Compassionate Communities:
Learnings from the Compassionate Connectors program in Western Australia

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Chair, Compassionate Communities Australia

Why we need Compassionate Communities?

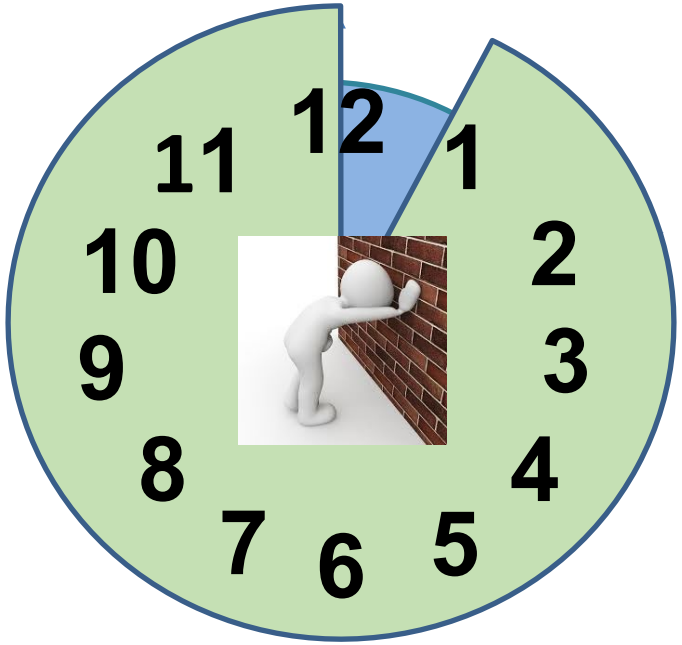
The Evidence

The Evaluation

The Translation

THE EVIDENCE

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



Adapted from Carpenter House model developed by

Formal Care

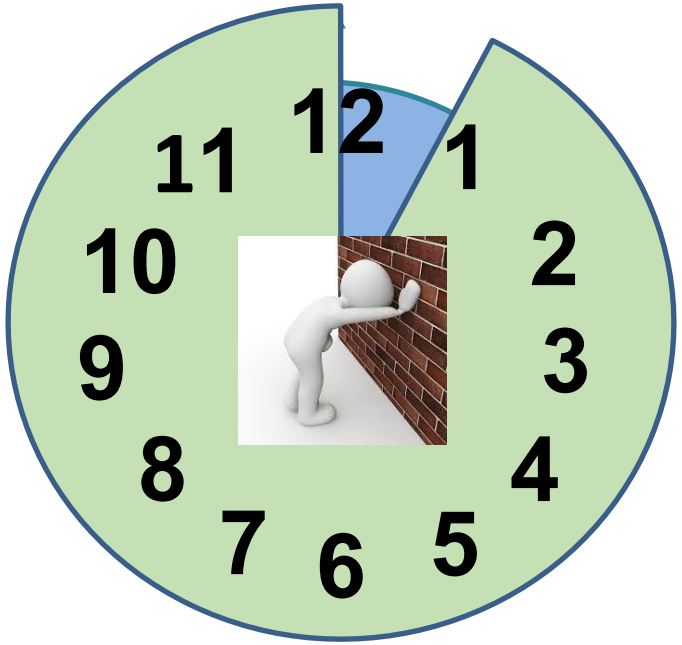
<5% of the Day

- ✓ 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

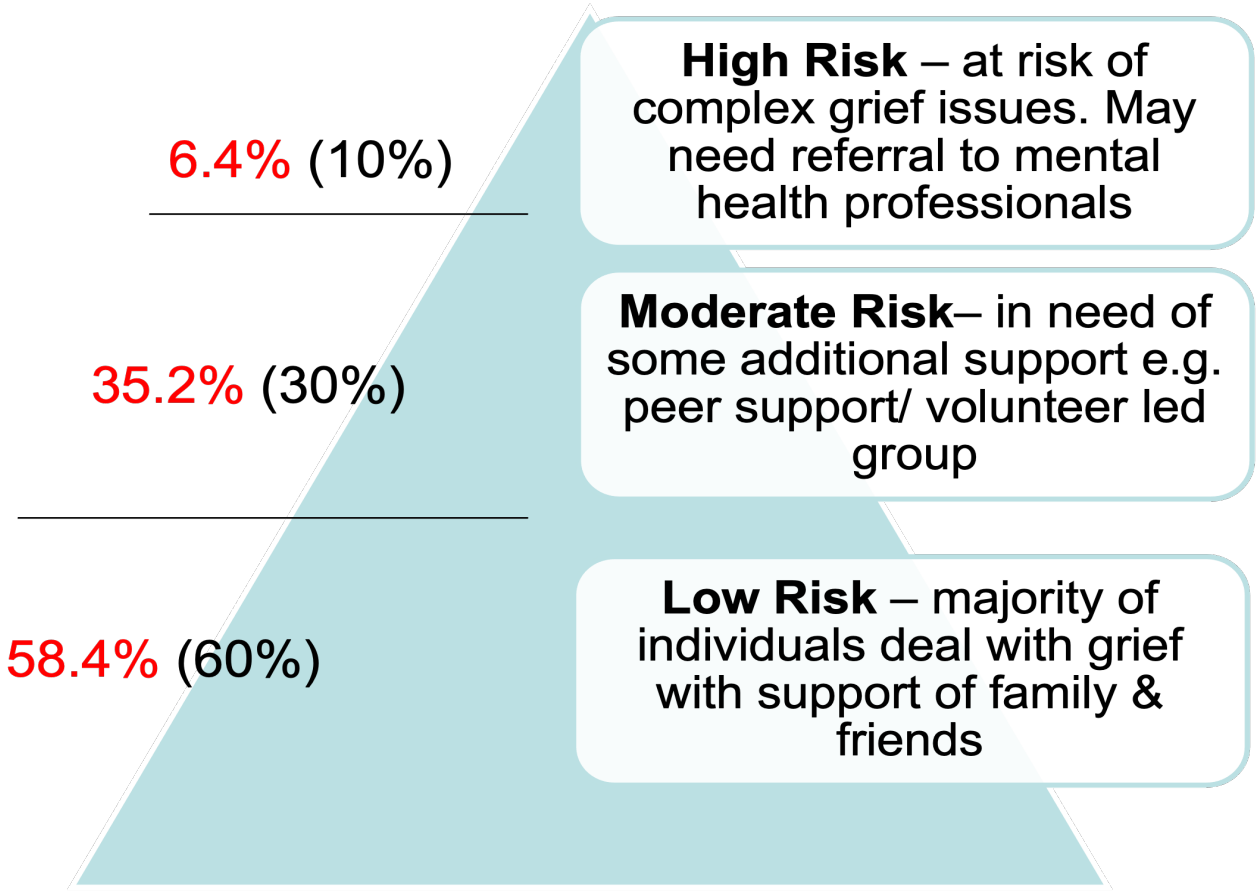


Adapted from Carpenter House model developed by

Formal Care
<5% of the Day

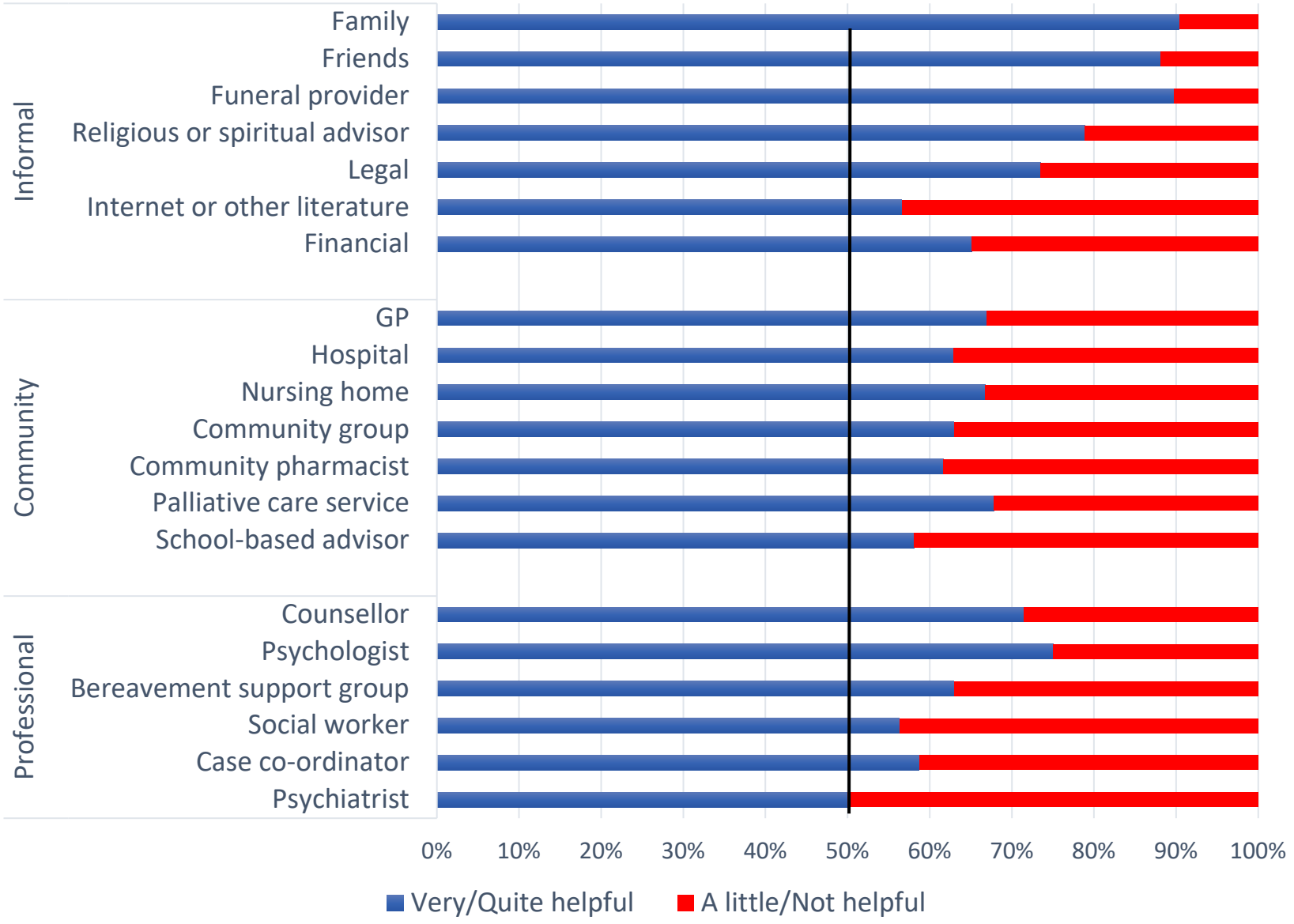
- ✓ Doctor
- ✓ Nurse
- ✓ Nurse Practitioner
- ✓ Personal Support Worker
- ✓ Social Worker
- ✓ Pharmacist

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



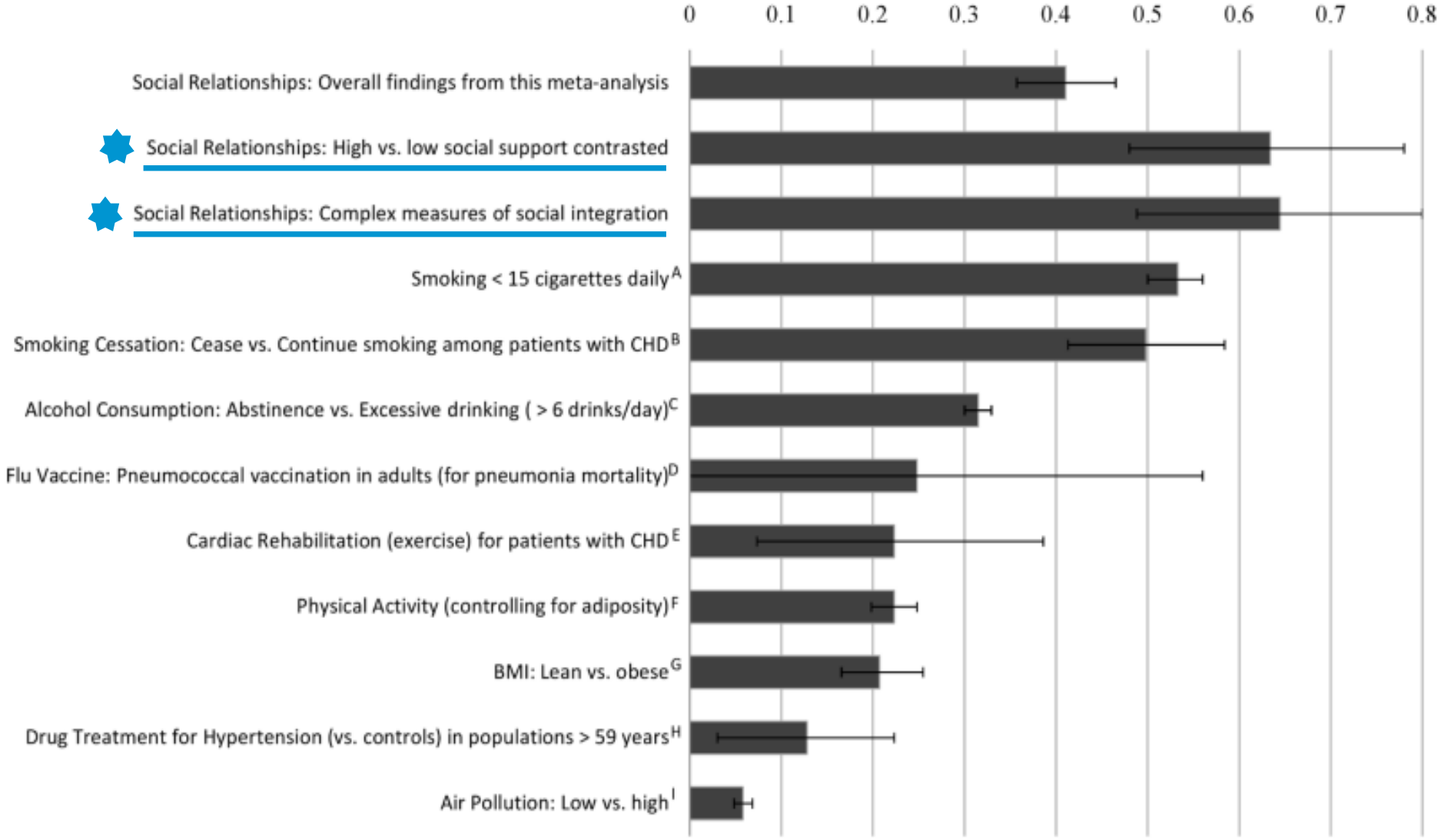
Sources of support perceived helpful or unhelpful

(Aoun et al, 2018)



Comparative impact of social relationships on reduction in mortality

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



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)

Prof Bessel van der Kolk – The Body Keeps the Score

Social support is not the same as merely being in the presence of others. The critical issue is reciprocity, being truly heard and seen by the people around us, feeling that we are held in someone's mind and heart. For our physiology to calm down, heal, and grow we need a visceral feeling of safety.

No doctor can write a prescription for friendship and love. These are complex and hard earned capacities.

THE EVALUATION

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

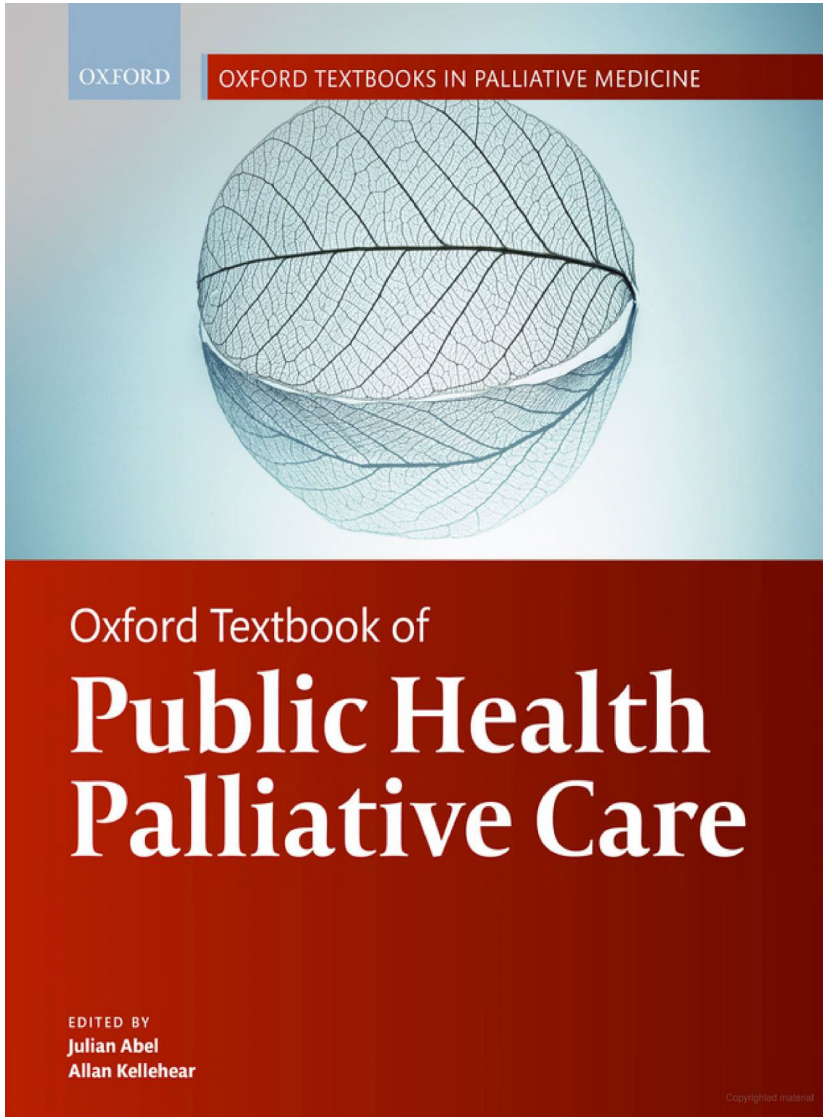
Objectives

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

Complexities and challenges in public health palliative care research

Public health palliative care interventions, such as this community-based intervention, are implemented in real world settings which are complex systems in which to undertake research, and so present a challenge to traditional research methodologies.

Vanderstichelen S, Deliens L, 2022.



Research Design

A mixed methods research design incorporated:

- A prospective cohort longitudinal design with two cross-sectional measurements, pre and post intervention.

- A qualitative design using semi-structured interviews with the three target groups: families, connectors and referring health professionals.

The Compassionate Communities Connector Program

Figure 1: Study Protocol flowchart – Intervention consists of up to six encounters (visits or phone calls) over a 12 weeks period

Pre-intervention

Patients/families that fit the inclusion criteria are screened by health service to enrol in study. Approval sought from patient/family to pass on contact details to Senior Project Officer (SPO)

Time 1 Assessment by SPO
SPO obtains written informed consent during a visit and completes the baseline assessment and outcome measures: social/practical needs, carer unmet support needs, social support and death literacy.

Intervention

Encounter 1 by Connector
Connector visits family, identifies support needs and maps the family's social networks and mobilises the Caring Helpers after the first encounter

Encounter 2 by Connector
Connector reports back to the person requiring support, to update them as to who will do what, and when, and revisit planning and mapping tools.

Subsequent Encounters (up to 4) by Connector
Connector determines if the new arrangements/systems are functioning well, or if there needs to be any changes to the plan/modified supports. Reviewing and updating planning and mapping tools.

Post-intervention

Time 2 Assessment by SPO and interviews with Patients/Carers
Follow up assessment of outcome measures undertaken by SPO during a visit within two weeks from final encounter. The visit incorporates interviews with patients and carers regarding feasibility and acceptability of this model of care.

Post-intervention

Focus group/ interviews by SPO with Connectors and focus group/survey for Caring Helpers
Assessment of the impact of their participation on their death literacy, social and emotional support, network enhancement skills, and general feasibility and acceptability of this model of care.

Inclusion criteria

Patients with cancer, chronic obstructive pulmonary disease (COPD), chronic heart failure or renal disease and other chronic conditions such as neurodegenerative conditions.

Patients aware of their advanced illness.

Patients with frequent hospital usage (more than two times in the past 2 months of hospital admissions or emergency department visits) or at risk of hospitalisation for palliative care.

Patients with unmet social, psychological and practical needs.

Patients who are socially isolated and rely on just one other person to meet the majority of their everyday needs.

Patients 18 years and older.

Patients with capacity to provide informed consent.

The Compassionate Communities Connectors model for end-of-life care: a community and health service partnership in Western Australia

Palliative Care & Social Practice

2020, Vol. 14: 1–9

DOI: 10.1177/2632352420935130

Samar M. Aoun, Julian Abel, Bruce Rumbold, Kate Cross, Jo Moore, Piari Skeers and Luc Deliens

Abstract

Background: There is an international drive towards increasing provision of community-led models of social and practical support for people living with advanced illness.

Aim: This feasibility project aims to develop, implement and evaluate a model of community volunteers, identified as Compassionate Communities Connectors, to support people living with advanced life limiting illnesses/palliative care needs. The aims also include the development and evaluation of a training programme for volunteers and assessment of the feasibility, acceptability and preliminary effectiveness of this model of care.

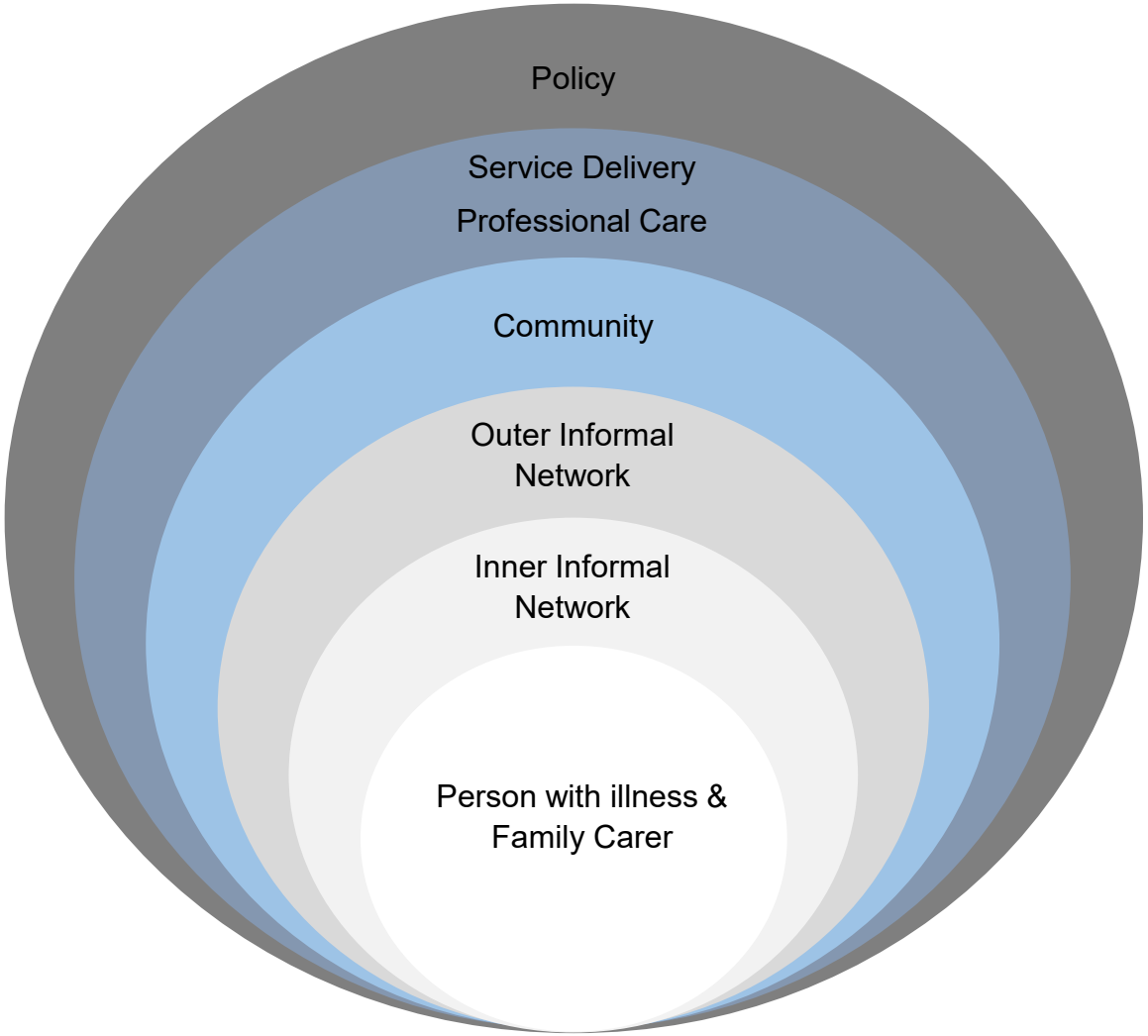
Methods: The approach seeks to map and mobilise people's personal networks of care through the Connectors enlisting Caring Helpers (community volunteers). Up to 10

Correspondence to:

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.



Connectors undertake network mapping

Who is your network?

How will they respond?

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.

Who is helping?

Who can you ask for help?

SOUTH WEST
Compassionate
Communities
NETWORK

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

RECRUITMENT PROMOTIONAL MATERIAL

The role of a Compassionate Connector

providing a network of support to those in your community experiencing caregiving, dying or grieving

"Compassion is the courage to descend into the reality of human experience"
Prof Paul Gilbert

Who can apply?

Anyone willing to give a minimum of one hour per week is welcome to apply.

As part of the application process you will be asked to submit an Expression of Interest.

All Connectors will need to complete the one day training course before commencing.

How does it work?

Individuals and families needing support can be referred by their service provider or they can self-refer to the Program Coordinator.

The service Coordinator matches individuals/families with Connectors based on location, need and skills.

As a Connector you will identify extra social and practical support needed by the individual/family. You will liaise with community

What our Connectors say

"So rewarding to watch their quality of life improve"

"Feels like you are making a difference"

"Opportunity to give back to the community"

"Learnt a great deal"

"You become part of their lives; it's very fulfilling"

"A lovely way to do volunteer work if you like being with and talking to people"

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Free support service by the community

Do you need help with

shopping
collecting prescriptions
transport
meals
social support
cuppa and chat
walking your pet
accessing formal services?

"They've become like friends. They tell me how much they enjoy doing it."

Who is eligible?

Anyone living within the South West region with a chronic or life limiting illness can access this free service.

Participation is voluntary and you can withdraw from the service at any time.

"It bridges the gap between formal services and family/friends."

How does it work?

Individuals or families needing support can be referred by their service provider or they can self-refer to the Service Coordinator.

Our trained volunteer Connector will identify extra social and practical support you need.

Your Connector will liaise with community members and formal services to provide you with the additional support you need. The Connector will be in touch regularly to ensure you are receiving all the support you need.

caring, aging and grieving is everyone's business

Who will be helping me?

Our Connectors are people from within your local community who have received training to be a Connector.

They will use their existing networks and others within the local community to find the support you need.

"It has reduced my isolation."

How do I participate ?

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Would you like to help spread kindness in your community?

Become a volunteer Caring Helper for Community Connectors Program

"It's bringing back that sense of community and village that we've lost in society" (Connector)

How does the Program work?

Individuals and families needing support can be referred by their service provider or they can self-refer to the Service coordinator.

The service coordinator matches individuals/families with trained volunteer Connectors based on location, need and skills.

Connectors identify extra social and practical support needed by the individual/ family and liaise with community members and services to provide individual/family with the

How can you help?

You can help an individual or family in need regularly or on an ad-hoc basis. You can choose the level/type of support you would like to provide.

If you are a member of a community group you might like to provide assistance as a group, e.g. meal train, garden blitz.

Ways that Caring Helpers provide support might include:

- social support, e.g. cuppa and a chat
- transport, e.g. to medical appointments/shopping/ social outings
- gardening

Client feedback

"I don't feel as isolated."

"Wonderful; they follow up on things and check up on me."

"Become like friends; they tell me how much they enjoy doing it."

"The dogs love her (dog walker) and get so excited when she comes. She's almost part of the family."

"I would miss them if they weren't coming."

"This community help was invaluable."

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SELECTION OF CONNECTORS

- Expression of interest
- Training program

Compassionate Community Connectors

Partnership between the community and health service in Western Australia

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

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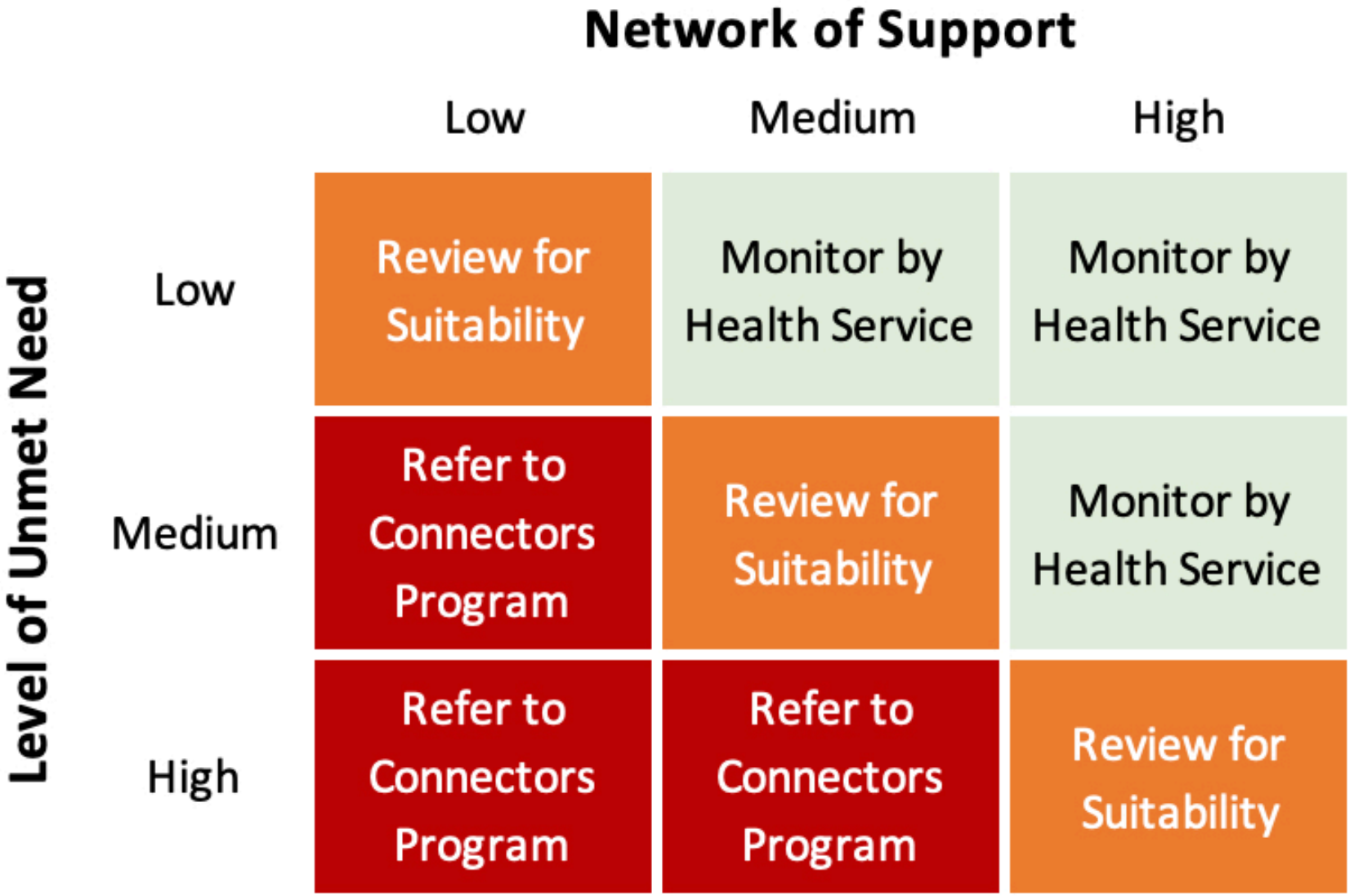
Community volunteers are trained to diagnose suffering not diseases

(Sallnow & Kumar 2010)

SELECTION OF FAMILIES

Assessment of unmet social and practical needs and social networks

Need Identified	Level of social and practical need*	Circle score	Person's Network of Support	Circle score
1. Personal Care • Shower • Dressing • Grooming (hair, teeth) • Toileting or other	Able to complete personal care independently	2	Members of the person's network provide regular help	2
	Requires some help to complete personal care	1	Members of the person's network provides ad hoc help or less than desired by the person	1
	Requires another person to complete all personal care on their behalf	0	Person has no-one to help them in their network	0
2. Medical • Transport to appointments • Buy or take medicines • Help with understanding • Discuss what is happening to make decisions	Takes care of all medical requirements independently	2	Members of the person's network provide regular help.	2
	Requires some support from another person	1	Members of the person's network provides ad hoc help or less than desired by the person	1
	Requires another person to complete all medical requirements	0	Person has no-one to help them in their network	0


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

Primary outcome:
Social Connectedness

m-MOS Social Support Survey

Pre and post intervention

	None of the Time	A little of the time	Some of the time	Most of the time	All of the time
1. Someone to help you if you were confined to bed.	1	2	3	4	5
2. Someone to take you to the doctor if you need it.	1	2	3	4	5
3. Someone to prepare your meals if you are unable to do it yourself.	1	2	3	4	5
4. Someone to help with daily chores if you were sick.	1	2	3	4	5
5. Someone to have a good time with.	1	2	3	4	5
6. Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5
7. Someone who understands your problems.	1	2	3	4	5
8. Someone to love and make you feel wanted.	1	2	3	4	5

Bunbury is Australia's regional centre for people living alone: Percent of single person households

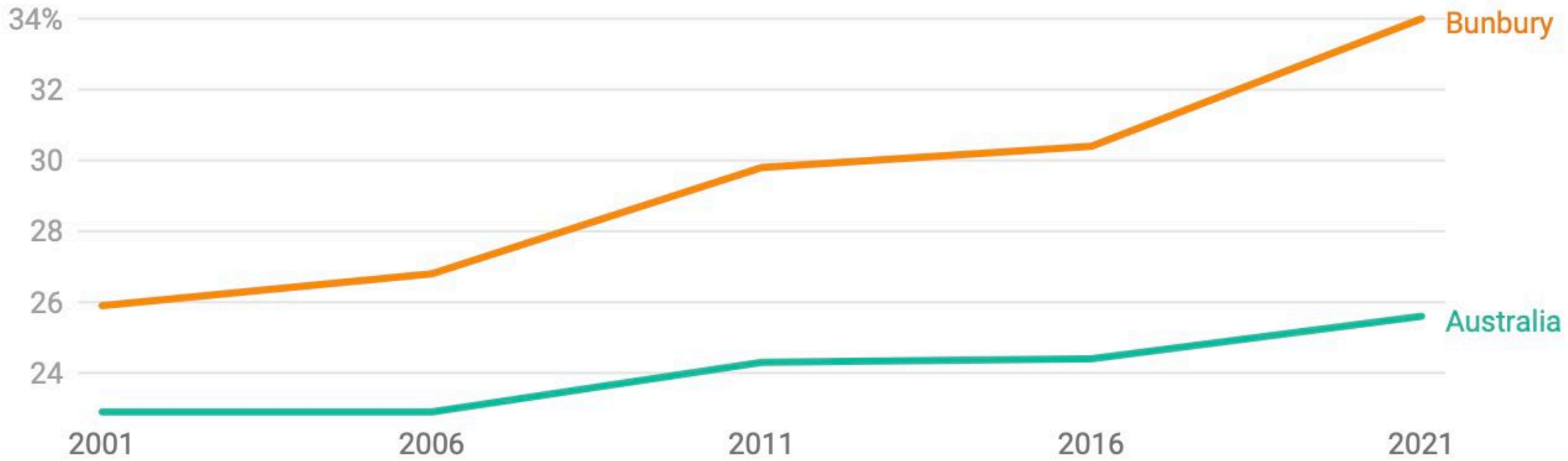
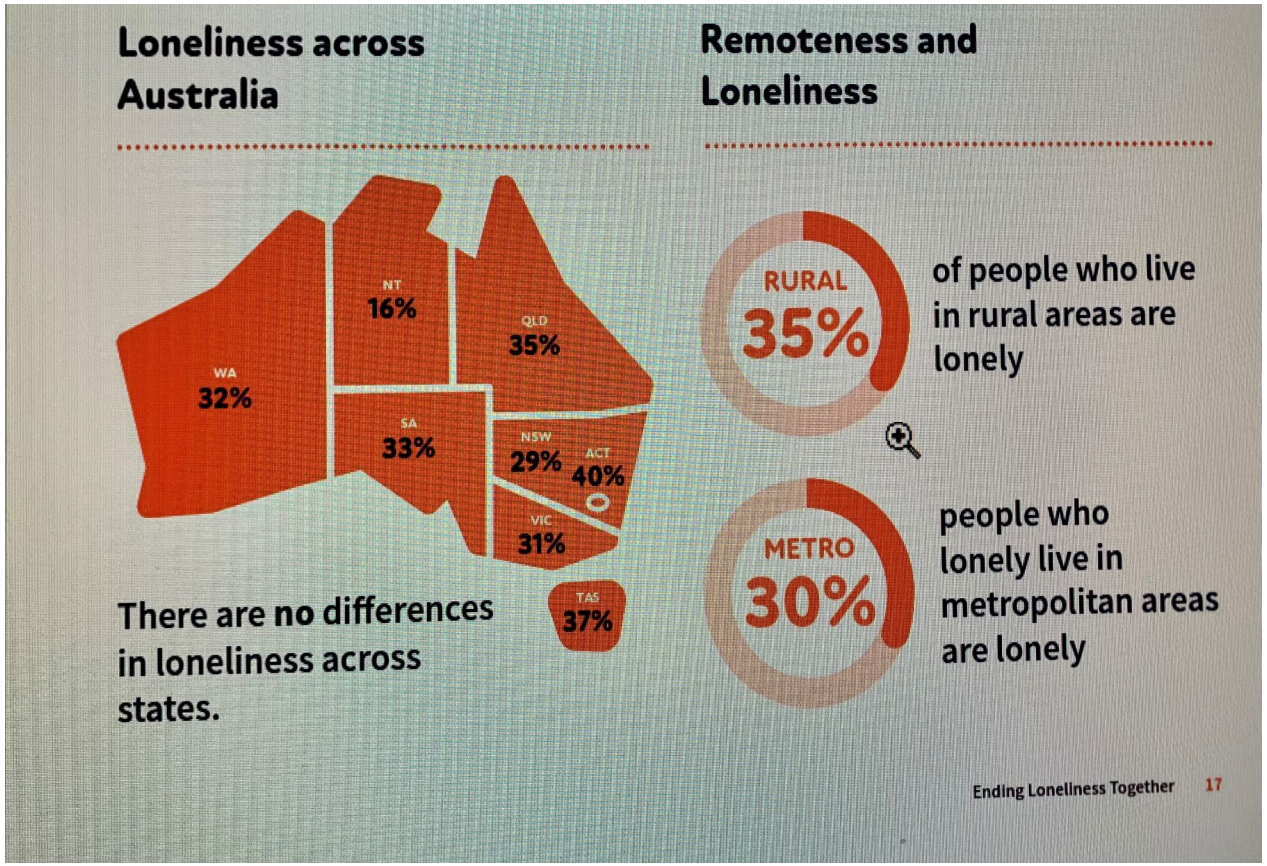
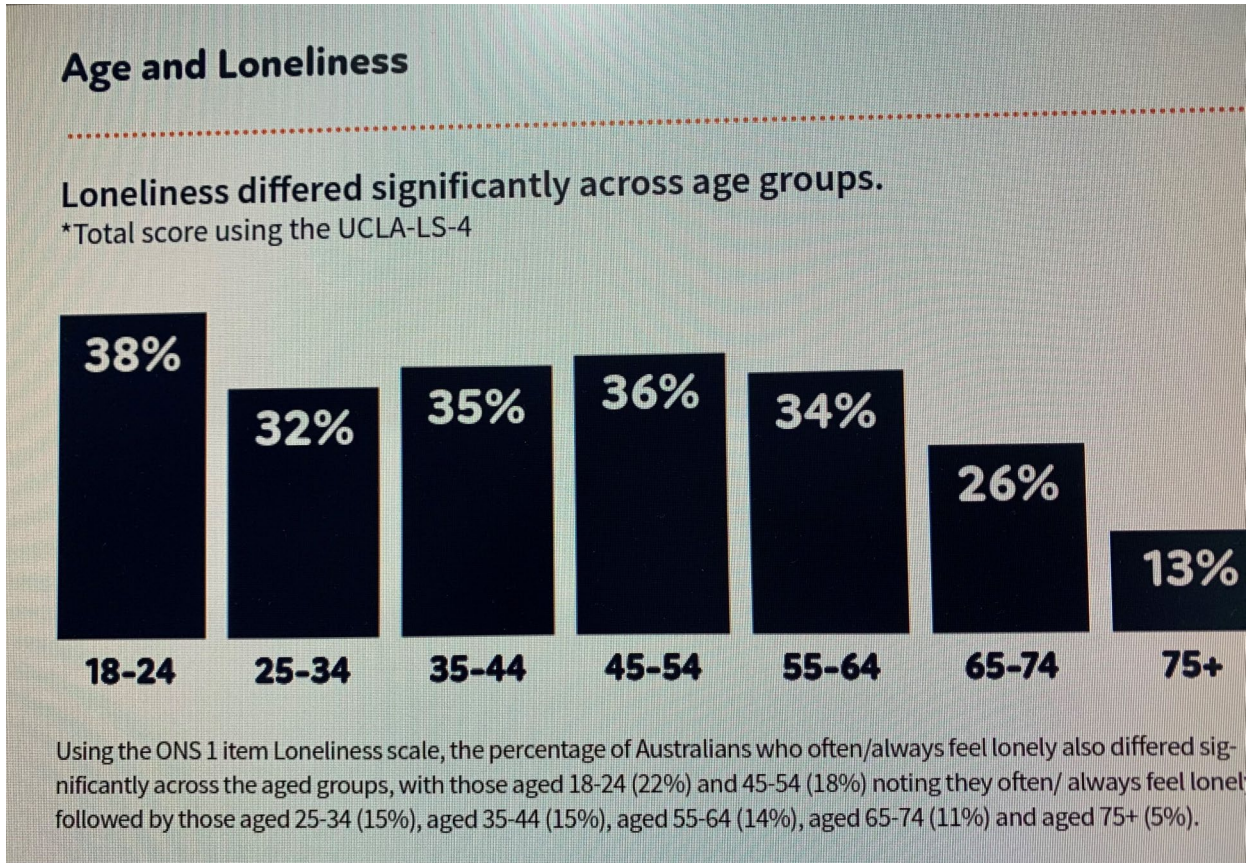


Chart: ABC South West • Source: ABS

Ending Loneliness Together (Aug 2023)





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

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Network Enhancement Tool (NET)

Data Collection September 2020- April 2022

Personal Care	☐ Shower	☐ Dressing	☐ Grooming (hair, teeth)
	☐ Toileting	☐ Other (specify)	
Medical	☐ Attend appointments	☐ Buy your medicines	☐ Take your medicines
	☐ Discuss what is happening to make decisions	☐ Other (specify)	
Home		☐ Gardening	☐ Laundry
	☐ Cleaning inside - Everyday - Spring clean	☐ Rubbish bins	
		☐ Other (specify)	
Transport	☐ Regular appointments	☐ Ad hoc appointments	☐ Other (specify)
Social	☐ Have a good time with, celebrate with	☐ Feel safe to talk about problems with	
	☐ Phone friend	☐ Friend to spend time with (in/out house)	☐ Social media
	☐ Groups the person belongs to or would like to belong to	☐ Other (specify)	
Food	☐ Shopping	☐ Preparing meals	☐ Other (specify)
	☐ Company during meals and/or help with eating		
Pet/Animal	☐ Take dog for walk	☐ Make sure they can go to toilet	☐ Visit from an animal companion
	☐ Other (specify)		
Preparation for end of	☐ Funeral	☐ Advance Care Plan	☐ Advance health Directive

RESULTS

Connectors

- 20 Connectors did the training 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).

Patients

85 families referred from Palliative Care and Chronic Disease teams

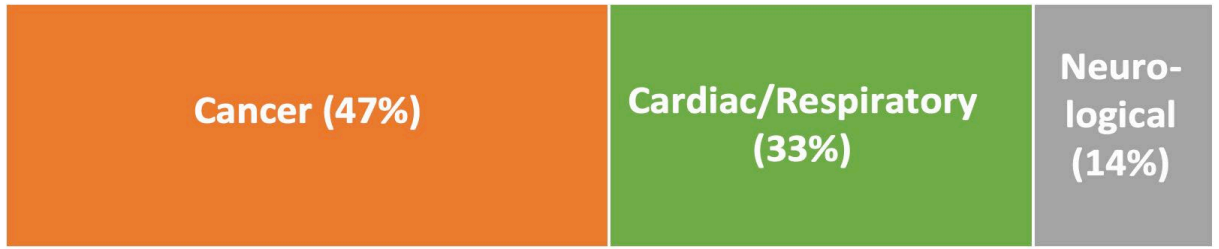
43 families participated (43 patients & 15 carers)

47% were home alone

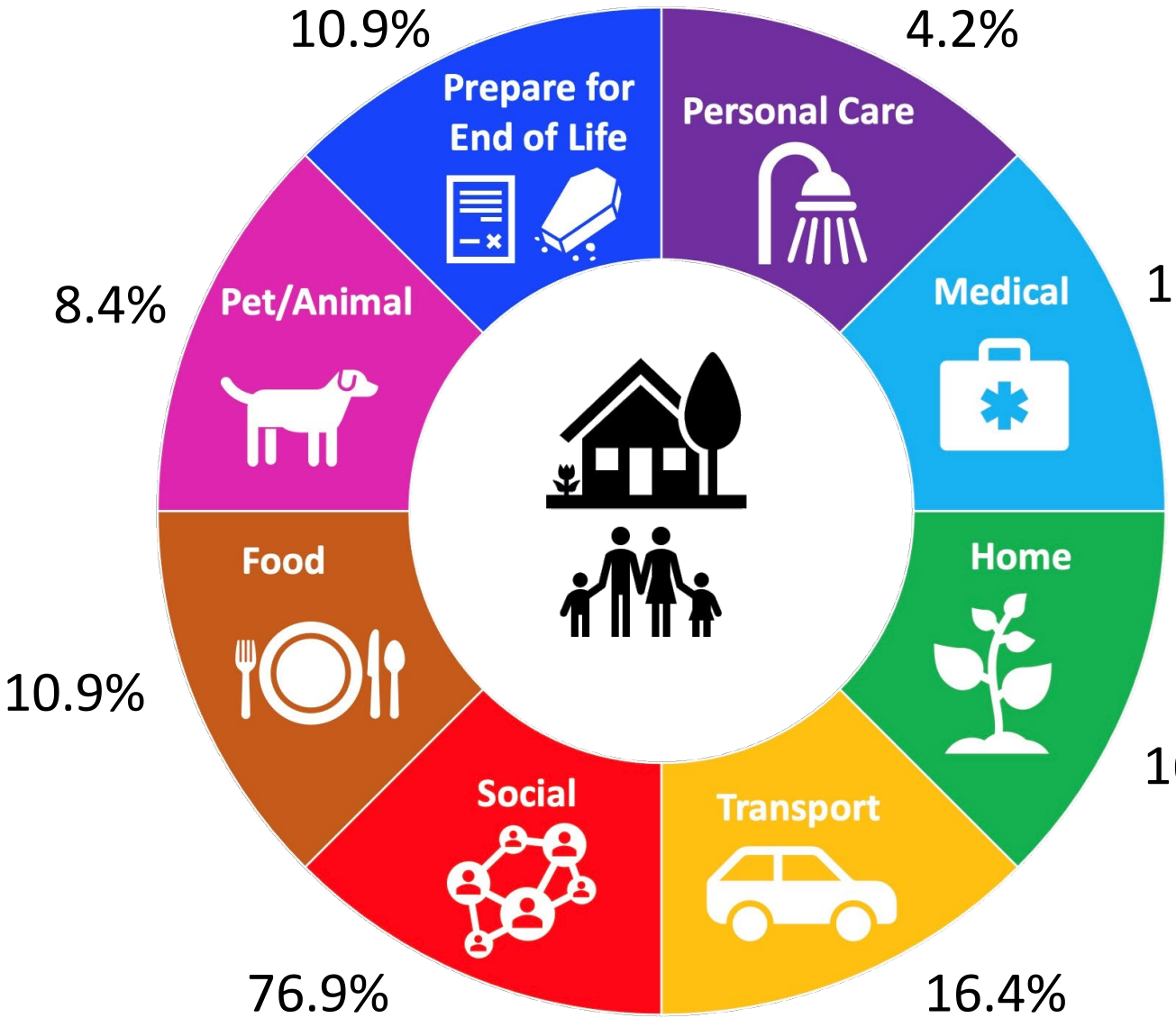
Median age of patients 74 years (34-90)

44% were male

Diagnosis



Type and frequency of support using NET



Connectors have helped or sourced help with (NET):

- 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/Firewood Delivery.
- Social visits.
- Empowerment and ownership, "you can do this".

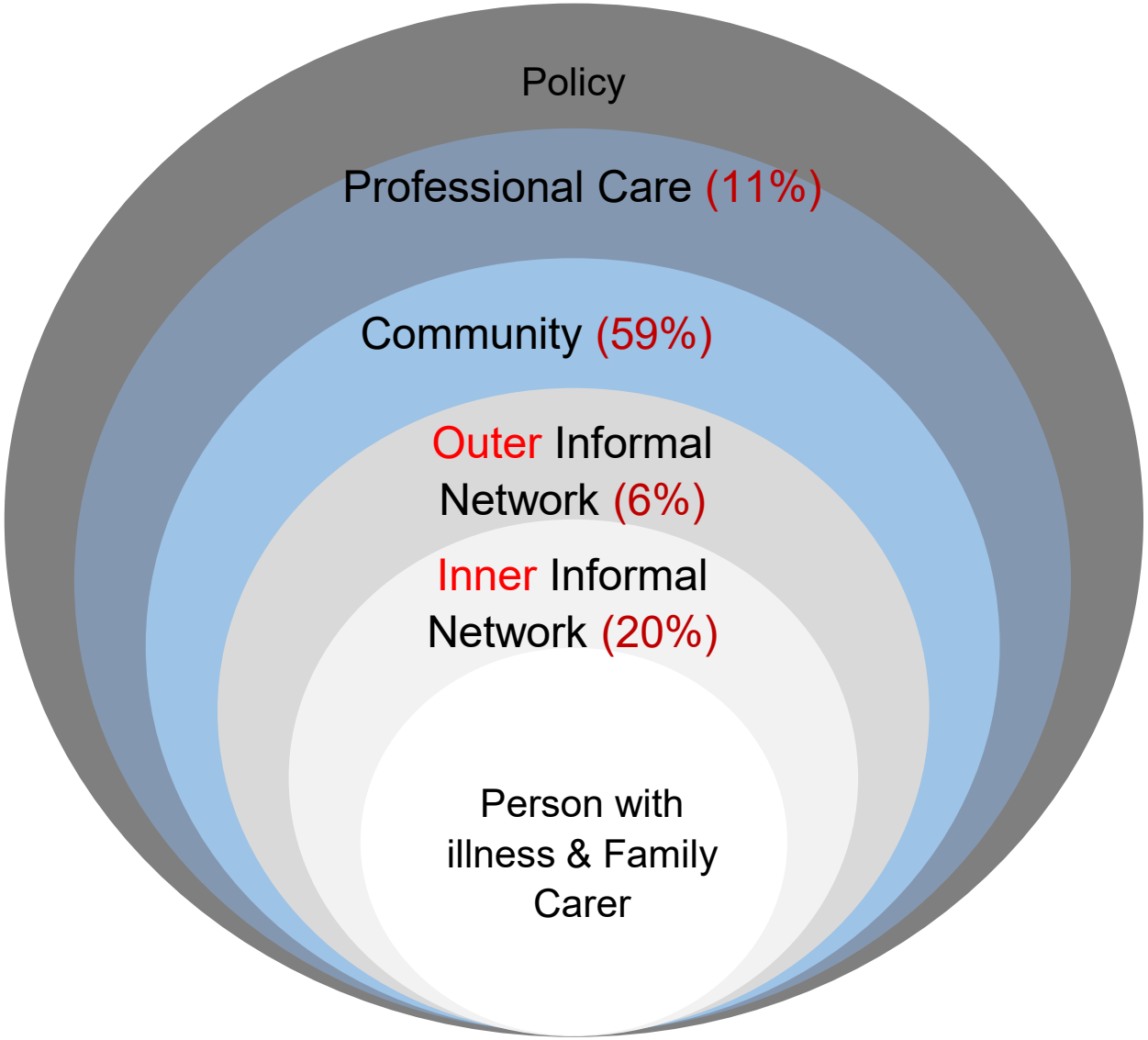





Type of caring helpers who supported the patients (NET)

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

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



Primary outcome
Social Connectedness (m-MOSS*)

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

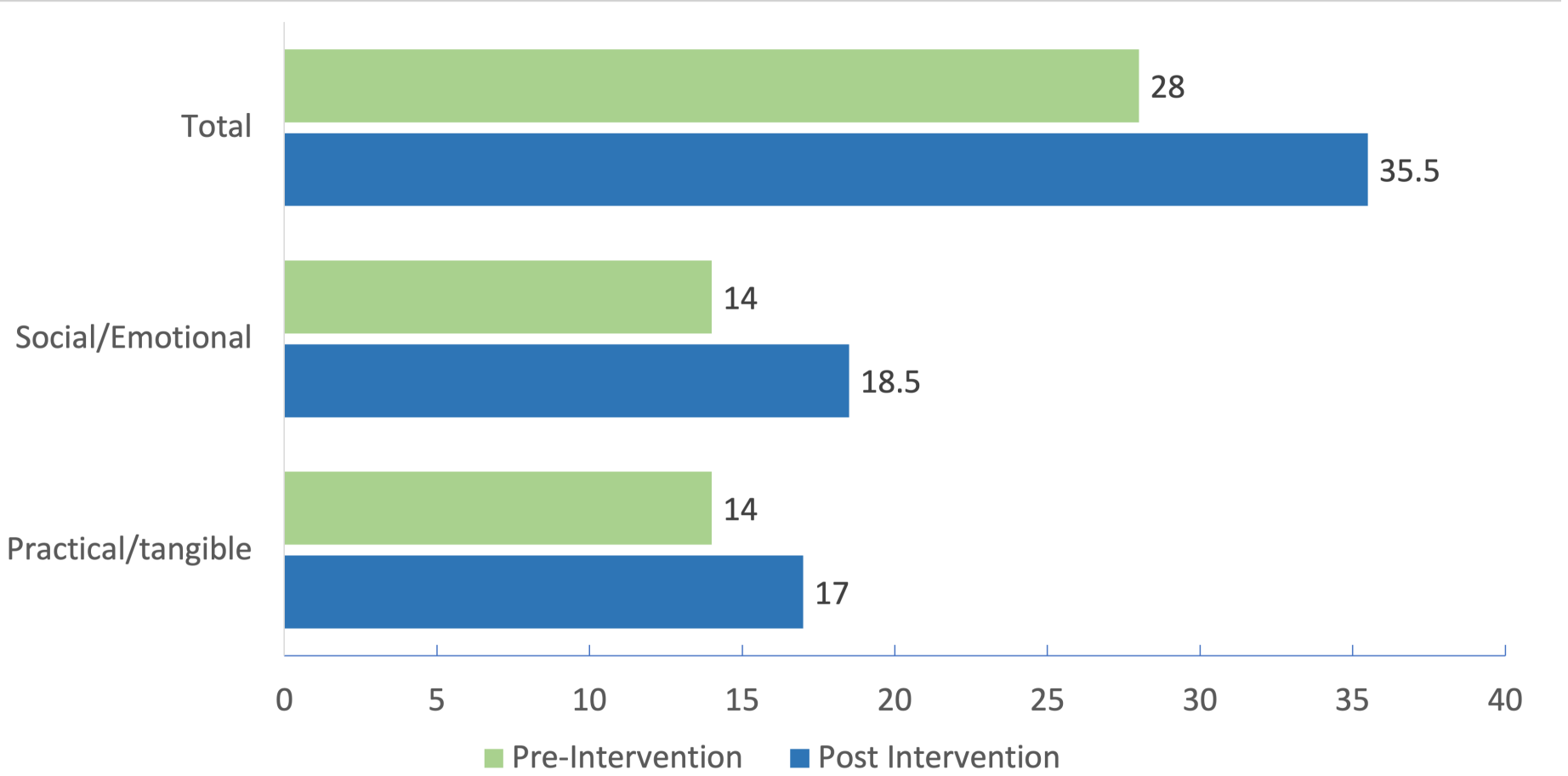
*modified Medical Outcomes Study Social Support Survey (Moser et al, 2012)

Primary Outcome:

Increase in Social Connectedness

P< 0.001

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



Median Difference (95 % CI)

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

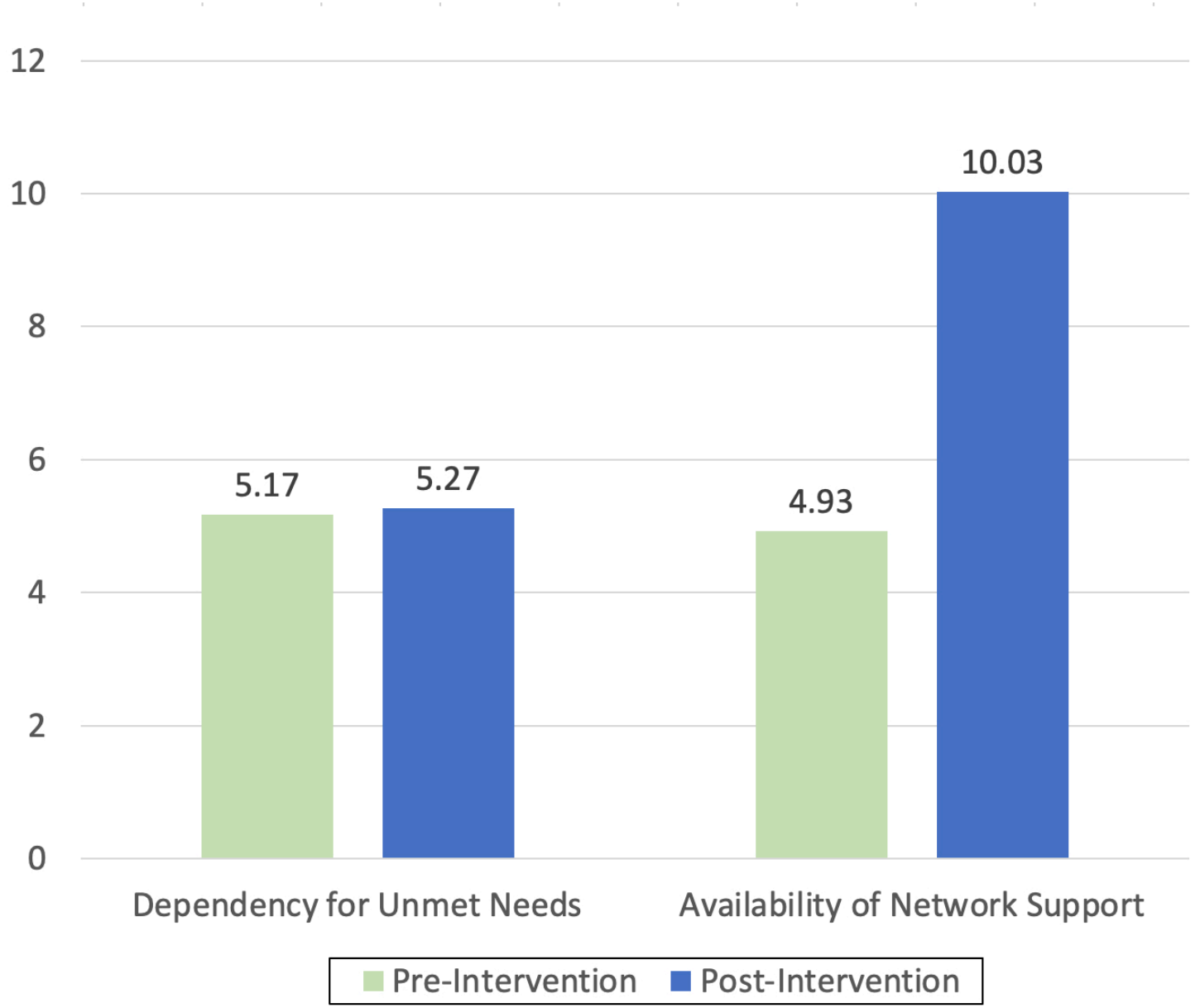
Secondary outcome:
Assessment of practical/social needs and support networks

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

Secondary outcome:

Dependency for unmet needs and availability of support networks

Supportive networks improved by two-folds
P<0.001



Secondary outcome: Self-reported impact

Questions for **Families:**

- How much do you think this initiative has helped you?

	Not at all	A little	Quite a bit	A lot
Reduce your social isolation				
Increase your social activity				
Increase your community links				
Improve your access to formal services as a consequence of Connectors liaising on your behalf				
Cope better with your daily activities				

Secondary outcome: Self-reported impact

Questions for **Connectors:**

- How much do you think this initiative has helped your patient/carer

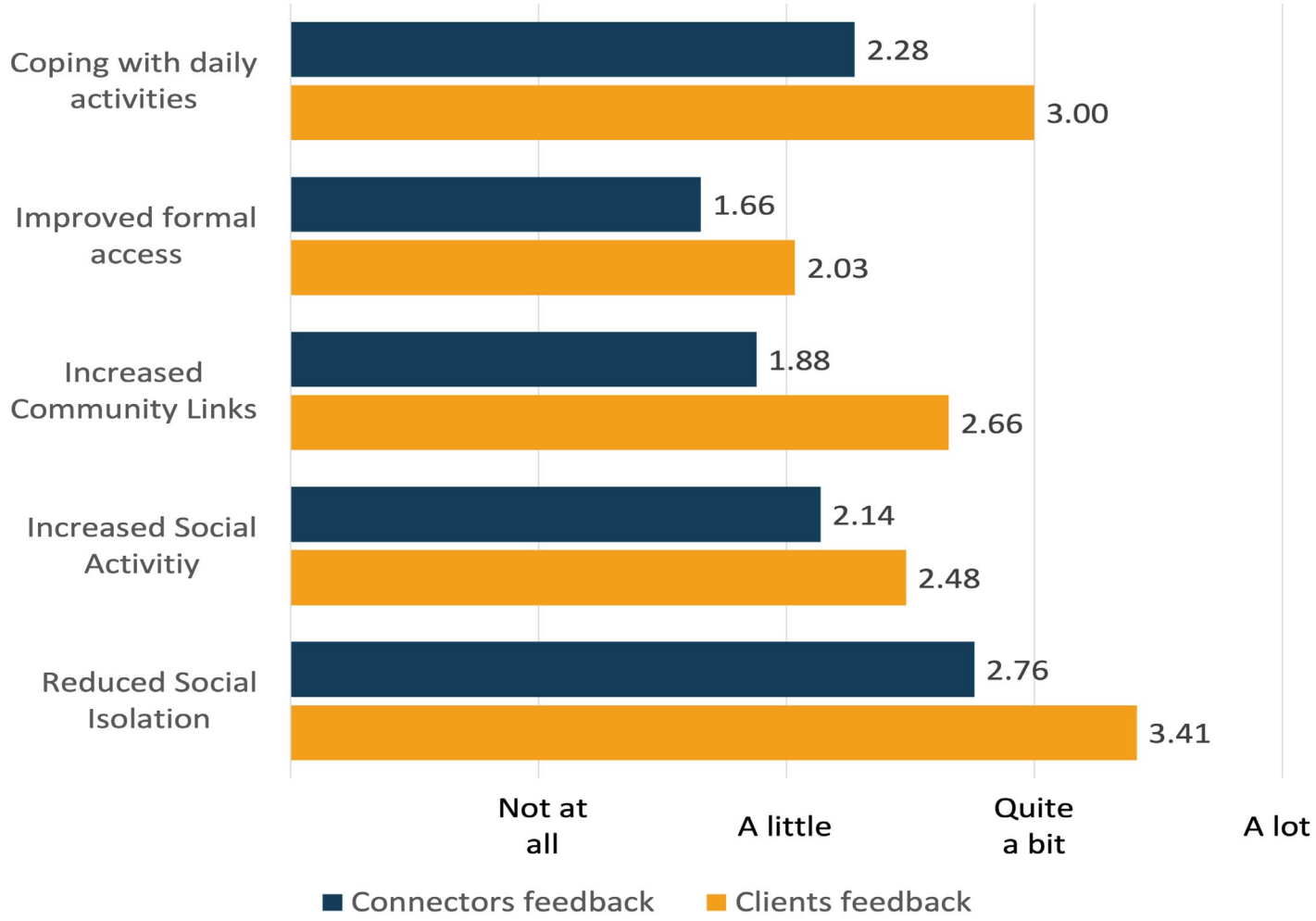
	Not at all	A little	Quite a bit	A lot
Reduce their social isolation				
Increase their social activity				
Increase their community links				
Improve their access to formal services as a consequence of having you liaising on their behalf				
Cope better with their daily activities				

Secondary outcome:

Self-reported impact on social wellbeing

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

highest impact on reduced social isolation



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

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

Palliative Care & Social Practice

2022, Vol. 16: 1–18

DOI: 10.1177/26323524221139655

Abstract

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

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

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Interviews

Total of 74 interviews were undertaken:

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

Key themes in patient/family carer feedback

- Someone having our back: connector as an advocate
- Opening up our world: increasing social connectedness
- Taking the pressure off us

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

Palliative Care & Social Practice
2023, Vol. 17: 1–12
DOI: 10.1177/26323524231173705

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

Abstract

Background and Aim: Comprehensive evaluations that include the experience of patients and service providers are vital if interventions are to be translated into the standard practice of health services and allow formal networks to work as partners with informal community networks. However, published evaluations are limited in the palliative care volunteering literature. The objective of the study is to explore the experiences and views of both patients and their family carers who received support and their referring healthcare providers concerning their participation in the Compassionate Communities Connectors programme, in the south-west region of Western Australia. Connectors identified and addressed gaps in community and healthcare provision by accessing resources and mobilising social networks of people with life-limiting illnesses. The perspectives of patients, carers and service providers concerning the feasibility and acceptability of the intervention were sought.

Methods: Semistructured interviews were undertaken with 28 patients/families and 12 healthcare providers, resulting in 47 interviews in total (March 2021-April 2022). An inductive content analysis was used in analysing interview transcripts to identify key themes.

Results: Families greatly appreciated the support and enablement received from the Connectors. Healthcare providers were impressed with the high level of resourcefulness exhibited by the Connectors and perceived a great need for the programme, particularly for those socially isolated. Three themes captured the patients'/families' perspectives: connector as an advocate, increasing social connectedness and taking the pressure off families. Healthcare providers' perspectives were captured in three themes: reducing social isolation, filling a gap in service provision and building the capacity of the service.

Conclusions: Perspectives of patients/families and healthcare providers demonstrated the mediating role of Connectors. Each group saw the Connectors' contribution through the lens

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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!

Key themes in feedback from healthcare providers

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

Health care team feedback

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

"I will be encouraging more people to make use of informal networks and support"

Easy to implement

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

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

Key themes in Connectors' experience

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

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

Palliative Care & Social Practice

2022, Vol. 16: 1–11

DOI: 10.1177/26323524221139874

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

Abstract

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

Objective: To explore the experiences and views of Connectors implementing this model of care with a particular focus on its feasibility and acceptability from their perspective.

Correspondence to:
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Connector feedback

Fabulous program

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

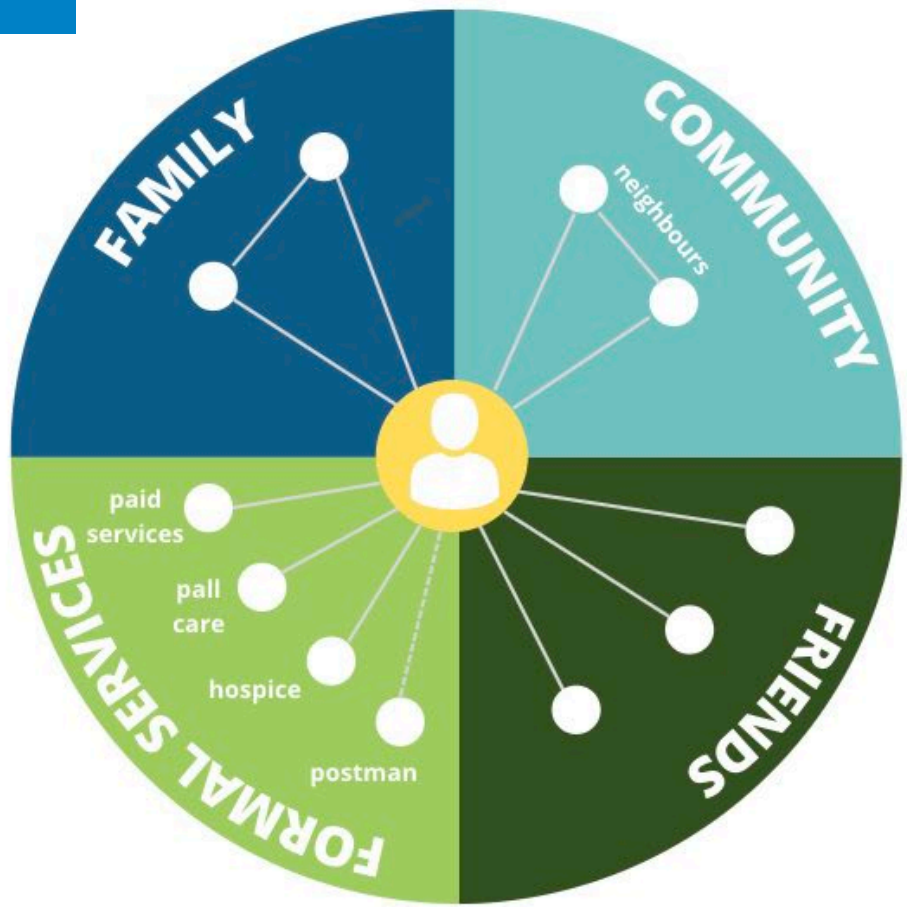
> *So rewarding to watch their quality of life improve*

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

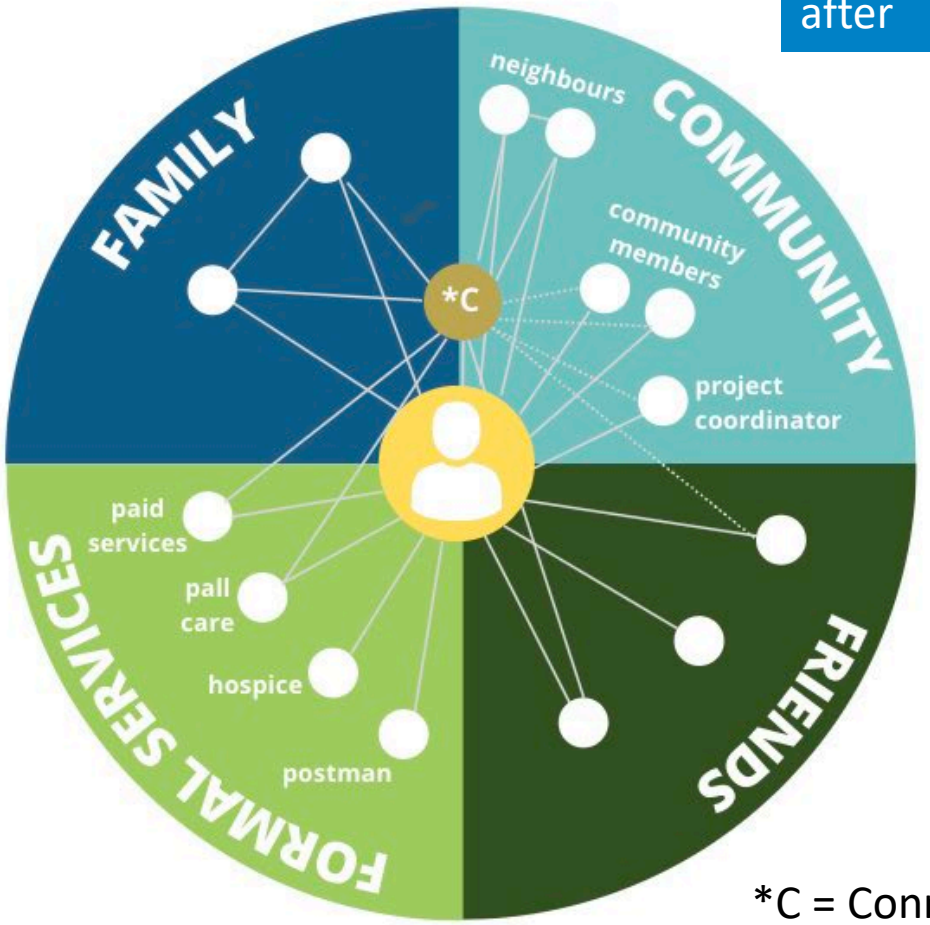
> *The more you give, the better the reward; the reward is greater than the effort*

Social Network Mapping for one family before and after the intervention

before



after



*C = Connector

What is so distinct about this form of volunteering?

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

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

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

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

Kerrie Noonan [1,2], **Bruce Rumbold** [3], **Samar M. Aoun** [1,3,4]

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Public health approaches to palliative care have long promoted the contribution of formal and informal volunteering to providing effective end-of-life care in neighbourhoods and communities. A central strategy for this is a 'compassionate communities' approach that focuses on building care networks and developing community members' capacities in end-of-life care. There is anecdotal evidence of differences in the motivations and life experiences of traditional palliative care volunteers and volunteers in compassionate community programs. There is however very little research into volunteers seeking a compassionate communities orientated role. This study describes the motivations, experiences and characteristics of volunteers participating in a program called compassionate connectors in Western Australia. Twenty volunteers with a variety of caregiving experiences participated in the pilot study through submitting an expression of interest for recruitment. Analysis indicated that the compassionate community connector role

Healthcare Utilisation

Comparison with a control group

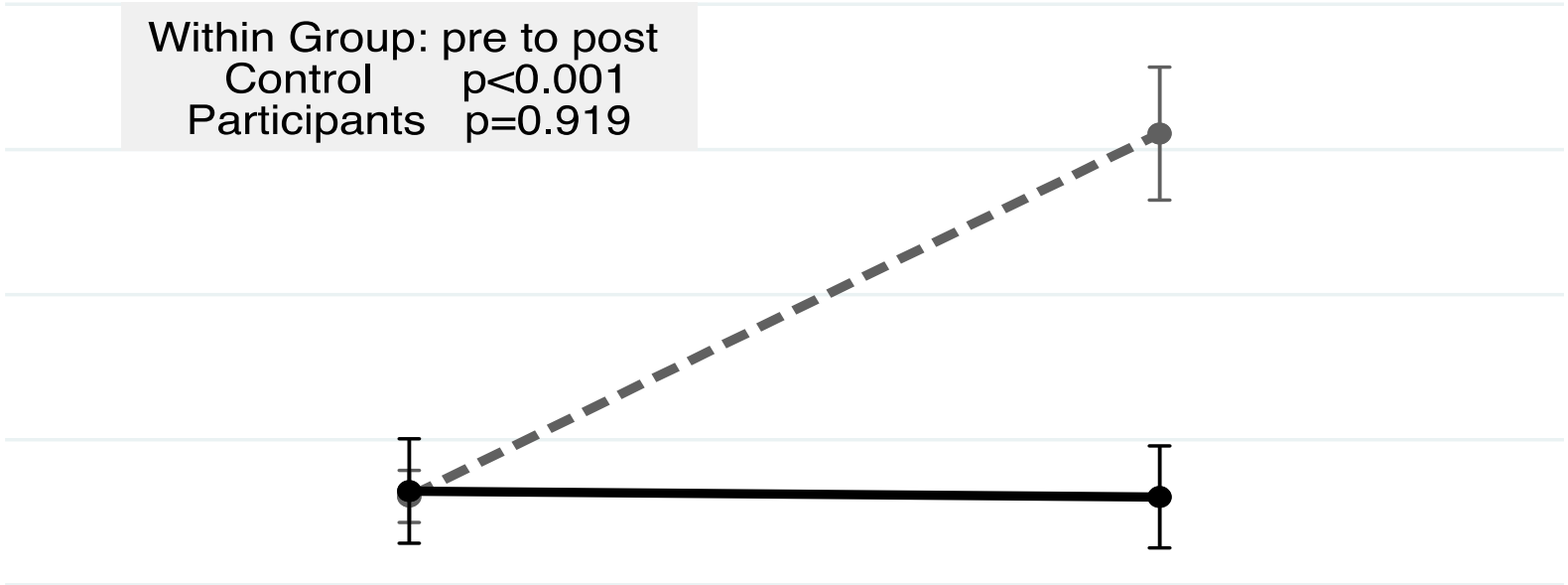
Characteristics of study population

Demographic/ clinical descriptor	Program participant group (n = 43)	Control group (n = 172)
Age in years: mean (SD*)	71.3 (11.9)	72.2 (11.6)
Gender (n; %)	M 19 (44.2%): F 24 (55.8%)	M 76 (44.2%): F 96 (55.8%)
Primary clinical classification (n; %)	Cardiovascular disorder: 14 (32.6%) Cancer: 19 (44.2%) Neurological disorder: 6 (14.0%) Other: 4 (9.2%)	Cardiovascular disorder: 56 (32.6%) Cancer: 76 (44.2%) Neurological disorder: 24 (14.0%) Other: 16 (9.2%)

Regression outputs for health service utilisation in intervention and control groups

Outcome	Group	Rate (per month)		Within Group comparison from pre to post program		Between Group comparison following program	
		Pre-program	Post-program	adjusted IRR (95% CI)	p value	adjusted IRR (95% CI)	p value
Frequency of hospital admissions (monthly)	Participants	0.19	0.17	0.98 (0.60, 1.58)	0.923	0.37 (0.18, 0.77)	0.007
	Control	0.20	0.42	2.56 (2.07, 3.16)	<0.001		
Inpatient length of stay (days per month)	Participants	0.73	0.76	1.01 (0.46, 2.20)	0.983	0.23 (0.11, 0.49)	<0.001
	Control	0.70	2.78	4.14 (2.87, 5.98)	<0.001		
Emergency department presentations (monthly)	Participants	0.23	0.23	1.00 (0.68, 1.47)	0.989	0.56 (0.34, 0.94)	0.028
	Control	0.24	0.55	2.36 (2.00, 2.80)	<0.001		
Outpatient contacts (monthly)**	Participants	1.33	7.11	5.49 (2.67, 11.29)	<0.001	2.07 (1.11, 3.86)	0.022
	Control	1.40	3.68	2.80 (2.24, 3.50)	<0.001		

Hospital Admissions



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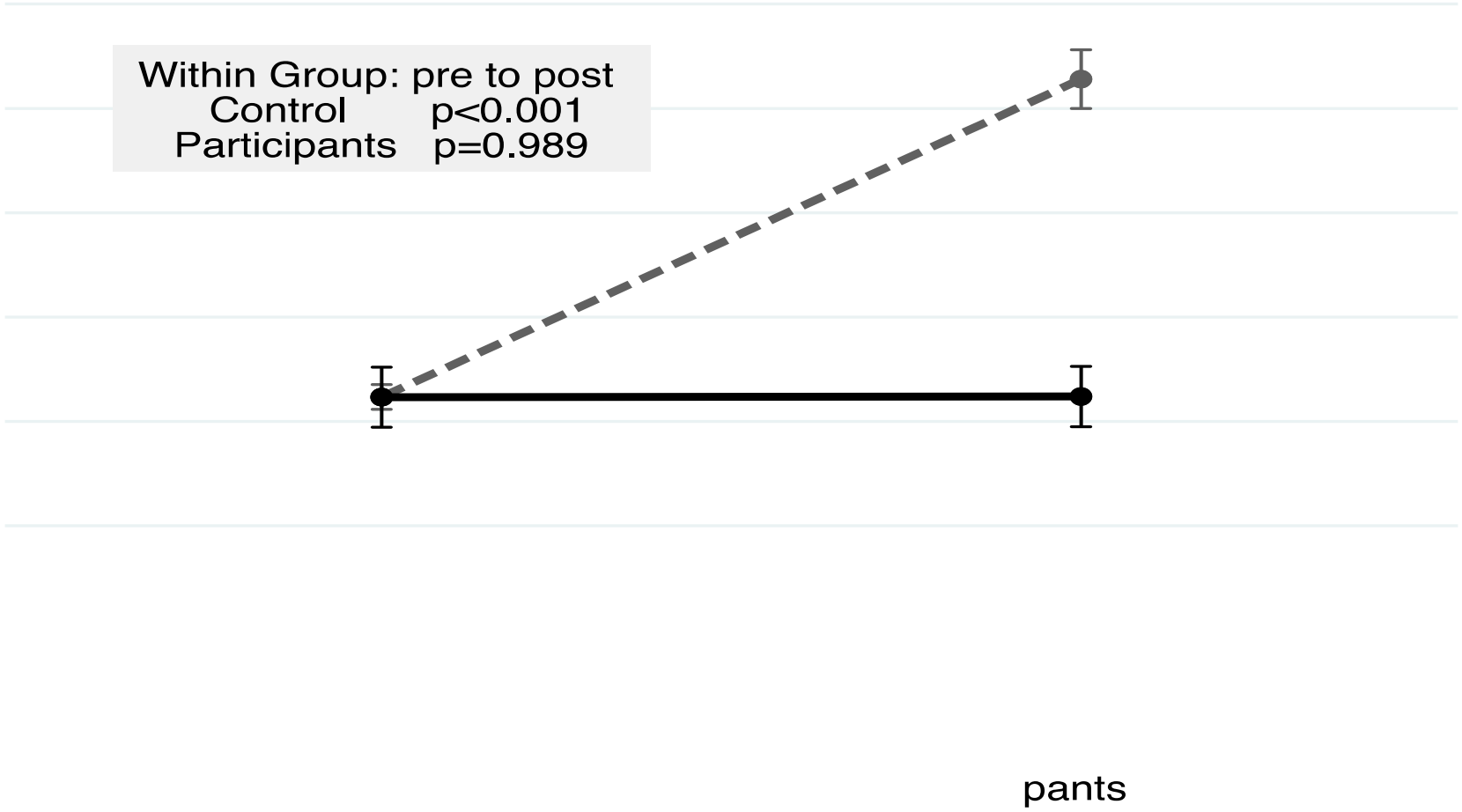
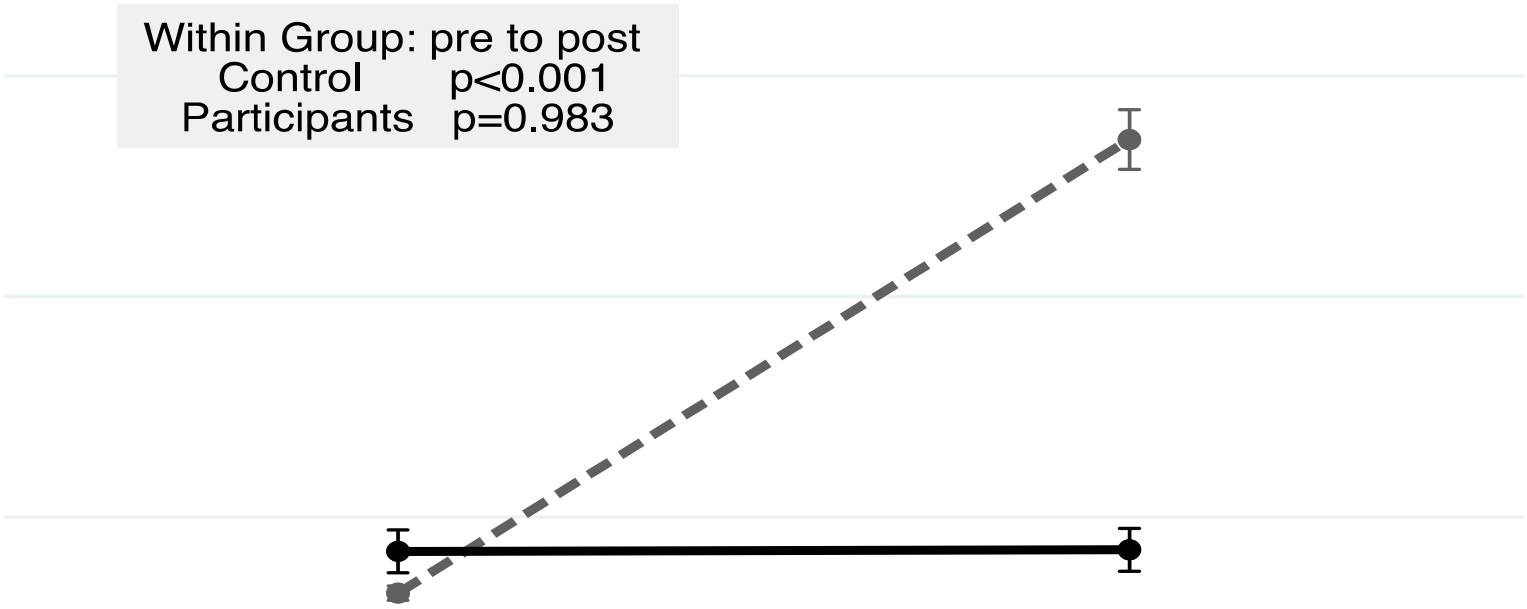
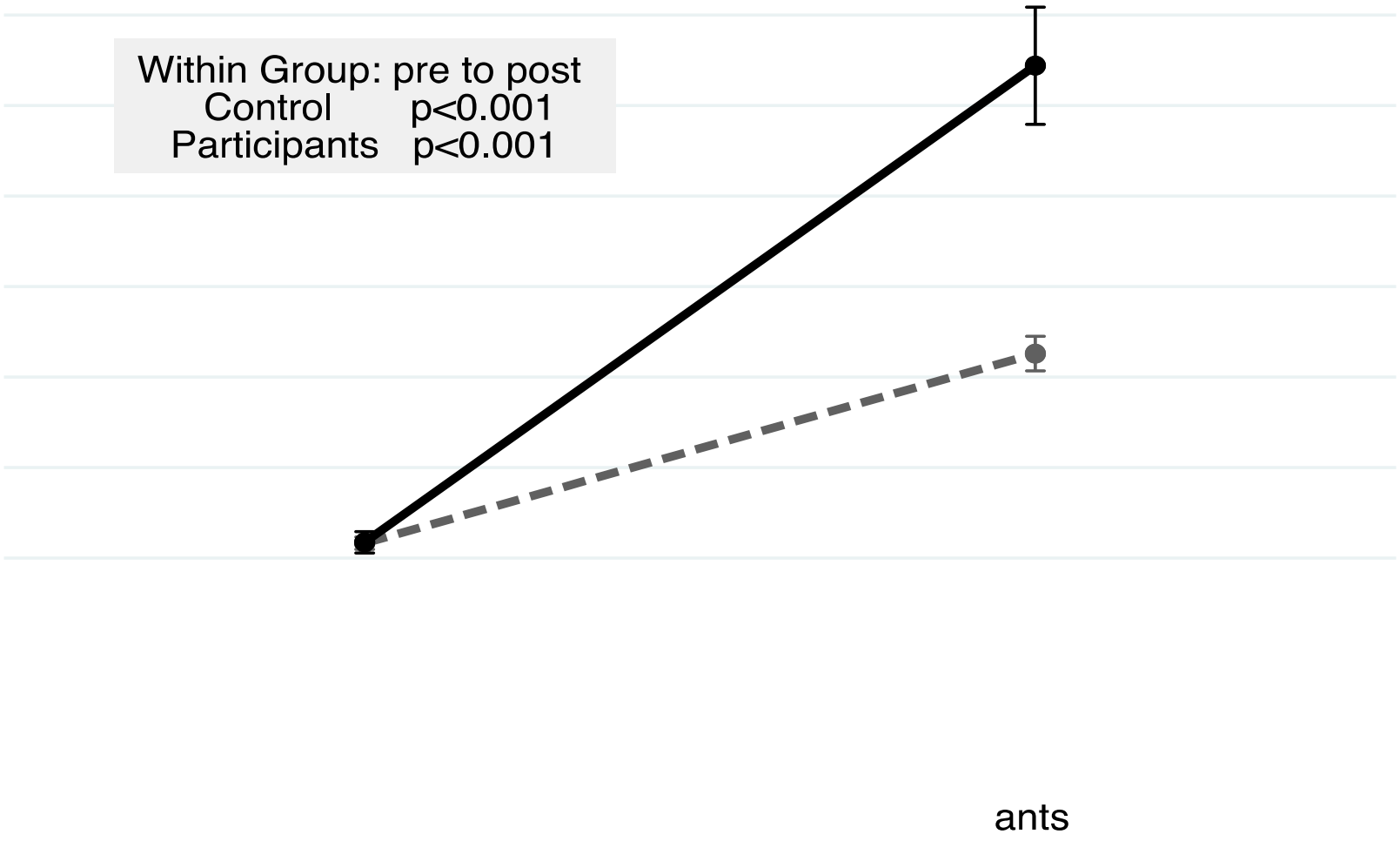
Emergency Presentations



ength of Stay



Outpatient


Within Group: pre to post
Control p<0.001
Participants p<0.001
ants

Costs and consequences for intervention vs. control groups for hypothetical population of 100 people with life-limiting disease over an average 6-month participation period.

Health service utilisation*	Control group* (standard care)	Connector program group*	Cost difference: Intervention vs. control group ($AUD)
Inpatient length of stay	$2,154,345	$1,368,189	-$786,156
Emergency department presentations	$422,013	$178,988	-$243,025
Outpatient contacts	$412,475	$815,432	$402,957
Total			-$626,224
Net Savings			**-$518,701**

Healthcare Usage and Economic Analyses-Summary

Significant decline in frequency of hospitalisations	*63% less admissions (p=0.007)*
Significant decline in number of hospital days	*77% less days (p<0.001)*
Significant decline in ED presentations	*44% less ED presentations (p=0.028)*
Significant 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**

The Compassionate Communities Connectors program: Effect on healthcare usage

Palliative Care & Social Practice
2023, Vol. 17: 1–11
DOI: 10.1177/26323524231205323

Samar M. Aoun, Natasha Bear and Bruce Rumbold

Abstract

Background: Public health approaches to palliative and end-of-life care focus on enhancing the integration of services and providing a comprehensive approach that engages the assets of local communities. However, few studies have evaluated the relative costs and benefits of providing care using these service models.

Objectives: To assess the effect on healthcare usage of a community-based palliative care program ('Compassionate Communities Connectors') where practical and social support was delivered by community volunteers to people living with advanced life-limiting illnesses in regional Western Australia.

Design: Controlled before-and-after study/Cost-consequence analysis.

Methods: A total of 43 community-based patients participated in the program during the period 2020–2022. A comparator population of 172 individuals with advanced life-limiting illnesses was randomly selected from usage data from the same set of health services.

Results: Relative to controls, the intervention group had lower hospitalizations per month [Incidence rate ratio (IRR): 0.37; 95% CI: 0.18–0.77, $p = 0.007$], less hospital days per month (IRR: 0.23; 95% CI: 0.11–0.49, $p < 0.001$) and less emergency presentations (IRR: 0.56; 95% CI: 0.34–0.94, $p = 0.028$. The frequency of outpatient contacts overall was two times higher for the

Example of a community-led solution: Compassionate Connectors program

- Improved social connectedness (practical and social/emotional)
- Increased support networks
- Reduced social isolation
- Increased community links
- Improved coping with daily activities
- Significant savings from reduced hospital usage:

  - 63% less likely to be admitted to hospital
  - spent 77% less days in hospital
  - 44% less likely to use an emergency department
  - twice more likely to use outpatient services.

SOUTH WEST Compassionate Communities NETWORK

caring, dying and grieving is everyone's business

THE TRANSLATION

Progressing Systems Change

Integration as standard practice in health services

Rolling it out to other communities – WA & Australia
-Connector Hubs
-Community Death and Grief Literacy

Local government
Compassionate Charter

Engagement with Primary Care

Maintaining System Change

Specialist and generalist palliative care,

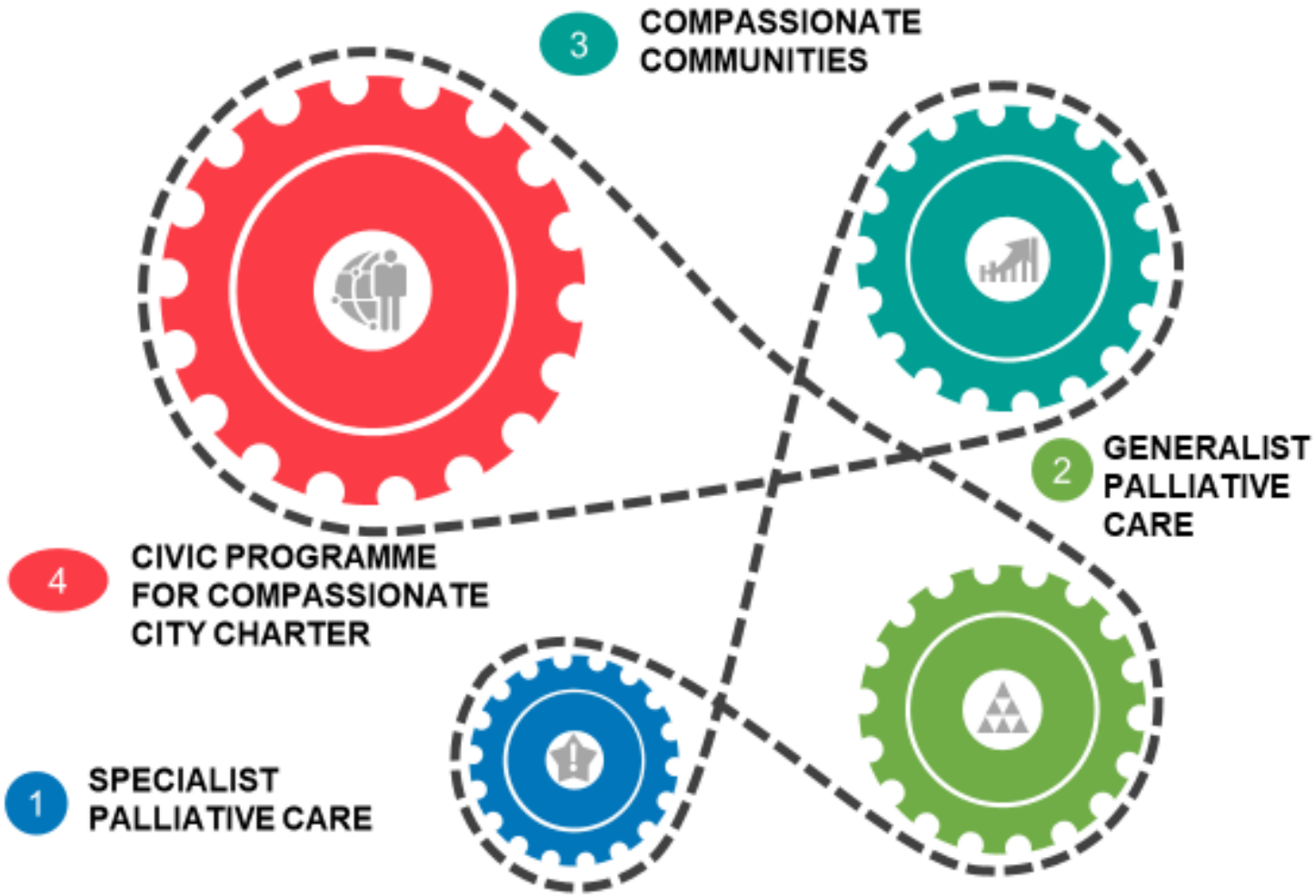
civic organisations and

community networks

must **collaborate** in order to create

an effective, affordable & sustainable end-of-life care system

Palliative Care – The New Essentials



Up to all of us to Connect the Dots

Public Health Approach to Palliative and End of Life Care

(Aoun et al, 2020)

ENABLERS

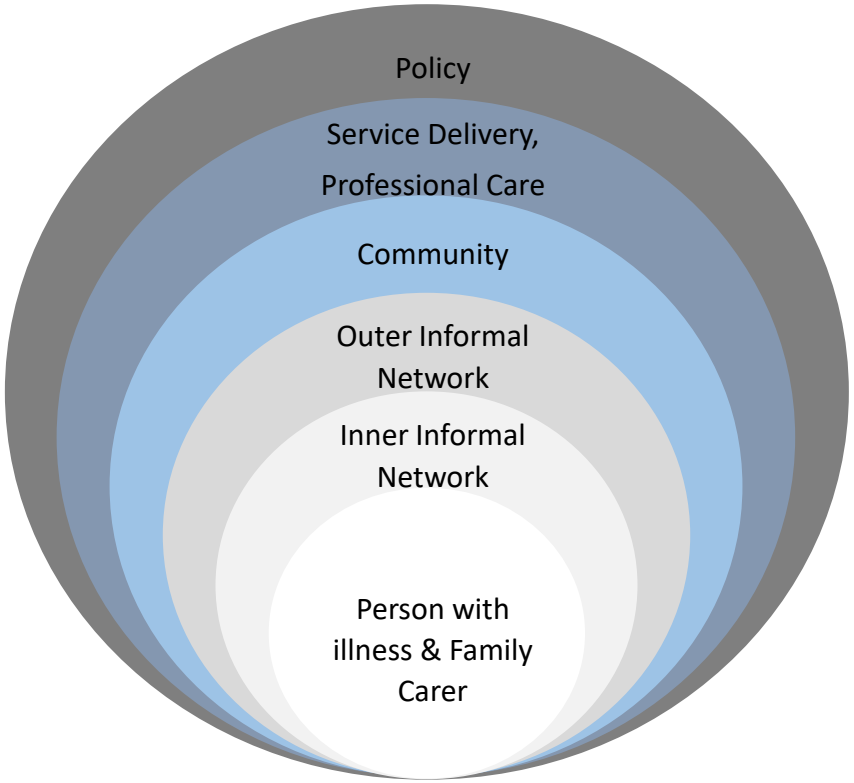
Digital and Assistive technologies:
Telehealth, Equipment

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

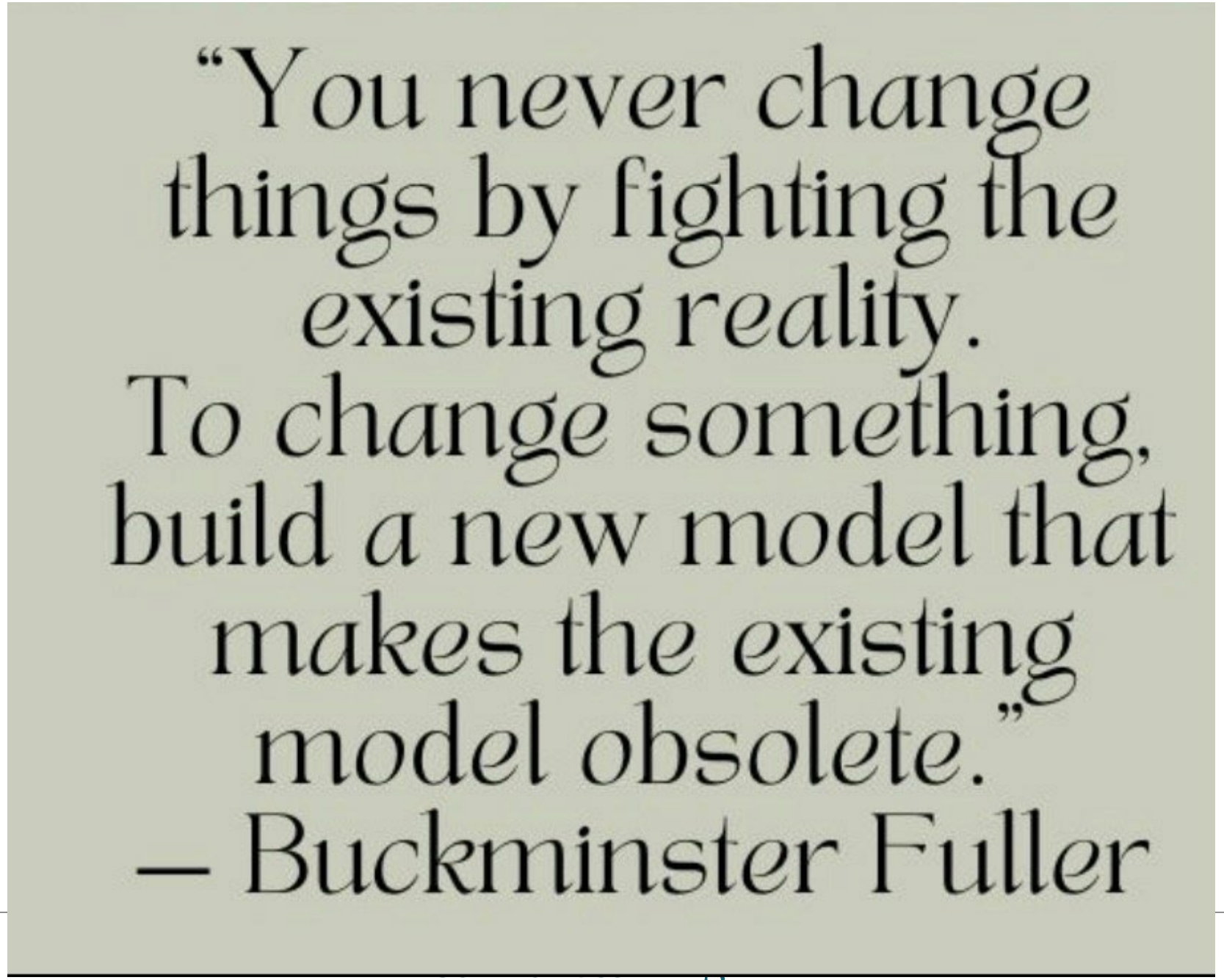
Aged Care Sector

Specialist Palliative Care

Generalist Palliative Care

Disease specific clinics

Primary Care & Allied Health Care


"You never change
things by fighting the
existing reality.
To change something,
build a new model that
makes the existing
model obsolete."
— Buckminster Fuller

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.

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)

Compassionate Bunbury Charter

Why we need a Compassionate Charter?

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

Educational institutions, workplaces, aged care, 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

Bunbury Mayoral Award

Individuals, families and friends

Workplaces

Community organisations, groups & neighbourhoods

Compassionate Bunbury Mayoral Award to Compassionate Connectors

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

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

July 17, 2023
11am - 2.45pm

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

GOVERNMENT OF WESTERN AUSTRALIA
SOUTH WEST DEVELOPMENT COMMISSION
bgcci Bunbury Geographe Chamber of Commerce and Industry
perron institute EST. 1982 for neurological and translational science

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
SEEK WISDOM

Youth Art Competition at Schools - 2020

Remembering our Dead ceremony with floating lanterns- 5 August 2023

Concert at Cemetery- Bunbury 5 Aug 2023

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

Cooling Blanket

Compassionate Communities Australia

Weaving compassion and connection across Australia as we live, die, grieve and care for each other

Compassionate Communities Australia

Compassionate Communities Australia is about

- Building the capacity of Compassionate Communities across Australia in their endeavours to enable people to care, die and grieve supported by their community.

- Actively promoting the role of community-based caregiving networks and our collective ability to engage with serious illness and death.

- Becoming a hub of knowledge and skills for **community-led solutions** that would lead to social and systems change.

The voluntary group reigniting a sense of community

Bringing comfort & calm to those facing their final days

and changing the way we talk and think about death

JESSICA EVENSEN

"It's amazing being greeted at the door by somebody who's absolutely delighted to see you, knowing they won't be seeing or speaking to anybody else that day."

That's according to Toni Jacobson, one of the dozens of volunteers involved with the Compassionate Communities program — a group working to reduce social isolation in the final months of a person's life.

"Connectors" work by visiting palliatively ill patients and providing support like helping with grocery shopping, gardening and finding suitable social activities.

At other times, it's as simple as sitting together in silence over a cup of tea.

Compassionate Communities co-founder Samar Aoun, pictured left, said she started the program in Bunbury in 2019 after noticing a void in free, community-led support.

"I felt like there were better ways to be helping the community and caring for someone who's dying or has a life-limiting illness," Professor Aoun told The West Australian.

"People do not have the confidence to help each other anymore . . . the community is not coming together the same way it used to in the olden days.

"The idea of the program is to build up the capacity of people to help each other and encourage people who need help, to ask for help.

"People do not feel like they can (ask for help), they feel like they need to be brave and stoic to their own detriment. When people say no to those who are offering help, they shut down all social networks around them."

Unlike other volunteer groups, the Compassionate Communities program has a more laissez-faire approach, allowing volunteers to be flexible with their time and help out when they can.

"They're not volunteers in the traditional way whereby they come at nine on Tuesdays and Thursdays . . . it's about helping your friends in the community," Professor Aoun said. "If you've got time, you pop in, and if you don't have time, you don't pop in . . . it's back to the organic, natural way of helping each other."

Ms Jacobson, 78, has been a Compassionate Communities connector for about four years and says the program "is not rocket science".

"It's about caring for other people and what's happening to them, like asking if somebody has put your bins out for you . . . because sometimes these people won't see another person for the rest of the day," the Geographe resident said.

"They are all such lovely people, and just because you're old and you're forgetful it doesn't make you boring . . . so many people are very lonely."

Ms Jacobson recalled one of her "favourite" clients; an elderly lady in Nannup who she would deliver home-cooked meals to.

"Nannup is one of those isolated towns where there are not a lot of services but a lot of older people," Ms Jacobson said.

"She was very, very special . . . She was always delighted to see me."

One patient spoke about how the program had opened up her world.

"If you can imagine a fully blown up football . . . that was my life, (but) it now feels like a golf ball," she said.

"Thanks to the program I can see my golf ball is sort of growing a tiny bit more, maybe to a tennis-ball size."

Another patient said the program had given her a more reasons to push themselves.

"There's a level of accountability if somebody's coming to see you . . . you've got to get up, get dressed and you've got to face the world," they said.

"You can't just lay curled up in your bed all day."

And it's not a program designed specifically for those in old age.

Professor Aoun spoke of one instance where the Compassionate Communities program connected a family of young siblings with a group of "surrogate grannies" while their mum went through chemotherapy.

"The mum couldn't send her kids to day care because of the germs . . . so this connector organised a group of surrogate grannies," she said.

"She contacted her friends her own age who were in their 70s and said, 'look, can we have your support and go look after those kids in their home so they don't have to be outside and bring in any germs while the mother is unwell?'"

Lotterywest has since funded an $800,000 grant over three years to help scale up the Compassionate Communities program through Western Australia.

"Lotterywest is proud to play a role in helping the Perron Institute for Neurological and Translational Science upscale the program and to create an online learning hub so other communities and organisations across WA can develop their own creator hubs," Lotterywest chief executive Colin Smith said.

"The three-year program will extend existing services and provide training for volunteers to be better placed to support each other."

Darlington local Shane Bailey will be one of the dozens of new connectors joining Compassionate Communities in 2025 as the program expands throughout the Perth metropolitan area.

"When someone has a terminal illness, about 90 per cent of that person's time is spent in the community . . . but that is a whole lot of time that generally, as a society, we haven't really considered," she said.

"During that time, a person's quality of life can be less than it used to be . . . (the program) is as much of a win for the person who's receiving the support as it is for the person who's giving it, because there seems to be something innate in us humans that we want to feel helpful.

"We have a shared responsibility to look after each other, because the way that society has evolved means that illness and dying has become medically focused and we've lost the skills on how to support and be around someone who's actually dying."

Ms Bailey said the program also aimed to improve the way in which death is talked about so that patients could feel a "degree of acceptance and comfort" in the final weeks of their life.

"We plan about what we're going to wear, we plan for weddings, we plan for births . . . we plan for all these milestones in life, and death is another milestone we're going to reach," she said.

"We're often quite fearful about our own death . . . and we will probably always have some degree of fear, but the more we have conversations about it, we can begin looking at it like, 'how do I want to approach this?'"

Despite 70 per cent of people wanting to die at home, only 14 per cent of palliatively ill Australians are able to do so.

"We do not need to die in hospitals if we have a community that is death literate," Professor Aoun said.

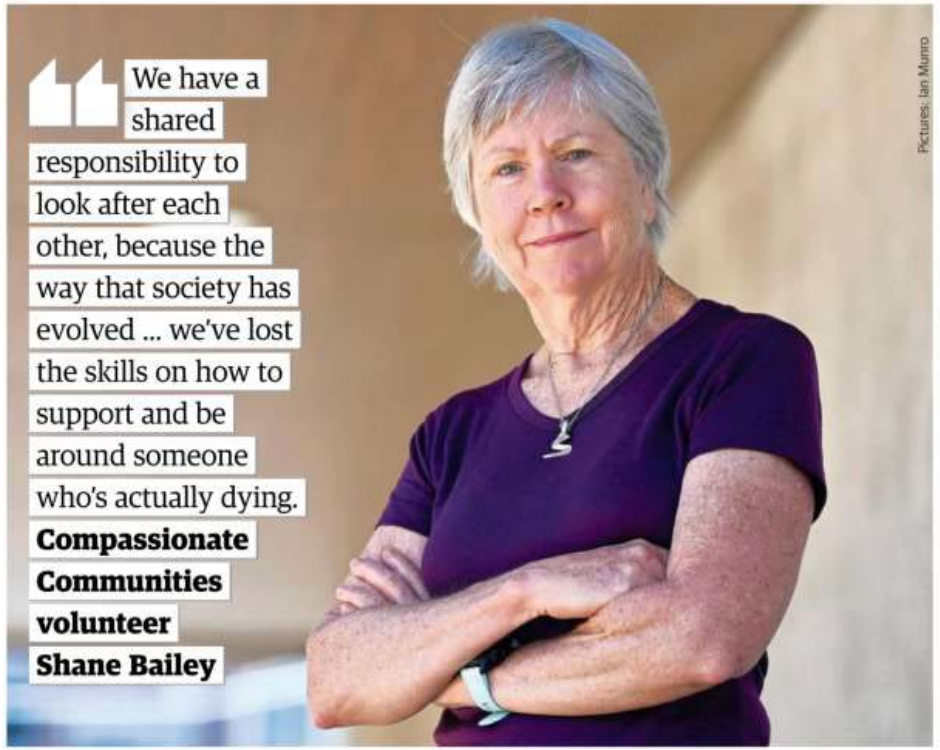
"Death is a social event with a medical component, it is not a medical event with a social component . . . we need to reactivate our social networks to be able to provide that support."

Professor Aoun said for some the recent festive season would have felt especially isolating, and urged Australians to reach out to elderly people in their own communities and "sit with them and just have a chat".

"I cannot emphasise the importance of having a warm body next to you . . . talking with you, smiling at you," she said.

"You don't have to say anything, it's just about your presence and being with them in their loneliness and in their grief.

"If you don't know what to say . . . just offer something in a tangible way that shows that you love them and that you care about them."



Connector Hubs