



Future of Cancer Survivorship – Evolution or Revolution?

Cancer Voices had a strong presence and a voice for people affected by cancer at the COSA Cancer Survivorship Conference, sold out weeks in advance and held in Sydney on 28-29 March 2019.

Members of the Organising Committee were Shirley Baxter, Deputy Chair of CV NSW and Chris Christensen, Chair of CV SA, with Executive Members, Lee Hunt, Lillian Lee and Deputy Chair Murray McLachlan co-chairing sessions. Lee and Lillian were also involved in session presentations.

Following three successful events in Adelaide, this was the inaugural conference to be held in Sydney by the Clinical Oncology Society of Australia (COSA), together with the Flinders Centre for Innovation in Cancer in Adelaide.

The provocative words in the title of *Evolution or Revolution* was apt and timely given the large numbers of people surviving cancer far longer than ever before. Living with and beyond cancer requires clear pathways and services for us to manage our health and wellbeing during treatment for cancer and beyond to live well.

The opening session, chaired by Prof. Bogda Koczwara and Murray McLachlan, featured Julie McCrossin AM and Dr. Ben Bravery, both of whom spoke openly and humorously about their cancer experiences, which set the tone for the entire conference of fresh and honest engagement around cancer issues.

Thought provoking and informative sessions were covered in areas such as *Managing Sexpectations after cancer, Conquering Stigma, Financial Toxicity, Carers, Beyond the Gym for people who don't wear lycra, Language and Cultural considerations*.

Lillian Leigh discussed how sensitive and mindful communication can conquer **stigma, marginalisation and fear**. Certain cancer types such as lung cancer face judgements by health professionals as well as the general public that can have a direct and adverse impact on a patient's outcome. Whilst Lillian acknowledged that it is human nature to have implicit biases, she also urged participants to stop and reflect on what they may be and how our physical and verbal language may communicate these biases.

Lee Hunt gave a personal account of the **financial toxicity** she has experienced since her first diagnosis of cancer 14 years ago. She also detailed the importance of the patient being informed of **treatment side effects, both early and late onset**. Knowledge is vital to help the cancer patient manage side effects as they emerge. Her cancer treatments, given many years ago have led to ongoing chronic conditions and out of pocket expenses of over \$100,000. Whilst informed consent may have improved in more recent years, out of pocket expenses have not and are growing.

Today there is an improved focus in research on ways to manage cancer treatment side-effects. The continued involvement of consumers in cancer research will ensure that research continues to benefit the patient. **Cancer Voices calls for all treating clinicians to present written information on known treatment side-effects at the initial consultation with the patient.** This document will then become a reference for the patient and their carers throughout treatment and beyond, enabling them to determine when to seek medical support. It is most timely that this was an issue during the federal election. The draft NSQHS Standards User Guide for Medication Management in Cancer Care, including informed consent standards, was out for public review earlier this year. Lee, along with other CVN EC members, contributed to the Cancer Voices Australia response by providing feedback for the review.

Shirley Baxter and Chris Christensen chaired the **Carers Session** with Dr. Ben Britton a Clinical Health Psychologist with carers as panelists. Gail O'Brien, Tania Rice-Brading, Leslie Shears and Sana Qadar. Ben discussed the critical role of the carer and the need for their self-care in providing support. The panelists each gave their personal insights and perspectives having been a carer. There was a great deal to understand, whether it be a researcher or clinician, concerning the often overlooked role and needs of carers. **Cancer Voices calls for a wider awareness and understanding of the vital role of the carer by providing easy and timely access to support and comprehensive information for them** as in the link <https://www.cancer council.com.au/get-support/caring-for-someone-with-cancer/>

The Cancer Voices trademarked **Consumers Included** (Ci) logo was approved for use at the Conference given consumer participation in organising, chairing and presenting sessions.

Our thanks to COSA and the Flinders Centre in Adelaide for bringing this event to Sydney and also to Cancer Council NSW, platinum sponsors of this event.

Shirley Baxter, April 2019

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Cancer Voices is the independent, volunteer voice of people affected by cancer - since 2000