Compassionate Communities Connectors: Distinct Form of End-Of-Life Volunteering

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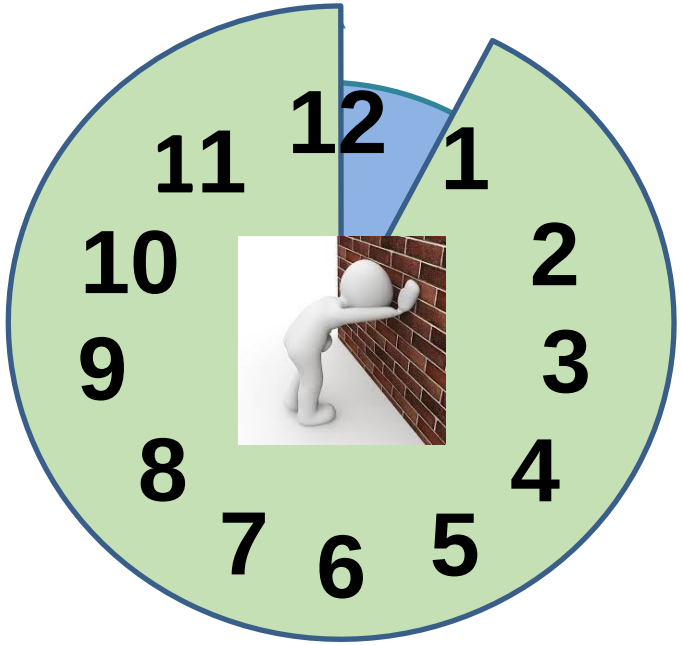
“Compassionate Communities” IS

- ✓ An aspiration and a practice
- ✓ Inclusive
- ✓ **Committed to system change**
- ✓ A key element of a public health palliative care approach- Community an equal partner

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 ´

Formal Care

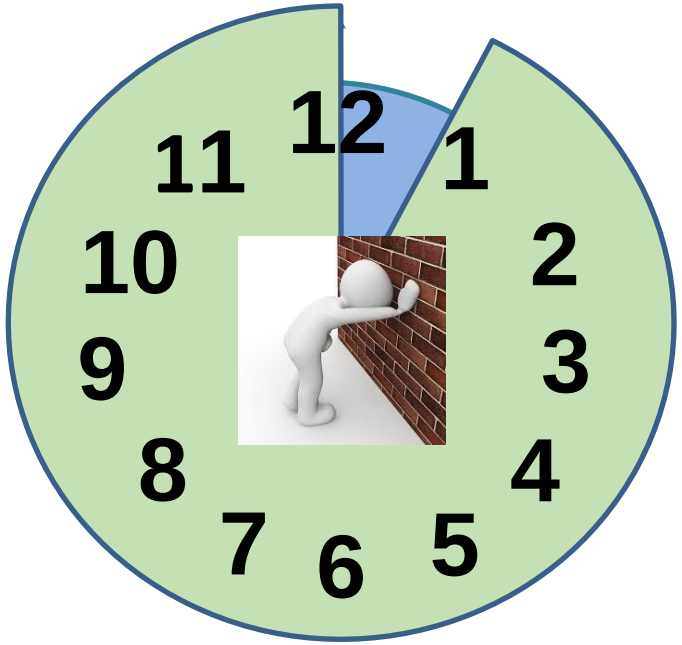
<5% of the Day

- ✓ 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



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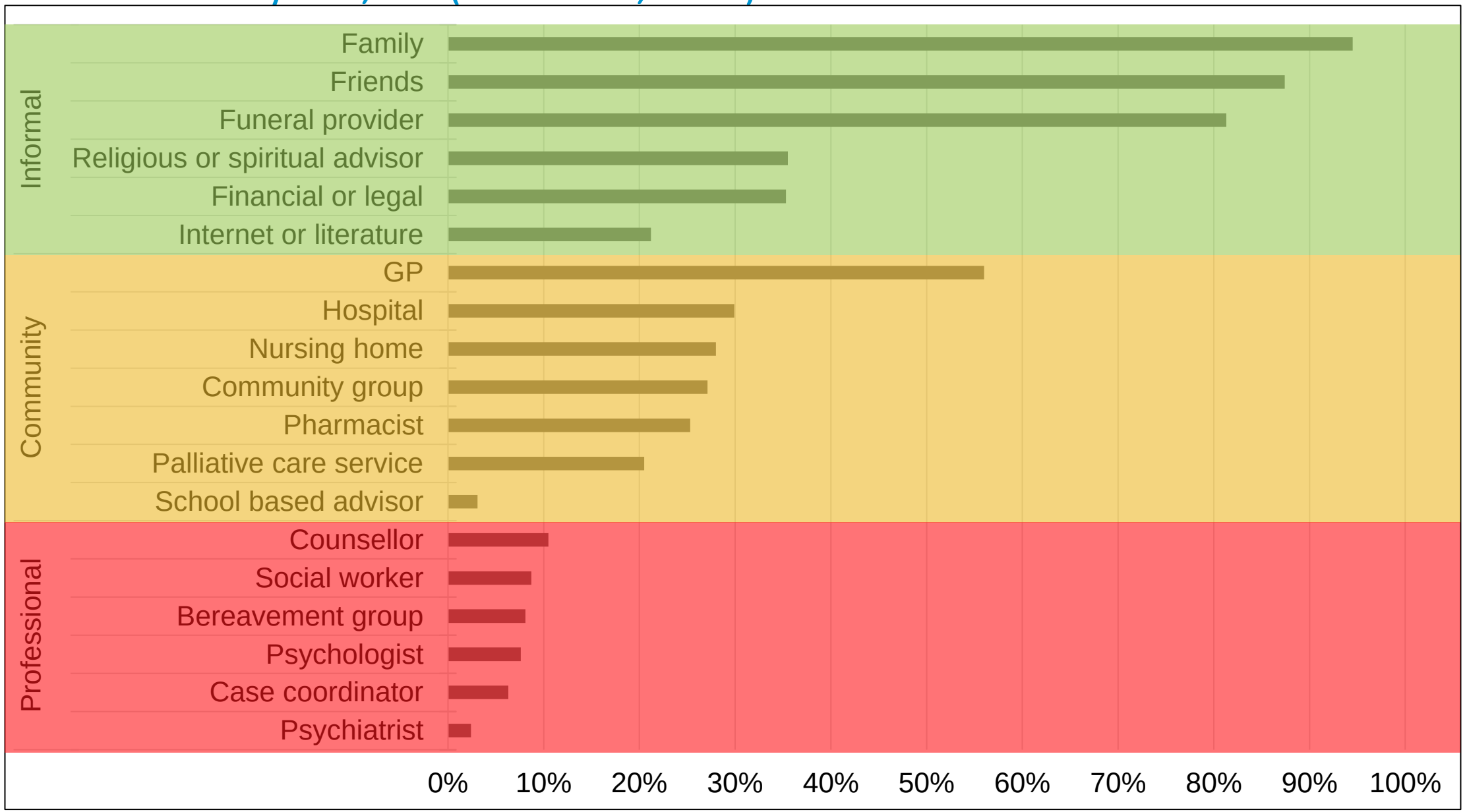
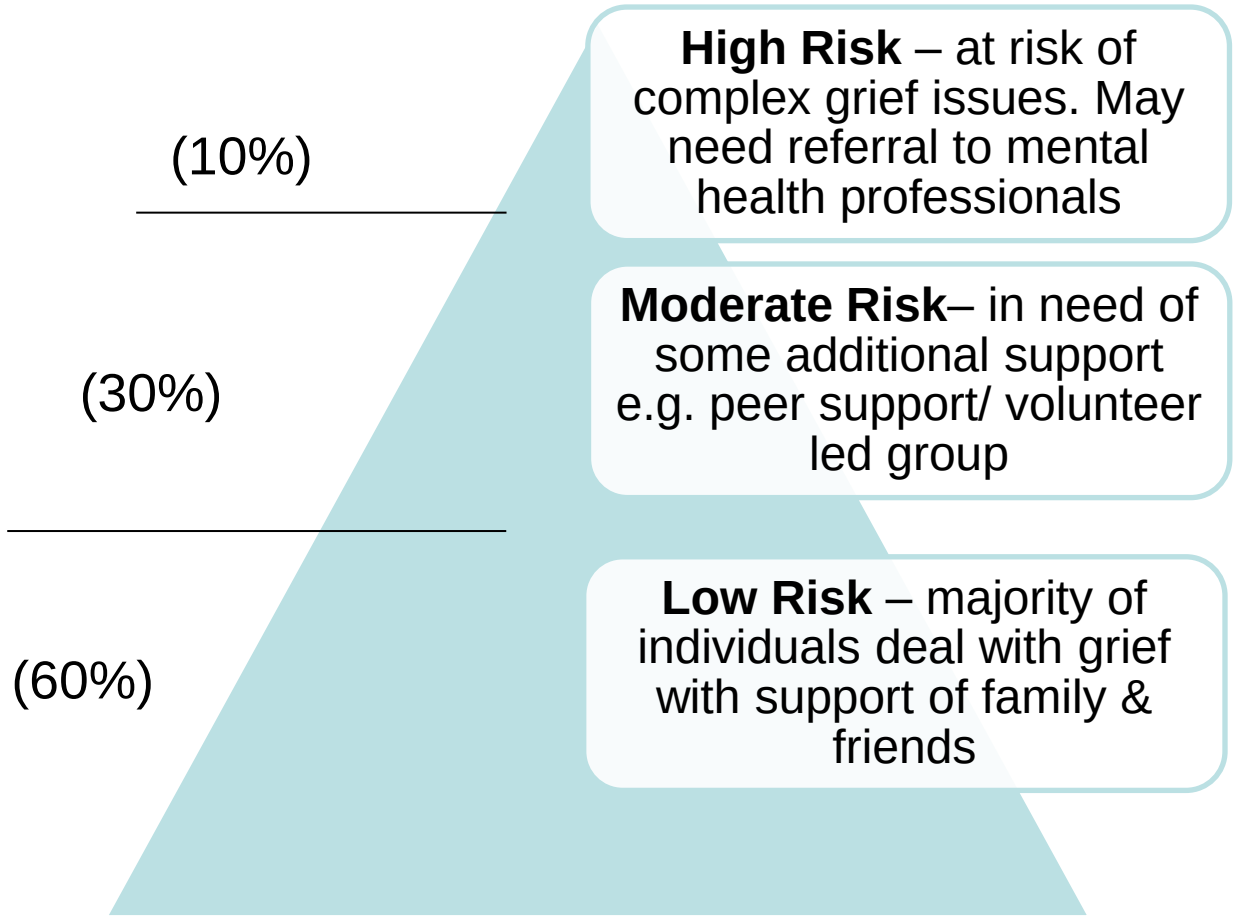
Where people get bereavement support

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

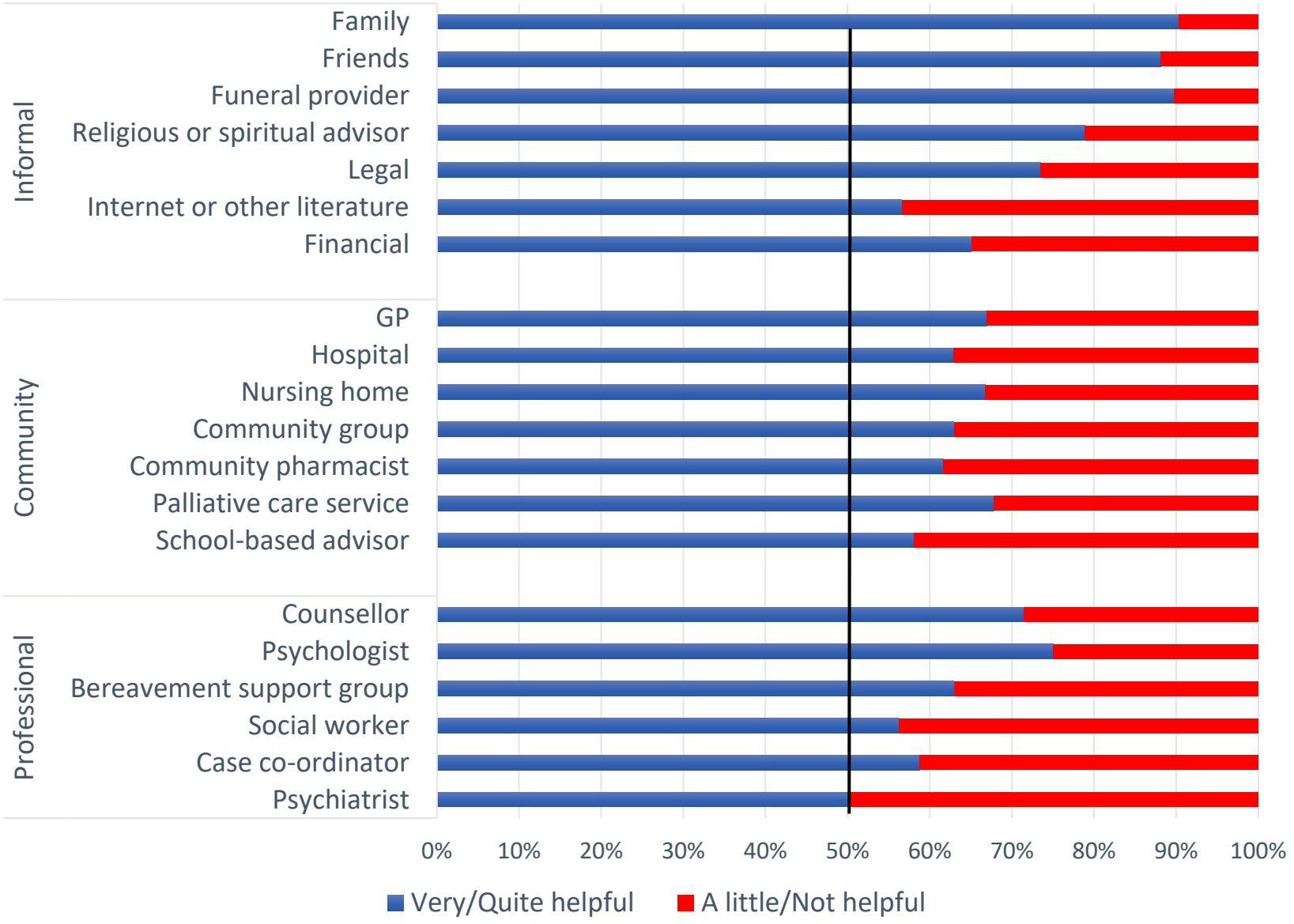


The Public Health Model of Bereavement Support (Aoun et al, 2015)



Sources of support perceived helpful or unhelpful

(Aoun et al, 2018)



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.

Sources: Swerissen H, Duckett, S. Dying Well, 2014.
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

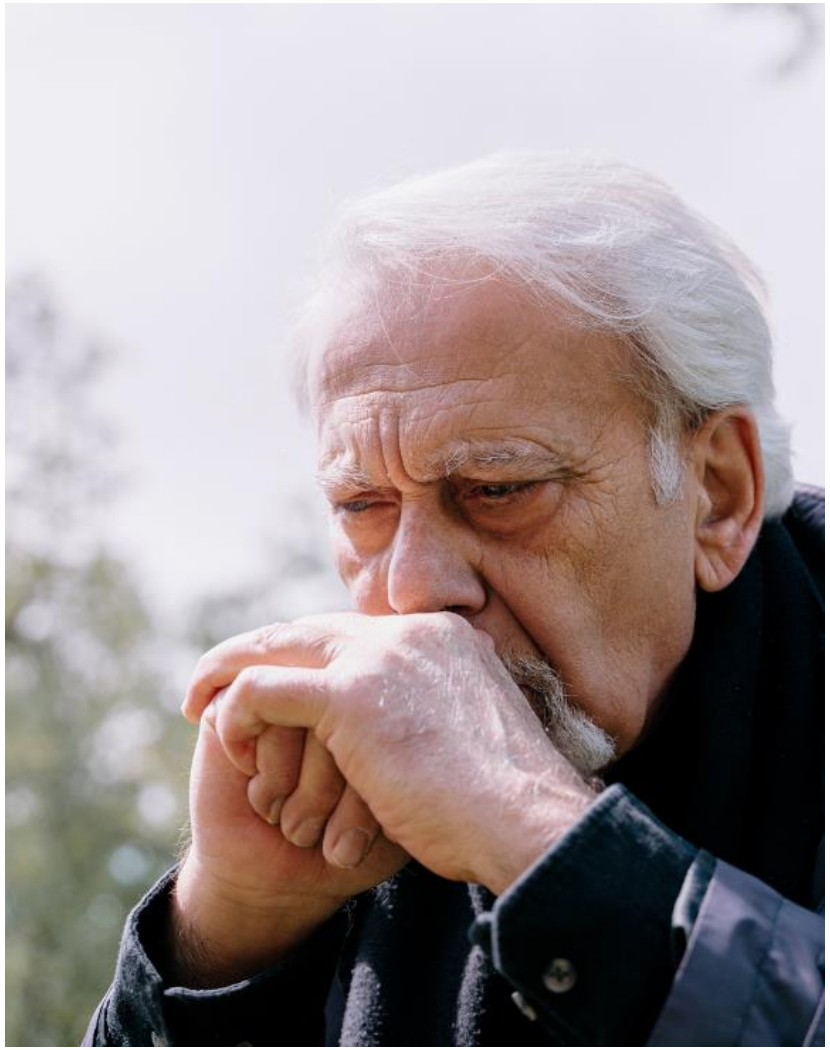
How are we doing in Australia (1)?

- Dying is increasingly becoming institutionalised (last 5 years) 23% increase in the number of palliative care-related hospitalisations compared to only 12% increase from all hospitalisations (AIHW, 2023).
- 65% of these palliative care hospitalisations ended with the patient dying in the hospital (AIHW, 2023).
- Modern death: cellular, curtained, individualised and obscured (Horsfall et al 2012).
- 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).

How are we doing in Australia (2)?

- 70-80% want to die at home but only 14-20% do.
- 75% of Australians have not had end of life discussions
- Less than 15% 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

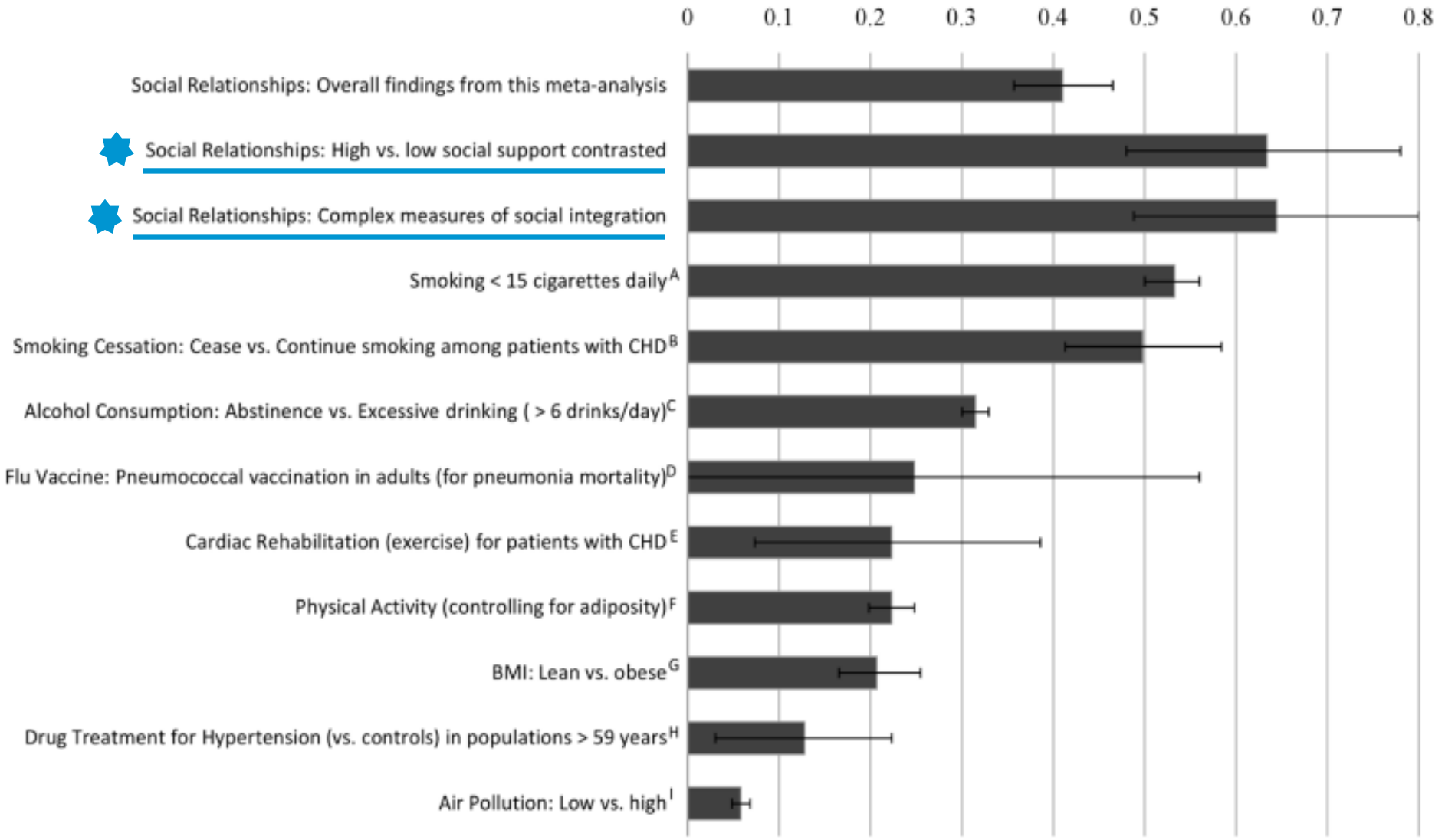
People who are more socially connected are happier, physically healthier, live longer.

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

- ✓ Building of resilient networks of support around families in need
- ✓ Skilling up of caring networks
- ✓ Increasing neighbourhood capacity to care for those who experience death, dying and loss
- ✓ Integrating and building of trusting relationships with health and social care teams
- ✓ Increasing equity of services.
- ✓ Financial savings can be realised through reductions in health service utilisation

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

Compassionate Community Connectors

Partnership between the community and health service in Western Australia

perron institute for neurological and translational science

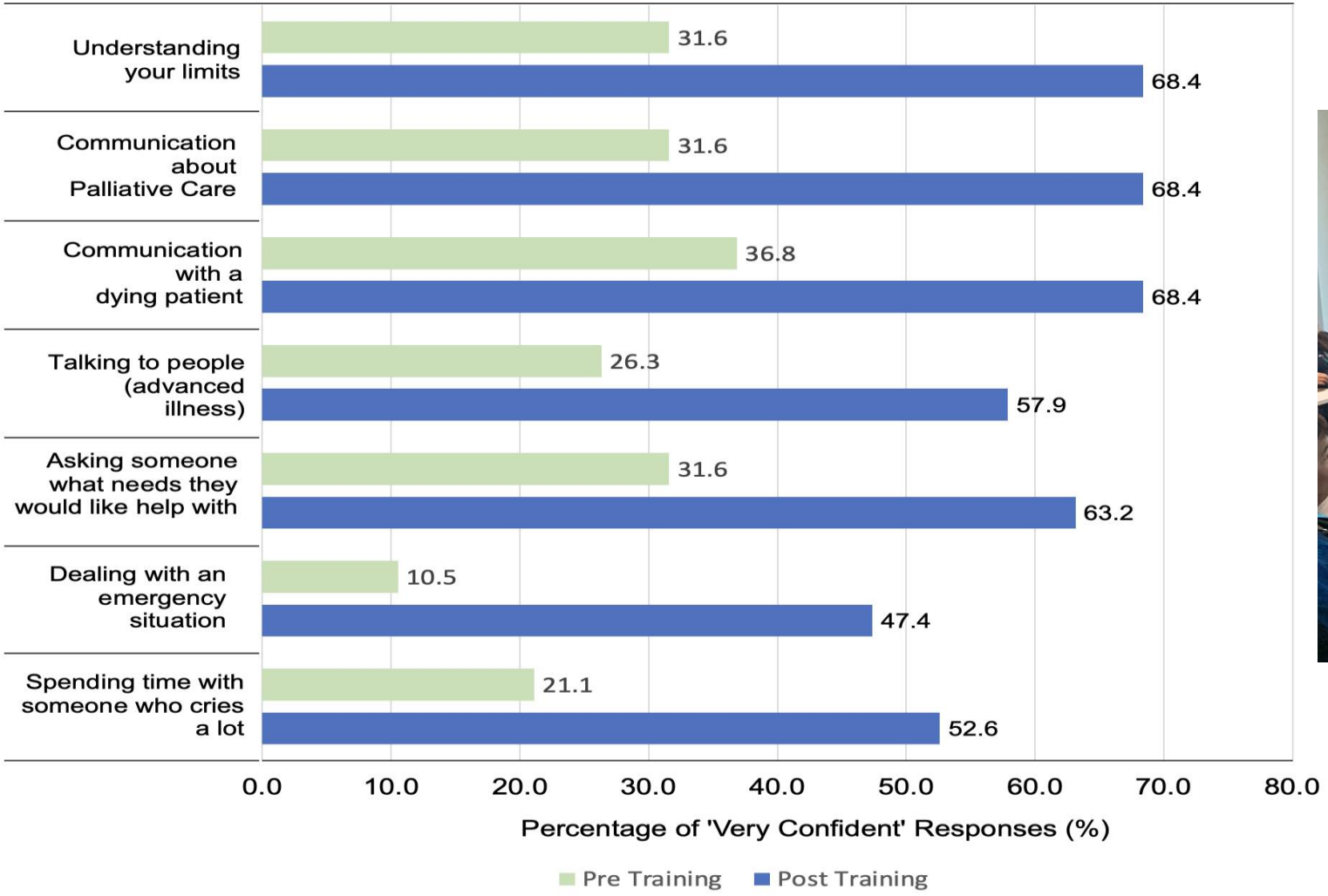
SOUTH WEST Compassionate Communities NETWORK
caring, dying and grieving is everyone's business

THE UNIVERSITY OF WESTERN AUSTRALIA

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)



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).

Connectors undertake network mapping

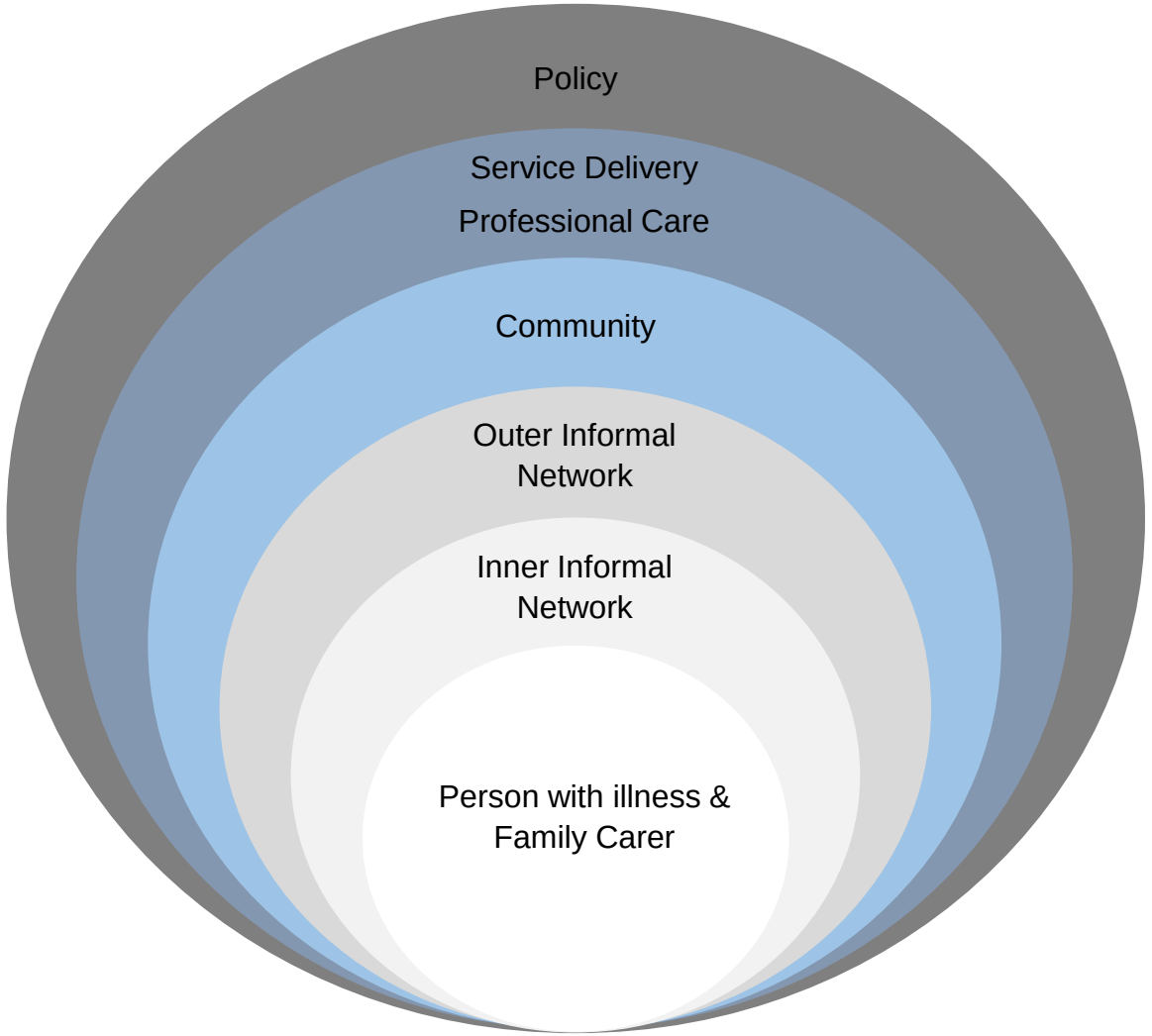
Who is your network?

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

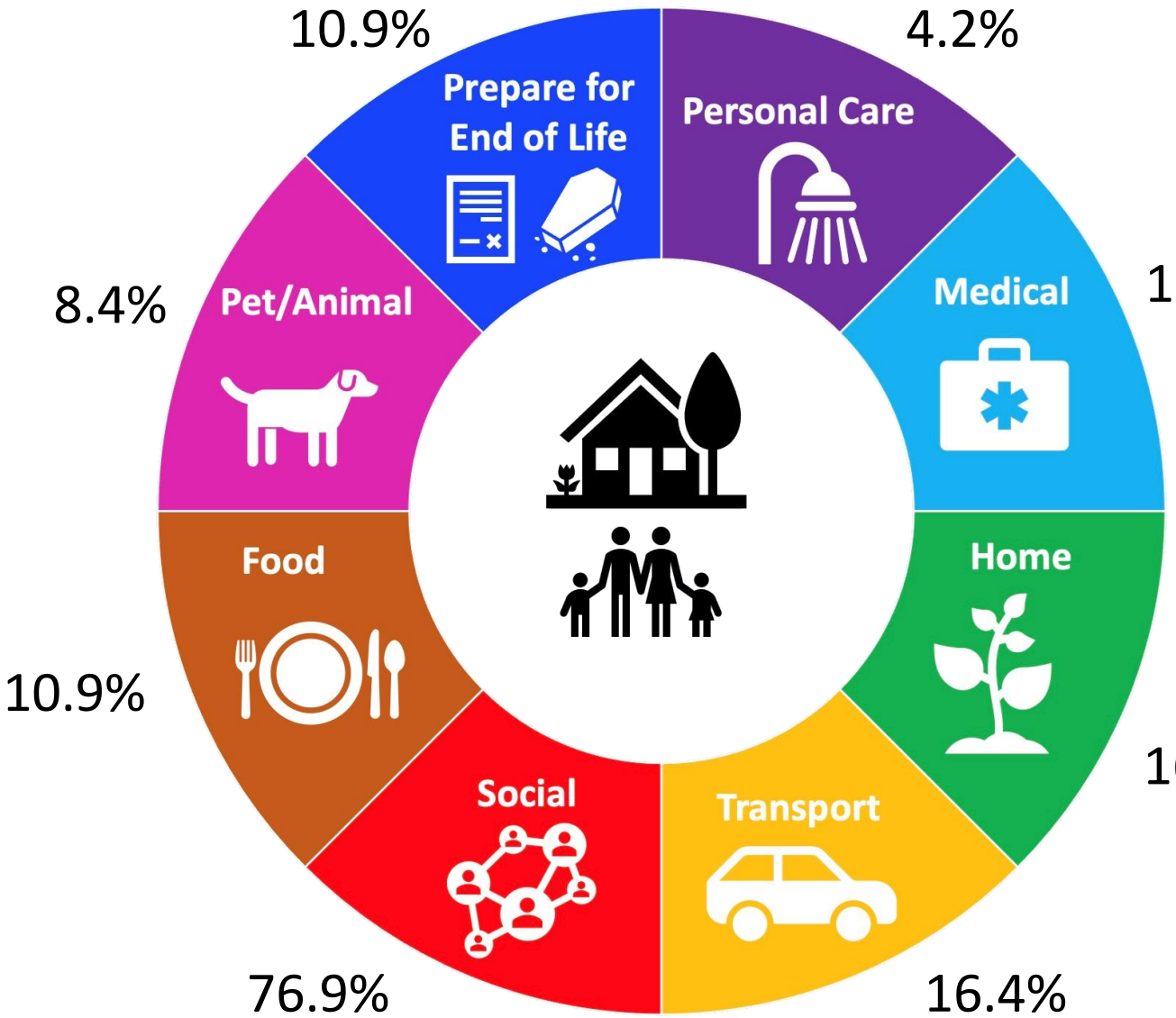
Caring Helpers can be members of the family, friends, neighbours or other people in the community who are willing and able to assist with activities such as:

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.

Community volunteers are trained to diagnose suffering not diseases

(Sallnow & Kumar 2010)

Type and frequency of support



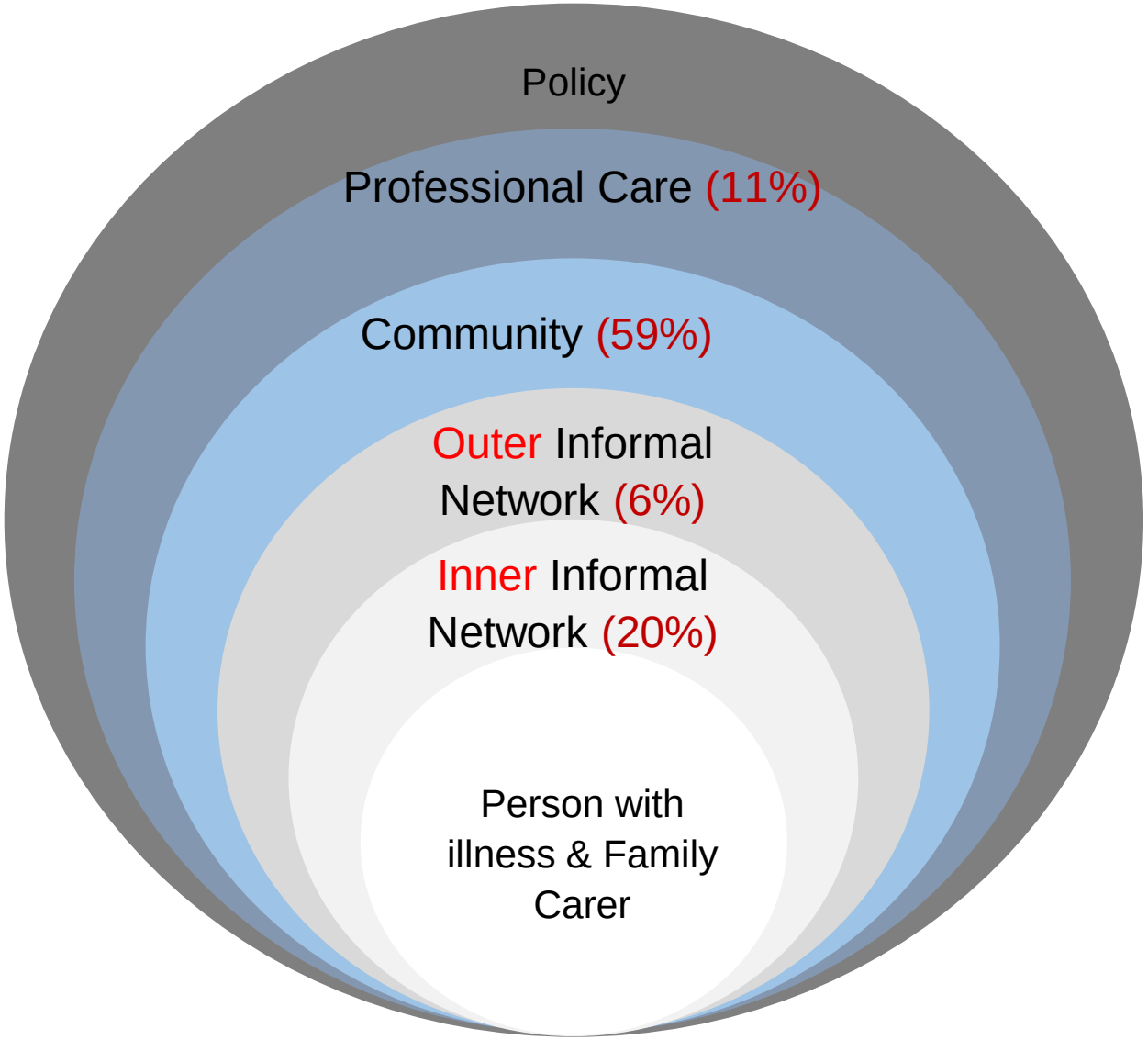
Connectors have helped or sourced help with:

- 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".






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

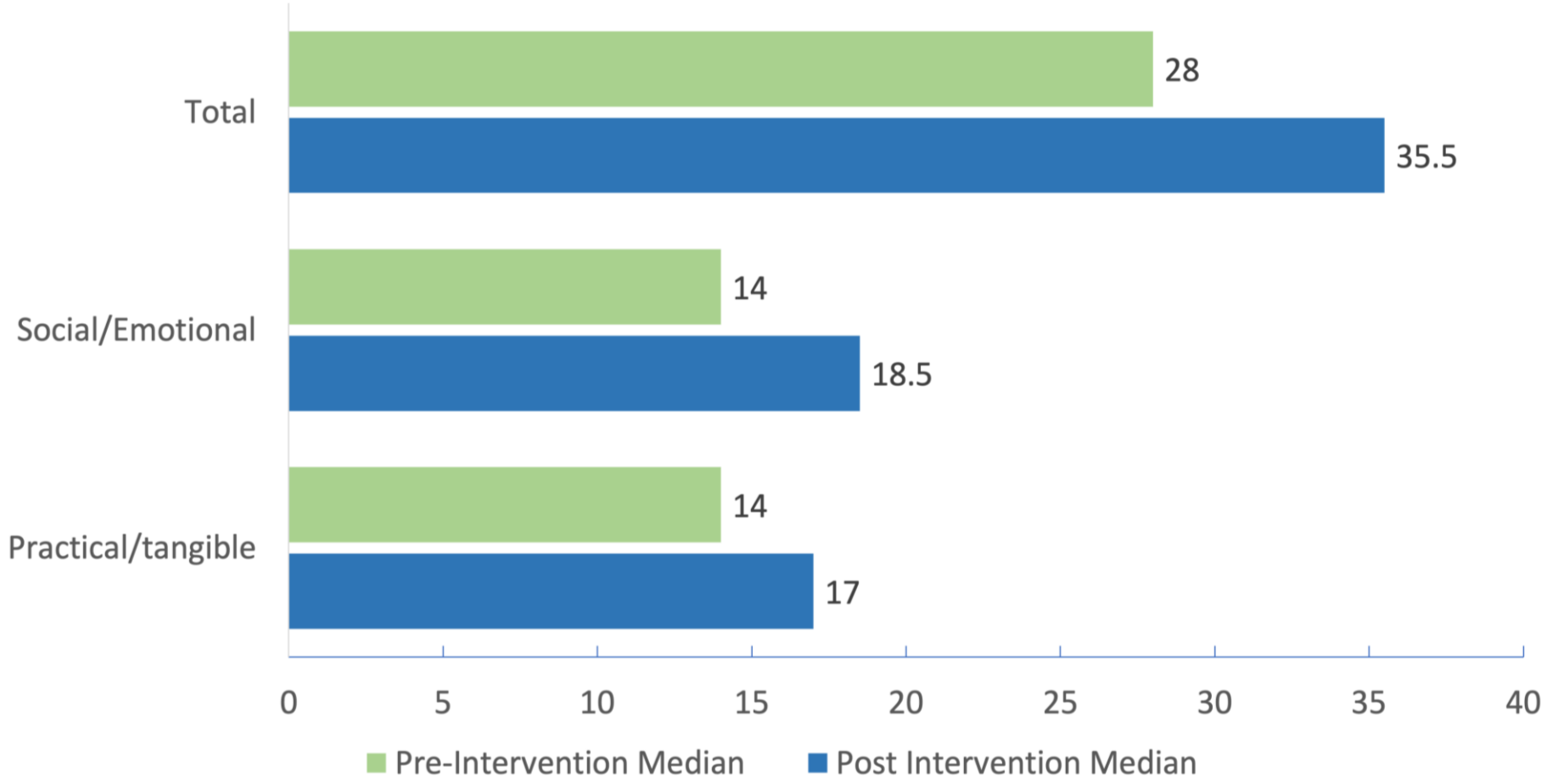


Primary Outcome:

Increase in Social Connectedness

P< 0.001

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



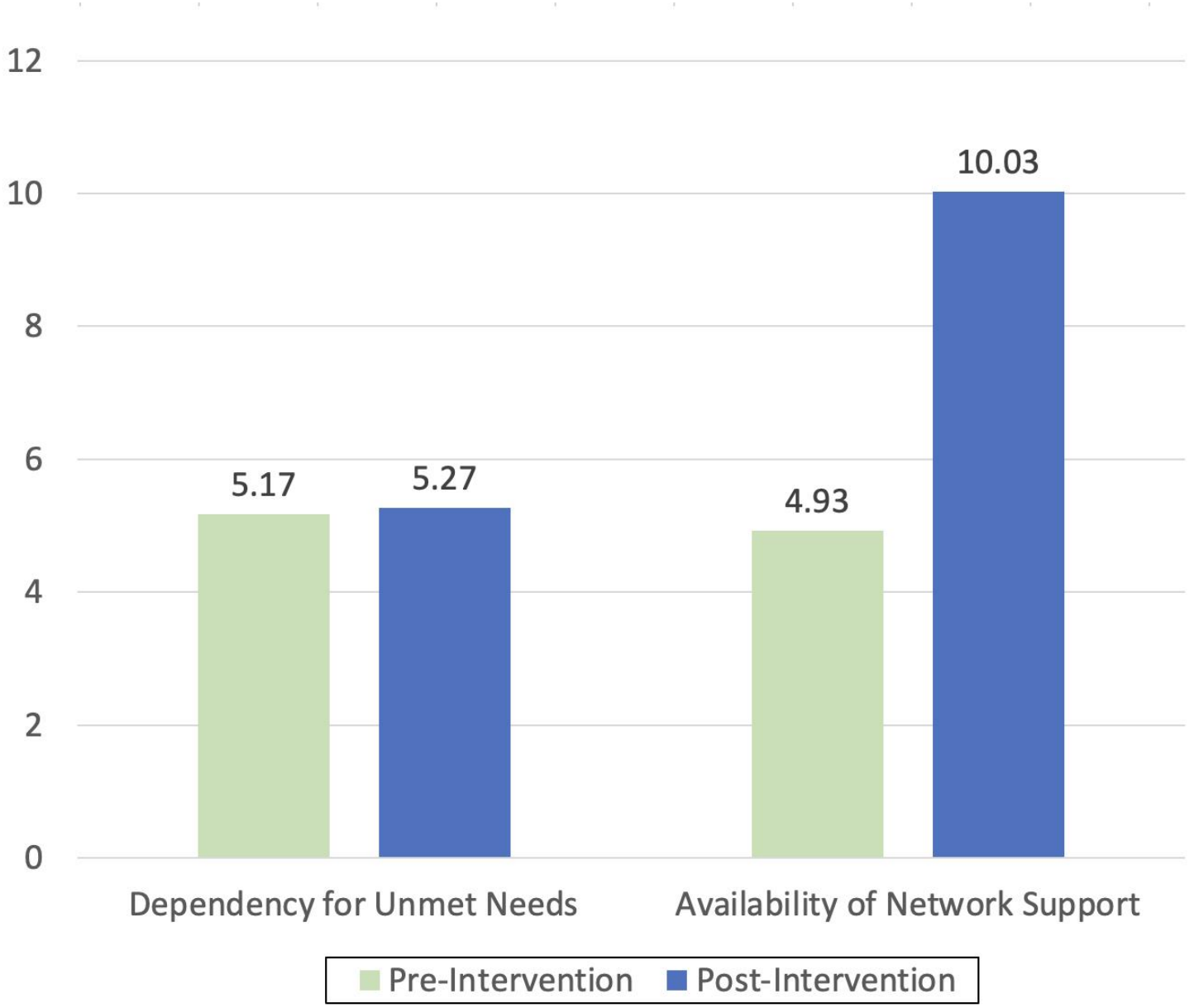
Median Difference (95 % CI)

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

Secondary outcome:

Dependency for unmet needs and availability of support networks

Supportive networks improved by two-folds
P<0.001

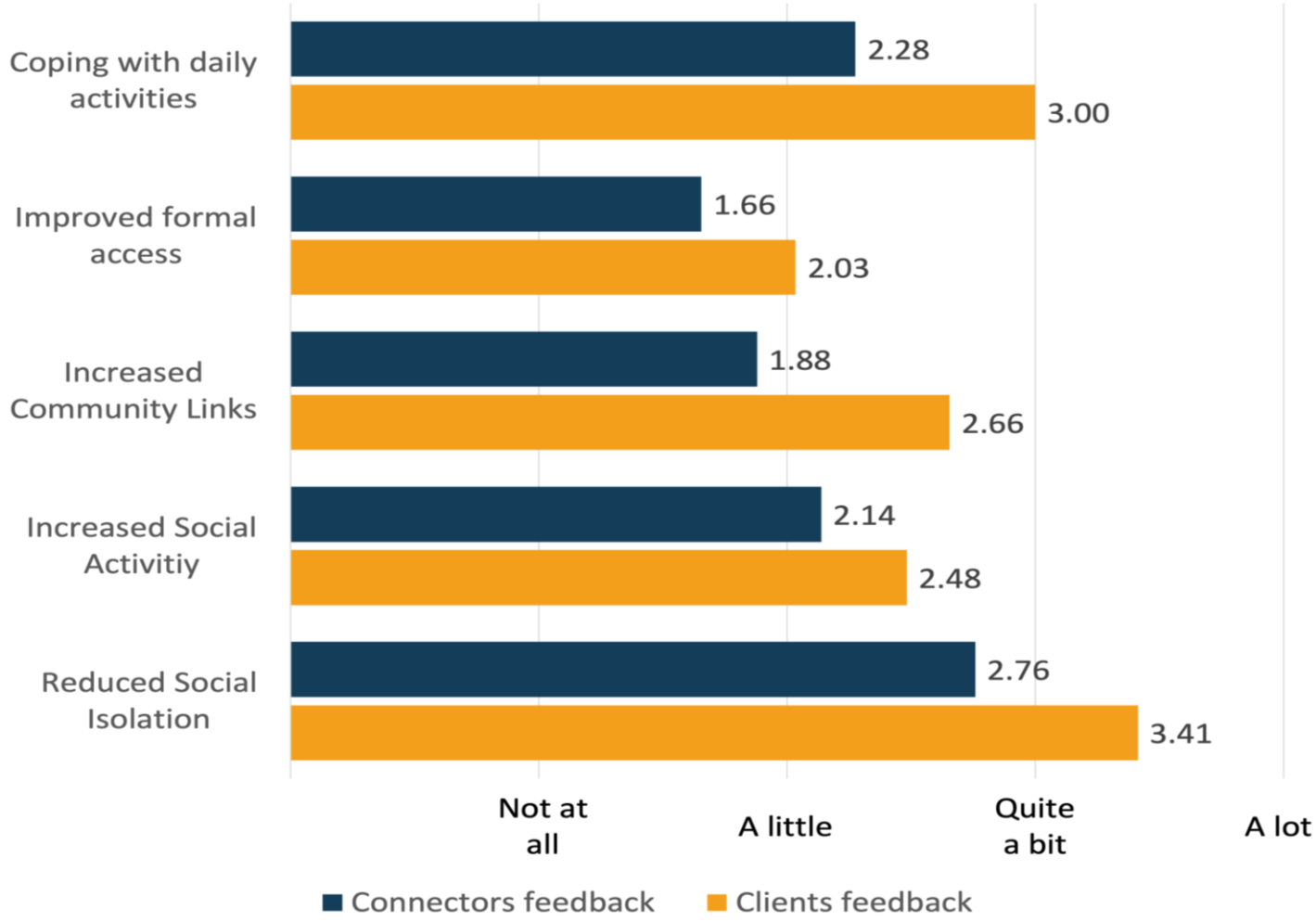


Secondary outcome:

Self-reported impact on social wellbeing

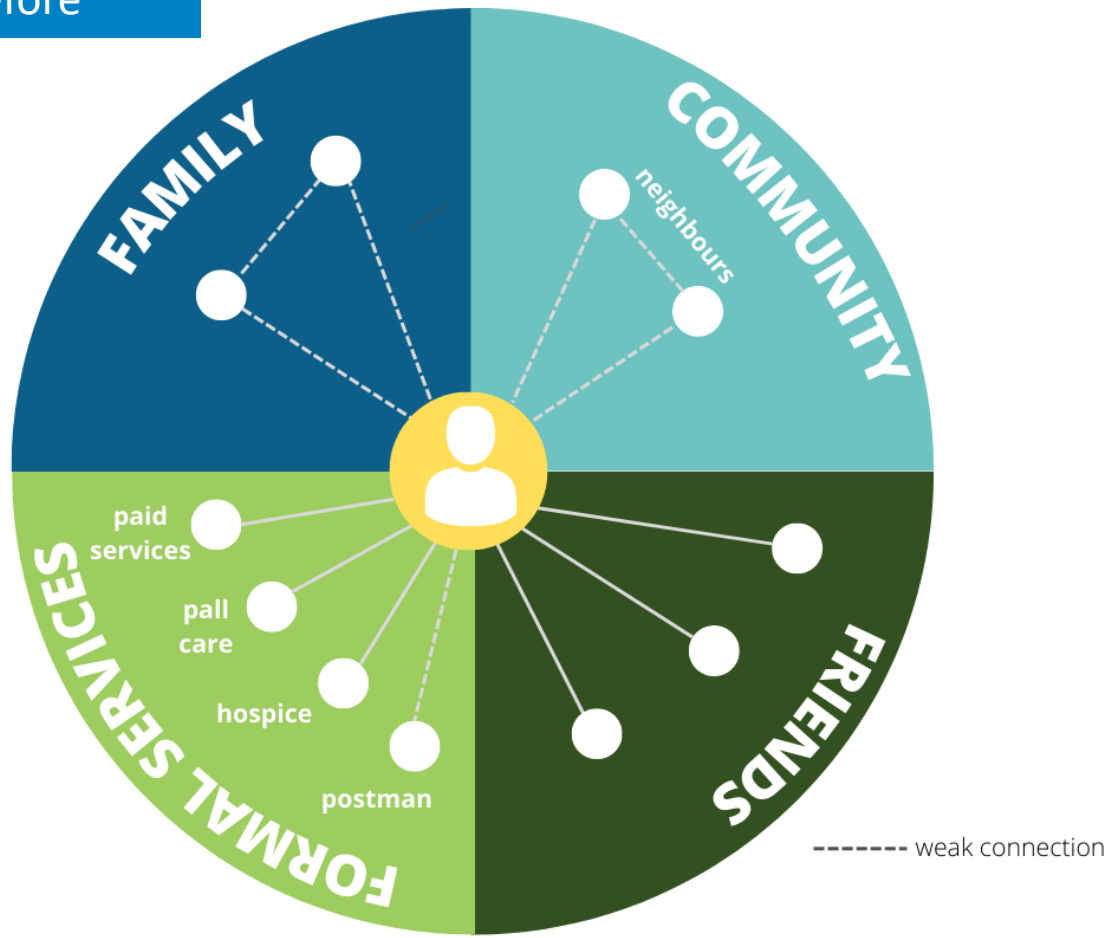
(scale: 1=not at all to 4=a lot)

highest impact on reduced social isolation



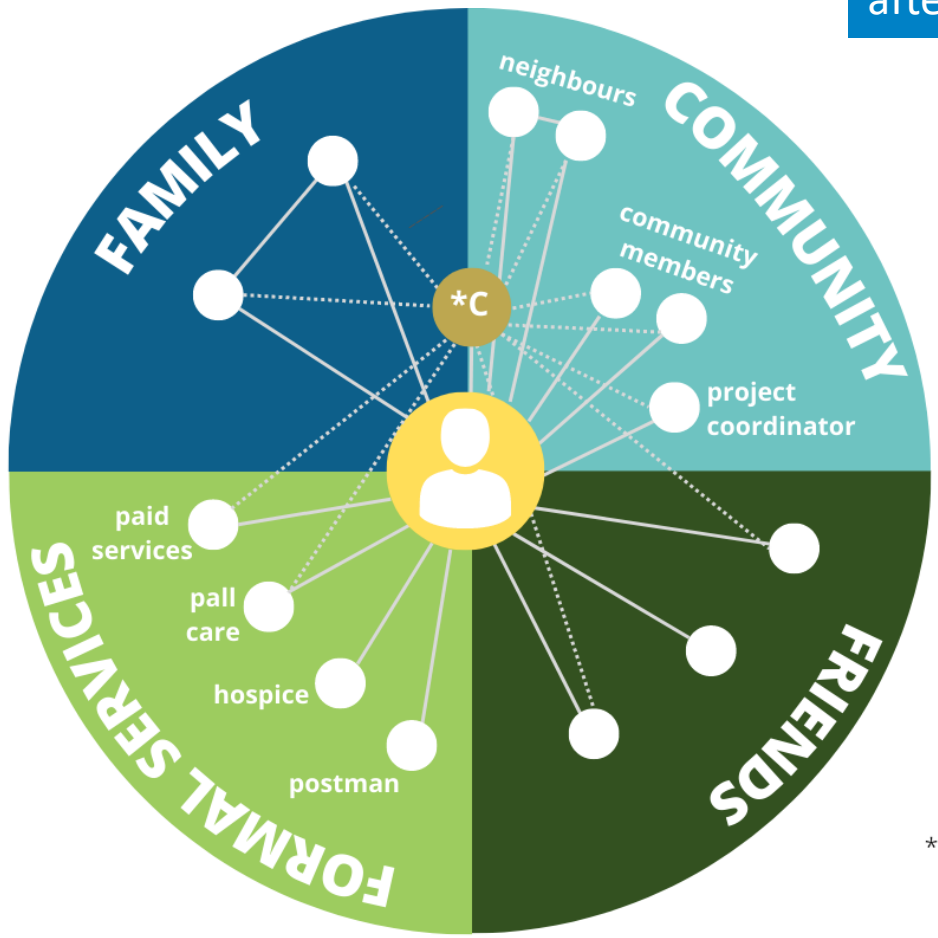
Social Network Mapping for one family before and after the intervention

before



------- weak connection

after



*C= connector

Healthcare Usage and Economic Analyses

Relative to Controls, the intervention group had (per month):

- Sig. decline in frequency of hospitalisations: 63% less admissions (p=0.007)
- Sig. decline in number of hospital days: 77% less days (p<0.001)
- Sig. decline in ED presentations: 44% less ED presentations (p=0.028)
- Sig. increased use of outpatient services: 2X higher (p=0.022)

➢Net savings over a 6-month period for 100 patients, 20 connectors and 2 coordinators = on average $AUD 518,701

Patient and carer feedback

Pretty Amazing

> *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*

> *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*

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

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"

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"

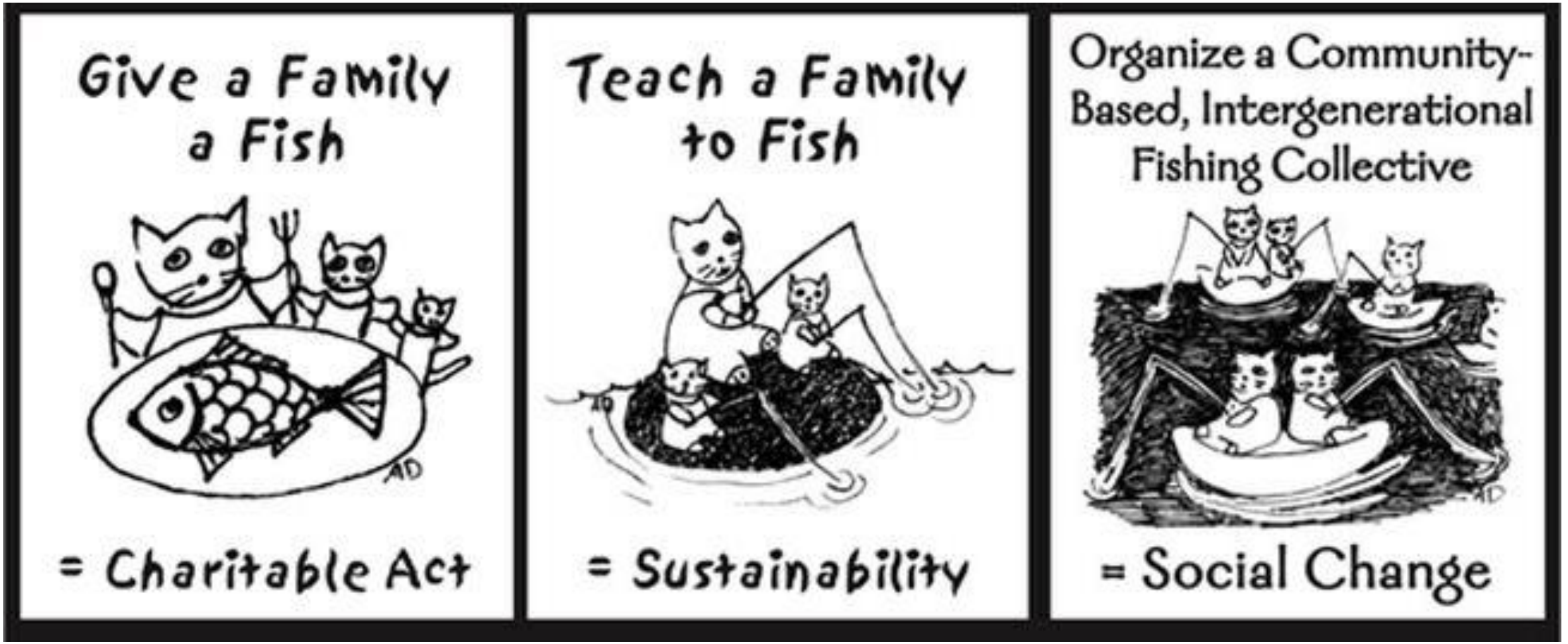
"It's a lovely way to do volunteer work. If you really enjoy being with people and talking to people…..you end up, I don't know being part of their lives. It's really fulfilling in that respect"

With the End in Mind!

We need to ensure that when caregiving, dying and grieving knock at our door

- *wherever we are, and whoever we are* –

that compassionate support will be found in all aspects of our lives and deaths.



Artwork: Alyce Dedge

END OF LIFE CARE
IS ABSOLUTELY EVERYBODY'S RESPONSIBILITY