



In Australia, the National Palliative Care Standards mandate that carers of people with a life limiting illness receive sufficient information to support them in their role. Up until recently, there was no systematic or consistent approach to the provision of information to family carers (Parker, D. Ivynian, S, 2020).

National Carers Week, 11-17 October is a great opportunity to celebrate and recognise carers in our community and highlight a new web-based resource “CarerHelp” (www.carerhelp.com.au), which may assist them when caring for a person with a terminal illness.

There are currently over 2.65 million unpaid carers in Australia who provide care and support to family members or friends. More than half of primary carers provide care for at least 20 hours per week, with one third of carers providing more than forty hours a week of care to someone.

Care is often provided to people who have a terminal illness, in their homes, by family and friends (Carers Australia, 2020). Over 70% of carers are female, and 1 in 11 are under the age of 25. Most people do not use the word carer to describe themselves, and do not recognise the important role they play in health care delivery. Carers are an integral part of Australia’s health system and are the foundation of our aged, disability, palliative and community care systems (Carers Australia, 2020).

Most carers have no formal training, and often take on the role of caring when a family member or a friend’s health deteriorates. It is not surprising that many carers find this a highly rewarding role, often strengthening their relationship with the person. But this role can also be challenging, and often restricts the carer’s individual life. Research has shown that carers experience the lowest wellbeing of any group in Australia, often ignore their own health and are 40% more likely to suffer from chronic health issues (Carers Australia,2020).

As a palliative care nurse working both in the inpatient and community setting, I have had countless conversations with carers, usually on the front porch, beside the letter box, or away from the person they have been caring for. Often these whispered conversations have related to what the carer can expect as the person’s condition deteriorates. Carers are often reluctant to have these conversations with the person, for fear of upsetting them. Carers often expressed concerns about having access to evidence based information relating to practical aspects of caring, at a time that suited them. Community palliative care services provide a vital role in supporting carers, and many have developed their own carer education programs. Unfortunately, there are many patients and carers who may not have access to a palliative care service, most commonly in regional and rural areas of Australia, or have been referred to a palliative care service extremely late in their illness.

In 2017 The Australian Family Carer Toolkit Project was funded by the Department of Health under the National Palliative Care Projects to improve access to information on providing care for people with a terminal illness. The project was a consortium led by the Centre for Palliative Care and a collaborative centre of the University of Melbourne. Other partners included CareSearch based at Flinders University, Carers Australia and Faculty of Health, and University of Technology Sydney (UTS).

The overall objectives of the Australian Family Carer Toolkit Project were to:

1. Increase family carers' preparedness and confidence to support their partner/friend/relative with a life limiting illness and thereby improving their psychosocial wellbeing.
2. Raise awareness for family carers of support services available for their partner/friend/relative with a life limiting illness and how to access them.

"CarerHelp" (www.carerhelp.com.au) an online resource providing evidence based information for carers was launched last year during Carers Week. The website provides up to date fact sheets, videos discussing practical aspects of caring by health care professionals, and links on caring which include information aimed to support and empower carers at different stages. There are short learning modules that are structured around a pathway approach recognising that not all carers will need the same information or be at the same point in caring (CarerHelp, 2019).

Videos with bereaved carers explore their experiences in caring for someone at end of life and cover different aspects of the carers' journey. CarerHelp has included information and links for carers relating to self-care and looking after themselves, and tips from carers currently caring for, or who have cared for, a person at their end of life.

"CarerHelp" has also produced specific factsheets to support carers during the COVID-19 pandemic, including care at home, in a hospital environment, information relating to telehealth, caring for yourself, funerals, and grieving during COVID-19.

I encourage all healthcare professionals to view "CarerHelp" (www.carehelp.com.au) and share with carers this comprehensive online resource to assist them in the vital role of caring for a person with a life limiting illness. This week is also a great opportunity to raise awareness in our communities about caring roles, acknowledge the enormous contribution carers make and show our appreciation for the vital work they do.

Regina Kendall

Nurse Practitioner

Grampians Regional Palliative Care Team

References

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CONTACTS

Grampians Regional Palliative Care Team

Ph 5320 3553 Fax 5320 6493

Ballarat Hospice Care Inc

Ph 5333 1118 Fax 5333 1119

Central Grampians Palliative Care

Ph 5352 9465 Fax 5352 9425

Djerriwarrh Palliative Care

Ph 5367 9137 Fax 5367 4274

Gandarra Palliative Care Unit

Ph 5320 3895 Fax 5320 3763

Wimmera Palliative Care

Ph 5381 9363 Fax 5362 3480

Grampians Region Palliative Care Consortium

Ph 0428 737 330

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