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Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House CANBERRA ACT 2600
By email: fchy.reps@aph.gov.au

Dear Committee Secretary

Inquiry into Better Support for Carers

Palliative Care Australia, the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all, thanks you for the opportunity to make this submission to the inquiry into Better Support for Carers, *Better Support for End of Life Carers*.

Carers are a critical element supporting end of life care for many Australians.

Care at the end of life should parallel the approach taken at the beginning of life. Caring for someone who is dying can be a privilege and an opportunity to share an important journey with a loved one. This is a personal experience and demands individual commitment. The caring experience, however, is shaped by the broader social context in which it occurs and is inextricably linked to the availability and responsiveness of support structures and services.

The contribution of carers to our society continues to be undervalued and to occur without adequate support, so that the needs of carers go unmet. As a society we can and must do better to support carers and through support prevent avoidable morbidity in carers and facilitate rewarding caring experiences.

I am pleased to enclose Palliative Care Australia's submission to the Committee on this important issue.

Yours sincerely

Donna Daniell
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BETTER SUPPORT FOR END OF LIFE CARERS

**Submission to the House of Representatives Standing
Committee on Family, Community, Housing and Youth
Inquiry into better support for carers**

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Executive Summary

Experiencing end of life is something that all Australians will experience. Care at the end of life should parallel the approach taken at the beginning of life. Caring for someone who is dying can be a privilege and an opportunity to share an important journey and a testament of love with a loved one. While this is a personal and individual commitment the caring experience occurs within a broad social context which can be a key determinant of the quality of that experience. Care at the end of life should parallel the approach taken at the beginning of life.

Care for the dying is the business of the whole community, which can and must do better in supporting carers by developing the foundations of a care-supportive social system.

Compelling evidence attests to the significant contribution that carers make to our society. Respecting people's care preferences and providing quality care at the end of life¹ for all cannot be realised without carers. Carers are a critical lynchpin supporting end of life care in the home for many Australians and providing ongoing physical, emotional and spiritual support to the terminally ill.

Yet the contribution of carers continues to be undervalued and marginalised in the Australian community. This is manifest in our failure as a society to provide the necessary support to enable all carers to care in a manner that also promotes their health, wellbeing and personal aspirations.

Our reliance on carers as individuals to provide ongoing care without appropriate support at a broader societal level is unethical and irresponsible. Caring can be a rich and rewarding experience and carers are generally strongly committed to providing the support to enable their loved one to realise their aspiration to die at home. Yet without adequate and appropriate support and training caring can weigh a heavy toll.

Carers' health and wellbeing is inextricably linked to the availability, quality, responsiveness and cost of support structures and services. As a society we can and must do better to support carers and through support prevent avoidable morbidity in carers and facilitate rewarding caring experiences.

Palliative Care Australia (PCA), the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all, believes that as a society we have a responsibility to do better to support and enable carers in providing end of life care by recognising and addressing carers' multi-faceted needs. We recommend six key first steps toward this achievement.

¹ The following definitions of end of life, end of life care and palliative care are used throughout this submission. Source: *Palliative Care Australia Strategic Plan 2008-2011*.

End of life: That part of life where a person is living with, and impaired by an eventually fatal condition, even if the prognosis is ambiguous or unknown.

End of life care: End of life care is care provided to people who are living with, and impaired by an eventually fatal condition. It is not limited by prognosis. End of life care can be provided by all health care professionals and is not limited to care provided by palliative care services or specialists. Quality end of life care is realised when strong networks exist between specialist palliative care providers, generalist health care professionals, other clinical specialists and support care providers and the community – working together to meet the needs of the population of people requiring care.

Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.

Key recommendations

PCA recommends that the Government acknowledge the critical contribution of carers to our society and their critical role in enabling quality care at the end of life, and commit to developing the foundations of a social system that supports and enables carers. PCA recommends the following initial steps towards this goal:

1. Supporting end of life carers by providing improved access to services to assist quality end of life care in the home through:
 - a) reform to Medicare Benefits Schedule (MBS) items and other health funding programs to help ensure affordable in-home access to a multidisciplinary team of care providers including palliative care specialists and allied health professionals, in accordance with PCA's needs-based policy (for a brief overview of PCA's policy regarding role delineation between services in a needs-based end of life care model see *Appendix 1: Population and needs-based planning for care at the end of life*);
 - b) adjustment to Pharmaceutical Benefits Scheme (PBS) prescribing criteria to remove barriers to general practitioners and other primary care providers prescribing appropriate, affordable pain and symptom management drugs;
 - c) introducing a framework for better coordination of the delivery of end of life care to patients across the varying members of a multidisciplinary care team;
 - d) increasing access to and quantity of in-home support, including access to 24/7 on call health professional advice and direct care;
 - e) access to respite care to enable time away from home for end of life carers;
 - f) employment of Care Liaison persons in GP Super Clinics to facilitate carer coordination and support.
2. Promoting the health and wellbeing of those providing informal end of life care in the home by:
 - a) supporting expanded access to overnight, weekend and emergency respite care services and providing additional funding for the National Respite for Carers Program;
 - b) funding the national roll out of an education campaign to support primary health care providers in the early identification of carers' emotional and physical health needs, including the identification, treatment, and better management of chronic and complex bereavement;
 - c) promoting carer health through the provision of free regular health check for carers;
 - d) increasing funding for the National Carer Counselling Program to provide adequate counselling services to carers in need and support to carers experiencing bereavement.
3. Meeting carers' information and education needs and supporting their role in providing end of life care through
 - a) the preparation of best practice guidelines for the use of palliative medicines in non-hospital settings
 - b) the development of best practice models for delivering nationally consistent carer education and training, and funding to support the development of infrastructure to

ensure its effective delivery.

4. Addressing carers' needs for greater financial support by:
 - g) waiving the requirement for individuals and families to reach the out-of-pocket expenses threshold for access to the MBS and PBS safety nets as soon as a person is diagnosed in the terminal phase of an illness²;
 - h) legislating to ensure the Carer Bonus become an annual, indexed payment;
 - i) increasing the weekly Carer Allowance to more accurately reflect the true costs of caring;
 - j) introducing a Carers' Superannuation Scheme for recipients of the Carer Payment.
5. Supporting participation of carers in the labour force by:
 - a) developing and promoting care-sensitive policies that support flexible working hours and leave arrangements for carers;
 - b) conducting a review of the feasibility of extended 'Carers' leave' (this could be thought of as "eternity leave") to enable those caring for a terminally ill loved one to take an extended period of leave without fear of job loss or associated penalties.
6. Developing strategies to strengthen community capacity building to support end of life carers, including through:
 - a) increased recognition of, and support for, charitable and not for profit organisations in supporting end of life carers;
 - b) referral of this question to the Government's Australian Social Inclusion Board.
7. Supporting measures to promote end of life planning for end of life carers to minimise 'surprises', and thus to help anticipate their needs in a timely manner.
8. Support for Carers Australia's recommendation to establish an 'Office for Carers', dedicated to establishing a 'carer-supportive community', conditional on its terms of reference including support for end of life carers.

² PCA outlined the case for this in its 2007-08 pre-Budget submission to Government.

1 Introduction

PCA believes our health care system can and should do better to make access to quality end of life care a reality for all Australians and that to achieve this we must do better to provide a care-supportive society.

An estimated 100,000 Australians die each year from an ‘expected’ death.³ Each of these Australians should be able to rely on a promise of access to quality care at the end of life that is based around meeting their needs and respecting their care preferences. This is not our current reality. Yet this is achievable through system reform towards needs-based and people-centred care that overcomes systematic barriers, including the provision of quality end of life care in the home.

PCA welcomes the innovations shown by this Government in driving reform for a more accessible, equitable and sustainable healthcare system. We support the work of the National Health and Hospitals Reform Commission (NHHRC) in developing a ‘road map’ toward a more effective and efficient care system and their identification of end of life care as a key challenge confronting the health system. Yet we stress that this challenge cannot be met in a manner that respects and upholds patients’ preferences of care location if carers are not better supported in their role in making the home a care setting option for many terminally ill Australians.

Supporting people’s preferences to receive end of life care in their home is dependent upon ongoing physical, emotional and spiritual support from their carer(s).

Caring for a loved one who is dying is often an act of love or duty and can be rewarding and fulfilling. Yet on a day to day basis caring can weigh a heavy toll. As a society we have an obligation to support carers and, most certainly, to begin dismantling the barriers and policy blindness that serve to compound these issues.

2 Critical contribution of end of life carers

End of life care in the home would be impossible for many people without the support of caregivers.

It has been estimated that there are close to 2.6 million carers, and nearly 500,000 primary carers in Australia (ABS, 2004). Carers provide close to 1.2 billion hours of care annually (Access Economics, 2005). This data highlights the significant, critical, and too often invisible, contribution of carers to our society, and to our systems of health and social care.

Estimates suggest that carers provide 76% of all services to people needing care and support (Carers NSW, 1998). Associated with the care performed by carers are significant cost savings to Government. The annual replacement value of care provided informally with formal aged and disability care is estimated to be over \$30.5 billion and the total cost to carers

³ There were 133,700 deaths registered in Australia in 2006. (Australian Bureau of Statistics, *Deaths: Australia 2006*. www.abs.gov.au/AUSSTATS [Accessed 30 April 2008.]) The Australian Bureau of Statistics does not code cause of death data according to ‘expected’ and ‘unexpected’ deaths. This estimate of ‘expected’ death rates is based on a basic analysis of ABS cause of death data for 2006 and subtraction of all assumed deaths that were accidental, resulted from suicide or could potentially be from acute illness. This figure is expected to be an under-estimation.

through wages lost in 2005 is estimated at \$4.9 billion (Access Economics, 2005).

The need for care within our communities is expected to increase with the rapid ageing of our population increasing the proportion of the population requiring care. Congruent with increasing demand is an expected ongoing decline in the caretaker ratio. The caretaker ratio of 2.5 carers to each individual in 2000 is expected to diminish over the next 50 years to below 1. (NATSEM, 2004 and AMPNATSEM, 2006).

Further confounding this situation is the continuing increase in life expectancy of Australians and the accompanying changing nature of the last phases of life. Australians live longer than ever before but the changing nature of causes of death alongside increased medical interventions means increasing numbers of Australians live out the final stages of their life with chronic, complex conditions and, often, co-morbidity. The pragmatic reality is that many elderly Australians may live extended periods of time before death with disability and reduced quality of life. For those providing informal care to a terminally ill loved one this can mean that the care period lasts years, rather than days or months as it may have 50 years ago.

Assessment of the contribution of carers emphasises that the role performed by carers is critical to the long-term sustainability of the Australian health and community care systems and to our capacity to provide quality end of life care.

2.1 Caring and reform toward quality end of life care

Respecting people's preferences at the end of life means providing meaningful choice in the location of that care. Fifty to seventy percent of terminally ill Australians may prefer to die at home in the comfort of familiar surroundings (Grande et al, 1998).

Establishing the home as a real choice in care location for all Australians at the end of life promises to ease the burden on the acute care system and there is compelling evidence to indicate that home based end of life care is more cost effective than hospital-based care (Chochinov & Kristjanson, 1998).

Supporting people's preferences to receive end of life care in their home is dependent upon ongoing physical, emotional and spiritual support from the community, and, most often, from individual carers. Carers are generally highly committed to providing this support which can be experienced as a final act of love and commitment. However the quality of this experience for the carer and their loved one will continue to be jeopardised without substantial enhancements to social support and access to support from the health and care systems.

PCA welcomes the innovations shown by this Government in driving reform for a more accessible, equitable and sustainable healthcare system. In particular, we welcome the identification in the NHHRC's first report of "care for and respect of the needs of people at the end of life" as a key challenge confronting the healthcare system and embraces this as a first step toward planning for a healthcare system that can promise access to reliable, evidence-based, end of life care that accords with patients' preferences.

This challenge cannot be met in a manner that respects and upholds patients' preferences of care location if carers are not better supported in their role in making the home a care setting option for many terminally ill Australians.

3 Caring without sufficient support

Carers often express strong positive emotions about their caregiving – many describe an opportunity to express their love through caregiving and find significant meaning in their roles (PCA, 2004). Carers' caregiving experience, health and wellbeing are inextricably linked to the availability and quality of the support they receive and those fortunate to have sufficient support mostly feel positive about their caring experience (PCA, 2004).

However, there is considerable evidence that ongoing caregiving adversely affects family caregivers who are not sufficiently supported and lack adequate resources in undertaking this complex role (PCA, 2004). Unfortunately adequate support is not a reality for many carers and this is associated with physical, emotional and financial costs to their wellbeing.

3.1 Health and well being

The largest survey of carers' health and wellbeing conducted to date found that carers have the lowest level of wellbeing of any population group, the wellbeing of carers has a negative linear association to the numbers of hours spent caring. Over one third of carers have severe or extremely severe depression and carers are not receiving appropriate treatment for themselves due to time or fiscal poverty (Deakin University, Australian Unity and Carers Australia, 2007). This should be recognised as a telling sign of a societal failure to provide adequate support for carers.

PCA conducted an inquiry into the Social Impact of Caring for Terminally Ill People (2004) to gather policy, opinion, experience and research related to the social impact of unpaid caring for the terminally ill. This national inquiry, consisting of a review of the literature and an analysis of public submissions from individual carers, identified a heavy emotional strain often associated with caregiving. Carers experience fatigue, resentment, social isolation and stress associated with lack of control over everyday life, changes in paid employment, reduction in leisure time and deterioration in their own health. Identified key sources of stress for carers included:

- uncertainty about treatment
- lack of knowledge about patient care
- role changes within the family
- lack of transportation for treatment
- strained financial resources
- physical restrictions
- lack of social support
- fears of being alone (PCA, 2004).

Providing care to a patient with a terminal illness may require the carer to adapt to altered family circumstances such as moving location, reducing or ceasing paid employment or modifying the home, all of which potentially impact upon the health and wellbeing of the carer.

There is strong evidence suggesting that the physical health of carers can be adversely affected by adopting a carer role if sufficient support is not provided. O'Connell et al (2003)

for example, provided baseline information on a sample of older carers' physical and mental status, and showed an association between poorer physical and mental health measures and being a caregiver. Schulz and Beach (1999) similarly identified that older spousal caregivers who experience stress from caregiving were 63% more likely to experience early mortality than non-caregivers.

3.2 Financial security and employment opportunities

Further, as a result of our failure to appropriately support carers, caregiving is too often associated with a negative impact on financial security and wellbeing. The primary caring role reduces a person's chances of being employed (ABS, 1999). Caring commitments mean that some carers are unable to work, or have to work fewer hours or in a lower paid job. Limited employment opportunities for primary carers are reflected in their incomes, with over half reporting in a 1999 study by the ABS a government pension or allowance as their principal source of income (ABS, 1999).

Further, lack of flexible working arrangements for those caring for someone who is dying or for those experiencing bereavement unnecessarily compound the stress and distress often experienced by carers (PCA, 2004).

Caring for a loved one who is dying is a one-off opportunity and often seen by carers as a final act of love or as an undeniable duty. Demanding that carers prioritise work and financial security in these situations is stress-inducing and unrealistic. As a society we can do better to support carers who wish to fulfil a dual role of carer and employee.

Without appropriate societal supports, caregiving can have an economic burden on carers in addition to the negative impact on their employment, with significant costs incurred through medication and health care costs, fees for community services and payments towards residential care and respite (PCA, 2004).

There are also long-term financial impacts of caring, such as loss of superannuation and the ability to save for retirement or to realise personal aspirations or goals.

4 Creating a care-supportive society

Caring for someone who is dying can be both a rewarding and challenging personal journey. The caring experience occurs within, and is shaped by, a broad social context. The extent and quality of support provided within this social context to the carer and the dying person is a key determinant of both of their experiences.

Yet too often and in too many ways we expect, and indeed rely on, carers performing their role as relatively isolated individuals. A carer both provides and needs support, yet the needs of carers are often overlooked. Indeed, the current provision of support services for informal carers has been described as 'crisis intervention', as it is often only in crisis situations of imminent or apparent breakdown that services respond (PCA, 2004).

Too often carers who appear to be coping in their role do not request support or services and are so assumed to have no unmet support needs. Typically, carers for dying people 'make do' with whatever information and support are available to them or come to their attention. (PCA, 2004). Many carers are not equipped with adequate support, training and resources to enable them to carry out their end of life care responsibilities effectively and without detrimental

impact to their own health and well being.

The first step toward better support for carers is acknowledgement of the critical contribution of carers. We must be realistic about acknowledging the role carers play in our society and as part of the health and care systems. It is imperative to the long term sustenance of the health care system that we provide adequate support to carers.

The role and needs of carers should figure centrally in whole of government planning and in the Government's health reform considerations. PCA recommends that governments formally acknowledge carers as essential partners in the health care system and as key contributors to society with specific, and too often unmet, need.

PCA joins Carers Australia in recommending that this acknowledgement is given an initial practical reality through the establishment of an 'Office for Carers' dedicated to establishing the foundations of a care-supportive society, including by raising the profile of carers' needs across the whole of government and assessing the impact of wide-ranging government policy on carers (Carers Australia, 2008). This PCA support is conditional on the terms of reference for the Office for Carers' including support for end of life carers.

To date there has been little coordination of service funding and service provision across federal, state and local government areas and limited co-ordination between voluntary agencies, leading to unequal social and geographical distribution of services. PCA believes a key contribution of an 'Office for Carers' could be to support better outcomes through greater coordination.

It is vital, and PCA recommends that:

- *measures be developed to promote end of life planning for end of life carers to minimise 'surprises', and thus to help anticipate their needs in a timely manner;*
- *strategies be developed to strengthen community capacity building to support end of life carers, including through:*
 - a) *increased recognition of, and support for, charitable and not for profit organisations in supporting end of life carers;*
 - b) *referral of this question to the Government's Australian Social Inclusion Board.*

4.1 Support to address end of life care needs

To be effective in their role in providing end of life care, carers need to be more adequately and consistently supported to meet end of life care needs. Capacity to meet needs directly impacts the quality of care received by the patient as well as the caring experience and quality of life of the carer.

Concerns about capacity to facilitate patients comfort have been identified as a key source of stress and distress for end of life carers (PCA, 2004). Too often the failure of the health care system to adequately facilitate quality end of life care in the home results in suboptimal pain and symptom relief causing distress for both the patient and the carer and often leads to unnecessary hospitalisations which can further compound distress. Too often carers are placed in the position of having to negotiate the complexities of the care system to ensure access to appropriate care for their loved one without sufficient information or support and in the face

of service barriers that inhibit continuity of care.

Effectively supporting carers as a key part of the end of life care team will require fully acknowledging the home as a primary site of end of life care. Supporting the home as an appropriate place of choice for end of life care will require a re-prioritising in resource distribution to support enhanced coordination of service provision through community care. This must be accompanied by:

- *reform to Medicare Benefits Schedule (MBS) items and other health funding programs to help ensure affordable in-home access to a multidisciplinary team of care providers including palliative care specialists and allied health professionals, in accordance with PCA's needs-based policy (for a brief overview of PCA's policy regarding role delineation between services in a needs-based end of life care model see Appendix 1: Population and needs-based planning for care at the end of life)s;*
- *adjustment to Pharmaceutical Benefits Scheme (PBS) prescribing criteria to remove barriers to general practitioners and other primary care providers prescribing appropriate, affordable pain and symptom management drugs;*
- *introducing a framework for better coordination of the delivery of end of life care to patients across the varying members of a multidisciplinary care team;*
- *increasing access to and quantity of in-home support, including access to 24/7 on call health practitioners for advice and direct care;*
- *access to respite care to enable time away from home for end of life carers;*
- *employment of Care Liaison persons in GP Super Clinics to facilitate carer coordination and support.*

4.2 Promoting carers' health and well being

Caring can be emotionally and physically demanding. Carers frequently subordinate their own emotional and health needs beneath those they are caring for and these needs are frequently also overlooked by health and care workers who are not trained to recognise them (PCA, 2004). Yet strategies that promote carer health and well being can be effective.

While palliative care acknowledges the carer as both part of the care team and as a recipient of care, end of life care does not necessarily involve, nor require, the services of a specialist palliative care team. (For a brief overview of PCA's policy regarding role delineation between services in a needs-based end of life care model see *Appendix 1: Population and needs-based planning for care at the end of life*). The capacity of primary care providers, who may be supporting the carer in the provision of end of life care, to identify and address carers' physical and emotional health needs is often inhibited by lack of awareness and education as well as systematic barriers, such as lack of appropriate MBS items.

Further, quality end of life care recognises that the needs of the carer do not stop with the death of their loved one, but include care and support to deal with bereavement and grief. Adequate care and support at times of loss is associated with decreased risk of complex grief and associated morbidity (PCA, 2004). Grief and bereavement care is often offered as part of palliative care services, however to ensure all carers are offered adequate support it is necessary that provision of bereavement care is seen as the domain of all health care.

Research undertaken by PCA suggests that many high intensity carers see respite care as the

most important service to promoting their health and well being (PCA, 2004). Information about various respite options, and the availability of affordable, reliable and flexible programs and day-care arrangements are high priorities in enhancing carer wellbeing.

Access to respite care is disparate across the nation, frequently not available in ‘emergency’ situations or on a short notice, and may be inhibited by eligibility criteria. Further, respite places for palliative patients are often further limited due to specific care needs.

PCA urges the Government to:

- *support expanded access to overnight, weekend and emergency respite care services and providing additional funding for the National Respite for Carers Program;*
- *fund the national roll out of an education campaign to support primary health care providers in the early identification of carers’ emotional and physical health needs, including the identification, treatment, and better management of chronic and complex bereavement;*
- *promote carer health through the provision of free regular health check for carers;*
- *increase funding for the National Carer Counselling Program to provide adequate counselling services to carers in need and support to carers experiencing bereavement.*

4.3 Meeting Information and education needs

To be effective and confident in undertaking what can be a demanding and complex role of the informal carer at the end of life, carers’ informational and educational needs must be better met.

Research undertaken by PCA has identified that carers commonly have critical unmet information needs:

- for more information and support from health care professionals about how to provide practical care. This may require training in specialised medical and treatment management skills to enable them to provide the appropriate level of care
- regarding where and how to acquire practical aids like walking frames, wheelchairs and hospital beds
- for preparatory information on typical aspects of the caring role and carer rights
- for information on how to access often critical resources like financial aid, respite and emotional support
- for accurate information about the trajectory of the illness, symptoms the person is likely to experience, treatments and related medical information so that they can plan for the needs of the terminally ill person. (PCA, 2004.)

Not only are there widespread unmet informational needs for carers providing end of life care but there are currently no long-term, nationally consistent education and training packages for carers and limited infrastructure to maintain a sustainable education and training program (Carers Australia, 2008.) This is despite very real needs for carer education on how to safely and effectively provide appropriate care while promoting personal wellbeing and evidence attesting that education is effective in supporting carers to provide care (Carers Australia, 2008).

Similarly, and as noted above, there is very little training for health providers around the role and contribution of carers and how to effectively support them and meet their information and education needs.

To better meet carers' informational and education needs and support their role in providing end of life care PCA recommends:

- a) *the preparation of best practice guidelines for the use of palliative medicines in non-hospital settings;*
- b) *the development of best practice models for delivering nationally consistent carer education and training, and funding to support the development of infrastructure to ensure its effective delivery.*

4.4 Acting to meet financial needs

The contribution of carers to health and social care significantly reduces the burden on the public purse. However, without adequate support this can be at significant financial cost at an individual level. It has been long established that carers as a population group have major unmet income support needs, yet there has consistently been insufficient government responses to sufficiently address this need.

Further, and as noted above, the negative financial impact experienced by many carers has financial consequences not just for their time as caregivers, but through loss of time in the workforce, for capacity to repay loans and mortgages, accrue superannuation and save for the future.

Financial pressures in particular, exacerbate the physical and emotional hardships of terminal illness and significantly increase the risk of adverse impacts for patients, their families and carers - before and after death.

PCA recommends that carers' needs for greater financial support be addressed through:

- *waiving the requirement for individuals and families to reach the out-of-pocket expenses threshold for access to the MBS and PBS safety nets as soon as a person is diagnosed in the terminal phase of an illness⁴;*
- *legislating to ensure the Carer Bonus become an annual, indexed payment*
- *increasing the weekly Carer Allowance to more accurately reflect the true costs of caring for a person at the end of life*
- *the introduction of a Carers' Superannuation Scheme for recipients of the Carer Payment.*

PCA further recommends the Government work with commercial banks to facilitate flexible options for carers who's changing work circumstances make it difficult for them to service current mortgages and debts.

4.5 Facilitating greater carer participation in the workforce

Carers experience significantly lower levels of workforce participation compared to those

⁴ PCA outlined the case for this in its 2007-08 pre-Budget submission to Government.

who are not in a caregiving role and face significant barriers to workforce participation, particularly lack of suitably flexible working arrangements to enable them to fulfil their multi-roles of carer and employee. Yet increasing carer participation in the workforce benefits carers through enhanced financial security and social support networks and offers potential benefit to the national economy.

PCA welcomes initiatives such as the funding of the Innovation Fund which can support Employment Service Providers to work with carers to develop solutions to aid their return to the workforce, however emphasises that further innovative policies and programs are essential to support carers to participate in the labour force and to return to work when their caregiving load lessens. It is well past time to realise the benefits of committing to care-supportive workplaces.

There is great need for more flexible employment arrangements to reduce work conflict and give carers more options in combining paid employment and caring. These arrangements must acknowledge that dying is different and that when caring for someone who is dying there is often not the time (or emotional energy) to engage in ongoing negotiations with employers about work schedules.

PCA urges the Government to take leadership on this front, in the first instance, by:

- *Developing and promoting care- supportive policies that support flexible working hours and leave arrangements for all carers.*
- *Conducting a review of the feasibility of extended ‘carers’ leave’ to enable those caring for a terminally ill loved one to take an extended period of leave without job loss and effective with short notice.*

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Appendix 1: Population and needs-based planning for care at the end of life

The goal of care at the end of life is to maximise quality of life through appropriate need-based care for each person at the end of life.

End of life is that part of life where a person is living with, and impaired by an eventually fatal (or terminal) condition. End of life is not always a finite point, however the principles of care applies even if the prognosis is ambiguous or unknown.

All health professionals and the community have a responsibility to care, when required, for people at the end of life and thus require a level of knowledge and skill in the philosophy and practice of palliative care. For quality care to be realised for all, recognition of the body of evidence and expertise in palliative care is essential for enabling appropriate referral and access.

Quality care at the end of life is provided by health professionals along a continuum of care – from primary or generalist care providers to specialist palliative care providers, based on the individual needs and choices.

The Council of Palliative Care Australia endorsed a national policy document in February 2005, *A Guide to Palliative Care Service Development: A population based approach*. This document suggests a plan for providing equitable access to care in the context of efficient, effective and ethical use of resources. The following diagram, from this document, illustrates the conceptual model for consumer focused care, based on defining this population and their needs.

The end of life population is not a homogenous population group – it is time to define the populations more precisely.

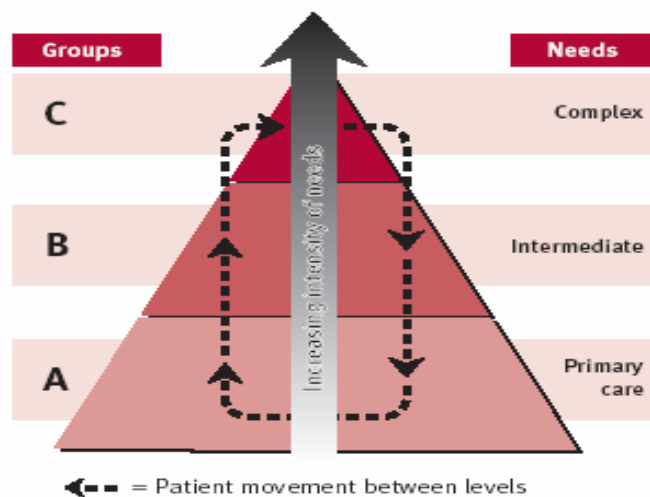


Figure 1: Conceptual model of level of need within the population of patients with a life limiting illness.

For the purposes of population based service planning, it is proposed that all people at the end of life (including their family, caregiver/s and community) be conceptualised as falling within three broad subgroups. Based on the best available estimates of expected deaths in Australia

per annum, the population represented in the conceptual model is 110,000.

The largest **sub-group (A)** are those patients who do not require access to specialist care as their needs are met either through their own resources or with the support of primary care providers (for example generalist medical and nursing services as well as other specialist staff – oncologists, cardiac services, geriatricians and so on). Currently, almost two-thirds of all people whose death is expected fall within sub-group A and are not seen by a specialist palliative care service prior to their death.

Just over 37.5% of patients represented in the model are currently seen by palliative care services. These patients are distributed between sub-groups B (those patients requiring consultation care) and C (those requiring ongoing specialist care). It is not known how they are proportionally distributed between sub-groups B and C.

In **sub-group (B)**, patients may have sporadic exacerbations of pain or other physical symptoms or may experience social or emotional distress. This temporary increase in their level of need may require access to specialist palliative care services for consultation and advice. They will continue to receive care from their primary care provider.

Sub-group (C) are those palliative care patients who have been identified as having complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of care. They usually require highly individualised care plans developed, implemented and evaluated by knowledgeable and skilled specialist practitioners, in partnership with primary care providers. This sub-group is likely to be the smallest of the three sub-groups of the population.

Palliative Care Australia believes:

- Every Australian at the end of life should have timely and equitable access to quality, needs-based and evidence-based care
 - timely is determined by the needs of the patient and their family and caregivers
 - equitable access should be ensured regardless of age, ethnicity, location, diagnosis, or disease prognosis
- Patient, family and caregiver needs (physical, social, emotional, spiritual, cultural), balanced with an assessment of individual and collective resources and limitations, should be the criteria used to determine access to appropriate levels of care for people.