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Standing Committees on Community Affairs
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TO WHOM IT MAY CONCERN

Senate Inquiry into Out-of-pocket costs in Australian Healthcare

Cancer Voices Australia, the voice of Australians affected by cancer, wishes to offer a brief submission on the matter of out of pocket costs experienced by people being treated for cancer.

Cancer now accounts for 30% of Australian deaths (ABS 2012). In 2012, 121,000 people were diagnosed with cancer, 43,500 died of it and several hundreds of thousands continue to live with their cancer. Due to earlier diagnosis and improved treatments, cancer is becoming in many instances a chronic disease with a longer lifetime. More cancer diagnoses due to the aging of the population, combined with better prognoses, means an increasing need to access treatment, adding to out of pocket expenditure levels.

Cancer is peculiar in that, being not only a major health burden for Australians, it is also the least understood of diseases. An outcome of this is that many diagnostic, curative and life-prolonging treatments are not yet subsidised via the PBAC or MSAC processes. As a result, cancer patients by and large have to cover a greater proportion of their health costs themselves. Those using their private health insurance cover will be affected the most by extra out of pocket expenses, itself a strong discouragement to insure.

Consumer experiences

For example, a woman diagnosed and treated for breast cancer will need regular follow-ups to ensure her cancer does not return or develop further. While her initial diagnosis via Breast Screen is free, her follow ups are not – and only some are Medicare rebatable, still leaving an out of pocket cost. If she developed metastatic breast cancer, she receives no rebate for a PET scan – often essential technology for determining the extent and positioning of her cancer. I am myself, currently facing regular PET scans costing around \$600 each time from my pocket with no MBS rebate. If I don't have them, my clinician and I will not be able to make an informed decision as to the best next treatment for me. I was first diagnosed in 1995, and have lived of 19 years with my cancer. The next PET scan will tell us if I should progress to a drug which will boost the action of the one I currently take. Fortunately for me it is has just been added to the PBS list, or my family and I will be looking at an out of pocket expense of approx. \$50,000 per annum. There are many cancer drugs which are prescribed by medical oncologists, but for one reason or another have not yet received Pharmaceutical Benefits Advisory Committee approval to be accessed via the PBS. Families' finances are severely depleted if a decision is made to take an unsubsidised cancer drug.

Comment on selected Terms of Reference

Cancer Voices will restrict itself to comments regarding the specific out of pocket problems faced by people with cancer as we know them. We support the Consumers Health Forum of Australia's response relating to more general health needs and related costs.

ToR (a) The current and future trends in out-of-pocket expenditure by Australian health consumers

Cancer Voices recommends that the Senate Committee adds an important report to its reference material. This is *Cost of Cancer in NSW* (April 2007), undertaken by Access Economics for the Cancer Council NSW, with strong support from Cancer Voices NSW. This report details financial and economic costs borne by cancer patients during and after their treatment, and by cancer type – some being much more costly than others. We recognise that the Senate Inquiry is especially interested in out of pocket costs borne personally by people with cancer, rather than the far greater cost to the economy due to lost productivity – also calculated by the AE Report. This report summarises the situation as: “financial support is available from government to cover some of these costs; however, as this report shows this does not go far in covering the real costs of cancer”. While the data on which the AE Report is based is dated, the situation and outcomes have not changed.

Re ToR (b) The impact of co-payments on: consumers’ ability to access health care, and health outcomes and costs

Co-payments for chemotherapy and associated drugs in some states (eg NSW) are applied repeatedly for each infusion which adds to out of pocket costs considerably. NSW allows this to occur as it regards chemotherapy treatment at public hospitals as an out-patient service, unlike other states.

Australia has a system of patchwork schemes (eg PATS / IPTAAS) to subsidise patient travel and accommodation required to access treatment. These do not meet the out of pocket expenses accrued by country cancer patients needing to be treated at city or regional cancer centres. Neither do they allow for any support to attend clinical trials, not accepting them as “treatment”.

Re ToR (d) The implications for the ongoing sustainability of the health system

If cancer is diagnosed early and treated well and quickly, future public and private costs will be limited and potentially reduced. We suggest that support for early intervention and regular monitoring would positively influence the sustainability of the health system.

Re ToR (e) Key areas of expenditure, including pharmaceuticals, primary care visits, medical devices or supplies, and dental care

As mentioned above, specific key areas of expenditure for people with cancer are diagnostic procedures, scans, curative surgery, reconstructive surgery, drugs, specialist fees, lymphoedema treatment and supplies. Medicare rebates commonly meet only a portion of specialist fees once a patient is no longer in the care of a public hospital.

Some of these key areas are subsidised to an extent but many are not. For example, if lymphoedema develops following breast or melanoma cancer surgery, resulting in a painful and swollen limb, garments worn to make the condition more manageable are not covered by Medicare which does not regard lymphoedema as a “medical condition”. Treatment at public hospitals for lymphoedema is very limited and private treatment is poorly supported by ancillary private health cover. One member with private health cover reports that she finds she must pay \$800 per annum for lymphoedema massage treatment after a private insurance rebate, and rebates for garments (sleeves, hand gloves etc) cover about two third of costs at best.

Some parents with children who have been treated for childhood cancers face major out of pocket expenses for rehabilitation, psychological treatment and other support – not to mention loss of ability to work due to demands of full time care.

Patients report cost burdens associated with special dietary requirements caused by their cancer treatment, eg PEG feeds for gastric tube feeding for head and neck cancer patients.

People with cancer face substantial costs associated with accessing their treatment at recognised cancer centres, especially if resident in rural and remote areas. They include transport costs, accommodation while being treated (eg if receiving radiotherapy, accommodation will have to be found for up to 6 weeks).

Re ToR (f) The role of private health insurance

Another area which we suggest should be separately examined is those out of pocket costs associated with having cancer treatment through the private sector. Cancer patients are often, in fact usually, very surprised to find that their out of pocket expenditure, despite private health insurance, becomes much greater than they expected. Private health insurance basically assists with in-hospital costs, and there are grey areas for privately insured patients being treated as out-patients by hospitals, substantially increasing their personal outlay.

Privately insured members report frequent lack of up front disclosure of the total out of pocket costs for surgery, drugs and particularly for radiotherapy. It is also not made clear to cancer patients that the same treatment could be had without charge if they were treated at their local public hospital. Many cancer patients cross over between the two systems during their treatment and check-up pathway, which will also incur unexpected costs.

Conclusion

Out of pocket costs are many and varied for the 120,000 Australians who find themselves diagnosed with cancer each year. Many of those costs are unexpected. If the 2014 Health Budget includes co-payments for GP visits, this will obviously add to these costs: the impact on cancer specialist fees is not yet known. The fear associated with a cancer diagnosis may mean that out of pocket costs are ignored as they mount up, in hope of gaining a hold on survival and quality of life, a situation which may have an adverse financial impact for their whole family. It may also mean that follow-up monitoring and treatment is not continued, leading to worse health outcomes.

Cancer Voices Australia thanks the Senate Committee for deciding to look into this very important aspect of Australian healthcare. We trust our contribution is helpful.

Yours sincerely

Sally Crossing AM
Executive Committee
5 May 2014

Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy.
To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000.
The CVA network shares objectives and works together on national issues identified as important by their members, with consumers working to help others affected by cancer.

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