



LA TROBE
UNIVERSITY

**HEALTHY
END OF
LIFE
PROJECT**



The Healthy End of Life Project (HELP)

*Supporting communities to generate local
solutions to their end-of-life concerns*

Information Guide

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This guide provides background information on the evidence-base and research findings that inform the Healthy End of Life Project (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.

About HELP

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

The Healthy End of Life Project (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.

We aim to identify and build on local values and structures (community capacities) that will form, 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.

The HELP Project

Objectives

The HELP Framework fills a gap in the public health palliative care field. It 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 seeks to achieve its objectives in three key domains: culture, capacity and collaboration.

Culture

- Shift community culture around death and dying
- Shift social norms around offering and accepting help
- Change practice and attitudes towards palliative and end-of-life care

Capacity

- Increase capacity around death, dying, loss and care
- Support those who wish to receive palliative and end-of-life care at home, or home-like settings
- Provide support that complements that of existing formal services
- Sustain carers within home or community-based settings

Collaborative communities

- Ensure the inclusion of those facing illness, ageing, frailty or loss
- Promote discussion and development of social care networks
- Encourage new and constructive action towards palliative and end-of-life care



The greatness of a community is most accurately measured by the compassionate actions of its members.

- Coretta Scott King

The development of HELP



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

HELP is the product of ongoing research commencing 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.

Download the HELP research paper at www.latrobe.edu/pcu



HELP Outcomes - Individual

HELP asks the question: how do we unlock individual and community support networks and, for those with few networks, where can social support be found?

At the individual level, HELP encourages participants to reflect on the two social norms 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.

HELP Outcomes - Communities

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

Facilitate caring networks

HELP identifies, unlocks, activates 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 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

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

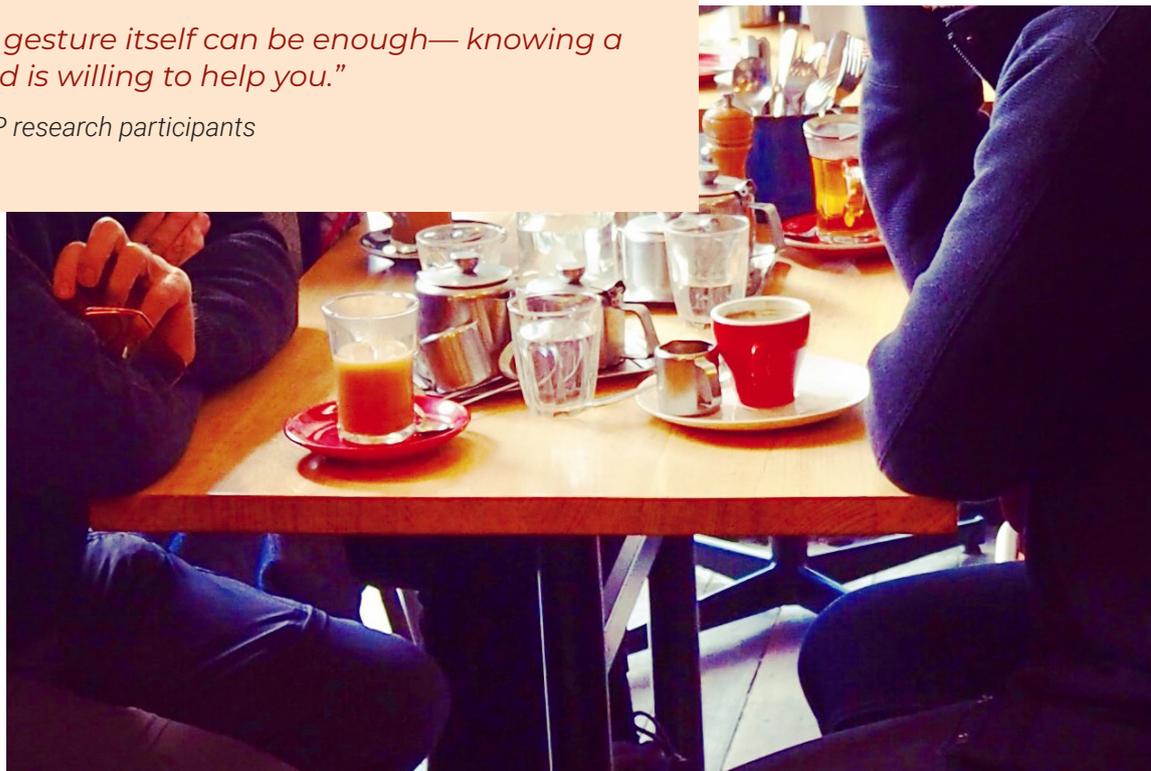
Participants shared a concern about the low understanding of palliative and end-of-life care within their community. Encouraging individuals to acknowledge their vulnerability and to ask for help was seen as an effective strategy to support local people during times of need.



"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



Revisiting social norms

The findings demonstrate that social norms about helping may be a significant barrier to creating a collaborative community culture, which has implications for public health approaches to palliative and end of life care.

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. Whilst some experience a loss of independence and control as a loss of autonomy, the reality is that interdependence is inherent in communities. Learning to accept this interdependence 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, that end-of-life matters should be incorporated into existing community networks, and that gaps that are identified should be seen as opportunities for developing new initiatives.



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

– Phil Jackson

The HELP framework

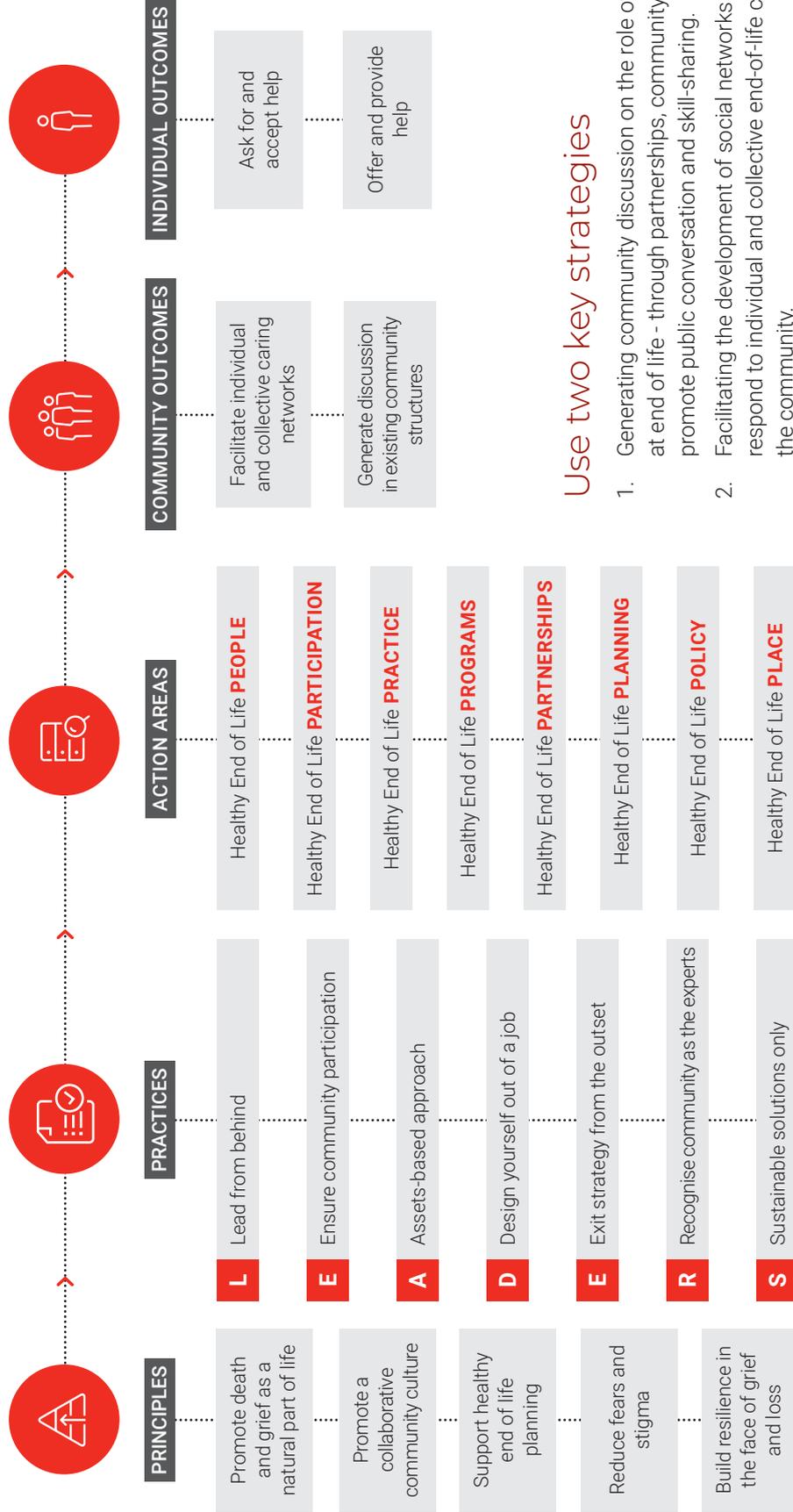
HELP is underpinned by five healthy end-of-life principles:

- Promote death and grief as a natural part of life
- Promote a collaborative culture for community support
- Support individual and community healthy end of life planning
- Reduce fears and stigma associated with illness and death
- Build individual and collective resilience in the face of grief and loss

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.



Use 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.

Community development practices

HELP is based on seven community development practices that underpin eight areas for community-driven 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

of 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. Decisions should be made by community members wherever possible.

E EXIT STRATEGY

designed 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

Community Development Action Areas (The Eight 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.

8 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, 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.

HELP PRACTICE & PRACTITIONERS to develop local initiatives that promote healthy end-of-life community practice. Work in this area includes practical support for dying people and their carers, home-based and community funerals and healthy bereavement support. This involves palliative care services not only informing clients about the care they *do* provide, but also the care they *don't* provide such as the social and practical support that can only be provided by family, friends and neighbours.

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, organizations, 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 is included in Partnerships.

HELP PLANNING Coordinated local responses to overcoming structural barriers, changing community culture and improving individual healthy end-of-life planning. 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, township planning (public bereavement initiatives, for example) 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, which itemise the care to be performed by paid professionals. Healthy End of Life Planning enhances traditional Advance Care Planning by incorporating informal care and documenting assistance provided by the patient and carers' wider social networks.

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 recognises that local initiatives need to be shaped by community resources, assets, infrastructure, culture, values and leadership, and that the generation of new and constructive ways to act in communities is collaborative.

– Grindrod A., Rumbold B. 2018

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/pcu**

HELP Project evaluation

Expected outcomes

Anticipated outcomes from implementing HELP in your community include:

- Community meetings and partnerships, where participants start to work with each other and with their networks to change their approaches to offering and receiving help
- Activities that address community concerns at end of life and raise awareness about death, dying, loss and care
- Improved reach and effectiveness of your current palliative end-of-life care services (because people are engaged and awareness is increased)
- Increased social support that improves individuals' experiences with death, dying, loss and caregiving,
- Sustainable changes to your community's palliative and end-of-life care practices

We can provide guidance to assist in evaluating and reporting your own work. We can connect you to other communities using HELP and use our platforms to promote your work.

HELP Resources

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. Download at www.latrobe.edu.au/pcu

Proposals for collaborative projects are welcome. Contact us about using the HELP framework and adapting HELP resources for local settings.

Contact us

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