



Healthy End of Life Program

Building capacity for collaborative end-of-life care across health and community sectors



The Healthy End of Life Plan | Individuals and Families is available as the HELP App.

Information Guide



To cite this document

Public Health Palliative Care Unit. *The Healthy End of Life Program (HELP): Supporting communities to generate local solutions to their end-of-life concerns* [Information guide]. Victoria, Australia: Public Health Palliative Care Unit, La Trobe University. Retrieved from <https://www.latrobe.edu.au/public-health/research/centres/palliative-care-unit/research/help>

Acknowledgement

The Public Health Palliative Care Unit would like to acknowledge the support of the J.O. & J.R. Wicking Trust (The Wicking Trust) and Victorian State Government.



Contents

The origins of HELP	5
The HELP framework	6
HELP: Key research findings	8
Asking for, and offering help	8
Revisiting social norms	9
Rethinking independence	9
Involve the community	9
The HELP framework:	10
LEADERS	10
Actions	11
HELP Digital Become a HELP partner	12
Further reading Contact us	13



About the Healthy End of Life Program (HELP)

People's end-of-life journeys begin in the midst of their everyday lives.

The Healthy End of Life Program (HELP) is an evidence-based community development framework that aims to increase community capacity and stimulate community collaboration around death, dying and bereavement.

Our intention is to promote health in end of life care and to shift social norms around offering and accepting help. The Healthy End of Life Program identifies and builds on local values and structures (community capacity) that will inform, maintain and sustain a collaborative community.

HELP can be used by community groups, health service providers, researchers, policy-makers, local councils, community houses, disability services, and homelessness services to develop public health palliative and end-of-life care strategies that draw upon the assets, and address the particular needs, of your community.

This information guide provides the evidence base that informs the Healthy End of Life Program (HELP).

HELP supports the delivery of strengths-based, sustainable community development initiatives, designed to create a collaborative community culture that attends to local end-of-life care needs.

Communities are guided through how to work cooperatively with carers, family, friends and neighbours, to support residents who wish to receive end-of-life care in their home, or community setting.

HELP is regarded as a Public Health Palliative Care (PHPC) intervention.

For guidance on implementing a Healthy End of Life Program in your community, download the HELP | Local Community Guide or contact us to become a HELP partner. healthyendoflifeprogram.org



The Yarra Ranges, Victoria - where it all began

The origins of HELP

HELP is the product of ongoing research that began in 2016, seeking an answer to the question:

What is involved in building individual capability and community capacity for palliative and end-of-life care?

This research gathers evidence to inform the practice of public health approaches to palliative care. The intent was to develop and evaluate an approach that offered community members choice, self-direction and supported facilitation to engage in palliative and end-of-life care in their community.

HELP aligns with government palliative and end-of-life care policies that propose increasing community capacity through the sustainable development of skills, structures and resources, to encourage members of the local community to take ownership of and manage palliative and end-of-life initiatives.

The goals of a public health approach should be to create sustainable community environments with the capacity to engage in end of life discussion, support and practical care, whilst developing community norms that ensure citizens know about and can draw upon these assets when needed.

– Grindrod A.,
Rumbold B. 2018

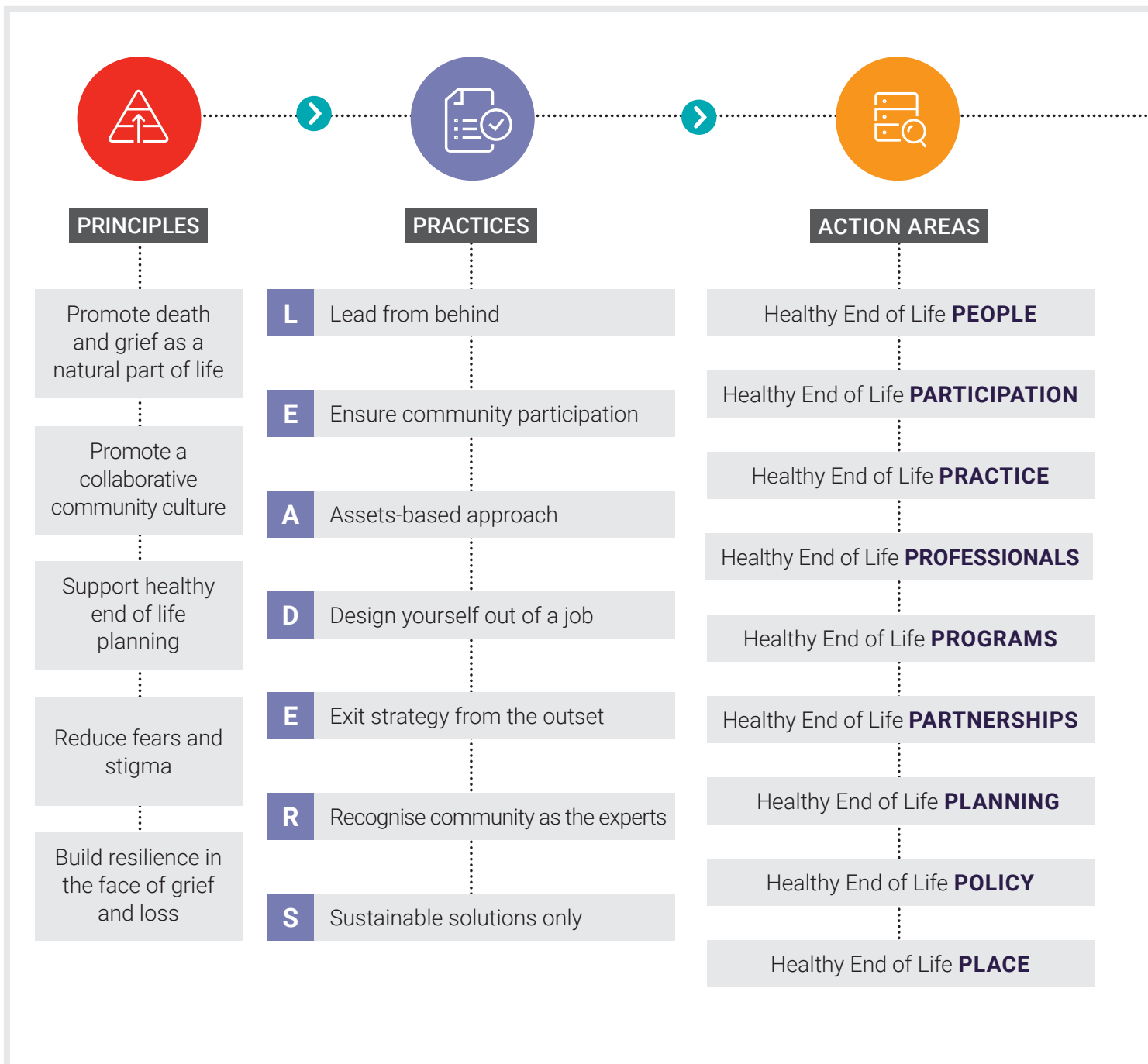
The HELP framework

The HELP Framework contributes to the development of a public health palliative care approach, where end of life is everybody's responsibility and everyone can play a role. This framework supports individuals and communities to act in new and constructive ways, to cooperatively generate pathways that support caring at end of life in community and home-based settings.

HELP is designed to modify two social norms, using two key strategies to mobilise a collaborative community culture.

CHANGE TWO SOCIAL NORMS ...

1. Shift the culture from one where members instinctively decline help from personal and community networks to one that 'asks for and accepts help'
2. Reinforce and create a community culture that is confident and capable of offering and providing help.



... USING TWO KEY STRATEGIES ...

1. Generating community discussion on the role of community at end of life - through partnerships, community forums that promote public conversation and skill-sharing.
2. Facilitating the development of social networks that can respond to individual and collective end-of-life care needs in the community.



... TO ACHIEVE COMMUNITY AND INDIVIDUAL OUTCOMES

HELP asks these questions in regards to creating well supported caring community: ***How do we unlock individual and community support networks? For those with very few connections, where can social support be found?***



COMMUNITY OUTCOMES

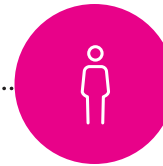
At the community level, HELP facilitates the connection of existing networks, and creates new networks, for practical caring, and to encourage the development of collaborative/cooperative community culture.

Facilitate caring networks

HELP identifies, unlocks and connects the community's assets to mobilise informal care networks that support and complement the provision of formal services.

Generate discussion in existing community structures

HELP builds end of life conversations into the existing structures, assets and networks of communities, with a particular focus on asking for and providing help.



INDIVIDUAL OUTCOMES

At the individual level, HELP encourages participants to reflect on the two social norms below that are barriers to creating collaborative communities.

Ask and Accept Help

HELP seeks to shift the dominant community culture from one where members instinctively decline help from personal and community networks to one that 'asks for and accepts help'

Offer and Provide Help

HELP promotes a community culture that is confident and capable of offering and providing help in ways that allow carers and those that are being cared for to determine what help they need, and when they need it.

Individual capability without public messages about shifting community culture limits the growth of collective action, while community awareness alone will not necessarily translate into practical caring networks that support homebased dying. Both are needed.

– Grindrod A., Rumbold B. 2018

HELP: Key research findings

People didn't **ask** for help

Despite carers' existing support networks of family, friends and neighbours, asking for help was not considered an option, even when it was clearly needed. Requesting increased support from formal services was perceived as an easier and more acceptable alternative.

People didn't **accept** help

Almost without exception, carers were either reluctant to accept help or declined help when it was offered by friends and family. In these instances, refusing support was overwhelmingly described as an instinctive response made without considering the value or necessity of the assistance. When participants were asked why they refused help, the three most common responses were to avoid 'being a burden', because dying was a 'private matter' and because 'needing support' was perceived as 'not coping', and therefore socially unacceptable.

People didn't **offer** help

Participants in extended support networks and broader community networks reported that their willingness to offer help or support was hindered by uncertainty about the appropriateness of their

proposed assistance. They were also hesitant to infringe on others' privacy, echoing the carers' sentiments that dying is a private matter.

People **want** to help

Participants shared a concern about the low understanding of palliative and end-of-life care within their community. Encouraging individuals to acknowledge their vulnerability and to ask for help was seen as an effective strategy to support local people during times of need.

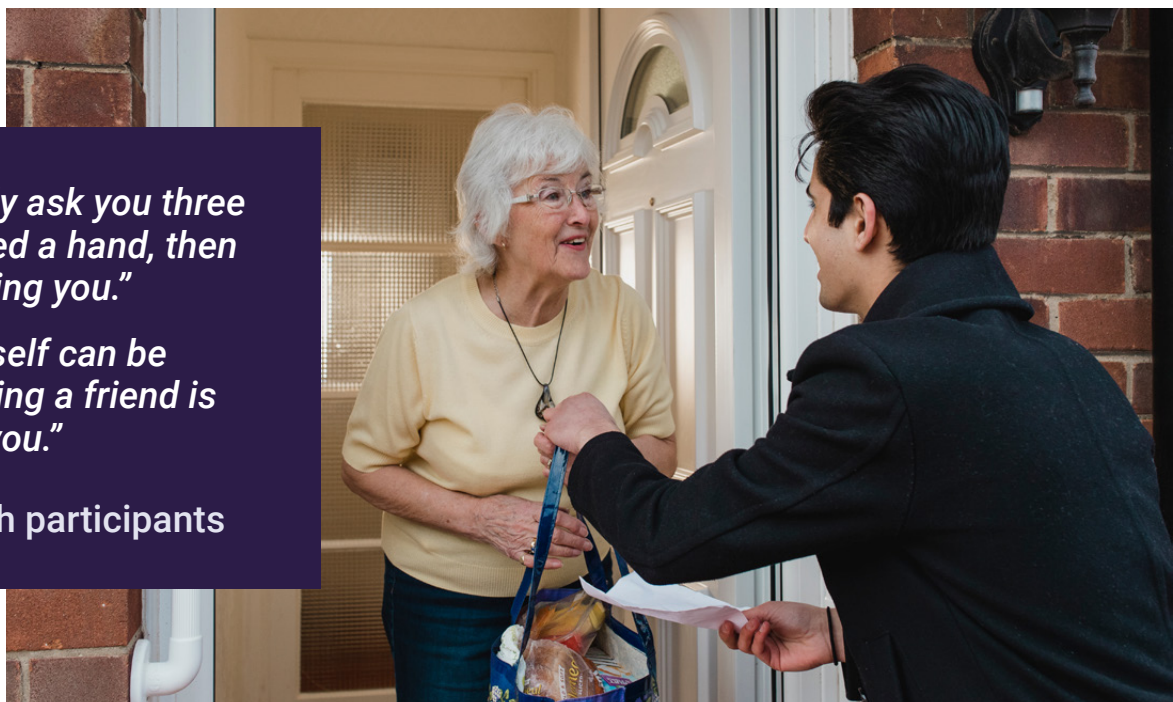
When **help** becomes unhelpful

To create a healthy collaborative community culture around asking for and accepting help, it was imperative that the person and their carer retained control and autonomy over exactly what that help and support looked like. It was up to the community to establish this from the outset and make explicit what this culture entailed and how the desired social norms could be upheld without causing conflict. Carers were more likely to accept help when the community culture supported them in maintaining their boundaries to prevent unwanted or intrusive behaviour from often well-meaning helpers.

"People will only ask you three times if you need a hand, then they'll stop asking you."

"The gesture itself can be enough— knowing a friend is willing to help you."

- HELP research participants





"The strength of the team is each individual member. The strength of each member is the team."

- Phil Jackson

Key research findings

Revisiting social norms

The findings demonstrate that social norms about helping may be a significant barrier to creating a collaborative community culture.

A public health practice model must modify these social norms if community capacity is to be mobilised effectively.

HELP seeks to shift current attitudes and perceptions by directly addressing the social norms of offering, accepting and asking for assistance.

Rethinking independence

Identifying as someone who requires and requests support can make people feel vulnerable. Learning to accept the inherent interdependence of community is a skill that sustains autonomy during periods of vulnerability and is often developed through first providing support to others.

HELP facilitates this exchange as community members are encouraged to offer their support to others at a time of need. In addition to the value of the support offered at the time, there is a longer-term benefit for those who offer support and learn to engage constructively with their own vulnerability.

Involve the community

All those who participated had a genuine desire to provide care to members of their community at the end of life. However, this desire was undermined by a shared perception that enquiring about community members' support needs as they neared the end of life might breach their privacy.

HELP contends that end-of-life care is everybody's business, and should be incorporated into existing community networks, and that gaps that are identified should be seen as opportunities for developing new initiatives.



The HELP Framework: Practices

HELP is based on seven community driven practices to ensure community leadership. These practices underpin nine areas for community lead action.

LEADERS:

L LEAD FROM BEHIND

Enable others through coaching, mentoring and encouragement. Paid workers should avoid tasks that can be undertaken by community members, and initiatives taken should not increase dependency on professionals.

E ENSURE PARTICIPATION

Ensure people from all parts of the community participate; people from all parts of the community; particular efforts should be made to engage citizens who are often excluded from involvement in community initiatives, such as, but not limited to, LGBTQA+ people, people living with physical and intellectual disabilities, people with mental health issues, homeless people, newly-settled people, culturally and linguistically diverse and indigenous people.

A ASSET-BASED APPROACH

Build on existing strengths of the community. Asset-based individual and community mapping is the first step in HELP, identifying ways end-of-life care is already provided, and canvassing other assets that could contribute to improving local end-of-life care. Assets can be structural, cultural, economic, human and services. HELP resources include a community asset mapping tool.

D DESIGN YOURSELF OUT OF A JOB

In every step, every aspect and every decision, design yourself out of a job. Decisions should be made by community members wherever possible.

E EXIT STRATEGY

Design your exit strategy in from the outset. The first step in planning is to incorporate participatory approaches that will encourage community ownership, particularly by forming creative partnerships that will sustain development.

R RECOGNISE COMMUNITY AS EXPERTS

Communities should encourage leadership and have confidence in their capacity to respond effectively to local issues. Professionals need to be reminded of community members' local knowledge and capacity to generate tailored solutions based on their shared wisdom.

S SUSTAINABILITY

Ensure sustainable outcomes by generating and supporting long term solutions. Only start what the community can finish.

Leadership is not about you; it's about investing in the growth of others.

- Ken Blanchard



The HELP Framework: Action Areas (The Nine Ps)

The HELP framework sets out strategies that provide practical guidance in creating collaborative end-of-life care in communities.

These areas for community-driven action are based on the Ottawa Charter for Health Promotion. The charter asserts that, for population impact, working across all these areas is important. Working in one area alone will not produce sustainable change in community beliefs and practices.

9 Ps for Healthy End of Life (HELP)

HELP | PEOPLE Identify, engage and support local people who are willing and able to enable and encourage their community to shift towards a sustainable collaborative culture for end-of-life care.

HELP | PARTICIPATION Ensure participation of people from all parts of the community. Strategic planning and targeted efforts should be made to engage citizens who are often excluded from involvement in community initiatives.

HELP | PRACTICE Develop local initiatives that promote healthy end-of-life community practice. HELP Practice recognises the critical role played by health and palliative care services but focuses on the many and varied contributions of other sectors, organisations, communities, and citizens. Work in this area includes social and practical support for dying people and their carers, home-based and community funerals, and healthy bereavement support.

HELP | PROFESSIONALS Adopts a health promotion approach to palliative and end of life care enabling citizens control over their own end of life care outcomes and ensuring services target the most disadvantaged citizens in their catchment area. HELP Professionals recognise the role everyone has in palliative and end of life care and uses their expertise to build this capability in others. This involves informing clients not only what services they do provide, but also what care they don't provide, such as social and practical support that can only be provided by their social networks.

HELP | PROGRAMS Design creative community initiatives based on local strengths and interests. Community members can be creative and imaginative with programs and have fun with their collaborations, which help stimulate public conversations that can further generate resources and connection.

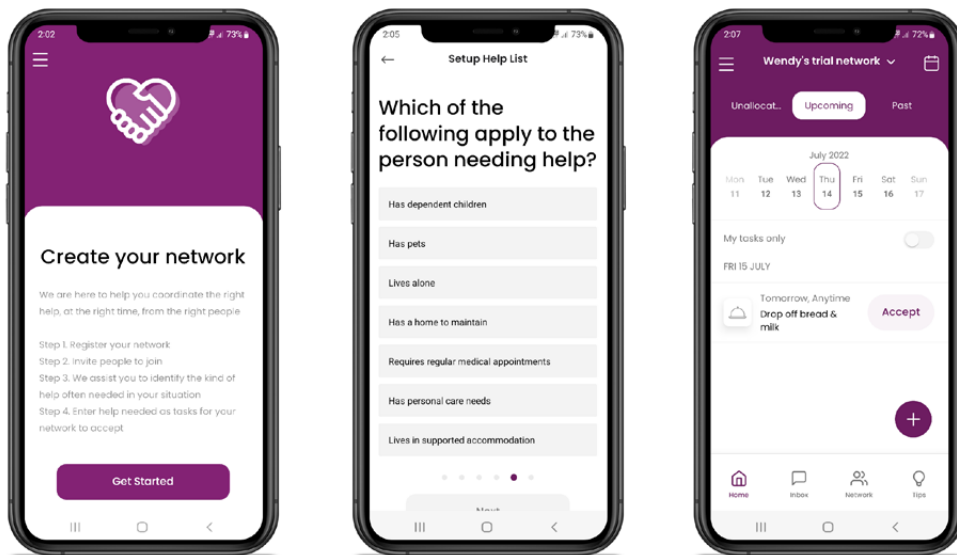
HELP | PARTNERSHIPS Develop local solutions through creative collaborations between health and community sectors, organisations, communities and individuals. Partnerships build sustainable community capacity and are crucial to successful community development programs. Particular strategies that identify, map, enhance and create links between formal health networks and informal community networks are included in Partnerships.

HELP | PLANNING Coordinated local responses to overcoming structural barriers and changing community culture. End-of-life care planning in communities has been categorised in two areas:

1. Community level: includes strategic plans for community organisations, collaborations with local health services, local government planning, and strategic collaborations that facilitate providing end-of-life care in the community. These plans also address barriers such as inadequate access to medical services and social support.
2. Individual Level: initiatives that support local people to plan for and mobilise personal and community supports that meet end-of-life wishes. These plans complement formal care plans. Healthy End of Life Planning enhances traditional Advance Care Planning.

HELP | POLICY Insert healthy end-of-life principles into existing and new policies and remove unhelpful policies that undermine good outcomes in palliative and end-of-life care. Policy settings include local government, community health services, primary health and medical practitioners and community service organizations.

HELP | PLACE Place-based approaches incorporate end-of-life support into existing social and community structures and settings to meet local need. Community members want to remain connected to the people, places and possessions that are important to them.



HELP Digital - Evaluation and Impact

The Healthy End of Life Program has been digitised for government, organisations, communities, and individuals to use the HELP Framework to implement public health approaches to palliative and end-of-life care and evaluate impact via a set of indicators. HELP Digital allows partners to capture data, both organisational and community data, easily and systematically via web portal and our HELP App. The HELP App is a digitised and enhanced version of the HELP Individuals and Families Planning Guide and can be downloaded from the App Store or Google Play. HELP partners gain access to our full education and training program, as well as exclusive resources to support your HELP Program.

Become a HELP Partner

We invite interested communities, organisations and services to use HELP to support the facilitation of collaborative communities in your local area.

There are HELP resources available to assist you. Discover them at healthyendoflifeprogram.org

Proposals for collaborative projects are welcome. Contact us about using the HELP Framework and to learn about measuring your impact with our digital resources.

Further reading

Foundational works:

Kellehear, A. (1999). *Health Promoting Palliative Care*. Melbourne: Oxford University Press, and
Kellehear, A. (2005). *Compassionate cities: Public health and end-of-life care*. London: Routledge.

Further details about the research study can be found in the following article:

Grindrod A, Rumbold B. Healthy End of Life Project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia. *Ann Palliat Med* 2018. doi: 10.21037/apm.2018.04.01. **Download at www.latrobe.edu.au/public-health/research/centres/palliative-care-unit**

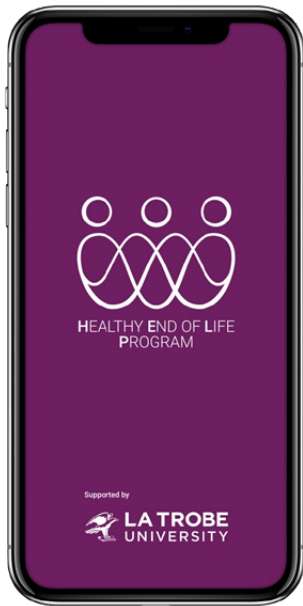
Contact us

Public Health Palliative Care Unit

School of Psychology & Public Health

La Trobe University, Kingsbury Dr, Melbourne VIC 3086

E: phpcu@latrobe.edu.au



The Healthy End of Life Planning | Individuals and Families is available as the HELP App.

Visit the Apple or Google Play store. Search for "Healthy end of life" and download it to your device.



Public Health Palliative Care Unit, La Trobe University

Address: Kingsbury Dr., Bundoora, Victoria, 3086, Australia

Mail: HS2, La Trobe University, Bundoora, Victoria, 3086, Australia

Email: phpcu@latrobe.edu.au

Web: healthyendoflifeprogram.org

ABN: 64 804 735 113

© La Trobe University 2022

All rights reserved. No part of this publication may be reproduced or transmitted without the acknowledgment of the author(s) and La Trobe University or as expressly agreed within terms negotiated with the author(s). Applications for permission to reproduce or adapt any part of this publication should be addressed to Andrea Grindrod at a.grindrod@latrobe.edu.au.



The La Trobe University Public Health Palliative Care Unit acknowledges the support of the Victorian Government and The Wicking Trust.