



Cancer Council Australia

Clinical Oncological Society of Australia

Submission: Towards a National Carer Strategy

Cancer Council Australia is the nation's peak non-government cancer control organisation. Cancer Council Australia advises the Australian Government and other bodies on practices and policies to help prevent, detect and treat cancer and also advocates for the rights of cancer patients for best treatment and supportive care. Cancer Council Australia and its member organisations, the eight State and Territory Cancer Councils, also advocate for and provide services to support carers of cancer patients so that they are able to carry out their role and maintain their own physical and mental health and wellbeing through the caring period and beyond.

The Clinical Oncological Society of Australia is the peak clinical body representing the multidisciplinary cancer health professionals. The overarching mission of COSA is to develop and maintain high-quality clinical care of cancer patients in Australia. The membership of COSA is involved in 22 cancer professional groups and the 14 national cancer cooperative trials group across Australia. COSA promotes clinical innovation, advocacy, research, professional development, collaboration, networking and all notions supporting the encompassing goal of maximising cancer care outcomes for all Australians.

22 December 2010

Summary of Recommendations

Cancer Council Australia and the Clinical Oncological Society of Australia welcome the development of the National Carer Strategy. We recommend that the National Carer Strategy is underpinned by a detailed implementation plan that includes targets and accountability provisions and is supported by dedicated and appropriate funding.

The programs, policies and services developed under the Strategy need to take into account the specific needs of cancer carers, including information needs, access to care co-ordinators, improved income support and financial assistance, and timely access to practical and emotional support services.

Cancer Council Australia and COSA generally support the vision and goals for the Strategy outlined in the discussion paper. However, we recommend that an additional goal is added to the Strategy to specifically address the critical need to improve financial support for carers, as follows:

“Better financial support for carers.

Achieving this goal will result in:

- Eligible carers who are unable to work being supported by the income support system;
- Eligible carers who are experiencing financial distress receiving financial support to assist them to meet expenses associated with their caring role;
- Eligible carers receiving financial concessions such as tax deductibility for expenses such as home modifications and equipment which assist them in their caring role.”

We also recommend that the needs of certain disadvantaged groups of carers are specifically recognised within the goals of the Strategy, by including the following objective under Goal 1 of the Strategy: “Better recognition for carers”:

“The needs of disadvantaged carer groups such as Indigenous and CALD carers and those living in rural and remote areas being recognised and acknowledged and these groups being actively consulted in the development of appropriate policies, programs and services to meet their needs.”

We recommend that the Strategy recognises the need to assist carers to return to work by including the following objective under Goal 2 “Better support to help carers work”:

“Carers being supported to return to the workforce once their caring responsibilities reduce or cease”.

Key priority areas under Goal 3: “Better information and support for carers” should include:

- Improved provision of information to cancer carers regarding the disease and medical management of the person they are caring for and about the support services, including financial support that are available
- Greater access to cancer care co-ordinators to assist cancer patients and their carers to co-ordinate care and to access practical, technical and psychosocial support
- Improved access to income support and financial assistance for cancer carers, including the possible development of a new category of income support payment for people experiencing financial distress as a result of an acute or terminal illness
- Increased access to generalist and specialist medical care, especially home visits and after-hours and emergency care and advice to support carers in their role
- Better access to emotional and practical support services including respite in-home care services, specialised equipment, cleaning, housekeeping and meal provision services.

Summary of Recommendations (continued)

A key priority under Goal 4: “Better education and training for carers” should include the provision of education and training to cancer carers so that they have the skills they need to provide necessary nursing and medical care to cancer patients at home.

A key priority area under Goal 5 “Better health and wellbeing for carers” should include the provision of specific programs to improve awareness among health professionals of the health and psychosocial needs of carers and improved access to carer support services and especially to respite care.

Introduction

Cancer Council Australia and the Clinical Oncological Society of Australia congratulate the Commonwealth government on its commitment to develop a National Carer Strategy to improve recognition and support for carers and to guide measures to improve their wellbeing. We welcome this opportunity to provide input to the development of the Strategy.

While the development of a guiding Strategy is a valuable first step it is critical to ensure that the Strategy is underpinned by a detailed implementation plan which sets out the practical measures that will be put in place to better support carers, and that the implementation plan includes targets and accountability provisions. It is also important that dedicated and adequate funding is provided to support the Strategy.

Cancer Council Australia and COSA would also like to highlight the specific needs of cancer carers to ensure that they are appropriately addressed within the National Carer Strategy.

Background

Cancer in Australia

Around 105,000 new cases of cancer are diagnosed in Australia each year. Incidence rates are expected to increase at over 30% per decade until population aging peaks in the middle of the century. (1)

The survival rate for many common cancers is also increasing and has improved by more than 30 per cent in the past two decades. More than 60% of cancer patients will now survive more than five years after diagnosis.(2) Consequently, cancer is increasingly being viewed as a chronic disease, requiring long term treatment and care.

There are currently about 300,000 people living with a diagnosis of cancer (based on 5-year prevalence data for 2004) (2) and this number is expected to increase substantially as cancer incidence and survival rates increase.

Cancer carers

Cancer is one of the 10 most common health conditions in receipt of informal care giving in Australia.(3) The demand for informal care for people with cancer will increase as cancer incidence and survival rates increase, creating a continuing need for care.(2) In addition as cancer care is increasingly transferred from the inpatient to the outpatient setting, with more care being provided in the home, the burden of care on informal carers is increasing.(4).

A cancer diagnosis is a devastating and often life-changing experience, both for the patient and for their family and caregivers. Treatment for cancer can be severely disabling and can last for extended periods, with an uncertain prognosis. People with cancer and their carers face a range of psychological, emotional, social, financial, practical and other issues as a result of the cancer and its treatment (5).

Informal carers play an important role in cancer care, often at great cost to their own health and wellbeing. Usually partners or close relatives of the person with cancer, cancer carers take on the daunting task of providing practical and emotional support for the cancer patient at a time when they themselves are also emotionally stressed. In addition, they are often required to navigate and coordinate care for the care recipient across a complex and often disjointed medical system without assistance or advice and to assist in the provision of nursing and medical care, for which they may be poorly equipped.(6)

The need for care can continue even if cancer treatment is successful. Some cancer survivors resume a relatively normal life once their treatment is completed, but others may face longer-term or permanent physical and emotional effects as a result of their cancer or its treatment which require ongoing care. These effects can range from mild to very severe, depending on the type of cancer and the treatment received. While research in this area is limited, it appears that overall 20-30% of cancer survivors are likely to be at risk of ongoing poor health as a result of their cancer.(7) In 2003 there were 62,400 people in Australia who were disabled due to cancer, of whom 22,500 had a severe or profound disability.(8)

If the cancer progresses, the patients' needs and the burden on carers can increase dramatically as the patient nears the end of life. Up to 90% of terminally ill cancer patients now spend much of their last year of life in the community cared for by lay carers. (6)

The specific needs of cancer carers need to be adequately addressed under the National Carer Strategy

Impact of care giving

Caring affects the physical, emotional, social and financial wellbeing of carers.

The physical impact of caring can include high blood pressure, tiredness, stress, burnout and physical injury as well as poorer overall health compared to the general population and reduced life expectancy. (3;6) Cancer carers can also experience elevated rates of anxiety, depression and distress and poor quality of life. (3;9) Up to 70% of carers of advanced cancer patients have been found to experience distress or depressive symptoms at a level suggesting clinical depression. (6) Reduced opportunities for social and leisure activities can also affect carer wellbeing.(3;9)

Carers can continue to face difficulties following bereavement and the burden of grief can last for years. While grieving following bereavement is normal, some carers can experience complicated grief reactions that may compromise their health.(10) A recent audit of carers of dying patients in palliative care services at the Royal Melbourne Hospital found that this group of carers were more likely to experience complicated bereavement than the general population with nearly half of main carers assessed to be at medium or high risk of complicated bereavement. (11)

Certain groups of carers such as Aboriginal and Torres Strait Islander people, those from culturally and linguistically diverse backgrounds and those living in rural and remote areas face added challenges arising from linguistic and cultural differences and the need to travel to access services.(12;13)

Financial impact

Care-giving imposes a major financial burden in terms of lost income and extra expenses. Access Economics has estimated that the average lifetime financial cost of cancer to a household is \$47,200 per person, although this cost varies substantially by age and gender and by cancer type.(14)

Many households in which a person is diagnosed with cancer already face a substantially reduced income because the person with cancer is unable to work during their treatment and rehabilitation. This financial burden is compounded when the carer is also unable to work, or has to work fewer hours or in a lower paid job to be able to meet their caring commitments.(3) Only 39% of primary carers in Australia in 2003 were employed, mostly part-time, compared to 68% of non carers while over half of primary carers listed a government pension or allowance as their principal source of income.(8) Preliminary results from a research study into the specific needs of partners and carers of cancer survivors over the first five years from the cancer diagnosis found that a third to a half of carers reported a net household income of less than \$500 per week and many carers received a government pension or benefit.¹

Financial stress as a result of reduced income is compounded by the extra expenses incurred in a household affected by cancer. Approximately three-quarters of cancer carers report having significant out-of-pocket costs associated with caring, often met through savings or loans. Expenses faced by households affected by cancer include treatment and medications, childcare and housekeeping, transport and accommodation costs where travel is required to receive treatment, household modifications, specialist clothing and mobility devices, prostheses, respite care, counselling and support programs and, if the patient succumbs to their disease, funeral costs.(14) As well as lost income, a household in which a person has been diagnosed 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, mostly incurred in the first year after diagnosis. (14)

The financial impact of caring can make itself felt long after caring responsibilities cease. Carers experience difficulties in returning to the workforce once their caring duties have reduced or ceased, especially after long periods of caring and can suffer longer term financial consequences such as reduced income earning potential and reduced superannuation and retirement savings. (3)

Difficulties in accessing financial support

Despite the financial impact of a cancer diagnosis, cancer patients and their carers are often unaware of available financial assistance arrangements, or report difficulties in accessing income support because of confusion regarding eligibility requirements, or onerous and stressful application processes out of proportion to the level of support provided.(9;15) These issues apply to both income support payments provided through Centrelink and to the government funded travel and accommodation assistance schemes that apply in each jurisdiction in Australia.(15;16)

For example cancer patients can appear to be ineligible for either Sickness Allowance or the Disability Support Pension because their illness is neither temporary nor expected to last for over two years, or the duration of their illness is difficult to ascertain even by medical experts. If they are deemed ineligible then their carer is also ineligible for Carer Payment. The uncertainty and difficulties created when these situations arise can place significant additional emotional and financial stress on the household of the cancer patient, especially if they are the main source of income, at a time when stress levels are already high as a result of the cancer diagnosis.

¹ Information about the Partners and Caregivers Study is available at <http://www.caresearch.com.au/Caresearch/LinkClick.aspx?fileticket=k%2F2f7YInZME%3D&tabid=515>

These issues highlight the importance of ensuring that eligibility criteria and policy guidelines for access to income support arrangements take into account the particular needs of cancer patients and their carers who are experiencing financial hardship. In response to these issues, changes to Disability Support Pension assessment processes have recently been introduced to fast-track more claimants with cancer, although the effectiveness of these changes is as yet unclear.

In a recent review of the assessment of claims for disability support pension from people with acute or terminal illness the Commonwealth Ombudsman recommended that consideration should be given to developing a new category of income support payment. This payment should be available to people experiencing an illness that requires a lengthy period of treatment or recovery, or requires additional investigation to identify a more conclusive prognosis, but who would not otherwise be eligible for income support under existing arrangements.(17) Cancer Council Australia and COSA support this recommendation.

An associated issue is eligibility for financial support for carers of patients who are receiving treatment through clinical trials. For example no jurisdiction provides a subsidy under their patient travel and accommodation schemes for isolated patients (and their carers) being treated in cancer clinical trials, despite clinical trials presenting significant benefits for participating patients.(18) It is essential that the needs of carers of people receiving treatment through clinical trials are not overlooked or excluded in any financial support arrangements provided for carers.

Cancer carer needs

Carers of cancer patients are identified as a vulnerable group with many unmet needs for information and emotional and practical support, especially during the palliative and end-of-life stages of care.(19)

In a comprehensive review of the impact of caring for terminally ill people, Palliative Care Australia identified four key service gap categories:

- Information and education
- Financial and employment difficulties
- Respite and other support services
- Community recognition. (3)

Formal research and community consultation by Cancer Councils confirm that carers of cancer patients require improved access to information and emotional and practical support including financial assistance, income support and job protection.

Carers report the need for more information about the disease and medical management of the person they are caring for. They also require more information about the support services including financial support that may be available both for the care recipient and the carer and how to access them. (9) They require information and education about how they can provide certain types of medical care (such as pain relief and wound dressing) for their relative or friend at home. There is also a need for increased access to generalist and specialist medical care, especially home visits, after-hours care and emergency care and advice 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.

The financial impact of cancer on a household is regularly identified as one of the key challenges facing cancer patients and their carers so access to adequate income support and financial assistance, as well as to information about what support is available, is of great importance.

Eligibility criteria and policy guidelines for access to financial support need to take into account the particular needs of cancer patients and their carers who are experiencing financial hardship.

Improved access to practical support measures for carers is essential. In particular, greater availability of in-home help, respite care and specialised equipment to assist carers is required. It is important that access arrangements for these support services takes into consideration the particular needs and sensitivities of people facing a life-threatening illness of uncertain prognosis or those whose illness is likely to be terminal. For example an important issue for cancer patients and their carers is the need for specialised equipment to be immediately available. 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.

Bereavement support and care is also important to help carers to deal with their grief following the death of the care recipient and to identify and assist people at risk of complicated grieving.

CASE STUDY: The cancer carer's experience

Jill is a 63 year old carer for her husband who was diagnosed with bowel cancer in 2002. She has identified a range of issues that made their journey very difficult.

"Overall I believe the clinical care and the services in both the metropolitan and regional areas were very good, it is just the system itself that is very challenging. There is so much complexity and that's what knocks you down dreadfully. There is so much information out there but no direction. Looking back on things, I see my experiences to be part of what I call a 'chase pyramid'. You know, you have to chase for everything and using a pyramid to organise those experiences gives clarity to the maelstrom surrounding a diagnosis of cancer.

The Chase Pyramid :

The discovery chase - what happens before, during and immediately after diagnosis.

The money chase - the juggling act to find means and a 'road map' through multiple billing and rebate systems, gap and other associated costs, plus cash flow difficulties ramped up by pay first / claim later and lag times attached to rebates.

The treatment chase - is not only the what, where, how often and how far away of available treatments, but the costs and demands on family, friends and finances.

The paper chase - getting on top of the organising maze attached to the mix of facility specific requirement (for outpatient, inpatient, scheduling, etc.), treatment management and commuting, plus whatever billing and rebate systems apply to each.

The help chase - mining the mass of available information to find where, how, from whom and where help can be accessed.

The survival chase - building a mind map and resilience over unfolding life changing experiences fuelled by adversities of unsympathetic health and business systems."(20)

The National Carer Strategy

Cancer Council Australia and COSA strongly support the development of a National Carer Strategy to improve recognition and support for carers and to guide measures to improve their wellbeing. However it is critical that the Strategy is underpinned by a detailed implementation plan which sets out the practical measures that will be put in place to improve carer wellbeing and which includes targets and accountability provisions. Given the increasing demand for informal care for people with cancer as cancer incidence and survival rates rise, it is important that the National Carer Strategy and its implementation plan address the needs of cancer carers.

It is also critical that adequate funding is made available to enhance the availability of support services for carers so that a real improvement in carer wellbeing can be achieved. Cancer Council Australia and COSA note that the introduction of a national disability insurance scheme as the central element of new disability care and support arrangements, as currently being considered by the Productivity Commission, could provide much needed funding for essential care, support, therapy, aids, equipment, home modifications, respite care and access to the community, education and training for people with disability and their carers.

Q1. Do you think that the Strategy as outlined in this discussion paper sets the right direction to meet the vision and aim to better support carers?

Q2. Do you agree with the five goals outlined in this discussion paper?

Cancer Council Australia and COSA generally agree that the discussion paper sets the right direction to meet the vision and aim of the Strategy to better support carers, with one important exception. We consider that the goals as currently stated do not adequately address the financial burden of caring, which is consistently raised as one of the key issues facing carers.

We consider that the lack of a specific goal relating to better financial support for carers will be a barrier to prioritising action on this issue under the Strategy and will undermine the potential for the Strategy to fully achieve its vision. Consequently, we recommend that a separate goal be included in the strategy to emphasize the importance of providing better financial support to carers in need.

As highlighted above, people with cancer and their carers often face a significant financial burden as a result of both reduced household income and increased expenses at a time of intense emotional and physical distress. The availability of appropriate financial assistance can reduce stress during this time and allow carers to take time off work as necessary to meet their caring obligations.

At present, financial support is addressed only under Goal 2 "Better support to help carers work". This goal includes the objectives of supporting carers to balance caring and work responsibilities and the provision of income support for eligible carers who are unable to work. The latter objective does not seem to fit under a goal which is primarily about assisting carers to maintain paid employment and should be shifted to a goal focussing on financial support. Nor does it recognise that financial support may still be required, for example to help meet out-of-pocket expenses, even if a carer does manage to maintain some employment.

It is critical to include a goal that addresses the provision of better financial support for carers if the Strategy is to foster the development of policies and programs that appropriately address this critical aspect of carer wellbeing. This may include the development of other methods of providing financial support such as one-off payments or allowances, tax deductions for equipment or home modifications or automatic provision of a Health Care Card for people with cancer and their carers. The development of a new category of income support for people with an illness that requires a lengthy period of treatment or recovery, or requires additional investigation to identify a more conclusive

prognosis, as recommended by the Commonwealth Ombudsman, (17) could also be considered under this goal.

Consequently we recommend the inclusion of an additional goal and objectives within the National Carer Strategy to specifically address financial support as follows:

Goal: Better financial support for carers

Achieving this goal will result in:

- Eligible carers who are unable to work being supported by the income support system;
- Eligible carers who are experiencing financial distress receiving financial support to assist them to meet expenses associated with their caring role;
- Eligible carers receiving financial concessions such as tax deductibility for expenses such as home modifications and equipment which assist them in their caring role.

Q 2. Do you agree with the goals outlined in this discussion paper?

Q3. Do you have suggestions about how the goals could be improved?

Q4. What should the Australian Government focus on under the goals to better support carers now and into the future?

As noted above, Cancer Council Australian and COSA recommend the inclusion of an additional goal under the Strategy to specifically address improved financial support for carers.

In addition, we would like to highlight that the specific needs of certain groups of carers, such as Indigenous carers, carers from a culturally and linguistically diverse (CALD) background and those living in rural and remote areas need to be appropriately recognised and addressed within the strategy. We recommend that recognition of the special needs of these groups of carers is addressed under Goal 1: Better recognition for carers.

Apart from these points, we generally support the five goals outlined in the discussion paper and provide comments relevant to the questions posed in the discussion paper for each goal as follows.

Goal 1: Better recognition for carers.

Cancer Council Australia and COSA support the inclusion of this goal and its stated objectives in the National Carer Strategy.

Fostering recognition of the role and contribution of carers within government policy and programs as well as workplaces, in the healthcare system and in the community is essential to improve the wellbeing of both carers and care recipients. Several studies of cancer caregivers and cancer survivors have found that the distress and quality of life of caregivers influence that of care recipients and vice versa, so it is essential that the needs of both are recognised and addressed.(21;22)

In particular, we strongly support the need for better recognition and acknowledgement by the health system and health professionals of the role of carers as partners in the provision of care. The health system implicitly depends on carers to co-ordinate care for patients, but medical practitioners don't always treat carers as partners in the provision of care and do not always provide enough information to carers to assist them in their role. The information that carers can provide about the patient and how they are coping with treatment is also often disregarded. (12;15)

In addition, the needs of carers are often overlooked in the medical system with support rarely offered to carers. (12;15) Proper recognition of the role and contribution of carers is essential to ensure that the needs of carers are adequately addressed.

Cancer Council Australia and COSA consider that an additional objective should be included under this goal to ensure that the special needs of certain groups of carers, such as Indigenous carers, carers from CALD backgrounds and those living in rural and remote areas are appropriately recognised and addressed.

Carers in rural and remote areas can carry a heavier burden because of the reduced availability of services; for example, rates of admission to palliative care services in regional areas are 30-35% lower than in metropolitan areas.(3) CALD carers face additional disadvantages such as lack of proficiency in English which impedes access to appropriate information, reduced family and support networks due to migration as well as lack of culturally appropriate services. (3;23) Appropriate recognition of the specific needs of Indigenous carers is also essential to ensure that additional and culturally appropriate services are made available to support Indigenous carers. (3;13)

Consequently we recommend that an additional objective under this goal is included as follows:

“The needs of disadvantaged carer groups such as Indigenous and CALD carers and those living in rural and remote areas being recognised and acknowledged and these groups being actively consulted in the development of appropriate policies, programs and services to meet their needs.”

Goal 2: Better support to help carers work

Cancer Council Australia and COSA support the goal of providing better support to help carers work where they want and are able to do so. It is clear that being a primary carer does affect a person's chances of being employed (3;8) More carer- friendly workplaces which provide the flexibility for carers to balance their workplace and care-giving responsibilities improve the chances of carers retaining employment and can help secure their financial well-being as well as their long-term productivity.

However, it must be recognised that some carers will be unable to work while they are providing care. In addition, while work may be a relief from care giving and may provide much needed social interaction and income for carers, it can also be a source of conflicting demand which can aggravate anxiety and distress for caregivers. (9;15) Where it is too difficult for a carer to continue working, it is important that appropriate and adequate income support measures are available. As highlighted previously, Cancer Council Australia and COSA consider that the objective relating to the provision of income support for carers who are unable to work would should be placed under a separate goal relating to improving financial support for carers.

Where a carer finds it necessary to cease employment due to their caring responsibilities, it is important that measures are in place to help provide better opportunities for them to return to the workforce once their caring role reduces or ceases, including the opportunity to participate in employment related education and training.

Consequently, this goal should include an objective such as:

“Carers being supported to return to the workforce once their caring responsibilities reduce or cease”.

Goal 3: Better information and support for carers

Cancer Council Australia and COSA strongly support the inclusion of this goal and its objectives within the National Carer Strategy.

Cancer care can be complex, involving a myriad different medical and health practitioners and support services. Carers are often required to navigate and co-ordinate care for the care recipient across this complex and often disjointed system without assistance or advice and to assist in the provision of nursing and medical care, for which they may be poorly equipped.(6)

Despite their important role, carers often report being left out of the loop in relation to information affecting the patients' treatment, care and prognosis or in relation to information on support services that may be available for both patient and carer and the range of assistance that people could receive.(12) Lack of adequate information about the patient's medical condition, the course and prognosis of the disease and its treatment and the availability of psychosocial and practical support, has been identified as a major concern for carers of patients with advanced cancer. However improved information and understanding in these areas and the perception that medical practitioners are listening to their views regarding the patient's needs have been shown to help caregivers cope. (9;15)

Carers need more information about the cancer patient's illness, treatment and prognosis as well as more information about the support services, including financial support, that may be available to them. (9) There is 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 and to assist them with emergencies that may arise.

Greater access to professional cancer care co-ordinators to help patients and their carers navigate through the complex cancer journey and to provide guidance in accessing practical, technical and psychosocial support is also essential.

Carers also require better emotional and practical support.(15) Emotional support can come from friends and family or from counselling and support groups. One study found that the provision of a variety of emotional support options including support groups, information seminars, referrals to counselling and online support groups could assist in meeting the different needs for emotional support amongst carers. (15) It is important to recognise that carers of terminal cancer patients also require bereavement support.

Practical support measures include: better access to respite care services and services that provide assistance with physical care in the home; improved financial support, better access to specialised equipment (a terminally ill patient being put on a waiting list to receive specialised equipment is untenable); cleaning, housekeeping and meal provision services; and assistance in maintaining or returning to employment. (15)

Improved service funding and co-ordination will be critical to improve access to the support services required to assist carers in their role.

Goal 4: Better education and training for carers

Cancer Council Australia and COSA strongly support the inclusion of this goal and its objectives within the National Carer Strategy.

Cancer carers are often required to assist in the provision of nursing and medical care for cancer patients in the home. Their role can include assessing and monitoring patient symptoms, identifying treatment side-effects, administering medications, identifying and handling emergencies and

managing patient controlled analgesia pumps, epidural catheters and home infusions.(6) However carers regularly report feeling ill-prepared to provide the care required and overwhelmed by their responsibilities.(6) The provision of relevant education and training is important to provide carers with the skills they need to meet their caring responsibilities as well as to reduce the stress and anxiety associated with not knowing what to do.

However it is important to recognise that there are limitations to what can be expected of carers and that they cannot replace qualified nursing and medical practitioners. In addition existing workforce shortages will limit the ability of nursing and medical staff to train and educate carers, Careful consideration needs to be given to the content and methods of delivering appropriate training and education for carers to assist them with their caring role.

The opportunity to participate in employment related education and training is also important to improve employment prospects for carers once their caring responsibilities reduce or cease.

Goal 5: Better health and wellbeing for carers

Cancer Council Australia and COSA strongly support the inclusion of this goal and its objectives within the National Carer Strategy.

It is well documented that caring can be detrimental to a carer's health and wellbeing. Carers often ignore or diminish the importance of their own health problems or needs and may have difficulty expressing their own needs, unless asked specifically away from the hearing of the patient. (9) Carers can also experience more distress, anxiety and unmet psychological needs than patients, reflecting their overlooked position within the medical system. (15)

Specific programs to improve awareness among health professionals of the health and psychosocial needs of carers will be important to achieving this goal as will improved access to carer support services and especially to respite care.

It is also important to recognise in this context the needs of those carers who are ill themselves. The issue of carers who are caring for other family members with chronic diseases or disability and who themselves are diagnosed with cancer is increasingly being reported through Cancer Council networks. The challenges for carers who have cancer are significant and there is anecdotal evidence that individuals in this position may decide not have optimal treatment so that they can continue caring for another person. Additional respite care needs to be available for carers with cancer or other debilitating disease to support them during treatment or when they require palliative care.

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