

# Compassionate Connectors Program

A distinct form of end-of-life volunteering



**Facilitator:** Bonnie Tompkins, BPH

**Presenters:** Professor Samar Aoun and Professor Bruce Rumbold

**Date:** May 3, 2023

# Territorial Honouring



# The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

**Stay connected: [www.echopalliative.com](http://www.echopalliative.com)**

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.



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Canada



BY



Pallium Canada



# Introductions

## Facilitator

**Bonnie Tompkins, BPH**

Compassionate Communities National Lead, Pallium Canada  
PHPCI Council Member

## Presenters

**Professor Samar Aoun, BSc (Hons), MPH, PhD**

Perron Institute Research Chair in Palliative Care - University of Western Australia/Perron Institute  
Chair, South West Compassionate Communities Network, Western Australia

**Professor Bruce Rumbold, MSc, PhD, BD(Hons), PhD, MA**

Adjunct Professor, School of Psychology and Public Health, La Trobe University  
Senior Research Fellow, Perron Institute

# Conflict of Interest

## Pallium Canada

- Charitable Organization
- Partially funded through a contribution by Health Canada
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Pocketbook

## Facilitator/Presenter

- **Bonnie Tompkins:** Work for Pallium and council member of PHPCI.
- **Professor Samar Aoun:** No conflict of interest.
- **Professor Bruce Rumbold:** No conflict of interest.

# Welcome and Reminders

- For comments, please use the chat function.
- For questions, please use the Q&A function, these questions will be addressed at the end of the session.
- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week.

# Acknowledgement

This webinar is co-hosted by **Public Health Palliative Care International.**

W: [www.phpci.org](http://www.phpci.org) E: [info@phpci.org](mailto:info@phpci.org)



# Who is PHPCI?

## Our Aims

- Health promotion
- Educational and practice
- Biennial conferences
- Research and evaluation
- Professional links and knowledge exchange
- Global forum
- Support, network and mentor students
- Collaborate effectively



# Compassionate Connectors Program: A distinct form of end-of-life volunteering

**Prof Samar Aoun**

Perron Institute Research Chair in Palliative Care

University of Western Australia/ Perron Institute

Chair, South West Compassionate Communities Network



**LA TROBE**  
UNIVERSITY



**perron**  
institute

for neurological and  
translational science



THE UNIVERSITY OF  
**WESTERN**  
**AUSTRALIA**

**Prof Bruce Rumbold**

La Trobe University, Melbourne

Perron Institute, Perth



## “Compassionate Communities” IS

- An idea, a practice, an aspiration.
- Inclusive.
- Committed to systemic change.
- A key element of a public health palliative care approach.



## Public Health Palliative Care

A public health approach to palliative care is a health promotion approach to end of life care, one that views the **community as an equal partner** in the long and complex task of providing quality health care at the end of life.



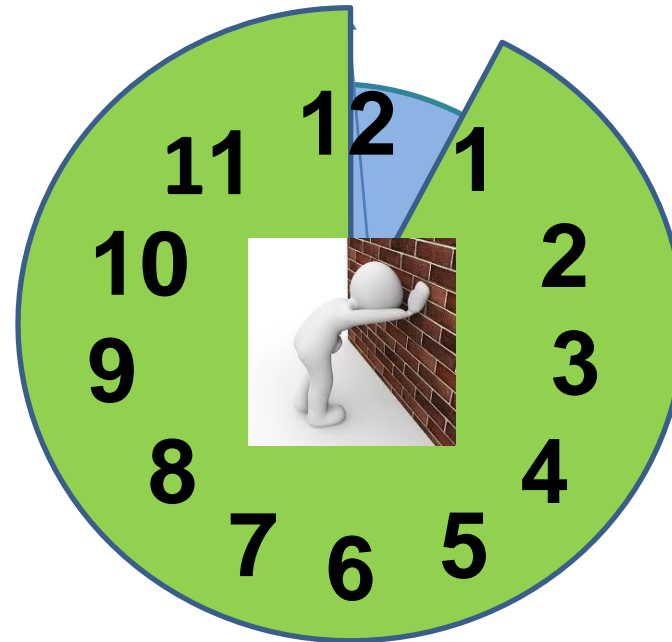
# END OF LIFE IS EVERYONE'S BUSINESS

Internationally,  
models of social  
and practical  
support  
at the end of life  
are gaining  
momentum as a  
result of the  
Compassionate  
Communities  
movement.



- A shift in the culture of care and support.
- Care that is more sustainable and affordable.
- High levels of community control and ownership.

# Only less than 5% of a person's day is contact with formal care



Adapted from Carpenter House model developed by Bonnie Tompkins

## Formal Care

*<5% of the Day*

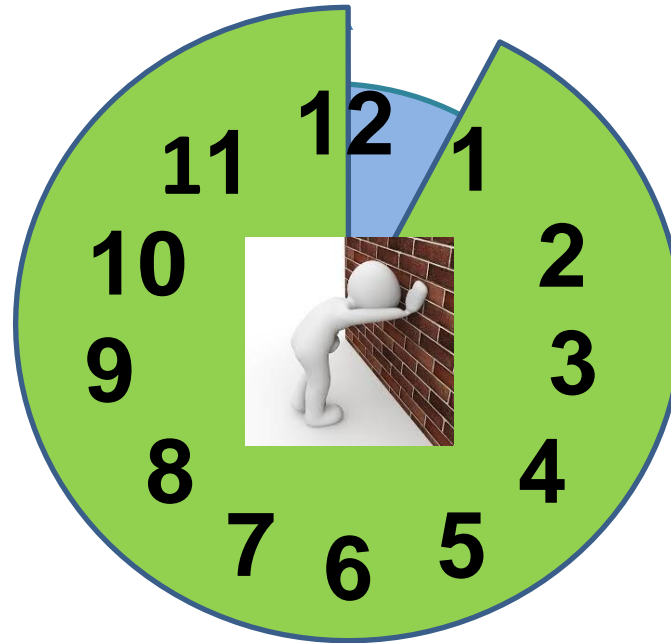
- ✓ Doctor
- ✓ Nurse
- ✓ Nurse Practitioner
- ✓ Personal Support Worker
- ✓ Social Worker
- ✓ Pharmacist



# The other 95% of the day is about informal care

## Informal Care *95% of the Day*

- ✓ Spouse
- ✓ Caregiver
- ✓ Family & Friends
- ✓ Neighbours
- ✓ Workplaces & Schools
- ✓ Community Agencies
- ✓ Municipalities
- ✓ Faith Communities
- ✓ Hospices & Volunteers



Adapted from Carpenter House model developed by Bonnie Tompkins



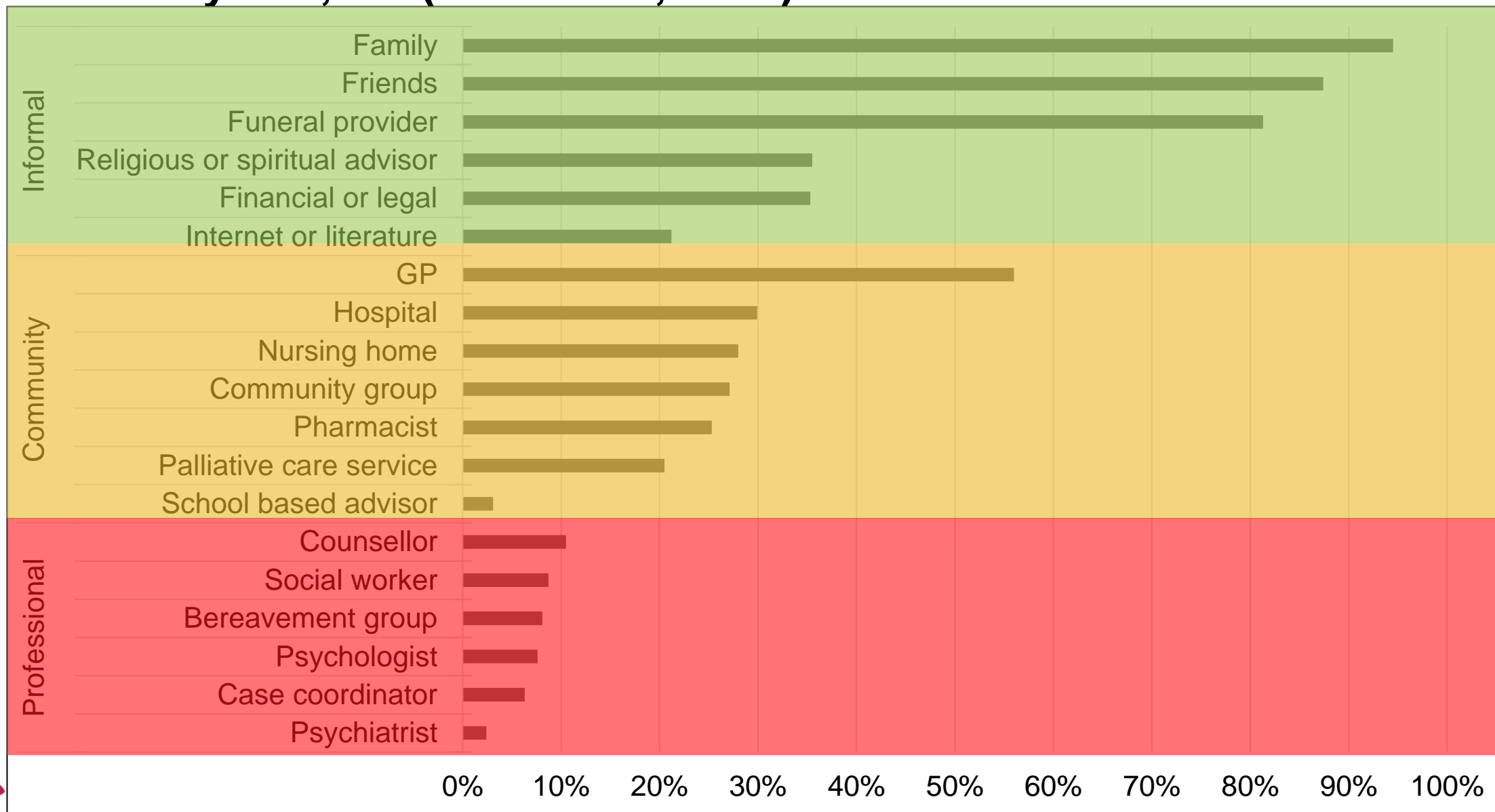
## Formal Care *<5% of the Day*

- ✓ Doctor
- ✓ Nurse
- ✓ Nurse Practitioner
- ✓ Personal Support Worker
- ✓ Social Worker
- ✓ Pharmacist



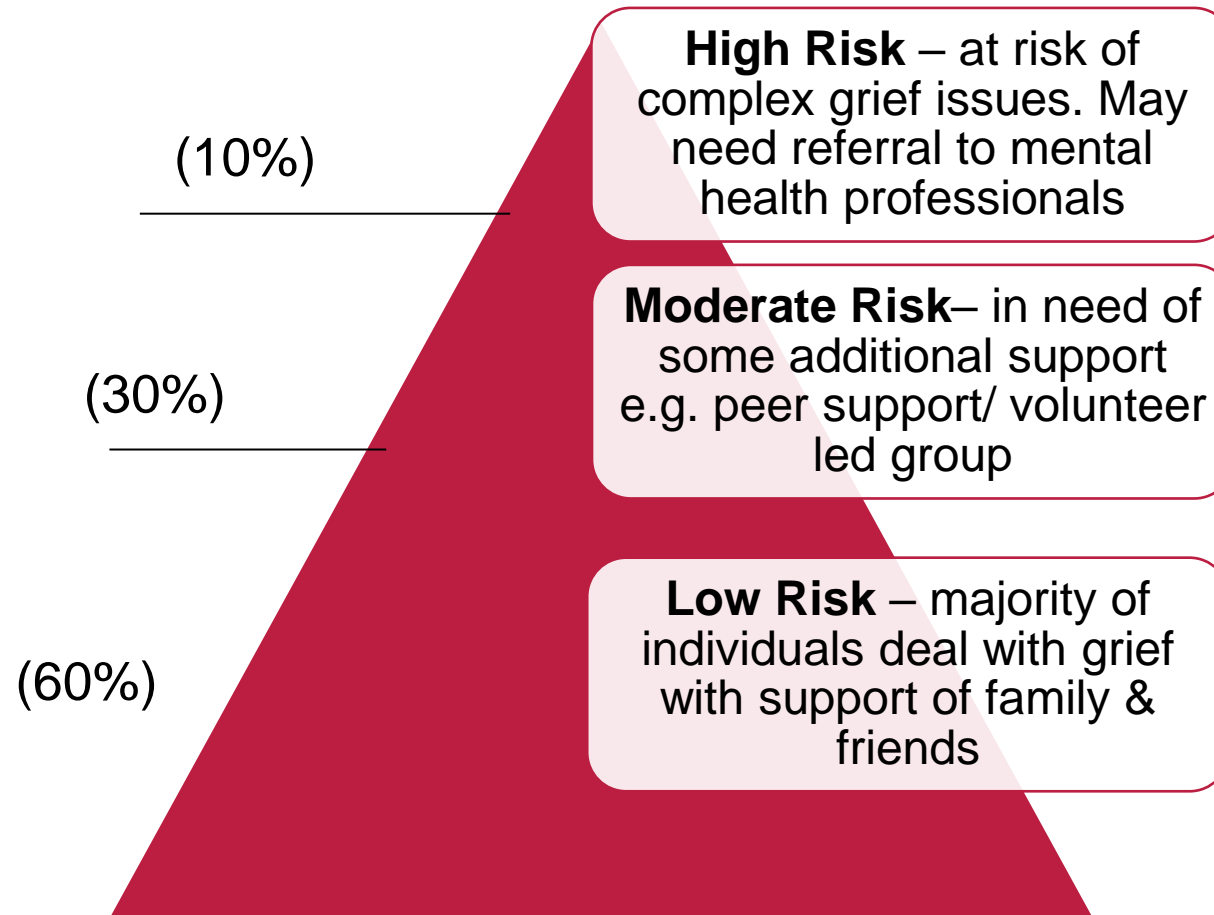
# Where people get bereavement support

## National survey n=1,000 (Aoun et al, 2018)



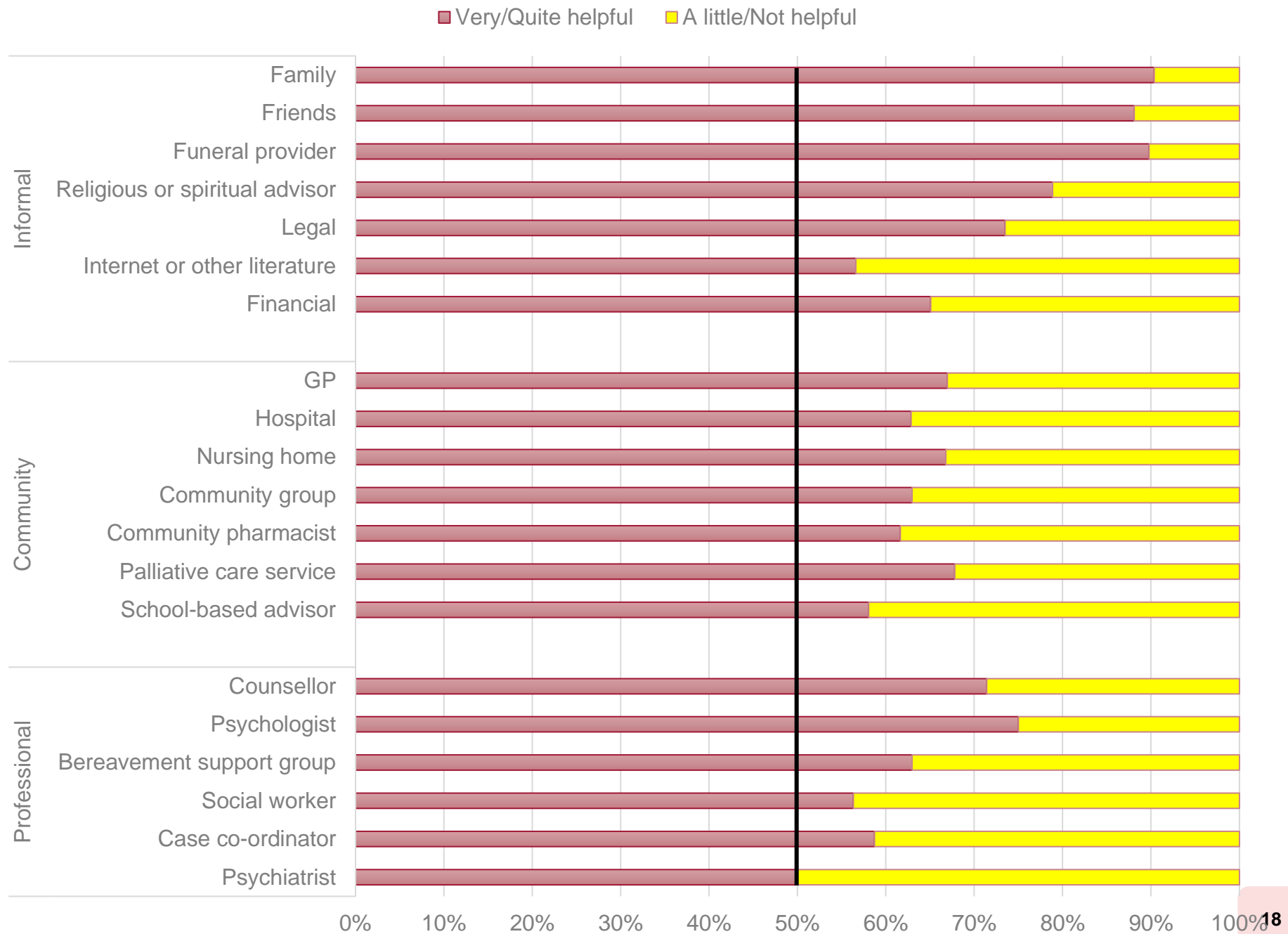


# The Public Health Model of Bereavement Support (Aoun et al, 2015)



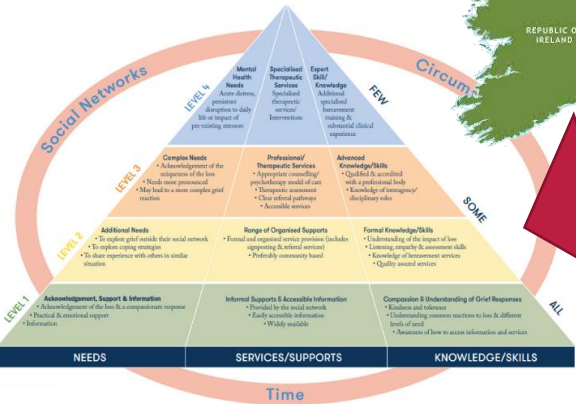
# Sources of support perceived helpful or unhelpful

*(Aoun et al, 2018)*



# The Public Health Model for Bereavement Support-Translation

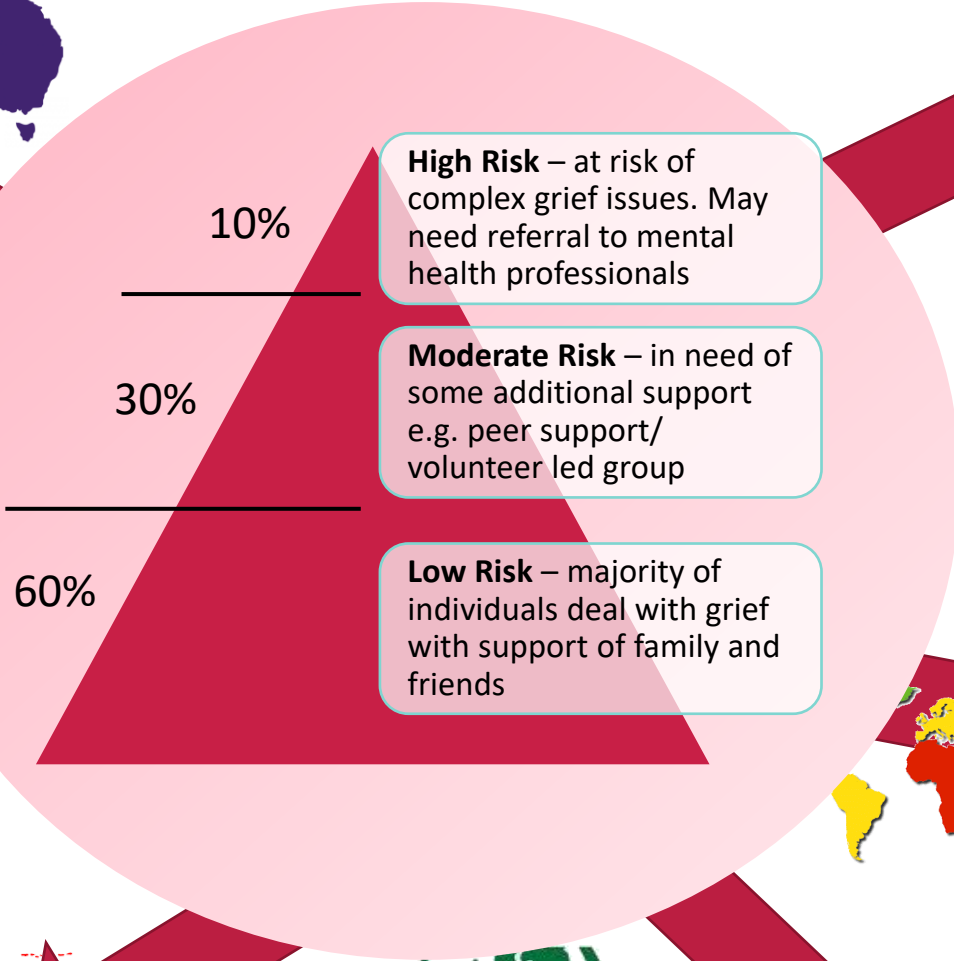
Palliative Care Australia Standard 6: Grief Support



Irish Hospice Foundation  
Pyramid of Adult Palliative Care



Bereavement Care Taskforce of the European Association of Palliative Care



UK National Bereavement Alliance



**From Health practitioners ...**  
Thanks so much. I am enjoying your research so much!  
we've been using it at the service too-  
That triangle says so much.  
Cheers.



Voted best external paper 2018, Cecily Saunders Institute For Palliative Care

# X2 The number of Australians dying will double in next 25 years

Many Australians are dying in a way and in a place that does not reflect their values or their choices and their end-of-life journey is punctuated with avoidable, or unwanted, admissions to hospital with the confusion, loss of dignity and loss of control that comes with it.

Source: Productivity Commission Report, 2017

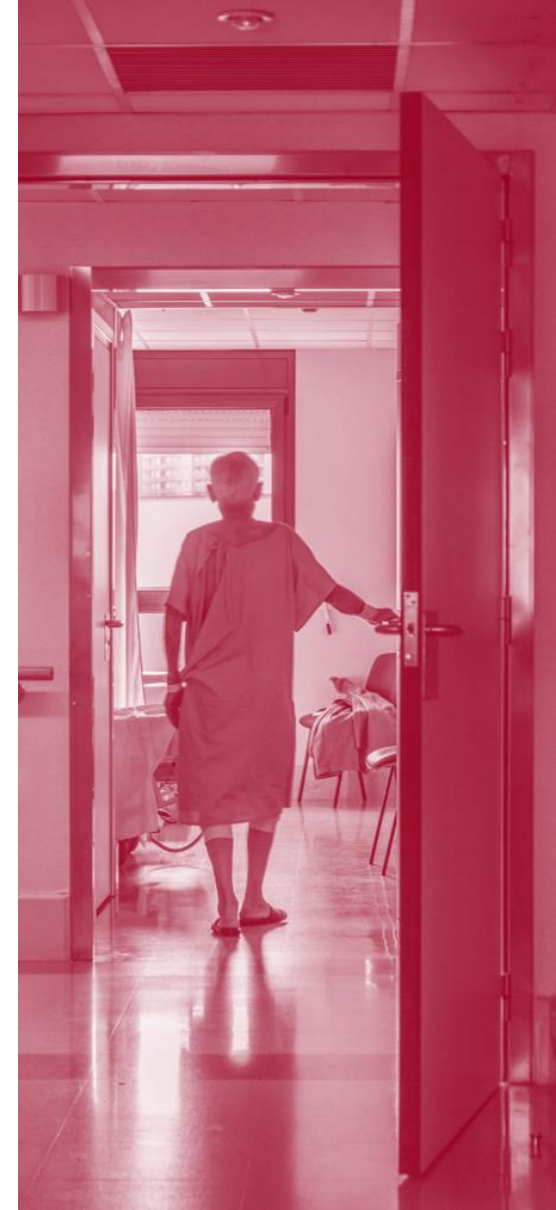


Photo by Isaac Quesada on Unsplash

***Death is a social event with a  
medical component,  
not a medical event with a  
social component.***

Professor Allan Kellehear



# How are we doing in Australia

- Dying is increasingly becoming institutionalised with 25% increase in hospital palliative care admissions (AIHW).
- Spending on key health services is 14 times higher for Australians in their last year of life than for other Australians, (\$24,000 vs \$1,700 per person, AIHW 2022).
- Hospital 3X the cost of community palliative care.
- 70-80% want to die at home but only 14-20% do.
- 75% of Australians have not had end of life discussions
- Less than 10% of us die with an Advance Care Directive.
- Nearly 50% of over 60 years old are at risk of social isolation.
- One third will experience some degree of loneliness later in life.





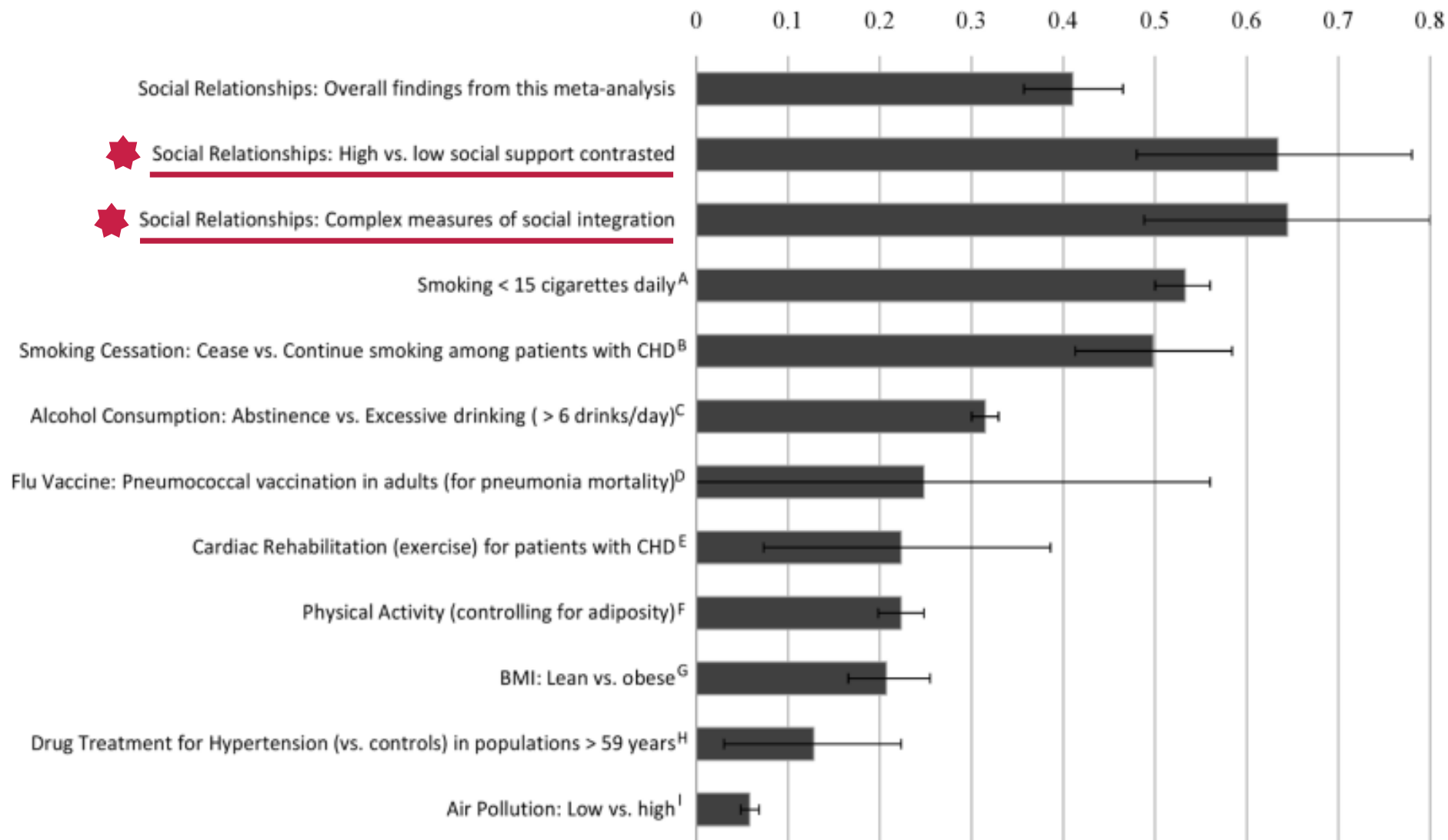
## Social Connectedness impact cannot be overlooked: Health Determinant

People who are more socially connected are happier, physically healthier, live longer.  
People who are socially isolated are less happy, health declines earlier in midlife, brain functions declines sooner and live shorter lives.

(Waldinger, 2015)

# Comparative impact of social relationships on reduction in mortality

*Holt-Lunstad J, Smith TB, Layton JB (2010)*





# Benefits of a compassionate community

- People with a life limiting/chronic illness and their carers are supported.
- Increased equity of services.
- Community members have a sense of purpose in supporting their community members.
- People learn how to care for one another at end of life and can share this with others.
- Financial savings can be realised through reductions in hospital admissions and emergency presentations.



# Research

Julian Abel, Helen Kingston, Andrew Scally, Jenny Hartnoll, Gareth Hannam, Alexandra Thomson-Moore and Allan Kellehear

## Reducing emergency hospital admissions:

a population health complex intervention of an enhanced model of primary care and compassionate communities

### Abstract

#### Background

Reducing emergency admissions to hospital has been a cornerstone of healthcare policy.

### INTRODUCTION

Reducing emergency admissions to hospital has been a cornerstone of healthcare policy in an attempt to shift care from the most expensive part of the healthcare system, secondary and tertiary care, into

and social prescribing. The House of Care model has played a central role in developing care planning.<sup>6,7</sup> Care planning alone has a limited impact on improving outcomes.<sup>8,9</sup> Community-centred approaches have generated significant recent interest, with



SOUTH WEST  
Compassionate  
Communities  
NETWORK

*Every person, every family and every community knows what to do when someone is caring, dying or grieving.*

# Groundbreaker communities located around Australia





# Compassionate Community Connectors

Partnership between the community and health service  
in Western Australia



# The Compassionate Communities Connectors Model For End-of-life Care:

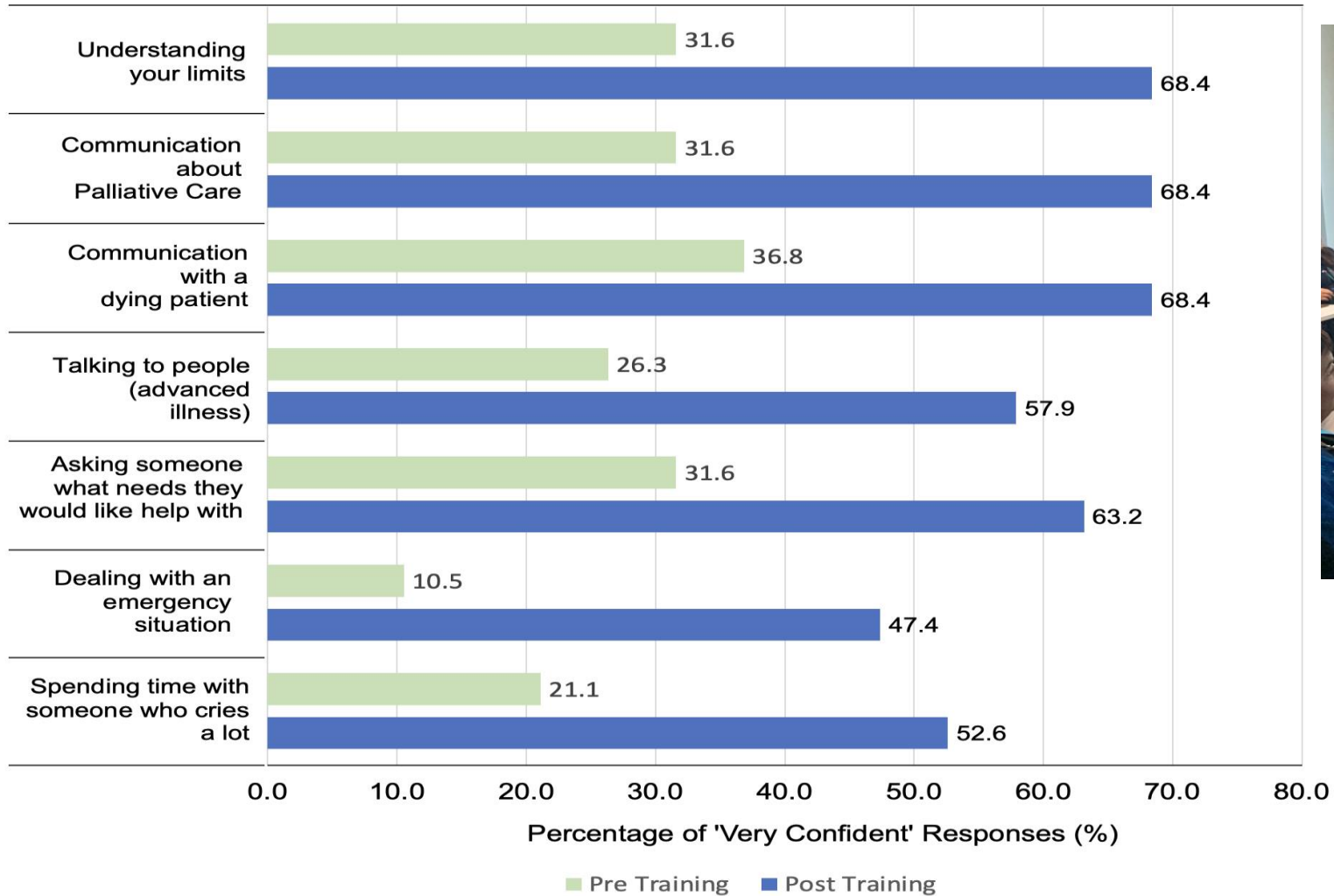
## Objectives

- To develop, implement and evaluate a model of community volunteers to support people living with advanced life limiting illness / palliative care needs.
- To develop and evaluate a training program.
- To assess the feasibility, acceptability and preliminary effectiveness of this community model of care.

# CONNECTOR Training Program And Manual

- Understanding the public health palliative care approach and Compassionate Communities.
- Understanding advanced illness and the role and capacity of the Chronic Disease and Palliative Care Teams.
- Death literacy, Advance Care Planning, Grief Literacy
- Communication skills and confidentiality
- Self-care, boundaries and endings
- Research protocol, process and evaluation tools
- WA Country Health Service Volunteer program rules and regulations

# Feedback of connectors on training program (P<0.05 - P<0.001)





# The Compassionate Communities Connector Program

## Patients and family carers

People with a  
chronic or life  
limiting illness

## Connectors

trained  
members of the  
community

## Caring Helpers

caring  
community  
members willing  
to help

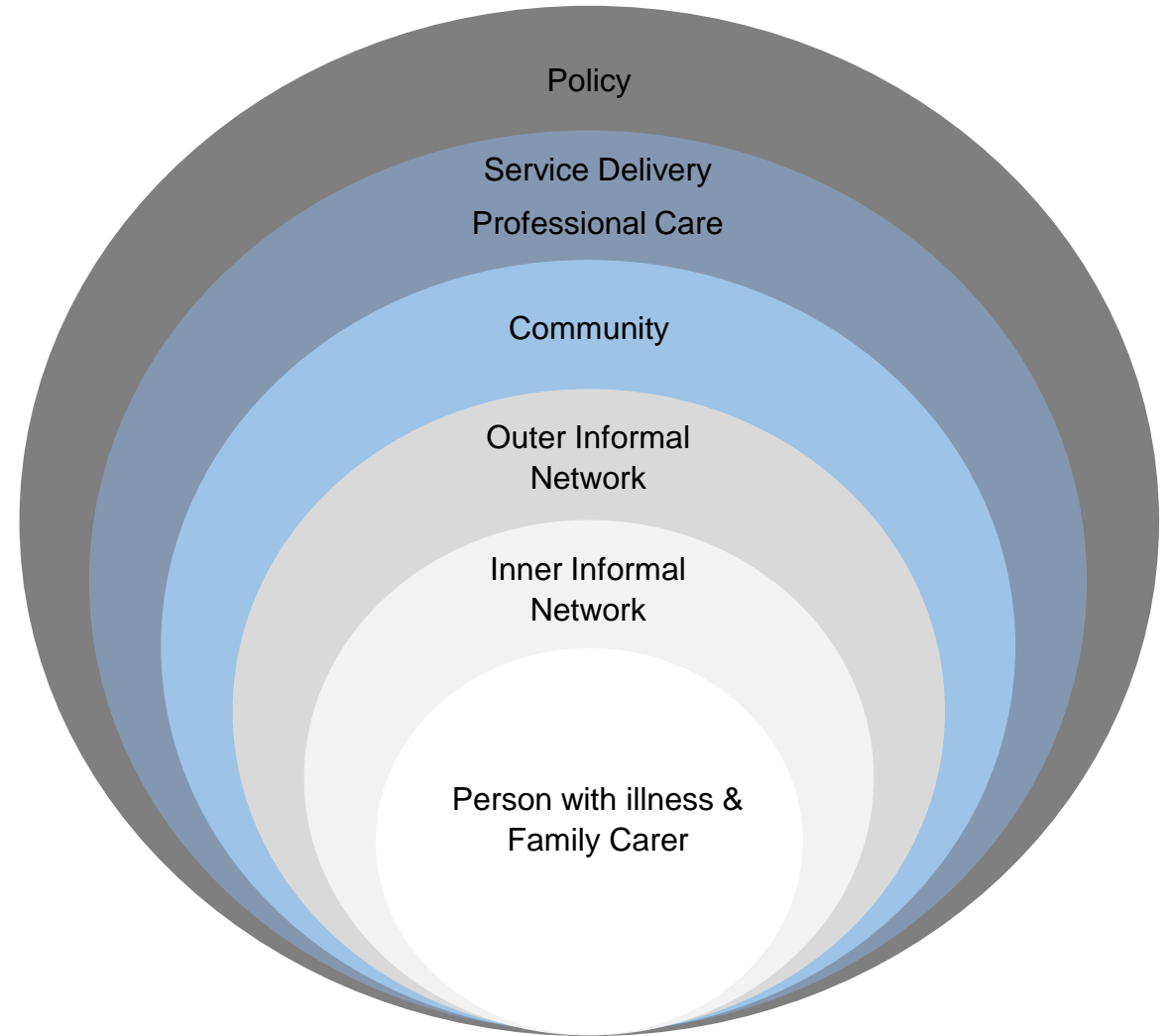
# Connectors undertake network mapping



Who is your network?  
How will they respond?

# Role of connector: *Enhance networks within circles of care*

Connectors provide assistance to the person affected by advanced illness and their family by identifying the additional social and practical support they may require from within their local community and tap into formal and informal sources.





# Role of caring helpers

Caring Helpers can be members of the family, friends, neighbours or other people in the community who are willing and able to assist with activities such as:

*walking the dog, doing the shopping, collecting a prescription, going to the library, mowing the lawn, making a snack, tidying up or sitting with a person who needs a break.*

# Network of Support

		Network of Support		
		Low	Medium	High
Level of Unmet Need	Low	Review for Suitability	Monitor by Health Service	Monitor by Health Service
	Medium	Refer to Connectors Program	Review for Suitability	Monitor by Health Service
	High	Refer to Connectors Program	Refer to Connectors Program	Review for Suitability

# Who is helping?

# Who can you ask for help?



# Connectors

- 20 Connectors did the training since July 2020
- 13 Connectors participated (12 female, 1 male)
- Median age of connectors: 62.5 years (28-74)
- Follow up of families for median 18 weeks (3-52 weeks).
- Average number of families per connector 3 (1-9 families).
- Connectors: Total 1055 contacts with families and caring helpers and 402 hours (quite an underestimate).



*Community volunteers  
are trained to diagnose  
suffering not diseases  
(Sallnow & Kumar 2010)*



# Patients- Data collection July 2020- April 2022



**85 families referred** from Palliative Care and Chronic Disease teams  
**43 families participated** (43 patients & 15 carers)



47% were home alone



Median age of patients 74 years (34-90)



44% were male

## Diagnosis



# Bunbury region has Australia's highest percentage of single person households

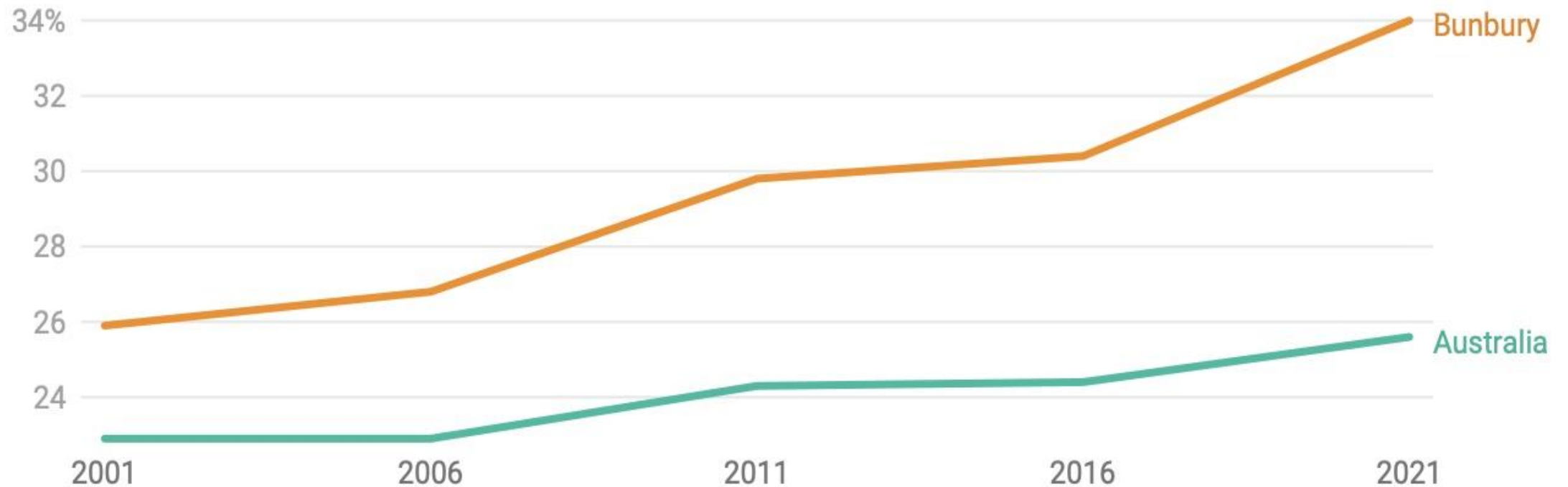
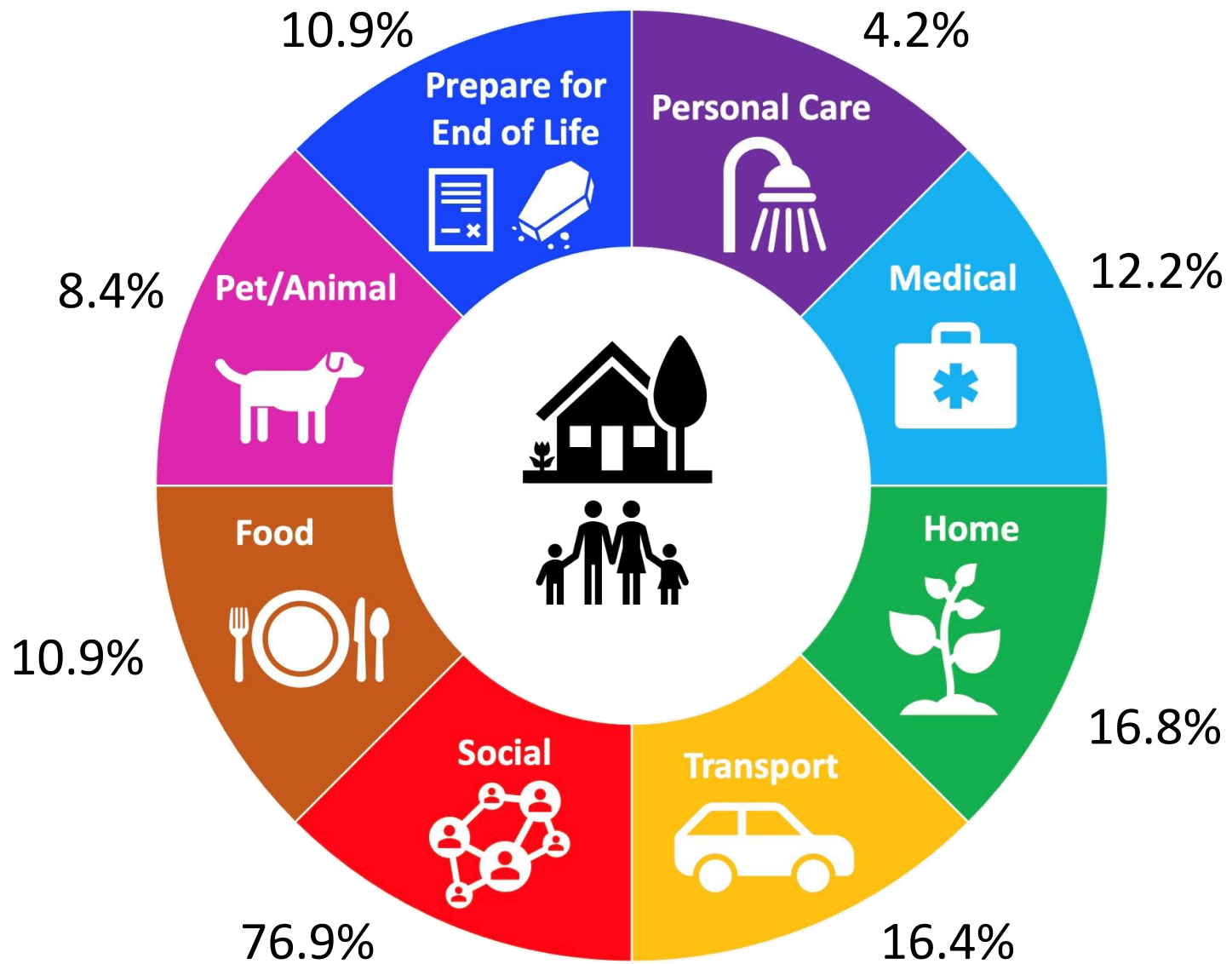


Chart: ABC South West • Source: ABS

# Type and frequency of support



# Connectors have helped or sourced help with:

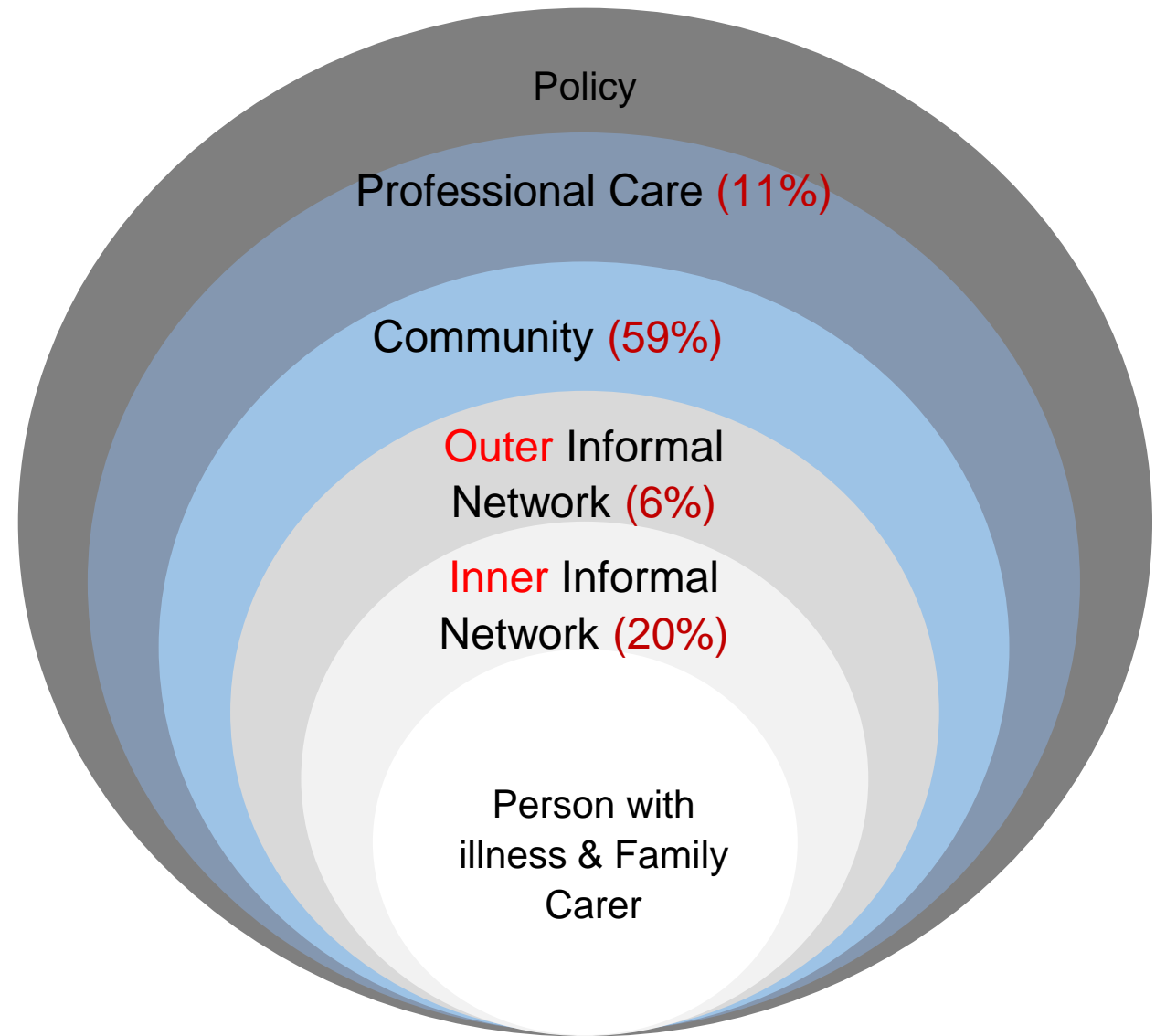
- Professionals to home visit for Wills, Advance Health Directives etc.
- My Aged Care application/ prompting to establish or increase services.
- Service provider liaison
- ACROD (Disability) application for parking permit.
- Equipment access.
- Meal Delivery/ organising meal train.
- House cleaning
- joining community groups - old time dancing, crafts, walking groups, men's shed.
- Surrogate grannies for family with kids
- Transport- medical appointments or social occasions.
- Gardening/Fire Wood Delivery.
- Social visits.
- Empowerment and ownership, "you can do this".



# Type of caring helpers who supported the patients

Category of Caring Helpers	Number of Helpers	% Helpers
Family	13	8%
Neighbour	10	6%
community service group	28	18%
Health care providers-formal services	7	4%
Paid services (dog walker, mobile hairdresser, legal service...)	11	7%
individual community member	39	25%
Friend	18	12%
connector helping	25	16%
Not specified	6	4%
<b>Total</b>	<b>157</b>	<b>100%</b>

Naturally Occurring  
Networks (26%)  
VS  
Facilitated Networks  
(59%)



# Social Connectedness (m-MOSS\*)

Practical/tangible Support	Social/emotional Support
Someone to help you if you are confined to bed	Someone to have a good time with
Someone to take you to the doctor if you need it	Someone to turn to for suggestions about how to deal with a personal problem
Someone to prepare your meals if you are unable to do it yourself	Someone who understands your problems
Someone to help you with daily chores if you were sick	Someone to love and make you feel wanted

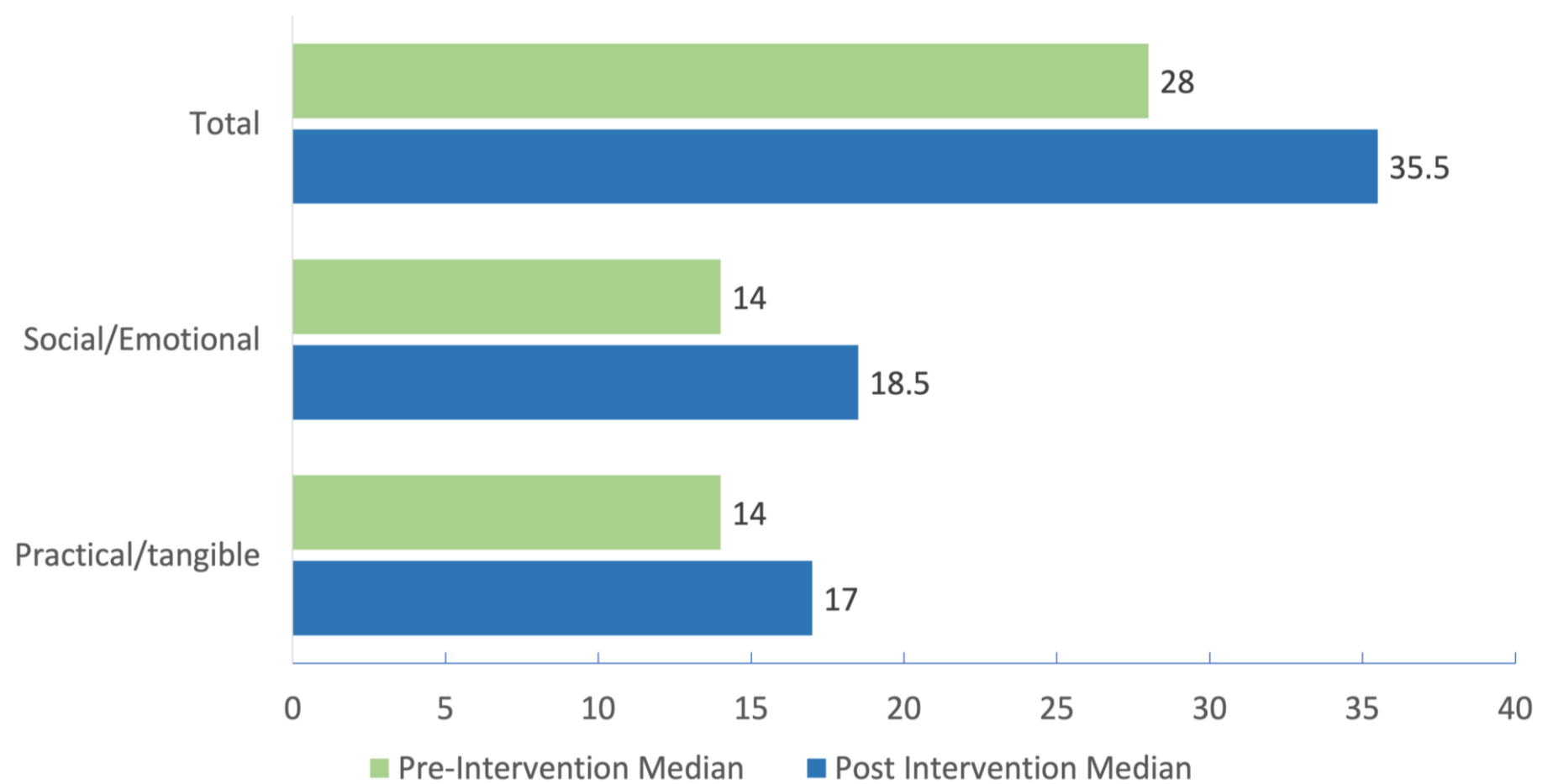
\*modified Medical Outcomes Study Social Support Survey (Moser et al, 2012)

# Primary Outcome:

## Increase in Social Connectedness

$P < 0.001$

Medical Outcomes Study Social Support Survey (m-MOSS\*)



### Median Difference (95 % CI)

- Total: 5.0 (4.1 – 9.9)
- Social/emotional: 3.0 (1.1 – 5.0)
- Practical/tangible: 2.4 (1.9 - 4.9)



# Assessment of practical/social needs and support networks

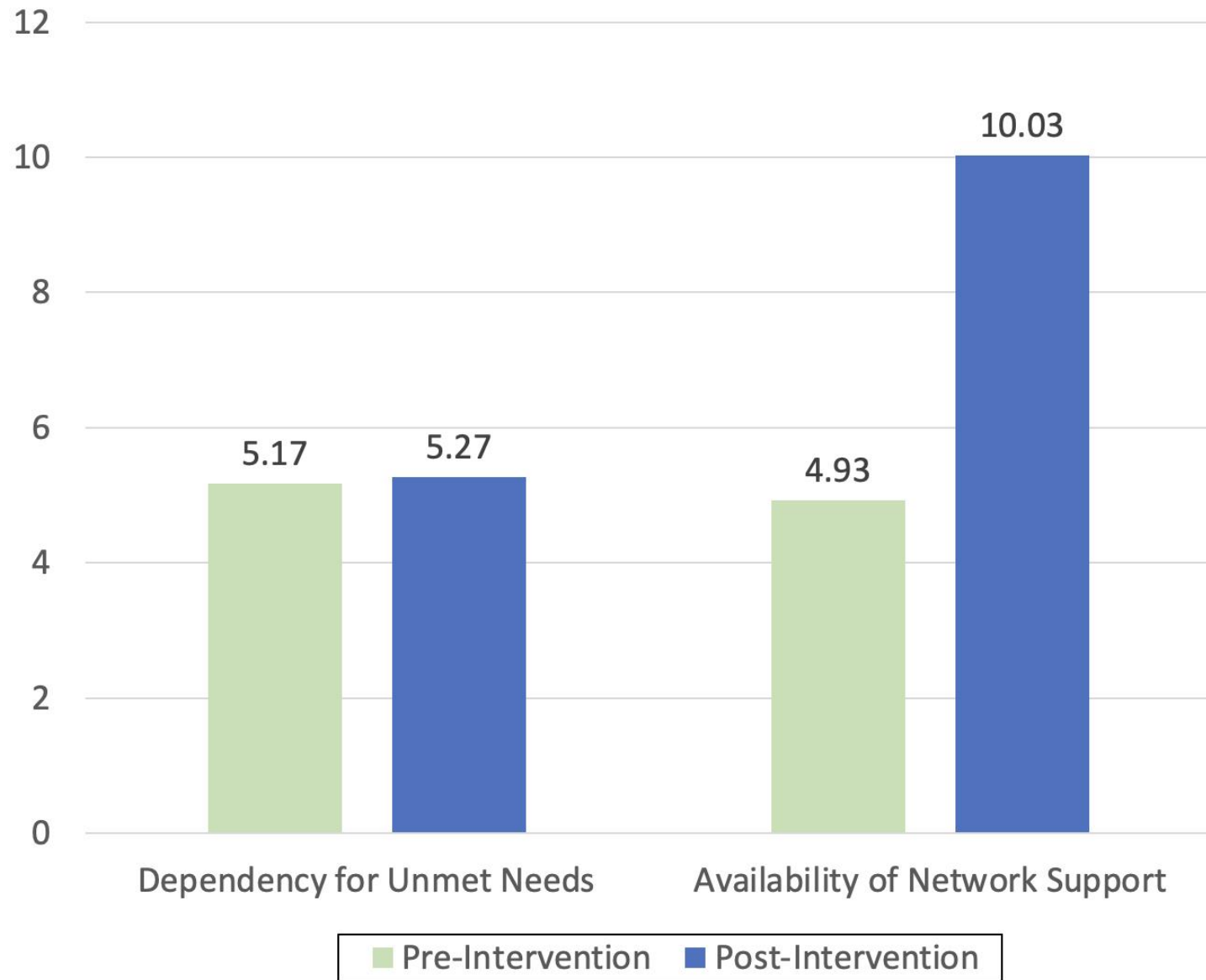
Scale	Dependency to meet their needs	Availability of support networks
2	Able to complete tasks independently	Members of the person's network provide regular help
1	Requires some help to complete tasks	Members of the person's network provides ad hoc help or less than desired by person
0	Requires another person to complete all tasks on their behalf	Person has no-one to help them in their network

Secondary  
outcome:

Dependency for  
unmet needs and  
availability of  
support networks

Supportive  
networks  
improved by two-  
folds

$P < 0.001$

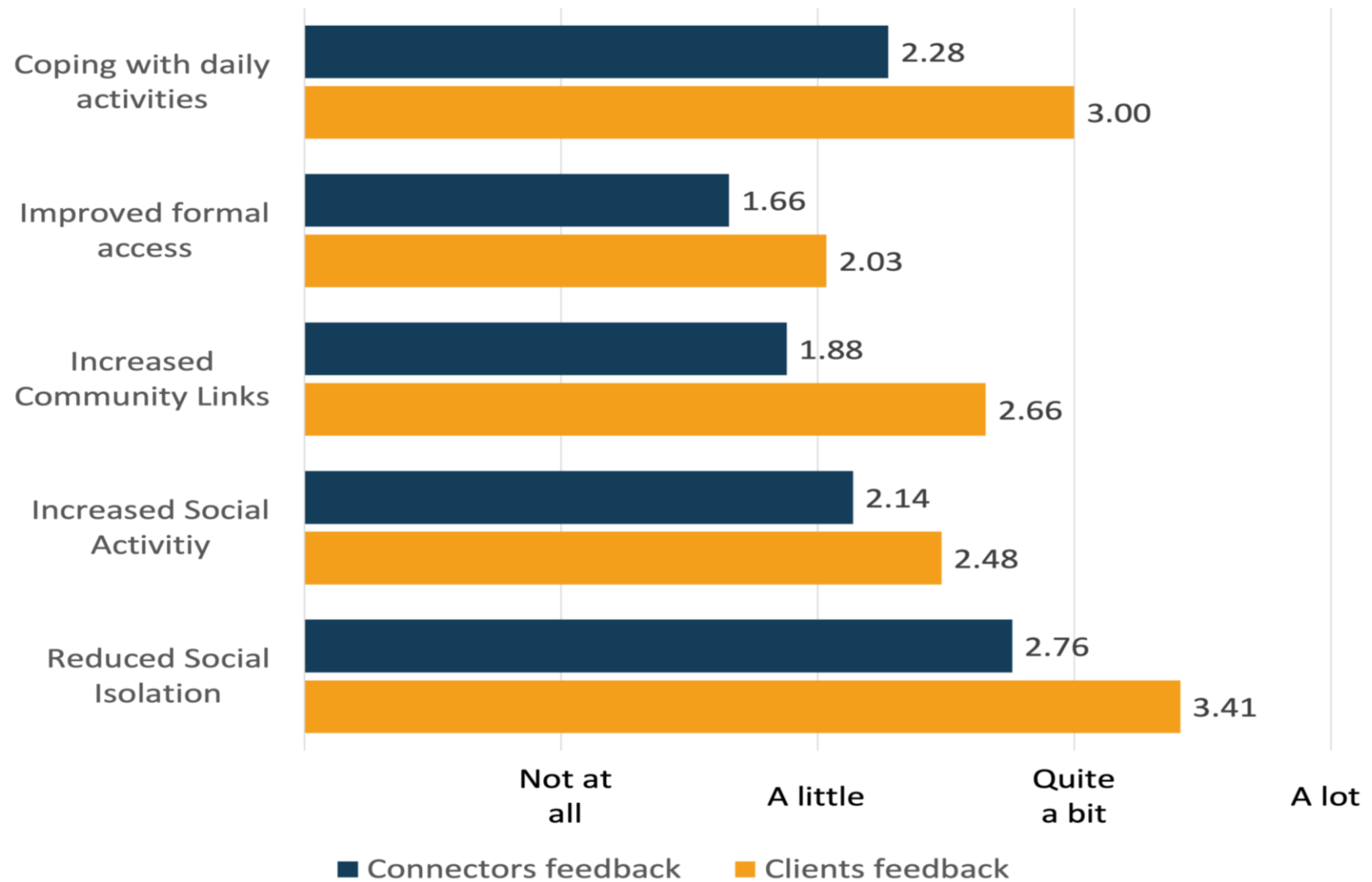


Secondary outcome:

Self-reported impact on social wellbeing

(scale: 1=not at all to 4=a lot)

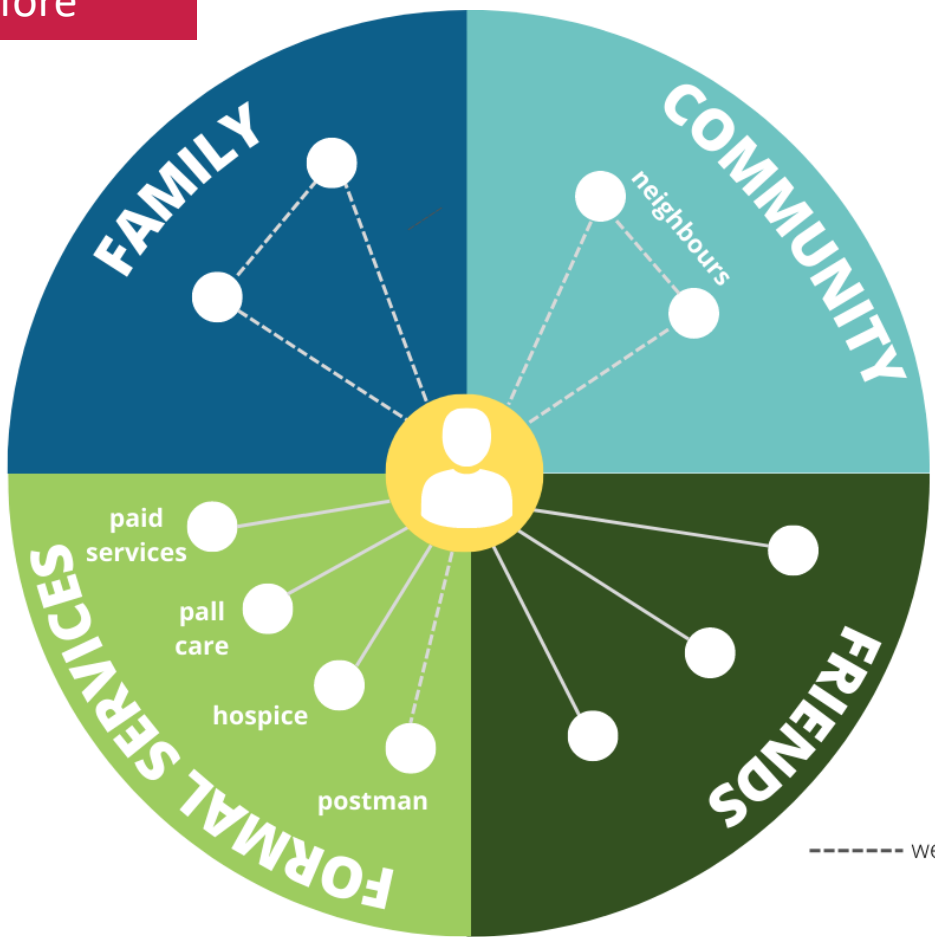
highest impact on reduced social isolation



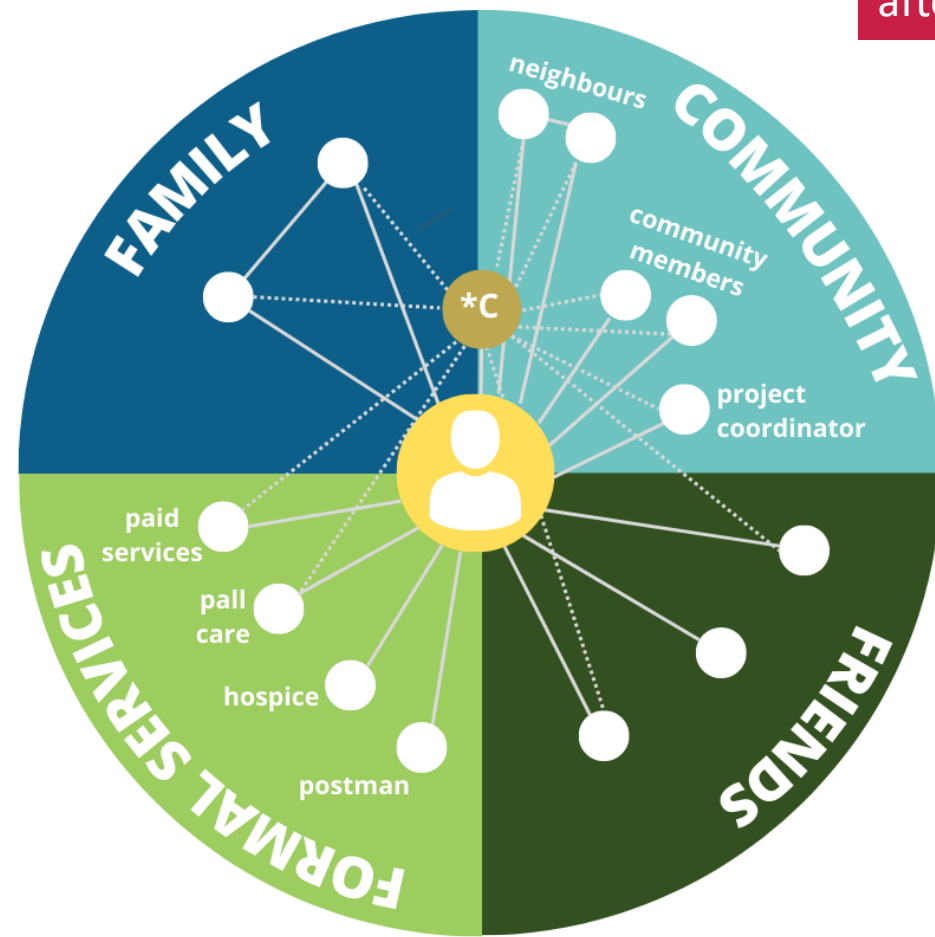
# Social Network Mapping for one family before and after the intervention

before

after



----- weak connection



\*C= connector

# Interviews

Total of 74 interviews were undertaken:

- 28 interviews with families
- 27 interviews with 11 connectors (covering 37 patients/carers)
- 19 interviews with 8 health professionals (covering 20 patients)



# Patient and carer feedback

*“ Always keeps her promises. A lot of paid carers really don't care, just filling in the hours – she goes above and beyond and seems to care ”*

*“ She knew when we were a bit overwhelmed; knew when to get involved and when to step back ”*

**Pretty  
Amazing**

*“ Necessary for people who don't have strong, existing networks . . . For people who are isolated it will help 'open up their world' ”*

*“ I can ask her anything, no matter what I talk to her about she always has a sensible answer ”*

# Key themes in feedback from healthcare providers

- Reducing social isolation – life changing for some patients
- More layers of support – filling a gap in service provision
- Another string to the bow – building the capacity of the service

# Home card making



I love it  
when  
Annette  
comes, she  
is my legs



*DM spoke of a 'blackness' that would flood over him and loom for days like a heavy rain cloud. That blackness has gone!*



# Health care team feedback

*“Really positive, especially for clients who are early in their journey and for those who are isolated/ don't have good family support ”*

*“I will be encouraging more people to make use of informal networks and support ”*

**Easy to implement**

*“She is very socially isolated and our professional service is not enough to meet her social needs so I am very happy for her that she has a consistent person to talk to ”*

*“Added another string to our bow, especially in small rural areas where there is a lack of formal services ”*

# Key themes in feedback from healthcare providers

- Reducing social isolation – lifechanging for some patients
- More layers of support – filling a gap in service provision
- Another string to the bow – building the capacity of the service

# Connector feedback

*“ Great to be given someone specifically to help fill their needs and tick their boxes ”*

*“ So rewarding to watch their quality of life improve ”*

***Fabulous program***

*“ Being able to connect to those in need has brought very obvious benefits to both the volunteers and the receivers ”*

*“ The more you give, the better the reward; the reward is greater than the effort ”*

# Key themes in Connectors' experience

- Mutual benefits from connection and reciprocity
- It is OK to ask for and receive help
- Sense of community as being part of a village
- Making a difference in social connectedness
- Frustrations when not achieving everything you want to
- Reflecting on the difference with traditional volunteering

# Key Outcomes-Effectiveness Analysis (Cook & Aoun, 2023)

- Significant decline in frequency of hospitalisations per month:  
(-0.509 events/month; 95%CI: -0.752,-0.266)
- Significant decline in number of hospital days per month  
(-0.475; 95%CI: -0.615,-0.335)
- Increased use of outpatient services (+1.180; 95%CI: 0.957, 1.402)

Net savings of the Connector program was on average \$AUD 561,256 over a six-month period.



# What is so distinct about this form of volunteering?


- Exercise more **autonomy** and have more **agency** in providing care.
- Sustainable **social capital** emerging from **genuine social encounters**.
- **Fresh** ways of engaging with the community.

*“It’s not a ‘walk in the park’ like other voluntary positions I’ve had; a whole different level of commitment. But I would do it again, highly recommend it”*

*“It’s a lovely way to do volunteer work. If you really enjoy being with people and talking to people.....you end up, I don’t know being part of their lives. It’s really fulfilling in that respect”*



# Compassionate community connectors: a distinct form of end-of-life volunteering

Kerrie Noonan <sup>1,2</sup>, Bruce Rumbold <sup>3</sup>, Samar M. Aoun <sup>1,3,4</sup>

<sup>1</sup>Perron Institute for Neurological and Translational Science, Nedlands, Australia, <sup>2</sup>School of Social Sciences, Western Sydney University, Kingswood, Australia, <sup>3</sup>Public Health Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, Australia, <sup>4</sup>University of Western Australia, Western Australia, Australia

Public health approaches to palliative care have long promoted the contribution of volunteering to providing effective end-of-life care in neighbourhoods and communities. For this is a 'compassionate communities' approach that focuses on building care community members' capacities in end-of-life care. There is anecdotal evidence of motivations and life experiences of traditional palliative care volunteers and volunteer community programs. There is however very little research into volunteers' and communities' orientated role. This study describes the motivations, experiences of volunteers participating in a program called compassionate connectors in which volunteers with a variety of caregiving experiences participated in the pilot study. Expression of interest for recruitment. Analysis indicated that the compassionate connectors attracted experienced community volunteers who were already familiar with care



*Palliative Care & Social Practice*

*Original Research*

## The Compassionate Communities Connectors model for end-of-life care: implementation and evaluation

Samar M. Aoun , Robyn Richmond, Kerry Gunton, Kerrie Noonan , Julian Abel and Bruce Rumbold

### **Abstract**

**Objectives:** This pilot project aimed to develop, implement and evaluate a model of care delivered by community volunteers, called Compassionate Communities Connectors. The Connectors' principal task was to support people living with advanced life-limiting illnesses or palliative care needs by enhancing their supportive networks with Caring Helpers enlisted from the local community.

**Methods:** The project was undertaken in Western Australia, 2020–2022. A mixed methods research design incorporated a prospective cohort longitudinal design with two cross-sectional measurements, pre- and post-intervention. The primary outcome was the effect of the intervention on social connectedness. Secondary outcomes were the effect of the

*Palliative Care & Social Practice*

2022, Vol. 16: 1–18

DOI: 10.1177/  
26323524221139655

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Correspondence to:  
Samar M. Aoun  
The University of Western

# The Compassionate Communities Connectors programme: experiences of supported families and referring healthcare providers

Samar M Aoun , John Rosenberg, Robyn Richmond and Bruce Rumbold

## Abstract

**Background and Aim:** Comprehensive evaluations that include the experiences of patients and service providers are vital if interventions are to be translated into practice. Formal networks of health services and allow formal networks to work as partners with informal networks. However, published evaluations are limited in the palliative care literature. The objective of the study is to explore the experiences and views of patients and their family carers who received support and their referring health professionals concerning their participation in the Compassionate Communities Connectors programme in the south-west region of Western Australia. Connectors identified an opportunity to improve community and healthcare provision by accessing resources and mobilising community members to support patients and their families.


*Palliative Care & Social Practice*

2023, Vol. 17: 1–12

DOI: 10.1177/  
26323524231173705

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# ‘The more you give, the better it is for you. You know the reward is greater than the effort’: the Compassionate Communities Connectors’ experience

Samar M Aoun , Robyn Richmond, Kerrie Noonan, Kerry Gunton and Bruce Rumbold

## Abstract

**Background:** The Compassionate Communities Connectors programme is a volunteer-led initiative designed to enhance the social networks of families living with chronic or life-limiting illnesses. Specially trained volunteers supported existing members of the families’ social networks and also enlisted the support of community members, Caring Helpers, to address the social and practical needs of these families. The programme is an initiative of The South West Compassionate Communities Network in Western Australia, in partnership with the health service.

**Objective:** To explore the experiences and views of Connectors implementing this model of

*Palliative Care & Social Practice*

2022, Vol. 16: 1–11

DOI: 10.1177/  
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**Finalist:** Outstanding regional/rural team delivering holistic palliative care and/or a compassionate community approach in any setting



# Translation in Progress

WACHS integrating program as standard practice

Local government engagement-  
Compassionate  
Bunbury Charter



Rolling it out to other communities throughout Western Australia

Engagement with Primary Care

*To guide and encourage the Bunbury community, including individual consumers, service providers, businesses, community groups and clubs to work together to create a more compassionate Bunbury that is resilient, responsive and understands the need for community support to get through difficult times.*



# Compassionate Bunbury Charter



# Sustainability of the Compassionate Charter

- It will be used by the community to bring values to life and death.
- Conduit to inform sustainable skills, policies, structures and resources to support members of the community in caring for each other.
- It will inform future strategic community plans and empower the compassionate communities' values to be embedded in such plans.
  - Services, facilities and programs will support quality of life of people who are experiencing hardship, illness, death and bereavement.

State wide review  
from consumers'  
perspective-

**Pressure points**  
**in palliative care**

*Aoun et al, 2020*



**Non-cancer  
Conditions**

**Health and Death  
Literacy of Consumers**

**Family Carer  
Support**

**Workforce Education  
and Training**

**Grief and Bereavement  
Support**

**Models of Integrated  
Care**



# Up to all of us to Connect the Dots

## Public Health Approach to Palliative and End of Life Care

(Aoun et al, 2020)

### ENABLERS

Digital and Assistive technologies:

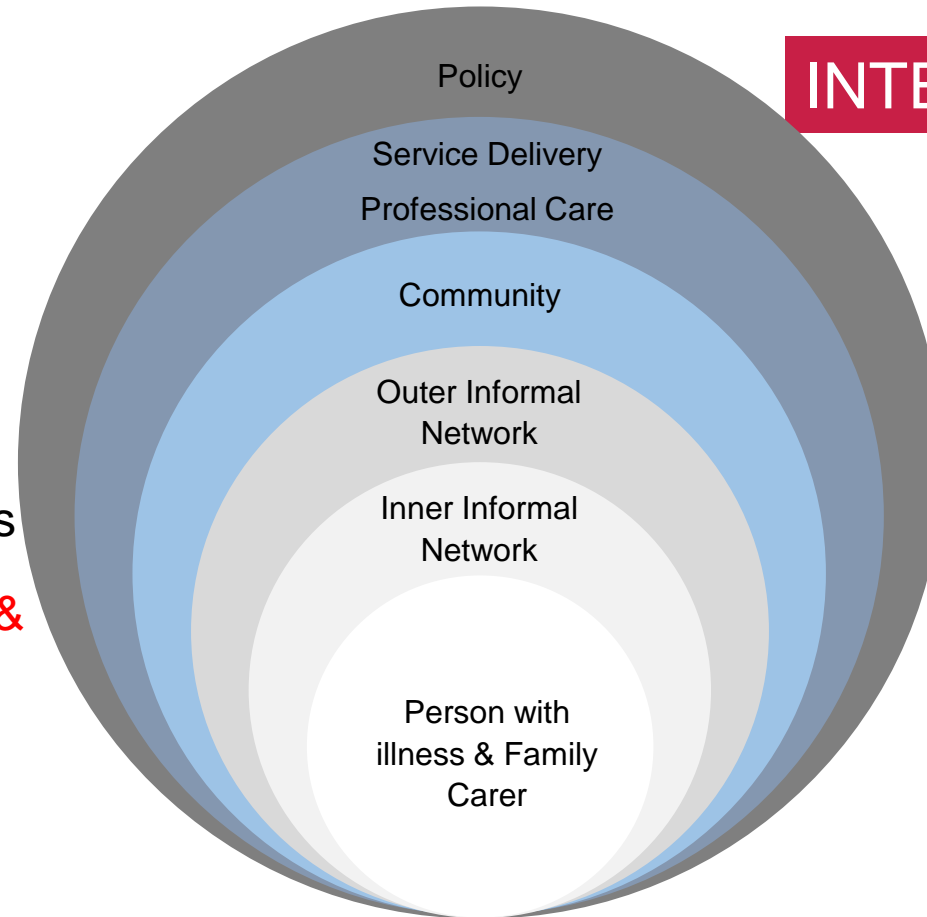
Telehealth, Equipment

Advance Care Planning

Education & Training Programs

Compassionate Communities & Social Network Enhancement

Not For Profit organisations & Other NGOs



### INTEGRATION OF SERVICES

Disability Sector, NDIS

Aged Care Sector

Specialist Palliative Care

Generalist Palliative Care

Disease specific clinics

Primary Care & Allied Health Care

### CIRCLES OF CARE

Give a Family  
a Fish



= Charitable Act

Teach a Family  
to Fish



= Sustainability

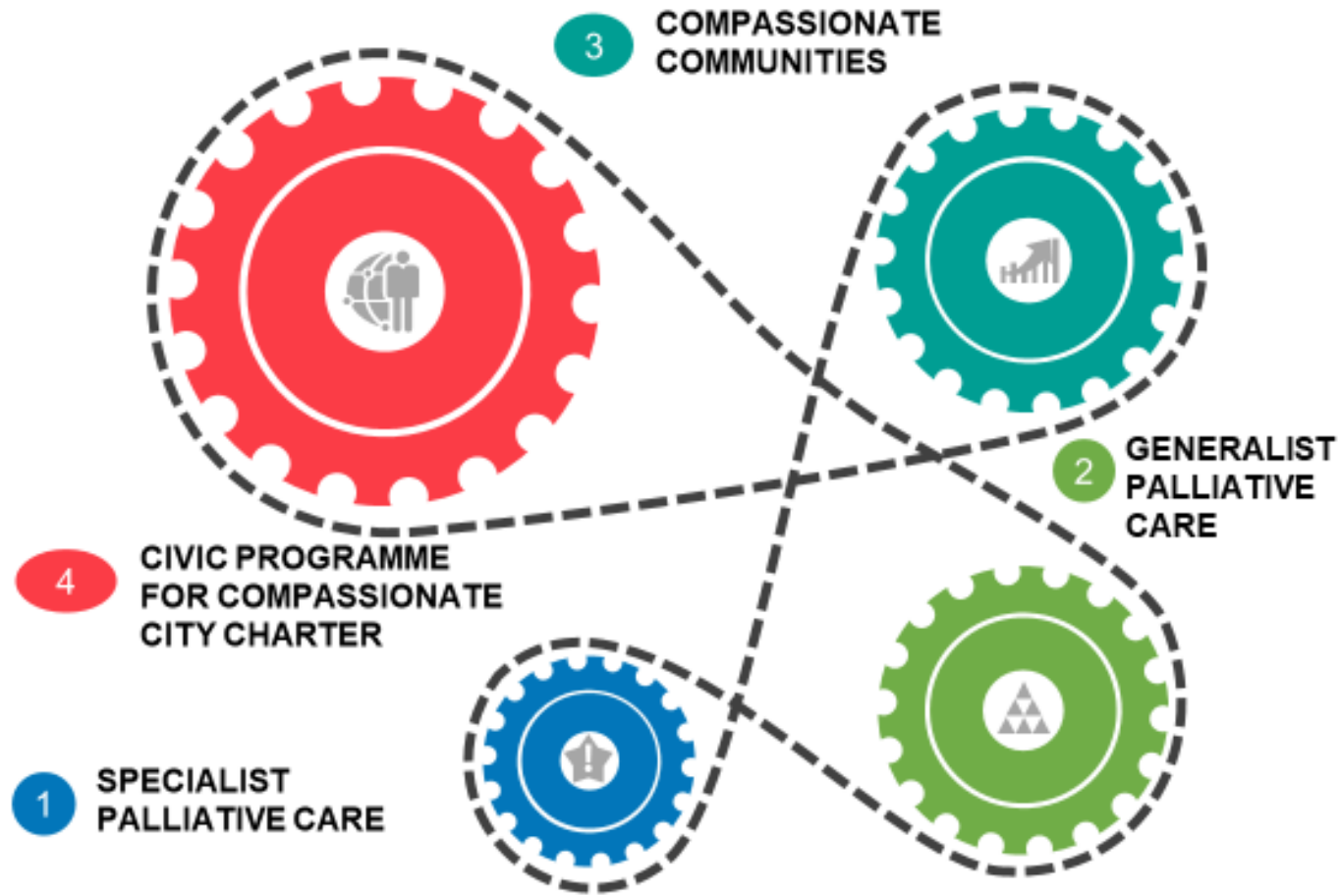
Organize a Community-  
Based, Intergenerational  
Fishing Collective



= Social Change

Artwork: Alyce  
Dedge

# Palliative Care – The New Essentials



# Maintaining social change includes:

- Ensuring that each setting has processes that connect informal care networks, community care programs, primary care, and specialist palliative care in collaborative, not controlling, ways.
- Supporting Connectors to be network enhancers and to resist being recruited to helper roles.
- Reminding health services they are partners in the program, not owners of the program.
- Understanding that the dots are connected by policies and collaborative partnerships, not a centralized bureaucratic structure.

# Acknowledgements



THE UNIVERSITY OF  
**WESTERN  
AUSTRALIA**



Government of **Western Australia**  
**WA Country Health Service**

Q & A

# Upcoming Conference: Bern Switzerland



**BUILDING BRIDGES**  
8th PUBLIC HEALTH PALLIATIVE CARE  
INTERNATIONAL CONFERENCE  
BERN, SWITZERLAND

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QR code

**SAVE THE DATE**  
22 – 25 October 2024



**MORE INFORMATION**  
[www.phpci2024.org](http://www.phpci2024.org)



BY



# PHPCI Webinar – Examples of Community Connector Initiatives

**Next webinar** – examples of Community Connector initiatives

**When:** Aiming for June 2023

Do you know of an example we should explore? If so, let us know in the chat.



# Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat.

# Thank You



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