equally transferable to other diseases and cancers. Certainly the loss or disfigurement of a breast has unique issues in terms of femininity, self-image and sexuality and these can be better dealt with by a specially trained breast care nurse. There are however also other psychosocial and practical issues, such as anxiety and depression or financial and transport matters, which may impact on many cancer diagnoses, not just breast. Therefore the nursing models of supportive care, provision of information and referral linkages are equally valid for other cancer types.

*It is recommended ...*

- 9.1 That women have increased access to breast care nurses through services providing more specifically funded breast care hours which may be as part of a cancer nurse specialist role
- 9.2 That clinicians and other health professionals increase referrals to specialist trained breast care nurses from the point of diagnosis through the continuum of care
- 9.3 That breast care nurse services and availability are promoted to clinicians and other health professionals through marketing, in-service professional development opportunities and clinical meetings

## 10 Professional support

Given that the majority of breast care nurses in the region do not have dedicated hours as breast care nurses, and many health care professionals are extremely busy, it is imperative to have a network which provides them with resource updates and current breast care knowledge. It is equally important for health care professionals to know what services and products are available for their consumers in their local community, the region and elsewhere. Networks offer a great deal to health professionals and contribute to good practice. They can act as a debriefing mechanism; transfer learnings and outcomes from other events; offer a broad experience base; and importantly, provide a sense of belonging, which is essential for health professionals working in isolation.

There is an opportunity for networking and professional development for breast care and oncology nurses and other health professionals to be formally coordinated. This role is best taken on by people with a genuine interest in supporting the benefits of networking; who believe in continuous quality

improvement through learning and its application to professional practice; and who are able to foster environments conducive to networking.

Determining the needs of health care professionals, engaging appropriate guest speakers, coordinating venues and catering and promotion of the sessions can be done by people with organisational and marketing skills.

The benefits to health professionals of sharing knowledge and expertise through networks, and ongoing professional development are well documented. The flow on benefits to consumers is equally clear.

*It is recommended ...*

- 10.1 That professional development, networks and networking opportunities be made available and taken up by rural breast care nurses and other health professionals in their own region
- 10.2 That the Breast Care Nurse Networking Days established by Hume Breast Services Enhancement Program be sustained within the Victorian and NSW Cancer Framework implementations, and be expanded to include professional development opportunities for oncology nurses and other health professionals

## 11 Travel assistance

Despite the existence of several schemes for assisting rural women to receive funding for travel, accommodation and access to the full range of breast cancer treatments, there is still considerable variation in the access women have to this assistance.

Many women travel extensive distances within the region for treatment, for example 190 kms roundtrip each day for five weeks of radiotherapy, yet they are ineligible for travel reimbursement. Some women indicated they were less out of pocket by choosing to travel to Melbourne for treatment, than travelling within the region and staying where their support systems were in their community. The anomaly of travelling further to the metro area for treatment arises when women live less than the required claimable 100 km radius to their closest treatment centre. Frequency of travel - not just distance per trip – should be counted in determining eligibility for assistance. Number of kilometres per month, for example, would be one way of more equitably determining travel reimbursement.

It is perhaps worth considering a cost-benefit analysis of providing services within the region where the woman lives in comparison to reimbursing costs associated with travelling to Melbourne for extensive treatment.

It is recommended ...

- 11.1 That frequency of travel be considered in determining eligibility for travel assistance

## 12 Holistic approach

Increased access to affordable counselling services, and family focussed care were significant issues for women. Women wanted care that met the needs of children, partners and other family members, and they wanted counselling for themselves and their families. This holistic approach to a woman's care was frequently identified as an issue in this research.

Women valued one-to-one support and advocacy from a peer. This kind of individual and intimate contact with someone who has been through a similar situation was a comfort to women - distinct from support within a group setting.

While many women appreciated the personal and emotional support they often received during chemotherapy treatment, there were negative comments about the physical environments where treatment was given. Where capital works improvements are required, these could be planned for, and intermediate minor renovations and new furnishings could be budgeted, or lobbied for within service clubs and other community organisations.

It is important that psychosocial issues be taken into account during management of breast cancer and treatment decisions. Both editions of the Psychosocial Clinical Practice Guidelines (*Adults with Cancer and Women with Breast Cancer*) are a sound resource for health care professionals and encourage awareness of life issues for women beyond the illness.

Multidisciplinary breast team meetings have been established within Hume region. A focus on psychosocial issues could be promoted within these team meetings. Strategies could be developed and implemented to forge links and encourage the sharing of resources and knowledge amongst clinic members and counsellors, social workers, psychologists, grief counsellors and palliative care workers.

Perhaps further investigation could be done into the clinic agenda forms designed by Inner & Eastern BSEP to incorporate psychosocial risk factors from the clinical guidelines, with a view to adapting them to the Hume clinics.

It is recommended ...

- 12.1 That free or minimal cost counselling be accessible within two weeks of contact for Hume region women with breast cancer and/ or their family members

- 12.2 That every woman diagnosed with breast cancer who wants support be given access to peer support, for example, through the Cancer Connect Program of the Cancer Council or BreaCan's free call support program or arranged locally
- 12.3 That the physical environment of the areas where treatment is administered should be examined to ensure adequate space, comfort and privacy, and improvements planned where necessary
- 12.4 That multidisciplinary breast care teams encourage a psychosocial approach both within their practice, and amongst health and community networks. The Hume region multidisciplinary breast clinic agenda forms should also be revised to incorporate psychosocial risk factors
- 12.5 That education and training sessions covering psychosocial factors and communication be offered to regional health professionals to ensure appropriate skill sets