# BreaCan – developed by consumers

Service of Women's Health Victoria For people affected by a gynaecological or breast cancer across Victoria



Service model is:

- **support** delivered by trained Peer Support Volunteers
- information holistic program of information, creative and wellbeing focussed sessions including webinars, provision of information about cancer topics and services available (eg. OCA, CCV, BCNA, Cancer Australia), library of resources



#### FEBRUARY MORNING TEA AND REFLEXOLOGY WEDNESDAY 15 FEBRUARY

#### 10.30AM – 12.00PM

A special morning tea to commemorate Ovarian Cancer Awareness month. We invite all women diagnosed with a gynaecological cancer to enjoy morning tea and chat with BreaCan volunteers and others who've had a similar experience. You can also enjoy a relaxing reflexology treatment on this day. Please RSVP so we can book your reflexology time.

#### INTRODUCTION TO WELLNESS

#### OUTREACH SESSION

#### TUESDAY 21 FEBRUARY 4.00PM – 6.00PM Location: Mulgrave Community Centre 355 Wellington Rd, Mulgrave

What really defines wellness? How do things like meditation and exercise improve our treatment of illnesses such as cancer, as well as enhancing our lives on a daily basis? Dr Leon Tan, an experienced medical practitioner who specialises in Wellness Medicine, will present on this topic and answer your questions. BreaCan is partnering with the Specialist Service at The Valley Private Hospital for this session.

#### UNDERSTANDING YOUR PATHOLOGY REPORT

#### **MARCH** FERTILITY PRESERVATION WEBINAR MONDAY 20 MARCH 12,00PM – 1,30PM

In this session we will hear about the issues that are important

in considering fertility preservation, current methods available and upcoming developments, and where to get more information. Our presenter is Franca Agresta, Melboure IVF's Clinical Research Manager.

#### **SHRINKING THE WORRIES**

#### OUTREACH SESSION

THURSDAY 23 MARCH 10.30AM – 12.30PM Location: Education Centre (Ambulatory Care

Entrance), Northern Hospital, 185 Cooper St, Epping

We all worry occasionally. But sometimes, especially after a major event in our lives such as a cancer diagnosis, we can find ourselves worrying more about all manner of things. This session will look at a variety of ways to help you worry less. *BreaCan is partnering with the Breast Clinic at the Northern Hospital for this session.* 

#### LYMPHOEDEMA

WEBINAR THURSDAY 30 MARCH 12.30PM – 2.00PM

After having surgery to remove lymph glands there is a risk of developing lymphoedema. Our presenter

#### APRIL FELDENKRAIS MONDAY 3 APRIL 10.30AM - 12.00PM

This session will provide an introduction to the Feldenkrais Method which involves very gentle but unusual movements, designed to discover more comfortable and efficient ways to move. These movement lessons tap into how the brain organises movement. Thalia Castles has been a Feldenkrais practitioner for over 25 years.

#### MANAGING CHRONIC ILLNESS



11.00AM – 12.30PM What does this term mean and

what relevance does it have after a cancer diagnosis? This session is about being an active participant in your own health care and the skills that are needed in order to do this. Presented by Mary Macheras-Magias from the Health Issues Centre.

#### VITAMIN D AND CANCER WEDNESDAY 26 APRIL 11.00AM – 12.30PM Location: Women's Health Victoria Level 8, 255 Bourke St, Melbourne

Dr Allison Hodge from the Cancer Epidemiology Centre will present on the latest research about the links between Vitamin D and cancer.

.....





- Data on people being diagnosed with a cancer recurrence not captured – this means no data available to know numbers of people affected
- BreaCan specific data shows that in 2015/16 we had 169 contacts with women who had identified as having an advanced cancer diagnosis.



- From the outset, women with advanced cancer wanted to use the services of BreaCan.
- Women were telling us they:
- Feel isolated
- Want to live as well as possible
- Want to talk with other women who
  understood what they were going through
- Want information to support their own decision making and choices
- Have health issues that were variable, sometimes difficult and often cause disability

- Want to contribute to the work of BreaCan
- Live with uncertainty
- Live with cancer that they will likely die from



# BreaCan's response

- Developed a program specifically for women with advanced cancer that was multi-dimensional so women can access as their interest and health allowed. We called this *Making Connections*.
- Staff and volunteers able to provide support
- One staff member oversights advanced program and women
- Programs of interest with a social aspect to break down isolation
- Library acquisitions based on areas of interest
- As well, women have access to other BreaCan programs and services
- Increasing number of information programs being delivered as webinars



### Events for Women Living with Advanced<sup>\*</sup> Breast and Gynaecological Cancers

\* Advanced cancer can also be called Secondary or Metastatic Cancer

### **Breast Cancer and Bone Metastases**

Wednesday 8 March 12.30pm – 2.00pm



Metastatic breast cancer commonly involves bone metastases. As a result, several complications can arise: bone pain, fractures and high blood levels of calcium. In addition, the treatments for metastatic cancer can increase the risk for osteopenia and osteoporosis. In this session Yoland will detail the current and upcoming treatments available to strengthen bone and prevent complications arising from bone metastases. There will be an opportunity to ask general questions.

Yoland Anthill is a Medical Oncologist at Cabrini Health and Peninsula Health services, as well as doing research and clinical work in cancer genetics at Royal Melbourne Hospital.

### Morning Tea for Women Living with Advanced Cancer

Monday 24 April 10.30am – 12.00pm Join us for a lovely morning tea and an opportunity to chat with BreaCan volunteers and other women who are living with advanced cancer.

There are real benefits to connecting with others who really understand your situation in a way that others, however well meaning, may not. Some of these include not feeling so alone and isolated, learning tips and strategies from other women about what helps them, being able to 'be real' and express how it is for you without having to be stoic and protect others, and last but not least finding the humour in spite of it all.



- Recognition that Peer Support Volunteers may receive an advanced cancer diagnosis and that this would not preclude them from continuing to volunteer.
- Over time, women with advanced cancer were recruited as Peer Support Volunteers.
- Having Peer Support Volunteers with advanced cancer:
  - Acknowledges the right of all to volunteer
  - The special perspective some women have on life and death
  - The empathic support they provide to people affected by advanced cancer



Peer support volunteers with advanced cancer:

- 10 women with advanced cancer recruited as Peer Support Volunteers
- A further 8 women have received an advanced cancer diagnosis while volunteering
- Currently, 6 volunteers with advanced cancer working as Peer Support Volunteers
- Range of years of volunteering between 6 months and 5+ years

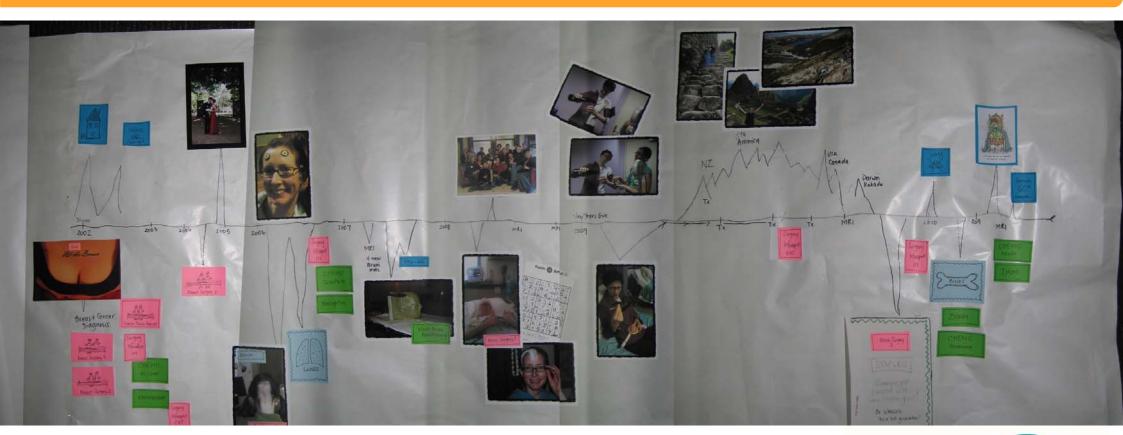


Peer Support Volunteers with advanced cancer support BreaCan in many ways:

 They educate and inform other BreaCan volunteers and staff about the diversity and realities of cancer experiences, including providing a formal component within the Peer Support Volunteer training.







Paula's timeline



2. Provide 'lived experience' support to women with advanced cancer including: supporting their decisions about how they want to live their lives following an advanced diagnosis

Peer support volunteers have:

- knowledge about the emotional impact of making decisions
- things to consider when thinking about participating in clinical trials,
- well-developed understanding of the services available to women with advanced cancer and
- experience in talking with and supporting family and friends







3. Inform BreaCan's service delivery through input into programming. They participate on the BreaCan Advisory Group providing input into policy and strategic direction.

Volunteers may also contribute to research projects of other organisations.

These volunteers can reflect on the experiences of the women they talk with as well as their own.



# Challenges for Peer Support Volunteers and BreaCan

- These women experience some extreme variations in health and this can make regular volunteering difficult. For some volunteers this is a loss.
- For some they make the decision to concentrate on other aspects of their lives
- If wanted, volunteers with advanced cancer continue to receive support from BreaCan's Volunteer Coordinator and some continue to use BreaCan's services.



Role of Volunteer Coordinator and BreaCan staff

- Provide emotional and practical support where useful and wanted
- Provide information to rest of volunteer pool based on the wishes of the individual
- Support other volunteers who feel vulnerable and sad about re-diagnosis and declining health of their colleagues





 When volunteers die it is extremely important to all at BreaCan — staff and volunteers — that we take time to commemorate and reflect on the life that was lived.



- Specialised and personalised processes for communicating with volunteers have been developed.
- We recognise that this news will affect volunteers differently depending on their individual relationships, own emotional, physical and spiritual situation.

## Important to commemorate women appropriately:





- Circle of women
- Shilling Wall
- Remembered in publications (eg. *BreaCan Year in Review*, tributes in newspapers)



What the term survivorship means to some of BreaCan's Peer Support Volunteers living with advanced cancer:

I think that survivorship is a strong word that shows we are living, possibly longer than expected. We are living happy, productive, contented lives where we are valued for ourselves and our resilience

— Denise

Living my life as I want to including making decisions about receiving (or not) treatment

— Aaltje



BreaCan's Peer Support Volunteers provide a unique service — a safe and nurturing environment where women, their family and friends can receive compassionate support, be informed and empowered to live well.



Thank you to:

- BreaCan's Peer Support Volunteers including: Aaltje, Denise, Pam, Janice and Victoria
- BreaCan colleagues especially Kellie Holland and Wendy Pullan



BreaCan is a service of Women's Health Victoria



BreaCan is primarily funded by the Victorian Department of Health and Human Services

www.breacan.org.au