Men get breast cancer too: a consumer consultation project to strengthen information and support


>> Introduction
While men make up less than one per cent of all Australians diagnosed with breast cancer, a diagnosis can bring very specific challenges for men. It can be more difficult for men to access appropriate information, as well as emotional and social support. Low awareness of male breast cancer can also contribute to stigma and isolation for men.

In 2016 Breast Cancer Network Australia (BCNA) developed a booklet, Men get breast cancer too, for men diagnosed with breast cancer. In 2016, BCNA undertook more work to better understand the challenges men face, based on feedback from members suggesting that more can be done to improve outcomes for men.

>> Objectives
This consultation project was undertaken by BCNA with the aim of identifying strategies and practices that BCNA and the broader Australian community can undertake to help men feel more included, informed and supported after a diagnosis.

>> Description
This project involved in-depth telephone interviews with five men from around Australia who had been diagnosed with early or metastatic breast cancer, to identify areas of unmet need in terms of information provision, emotional support and awareness. The project also involved a detailed literature review, which focused on identifying broader issues and challenges for men diagnosed with breast cancer.

BCNA recruited men to take part in the interviews through their network of members and through links with health professionals. Through the interviews, men were invited to talk about their diagnosis and treatment journeys, information needs, health care experiences, and gender, sexuality and identity issues that shaped their breast cancer experiences. The interviews also aimed to identify what BCNA, and the community more broadly, can do to improve outcomes and experiences for men.

>> Findings
From the interviews, men diagnosed with breast cancer told us their main challenges were:

- Finding breast cancer information specifically for men
- Delaying in seeing their GP and being diagnosed
- Dealing with the stigma of having what is seen to be a ‘woman’s disease’
- Feeling isolated and alone, due to a lack of support.

The men
In-depth qualitative telephone interviews with five men from around Australia who had been diagnosed with early or metastatic breast cancer.

Age
Men were aged between 59 and 74 years. The youngest age at diagnosis was 38 years, and the oldest 64 years. Year of diagnosis ranged from 1998 to 2014.

Location
The men were from around Australia: two from NSW, and one each from QLD, WA and SA. Most lived in regional areas/towns.

Diagnosis
4/5 men had early breast cancer. One man was diagnosed with metastatic breast cancer, four years after initial breast cancer diagnosis in 2010.

Employment
4/5 men were recently retired, with one self-employed. Occupations included banking/finance, writing/editing, farming, building, education and small business.

Family and relationships
All of the men were married/living with a partner of the opposite sex. All men had at least one child.

>> Outcomes
This project highlighted the need for male-specific information resources to be readily available at time of diagnosis, and for breast cancer organisations to be more active in raising awareness that men can get breast cancer. Also key was the need for newly diagnosed men to have better access to appropriate peer support.

BCNA now provides male-specific resources for newly diagnosed men, to ensure that information that is tailored to their needs. The project has fostered opportunities for men to gain skills in consumer advocacy, peer support and awareness-raising projects. BCNA is also raising awareness of male breast cancer through social media and featured stories, and disseminating the findings of the project to our network of health professionals.

>> Conclusions
It is important that cancer organisations take a lead role in challenging the stigma of male breast cancer, and improving information and supports available to newly diagnosed men.

Recommendations

Recommendation 1: Improve access to gender-appropriate information
Offer tailored resources for men as soon as possible after diagnosis, as they provide men with information that is designed to meet their specific needs. BCNA’s Men get breast cancer too booklet and Professor John Boyagans book, Male Breast Cancer: Taking Control are two resources which men have told us are particularly helpful.

Recommendation 2: Raise public awareness of breast cancer in men
Highlight the signs and symptoms of male breast cancer, encourage men to seek medical advice early, and promote stories and accounts from other men which help to reduce the stigma of a breast cancer diagnosis.

Recommendation 3: Improve access to psychosocial supports
Men should be screened for psychosocial distress after diagnosis, and should be offered information and/or a referral to appropriate counselling or psychological interventions. Encourage men to seek out cancer support groups, and provide information on local cancer support services. This may include breast cancer support groups that are inclusive of men, general cancer support groups, and recreational clubs such as breast cancer survivors’ dragon boat teams.

Online support groups and forums are a good way for men to access psychosocial support. If they cannot find other men to connect with locally.

Health professionals and patient organisations can play a role by connecting newly diagnosed men with other men who have been diagnosed with breast cancer, who are willing to offer informal peer support.

Further information
See BCNA’s Men with breast cancer web page at bcna.org.au.

Acknowledgements
BCNA is grateful to the men who participated in the consultations for their assistance.

>> Footnote:
A photo of a man wearing a blue shirt at a breast cancer event in Toowoomba Queensland.