Submission
No 73

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

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Date received:	17/09/2008

Cancer
Council
New South Wales

17 September 2008

The Hon Robyn Parker MLC
Chair
General Purpose Standing Committee No. 2
Parliament House
Macquarie St
Sydney NSW 2000

Dear Ms Parker,

Inquiry into the Program of Appliances for Disabled People (PADP)

The Cancer Council NSW welcomes this opportunity to provide a submission to the General Purpose Standing Committee No.2 *Inquiry into the Program of Appliances for Disabled People (PADP).*

The Cancer Council NSW is the leading cancer charity in NSW. Our mission is to defeat cancer. The Cancer Council NSW envisages a future where no life is cut short or its quality diminished by cancer. The work of the Cancer Council NSW brings us into close and continuous contact with cancer patients and their carers, cancer consumer groups, health professionals, service providers and the community.

The financial costs associated with cancer can cause lifelong hardship, especially for families on low incomes. The PADP, which is administered by NSW Health, is the often the main government support program which provides for the following items needed by cancer patients:

- Tube feeding equipment (not formula) for people who are unable to ingest food by oral intake, including people with head and neck cancers
- Compression sleeves for the treatment of lymphoedema (swelling of the limbs), a condition that affects cancer patients whose lymph nodes are removed as part of treatment
- Aids and equipment for use in caring for people who wish to remain at home during the late and end stage of cancer.

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The Cancer Council NSW believes that there is a need to:

- Clarify the eligibility criteria for the PADP,
- Remove the co-payment associated with the program, and
- Increase the types of items available under PADP so that cancer patients can adequately access the equipment, aids and appliances they require.

Ensuring greater access to items supplied by the PADP, and expanding the program to include Home Enteral Nutrition formula will ensure a greater quality of life for all cancer patients.

Yours sincerely

Dr Andrew Penman
Chief Executive Officer
Cancer Council NSW

Cancer
Council
New South Wales

Parliament of NSW
General Purpose Standing Committee No.2

Inquiry into the Program of Appliances for Disabled People (PADP)

Submission from the Cancer Council NSW
September 2008

Introduction

The Cancer Council NSW is the leading cancer charity in NSW. Our mission is to defeat cancer. The Cancer Council envisages a future where no life is cut short or its quality diminished by cancer.

The work of the Cancer Council brings us into close and continuous contact with cancer patients and their carers, cancer consumer groups, health professionals, service providers and the community. Our strong and multifaceted connections gives Cancer Council a 360 degree perspective of cancer control challenges and opportunities. Our perspective is informed by 20,000 calls per year to the Cancer Council Helpline, our nine Regional Advisory Committees across the state, local community networks associated with our ten regional offices, and our links with 280 cancer support groups.

The financial costs associated with cancer can cause lifelong hardship, especially for families on low incomes. The Program of Appliances for Disabled People (PADP) provides equipment, aids and appliances to people with a life-long or long-term disability in order to support them to live independently in the home. The PADP, which is administered by NSW Health,* is the often the main government support program which provides for the following items needed by cancer patients:

1. Tube feeding equipment (not formula) for people who are unable to ingest food by oral intake, including people with head and neck cancers
2. Compression sleeves for the treatment of lymphoedema (swelling of the limbs), a condition that affects cancer patients whose lymph nodes are removed as part of treatment
3. Aids and equipment for use in caring for people who wish to remain at home during the late and end stage of cancer.

The Cancer Council welcomes this opportunity to provide comment to the General Purpose Standing Committee No.2 *Inquiry into the Program of Appliances for Disabled People.* We believe that there is a need to:

- clarify the eligibility criteria for the PADP,
- remove the co-payment associated with the program, and
- increase the types of items available under PADP so that cancer patients can adequately access the equipment, aids and appliances they require.

This submission was informed by consultation with the Greater Metropolitan Clinical Taskforce (Home Enteral Nutrition Network), Council of Social Service of NSW (NCOSS), research groups, cancer patients and advocacy groups.

Background

A cancer diagnosis can be a devastating and life-changing experience. Financial pressure can place additional stress on patients and their families at a time when they are already struggling to cope with a cancer diagnosis. In the past six months alone, over 550 people telephoned the Cancer Council Helpline regarding financial issues. Over the past year, Cancer Council has provided financial assistance to 1,910 cancer patients and their carers, with small grants of $300 (total of $525,000) to assist with urgent bills.

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* The Department of Ageing Disability and Home care administers a smaller program to provide equipment for people living in DADHC funded and operated group homes.

The Cancer Council also commissioned Access Economics to compile an report defining the total cost of cancer to affected individuals, their families and society.[1] Access Economics reported that households face average costs of $47,200 when one of its members is diagnosed with cancer. This includes approximately $38,000 in lost income as well as $9,000 in health care and other out-of-pocket costs such as transport and specialised clothing and equipment. These costs are borne at a time of great stress and illness.

Government programs such as the PADP can go someway to alleviating the out-of-pocket costs faced by people with cancer and their households. However, a review by PriceWaterhouseCoopers (PWC), commissioned by the NSW Department of Health and released in June 2006, noted that the level of government funding for the PADP meant that the program could not reliably satisfy consumer expectations. This under-funding could lead to a material decrease in the quality of life for those who miss out on necessary items.[2]

The review estimated that there are approximately 6,269 people with cancer in NSW (not in hospitals or assisted accommodation) who could be classified as having a severe and profound disability and may require an aid or appliance under the PADP program.

The NSW Government has made a ten-year commitment to improving the survival rates and quality of life for people with potentially fatal or chronic illness, as outlined in the NSW State Plan.[3] Some of the particular issues faced by cancer patients regarding the PADP and potential avenues for improvement are outlined below.

Ann, carer
"As well as a very emotional time it is also very expensive if you're not on a pension or health care card - everything costs you. My husband is self employed and from the day he found out he had cancer he had to stop work for six months, hence the money runs out. It would be good if there were no out of pocket costs for x-rays and scans for cancer patients. I am lucky that I could take all these 'chemo days' off without losing pay or more of our savings would have gone."

Compression sleeves for lymphoedema

Lymphoedema is the swelling of the arms and legs which can happen after the surgical removal of lymph nodes, for example as part of cancer treatment. Lymphoedema occurs in over 20% of all cancer patients who have undergone lymph node removal.[4] Although exact numbers are hard to determine, the Australian Physiotherapists Association has estimated that there are 25,000 cases of lymphoedema in Australia each year from cancer treatment and other causes. [5]

The use of compression sleeves in conjunction with lymph drainage massage by a physiotherapist can reduce the symptoms of lymphoedema and improve quality of life for cancer patients.[4] This is one of the few evidence-based treatment options for this condition.

The cost of a pair of compression sleeves is approximately $600; these need replacing at least once each year. Those cancer patients for whom more than one limb is affected by lymphoedema, two or more compression sleeves will be needed at any one time. Some of the costs of lymphoedema sleeves are borne by the private health insurance industry. Patients with certain types of private health insurance cover may be able to claim some of the cost of these sleeves.

Under the proposed changes to the PADP income tiers, as outlined in the NSW Government's response to the PWC inquiry,[6] only those with an income of less than $30,000 would be eligible for compression sleeves, as they are classified by the PADP as a 'medium cost item.'

Home enteral nutrition

Home Enteral Nutrition (HEN) refers to food in liquid form given through a tube into the stomach or the small intestine, provided in the home setting. HEN supplies are used by people who are unable to ingest food by oral intake, such as those with head and neck cancer. An inquiry by the Greater Metropolitan Clinical Taskforce Home Enteral Nutrition Network estimated that there are a maximum of 10,000 patients receiving HEN therapy in NSW; of which approximately 34% are cancer patients.[7] The inquiry also found that although half of all HEN recipients are financially disadvantaged, only 20% of tube-fed HEN patients received PADP assistance. The PADP provides some subsidy towards tube-feeding equipment (feeding pump and bags), but does not include provision for the supplement formula.[8]

Presently the cost of HEN formula is borne by patients, although they are now able to purchase the supplies at the lower government contract prices. For tube fed HEN, this can cost patients is approximately $300 per month, depending on the feeding apparatus involved.[9] The costs to patients and NSW Health (under a fully-funded model) as estimated by the GMCT are outlined in Table 1.

The GMCT report noted that HEN tube feeding equipment is sometimes re-used by patients due to its cost; the Therapeutic Goods Administration recommends that the equipment is replaced on a daily basis to comply with safety guidelines. HEN products are not covered by private health insurance.

Table 1. Cost to NSW Health to fully fund HEN products (in 2005 values)[9]

Type of HEN	**Number of NSW HEN patients**	**Average cost/patient/month** (NSW contract price)	**Cost for NSW HEN population per year**
Oral HEN	7,000	$70.50	$5,922,000
Tube fed HEN	2,800	$281.20	$9,448,080
Total cost to NSW Health			**$15,424,080**

Palliative care

The Cancer Council brings to the committee's attention those people with cancer who are in the end stages of their illness. Palliative care is any form of treatment that concentrates on reducing the severity of the symptoms of a disease or slowing its progress, rather than providing a cure.[10] People with cancer constitute approximately 85% of palliative care patients. The pattern of care of people with a life-limiting illness has changed from an emphasis on institutional care, to care in the home supported by community health and support services.[11] Up to 90% of people with a life-limiting illness spend the majority of their last year of life at home, and approximately one third of people who receive palliative care services actually die at home.[11]

Therefore there is a increasing reliance on programs such as the PADP which provide equipment and aids which enable the carers of cancer patients to care for their loved one at home.

Addressing the Terms of Reference

TOR 1: Adequacy of funding for present and projected program demand

The PWC review concluded that the PADP budget of $24 million (in 2005/06) was inadequate to meet the needs of the disabled community. The review estimated that at least $50 to $100 million (before co-payments and expenses) would need to be allocated towards the PADP in order to meet current demand.[2]

To access the PADP currently requires a co-payment of $100 per year from clients; the NSW Government has suggested this will rise to $200 per year.[6] For lower or medium cost items such as lymphoedema sleeves, the co-payment represents a significant proportion of the total cost of the item.

Peak welfare groups such as the Council of Social Service of NSW (NCOSS) have noted that the current system of co-payments does not recognise the low income generally experienced by the clients of the PADP who have a disability. We agree that the current scheme does not adequately assist people in need of equipment, aids and appliances, and that the co-payment places an unreasonable burden on people with low incomes or high needs. Many cancer patients face significant out-of-pocket costs as a result of their diagnosis and treatment. Several options exist for the NSW Government to reform the PADP system to provide greater equity for its clients.

Recommendation regarding income eligibility criterion

In order to recognise the financial difficulties faced by PADP clients including cancer patients, the Cancer Council supports removing the PADP co-payment requirement for those on lower incomes or with demonstrable financial difficulty. We recommend that the cut-off income tier for this provision be increased to $45,000 (single income); this represents approximately 75% of the national average wage.[12] An additional funding of **$17 million** would be required in 2009/10 as an intermediate step to cover the increase in the income eligibility criterion - as per the calculations in the PWC review. We recommend that the total budget should then rise to $76 million in 2014/15 to meet this increase completely.

Recommendation regarding Home Enteral Nutrition

The Cancer Council supports the Greater Metropolitan Clinical Taskforce HEN Network recommendation that NSW Health expand the PADP to include HEN formula, to relieve the cost burden on cancer patients and others who rely on tube feeding for all or part of their nutritional needs.

Some states in Australia such as the ACT and Queensland require HEN clients of similar programs to provide a contribution which equates to the average cost of food they normally would have purchased. However, the GMCT reported that only 16% of HEN patients require nutritional supplementation to replace food completely, and many of these patients are financially disadvantaged.[9] In Victoria, tube fed HEN is fully funded. For more detail on HEN supplementation, please see the GMCT submission to this inquiry.

A co-payment should only be considered for the small minority of patients who rely on HEN for their total nutritional intake and have higher incomes. The GMCT have estimated that expanding the HEN nutritional assistance program to include formula, as well as consumables and equipment, would cost NSW $17.1 million[*] as a fully-funded model.[9] Currently, the PADP spends approximately $300,300 per year on

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[*] Figure derived from the GMCT report (2006) and adjusted for inflation to 2008 values.

supplying new HEN equipment to its clients,[2] an amount which is woefully inadequate. Thus an additional **$16.8 million** would be required to expand the nutritional aids program for the 2009/10 NSW State Budget.

Thus implementing the above Cancer Council recommendations would require a budget increase of **$33.8 million** towards the PADP in the 2009/10 NSW State Budget.

TOR 2: Impact of client waiting lists on other health sectors

The Cancer Council, in conjunction with Newcastle University, is currently engaged in two large research projects examining the experiences of people with cancer (including those at the end-stage of disease) and their carers. Preliminary results from these research studies show that cancer patients and their carers require emotional as well as practical support including financial assistance, improved access to medical care and a greater availability of in-home support services. These findings support those also contained in an issues paper which assessed the opinions of health professionals regarding palliative care services in NSW.[13]

One of the most important issues to have emerged from these initiatives is the need for specialised equipment to be immediately available to both adult and paediatric palliative care patients and their carers. Equipment to assist carers in their tasks of lifting and carrying out personal care is essential for maintaining the carer's own physical health during the caring period.

Cancer patients or their carers have told the Cancer Council that they could remain at home for longer, and in some cases even die at home, if greater services and equipment were available to them. Specialised equipment to help in the care of the person with cancer is a factor affecting the capacity to remain in the home and therefore prevent the patient's unnecessary transfer to a hospice or hospital. The review of the PADP noted that under-funding of the program led to long waiting lists for some items. Being placed on a waiting list is untenable for those cancer patients who are in the palliative stage or end-stage of illness.

The Cancer Council recommends that those in the end-stage of illness be placed on a 'high priority' list, so that they are able to access the equipment they need in a timely manner.

Service provider, Sydney
"Even with all other possible supports in place, the lack of access to enough, affordable and appropriate equipment for patient care can be the stumbling block to continued successful care of the palliative patient at home. Equipment is expensive to hire or purchase and the sources we have now for procuring equipment on loan do not stretch far enough. Apart from patient care, the correct equipment is key to maintaining the health and safety of both unpaid and paid carers."

TOR 4. Appropriateness and equity of eligibility requirements

There is confusion surrounding the eligibility criteria of cancer patients for the PADP, and especially palliative patients, as noted in the PWC review.[2] As per the PADP policy guidelines, the target population for PADP is those individuals living in the community who have a disability of permanent or indefinite nature (e.g. a disability likely to last more than 12 month regardless of the cause of the disability) as defined under the *Disability Services Act 1993*. Hospitals are required to provide certain items for short terms use (approximately three months) for people with cancer and other advanced conditions.[8]

However, for many cancer patients the length of time that they may require PADP items is for longer than three months, but may be less than twelve months. In many cases, the prognosis is uncertain. In addition, the Cancer Council Helpline has noted that many callers are unaware of the existence of the PADP when requesting assistance for various items. Greater awareness of the PADP amongst health professionals and cancer patients would assist people to access the equipment they need.

Julianne Whyte, a palliative care social worker from the Riverina Murray area, has told the Cancer Council that for some types of equipment the PADP requires a referral from a general practitioner as well as an occupational therapist (OT). Ms Whyte noted that in rural areas,

> "Public OTs are not available in all communities, and there is a waiting time for accessing private OTs. For clients with palliative care needs, there is not the time to wait for an OT assessment unless there is one associated with the local health service, and the wait time for a GP appointment can be 1-3 weeks in many communities.
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> Our experience, which has been across the large geographic region of the Riverina Murray is that clients, their families and carers do not access PADP unless they have a case manager, have an advocate, have assistance with the application process, have a local OT, and definitely not when they are palliative and do not have access to any of the above assistance.
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> Oxygen is another issue. PADP provide oxygen if a person fits the criteria for lung function and oxygen perfusion. Many palliative care clients can benefit from oxygen but do not fit either requirement for PADP, however it is often a first line treatment for anxiety, pain and breathlessness once a patient is admitted to hospital. Many palliative care patients are admitted to hospital, possibly unnecessarily, for oxygen therapy to relieve anxiety, pain and other symptoms that having oxygen at home has been known to relieve. Not many patients are able to access this (at home), as they have to pay monthly fees for concentrators, and portable cylinders, on top of other major medication and travel costs."

The Cancer Council recommends that the PADP policy guidelines are altered to ensure the eligibility of cancer patients, including palliative patients, for PADP items. For those regions where an occupational therapist is unavailable, it would expedite the process if the assessment could rely solely on the existing health professional or social worker's advice.

Summary of CCNSW Recommendations

The Cancer Council recommends that the NSW Government:

1. Delivers its promise to improve survival rates and quality of life for people with potentially fatal or chronic illness, as outlined in the NSW State Plan.
2. Increases the funding for the Program of Appliances for Disabled People to $33.8 million for the 2009/10 State Budget.
3. Removes co-payments for people earning less than $45,000 (single income) per year, as they inflict unnecessary financial hardship and may delay people applying for necessary equipment.
4. Expands the program to include provision of home enteral nutrition formula, in addition to the tube feeding equipment.
5. Ensures the eligibility of cancer patients and those in the palliative stage of their illness for PADP items.
6. Ensures that those in the palliative stage of their illness are placed on a 'high-priority' list to receive PADP items.
7. Develops and implements an information strategy that increases awareness of the PADP scheme amongst health professionals and cancer patients.
8. Simplifies the assessment process for people living in rural and regional areas which do not have an occupational therapist or general practitioner.

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