

PARTNERSHIPS

As at February 2007 there are five national reports, including two Senate Reports, which have outstanding recommendations that are yet to be addressed.

In addition, there are outstanding recommendations from the now defunct National Cancer Strategy Group and reports from the National Cancer Control Initiative which ceased operating in 2005.

There is a wealth of information and knowledge in all these reports which can assist the reorganisation of cancer services in Australia. They can help towards existing funds for cancer services being spent more effectively.

CVA calls upon both levels of government to resolve funding issues as they relate to cancer services and for new initiatives to be developed, under the auspices of Cancer Australia.

February 2007

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

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

OBJECTIVES

- To promote the fundamental rights of Australians affected by cancer
- To effect improvements in cancer treatment, care and support by contributing to national cancer policy and program development, management and evaluation
- To promote the value and benefits of consumer participation in the development of national cancer policy and programs
- To provide a forum for member organisations to network and contribute to national activities

CANCER IN AUSTRALIA

Cancer kills more Australians than any other single cause, and opinion polls have found cancer to be the disease that causes most concern in the community. (The Cancer Council Australia, 2003)

The burden of cancer in Australia is rising, with 88,398 new cases (excluding non-melanoma skin cancers) and 36,319 cancer deaths in 2001, compared with 65,966 new cases and 30,928 deaths in 1991. Cancer currently accounts for 31 per cent of male deaths and 26 per cent of female deaths in Australia and the loss of an estimated 257,000 potential life years. (Australian Institute of Health and Welfare, 2001)

More than 267,000 Australians are living with cancer, many with persistent and incurable forms.

For most cancers, the highest incidence rates are in the older groups, so that even with the relatively stable trends in the incidence rate, the projected increase in the Australian population (particularly in the older aged groups) will lead to large increases in the total number of new cases of cancer.

For men, the number of new cases of cancer for all cancers is projected to increase by 32% from 2001 to 2011. For women, the number of new cases of cancer for all cancers is projected to increase by 29% from 2001 to 2011.

These numbers are of concern and with the aging population the impost on services and costs in Australia is significant. The available funding for cancer services in Australia must be spent in the most effective way in order to achieve meaningful outcomes for cancer patients.

In essence, the burden of cancer in Australia will continue to rise. As a national cancer consumer organisation with links to state member groups we are able to provide valuable input to the cancer debate.

THE PRIORITIES OF CANCER VOICES AUSTRALIA

The following priorities for Cancer Voices Australia were stated at the launch of Cancer Voices Australia on World Cancer Day, 4th February 2007.

We believe that these priorities are achievable at little extra cost to the health system provided there is good will between all the parties involved at the State and Federal levels of government.

Australia as a developed country should offer it's citizens world's best practice cancer treatment and care.

Access and Equity

All Australians, regardless of location, income or age, have the right to world's best practice cancer care.

- The world's best practice cancer care is Multidisciplinary Care (MDC). MDC is acknowledged internationally as the best and most effective way to treat cancer.
- Patients living in regional, rural and remote areas do not have the same opportunities for treatment and as a result do not have the same outcomes as those living in capital cities.
- Many patients face significant economic problems when confronted with the diagnosis of cancer. There is clear evidence that people from lower socio-economic backgrounds have worse outcomes than those from higher socio-economic groupings.
- With increasing use of expensive therapies which are approved but not available on the Pharmaceutical Benefits Scheme (PBS), Australia is developing a three tiered cancer system:
 1. Those who are treated on Medicare
 2. Those whose health funds will fund treatment
 3. Those who can either afford, or reduce their assets in order to afford, new approved therapies.

- An example is Taxotere for advanced prostate cancer, approved but not on the PBS and costing \$3,000 per month. There is a case to be made for a means-tested allowance, or easing of disability criteria, for patients during the period of their treatment.

- Another example is the use of SirSpheres for the treatment of secondary liver cancer. Numerous patients develop secondary cancer in the liver, however most public hospitals do not offer this treatment for public, uninsured patients. They need to be privately insured or be prepared to pay \$8000.

- Adolescents and young adults are a group where there has been no significant increase in survival over the past thirty years. Adolescents and young adults being treated for cancer are too old for treatment in children's hospitals where they automatically receive treatment based on international trial protocols but more often end up in unsuitable environments in adult hospitals receiving therapies, which may greatly reduce their chance of extended survival.

- In Australia there are no national standards that are enforced. There are guidelines which are voluntary, with no measurement of outcomes through clinical audits.

- There is neither official accreditation of clinical services nor credentialing of the health professionals who work in them.

- Patients don't know where to go in order to receive up-to-date treatment where national guidelines are observed and audited.

- General Practitioners (GPs) do not have clear referral pathways.

- Some teaching and other hospitals in the public sector offer different therapies for the same cancer.

- Numbers of patients travel to other states in order to ensure that they receive the best available, multi-disciplinary treatment.

CVA supports the introduction of Multidisciplinary Care (MDC) throughout Australia

Availability of new cancer therapies

There is a need for greater transparency and consumer involvement in decision-making processes regarding new cancer therapies and their availability.

- Industry networks of clinicians, and others, lobbying for new cancer drugs to be on the PBS or for other therapies to be available should be public knowledge.

- Consumers should be involved in the decision making process.

- Approved therapies for a particular cancer should be available on the PBS or Medicare funded.

CVA supports the need for greater transparency and consumer involvement in decision making processes regarding new cancer therapies

Consumer Involvement

CVA will ensure through our state member organizations, that trained consumer advocates are part of the government process in making decisions about cancer and treatment services throughout Australia.

- 'Informed Decision Making' is an integral element of medicine in 2007. Some cancer specialists are unaware, even in their own state capitals, of what is available as an option for patients. Patients should be offered access to clinical trials, new therapies and best, evidence based medicine.

- Consumers have experienced the problems first hand. We can identify the issues and offer solutions to help resolve them.

CVA seeks consumer involvement at all levels of the decision making process.

Travel and accommodation access

All cancer patients from rural and remote areas of Australia should receive access to the same travel and transport scheme entitlements regardless of their state or territory.

- Funding for isolated patients is one of the longest running health issues in Australia. Numerous studies and reports have recommended changes to the system to ensure that patients who travel to state capitals for treatment over many weeks or months receive sufficient funding.

CVA seeks appropriate travel and accommodation funding throughout Australia for rural and remote patients.

WHAT ARE THE MAJOR OBSTACLES TO MAKING IMPROVEMENTS?

As cancer patients we have experienced some of the problems first hand; some of us have been full time carers of partners and relatives who have been treated for cancer over an extended period.

In addition, most of the Cancer Voices Management Committee have served on national and state committees as consumer representatives and also helped write national reports and recommendations.

We are well aware of the issues.

THE ROLE OF GOVERNMENT(S)

The continuing issue remains - where does responsibility for cancer in Australia lie - with the Australian Government or with the state and territory governments?

In the past decade many national reports have highlighted the gap between the Australian Government and its Dept of Health & Ageing and what are known as "the jurisdictions" - the state and territory health departments.

National reports consistently and accurately identify the problems but the chasm between the Australian Government and the states and territories, in terms of 'action,' prevents effective resolutions. The result is limited progress and cancer patients not being provided with well co-ordinated multi-disciplinary care.

FEDERAL GOVERNMENT - CANCER AUSTRALIA

The Australian Government's initiative in setting up Cancer Australia provides a threshold for effective change, hopefully at all levels of government and with support from the non-government sector. It is essential that Cancer Australia is well funded, otherwise fundamental changes will be unachievable.

STATE GOVERNMENTS

The NSW Government through the Cancer Institute NSW has invested significant funding throughout its cancer services network in order to reorganize its treatment services. This remains a 'work in progress'.

Victoria has also taken initiatives to re-organise its services in having a Ministerial Task Force for Cancer, in setting up eight integrated cancer services and establishing the Victorian Cancer Agency.

Other states have or are in the process of, developing cancer plans but are facing problems relating to lack of skilled personnel and appropriate funding.

Collaboration between the states and territories is recommended to help alleviate these problems.