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Family carers encouraged to be the best they can be

Australia's thousands of family carers are the focus of an educational campaign to empower them with the knowledge to provide a high quality of care whilst supporting them emotionally for what many describe as one of life's toughest challenges.

The ***Be the best carer you can be*** campaign is being promoted as part of National Palliative Care Week 2020 and is an initiative of CarerHelp, Australia's first comprehensive online resource dedicated to supporting those people who provide end-of-life care. The announcement of the campaign marks three months of awareness activity in which the health community, non-profit organisations and everyday Australians will be encouraged to help spread the word about CarerHelp.

CarerHelp (www.carerhelp.com.au) is a web portal offering an extensive range of advice and support for Australians who have taken on the role of caring for a terminally-ill parent, partner or friend. The initiative is led by St Vincent's Hospital Melbourne's Centre for Palliative Care in partnership with Flinders University's CareSearch, University of Technology Sydney and Carers Australia, the peak body for unpaid carers in Australia.

"At any given time, there are many thousands of Australians supporting a person in their final weeks and days of life - an undertaking that most are not personally prepared for emotionally or in terms of skills and experience," explained Professor Jennifer Tieman of Flinders University.

"Family carers come from all walks of life and this means there is no easy way of communicating with them," added Prof. Tieman. "We are relying on support from the community in general to help us get the word out that this fantastic resource exists."

More than 160,000 Australians are expected to die each year – almost all of these will need the support of a family carer, particularly those that die at home, which is why the Centre for Palliative Care's Professor Peter Hudson and other project leaders believe CarerHelp meets a very real need.



“For the first time, family carers have access to a comprehensive and dedicated online resource covering all aspects involved in caring for a terminally-ill parent, partner or friend so that they be as prepared as possible also hopefully reflect on the experience as rewarding one,” explained Prof. Hudson.

“CarerHelp addresses the information needs that carers have told us are important when someone is coming to the end of their life - what to expect as a terminal illness progresses, the practical aspects of caring, how to access community services and the obligatory legal and financial considerations involved in caring, dying and funerals.”

The information is available through a library of videos and downloadable information in article, factsheet and checklist format for family carers. It was developed in conjunction with a large group of family carers and community organisations* who shared their knowledge and experiences with the project team.

The website includes a page called *Carer Voice* which hosts a series of videos featuring carers who reflect on their own real-life experiences, offering insight into all parts of the carer experience from deciding whether you are the right person to provide care, to how to cope with grief and loss.

The project team believes that CarerHelp is one of the most comprehensive of its kind in the world. It even includes a host of information on how COVID-19 has affected the delivery of palliative care and offers a range of advice for carers to consider during these unprecedented times.

“Dying is a reality of life and many of us will be involved in caring for someone we love. We know that many people who are terminally ill can only remain at home because family and friends support them by caring,” added Prof. Tieman.

“Our goal with CarerHelp is to be a very useful resource for very special people who provide care and comfort to loved ones when they need it the most. Carers are vital members of the Australian community and we are so thankful for what they do.”

Former Governor-General of Australia and supporter of CarerHelp Dame Quentin Bryce said that the selfless work of end-of-life carers must be acknowledged.



“People who care for a family member, friend or relative are likely to be unpaid and face many challenges,” explained Dame Bryce.

“Caring for someone can involve medication management, financial and legal issues, system management and general care and support. The CarerHelp website will be a great benefit to our palliative care and health system.”

CarerHelp was built by the Australian Family Carer Toolkit Project.
The project is funded by the Australian Government Department of Health.

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Note to editors:

CarerHelp was developed in conjunction with end-of-life family carers and representatives of the following organisations:

1. Australian Centre for Grief and Bereavement
2. The Federation of Ethnic Communities' Councils of Australia (FECCA)
3. Palliative Care Australia
4. Chronic Illness Alliance
5. Cancer Australia
6. Lung Foundation Australia
7. Neurological Alliance Australia (NNA) and Multiple Sclerosis Australia
8. MND Australia
9. Dementia Australia
10. Parkinson's Australia
11. The Stroke Foundation
12. Primary Care Faculty of Medicine University of Queensland
13. National LGBTI Health Alliance
14. Health Direct Australia
15. Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
16. Centre for Palliative Care Medical Director
17. Nurse Practitioner Regional Palliative Care Team



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