

Newsletter February 2018

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

WELCOME

This is our first newsletter for 2018 and I wish you all the very best for the year ahead. It is already shaping up to be a year of ongoing advocacy for people affected by cancer and we look to our members and supporters for ongoing assistance, both financially and in kind, as the year progresses. A special welcome to those of you who are reading our newsletter for the first time. Please go to our website for further information about Cancer Voices SA, the programs we run and the projects in which we collaborate. Membership is open to everyone and is free.

As Cancer Voices SA enters its 11th year of advocacy, we are working on documenting the work of the past 10 years with a view to launching and publishing the document (yet to be named) this year as a way of celebrating the achievements to date and projecting forward to directions for the next 10 years.

Our Survivors as Teachers program continues to grow and we have been invited to further develop the program as a module or package for use by university students. This reflects the esteem in which the program is held and has the potential to spread the impact of the current program more broadly.

We have a full year of advocacy ahead and will endeavour to keep you up to date via our newsletter, website and social media platforms as the year progresses.

THOUGHTS

Cancer as a Health Priority in the forthcoming election and beyond

Cancer Voices SA Executive Team members drafted a letter seeking an appointment with the Minister for Health, the Honourable Peter Malinauskas MP, the Opposition Health Spokesperson, the Honourable Stephen Wade and the SA Best party leader, Mr Nick Xenophon, to discuss key areas where we believe the next state government can lead the way in improving health outcomes across the cancer continuum.

While South Australia cancer survival rates are considered high by world standards and the quality of treatment is generally good, there are inequalities and areas for improvement. Cancer Voices SA believes there is a significant obligation and an opportunity for the next government to ensure cancer remains on the agenda and that South Australia leads the way in improving outcomes for people affected by cancer.

In summary we highlighted:

- the urgent need for state wide leadership, oversight and governance of cancer services across South Australia, including the publication and implementation of a State Cancer Plan
- the need to reduce the variation in access to specialist cancer treatment services
- the importance of focusing on coordinated, person-centred cancer treatment and care from the time a person is diagnosed with cancer and throughout their survivorship period through to end of life care

- the importance of continued government funding for cancer research, of involving cancer consumers in all stages of cancer research and of providing research trials as an integral option for treatment regardless of where you live
- the need for a Palliative Care Services Plan for South Australia and increased funding for palliative care services
- the need for all people diagnosed with cancer to be provided with a cancer survivorship plan which at the very least contains a treatment summary, needs assessment and care plan that is cognisant of not only the cancer diagnosis, but also co-morbidities, social, psychological and practical needs.

Further detail of the letter to the Members of Parliament mentioned above, is available through the following link: http://www.cancervoicessa.org.au/assets/documents/Position_Papers/letter-to-sapoliticians1dec2017.pdf

RECENT EVENTS

Cancer Voices SA Annual General Meeting

Our AGM was held on 3 December 2017 and following written reports from the Chair and Treasurer, elections for membership of the Executive Team were called. We are very pleased to welcome our new Executive Team members Courtney Oake, Jackie Barreau, and Karen Van Gorp. They bring a rich and diverse experience to the team and we are most appreciative of their commitment to volunteering with CVSA to progress advocacy for people affected by cancer.

Over the year we will profile our Executive Team members so that you can see what knowledge, skills and experience we bring to the team and to CVSA as a whole. The Executive Team members for 2018 are:

Chris Christensen	Chair	Stephanie Newell	Member
Julie Marker	Deputy Chair	Agnes Vitry	Member
Eric Browne	Secretary	Courtney Oake	Member
Maurice Woolard	Treasurer	Jackie Barreau	Member
Con Nakos	Cycling Group Manager	Karen Van Gorp	Member

Our 2017 Annual Report is available at :

<http://www.cancervoicessa.org.au/assets/documents/AGM/cvsa%20annual%20report%202017.pdf>

CURRENT MATTERS

National Cervical Cancer Screening Program Changes

The National Cervical Screening Program has now changed. From December 1st, the two yearly Pap test for people aged 18 to 69 was replaced by a five yearly Human Papillomavirus (HPV) test for people aged 25 to 74. People will be due for the first Cervical Screening Test two years after their last Pap test. These changes are a result of new evidence, better technology and will help improve early detection of cervical cancer thus saving lives. The new program will:

- replace the Pap test with the more accurate Cervical Screening Test
- invite women aged 25 to 74 years to undertake the test
- increase the time between tests from two years to five years

Further information about the new National Cervical Screening Program is available at the following link: <http://www.health.gov.au/internet/screening/publishing.nsf/Content/renewal-ncsp-pres>

Medicinal Cannabis

Many thanks to our Queensland colleague Dan Kent for forwarding the following links to information and presentations from the Therapeutic Goods Administration (TGA) on medicinal cannabis.

1. New medical cannabis clinical guidance documents for nausea and vomiting, epilepsy, multiple sclerosis, palliative care, as well as an overview document is available at:

<https://www.tga.gov.au/access-medicinal-cannabis-products>

2. Guidance from the TGA for the use of medicinal cannabis in Australia: Patient information:

<https://www.tga.gov.au/publication/guidance-use-medicinal-cannabis-australia-patient-information>
<https://www.tga.gov.au/sites/default/files/guidance-use-medicinal-cannabis-australia-patient-information.pdf>

3. Presentations available on the TGA Website

- Dr Tony Gill Principal Medical Adviser Pharmacovigilance and Special Access Branch Medicines Regulation Division, TGA – October 2017-Clinical evidence and access to medicinal cannabis products: <https://www.tga.gov.au/presentation-clinical-evidence-and-access-medicinal-cannabis-products>
- Adjunct Professor John Skerritt, Deputy Secretary, Health Products Regulation Group, Commonwealth Department of Health – July 2017 -Medicinal cannabis cultivation and manufacture update: <https://www.tga.gov.au/presentation-medicinal-cannabis-cultivation-and-manufacture-update>

Victorian Assisted Dying Laws

The Victorian Parliament passed the Voluntary Assisted Dying Bill on 29 November 2017.

The legislation will now go through an 18-month implementation period before it comes into effect in June 2019.

Victorians living with a terminal illness will have access to voluntary assisted dying after detailed deliberations resulted in amendments that strengthened the Bill, and maintained its vital integrity and compassion.

Some of the amendments include:

- Voluntary Assisted Dying will be limited to those whose death is expected in weeks and months, but no longer than six months – a reduction from 12 months. There will be exceptions for those who are suffering from a neurodegenerative condition and whose death is expected within weeks and months but for a period no greater than twelve months to access it
- A person must have lived in Victoria for at least 12 months before being able to make a request
- A person with a mental illness must be referred to a psychiatrist for an assessment

- The assessing doctor must encourage the person to inform their regular doctor of their intention to access voluntary assisted dying, if the assessing doctor is not the person's regular doctor
- The contact person is required to return any unused voluntary assisted dying substance within 15 days (not 30)
- The Review Board has a role to follow up with the contact person to advise on the safe return of any unused medication
- The coroner will be informed of voluntary assisted dying deaths
- Death certificates for people who have chosen voluntary assisted dying will record the manner of death as voluntary assisted dying.

Further information can be obtained at the following link: <https://www.premier.vic.gov.au/victoria-first-state-to-pass-voluntary-assisted-dying-laws/>

CVSA ADVOCACY, INVOLVEMENT, AWARENESS, INFORMATION

South Australian State Election

There is the state election on 17 March and we have forwarded letters to the Minister for Health, the Honourable Peter Malinauskas MP, the Opposition spokesperson for Health, the Honourable Stephen Wade and the SA Best party leader, Mr Nick Xenophon, outlining key areas CVSA believes are important for the next State Government to improve health outcomes across the cancer continuum. We have also had face to face meetings with Mr Xenophon, the Honourable Stephen Wade and a Liaison Officer from the Office of Minister Malinauskas. Further information about CVSA priorities are included in our Thoughts section (page 1) above.

The 2nd Victorian Cancer Survivorship Conference

This conference is being held from 7-9 February with the theme of *The Survivorship Equation – Evidence + Best Practice = Better Outcomes*. Cancer Voices Executive Team members Julie Marker and Chris Christensen have had a poster presentation accepted for the conference titled: *Survivors in the survivorship equation: survivor evidence + survivor views of best practice = better outcomes*. We will provide a summary of the conference in our next newsletter.

Research Participation Opportunity

An Online Study Exploring Your Thoughts and Behaviours about Physical Activity

The study is designed to increase physical activity in women previously affected by breast cancer. The project is being undertaken by researchers at the Flinders Centre for Innovation in Cancer (FCIC). Part of the study will explore the beliefs and attitudes women have about physical activity. If you participate in the project, the researchers may also ask you to trial a short technique designed to increase your levels of exercise over one month.

The researchers are still looking for research participants so if you have not already participated you may like to take the survey now.

You can participate in this study if you:

- Are aged 18 years or older and have previously been diagnosed with early breast cancer

- Have completed active treatment (i.e. surgery, radiotherapy and/or chemotherapy) two or more years ago. Please note – you are still eligible if you are currently receiving hormone therapy (e.g. tamoxifen, Arimidex, Femara, Aromasin).
- Are interested in increasing your physical activity
- Are able to participate in regular moderate-to-strenuous physical activity (e.g. free from any health condition that prevents physical activity).

You can take the survey here: <https://tinyurl.com/justdoit-survey1>.

For more information, read the *Participant Information Sheet* about the study or contact Chloe Fletcher, Research Assistant, Flinders Centre for Innovation in Cancer, at chloe.fletcher@flinders.edu.au or (08) 7421 9957.

Fear of cancer Recurrence: A practical guide for clinicians

After a diagnosis of cancer, fear of cancer recurrence (FCR) is one of the most prominent concerns for people. It may be a problem for people with curable disease who fear recurrence and for those with advanced disease who fear progression.

Australian research by Prof Phyllis Butow et al has culminated in this ‘practical guide for clinicians’ and advise the following key points:

- Fear of cancer recurrence (FCR) is fairly common, normal, and distressing
- FCR is not strongly linked with prognosis, and may even occur in individuals with a relatively good prognosis
- Severe FCR does not improve without intervention, and oncologists can play an important role in helping patients to better manage it
- Screening for FCR helps in detection of this condition and guides patient referral
- Providing adequate information, normalizing FCR, encouraging disclosure, and making appropriate patient referrals are important ways that oncologists can contribute.

The guide is available at: <http://www.cancernetwork.com/oncology-journal/fear-cancer-recurrence-practical-guide-clinicians>

Cancer and the Immune System

With more people diagnosed with cancer looking into immunotherapy as a potential treatment option this guide may assist in answering a number of frequently asked questions about cancer, the immune system and immunotherapy. The guide has been developed by the Cancer Research Institute in New York. It considers the use of the immune system to fight cancer and the approach to treatment called immunotherapy, which treats the patient rather than the tumour. The guide can be found at the following link:

https://www.cancerresearch.org/CRI/media/PDF-Content/Cancer-and-the-Immune-System_2016-final_print.pdf

Delivering the news no patient wants to hear

An insight into doctors delivering bad news from Dr Ranjana Srivastava an oncologist working in Dandenong Hospital's cancer ward. Dr Srivastava highlights the thoughts that go through a person's mind when they receive a cancer diagnosis and the vulnerability of people at this time; the need for whole person care; the need to provide assistance in navigating the health system; the importance of

empathy with patients; the value of recognising the key role of carers; and of always being kind and compassionate as a clinician.

The program was presented on the ABC as is available through the following link:

<http://www.abc.net.au/7.30/delivering-the-news-no-patient-wants-to-hear/9299836>

LOOKING AHEAD

Upcoming Meetings/ Events

Digital Health Research Project Meeting – 6 February

SA Pathology Safety and Quality Meeting – 12 February

Survivorship Conference - 2nd Victorian Cancer Survivorship Conference 8-9 February

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 Taylor Blend cafe on Hallett Road.

CVSA Walking Group – Walks start every Tuesday at 9.30am from the Belair Golf Club car park off Upper Sturt Road, Glenalta. Walks are usually 1 hour duration in the beautiful Belair National Park and followed by coffee and a chat, usually at Sheoak Cafe, Belair.

Cancer Voices Executive Team Meeting – Monday 19 February. Meetings are held at Health Consumers Alliance, Level 1, 12 Pirie Street, Adelaide.

For more details on any of these activities:

email info@cancervoicessa.org.au or ph Chris on : 0431691956

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

Chris Christensen

On behalf of the Executive Team, Cancer Voices SA
