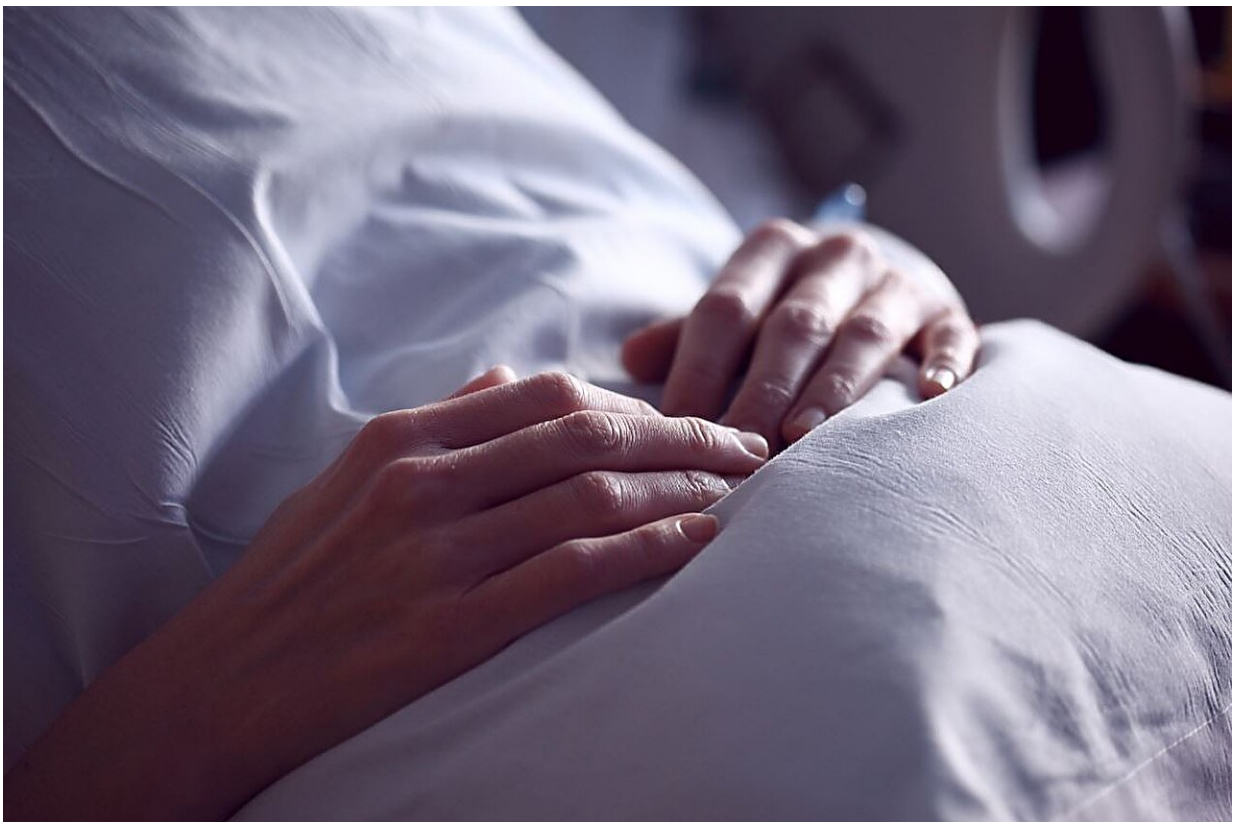


Researchers evaluate website to support well-being of those caring for end-of-life family members

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Credit: Pixabay

Most people living with a terminal illness and approaching death need the assistance of a non-professional caregiver such as a family member,

friend, or neighbor to provide physical, emotional and practical caring support. A project led by Flinders University's Research Center in Palliative Care, Death and Dying (RePaDD) has developed an effective online resource that can help ease the burdens facing these caregivers.

"A significant portion of these caregivers can feel overwhelmed, isolated and experience psychological, along with financial, distress. Caregivers can have unmet information needs and these can change across the caring period, so they need easy access to support materials," says Flinders University's Professor Jennifer Tieman, Director of RePaDD.

The Flinders team's research project undertook the development of the CarerHelp website (www.carerhelp.com.au) as part of a national collaboration led by St Vincent's Melbourne, University of Technology Sydney and Caregivers Australia. This [open access](#) online resource was designed for use by caregivers and families caring for a person who has [palliative care](#) needs.

Web metrics have demonstrated substantial use of these resources during the project test period. The CarerHelp website was released in October 2019 and attracted 5,701 users, 25,214 webpage views and 7,881 web sessions through the test period to 30 June 2020 (an average of 633 web users and 2802 web page views each month).

Sometimes, it can be difficult to know what goes into building a website, let alone one that deals with providing care and caring for someone in the last months and days of their life. A new research paper focuses on what lies behind CarerHelp website and the effectiveness of the development and test program.

The study, "Who cares for the caregivers? CarerHelp: development and evaluation of an online resource to support the wellbeing of those caring for family members at the end of their life," by Jennifer Tieman, Peter

Hudson, Kristina Thomas, Di Saward and Deborah Parker, has been published in *BMC Palliative Care*.

To best understand considerations for family caregivers supporting someone with a [terminal illness](#), the researchers developed the CarerHelp online caregiver resource after conducting interviews and focus groups with caregivers to understand their needs and context of caring.

"Caregivers of people with advanced disease facing death have ongoing and changing information needs," says Professor Tieman. "Being able to identify their issues through consultation with caregivers has ensured trustworthy resources that are relevant to the caregiver group themselves."

The researchers identified caregiver needs for practical and psychological support, along with better education and strategies to improve communication. They then used a testing survey and usability assessment of the CarerHelp website to assess and optimize functionality before it was formally released for public use.

"Our study of currently available online resources suggested that while information available to caregivers is plentiful, much of that which is provided is general, disparately located, inadequately detailed and disease specific," says Professor Tieman.

The caregivers who were interviewed highlighted the need for helpful information on: services, symptom management, relationships, preparation for death, managing the emotional and psychological burden that often accompanies caring, and support during bereavement.

User testing and usability assessment of the prototype resource led to changes to improve the CarerHelp website—but it also highlighted a

lack of awareness about existing resources and the need for marketing and communication to address this problem by further promoting the CarerHelp [website](#).

"CarerHelp's marketing strategy seeks not only to build [brand awareness](#) but also to utilize broker agencies including specialist palliative care services, care organizations and consumer groups who provide a bridge to caregivers who may not have had [direct access](#) or interest in online resources," says Professor Tieman.

More information: Jennifer Tieman et al, Who cares for the carers? carerhelp: development and evaluation of an online resource to support the wellbeing of those caring for family members at the end of their life, *BMC Palliative Care* (2023). [DOI: 10.1186/s12904-023-01225-1](https://doi.org/10.1186/s12904-023-01225-1)

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