

## BCNA Wollongong Forum – 7 November 2011 Women's key issues of concern



At BCNA's Forum in Wollongong on Monday 7 November 2011, BCNA invited those present to write down for us one key issue or problem they felt affected women with breast cancer.

This feedback will be used by BCNA's Policy Team to inform our advocacy priorities and to help us identify any new or emerging issues for women with breast cancer. It also allows us to direct women to any existing information or work that may already have been done on these issues by BCNA, or another organisation, so that women can feel informed and up to date.

A number of women responded to our request to highlight a key issue or problem, and the issues that were identified as being important are discussed below.

- There were a few queries regarding the 'right' diet following a diagnosis of breast cancer. There is no scientific evidence that women with breast cancer need a special diet, but women are encouraged to eat a balanced diet. For your information about diet and nutrition following a breast cancer diagnosis, you may like to visit the Nutrition page our [website](#).
- One woman asked about the symptoms of a breast cancer recurrence. Every woman's experience of secondary breast cancer is different, and symptoms depend on the part of the body that is affected. In general, it is recommended that you see your doctor if you have an ache or pain that does not go away. For more information about secondary breast cancer, including symptoms, you may like to visit [Cancer Australia's website](#). In addition, Issue 55 of [The Beacon](#) (Winter 2011) focussed on emotional wellbeing and includes an 'Ask the Expert' article about managing anxiety and fears regarding breast cancer recurrence.
- There was a question asking which private health insurance companies provide reimbursements for post-mastectomy bras. BCNA is unable to provide information on specific private health insurance funds, however you may like to phone your health insurance provider and ask them whether they provide entitlements for bras. Some private health insurance funds will also provide a rebate for other post-mastectomy garments, such as swimsuits. If you are unhappy with the cover your fund provides, you may like to consider changing to a different private health insurance provider who can offer you cover for these items.
- One woman raised a concern about the difficulties that some older women face in connecting with other women diagnosed with breast cancer, particularly if they do not use the internet. Cancer Connect is a free service provided by the Cancer Council, where you will be paired with a trained volunteer who has had a similar cancer experience to you, and who will provide you with emotional and practical support. To contact the Cancer Council, you may like to call them on 13 11 20. You may also like to connect with other women by joining a support group. To find a support group in your local area, visit [BCNA's Local Services Directory](#).
- One woman asked for more information about the out-of-pocket costs of breast reconstruction. Issue 53 (Summer 2010) of [The Beacon](#) 'Breast reconstruction: no right or wrong way' includes information on the out-of-pocket costs of breast reconstruction. Issue 56 (Spring 2011) of [The Beacon](#) 'The dollars and sense of breast cancer' includes

information on the out-of-pocket costs of breast reconstruction in the public and private health systems.

- There was a concern about being unable to ask health professionals medical questions once regular contact with treating doctors has stopped. For women who have medical questions or concerns about breast cancer, you may like to call the Cancer Council helpline on 13 11 20. The hotline is staffed by Oncology Nurses who may be able to assist you by providing you with information. You may also like to contact the breast care nurse at your local hospital, who may also provide you with information and support.

### **BCNA fact sheets and booklets**

A number of other issues were raised by women that are addressed by BCNA fact sheets and booklets. These are all available on our [website](#), however if you would like a hardcopy version please call us on (Freecall) 1800 500 258 and we will send a copy to you.

- There were a couple of queries regarding breast cancer and sexual wellbeing, which we know is an issue that affects many women. Some women may experience physical changes such as hot flushes, while other women experience emotional changes such as not feeling confident about their body. We know that for many women vaginal dryness can also be an issue due to the effects of chemotherapy or hormonal therapies. Other women tell us that they often lack the energy and desire for sex due to fatiguing treatments or changed hormone levels. Very often it's a combination of many of these different issues. BCNA has developed a [Breast Cancer and Sexual Wellbeing](#) information booklet to help you identify the issues that may affect you during and after treatment. The booklet suggests strategies you can try to help deal with some of these issues. Issue 50 [The Beacon](#) (Autumn 2010) focused on the topic of sexual wellbeing and includes personal stories from women, and other articles of interest.
- There was a query regarding depression following a breast cancer diagnosis. Depression in women with breast cancer is common, but is often overlooked and, therefore, undertreated. Breast Cancer Network Australia and *beyondblue*, the national depression initiative, have developed a [fact sheet on depression](#), detailing its links with breast cancer, available treatments and how to help yourself or someone close to you.
- There were a number of queries regarding lymphoedema, including a question about subsidies for compression garments. BCNA has [information on our website](#), including reducing your risk of developing lymphoedema, symptoms of lymphoedema, and managing lymphoedema. We also have a number of [lymphoedema fact sheets](#) available on our website, including one that contains information on the state and territory run subsidy schemes that may assist some women with the cost of lymphoedema garments.

One woman raised concerns about being unable to access past test results and being unable to explain her medical history to a new doctor after moving house. Women can obtain copies of their pathology reports, even months or years after breast cancer treatment. For more information on how to get copies of your pathology reports, you may like to read our [Breast Cancer Pathology fact sheet](#). Also, while doctors often do not share their notes with patients, if you move to a new area and change doctors, your new doctor can ask your old doctor for a copy of your file.