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Submission No. 998
(Inq into better support for carers)



16 July 2008

Mr James Catchpole
Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
Canberra ACT 2600

Dear Mr Catchpole,

**Standing Committee on Family, Community, Housing and Youth:
Inquiry into better support for carers.**

The Cancer Council NSW and HOME Hospice Inc welcome this opportunity to provide a submission to the Standing Committee on Family, Community, Housing and Youth *Inquiry into better support for carers*.

The Cancer Council NSW is the leading cancer charity in NSW. Our mission is to defeat cancer. HOME Hospice is a free community program that empowers the community to provide support to people caring for relatives or friends with a life-limiting illness at home.

The Cancer Council and HOME Hospice have been aware for some time that carers of people with cancer undertake a daunting role – caring takes a toll on their well-being and health, and they face difficulties in obtaining necessary services and support. In addition, the wish of many patients and their carers is for those in the end-stage of disease to be able to die at home. However, most deaths in Australia still occur in hospital.

Overall, our formal research and community consultation has confirmed that carers of cancer patients require emotional and practical support including financial assistance, income support and job protection. There is also a need for increased access to generalist and specialist medical care, especially home visits and after-hours care in order to support carers in their role. In addition, greater access to professional cancer care co-ordinators to help patients and their carers navigate through the complex cancer journey is essential.

Carers report the need for more information about the disease and medical management of the person they are caring for. They require information about how they can provide certain types of medical care (such as pain relief and wound dressing) for their friend or relative at home.

July 16, 2008

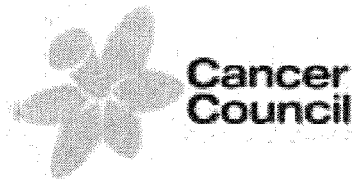
Greater availability of in-home help, respite and specialised equipment to assist carers is also needed to ensure the health and well-being of carers in their role.

Ensuring greater access to social security benefits, professional medical care in the home and expansion of the HOME Hospice program will overcome many of the above issues and will ensure that enabling death at home whilst caring for those with a life-limiting illness, becomes a normal part of living.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Andrew Penman', with a large initial 'A' and a long horizontal stroke.

Dr Andrew Penman
Chief Executive Officer, Cancer Council NSW



Parliament of Australia House of Representatives
Standing Committee on Family, Community, Housing and Youth

Inquiry into better support for carers

**Submission from the Cancer Council NSW and
HOME Hospice**

July 2008

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1. Summary

The Cancer Council NSW is the leading cancer charity in NSW. Our mission is to defeat cancer. HOME Hospice is a free community program that empowers the community to provide support to people caring for relatives or friends with a life-limiting illness at home.

The Cancer Council and HOME Hospice have been aware for some time that carers of people with cancer undertake a daunting role – caring takes a toll on their well-being and health, and they face difficulties in obtaining necessary services and support. In addition, the wish of many patients and their carers is for those in the end-stage of disease to be able to die at home. However, most deaths in Australia still occur in hospital.

Overall, our formal research and community consultation has confirmed that carers of cancer patients require emotional and practical support including financial assistance, income support and job protection. There is also a need for increased access to generalist and specialist medical care, especially home visits and after-hours care in order to support carers in their role. In addition, greater access to professional cancer care co-ordinators to help patients and their carers navigate through the complex cancer journey is essential.

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Greater availability of in-home help, respite and specialised equipment to assist carers is also needed to ensure the health and well-being of carers in their role.

Ensuring greater access to social security benefits, professional medical care in the home and expansion of the HOME Hospice program will overcome many of the above issues and will ensure that enabling death at home whilst caring for those with a life-limiting illness, becomes a normal part of living.

2. Recommendations

The Cancer Council NSW and HOME Hospice make the following recommendations to this inquiry, with the emphasis on supporting carers in their role of caring for a cancer patient at home.

Community support for carers of home-based cancer patients.

To ensure adequate support for carers of home-based cancer patients, it is recommended that the Commonwealth Department of Health and Ageing:

1. Invest in and support the expansion of the community-based mentoring program, HOME Hospice on a national basis. This would include collaborating with HOME Hospice on policy initiatives relating to home-based palliative care. This HOME Hospice model empowers carers, family and friends to care for their loved ones at home until they die.
2. Ensure cancer patients and their carers are eligible for Home and Community Care-funded services and that services are fast-tracked for palliative patients.
3. Continue and expand programs which provide specialised equipment to assist people with cancer who are being cared for at home.

Financial issues

Both state and federal governments have a responsibility to alleviate cost burdens on cancer patients and their families. In particular, the following actions are recommended for the Department of Human Services:

4. Ensure easier criteria and clearer policy guidelines for access to Social Security payments for cancer patients and carers.
5. Increase the amount of assets people can hold before being entitled to social security payments. It is recommended that the Centrelink 'liquid assets' criteria is doubled to \$10,000 for households with a member diagnosed with cancer, and to \$5,000 for a single person.
6. Expand Centrelink outreach services which allow people to send in their claims with accompanying medical information if too ill to attend in person. Adequate privacy and easier queuing systems for cancer patients and carers attending a Centrelink office is needed.

Several government agencies and would be involved in the following actions, which may include changes to federal industrial relations and health provision laws:

7. Better employer support via extended sick leave entitlements for both carers and cancer patients. Psychosocial and practical support and training to enable people to return-to-work after their caring role has finished.
8. A national overhaul of the isolated patient travel and accommodation schemes, including a substantial increase in subsidy and streamlining of bureaucratic processes.
9. A state-based or national expansion of community transport schemes, including increases in funding and better monitoring of service provision and unmet need. This should include improvements to health transport options for Indigenous people, by providing dedicated services to Aboriginal communities and including increasing the network of Aboriginal transport coordinators.
10. Greater requirements for financial disclosure by medical professionals, including options regarding publicly-available services for privately insured patients.

Recommendations surrounding medical care

It is recommended that professional medical bodies and the state and federal health departments collaborate to:

11. Enhance the medical communities' understanding of the desire and ability of the community to care for their friends or loved one at home in the event of a serious illness. This may include changes to undergraduate medical courses.
12. Implement clear standards and guidelines which ensure the delivery of appropriate information and training for carers who are providing basic medical care for their friend or relative with cancer.
13. Continue and expand Medicare Benefits Schedule items to allow for multidisciplinary care and encourage after-hours services and home visits by medical professionals.
14. Expand the medical workforce to meet community needs, especially with regard to general practitioners, community nurses and palliative care specialists.
15. Expand funding for outreach services to rural, regional and isolated areas by medical specialists, including medical oncologists and palliative care specialists.
16. Establish 24 hour tele-health palliative care advice services as a backup for the generalist medical workforce in rural, remote and isolated areas.
17. Increase the number of case co-ordinator positions to help people with cancer and their carers navigate and understand complex medical treatment pathways.
18. Continue and expand existing palliative care training programs to ensure an adequate specialist palliative care medical workforce.

3. Introduction

This submission has been compiled as a collaboration between The Cancer Council NSW and HOME Hospice (Inc). The Welfare Rights Centre (NSW) kindly provided advice as to Centrelink requirements for cancer patients.

The carers of cancer patients undertake a daunting role – caring takes a toll on their well-being and health, and they face difficulties in obtaining necessary services and support. Up to 90% of people with a life-limiting illness spend the majority of their last year of life at home.¹ In addition, the wish of many patients and their carers is for those in the end-stage of disease to be able to die at home; however, most expected deaths occur in hospital.

Jill, carer

As a carer, I feel I am suffering the same disease, walking every step with my partner, feeling their fear, anxiety and depression. I feel so overwhelmed at times, and feel our lives will never be the same.

The Cancer Council provides services to support carers of cancer patients to carry out their role and maintain their own physical and mental health and wellbeing through the caring period and beyond. The Cancer Council has a particular interest in those caring for people with a life-limiting illness at home. In recognition of the needs of carers, over the past year the Cancer Council has been supporting HOME Hospice to expand the reach of its community-based mentoring program.

As several large-scale studies have outlined in detail the psychosocial, medical and practical needs of carers of those with a life-limiting illness,¹⁻³ this submission focuses on the most urgent needs of those with whom the Cancer Council is currently directly engaged with, either in a consultative capacity or in formal research.

In many cases it was not possible to name the organisations or people who provided input, due to the confidential nature of the consultations. In addition, although people with cancer constitute approximately 85% of palliative care patients, the Cancer Council NSW and HOME Hospice believe that the issues outlined in this submission will also be shared by others who are cared for at home during a serious illness.

This submission addresses the following terms of reference of the House of Representatives Standing Committee on Family, Community, Housing and Youth *Inquiry Into Better Support for Carers*:

1. The role and contribution of carers in society and how this should be recognised.
2. The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.
3. The practical measures required to better support carers, including key priorities for action.
4. Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

4. Sources of information for this submission

4.1. The HOME Hospice program

HOME Hospice is a free community program that provides support to people caring for those with a life-limiting illness at home. To achieve this, HOME Hospice provides carers with a trained volunteer Mentor, who guides them through the caring journey, providing information, education and links to the support services needed at this physically and emotionally demanding time. The Mentor also guides the carer to connect with and coordinate the goodwill of friends and neighbours.

The Home Hospice vision is a world in which family and community are able to perform their traditional role of caring for loved ones with a life-limiting illness to die at home where they belong and to transform the 'crisis' of death and dying into a catalyst for personal communities to come together in service and care for one another. The Cancer Council NSW and Home Hospice believe that people with a life-limiting illness should be able to remain at home until they die, if that is their wish. HOME Hospice was endorsed by the World Health Organisation in 2001.

The essence of the carer's support by HOME Hospice Mentors is that it is provided by friends in the context of love. Through the carer's invitation for the Mentor to be involved at this significant time, the Mentor's role of knowledgeable friend and guide is eventually established. That takes time and much more. The real support for the carer then comes from the engagement of friends of the carer and dying person. That is the essential dynamic that becomes transformative both for the carer and for the involved friends.

In the last 12 months, since partnering with the Cancer Council NSW, the number of HOME Hospice Mentors has increased by 600%. For this submission, the HOME Hospice Mentors were surveyed as to their opinions regarding client needs in their communities; these included Mentors who are currently engaged in caring for families, as well as those who assisted a family whose loved one has since died.

Peter's last Christmas

Peter is a father of three young children aged two, four and six years, and is dying of lung cancer. He is married to Julie who has been caring for him throughout his illness as well as looking after the needs of their children.

Peter does not want to die in a hospital. He wants to die at home and Julie really hopes to be able to care for him and grant him this wish. Peter and Julie have connected with HOME Hospice and have a volunteer Mentor, Linda, who is supporting Julie and guiding them through this emotionally, physically and spiritually difficult journey. Linda supports Julie as a knowledgeable friend and helps Julie make the most of the precious time her family has left together. Although it is a very sad time for everyone, Linda is able to suggest ways they can use it as an opportunity to bond as a family, remember the good times, and gather their community of family, friends and neighbours to support Julie in her caring role. Linda has helped Julie gather a group of 30 people around her who help with the washing, taking the kids to school and day-care, cooking meals, taking their eldest son Tom to cricket practice and sometimes sitting with Peter while Julie gets out for a walk.

Julie feels overwhelmed in a joyful way with the support her family has, and the closeness she feels from sharing this experience with others. She feels safe knowing that long after Peter dies, they will be there for her, and have an intimate understanding of her pain and grief, and that of the children, because they shared it so closely with her.

What is happening around me is quite extraordinary. I knew this would be tough but I didn't know so much joy could come out of it, from Pete's dying days. I feel an immense sadness that the children will soon not see their dad again, but what we have here is precious and the kids are gaining something important from having Pete at home, living with us while we all have to get on with life. – Julie.

Marc and Jana's story, by their HOME Hospice Mentor

Marc had been in hospital and very unwell for two weeks until Jana finally brought him home. It was not an easy thing for her to do and she relied on me somewhat to reinforce the plans that we had put in place and the importance of bringing him home. Marc's brother and sister have both decided he is better off in hospital – we suspect that it is their own individual fears playing out.

Jana and her two daughters are today over the moon that he is home – Jana's words to me this morning through tears were that he was not going to be around for much longer but it was wonderful to have him where he belongs. She has all of the possible services in place in the home – nursing visits twice daily are a huge help and she also has in-home respite care, all the equipment she needs, and the support of her family GP who has backed her all the way in her dream to have him at home.

Just to let you know Marc died at home on Saturday.

If death is perfect it certainly was. He was home and how wonderfully normal life seemed during those last days, don't let anyone say or discourage people not to try to bring their loved one home, what a blessing it was to be able to cuddle Marc, kiss him and release him to the angels and to have him resting in his bed for a number of hours before I was able to release him to the funeral home. As you know there were many that thought bringing him home was not something that I should do – so I thank you for the encouragement having Marc die at home amongst the things and people he loved, this will help lessen the burden of our loss. Will keep in touch, I certainly would like down the track to encourage many, many more to experience the peace of allowing a loved one pass and also stay in your life. – Jana, five days later.

4.2. Community perspectives

The Cancer Council NSW has access to a wide range of information about the experiences of cancer patients and their carers. These include several levels of consultation with the community, health professionals and service providers, information gathered from over 20,000 calls per year to the Cancer Council Helpline and from our established networks of community representatives and volunteers across NSW. The Cancer Council also receives feedback from various cancer support groups and from affiliated organisations.

In 2006, the Cancer Council published an issues paper regarding home-based palliative care to assess the opinions of health professionals regarding palliative care services in NSW.³

4.3. Formal research

The Cancer Council NSW is currently undertaking several formal research studies into palliative care, cancer survivors and their carers.

The Centre for Health Research and Psycho-oncology (CHeRP) is a behavioural research centre jointly funded by The Cancer Council NSW and The University of Newcastle. Its researchers are part of the Hunter Medical Research Institute (HMRI) Public Health Research Program.* Two of the many studies CHeRP are conducting are used in this inquiry. However, only the preliminary results are currently available, further details regarding methods and results will be released in due course.

The Partners and Caregivers (P&CG) Study

A longitudinal population-based study of cancer survivors is currently being undertaken in NSW and Victoria. A longitudinal study of the psychosocial outcomes of their partners and caregivers is being conducted in parallel. The partner/caregiver is invited to complete a survey at baseline (6-months post-diagnosis of the cancer survivor), 12 months, 2 years, 3.5 years, and 5 years post-diagnosis. The study will identify changes in the levels of anxiety, depression, quality of life and unmet needs over the first five years since the cancer diagnosis. The personal factors, such as social support, coping style, personal characteristics, work and financial situation, associated with these outcomes will also be identified.

Palliative Care Needs Assessment Project (PCNAP)

CHeRP is conducting a program of research to facilitate needs based access to palliative care. To support the identification of patients and families with high levels of unmet needs and promote needs based referral to specialist palliative care and other support services, the research team developed the Palliative Care Needs Assessment Guidelines.*

People with advanced cancer and their caregivers are participating in second monthly telephone interviews over a period of up to two years. After an initial baseline period, the guidelines and PC-NAT are being used during consultations with the person with cancer, to assess their levels of needs. Changes in patient and caregiver outcomes and service utilisation will be compared pre and post-intervention across the study sites.

* For more information, please go to www.newcastle.edu.au/centre/cherp/index.html

* Summary version available from: www.newcastle.edu.au/centre/cherp/professionalresources/index.html

5. The role of carers

Research indicates that cancer survivors rely strongly on their partners and families for emotional support, rather than psychologists or other health care providers. To ensure the ongoing support provided by informal carers, it is important that they are supported in that role. Carers are often working while providing many hours of care each week, with some carers needing to take periods of leave to maintain the role. Care-giving imposes a financial burden in terms of lost income as well as extra expenses, hence increased levels of financial support for carers are needed.^{1,4-6}

Leanne, Carer

Coming to terms with my husband's cancer has been made more difficult by my diagnosis and treatment for breast cancer. I also have several health issues which require hospitalisation but these have to be shelved until his immediate treatments are over.

Care giving has been associated with poorer levels of overall health compared to the general population,^{7,8} with a higher risk of injury, stress, tiredness, burnout, and high blood pressure reported amongst carers.⁹

The Partners and Carers Study

Preliminary results from the Partners and Carers Study (P&CG) have found that most carers reported providing the following assistance to the cancer survivor:

- Provide emotional support
- Perform household tasks (eg. cooking, cleaning)
- Do other odd jobs around the house
- Manage money (eg. household bills)
- Provide transport.

A significant proportion of the P&CG respondents also provide some or all of the following:

- Manage medications
- Liaise with doctors and find out information
- Assess the need for medication or treatment
- Provide financial assistance
- Organise appointments
- Provide wound or stoma care
- Assist with personal care (eg. bathing, dressing)
- Help with mobility.

Leah, carer.

There's tonnes of support for the patient, but not always much follow-up for the carer down the track when they are out of hospital (especially if a carer is weary and finds it hard to ask for help). I think our society finds it hard to deal with long-term and ongoing illnesses. People want you to be well quickly. Years of recovery are hard for people to follow up. There's an initial surge of support, then it fades as people move on with their lives

The study has so far found that over one-third of carers met levels of borderline or clinical anxiety. Many carers reported a feeling of isolation and loneliness because of their caring role. Many carers also have health problems themselves, some are also cancer survivors and some care for many people at once, including children, and other relatives and friends.

Palliative Care Needs Assessment Study

Preliminary results of the Palliative Care Needs Assessment Study (PCNA) are supportive of the above Partners and Carer study findings. Carers involved in the PCNA study are caring for people with advanced cancer where there is no expectation of cure. The majority of carers in this study are over 60 years of age, female, and the spouse of the person they are caring for.

Most carers of those with advanced cancer reported spending more than 32 hours per week providing care for someone with a life-limiting illness. This was mostly provided on an everyday basis.

For those caring for a friend or relative with a life-limiting illness, almost half of carers were defined as either borderline or clinically anxious. Also, half of the carers surveyed in the PCNA study reported at least one health problem themselves; many reported having arthritis and/or high blood pressure.

6. Financial issues

Cancer patients and their households face significant financial costs at a time of considerable stress. Over 550 people telephoned Cancer Council Helpline regarding financial issues in the past six months. In addition, Cancer Council NSW has a financial assistance program which helped 1,910 cancer patients and their carers with small grants of \$300 who were in financial difficulty last year. The Cancer Council gave out a total of \$525,000 in financial assistance grants for the year.

Preliminary results from the P&CG and PCNA study found one-third to a half of carers reported a net household incomes of less than \$500 per week and many carers received a government pension or benefit.

Almost half of the P&CG study group was currently employed (full-time, part-time, casual, self-employed). Almost half of the people in the P&CG study had taken leave or had changed their work situation because of their caring role.

Some P&CG study subjects noted particular issues if they were self-employed. They were unable to apply for new contracts if unwell or if they had to look after their partner, and some had to sell their business.

The Partners and Carers study found that approximately three-quarters of carers reported having significant out-of-pocket costs associated with caring:

- Almost half of carers paid for costs when the cancer survivor visited health care professionals. Average cost \$1,700, ranging up to \$14,000.
- Almost half of carers paid for prescription medication for the cancer survivor, and/or over-the-counter medication for the cancer survivor.
- A third of carers paid for travel costs when the cancer survivor visited health care professionals. Average cost \$415, ranging from \$20-\$5,000.
- The majority of carers reporting costs paid for these from income, savings, and loans.

As a result of reported financial issues, Cancer Council NSW commissioned Access Economics to undertake a systematic analysis of the nature and extent of the financial impact of cancer on individuals and society in NSW.⁶ Access Economics found that households on average bear 41% of the total financial cost of cancer. Governments pay approximately 42% of the cost of cancer, with society taking up the remaining portion.

The average lifetime financial cost of cancer faced by households for each person diagnosed in 2005 includes the following costs:

- A reduction in income including lost productivity and carer costs.
- An increase in out-of-pocket expenses including health costs and other financial costs.

Access Economics found that on average, a household can expect to lose **\$47,200** as a result of one of its members being diagnosed with cancer.

Ahn, 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.

Although this amount represents the lifetime financial costs, it is expected that the bulk of the out-of-pocket costs are incurred in the first year of diagnosis and treatment. As well as lost income, a person with cancer can expect to pay an average of **\$9,900** in health care costs (medical gap payments, pharmaceutical products etc.) and in other out-of-pocket expenses such as transport, communication, equipment, specialised clothing, respite care and home modifications. The study found that the costs due to lost income can be as much as \$275,000 for those of working age.¹⁰

6.1. Social security payments

Centrelink is a statutory authority responsible for administering social security payments including, Disability Support Pension, and Carer and Family Payments. Several cases have been reported in the media regarding the treatment of cancer patients by government Centrelink staff. In general, these issues include confusion surrounding eligibility of cancer patients for payments after a cancer diagnosis. This places a lot of financial stress on the household of the cancer patient, especially if they are the main source of income. Those payments of relevance to cancer patients generally include:

Mike, carer
 There is no-one dedicated to advising the patient of likely overall costs of treatment. Including pre-op chemo and radiotherapy, per operation in-hospital costs, post-op chemo and all the pathology that's done, no-one to advise how these costs can be managed or how and when to apply for sickness benefit.

Disability Support Pension	For people unable to work 15 or more hours per week for at least 2 years due to illness, injury or disability. This has an income/assets test requirement. Recipients must have a physical impairment that has a rating of at least 20 points under the statutory Impairment Tables, which are used to assess ability to work.
Sickness Allowance	For people temporarily unable to work due to temporary illness, injury or disability who have a job or study to return to.
Newstart Allowance	For unemployed people aged over 21 who are looking for work. An exemption to activity requirements is available for people who are temporarily unable to work due to illness, injury or disability and principal carers (of a child under 16).
Carer Payment/ Carer Allowance	Carer Payment is for people who provide constant care for a disabled person (adult or child) at home. The Carer Allowance is a fortnightly payment of \$100 which can be paid in addition to Carer Payment or on its own.

There have been many reports regarding the confusion of patients whose illness is neither temporary nor expected to last for over two years. For many people with cancer the duration of illness is actually difficult to ascertain, even by medical experts. Several people with cancer have told the Cancer Council that they were initially denied the Disability Support Pension because Centrelink claimed that cancer was 'a temporary illness.' This meant that they were asked to seek work whilst undergoing cancer treatment, under the terms of the Newstart Allowance. In most cases, although payments were finally granted, it demonstrated confusion on the part

of Centrelink staff as to correct criteria, and cancer patients and their carers had to make unnecessary visits to the Centrelink office during a time of illness.

In addition, the Cancer Council has heard complaints that the waiting periods that may effect a person when they get their first payment. If a person with cancer receives annual leave, sick leave, long service leave or redundancy pay at the time they leave their job, this money is counted as income for the length of time covered by these entitlements. This may reduce or cancel a person's Social Security payments for some time. The income maintenance period can be reduced, but only if a person can prove that they are in financial hardship, and meet a very strict test. The 'Income Maintenance Period' applies to many payments, including Sickness Allowance, Newstart Allowance and Disability Support Pension.

Anthony, carer

Apart from the emotional impact - the financial impact is important as well. To go from two salaries to one while raising three kids is incredibly tough and no Centrelink support when you have to 'draw down' on your superannuation because private health insurance doesn't cover it all (even with top hospital and extras cover).

Complaints are also made about having to serve a 'liquid assets waiting period' of up to 13 weeks. 'Liquid assets' are funds that you can get at short notice (i.e. within 28 days). A person who has liquid assets above \$2,500 (as a single person) or \$5,000 (for a couple or a single person with a child) will face a Liquid Assets Waiting Period (LAWP). For each \$1,000 over the limit, a person will face a one week waiting period up to a maximum of 13 weeks.

The maximum amount of liquid assets a couple may hold and still be entitled to a Social Security payment without serving a waiting period is \$5,000. This is a very low amount for households facing medical bills which can be considerable, as shown in the Access Economics study. It is counterproductive to force people with significant illnesses to essentially use all of their savings at the same time that they are facing an uncertain future, with an unclear diagnosis about how their illness may progress. These waiting periods strip often very sick people of often modest levels of savings at the very time that they may be facing higher medical expenses and transport costs as a direct result of their illness. Money put aside for home modifications, or to purchase care services is eaten away by these unfair and harsh waiting periods. The exempt amount, of \$5,000 for a couple, is hardly enough to cover the costs of an even basic funeral if a member of a couple succumbs to their illness.

Other Centrelink issues include the lack of privacy for claimants whilst attending a Centrelink office (Centrelink does not generally provide private offices for people to discuss their medical issues); and, at some offices, being forced to queue up for several hours without a chair to sit on. In theory, if people are very ill they are allowed to fax in their medical forms rather than attend an office in person; however, this practice is discouraged by Centrelink, causing people who are ill and their carers undue hardship in having to attend the office in person at a time of great difficulty.

The Welfare Rights Centre submission to this inquiry examines these issues in more detail, especially regarding better arrangements for people with chronic illness who relinquish Social Security benefits and are no longer entitled to a Health Care Card, although their earning capacity may be very low.

6.2. Transport costs

Transport to medical care and the cost of travel is a major issue for people with cancer and their carers. Transport not only imposes a financial burden, but issues surrounding the eligibility of carers to access government-funded transport schemes can cause a great deal of stress. In many cases, the carers provide transport directly for their friend or relative with cancer. The Cancer Council NSW has joined other organisations¹¹ in campaigning for improvements to government-funded schemes relating to non-emergency health-related travel. In general two government funded schemes are of importance to people with cancer:

Case study

A resident of a town which is 99km from Sydney, whose carer drives them to radiotherapy treatment in Sydney every day for a period of six weeks, would face out-of-pocket petrol costs of at least \$900 and would not be eligible for reimbursement from the government.

1. **Patient assisted transport schemes (PATS):*** each state or territory operates a subsidy scheme for isolated patients to access medical specialists. A federal inquiry into the operation of patient assisted travel schemes such as IPTAAS found that these schemes do not adequately compensate patients and do not overcome distance as a barrier to medical treatment.¹¹
2. **Community transport schemes** typically provide one-to-one or group transport to isolated families, the frail aged and people with disabilities in order to facilitate access to a range of services. Each state or territory generally operates a community transport program which utilises one or more sources of formal funding from federal, state and local governments. In New South Wales, Queensland and South Australia, community transport is co-ordinated by the state departments of transport. In Victoria, Western Australia and the Northern Territory, it is co-ordinated by the state departments of health. A recent inquiry into community transport commissioned by The Cancer Council NSW estimated that approximately 90,000 people are refused community transport for health-related trips each year in NSW.¹²

* Known as IPTAAS in NSW.

7. Palliative care issues

In Australia, one in two people will be diagnosed with cancer before the age of 85.¹³ Approximately 40% of cancer patients will die of cancer-related causes within five years of diagnosis.¹⁴ 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.¹⁵ The palliative approach focuses on improving the quality of life of people with a life-limiting illness and their families, through the prevention and relief of suffering.¹⁵

The pattern of care of people with a life-limiting illness has changed from an emphasis on institutional care, to care at home supported by community health and support services. Cancer is one of the ten most common health conditions in receipt of informal care giving in Australia.¹

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.¹ Home palliative care would be impossible for many people without the support of informal carers.¹⁶ However, the success of home-based palliative care depends on access to appropriate medical and allied health services, and domestic care services.¹ For example, a survey of home-based palliative carers in Sydney found that most carers said they needed more information and advice, in-home respite, help with household tasks and financial support.¹⁷

7.1. Place of death of cancer patients in NSW

There have been several international studies demonstrating that the majority of people wish to have a home death [refs]; Australian data on this is mostly anecdotal. Several Indigenous people have told their HOME Hospice Mentors that “coming home to country” to die is extremely important to them, as are the community rituals that prepare the dying person for death. These spiritual rituals are vital to so many cultures and are often impossible to honour and observe within an institution. Health and safety regulations, restricted visiting hours for the patient’s extended community and lack of privacy within a shared ward are some of the reasons that specific cultural and religious rites around dying are not able to be expressed at this significant time.

Kate, HOME Hospice mentor

In a hospital or hospice, there is rarely any provision made to accommodate the primary carer. One 70-year-old carer mentored through the HOME Hospice program had spent 20 nights sleeping on a hospital floor to be close to her husband in the final stages of cancer.

For many families, it is vital that the dying family member is surrounded by family and friends throughout their dying process, and for an extended period following the death. These needs are more easily met within the home of the dying person and friends and neighbours are free to come and pay their last respects to the deceased. In this context, the event of death is normalised and supported. HOME Hospice and the Cancer Council believe that these same possibility simply cannot be met within a hospital or hospice.

Recently, a report into the place of death of cancer patients in NSW found that less than 20% of people with cancer had a home death. Approximately 63% of NSW cancer patients died in public hospitals.¹⁸ As well as possibly not representing a patient’s wishes, this places a huge financial burden on the economy. It is potentially more cost-effective to treat patients at home rather than in acute-care settings.

This report examined over 317,000 deaths using the NSW Central Cancer Registry from 1972 to 2003. Although there has been a large increase in the number of

cancer-related deaths over the 32 year study period, the proportion who died at home has not changed significantly. The Cancer Institute report found that factors which affected the place of death included the type of cancer, Indigenous status, remoteness of residence, sex and age. Socioeconomic factors also influenced the place of death; the more financially and socially advantaged a person with cancer is, the more likely they were to die at home or in a private hospital.¹⁸

However, the report found that the most important explanatory variable for influencing place of death was location of residence at time of diagnosis. This reflected the fact that the types of institutions in which terminal care takes place are not evenly distributed across NSW. For example, the major hospices are located in the Sydney metropolitan area.

The Cancer Council NSW has heard that residents of rural NSW have higher rates of home death, however this may be due to lack of palliative care beds in these regions and does not necessarily reflect the adequacy of community resources to enable a "good death." HOME Hospice mentors and palliative care professionals have also commented that the public perception of palliative care services is that they are only for the final days of a terminal illness. Carers and patients can be reluctant to engage the services of palliative care and support services early in the cancer journey, which leads to carer burn-out and the patient being moved into hospital.

7.2. Access to medical care.

Mary-Kate, Carer

When I cared for my father until his death at home three years ago, I was astounded by how hard it was for me to get information to support me as the carer. If I had not been so determined to care for my father at home until the end of his life, I would never have learnt of the supports available.

The GP did not mention palliative care or our ability to access community nursing, in-home respite, home-care or other services. The only suggestions that this GP made were a nursing home – or calling the ambulance if I was scared about symptoms. Like many GP's I now realise that this one did not want to involve herself in the complexities of end-of-life care. Nor did she seem to recognise the importance of referring me to someone who was happy to provide this service. I was too worn out with my caring duties to even think clearly about this at the time.

Carers need access to after-hours GP services if they are to care for a frail or terminal person at home. This is an issue that requires urgent attention.

The Cancer Council Helpline database, formal research and community consultations have identified the following issues regarding access to medical care (aside from financial problems). Carers are often responsible for organising and even performing some of the medical care (e.g. provision of pain relief medication, wound care) for their relative or friend with cancer; however many felt they did not receive adequate training in this. Many carers reported problems with access to adequate information regarding the medical care of the person they are caring for, which causes a lot of additional stress. Some carers were unaware that the medications available in hospital to aid in a "good death" could be administered in the home setting.

There are inconsistencies in access to generalist and specialist medical care across NSW. In some cases, these services are available, however carers are unaware of them as there appears to be no responsibility for ensuring that this information is

adequately disseminated. Medical staff need to recognise that the wishes of people with a life-limiting illness and their carers is to remain at home for as long as possible, and in many cases, for the patient to be able to die at home.

Access to the following services are of particular importance in supporting carers to care for their loved ones at home for as long as they wish:

- Community nursing and other community health services – yet these may not be available in some areas or carers are not aware of this service.
- Timely access to medical care including general practitioners and medical specialists such as oncologists. However, waiting lists for oncologists can be up to eight weeks in some rural and regional areas.
- Access to general practitioners outside of standard work hours and for home visits, but these are not widely available and some rural towns do not have a local GP.
- Advice for GP and community nurses by palliative care specialists. It is recognised that in some areas such as rural and remote areas, a palliative care specialist will not be available. However, established networks for specialists to provide advice to generalist medical staff are needed, for example the pilot Griffith Area Palliative Care Service telephone hotline.
- 24-hour, 7-day-a-week medical support, including telephone advice for carers who are looking after their loved ones at home.
- Multidisciplinary care and case co-ordination. Issues regarding navigating the complex system of medical care for those with cancer have emerged consistently as an issue by Cancer Council consultations. The fragmented nature of treatment with a perceived lack of continuing of care causes a great deal of stress for people with cancer and their carers. The role of the cancer care co-ordinator is to facilitate the continuity and quality of care for people diagnosed with cancer, and to provide support for their individual needs, as well as those of the patient's family and carers. Cancer Council NSW has welcomed the addition of 60 case co-ordinators by the Cancer Institute in NSW;¹⁹ however, the number of co-ordinators needs to be increased to meet the needs of cancer patients with complex treatment regimes.

7.3. Availability of HCS and other HACC-funded services.

Community and service provider consultation has found that there is confusion surrounding the eligibility of palliative cancer patients for the Commonwealth/state-funded Home and Community Care (HACC) program. This filters down to problems with access to the NSW Home Care Service, which provides domestic assistance, as well as community transport services for those needing to travel to attend medical treatment.

Several service providers told Cancer Council NSW that their clients were unable to access Home Care Services before they died. This can often be due to long HCS waiting lists; palliative clients often die before a service becomes available. In some areas, the HCS centres have closed their books due to inadequate funding. People with cancer have reported that access to respite care can be problematic, due to lack of available beds in some areas. In-home, over-night respite care is requested by many carers when contacting the Cancer Council Helpline.

Recent Commonwealth and State respite funding may overcome some of these problems; however, it is not clear whether this funding is directed solely at those with a disability, and will be available for palliative patients. Palliative patients need to be given priority for these services, in recognition that often their need for services will not be of as long duration as other clients. A move towards the HOME Hospice model will ensure the community has capacity to provide many of these services, thus lessening the burden on governments.

7.4. Access to specialised equipment

One of the most important issues to have emerged from our consultation processes 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 carers own physical health during the caring period. People who are in the last stage of their illness being put on waiting lists to receive necessary equipment is untenable for both patient and carer.

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.

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