Senate Community Affairs Committee

Inquiry into services and treatment options for persons living with cancer

Submission by the Breast Cancer Action Group

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Breast Cancer
Action Group

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Executive Summary

This submission rises to the challenge to "stand in the shoes of patients" by using the voices of women diagnosed with breast cancer to argue that multi-disciplinary care should be the preferred method of treatment for all women.

It particularly focuses on the needs of women in rural areas and those living with advanced breast cancer.

But it gives voice to the need for breast care nurses to co-ordinate the treatment of women and advocate on their behalf.

It also argues that multidisciplinary care, involving social and psychological need's should be considered in the broad, community context and not just as part of the hospital/medical model.

The needs of individual women should be considered and information and resources "packaged" to suit the needs of the individuals and their families.

Barriers to care are based on major attitudinal issues and access to resources, in particular the inability to access Medicare rebates for psychological and counselling services and access to social services.

This submission argues that the sue of multi-disciplinary teams should be part of the measurement of performance of hospitals and that the performance measurement should be carried out with consumer representatives as part of the team.

Preamble

For a woman diagnosed with breast cancer, her 'journey' may often necessitate direct personal contact with some, or all, of the following health professionals and allied services

1. surgeon
2. radiation oncologist
3. radiotherapists
4. medical oncologist
5. breast care nurses
6. oncology nurses
7. physiotherapists
8. plastic surgeon
9. palliative care practitioners
10. social worker
11. psychologist/psychiatrist
12. dietician
13. genetic counselor
14. pharmacist
15. local GP

In addition to the above list of specialists, her 'case' may at certain times, also be in the hands of pathologists, radiologists, and/or geneticists with whom she may or may not have direct physical contact.

For each case of breast cancer, the individual woman will be confronted with practitioners from 6 medical disciplines, as well as numerous sub-specialities. Given the increasing 'specialisation' of modern medicine it becomes crucial from both logistics and quality outcomes perspectives, that the multidisciplinary team becomes the framework for the management of individuals.

There are many issues which affect the treatment of women with breast cancer so in this submission we will focus on two specific issues:

- the need for multidisciplinary care to be effectively extended to women in rural areas and
- the need for the multidisciplinary approach to be extended to women with advanced breast cancer,

We intend to do this by using the voices of women to exemplify the issues.

We gratefully acknowledge the work of Angela Verde, a breast cancer survivor, who has documented the issues for women in north-eastern Victoria.

We thank all the women who have told their stories.
We will remember them, always.

ISSUE 1
The efficacy of a multidisciplinary treatment approach to cancer treatment

The benefits of working in teams with larger case loads are shown by the following study of the value of clinical practice guidelines in breast cancer in Australia.

> "The results of this study suggest that CPGs [clinical practice guidelines] can lead to improvements in the use of adjuvant therapies and breast conserving surgery, particularly among surgeons with heavier breast cancer caseloads" [1]

Women are increasingly understanding the advantages of multi-disciplinary care and its potential in alleviating the frustration of going to different doctors who do not know their particular case and who sometimes give contradictory advice. Women are asking to be treated as a person, holistically, not just to be a case which is passed from one clinician to another with no co-ordination or communication. Furthermore, the benefits of a multidisciplinary team discussion are most important with complex and difficult cases where the evidence is not clear cut. The following quotations clearly enunciate these concerns:

- "I was just passed form one clinician to another like a piece of meat, my breast. They were not interested in me as a person and did not communicate with each other except by letters sent long after my consultation."[2]
  Sue, diagnosed 13 years ago

- "There were enormous problems with communication between medical oncologists, surgeons and other staff. My original diagnosis was that I need an operation, I would need chemotherapy and I would need radiation therapy. I asked for a referral to Melbourne. Reluctantly, that was given, but they asked – or demanded – that I go back to my regional hospital for chemo……

  I have a brother who works with the Cancer Council. Without him and his knowledge, I don't know where I would have been. My local team didn't co-ordinate, changed their minds mid stream, they told me in the beginning I needed radiation therapy and then one of the visiting oncologists in the St Vincent's team decided I didn't need it because there was no evidence that it worked!. That was in the middle of chemotherapy when I just didn't want to know. I didn't want to be put in the position where I had to make those

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[1] White V, Pruden M Giles G, Collins J, Jamrozik K, Inglis G Boyages J Hill D The management of early breast cancer before and after the introduction of clinical practice guidelines **Cancer** Volume 101, Issue 3, Date: 1 August 2004, Pages: 476-485

[2] Personal communication March 2005

decisions……

It was the use of the Internet and the searching that made me decide to go through with the radiation and chemotherapy treatments. It was the statistics provided with from the Cancer Council that convinced me.”[3]

Sonya, who experienced a recurrence 11 years after her initial diagnosis with Paget’s disease.

Some women however, have the opposite experience -

- I had such a good medical team, they were my support. They were at the other end of the phone, even my specialist. My strategy was relying on them. Because you’re having a whole team opinion you know you’re taking the right course don’t you?
  Gail who was diagnosed in July 2001[4]

The advantages of multidisciplinary care have been well documented in the international literature and in studies carried out across Australia. Studies undertaken by the National Breast Cancer[5] and the Cancer Co-ordination Unit of the Victorian Department of Human Services[6] have assessed the benefits, costs and sustainability of multi-disciplinary care in the treatment of women with early breast cancer. These advantages are documented in both the clinical practice guidelines for the management of women with early breast cancer and advanced disease.[7][8]

It should be understood that multidisciplinary care is a means to an end, not an end in itself. It is a means of delivering high quality care to cancer patients. As such, to ensure that multi-disciplinary care is being offered, some form of measurement of the performance of hospitals and breast units is required. We would argue that performance indicators used to measure the quality of care given to women should always include a measure of multidisciplinary care. Such a measure could include evidence to show

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[3] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women’s Health Goulburn North East. 2004. page 27

[4] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women’s Health Goulburn North East. 2004. page 38

[5] http://www.nbcc.org.au/resources/mdc.html and http://www.nbcc.org.au/bestpractice/resources/MSS_multidisc-sustainability.pdf

[6] Details of some of some of the work of this unit can be found at http://www.health.vic.gov.au/breastcare/projects/multi.htm and http://www.breastservices.lmha.com.au/info/guidelines.htm A document of the learnings from this work for use by all cancer services is currently under development.

[7] NHMRC Clinical Practice Guidelines For The Management Of Early Breast Cancer. 2nd edition 2001.

[8] NHMRC Clinical Practice Guidelines for the Management of Advanced Breast Cancer 2001

discussion of individual cases at a multidisciplinary care meeting.[9] Such an indicator has been developed within Victoria and is currently being trialled in a Performance Indictors and Standards project.

The work which has been done in Victoria on the development of multidisciplinary care has included the voices of consumers, women with breast cancer, as an integral part of the projects. We believe that these voices have been an effective means of emphasizing the importance of multidisciplinary care as a means of developing high quality services for Victorian women.

Rural Areas

The lack of multidisciplinary care in rural areas leads to the movement away from local services. One of the consequences of this move is a reduction in the quality of the care for those women who remain in the rural area, as well as a reduction in the quality of the service which local medical practitioners can offer because they are not seeing as many women as they might.

- "One of the factors which made me decide to go the Melbourne for treatment was the fact that multi-disciplinary care was not available in North-east Victoria."[10]
  Angela diagnosed 3 years ago with early breast cancer.

Women with advanced breast cancer

The work done in Australia so far on multidisciplinary care has focused on women with early breast cancer. These women are the majority of women diagnosed with breast cancer. But it is the women with advanced breast cancer, those whose cancer has spread to other parts of their body and who die of their disease , who need access to effective multidisciplinary care. Current national figures suggest that up to one in three women will die of the disease – a staggering statistic when 11,000 women each year are diagnosed. The multidisciplinary team should be a vital component of caring for the woman with advanced disease. One example of some work which has been done in this area is the setting up of a multidisciplinary care approach for women with advanced disease in the eastern suburbs of Melbourne.[11]

- "A multi-disciplinary approach has been demonstrated to be beneficial to women with early breast cancer. It could be argued that for women with advanced breast cancer, an extended multi-disciplinary team managing her

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[9] http://www.health.vic.gov.au/breastcare/downloads/performanceindicator.pdf

[10] Angela Verde. Personal communication. March 2005

[11] http://www.health.vic.gov.au/breastcare/downloads/chirgwinstephens.ppt#289,16,Eastern Health ABC Project

care is more important. Appropriate members from relevant community services as well as clinicians should constitute such teams.

Once a woman is diagnosed with advanced disease her need for medical and community services, psycho-social support, and information services expands and compounds, and the need for the integration of such services is increased.

The integration of medical/hospital and community services such as palliative care, hospital in the home, district nursing etc is of particular importance. Because they have usually been through the experience of early disease, it is likely that many women will be more familiar with available medical/hospital services, but may be less informed about the availability of and eligibility for community services.

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Palliative care services are a perfect example where a woman may miss out on such services because she does not understand her eligibility, or rejects such services because of the association many people make between palliative care and end-stage treatment. “

Anne from Benalla who died of breast cancer in December 2004[12]

Anne's summation is further endorsed by the following:

- “We (Mum and I) battled through those first four weeks. If it were not for my friend who is an oncology nurse providing support and advice I'm not sure how we would have coped, but we were lucky to have her to help – most women would not. She suggested that Mum take me to her local doctor and he was wonderful. He put me in touch with palliative carers who have been helping over the past three weeks – but we were not in touch at the crucial stage when needed. However, I am glad to have them now.”

Judy who runs a support group and is living with advanced breast care in Echuca[13]

The Clinical Practice Guidelines for the Management of Advanced Breast Cancer make specific mention of the need to view palliative care, as well as the other disciplines, as an integral component of the multidisciplinary team. They also state that multidisciplinary care improves outcomes for women with advanced disease[14]

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[12] http://www.health.vic.gov.au/breastcare/downloads/annepennington.doc

[13] Breast Cancer Action Group Newsletter. March 2005

[14] NHMRC Clinical Practice Guidelines for the Management of Advanced Breast Cancer 2001 page 36-7

ISSUE 2 The role and desirability of a case manager / case co-ordinator to assist patients and / or their primary care givers.

Care managers or co-ordinators are important for women with breast cancer. To date this role, has largely been carried out by the breast care nurse – but only where hospital management has seen fit to employ breast care nurses. Currently, an appallingly small number of institutions set aside funding specifically for the employment of breast care nurses.
There is no doubt that where the breast care nurse role is carried out well, they work very effectively in providing support, information, and reassurance for women.

- The day I actually found out that the diagnosis was positive from the surgeon, the breast care nurse met my husband and I……It was good to talk to someone else. Someone with time. Andrew and I knew that the surgeon squeezed us into an appointment and we were very conscious of that, whereas we got the feeling that she was there to talk – no time limit.

  Dee, mother of Sophie who was 3 months at the time of Dee's treatment with 2 other girls under 5[15]

The value of breast care nurses in the early recognition of social support needs, decreasing psychological distress, improving understanding of the issues relating to breast cancer and providing continuity of care throughout the treatment process are documented in the psychosocial guidelines for women with breast cancer.[16]

But some women never see a breast care nurse

- "I still to this day, after twelve months, don't know what the role of the breast cancer nurse is…..I haven't seen much of her and it's never been discussed what the issue is."

  Sonya, who experienced a recurrence 11 years after her initial diagnosis with Paget's disease.

Often the care by breast care nurses does not continue past the time of initial treatment. As women will tell you, and the literature on survivorship confirms, there is a need for support long after the treatment has ceased. [17],[18]

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[15] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women's Health Goulburn North East. 2004. page 62

[16] NHMRC Psychosocial clinical practice guidelines: information, support and counseling for women with breast cancer. 2000.

[17] Vos, Petra et.al (2005). "Effect of delayed psychosocial intervention versus early psychosocial interventions for women with early stage breast cancer", *Social Science & Medicine. (IN PRESS).*

- “After all my treatments, probably two or three months later, I was feeling as flat as flat.

  I ran into the oncology nurse. ‘I was waiting for you ‘she said. ‘I couldn’t go to you. I had to wait.’ I thought that there would be follow-up. But that’s part of the therapy, they tell you, you’ve got to reach out after being on the merry-go-round for the surgery, chemo and radiotherapy for four months. All of a sudden there’s no appointment and you just feel deserted. She said, ‘I knew you would feel this way. Most women do.’

  I have all the paperwork of what was available, but you tell yourself you’re well, you don’t need it. You think, ‘I’m just having a down day.’

  She sent me to a counsellor.

  It was wonderful.”

  Gail, whose husband was made redundant while she was having treatment.

Rural Areas

- BCNs provide valuable support and information. Many BCN roles are not funded in rural areas. But there dedicated nurses continue to provide support at ‘grass roots level’ where most needed. One such nurse spends her day off each week providing support and follow-up to patients and families – unpaid, but most sincerely valued by the women….she supports.

  Many rural women who choose to have surgery performed in a metropolitan area slip through the system, and the local BCN is not aware of them. There needs to be better communication between city and rural BCNs to ensure continuity of care and support. [19]

  Judy who runs a support group and is living with advanced breast care in Echuca[20]

There is a need for co-ordination of care or continuity of care during treatment, but also a mechanism for following up patients once they have left the acute care services. In rural areas the situation is exacerbated by the difficulties of maintaining good communication between the breast care nurses who may see the women during her initial treatment and, community health nurses who are the only means of following up women once they have returned home to areas outside the town or city in which they have been

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[18] Pennery, Emma & Mallet, Jane. (2000). “A preliminary study of patients’ perceptions of routine follow-up after treatment for breast cancer”. *European Journal of Oncology Nursing, 4 (3): 138-145.*

[19] Breast Cancer Action Group Newsletter – November 2002 Page 11

[20] Breast Cancer Action Group Newsletter. March 2005

treated. It appears that there is very little co-ordination between the acute care sector and community health nurses.

In some parts of Gippsland, the details of women who have been treated and are returning home are not passed on to the community health nurses who are the only female nurse in some smaller country towns and who serve a large area. Thus the community health nurse may find out about a woman by word of mouth and have to speak to her about her needs without any briefing from the hospital which has been responsible for the woman's care. Many women fall though the cracks.[21]

There is a particular need for increased numbers of breast care nurses in rural areas. In the north east of Victoria and in Gippsland, the numbers of breast care nurses have been reduced following the end of the Breast Services Enhancement Programs across the state. In both these areas, where the distances are large and where it would be preferable for breast care nurses to be able travel and see the women, there are no full time breast care nurses.

- "I think the only thing is the hours of the breast care nurse. That maybe that needs to be either a full-time position or someone that's on call, or something like that……I just think that's a really good service and needs to be expanded."[22]

In north east Victoria, the nurses are employed part time on annual contracts, so the women in the community are forced to argue for the continuation of the breast care nurse every year[23]. This is an intolerable situation.

A part-time breast care nurse is lucky to be able to see women at the time of surgery. If a woman is operated on when the nurse is not on duty she may not see a breast care nurse. It is certainly impossible for the nurses to provide any continuity of care for the woman and where multi-disciplinary meetings are non-existent, there is no opportunity for nurses to advocate on behalf of women.

Women with advanced breast cancer

But the situation is worse for women with advanced disease. There are no breast care nurses or any form of care co-ordinators for them, unless the GP takes on this role.

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[21] Personal Communication from Waratah Support Group, based in Sale Gippsland and discussions with a local community nurse.

[22] Victoria: Department of Human Services, Hume Region. 2004 Woman to Woman: A Research report on the experience of rural women with breast cancer and the implications for the provision of health services. Published by DHS Hume in conjunction with Women's Health Goulburn North East. . page 26

[23] Angel Verde Personal communication March 2005.

- A case manager approach would be an ideal solution. Such a person could inform the women of appropriate services available to her including both medical/hospital and community services and, where applicable, access such services for her. This person would be able to navigate the territorial nature that can sometimes occur around some services. Women with advanced disease are often vulnerable, physically and emotionally, at the time they require such support, and may not be in a position to access such services for themselves.

  It is however critical that the woman has a good rapport with whoever fills this case-manager role. She needs to be able to communicate openly and honestly about her physical and emotional needs and her fears. She needs to be able to ask questions whenever she has the need for information. Many women are reluctant to ask their treating specialists questions they consider to be of a minor nature or those that occur between appointments in order not to waste the clinician's time. A case-manager would be the ideal person to whom the woman could field such questions, and either have them answered directly, or referred to a relevant clinician/agency as appropriate……….

  It needs to be said that for the woman with additional health issues, such as heart disease or diabetes……., the need for integration and coordination of services is heightened. It is also heightened in those instances where women access both public and private services.

  The GP is a critical person to be in the team because for many women, their GP is more accessible than their treating specialists. This is particularly the case for rural women where distance may separate them from their treating specialists.

  Anne from Benalla who died of breast cancer in December 2004[24]

- My GP is great. She is interested in me and has tried to develop a holistic approach to my care. This is important to me, because women with advanced breast cancer have so many needs, some-one needs to co-ordinate their care. But she had some difficulty getting information from my oncologist. This is not satisfactory and makes it more difficult to co-ordinate my treatment.[25]

  Dorothy who died of her breast cancer in 2003

Some women who are treated the city do have access to breast care nurses and their roles are really appreciated.

- I found my breast care nurse the most honest person. she was totally honest with me. I mean, I asked her to be honest. She would come in and say, "this is what's happening to you" depending on each diagnoses I've had. Which is

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[24] http://www.health.vic.gov.au/breastcare/downloads/annepennington.doc

[25] Breast Cancer Action Group Newsletter – March 2003 Page 8

good. I mean like last time, 12 months ago actually, she said ‘This is not good. This is really bad. Go get your affairs in order, working out what you’re doing”. The doctors didn’t come out and say that, whereas Andrea, she’s known me now for over three years, she knows that’s what I want. And if I want anything, I noticed she’ll give me the straight truth and not sort of fluff it up and say “It’s okay dear. Don’t worry about medication. We’ll look after you” and pat me on the knee, which I’ve had doctors do to me, which I hate. But Andrea, the breast care nurse has been the best - for honesty and help finding information, whatever I need. I don’t think I could survive without her. [26]

Judith a woman living with advanced breast cancer

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[26] Unpublished data. Consumer focus groups. Australian Research Council Linkage Grant (2002-2003), An Intelligent User-Sensitive Portal to Breast Cancer Knowledge Online, , Monash University, School of Information Management & Systems, BreastCare Victoria, Breast Cancer Action Group

ISSUE 3 Differing models and best practice for addressing psycho/social factors in patient care,

The basis for many models of care and best practice is an accurate assessment of the psychosocial needs of individual women. Currently there are no mechanisms or standards for undertaking such an assessment. Women's needs are consequently identified only on the basis of 'chance' and the perspicacity of individual health professionals. [27]

There also needs to be a clear and uniform understanding and acceptance of the role, function and skill levels of the breast cancer nurse which is then applicable across both the acute and community health sectors. This does not exist at the present time and hence has directly contributed to the great variability in the quality of care which women have received.

Many services focus on the stress and anxiety of the initial diagnosis of breast cancer. As suggested above, it is often after the initial treatment has ceased that many women find a need for some assistance.

Countless studies have documented the relationship between a diagnosis of cancer and the increased risk of psychological distress. Identifying, treating and addressing such needs must therefore be endorsed as a central and integral component of the cancer experience

> "it is imperative that members of the treatment monitor the emotional and psychological impact of breast cancer on women……depending on the initial information given by the woman, the nature, severity, and impact of her concerns can then be further explored."[28]

It is undoubtedly a truism to state that different individuals experience the onset of cancer differently. However, there are also clear 'points' in the cancer journey where the potential for increased distress has been documented – such as at the time of diagnosis and at recurrence.

- I'm a recurrent sufferer and the first time around, boy, I was right on top of it, I wanted to know everything and I spent a lot of money on all sorts of therapies and food biodynamic and then I got a recurrence and there's an emotional sort of feeling and then you get this trough. You know, there is a

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[27] The Cancer Corordination Unit (2004). The C-Care Psychosocial Assessment in the Clinical Practice of Breast Care Nurses: Summary Report on the Multi-Centre Trial. p.3

[28] NHMRC 2000 Psychosocial clinical practice guidelines: information, support and counseling for women with breast cancer. Page 28

sequencing of emotional behaviour through all of this. So at different stages you need different things[29]

Gerri talking about her information needs at a focus group.

The needs of other family members are usually not considered by the treatment team at the present time.

- I really think there also needs to be something done for the children of people that suffer cancer and a lot of the young mothers that have breast cancer agree. Their kids do suffer the same symptoms as mine. They're angry, they're aggressive, their mood changes, they get upset, they think you're going to die.

  Because I've got three children I could see their need and their pain. When I could see my children falling apart, I wanted family counseling for the whole family. It was too big a problem. You know you can't cope. Because they're not ADHD, there's not a category to put them in. So there needs to be that base of the family. My marriage might still be together if we went and had counseling. I think a lot of marriages fail in this situation."[30]

  Julie a young woman with breast cancer

It has been shown that support groups in the community sector have provided women with the opportunity to discuss issues which are affecting them. This opportunity is very beneficial.

- "I have learnt a lot through a support group. We go away once a year for a weekend and our facilitator does a lot of emotional work and meditation. We talk about what makes us angry. Some ladies have been diagnosed with secondaries. We do a lot of brain storming and writing and drawing and walking."

  Dee, mother of Sophie who was 3 months at the time of Dee's treatment with 2 other girls under 5[31]

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[29] Unpublished data. Consumer focus groups. Australian Research Council Linkage Grant (2002-2003), An Intelligent User-Sensitive Portal to Breast Cancer Knowledge Online, , Monash University, School of Information Management & Systems, BreastCare Victoria, Breast Cancer Action Group

[30] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women's Health Goulburn North East. 2004. page 67

[31] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women's Health Goulburn North East. 2004. page 62

Counselling can also be effective.

- I spoke to a grief counsellor who made such a difference to me. When I was first diagnosed, I thought I had breast cancer and I was going to die. The grief counselor worked through the reality of it all…….The counsellor just took away the scariness of dying – talking about it in a lighter way and she spoke to my children.

  Dee, mother of Sophie who was 3 months at the time of Dee's treatment with 2 other girls under 5[32]

Rural areas

Women in rural areas need to have the same access to services as women who live in the city. In some cases it appears that support is more easily available in country areas than the city. (See Robyn's story below.) But in other cases, women are unable to access counselling and other support services. In some areas, support groups are struggling to stay alive because of the demands made on a small number of women in country areas.[33]

- Another member having treatment in a large regional centre requested to speak with a social worker, to be told none was available. Support is also needed for most partners, children (especially teenage children), and even parents of the woman diagnosed….. (P)rovision of support services for women and their families should be an integral part of care at all stages of the breast cancer journey.

  Judy who runs a support group and is living with advanced breast care in Echuca[34]

Other women become very lonely because they are staying in Melbourne for treatment and have no satisfactory support from family or friends.

- "Then I started 6 weeks of radiation at [Peter MacCallum Cancer Treatment Centre]. I lived at Peter Mac for six weeks and never came home.

  Twice my husband came down to see me as it was impossible for him to stay with me – we run our own business which requires someone to be there 24

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[32] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women's Health Goulburn North East. 2004. page 62

[33] Personal communication. Women in the Grampians region of Victoria. 2004/2005.

[34] Breast Cancer Action Group Newsletter. March 2005

hours…..It was a lonely time. At times it hurt me. I'm a person who can exist by myself, but sometimes you need someone…."[35]

Ann who decided to have treatment in Melbourne because of the distances she would have to travel

Access to palliative care is often difficult for women in rural areas.

- One of our members spent her last six weeks in Melbourne away from her parents and support network, placing enormous emotional stress on her family. Her husband also spent this time with her in Melbourne as her carer. Because he was self employed this had a detrimental effect on his business which would not have occurred if a facility had been available locally. Problems were encountered with the availability of trained staff, and the administration of drugs as ordered by the oncologist. They felt their only option was to return to Melbourne where care was available 24 hours a day under close supervision of the oncologist.

Judy who runs a support group and is living with advanced breast care in Echuca[36]

Women with advanced disease

Women with advanced breast cancer have to face the fact that they are dying. This is very confronting, particularly when some of their friends die before them.

- I had a friend who had ovarian cancer. She was very up-front about the fact that she was going to die, and we used to have daily contact. You had someone on the road with you. But since she's gone, there isn't anyone on the road…..

  That's a big black, misty hole, when there's no-one to talk with.

  Robyn who's daughter was diagnosed with bipolar disorder after her initial diagnosis of cancer.

Some need access to counselling, for others there are other forms of support.

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[35] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women's Health Goulburn North East. 2004. page 21

[36] Breast Cancer Action Group Newsletter. March 2005

- One of the first things I thought was that I had to find out what services were available because it is very stressing. So a counseling lady came……I thought she came from the Shire, but in the end it turned out that she was actually funded by palliative care.

  So I had some counseling and that was good.

  In fact, I don't know how people survive without it. Because I see people even at my age who won't discuss it with anyone……not the real facing up to the fact that you're going to die, in any sort of way.

  Robyn who's daughter was diagnosed with bipolar disorder after her initial diagnosis of cancer.

- I've tried some counselling, but I didn't find that very satisfactory. Perhaps I'm not the right sort of person for counselling, but I thought I knew as much as the counsellor. I might have some more later on. ….

  I have always felt that I needed to know more. My original surgeon did not give me the information I felt I needed. So when I discovered the Breast Cancer Action Group, I decided to join it and to get the newsletter because I thought this might provide me with some of the information I needed. When my breast cancer got worse, my information needs increased. I needed to know more about the drugs which were being given to me and the options I had for treatment. I knew enough from my contact with BCAG to know that there were a wide range of options for chemotherapy.

  Dorothy who died of her breast cancer in 2003[37]

Dorothy is saying that the support of other women rather than the medical services was important for her. Different women have different needs which need to be met by a range of different services.

For many women with advanced disease, access to family and support for their children and partners is of prime importance.

- "I sometimes feel that there is a shield there. It's very hard to put into words. I can just feel that he [my husband] doesn't want to know what is going to happen to me. He won't let it register in his mind"[38].

  Jessie who has experienced many different forms of cancer but now has advanced breast cancer

- One of my major concerns is for my children. They were very distressed when we told them that I was dying. Alice is doing her VCE this year. I would like

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[37] Breast Cancer Action Group Newsletter – March 2003 Page 8

[38] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women's Health Goulburn North East. 2004. page 11

> to be around to help her with her studies. She would like to have me here to help. Robin is still very young so it is hard for him. I don't know what will happen to them in the future. [39]
>
> **Dorothy** who died of her breast cancer in 2003

So far there have been virtually no support groups available for women with advanced breast cancer. There is one ongoing group which developed from a research project but there is only one support group which has just begun for women with advanced disease. Support groups which may cater for both early and advanced disease are not feasible options given the fact that i. often the issues are vastly different and women with early disease may tend to find the possibility of group members dying very confronting and distressing. The presence of women with early breast cancer may also inhibit the free wheeling discussions so needed for those women confronted with the finitude of existence.

> "Women consulted felt very isolated with limited opportunity to meet other women in a similar situation. However meeting other women with advanced breast cancer for the first time was an empowering experience, enabling women to share experiences, knowledge and provide informal support."[40]

Different women have different needs for support. This is in part due to their individual circumstances, age and social supports. But it is also just a different way of approaching the issues relating to their disease. This is largely based on their own individual value set. So range of different services need to be made available in the community and in hospitals.

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[39] Breast Cancer Action Group Newsletter – March 2003 Page 8

[40] BreaCan 2004. Advanced Breast Cancer: Supporting women' needs. A model of care. Pilot project, summary report November 2004.

ISSUE 4 Differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians.

There is some understanding of the options for providing multidisciplinary care using electronic technologies in Victoria.[41] This understanding was generated during the Breast Services Enhancement Program and the National Breast Cancer Centre Multidisciplinary Care Demonstration Project. Electronic technologies can assist in the provision of multidisciplinary conferences when clinicians are geographically dispersed. This is an obvious model to use and its value has been demonstrated. However the so-called "cost " of these services is regarded as expensive. However the costs have not been compared with the current services nor have any sensible cost-benefit analyses been undertaken.

The use of electronic technologies is part of the current Commonwealth government initiatives to improve access to high quality care in regional Australia. Multidisciplinary care is just another one of the services which can be successfully offered in this way.

The important role of breast care nurses in providing co-ordination of care means that some more thought has to be given to the role they play in supporting women living in rural and regional areas. Some of the issues have been described earlier and it is clear that far more effort needs to go into the co-ordination of the services provided by the acute and community care sectors. One of the more important parts of this need is for full time, permanent, appointments of breast care nurses.

Some co-ordination of the roles of nurses through a regional breast care nurse co-ordinator has been shown to be successful in Victoria. But once funding ceased for this role, the positions were abolished by the hospitals. This role needs to be re-instated.

Unfortunately the role of breast care nurses has not been clearly defined as yet and much more effort needs to be put into the training and further development of the skills of breast care nurses.[42] This is an urgent task for the nurses and their employers, the hospitals and community health services.

In Victoria the BreaCan drop-in center offers women this avenue for support, information and where necessary, referral through the use of volunteers who have themselves experienced breast cancer. The growth and success of this

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[41] http://www.health.vic.gov.au/breastcare/pubs/resources.htm

[42] http://www.health.vic.gov.au/breastcare/pubs/resources.htm

model shows the demand for a service of this nature outside of the medical system. This may provide a workable model for other states.[43]

One of the key issues relating to the delivery of all breast cancer services, is the assessment of the quality of the services offered. This is vital to allow services to know how well they are doing and to allow themselves to compare their performance with other similar services. It is also important that any formal quality assessment is made available to women to ensure that they can choose a breast unit which meets their needs and is of high quality.

We do not wish to comment on the needs of indigenous women because, although we acknowledge their special and important needs, we do not have a good understanding of their needs.

- "We choose to live a rural lifestyle and enjoy many beautiful and enriching aspects that rural living has to offer. However, we do not choose to have breast cancer and our treatment paths can often be fraught with obstacles and difficulties because of our lifestyle choice".

  Judy who runs a support group and is living with advanced breast care in Echuca[44]

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[43] BreaCan. 2004 BreaCan – Breast Cancer Support Evaulation Report. October 2004.

[44] Breast Cancer Action Group Newsletter. March 2005

ISSUE 5 Current barriers to the implementation of best practice in the above fields:

There are 4 major barriers to implementing best practice

1. **Attitudes to care by the medical profession and hospital administrators - physical / medical / clinical issues take priority over psychosocial needs**

It is no longer sufficient in 2005, to view the practice of medicine using the biomedical model alone. Consumer advocacy and widespread access to information, consumer rights and other social trends have combined to ensure that disease should be considered in a broad social context.

- “I know I’ve been lucky. I have people who care for me and support me. I know that I know a lot more about what is happening to me, and my family, than many other women do. I have had good quality treatment and clinicians who have been kind, supportive and professional.

  But somehow, I still feel that my needs have often been left out of the discussions. That I was not treated as an individual who wanted information, wanted discussions about my prognosis, wanted options for treatment, wanted to participate in making decisions about my care, wanted the best for my family. “[45]

Dorothy who died of her breast cancer in 2003

Solely being concerned for the physical health of a person is no longer acceptable. However it takes time to change medical practice and its associated mind sets. Women, consumer representatives working with medical schools have started to change these attitudes but it is a long slow process. Further investment, by policy development and resource allocation, by government in attitudinal change management programs would be of assistance here.

Except for the provision of breast care nurses and regional breast care nurse co-ordinators and perhaps the use of electronic technologies, we do not believe that more resources are needed to undertake multidisciplinary care. We believe that if the necessary studies were undertaken it could be shown that multidisciplinary care is cost-effective for hospitals. Indeed it can probably be shown that breast care nurses actually reduce hospital costs by reducing length of stay. But until suitable studies have been done, it will be difficult to convince hospital administrators of this reality.

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[45] Breast Cancer Action Group Newsletter – March 2003 Page 8

2. **Resources for psychosocial care, i.e. more psychologists, psychiatrists, counsellors within hospitals and palliative care services for women with advanced disease**

We have shown in this document that counseling, support groups for women, assistance for children and partners are all needed. There are difficulties in providing this care because of the lack of social and psychological support services in hospitals and community health services across the state. Palliative care is a major problem in some areas. Resources for these services need to be improved. The costs are too high for many women and their families to access and there are noMedicare rebates for these psychological services. With multidisciplinary care, there should be no difference in the level of support which is available for medical care whether it be psychological or physical care.

- There are difficulties in providing palliative care, due in part to a shortage of services in rural areas, which in turn is due to funding allocations. The demand for palliative care has increased in the last two to three years and the length and complexity of required stay has also increased. Costs have risen and government funding has remained relatively fixed, according to Allen Kellehear, Professor of Palliative Care from La Trobe University (personal communication).

> (P)rovision of support services for women and their families should be an integral part of care at all stages of the breast cancer journey.
>
> **Judy** who runs a support group and is living with advanced breast care in Echuca[46]

3. **Lack of inclusion of the costs to medical practitioners involved in multidisciplinary care and lack of Medicare rebates for patients for psychological services, apart from psychiatric care.**

For GPs who wish to be involved in the multidisciplinary team meetings for one of their patients, there are no Medicare rebates available. This is a distinct disadvantage for these GPs and their patients.

The costs of services for women using the private health system can be overwhelming. The costs associated with counselling are often too high for many families. This is especially the case if women are needing to deal with many different issues relating to their families as well as their own needs

- One of our members recently diagnosed with advanced disease was referred to a professional counselor by her GP. On inquiring she was told the cost of her first consultation was $80, making the service unattainable due to her financial circumstances.

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[46] Breast Cancer Action Group Newsletter. March 2005

Judy who runs a support group and is living with advanced breast care in Echuca[47]

4. Lack of access to support services for child care, home help etc via Health and Community Care Services

- "So basically Mum took over. She did everything. She did my housework, my cooking, my childcare, she got up thought the night, she did not expect me to do a thing. She did not expect Andrew to do extra either. She was fantastic.

  There was nothing out there to support her. She came to help us and we were trying to get her a carer's Allowance. We applied for that but she was ineligible. She wasn't my carer, she was Sophie's carer, so they wouldn't give it to her. I actually went in to Centrelink several times and tried to get them to understand our unique situation, and they just couldn't understand. They would not budge from their criteria.

  ……..

  One service that we found helpful was our local childcare center, where my girls were going at the time of my diagnosis. The office manager rang me and told me there was assistance if I wanted to put my 3 girls into childcare full time for 13 weeks. I did not want to do that. I did put the girls into childcare one day a week, just to give Mum a break…."

  Dee, mother of Sophie who was 3 months at the time of Dee's treatment with 2 other girls under 5[48]

This story is repeated many times over in all parts of the state. Funding for most of these services is limited and often home help is only available for women who are elderly.

It is a particular problem for young women with children.

Far more effort needs to given to finding alternatives to this situation. Young Action on Breast cancer in Victoria, is looking at some options which would need some seed funding and some administrative funds, but which would allow women to have access to services such as home help gardening, cleaning, taxis etc at virtually no cost to the government. Such ideas need to be supported and evaluated[49].

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[47] Breast Cancer Action Group Newsletter. March 2005

[48] Victoria: Department of Human Services, Hume Region. Woman to Woman: insights from rural women with breast cancer. Published by DHS Hume in conjunction with Women's Health Goulburn North East. 2004. page 62

[49] Personal communication. Young Action on Breast Cancer March 2005

ISSUE 6 How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

(i) the extent to which less conventional and complementary treatments are researched, or are supported by research'

(ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and

(iii) the legitimate role of government in the field of less conventional cancer treatment.

We do not wish to comment on this issue.

Recommendations

1. All women with breast cancer should be treated by multidisciplinary teams no matter where they live.

2. Multidisciplinary team meetings can be convened using video- or tele - conferencing. The costs and benefits of such technologies should be rigorously evaluated to demonstrate the benefits to hospital management. This should include an estimate of the benefits to the woman of reduced traveling and improved outcomes.

3. Medicare rebates should be used to encourage GPs to participate in multidisciplinary teams.

4. Permanently appointed breast care nurses should be adequately funded and made available to all women no matter where they live.

5. The costs and benefits of breast care nurses should be assessed and made available to all hospital administrators.

6. A range of different psychological and social support services should be available to meet the needs of individual women.

7. A program of identifying and funding imaginative responses to the needs of women outside the current hospital medical services should be developed.

8. Convening of an expert committee to evaluate the needs of indigenous and CALD groups through direct consultation with women with breast cancer in these groups.

9. Consumer groups, working with medical professionals, can bring about change in attitudes, at a faster rate than just medical professionals on their own. Consumers should be included on all panels identifying the needs and resourcing of new services.

10. Measurement of performance by continuous improvement programs within and between hospitals is crucial to the development of improved services. This should be done with the assistance of consumers on peer review panels. When suitable measures have been developed, the outcomes of these measures should be released to the public.

Appendix 1 Breast Cancer Action Group

Giving a Voice to People with Breast Cancer

The **Breast Cancer Action Group** was formed in 1994 by women committed to reducing the impact of breast cancer in the Australian community.

The **Breast Cancer Action Group** believes

- that people with experience of breast cancer have much to contribute to all aspects of breast cancer research and treatment. The perspectives of these consumers need to be heard by those involved in the decision making for research, funding and social support programs.

- that all Australians should have access to the highest quality breast cancer detection, diagnostic and treatment services.

- in working with breast cancer services and community support activities at both state and commonwealth levels. Its intention is to work together with all interested groups to improve the standard of care and choices for all.

Using our voices

The **Breast Cancer Action Group** trains women to participate in the work of different groups involved with breast cancer and now has trained women on many different committees in hospital networks, state, national and international organizations. It advocates for change through the media and by informing women about their rights, responsibilities, treatment options and research developments through the newsletter and developing brochures on specific topics.

Breast Cancer Action Group members work in partnership with organizations such as the Department of Human Services, BreastScreen Australia, the National Breast Cancer Centre, the Cancer Council of Victoria, the Victorian Breast Cancer Research Consortium and specific hospital departments, both in metropolitan Melbourne and rural and regional Victoria. In this way it influences health service provision and the research community. Efforts are made to ensure the voices of these women are representative of the views of a range of women and not their own personal views. It also works in partnership with other breast cancer consumer organizations.

A newsletter is produced quarterly to inform our members of events and of new approaches to the treatment of disease and give them information which may assist them in their breast cancer journey. All members have the opportunity to contribute their views to the newsletter, we encourage original contributions and personal stories.

Membership

Membership of the **Breast Cancer Action Group** includes women of all ages and a variety of backgrounds. Many members are women with direct experience of breast cancer. Membership also includes those who have not had breast cancer but share the aims and objectives of the group. It is free and open to all interested people. There are 650 members from all over Victoria and in other parts of Australia and overseas. New members are welcome.

The **Breast Cancer Action Group** is a founding member of the Breast Cancer Network Australia which was formed in 1998 to bring together advocacy groups, support groups and interested individuals to give a national voice to those affected by breast cancer.

Our influence

Some of the areas in which we have worked recently include:

- performance indicators for public hospital breast units
- waiting times for radiotherapy
- development of lymphoedema services
- reporting of breast cancer issues in the media
- access to breast care nurses across the state
- effective and efficient provision of external breast prostheses
- provision of Herceptin to women with advanced breast cancer in conjunction with Breast Cancer Action Group NSW and Breast Cancer Network Australia
- services for women with advanced disease
- a drop in center for women, their partners and children
- improved information resources designed especially for the needs of women
- guidelines for women with early and advanced breast cancer and women with ductal carcinoma in situ, lobular carcinoma in situ and atypical hyperlasia
- services for women under 40.
- speaking to national and international conferences and clubs and societies
- messages on early detection of breast cancer

Funding and Organisation

The **Breast Cancer Action Group** is a grass roots group which receives most of its funds from donations by members. It also receives a small amount from the Victorian government and some services clubs. All its activities are carried out by volunteers.

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