

## Newsletter June 2017

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

### **YOU ARE INVITED!**

***PLEASE support Cancer Voices SA Movie Fundraiser SUNDAY 16 JULY PALACE NOVA 5.30pm***

We value your support to ensure Cancer Voices SA can continue to provide advocacy and information for people in South Australia affected by cancer. Cancer Voices SA is a 100% independent volunteer organisation reliant on public donations for our continued operation. Your attendance at what should be a great movie will assist us to continue our work at the local, state and national levels.

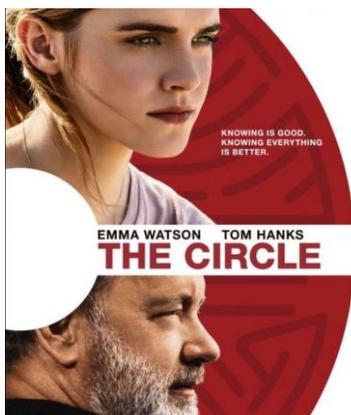
If you are not able to attend but would like to make a donation to Cancer Voices please go to our website <http://www.cancervoicessa.org.au/involvement/donate>  
Donations of \$2 or more are tax deductible.

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

*A young woman (Emma Watson as Mae) sees the opportunity of a lifetime when she lands a job at the world's largest and most powerful tech and social-media company. The company preaches the value of complete transparency and inspires a cult-like devotion in its employees. However, she soon learns that the corporation and its messianic founder (Tom Hanks as Eamon Bailey) are experimenting with pushing the boundaries of privacy, ethics and ultimately personal freedom. Her participation in the experiment, and every decision she makes, begin to affect the lives and future of her friends, family and that of humanity.*

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

**Sunday 16<sup>th</sup> 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](mailto:info@cancervoicessa.org.au)

### **THOUGHTS**

#### ***About Cancer Survivorship***

Cancer Voices SA is, as you might imagine, keenly interested in cancer survivorship. The opportunity to work in partnership with others to develop a state-wide Survivorship Framework outlining the minimum agreed standard of care for all patients treated with curative intent was a great opportunity .

The project team, funded by the Australian Health Ministers' Advisory Council (AHMAC) and reported to the National Cancer Expert Reference Group (NCERG) began in 2015 and concluded in December 2016.

Following a diagnosis of cancer, a cancer survivor is in a spotlight. Tests are done, advice is provided, and decisions are made about how best to respond to the diagnosis. Many cancer survivors lament that instead of being the whole person they were, they become their diagnosis and placed on the cancer treatment rollercoaster.

The framework has the power to change this. We hope that the cancer treatment summary and the survivorship care plan will become the pivotal documents for all cancer survivors and their health team. While attempts to improve the quality of life for cancer survivors through a Survivorship Framework may result in challenges, unintended consequences and people who do not want to be involved, it is useful to remember the words of Albert Einstein who said, "No problem can be solved from the same level of thinking that created it."

Implementation of any new framework is hard. Even with the best policy, planning, resources and bureaucratic control mechanisms, organisations mainly function in a creative, self-organising manner and the challenges are many. The South Australian health system is a living system which to a large degree self organises, continuously changes, learns and adapts. First and foremost it is people who change systems, using information available to them that has meaning.

Implementation of the framework will require collective commitment to the intent of the framework, the provision of information and the building of networks, to enable people to contribute creatively, autonomously and collaboratively. Cancer survivorship is everybody's business, especially the business of cancer survivors. The stories of survivorship are ours to tell.

Cancer Voices SA advocates for a sustainable and enduring approach to cancer survivorship. We are not a negotiable commodity but people who live with and endeavour to manage uncertainty following a cancer diagnosis. We need the implementation of the framework to really mean something now and to develop more into the future so that there are compelling reasons for it to be the way we do things for cancer survivors in South Australia.

Critical to the successful implementation of the SA Cancer Survivorship Framework from a cancer survivor perspective are, I believe, the need to focus on identity, information and interconnectedness.

By identity I mean making sense of the Survivorship Framework for ourselves and for others. The project partners need to promote the intent of the framework, the belief that something better for cancer survivors will come from implementing it. The framework needs to have identity, be a reference point, for all involved. Cancer Voices SA believes we need to focus on embedding the central elements and intent of the framework. That is, that all cancer survivors will have a treatment summary, a needs assessment and a care plan to have, to hold and evolve from the point of diagnosis and throughout the cancer continuum with input from all health professionals and relevant others.

By information I mean data, facts, knowledge which is communicated or received about a topic or circumstance, in this instance knowledge gained through study, research and the lived experience of cancer survivors. For cancer survivors information makes the most difference when it is provided in such a way as to match their individual information needs and this can vary across their lived experience of cancer.

The framework offers the potential for all critical information to be collected in one document. For the information to be the difference which makes a difference we would like it to be through of as a Trip Advisor or babies Blue Book, where each person in the treatment team provides their input at points in time, where history is accumulated and future pathways documented from diagnosis and throughout the cancer continuum. This has the potential to be in electronic form but it is yet to be

proven that this is achievable with existing systems and with many cancer survivors straddling both the public and private health systems.

Information is important, particularly so if one of our goals is to support cancer survivors to self manage. For example, it may be useful to prepare them for appointments by helping them to think about what questions they have or might ask and what their needs and goals are so that appointments can be as productive as possible.

We know the Optimal Care Pathways are gradually being introduced in South Australia starting with 2 tumour streams and we believe that while this provides an opportunity to integrate the implementation of the survivorship framework with these pathways, it should not be the only way to manage implementation.

To understand the impact of the implementation of the Survivorship Framework, we need information and measurement systems as well as being alert to new information. Sustainability of the framework requires that we can demonstrate the cost benefit from the full range of the perspectives of those involved. Cancer Voices SA believes this must include survivor reported outcomes and we are particularly keen to be part of any work to establish survivor reported outcomes in South Australia.

There are also opportunities for research to understand the implementation from a range of perspectives, with research questions being co-designed with cancer survivors.

Finally I come to the concept of interconnectedness. By this I mean that it is relationships that enable the transference of information. Learning is a social experience. It is natural for people to look for other people with the knowledge, skills and experience they need in order to learn and develop. When people connect they not only transfer knowledge, skills and experiences, they have the capacity to create new knowledge.

It is important therefore, as we move to implementation that we understand who knows what and how we can grow connections. While champions can build the impetus for change they need to bring people with them. The more access people in the health system, including cancer survivors, have to one another, the more the possibility for the transfer of information.

This needs to include General Practitioners. If they are to be an integral part of the survivorship framework they need to see what is in it for them. We believe they will engage when they see value and benefit of giving and receiving information about the cancer survivors in their practice and of being an integral part of the evolving treatment summary and care plan.

Implementing the framework requires people who are resilient, adaptive, aware, collaborative and creative. We believe that good relationships between such people will provide the impetus for expanding the implementation of the framework and for greater interconnectedness across the system.

All those who have a cancer diagnosis and all those involved in the diagnosis, treatment and care of cancer survivors need to be invited to participate, to co-design the process work required to implement the framework. There is potential for further pilots to be undertaken in centres that were not involved in the initial pilots, however the label of pilot can often result in short bursts of action, but no sustainable change of behaviour.

Organisational psychology tells us that people support what they create. We cannot deliver change, but we believe that implementation will be fast tracked when people are involved in the design of the change. It is through involvement that connections are made, information is exchanged and commitment to the intent is cemented.

We need to form relationships within and across systems to better support individuals in the system. We have structures, we have networks of communication, we have a way of doing things. We all

need to look at these things and decide which may need to improve or change to enable effective implementation of the framework.

We have built our relationships during this project based on a shared intent. We have exchanged ideas, learnt from each other, adapted our ideas, been cognisant of the wider changes in the health system and crafted our collective knowledge into a document of which we can be proud.

We believe that the establishment of a Survivorship Community of Practice could support those involved in implementation, to exchange ideas and to develop new knowledge of the benefits of the central elements of the Survivorship Framework.

We can use information, identity and interconnectedness to get the work done. It is the behaviours, processes and structures that are usually looked at when a problem occurs but it is at the level of information, identity and interconnectedness that we can begin to progress solutions.

Leadership of the implementation process is needed and will require a strong sense of identity and intention, the capacity to provide information and transfer knowledge, a belief in the people who need to be involved, and an ability to create the circumstances for success. We are all in leadership positions and therefore are well placed to influence what happens next.

The framework references self management, which implies that the cancer survivor becomes an integral part of the survivorship process from the point of diagnosis. From then it is, for the cancer survivor, a case of living with cancer 24/7/365 or 366 every leap year. They say no man is an island, but it has struck me over the past 6+ years of being a cancer survivor that more often than not we are in this together, alone. Again I believe that the framework has the power to reduce the sense of isolation felt by cancer survivors throughout their cancer experience.

I hope that the boundaries that currently define us be the place where we connect, exchange information and grow, as we learn from each other. We need to be both our individual selves and connected to one another. Together we have created an identity – cancer survivorship. We now need to spread information about our intent.

We have agreed a baseline of information that all cancer survivors in South Australia can expect – treatment summaries, needs assessment and care plans. We now need to work on what needs to be done to make this happen. We also need to consider how we will know if we have been successful.

We have established significant interconnections – all those involved in this project. We need to commit to growing these relationships, by sharing matters of significance related to the implementation of the framework and cancer survivorship more generally.

As Roger Rosenblatt said, *“The best in art and life comes from a centre, something urgent and powerful, an ideal or emotion that insists on its being. From that insistence a shape emerges and creates its structure out of passion. If you begin with a structure, you have to make up the passion, and that's very hard to do”*.

I believe we have the passion. Leading change will require listening to multiple and divergent views, especially those of the cancer survivor. In this way the diversity of what is meaningful to people, highlights ideas, proposals and issues for discussion and becomes visible. From this point we can begin to disturb the system, hoping that it will take in the information and that it rapidly circulates through the system so that it becomes the new way of working with cancer survivors and that cancer survivors report that the system is much improved.

It has been valuable for our 100% volunteer consumer organisation Cancer Voices SA to be able to co-create a cancer survivorship identity, to exchange information and to build connections across South Australia's health community. We have stayed the course and believe our input has made a difference to the intent and content of this important document.

It was a great collaboration with partners in the project from the South Australian Cancer Service, Cancer Council SA, Cancer Voices SA, Cancer Services, Flinders Centre for Innovation in Cancer, Central Adelaide Local Health Network, Women's and Children's Health Network and Country Health SA Local Health Network. Cancer Voices SA looks forward to working on the implementation of this important document.

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## **RECENT EVENTS**

### ***Survivors as Teachers – Adelaide University Medical Students***

Our highly successful Survivors as Teachers program is in full swing for 2017. Thank you to our members who have volunteered their time to talk with third year medical students about their lived experience of cancer. Now in its 6<sup>th</sup> year, 14 tutorial sessions will be held with 12 students per tutorial group. Contact [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au) if you wish to become involved or learn more about this important program.

### ***Cancer Voices Australia (CVA) teleconference with the Senate Select Committee into Funding for Research into Cancers with Low Survival Rates***

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

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. We were subsequently invited to speak to the inquiry on 18 May and were represented by members, Jackie Bateau, Julie Marker and Chris Christensen.

### ***The Hidden Costs of Cancer***

Flinders Centre for Innovation in Cancer hosted a lecture on The Hidden Costs of Cancer on 23 May 2017.

Dr Alison Pearce, from the Centre for Health Economics Research and Evaluation University of Technology, Sydney spoke on the topic of Work after Cancer – the value and the cost. Dr Pearce's PhD was on the costs of chemotherapy side effects and her current work examines some of the societal costs of cancer. This includes estimating cancer related productivity losses in Australia, and exploring the differences between how individuals and society make trade-offs between the outcomes of cancer treatment and quality of life.

Acting Professor Billingsley Kaambwa, Head, Health Economics Unit, School of Medicine, Flinders University spoke on the topic of How can Health Economics Improve Cancer Care? A/Professor Kaambwa's main research interests are in decision analytic modelling and economic evaluation of new and existing health care technologies. He has substantial expertise in the use of economic evaluation and discrete choice experiments for assessing costs and benefits of health and non-health interventions. His research includes public health and management of chronic conditions.

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**

### ***Cognitive Consequences of Cancer Treatment***

Cancer Voices SA endeavours to answer queries we regularly receive. In response to one of these queries I thought many people would be interested in this topic and provide the following articles.

- 1. *Evaluation of a Web-Based Cognitive Rehabilitation Program in Cancer Survivors Reporting Cognitive Symptoms After Chemotherapy.*** (Bray, V., Dhillon, H., Bell, M., Kabourakis, M., Fiero, M., Yip, D., Boyle, F., Price, M., Vardy, J. (2016) *Journal of Clinical Oncology*, 35(2), 217-225.

This study evaluated a cognitive rehabilitation program (Insight) and compared it with standard care in cancer survivors self-reporting cognitive symptoms. The study concluded that the intervention (Insight) led to improvements in cognitive symptoms compared with standard care. For further information about the study click on the following link:

<http://ascopubs.org/doi/pdfdirect/10.1200/JCO.2016.67.8201>

- 2. *Chemo Brain and Cognitive Decline after Cancer – The Conversation***

It is known that cancer and its treatment cause a number of side effects, some short term, some longer term. About 70% of cancer survivors report difficulty with memory and concentration, commonly known as chemo brain. While cancer survivors self report these symptoms, formal cognitive assessment often show their performance is still within the normal range. No interventions have yet proven to prevent cognitive impairment from occurring in people with cancer, or to treat it once it has occurred. Studies are underway to evaluate different types of interventions. For further information about this work click on the following link: [theconversation.com/chemo-brain-and-cognitive-decline-after-cancer-13199](http://theconversation.com/chemo-brain-and-cognitive-decline-after-cancer-13199)

- 3. *An Interview with Associate Professor Janette Vardy – News Medical***

This study evaluated cognitive function in colorectal patients, characterizing the incidence and severity of cognitive impairment in people with colorectal cancer compared healthy controls. Patient reported outcomes were also evaluated. Assessments were completed after diagnosis but prior to treatment and at 6, 12 and 24 months. There was more cognitive impairment in people with colorectal cancer than healthy controls at every time point, but no significant effect of chemotherapy on cognitive impairment. The interview can be found at the following link:

[www.news-medical.net/.../Does-cancer-affect-memory-An-interview-with-Associate-P...](http://www.news-medical.net/.../Does-cancer-affect-memory-An-interview-with-Associate-P...)

### ***Recent Announcements from the Commonwealth – Proton Therapy Facility for South Australia***

Cancer Voices SA was pleased to see the announcement on 6 May 2017 of Commonwealth support (\$68 million) for the establishment of Australia's first Proton Beam Therapy facility at the South Australian Health and Medical Research Institute (SAMHRI) in Adelaide by Greg Hunt MP, Minister for Health, Minister for Sport. It is expected to be operational by 2020 subject to funding of supporting infrastructure by the South Australian Government.

Proton Beam Therapy (PBT) is a radiation therapy that uses heavier particles (protons) instead of xrays, which are used in conventional radiotherapy. A proton beam can be much more finely controlled so higher doses of radiation can be more safely delivered to tumors with less risk to healthy tissue. PBT involves a particle accelerator targeting the tumor more accurately with a beam of protons.

This therapy has been shown to be beneficial for tumors including brain, spine, soft tissue and many pediatric cancers. Children with cancer stand to benefit the most from proton beam therapy as they can have the greatest long-term harm from conventional radiation therapy as their organs are still developing. You can read the media release at the following link:

<http://www.greghunt.com.au/Media/MediaReleases/tabid/86/ID/4241/Budget-to-support-establishment-of-world-leading-proton-beam-therapy-facility.aspx>

### **Medical Research Reforms**

Cancer Voices SA was also pleased to see the announcement on 25 May 2017 by Greg Hunt MP, Minister for Health, Minister for Sport that the Commonwealth Government would provide \$800 million plus, through the National Health and Medical Research Council (NHMRC) each year to fund research. The funding however will not begin until late 2018, early 2019.

It is anticipated that the new funding program will reduce the burden on researchers in applying for funding across different funding schemes by providing consolidated, five-year grants for high-performing researchers across their careers, thus giving greater flexibility to collaborate and to focus on research. This should support full time researchers as well as clinical researchers who divide their time between research and patient care.

Of particular importance was that there will be a new scheme for clinical trials and cohort studies, to ensure investment in the most efficient high-quality trials to test new treatments.

To access the media release click on the following link:

<http://www.greghunt.com.au/Media/MediaReleases/tabid/86/ID/4266/Medical-research-reforms-to-improve-our-future-health.aspx>

### **Exercise and Cancer**

Our walking group has just been successful in applying for a grant from Mitcham City Council to support our Cancer Voices SA wellness priority. We are most grateful for being a recipient of the community grant and will be using the \$500 to promote the group with a view to increasing our numbers.

It was good therefore to come across an article by Megan Garlapow, PhD, titled "*Walking Improves Quality of Life in Patients with Advanced Cancer*" which reports that patients with advanced cancer that walked several times per week experienced improved physical and emotional well-being. The article notes that people typically decrease their exercise levels during cancer treatment and that these levels remain low afterward.

A pilot study examined the impact of walking on quality of life and symptom severity in patients with relapsed or metastatic disease and involved people with advanced breast, prostate, gynaecologic, or hematologic cancers. Findings show that the study group experienced improved quality of life including improved cardiovascular health, increased energy levels and emotional well-being when they walked for 30 minutes 3 times a week over the study period. In addition participants noted an improved attitude to cancer and the social benefits of participation in a walking group.

On the downside there was a 45% attrition rate by the end of the 24-week study, suggesting that people's commitment to physical activity during cancer care is a major challenge despite its health benefits.

Cancer Voices SA supports exercise as a part of cancer treatment and in the importance of exercise in preventing or prolonging recurrence. Further information about the study can be found at the following link:

<http://www.oncologynurseadvisor.com/general-oncology/periodic-walking-increases-quality-of-life-for-patients-with-cancer/article/643042/>

## **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 **April/June 2017**

- Consumer and community Involvement in Research Training Workshop – 20 June 2017
- Cancer Nurses Society of Australia Annual Congress – 15-17 June 2017
- Bowel Cancer Research Interest Group Meeting - 14 June 2017
- UNISA Allied Health Outcomes Calculator Launch – 13 June 2017
- SAHMRI South Australian Clinical Collaborative Research Meeting – 7 June 2017
- Mitcham Council Presentation of Community Grants – 5 June 2017
- South Australian Cancer Services Strategy Committee Meeting – 2 June 2017
- PC4 Concept Development Workshop – 1 June 2017
- Safety and Quality – presentation to Flinders University Masters Students – 25 May 2017
- Senate Inquiry into funding for research for cancers with low survival rates – 18 May 2017
- Consumer Health Forum (CHF) Medicinal Cannabis Forum – 18 May 2017
- PoCOg Concept Development Workshop – 17 May 2017
- PC4 Scientific Symposium – 10 May 2017
- AGITG Consumer Advisory Panel – 11/12 May 2017
- Health Consumer Alliance (HCA) Consumer Advocate Network Digital Health Update – 3 May 2017
- UNISA Consumer Engagement in Health Care Presentation to Professional Certificate Students – 27 April 2017
- Patients as Teachers – Adelaide University 3<sup>rd</sup> Year Medical Student Tutorials – ongoing March to September 2017
- CVSA Cycling Group – every Sunday from 8.00am
- CVSA Walking Group – every Tuesday from 9.30am

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### **Looking Ahead**

#### ***Upcoming Meetings/ Events***

***CVSA Fundraiser Film Night*** – Sunday 16 July, 5.30pm Palace Nova Cinema, Adelaide.  
Tickets \$20 available online through Eventbrite: <https://www.eventbrite.com.au/>

***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 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.

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**Best wishes and please feel free to circulate our newsletter**

***Chris Christensen***

**On behalf of the Executive Team, Cancer Voices SA**