

HOW WELL DOES THE AUSTRALIAN HEALTH CARE SYSTEM SUPPORT QUALITY END-OF-LIFE CARE FOR PEOPLE WITH CHRONIC DISEASE?

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Background There is mounting evidence end-of-life care for people with advanced chronic disease is neither adequate nor appropriate. Chronic disease management initiatives have focussed on prevention and systematic care processes, with little or no attention to end-of-life care planning or delivery.

Aim To determine how the Australian health care system supports end-of-life care for people with advanced chronic disease and their carers and determine the suitability, availability and accessibility of care.

Methods Using a qualitative case study methodology, nine people with end stage heart, renal and neurological disease identified as likely to be in the last year of life, were interviewed three times over 9 months. Their carers and key service providers were also interviewed.

Results None of the participants had discussed their prognosis with a clinician and none were supported by specialist palliative care. Participants aged under 65 years of age were more disadvantaged, particularly regarding access to ADL support. Four participants had undertaken advance care planning, at their own instigation. Service providers identified access to services, lack of advance care planning discussions and failure to recognise the terminal nature of many chronic diseases, as key issues.

Discussion Lack of clarity around responsibility for care planning and co-ordination of end-of-life issues meant participants did not have the opportunity to discuss their care needs and frequently did not access appropriate services.

Conclusion The Australian health care system is compartmentalised, with a lack of coordinated, practical policy and service delivery responses acting as significant barriers to best practice end-of-life care