



To: Health Minister Milanauskus, cc Vikki Kaminsky, Stephen Wade, Nick Xenophon

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Re: Cancer Services in South Australia

Dear xxxxx

I am writing to you in this pre-election period to seek an appointment to discuss the following matters of importance identified by members of Cancer Voices SA, a 100% volunteer organisation dedicated to raising a voice for people affected by cancer in order to improve their quality of life and outcomes.

Cancer Voices SA is calling on all political parties to ensure cancer is a priority health issue heading into the March election and beyond. This letter highlights key areas where the next state government can lead the way in improving health outcomes across the cancer continuum from prevention, to diagnosis and survivorship, through treatment and to palliative/end of life care, underpinned by funding for cancer research.

State wide oversight and governance

Cancer Voices SA has witnessed a general reduction in staffing and status of the statewide governance for South Australian Cancer Services (SACS), a group we are a member of and deem of be of vital importance in leading and overseeing cancer policy and practice across South Australia. Cancer Voices SA believes this group should have carriage and oversight of the provision of quality, evidence-based cancer care in South Australia. It is of deep concern to South Australians living with cancer that there has been no State Cancer Plan, with the exception of the Aboriginal Cancer Control Plan, since 2015. This must be addressed with strong leadership and written commitment, given by all South Australian cancer services, to ensure its implementation.

Key matters of concern raised by our members that need to be addressed in a well funded and led state wide cancer plan include:

1. variation in access to specialist cancer treatment services
2. lack of 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
3. consumer involvement in cancer research and access to research trials as a treatment option
4. palliative care services
5. data and information.

1. Variation in access to specialist cancer treatment services

Treatment for cancer is usually complex, involving different disciplines and therapies, which can

make it more difficult for rural and remote South Australians to access the full range of care they require, within their local community. In these areas, where hospitals and practitioners do not have ready access to professional cancer networks, the challenges of providing quality, evidence-based cancer care can be significant. Whilst the joint federal and state government funding for regional cancer centres is welcome, we advocate for funding to support better models of survivorship care outside the metropolitan area. There remain opportunities to produce better outcomes and quality of life for people with cancer living in non-metropolitan areas of the State, by improving the organisation and delivery of cancer services across the cancer continuum and through better engagement with health stakeholders and consumers.

Even when screening is readily available, as in the case for bowel screening, Bowel Cancer Australia (January 2017) noted that less than 20% of bowel screening participants who require a colonoscopy are getting it within the recommended 30 days and that some patients are waiting up to a year for one in the public health system. Cancer Voices SA believes this is unacceptable and could lead to unnecessary deaths. We therefore advocate close scrutiny of the screening program and of the time taken for people requiring referral to access specialists, with a view to ensuring all South Australians requiring a colonoscopy are seen within the recommended 30 days or sooner.

Cancer Voices SA seeks your commitment to:

- improving outcomes and quality of life for people diagnosed with cancer in non-metropolitan areas of South Australia by improving the organisation and delivery of cancer services across the cancer continuum
- working with cancer survivors in non-metropolitan areas to understand and better meet their needs for cancer services across the cancer continuum
- closely monitoring all screening programs and subsequent referral times to ensure all South Australians have timely access to specialists and evidence based treatment and care

2. Lack of 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 most consistent message from Cancer Voices SA members is that there is a significant lack of coordination of person-centred cancer treatment and care. Cancer consumers need the multiple health professionals involved in their care to communicate effectively, with the consumer and with each other. To achieve this Cancer Voices SA advocates funding for a model of care that uses what are variously called cancer nurses/care coordinators/consumer navigators, accessible for all those diagnosed with cancer, in both the public and private systems in order to achieve an integrated and holistic system. In addition CVA believe a holistic integrated health care system is transparent with public access to information about treatment outcomes across different cancer services in order to inform consumer choice, through the establishment of a registry which tracks and reviews treatment and outcomes across cancer treatment centres.

We therefore advocate for the state cancer plan to provide funding to integrate cancer services that include consumers and clinical services in local health networks, and comprise clusters of hospitals and local health services, including hospitals, community based services, general practitioners, pathology and radiology services, primary health services, private hospitals, rehabilitation and support services and palliative care and end of life services. We propose that the government provide grant funding for local health networks to establish and evaluate models of integrated person centred care, across the cancer continuum, to improve the effectiveness of cancer treatment and care, and to monitor the systems through clinical and patient reported outcomes.

Investment in the latest quality medical technology is also supported, as access to the best diagnostic and treatment equipment is vital in delivering the best outcomes. Cancer Voices SA advocates for accreditation of cancer services in our state and nationally so that people diagnosed with cancer can be assured of the safety and quality of cancer services in relation to such elements as treatment planning, staff education, treatment orders, drug safety, preparation and administration, assessment and monitoring of the well-being of the person receiving treatment.

Cancer Voices SA seeks your commitment to:

- investment to support improvement in the integration and coordination of cancer services in the form of grant funding to establish and evaluate models of integrated and coordinated care
- investment in the latest medical technology
- accreditation of cancer services
- enabling public access to information about treatment outcomes across different cancer services in order to inform consumer choice, through the establishment of a registry which tracks and reviews treatment and outcomes across cancer treatment centres.

3. Consumer involvement in cancer research and access to research trials as a treatment option

While we know that survival rates for more common cancers are improving, there are still too many cancers with low survival rates including the pancreas, brain, ovary and bladder. We also know that the area of genetics will inform diagnosis and treatment into the future. Cancer Voices SA advocates therefore for sustained state government investment in long term research into high mortality cancers in order that there is an increase in the survival outcomes for all cancer types and that South Australia seek to be a national leader in genetics research.

Further, we seek to have equitable access to cancer trials as an integral option for cancer treatment, regardless of where they live. We advocate for government to actively attract researchers to South Australia so that people with cancer do not have to access and pay to participate in cancer trials interstate.

Further, we seek to have equitable access to cancer trials for people diagnosed with cancer as an integral option for cancer treatment, regardless of where they live. We advocate for government to actively attract researchers to South Australia so that people with cancer do not have to access and pay to participate in cancer trials interstate.

We also advocate for the voice of the lived experience and active involvement of consumers in prioritising, advising, design, monitoring, evaluation and dissemination of research, as well as being participants in research trials, will assist in ensuring research is relevant to the needs of people diagnosed with cancer and assist in decreasing the time between establishing evidence of new treatments or procedures and translation into practice. Cancer Voices has a well established initiative matching consumers to cancer research projects and researchers now seek our trained consumers involvement in all areas of cancer research.

Cancer Voices SA seeks your commitment to:

- sustained government investment in long term research, particularly into high mortality cancers and genetic factors underlying cancer
- promotion of active involvement of consumers in all aspects of research
- increase the participation of South Australians with cancer in research trials as part of their treatment
- attracting cancer research funding and researchers to South Australia

4. Palliative care services

The latest Palliative Care Services Plan for South Australia concluded in 2016. Cancer Voices SA calls for increased funding for palliative care services to support South Australians access support at the end of life care. It is vital the South Australian Government ensures that our palliative care services support all those who need assistance. No-one should miss out because of where they live, their diagnosis, ethnicity or socio-economic status. Gaps in services need to be identified and addressed. Increased funding for education about palliative care is needed to enable South Australians to plan for their end of life care needs. All health professionals need training in palliative and end of life care matters to ensure they are knowledgeable about issues and able to support people in accessing appropriate services in their preferred setting.

We note that the Victorian Government has allocated approximately \$56 million over the next five years to support specialist doctors and nurses in regional areas; home-based palliative care; a 24 hour palliative care advice line; one-off funding for charities of palliative care services to support models of care that include dying at home. We urge the South Australian Government to make a similar commitment.

Cancer Voices SA seeks your commitment to:

- developing a new Palliative Care Services Plan for South Australia written in consultation with health consumers that addresses gaps and services access
- Increasing funding for palliative care services in South Australia so that no-one misses out on access to quality end of life care services.
- allocating funding for training of health professionals in palliative and end of life care services.

5. Data and Information

Cancer Voices SA believes that all people diagnosed with cancer should be provided with survivorship plans which at the very least contain a treatment summary, needs assessments and care plan. People with cancer often have other health co-morbidities and cross a range of health services: primary and acute; pharmacology, radiology, pathology and other areas of the health system. To achieve this it important that consumer records link all these isolated pieces together and include accredited community based services as well as health services. It is also important that people with cancer have full access to their health records.

Cancer Voices SA seeks your commitment to:

- supporting the implementation of cancer survivorship plans for all people diagnosed with cancer
- enabling people with cancer to have full access to their health records
- ensuring all consumer records are linked into one system.

Background Information

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.

Cancer Data

In 2014 there were 10073 new cases of cancer diagnosed in South Australia (age standardised rate

521.7 per 100 000 population), while there were 3629 cancer deaths (180.3 per 100 000). Between 2010 and 2014 male incidence rates increased by 0.6% per annum, while female rates increased by 3.4% per annum. Mortality rates in males have shown an increase of 0.2% per annum, while female rates have increased by 0.4%. The most common cancers in South Australia are prostate, colorectal, melanoma and lung for males and breast, colorectal, lung and melanoma for females. It is of ongoing concern to Cancer Voices SA that cancer data is at best 3 years behind and missing some vital aspects of importance in understanding the various manifestations of this disease, such as, stage and recurrence.

Historical issues of concern - Lessons not learnt

Cancer Voices SA monitor the issues associated with cancer treatment and are concerned that the lessons from critical incidents do not become embedded in the system. In the past ten years there has been a significant number of critical events and subsequent reviews:

- July 2008 – Radiotherapy under-dosing (869 people and 2 reviews)
- December 2008 – Etoposide Chemotherapy over-dosing (11 children)
- April 2009 – Review of SA Cancer Services
- June 2012 – Review of Governance of Clinical Services
- December 2012 – Breastscreen SA under-reporting (72 cases of cancer from 570 women recalled)
- July 2015 – Cytarabine under-dosing (10 people, Marshall Review)
- 2016 – 100 patients given false positive results for prostate cancer by SA Pathology
- 2017 – report of issue (Advertiser 11 November 2017) with nRAH haematology diagnosis, reporting and patient care.

Cancer Voices SA believes such incidents will continue without strong state wide planning, leadership and governance of cancer services.

Members of Parliament have the power to make decisions that directly impact the lives of cancer survivors and their families. It is therefore important for people affected by cancer and the general public to understand where you stand on issues critical to improving the outcomes associated with a cancer diagnosis.

I look forward to discussing these matters with you.

Yours sincerely

Chris Christensen

Chair

Cancer Voices SA

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