

Official Launch Speech delivered by Ashleigh Moore
Executive Cancer Voices SA, 13th Nov 2008

The Honourable John Hill, Minister for Health, Professor David Currow CEO Cancer Australia, Brenda Wilson CEO The Cancer Council SA other distinguished guests, members of COSA the medical fraternity, patients, carers, friends and family members affected by cancer – “welcome” one and all to what is certainly a milestone for cancer consumers in this state.

We know that a third of men and a quarter of women in Australia get cancer and almost everyone else is affected by it. “Raising a voice for those affected by cancer” is what Cancer Voices SA will do through ‘advocacy’, by ‘involvement’ and contributing to policy and decision-making at all levels, by ‘awareness’ in the general community and where systems need to be fixed and with ‘information’ for informed decision-making at all levels.

This afternoon’s Consumer Forum highlighted the value of the “consumer voice”.

The Forum has been about clearing the obstacles in the road encountered during the personal journey and subsequent life changing transformation that a cancer diagnosis brings. For most of us, life during and after treatment involves coping with and adjusting to a ‘new normal’. We may have scars to heal, physical limitations, uncertain future, financial instability, social isolation and yet some survivors want to make a difference once treated as part of getting on with their 'new life'. ..why me, why cancer, how can I turn my experience into something worthwhile?

An individual’s cancer and possible outcomes are unique. Each individual diagnosed with cancer will travel a different path, the “cancer journey”, but eventually many of us arrive at the same place. This is a place where we seek

to join forces and make a real difference for those who will come after us - to change what we have seen as not right, nor just, or even humane and raise our voice which will ensure no-one will experience the not-so-good things that we have been through.

The power of the consumer voice is in our diversity – cancers are as different as individuals, no diagnosis is the same and every patient’s personal circumstances and outcomes are different.

I would now like to introduce our Cancer Voices SA Executive team – 6 members with the ‘lived experience’ of cancer that we can draw upon as patients and carers. Pam Sandys, Marcus Beresford, Cholly Winter, Jennifer Pettigrove, Julie Marker, Susie Tonna, David Chapman and myself.

However, we also bring diversity in skills, knowledge and qualifications developed during our pre- and post- cancer lives. Amongst our Executive group alone we represent survivors of breast, head and neck, prostate, colon cancer, non-hodgkins lymphoma and a mesothelioma carer; with diverse backgrounds including non-English speaking, married, gay, young kids; our skills and qualifications include Law, Public Health, 2 have MBAs, a Clinical Researcher, Chemistry, Safety and Quality Management qualifications; the list goes on - essentially we a broad cross section of the community.

Cancer is the ‘glue’ that brought us together. We are all very different and yet we are totally committed and united to one predominant goal of achieving ‘world’s best practice care for those affected by cancer’. Consider this diversity and dedication multiplied many times over and we see the richness and value of the Cancer Voices ‘community’.

I mentioned earlier today how Cancer Voices SA is a ‘new’ consumer advocacy group that represents the views of South Australians whose lives have been affected by cancer.

We encourage those with experience of cancer to contribute to all levels of decision-making about the disease and we seek good representation of consumers to health professionals, government and the public; through involvement at the Local, State and National levels as advocates. Cancer Voices membership provides the opportunity to make that real difference. We receive many requests to provide consumer reps on committees. We aim to encourage and support our members who wish to participate in this type of role. There are other roles available to members. We want our members to inform us of issues, tell us about new resources that can be shared with others via our website, volunteer their time or skills to help; eg drafting letters, newsletters, articles or researching issues.

We believe cancer patients, carers and supporters must receive the best possible information and world’s best practice treatment, care and support.

We aim to see that everyone affected by cancer is treated equally regardless of their geographical location, social or economic status, age, ethnicity, sexuality, gender and stage or type of cancer.

I am pleased to say that although our group may be new it already has strong representation on peak health care advisory groups to pursue these objectives at the State and National levels. Our members are on Cancer Australia’s National Advisory and Reference Groups, the Cancer Clinical Network, the Safety and Quality in Healthy Care Advisory Committee and Cancer Voices Australia to name just a few.

Much of our work until now has been to establish a solid foundation and operational framework. We have developed working relationships with Cancer

Councils, Government and other groups. Operational policies and procedures have been drafted and we have surveyed consumers across the state to better understand their needs and in turn our role.

In 2008 we will build upon this foundation to deliver improved communication and consultation via our website and the traditional means. Regular meetings and forums will keep members informed and involved. More members will undergo formal advocacy training to support their roles and we hope to expand membership to be inclusive of all groups and cancer types. Outcomes of today's consumer forum and our surveys and workshops provide a rich amount of information that we will use to target priority areas for action.

Cancer Voices SA is the result of hard work and support of too many people to mention individually. I would therefore like to acknowledge the support of the staff at the Cancer Council SA and the Health Consumers Alliance. As a member of the Cancer Voices Australia network we have received invaluable guidance and support from our peers. Other State Cancer Voices groups and Cancer Council's assisted us to fast-track our progress and gave us confidence in our direction. And of course I must thank the Executive team and broader membership for their dedication and belief in making Cancer Voices SA a reality.

My closing message is that health services and associated organisations must shift their thinking to 'really' listen to consumers and their invaluable "lived experience" – the experience that not everyone can imagine or ever know until they have walked in our shoes; and to fellow consumers it is a message to not be afraid and "raise your voice" – if you are unable to directly then approach a fellow member of Cancer Voices SA and we will certainly carry the baton and raise our voice on your behalf.

It is only through this legitimate shared partnership that we will contribute to achieving optimal cancer care for South Australians, with the community receiving what they really wish and need as we all work towards world's best practice care for our future generations.

Thank you!!