breast cancer
action nsw

SUBMISSION TO THE
SENATE CANCER INQUIRY

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Introduction

The Breast Cancer Action Group NSW is the state level voice for women affected by breast cancer in NSW. Funded in 1997, our 750 members live across NSW, about a third living in rural and remote areas. We work to make a difference for all women living with our disease. There are around 4,000 new diagnoses each year in this state. We attach a backgrounder for further information about our activities and a listing of our current priority issues, developed from BCAG's recent operational planning process.

Please note our full support for the submission made by our state peak group for cancer consumers, CANCER VOICES NSW (attached). Many issues faced by people with cancer are shared, but the comments below are additional, reflecting those matters specifically affecting women with breast cancer. We commend them to the Senate Cancer Inquiry.

a. The delivery of services and options for treatment for persons diagnosed with cancer with particular reference to:

1. Getting onto the right treatment path from diagnosis onwards

Members of BCAG NSW identified that a major treatment problem was trying to find the most appropriate breast cancer specialists for their treatment. General Practitioners, the traditional source of referrals, were not always aware of which breast cancer specialists had the best outcomes, worked with multidisciplinary teams, were more likely to use Guidelines and had a higher case load or were associated with breast clinics. Women were becoming increasingly aware that specialists were associated with better outcomes. BCAG NSW found an excellent partner in the NSW Breast Cancer Institute, located at Westmead Hospital. Together we developed, implemented and disseminated the Directory of Treatment and Services for NSW Women. In 2003, all NSW GPs and participating specialists received a hard copy, and this is now updatable via the electronic version housed on the website of the NSW BCI and our own www.bcagnsw.org.au.

This effort by women with breast cancer, to help their sisters and the medical profession, was recognised by the NSW Minister for Fair Trading's Consumer Protection Awards in 2001.

2.. Falling between the Stools? A Survey of Women's Experiences of Breast Cancer in NSW (Nov 2001) ISBN 186507 071 8.

We submit a copy of the Survey we undertook of our members' experiences of their treatment journeys. This survey has been quoted a number of times in the literature surrounding this topic. We believe it will be useful to the Senate Inquiry to have a full copy of this document, as well as the published article it generated in the NSW Public Health Bulletin. The survey documents the difficulties experienced by ordinary women as they grappled with their mostly unco-ordinated treatment pathways.

3. Expansion of Multidisciplinary Care & Care Co-ordinators

The Breast Cancer Action Group NSW has long supported the introduction of the multidisciplinary care (MDC) approach in the treatment of all patients with cancer and the *Falling between the Stools* report referred to above highlighted the need for a more coordinated approach to care. While recognising this is not always practical, especially in rural and remote Australia, we commend the use of technology to overcome the tyranny of distance – via video conferencing with larger centres. Expensive, but cost efficient in terms of lives saved and use of most appropriate treatment.

As outlined in more detail in the Cancer Voices submission attached, MDC at all stages in the person's cancer treatment journey is important for women with breast cancer, including women with advanced breast cancer. For all women with breast cancer the linkage of the MDC team to related practitioners is also important, including familial cancer clinics, services addressing lymphoedema and practitioners working in the fields of fertility and menopause. As is the case with other cancers, the inclusion of appropriate psycho-social support as part of the MDC team is particularly important.

Also related to the need for MDC is the role that the Breast Care Nurse plays in *the coordination of care*. This role has operated in some breast cancer centres for some years and has proven very beneficial. There is a need for the role to be expanded to all centres, to be set up in a way it can work across the public and private systems and be provided with security of funding so that suitable nursing staff are attracted to take on these roles and undertake training needed

4. Breast cancer: Life after Diagnosis – what you need to know, ask and expect
A leaflet written by BCAG NSW to address the uncertainties and lack of information about the breast cancer treatment journey was published in 1998 and again in 2000. These uncertainties and lack of information remain today, especially where care is not co-ordinated or a mutlidisciplinary team put in place.

5. Breast Prostheses and Lymphoedema sleeves and treatment

Breast Prostheses: A major issue for those women who have had to have a mastectomy due to the extent of their breast cancer, or due to preference (often the case for rural women who are far from radiotherapy centres). Although the use of a breast prosthesis is medically indicated to preserve women's spinal balance as well for psychosocial reasons, breast prostheses are not regarded as prostheses for subsidy by the Commonwealth Government. This is almost a scandalous situation, with women who are unable to make the financial investment having to resort to making packages of similarly weighted bird seed to prevent skeletal and muscular deterioration. Of course the end cost to the public purse is much greater than the cost of supplying a prostheses would have been.

We understand that this Senate Committee considered the provision of prostheses during its Inquiry on the National Health Amendment (Prostheses) Bill 2004, but we do not know the results. The Cancer Inquiry should make sure that breast prostheses are included along with other necessary prostheses for those missing a body part. To deny this would be medically and socially wrong.

Access to Lymphoedema treatment and sleeves
Another vexed difficulty for women with breast cancer, who have developed lymphoedema - the painful swelling of the arm, when axillary nodes are cleared or removed. There are very few therapists who are able to treat this condition, suffered by about up 20% of women. Their fees are not covered by Medicare, and the pressure controlling sleeves which are used for everyday wear are another out of pocket expense. Some private health insurance ancillary cover provides some assistance, but not enough – for those who can afford this insurance.

Lack of access to PET scans
While the Commonwealth subsidises PET scans for most cancers via Medicare – the list itemises 43 services for subsidy, it does not do so for breast cancer, the most common cancer for women. Each PET scan costs a woman with advanced disease $900 out of her own pocket. We understand that there is substantial evidence for inclusion of PET for

advanced breast cancer as an integral part of understanding the stage of her disease, which in turn assists treatment options and decisions. PET scan results can obviate the need for more expensive therapy. We would like to see the Inquiry recommend fast-tracking of this anomaly.

6. Specific needs and experiences of Rural & Remote Women

BCAG NSW is currently surveying the experiences of our rural and remote members in order to improve those aspects of their treatment and recovery journeys which makes dealing with a breast cancer diagnosis and accessing treatment particularly difficult for these women. The report will be available in June.

b. How less conventional and complementary cancer treatments can be assessed and judged with particular reference to:

We understand that the National Breast Cancer Centre is undertaking a study, via a series of focus groups and a survey, to identify those complementary and less conventional therapies most frequently used by women with breast cancer. The next step will be to compile the evidence where it exists and advise women whether it exists, its level and if no evidence exists. A report is expected by July 2005, and we commend this to the Inquiry.

Provision of a central and authoritative information authority should be a responsibility of government. We suggest that the NBCC findings could be translated to all cancers and be centralised under the auspices of the new Cancer Australia, or the Cancer Council Australia, if provided with funding to do so.

Thankyou for the opportunity to address some of the specific issues faced by women with breast cancer in Australia. We attach a list of priorities identified by our members in 2004. We would be pleased to provide further information to the Inquiry, and to appear at its hearings if requested.

Yours sincerely

SALLY CROSSING
Chair

15 March 2005

Our Priority Issues 2004

Information

1. Easy and timely access to the current information you need for decision-making.
2. Development of balanced information, including about risks, for those diagnosed with or concerned about breast cancer, as well as for the media and the community.
3. To avoid dissemination of misleading information, develop a Community Impact Statement to be used by researchers seeking publication
4. Ensure maintenance, updating and extension of our Breast Cancer Directory.

Treatment

5. Adoption of the multidisciplinary care (MDC) model for breast cancer treatment at all major NSW hospitals and publish lists of MDCs
6. Breast nurses as part of the MDC team, with necessary training and funding
7. Seek more equitable and timely access to radiotherapy services
8. Seek improved access to new unlisted drugs; engage in discussion re the PBS and transparency of its processes
9. Lymphoedema - advocate for better access to treatment and information
10. Prostheses & lymphoedema sleeves: seek a review of access to and financial assistance

Research

11. Research: develop, update and advocate for our priority issues for breast cancer research.
12. Promote informed consumer participation in clinical trials.
13. Seek a national register of cancer clinical trials, which is publicly accessible.
14. Seek greater role for consumers at all stages of research.

Special needs

15a. Younger women

15b. Advanced breast cancer

15c. Rural and isolated

15d. Familial breast cancer

15e. Specific support, information and recognition of special needs (eg financial support, review of IPTAAS)

15f. Needs of people from CALD backgrounds

15g. Needs of Aboriginal and Torres Strait Islander people

General

16. Consumer representation: A “seat at the table” wherever decisions are being made about breast cancer.
17. Contribute to discussion on all issues for women/men affected by breast cancer, as they arise.