

Newsletter September 2017

10 years of consumer advocacy for South Australians affected by cancer.

Thank You!

I'd like to start this Newsletter by saying a big thank you to all those people who made our Movie Fundraiser – The Circle such a success. We raised \$1400 and have already been able to use some of the money to enable me to attend the Consumer Health Forum Ministerial Roundtable with the Federal Minister for Health, the Honourable Greg Hunt. Further information on the Roundtable and the Movie night is included in this newsletter.

THOUGHTS on 'Survivors as Teachers' (Julie Marker)

'You have cancer' for many, ie. more than 10,000 South Australians each year, that is the start of an unexpected major detour in our life trajectory. It is like arriving in a foreign country of specialist healthcare, where everyone is speaking a foreign language; we are unprepared, have no phrasebook, maps, GPS navigation or guide. From this starting point, and where we (and our families and friends) go from here, is the essence of the experience that 'Survivors as Teachers' describe to audiences.

For the past 6 years Cancer Voices SA has facilitated a series of 12-15 'Survivors as Teachers' tutorials involving about 150 third year medical students per year at Adelaide University. In small groups of 8-12 students, our volunteer 'Teachers' describe their diverse, unique circumstances, experiences, consequences of their cancer diagnosis, treatment, encounters with clinicians and the health system.

More than 30 volunteers per year are involved in this program, telling their story or helping by chipping-in to provide additional anecdotes, observations or contrasting viewpoints. We talk about the impact on our lives – positive and negative, for example, immediate and evolving physical changes and scars, the effect on relationships, emotional and psychological consequences, financial hardships. We often speak of the decision-making dilemmas, seeking a second opinion, uncoordinated care, examples of great and poor communication, the need for information for patients and carers, and the things we do and find for ourselves to help cope and manage in this new reality in our life.

Evaluation consistently shows these tutorials often have a profound impact on students, providing a window into the healthcare system, clinicians behaviour and procedures – as seen from 'our receiving end'! Feedback indicates it helps students understand they need to see us as a 'whole person, and not just as a case to solve'. Speakers often say they find it 'challenging but cathartic', a chance to 'give back' and help the next generation of young doctors, nurses or other health professionals.

Cancer Voices SA sincerely thanks everyone who has contributed to these 'Survivors as Teachers' sessions over the years, with special mention to Cath Caon for helping to facilitate so many of these tutorials. A special mention also to Tony Hamdorf who spoke on many occasions at a number of events in addition to these student tutorials. Sadly Tony passed away recently after a long, hard battle, but his story, tips for clinicians and description of all the strategies he adopted to 'live as well as he could' will have an enduring influence on all he spoke to.

RECENT EVENTS

Movie Fundraiser – The Circle

I cannot tell you how much we appreciate your support for this event. It is not easy being an unfunded not for profit organisation! On behalf of the Cancer Voices SA Executive team I would like to thank you for your kind support for our movie fund-raiser, The Circle.

We are very pleased with the outcome of the event, selling all tickets and raising \$1400 thanks to the support and kindness of people who bought tickets and/or generously gave donations for our raffle.

This funding will assist our continued advocacy work raising a voice for people affected by cancer and using their lived experience to assist in educating and working with health professionals, researchers and members of parliament to improve cancer policy and practice.

We really appreciate your support of the work of Cancer Voices SA on behalf of South Australians affected by cancer.

A special thanks to those who donated raffle prizes:

- Cath Caon - Cancer Voices member
- Jackie Bateau – Cancer Voices member
- Sue and Alex Smithson – Cancer Voices supporters
- Jeff Ramsay – Ramsay Pharmacy
- Antony – Euride Cycles
- Damien - Totino Estate Wines

Consumer Health Forum (CHF) Ministerial Roundtable – 23 August 2017

I was most fortunate to be one of twenty health consumers from around Australia who met with the Minister in Melbourne to highlight the need for greater government focus on the value of consumer-centred primary care within the National Health Plan.

The CHF proposal to establish a bi-annual Consumer and Community Roundtable to continue this work was wholeheartedly supported by the Minister who also thanked CHF for developing an issues paper which he said would be carefully reviewed.

In brief the issues paper sets out consumer priorities for a National Health Plan featuring two essential starting points:

- reforms to strengthen Australia's primary health care system to make it more consumer-centred, prevention-oriented, better integrated with hospital and social care and added capacity to support transitions of care; and
- boosts to investment in health systems research, shaped by consumer and community priorities, to stimulate services that reflect advances in health sciences and knowledge.

The issues paper and summary can be found at the following links:

https://chf.org.au/sites/default/files/chf_ministerial_roundatable_issues_paper_final_0.pdf

https://chf.org.au/sites/default/files/national_health_plan_consumer_priorities_summary.pdf

Many thanks to Cancer Voices supporters (Julie Marker, Elisabeth Kochman, Debra Kay, Diana Voss) who provided me with feedback on the issues paper and enabled me to bring well considered input to the roundtable. I would also like to thank Cancer Voices New South Wales for funding my flight to the meeting and Cancer Voices SA who paid for my accommodation. We were able to cover this thanks to all those who supported our Movie Fundraiser in July! Thank you for your support.

Cancer Voices SA is an independent consumer advocacy group
representing South Australians affected by cancer.

www.cancervoicessa.org.au

Meeting with SA Pathology re: EPLIS and changes to pathology services

Cancer Voices SA executive team members Julie Marker and I, along with Michael Cousins and Ellen Kerrins from Health Consumer Alliance recently met with SA Pathology Chief Executive Glenn Edwards, Paul and Dr Janice Fletcher.

At this meeting we raised concerns about the new electronic results system EPLIS, which is being introduced into the newRAH along with the new pathology-test-request module of EPAS. Cancer patients are especially aware of the critical importance of safety; quality and timeliness of SA Pathology services, testing and reporting of results. A recent 'Auditor Generals Report' had flagged additional issues.

The meeting was very constructive and we particularly appreciated the way SA Pathology responded to our queries and allayed many of our concerns. We were assured that highly significant clinical results will be clearly flagged and appropriate notifications escalated, that consumers using the service will be able to directly receive their own test results, if they wish to, and that the services will be faster, more consistent and improved by the proposed technological innovations and 24/7 automation in a single centralised location.

We agreed to an ongoing working relationship and are particularly pleased of their agreement to include consumers in SA Pathology governance arrangements.

CURRENT MATTERS

CareSearch – www.caresearch.com.au for Palliative Care information

CareSearch is a Commonwealth funded evidence based website providing information for anyone providing palliative care and anyone affected by the need for palliative care whether a patient, carer, family member or member of the community.

CareSearch are currently undertaking a survey aimed at the Australian public to find out their views on death and dying, their awareness of palliative care and of CareSearch; and of how they find and use online health information. Please consider taking the survey. Further information on the survey can be found on the CareSearch website:

<https://www.caresearch.com.au/caresearch/tabid/4234/Default.aspx>

Breast Screening

I have wondered why the Breast Screening form for those having a mammogram does not have a question about any known genetic mutations or existing cancers. So I put this query to BreastScreen Australia and was surprised to learn the following information about the screening.

The breast screening is for asymptomatic women, and was not designed to screen women with a family history of breast cancer, or women with an increased risk of cancer due to genetic mutation (BRCA1 or BRCA2).

I was informed that women with a family history, an increased risk of breast cancer and women with symptoms require different care and services that are not part of screening, including more regular check-ups involving a thorough clinical examination and annual mammograms, which are best managed by consultation with a medical practitioner.

Further, these women may have mammograms undertaken by private radiology services on referral from a doctor, and a Medicare rebate is available for this service. If the imaging provider chooses to bulk bill the service, there will be no charge to the patient. The Australian Government provides a bulk billing incentive for these services, but it is at the provider's discretion whether or not to bulk bill.

In terms of identifying high-risk women there is a range of information available from Cancer Australia.

- Breast cancer risk assessment tool: <http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/your-risk-and-breast-cancer>
- family history risk assessment tool for use by health professionals: (<http://canceraustralia.gov.au/clinical-best-practice/gynaecological-cancers/familial-risk-assessment-fra-boc>)
- genetic testing for breast and ovarian cancer risk: <https://canceraustralia.gov.au/clinical-best-practice/gynaecological-cancers/familial-risk-assessment-fra-boc/genetic-testing>

Cancer Australia – Principles of Cancer Survivorship

5 key principles are outlined in the new Cancer Australia Principles of Cancer Survivorship –

https://canceraustralia.gov.au/system/tdf/publications/principles-cancer-survivorship/pdf/pocs_-_principles_of_cancer_survivorship.pdf?file=1&type=node&id=5341

- consumer involvement in person-centred care
- support for living well
- evidence based care pathways
- coordinated and integrated care
- data-driven improvements and investment in research

CVSA ADVOCACY, INVOLVEMENT, AWARENESS, INFORMATION

Whilst much of our volunteer work is not evident in the public arena our advocacy, involvement, awareness raising and provision of information in a range of health contexts continues unabated! Some of our activities during **July/August 2017**

- Launch of SA Genomics Health Alliance 30 August
- Presentation to the Adelaide and Mitcham Prostate Cancer Group – 24 August 2017
- Ministerial Roundtable 23 August 2017
- UniSA Cancer Care Research Symposium 21 August
- SAHMRI-HCA Consumers in Research Committee meeting – 16 Aug
- SAHMRI Bowel Cancer research interest group 9 August
- Meeting with SA Pathology – 17 July 2017
- Advanced Care Planning Meeting – 10 July
- Patients as Teachers – Adelaide University 3rd Year Medical Student Tutorials – ongoing most Tuesdays, March to September 2017
- CVSA Cycling Group – every Sunday from 8.00am
- CVSA Walking Group – every Tuesday from 9.30am

Looking Ahead

Upcoming Meetings/ Events

CVSA Cycling Group – Rides start every Sunday morning at 8am from St Peters Girls College car park off Hallett Road, Stonyfell. Rides are usually 2 hours duration/ 40-50km through the beautiful Adelaide Hills and followed by coffee and a chat at Taylors Blend on Hallett Road.

CVSA Challenge Ride – 22 October 2017 – free, 20km, 35km, 67km or 75km ride options to challenge yourself. It is a ride, not a race, celebrating the benefit of being active and for many, a ride to reflect on people affected by cancer and inspire us to do things beyond our own expectation. Registration opening soon at www.cvsacyclingteam.org.au

CVSA Walking Group – Walks start every Tuesday morning at 9.30am from the Belair Golf Club car park (next entrance past the Belair National Park entrance, Upper Sturt Road Belair. Walks are usually 1 hour duration through the park followed by coffee and a chat at Sheoak Cafe, Belair.

Cancer Voices Executive Team Meeting – to be confirmed. Meetings are held at Health Consumers Alliance, Level 1, 12 Pirie Street, Adelaide.



Best wishes and please feel free to circulate our newsletter through your networks

Chris Christensen and Julie Marker

On behalf of the Executive Team, Cancer Voices SA