

Community cancer support for women with breast cancer: the development of a self-help breast cancer support group

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INTRODUCTION

Breast cancer is a major problem in our society. As more women are surviving, the need for ongoing support increases. Often rural women are at a disadvantage in relation to access to appropriate services for cancer treatment and ongoing support. The health care system cannot meet all needs, at times only others who have been down a similar path can provide the support required.

This paper shows how a consumer identified the need for ongoing support for women with breast cancer, enlisted the help of professionals, and successfully set up and maintains a breast cancer support group for women in her local area.

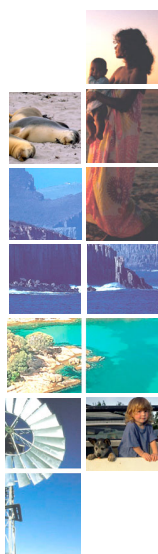
THE PROBLEM OF BREAST CANCER

In Australia breast cancer is the most frequently diagnosed cancer in women. Each year 10 000 women will be told they have the disease, and 2500 women will die. In Victoria just over 2800 women were diagnosed in 2000. Male breast cancer is a rare event, with an average of twenty new cases per year. The lifetime risk of contracting breast cancer before the age of seventy-five is one in eleven women. (*Canstat: Breast Cancer*. The Cancer Council Victoria Epidemiology Centre. 2002.)

One third of all women diagnosed with breast cancer live in rural or remote Australia. Five-year survival rates are lower for rural women than their urban counterparts. (*Cancer survival in Australia 2001. Part 1: National Summary Statistics*. Australian Institute of Health and Welfare.)

The breast cancer mortality rate is falling, which means more women each year are becoming cancer survivors, and living with breast cancer. The relative survival five years after diagnosis is now eighty-four per cent. (*Canstat: Breast cancer*. The Cancer Council Victoria Epidemiology Centre. 2002.)

Judy's personal journey with breast cancer started nine and a half years ago, at age thirty-seven. Following a year of intensive treatment – surgery, six months of chemotherapy and six weeks of radiotherapy – she made an attempt to move on. Children aged five, seven, nine, and eleven years gave great incentive to go forward. Twelve months later another tumour was diagnosed in the region of the clavicle – more surgery and radiotherapy followed. Eight months following this, in an attempt to slow the progression of the disease, Judy's ovaries were ablated with radiotherapy. A diagnosis of pleural and lung disease has since been made.



Three years ago, Judy, her husband, and two of her children moved to a border town on the Murray River in northern Victoria. They opened a small business. Her two eldest sons remained in Melbourne.

DIFFICULTIES FOR RURAL WOMEN WITH BREAST CANCER

Whilst all women will face problems following a diagnosis of breast cancer, rural women have some difficulties which are relatively unique to them.

Some of these concerns, identified through personal experience and discussion with affected women are:

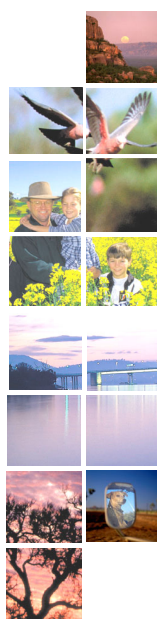
- having to travel to major metropolitan centres for treatment, with associated accommodation and travel expenses
- financial and employment issues, especially for self-employed, farming, and single parent families
- a limited knowledge of specific cancer-related issues by some health professionals, eg the management of lymphoedema
- a shortage of qualified medical staff
- long waiting times to access specialist medical services
- cross-border issues (in Judy's case) such as reimbursement for travel
- a lack of appropriate palliative care facilities
- psychological support issues
- inadequate provision of information.

The last points may be due, in part, to a lack of dedicated oncology centres in country areas, and inadequate numbers of appropriately trained staff.

Breast care nurses (BCNs) can be taken as an example. The Loddon Mallee region in Victoria is the largest country region, covering nearly 60 000 square kilometres, or twenty-six per cent of the state's area. There are twenty-nine accredited BCNs in this region, but sixteen of them are situated in the major town of approximately 25 000 people. (Up until recently only two visiting medical oncologists serviced this major town.) The remaining population of 74 000 people are serviced by thirteen BCNs, most of whom do not have dedicated roles in this area. (*Cancer Information and Support Service Distance Learning Program Database*. The Cancer Council Victoria. 2002.)

The needs for psychological support are now well-recognised (Spiegel, D, Classen, C. *Group Therapy for Cancer Patients – A Research-based Handbook of Psychosocial Care*. Basic Books. USA. 2000). Support is especially important at the time of diagnosis and initial treatments, and also into the long term.

As previously mentioned, more people are now living longer with their disease. Survival can last for months, years, or decades. There can be a negative side to this



good news. Whilst there are many inspirational stories of survival, there is also the darker side. A cancer diagnosis tends to stick, and survivors live with an awareness of the limitations of the human body, and the fear of recurrence. They are vulnerable, and this can affect their ongoing lives. They know their experiences can only be shared fully with someone who has undergone something similar. (Nathan, J. *What to do when they say "It's cancer": A Survivor's guide*. Unwin Hyman. Australia. 1998. Little M, Jordens C, Paul, K, Sayers, E. *Surviving Survival – Life After Cancer*. Choice Books. NSW. 2001.)

IDENTIFYING THE NEED FOR SUPPORT—THE ECHUCA MOAMA BREAST CANCER SUPPORT GROUP

Often the consumer is in a much better position to identify support needs, especially in smaller towns as the word can spread more easily about a person's situation.

Through the business, it became known in the local community that Judy had breast cancer. Since her diagnosis she had also promoted the work of the Breast Cancer Action Group (BCAG) in her shop. Local women began to call in to talk to Judy and share their stories. There seemed to be a great need for a place where women could meet, and for more formalised support. Women had said they wanted:

- emotional, practical and social support
- access to timely and relevant information
- to learn how to access information.

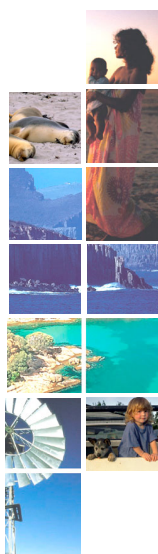
So with much encouragement the Echuca-Moama Breast Cancer Support Group was started. It has now been going for two and a half years.

Community support groups are not new. The Cancer Council Victoria has been co-ordinating a state-wide network of cancer support groups since the mid eighties, and survivorship needs have been recognised in the United States since the seventies. There are currently one hundred and twenty groups, attesting to the fact that consumers want the opportunity to speak to other consumers.

Judy had people approaching her, but other ways of assessing need for a local group include:

- talking to local health care providers such as GPs and nurses
- holding focus groups with cancer survivors to discuss their ongoing needs
- holding an information evening and gauging support here. These need to be advertised in local papers and flyers placed in health and community settings.

The Cancer Registry at The Cancer Council Victoria can provide accurate information regarding incidence and mortality for specific cancers which will assist in identifying the size of the cancer problem in particular areas.



THE FIRST MEETING

Any community group is there to meet the needs of its members, so the first meeting is important in setting the scene, and discussing expectations. Practicalities such as membership, how often, and when the group will meet also need to be decided.

The Cancer Council Victoria can provide guidance to groups at this stage. It is recommended that a core group is identified who will be responsible for ongoing management of the group. The ongoing needs of those with cancer and their families, as identified through research, must be the prime focus for the development of group activities. (*The Cancer Council Victoria Guidelines for Accredited Cancer Support Groups*. 2002.)

Twenty community members attended the first meeting, including the local general surgeon. Having support in this way from health professionals is advantageous in creating a source of referral for new members. If this is not happening, groups have a tendency to become social groups with a closed membership, limiting their potential benefit to the community. Lera and Judy co-facilitated this meeting. The needs and expectations of members, and the format of the group were discussed.

Community awareness of the group (and the first meeting) was achieved by an article in the local newspaper, and by community radio. Local papers seem to be happy to give space for personal cancer stories, especially if they appear at a time when other cancer-related activities are occurring, such as Daffodil Day. Advertising cannot be a one-off activity, it must be conducted on a regular basis.

GROUP MEMBERSHIP

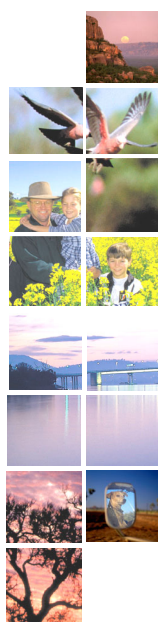
The Echuca Moama group is open to all women with breast cancer and their carers, regardless of the stage of their disease. Since the inception of the group, six members have been re-diagnosed with advanced breast cancer, and three members have died. This, sadly, also included one of the core members. Unfortunately this is sometimes the reality of breast cancer, and the nature of cancer support groups.

For a woman newly diagnosed this can be confronting. Some have found that issues raised by members with advanced disease are too difficult to deal with, and find they are no longer able to attend the meetings. However, most members agree that the women with advanced disease are very valuable and important members – they have taught so much in terms of friendship, courage, strength, and spirit.

HOW THE GROUP IS RUN

The group is run and facilitated by the members and the direction of the meetings is governed by the needs identified at the time. There is a steering committee that consists of a co-ordinator, treasurer, secretary, and three group members. All in all there are thirty-five members.

Group meetings are held monthly in the evenings, and usually start with dinner. For some members this is most important as they live alone and enjoy this social time together. Following this, group business is attended to. This may be correspondence



received, treasurer's report, or reporting on breast-cancer related events in other rural areas and in Melbourne.

Members are then given a chance to talk, to say how they are feeling, what has happened in the last month, or raise issues of concern. New, first time members are encouraged to speak for the length of time they require.

HOW THE GROUP MEETS THE NEEDS OF WOMEN WITH BREAST CANCER

The group attempts to meet some of the needs of women through the provision of up-to-date information and activities about breast cancer.

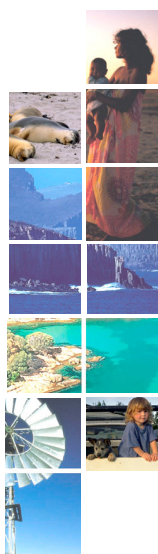
Speakers are invited to talk on topics of interest identified by members, such as lymphoedema and psychosocial support. There would be speakers approximately six times per year. These have included:

- a local general surgeon
- the Director of Community Nursing
- BCNs
- The Cancer Council Victoria Support Groups Co-ordinator
- members of other support groups.

A library and resource of information has been gathered which is available for borrowing by members.

The main reason people join cancer support groups is to be able to share experiences with others in a similar situation. Groups become a safe place to talk, and close friendships are formed, often of a lifelong nature (Holland, J, Lewis, S. *The Human Side of Cancer: Living with Hope, Coping with Uncertainty*. Quill. USA. 2000.). The use of supportive-expressive communication skills allows for the exploration of all feelings, both positive and negative, and this is known to be healing for those with cancer (Spiegel, D, Classen, C. *Group Therapy for Cancer Patients – A Research-based Handbook of Psychosocial Care*. Basic Books. USA. 2000).

The group has had a profound effect not only for group members, but also partners, carers and family members. It has provided a confidential and safe place to share experiences, validate emotions, talk about fears, and ask questions. Importantly also friendships have developed between partners which has provided them with much needed support. It has provided up-to-date information, which in turn has empowered members, and assisted them with making informed choices and decisions in a partnership with doctors and medical teams.



SUPPORT OUTSIDE OF MEETINGS

Some ladies feel monthly meetings are not enough, and have initiated fortnightly morning teas. These are usually attended by approximately ten members, some of whom do not like to come out in the evenings, especially during the winter months. This get together helps meet their support needs.

A monthly newsletter is produced. For members unable to attend meetings, regular contact is still maintained in this way. It is also sent to Community Health, local surgeons, BCNs, and associated Melbourne contacts. Initial group promotion is not enough, health professionals must be continually reminded of the group's presence, and what it is doing.

Other activities have also been organised throughout the years:

- a public lunchtime meeting with an eminent speaker from Melbourne providing information regarding breast cancer
- a weekend retreat to address issues of living with uncertainty – life after a cancer diagnosis, relationships, sexuality issues, lymphoedema, and prosthesis issues. It finished with an aromatherapy session. It was attended by seventy women from all over metropolitan and regional Victoria.

These events are most important for rural women to have the opportunity to share experiences, gain information, network, form friendships and to celebrate living. It extends the support to women in other country areas who cannot attend meetings. Ongoing telephone contact can then be maintained.

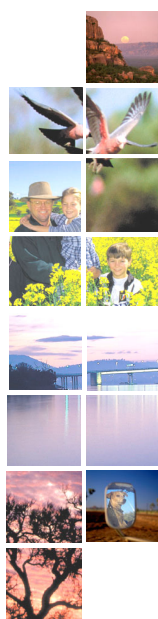
STRENGTHENING THE NETWORK OF SUPPORT AND ADVOCACY

People touched by breast cancer (or any cancer) need a forum to ensure that their voices are heard, and that their needs are addressed by those planning and providing services. Their experiences can be used to assist other women now and into the future. By making links with other organisations, the network of support for individual women, and advocacy is strengthened.

The group has made links with a number of other breast cancer support groups, both in Melbourne and country areas. These links can assist women in achieving positive outcomes following a cancer diagnosis. As Judy has stated:

The most positive aspect I take from the [breast cancer] experience is the beautiful women and men I have met along the way – without this life-changing experience our paths may never have crossed. The amazing network of women sustains one's spirit and nourishes the soul – the strength of friendships, more honest and meaningful.

Members from these groups often spend time in Echuca-Moama, and great friendships and networking has ensued. This has been very important. If one has to spend time away from home and family, members of these Melbourne groups have provided a place to stay, plus friendship and support. This decreases the feeling of isolation that can be experienced at these times.



The group is a member group of the BCNA, the national voice of Australians personally affected by breast cancer. Judy is a consumer representative of BCNA, and the network's contact for her rural area. She provides BCNA with the local voice of personal experience, and they provide the group with much support, guidance and assistance. She is also a consumer representative for the steering committee of The Loddon Mallee Breast Services Enhancement Program. In addition, she is a board member of the Otis Foundation, which provides two respite units outside Bendigo for women living with a diagnosis of breast cancer.

The Cancer Council Victoria also provides support to accredited groups within its network. The co-ordinator of support groups for Victoria provides hands-on support, up-to-date information, and educational seminars for group facilitators and members. Contacts with other groups in the local areas are shared, and communication at this local level encouraged.

The group has helped raise community awareness of breast cancer – advocated for change regarding issues and difficulties that affect their well-being. This has been achieved through such activities as writing to local and federal government members regarding difficulties for rural women. An example is lobbying government members for inclusion of drugs such as Herceptin to the PBS listing. Members also present an example for newly diagnosed women – that there is life after breast cancer, the road is rough and rocky for a time, but with support and friendship the road may be smoother.

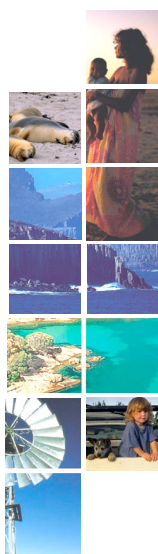
COMMUNITY SUPPORT FOR THE GROUP

Community support is essential for small non-profit groups to function in an ongoing manner. Ongoing costs include:

- venue hire and refreshments
- group resources such as a TV/VCR, CD/tape deck
- social outings
- speakers
- newsletter and mailing costs
- phone calls.

Members should not be out of pocket for group expenses. Local council, businesses, health care services, and individuals can all be approached for assistance with venues, funding, and ongoing costs. Financial assistance and group promotion are needed.

Judy gained much community support. This may be due in part to the fact that many know a friend, family member, or work mate who has been touched by breast cancer. A local councillor was instrumental in encouraging and supporting her with the evolution of the group. This continues today. An hotel provides a free venue and refreshments for monthly meetings, the newsagency assists with photocopying, the group brochures were designed by a prominent artist, and printed at no cost by a local printer. The group has also received donations from community members and groups,



which have assisted with building the resource library. Community members have donated clothing and other items to be sold in Judy's business, with all funds received by the group. A small grant is received each year from the Department of Human Services to assist with running costs.

Two BCNs attend group meetings and provide much support for members. They are always accessible and support the group with genuine commitment, as well as assisting with its promotion.

MEASURES OF SUCCESS

The Echuca Moama Breast Cancer Support Group has been meeting for nearly three years now. Membership started with fifteen women, and they now number thirty-five. Meetings usually attract fifteen to twenty members.

Support groups are not for everyone, but the growth of this group shows it is meeting the needs of the majority of women who attend. Some members initially had secluded themselves after their diagnosis – not leaving the house, and feeling unable to move forward with their lives. The bonds of friendship and caring which have developed have banished these feelings of isolation.

The group is well known in the local community, and Judy has spoken to community groups such as the Lions Ladies, and at fundraising morning teas organised for The Cancer Council Victoria. She has also presented at cancer forums in surrounding country areas, and presented at rural conferences, highlighting the difficulties for rural women with breast cancer.

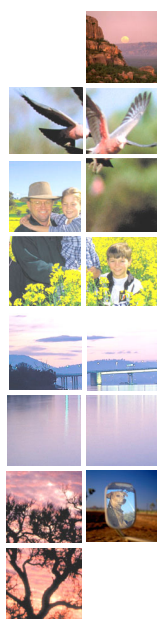
The group's efforts were rewarded by The Murray Shire 2001 in The Year of The Volunteer, which recognised the valuable contribution the breast cancer support group has provided to members and families of their rural community who are living with a diagnosis of breast cancer.

CONCLUSION

Rural women have many special needs in relation to receiving optimal care for breast cancer. The need for psychological support is well recognised, and support groups can help fill that need, in part, for a number of women.

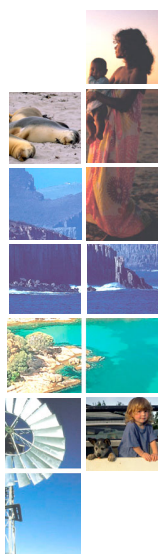
Health professionals and consumers can effectively form working partnerships to help meet the support needs of local communities through the provision of local cancer support groups. Research is required to determine if this presents the ideal model for consumer satisfaction. Consumers are instrumental in recognising unmet needs. They are an essential part of the process to ensure participation, and that the needs of those involved are addressed. Decision making must do more than pay lip service to consumer participation. A working partnership is required.

Primary care partnerships are addressing these issues in some areas. Local health care providers are joining forces to try and co-ordinate their services to meet the needs of consumers. Consumer representation is an important aspect of these.



RECOMMENDATIONS

- Develop local cancer support groups to help meet psychological needs of women with breast cancer.
- Do not underestimate the power of the consumer voice. It will resonate much more deeply than others for those who are diagnosed with a similar condition. Find at least one passionate consumer who is willing to devote ongoing time and energy to the group.
- Develop collaborative arrangements between local health professionals and consumers in all rural areas to facilitate group start-up, and ongoing functioning.
- Getting new members is a task for local health professionals, such as specialist nurses and GPs, and consumers.
- Enlist community support for the group. Communities must be prepared to provide some financial support for groups to be viable.
- Involve consumers at the planning stage for all health services. This can be as members of planning committees and working parties, who have their designated tasks like other members.



PRESENTERS

Lera O'Connor is a registered nurse with 15 years' experience in cancer care. She has worked in both inpatient and community settings, and has been involved in teaching nurses and cancer survivors for many years. Her main area of interest focuses around survivorship issues, and enhancing coping in those with cancer and their carers. She currently works at The Cancer Council Victoria co-ordinating a state-wide network of cancer support groups.

Judy Shepherdson is a cancer survivor who has been living with breast cancer for over nine years. She started the Echuca-Moama Breast Cancer Support Group three years ago to provide a supportive forum for women experiencing the disease. Judy is also a member of the steering committee of The Loddon Mallee Breast Services Enhancement Program, and a Board member of The Otis Foundation, providing country respite for women and their partners.

Judy has lived in the rural community of Echuca-Moama for nearly four years and is married with four children.

