

Cancer Voices Australia is a national consumer organisation representing Australians affected by cancer.

We aim to ensure the voices of people affected by all the different types of cancer are heard at a national level.

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THE ROLE OF THE CONSUMER AS PARTICIPANT

According to an earlier NCCI Report, more than half the patients diagnosed with cancer are alive more than seven years after their diagnosis. This corresponding change in the outcome of cancer and cancer care in Australia necessitates a redefinition of the impact of cancer from the consumer perspective.

At the same time, with an ageing population, more people will be challenged by cancer diagnosis than ever before and more will survive.

Longer survival brings greater prominence to these issues:

- Cancer as a chronic disease
- Rehabilitation
- Pain and Fatigue
- Body Image
- Community care
- Palliative care
- The role of the carer

It follows then, that these for consumers must be reflected in the cancer programs and services provided by our respective governments and the bodies they support or regulate. As a result, governments have embraced and are promoting the concept of involving 'those affected by cancer' in the decision-making process about their own health care, health service planning, policy development, and quality issues in the delivery of cost effective health services.

We are then confronted with the questions, are we a consumer representative or a representative consumer? There is a difference:

A consumer representative:

- Is appointed by a consumer organisation
- Has obligations to that organisation
- Represents the views of that organisation
- Reports back to that consumer organisation

A representative consumer:

- May be appointed either by a consumer organisation or a health body
- Does not represent that organisation but brings a wide consumer perspective of their own or of others
- Brings skills and expertise to the body that complements that of others
- Ensures diversity on the body

Does the difference matter so much any longer? As consumers we are now much better established as part of the formal process. A review of consumers and consumer groups identifies membership of focus groups, project/working groups, research teams, steering committees, advisory groups, ministerial task forces, boards and statutory authorities across all levels of government and clinical groups. We are moving from more passive consumer involvement to more active consumer engagement.

This is how our voice is now being heard! We need to be sure that the new consumer has the skills to participate effectively in the cancer arena.

From the Chair

It would be inconceivable to write a report at this time that did not include some observations on Labor's first budget since 1996.

First, the Government appears to have largely honoured its election health promises. Adding in the post budget \$150m it promised two weeks after the budget to further reduce waiting times for elective surgery (now \$750m), it has committed more than \$3.5 billion in additional health spending over the next four years.

Of that we can identify new spending of \$271m on direct cancer initiatives. That's 7.8% of the total spend. Sounds good but it still does not match on paper cancer's high incidence, mortality and morbidity rates. However, when one takes into account the indirect benefits to cancer sufferers from other initiatives such as hospitals, GP Super clinics, aged care and community health, the picture looks somewhat rosier. Cancer in this budget has become the seventh of eight budget big ticket items. Where are the cancer dollars going?

- Bowel cancer screening will be extended to include people attaining their 50th birthdays.
- \$11.5m will be spent on supplying breast prostheses.
- Additional funds for research for upgrading some radio therapy facilities.
- Commendably, \$15m has been allocated to CanTeen to improve support for teenagers and young adults with cancer.

- And Cancer Australia - allocated an additional \$20.2m.
- \$50m to upgrade facilities at Royal Prince Alfred Hospital in Sydney to a state of the art, comprehensive cancer centre.

The latter may be in response to the intense advocacy by former head of the centre, Prof. Chris O'Brien, who was forced to step down at the end of 2006 with advanced brain cancer. This development is the only such centre over the four years of the budget! As Prof. O'Brien said himself in the month before the budget, a Sydney cancer centre should only be the first of several spread across the country. We see an opening in Year 3 of the budget program to press for funding for a second second Cancer centre initiative.

The quality of the benefit from all this will depend on the successful reshaping of Australia's multi-tiered health system. We are already engaged in this process and will be seeking maximum, consumer focused benefits from the changes.

In April the CVA Executive met in Melbourne for two days. This was an important meeting as Queensland, South Australia and Tasmania were officially launched since we last met. It was an opportunity to review our organisation and to seek organisational improvements and efficiencies.

We had a morning session with Prof. Nora Kearney of Stirling University in Scotland. Nora is engaged with the UK equivalent of Australia's CanNET project in which six States plus the Northern Territory are working together in collaboration with Cancer Australia to better link regional and metropolitan cancer services. CanNET is intended to provide improved access to quality, clinically-effective cancer services throughout Australia, particularly for specific population groups who may currently have poorer cancer services, such as Aboriginal and Torres Strait Islander peoples and people living in rural and regional areas.

Scotland is ahead of Australia in providing such a service and, of course, has its own remote places. In comparing the two experiences we found that the more mature UK experience was more patient-focused than Australia's, with greater integration/interdependence of the various elements of the patient's journey:

- Comprehensive, integrated research strategy
- Partnerships in care
- Driven by experience

- Resulting in reduced incidence and morbidity
- Meaningful "engagement" with consumers, not just "involvement"
- Better experience and outcomes for patients.

We are, of course, represented on all the CanNETs except Northern Territory where there is no Cancer Voices as yet. We will focus our efforts to improve the gap in our membership to be more involved in the reshaping of Australia's overall health system.

A major issue for Cancer Voices is the emerging demand for consumers trained to make assessments of and collaborate with cancer research projects and clinical trials. Nearly three quarters of all cancer research takes place in the two most populous States – Victoria and NSW. Others are developing their capacity.

For some years the National Health and Medical Research Council has enjoined research organisations to work with consumers. Cancer Australia has gone further and allocates 20% of funding assessment marks to the quality of consumer engagement. In NSW the Cancer Council and Cancer Voices have appointed a committee of specially trained consumers to contribute 50% of the assessment for funding of any project.

These pressures for consumer engagement in research are most welcome. But they carry with them a need to recruit and train more consumers. We are holding discussions with a number of Cancer Councils and research organisations to step up the availability of capable consumers.

In recent months CVA has entered into collaboration with the Australian Gastro-Intestinal Trials Group (AGITG) which for some time has had a consumer on its board. In May AGITG went the next step and formed a 10 person Consumer Panel, of which I am the interim chair, to meet with and advise the AGITG Scientific Council on consumer preferences and experiences. This model we expect will need to be tested and then reproduced many times over coming years.

Collaborations

CVA has adopted a strategy of forming partnerships and collaboration with organisations including the Cancer Council Australia; Cancer Councils in each state and territory; Australian Gastro-intestinal Trials Group; Australia Leukaemia Lymphoma Trials Group; Breast Cancer Action Group; HIV Aids Groups; the Clinical Oncological

Society of Australia; the Federal and State governments and of course Cancer Australia.

Through our representation on these national bodies we believe we provide the considered input required to assist in shaping the way cancer treatment is undertaken in this country. We adhere to the policy that consumers and clinicians working together can make a difference.

A further example of collaboration was the announcement by the Federal Government in September 2007 to amend the legislation to enable terminally ill patients' access to their superannuation tax-free. The PeterMac, breast cancer groups, cancer councils and CVA partnered to achieve this legislative change.

In March 2008, in response to a demand by consumers and other health groups a seminar was held in Sydney to review the issues relating to access to superannuation for the chronically ill. Following this important meeting which included presentations from lawyers, the superannuation industry, the Human Rights and Equal Opportunity Commission, Chronic illness Alliance and AIDS groups, a formal communiqué was issued and a working party established to review the current legislation and develop a formal response to Government.

During the period under review, CVA has attended, provided keynote addresses, spoken at eight international conferences (held in Australia), 27 seminars, eight board meetings, 18 government committees and 8 board meetings. In total, 67 CVA consumer representatives have continued to provide policy and advice and promote the value of consumers.

Cancer Voices Victoria

Those who advocate on behalf of people affected by cancer must never rest on their laurels no matter how hard earned those laurels are. As the American Slavery Abolitionist, Wendell Phillips has said "Eternal vigilance is the price of liberty; power is ever stealing from the many to the few". Perhaps we should go to the original quotation which is actually from an Irish judge, orator and statesman, living in the eighteenth century, John Philpot Curran "The condition upon which God hath given liberty to man is eternal vigilance; which condition if he break, servitude is at once the condition of his crime, and the punishment of his guilt". The situation in Victoria illustrates this well. Nearly five years ago we had a cancer services reform

agenda and a very farsighted program developed. It involved those actually affected by cancer, in setting up policy, in the establishment of treatment protocols and in research policy. Out of it came a cancer plan, the establishment of eight integrated cancer services across the state, patient management frameworks for sixteen tumour types and the Victorian Cancer Agency to integrate research. All had ongoing consumer involvement. We used to boast that in Victoria we were invited to the table and the problem was finding enough consumers to sit at all the tables.

How quickly things can change. Last year we suddenly heard that there was to be a new cancer plan. At the same time there was to be a review of the governance of the integrated cancer services and an evaluation of the patient management frameworks. You would think that with a track record of engaging with those affected by cancer that there would be consultation with consumers and consumer groups. So far there has been none. More worrying is the appointment of a Cancer Clinical Network Advisory Committee with little consultation. Two 'consumers' have been appointed to this committee but as far as we can ascertain they are not connected with any cancer consumer organisation. One is a senior public servant within the Department of Human Services. We look forward to working with these people but wish that the spirit of the Department's own publications was being followed.

Like Cancer Voices organisations in other states we are concerned about the provision of radiotherapy services. A lot has happened in Victoria over the past fifteen to twenty years that must be acknowledged. There are now radiotherapy units in regional areas. Existing centres in the metropolitan area have been expanded and ageing linear accelerators replaced. However, there has also been a consistent pattern of private radiotherapy facilities being established in areas of high socio-economic disadvantage. Individuals presented with huge bills and significant out of pocket expenses.

We continue to hear such stories and also those of people refusing to have treatment because of the cost at private facilities or the distance required to travel to public facilities. The latest proposal is to allow for a private facility to be located adjacent to the Northern Hospital at Epping, which serves an area that all welfare agencies agree is the most socio-economically disadvantaged area of Melbourne. People within our Department of Human Services believe that public patients may access private facilities at Medicare cost however we remain skeptical.

We believe that the proposed facility at the Northern hospital should be a public facility.

On a more positive note the PROSPECT (Patient Response: an Ongoing Study of People Experiencing Cancer Treatment) study is about to commence. An initiative of the Cancer Council Victoria, this survey of people who have experienced cancer will reveal the effects of cancer service reforms on outcomes, including those in the psychosocial domain. Cancer Voices Victoria has been involved with the development of the survey instrument.

To return to the original quote of Wendell Holmes "Eternal vigilance is the price of liberty; power is ever stealing from the many to the few". As consumer advocates we wish to ensure that power within cancer services is shared with those who are affected by cancer. We do not wish to see a return to power being located with the medical elite or health bureaucrats. So we have to be vigilant and ensure that the voice of those affected by cancer is loud enough to be heard.

Cancer Voices NSW

Cancer Voices NSW (CVN), established in 2000, is a coalition of cancer support and advocacy groups. CVN provides a voice for people affected by cancer in NSW.

CVN works closely with "cancer world" stakeholders, in particular with the Cancer Institute NSW and the Cancer Council NSW. CVN provides cancer consumer representatives to 93 working parties, committees and research projects namely:

- Consumer Advocacy Training Courses and Consumers Involvement in Research Training, both through the Cancer Council NSW
- Consumer Priorities for Research
- Financial Challenges, in superannuation, benefits and insurance
- Access to Radiotherapy Campaign
- Radiotherapy
- Private Health Insurance Options
- Review of Optimising Cancer Care in NSW – 5 years on

www.cancervoices.org.au

Cancer Voices SA

2007 was a significant year for cancer consumer advocacy in South Australia. The year began with a workshop for people interested in forming a Cancer Voices group. An Executive team of eight was elected to manage the group and implement ideas and strategies to get the group up and running.

"Raising A Voice For Those Affected By Cancer" became our slogan with membership open to anyone affected by cancer.

By August Cancer Voices SA (CVSA) became an incorporated body. On the 13th November the Minister for Health, Hon John Hill officially launched CVSA. A major event for Cancer Voices SA, a Cancer Consumer Forum, was held on the day of the Launch. More than 100 people attended the forum titled "Raising a Voice" which was led by several international guest speakers who were in Adelaide for the annual, national conference of the Clinical Oncology Society of Australia.

The New Year brought the development of a draft 3-year Strategic Plan for CVSA. The Executive team had listened to cancer consumers and developed strategies based upon priority issues raised in a 2006 CVSA Survey.

A CVSA website is now on-line and features a "Finding Resources" section to facilitate easy access to quality verified information for newly diagnosed patients and carers. Other activities include expanding membership (from the current 120), clarifying operational and support arrangements, campaigning for "holistic" cancer treatment with multi-disciplinary care and conducting regular events and forums that benefit members and others affected by cancer. Fortunately, members are also strongly represented on change initiatives that include the State-wide Cancer Clinical Networks and the Cancer Australia National and Advisory Committees aimed at improving cancer treatment and care.

The year ahead promises to be exciting and busy with further details on the work of Cancer Voices SA available at www.cancervoicesa.org.au

Cancer Voices TAS

Cancer Voices Tasmania Inc has over the last 18 months been working through governance issues in order to set the organisation up on a firm footing. Despite having relatively few members at present, CVTas is already involved in lobbying government about current local issues in particular access to PET scans and transport and accommodation.

Large events around the state such as the Relay For Life and AgFest have provided a focus for promotion of the organisation and it is hoped that the official launch in mid June will attract more members. Later in the year it is hoped to offer advocacy training.

CVTas is currently working with the Health Issues Centre from Victoria trying to attract funding to run these workshops.

Cancer Voices ACT

Cancer Voices ACT is unique among the State and Territory Cancer Voices organisations in so far as it is supported by the Health Care Consumers Association of the ACT (HCCA), not the local Cancer Council. We work with another cancer patient organisation called the ACT Eden Monaro Cancer Support Group which distributes funding support to patients and their families and offers emotional support. Additionally, the cancer services based at Canberra Hospital service an area outside of the ACT, stretching to the Coast and being part of NSW health services.

While cancer funding was increased in the recent ACT Budget it was thought that there might be a firm start made on a Cancer Centre, which has been supported in principle by the Minister and ACT Health. But this was not the case. The Budget did include funding for three extra beds in Ward 14B, the inpatient oncology ward.

A new prostate and urology nurse care coordinator's position in oncology services has been announced. This is in addition to the existing positions for haematology, lung, gastro intestinal, and head and neck cancer. There are also three breast cancer care nurse coordinators in the ACT.

CVACT gave a talk to 100 neurological nurses at St George Hospital in Sydney in May. We recently attended a Workshop held in Canberra prior to the Health Outcomes Conference on Health-Related Quality of Life (HRQOL) measurement. The Workshop was small but attended by a broad range of representatives.

Cancer Voices WA

Following a major Consumer Forum in 2007 where numerous concerns were aired relating to WA's cancer treatment services, Cancer Voices WA made a submission to the Cancer Council expressing its concern about the ability of the services to provide adequate treatment until new cancer centres and services became available. As a result, the Cancer Council of WA is funding a "Capacity Audit" which is to be undertaken by Professor Michael Barton of the South Western Sydney Health Service. The Audit will involve accessing data from state and federal records, interviews with clinicians and consumers, comparative studies focusing on common cancers and adherence to treatment guidelines.

The Audit should be available in August 2008 and will be presented to the Minister for Health and the Director General. The State's Cancer & Palliative Care Network has welcomed the audit. It will cost approximately \$85,000.

In Western Australia major plans were announced in 2005 for the setting-up of major comprehensive cancer centres at two locations in Perth, three in the outer suburbs and one in a regional centre. In addition a Cancer & Palliative Care Network was established to co-ordinate services throughout the state. Since then there have been numerous delays and the only real step forward has been the opening of a refurbished and re-equipped radiotherapy department at a major teaching hospital. Despite the new radiotherapy facility waiting times have, once again, started to escalate and numerous other problems have been identified which impact on patients and their carers. Each year in WA approximately 9,500 patients are diagnosed with cancer and there are over 50,000 currently being treated. With the stresses facing the existing services and the increasing numbers of patients the Capacity Audit will hopefully assure consumers that treatment standards are being maintained both now and until new facilities become available.

Further delays in WA's Upper House have prevented the passing of the Consent to Medical Treatment Bill which has been eagerly anticipated for over 7 years. WA is the only state where Living Wills or Advanced Health Directives have no legal status. With control of the Upper House now in the hands of independents it is unclear when the legislation is likely to be passed.

Cancer Voices QLD

Cancer Voices Queensland (CVQ) is grateful to The Cancer Council Queensland for its continuing support and for allowing us to use its facilities, including telephones.

CVQ now has a direct number 0401 001 365 and will call you back.

Locally CVQ is continuing to raise awareness of its role through the media and by participation in community events. Significant improvements have been made to the CVQ website www.cancervoicesqld.org.au where you will see that submissions on current issues for inclusion in future CVQ publications and programmes may attract a double movie pass.

The next CVQ Public Forum will be held in Emerald later this year. Cancer patients, survivors, family members and health professionals working in cancer care are invited to attend these free Public Forums to identify issues in a supportive environment. The issues, experiences and ideas common to all cancer types elicited at these Forums assist CVQ to be truly a voice for all Queenslanders affected by cancer.

The 3rd CanNET National Workshop in Adelaide, attended by an Advocate from CVQ, focussed on the establishment of Multidisciplinary Teams (MDTs).

The Workshop identified that this is what consumers need:

- Access to MDT assessment and review for all cancer patients, with an emphasis on the full ambit of care. Treatment and Care Plans to be provided to GPs and patients. Readily accessible information, directories, education and guidelines for GPs and patients. Routine engagement of health services with consumers.
- Carers must have access to support: they are pivotal partners, providing valuable care on the patient's journey.
- Health services must recognise and address the Tyranny of Distance. Consumers need access to second opinions, access to GPs, help with financial challenges (including overhauling of the PTSS - see below), and contact with care co-ordinators.

As part of CanNET, Qld Health has committed to meeting some of these needs and has asked CVQ to assist in recruiting consumer representatives for the working parties. The success of these activities will rely on the leadership and active participation of clinicians and consumers who are dedicated to multi-disciplinary cancer care. AND ... a plea to health service providers - Remember this may be a whole new world for most of us newly diagnosed with cancer - speak to us in terms we understand and address our needs.

CVQ was again represented by two Advocates at the latest Cancer Control Planning Forum with Qld Health. The draft 'Queensland State-wide Cancer Treatment Services Plan 2008-2016' has now been submitted to Cabinet and QVC welcomes continued engagement with the Government on cancer issues.