

# Home-based support for palliative care families: challenges and recommendations

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THERE IS A GROWING TREND in Australia for people with a terminal illness to remain at home, where practicable.<sup>1</sup> Most deaths occur in hospital, but much of the dying phase occurs within the home.<sup>2</sup> Despite the input offered by professional palliative care services, care within the home usually relies primarily on a family member or friend. Indeed, without the support of caregivers, home palliative care would be impossible for many people. Here I outline current issues related to home-based palliative care and recommend ways of enhancing the quality of this care.

## Family and family caregivers

“Family” encompasses more than biological relatives or people related by marriage, and can include those identified by patients as key people in their lives.<sup>3</sup> The term “family caregiver” is often used for an important relative or friend who provides psychosocial and/or physical assistance to a patient needing palliative care.

My recent Australian study of 106 family caregivers involved in metropolitan home-based palliative care found that two-thirds were women and two-thirds were caring for a spouse or partner. Their mean age was 60 years (range, 21–84 years), three quarters were born in Australia and a fifth had a household income of less than \$10 000 per annum. Less than half were retired, and about a quarter had stopped work or taken part-time work in order to care for the patient at home.<sup>4</sup>

These bare statistics indicate the considerable commitment required by those who assume a home caregiver role, and health professionals who support home care need to appreciate this level of commitment and the stress that it may engender.

## The roles of families in home-based palliative care

The focus of home-based palliative care by families has changed from a simple caring role to more complex care, often involving advanced skills such as opioid administration and symptom management. The level of responsibility of a family caregiver depends on the physical and psychosocial needs of the patient and the dynamics of the relationship between caregiver and patient.

## ABSTRACT

- Providing adequate supportive services for the families of palliative care patients is a core principle of palliative care.
- Caring for a patient with terminal illness at home involves a considerable commitment on the part of family caregivers, and attention must be given to the caregiver's needs as well as those of the patient.
- Although a home death may be preferred by patients and promoted by healthcare agencies as a cost-effective option, it may be an ideal that is not often realised.
- Enhanced supportive care strategies can ameliorate the challenges facing families of palliative care patients cared for at home.
- All health professionals need to improve the standard of family-centred palliative care, and more evidence-based approaches are required.

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The responsibilities of a family caregiver may encompass some or all of the following:

- personal care (hygiene, feeding);
- domestic care (cleaning, meal preparation);
- auxiliary care (shopping, transportation);
- social care (informal counselling, emotional support, conversing);
- nursing care (administering medication, changing catheters); and
- planning care (establishing and coordinating support for the patient).<sup>5</sup>

## Impact on families caring for a dying relative at home

For many families, the diagnosis of a life-threatening illness of a family member is their first major confrontation with death. For family palliative caregivers, the physical, emotional, financial and social impact of providing care for a dying relative may be accentuated by social burdens such as restrictions on personal time, disturbance of routines and diminished leisure time. For example, a caregiver may need to maintain a constant presence, becoming as housebound as the patient. There is potential for conflict and poor role resolution as the caregiver attempts to manage multiple responsibilities and forgoes his or her own needs in favour of those of the patient. Studies of the emotional consequences of caregiving reveal that relatives of cancer patients may experience as many (if not more) psychological problems as the patient.<sup>6</sup> These include anxiety, depression, reduced

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### 1: Key recommendations for improving family-centred palliative care<sup>17-19</sup>

- Determine key family members, as identified by the patient.
- Include key family members in the documented multidisciplinary care plan.
- Involve members of the wider multidisciplinary team.
- Assess the need for family meetings.
- Prepare family members for roles associated with supporting a dying relative.
- Provide written information to supplement verbal guidance in a structured manner.
- Assist family members with skills to optimise patient comfort.
- Regularly review the goals of care.
- Regularly assess the appropriateness of the site of care.
- Regularly assess the family's need for respite, information and support.
- Regularly assess individual family caregiver needs.
- Offer to advise the family of the typical signs of imminent death.
- Assess the need for bereavement support prior to the patient's death.

### 2: Key challenges for optimal home-based palliative care

- Equality of available resources for metropolitan and regional/rural palliative care.
- Evidence for the most appropriate models of care delivery.
- Appropriate recognition of varying cultural needs, and strategies to meet these needs.
- Enhanced interdisciplinary collaboration.
- Appropriate inclusion of advance care planning.
- More helpful strategies to determine the terminal phase of life.
- Suitable respite options, including overnight and evening services.
- Greater continuity among the healthcare professionals making home visits.
- 24-hour availability of general practitioners and palliative care specialists.
- Multidisciplinary care plans and databases applicable across different care sites.
- Improved assessment tools to accurately determine patient and family needs.

self-esteem, feelings of isolation, mental fatigue, guilt and grief.

Family caregiving can have a negative impact on the family's quality of life.<sup>7</sup> Almost a third of 106 Australian family caregivers reported confronting significant anxiety, and 12% experienced significant depression.<sup>4,8</sup> Being a family caregiver may also predispose a person to health problems, such as physical exhaustion, fatigue, insomnia, burnout and weight loss.<sup>9</sup>

### The needs of family caregivers

Because family caregivers play a central role in the wellbeing of most people with a terminal illness, it is important that attention is given to their needs and experiences. However,

the principle of regarding the needs of the family and the patient as equally important in care provision is not always upheld, with caregivers' needs usually overshadowed by concerns about the patient's comfort, practical care, information needs, and emotional support.<sup>10</sup>

### Should home death be viewed as the gold standard?

The benefits of palliative care at home include a sense of normality, choice, and comfort. Home death is commonly viewed as a more dignified and comfortable experience than death in hospital. Furthermore, many healthcare agencies promote home-based palliative care because it is more cost-effective than hospital care. In fact, home death is a reality for only a small proportion of patients; for example, one study has shown that 16% of cancer patients in South Australia die at home,<sup>11</sup> and a study of where people die in Victoria found that 21% die at home.<sup>12</sup>

A study of the factors associated with successful home palliative care and dying at home found that men rather than women are more likely to die at home. Other factors included having adequate financial resources, having cancer or AIDS, having a healthy full-time caregiver, not living alone, having personal needs that could be managed at home, and expressing a preference for dying at home.<sup>13</sup>

While home death may be the desired goal for some families, it may also be a romantic ideal inappropriately encouraged by health professionals. Advocacy for home care should not put pressure on families, and a desire for home death ought not be assumed;<sup>9,14</sup> families and patients need to be able to make an informed choice about where death should take place and to recognise that the best place for death to occur may change over time.

### Supportive strategies for effective home-based palliative care

A meta-analysis has shown an advantage for patients and caregivers who receive support from designated palliative care teams.<sup>15</sup> The burden of caring for a dying relative can be detrimental to family caregivers and there has been a dearth of intervention studies undertaken to address their unmet needs. Many publications recommend improved support for families, but few of these approaches have been formally evaluated.<sup>16</sup> A synthesis of key recommendations from recent general Australian guides for health professionals to improve family-centred palliative care is given in Box 1.<sup>17-19</sup> A key point, however, is that family-centred palliative care is as relevant for inpatient settings as it is for home care.

### Future challenges for optimal home-based palliative care

There is no single suitable definition of a "good death",<sup>14</sup> as a death can only be judged by the extent to which individual patient and family priorities are met. Assessment of a home death should incorporate the earlier phases of care, when the focus first changed to palliative care. The numerous

challenges to the future of optimal palliative home care are summarised in Box 2. A recent review identified a need for general practitioners to improve both symptom management skills and teamwork,<sup>20</sup> but all palliative care providers must accept responsibility for ensuring that the principles of palliative care are widely operative and clearly demonstrated.



## Conclusion

Meeting the needs of families is central to providing good palliative care, but the reality is that current strategies are suboptimal. The way forward is to establish partnerships between government, service providers, GPs, families and researchers to collaboratively explore appropriate evidence-based best practice approaches to home-based palliative care.

## Competing interests

None identified.

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