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ABSTRACT

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The capacity to care in the community and to support unpaid carers is a critical issue. We highlight some recent reviews on effectiveness of interventions to support carers. While there is an incomplete evidence base associated with the needs, appropriateness of supports and effectiveness of carer interventions, there is an ongoing need to provide information and services to carers.

Carers are people who provide unpaid care and support to someone who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems. Carers can be a friend, neighbour, extended family, spouse, sibling, child or parent¹.

The 2018 National Palliative Care Strategy recognises that carers are critical to palliative care and often will provide extensive care and support to a person at the end of life. The Strategy explicitly requires that carers are valued and receive the support and information they need.^{2 p10}

There is a growing awareness that the ageing population will place increasing demand on the need for carers and on the availability of carers. In 2017, 15% of Australians (3.8 million) were aged 65 and over and this number and proportion will grow steadily over the coming decades³. One Australian economic study suggests that in the ten years to 2025, the carer gap (the gap between the supply of informal carers and the need for informal carers) will increase in each year, and the carer ratio will decrease in each year. This occurs as the growth in the supply of carers is slower than the growth rate in the demand for carers⁴. Given that the rate of dying is projected to increase over the coming decades primarily due to the ageing of the Australian population, capacity to care in the community is a critical issue.

There is a growing body of literature around carers and informal caregiving in palliative care including a significant volume of work relating to caring for people with dementia. The CareSearch Review Collection details a wide variety of reviews in this area that covers carer topics ranging from disease specific needs and interventions to the role of telehealth in supporting carers to the utility and effectiveness of tools in measuring carer needs, carer burden and carer coping⁵. Within this accumulating database there is still uncertainty about the most effective forms of interventions to enable and support carers to continue to care and to prevent potentially negative outcomes from caring^{6,7,8}.

An updated systematic review suggests that there is no 'one size fits all' intervention to support carers. The authors noted that the evidence suggests there were differences in matching support approaches and carer needs. For example, shared learning, cognitive reframing, meditation, and computer-delivered psychosocial support appeared beneficial for carers of people with dementia while for carers of people with cancer more effective supports included psychosocial interventions, art therapy, and counselling⁹.

Studies and reviews do continue to note that there appears to be both known and unmet information needs for carers. These needs include information about the disease and the disease

trajectory, what to expect associated with dying, practical knowledge about caring, and details on available services and resources^{10,11}. The complexity of caregivers trying to be prepared for the death and loss while feeling overwhelmed with demands of caregiving throughout an unpredictable illness trajectory was identified in an Australian study which cautioned against services presuming that all family caregivers are well-prepared for the death¹². Carers can subsequently face bereavement exhausted with few supports, limited resources and a significant proportion may develop negative psychological and social outcomes¹³.

Given an ageing population and increasing rates of dementia which could mean longer periods of caring, some carers may not be able to continue to provide care at home until death. Carers need to be able to address the complexity of transfer of caring from home to residential aged care or to other care arrangements^{14,15}. Discharge from hospital or hospice to aged care is another form of transition, which can affect carers¹⁶.

The literature suggests that there is an incomplete evidence base associated with the needs, appropriateness of supports, and effectiveness of carer interventions. However, given the critical role that carers play in supporting people with life-limiting illnesses and in enabling them choice in their place of care, there is an ongoing need to provide information and services to carers. It is also important that their contribution not only to the person but to the community is recognised and acknowledged.

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