

Full Report of the National Inquiry into the Social Impact of Caring for Terminally Ill People

Incorporating a Literature Review and
Analysis of Public Submissions

Prepared by Dr Samar Aoun

for Palliative Care Australia May 2004



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- Professor Linda Kristjanson Chair from October 2003
- Professor Allan Kellehear Chair from March to September 2003
- Professor David Currow Vice Chair
- Dr Paul Dunne
- Dr Peter Hudson
- Mr John Rosenberg
- Ms Margaret Box
- Dr Samar Aoun
- Ms Tonia Barnes

Members of the Working Party gave freely of their valuable time to ensure the quality of this Report.

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Lastly, and **most importantly**, Palliative Care Australia thanks those carers who provided such moving and informative submissions to the National Inquiry. This information grounded and enriched the Working Party's work.

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The Executive Director,
Palliative Care Australia,
PO Box 24, Deakin West ACT 2602.

Phone 02 6232 4433

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The Hardest Thing We Have Ever Done - The Social Impact of Caring for Terminally Ill People in Australia 2004: Full Report of the National Inquiry into the Social Impact of Caring for Terminally Ill People

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Design: Design Edge

Palliative Care Australia adopted 'Purple Patchwork Quilt' as the graphic identity for our carers program. The Quilt was designed by Anji Hill, who writes:

'The patches of the quilt represent interconnectedness, community, parts making up a whole, and the empty square shows the importance of each part in that whole. The eye comes to rest on the absent square, (which) represents the unknown beyond this life.'



Foreword

This report is presented by Palliative Care Australia to honour the contribution of the many thousands of Australians who provide high quality care to people who die from a terminal illness each year.

Dedicated effort continues to improve the quality of care offered to people at the end of life. We know that their partners, parents, sons and daughters, siblings, friends, neighbours, colleagues and communities continue to provide most of this care.

'The Hardest Thing We Have Ever Done' presents evidence that many carers regard caring for dying people as a privilege and are able to reap important rewards from the experience. Our research has brought to light the resilience, resourcefulness and commitment of carers, many of whom are aged, unwell and economically disadvantaged. Palliative Care Australia is, more than ever, convinced that such people require recognition and better services. We have initiated, using the evidence in this report, a campaign for broad social change, which, in the medium-to long-term, will improve outcomes for those who care for dying people. Palliative Care Australia will work with the community, governments, the media, stakeholder organisations and service providers to help them understand the problems with which carers contend every day and to improve their services, processes and communications.

The report is entitled 'The Hardest Thing We Have Ever Done', a direct quote from a woman whose father died of prostate cancer, and it highlights just how gruelling and exacting caring responsibilities can be. It demonstrates that individuals, and consequently society as a whole, experience significant negative effects if carers don't receive the support and care they require. The most powerful message in the report is that the Australian community, policy-makers and health service providers in particular need to pay attention to supporting carers and better tailor their services to meet their unmet needs.

I encourage all of us to take on board the recommendations and suggestions for reform in this document and to contact Palliative Care Australia to learn more about our vision of improved support for carers.

Lastly, I thank, on behalf of all at Palliative Care Australia, all the carers who do such a magnificent job in caring for dying people in our community, especially those who have contributed to this document.



Professor David Currow

President

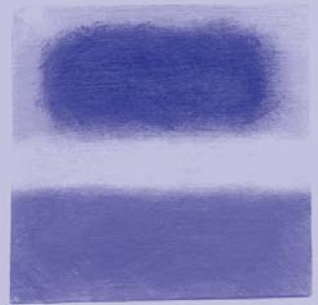




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Recommendations

A systematic review of Australian and international literature that addresses the needs of caregivers in general, and those involved in the delivery of home palliative care in particular, together with an analysis of public submissions to Palliative Care Australia's National Inquiry into the Social Impact of Caring for Terminally Ill People, points to a range of initiatives and reforms designed to decrease the negative individual and social impacts of caring for dying people in Australia. Palliative Care Australia has identified the following needs:

1. policy developments in the taxation, social security and income/pension benefit domains, to ease the financial hardship of carers
2. more carer-friendly workplaces, with flexible employment arrangements and better opportunities to go back into the workforce, particularly for women who make up 70% of the unpaid caring workforce
3. coordinated service funding and service provision across all levels of government (federal, state and local) to ensure equitable social and geographical distribution of services
4. a comprehensive and coordinated approach to the evaluation of services, to ensure closer links between policy and practice, and develop standards for service quality for carers
5. education at a community level, to promote the social value of caring and an awareness of the demands and impact of the caring role
6. educational materials geared specifically to caregivers using appropriate methods of information delivery
7. education of health professionals, to improve communication and timely access to support services
8. focused strategies that address the barriers carers experience when attempting to seek support
9. specialised strategies which address the needs of special groups, such as younger and older carers, those from Indigenous and CALD backgrounds, those living in rural areas and those with chronic disabling conditions whose eligibility to access palliative care is restricted
10. multidisciplinary research leading to evidence-based practice approaches to home-based palliative care
11. partnerships and collaborations between government, service providers, GPs, families and researchers to meet the needs of families for good palliative care.





Executive Summary

Palliative Care Australia launched the National Inquiry into the Social Impact of Caring for Terminally Ill People in mid 2003 to gather policy, opinion, experience and research related to the social impact of unpaid caring for the terminally ill. The National Inquiry project consisted of two parts:

- a review of the literature to highlight the contribution made by unpaid carers to Australian society, to investigate the impact of caring on their lives and the challenges and difficulties they face
- an analysis of the public submissions from individual carers and/or their support organisations or service providers.



Although the role of carer can be rewarding, national and international studies have reported that there are also many negative impacts of caring over time. These studies also report that caregivers have significant needs related to their caregiving role, many of which are unmet. Compelling evidence reveals the significant, yet often invisible, contribution that carers make to the national economy. Carers, in general, contribute over \$20 billion to the Australian economy, and the unpaid workforce is estimated to be about five times the paid workforce, in terms of full-time equivalents.



Carers in general – and those in palliative care in particular – experience difficulties in maintaining employment, and are forced to give up work and rely on government assistance, which is frequently inadequate, particularly in light of the increased expenses they encounter on a daily basis. The cost of drugs and equipment hire for palliative care can be extremely expensive and place an enormous financial burden on carers who try to maintain their family member at home. Carers experience an increase in adverse health effects related to stress, a change in eating patterns leading to weight loss, and a disruption in sleeping patterns leading to carer fatigue. Carers have reduced opportunity for social and physical activities, further reducing their own physical wellbeing, which can lead to their social isolation, even to the point of becoming home-bound. Carers often ignore or diminish the importance of their own needs and forego their own health checks. Lack of respite care and other support services leads to social isolation, exhaustion, illness and negative feelings towards the dying patient and carers putting their own health at risk. Carers report feelings such as guilt, fear, frustration, anger, resentment, anxiety, depression, loss of control and a sense of inadequacy. Periods of caring may be brief or quite long and protracted, with a roller coaster of emotions, reactions and frequent crises.



The picture that emerges from the public submissions is that carers for dying people 'make do' with whatever information and support is available to them or comes to their attention, should they happen to be at the right place and at the right time, or have the know-how to navigate the system. Those fortunate to have sufficient support mostly feel positive about their caring experience, while those less fortunate undertake caring responsibilities at the expense of their physical, emotional and financial wellbeing. The experiences of carers suggest that a considerable amount of service contact/access occurs on a random or ad-hoc basis.



Recurring themes emerging from the submissions by carers and support organisations on service gaps can be grouped into four interrelated categories:



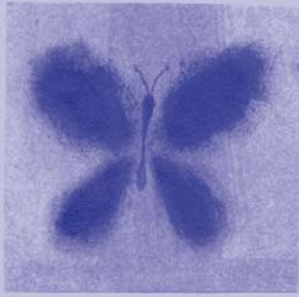


- information and education
- financial and employment difficulties
- respite and other support services
- community recognition.

These themes support the findings of the literature review. Carers' health and wellbeing seems inextricably linked to the availability, quality, responsiveness and cost of support from health and community services. Carers reported a need to access adequate and flexible resources, fairer remuneration, more respite care, better training and equipment, counseling and bereavement support, personal and home help and improved access to the paid workforce. The needs of special groups have also been highlighted in this report, in particular older and younger carers, those from indigenous and CALD backgrounds, those living in rural areas and those with chronic disabling conditions whose eligibility to access palliative care are restricted.

In conclusion, there is compelling evidence to indicate that the work of carers is undervalued and marginalised in the Australian community. Evidence collected by the National Inquiry reinforces the importance of policy responses and resources allocations that are focused on helping carers perform a vital and important role into the future, particularly as carers are increasingly replacing skilled health workers in the delivery of unfamiliar and complex care for terminally ill people.





Literature Review

Background

Relatives and other unpaid caregivers providing informal care in the home are major sources of support for people with long-term illness and severe disabilities. With an ageing population, increasing rates of disability and the growth in community care, the role of the family caregiver has changed and expanded in recent years. It is not surprising therefore that family caregiving has become a major focus of research interest overseas and in Australia (Briggs & Fisher, 2000; Schofield et al, 1997a; Morris et al, 1999; Princess Royal Trust for Carers, 2003; National Alliance for Caregivers, 1997).

We live longer, but with compromising medical conditions and increased costs of health care. Consequently, many individuals are finding themselves becoming the primary care providers for ill and disabled family members. Families are increasingly replacing skilled health workers in the delivery of unfamiliar complex care. The caregiver role has changed dramatically from promoting convalescence to providing high technology care and psychological support in the home (McCorkle & Pasacreta, 2001). There is considerable evidence in the literature that the burden of caring is adversely affecting family caregivers who lack adequate resources or who are insufficiently prepared for this new complex role (Aranda & Hayman-White, 2001; McCorkle & Pasacreta, 2001; Yates, 1999; Kristjanson, Hudson & Oldham, 2003).

Information in Australia about basic issues such as the range of services available to carers, patterns of service use and evaluation of existing services is limited (Schofield et al, 1996). The carer can be seen as holding a unique position of both providing and needing support, and it has been suggested that it is sometimes unclear who is the 'patient' (Harding & Higginson, 2003). On the one hand, carers are regarded as providers within the network of care, on the other, when practical assistance is needed to protect their health and wellbeing; they are regarded as service users and are dependent on means-tested, rationed services (Lloyd, 2003). Carers tend to be overlooked and often referred to as 'hidden patients' (Wiley, 1998). Clearly, carers are still in an ambiguous position in relation to service providers.

Study Objectives and Methods

Despite the significant contribution of carers, there is considerable evidence in the national and international literature, of the physical, psychological and social morbidity associated with caregiving, highlighted in studies with negative titles, such as: 'Caring enough to be poor' (Carers Association of Australia, 1997); 'Ignored and invisible' (Henwood, 1998); 'Caregiving as a risk factor for mortality' (Schulz & Beach, 1999); 'For love, for faith, for duty, for deed' (Cole and Gucciardo-Masci, 2003); 'Warning - caring is a health hazard' (Briggs and Fisher, 2000); 'Family caregivers and leisure: an oxymoron?' (Bedini, 2000).

It is in this national and international context that Palliative Care Australia has undertaken a National Inquiry to gather policy, opinion, experience and research related to the social impact of unpaid caring for terminally ill people.

The first section of this report focuses on the literature review, which addresses issues in the wider population of carers, and more particularly those in palliative care. Database searches from Medline and CINAHL were undertaken in December 2003 and January 2004 using the following key words: family caregiver, palliative care, terminal care, supportive care, interventions, carer support, psychosocial support, caring impact, caring burden, caregiver stress, needs, home care, work conflict, emotional wellbeing, multicultural, diversity, cancer, rural, information, informal carers, ageing and carers and Indigenous carers. Database



searches were supplemented with manual searches of journals, reviews of reference lists of identified papers, contributions from key researchers in the field of palliative care in Australia and published and unpublished reports from government and support organisations. The objectives of this review were to:

- capture the diversity of caregiving roles and the differing levels and types of support, by providing a socio-demographic profile of carers and care recipients and the range of their disabling conditions, time spent caring and tasks performed by carers
- describe the nature and extent of the impact of caring on the physical, mental and emotional, social and economic aspects of life of carers
- highlight expressed needs of carers and existing gaps in assistance and support
- identify interventions aimed at enhancing the knowledge, skills and/or support of carers
- present policy suggestions and strategies to ease the burden of caring.



Contribution of Carers to the Economy

The impact of the emerging information on the contribution of carers to the Australian economy cannot be underestimated. According to the Australian Institute of Health and Welfare report 'Australia's Welfare 2003', in 2000-1, the total contribution of unpaid welfare work was calculated at \$28.8 billion or nearly seventy percent of total resources spent on welfare services. In terms of type of care provided by this unpaid work, 66.6% of the gross value (19.3 billion) was for care provided to other family members, friends or neighbours, 28.6% (\$8.3 billion) was for child care-related activities, and the remaining \$1.4 billion was for voluntary welfare assistance through community service organisations. The unpaid workforce was estimated to be about five times the paid workforce in terms of full-time equivalents, and informal unpaid care has been referred to as the 'invisible welfare state' (AIHW, 2003).



In the UK, the current value of the support given by carers has been put at around the same level as the total of UK spending on health, about 57 billion pounds in 2001-2. The number of carers with heavy caring commitments is over one million, a figure similar to the number of those employed by the National Health Service in England and Wales (Princess Royal Trust for Carers, 2003).



Not only do carers contribute over \$20 billion a year to the Australian economy, they provide 76% of all services to people needing care and support. In comparison, the Home and Community Care [HACC] program, worth \$800 million nationally, meets only 9% of needs (Carers NSW, 1998). Fried (2001) highlighted the hidden costs of informal care, which are translated into considerable savings to the public purse. The value of unpaid care for the disabled care recipients amounted to \$6 billion per year when using the 'replacement cost' approach, which calculates an hourly wage rate for care, or else it amounted to \$3.3 billion per year when using the 'opportunity cost' approach, which assessed earnings forgone by the carer (Office of Women's Affairs, 1994).



The project on carers of people with mental illness (Mental Health Council of Australia, 2000) also highlighted the scale of the carers' contribution. The average individual caring time of 104 hours per week indicates "it is primarily carers who are sustaining the fabric and operational effectiveness of mental health service systems across Australia". Consultations with carers identified a strong perception that carers often fill a void in consumer care and treatment due to poor practice in the professional/formal delivery of mental health services.



Carers in Palliative Care

Palliative care is the specialised health care of dying people, which aims to maximise quality of life and assist family and caregivers during and after death of a loved one (Palliative Care Australia, 2000). The World Health Organisation defines palliative care to be "an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems" (WHO, 2004). In Australia, this type of care is most often provided for patients at the end of life, usually within the last three to six months of life (Kellehear, 2001). Although approximately one third of all patients receiving palliative care services die at home, up to 90% of terminally ill patients spend the majority of their last year of life at home (Palliative Care Australia, 1999a; Robbins, 1998). Thus, home palliative care would be impossible for many people without the support of caregivers (Hudson, 2003).



The demand for palliative care services within the home has increased due to reduced availability of hospital beds, a desire for less institutionalised care and an ageing population where the morbidity and mortality associated with illnesses such as cardiovascular disease, cancer and respiratory disease increase with age (NSW Health, 1998). The emphasis that palliative care places on supporting the care choices made by patients and their families has created some expectations about dying at home and meeting these expectations depends on the availability of informal carers and appropriate care support (Fried, 2001). Fifty to seventy percent of terminally ill patients may prefer to die at home in the comfort of familiar surroundings (Grande et al, 1998). Factors found to be associated with successful home palliative care and dying at home included (Maida, 2002):



- being male
- having cancer or AIDS
- having a healthy full-time caregiver
- not living alone
- having adequate financial resources
- having personal needs that could be managed at home
- expressing a preference for dying at home.



The preference for a home death is compatible with government's objective to shift health care away from public institutions and into the community. There is compelling evidence to indicate that home based palliative care is more cost effective than hospital-based palliative care (Chochinov & Kristjanson, 1998). These changes in the delivery of health care require new concepts, new policies and a redistribution of health resources.

Definition and Characteristics of Carers

The Australian Bureau of Statistics defines primary carers as people who regularly provide the most assistance with one or more of the core activities of communication, mobility, transport, housework and self-care (ABS, 1999). The definition of carers used in the Victorian Carers Program was also not stringent (Schofield and Herrman, 1993): a carer could be a mother or a spouse providing 24 hours a day, seven days a week care, or a daughter with her own family and work commitments helping an aged parent with shopping and/or household chores for a minimum of four hours per week. Carers were selected on the basis of self-identification as the initial screening question asked whether the person had the main caring responsibility for someone who is aged or has a long-term illness, disability or other problems, even if they live elsewhere. The Princess Royal Trust for Carers in the UK (2003)



defined a carer as someone who, without payment, provides help and support to a friend, neighbour or relative who could not manage otherwise because of frailty, illness or disability. They may be juggling paid work with their unpaid caring responsibilities at home.

The most reliable information on the prevalence and nature of caregiving and the socio-demographic characteristics of caregivers and care recipients is provided by surveys of disability and ageing conducted by the Australian Bureau of Statistics in 1988, 1993 and 1998. Other Australian large-scale surveys include the 1993 Victorian Carers Program (Schofield and Herrman, 1993; Schofield et al, 1997a), which is a population-based survey of 976 respondents, and the 1999 Carers Association Survey (Briggs & Fisher, 2000) with a sample of 1449 respondents drawn from support organisations and service providers.

In Australia, nearly 2.3 million people aged 15 years and over are involved in informal care of children, adults and older persons with disabling chronic and terminal conditions (ABS, 1999). This comprises approximately 15% of all people living in households. Of those, 1 in 5 or approximately 450,900 were primary carers. It is estimated that in 2002, 2.5 million people would have performed informal caring, including nearly half a million primary carers (490,700) (AIHW, 2003).

Some of the socio-demographic characteristics of primary carers are summarised in Table 1. The majority of caregivers are middle aged women who live with the care recipient. Compared to non-carers, carers have significantly lower employment rates and this aspect will be discussed in more detail in this report.



Table 1: Profile of primary carers

Characteristics of carers	Percent
Age of carers	35% 15-44 yrs, 43% 45-64 yrs, 22% 65+ yrs
Carers 15-44 yrs	43% caring for children under 15, 37% for recipients of same age
Carers 45-64 yrs	46% caring for recipients of same age, 31% for recipients aged 65+ yrs
Carers aged 65 and over	81% caring for recipients of same age
Gender	71% women, as partners, daughters or mothers
Not working or looking for work	59% (compared to 32% non-carers)
Employed in general	36% (compared to 62% non-carers)
Employed in part-time work	53% (compared to 29% non-carers)
Principle source of income is pension/allowance	56%
Carer lives with care recipient	79%
Relationship of recipient of care	43% partner, 25% child, 21% parent, 11% other
Years of caring	32% 0-4 yrs, 29% 5-9 years, 26% 10-24 yrs, 13% 25 yrs or more

Source: Compiled from ABS (1999), Catalogue No. 4430.0.



In the USA, according to the National Survey of Families and Households (Arno, Levine & Memmott, 1999), there were almost 26 million informal caregivers and projections from the 2000 census suggest the number to be as high as 54 million. The average age of a caregiver is 46 years old, over 75% of family caregivers are female, two-thirds are married and 41% also have children under the age of 18 living in the home. Additionally, 64% of caregivers are working and 52% of these caregivers work full-time.



The most common reported reason for being a carer was family responsibility (72% of children and 59% of parents) followed by feeling that carers could provide better care than would otherwise be available (53% of children and 49% of parents), emotional obligation (43%), the absence of other family of friends (30%) or their lack of willingness to take on the role (19%) (ABS, 1999).

In palliative care, 50 to 70% of caregivers are spouses with two-thirds being wives and 20% daughters or daughters-in-law, and half of them aged less than 60 years (Robbins, 1998; McIntyre, 1999). Caregivers experience ambivalence towards their role. Although 85% of family caregivers of cancer patients reported that they resented having to provide care (Barg et al, 1998), 97% acknowledged that it was important, with 67% reporting getting enjoyment out of their role. Nevertheless, some caregivers may feel forced to take on roles they may not want to assume or for which they do not feel capable (Yates, 1999), or they may not be offered a choice regarding their role (Aranda & Pearson, 2001).



Tasks Performed by Carers

The carers' role includes managing medications, therapies and medical emergencies, providing supervision and emotional support, assisting with personal care, mobility and household tasks (Briggs & Fisher, 2000). Bathing and dressing were the most frequent personal tasks requiring assistance whereas cooking and washing clothes were the most frequent household tasks requiring assistance (Wiley, 1998). Schofield et al (1997a) reported that the most frequently needed tasks were organising appointments and social services, going out, and managing money. Half of the care recipients needed considerable help in taking medication, changing dressings and bathing. One in four needed help with getting in and out of bed and toileting.



Carers estimated the time they spent on several aspects of caring (Briggs & Fisher, 2000):

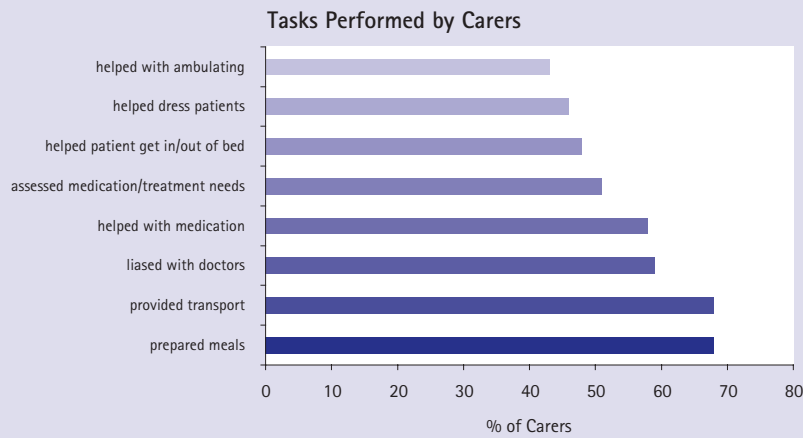
- 34% of their time was spent on direct personal care such as help or supervision for dressing, bathing, toileting, eating, moving around, nursing care, medications, rehabilitation activities, assisting with communication
- 31% of their time was spent on other aspects of care such as supervising to prevent wandering, self-harm, harm to others or damage to property, encouraging and promoting to do things, providing emotional support and companionship, activities to enhance development of children with certain disabilities
- 35% was spent on necessary support activities such as organising health treatments or services, transport (to medical appointments, day centres, etc), managing finances, additional household work such as laundry and preparing meals.



Similarly, palliative family caregiver roles may encompass some or all of the mentioned tasks. A study of 750 caregivers of cancer patients, with 26% receiving home palliative care, revealed that 68% of caregivers prepared meals for care recipients, 68% provided transportation, 58% helped with medication, 59% liaised with doctors, 51% assessed the need for medication or treatment, 46% helped to dress patients, 43% helped with ambulating and 48% assisted the care recipient to get in or out of bed, as shown in Figure 1. A significant proportion (62%) felt they had to be available 24 hours a day and 80% felt primarily responsible for caregiving (Barg et al, 1998).



Figure 1: Tasks performed by carers of terminally ill people



Characteristics of Recipients of Care

Whereas caregivers concentrated in the middle age ranges, care recipients were predominantly in the older age groups, two-thirds were over 60 years of age and almost half were over 75 years (Schofield et al, 1997a). Consistent with the greater longevity of women, adult children were more likely to be caring for an ageing mother. At the other end of the age spectrum and consistent with the differential rates of disability between boys and girls, parent caregivers were more likely to be caring for a son than a daughter.

Care recipients had a wide range of congenital, degenerative and traumatic conditions, which included diabetes, stroke, dementia, heart disease, cancer, arthritis, asthma, multiple sclerosis, musculoskeletal problems, cerebral palsy, Down's syndrome, developmental delay and various psychiatric disorders. Half the care recipients had multiple conditions (Schofield et al, 1997a). The moderate and severe disabilities related to mobility (57%), sensory loss (45%), long-term health status (40%) and coordination (37%). The diversity in those cared for in terms of illnesses and disabilities has also been highlighted in the Carers Association Survey and summarised in Table 2.

Table 2: The ten most common health conditions of recipients of care

Health Conditions	Number	Percent*
Alzheimer's disease/dementia/memory loss	326	23
Frailty in older age	326	23
Intellectual disability	251	17
Stroke	240	17
Neurological disorder	228	16
Heart condition/blood pressure	180	12
Mental/emotional illness	164	11
Respiratory	111	8
Musculoskeletal	104	7
Cancer	82	6

* Totals do not add up to 100% due to multiple responses.



A common feature of caring for individuals with these types of disabilities is the challenge of managing problem behaviour (Schofield et al, 1997a): 38% of carers found their care recipient's behaviour difficult or very difficult. The most common behaviour problems were repetition of questions and stories, listlessness and fatigue, inability to concentrate, crankiness or irritability, forgetfulness or confusion, hyperactivity, uncooperativeness, depression and fearfulness. Over one in four carers reported aggression and one in ten reported physical violence in their care recipient.



The issues of abuse of care recipients by carers have been highlighted by Fisher (2003), based on reviewing the literature on abusive caregiving relationships in the elderly. In the Australian population in general and more specifically among social services recipients, about 5% to 13% of older people are victims of financial, psychological or some form of physical abuse, perpetrated mostly by family members and those who are in caregiving relationship with them (Kinnear & Graycar, 1999; Reis & Nahmiash, 1998). Fisher (2003) has identified the potential for abuse to exist within palliative care families. The invisibility of this issue has important implications for the delivery of palliative care services as the psychological impact of such abuse may manifest in greater emotional distress and poorer quality of life for the victim.



Impact of Caring on Carers: Physical, Social & Psychological

Research related to the demands of caregiving was primarily based upon studies of caregivers of cancer patients and palliative care patients, elderly patients with Alzheimer's disease or children with a chronic or terminal illness. Many of these studies, Australian and international, were mainly descriptive, with small sample sizes, identifying the expressed needs of carers and family members of the recipient of care, particularly needs for information and psychological support. Table 3 presents a selection of recent studies and reviews undertaken in the last ten years, in Australia, Canada, the USA and the UK. Although the list is not exhaustive of all the relevant literature addressing the impact of caring, the issues covered by this selection are representative of those addressed in the national and international literature in the last ten years in cancer and palliative care.



Sources of stress include 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, and fears of being alone. Disruptions and emotional strains associated with caregiving are common experiences for families of people with cancer. Feelings of tiredness, difficulty getting enough sleep, and feelings of resentment and isolation were the most commonly reported disruptions and emotional strains and among the most difficult coping challenges. Carers suffered from lack of control over everyday life, lack of self-confidence, changes in paid employment, reduction in leisure time, deterioration in their own health, exacerbation of a previous health problem, postponement of their own health care, and feelings of distress. 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.



Recent surveys and larger-scale studies in several countries have provided more quantitative information on the impact of caring using larger sample sizes. In Australia, the 1999 Carers Association Survey included a total of 1,449 respondents, representing less than one percent of the carer population identified by the 1998 ABS survey. Although the respondents were significantly older than the ABS population, were more long-term carers (10 years or more), lived in rural and remote areas (19%) and were more often providing care for partner or were carers of children with disabilities, the reported impact on their lives is applicable to the general population of carers.



Table 3: A selection of recent national and international studies/reviews on carers in cancer and palliative care

Authors	Year	Country	Sample
Leonard, Enzle, McTavish et al	1995	USA	Review
Davis, Cowley & Ryland	1996	UK	56
Mastrian, Ritter & Deimling	1996	USA	180
Steele & Fitch	1996 a,b	Canada	20
Kristjanson, Leis & Koop	1997	Canada	72
Vachon	1998	Canada	Review
Payne, Smith & Dean	1999	UK	39
Rose	1999	UK	10
Yates	1999	Australia	105
Aranda & Hayman-White	2001	Australia	42
Grbich, Parker & Maddocks	2001	Australia	86
Kristjanson & White	2002	Australia	Review
Nikoletti, Kristjanson, Tataryn et al	2003	Australia	141

Impact on Physical, Mental and Social Wellbeing

The 1999 Carers Association Survey (Briggs & Fisher, 2000) highlighted that carers' health and wellbeing suffers significantly. Carers often feel exhausted, isolated and burdened by their responsibilities. Carers may forgo their own health checks or treatment plan because of the pressures of caregiving. Nearly sixty percent of carers reported that their physical health had been adversely affected; a third had sustained a physical injury and virtually none had received any financial compensation; more than 70% felt that they had low energy levels; over half reported worse mental and emotional health and nearly 60% experienced major negative effects on their life opportunities, especially travel, pastimes and paid work. Tables 4, 5 and 6 summarise the effects of caring on the physical, mental and social wellbeing of caregivers.

England and Wales have more than five million unpaid carers and over a million provide care for more than 50 hours a week. Two-thirds of these unpaid carers reported that their health has been affected by caring and 40% of them have an illness or disability themselves (Princess Royal Trust for Carers, 2003). A study about caregiving in Canada reported that 48% of carers found it very difficult to balance their personal and job responsibilities, 42% of them experienced a great deal of stress in trying to juggle their various roles, 57% felt they did not have enough time for themselves, 53% cut back on sleep and 44% had experienced minor health problems in the past six months (The Standing Senate Committee on Social Affairs, 2002). Ramirez et al (1998) reported that, in the year before the death of a cancer patient, the prevalence of anxiety among informal palliative carers was as high as 46% and the prevalence of depression as high as 39%. Approximately half of carers reported problems sleeping and about a third reported weight loss during the year. Carers' anxiety was rated alongside patients' symptoms as the most severe problem by both patients and families.

Table 4: Effects of caring on the physical health of carers *

Details of changes/problems	Number	Percent
Rating of present health and wellbeing as fair or poor	669	46
Caring has directly affected physical health	861	59 (of those 95% affected to the worse)
Tired/exhausted	438 (n= 803)	55
Back/neck/shoulder problems	271 (n= 803)	34
High blood pressure/heart problems	101 (n= 803)	13
Reasons for effects on physical health attributed to caring	296 (n=717)	41
Constant pressure of caring	237 (n=717)	33
Stress	227 (n=717)	32
Disturbed/loss sleep	220 (n=717)	31
Lifting/pushing/supporting while walking	474	33 (69% sprain/strain of joints/muscles)
One or more injuries in the course of providing care	282 (n=471)	60
Recurrence/aggravation of injury by continuing care	464 (n=488)	98
Received no financial compensation for injury	1085	75 (of those 94% affected to the worse)
Caring has directly affected energy levels	471 (n=801)	59
Not enough free time/rest	312 (n=801)	39
Lots/too much to do	125 (n=801)	16
High need/demanding care recipient		

Source: Information compiled from Carers Association Survey (Briggs & Fisher, 2000).

*most common responses.

Totals do not add up to 100% due to multiple responses.

n=1449 unless specified in the table.



Table 5: Effects of caring on the mental health of carers *

Details of changes/ problems	Number	Percent
Caring has directly affected mental & emotional health	965	67% (of those 85% affected to the worse)
Sad/depressed	240 (n=856)	28%
Worried/anxious	227 (n=856)	27%
More emotional/easily upset/irritable	141 (n=856)	17%
Frustrated/bored	118 (n=856)	14%
Exhausted	109 (n=856)	13%
Stressed	101 (n=856)	12%
Reasons for effects on mental health attributed to caring		
Stress of caring	459 (n=894)	52%
Social isolation/loneliness	301 (n=894)	34%
Changes in family/other relationships	227 (n=894)	25%
Sense of grief/loss	219 (n=894)	25%
Loss of paid work	124 (n=894)	14%
Difficulties or delays with treatments due to caring	439	30% (32% doctors' visits, 30% operation)

*most common responses.
Totals do not add up to 100% due to multiple responses.
n=1449 unless specified in the table.



Table 6: Effect of caring on life opportunities *

Details of changes/ problems	Number	Percent
Major/dramatic effect on carers' lives and choices	845	58
No or fewer holidays/weekends away	488 (n=1076)	45
No or less travel/visits	325 (n=1076)	30
No or reduced social life	168 (n=1076)	16
No or less community involvement	137 (n=1076)	13
Limited time for personal relationships	119 (n=1076)	11
No or less time for hobbies and pastimes	276 (n=1076)	26

Source: Information compiled from Carers Association Survey (Briggs & Fisher, 2000).
*most common responses.
Totals do not add up to 100% due to multiple responses.
n=1449 unless specified in the table.





Impact on Economic Wellbeing

It appears that the primary caring role does reduce a person's chances of being employed (ABS, 1999). The proportion of primary carers who were neither working nor looking for work was almost double that of those who were not in the caring role (Table 1). Age and sex alone do not explain the lower employment rate for primary carers; although most carers are women between the ages 15 to 64, their employment rate is still lower than that of all women in the same age group (46% compared to 61%). Schofield et al (1997a) reported that caring commitments meant that some carers were unable to work, or had to work fewer hours or in a lower paid job with financial consequences (Table 7).



Table 7: Effect of caring on the employment and financial status of carers

Details of changes	Percent
Worried about care recipient while at work	59
Working fewer hours	29
Had to give up their job	17
Having less energy for work	29
Being interrupted repeatedly during working hours	28
Taking periods of unpaid leave	22
Settling for a less responsible job	16
Refusing promotion	13
Working from home	14
Difficulty meeting everyday living costs	25
Financial loss due to extra expenses	26
Reduction in income	18
Time spent caring per week	27% for over 100hrs; 15% for 31-100hrs; 22% for 10-30hrs; 35% for under 10hrs.

Source: Information compiled from Schofield et al (1997a). n=976.
Totals do not add up to 100% due to multiple responses.



The limited employment opportunities for primary carers are also reflected in their incomes, with over half reporting a government pension or allowance as their principal source of income (Table 1). The 'Caring Costs' study also confirmed the low-income levels of most carers (Carers Association of Australia, 1997). Almost two-thirds listed a government pension or benefit as a main source of income. More than half of all carers had incomes less than \$200 per week, and over two thirds had incomes less than \$300 per week, when average weekly full-time earnings at the time were approximately \$550. Similarly, nearly 60% of all carers had too little taxable income to pay personal income tax, and over two thirds paid less than \$20 a week income tax. Only 15% of carers listed paid work as a main source of income.



Caregiving is also reported to have an economic burden on carers in addition to having a negative impact on their employment. The 'Caring Costs' study estimated that the extra costs associated with illness and disability amounted to \$119 per week in 1997 or around 26% of all weekly household expenditures, which is a very high proportion. Medications and other health care costs were the largest component at \$36 per week, followed by private health insurance at \$24 per week. Fees for community services averaged \$22 per week and disability/illness items averaged \$16 per week in addition to payments towards residential care and respite. There are also long-term financial impacts of caring, such as loss of superannuation and the ability to save for one's retirement.

In the USA, many carers of terminally ill patients with moderate or high care needs reported spending 10% of their household income on health care costs, that they or their families had to sell assets, take out a loan or mortgage or obtain an additional job to meet health care costs (Emanuel et al, 2000). The economic impact of day-to-day family involvement in living with cancer can be profound, especially due to the unavailability of support services in many geographic areas (McCorkle & Pasacreta, 2001). Findings from the few cost-estimate studies indicate that families find themselves responsible for purchasing medications and home care supplies, for renting equipment and for paying for transportation and respite services (Given et al, 1994). In Canada, the financial costs associated with the move from institutional care to home care were borne by recipients and their carers (Morris et al, 1999). Many of these costs would be absorbed by the government if the recipient were in hospital, especially expenses related to medical equipment, special meals, renovations to accommodate disabilities, repairs and maintenance of the care setting, and, in some instances, prescription and non-prescription drugs.

Positive Aspects of Caring

Although general research focused on the stress of caregiving, caring is not necessarily an exclusively negative experience. Without recognition of the potentially positive elements, there is a danger of labeling caregiving as completely burdensome (Hudson, 2004). Carers expressed strong positive emotions when asked about their caregiving experiences and many described this as an opportunity to express their love through care. They found significant meaning in their roles and felt satisfied knowing that they were doing a good job and providing comfort to their loved ones (Grbich, Parker & Maddocks, 2001; Aranda & Hayman-White, 2001). Folkman (1997) reported that people draw on their positive emotions to enhance and maintain their coping resources when confronted with an ongoing stressor such as caregiving. Hudson (2004) sought feedback from 47 primary family caregivers of advanced cancer patients on key challenges associated with their role and whether they could identify any positive aspects. Sixty percent of the caregivers acknowledged positive or beneficial aspects associated with their situation such as becoming stronger or feeling closer to care recipient. Nevertheless, 40% of these caregivers were unable to identify any positive aspects and it has been postulated that these are the ones most in need of therapeutic interventions (Cohen et al, 2002; Hudson, 2004).





Coping with Caregiving

Caregivers of home palliative care use multiple coping strategies to help them deal with the demands of their tasks. Coping strategies include pursuing existing hobbies, talking the problem over with family and friends, actively denying the situation, trying to think positively, using faith, trying to normalise circumstances, handling things one step at a time, using humour, and confronting the situation with a spirit of togetherness with the patient (Grbich et al, 2001; Steele & Fitch, 1996a; Rose et al, 1997). Table 8 highlights the most common coping strategies used by carers in general.

Finding out what seems to assist or hinder caregivers in their role may be valuable in determining where resources should be allocated and what strategies should be incorporated in developing interventions.



Table 8: Carers' way of coping with stress on their own or involving informal or formal support *

Coping Mechanisms	Percent
Gardening/enjoy nature/take a walk	31%
Reading	18%
Craft/hobbies	13%
Have regular planned activities with family & friends	31%
Use partner/other family to provide emotional support	26%
Talk to friends to let off steam	21%
Carer support group meetings/activities	28%
Involvement in community organisations	26%
Involvement in church activities	17%

*most common responses. Totals do not add up to 100% due to multiple responses.
Source: Information compiled from Carers Association Survey (Briggs & Fisher, 2000).



Issues of Special Groups of Carers

Women carers

The impact of caregiving on women's lives is particularly important because 7 in 10 informal caregivers are women. Although an average woman could expect to spend 17 years caring for a child, she will likely spend 18 years caring for a parent (National Alliance for Caregiving survey, 1997). Caregiving responsibilities take a heavy toll on women's time, health and employment obligations. Although an average caregiver provides assistance for 18 hours per week, 19% of women provide at least 40 hours of care per week. More than half of employed caregivers have made changes at work to accommodate caregiving and one-fifth gave up work, with the resulting financial strains exacerbating already stressful circumstances.

Some costs of palliative care service provision are being shifted from the government and its institutions to the community and private individuals and the cost burden lies disproportionately on women (Fried, 2001). According to Office of Women's Affairs (1994), women are more likely to be 'sole' carers and men to be 'peripheral' carers. Women are more likely to provide personal care including washing, cooking, feeding, assisting communication and mobility, whereas men are more likely to do paperwork, provide financial advice and help with home and garden maintenance. Women carers are more likely than men to be disadvantaged by low income and to experience and accept significant restrictions on their lives. Schofield et al (1997b) found similar findings in their study of 976 carers, reporting that women were more adversely affected than men in emotional wellbeing and employment opportunities.

In Canada, research points to an extreme gender imbalance in every aspect of home care (Morris et al, 1999). Women's roles as unpaid and underpaid caregivers contribute to the income gap between men and women. Women family members were expected to supplement home care services without pay and at great expense in terms of their own health, incomes, benefits, career development and pension accumulation, whereas men were not under as much pressure to do so. The study concludes that current home care policies and practices in Canada have a significant negative financial impact on women.

Carers in rural and remote areas

Rural areas have particular needs associated with the lack of appropriate services and issues related to isolation, distance and transport, in addition to a culture of self-reliance associated with concerns about privacy and confidentiality. The National Census of Palliative Care Services (PCA, 1999a) identified that population-based rates of admission to palliative care services in regional areas are 30 to 35% lower than in metropolitan areas. Sixty percent of metropolitan services reported access to specialist palliative medicine resources compared to 36% in regional areas. Similarly, eighty percent of metropolitan services reported access to a Clinical Nurse Consultant, compared to 61% in regional areas.

Rural carers have the added stress of relocation to metropolitan centres for specialist treatment required for care recipients with cancer (McGrath, 2000a; McGrath, 2000b). The non-availability of regional or rural specialist treatment means that patients and their families must cope with the additional stress of relocating from their homes for lengthy periods of treatment. This entails significant financial problems in meeting travel and accommodation costs, additional medical costs, double grocery bills for family at home and family in the city, and loss of employment. Often rural and remote patients and carers learn about transport assistance schemes during or at the completion of treatment or when they reach financial crisis. Travel expenses of carers are not automatically reimbursed because an





escort may not be considered medically necessary (Cancer Nurses Society of Australia, 2003). Rural people may not know information is available and without it they report feeling out of control and have difficulty making decisions (Wilkes et al, 2000).

Upon returning to rural areas after specialist treatment in a metropolitan centre, the highest reported needs of carers are related to emotional support, the need to talk to someone who understands the patient's situation. Having left the comfort of the supportive relationships established with metropolitan health professionals, carers may not feel confident about local knowledge levels and medical expertise within the limited resources of rural health professionals (McGrath, 2001a; McGrath, 2001b). Silveira and Winstead-Fry (1997) reported that carers' needs in rural settings were three times more likely not to be met, compared to patients' needs. This lack of support may occur, in part, because family caregivers in rural settings are viewed as resources rather than as recipients of care themselves (Kristjanson & White, 2002). However in some rural areas, community networks may be strong and provide an opportunity for formal and informal carers to work together to provide respite care.



Carers from culturally and linguistically diverse backgrounds (CALD)

In general, CALD carers and families with a disability or an illness experience additional layers of disadvantage (Federation of Ethnic Communities Councils of Australia, 2003):

- culturally and linguistically challenging environments
- lack of experience and knowledge of how the system works
- disruption to the family as a result of migration
- diminished support networks and lack of appropriate services.



More than half a million Australians have little or no proficiency in the English language (PCA, 1999b).

Caring often starts earlier for carers from CALD communities. Migrants in Victoria require some level of caring and assistance at around middle age, for example with organising appointments and assistance with communication. Because caring responsibilities are better shared among family members, young carers and male carers are more common in these communities. In addition to the pressure of caring, carers from CALD backgrounds face mental health challenges associated with the impact of immigration and re-settlement, loss of identity and status, loss of independence due to cultural and language barriers and loss of social and emotional support networks (Chan, 2003).



Although under tremendous pressure, carers are often reluctant to ask for help or access services for different reasons, which include the carers' values and attitudes, practical barriers, information and communication barriers and conflict with the care recipient (Chan, 2003). Carers with limited proficiency in English face extreme difficulty in accessing information in comprehensive and understandable community languages. This results in restricted access to services for the person requiring care or carers themselves including respite. Recently, carer support kits became available in 13 community languages through the Commonwealth Carer Resource Centres. Each kit includes eight fact sheets on topics relating to caring, an emergency care kit and a card to list medications. Brochures about palliative care in Australia are available in 20 languages. The content provides a culturally sensitive explanation of palliative care, together with a brief description of services available (PCA, 1999b). However, the provision of written material does not address the problem entirely.



Beliefs and values have a direct bearing on the way carers sought professional help. Respondents from Vietnamese background saw residential care only as an option if there were no other family members available, and it was only an option for Greek people if the carer(s) had died. These values are reflected in the statistics on the use of nursing homes which show significantly lower levels of use by these groups compared to those from an English speaking background (Cole and Gucciardo-Masci, 2002). Carers from Greek background were notable for refusing HACC or home nursing services due to their care recipients' unwillingness to accept professional help, and because accepting services was perceived as a failure in their carer role. In terms of respite care, the carers were keen to respect the preferences of their care recipients even if they wanted a break from their carer's role. They spoke of guilt at leaving the care recipient with professional service providers (Cole & Gucciardo-Masci, 2002). Carers often neglect their own needs. It is not uncommon for older carers to request to be discharged from hospital immediately after an operation because they cannot leave their spouse who requires care at home.



Indigenous carers

Indigenous Australians generally have poorer access to services including medical care, domiciliary nursing care, palliative care, allied health care, bereavement support and home care support, than do non-indigenous Australians (Sullivan, 2003). This is a particular issue for people living in remote areas. In addition, for some indigenous Australians, there are cultural restrictions on who is able to care for a family member and what types of care they can provide. These are specific to the locality, community and family involved and can mean that gender, age, biological kinship and cultural relationship may all impact on the availability of care (Prior, 1999; Sullivan, 2003). Dispossession from traditional lands and previous government policies that created the 'Stolen Generations' have broken up families and communities, fracturing those networks that would normally have supported sick relatives (Fried, 2003). In some communities, Aboriginal health workers may be subject to blame if they engage in the care of a person who subsequently dies (Fried, 2003; Maddocks & Rayner, 2003). Many Aboriginal health workers nurse their extended family, and might have insufficient time to deal emotionally with the high number of deaths while caring for other clients (Sullivan, 2003). This can have significant personal (and professional) consequences and may impact on the availability of care. The prevailing high morbidity and mortality rates (Dodson, 1995) amongst indigenous Australians reduce the availability of carers who are well enough to provide caregiving. Premature adult mortality impacts on the care of the young, the frail old, and the ill (Fried, 2003).



In many Aboriginal communities, there are cultural requirements for family members to travel to visit and pay their last respects to a terminally ill person. The costs associated with travel, accommodation and food may fall on the sick person's immediate family. There may be taboos related to housing a person who subsequently dies, impacting on where a person can be cared for, whether families have to move after a death, and whether and when such an accommodation can be used again (Sullivan, 2003; Prior, 1999; Maddocks & Rayner, 2003). Such customary issues do not sit well with the requirements of public housing authorities (Fried, 2003). Many Aboriginal communities require attendance during extended periods of 'Sorry Business' and funerals, which can take precedence over other life business (jobs, education, sometimes one's own health) (Maddocks & Rayner, 2003). This has significant implications for an Aboriginal person's ability to hold a job while also meeting community and family caregiving and grieving requirements (Fried, 2003).





Carers of children and children as carers

Parents caring for a child with a terminal illness, chronic illness or disability have their own unique issues ranging from social isolation to marriage disruption to being physically and emotionally absent for other children in the family. The impact of the child's illness on the family, particularly the parents, was highlighted by Mastroyannopoulou et al (1997) who reported high levels of depression, considerable effects on employment and an impaired social life, set within a family environment charged with high conflict and low support. Stallard et al (1997) reported on the impact of the child's illness on healthy siblings. They found that healthy children were constantly worrying about their ill sibling with the predominant feeling being one of sadness. Although 38% of well siblings were able to talk to their parents about the illness and 14% were able to talk to their grandparents, a significant 48% did not talk to anyone about their illness. Deeley et al (1998) recommended a family-centered approach to palliative care where the needs of all family members are addressed and not only the ill child.



McGrath (2001c, 2001d) reported that parents have a strong need for practical assistance during the initial stage of treatment and for emotional support to be able to cope with the challenges of caring for their child during the long and invasive treatment protocols. Important sources of support noted were partners, family, friends, employers, hospital staff and other parents in the same situation. Poor family or social support is a risk factor for poor family coping and parental psychological distress. As the treatment protocols are long, offers of support tend to decrease over time and parents find it difficult to continue the imposition on others.



Young carers aged 16 to 24 caring for a dying parent may experience the loss of opportunities to study or work and loss of peer friendships in addition to the grief of losing a central relationship (The Australian Psychological Society, 2003). Children can sometimes be hidden caregivers when they are expected to take on jobs and responsibilities beyond that which is normally expected of a child. This is done at the expense of their developmentally appropriate needs and pursuits and this was particularly likely if the carer was a girl (The Australian Psychological Society, 2003).



Older carers

The ageing carer population deserves special attention because 22% of primary carers in Australia were aged 65 and over, with 81% of these older carers caring for people in their own age group, most often their partner (ABS, 1999). O'Connell et al (2003) provided baseline information on a sample of older carers' physical and mental status, using the SF-12 quality of life measure and their engagement in social and health related activities. Seventy-three percent of carers' physical health scores fell below the cut-off score of 50 and 31% were below the mental health cut-off point, indicating compromised physical and mental health. Older carers' mean mental health scores were significantly lower than a similar aged non-carer group. One third of carers did not participate in social and health related activities, because they were unable to leave the care recipient on their own and only fifty percent used respite facilities. The study pointed to the level of dependency of care recipients where some carers provided more than 15 hours of care a day, and the potentially negative effects this can have on carers.



Schulz and Beach (1999) identified that older spousal caregivers who experience stress from caregiving were 63% more likely to experience early mortality than non-caregivers. The relationship between caregiving and mortality was tested in the Caregiver Health Effects Study using approximately 400 spousal caregivers and 400 matched controls aged 66 to

96 years. A combination of loss, prolonged distress, the physical demands of caregiving, and biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for physical health problems leading to increased mortality.



Navaie-Waliser et al (2002) examined the characteristics, activities and challenges of 1002 informal caregivers with poor health or a serious health condition. Compared to non-vulnerable caregivers, this vulnerable group was more likely to provide higher-intensity care, to report that their physical health had suffered since becoming a caregiver, to be aged 65 years or older, to be married and to have less than twelve years of education. The authors cautioned that reliance on informal caregivers without considering their ability to provide care can create a stressful and potentially unsafe environment for both the caregiver and the care recipient. Livingston et al (1996) compared the mental health of a representative community sample of carers of elderly people with dementia, depression or physical disability with the mental health of other adults living in the household and of those living alone. Depression was more common in the carers of people with a psychiatric disorder (24%) than in co-residents (11%) and in those living alone (19%). Depression was most common (47%) in women carers of people with dementia. Being a woman carer was a significant predictor of psychiatric illness.



Even when care recipients are admitted to residential aged care, carers experience guilt and grief, suffer from loneliness, feelings of failure and feelings of financial and emotional insecurity. Family members of residents with dementia tend to have poorer wellbeing than family members of other residents (Nay, 1997; Toye et al, 2003).

Carers of people with neurodegenerative conditions



Carers of people with Motor Neurone Disease (MND) are at particularly high risk of burnout due to the complex nature of the disease, the degree of potential disability involved, its uncertain course and its potentially rapid rate of progression, thus leaving many carers unprepared and floundering with high levels of anxiety, stress and fatigue (Richter, 2003). The complex physical needs of people with MND are inadequately met in residential facilities. Many families of individuals with chronic and progressive conditions such as MND and Muscular Dystrophy (MD) may not be usual recipients of palliative care services (Dawson & Kristjanson, 2003). Professional services usually focus on the medical and physical needs of patients with these conditions and carers receive little guidance for their role (Denham, 1999). With the progress in medical technology increasing the lifespan of the care recipients and the period of dependency on receiving care, carers indicated a sense of isolation, loss of contact with family and friends and loss of social networks in general, loss of the retirement years and loss of dreams. Carers stated that their lives were on hold and totally occupied with their carer role. Therefore, they were concerned about their future and how to reintegrate into society once their role as carer came to an end, needing information on rebuilding their lives (Dawson & Kristjanson, 2003).





Needs and Barriers

Information and support needs

Although the impact of caring has been well reported in the literature, research conducted for more than a decade demonstrates that caregivers report unmet needs mainly for more information and support from health care professionals.

In palliative care, four types of family care needs are consistently reported (Kristjanson, Hudson & Oldham, 2003):

- patient comfort
- information needs
- practical care needs
- emotional support.

Carers desire information about how to provide practical care for a patient, how to ease a patient's discomfort, what to expect in terms of both the patient's and the carer's emotional responses to the terminal illness, where and how to acquire practical aids like walking frames, wheelchairs, hospital beds and so on. The provision of information is therefore recognised as a central form of support for a caregiver (Hudson et al, 2002).

Hudson, Aranda and Kristjanson (in press) undertook a comprehensive evaluation of the literature on key information needs as identified by family caregivers. These were reiterated in focus groups aimed for the development of a nursing intervention to enhance the guidance and support to lay caregivers of persons dying of cancer at home (Hudson et al, 2002). The key information needs included: preparatory information on typical aspects of the caring role, caregiver rights, the patient's medical condition and treatment plan, acknowledging the difficulties of responding to a relative's palliative diagnosis, assessment and management of patient symptoms, hygiene and ambulatory care, financial implications of caregiving and potential reimbursements, coping skills, how to access resources, problem solving skills, potential caregiver rewards and satisfaction, enhancing caregiver competence, respite, signs that death may be approaching, responding to the dying process, and death and bereavement.

However, the approach adopted to deliver this information to carers is also important (Hudson, Aranda & Kristjanson, in press). There needs to be an optimal environment for communication exchange between the health professional and the caregiver. It is also best to deliver the information in a dose appropriate to the caregiver's needs; to provide it in a variety of media (eg verbal, written, audio and videotapes); to tailor it to the caregiver's education level and learning style; to provide it at critical caregiving points, such as when the patient requires hospitalisation, when the caregiver is finding the role difficult, and when the patient's death becomes imminent.

To date, there are few family-specific resources available to caregivers such as supportive information tools in the form of written materials, videotapes and audiotapes (Hudson, 1998; Hudson et al, 2004). Often these are geared towards patients. In the UK, Payne et al (2000) evaluated the quality and type of information provided in more than one thousand different leaflets on palliative care. It was estimated that only 40% of the British population could understand the content and 97% of these leaflets dealt with general hospice information. Therefore, caregivers need their own educational materials that incorporate problem solving strategies, how to care for their family member, how to maintain their own health and how to deal with bereavement (Hudson et al, 2004).



Such educational material was recently developed by Oldham and Kristjanson (2004), for a cancer pain management education at home to support family carers. The 'user friendly' education program consisted of a Daily Comfort Diary to help family carers assess and monitor pain and record their pain management strategies. A short video was included to help family carers when moving their care recipient in or out of bed, walking with someone who is unsteady and what to do if someone falls. Participating families were most appreciative of the opportunity to learn how to care for their ill relative, reporting that the program has eased some of the burden experienced by carers when it comes to pain relief. It is ironic that while home health aides or personal care attendants require training before they begin their caring role, informal carers provide similar services without the benefit of formal preparation, and therefore much of their learning occurs on a trial and error basis (Hudson, 1998).

In a randomised controlled trial to assess the efficacy of a psycho-educational intervention for primary caregivers of cancer patients dying at home, primary caregivers reported that the most challenging aspects of their role related to inadequate health professional support (Hudson et al, 2004). Approximately one quarter of caregivers were disturbed by poor continuity, inadequate information, limited respite, lack of symptom management education and health professional role related issues. This research further found that most caregivers, if given the opportunity, were willing to talk about issues specific to their needs and concerns, and they chose to be interviewed without the presence of their care recipient, thus emphasising the importance of more structured approaches to family care.

A consistent theme in the family-needs literature is the importance of communication between health professionals and families (Kristjanson, Hudson & Oldham, 2003). Family members need to feel confident that the patient's comfort needs and perceptions of symptoms are attended to, requiring liberal amounts of information about both disease and treatment, provided in doses that they can process and at a pace that is comfortable to them. Carers also benefit from information about diagnosis, prognosis, treatment options and expected course of recovery to help lessen their fears and increase their sense of predictability.

Barriers to seeking support

Barriers confronting health care professionals, regarding provision of support, need to be acknowledged in order to design and implement interventions that are relevant and more effective. Carers are often reluctant to disclose their needs to health professionals for reasons that include not wanting to put their needs for care before those of the patient; not wanting to be judged inadequate as a carer, and believing that concerns and distress are inevitable and cannot be improved (Ramirez et al, 1998).

Payne and Ehrlich (1998) investigated three types of barriers which lead to carer reluctance in seeking help: information-based, service-based and value-based. Lack of information about the availability of services, including respite services, is the most common reason for non-use of needed services. Service-based barriers include lack of flexibility in service delivery. Value-based barriers involve caregiver guilt and commonly held beliefs and misconceptions: carers may be reluctant to relinquish the caring role to others and may experience a level of guilt in leaving their care recipients to seek support for their own needs.

In palliative care, Hudson et al (2004) identified three types of barriers that present challenges to health professionals: communication process barriers, health system barriers and family-related challenges. 'Communication process barriers' referred to the possible *impaired concentration* of caregivers due to anxiety and sleep deprivation or other stresses;





to *conspiracies of silence* where both caregivers and health professionals avoid talking about emotional and existential issues; to *timing and amount of information* where too much information too soon could be perceived to cause more harm than good; to caregivers *not wanting to bother health professionals*; and to *rejection of support* by caregiver.

These barriers are shown in a recent study in Western Australia, where communication problems between dementia carers and GPs led to a delay in accessing community support services (Bruce et al, 2002). Most referrals took place after carers had been experiencing stress and were precipitated by crisis situations. Carers failed to discuss their difficulties with the GP because they believed that they should cope and it was their duty. They also felt that their doctors were too busy, uninterested or preoccupied with medical matters. The GPs found it difficult to know how the carers were coping or when to intervene, particularly when some carers resisted help. The authors concluded that attitudinal barriers in both carers and GPs, combined with time constraints, often lead to inadequate assessment of carers experiencing difficulties. The authors recommended that GPs assume that dementia carers are at risk of carer stress and attempt to involve them with appropriate support services, thus avoiding a crisis-driven approach to dementia care.



The second type of barrier identified by Hudson et al (2004) were referred to as 'health system barriers': the characteristics of the health care system within which palliative care is delivered. Barriers include *insufficient resources*, where within the existing care models and without additional family oriented strategies and resources, health professionals would find it difficult to meet the needs of both patients and their families. *Continuity of care* is another health system barrier, where the provision of care may be provided by more than one service and a variety of health professionals, thus hindering the development of trusting relationships between the caregiver and the service provider. Health professionals may also lack the *appropriate skills* to confidently assess and evaluate caregiver support needs, and their capacity to *plan, deliver and evaluate* supportive care services is less than optimal.



The 'family related challenges' referred to *family functioning*, where the dynamics of relationships within the family restrict communication with the health professional, to *incongruent patient and caregiver needs* where differing needs makes it difficult for service providers to determine whose needs take priority. Finally, practitioners often have difficulty applying a suitable framework for guiding their care decisions, due to *underdeveloped frameworks* for conceptualising family caregiving in palliative care.



Financial needs

Carers feel they should be better rewarded financially for what they do, often saving taxpayers huge amounts of money by keeping their family members out of residential care. Apart from carers needing more respite and substitute care (27%) or an increased range of respite/substitute care to be available (20%), increased payments (19%) rated the third most common need (Briggs & Fisher, 2000). In both reports, 'Caring enough to be poor' (Carers Association of Australia, 1998) and 'Caring costs' (Carers Association of Australia, 1997), carers expressed concerns about the overall adequacy of pension rates and the rate of the then Domiciliary Nursing Care Benefit (now known as the 'Carer Allowance') and its very tight eligibility criteria, the effect of means tests and in particular the pensions income and assets tests, and the lack of superannuation coverage for long term carers. A non-means tested Carer Allowance can be paid to the carer of someone who would otherwise qualify for nursing home placement. However, criteria are stringent and the time frame for accessing such financial assistance can be incompatible with the onset and progress of a terminal illness (Fried, 2001).



Findings from 'Caring Costs' confirm that income support, health care and community services/support are carers' major needs. There are significant problems for many carers and their families with current health costs and private health insurance arrangements, particularly with gaps in the range of insurable health services which lead to 'gap costs'. Although health benefits are paid at present for doctor treatment, many costs of nursing and other care are not covered. These costs are a major burden and have been compounded by the shifting of post-acute care and care costs to the community care sector and families. Early discharge from hospitals and the closing of institutions in the disability and mental health care sectors has greatly pressured HACC and other disability services programs which provide care in the community. Waiting lists are long and many carers and care recipients are missing out. Adequate resource transfers to meet the needs of care recipients and their informal carers have not accompanied policy changes in these areas, which have seen institutional care replaced by community care. In fact, carers feel that the shift from residential to community care has been implemented without adequate regard for the impact on families and support needed by carers.

Gaps in Service Provision and Support

The current provision of services for informal carers has been described as 'crisis intervention', as it is only in crisis situations of imminent or apparent breakdown that services respond (Harding & Higginson, 2003). Those carers who appear to be coping in their role and do not request services are assumed to have no unmet support needs.

According to Schofield et al (1996), use of and satisfaction with medical services and professionals such as GPs remains under-researched even though medical services are likely to be the most commonly used services by caregivers. Most research indicates that the use of formal services by family caregivers is not widespread, for reasons already mentioned in the section about barriers, above. They include being unaware of their existence, or having access problems or because the service is inappropriate for their needs. While research was mainly based on samples of carers attached to a service provider, the views of a large group of carers not using services remain untapped. Carers' views on broader mainstream service provisions such as housing, childcare and rehabilitation programs, which clearly have a direct impact on the experience of caregiving, are often neglected.

Nationally, carers of the mentally ill expressed extremely low levels of satisfaction with service provision in key support areas (Mental Health Council of Australia, 2000). These included: access to respite care and home care services; clearly defined mental health information/education access points; access to counseling, debriefing, emotional and social support to sustain their caring capacities; support for their roles in helping to assist consumer medication programs; a variety of improvements in professional mental health practice that directly impact on their effectiveness, including timely and practical access to consumer information and engagement in consumer assessment and treatment/care planning decisions.

Nankervis et al (2002) called for a more proactive approach by GPs to help ease the burden of family carers by addressing their support needs. Carers have identified that GPs can help by:

- recognising their carer status and care responsibilities and including them in care planning and decision-making
- providing plain-language information to the carer on the patient's condition, prognosis, treatment, care needs and management





- providing information and referrals relevant to carers (eg in-home and residential respite care options, counseling, peer support groups, financial entitlements, self-care and coping strategies)
- discussing and where appropriate assessing the carer's own physical and psychosocial health needs
- engaging other family members in understanding and sharing care responsibilities
- recognising grief and loss on cessation of caring (Payne, 1999; Carers NSW, 1998).

Similarly, Schofield et al (1997b) emphasised the importance of education of doctors, other health professionals and service providers, given their role in carer access to practical support. Many high intensity carers see respite care as the most important service. 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. In addition, carers need support in coping with their role through help lines, educational programs, support groups, family and individual counseling (Schofield et al, 1997b).



Given the absence of clear strategies, clinical practice guidelines and policy positions by governments and peak practitioner bodies, Nankervis et al (2002) suggested using current schemes that provide an opportunity to focus on carers in general practice. Such opportunities exist in the Enhanced Primary Care (EPC) Medicare Benefits Schedule, where the carer is included in care planning and case-conferencing activities. The Better Outcomes in Mental Health Initiative provides incentive payments for mental health needs assessments and could include educational material on carer mental health issues. The Commonwealth-funded Primary Health Care Research Evaluation and Development Strategy provides an ideal opportunity for collaborative research in this area (Nankervis et al, 2002).



Gaps in Research Enhancing Knowledge and Support for Carers

A substantial number of studies have identified caregiver needs and psychological morbidity but the development and evaluation of research-based interventions focused on reducing negative aspects of caregiving is required (Barg et al, 1998; McCorkle & Pasacreta, 2001; Hudson et al, in press; Yates, 1999; Harding & Higginson, 2003). Evidence is also required to support the development of clinical protocols, best practice guidelines and to guide service developments. However, palliative care research has been fraught with methodological difficulties such as recruiting patients, reaching sample target numbers, high attrition rates, rapidly changing clinical situation, limited survival times, ethical dilemmas and the gate-keeping exercised by professionals (ie reluctance to contribute patients for research studies) (Palliative Care Australia, 2000; Hudson et al, in press; Harding & Higginson, 2003). Nevertheless, the scoping study in palliative care research (Palliative Care Australia, 2000) has called for palliative care researchers to develop "methodological approaches that capture the complexity of patient and family needs in palliative care and determine the best means of meeting these needs".



In the domain of carers, PCA's scoping study in palliative care research has identified research priorities in family care during the active palliative care phase and during the bereavement period. More specifically, research should aim to address the following questions:



- How is family-centered care practiced in the delivery of specialist palliative care?
- Can a targeted support and education program improve the experience of family members caring for a dying person at home?
- What is an appropriate system of screening for anxiety and depression in families of people receiving palliative care?
- Does improving the support offered to family members during palliative care improve bereavement outcomes as measured by levels of anxiety, depression and anger?



Many publications recommended improved support for families but few supportive palliative stage family interventions have been conducted and rigorously evaluated. In a critical review of supportive interventions for family caregivers of palliative stage cancer patients, Hudson (2004) advocated incorporating recommendations from intervention studies conducted with general family caregiver studies, "as lessons learnt would assist intervention development related to palliative care families". The following strategies for the inception and evaluation of support-focused interventions were suggested:



- testing interventions with palliative care families, where pertinent, via randomised controlled trials with a large enough sample size to conduct inferential statistical analyses
- incorporating multiple rather than single approaches into interventions, as these have been more successful in producing positive caregiver outcomes
- focusing on support strategies which minimise the negative psychosocial impact of care rather than the current tendency to focus on the task-oriented aspects of care
- targeting interventions toward carers who demonstrate a need for it – therefore, interventions would benefit from measuring very specific as well as global dependent variables, which means that researchers screen participants for variables related to the intervention
- developing and testing interventions for individuals as a priority, as according to meta-analyses of the effectiveness of caregiver interventions, individual interventions proved to be more successful than group interventions – the supporting argument is that caregivers who attend groups may represent those least in need of interventions, having demonstrated their ability to use social support and/or access respite care in order to attend group programs
- adopting a participatory research strategy – this means engaging the family members of palliative stage patients at the design stage of interventions and using focus group interviews as a vehicle to achieve this
- involving caregivers independently of patients, as caregivers' perception of need may be different
- adopting longitudinal approaches to examine the impact of health professional strategies aimed at enhancing caregiver support needs at different time periods
- using longitudinal evaluation of interventions with palliative families after patient death, for example via a baseline assessment when the patient is referred for palliative care, after the intervention and then during bereavement.



In a review of cancer care literature specific to caregiver interventions, Pasacreata and McCorkle (2000) and McCorkle and Pasacreata (2001) also reported limited research on evidence-based interventions aimed at caregivers. The authors concluded that "the notion of identifying caregivers who are at risk of having problems in specific areas and tailoring interventions to their special needs seems to be an important direction for research as



implicated by the lack of positive findings in some of the studies reviewed". The authors further recommended testing caregiver interventions over time with homogeneous groups of patients at specific points on the illness trajectory (trajectory onset, crisis, acute, stable, unstable, downward and dying). Some interventions could be most effective at certain points in the illness trajectory while others could be preventive across several stages. Because research on the efficacy of caregiver interventions is still in its infancy, the field would greatly benefit from multidisciplinary efforts combining a variety of theoretical orientations and clinical strengths.



Harding and Higginson (2003) also lamented the lack of outcome evaluations in the caring population and lack of evidence to ensure cost-effective allocation of resources. The authors argued that, in light of the methodological and ethical issues of randomised clinical trials (RCTs) of carer interventions in cancer and palliative care, other designs should be considered. Quasi-experimental evaluation methods may offer more feasible research protocols that can be successfully implemented. The authors recommended that carers' interventions be feasible (grounded in theory), acceptable (in a useful and appropriate format for carers) and accessible to carers. Furthermore, interventions need to be effective (i.e. shown to improve intended outcomes), using rigorous evaluation methods such as using repeated measures from baselines and comparison groups. Researchers need to have clear and modest aims, which should not necessarily be multidimensional, and keep in mind that there is no single service model that will be acceptable to all carers or meet all the needs of individual carers.



Impact of Policy on Carers' Wellbeing

The effects of providing care on the health and wellbeing of carers are often subtle and personal and less easily addressed by particular targeted recommendations; yet they go to the heart of issues surrounding community care policies adopted by governments all over Australia. Enough is known about carers to acknowledge that their work has been undervalued and marginalised in the Australian community.

Schofield et al (1996; 1997b) have investigated the impediments to effective policy and service development for family carers in general. Some of these impediments could shed light on factors which impact on policy and practice related to palliative care families. The authors question whether "policy is concerned with improving the quality of life for carers, or is the prevention of institutionalisation the key measure?"

A wide array of policies have ignored the needs of carers, including the taxation and social security income benefit structure as well as employment and labour market policy relating to women and care. This has occurred due to the perception of carers by public service agencies as free resources available to care for people with disabilities, the ill and frail elderly. *Policy developments have resulted in the marginalisation of carers in the social welfare system.*

Part of the problem is "inadequate knowledge about family carers and their *ambiguous position*, both conceptually and practically in relation to social policy and service provision". Research has focused on carer perceptions and use of a narrow range of services such as respite care and home help, despite the fact that most services that support carers are directed to the care recipient. Some of the explanation may lie in confusion surrounding what counts as a service for carers.

There has also been little *coordination of service funding and service provision across federal, state and local government areas*. "Policy development and funding remain a federal responsibility, administration a state responsibility and service delivery a non-profit organisations and family responsibility". There is little to no co-ordination between the voluntary agencies, leading to an unequal social and geographical distribution of services.



Federal policy development has occurred in isolation from service delivery. Thus, there is a practical difficulty in identifying the existing scope of services for carers, with funding, administration and delivery of services for carers scattered across different levels of government.



Moreover there are no *agreed standards by which to measure service quality for carers*. The geographical locations of services are determined at agency level. The basis of funding has led to a maze of services and eligibility criteria as well as difficulties in targeting specific needs groups.

Other impediments relate to not maintaining effective links between practice, evaluation and policy. Comprehensive service evaluation reports are often not available. Evaluation of carer services is often difficult because of a lack of clarity in the definition of carer service provision as the care recipients are clearly the main target group. Evaluation of carer services is important to our understanding of services and their effectiveness and for future policy planning and service delivery initiatives. To achieve this, organisations need to clarify the role of carers in relation to their service delivery and collect appropriate data about this group. Therefore *a comprehensive and integrated approach to the evaluation of services will ensure closer links between policy and practice*.



There is a need for *more flexible employment arrangements* to reduce work conflict and give carers more options in combining paid employment and caring. For women especially, care-sensitive policies are needed to help maintain job skills and workforce participation and to create an employment context in which men can more equitably participate in caregiving responsibilities. A greater emphasis on the importance of sharing special care responsibilities within families is needed to challenge current gender stereotypes and to ameliorate the isolation of many high intensity carers.



In this context, the Carers Association of Australia (Briggs and Fisher, 2000) has recommended developing education programs for employers and employees and amending awards and conditions where necessary to make work places more carer-friendly. Carers returning to the workforce need to be recognised as a group of job seekers needing intensive employment assistance.

In Canada, the Standing Senate Committee on Social Affairs (2002) has called for the federal government to minimise the amount of lost income by examining the feasibility of providing employment insurance benefits for a period of six weeks to employed Canadians who choose to take leave to provide palliative home care. The Committee also called for the amendment of the Canada Labour Code to allow employee-leave for family crisis situations, such as care of a dying family member. In the USA, McCorkle and Pasacreta (2001) have used their research outcomes to influence policy. They were involved in gathering legislative support in 1993 for the Family Leave Bill, which provided "family caregivers with the right to take a leave to care for an ill family member with the assurance that a job will be available upon return". Thus, increased assistance to caregivers would ensure that they have the knowledge, skills, income security, job protection and other supports to provide care while maintaining their own health and well-being throughout the dying and grieving process.



People from CALD backgrounds with a disability or a terminal illness can be among the most disadvantaged and marginalised groups in society. According to the Federation of Ethnic Communities Councils of Australia (FECCA, 2003), the issues and needs of CALD family members and carers have not been understood or addressed by successive governments, the community sector and the general population. A whole-of-government approach to disability on one hand and a whole-of-government approach to ethnicity on the other, has led government agencies shuffling responsibility for CALD, people with disability or those caring





for a terminally ill family member. This 'silo mentality' means that CALD clients fall into the notorious service 'crevices' as the core business of government focuses on 'mainstreaming'. It appears that core business allows only for the experience of one type of disadvantage, in this case, either disability or CALD. Funding arrangements for services lack the contractual obligations to ensure providers make services available in an accessible and equitable manner. FECCA (2003) concluded that "our human services infrastructure is still learning to come to grips with the challenges posed by diversity. CALD families and carers are generally excluded from the policy development and service planning processes".



At a general community level, education is needed to promote the social value of caring and an awareness of the demands and impact of the caring role (Schofield et al, 1997b). In this vein, Palliative Care Australia is organising National Palliative Care Week in May 2004 with the theme 'Caring for a person with a terminal illness', and together with this National Inquiry into the impact of caring, both strategies will help ensure carers gain greater exposure and visibility in the community. In future editions, Palliative Care Australia could consider including sections dedicated separately to carers in the Planning Guide (PCA, 2003) and Standards for Palliative Care Provision (PCA, 1999c) to reinforce the important role informal carers play in home palliative care and explain how they can have an impact on formal staffing levels. The Carers Association of Australia (Briggs & Fisher, 2000) has recommended developing an information strategy to ensure that the role of carers is better understood and supported in the wider community and to promote recognition of the contribution made by carers to Australian society. This could be achieved in partnership with governments and other organisations.



Conclusion

This literature review has exposed the nature and extent of physical, social, and psychological morbidity and economic disadvantage that caregivers suffer as a direct result of their caring role in general, and home palliative care role in particular. Many studies, both national and international, have reported the negative impact of caring and that caregivers have significant needs related to their role which remain unmet, despite the significant contribution of carers to the economy. In Australia carers in general, contribute over \$20 billion to the national economy, and the unpaid workforce is estimated to be about five times the paid workforce, in terms of full-time equivalents.

This review outlined the demographic characteristics of nearly half a million primary caregivers involved in the informal care of children, adults and older persons with disabling chronic and terminal conditions and the common tasks associated with caring. Seventy percent of carers are women of middle age. In addition to women, issues of added disadvantage of special groups of carers have been highlighted such as those living in rural and remote areas, those from culturally and linguistically diverse backgrounds, indigenous carers, carers of children, elderly carers and carers of neurodegenerative conditions.

For carers, the two highest-priority unmet needs are for information and for support from health care professionals. Carers' health and wellbeing is inextricably linked to the availability, quality, responsiveness and cost of support from health and community services. Carers need to access adequate and flexible resources, fairer remuneration, more respite care, training and equipment, counseling and bereavement support, personal and home help and improved access to the paid workforce.

The national and international literature, which addresses the needs of caregivers in general and those involved in the delivery of home palliative care in particular, points to the following recommendations to decrease the burden of caring:

- policy developments in the taxation, social security and income/pension benefit domains, to ease the financial hardship of carers
- more carer-friendly workplaces, with flexible employment arrangements and better opportunities to go back into the workforce, particularly for women who make up 70% of the unpaid caring workforce
- coordinated service funding and service provision across all levels of government (federal, state and local) to ensure equitable social and geographical distribution of services
- a comprehensive and coordinated approach to the evaluation of services, to ensure closer links between policy and practice and develop standards for service quality for carers
- education at a community level, to promote the social value of caring and an awareness of the demands and impact of the caring role
- educational materials geared specifically to caregivers using appropriate methods of information delivery
- education of health professionals to improve communication and timely access to support services
- focused strategies that address the barriers carers experience when attempting to seek support





- specialised strategies which address the needs of special groups, such as younger and older carers, those from Indigenous and CALD backgrounds, those living in rural areas and those with chronic disabling conditions whose eligibility to access palliative care is restricted
- multidisciplinary research leading to evidence-based practice approaches to home-based palliative care
- partnerships and collaborations between government, service providers, GPs, families and researchers to meet the needs of families for good palliative care.

Finally, the analysis of public submissions that follows sheds light on more specific challenges and difficulties pertinent to home palliative care.



Public Submissions

Introduction and Overview

As part of the National Inquiry into the Social Impact of Caring for Terminally Ill People, submissions were invited from individuals, families and organisations in the form of one or more of the following:

- letters or case studies describing unpaid carers' stories and experiences
- descriptions of unpaid carers' needs and the extent to which they are being met
- policy statements and/or recommendations relating to unpaid carers of the terminally ill
- information relating to the needs of unpaid carers and the extent to which they are currently being met by government, other institutions and the community
- copies of recent relevant reports or publications
- relevant research data and/or literature reviews.

A total of 131 organisations were contacted via letter and/or e-mail and invited to make a submission. Champions were assigned to follow-up with a total of 23 organisations. In addition, a national advertisement was placed in the Australian newspaper and also circulated through:

- the PCA newsletter
- PCA Member Association newsletters
- PCA's e-mail list
- stakeholders newsletters and e-mail lists
- the PCA website
- professional magazines
- community newspapers around Australia.

This analysis is based on submissions received from 20 individual carers, six volunteers in palliative care and 23 support organisations/ service providers. A further twelve submissions were in the form of newsletters and other printed material, published articles and conference presentations, the content of which was incorporated into the literature review where appropriate. The list of contributors to the inquiry is in the appendix.

In the first part of this section carers describe, in their own words, the impact that caring has had upon their lives in terms of mental, emotional, physical and social issues, work opportunities and financial costs, and in particular if they lived in rural areas. Carers also expressed their need for support services, and voiced their feedback on palliative care services and the role of caregiving. The majority of carers who responded to the inquiry were female, either wives or daughters, caring for husbands or parents with mainly cancer or dementia. Two males were caring for their wives with Motor Neurone Disease (MND).

In the second part of this section, support organisations and other service providers describe the needs of unpaid carers and gaps in service provision and support, and in particular those of special groups. The two parts conclude with recommendations to ease the burden of caring and improve the status and quality of life of carers, in the domains of information and education, financial and work-related issues, support services and community recognition.





The Impact of Caring Through the Voice of Carers

Telling our stories is a political act.

Without stories, there is no articulation of experience.

Without stories, we don't learn the value of our struggles or comprehend our pain.

Without stories, we cannot understand ourselves or dance in the rain.

We are closed in our silence.

By Carol Christ

For every case of cancer, there is a personal story.

Some like mine and some different.

But each one is unique and touching.

In each case we would prefer it hadn't happened.

But at some stage we have had to accept that it did happen,

and that that person's life was changed forever as a result and ours too.

By Chris Archibald



The mental and emotional impact of caring

Carer for both parents with cancer

When mum died, it was to go back to normal. Sadly for me, there was no longer normality. I'd lost my foundation, I was an orphan, no job, financially in debt. I wanted to die but I couldn't do that to my brother, so I existed, I was not living. If anything I was getting further into debt because I was spending to try and get some sort of happiness which didn't work. Tried drinking to ease the pain and that didn't work either. Lost my license through speeding because I didn't care. People didn't and still don't want to believe that suicide is a reality for me, because it's out of their comfort zone and I'm nothing to them.

The cost of vitamins to keep the depression under control is \$100 per week as anti-depressants weren't the answer for me, plus \$110 per hour for a psychologist, all of which I pay for and the sense of not belonging because people don't want to be confronted with death.

It's been a life experience I'll never forget, never wish to relive and wouldn't wish on my worst enemy because unless you've lived it you don't really know what it's like.

Carer for mother with renal cancer

For me the greatest emotional impact followed Mum's death. I felt incredibly empty, and I found it extremely difficult to return to my home interstate, and then even more difficult to return to work. My health suffered as I suffered disrupted sleep, and was forced to take considerable time off work, much of which I was not paid for. My request for short-term part-time work in order to be able to perform my duties more competently until my health improved was refused, and I became quite depressed.

Carer for wife with MND

In the case of an incurable progressive disease, the emotional strain on family members starts well before they become carers, for first there is a period of uncertainty, confusion and worry to negotiate. What follows, however, is a desperate sense of futility: no matter what you, or anyone else does, no matter how hard you try, or how tenderly you look after your loved one, nothing can stop the disease. In the case of motor neurone disease, it means the grieving starts early: as the weeks and months go on, so much is lost that can never be regained.



Carer for father with prostate cancer

The hardest part of being a carer is 'feeling his pain' or in other words seeing him suffer. Other 'hard to take times' were the self-centredness repetition of stories, hard of hearing, the responsibility of knowing when to contact the hospital, the hormonal sweats, one minute being too hot and taking a cardigan off to the next being cold and putting it back on.

To help me not take things so personally when he was being grumpy, I reminded myself of a quote which says "the language of pain is hurtful anger". I had a piece on my fridge called the carers 10 commandments and when I was feeling things getting too much for me, I used to read this through- which was almost every day. Also a doctor mentioned the 4C's which was of help: Commitment- don't take anything you can't see through; let them Control their own lives as much as possible; have an outside Challenge and Connect with a belief system or develop a passion.

Since I no longer have my father, it's like missing a handbag on your arm. My lifestyle has changed from cooking to talking and experiencing in a real way, what makes the difference in the way we feel about things, is knowing the depth of the loss.

Carer for mother with MDS and father with dementia

My father became quite aggressive and often threatened both myself and my sister. At one stage he was threatening to kill himself with a knife. We finally got some assistance and medication to calm him down. This was very distressing to Mum.

My sister returned home due to family and work commitments and I was left on my own. I found this to be an extremely lonely time with little support except for short visits from friends. I also missed being with my husband and three children. Nights were difficult as Mum's pain became hard to control and Dad became more confused. I had little sleep and was exhausted.

Carer for wife with MND

From the carer's perspective, there are several areas of angst that I am sure every carer feels: carer burnout (there just aren't enough hours in a day), the monetary crisis that besets everyone and the anticipated grief, while at the same time trying to put on a good positive upbeat and uncomplaining attitude. Respite for the carer (and therefore for the patient too) is necessary lest one ends up being like a robot mechanically and in total fatigue, but performing the duties demanded by the situation. I also wonder who is most affected by depression from this disease, the carer or the patient.

The physical impact of caring

Carer for wife with MND

I was about learning something that you know only too well: being a carer is very hard. Physically caring for my wife got hard very quickly. We had to learn new skills of lifting, showering, dressing and feeding. We learned on the run, for virtually every day presented a new challenge. I remember an incident on one morning that visually, at least, was like a scene from a madcap movie. I lifted my wife out of bed and put her in the wheelchair. But her muscles had stiffened and as I lent down to fix her feet on the footrests, she slid out of the chair. That went on three or four times before I worked out how to handle it. I was seized by panic at the time.





Carer for husband with Multiple Myeloma

He was going to bed when he had a fall, landing on the floor. No way I could lift him and I thought of ringing the neighbour to help me. But I managed to get him onto low, then onto a bigger box, then onto his feet. His back was a bit sore, so was mine... He spilled his bottle in the bed so I had to do a load of washing. Nurse said empty bottle into a bucket each time... He was walking from lounge to bathroom with Rollator, luckily I met him near hall as he became very wobbly, I was able to support him with help of Rollator and get him to toilet. My back was aching!

Carer for husband with Leukaemia

I cancelled my mammogram as I could not afford the petrol required to travel to the appointment and the cost of seeing the doctor. I later found a lump in my breast and was diagnosed with advanced breast cancer.



Carer for wife with brain tumour

It is my belief that the nature of the carer's journey leads to a cumulative effect on stress levels which is sometimes suppressed. In my own case, I believe that the stress of being a carer resulted in the development of type 2 diabetes following my wife's death.

Carer for son with brain tumour

I put on about 10 kilos over 2 years – I eat when stressed. Putting time and energy into supporting my son's spirits was very tiring emotionally – trying to be positive and supportive, even when you are terrified, takes its toll.



The social impact of caring

Carer for husband with lung cancer

The effort of taking him out to make small purchases was enormous. Our checklist included oxygen cylinders, oxygen conserving device, wheelchair, Roho cushion, mask as well as nasal prongs, morphine, nasal spray, ventolin, mobile phone in case of breakdown, it seemed endless. For a doctor's appointment at 11.00am, we needed to make a start at 7.30am. The care was constant. While for a couple of months, we were able to leave him at home alone for about half an hour, as time went on, we all felt increasing discomfort leaving him alone and made sure someone was there all the time. At this late stage, he really needed the three of us to provide his care, if we were to remain 'sane.'



Carer for husband with lung cancer

There is also more to do when your partner is ill, jobs which we used to share as well as caring for him. I find my time to myself is very limited, even grocery shopping.

Carer for wife with MND

The daughters were helping mainly in getting their mother to bed. This was a two-person operation that took as long as 45 minutes. I virtually had a form letter for their school, explaining their absence from the early lessons.

Carer for husband with cancer of the bile duct

I did not leave the house except to go to the local shop for ? an hour. I was worried about going too far because he was so far out of it, he would have been unable to help himself in an emergency. I wasn't coping very well with the long hours being confined to the house and I finally approached palliative care for respite. This was offered as either moving my husband to a hostel for the week or alternatively they would send a carer to the house once a week for the afternoon. He wasn't happy about moving out to a hostel but agreed to a visitor sitting in for the afternoon. The first time this happened I went to the movies. I think he was asleep most of the time I was gone.



The impact of caring on work opportunities

Carer for husband with lung cancer

My first daughter left her job in Sydney to become a carer for her father as we lived in the country. She was not eligible for the Carer's Allowance and Benefit but received Newstart Allowance after some delay... My second daughter interrupted her university degree to become a carer and lost on her Youth Allowance... I was not allowed to take all my sick leave at work and had to exhaust my extended leave. There was no flexibility in my workplace despite receiving a brochure on 'Family Friendly Workplaces'... I was away from home for many weeks while husband was having his treatment in Sydney, which made it impossible for me to work part-time... Every time the mobile phone rang at work, my heart would sink – what had happened at home?

Carer for mother with cancer

I strongly believe the caring experience should be available to family members who wish to care for a loved one. It is interesting that there is a push for paid maternity leave, but never a mention of paid leave for caring for parents or other loved ones who are vulnerable and unable to cope without such help. Unfortunately our society seems to have little respect for its elderly and it is more acceptable to put them into hospitals and nursing homes than to care for them in their own homes.

Carer for son with bowel cancer

I am sure that more people would be able to die at home if some provision was made for carers who work, and have to take leave without pay, could be given some financial support. I feel sure that if this provision was made, more people would choose to die at home.

Carer for mother with MDS and father with dementia

I had leave from work at numerous times during my mum's illness and when she passed away I had no sick leave, holidays or long service leave left. The leave that I took after she died was all unpaid.

Carer for wife with MND

The carer's days just become longer and longer as the carer takes over more and more of those responsibilities that were once that of the patient, plus assisting the patient. Gradually though, full-time work is impossible to continue and thus only part-time work may be conducted usually from a home office aided by good communications and computers... As the MND progresses and care demands rise, at each stage income decreases whilst at the same time, costs and expenses rise. Savings are soon enough used up and assets too are sold and the income directed to alleviate the impact of rising costs... The local Church, seeing our plight, made a most welcome grant... Finally, and in my case a very personally demoralising aspect, we were forced to become pensioners as my availability to perform part-time work became less and less as my care became more than full-time.





The financial impact of caring

Carer for husband with lung cancer

As my husband had less than 12 months to live, doctors were not prepared to place him on a 'terminal account' for his oxygen needs, stating that to be 'terminal' you should only live three months. We were forced to buy two oxygen concentrators at a total cost of \$6,000. My husband needed equipment that were not available in country loan pools such as Roho mattress and wheelchair seat, electric hi-lo bed, special padded commode/bathseat with back, high backed manual wheelchair and electric wheelchair... The emotional stress of purchasing all these items to enable us to return home in the country was huge and I spent three weeks in Sydney running around purchasing all the items from various suppliers.



Carer for both parents with cancer

I gave up a successful well paid job (to look after the two parents who died of cancer). The Carers' pension is way too low. If you have financial commitments you can't live on the pension. The person who is ill has enough to worry about without your financial situation... Maintaining the garden, washing, ironing or housework came out of my pension. I wanted to keep life as normal as possible and some days I just could not do it all, so I'd pay someone to do it. Needless to say I used up all my savings.



Carer of mother with renal cancer

I would have loved to have someone come in, for a couple of hours a day, to help with the dishes, washing, vacuuming, ironing or preparing a meal. I felt this was certainly too costly to be able to afford. However, apparently Mum's health cover did indeed allow such an opportunity - but this was something the health fund did not advertise, and we only found out about it too late. It was a great disappointment to me that Mum, who had always paid for top cover to her health fund, did not realise this opportunity, which would have alleviated the stress for me considerably, and allowed me to spend more time with her as a daughter and less as a housemaid!



Carer for mother with renal cancer

I was incredibly grateful that Centrelink provided me with a Bereavement payment which allowed me time before returning to work, but this period of readjustment was lengthy and isolating in that very few people could understand what I was going through.



Carer for wife with MND

If the Government is half way serious about encouraging home care for those with a serious disability and/or terminal illness rather than impose increased demands upon a public hospital system already under considerable stress, then I believe it's time to revisit the Australian tax laws to enable the ATO to provide fair and reasonable tax relief for those who make a genuine effort at caring for their loved ones at home for as long as is possible. (The carer undertook a major renovation of the bathroom into a disabled shower/wet room, made necessary to meet the home care standards required for his wife who is terminally ill and seriously disabled requiring 24-hour care. The ATO did not allow the carer to claim the renovation costs of \$14,000 as a tax-deductible item).



Carer for wife with MND

I am sure every MND family is caught in a cash-squeeze. Some income arises from the pension kicking in (at 1/2 rate as I'm expected to earn). But aside from the low cost drugs when being a pensioner, so much of the daily/monthly costs still fall between the cracks provided by private health insurance, the public health system (Medicare) and support from the over-stretched organisations such as the MND Association and the Community Care providers. Costs falling through the cracks are those related to co-payments for Community Services, hire of Bipap ventilation and medications, all in addition to normal costs of running a household. These

added costs are in excess of \$6,000-\$10,000 per year over and above normal household and living expenses. Medical costs related to my wife's pneumonia episode alone, after all Medicare and MBF payments (and the dust is still settling) totalled more than \$6,000 out of pocket, thus adding crippling costs and certainly stress upon both the MND patient and the carer.



From a financial viewpoint though there is no solution available. In our case, we were forced to take a loan against the asset of our family home to generate cash to live on and pay the increasing costs, but of course this means that with my wife's passing, I will be forced to sell up and move away to simply relieve the debt.

Seldom a moment of the night-time when one is awake, disturbed by the irregular breathing of your spouse, is the matter of coverage of costs far from one's mind. On a USA Internet website among the many I have visited searching for MND information, it is stated that the MND condition costs about \$200,000 per year to be able to cope adequately. When you consider all those provisions of equipment by the MND Association, the subsidised 3rd party care from Community Care organisations, the value attributed to the MND Clinic additional out of pocket costs for hire of equipment – I think the total costs of \$200,000 per year are about right.



The impact of caring in rural areas

Carer for husband with lung cancer

My husband required two oxygen concentrators to supply him with enough oxygen and was lying in an electric bed which he relied upon to sit him up to get out of bed. The stress of electricity blackouts in the country without warning was always present, up to 12 hours at a time, despite as palliative family having registered with the electricity supplier to obtain rebate for electricity. Surely an updated database with personal warnings was not too much to ask.



Having come from a wonderful rehab unit in the city, by contrast the facilities in the country rehab unit were appalling and staff morale seemed low and the experience was depressing. My husband could not receive the drip at home. We went to the 'day procedures' which did not have a bed to lie on, just a very hard recliner chair. There was a feeling of "how dare you ask for a bed?"



Carer for father with prostate cancer

Country people have to go away from their homes to see specialists, have tests, operations and treatments. It is very expensive and not often do we have people to stay with, so it is very taxing on the patients, their families and their pockets.

Our biggest problem was getting the large quantities of morphine from the chemist. A pump was connected to administer the morphine at regular intervals over a 24 hr period plus we were taught to administer extra morphine as required. We would go to the chemist in the morning and most times they would have to get what was required from chemists in larger regional centres and deliver to the house later in the day, sometimes after dark.



Carer for husband with lung cancer

Everyone needs support when there is a serious illness especially country people who have the added expense of travelling and the upheaval of leaving their own home and all that is familiar.



The need for support services

Carer for both parents with cancer

There needs to be more practical support. I was given the equipment and left to work it out on my own. I had to work out levels and doses of medication. Need more support from people who have been in the situation themselves and not got their information out of a book. There should be a book for carers, what sorts of easy to eat meals to prepare, a list of things to buy ie stable tables, seats for bathrooms, non-spill cups. Things that make life easier for both patient and carer. Especially when you live in the country often things are hard to obtain.

Carer for mother with renal cancer

I also believe the General Practitioner has a vital role to play in the total support team. Unfortunately I felt my mother's GP of 40 years let her down badly. Palliative care was an area in which it appeared he had little knowledge of and interest in, and was uncomfortable with. He would leave it to the nurses whenever possible, and breeze in and out, with a light-heartedness that was not always appropriate.

Carer for mother with renal cancer

I cannot imagine how difficult it would have been without the wonderful support from a grief counsellor and a general practitioner (both of whom were female) and a bereavement group, which I only attended on two occasions.

Carer for husband with prostate cancer

I would like to comment on the lack of adequate support services (hospice, palliative care wards), counseling services available for patient and carer, services to improve the quality of life (eg meditation, art therapy and aromatherapy), respite care, home visits by health care professionals particularly on weekends, reliable communication and follow-up from support services, communication between all health care professionals.

Carer for father with prostate cancer

I feel many doctors, specialists etc don't explain enough to patients and don't explain what options are available as to treatments and where these treatments can be given (ie in centres closer to the rural area than Sydney is).

We had a palliative care lady call on us a couple of times and this irritated Dad. He didn't need someone to come in and tell him (more than once) to "get his affairs in order". We needed to know more of who to contact for assistance, what to do after the death, who to call first etc. Fortunately a friend was an RN and she was with us soon after Dad died and helped with everything.

Carer for husband with cancer of the bile duct

At times I found the students to be a bit intrusive in a teaching hospital. I thought it unnecessary for several Dieticians to be calling into the room to plan his meals. I was concerned about this after a while and so I requested no students.

But once again things had not been properly explained and I was expecting the Nurse to arrive Saturday night for his treatment. This didn't happen and I had to ring around trying to get instruction on his medication as it seemed to be different to what I had been told at the teaching hospital

Looking back after 3 years I now realise that probably respite care was just starting here in Australia. And I think that had it been offered earlier I wouldn't have felt so isolated.

There does not appear to be any follow up on the grieving family after a death and it is only through friends and the Urban Ministry Network that I have received any counselling. I now feel better and have more acceptance about it and after three years my nightmares seem to have stopped.



Carer for husband with Multiple Myeloma

Community Health is very helpful but they know nothing about the condition. All the literature is about the treatment, not what happens when it is not working any more.



Carer for mother with MDS and father with dementia

I continue to feel guilty that I was unable to fulfill Mum's wish to die at home. If there had been more support available perhaps this would have been possible. To be offered a nurse at night so that carers could get some sleep or just spend time with their own family would make a huge difference.

There has been no follow-up since Mum died despite many health care professionals being aware of my Dad's dementia and I now continue to be a carer for him, work full-time and occasionally spend time with my family (husband and three children). Palliative care cannot be only about the patient. Carers need to be cared for so that they are physically and emotionally able to care for their loved one.



Carer for wife with MND

MND patients and their carers should be presented with the new information, the changes that will be needed to continue a positive life style and the decline to be expected in a more positive manner. Too many MND patients are still being told, "go home and make out your will" and that is just unsatisfactory as well as unnecessarily harsh.

Positive feedback about palliative care and other services

Carer for husband with lung cancer

We were lucky to have a team of 3 people who provided the medical care needed, and these became our lifeline in keeping him at home, and provided excellent support regarding medication, diet, pressure care etc...



Carer for husband with lung cancer

I can't speak highly enough of these places (hospices) and the care and love and support they have given us. Cancer Patients Assistance Society (CPAS) has been a godsend and I am comforted that CPAS is so supportive and caring and available when needed.

Carer of mother with renal cancer

I have to commend the Royal District Nursing Society for their tremendous help and support from the moment they entered our lives approximately 2 months before Mum died. They made regular contact and were sincere, gentle and incredibly supportive on a number of levels - Mum's physical and emotional needs, support for me as carer, and as an advocate for obtaining the proper equipment and support.

Her new oncologist was everything that both Mum and I needed, besides his professionalism and expertise, he was accessible, approachable, understanding and gentle! We felt that we had our questions answered, and were very appreciative of his efforts on her first visit to him to have her linked to the Hospice and its outreach services.



Carer of wife with MND

I should add here that I'm grateful to those who help carers, particularly the wonderful people from the Motor Neurone Disease Association.



Carer for husband with prostate cancer

I have no doubt that the palliative care team do their best within a flawed and under-funded system.



Carer for brother with bowel cancer

None of this could have happened without the help of the family, palliative care team, family doctor and the local nursing community being prepared to help my brother die in the manner he wanted. He was able to have the death he wanted and was able to take control of the last few weeks of his life, we certainly had some pretty amazing times together in these last few weeks.

Carer for husband with cancer

The palliative care service working in tandem with our doctor gave me the confidence to see this thing through to its inevitable conclusion. Nothing was too much trouble for them and they gave me advice any hour of the day or night. When I was able to collect my thoughts later on, I had this tremendous feeling of satisfaction that I had been able to do this for the man I loved – due mainly to the confidence Palliative Care gave me. God Bless Palliative Care! It didn't end with my husband's passing as the counselor continued to contact me regularly for the next 12 months to make sure I was coping with my grief. How's that for caring?



Carer for husband with prostate cancer

Consideration and support given to me during that difficult time by the whole palliative care team could never be overstated. They also encouraged us to join the cancer self-help support group and friends from there were of great comfort after my husband's death. The loving friendships formed with my volunteers continue. If I am able to bring comfort and peace to any client, my work for palliative care will have been worthwhile and I feel I have repaid some of the commitment shown to me.



Carer for wife with MND

I wouldn't be here today had it not been for the support from the MND Association by means of the equipment loans, the educational information (especially the Care of Carer's Course) and the emotional support. Support for the MND patient is most obvious in the equipment provided. In our case that includes; hoists, sling, adjustable hospital bed, single bed RoHo mattress, motorised wheelchair, shower/commode chair + cushion and carer's handbook. The coordination by the MND Association is invaluable in arranging the Community Care agencies to make their assessments when 3rd party personal carer become necessary as the disease progresses.



Positive feedback about the role of caring

Carer of mother with renal cancer

I need to stress that caring for Mum has been one of the most rewarding things I have ever done – it was a beautiful experience, and one that I will value and cherish always. It has made the grieving journey harder in some ways, but I am left with the most wonderful memories of my Mother whom I got to know in a way that was so much deeper than I could ever have imagined. It was a privilege and a joy, and I hope that many others may take this path and reap the same rewards.

As you define 'social impact' for the purposes of this inquiry, you talk about factors that 'subtract' from the quality of life of the carers. However, it is hard for me to see that anything subtracted from the quality of my life. For I feel that every factor, every experience, no matter how difficult, all added to the total experience and enriched me. I could talk about the negative things, but these seem out of place without balancing them with the positive – and the positive far outweighed the negative. I could see that there could have been certain improvements in the health system that could have served to increase my mother's and ultimately my own comfort. And I realise that I had the skills to navigate the system where many others may not have. I had the advantage of being younger and stronger than many carers, and also I came into the situation willingly, it was not forced upon me.

Carer for son with bowel cancer

I feel very passionate about being able to die at home, that I have joined the Palliative Care Volunteers Support Group. I hope, with all my heart, that I can pass on my experience to as many people as possible and to help them die well.

Carer of wife with MND

I have the deepest admiration for carers, for I now know what they have to cope with, in many cases for much longer periods of time that I had to. Few people ask to be carers, in the sense in which you use the word. But being a carer is one of the greatest gifts we can give to those we love – even though we wish it were a gift we never had to give.

Carer for father with prostate cancer

On the whole we feel we managed quite well. It was the hardest thing we have ever done. We are a very close family and everyone pulled together to do what we all thought was best for Dad and Mum. Unfortunately many families do not have the support of each other as we did. I know a lot of people might like to stay in their own homes but do not have the support from families and friends. It is a big big job and everyone deals with it in a different way.

Carer for son with bowel cancer

His sister and brother took leave without pay to care for him. It was the most wonderful thing to witness as the bond between the three children became so strong.

Carer for father with prostate cancer

Many people today on hearing about palliative care think of it as full of sadness- and there is this element in it- but actually it also holds many light moments of joy and pleasures in meeting relatives, sharing a joke, recipes... Reaping the experiences of new ideas and obtaining values, challenged by the unexpected, and gaining a new slant at looking at life. Speaking for myself, I have found it to be a most rewarding sincere venture. I did my palliative care training after my dad died and I am continuing as a palliative carer.





Seeking community recognition: suggestions to publicise the impact of caring

Carer for wife with MND

How do we convey to those outside the world of carers the physical, mental, financial, emotional and moral mountains that carers have to climb? Coming from the media, I should be able to roll out the advice but I have to admit I don't have the answer to that question. You might feel that carers don't get the publicity they deserve and you would be right. But every interest group feels it doesn't get the publicity it should and in many cases they are right, too. Getting publicity in the media is a highly competitive endeavour.



We have to deal with the media the way it is and not the way we might want it to be. The media world is, by and large, fairly tough. Except in times of great tragedy – as with the Bali bombing – reporters and editors don't sit around thinking of people who do good works. Apart from the ABC, the media runs as a business and there is only so much reader or viewer appetite for stories about good works, particularly when the names and details might change but the underlying message is the same.



I think that success in using the media to get your messages across is not a matter of column inches or minutes of TV but is more strategic in nature. Can you get access to the media when you need to? The more contacts you can develop in the media – reporters, columnists, opinion page editors, news editors, talkback radio, current affairs and chat show hosts, and their producers – the better chance you have of putting your point of view and of telling your stories as relevant issues arise.

There is no formula. It is a matter of working hard and working smart and being able to bounce back when your strike rate is less than 100 per cent.

Summary of Carers' Suggestions to ease the Burden of Caring

Based on the experience of carers, their needs, and therefore suggestions to address these needs, can be grouped under the following headings: information and education, support services and respite, financial support, support from workplaces, issues for rural people and community recognition.



Information and Education

Carers suggested the following is required for carers:

- information, in the form of a publication, preparing them for their role in a practical way, covering a list of equipment to purchase such as stable tables, seats for bathrooms, non-spill cups and easy-to-eat meals
- more information from health professionals on the condition, the treatment options, medication etc for the person for whom they care
- better communication between all health care professionals involved in service provision.



Support services and respite

Carers suggested the following:

- increased access to specialised counseling services such as psychologists for carers and care recipients, and not relying on community nurse or palliative care staff to have the skills for this specialised service
- improved access to allied health services in provision of care in the home to palliative/terminal patients
- clarification of the difference between 'palliative' and 'terminal', as at the moment it is blurred, thus potentially limiting access to services such as Home Care
- more respite care particularly at night and at weekends
- more bereavement counseling.

Financial support

Carers suggested the following:

- better support from government agencies to assist families care for those with a terminal illness and a review of protocols in Centrelink in terms of reliable information as well as flexibility for short-term situations
- fair and reasonable tax relief for those who make home renovations/modifications to accommodate the physical needs of care recipients at home
- support for costs related to medications, co-payments for community services and hire of equipment, as these costs fall through the cracks of the public health system and the private health insurance.

Support from workplaces

Carers suggest that flexibility and understanding in the workplace is required so that all Sick Leave can be used as Carers Leave if necessary.

Support for rural people

Carers suggested the following:

- improved mobile phone coverage in rural areas, as mobile phones provide reassurance for caregivers should they need to leave their care recipients home alone for a short while
- warnings about planned blackouts for those using life support equipment
- support in travel and accommodation expenses when seeking treatment in metropolitan centres
- more home-based 'hospital type' services in the home in rural areas eg use of IV drips at home
- more palliative care workers who can support each other and provide cover to clients they know when their co-worker is on-leave.

Community recognition

Carers are keen "to convey to the outside world the physical, mental, financial and emotional mountains that carers have to climb".





The Needs of Carers through the Voice of Service Providers

When a society loses its rituals and traditions and grief processes surrounding an aspect such as dying and death, death is experienced in intense isolation, dehumanised, institutionalised and depersonalised.

Margaret Somerville
Professor of Law and Ethics, McGill University

The benefits provided by carers stretch not only to the people they care for, but to society generally.

It is a measure of the health of our society how we value carers, And what assistance governments and the community provide to carers, To help them in their role and to meet their unique and personal needs.

Francis Sullivan
Catholic Health Australia



Description of impact of caring for dying people on carers by service providers

The National Inquiry sought the input of providers of palliative care services about their experiences of working with carers. Many if not all aspects of the impact of caring have been highlighted by most organisations. The financial, social, emotional and physical aspects of caring are interwoven and many are inextricably linked.

Organisations emphasised that the need for carers is increasing. As the population ages, the number of people requiring palliative care will also increase as will the need for people caring for them. Demographic changes and the increased participation of women in the workforce have reduced the availability of carers and the pressure on acute hospitals to discharge patients early has increased the expectation that families will assist in the recovery or palliative phase of an illness or procedure, despite often having many other commitments.

Carers experience difficulties in maintaining employment, particularly full-time employment and may be forced to give up work and rely on government assistance. Carers find it very difficult to live adequately on the government allowance for carers, particularly in light of the increased expenses they encounter on a daily basis. For those carers able to maintain their employment, they often experience many additional stresses. They may require access to flexible working conditions and hours, which may be difficult to negotiate particularly for those in low income employment. Carers who take time away from work to care for their family member find that they run out of paid leave 3- 4 months on in undertaking this care. Their options are to either return to work or resign and as a consequence lose income. The carer may experience distress about continuing work when they feel that they would prefer to be at home with the care recipient. However they often need to continue to work to protect their job security after the person cared for dies.

The cost of drugs in providing palliative care, whether they be on the PBS or sold over the counter, can be extremely expensive and place an enormous financial burden on carers. They may have to fund the hiring of equipment and buy care from a private agency to help maintain their family member at home, particularly if the patient is not eligible or cannot access resources through community care programs. Some self funded retirees caring for a family member have suggested that their inability to access reduced fees for Community Health Nursing and GPs, drug costs and health card benefits adds to their increased risk of adverse health effects.



This financial pressure may mean that carers are not able to meet their own needs if they are not able to afford to participate in social activities or go without clothing, toiletries and other necessities of daily life.



Feedback from carers highlights that they are experiencing an increase in adverse health effects related to stress such as shingles, CVD and other stress related disorders. Eating patterns often change and weight loss is not uncommon. There is often a change in sleeping patterns and reduced sleep for the carer leading to fatigue. Carers have reduced opportunity for social activities (including access to sport and recreation activities) thus further reducing their own physical wellbeing. Carers ignore or diminish the importance of their own needs and forego own health checks.

Carers become quite socially isolated and often home bound, as home becomes workplace instead of sanctuary. The lack of respite care may also prevent a carer being able to attend carer support groups or social functions, which might provide an outlet to the daily stress and demands of their caring role. Therefore, lack of respite care can lead to social isolation, exhaustion, illness and negative feelings towards the dying patient and carers putting their own health at risk. Carers may also experience feelings such as guilt, fear, frustration, anger, resentment, anxiety, depression, loss of control and sense of inadequacy. Periods of caring may be brief or quite long and protracted, with a roller coaster of emotions, reactions and frequent crises. They experience losses such as intimacy, freedom, identity, dreams, visions, choices, lifestyle and status.



Gaps in Services and Recommendations By Service Providers

The recurrent themes emerging from the submissions by support organisations and other service providers, on needs of carers and gaps in services, can be grouped into four categories, quite interrelated at times: Information and education, financial and employment difficulties, respite and other support services and recognition. These categories of recommendations mirror those suggested by carers in the previous section of the report.



Information and education

Service providers suggest that the following is required for carers:

- information and education about the patient's condition and its implications and recognising and reporting changes in health/functional status
- training in specialised medical and treatment management skills to enable them to provide the appropriate level of care in the following areas:
 1. symptom management such as administering medication both oral and subcutaneously – part of this role also requires the carer to determine which drugs to use for different pain components eg Buscopan or morphine
 2. management of urinary catheters and stomas
 3. management of nutrition and hydration
 4. hygiene care – this is an area where carers are often stretched because patients are often reluctant to have help from outside agencies.
- information about available services and how to access them in order to stay emotionally and physically healthy and provide appropriate care for the terminally ill person, including information on how to access individual and family counseling services as well as how to access physical support, such as appropriate respite care for themselves and their care recipient





- 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 – professional organisations such as the National Cancer Control Initiative, Carers Associations, National Association of Loss and Grief, and the National Heart Foundation provide appropriate information
- psycho-educational programs and support and strategies from specially trained counseling and health psychologists, palliative care organisations or specific illness programs such as those conducted by the Cancer Council in some states to assist carers in communications and their role as patient advocates
- information on how to access palliative care organisations for the last stages of the illness to receive respite and quality care at times when the carer is most emotionally and physically vulnerable
- further support and resources to provide them with the necessary skills and expertise, which will enable them to fulfill their roles with confidence.



In addition, the Australian Psychological Society suggested the following strategies for carers to help them cope and manage the daily tasks of caring:

- sharing the tasks of caring if possible, feeling ok about delegating, giving specific tasks to family members and friends if they are willing, such as rostering, visits, childcare
- taking each day at a time, pausing to reflect on something positive each day (alone, with the person who is ill and/or supportive family members and friends)
- taking time each day to do something for oneself, to build in small rests and to learn to pace oneself where possible so that emotional and physical health is maintained
- obtaining support by seeking out people who are able to listen openly and be supportive
- talking to the person who is ill about positive shared experiences as well as the realities of the present and future
- helping the ill person plan for the future in a practical way
- facilitating good communication between the person who is ill and family members and friends.



Financial and employment difficulties

Service providers suggest that the following is required:

- more user-friendly and appropriate Centrelink forms – currently Centrelink forms for carers allowance and payments are generally aimed at long-term disability, not shorter, quicker deterioration as is the case with most palliative care patients, therefore the forms cause anxiety, distress and are more difficult to fill out: "Our staff normally do it to relieve the clients of the confrontational nature of the questions"
- a more flexible Carer's Benefit – ie increased amounts for shorter periods of time if needed
- according carers priority status when they require home modifications which enable them to provide care
- more cover for nursing care in private health insurance
- support for carers to meet the cost of medications, equipment hire, and additional support services which are not funded by government programs
- better employer support for carers and the development of practical ways of promoting and developing flexible employment policies which enable carers to balance work and care.



Support service funding and access

Service providers suggest that the following is required:

- more community services – services are often inadequate as care needs increase – Community Aged Care Packages and Extended Aged Care at Home programs provide more care, but the night time is rarely covered and there is little capacity to quickly increase the input – palliative care services may be added to these pre-existing arrangements, but there are sometimes issues about eligibility
- an exploration of the role of residential aged care facilities in providing terminal and palliative care – many service providers access these resources, many have developed considerable expertise
- easy access to expert advice and low cost equipment – eg occupational therapists, physiotherapists and equipment pools
- support for carers to cope with changing roles within the family, either taking on new and unfamiliar roles (eg managing finances, cooking, etc) or relinquishing roles (eg for the sick family member the loss of ability to contribute).
- support to deal with the impact of an advanced life threatening illness on relationships within the family / community – eg counseling services
- the incorporation into practice a tool to measure carer strain to assist staff to identify carers' unmet needs
- an expansion of overnight, weekend and emergency respite care services, which calls for increased resourcing of respite services – arrangements for funding residential respite care should be revised to establish greater incentives for providers to develop and maintain these services – respite is currently available for a short-time frame, usually 6-8 weeks, day respite is often only provided on a weekly basis unless the carer pays for a private service – government may fund overnight in-home respite only in extenuating circumstances
- better funding of nursing services funded through public hospitals to provide optimal holistic care to the client and carer
- training for volunteers – investing in an essential resource – trained volunteers can provide bereavement support, grief counseling and the myriad of care services including transport and meals for families in need – there is currently very little in the way of funded volunteer training and nurses with an interest in palliative care undertake most of the training voluntarily in their own time
- increased availability of domestic assistance – ie increased flexibility by HACC funded services to provide high-level short-term services.
- access for carers to continuing access and support in the form of facilitated carer groups and bereavement counseling services, as many experience loneliness and isolation after the death of the person for whom they have cared.

Service providers commented positively on two recent Federal Government initiatives:

- the provision of funds to the Carer Respite Centres specifically for individuals caring for palliative care clients, which has significantly increased the opportunity for individuals to be cared for at home
- the National Palliative Care Equipment Program which has recently provided additional funds, increasing the range of equipment available to home-based palliative care.





Recognition

Service providers suggest that the following is required:

- better awareness of and acknowledgment of loss and grief issues, "the great Australian taboo!"
- more public awareness of the burden of caring
- recognition of the value of unpaid carers and the benefit to our community of the unconditional, 24 hour a day, 7 day week dedicated service to people with terminal illness
- the introduction into undergraduate and postgraduate health care curricula of the concept of being a carer and the social cost of being an unpaid carer.



Issues for Special Groups

A number of groups required additional needs in view of their geographical location, their age, their health condition or their cultural and linguistic background.

People in regional and rural Australia

Within the rural and regional context, considerable differences exist in the level and type of support available to carers. The current systems of support can be substantially improved to ensure equitable access to regional and metropolitan based palliative care by patients and carers from rural areas:



- a review of reimbursement schemes for travel and accommodation with a view to national consistency in eligibility criteria and reimbursements rates appropriate to the cost of living in the city concerned
- access to reimbursement for patients and carers made available on the basis of specialist care received, not medical authorisation
- automatically eligibility for reimbursement for the travel and accommodation costs of a carer for patients requiring palliative care
- access to respite care services – which are often non-existent in rural areas
- backup plans in place in case the responsibility of caring for a terminally ill at home becomes onerous, or if the family did not realise what an enormous commitment of time and backup for the usual home duties is required
- the coordinated provision of equipment to assist the person to be cared for with dignity – there is often not enough locally available equipment such as commodes, shower curtains, mattresses, syringe drivers, mobility aids, etc – without appropriate equipment and training, the patient may be at increased risk of injury and pressure ulcers and carers may also be at risk of injury from inappropriate lifting.



Aged people

From the aged care perspective, the concept of terminal illness needs to be expanded from a cancer focus, to include dementia, degenerative neurological diseases (eg Parkinson's disease, motor neurone disease), cardiovascular disease (eg Congestive Cardiac Failure) and respiratory diseases (eg Chronic Obstructive Airways Disease). These are also important causes of mortality in the elderly group. These patients may be excluded from palliative care services because of the nature of their illness and the uncertain time frame. They may also be seen to be catered for by other community and residential care services, and perhaps not in need of the specialised pain relief and symptom control that palliative care services can offer. The final or terminal illness of older people is often superimposed on a number of chronic conditions and increasing disability and dependence. Carers are often old and frail themselves, and may have had already been providing substantial assistance before the final months or weeks.

Young people

The role of young carers lacks recognition. Young carers do not have specific programs geared to their needs and they are often not included in caring decisions, many lack recognition by the medical profession of their role. There is an inconsistency arising from terming young carers as being either 'primary' or 'secondary' carers, rather than looking at the type and amount of care being given. Young carers need assistance to cope with the psychological and other issues arising from dealing with the illness and the death of people in palliative care. They need domestic assistance as teenagers or young adults in a single parent situation caring for the parent, are not eligible for home care as they are classified 'able bodied'. Therefore as well as caring for the ill parent, they may be trying to continue studying and do all the domestic chores.

People with haematological conditions

Areas of concern impacting on patients with haematological malignancy, and by consequence their carers, are as follows:

- in some parts of Australia, local criteria for access to palliative care services limit access for haematology patients - a three-month qualifying period is too long to allow many patients to qualify
- there appears to be a lack of understanding about the meaning of palliative care amongst most health professionals treating haematology patients with malignant conditions. It seems normal for treating doctors not to consider patients as terminally ill but to see the patient as a person undergoing treatment for acute illness.

Further, the Leukaemia Foundation highlighted the needs of the 'forgotten carers' - those caring for the terminally ill in a centre a long way from home, often in an acute care setting or an aged care facility:

- carers often stay at the bedside of their loved one in an inappropriate setting such as a surgical ward thus lacking privacy, space and peace
- with the increased shortage of nurses, terminal patients need their family members to attend to their basic needs such as toileting, personal hygiene, emotional support and monitoring of pain and other symptoms
- as support organisations have a home-based carer focus, there appears to be no hospital, aged care facility or hospice based support targeting these forgotten carers
- access to professional help with psychosocial issues is limited on oncology wards due to the high level medical and emotional needs of patients





- for the terminally ill person who is unable to remain at home due to their particular circumstances, there is still a financial burden to the family in meeting the cost of accommodation and travel as well as child care and other services
- patients in acute care settings are not referred to palliative care services due to ignorance or reluctance to refer, and therefore suffer more symptoms such as pain, vomiting, constipation etc. and some even die in agony – drugs are given only on demand whereas in palliative care every effort is made to have pain and other symptoms managed and where possible absent
- while community-based services have a social worker or a dedicated bereavement care worker attached to the team, in the acute care settings, the social workers are unable to provide ongoing support and follow-up to the bereaved family.



People with neurodegenerative conditions

People with Motor Neurone Disease (MND) often fail to access services due to insufficient awareness of potential need, failure to access effective case management, lack of regional funding and prolonged waiting time for access to programs. These issues may be exacerbated by the small size and dispersion of client group, variability in rate of progression and lack of MND specific knowledge among care providers. As in other areas of management in MND, provision of responsive respite care involves informed and creative case management. The case manager must have a general understanding of the disease process, the ability to negotiate with the client regarding individual need and a comprehensive knowledge of potential funding options. Even at entry into the system of care provision, people with MND have the potential to enter the high special needs category within a relatively short space of time.



There is a need for a protocol for consistent delivery of care services for people with MND. This includes increased support at the time of diagnosis and early access to and review by a multi-disciplinary team. Integration of services necessary to support the complex and rapidly changing needs of people with MND could be achieved by an effective system of care management. Particular attention should be given to the provision of greater access to counseling, physiotherapy and respite services and early referral to rehabilitation and aged care teams with later transfer to palliative services.



Further, the MND Association recommends increased access to home care and other HACC services and also timely access to home modifications and to equipment and aids through PADP or through increased funding to the MND Association to continue service provision in this area. Early referral to the MND Association for support and assistance with access to services and equipment is vital to maintain the quality of life.



Indigenous people

The experiences of Indigenous Australian carers are fraught with challenges of distance, social isolation, poverty, and overcrowding, as well as different cultural needs. According to the Central Australian Palliative Care Service, a number of factors have impinged on the capacity of caregiving in indigenous communities:

- cultural restrictions on who is able to care for a family member and what types of care they can provide
- premature adult mortality, which has reduced the availability of carers
- dispossession from traditional lands, which has fractured the networks that would once have supported those in need of care
- customs which restrict who Aboriginal health workers can care for
- high levels of welfare receipt, which means indigenous Australians may not have the financial and material resources to provide some aspects of care such as buying medications, hiring equipment or payment for medical or domiciliary nursing services
- due to lack of information and the incapacity to process paperwork in good time (due to poor literacy), Aboriginal people often miss out on payments such as disability pension for the sick person, carer benefits, respite care funding, or funds from Centrelink or local community organisations
- the costs of transport and accommodation for grieving relatives who attend funerals – the high incidence of death and number of funerals in aboriginal communities means that these costs may recur frequently within the same family
- costs associated with bereavement practices such as requiring attendance during extended periods of 'Sorry Business', which can mean that jobs, education, sometimes one's own health may need to go on hold, with significant implications on ability to hold a job while also meeting cultural requirements
- in some places, customs related to housing a person who subsequently dies, which impact on where a person can be cared for, whether families have to move after a death, and whether and when such an accommodation can be used again – such cultural issues do not sit well with the requirements of public housing authorities, and families may need advocacy support.

According to the NT Carers Association, in some Indigenous communities, young people are sometimes not accepting their responsibilities and are not caring for the older people who get left alone a fair bit, placing a strain on local service providers. During the wet season, there could be around 15-20 people staying in a single house, as people leave the outposts for the central communities before they are cut off. During this time many communities are only accessible by air. As the carer's task becomes increasingly difficult, so does the task of providing them with support and respite. More often than not, the health of the carer, as well as of the care recipient, starts to suffer: "Providing respite in a house of 20 people is difficult – you can't replace the carer, and anyway, it can be impossible to identify that one person. So we try to help them cope by flying the care recipient into Darwin to give them a break and give the carers a chance to manage their own lives, but it is very expensive."





People from culturally and linguistically diverse backgrounds (CALD)

People from CALD backgrounds who care for a dying person may have specific needs which have not been understood or systematically addressed by policy-makers, the community sector and the general population.

Carers have reported adverse effects of their caring circumstances on all family members, such as family breakdown, domestic violence, depression, drug and alcohol dependence, suicide, limited life opportunities and missing out on education, training and work opportunities. CALD families with a dying person in their midst have the added psychological discomfort that the dead will lie in 'foreign fields' away from their culture, their homeland, the birth environment and their ancestors.



CALD carers have communicated to their peak organisations, Federation of Ethnic Communities Councils of Australia (FECCA) and the National Ethnic Disability Alliance (NEDA), the inadequacy of the Carer Allowance, which is in urgent need of review and increase. They require a just 'earned wage' payment for the caring they provide which is not means tested.

CALD families only seem to seek help when they are at crisis point and not before. This can be due to pride, the simple belief that help is not available or a fear that support will be culturally inappropriate. CALD carers, even more so than their Anglo-Australian counterparts, tend to have a 'grin and bear it' attitude. Asking for support is seen as a failing, not only in one's caring role, but also failing the family, the community and most importantly, the person with disability or illness.



As there are often no services involved in the families' lives, the early warning signs of exhaustion remain undetected and many GPs are not well informed about programs and support available for families. Another element that can be over-looked is the cultural and other prejudices of service providers. Cross-gender communication, home entry, issues associated with faith, just to name a few, can be extremely complex and it is important that they are included in service provider training.

Services such as the Translation and Interpreting Service (TIS) and the Ethnic Affairs Commission Language services have increasingly adopted the user-pays principle, severely restricting the number of free or subsidised on-site and telephone interpreting sessions available to people and non-profit service providers. Brokering and advisory services do exist, for example, the transcultural mental health centres, which have been established in several states. These services provide expert advice to service providers and are an effective model that could be replicated in the palliative care sector. However to promote these services for wider use requires additional funding.



Our human services infrastructure is still learning to come to grips with the challenges posed by diversity. CALD families and carers are generally excluded from the policy development and service planning processes.



Conclusions based on public submissions by carers and service providers

The picture that emerges from the public submissions is that carers for terminally ill people 'make do' with whatever information and support is available to them or comes to their attention. This is dependent on caring being at the right place and at the right time, or having the know-how to navigate the system. Those fortunate to have had the support have felt positive about their caring experience: "it was a beautiful experience, and one that I will value and cherish always". A number of carers even went on to train as volunteers for palliative care "to repay some of the commitment shown to them". Those less fortunate carried their caring tasks at the expense of their physical, emotional and financial wellbeing and as one carer put it, "it is an experience I wouldn't wish on my worst enemy". The experiences of carers suggest that a considerable amount of service contact/access is occurring on a random or ad-hoc basis. This has implications on carers' health and wellbeing, which are inextricably linked to the availability, quality, responsiveness and cost of support from health and community services.

On a social level, the challenge is to improve community understanding of the contribution carers make to society, by providing more opportunities for carers to speak for themselves and making available more information about caring to the community in general, so that carers' work and needs are not kept invisible behind the walls of their homes. On an individual level, carers need to access adequate and flexible resources, fairer remuneration, more respite care, training and equipment, counselling, personal support and home help and improved access to the paid workforce.

More work is required to ensure that carers' needs are fully identified and met. In particular, specialised strategies should be developed to address the needs of special groups, such as younger and older carers, those from indigenous and CALD backgrounds, those living in rural areas and those with disease conditions whose eligibility to access palliative care is restricted. To achieve this, existing programs such as HACC, community aged care packages, respite care and the various disability support programs will need more resources and the effective use of these resources. There is a need for a closer examination of the extent that carers can access services funded by the mentioned programs and how health and community care sectors can better meet the needs of carers dying people and their carers, in a socially and geographically equitable manner.

It is clear that some consistency needs to be achieved in carer information and education development as it is currently disparate and poorly integrated. Carer needs analysis, the specification of carer core and specific knowledge fields, educational design, resource development, product delivery, product evaluation and carer engagement in these functions need to be systematically facilitated, coordinated and monitored. A framework of national and state level cooperation for achieving consistency in carer education and information development would help deliver better quality outcomes for carers in this important support area.

Four additional areas have been highlighted as requiring attention by both service providers and carers:

- education and training for service providers in assessing and meeting carers' needs
- increased income support payments and allowances to relieve financial pressure on carers
- funding the training of more volunteers
- carer participation in policy and planning decisions.





It is worth noting that the Australian Government has recently made steps in the right direction in several of these areas of unmet need. A total of \$201.2 million was made available throughout the five years of the Australian Health Care Agreement for palliative care (2003–08). A further \$55 million was committed to support national activities through the National Palliative Care Program. Initiatives included: access to palliative care medications in the community; assistance for families and increased support to other care networks through the Caring Communities Program; increased resources to carer respite centres to provide respite for carers; carer focused palliative care information and education initiatives, ie production of fact sheets; palliative care equipment program ie grants to purchase equipment for loan to families and carers; a national palliative care education program in residential aged care facilities; palliative care volunteers and initiatives to benefit rural areas and indigenous communities.



These initiatives will be evaluated in due course. Hopefully those initiatives which the evidence suggests are successful will be replicated on a wider scale to reach and benefit carers across the country.

The last issue causing angst to carers is employment. Government leadership is required in developing policy that encourages employers to allow some flexibility around balancing caring responsibilities with the need to earn an income. A recent conference on carers and employment (Carers UK, 2004) has urged that "a discussion of the converging factors that serve to make the need for, and the needs of, carers as a labour force, and the skills gap in the workforce, is particularly pressing". The conference highlighted the following workforce projection in the UK, which should give food for thought for Australian policy-makers:



An estimated 2.5 million extra people will be needed in the UK workforce within the next 8 years but less than a quarter of these places will be filled by school and college leavers. Meanwhile, more than sixty percent of people will fulfill a role caring for sick or disabled relatives, either full or part-time, which will impact on their ability to work. Helping people to combine their caring and work responsibilities, therefore has the potential both to help fill a gap in the future workforce and prevent carers from becoming excluded from the workforce or trapped in low paid and inflexible jobs.

In conclusion, there is compelling evidence to indicate that the work of carers is undervalued and marginalised in the Australian community. The national inquiry in its two parts, the literature review and the analysis of public submissions, reinforce the importance that policy responses and resources be focused urgently on this area of service to help carers perform a vital and important role into the future, particularly as carers are increasingly replacing skilled health workers in the delivery of unfamiliar complex care for people with terminal illness.



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Appendix: List of Contributors to the National Inquiry

Service providers

- Australian Society for Geriatric Medicine
- Ballarat Hospice Care Inc.
- Blue Care (John Rosenberg)
- Brain Tumour Australia
- Cancer Council, South Australia
- Cancer Psychosocial Services, ACT Health
- Carer Nurses Society of Australia
- Carers Vic
- Catholic Health Australia
- Central Australian Palliative Care Service (Dr Ofra Fried)
- Council of Remote Area Nurses of Australia (CRANA)
- Department of Veterans Affairs
- Federation of Ethnic Communities Councils of Australia
- Geraldton Palliative Care, WA
- Home Hospice Inc., NSW
- Hopewell Hospice Services, Gold Coast
- Leukaemia Foundation
- Melbourne Citymission
- Motor Neurone Disease Association of NSW
- North and West Metro Commonwealth Carer Respite Centre, Adelaide
- Palliative Care Service, Hobart
- Palliative Care, Mid Western Area Health Service, NSW
- Private Health Insurance Ombudsman
- The Australian Psychological Society

Individual carers

- Alex's story
- Anne Williams (health professional)
- Bev Lord (health professional)
- Chris Archibald
- David Armstrong (the accidental carer)
- Dorothy Bremmer
- Gai Gibson
- Helen O'Connor
- Jack's story
- James Simpson





- Julie Murphy (health professional)
- Julie's story
- Kay Kennedy
- Lee Furlong
- Linda Hine
- Michael's story
- Ron's story
- Roy's story
- Ted's story
- Volunteer at Sacred Heart Hospice
- Volunteer at Very Special Kids House
- Volunteer from Caritas Christi Hospice
- Volunteer in Cittamani Home Hospice Palmwoods
- Volunteer, Bert Voskullen
- Volunteer's view on palliative care
- Wendy Dunston



Newsletters and other printed material

- Australian Doctor
- Australian Health Consumer
- Brain Tumour Australia
- Carers NSW
- FACS
- Family Caregiver Alliance
- Ipswich Hospice Care
- Media releases on Commonwealth Funding
- Motor Neurone Disease Association of NSW
- NT Carers Association (in Regional Health Check)
- Published articles
- Thesis



Glossary of Terms

CALD

CALD stands for Culturally and Linguistically Diverse and is used to describe Australians from such backgrounds.

Caregiver/carer/caring

Carers are people who regularly provide the most assistance with one or more of the core activities of communication, mobility, transport, housework and self-care. Also a carer is defined as someone who, without payment, provides help and support to a friend, neighbour or relative who could not manage otherwise because of frailty, illness or disability.

Carer Allowance

The *Carer Allowance* (Adult) helps parents or carers to care for adults with a disability at home. It replaces the former Domiciliary Nursing Care Benefit. Carer Allowance (Adult) may be paid on top of the Carer Payment or other payments, such as the Age Pension.

Carer Payment

The *Carer Payment* is available to those who provide constant care, in the home of the person under care, to a person aged 16 or over with a severe disability or medical condition, or an adult with moderate care needs and supervision of their dependent child if this child is: under six years of age, or between six and 16 years of age and attracts payment of Carer Allowance, or a child under the age of 16 with a profound disability or medical condition, or two or more children under the age of 16 with severe disabilities or medical conditions, and the applicant meets the income and assets tests, is an Australian resident or allowed to live here permanently (a two year waiting period may apply for recently arrived migrants).

Community palliative care

Community care settings include the patient's private home or a community living environment such as a residential aged care facility or supported care facility. Community palliative care services provide care, as much as possible, in the setting of the patient's choice.

End of life

End of life refers to that period of life leading up to death, and death itself.

Inpatient palliative care

Inpatient settings include hospices and hospitals. Some hospitals maintain a distinct palliative care unit, while others designate beds which are reserved for palliative care patients.

Neurodegenerative conditions

Neurodegenerative conditions are fatal diseases in which the nerve cells that control the muscles that enable us to move, speak, swallow and breathe degenerate and die. As the nerves die the muscles that they supply die. This results in increasing creeping paralysis.

Palliative care

Palliative care is the specialised health care of dying people which aims to maximise quality of life and assist families, carers and their communities during and after death.





Palliative care services

Palliative care services fall into two broad categories – primary and specialist. Primary services provide care to patients with non-complex care needs, and frequently include team-members with basic training in palliative care. Specialist services use cohesive interdisciplinary networks of palliative care specialists to provide comprehensive direct and consultancy care to patients with complex needs.

Social impact of caring

Social impact refers to the effects, negative and positive upon individuals, communities and the nation of the act of caring for dying people.



