

Care of the Dying is a community responsibility



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Chair, South West Compassionate Communities Network



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)

We need to put back
PASSION
into
COMPASSION



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**

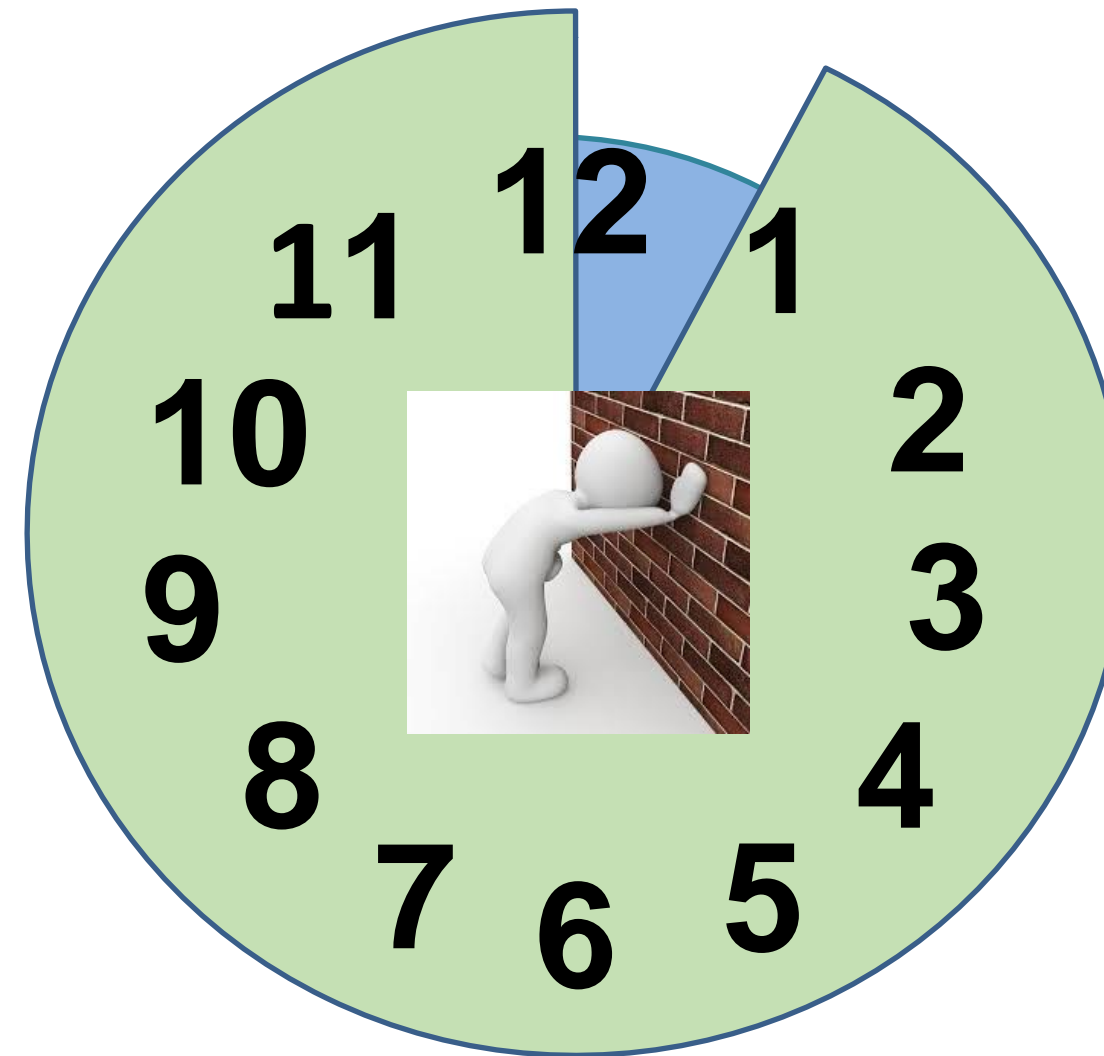
Internationally, models of social and practical support at the end of life are gaining momentum as a result of the Compassionate Communities movement.



- 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

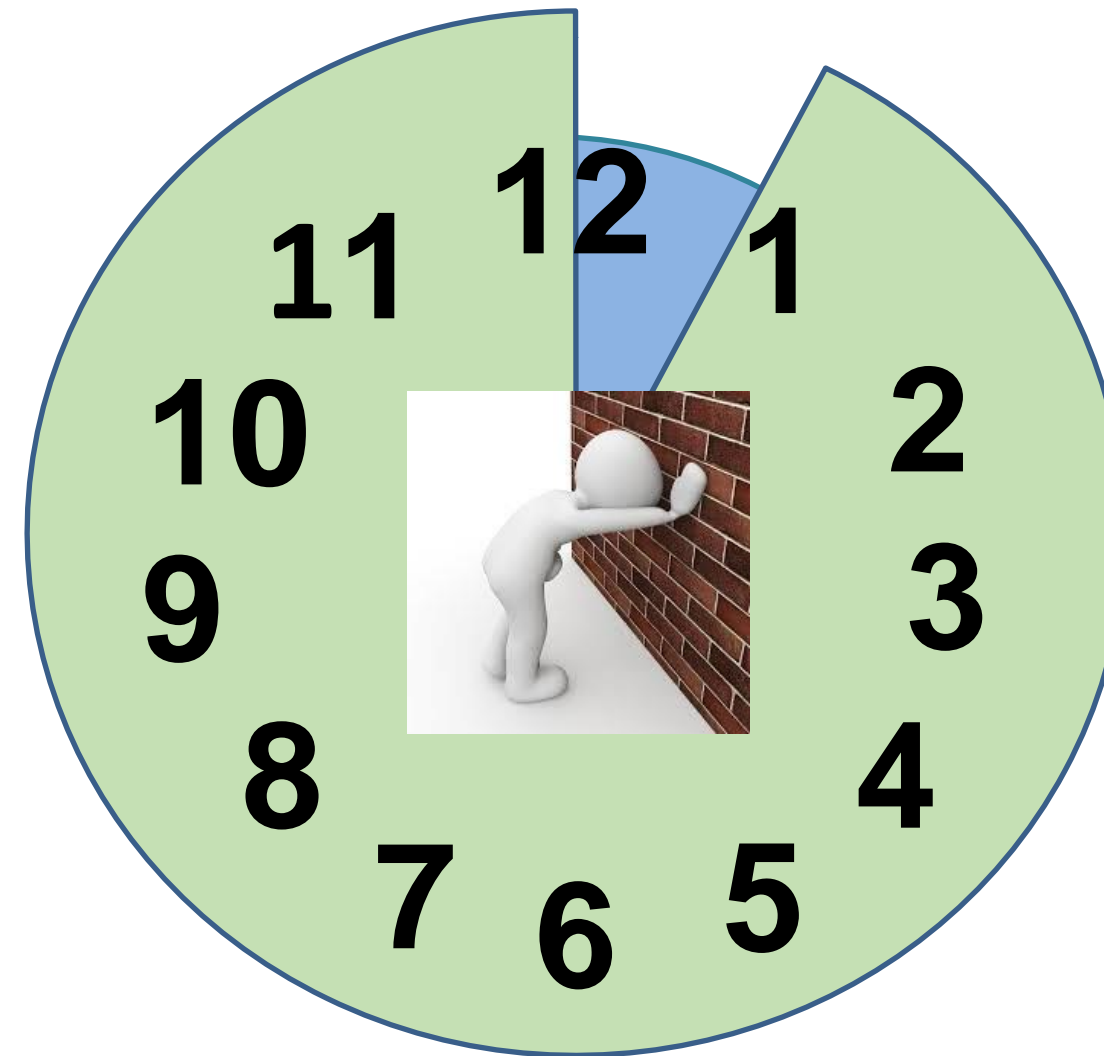
Adapted from Carpenter House model developed by



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



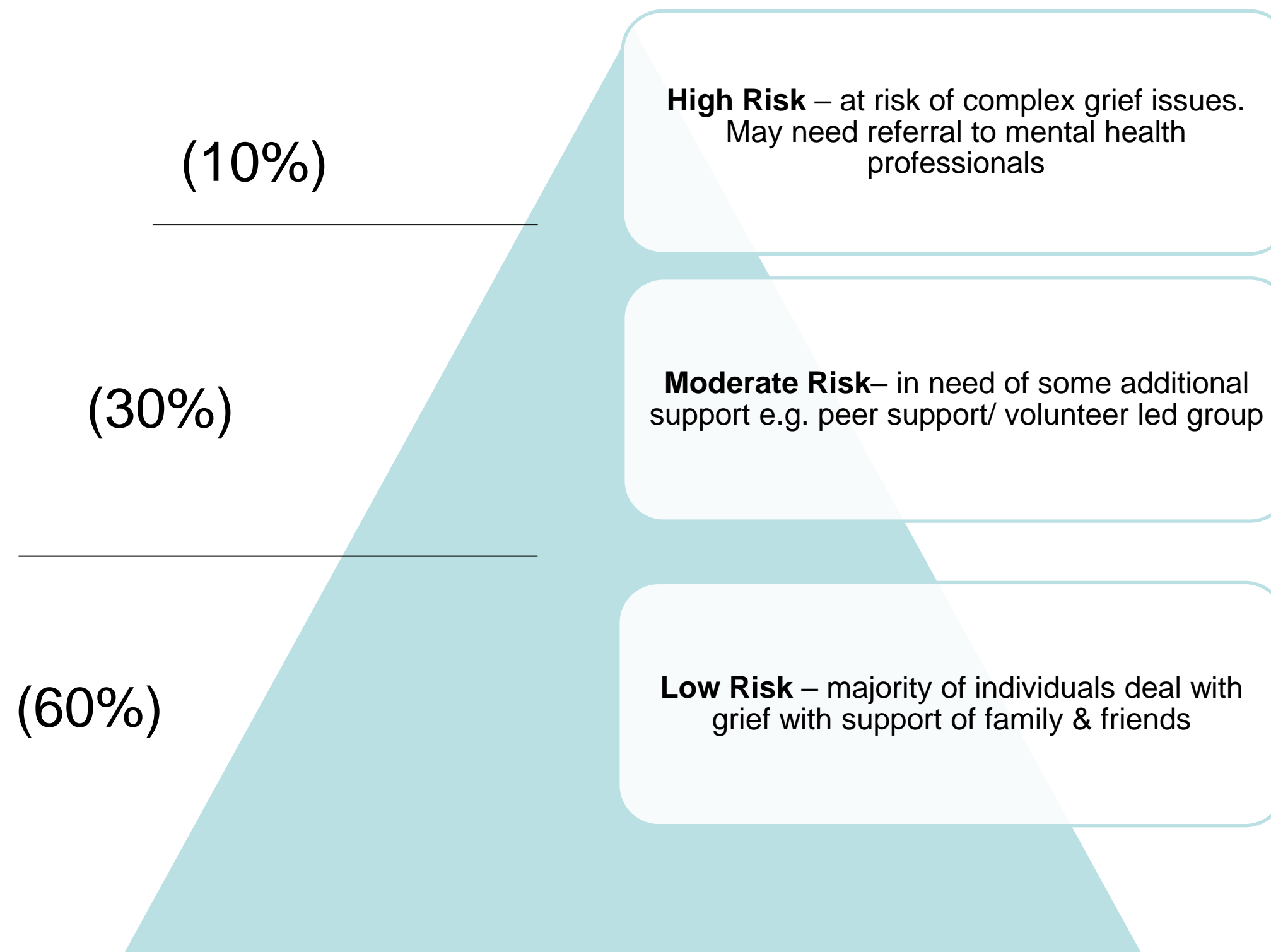
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Adapted from Carpenter House model developed by

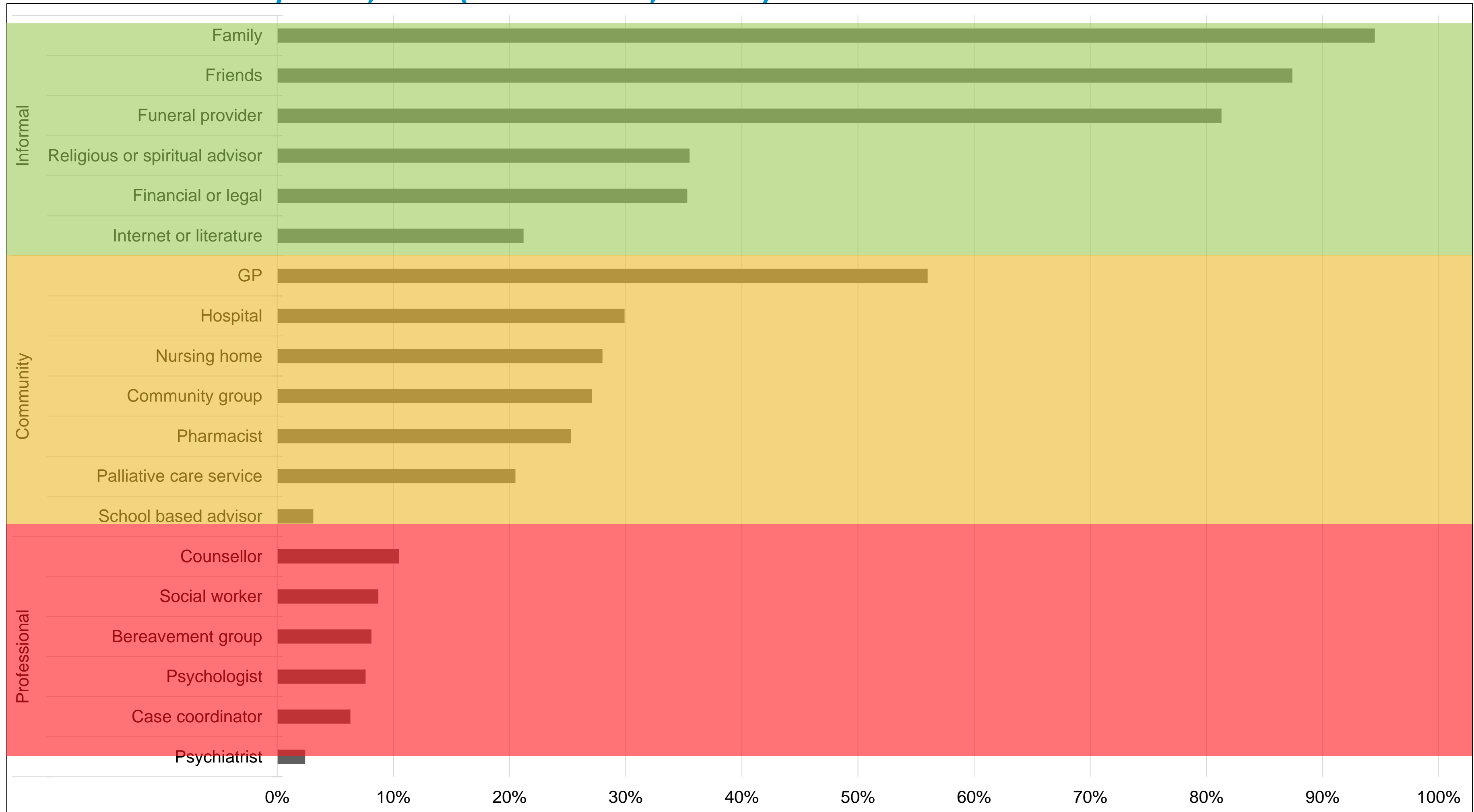


The Public Health Model of Bereavement Support (Aoun et al, 2015)



Where people get bereavement support

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



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



'GROWING AROUND GRIEF'

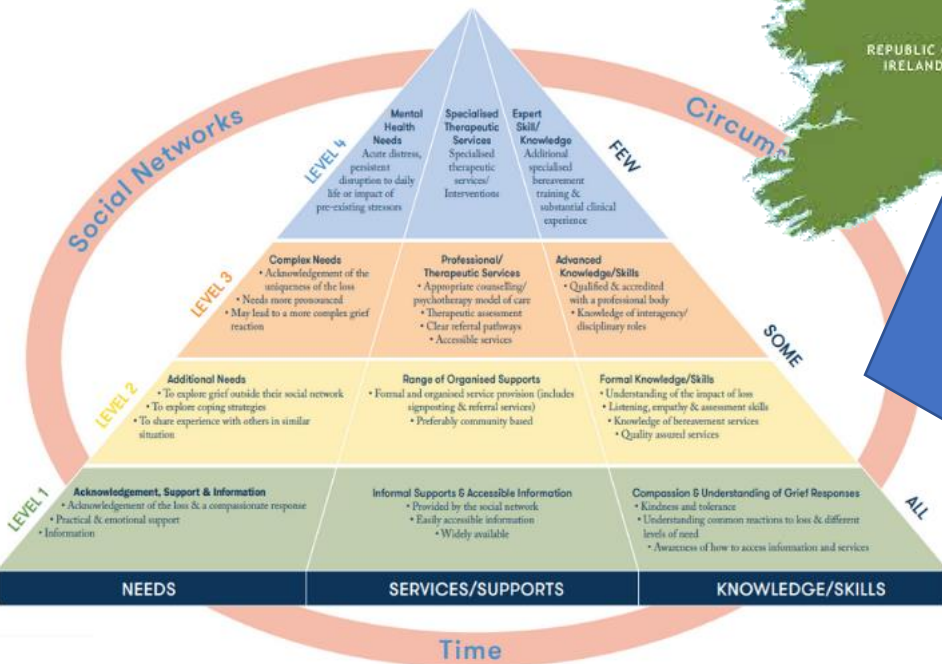
(LOIS TONKIN, 1996)

WHATSYOURGRIEF.COM



The Public Health Model for Bereavement Support-Translation

Palliative Care Australia Standard 6: Grief Support

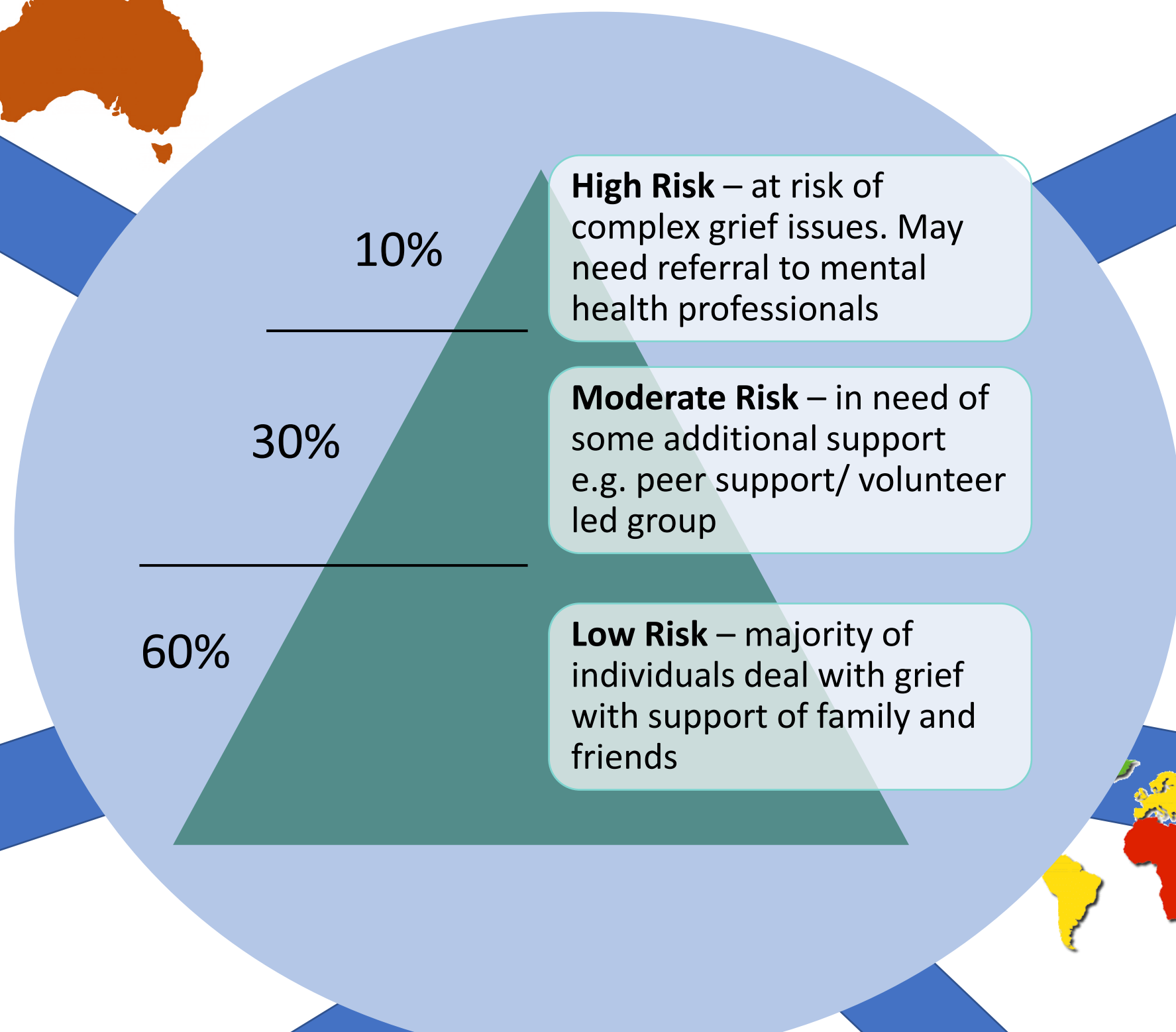


Irish Hospice Foundation Pyramid of Adult Palliative Care

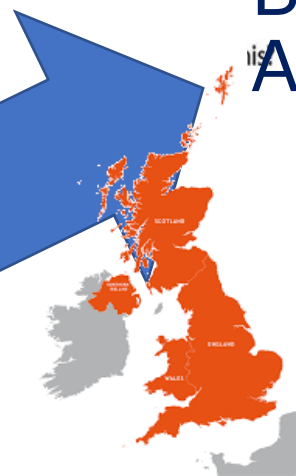
Bereavement Care Taskforce of the European Association of Palliative Care



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



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.

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

Supporting the dying is a community responsibility

Samar M. Aoun 

If death and dying are to be everyone's business and responsibility,¹ we have to change the way we speak about and organise end-of-life (EOL) care. Many people die in a way and a place that is not necessarily reflective of their values or their choices. Often their EOL journey is interrupted with preventable or unnecessary admissions to hospital and they do not feel in control of this part of their life.²⁻⁵ With the number of people dying expected to keep increasing,^{6,7} the question is who is going to provide the care that will be needed and what kind of death will people want to experience?

Although dying is a social process, in many industrialised countries the answer is often an ever-increasing professionalisation and medicalisation

improve the experience of dying for families, communities, and ultimately the person with a terminal illness using a public health approach.¹² This approach recognises that death is a social event with a medical component, not a medical event with a social component.⁵ The answer lies in supporting, looking after and caring for those who are unwell, dying, or grieving within their community network.^{1,13}

'Compassionate communities' is a term often applied to public health palliative care interventions that promote social outcomes such as network enhancement,^{13,14} partnerships between formal and informal organisations,¹⁵⁻¹⁷ death literacy,¹⁸ and civic engagement.¹⁹ A 'Compassionate Communities' approach recognises death and

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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**

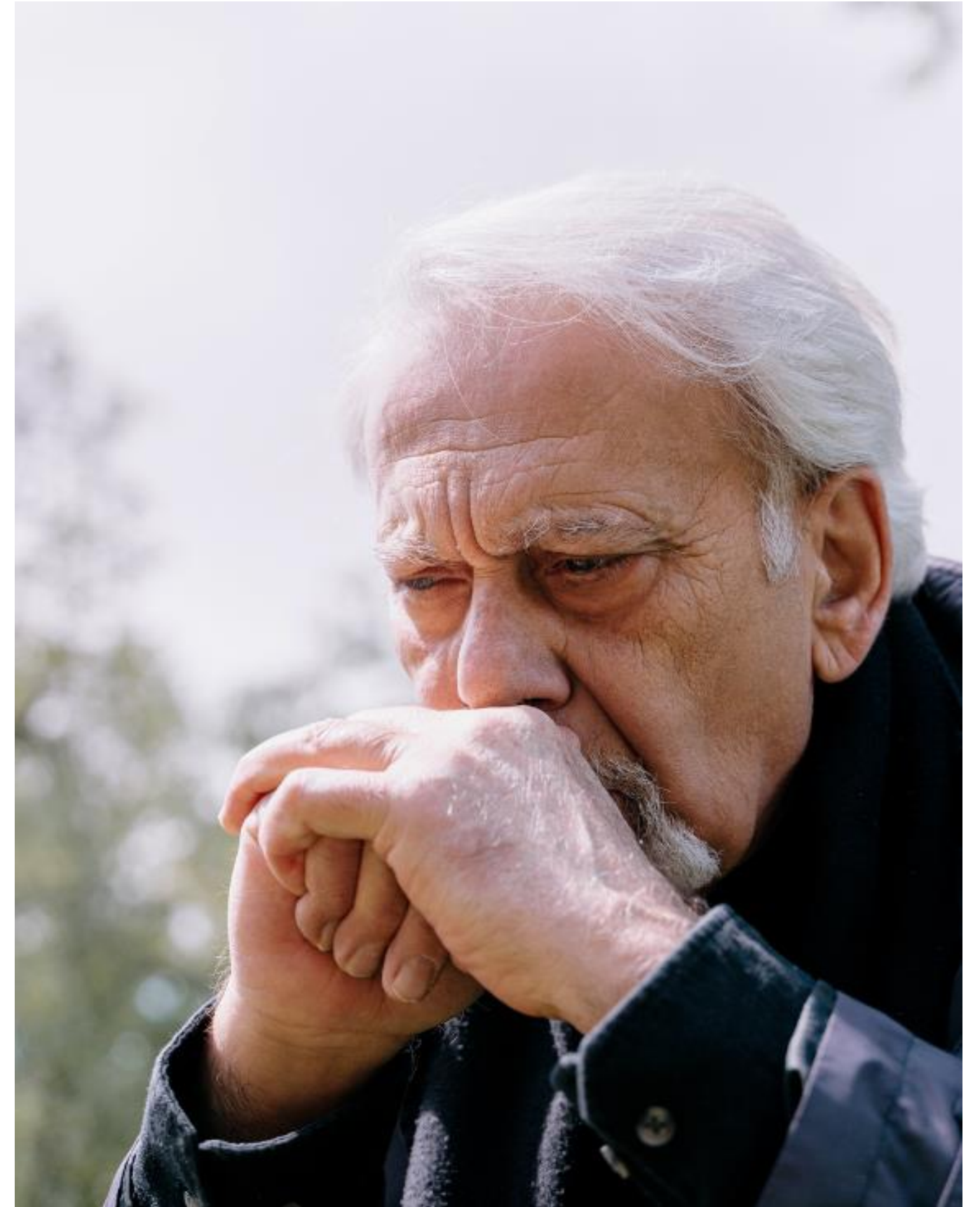
How are we doing in Australia (1)?

- 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

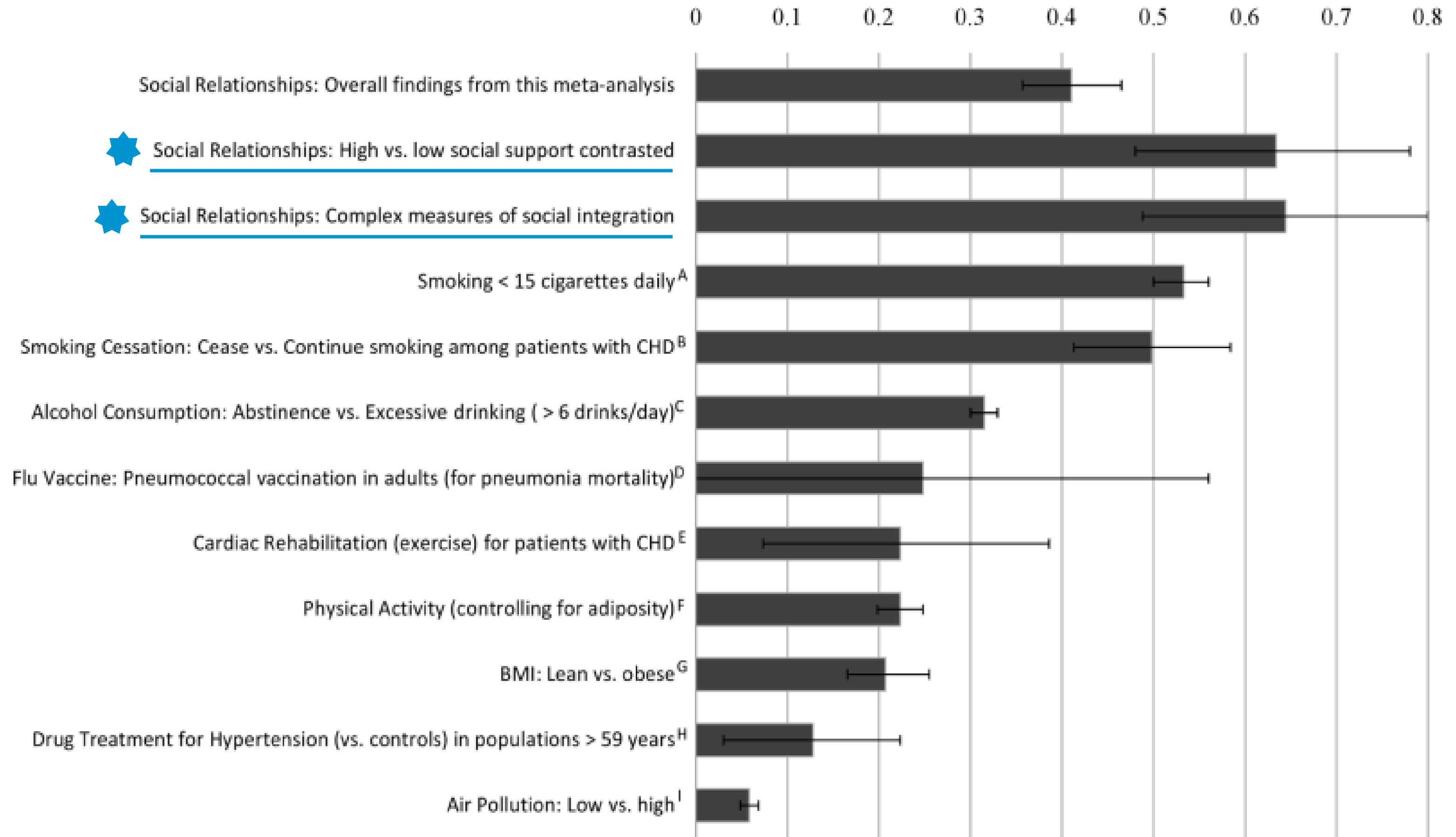
People who are more socially connected are happier, physically healthier, live longer.

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





SOUTH WEST
**Compassionate
Communities**
NETWORK

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

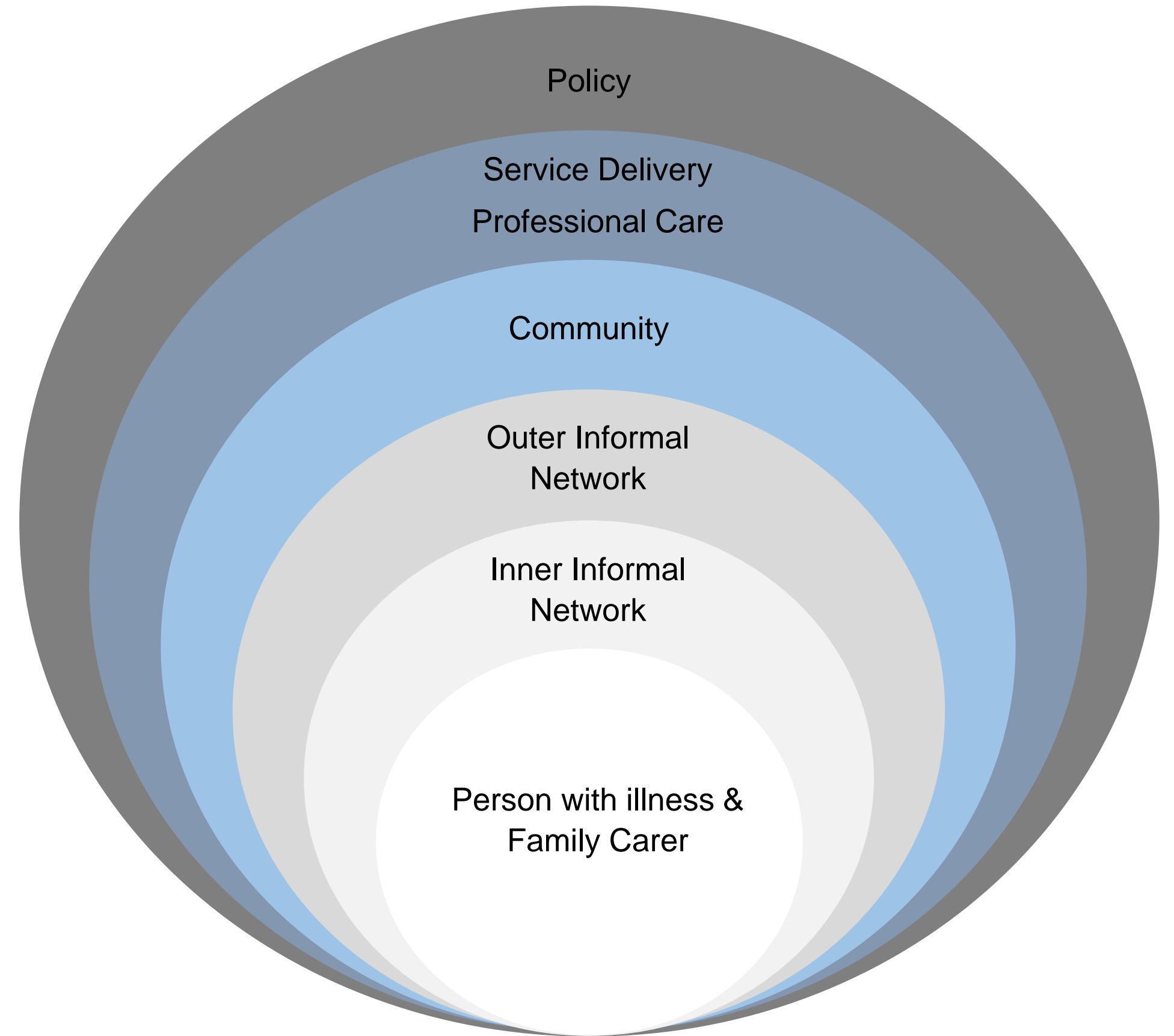


Compassionate Community Connectors

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

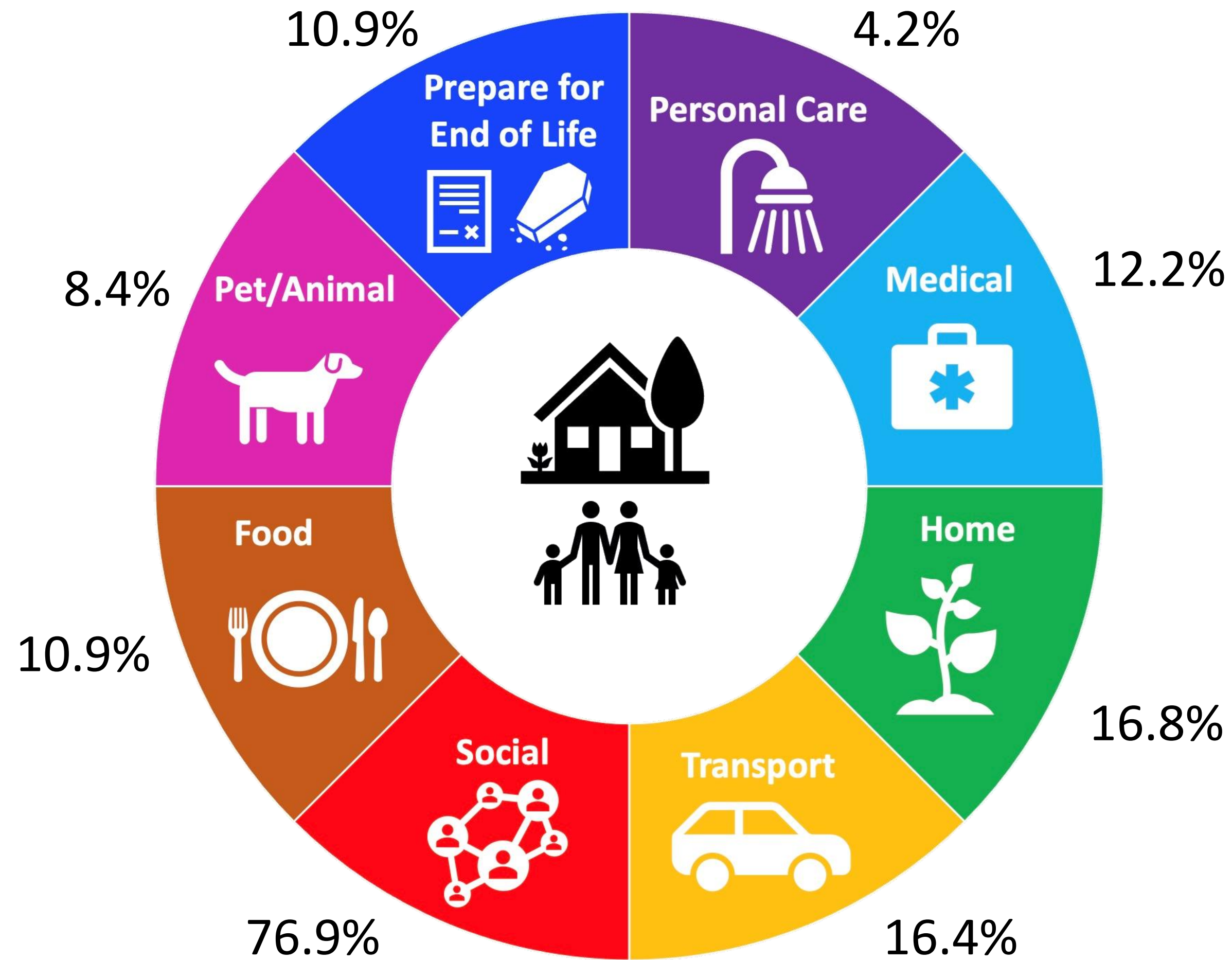
Caring Helpers can be members of the family, friends, neighbours or other people in the community who are willing and able to assist with activities such as:

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

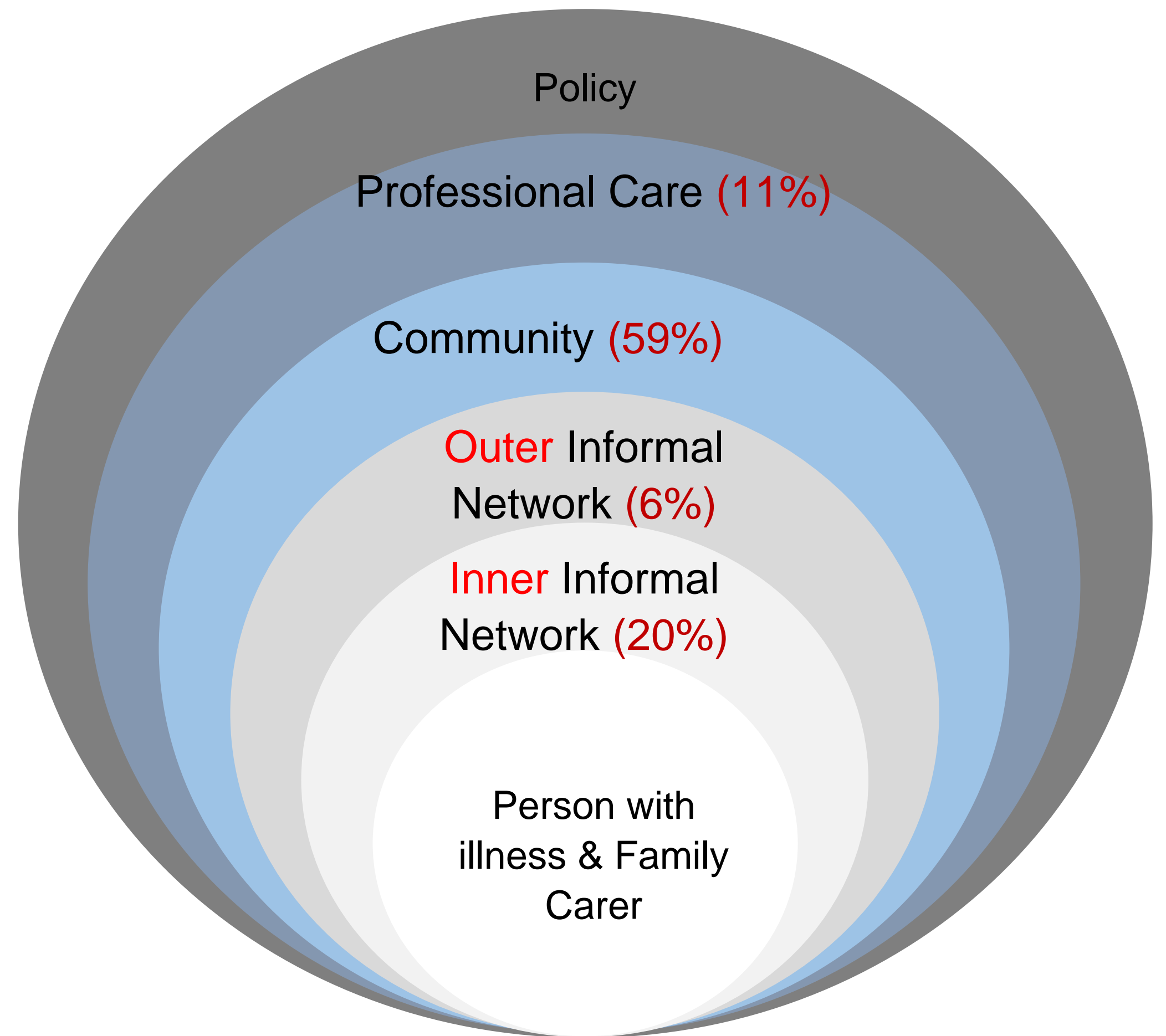


Connectors have helped or sourced help with:

- 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”.



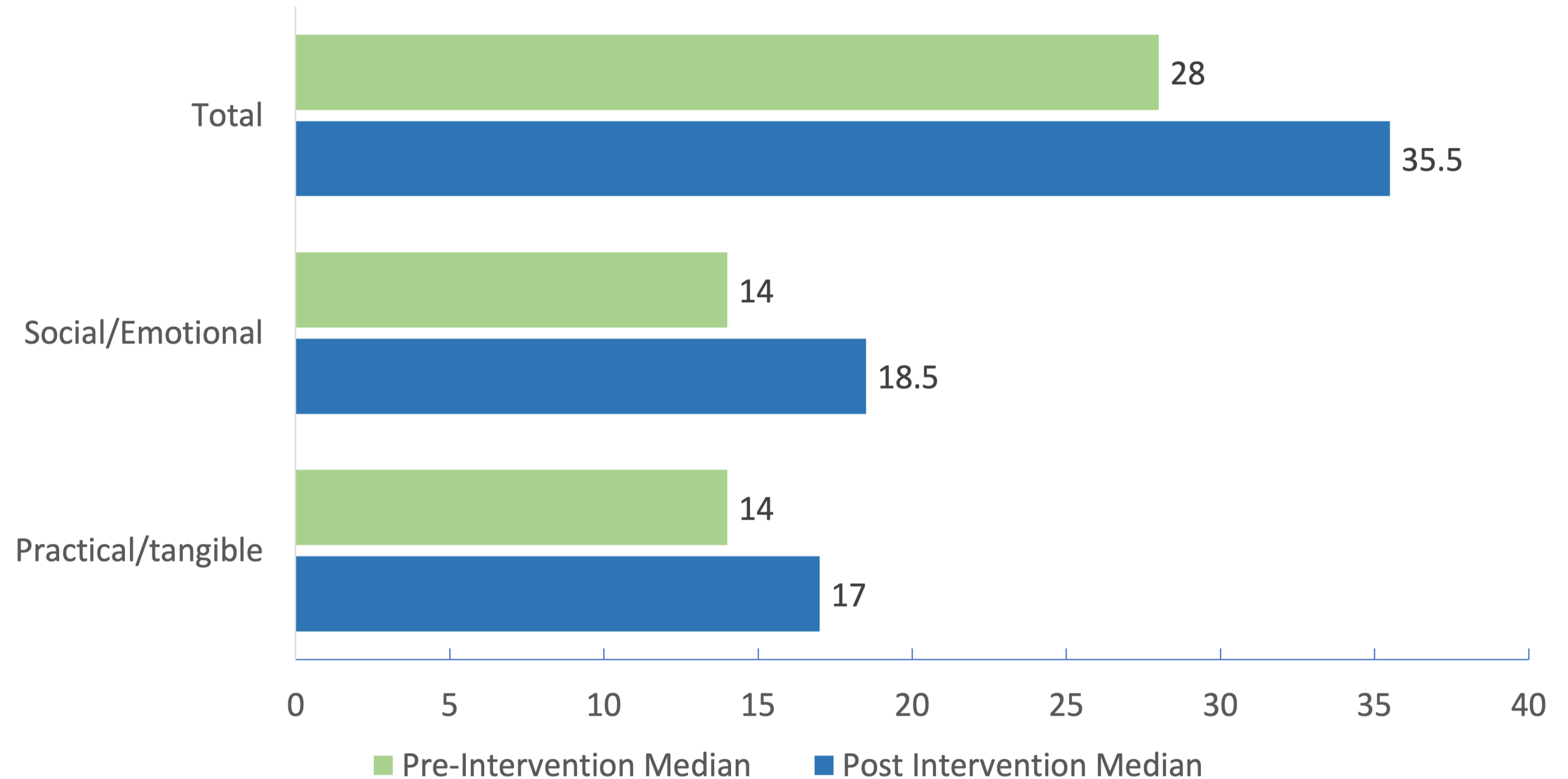
Naturally Occurring
Networks (26%)
VS
Facilitated Networks
(59%)



Primary Outcome: Increase in Social Connectedness

$P < 0.001$

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



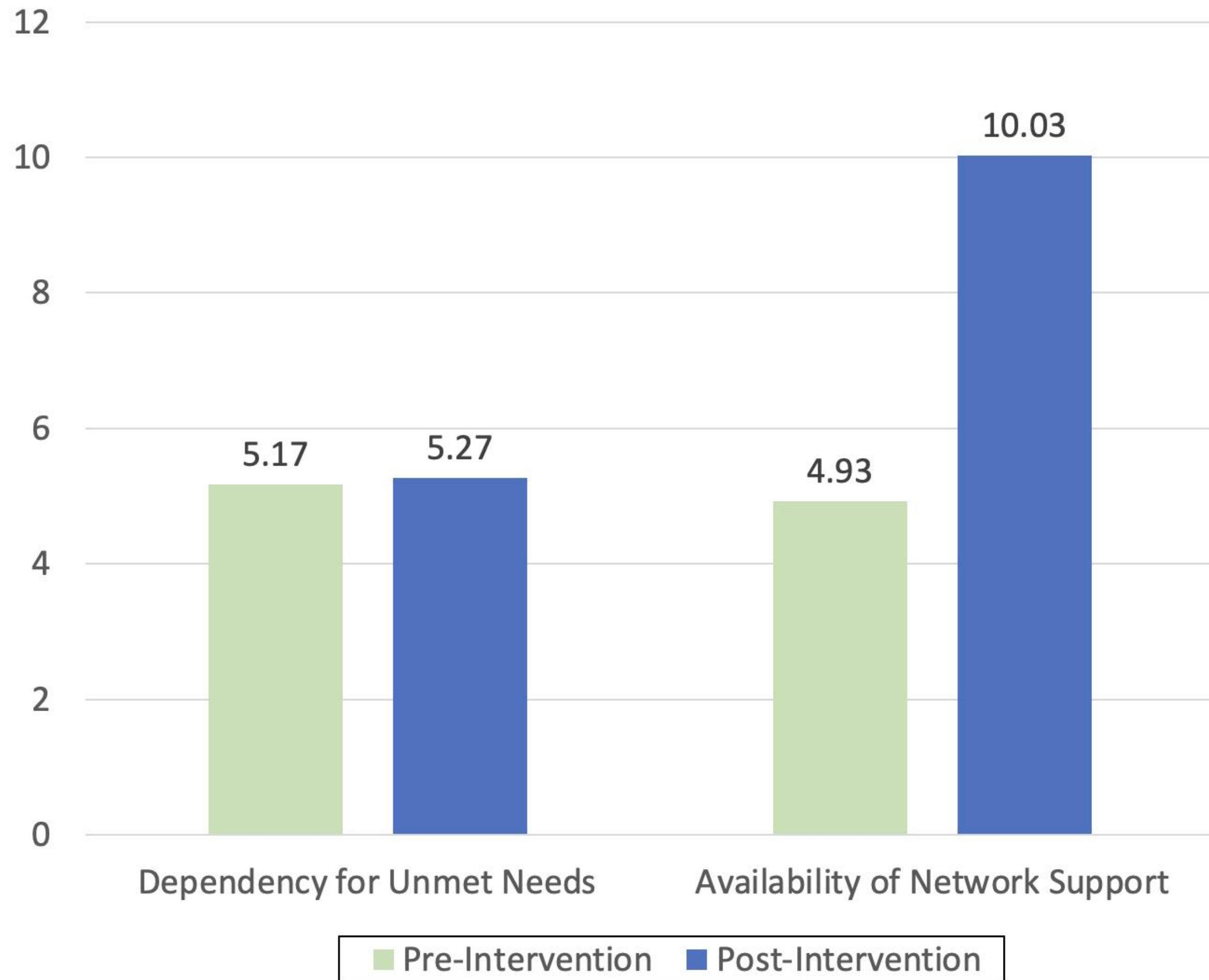
Median Difference (95 % CI)

- 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
 $P < 0.001$

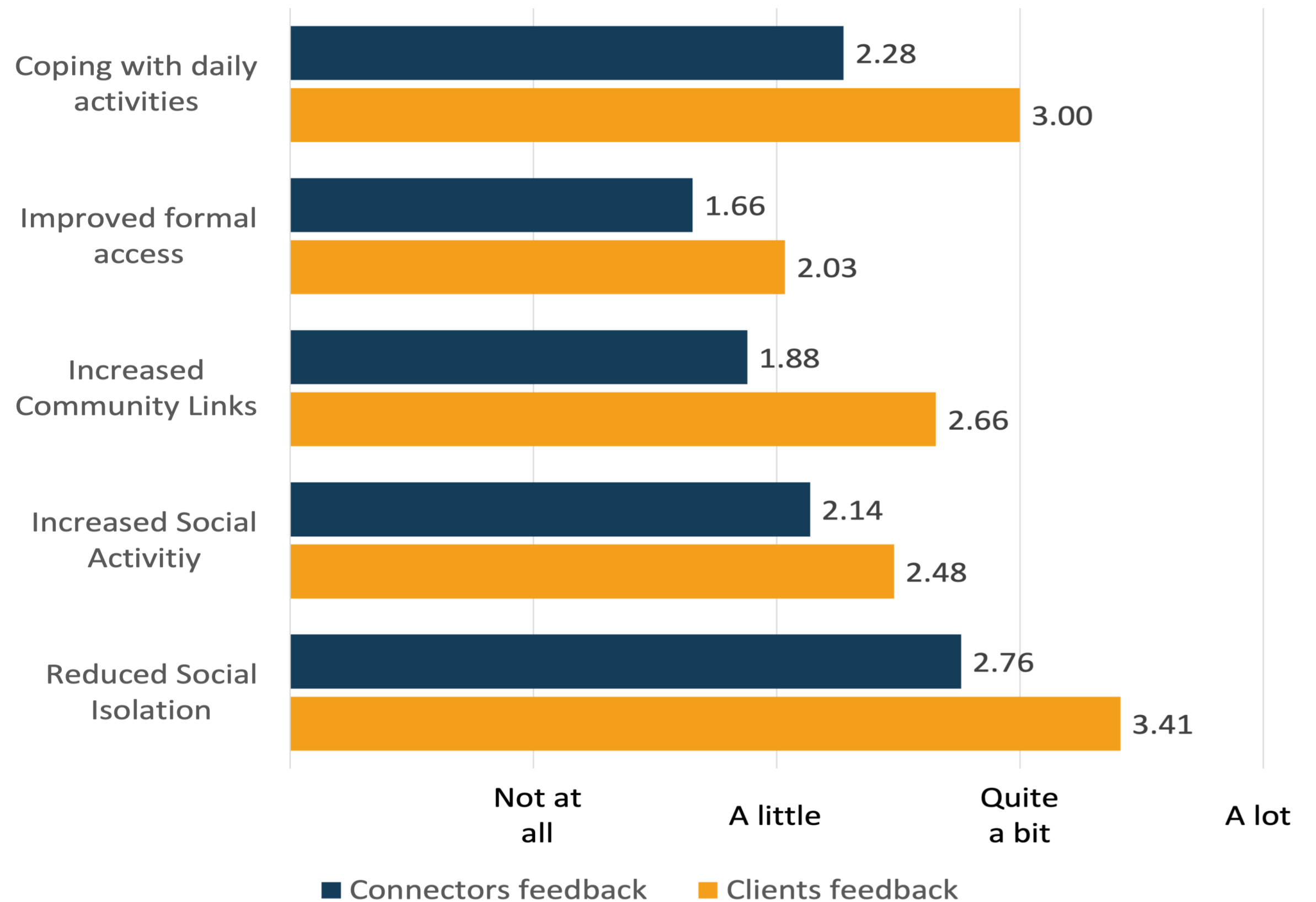


Secondary outcome:

Self-reported impact on social wellbeing

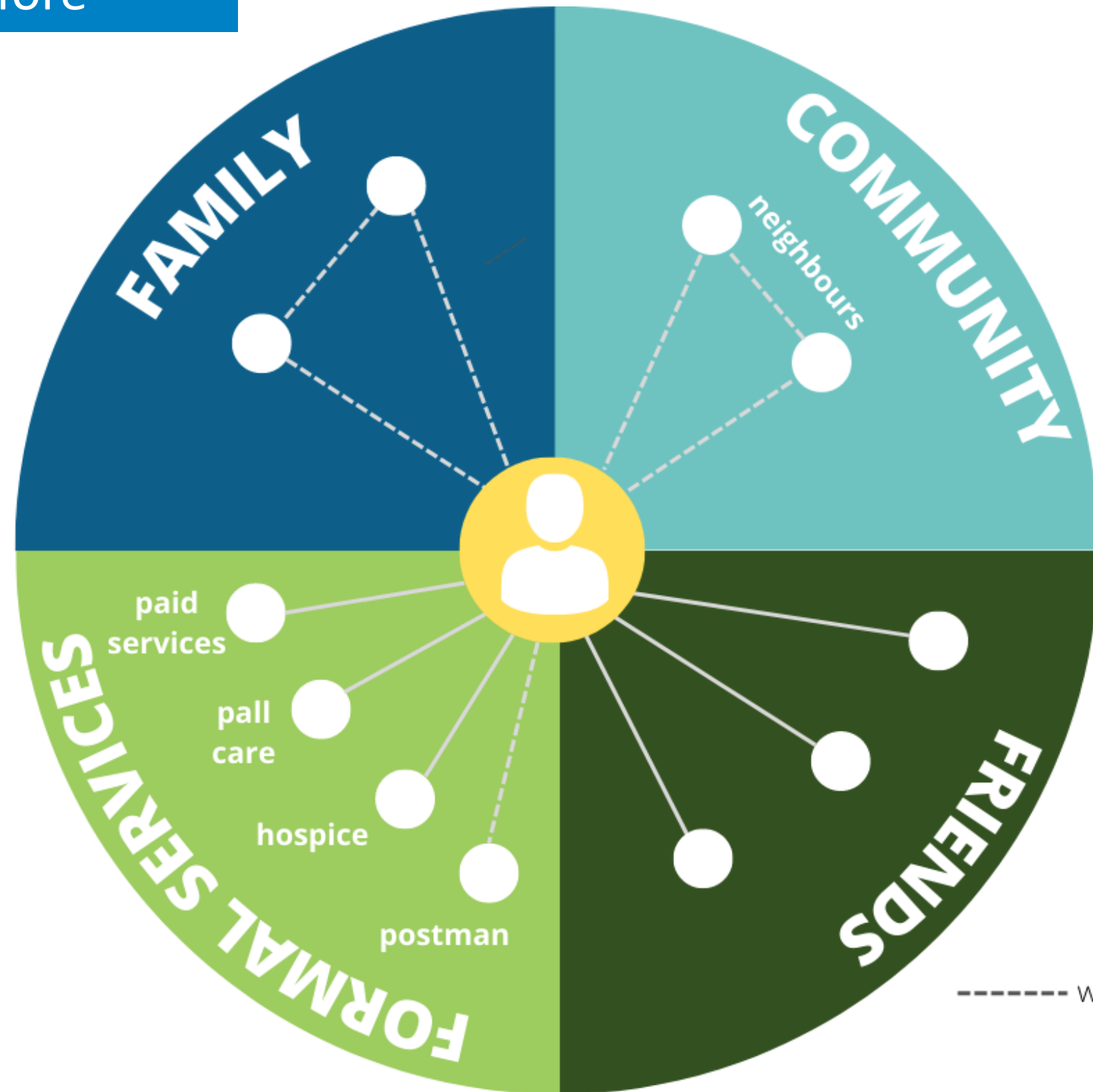
(scale: 1=not at all to 4=a lot)

highest impact on reduced social isolation



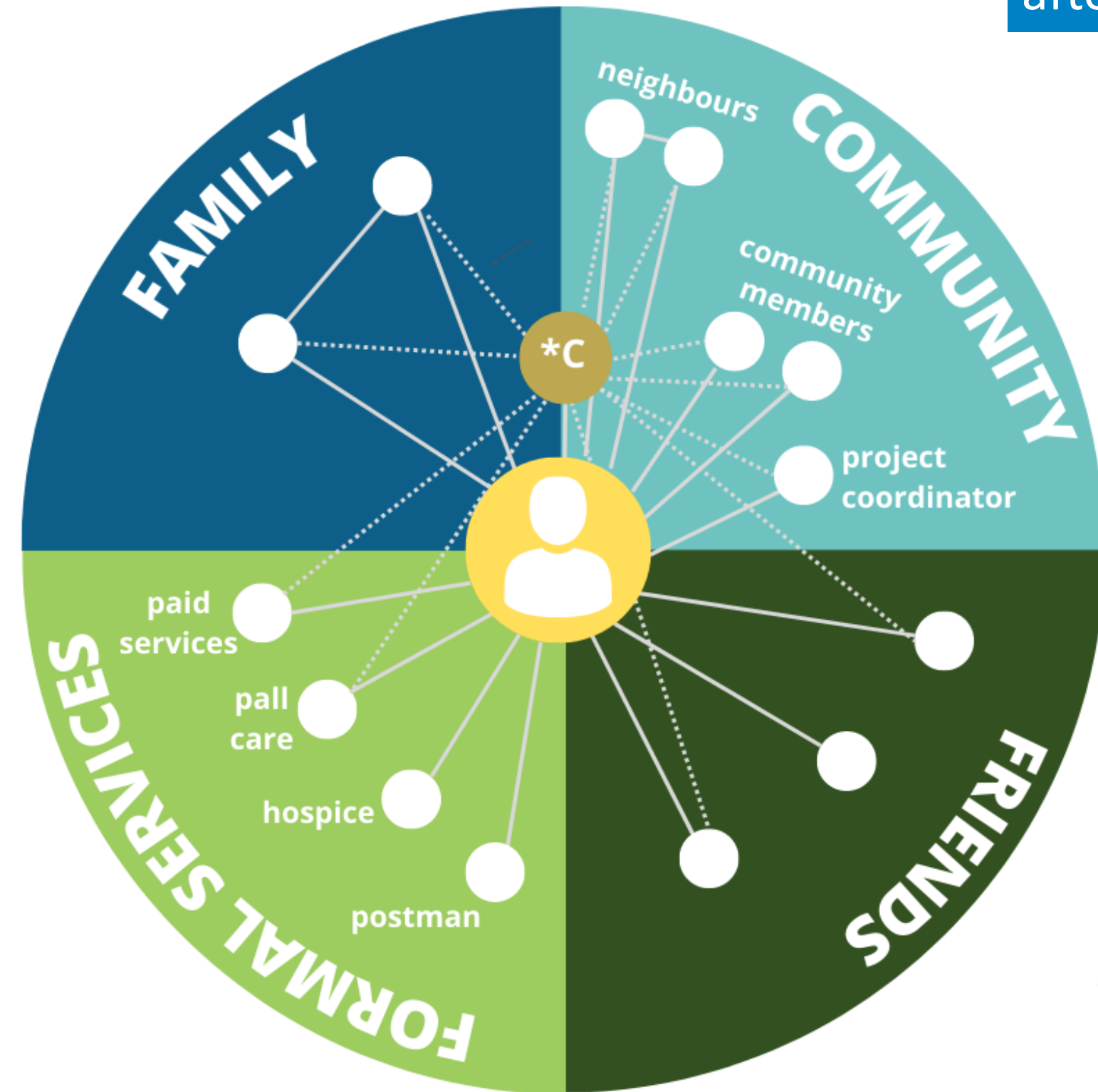
Social Network Mapping for one family before and after the intervention

before



----- weak connection

after



*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

Rolling it out to other communities throughout WA and Australia



Local government engagement-
Compassionate Bunbury Charter

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.

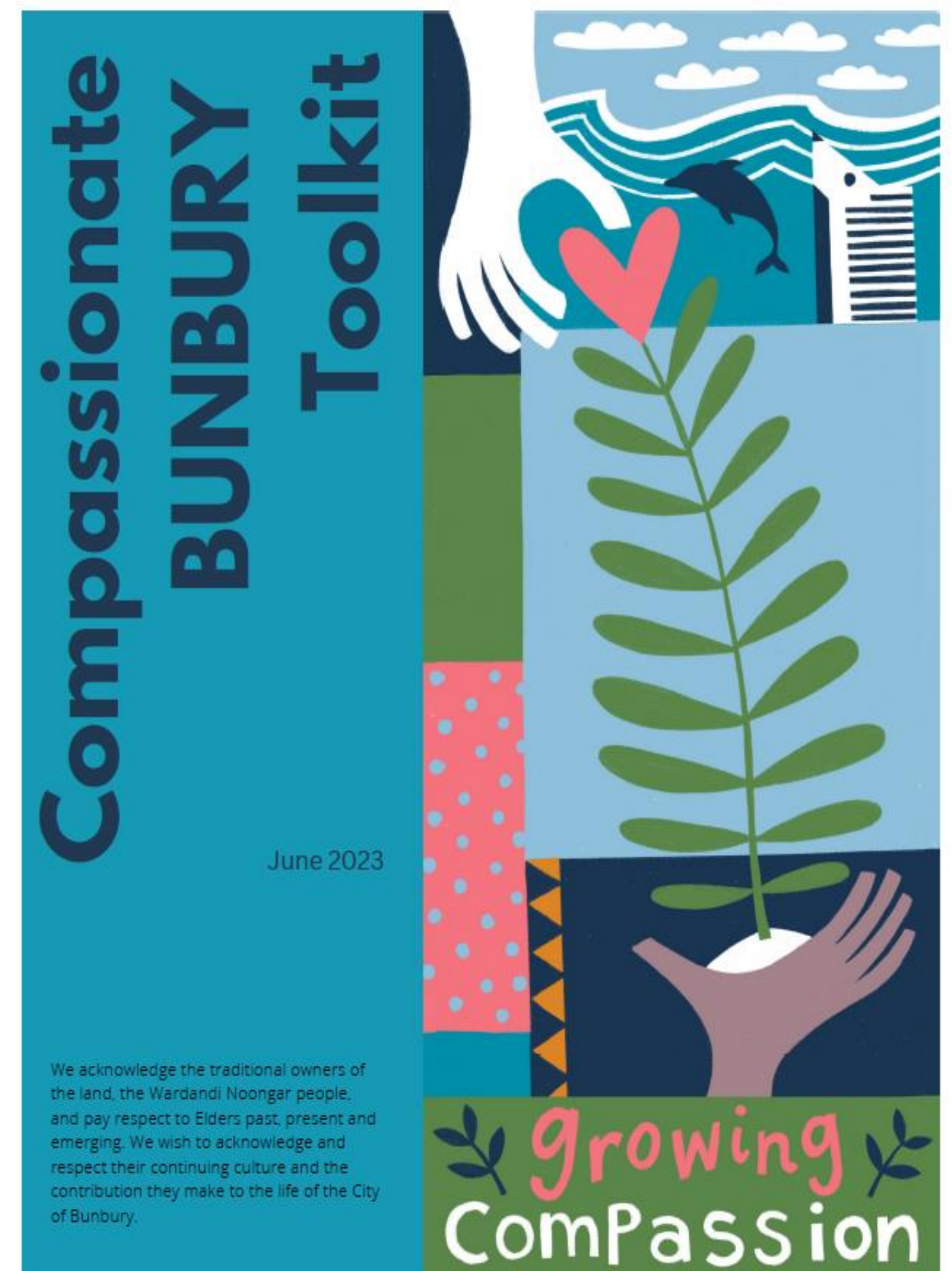


Toolkit: Set of Actions & pledges

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





Compassionate Workplaces

**Are you a member of a workplace
leadership team?**

Join us in exploring how we can build compassionate
workplaces in the South West of Western Australia

July 17, 2023
11am - 2.45pm

**Bunbury Geographe Chamber
of Commerce and Industry**
15 Stirling St, Bunbury



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

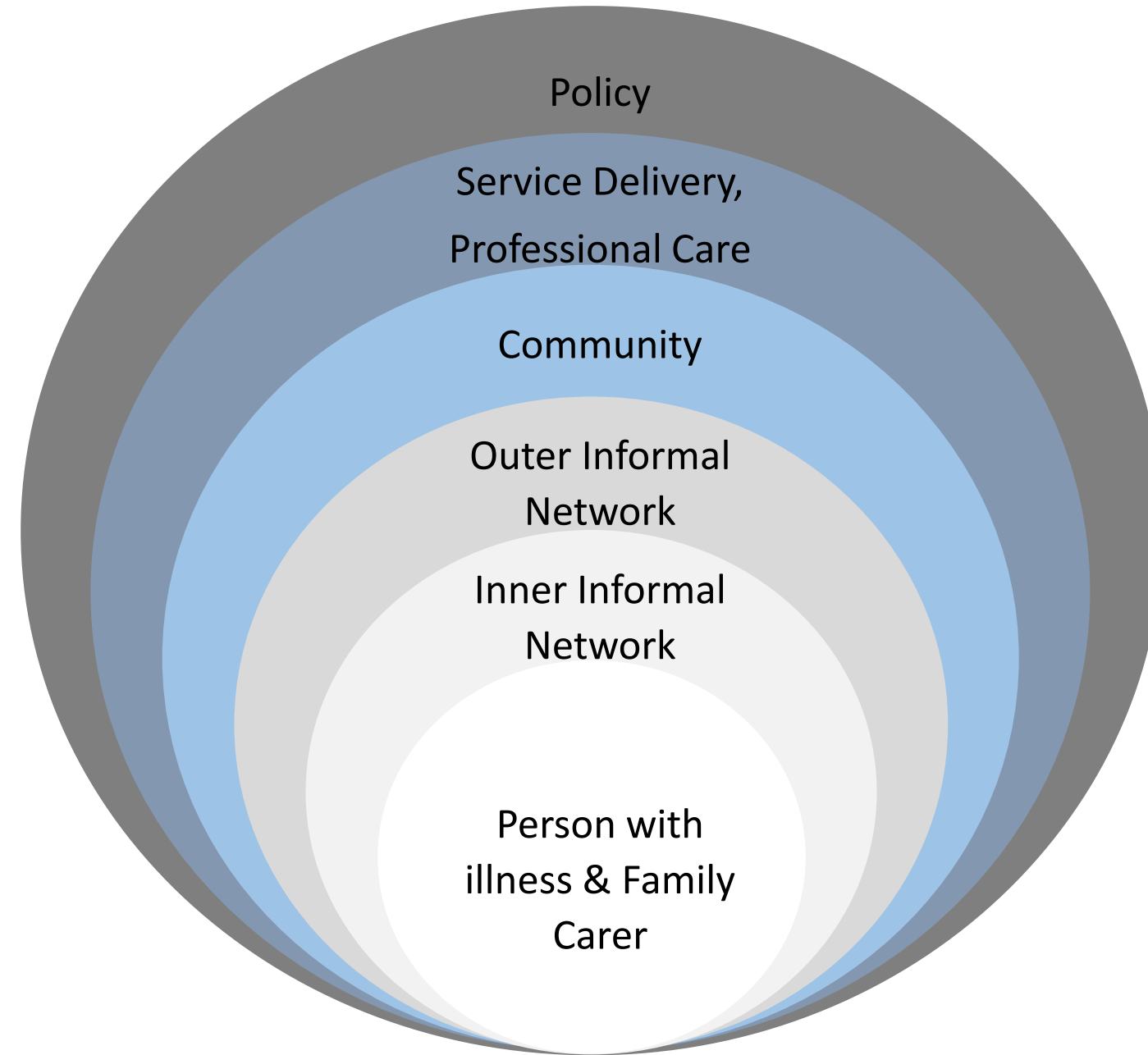
Up to all of us to Connect the Dots

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



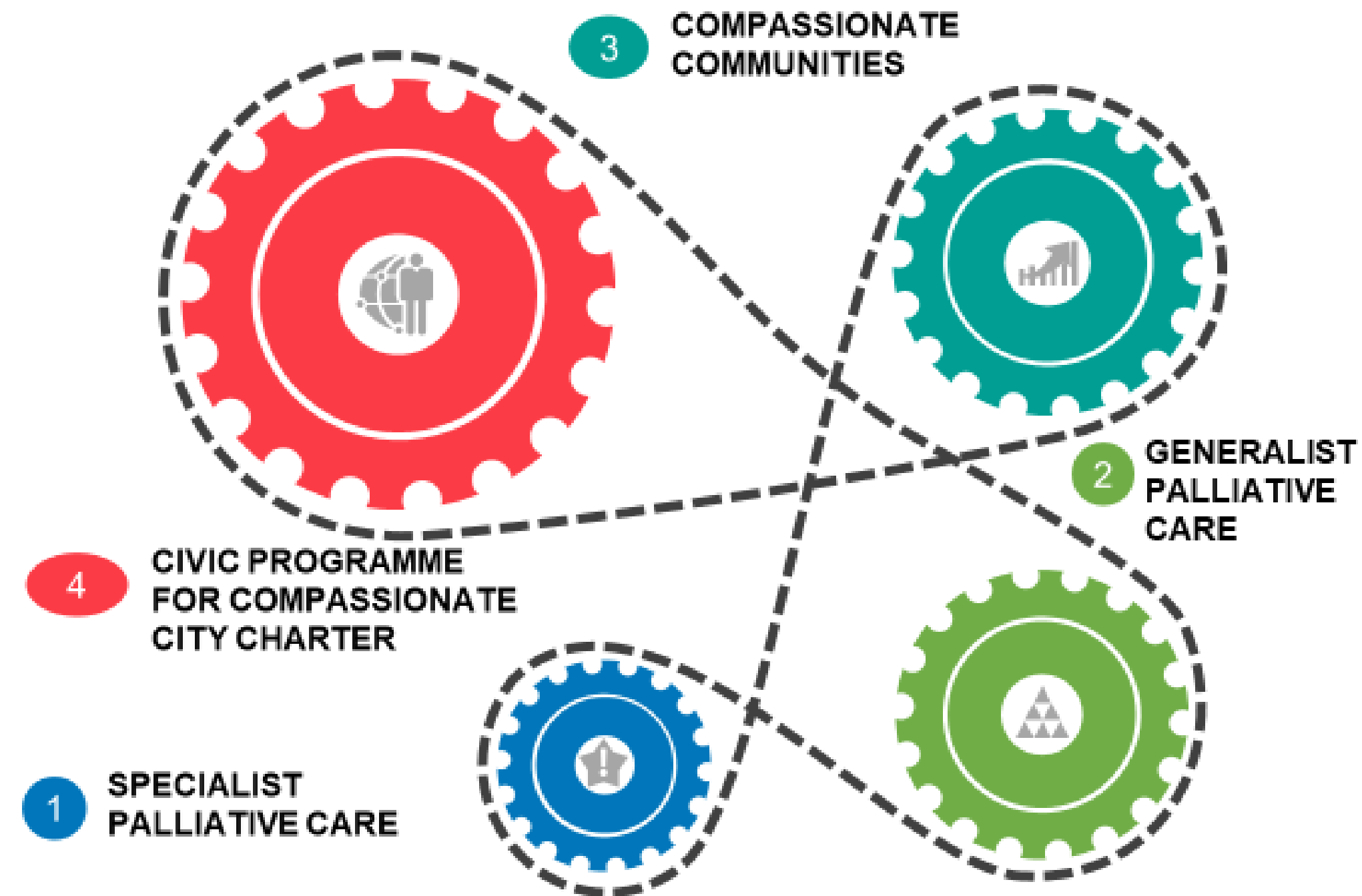
CIRCLES OF CARE

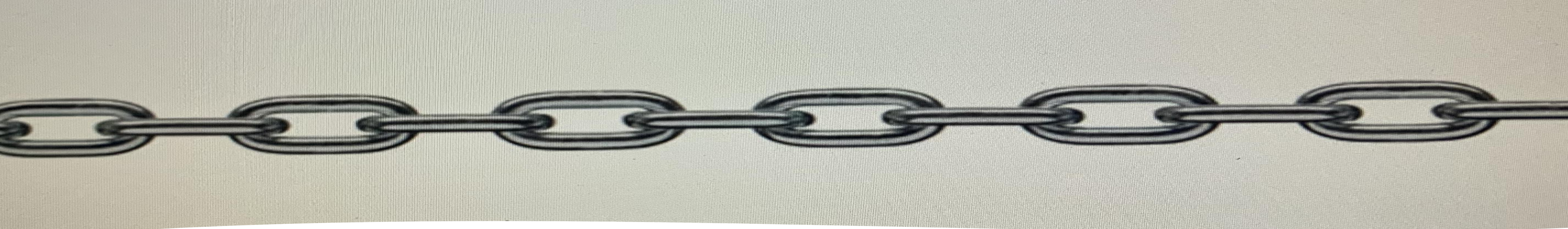
INTEGRATION OF SERVICES

- Disability Sector, NDIS
- Aged Care Sector
- Specialist Palliative Care
- Generalist Palliative Care
- Disease specific clinics
- Primary Care & Allied Health Care

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

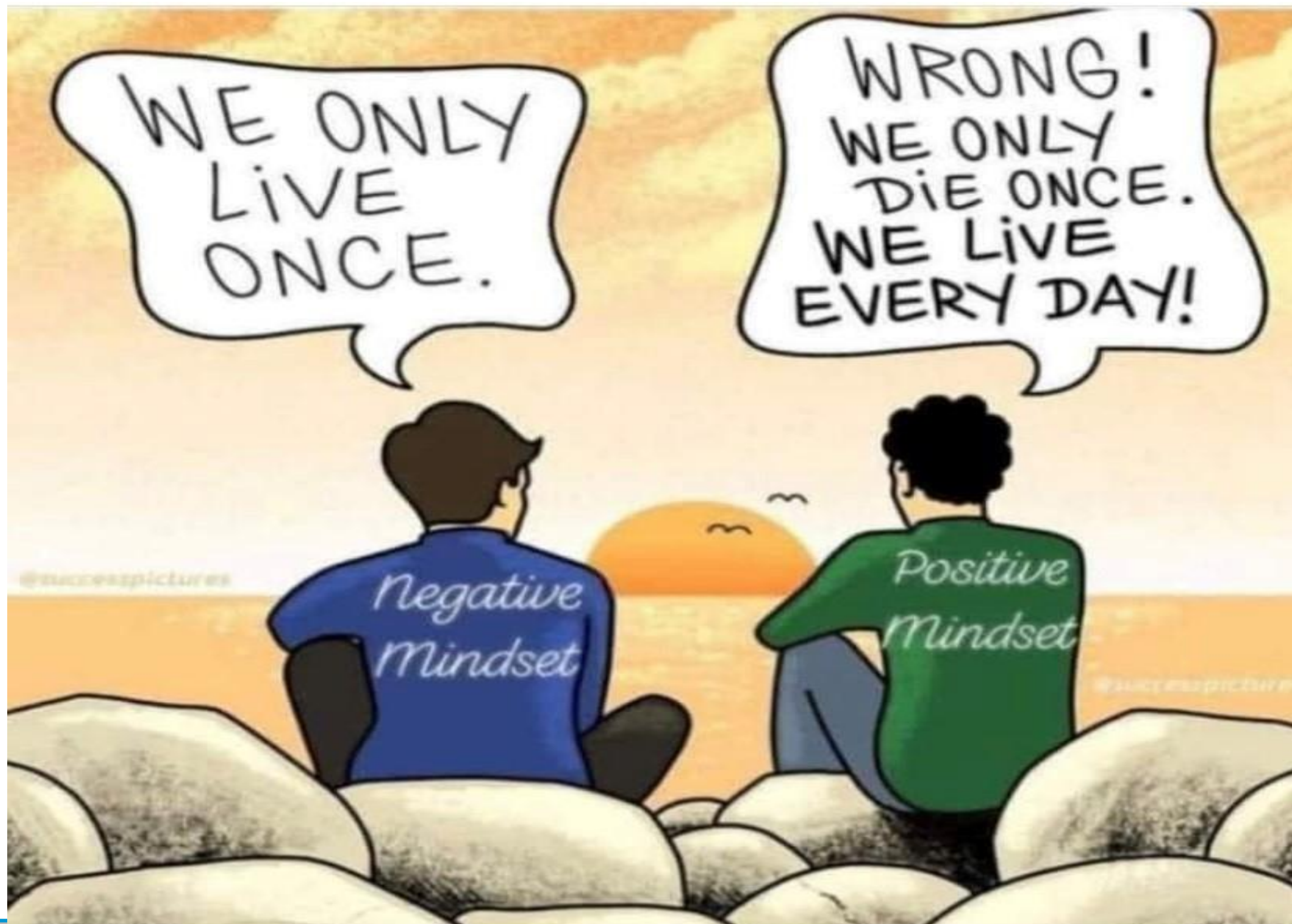
Palliative Care – The New Essentials





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





Thursday, July 19, 2018 swtimes.com.au

Death Fest brings touchy subject out into the open

■ Emily Ace

A MINI "Death Fest" will be held at Bunbury Regional Entertainment Centre on August 8 to kick-start a conversation about an uncomfortable topic – death.

Compassionate Communities Network, an initiative which aims to connect organisations and individuals in the community to better support each other at the end of life, will be launched at the festival. It coincides with Dying to Know Day and will begin with Death Cafe, where attendees can gather and discuss death over a warm cuppa.

Other activities will include learning how to make your own coffin, reading death letters, listening to poetry and helping the network to map compassionate people, groups and organisations in the South West.

It will also be a chance to receive information about...

Bunbury Mens Shed member and coffin maker Jeff Hookham, funeral director and event supporter Adrian Barrett, and network co-founders Dr Julieanne Hilbers and Dr Samar Aoun prepare for the Death Fest activities.
Picture: Jon Gellweiler

Death Festival in Bunbury 2018

Youth Art Competition at Schools - 2020

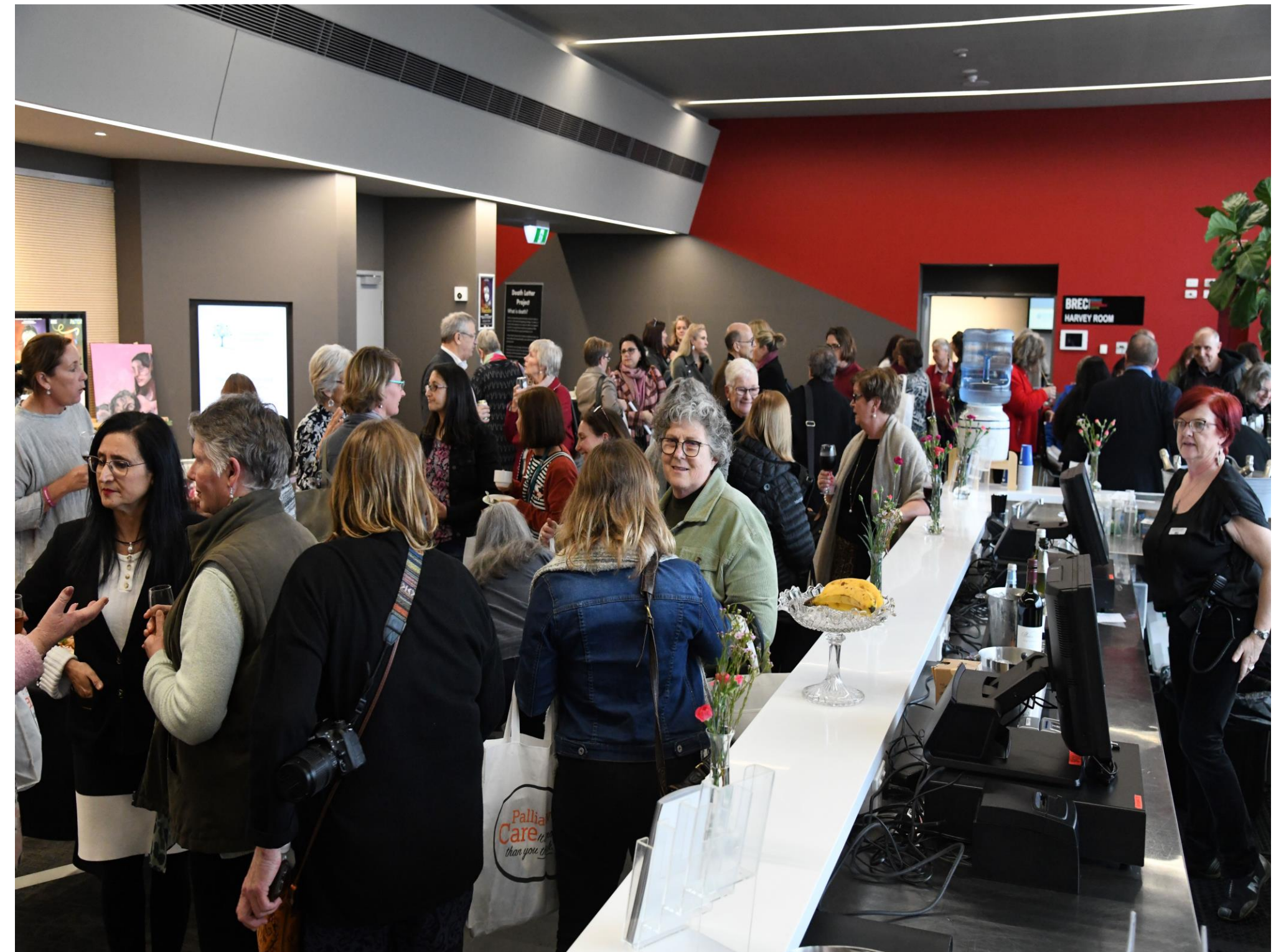


WA Forum on Building Connectedness - August 2021

*Let's Build a
Compassionate & Connected WA*

Saturday, 7 August 2021
Bunbury Regional Entertainment Centre
8.30 am to 5.00 pm
Register at XXXX

Community - Compassion - Connectedness



DTKD 2022

bun.

Wednesday July 20, 2022 BUNBURY MAIL 7

NEWS

Opening the door to death

DYING TO KNOW

BY NICKY LEFEBVRE

DEB Wraight believes we can all benefit from breaking down the barriers that prevent us from discussing one of life's true realities.

"We have sanitised death, as a society we have removed death from our lives in such a way that there is a fear and sense of not being able to discuss it openly," Ms Wraight told the Mail this week.

As a funeral celebrant who facilitates the regular 'Death Cafe' catch up at Mojos Bunbury, she said she frequently meets people from all walks of life and across all age groups who are seeking clarity and connection around death.

"We have been going for about two years now, we meet in a casual setting and it is really all about making those connections with others.

"We have special guests, such as death doulas and people from the industry who can answer questions relating to burials and cremations, end of life plans and more.



Deb Wraight (with grandson Jaxon), says talking with young children rather than shielding them from discussions about death is important to help them understand that it is part of the life process. Pictures: Supplied

"But mostly it's an opportunity for people to get together and ask questions, talk about people they've lost, talk about their own journeys and make plans for themselves."

Ms Wraight said it was important that children were not shielded from death, but educated in a way that allows them to understand at an appropriate level.

"Many children by the

time they reach school age have experienced the death of a pet, a grandparent or other relative, or even someone their own age," she said.

"By talking to them, reading some of the fabulous

children's books that are available on death and dying and by allowing them to take part in funerals, it helps to normalise the process and can leave them better prepared."

Ms Wraight said it was important that children were not shielded from death, but educated in a way that allows them to understand at an appropriate level.

"Many children by the time they reach school age have experienced the death of a pet, a grandparent or other relative, or even someone their own age," she said.

"By talking to them, reading some of the fabulous children's books that are available on death and dying and by allowing them to take part in funerals, it helps to normalise the process and can leave them better prepared."

The comfortable and community-driven setting of the Death Cafe allows people who are living with a terminal diagnosis, as well as their friends and family, to create end of life plans to suit their own wishes.

"We're helping people

plan, to get ready, to understand what they and their loved ones are going through, and what will happen after they're gone," Ms Wraight explained.

"We also welcome people who have lost children, partners, parents and friends, who find a real connection with others experiencing something similar.

"We can't underestimate the importance of just talking to each other, and how to best open the door to those conversations for everyone involved."

On Sunday, August 7 as part of the Dying to Know program, the Death Cafe will present 'Dying for a Cuppa' at the City of Bunbury function room at 4 Stephen Street from 10:00am. RSVP to swcommnetwork@gmail.com or phone 0483 802 915.

Bunbury Death Cafe meets regularly on the first Sunday of each month at Mojos, Victoria Street Bunbury from 10.30am. For more information and upcoming dates, visit www.facebook.com/Deathcafe



CONNECTORS: Carolyn Jones from Leschenault, Paul Edwards from Australind and Heather Wade from Bunbury. Picture: Supplied.

Reducing the social isolation for families >

THE Compassionate Community Connector program is a pilot project which sees volunteers supporting people living with advanced life limiting illnesses/palliative care needs.

The pilot has seen 23 people across the South West trained and helping families feel less socially isolated.

But more people are needed to put their hand up to do something positive in the community.

Perron Institute Research Chair in Palliative Care UWA and South West Compassionate Communities Network Chair Samr Aoun

said their research found 50 percent of families that were referred to the program were living alone.

She said some of the benefits seen included improvement in social connectedness between families and their social networks, reduction in social isolation, better coping with daily activities.

"It fills the gaps in social and practical support that formal services cannot, particularly for people who live alone, and those who are socially isolated in more rural communities," Professor Aoun said.

Connectors have said the

focus on mutual support and community development was what made the program important.

Professor Aoun said connectors felt there were clear benefits observed for people who were dying and their families.

"Connectors also encouraged people to become involved in the program because of the social benefits," she said.

"The connectors themselves have also benefited from the program talking positively about the impact it has had on them and how rewarding it was for them."

Feedback from families have included how the positive relationship formed with the Connector turned into ongoing friendship.

"Many families talked about the positive impact in terms of reducing social isolation which was apparent for both patients and their family carers," Professor Aoun said.

"Family carers talked about the positives for their family member (the patient) of having someone regularly for a chat as well as the benefit to themselves when these caring helpers enabled them to have some time off.

"One of the biggest initial hurdles for families was feeling comfortable asking for help and receiving help from neighbours and community members who they didn't know well."

To find out more and to express your interest, you are welcome to attend the presentation by Professor Aoun 'Improving social connectedness in our community - we are all in this together'. The presentation will be on August 7 from 11.30 at the City of Bunbury function room. To RSVP, visit swcommnetwork@gmail.com or phone 0483 802 915

Screening of Palliative Care Film- May 2023



Live the life *you please*

Host an event screening of the feature film

End of life care helps people and their loved ones live as fully and comfortably as possible. It improves their quality of life. It provides support, freedom, dignity, respect and joy.

So why aren't we talking about it?

This film will make you smile, laugh, laugh harder and occasionally shed a tear as it shares the stories of a diverse range of Australians experiencing their last chapter.

Remembering our Dead ceremony with floating lanterns- 5 August 2023





**Concert at Cemetery-
Bunbury 5 Aug 2023**

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