

# The Financial Costs to Families Caring for Family Members Receiving Palliative Care and End-of-Life Care

## KEY FINDINGS

- Reducing hospital use at the end of life and supporting people to die at home results in significant savings to the hospital system but the extent of cost-shifting and financial implications for families is less clear.<sup>7</sup>
- If informal carers are no longer available and have to be replaced with formal palliative and end-of-life care services then this would present a substantial cost to government.<sup>9</sup>
- The financial burden on families caring for a loved one at the end of life increases with increasing intensity of care and with advancing stages of illness.<sup>6,7,9,10</sup>
- The evidence base on the economic implications of immediate and extended family members caring for someone reaching the end of life is less well developed than other aspects of the economic evaluation of palliative care and end-of-life care.<sup>6,7</sup> More research is needed to fill this gap.

## WHAT IS PALLIATIVE CARE AND END-OF-LIFE CARE?

The WHO defines Palliative Care as “an approach that improves the quality of life of consumers and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.<sup>1</sup> Palliative care is for people of any age who have a serious illness that cannot be cured. Dying is a normal process with palliative care offering a support system to help people to live their life as fully and as comfortably as possible until death and to help families cope during this illness and in their bereavement. People are approaching the ‘end of life’ when they are likely to die within the next 12-months.<sup>2</sup>

## INFORMAL CARING AND PALLIATIVE CARE AT HOME

Seventy percent of Australians want to die at home<sup>3</sup> but in 2015, only 15% did so.<sup>4</sup> Family carers, who may or may not be family members, play a crucial role in the support and care at home of people approaching the end of life. However, while caregiving may be rewarding for many, the emotional and psychological impact may also be considerable. Providing end-of-life care in the home is particularly intense for family carers, and while carers are providing the physical and emotional support that a patient needs at the end-of-life, they are also managing their own grief and the grief of others.<sup>5</sup> Caring for someone with a life-limiting illness may also place heavy

demands on the carers’ and family’s financial resources. The economic cost to family carers in helping provide palliative care and end-of-life care in the home, including impacts on carers’ participation in the paid workforce, is not well researched.<sup>6,7</sup>

## ECONOMIC VALUE OF INFORMAL CARE

People with advanced cancer are the most common users of palliative and end-of-life care services, with many choosing to die at home. The total direct and indirect costs in England and Wales of caring for people with lung, breast, colorectal and prostate cancer approaching the end of life (defined as the period after which patients had started strong opioids) was estimated in an economic modelling study.<sup>9</sup> One-third of the total costs of care were found to be borne by informal family carers through the value of care they provided, the income lost from lower rates of employment and costs of carer’s allowances.<sup>9</sup> In Australia, as in England and Wales, these four cancers account for over 40% of all cancer deaths.<sup>8</sup>

The economic value of informal care provided in the last year of life has also been estimated in three areas of Ireland for people who had died and who had used specialist palliative care services.<sup>10</sup> While hospital care was the most costly component of care received in the last year of life, accounting for around 43% of total costs, the economic contribution of informal care was also significant. When valued at the cost required to replace family caregiving by formal palliative care services, the informal care provided in assisting family members with personal care and household tasks accounted for 26% of the total healthcare costs incurred during the last year of life.<sup>10</sup> In a Canadian study, consumers in home-based palliative care typically have much lower hospitalisation costs, yet they incur much higher unpaid caregiver time costs and home care service costs than hospital-based patients, with families and caregivers found to be shouldering more than half of the financial burden incurred in home-based palliative care.<sup>11</sup>

## FINANCIAL IMPACT TO INFORMAL CARERS

Given the economic value of informal care to the health system more needs to be done to address the financial hardship associated with a person’s desire to die at home, which often comes at a significant financial cost to the family, and for some results in substantial debt and even bankruptcy.<sup>12</sup> These financial costs of caregiving for family members at the end of life arise from three main economic consequences: work-related costs through changing employment circumstances; direct out-of-pocket expenses; and carer time costs i.e. costs arising

from the time carers invest in supporting their dying family member.<sup>7</sup> Carers often reduce the number of hours they work, take annual recreational or personal leave, or even give up work in order to meet care demands.<sup>12,13</sup> Out-of-pocket expenses include a range of costs such as visits to health professionals, medical equipment and aids, prescription and over-the-counter medications, private home care, transport, child care, food and personal care items.<sup>14,15</sup> The cost of caregiving time has been estimated to be as high as two-thirds of the costs incurred by families in providing palliative care.<sup>15</sup>

In Auckland, the costs of caregiving in the palliative care setting are significant for most families.<sup>12</sup> As in other studies, participants reported a wide range of experiences in terms of the direct and indirect costs they incurred. The direct cost that was most frequently mentioned by carers was parking and transport costs related to their family member's hospital appointments and admissions. Household funds were also spent on food, clothing, bed linen, medical treatment including medications, GP visits and alternative or complementary therapies. This particular study uncovered that carers had a sense of urgency about meeting the person's needs as death approached, regardless of cost.

## ROSE'S STORY

Wendy was a 55 year old woman who had metastatic breast cancer and had been unable to work for the past ten years due to the symptoms of her disease, treatment and treatment side-effects. While she remained at home, her partner Rose supported her and worked full time. Due to financial strain, they moved to a rural town, away from the oncologist and rest of the treatment team.

After two years Wendy's condition deteriorated to a point where Rose was required to provide more intensive care for her. After two months, Rose lost her job as she was not able to take any more leave. Rose received a carer pension, but with no palliative care services in the town, this was largely spent on the many trips to the city to access palliative treatment and for the equipment to help care for Wendy at home.

Wendy wanted to die at home with Rose. However, two years later she died in a hospice. Unfortunately, this was not the end of the struggle for Rose who, while grieving for her partner, no longer qualified for the carer pension. Rose was now over 60 years old and found it very difficult to find work, particularly in a rural location. Rose's own health deteriorated, she had to sell her home and became dependent on a disability pension.

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