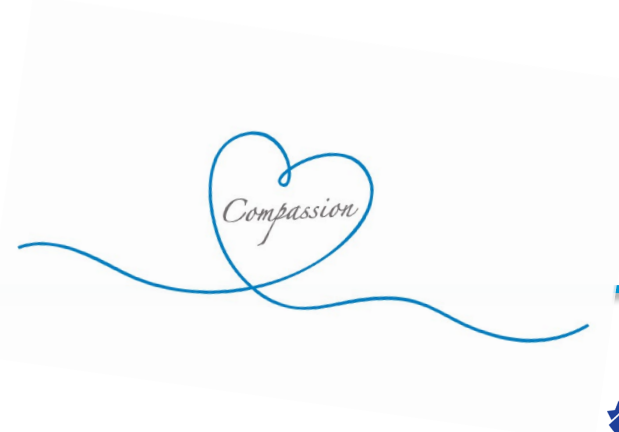


Compassionate Communities for ALS: Supporting those Caring, Dying and Grieving

Professor Samar Aoun

Perron Institute Research Chair in Palliative Care
Chair, South West Compassionate Communities Network

Les Turner ALS Foundation



What is Compassion?

- We respond with humanity and kindness to each person's pain, distress, anxiety or need.
- We search for the things we can do, however small, to give comfort and relieve suffering.
- We find time for those we serve and work alongside.
- We do not wait to be asked, because we care.

(National Health Service, 2010)



COMPASSION
IS ABSOLUTELY EVERYBODY'S
BUSINESS



“Compassionate Communities” IS

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

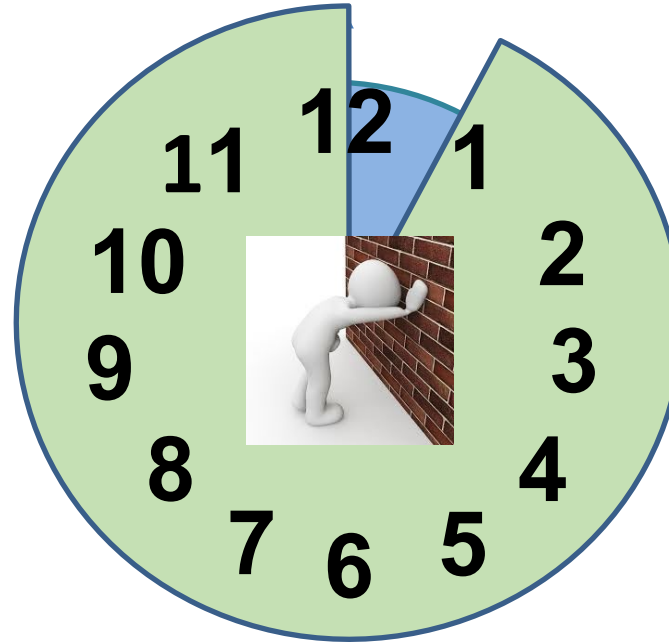
Internationally, models of social and practical support at the end of life are gaining momentum as a result of the Compassionate Communities movement.



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

EVIDENCE?

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



Formal Care <5% of the Day

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

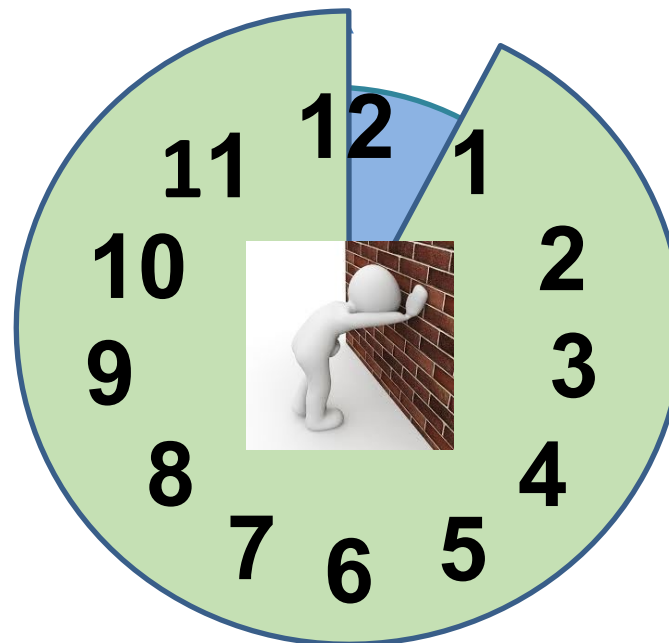
Adapted from Carpenter House model developed by ^r



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



Formal Care *<5% of the Day*

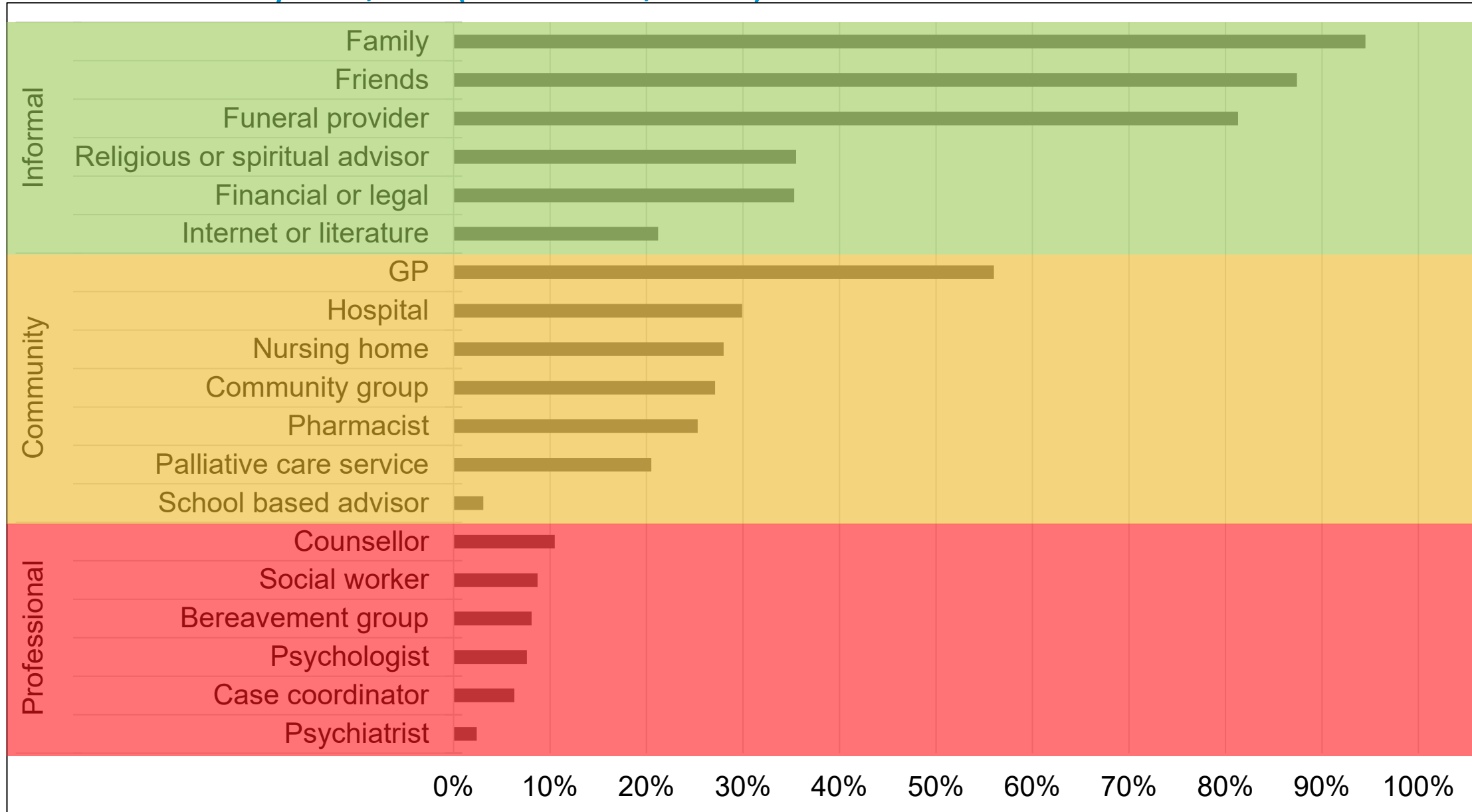
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- ✓ Pharmacist

Adapted from Carpenter House model developed by r

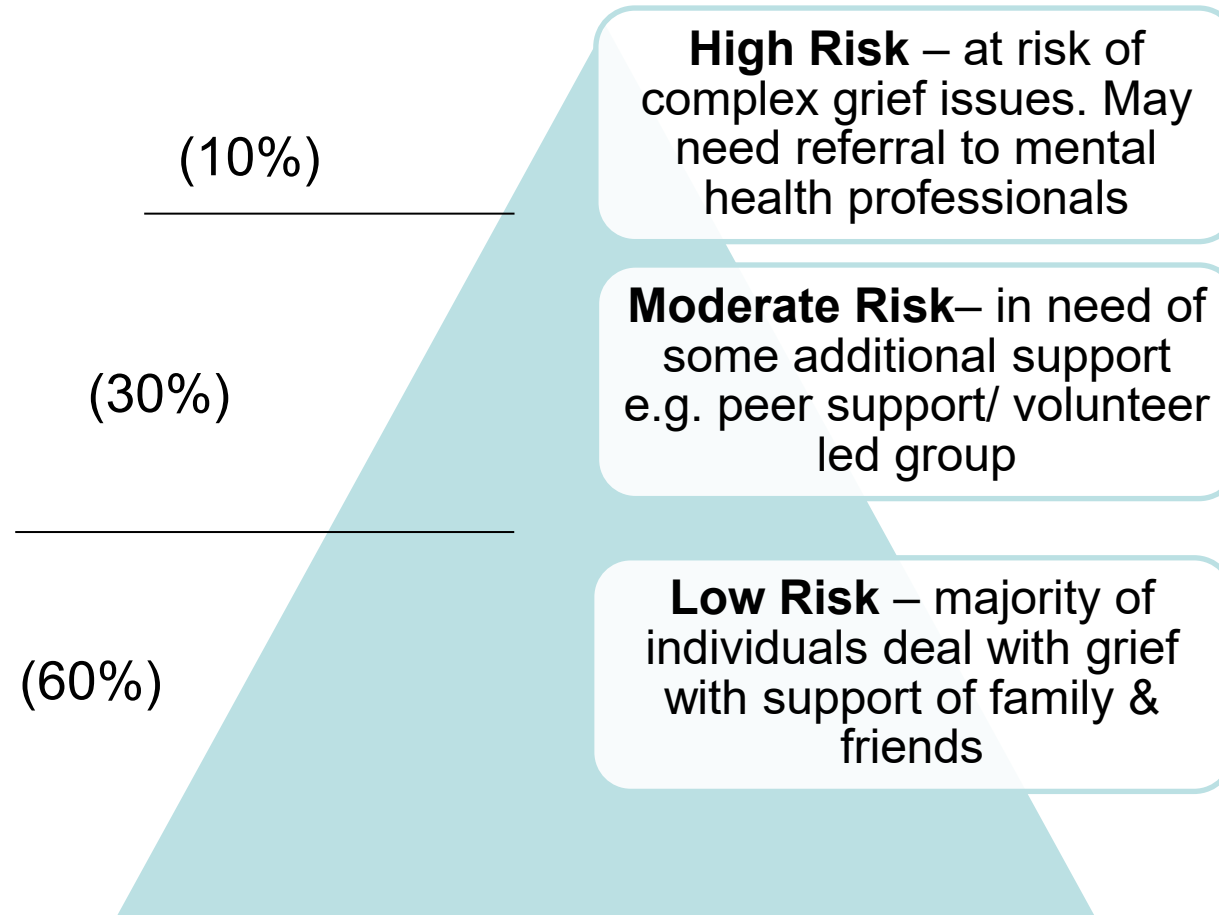


Where people get bereavement support

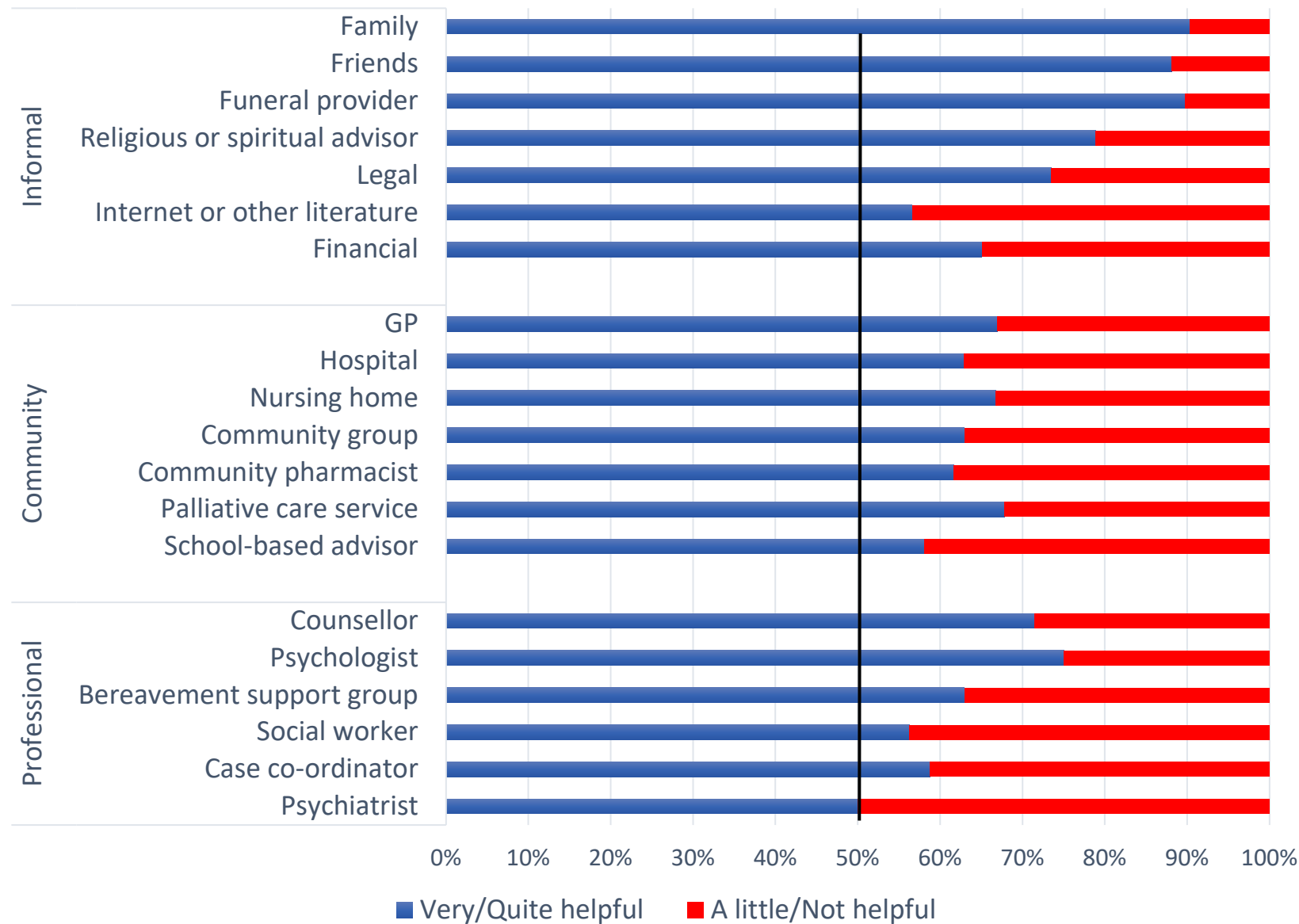
National survey n=1,000 (Aoun et al, 2018)



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



Sources of support perceived helpful or unhelpful (Aoun et al, 2018)



'GROWING AROUND GRIEF'

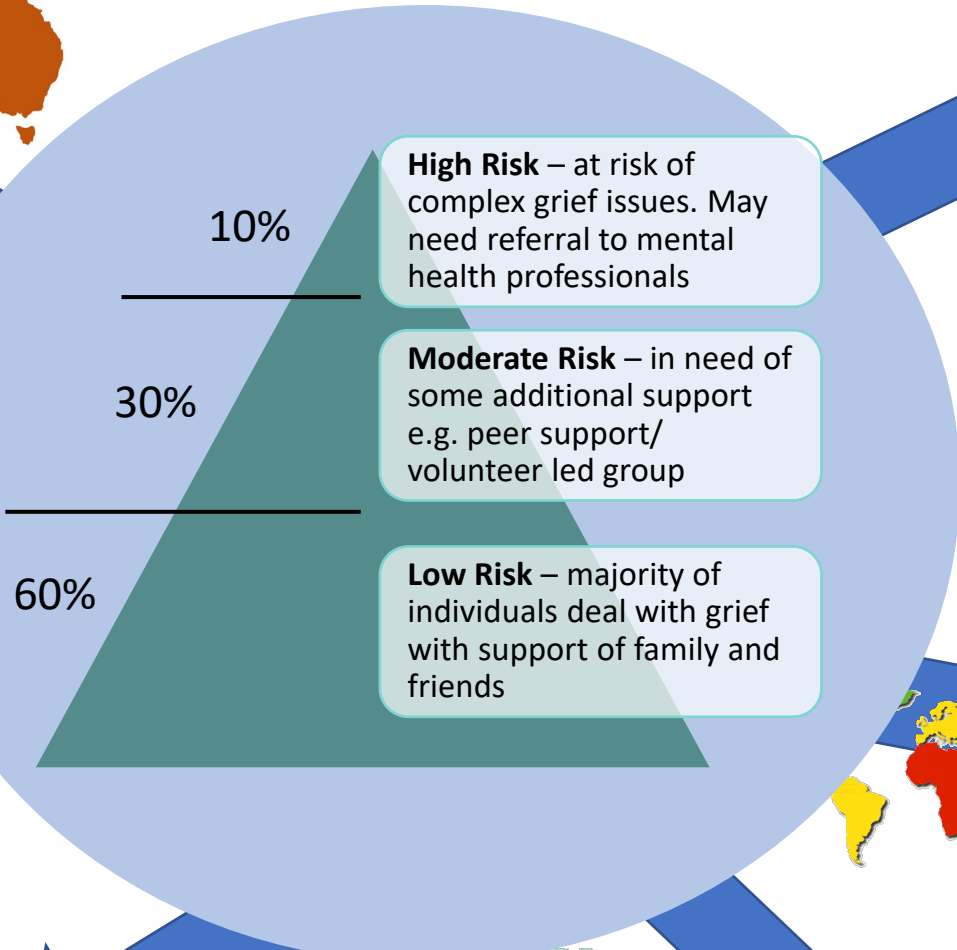
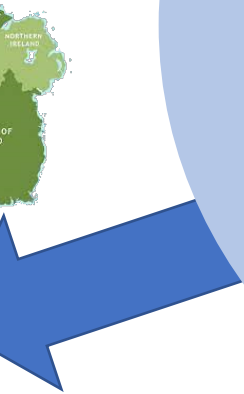
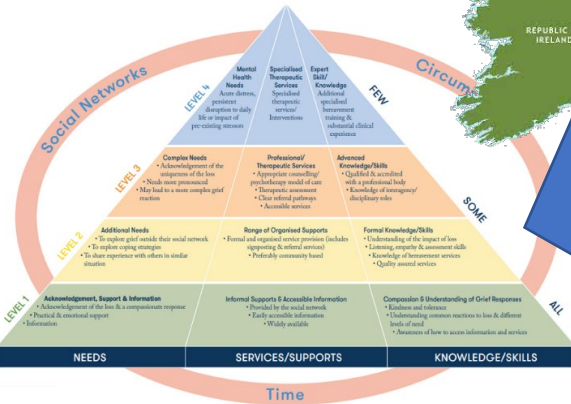
(LOIS TONKIN, 1996)

WHATSYOURGRIEF.COM



The Public Health Model for Bereavement Support-Translation

Palliative Care Australia Standard 6: Grief Support



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.

Irish Hospice Foundation Pyramid of Adult Palliative Care



Bereavement Care Taskforce of the European Association of Palliative Care



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

It won't kill us to speak openly about death and dying

**SAMAR
AOUN**



Once upon a time we were born at home and we died at home.

Death and dying — and their partners loss and grief — are still 100 per cent prevalent in Australian communities at any given time.

But today, the answer to end of life is the ever-increasing professionalisation and medicalisation of dying and its processes.

We forgot that death used to be a social event with a medical component, not as it has become now: a medical event with a social component.

Too many people are dying in a way and a place that is not reflective of their values or their choices — end of life is interrupted with preventable and costly admissions to hospital where control and even dignity are surrendered.

Only 5 per cent of a dying person's time is spent with a health professional, such as their doctor or a nurse. The other 95 per cent is spent with friends, families, churches, pets, their community — and sometimes, sadly, they face death alone.

To this day, I find it amazing that the one experience we all go through is left to chance in so many ways.

The inevitability of death and dying makes it everyone's business and everyone's responsibility at some point, so we need to have a serious rethink regarding the direction end-of-life care is heading.

Let's stop overestimating the importance of professional support, and stop underestimating what family, friends and neighbours can provide.

The number of people dying is expected to double in Australia in the next 25 years. For palliative care to be accessible to everyone and everywhere, the community

needs to be an equal partner in order to provide quality healthcare at end of life.

If we are to have quality of life and quality of death, the community and palliative care services need to work in partnership, from diagnosis of the terminal illness through to bereavement.

Let's connect formal care with informal care.

Because life continues, even for the dying; here is still a daily routine — walking the dog, doing the shopping, collecting a prescription, going to the library, mowing the lawn, making a snack, tidying up, or that all-important cuppa and a chat.

We may think these are little things but this is at the heart of what matters to people, that shows we love them and that restores their dignity.

Let's rebuild the capacity of Australia's communities to become compassionate communities. Compassionate Communities is a global movement that encourages

social networks to play a much stronger role in supporting those at the end-of-life: increasing people's sense of connectedness to their community, not isolating them at their greatest time of need.

As a co-founder and chair of the South West Compassionate Communities Network and the lead investigator of the Compassionate Connectors model of care, our research has demonstrated that when the community is better connected and there are strong social networks, people suffer less from social isolation, there are significant reductions in hospital admissions, shorter hospital stays and more contact with community-based health services, which are less expensive than hospital services.

So for this year's National Palliative Care Week: let's improve death literacy and grief literacy and normalise having such conversations — talking about death will not kill you.

Let's make sure that every person, every family and every community know what to do when someone is caring, dying or grieving — see below for some tips.;

Start by asking yourself the following questions: who is your network, how will they respond to your end of life and what kind of death do you want to experience?

Wouldn't you rather make this decision based on your needs and wishes, rather than a one-size-fits-all clinical model which fails to respect your autonomy and choice?

As communities we need to relearn the old ways of caring for one another — whether it's caring for those persons who are dying or those left behind.

We only die once, so let's make it a good one.

**Professor Samar Aoun is 2023
WA Australian of the Year and
Perron Institute Research Chair in
Palliative Care at the University
of Western Australia and Perron
Institute**

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

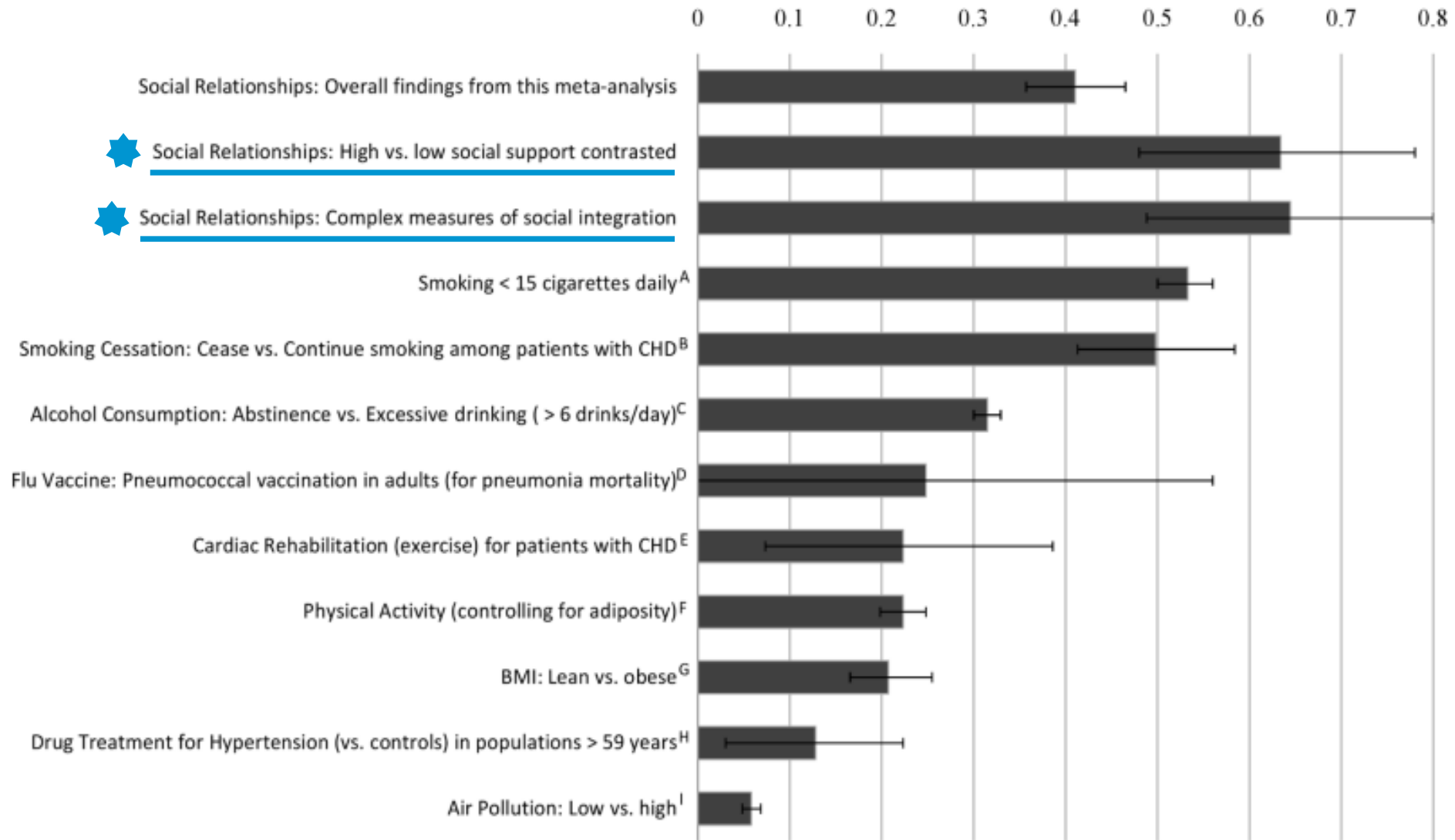
People who are more socially connected are happier, physically healthier, live longer.

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.



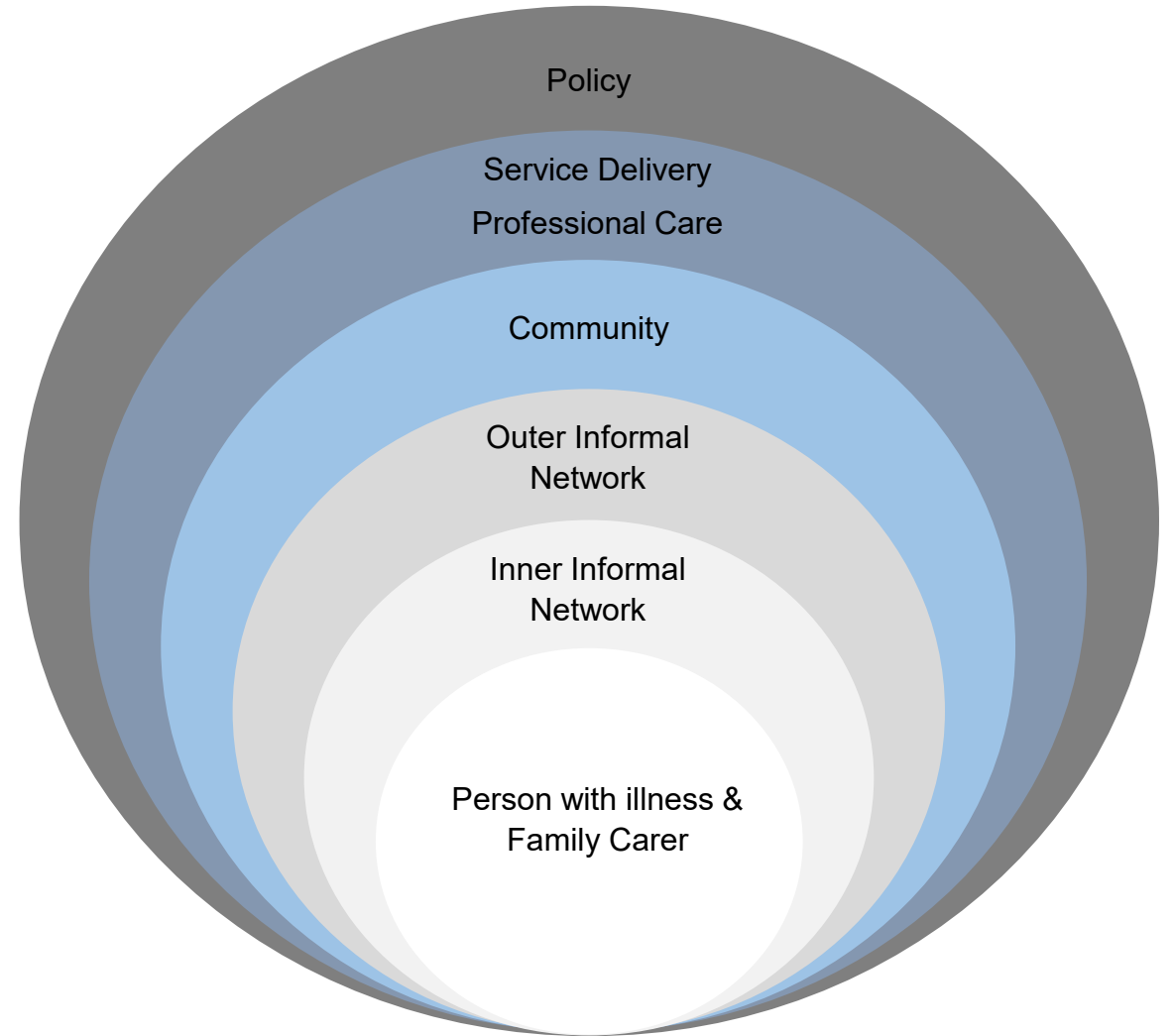
Compassionate Community Connectors

Partnership between the community and health service
in Western Australia

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

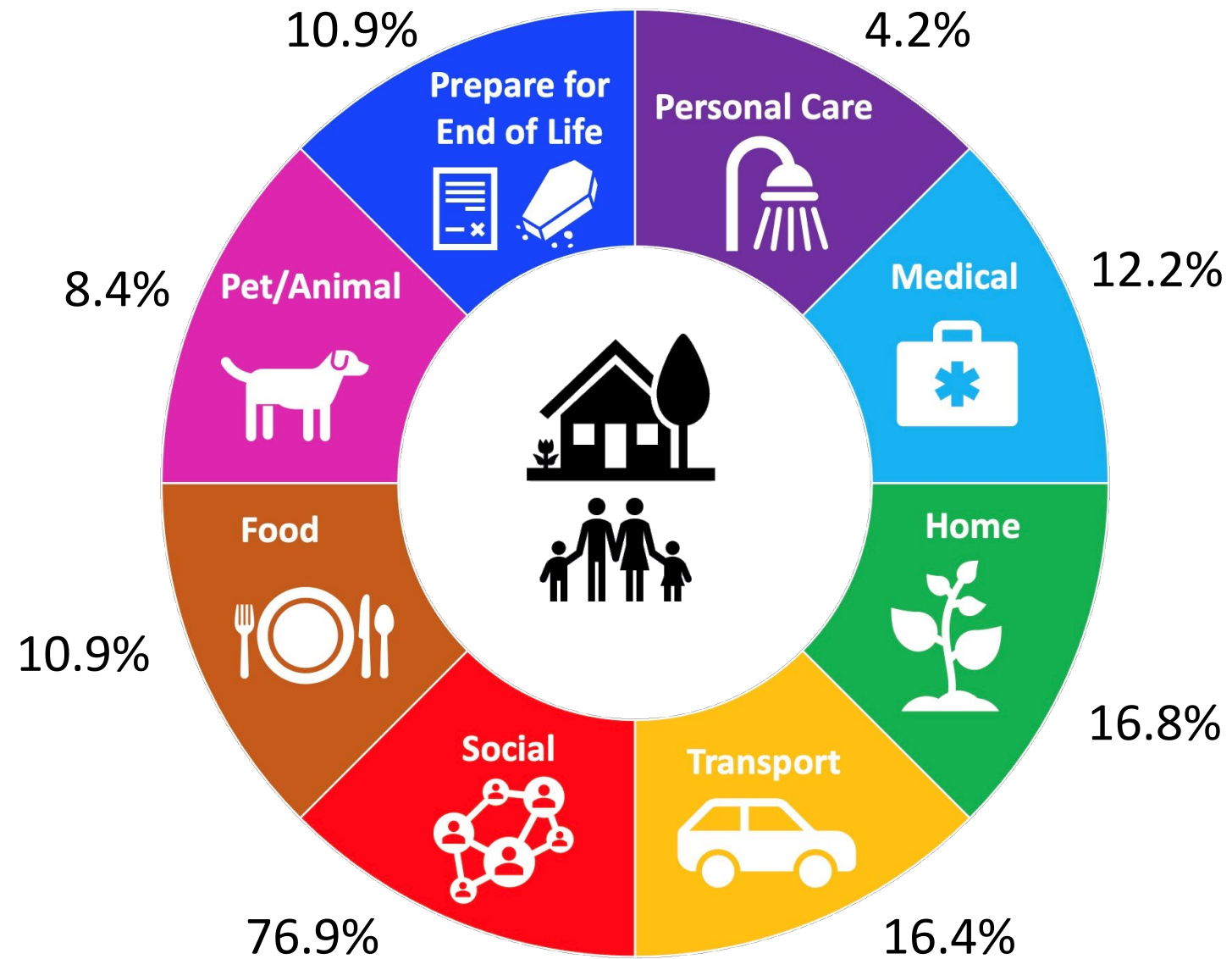
Caring Helpers can be members of the family, friends, neighbours or other people in the community who are willing and able to assist with activities such as:

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

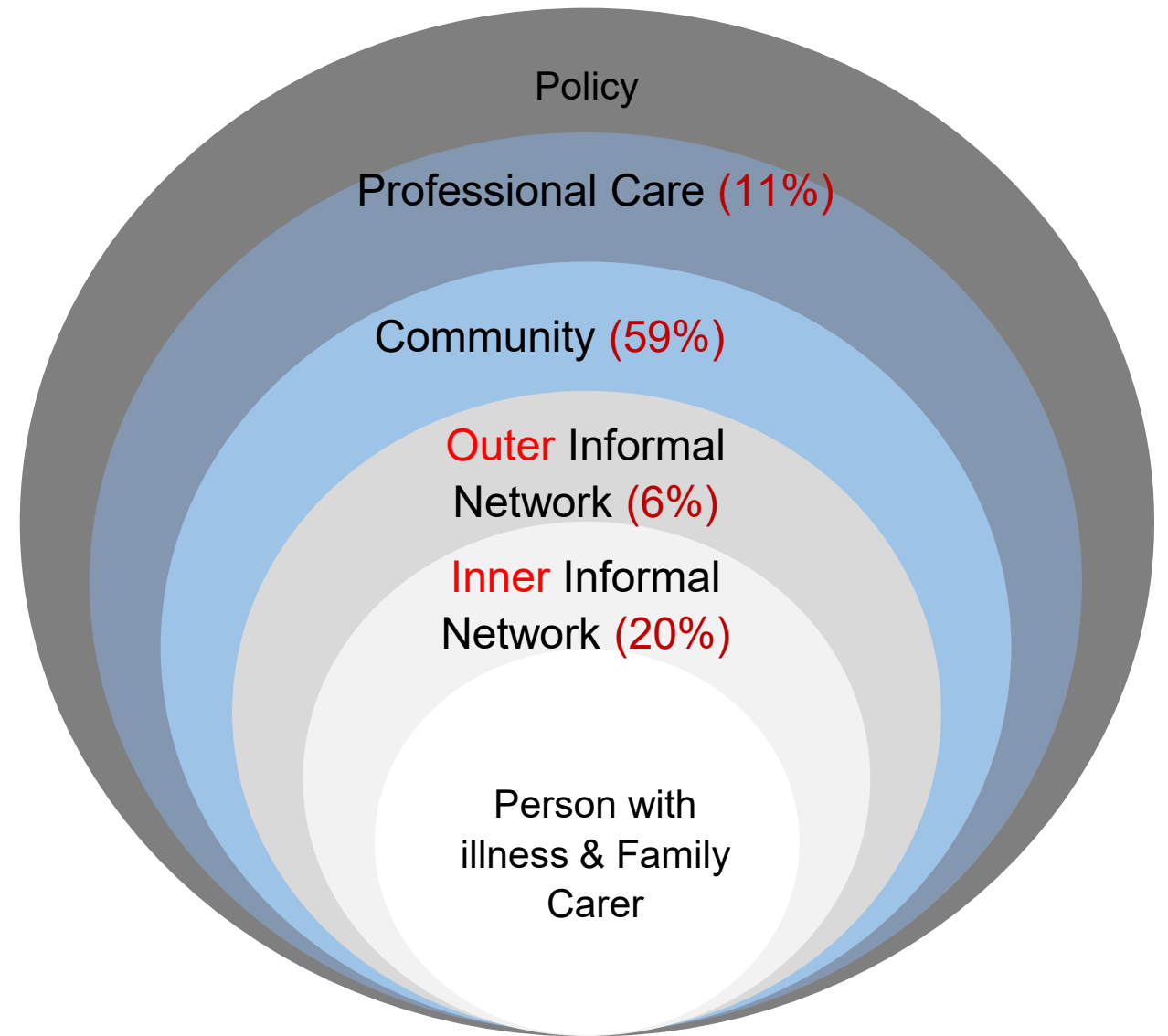


Connectors have helped or sourced help with:

- 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".



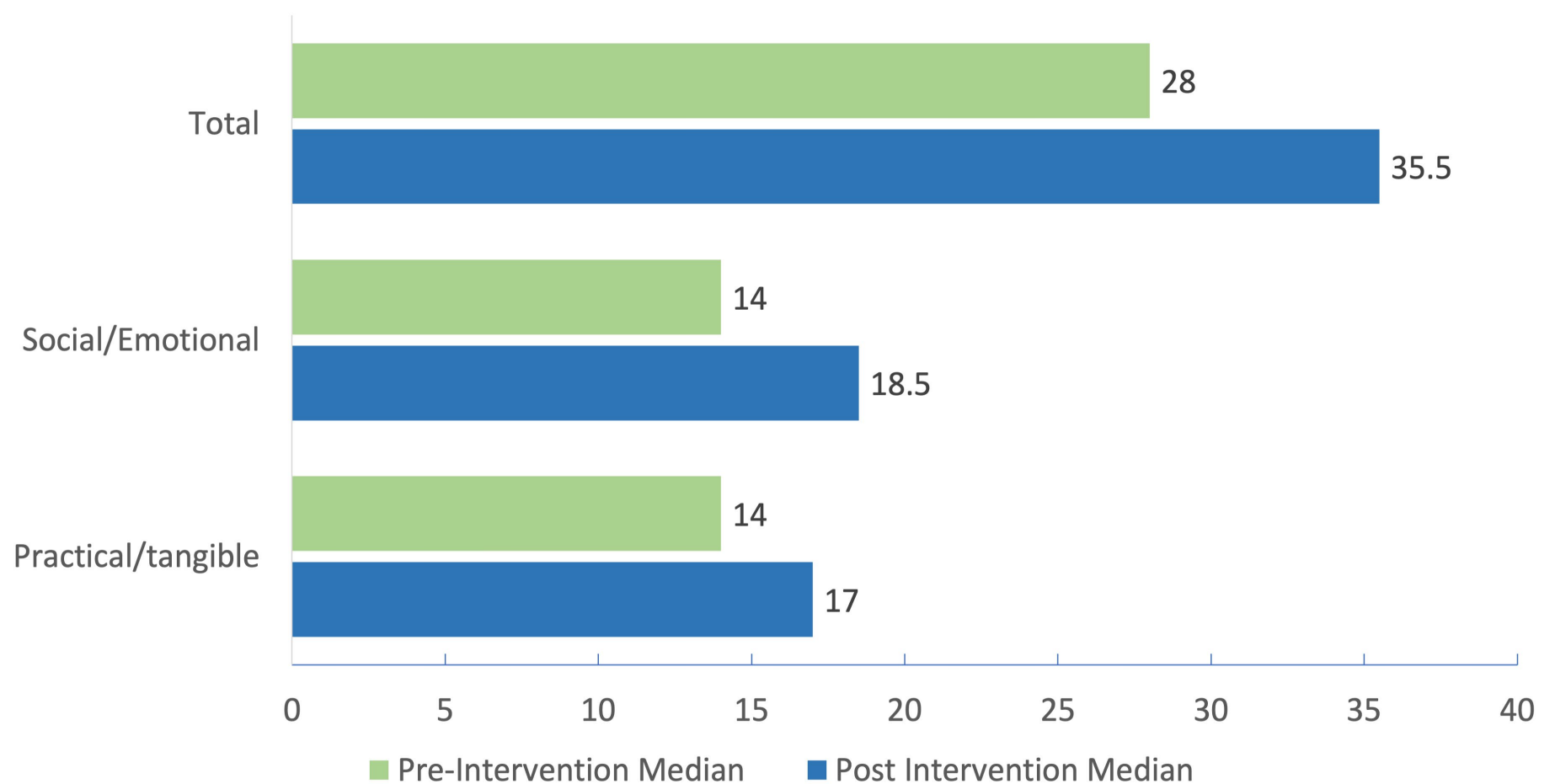
Naturally Occurring
Networks (26%)
VS
Facilitated Networks
(59%)



Primary Outcome: Increase in Social Connectedness

$P < 0.001$

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



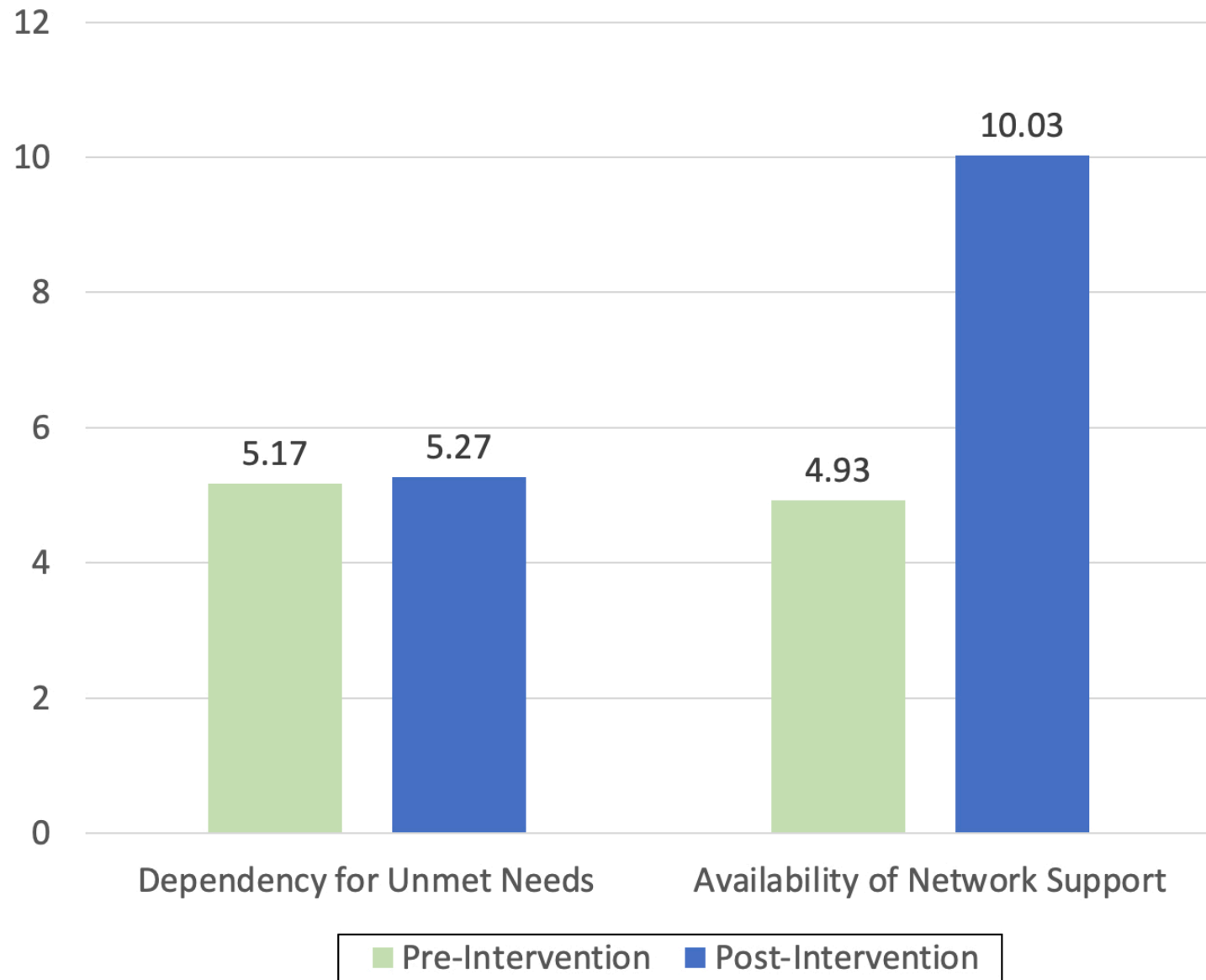
Median Difference (95 % CI)

- 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
 $P < 0.001$

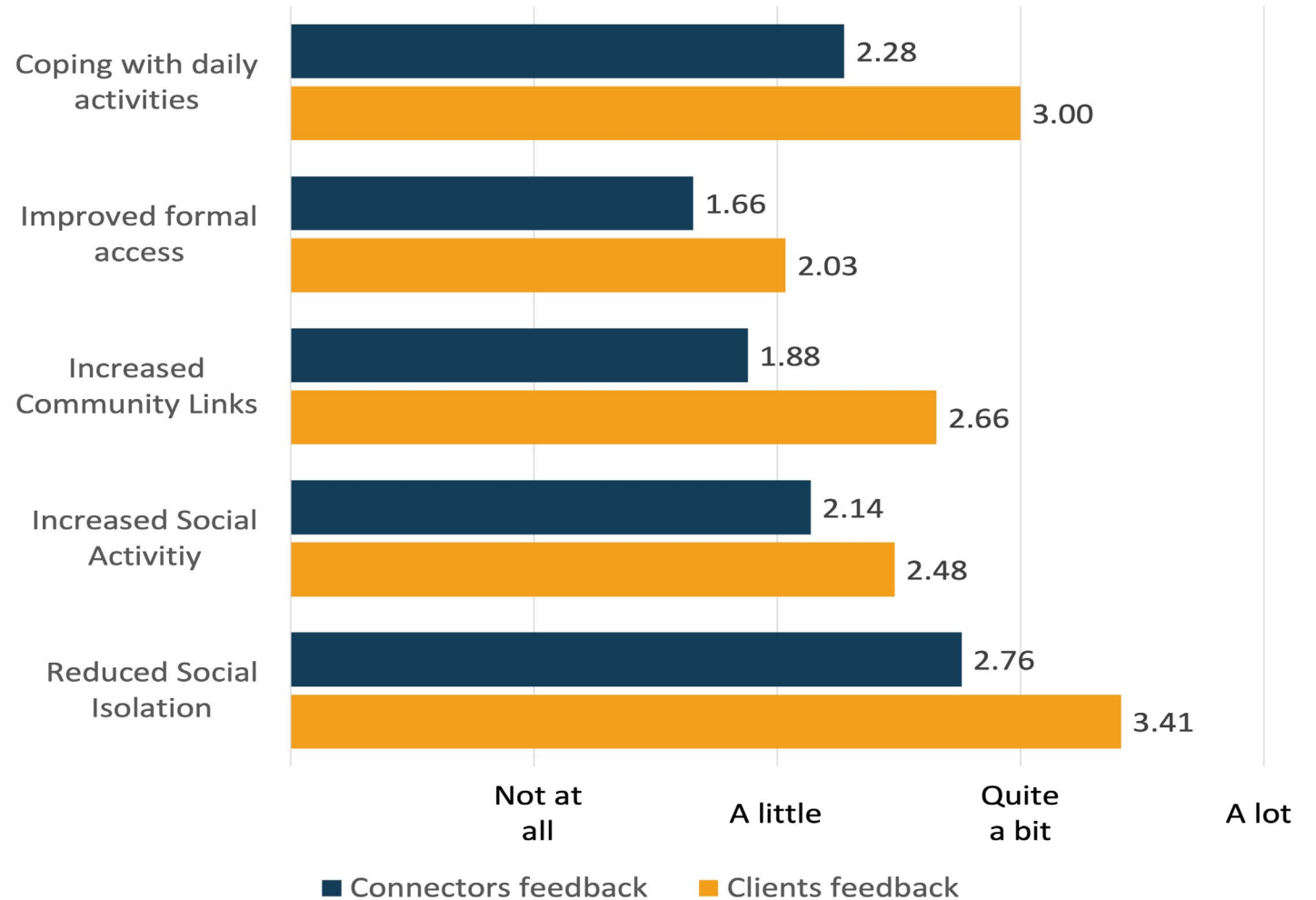


Secondary outcome:

Self-reported impact on social wellbeing

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

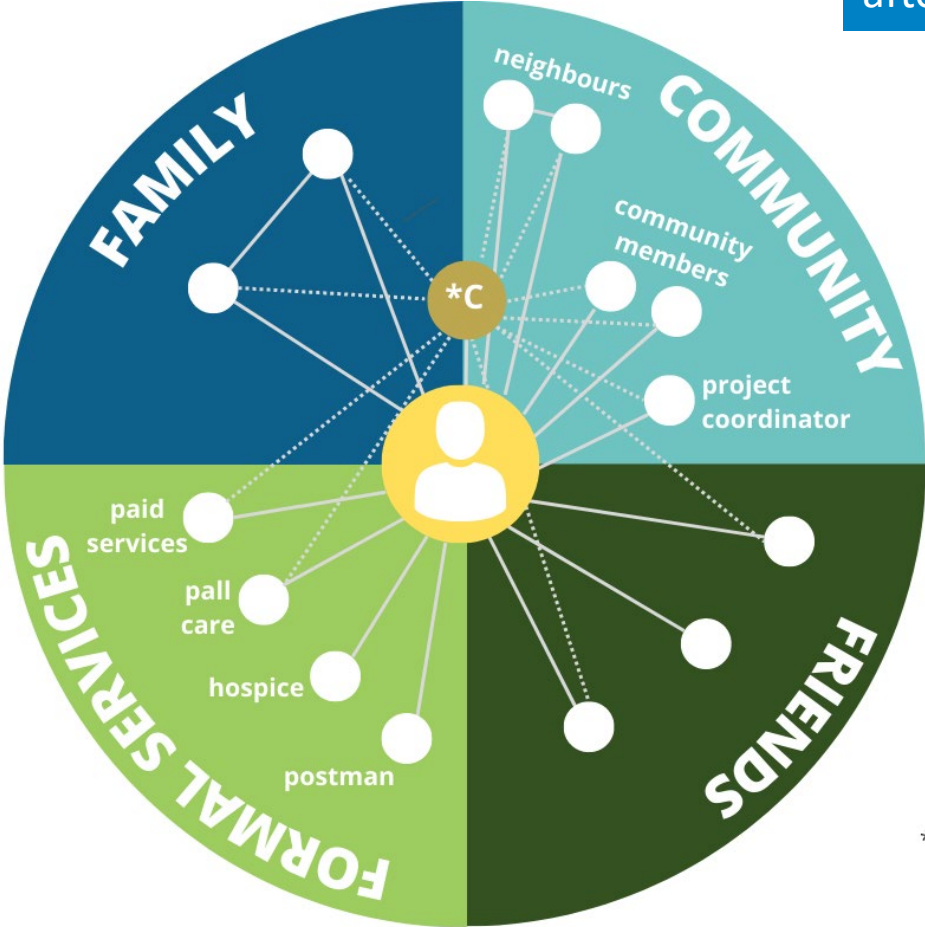
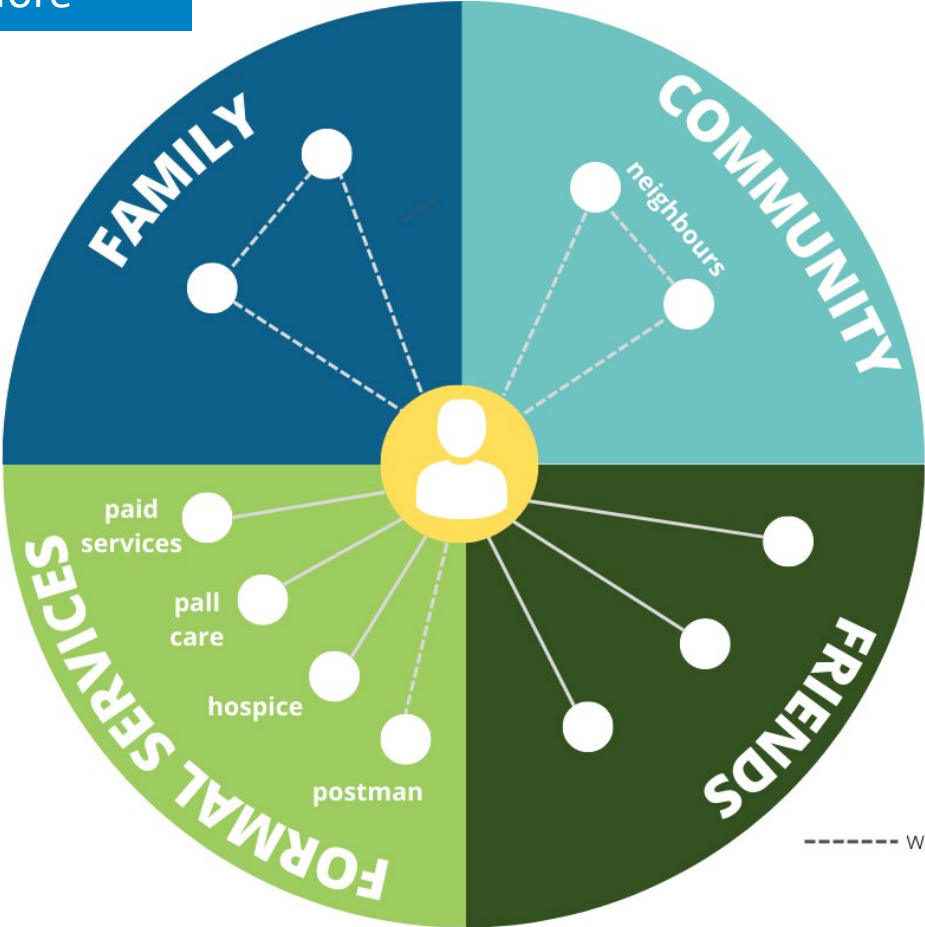
highest impact on reduced social isolation



Social Network Mapping for one family before and after the intervention

before

after



----- weak connection

*C= connector

Key Outcomes-Effectiveness Analysis (Cook and 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.

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 ”

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”

Website

- Compassionate Connectors Program

<https://comcomnetworksw.com/compassionate-connectors-program/>

- Publications

<https://comcomnetworksw.com/research/>



Translation in Progress

WACHS integrating program as standard practice: System Change

Local government engagement-
Compassionate Bunbury Charter



Rolling it out to other communities throughout WA and Australia

Engagement with Primary Care

Compassionate Bunbury Charter

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.



Toolkit: Set of Actions & pledges

Toolkit aims to provide inspiration for how you, or organisations you are part of, can grow Compassion.

You can make a pledge as an individual, family, group of friends, workplace or community organisation

- something practical and achievable.
- recommitting to something you are already doing or it might be something that builds your ability to support yourself or others.



Compassionate Bunbury Charter



Charter is drawn from the principles of OTTAWA CHARTER for health promotion

- Building healthy public policy (enable, mediate, advocate for health)
- Creating supportive environments (in the community)
- Strengthening community action (community capacity)
- Developing personal skills (in the community)
- Reorienting health care services (to better serve the community)

Why we need a Compassionate Charter?

- ❖ Systematic way of ensuring we build compassionate communities in all sectors

Educational institutions, workplaces, health and social care institutions, religious institutions, neighbourhoods, homeless and vulnerable amongst others

- ❖ Incentive schemes and awards at civic level

Practical expressions of compassion

- ❖ Concise way of organising a purposeful program of civic action oriented towards EOL

Endorsed by Bunbury
City Council-
6 June 2023
& Launched 4 August



ALS Family Carers

*Traumatised, Angry, Abandoned
but
some Empowered*

What makes a difference to the grief journey
that starts from diagnosis?

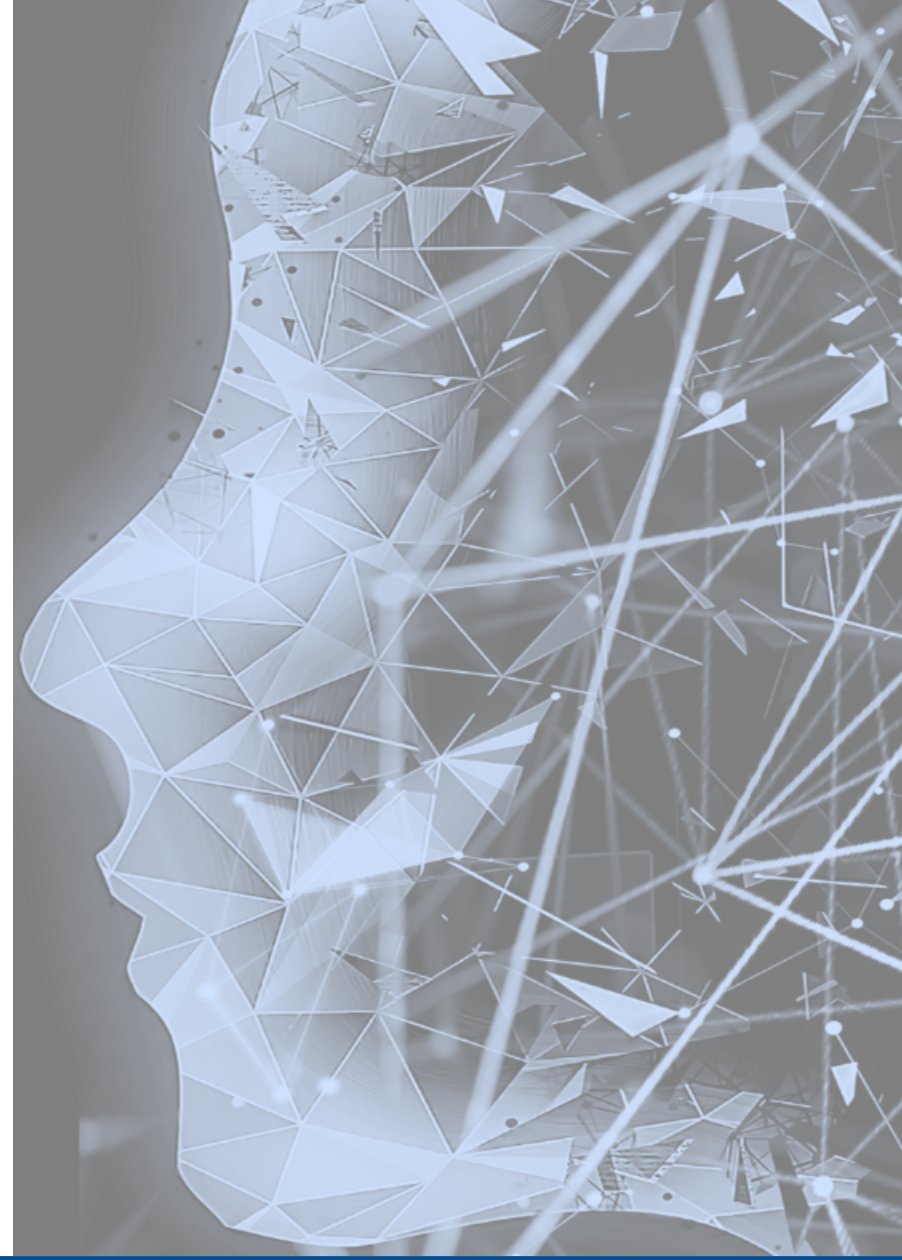
National MND Bereavement Survey

- An Australian-wide, population-based survey assessed the bereavement experiences of caregivers after the death of a relative/friend from MND between 2016 and 2018.
- Bereaved at least six months.
- A total of 1404 study packages were posted.
- 393 people completed the survey (response rate 30.5%).



Profile of the Bereaved

- Mean age 63·5 years (SD 12·3), range 22–91 years.
- Female (73·0%).
- Widowed (71·2%).
- Retired (53·6%).
- Australian (78·7%).
- Relationship: spouse/partner (73·7%) or child of deceased (18·9%).
- Mean period of bereavement 1·8 years (SD 0·8).
- Cared for a median of 1·5 years, range 0·4 to 22·5 years,
- 80% provided day-to-day hands-on care for an average of 18 hours per day in the last 3 months before death.





Measures of Psychological morbidity

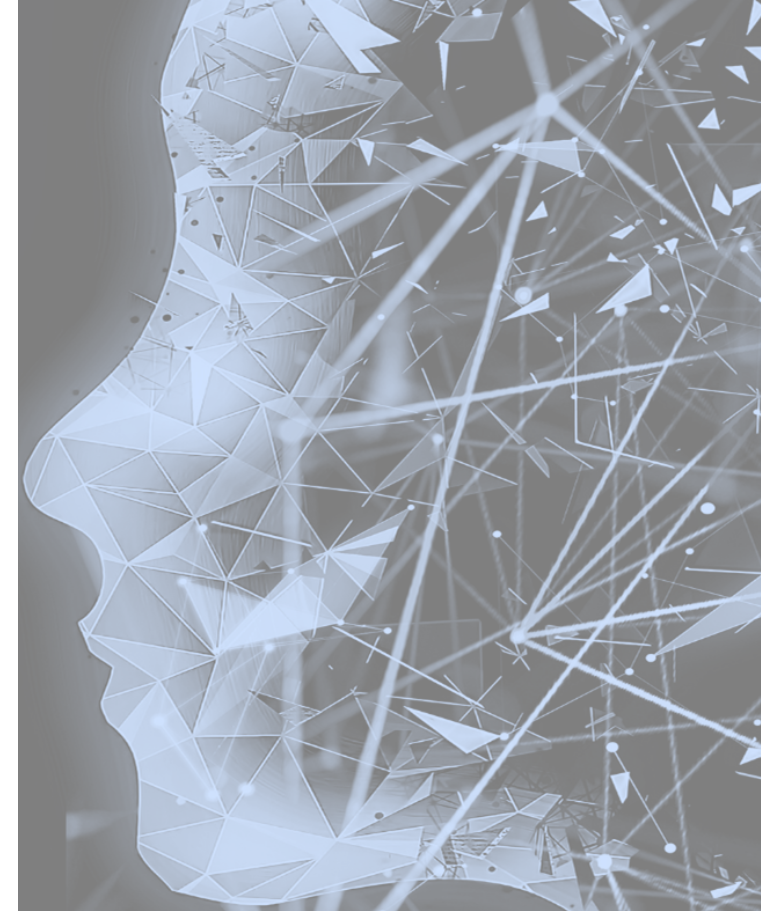
(Aoun et al, 2020)

- Prolonged Grief Disorder: 13-item PG-13
- Clinical depression: 9-item PHQ-9
- Clinical anxiety: 7-item GAD-7
- Family Functioning: The 12-item Family Relationships Index (FRI)

Psychological morbidity of bereaved MND carers

(Aoun et al, 2020)

- Moderate to severe anxiety =12.3%
- Moderate to severe depression =18.6%
- Family dysfunction = 18.7%



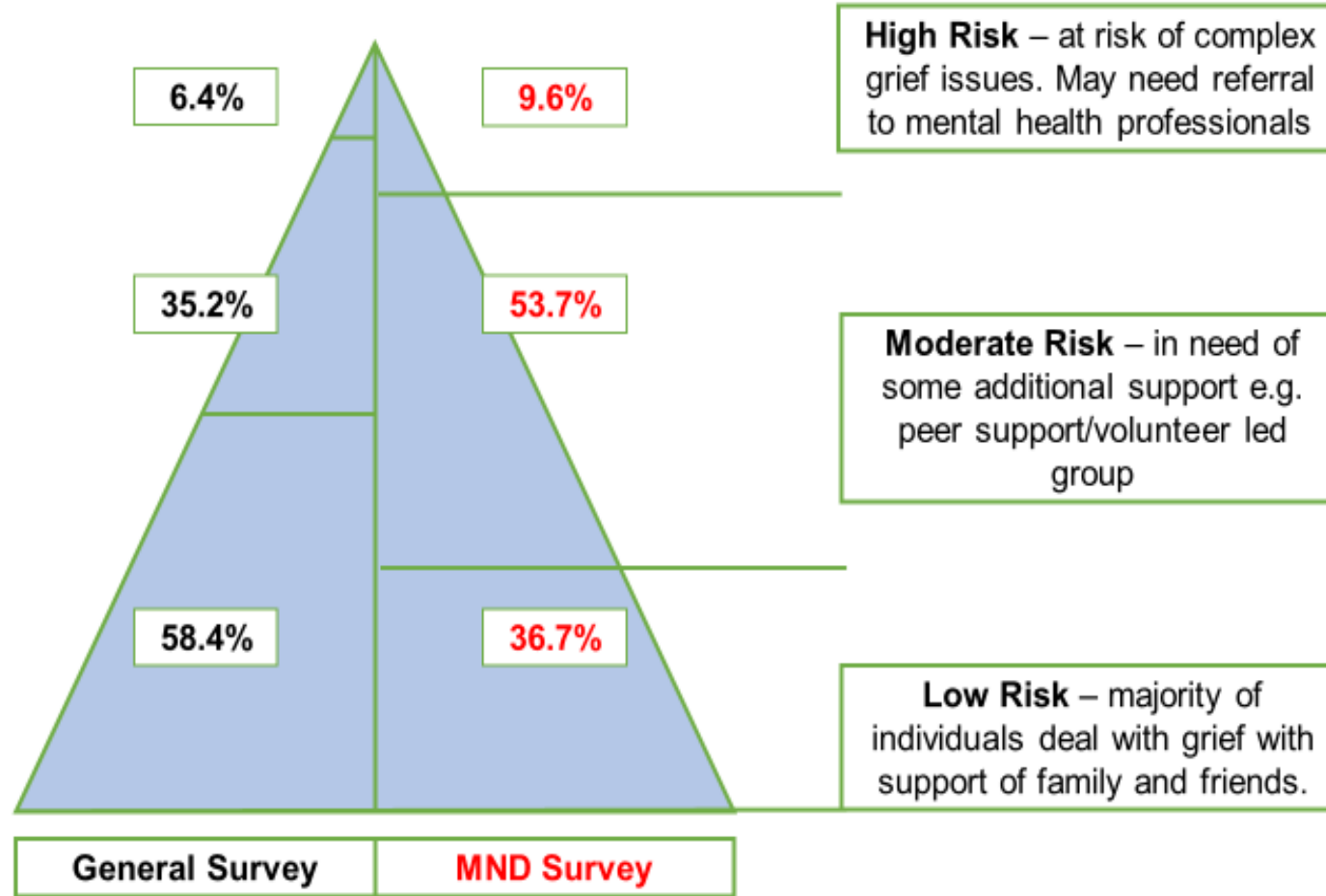
Risk factors for Complicated Grief

(Aoun et al, 2020)

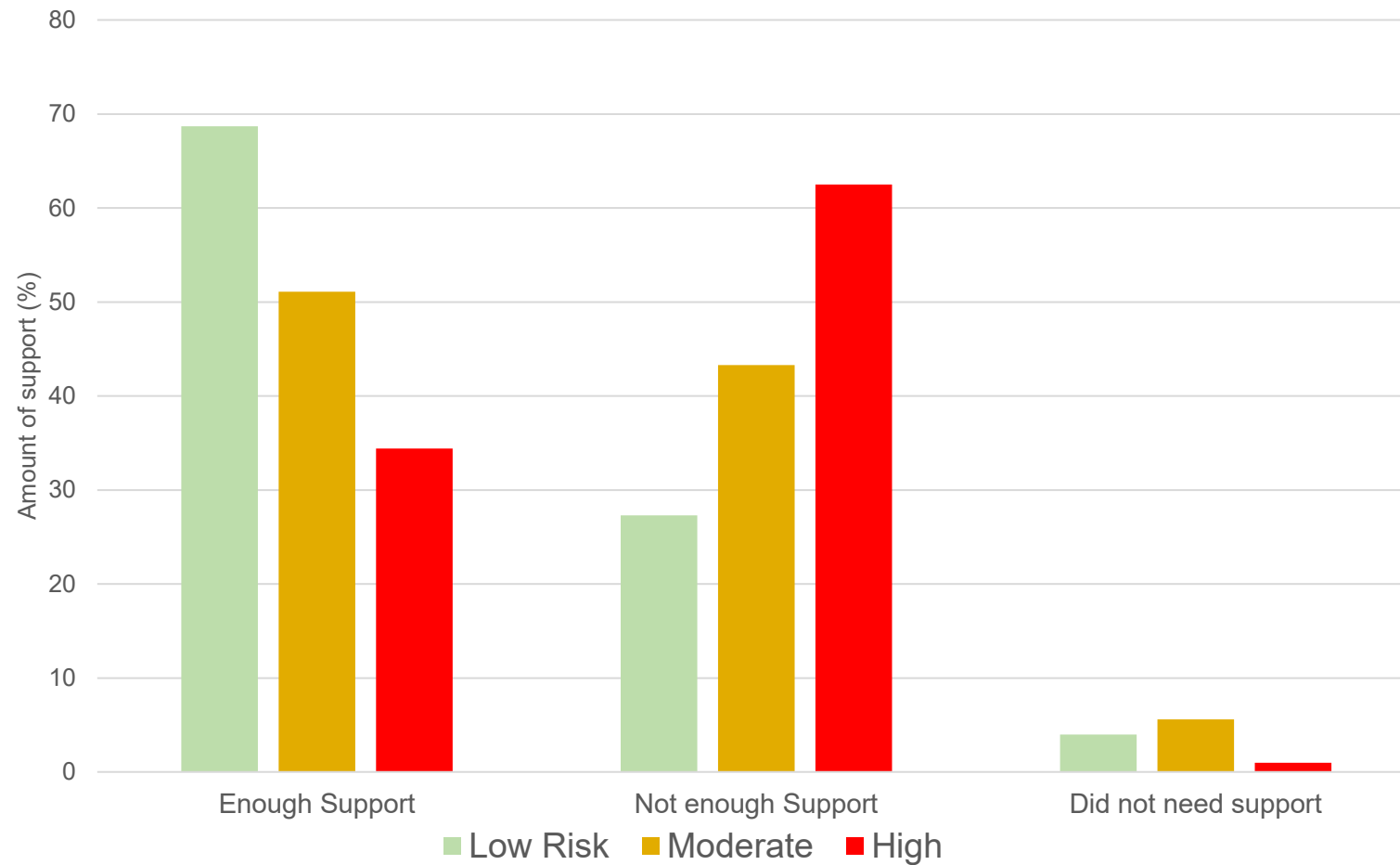
- 8 times more likely if carer had anxiety
- 18 times more likely if carer had depression
- 4 times more likely with poor family functioning
- A recent bereavement (<12 months)
- Being a spouse/partner of the deceased
- Deceased being under 60 years of age
- A shorter period of caring (<1.5 years)
- Insufficient support during the disease journey



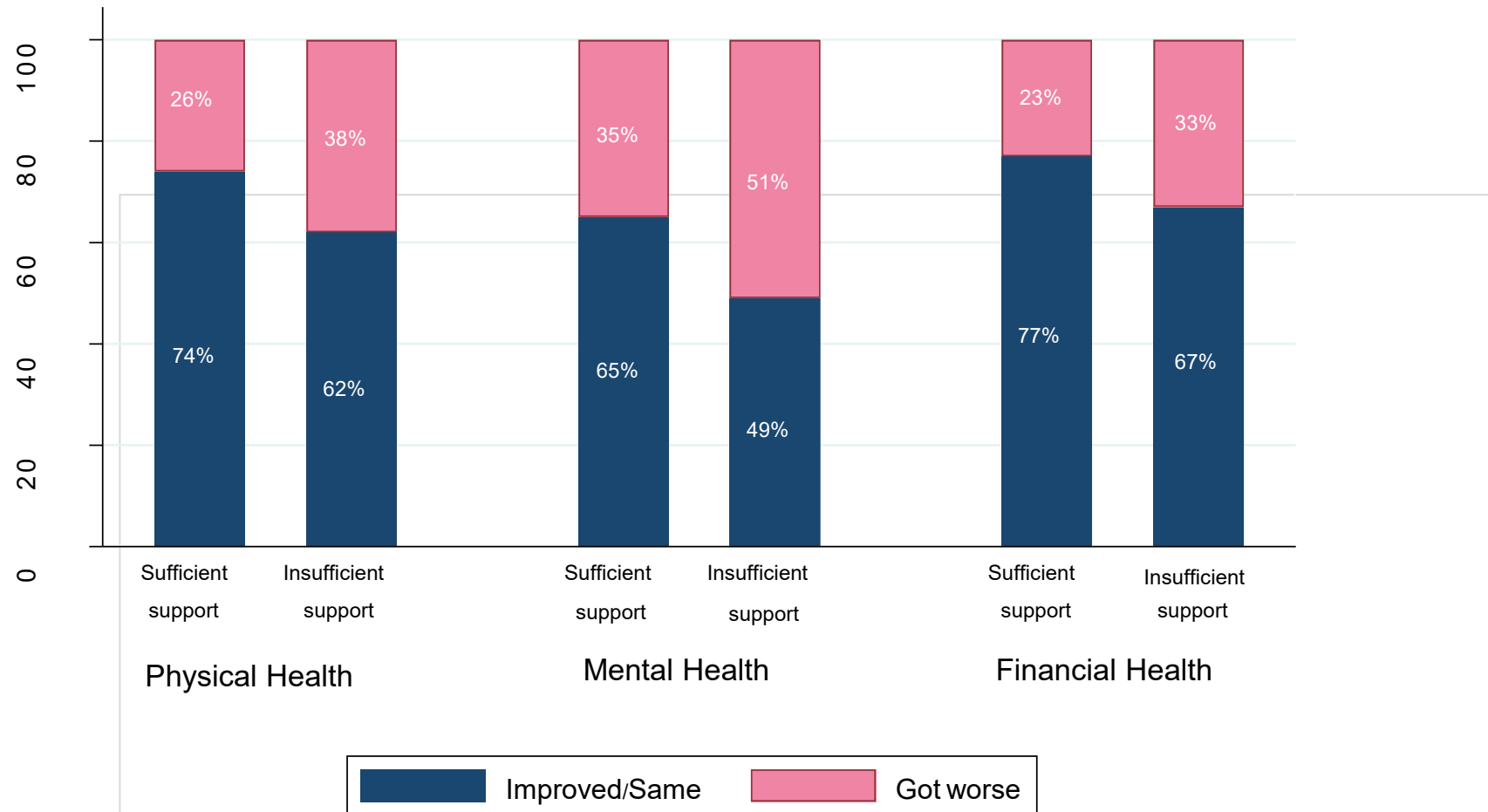
Proportions in the three grief risk groups of the **MND** bereaved population and the **general** bereaved population



Sufficiency of support by risk groups (Aoun et al, 2020)

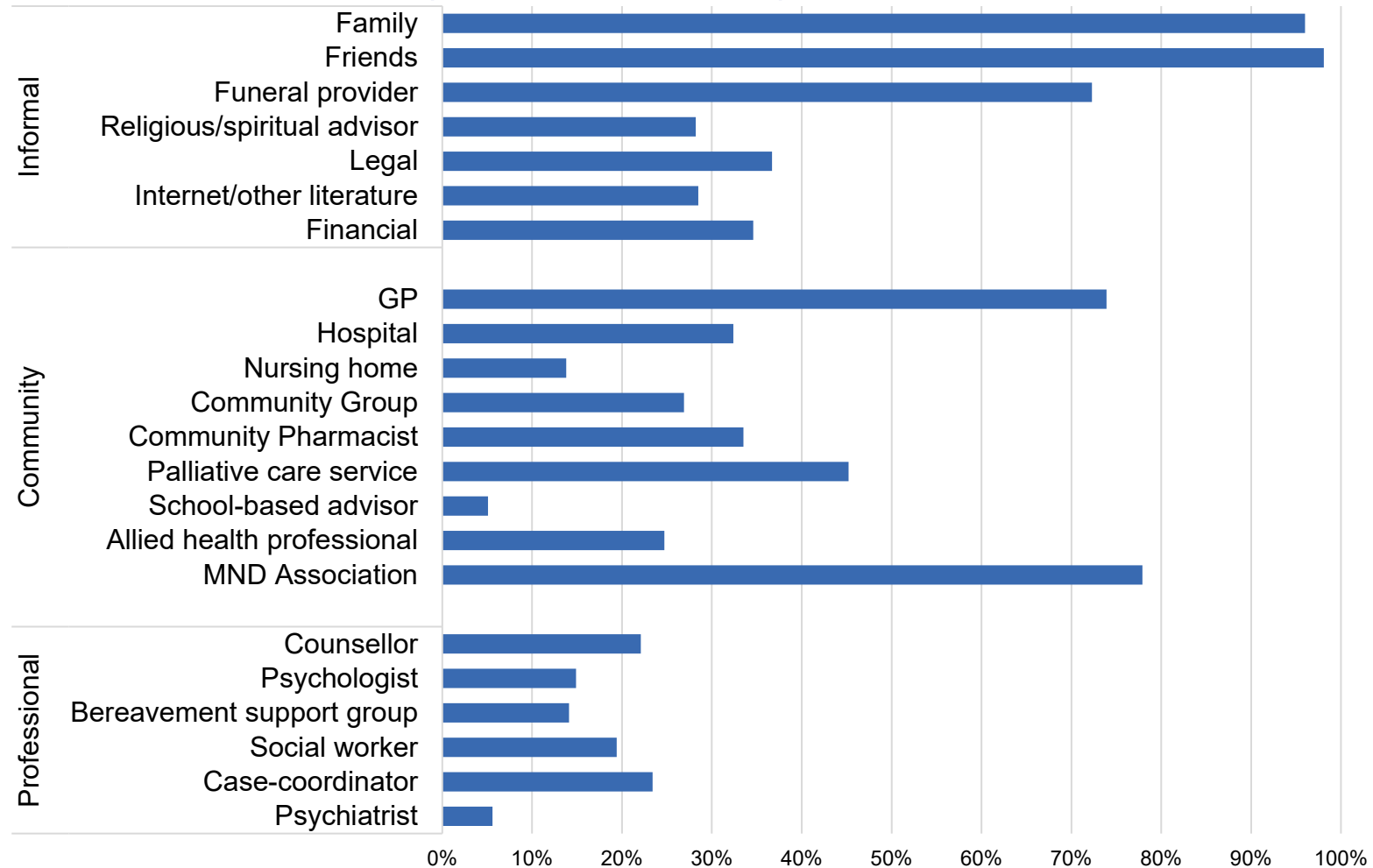


Sufficiency of support by self-reported impact on wellbeing (Aoun et al, 2020)

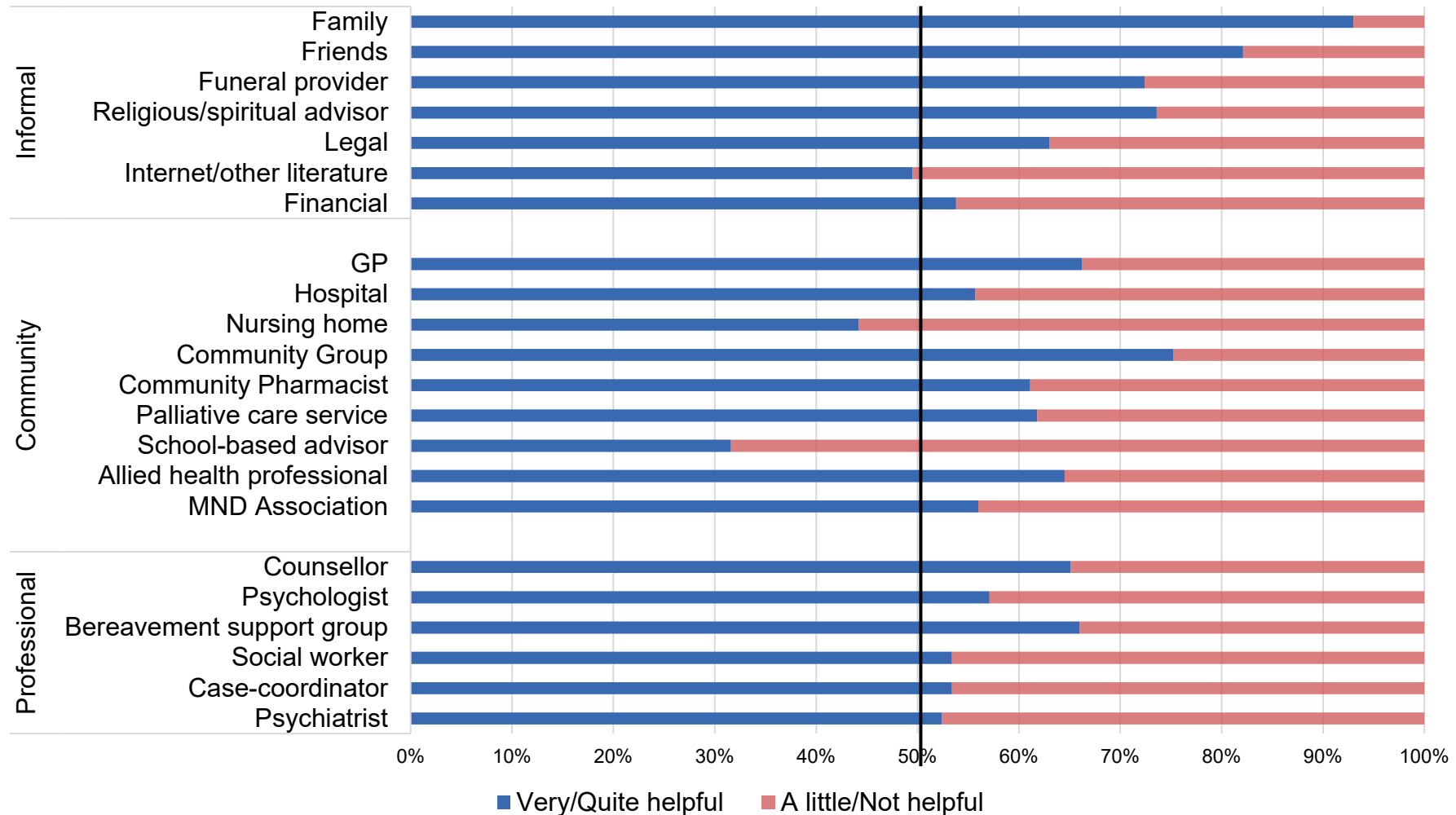


Sources of bereavement support accessed by MND family caregivers

(Aoun et al, 2020)



Sources of support perceived helpful or unhelpful by bereaved caregivers



Quotes from bereaved caregivers - Low Risk

I miss my husband every day, but I do not miss the MND illness. It made life very difficult at times (353)

I cannot change the past, there is no cure for MND, I appreciate every day I have and enjoy the small things in life (521)

I was very fortunate to have the friend and family I have. They have been with me whenever I needed support, distraction or someone to reflect with (184)

Quotes from bereaved caregivers - High Risk

Extraordinarily hard with the 'illness taking a toll on our lives' (338)

Not wanting to be here (210)

It is difficult suddenly living alone and a feeling of loss of purpose ... nothing prepares you for being alone (217)

People say go on a holiday but not having someone to share the experiences with makes it a sad experience, not a happy one. I spent a lot of time carving a small headstone for her grave' (236)



ORIGINAL ARTICLE

Grief, depression, and anxiety in bereaved caregivers of people with motor neurone disease: a population-based national study

SAMAR M AOUN^{1,2} , DAVID W KISSANE^{3,4} , PAUL A. CAFARELLA^{5,6,7} , BRUCE RUMBOLD¹, ANNE HOGDEN⁸ , LEANNE JIANG^{1,2}  AND NATASHA BEAR⁹

¹Public Health Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, VIC, Australia, ²Perron Institute for Neurological and Translational Science, Perth, WA, Australia, ³Palliative Medicine Research, The University of Notre Dame Australia, and The Cunningham Centre for Palliative Care Research, St Vincent's Hospital, Sydney, NSW, Australia, ⁴Cabrini Psycho-Oncology and Supportive Care Research Unit, Monash University, Melbourne, VIC, Australia, ⁵Department of Respiratory Medicine, Flinders Medical Centre, Bedford Park, SA, Australia, ⁶School of Psychology, Faculty of Health and Medical Sciences, University of Adelaide, Adelaide, SA, Australia, ⁷College of Nursing and Health Sciences & College of Medicine and Public Health, Flinders University of South Australia, Bedford Park, SA, Australia, ⁸Australian Institute of Health Service Management, College of Business and Economics, University of Tasmania, NSW, Australia and ⁹Institute of Health Research, Fremantle Campus, University of Notre Dame Australia, Fremantle, WA, Australia






Abstract

Background: Despite the traumatic and fatal nature of motor neurone disease (MND) and the caring experiences being described as unrelenting, little is known about risk of psychiatric morbidity and Prolonged Grief Disorder (PGD) for family caregivers. **Methods:** A cross-sectional survey of caregivers bereaved in 2016–2018 was distributed by the five MND Associations in Australia (2019). Validated tools for PGD (PG-13), anxiety, depression, and family functioning were included. Multinomial logistic regression was used to compare the factors associated with grief. **Findings:** Overall, 393 valid responses were received, a 31% response rate. The prevalence of ICD-11 PGD was 9.7%; moderate/severe anxiety 12.3%, moderate/severe depression 18.5% and 18.7% indicated poor family functioning. MND caregivers have higher bereavement risk prevalence than the general bereaved population, with 9.6% in the high-risk group (vs 6.4%) and 54% at moderate risk (vs 35%). Being in the PGD group was 8 or 18 times more likely when the respondent had anxiety or depression, respectively. Poor family functioning significantly increased the likelihood of PGD by four times. Other significant predictors of PGD were a recent bereavement (<12 months), being a spouse/partner of the deceased, insufficient support during the disease journey, the deceased being under 60 years of age, and a shorter period of caring (<1.5 years). **Conclusion:** In a large national population-based sample of bereaved MND caregivers, 63% required



RESEARCH ARTICLE

Who cares for the bereaved? A national survey of family caregivers of people with motor neurone disease

SAMAR M. AOUN^{1,2} , PAUL A. CAFARELLA^{3,4} , BRUCE RUMBOLD⁵, GEOFF THOMAS⁶, ANNE HOGDEN⁷ , LEANNE JIANG^{1,2} , SONIA GREGORY⁸ & DAVID W. KISSANE^{9,10,11} 


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Abstract

Background: Although Motor Neurone Disease (MND) caregivers are most challenged physically and psychologically, there is a paucity of population-based research to investigate the impact of bereavement, unmet needs, range of supports, and their helpfulness as perceived by bereaved MND caregivers. **Methods:** An anonymous national population-based cross-sectional postal and online survey of bereavement experiences of family caregivers who lost a relative/friend to MND in 2016, 2017, and 2018. Recruitment was through all MND Associations in Australia. **Results:** 393 valid responses were received (31% response rate). Bereaved caregiver deterioration in physical (31%) and mental health (42%) were common. Approximately 40% did not feel their support needs were met. Perceived insufficiency of support was higher for caregivers at high bereavement risk (63%) and was associated with a significant worsening of their mental and physical health. The majority accessed support from family and friends followed by MND Associations, GPs, and funeral providers. Informal supports were reported to be the most helpful. Sources of professional help were the least used and they were perceived to be the least helpful. **Conclusions:** This study highlights the need for a new and enhanced approach to MND bereavement care involving a caregiver risk and needs assessment as a basis for a tailored “goodness of fit” support plan. This approach requires continuity of care, more resources, formal plans, and enhanced training for professionals, as well as optimizing community capacity. MND Associations are well-positioned to support affected families before and after bereavement but may require additional training and resources to fulfill this role.

Keywords: Motor neurone disease, bereavement support, sources of support, social support, professional support, informal support, physical health, mental health, family caregivers, MND Associations, palliative care, compassionate communities, population survey, Amyotrophic lateral sclerosis

Traumatized, angry, abandoned but some empowered: a national survey of experiences of family caregivers bereaved by motor neurone disease

Samar M. Aoun , Kerrie Noonan, Geoff Thomas and Bruce Rumbold

Abstract

Background: There are few illnesses as disruptive as motor neurone disease, a fatal neurodegenerative condition, where diagnosis introduces a clinical narrative of inevitable decline through progressive immobilisation into death. Recent evidence suggests that bereaved motor neurone disease family caregivers are more likely to be at moderate or high risk of complicated grief.

Methods: Qualitative data from an anonymous national survey of bereaved motor neurone disease caregivers ($n = 393$) was examined through thematic analysis to explore the experiences of people who are at low, moderate, and high risk of complicated grief. Up to 40% responded to three open-ended questions: How caregivers viewed their coping strategies; the advice they had for others and what had been positive about their experience.

Results: Ten themes informed the narratives of illness and loss. All three groups shared similar experiences but differed in their capacity to address them. The low-risk group seemed to recognise the uncertainty of life and that meaning needed to be created by them. For the moderate-risk group, while motor neurone disease was a major disruption, they could with support, regroup and plan in different ways. The high-risk group did not have many resources, external or internal. They felt let down when professionals did not have answers and could not see or did not know how to change their ways of responding to this unwanted situation.

Conclusion: The differences in these three profiles and their narratives of loss should alert health and community service providers to identify and address the caregivers' support needs early and throughout the caregiving journey. Motor Neurone Disease Associations are involved throughout the illness journey and need to invest in a continuum of care incorporating end-of-life care and bereavement support. Community grief literacy and enhancement of social networks are keys to improved support from families and friends that can enable the focus to be on feelings of empowerment rather than abandonment.

Keywords: bereavement support, compassionate communities, coping, family caregivers, grief literacy, motor neurone disease, social support

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Why and how the work of Motor Neurone Disease Associations matters before and during bereavement: a consumer perspective

Samar M. Aoun , Paul A. Cafarella , Anne Hogden ,
Geoff Thomas, Leanne Jiang  and Robert Edis

Abstract

Background: Studies on the experiences of consumers with Motor Neurone Disease Associations at end of life and bereavement are lacking, and their role and capability within the broader sectors of health and disability are unknown.

Objectives: To ascertain the experiences and views of bereaved motor neurone disease caregivers with Motor Neurone Disease Associations about service gaps and needed improvements before and during bereavement and to propose a model of care that fits with consumer preferences and where Motor Neurone Disease Associations are effective enablers of care.

Methods: A national bereavement survey was facilitated in 2019 by all Motor Neurone Disease

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What can MND Associations do?

Carers' suggestions to improve support during bereavement (n=393)

(Aoun et al, 2021)

More contact and compassion from MND Associations post-death

MND Associations to provide referrals and links for counselling

Facilitate access to carer support groups and peer interaction

Provision of a genuine continuum of care rather than post-death abandonment

Guidance regarding post-death practicalities

Better staff training for provision of emotional support

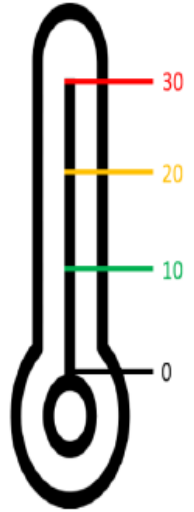
More access to bereavement support in rural areas - telehealth

Caring For Family Carers

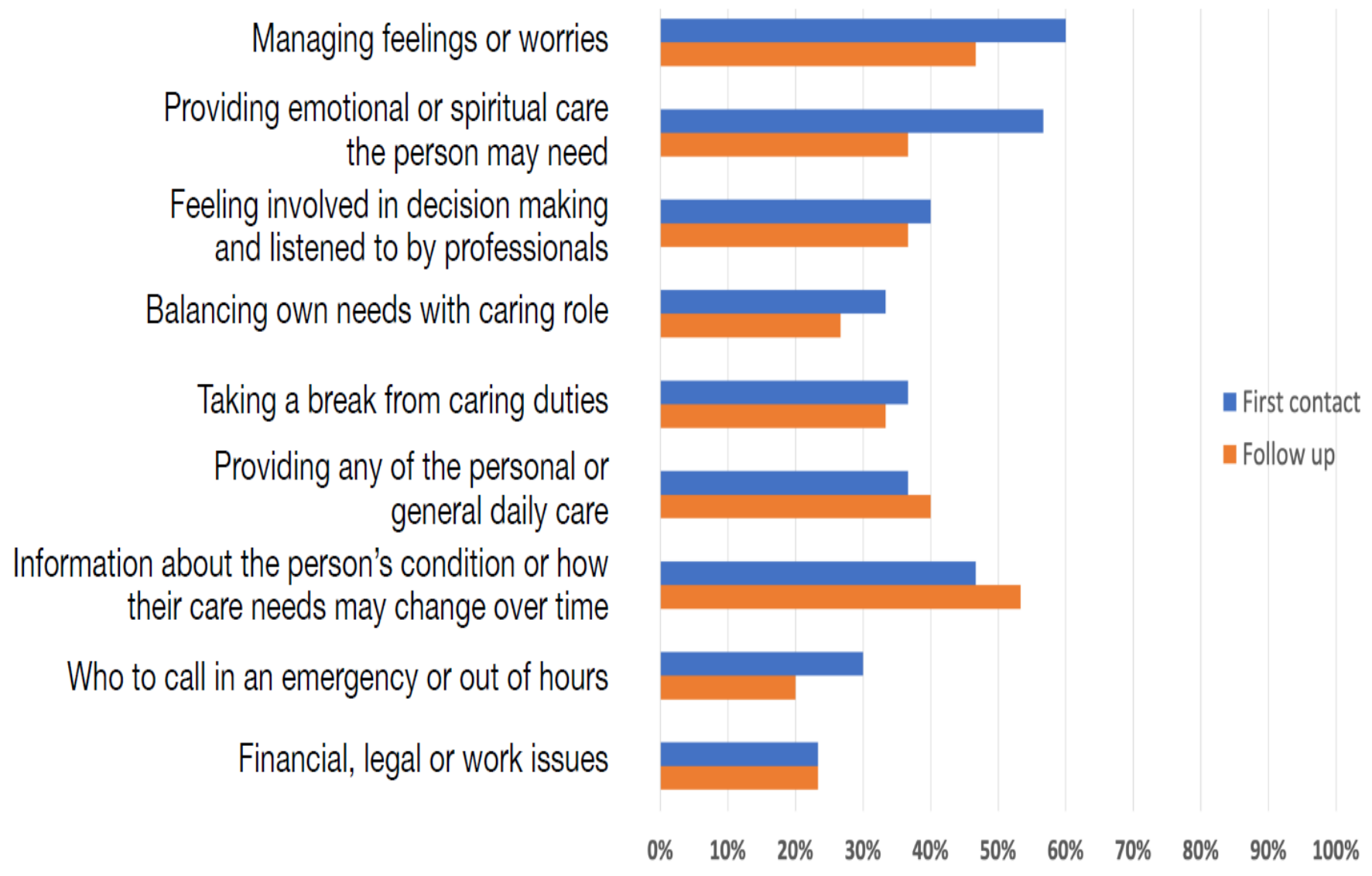
- Family Carers are vital partners in increasing the person-centeredness of health and social care systems.
- Policies all over the world emphasize the need to identify and address the needs of family carers but very few services have a focus on family carers.
- We need to systematically hold conversations about the practical, psychological, spiritual, and existential needs of carers in supporting their care recipients but also helping themselves.

SECTION 2: IDENTIFY AND ASSESS THE NEEDS OF THE FAMILY CARER

Carer and Advisor to discuss each question, even if no needs or concerns are identified at Q1, and circle the carer's level of *perceived need* for any alerts using levels of **N** NONE (Score of 0), **L** LOW need (Score of 1), **M** MODERATE need (Score of 2), or **H** HIGH need (Score of 3). **Please provide one response for all questions.**

1. Do you currently have any needs or concerns about providing care or your own health and well-being?		Yes	No	Unsure		
PART A: THE CURRENT CARING SITUATION	How much support do you need...	0	1	2	3	SECTION 3: Indicate total score for alerts identified for Q2-Q10 on or below the thermometer 
	2. ...with any information about the person's condition and how their care needs might change over time	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
	3. ...to provide any of the personal care or general daily care? (e.g. additional support, training for lifting and handling, equipment)	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
	4. ...to provide any emotional or spiritual care the person may need?	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
	5. ...to know who to call in an emergency, or out-of-hours, to discuss any concerns about the person?	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
	6. ...to feel involved in the decision making and listened to by professionals about the care needed by the person (consider if the person requires power of attorney)	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
PART B: CARER HEALTH & WELL-BEING	7. ...about financial, legal or work issues?	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
	8. ...to take a break from caring during the day or overnight (e.g. sitting service, respite)	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
	9. ...to balance your own needs with the demands of caring? (e.g. attend own health appointments, social activities, caring for others)	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
	10. ...to manage any feelings or worries that you may have? (e.g. a 'listening ear' or having someone to talk to)	<input type="radio"/> N	<input type="radio"/> L	<input type="radio"/> M	<input type="radio"/> H	
If appropriate include: Do you know the person's wishes and					TOTAL SCORE: <input type="text"/>	

Family Carers identifying high to moderate needs for support (n=30)



MND Family Carer Feedback



“Can see that in 5 years’ time when it’s an established tool and part of the process this will be a good thing.”

“At the onset you have no idea, so many new terms. You are so caught up in the diagnosis that you are not thinking ahead. Completing the assessment tool prompted me to find and seek relevant information much earlier”

“This really hit the mark in helping me address my needs and clarify actions.”

MND Family Carer Feedback



“I think it’s a brilliant idea. It is something that should be repeated regularly and would have helped alleviate (or prevent) some of the issues we faced. It also enabled the health professional to highlight to my husband so that he got a better idea of how I was feeling and what I was going through. If we had had this earlier, it might have stopped us getting to the point we got to.”

Family carer information and support toolkit on website



Family Carer Online Support and Information Toolkit



Understanding MND



Supports for providing personal & general domestic care



Emotional and spiritual support



Who to contact



Being involved in decision-making



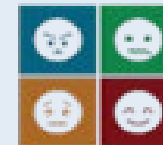
Financial, legal and work issues



Respite Options



Looking after your own needs



Managing your feelings and worries

www.mndawa.asn.au/family-carer-support

Feedback from MND carers on Toolkit

- *I feel like it will be of great benefit; it's not too wordy and doesn't go into minute detail but has follow up sites for those who need or would like more detail as well as sites for practical help.*
- *I like how it has both details of the disease, MND, and ways to help and support those with it, e.g. OT, equipment, NDIS, ACAT, hospital teams etc and then goes onto support for the carer.*
- *I found the practical examples of people seeking solutions to their situation helpful; it gave me a feeling of not being alone.*
- *I feel it will be a valuable tool to have and, being online, is available 24 hours a day as well as being able to be updated/amended as needed.*

This is a neglected yet seriously ill population
that calls
for better care provision

Recommendations

- The need for a new and enhanced approach to MND bereavement care involving a **caregiver risk and needs assessment** as a basis for a **tailored support plan**- Address caregivers' support needs **early and throughout the caregiving journey**.
- MND Associations are well-positioned to support affected families before and after bereavement. They are involved throughout the illness journey and need to invest in a **continuum of care incorporating end-of-life care and bereavement support**.
- MND Associations can connect both professional and community resources in a way that clinicians alone, or community actors, cannot. However, this requires MND Associations to include **bereavement care as an integral part of their role**, expand the period of support, and access additional training and necessary resources.

MND COMPASSIONATE COMMUNITY HELPERS NEEDED



MNDAWA are looking for community volunteers with a lived experience of motor neurone disease (MND) to support people with MND and their families.

Following a diagnosis of MND it can sometimes be difficult for people to know where to turn. These community helpers can give affected families the opportunity to talk about their feelings and let them know what help is available. This can help reduce the sense of isolation some people affected by the disease can experience.

The role provides:

- Free and confidential support for as long as it's required.
- Practical advice and accurate information, tailored to meet the individual needs of the family.
- Information about how MNDAWA can help and other sources of support
- Help for the family to identify problems as they arise and discuss options for how they might be managed.
- Acceptance and respect of the family's choices and wishes.



Feedback from families supported by similar programs

"having someone I can talk to honestly and openly that's there for me"

"I was feeling overwhelmed; their support helped me to make sense of my situation"

"a shoulder to lean on who's there because they care"

Rethinking Care at End of Life: A needed shift to a Compassionate Communities collaborative model

Public Health Approach to MND End of Life Care

ENABLERS

Digital Technologies:
Telehealth, Assistive

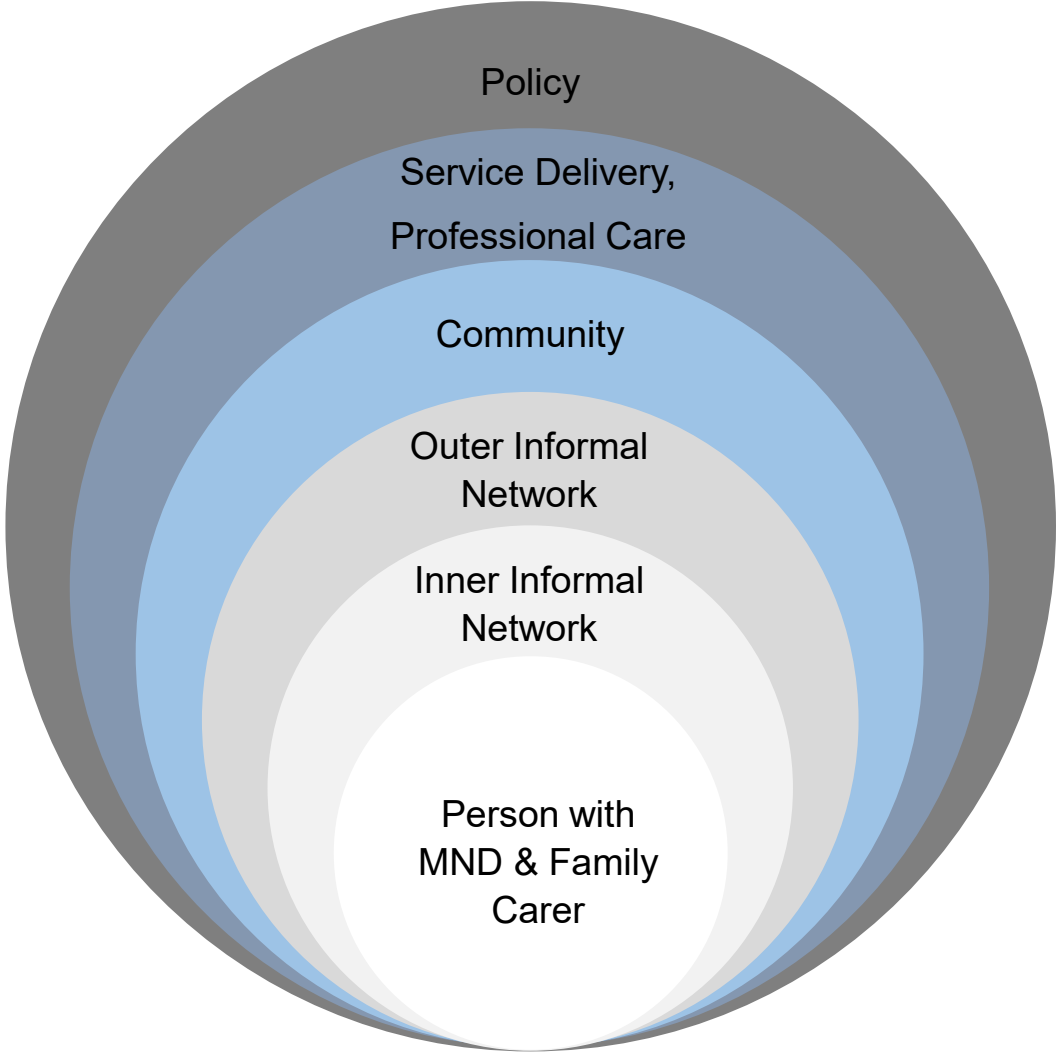
Advanced Care Planning

Education & Training Programs

Compassionate Communities

MND Associations

Other not for profit
organisations



CIRCLES OF CARE

INTEGRATION OF SERVICES

Disability Sector, NDIS

Aged Care Sector

Specialist Palliative Care

Generalist Palliative Care

MND Clinics

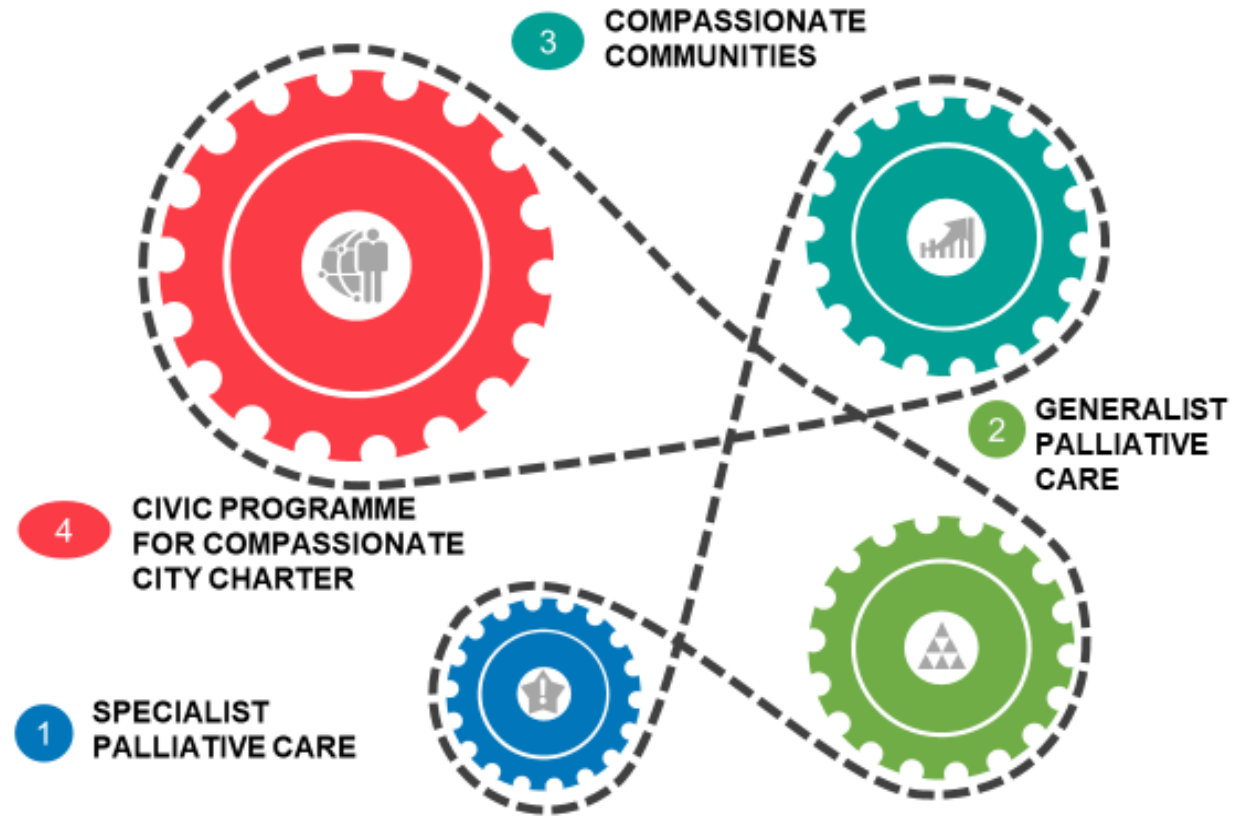
Primary Care

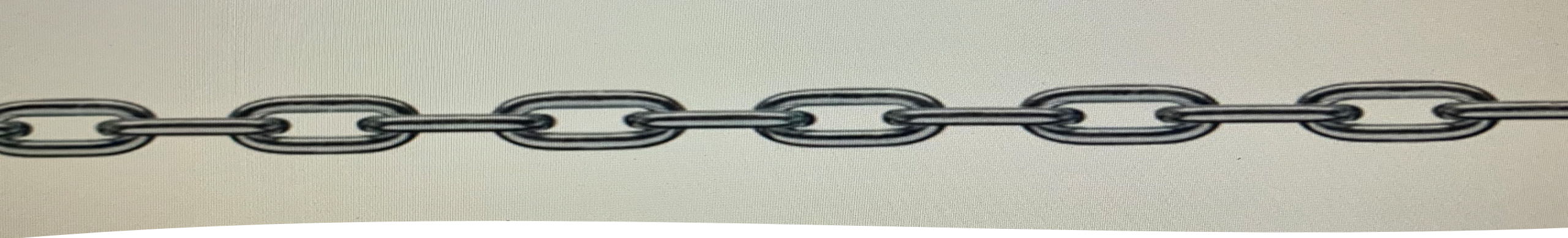
Maintaining system change includes

- 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.
- Understanding that the dots are connected by policies and collaborative partnerships, not a centralised bureaucratic structure.

Specialist and generalist palliative care, civic organisations and community networks must collaborate in order to create an effective, affordable & sustainable end-of-life care system

Palliative Care – The New Essentials





Health Depts Role in a Public Health Model

- Health Depts should encourage services to start conversations and allocate resources to developing relevant partnerships identified through these conversations.
- Health Depts need to get into community development as well as direct service provision and prepare the way by developing partnerships with civic and community networks.
 - Acting as the linkage- operating the chain joining the cogs

Preparing the community- awareness/education to build death/grief literacy

- Training programs in network mapping and network enhancement. These should be for both professionals and community members.
- Training to support the use of community-led advance care planning within the networks built to sustain community EOL care.
- Programs that train community members to support the EOL care and know how to use public resources for the benefit of people at EOL (e.g. Compassionate Connectors Program).
- Regular use of media to stimulate discussions on support needs for caregiving, dying and grieving.

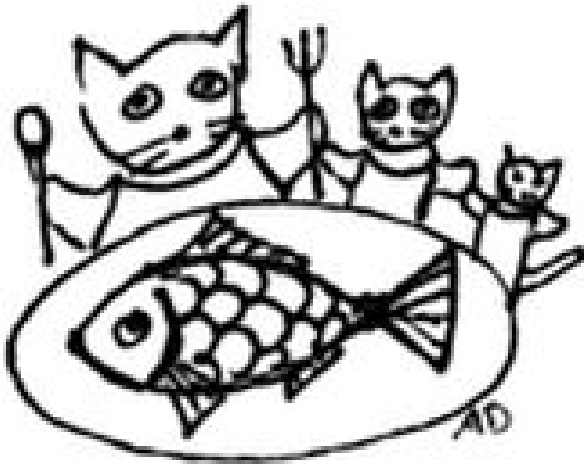
Dying to Know Day-
8 August



Dying to Know Day Bunbury program

Dying to Know Day is an annual campaign that brings to life conversations and community action around death, dying and bereavement. The campaign aims to

Give a Family
a Fish



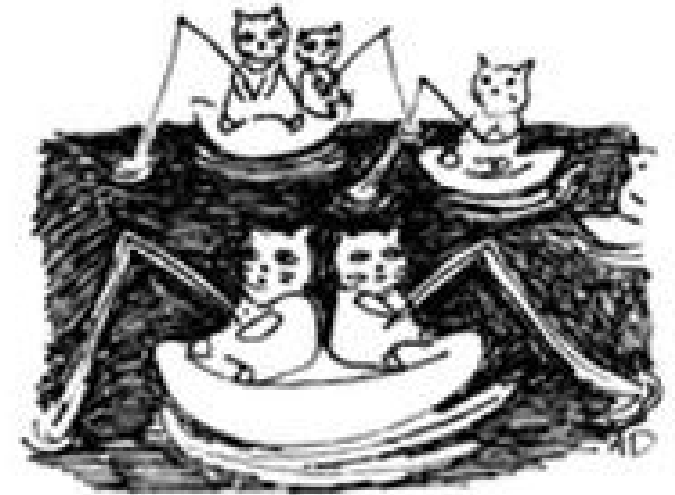
= Charitable Act

Teach a Family
to Fish



= Sustainability

Organize a Community-
Based, Intergenerational
Fishing Collective



= Social Change

Artwork: Alyce Dedge



Supporting those Caring, Dying and
Grieving
IS ABSOLUTELY EVERYBODY'S
RESPONSIBILITY

The Mountains Ahead To Climb!

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.

It isn't the mountains
ahead to climb that
wear you out; it's the
pebble in your shoe.

- Muhammad Ali