

## The experience of supporting a dying relative: reflections of caregivers

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*This article describes family caregivers' responses to a National Inquiry into the Social Impact of Caregiving for Terminally Ill, initiated by Palliative Care Australia, which aimed to influence policy and practice to support caregivers. Caregivers recounted their experiences of supporting a dying relative and reported their unmet needs and the impact that the caregiving role had on their financial, physical and psychosocial well-being. The issues raised by caregivers were consistent with data obtained from a wide cross-section of service providers and a number of findings were congruent with empirical literature related to family caregiving. Caregivers' reports confirm that, to maintain their health and well-being, they need adequate resources, fairer remuneration, quality*

*respite care, education about the role, equipment, psychosocial support, home-help, improved access to the paid workforce and to gain community recognition. Such collected evidence reinforced the importance of policy responses and resource allocations that are focused on helping caregivers perform a vital role into the future.*

**Keywords:** *Informal caregiving, unmet needs, impact of caregiving, service provision*

Recent trends in health care reform have focused on efforts to reduce expenditure in acute care settings. A consequence of this change is a shift of care location from hospital to home, with a concomitant transfer of caregiving burden to families (1,2). These family caregiving pressures are experienced as financial burdens, physical health changes and emotional strains. There is considerable empirical evidence to indicate that the burden of caregiving adversely affects family caregivers who lack adequate resources or who are insufficiently prepared for this challenging role (3–6). Caregivers tend to be overlooked and have been referred to as 'hidden patients' (7,8).

A caregiver 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 (9). A palliative caregiver refers to a person who supports someone who will die in the course of the caregiving role. Palliative Care Australia (PCA) is the main body representing palliative care in Australia. In mid-2003, PCA launched a National Inquiry into the Social Impact of Caregiving for Terminally Ill People to gather experience, opinion, policy and research related to the social impact of unpaid caregiving for the terminally ill. PCA invited public submissions from individual caregivers and their support organisations and service providers to complement a review of national and international literature (10). Although this article describes the experiences of caregivers that participated in this public submission process, a synopsis of the main summary points of the literature review is presented first. This literature review was undertaken as a background to: (i) inform the National Inquiry into the plight of caregivers of the latest national and international challenges and unmet needs; and, consequently, (ii) help influence policy and practice related to support caregivers.

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## METHODS

Database searches for the literature review were undertaken from Medline and CINAHL in December 2003 and January 2004 using the following key words: family caregiver, palliative care, terminal care, supportive care, interventions, caregiver support, psychosocial support, caregiving impact, caregiving burden, caregiver stress, needs, home care, work conflict, emotional well-being, multicultural, diversity, cancer, rural caregivers, caregiver information, informal caregivers, ageing and caregivers and Indigenous caregivers. 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.

Submissions were invited from individuals, families and organisations in one or more of the following forms:

1. Letters or case studies describing unpaid caregivers' stories and experiences.
2. Descriptions of unpaid caregivers' needs and the extent to which they are being met by government, other institutions and the community.
3. Policy statements and/or recommendations relating to unpaid caregivers of the terminally-ill.
4. Copies of recent relevant reports or publications, research data or literature reviews.

A total of 131 organisations were contacted via letter and e-mail and were invited to make a submission. 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 and community newspapers around Australia.

## RESULTS

The literature review described the nature and extent of the impact of caregiving on the physical, psychosocial and economic aspects of life of palliative caregivers. Research has demonstrated that caregivers providing support to individuals receiving palliative care report unmet needs for information, communication, service provision and support from health and community services (4,11,12). 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 (13–15). 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 (6,14,16–18). Caregivers 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 (17,19,20). 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 (21), 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 (22).

This literature review highlighted three sets of challenges that helped explain why such needs were largely unmet: (i) barriers to seeking help including communication process barriers, health system barriers and family-related challenges (23,24); (ii) a dearth of research-based interventions focused on reducing the negative aspects of caregiving (5,12,16,25); and (iii) a number of impediments to effective policy and service development for family caregivers (26–28). Recommendations for enhancing caregiver support consisted of policy developments in the taxation, social security and income/pension benefit domains, more caregiver-friendly workplaces, co-ordinated service funding and service provision, promoting social value of caring to the community, reducing barriers to seeking help, education of health professionals, education and training resources geared to the needs of caregivers, multidisciplinary research and inter-sectorial partnerships.

The analysis of public submissions was based on those received from 20 individual caregivers, six volunteers in palliative care and 23 service providers, describing caregivers' experiences and unmet needs. The majority of caregivers who responded were female, either wives or daughters, caregiving for husbands or parents with mainly cancer (lung, prostate, renal, leukaemia, brain tumour) or dementia. Two males were caregiving for their wives who had motor neurone disease (MND). Service providers came from a wide cross-section of services and support organisations such as cancer councils, caregivers associations, palliative care services, hospices, government departments, nursing and medical professional bodies. Volunteers' submissions were in the form of life and death stories of people they looked after, not commenting on impact of caregiving or unmet needs, as service providers and caregivers did.

Submissions highlighted many aspects of the caregiving experience. Most respondents were bereaved caregivers who had experienced the death of their relative about 1–3 years

previously. Data were collated by content analysis and grouping stories and accounts of the impact of the caregiver role. Although the key findings and related quotes are sourced from caregivers' submissions, recommendations to address these challenges were based from submissions by both caregivers and service providers and fell into four categories: information and communication issues, financial and employment needs, increased services and community recognition.

## Impact of caregiving

### *Challenging aspects*

Caregivers described the consuming nature of their role. Some caregivers indicated that they were insufficiently prepared for caregiving tasks and that this had impacted negatively on their quality of life. As one caregiver described it:

*Being a caregiver is very hard: physically, caregiving for my wife got hard very quickly. We had to learn new skills of lifting, showering, dressing and feeding. We learnt on the run, for virtually ever day presented a new challenge.*

Caregivers experienced difficulties maintaining employment, and many were forced to give up work and rely on government assistance, which was frequently inadequate, particularly in light of the increased expenses they encountered on a daily basis. The following reflections highlight these issues:

*I gave up a successful well paid job ... and I used up all my savings trying to buy help.*

*I had leave from work on numerous times during Mum's illness. When she passed away I had no sick leave, holidays or long service leave left.*

*... we were forced to become pensioners as my availability to perform work became less and less, and my care became more than full-time.*

*The caregivers' pension is way too low. If you have financial commitments you can't live on the pension.*

The cost of drugs and equipment hire for palliative care was expensive and placed a financial burden on caregivers who tried to maintain their family member at home:

*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.*

*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.*

*As care demands rise, income decreases whilst at the same time costs and expenses increase. Savings are soon enough used up and assets too are sold and the income directed to alleviate the impact of rising costs.*

Caregivers experienced an increase in adverse health effects related to stress, a change in eating patterns, and a disruption in sleeping patterns leading to fatigue:

*My health suffered as I had disrupted sleep ... and I became quite depressed.*

*I put on about 10 kilos over 2 years – I eat when stressed.*

*I found this to be an extremely lonely time with little support except for short visits from friends. Nights were difficult ... I had little sleep and was exhausted.*

Caregivers had reduced opportunities for social and physical activities, further decreasing their own physical well-being, which led to their social isolation to the point of becoming home-bound:

*I was not coping well with the long hours being confined to the house.*

*I find my time to myself is very limited, even grocery shopping.*

Lack of respite care and other support services contributed to social isolation, exhaustion, illness and negative feelings towards the dying patient and caregivers putting their own health at risk:

*I think that had respite care been offered to me earlier, I wouldn't have felt so isolated.*

*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.*

*Respite for the caregiver is necessary lest one ends up being like a robot mechanically and in total fatigue, but performing the duties demanded by the situation.*

Caregivers often ignored or diminished the importance of their own needs and deferred their own health checks:

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

Caregivers reported feelings such as guilt, fear, frustration, anger, resentment, anxiety, depression, loss of control and a sense of inadequacy. Periods of caregiving for some were brief and for others quite long and unpredictably protracted, with a roller coaster of emotions, reactions and frequent crises:

*The initial stage of uncertainty, confusion and worry is followed by a desperate sense of futility: no matter what you do or how hard you try to look after your loved one, nothing can stop the disease.*

*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.*

*There are several areas of angst that I am sure every caregiver feels: caregiver 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 up-beat and uncomplaining attitude. I also wonder who is most affected by depression, the caregiver or the patient?*

#### *Rewarding aspects*

Despite the negative burden that caregiving imposed, many caregivers also reported positive aspects of the caregiving role. These included: a strong sense of attachment to the ill relative and a feeling of responsibility and pride associated with the caregiving role:

*Being a caregiver 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.*

*Caregiving for Mum has been one of the most rewarding things I have ever done – 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.*

Caregivers who received palliative care services voiced their appreciation for the support they encountered:

*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 caregiver, and as an advocate for obtaining the proper equipment and support.*

*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.*

#### **Recommendations for enhancing caregiver support**

Recommendations to improve support for caregivers came from submissions of caregivers and service providers (quotes from caregivers). Identified strategies were categorised into four key areas.

##### *Information and communication*

Caregivers needed information and education about the ill relative's condition and its implications, the treatment options, managing medication and recognising and reporting changes in health and functional status of the patient. There was also a need for information on practical support 'in the form of a publication, preparing them for their role in a practical way, what equipment to purchase such as stable tables, seats for bathrooms, non-spill cups ... and easy-to-eat meals to prepare'.

Caregivers needed to have increased knowledge about available services and how to access them. They wanted information about how to access individual and family counselling services as well as how to access physical support, such as appropriate respite care and domestic help. Caregivers also recognised a need for better communication with health professionals and better co-ordination of services.

##### *Financial support and employment*

Caregivers required better support from government agencies to assist them in their role. Health care and social welfare (e.g. Centrelink) forms need to be more user-friendly and appropriate to the needs of palliative care recipients. Current forms for caregivers' allowance and payments are generally aimed at long-term disability, not shorter, quicker deterioration as is the case with most palliative care patients. Service providers reported that the forms caused anxiety, distress and were difficult to complete. More flexible caregiver's benefit schemes are needed to meet the unique needs of this population (e.g. increased amounts for shorter periods of time). Caregivers and service providers identified the need for assistance with the

costs related to medications, equipment hire and co-payments for community services.

Caregivers and service providers requested that the Australian Taxation Office provide a fair and reasonable tax relief for those who make home renovations/modifications to accommodate the physical needs of care recipients at home. As well, employers should be encouraged/expected to provide flexible employment arrangements for caregivers in the workplace, to enable caregivers to balance work and care. These difficulties are reflected by the following caregivers' quotes:

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

#### *Increased support services*

Caregivers called for increased access to specialised counselling services for themselves and their care recipients. One respondent indicated that it was not reasonable to: 'rely on community nurse or palliative care staff to have such skills'. They also identified the need for improved access to allied health services for provision of care in the home and a need for bereavement counselling as caregivers are often neglected after the death of their care recipients.

More respite care is required particularly at night and at weekends. A caregiver reported:

*I continue to feel guilty that I was unable to fulfil 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 caregivers could get some sleep or just spend time with their own family would make a huge difference.*

The experiences of caregivers suggested that caregivers for terminally-ill people 'make do' with whatever information and support was available to them or came to their attention. Some caregivers commented on 'the lack of adequate support services, respite care, home visits by health care professionals particularly on weekends, reliable communication and follow-up from support services'. It seems that the availability and access to support was dependent on caregiving being at the right place and at the right time, or having the know-how to navigate the system:

*I realised 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 caregivers.*

#### *Community recognition*

Caregivers reported that 'current policy and financial assistance to caregivers failed to recognise the value of unpaid caregivers and underestimate the benefit to our community of the unconditional, 24-hour day, 7-day week dedicated service to people with terminal illness'. Therefore, caregivers were keen 'to convey to the outside world the physical, mental, financial and emotional mountains that caregivers have to climb'. These feelings were supported by service providers.

## DISCUSSION

The evidence that emerged from the submissions gave extra weight and 'voice' to the literature review. Findings from the submissions depicted the issues reported in the literature but through the voices of caregivers.

The authors acknowledge that these findings are constrained by the small, self-selected group of caregivers who responded to the public submissions. However, the issues raised by these caregivers and reinforced by a wide cross-section of service providers and further supported by the review of the literature (10) confirm that the majority of caregivers share the same unmet needs and had experienced similar challenging aspects of caregiving.

Caregivers who were fortunate to have received comprehensive and co-ordinated health professional support felt positive about their caregiving experience as exemplified by the following caregiver: 'it was a beautiful experience, and one that I will value and cherish always'. A number of caregivers went on to train as volunteers for palliative care 'to repay some of the commitment shown to them'. However, those less fortunate carried their caregiving tasks at the expense of their physical, emotional and financial well-being and as one caregiver put it, 'it is an experience I wouldn't wish on my worst enemy'. Therefore, the availability, quality, responsiveness and cost of support from health and community services have implications on caregivers' health and well-being.

Caregivers need to access adequate and flexible resources, fairer remuneration and more respite care. Support for caregivers would also be enhanced with better training and preparation for the caregiver role, access to equipment for caregiving tasks, the availability of quality psychosocial support, home help, improved access to the paid workforce and more financial support.

On a social level, the challenge for the community is to improve understanding of the contribution caregivers

make to society, as exemplified by this feedback from a health professional:

*The benefits provided by caregivers 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 caregivers, and what assistance governments and the community provide to caregivers, to help them in their role and to meet their unique and personal needs.*

## CONCLUSIONS

Enhanced support for family caregivers of people with a terminal illness requires a distinct set of strategies to respond to the demands of caregiving to maintain the health and well-being of caregivers. This is particularly important, as caregivers are increasingly replacing skilled health workers in the delivery of unfamiliar complex care for terminally ill people.

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