

Newsletter April 2017

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

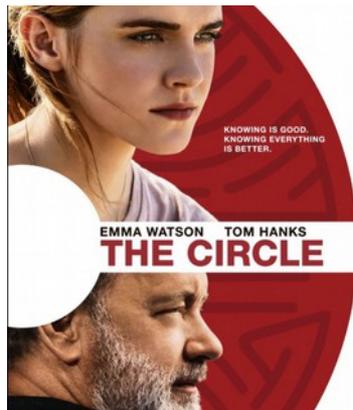
Advance Notice – YOU ARE INVITED!

Movie Fundraiser for Cancer Voices SA – NB date rescheduled to 16 July (not 7th May) due to cinema delaying release of this movie

We value your support to ensure Cancer Voices SA can continue to provide advocacy for people in South Australia affected by cancer. Your attendance at what should be a great movie will assist us in this endeavour.

If you are not able to attend but would like to make a donation to Cancer Voices please go to our website <http://www.cancervoicessa.org.au/involvement/donate>
Donations of \$2 or more are tax deductible.

The Circle - movie fundraiser event, Sunday 16th July 2017, 5.30pm



The Circle - starring Tom Hanks & Emma Watson (film based on best selling novel)

Sunday 16th July, 5.30pm Palace Nova, 3 Cinema Place off Rundle Street, Adelaide

5pm doors open, raffle prizes drawn at 5.20pm . Film ~90mins duration.

Tickets \$20 each + raffle on the night.

Bookings are essential and tickets are only available through the Eventbrite website: <https://www.eventbrite.com/e/the-circle-cancer-voices-movie-fundraiser-tickets-33306136551>

Queries to: info@cancervoicessa.org.au

THOUGHTS

About Wellness

In the past weeks I have been thinking about wellness and what it means to people who have been diagnosed with cancer. I don't claim to have any academic background in this topic but would just like to share some of my current thoughts with you.

I guess my thoughts have raised more questions about wellness than answers. Was I well before I was diagnosed with cancer? Have I been well since? Can I only be well when I don't have an illness? Do the concepts of wellness and quality of life mean the same thing? Can I have quality of life without being well? Who and what affects my wellness? Is wellness something that we can choose? Is it merely the absence of illness? Can we be well and ill at the same time? Do we have a responsibility to ourselves and others to be well? Does individual wellness have a beneficial effect on community, national wellness?

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

www.cancervoicessa.org.au

You can see my thinking is rather messy! Wellness seems to be a slippery concept, which is variously described as the quality or state of being healthy in body and mind, especially as the result of deliberate effort or an approach to healthcare that emphasizes preventing illness and prolonging life, as opposed to emphasizing treating diseases.

Being well is seen as an active process whereby people are aware of making choices about how they live and is not just the absence of illness. Wellness requires a conscious personal effort and has a number of dimensions. I think wellness is a very personal, dynamic concept which is affected by your age, culture, physical, psychological, social, intellectual, spiritual and economic context.

A quick look on the internet found a wheel of wellness, a circle of health and an ecological approach to wellness. All seem to agree on the multi-dimensional nature of wellness and that it is a good state of being. Wellness does seem to be a very personal and dynamic construct affected by personal circumstances and the context in which we live.

It does seem to me that we have an individual responsibility to maintain good health as far as it is within our control. What we do, how we feel, what we think and believe, affects our wellness. It is evident that good nutrition, physical exercise, healthy relationships and managing health risk factors are important elements of wellness and that our lifestyle has a significant effect on our wellness.

To end, a couple of quotes related to wellness:

Lack of activity destroys the good condition of every human being, while movement and methodical physical exercise save it and preserve it. (Plato)

Start by doing what's necessary, then do what's possible; and suddenly you are doing the impossible. (Francis of Assisi)

RECENT EVENTS

Launch of the Rosemary Bryant AO Research Centre – 8 February 2017

CVSA was represented at the launch of the Rosemary Bryant AO Research Centre by Julie Marker. The Centre is a partnership between the Australian Nursing and Midwifery Federation (SA Branch) and the University of South Australia. The Centre will provide the opportunity to develop, build and establish translational nursing and midwifery research into the future, thus supporting the profession and assisting in improving health outcomes for South Australians. We are looking forward to working with staff at the Centre through their strong focus on consumer engagement in cancer services, teaching and research. Activity and updates on the work of the Centre can be accessed through the website: www.unisa.edu.au/sansom/rbrc

Survivors as Teachers – Adelaide University Medical Students

Our highly successful Survivors as Teachers program has begun for 2017. Thank you to our members who volunteer their time to talk with third year medical students about their lived experience of cancer. Now in it's 6th year, 14 tutorial sessions will be held with 12 students per tutorial group. Contact info@cancervoicessa.org.au if you wish to become involved.

Survivors as Teachers – Difficult conversations in nursing: End of Life care

On Saturday 11 February CVSA members Maxine, Lesley, Chris and Julie presented to a group of University of South Australia third year nursing students and their Lecturer Dr Kevin O'Shaughnessy.

Maxine and Lesley spoke from the carer perspective, generously sharing their experience of their husbands diagnosis of Mesothelioma. The stories of the lived experience of cancer are powerful and it was evident that the students were moved by what they heard.

Australian Institute of Health Innovation (AIHI)

Cancer Voices Executive Team members Steph Newell, Julie Marker, Eric Browne and I were most fortunate to be invited to a symposium hosted by AIHI in Sydney on 17 March 2017. We were among a number of consumers and researchers attending the symposium to discuss research in the future of the health system and participated in consumer panel sessions.

AIHI is working on new research proposals through the three centres of the Institute, the Centre for Health Informatics, the Centre for Health Systems and Safety Research and the Centre for Healthcare Resilience and Implementation Science. There were presentations from each of these groups about research for the future and consumers were invited to discuss and critique the proposed research.

This was a great opportunity for researchers to incorporate the voice of the health consumer in thinking about their research from design through to future translation. Cancer Voices advocates inclusion of the consumer voice in all aspects of the health system and is supportive of research into the health system.

By including consumers in the discussion researchers were provided with a different perspective on the design and focus of their research. Key areas of research included preventing patient harm from new digital technology applications, consumer contributions to safe and high-quality test result management and safety in Emergency Departments.



Cancer Voices Australia (CVA) Submission to the Senate Select Committee into Funding for Research into Cancers with Low Survival Rates

Cancer Voices SA led the drafting of a submission to this Senate Select Committee on behalf of Cancer Voices Australia and Cancer Voices New South Wales. This was a great collaborative effort and I thank all those who contributed.

On 29 November 2016 the Senate established a select committee to inquire and report on the impact of health research funding models on the availability of funding for research into cancers with low survival rates. Submissions have now closed and can be found at:

http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Funding_for_Research_into_Cancers/FundingResearchCancers

The CVA submission (No. 61) recommends the inquiry consider:

1. articulating a clear definition of 'rare cancers' and 'cancers with low survival rates'
2. a national data collection that identifies clinical trials for low survival rate cancers and a national repository for cancer research projects
3. addressing the current variation in cancer research funding, so that cancers with low survival rates receive more than the current 20% of cancer funding
4. co-design of a National Cancer Research Strategic Plan with key cancer stakeholders
5. annual reporting to Parliament on progress towards targets in the plan and the establishment of routine reporting through the Australian Institute of Health and Welfare, of the categories of rare cancers, cancers with higher incidence, but low survival and cancers with low survival rates
6. changing funding criteria to include active collaborative research, within and across institutions and ensure equitable access to clinical trials for trial participants and their carers, particularly those in rural and remote areas
7. any public campaign to be conducted alongside a real increase funding and access for participants to clinical trials
8. a reserve for rapid funding of international collaborative work in priority areas of health and medical research be allocated and that Australia become a member of the International Rare Cancers Initiative
9. re-examination of funding criteria: reduce disparities in cancer survivorship outcomes; give priority to cancers with low survival rates, specifically for funding clinical trials with funding being sustainable to grow research expertise and realise translation into treatment guidelines; and consider giving funding to cancers by their mutations and not just their location.
10. re-examination of the review of research proposals to ensure that review panels include people familiar with rare cancers and cancers with low survival rates.

Cancer and Psychology – Getting your head around Cancer

Flinders Centre for Innovation in Cancer held a Cancer Insights public lecture on 12 February 2017. Speaker Professor Nick Hulbert-Williams, Professor of Behavioural Medicine Director, Chester Research Unit for the Psychology of Health Department of Psychology, University of Chester, UK, spoke on the topic *“I’m through with playing by the rules of someone else’s game”: how psychology needs to change to have real impact in cancer”*.

Highlights for me were his comments about the importance of keeping the individual as the focus and his reference to Maggie’s Cancer Centres in the UK. These are amazing architecturally and must have a positive effect on people affected by cancer just because of the environment that is created. The Centres provide personalised support from a range of professional people in one place. Do have a look at some of Maggie’s Cancer Centres at: <https://www.maggiescentres.org/>

Dr Lisa Beatty, Cancer Council SA Postdoctoral Fellow (Cancer Support), Flinders Centre for Innovation in Cancer and Flinders University is a recognised expert in e-health psycho-oncology interventions, spoke on the topic of *“Can surfing the net make you better”?* Highlights for me were the recognition of underscreening for distress in people with cancer and the Finding My Way web-based intervention that provides a user friendly way to obtain information about how to improve your physical and mental wellbeing following a cancer diagnosis. I recommend that you have a look at the program and resources at: <https://www.findingmyway.org.au/>

For upcoming events/speakers at Flinders Centre for Innovation in Cancer go to their website: <http://www.fcic.org.au/Events/2017/p217.aspx>



CURRENT MATTERS

Insurance

I don't know if you have had issues obtaining insurance due to your status as a cancer survivor. I certainly have. Legal Aid NSW is undertaking a research project exploring how people's health conditions affect their experiences with insurance products and have a survey you can complete outlining your story. It only take about 10 minutes and the information will be used by Legal Aid NSW to better understand the issues and guide efforts to achieve a fair go for consumers. Further information can be found at <http://www.legalaid.nsw.gov.au/about-us/news-and-media/general-news/taking-cover-we-want-to-hear-your-take-on-insurance> or you can take the [survey](#) now.

Commonwealth Cuts to Radiation Therapy

Significant reductions in the Commonwealth's investment in radiation therapy are proposed from July 2017. The Royal Australian and New Zealand College of Radiologists estimate that the changes will cut \$67 million from the sector over 3 years.

Read the [Fact Sheet for consumers](#), and [template letter](#), if you wish to write to your local MP to oppose this change in Federal Govt policy.

Radiation oncology is an essential treatment for a significant number of cancers. It is estimated to be involved in 40% of all cancer cures and is used in palliative care to relieve symptoms such as pain.

However, it uses a number of highly expensive pieces of equipment. The Radiation Oncology Health Program Grants Scheme was designed to help cover the cost of this equipment and ensure that this equipment is replaced when needed. Due to the high cost involved in replacing this equipment, without support from the Government, it is likely that hospitals and practices will delay replacement resulting in equipment becoming aged and out of date. Before the ROHPG Scheme was introduced radiation therapy equipment was rarely replaced due to the high cost, which compromised patient treatment.

We are concerned that these changes will threaten access to modern radiation therapy equipment and have a profound impact on the delivery of cancer care.

Prostate Cancer Treatment

All men with prostate cancer need to ensure that they have opinions for treatment from both a radiation oncologist as well as the surgeon who diagnoses the cancer. There is strong evidence now for radiation therapy being as effective as surgery in curing prostate cancer. Recent studies suggest that sexual and urinary side effects are better long term with radiation therapy compared to surgery. A referral to a radiation oncologist can be given by either the urologist or a General Practitioner. There is time to investigate the available information from experts before deciding on the treatment choice.

Cancer Council Australia have joined with Prostate Cancer Foundation Australia and NSW Cancer Institute in emphasising that men should see a radiation oncologist as well as surgeon before they make a decision and that it is important for men to be fully informed. See the information sheet [Prostate Cancer Management Options](#) . More information about radiation therapy can be found at: <http://www.targetingcancer.com.au/>

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 **February/March 2017**

- CVSA members presentations at the 2017 Survivorship Conference
- CVSA 'bowel cancer research interest group' meeting with SAHMRI researchers Dan Worthley and Susi Woods
- Australasian Gastro-Intestinal Trial Group Teleconferences
- Meeting with University of South Australia re consumer engagement
- Meeting with Health Consumers Alliance
- Health Consumers Alliance-SAHMRI 'Consumers in Research' Meetings
- Meeting of the South Australian Cancer Service Strategy Committee
- Meeting to discuss Cancer and Non-Government Organisations space at the newRAH
- CVA submission to the Senate Inquiry on funding for research into cancers with low survival rates
- Meetings with Cancer Voices NSW Executive Team members
- Meetings with new Cancer Voices SA members
- Attendance at presentation of visiting Professor Welslau about development and use of Patient Reported Outcomes during treatment in German cancer centres.
- Attendance at presentation "Preventing Colorectal Cancer – Is Aspirin the answer?"
- Meeting of SA Cancer Research Collaborative at SAHMRI
- Grant application submitted to Mitcham Council to support CVSA Walking Group
- CVA feedback re: updated draft of Clinical practice guidelines for the prevention, early detection and management of colorectal cancer
- CVSA Executive Team Meeting

Looking Ahead

Upcoming Meetings/ Events

CVSA Fundraiser Film Night – Sunday 7 May, 5.30pm Palace Nova Cinema, Adelaide (Tickets \$20 available online through Eventbrite)

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 through the beautiful Adelaide Hills and followed by coffee and a chat at Taylors Blend on Hallett Road.

CVSA Walking Group – Walks start every Tuesday morning at 9.30am from the 'free' car park as you enter Belair National Park, 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 – Monday 29 May 6pm at Health Consumers Alliance, Level 1, 12 Pirie Street, Adelaide.

Best wishes to all our members

Chris Christensen

On behalf of the Executive Team, Cancer Voices SA

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