

South Australia Compassionate Communities Conversation Series

Report 2023/24



Compassionate Communities SA

Program of Palliative Care SA

Series Lead



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In Collaboration with



We are inclusive.

We celebrate multiple approaches and points of view.

*When we say palliative care is everybody's business,
no matter their age, we mean everybody.*

Acknowledgements

Our organisation acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pays respect to Elders - past, present and emerging.

Palliative Care South Australia wish to thank all our collaborative partners, staff and board members who have supported the development of this document and our partners, stakeholders, event participants and PCSA members who have given their valuable time and expertise to help guide the development of this publication, Carol Hope Consulting for your assistance in theming the information. We greatly appreciate the contributions everyone has made in sharing experience, knowledge and time with us.

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**SA COMPASSIONATE COMMUNITY
CONVERSATION
VICTOR HARBOR ~ 1 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATION
WOODVILLE ~ 2 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATION
MT BARKER ~ 3 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATION
SOUTHERN ADELAIDE ~ 9 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATION
MT GAMBIER ~ 10 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATION
WHYALLA ~ 15 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATION
PT LINCOLN ~ 16 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATIONS
MURRAY BRIDGE ~ 20 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATIONS
BERRI ~ 22 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATIONS
TEA TREE GULLY ~ 23 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATIONS
KADINA ~ 30 NOV 2023**



**SA COMPASSIONATE COMMUNITY
CONVERSATIONS
PT PIRIE ~ 31 JANUARY 2024**

You're Invited

CCSA
Conversations
Activity of Palliative Care SA

TO A LOCAL COMPASSIONATE COMMUNITY CONVERSATION WITH FREE MORNING TEA

Location: 12 Communities across South Australia **Date:** Nov 2023 - Jan 2024
Time: 10:00am - 11:30am **Cost:** FREE

Win

ALL ATTENDEES GO IN THE DRAW TO
WIN A \$50 GIFT VOUCHER*

*Terms and conditions apply, \$50 gift voucher door prize drawn at the conclusion of each event



LOCATION: Victor Harbor
DATE: Wednesday 1st November 2023
LOCATION: Woodville
DATE: Thursday 2nd November 2023
LOCATION: Mount Barker
DATE: Friday 3rd November 2023
LOCATION: Marion
DATE: Thursday 9th November 2023

LOCATION: Mt Gambier
DATE: Friday 10th November 2023
LOCATION: Whyalla
DATE: Wednesday 15th November 2023
LOCATION: Port Lincoln
DATE: Thursday 16th November 2023
LOCATION: Murray Bridge
DATE: Monday 20th November 2023

LOCATION: Berri
DATE: Wednesday 22nd November 2023
LOCATION: Modbury North
DATE: Thursday 23rd November 2023
LOCATION: Kadina
DATE: Thursday 30th November 2023
LOCATION: Port Pirie
DATE: Friday 31st Jan 2024

EVERYONE IS INVITED. THIS IS AN IMPORTANT CONVERSATION FOR YOUR WHOLE COMMUNITY.

Join the conversation and discuss how together we can build a compassionate community in your local community. Compassionate communities are communities with networks of support around people at the end stage of life. You will receive information and participate in discussions about compassionate communities, including how to become a more compassionate neighbour and friend, what services and supports are currently available and explore what compassionate communities could look like within your local neighbourhood.

DO YOU KNOW PEOPLE WHO ARE EXPERIENCING A SERIOUS ILLNESS, AGEING, DISABILITY, DYING, GRIEF AND/OR CAREGIVING (EITHER PERSONALLY OR PROFESSIONALLY)? THEN IT IS ESSENTIAL FOR YOU TO ATTEND THESE MORNING TEAS.



**RSVP: www.palliativecaresa.org.au/compassionate-communities-sa
OR CALL 08 8271 1643**

Seats limited to 65 | Book your seat today | Everyone's invited

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South Australia

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Event Sponsor



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Initiative Rationale and Executive Summary

Initiative Rationale

A message from Palliative Care South Australia's CEO

Dying is a normal part of life. Whilst palliative care is generally recognised within the health system, there is a growing movement across Australia and globally to adopt a public health approach to serious illness, ageing, dying, grief and caregiving. This approach includes a community centric model which builds compassionate communities that integrate with health, social & community care services and civic agencies to support people approaching the end stage of life.

To support this expanding public health approach to palliative care* movement, PCSA established the Compassionate Communities SA (CCSA) program in early 2023 to work with community groups, local governments, health services and individuals to nurture a compassionate communities approach across the state. Within this CCSA program there are a number of projects, two of these are the 'Nurturing Compassionate Communities in Country SA project' funded by Country SA Primary Health Network (PHN) and the 'Nurturing Compassionate Communities in Adelaide project' funded by Adelaide PHN.

Between November 2023 and January 2024, the Nurturing Compassionate Communities in SA project team undertake the SA Compassionate Communities Conversation Series initiative, inspired by a similar activity undertaken by Palliative Care Queensland in 2019. This was hosted by PCSA, in collaboration with Carers SA and was supported by the South Australian Government, Country SA PHN and Adelaide PHN. The Hospital Research Foundation Group – Palliative Care sponsored the events. We facilitated 12 events across South Australia which brought together people from local communities to discuss and learn how they can nurture a compassionate community. In this initiative, we met with a total of 237 South Australians, we learnt about their needs, where they find supports, what local supports are available and what strategies could be used to nurture compassionate communities in their region. This report shares those findings and identifies key focus areas for individuals, groups, organisations and decision makers in nurturing compassionate communities across SA.

Palliative care is everyone's business and access to palliative care is a human right. The Compassionate Communities approach focuses on keeping love, laughter and friendship central to people's lives in the last chapter of life. This report is relevant to everyone in South Australia.



Adjunct Associate Professor Shyla Mills

Chief Executive Officer
Palliative Care South Australia

Executive Summary

The purpose

To host open community discussions to identify how compassionate communities can be nurtured across South Australia.

What are Compassionate Communities?

Compassionate Communities are networks of support around people at the end stage of life.

Who participated?



237 South Australians participated in free community morning tea conversations



12 locations

What South Australians told us

If they had a life threatening illness, they weren't sure that their physical, emotional, spiritual and social needs would be met with the current systems.

In addition to national and state based organisations & services, each local region of South Australia has a unique crop of local community groups and volunteer organisations that support the last chapter of life.

The top two places they look for information

about serious illness, dying, grief and caregiving are:

- #1 Their General Practitioner (GP)
- #2 Their Outer Circle Network (family, friends, neighbour or colleagues)

Although people assume not many people are comfortable to talk about death and dying, the majority actually do feel comfortable to talk about it.

If their neighbour has a life threatening illness, the majority of people would be willing to offer support, far fewer would be willing to accept help from a neighbour if they were in this circumstance.

Not all South Australians trust their Substitute Decision Maker to make the right decision if they were unable to.

They have many ideas and suggested activities that could help nurture compassionate communities locally and would be willing to be involved.

To go forward, we invite those interested in nurturing compassionate communities across SA to focus on the following areas:





Project Background

Organisations involved in this Project



**Palliative Care
South Australia**

Palliative Care South Australia (Project Lead)

Palliative Care South Australia (PCSA) is a leading charity and independent peak body representing palliative care providers, the community and people experiencing a serious illness, dying, grief and caregiving, as well as those with an interest in palliative care across South Australia.

www.palliativecaresa.org.au



Carers SA (Project Collaborator)

Carers SA Purpose: Addressing the challenges for current and future Carers so they can care for others.

Carers SA Vision: To be recognised as the key 'Carer organisation' in South Australia.

www.carerssa.com.au



An Australian Government Initiative

Country SA PHN (Project Funder)

Country SA PHN is the Primary Health Network covering the country regions of South Australia. The key goals of the Primary Health Networks are to increase the efficiency and effectiveness of health services for people, particularly those at risk of poor health outcomes, and to improve the coordination of health services, and increasing access and quality support for people.

www.countrysaphn.com.au



An Australian Government Initiative

Adelaide PHN (Project Funder)

Adelaide PHN is the local Primary Health Network for the Adelaide region, an independent, not-for-profit organisation funded by the Australian Government. Adelaide PHN works with primary health care professionals and communities to understand our region's health and wellbeing needs. Our work helps people access safe, equitable and timely health care where it's most needed.

www.adelaidephn.com.au



**Government
of South Australia**

SA Health

SA Health - Health Services Programs Branch (Project Supporter)

SA Health is committed to protecting and improving the health of all South Australians by providing leadership in health reform, public health services, health and medical research, policy development and planning, with an increased focus on well being, illness prevention, early intervention and quality care

www.sahealth.sa.gov.au

We also thank The Hospital Research Foundation – Palliative Care for providing event sponsoring which funded the catering for the 12 events and Flinders University Research Centre for Death and Dying (RePaDD) for providing the lucky door prize for the 12 events.

About the Conversations

Key Question We Asked

We framed the Conversation by beginning and ending each event with the same question:

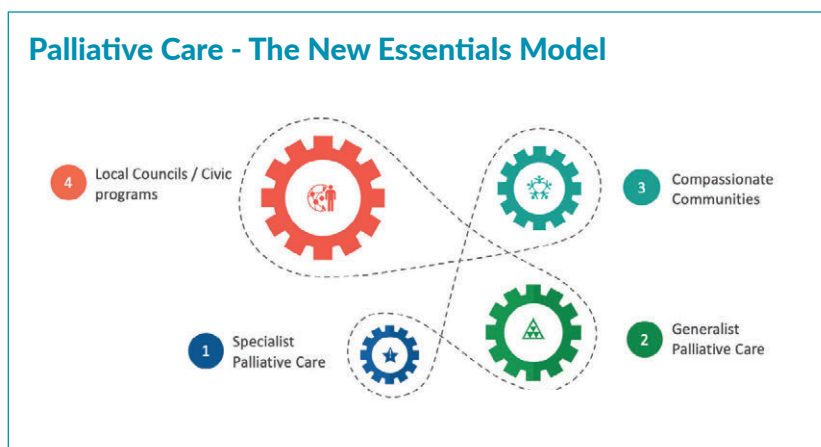
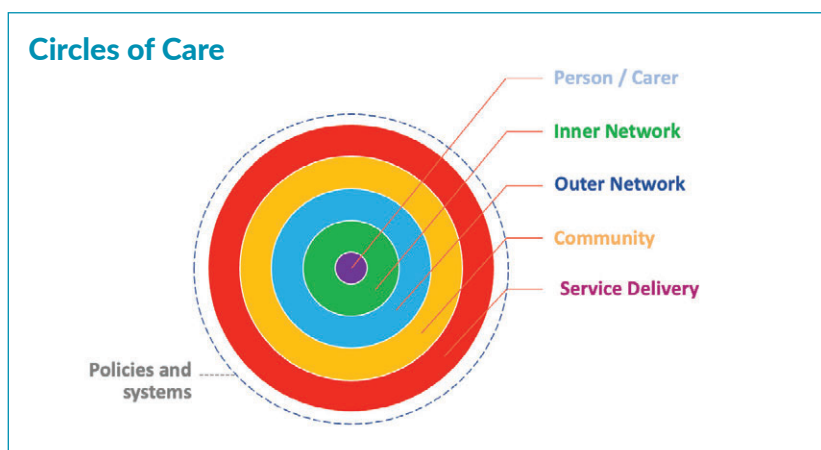


“How do we, together, keep LOVE, LAUGHTER and FRIENDSHIP central to the end chapter of life?”



Key Models Used

We used the New Essentials Model¹ to discuss palliative care and the Circles of Care Model² to discuss care networks.



Guest Speakers

We invited a representative from the local palliative care service and local council to present at each session.

We encouraged participants to reflect on the following statement

Living well is a daily choice.

Dying well takes planning and health, social and community supports.

¹ Abel J, Kellehear A, Karapliagou A. Palliative care—the new essentials. *Ann Palliat Med* 2018;7(Suppl 2):S3-S14. doi: 10.21037/apm.2018.03.04
² Adapted from: Abel J, Walterl, Carey B, et al, *BMJ Supportive & Palliative Care*, dr10, 1136/hmjsprare-20t2-000359



Project Strategies

Locations of Conversations

The 12 locations were chosen in collaboration with the project partners. Originally locations were based on one per Local Health Network across SA, however on review of population and geography additional locations were chosen. As the Women's and Children's Health Network was statewide, we did not host a specific event for this network, however encouraged people linked to all ages to attend.

Event Promotion

The events were promoted via the following mechanisms:

- Joint media release from the partner agencies and individual media contact
- Social Media posts and events, which were boosted in each area
- Health, Social and Community organisations in each area were contacted and encouraged to disseminate

As an incentive to attend, a \$50 voucher per event as a lucky door prize was provided and by Flinders University Research Centre for Death and Dying (RePaDD), this was included in the promotion.

Information collections

The events were promoted via the following mechanisms:

Registration for the event (prior to the Conversation)

- Basic demographic questions

One Individual Activity (during to the Conversation)

- Where would you go for information about serious illness, dying, grief and caregiving? (Ranking with 6 options)
- Do you feel your Substitute Decision Maker* would make the right decision for you if you couldn't verbalise them?
- How do you related to this statement "I feel comfortable with discussing death and dying"?
- If you had a life threatening illness, do you feel that the current system would meet your needs in relation to:
 - Physical needs, Emotional needs, Spiritual needs, Social needs?
- Do you feel that if your neighbour had a life threatening illness you would feel comfortable in offering them help and support?
- Do you feel that if you had a life threatening illness you feel comfortable in accepting help offered by others in your neighbourhood?

Two Group Desktop Activities (during to the Conversation)

- Please list existing groups, supports, organisations and services that are available locally to help people experiencing a serious illness, dying, grief and caregiving
- Please list what community initiatives, events, activities and support you would like to see in your community to help keep love, laughter and friendship central to the last chapter of life

Evaluation (at the end of to the Conversation)

- What is your level of satisfaction with this event?
- Please share a take home message from today's session
- Any other comments, feedback or suggestions

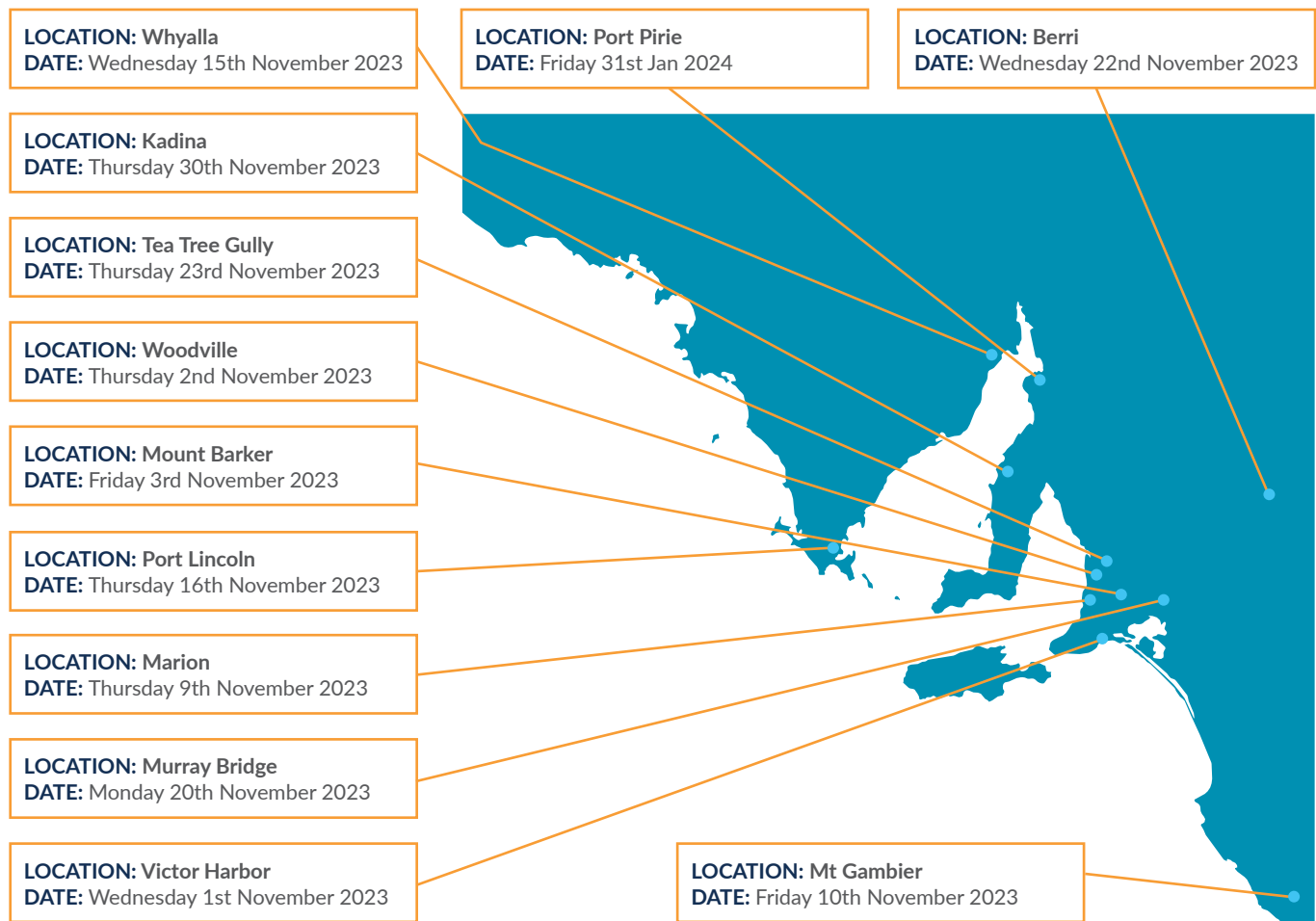
* <https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/conditions/end+of+life+care/advance+care+directives/information+for++advance+care+directive/substitute+decision+makers++advance+care+directive>



Statewide Findings

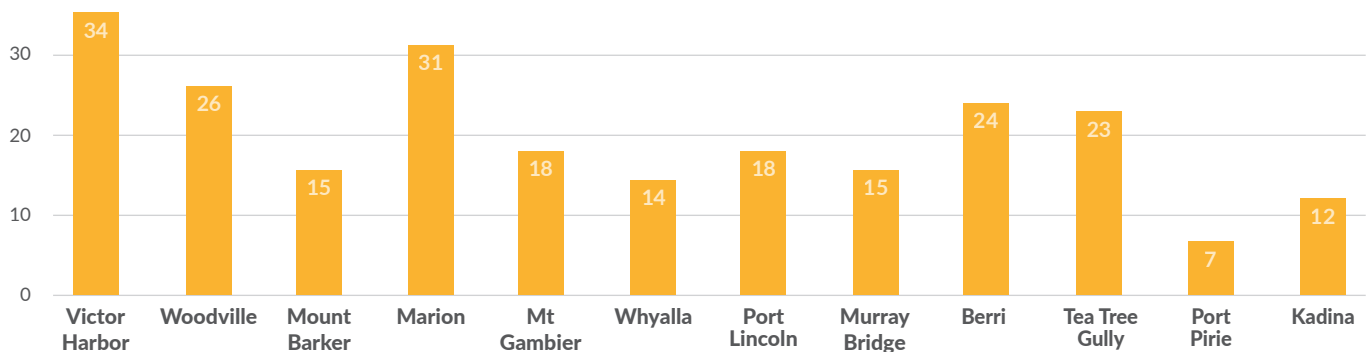
Who attended the Conversations?

How did we structure the 12 Conversations?



How many people participated in the Conversations?

237 people participated across the state.



How did people identify their gender?

Majority were female.

How did people identify in relation to examples provided?

The Conversations events were promoted broadly across health, carer and community channels. As such, we were interested in understanding the context in which our participants attended the Conversations. We gave our participants a series of statements and asked them to identify which statements apply to them. Participants were able to select more than one option.



Interestingly, almost two thirds of our participants work in the health, social or community services sector, perhaps indicating an appetite for health professionals and professional caregivers to engage with communities about serious illness, dying, grief and caregiving. Also, 58.8% of participants identified as a carer or had somebody close to them dying or had died recently. This may speak to their motivations for participating in the Conversations.

NOTE: this is not a research project, it's not a representative study, it is the results of a series of conversations across the state and what was told to us.

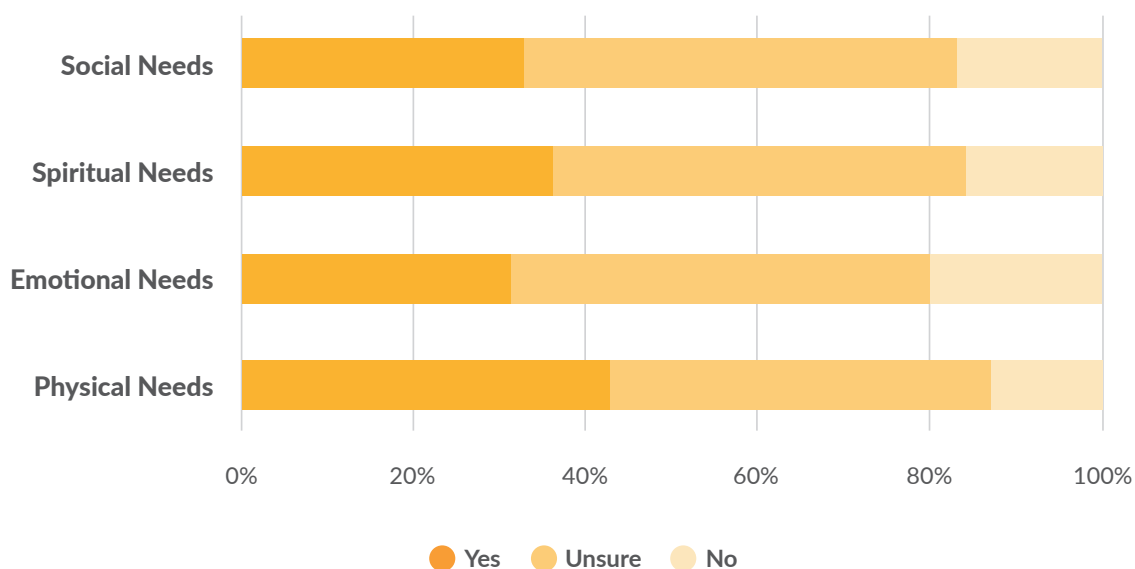
Findings Section 1: Information and Supports

Do South Australians feel that the current systems would meet their support needs if they had a life threatening illness?

What we did:

To understand how people feel their support needs would be met if they were at the end chapter of life. We asked individuals “if you had a life-threatening illness, do you feel the current system would meet your needs in relation to Physical needs, Emotional needs, Spiritual needs and Social needs”?

What we learned:



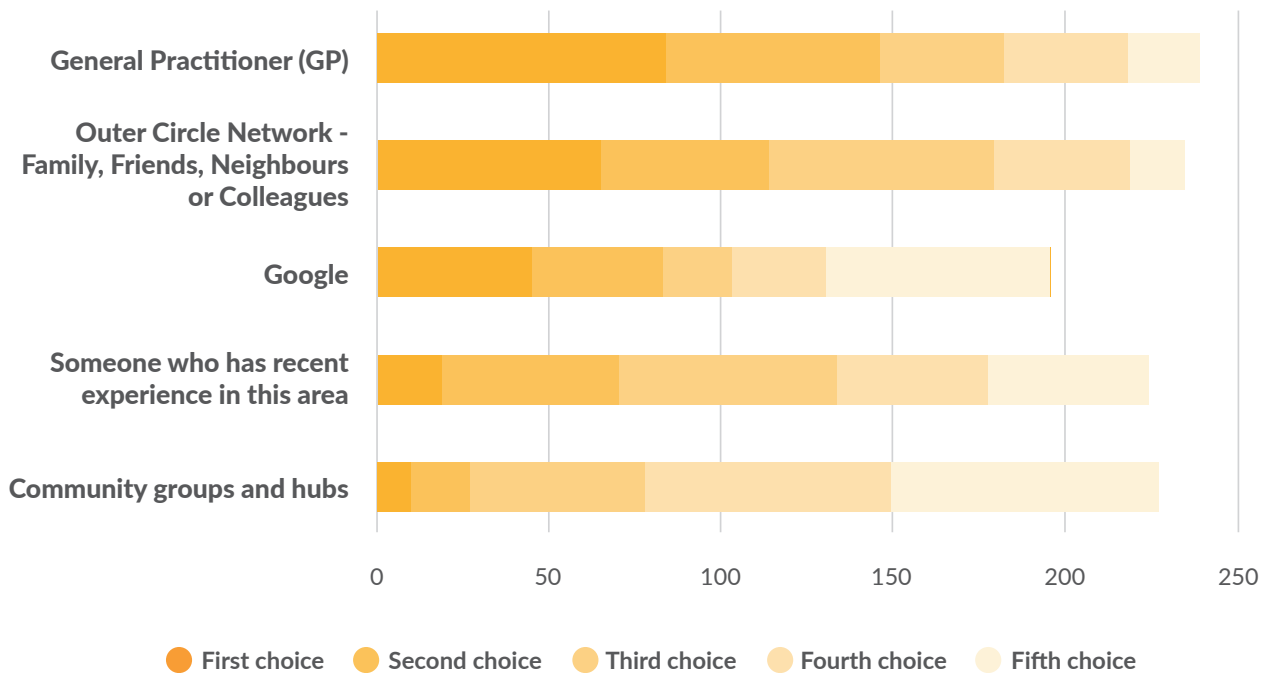
This could suggest that many South Australians do not know what the current systems are and may benefit from more information about available services and supports.

Where do South Australians look for information about serious illness, dying, grief and caregiving?

What we did:

To understand where people look for information, we asked participants to rank (in order of preference) where they would go for information about serious illness, dying, grief and caregiving.

What we learned:



The highest ranked source of information is the participant's GP, which demonstrates the importance of the GP's role in knowing and sharing this information. Interestingly, the second most popular source of information is those within the participant's trusted network (outer circle network) of family, friends, neighbours and colleagues.

It is important to note, that specialist palliative care and end-of-life services were mentioned in the 'other' option. In total, sixteen (16) participants mentioned such services as a source of information.

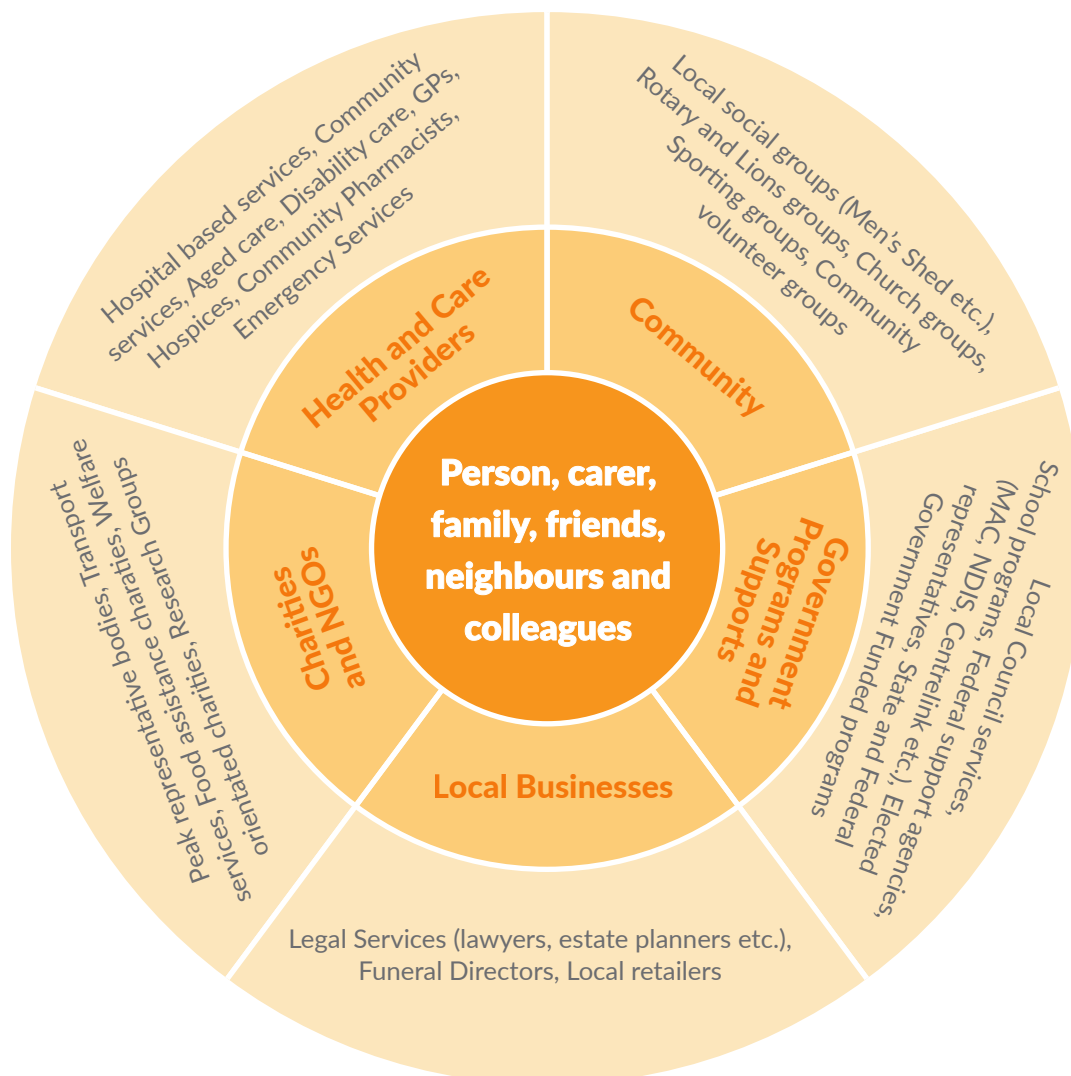
What community supports do South Australians already trust to help them navigate serious illness, dying, grief and caregiving?

What we did:

Understanding current state is important to identify strengths which may be shared across communities. We asked the participants to list existing groups, supports, organisations and services that are available locally to help people experiencing a serious illness, dying, grief and caregiving. We call this activity 'treasure mapping'.

What we learned:

South Australians have a multitude of organisations, services, agencies and businesses that can support them in their last chapter of life. In addition to national and state based organisations and services, each local area has a unique crop of local community groups and volunteer organisations.



Findings Section 2: Compassionate Citizens

Are South Australians comfortable with discussing death and dying?

What we did:

Palliative Care South Australia often hears that our society is uncomfortable with discussing death and this can lead to delayed access to support services. To understand if this is true in South Australia, we asked participants if they are comfortable with discussing death and dying.

What we learned:



Our participants overwhelmingly responded that they are comfortable with talking about death and dying. It is important to acknowledge that over 65% of our participants are health and care professionals which may have influenced the results. However, it could be an indication that the dial is shifting for the community.

Do South Australians trust their Substitute Decision Maker to make the right decision for them (if they couldn't themselves)?

What we did:

According to Advance Care Planning Australia, almost 50% of people will be unable to make their own end-of-life decisions. A Substitute Decision Maker is activated when a person no longer has the cognitive capacity to make a decision on their own behalf. To understand trust regarding the role of Substitute Decision Makers, we asked participants if they feel that their Substitute Decision Maker would make the right decision for them if they were unable to?

What we learned:



Not all South Australians trust their Substitute Decision Maker to make the right decision if they were unable to. The majority do, yet over one in five are not sure.

The results may suggest many are confused about the role of the Substitute Decision Maker or they may not have had specific conversations about their wishes and preferences to guide their decisions.

Are South Australians comfortable in offering their neighbours help and support if they had a life threatening illness?

What we did:

Developing compassionate communities includes supporting our neighbours in times of difficulty. To understand South Australian's readiness to offer help and support, we asked participants if they are comfortable offering help and support to a neighbour who has a life threatening illness.

What we learned:



Consistent with previous responses, our participants overwhelmingly responded that they would be comfortable to offer help and support to their neighbours. This result strongly indicates a generosity of spirit by South Australians through their collective willingness to support people around them who have a life threatening illness.

Are South Australians comfortable in accepting help offered by others in their neighbourhood, if they had a life threatening illness?

What we did:

Offering to support people in our neighbourhood is one thing, but how would South Australians react if the tables were turned? To understand if our community is comfortable to accept help, we asked our participants, if they had a life threatening illness, would they feel comfortable in accepting help offered from others in their neighbourhood?

What we learned:



The responses show that whilst the majority of participants would feel comfortable accepting help from others in their neighbourhood, the affirmative response is not as strong as in the previous questions. Furthermore, more than one in four South Australians are unsure. Whilst there is an overwhelming willingness to help others, the willingness to receive help is over 25% lower. This creates a contradiction and a challenge in developing compassionate communities, we need communities to offer help, but we also need individuals in communities to be willing to accept help.

Findings Section 3: Compassionate Communities

What community initiatives would help grow Compassionate Communities across South Australia?

What we did:

Having asked our participants to identify initiatives in relation to the last chapter of life in their communities. We seek to understand what new initiatives participants would like to see and be a part of. We asked participants to work in table groups to list community initiatives, events, activities and supports they would like to see in their community to help keep love, laughter and friendship at the centre of the end chapter of life.

What we learned:

A total of 273 Community Initiatives were suggested.

The majority of the participants also stated they would like to participate or be involved in these initiatives. The local Council was usually identified a key group to be involved with most initiatives identified. Examples of these Community Initiatives are provided below:

- | | |
|---|--|
| Street organised events to improve connection with neighbours | Festival of the Living and Dying |
| Welcome to the neighbourhood kits | Death, Grief and Compassion Cafes |
| Meal rosters for older or isolated neighbours | Establishment of new community groups (craft, sewing, friendship groups, yarning circles etc.) |
| Neighbourhood newsletters and social media groups | Groups specific to culturally and linguistically diverse communities |
| Advance Care Directive assistance | Increase in community volunteers |
| Improvement to public housing (air conditioning, heating etc.) | Pet care and pet visiting initiatives |
| Improvements to public spaces (accessibility) | Themed book clubs |
| Compassionate community champions and network activators | Community singing |
| Memorial events and initiatives | Reminiscence based activities (memory boxes, scrapbooking and collecting oral histories) |
| Art exhibitions | Improved transport options (community bus, patient transfer and volunteer ride share) |
| Printed resources in publicly accessible locations (library, medical centres and funeral directors) | Access to professionally facilitated community education (for example, Last Aid) |
| Intergenerational activities and events to foster connectedness | School programs about death and dying |
| Afternoon and morning teas | Spiritual focus retreats |
| Death and Dying expo | |

To go forward, we invite those interested in nurturing compassionate communities across SA to focus on the following areas:

What key themes could be taken forward to nurture compassionate communities across SA?

What we did:

The Compassionate Communities Conversation Series was designed to build awareness and understanding about community's role in supporting people with serious illness in their last chapter of life, and their caregivers. As well as to learn from the community what is existing in this space and what would they like to see in future. We asked participants to share a take home message, feedback and comments from the sessions. This in addition to other results was themed into focus areas. We asked participants to share a take home message, feedback from the session they attended.

What we learned:

Five focus areas were identified for individuals, groups, communities, organisations and decision makers across SA in relation to nurturing Compassionate Communities across SA.



Note these are in no particular order of priority.

Findings Section 4: Compassionate Conversations

Do South Australian local communities have an interest in this topic?

What we did:

To bring about change, we used marketing engagement methodologies including a media release, social media and network marketing.



7 media interviews



15k+ social media reach



Port Lincoln Times article 26 October 2023



Murray Bridge Pioneer article 25 October 2023



Yorke Peninsula Country Times article 5 December 2023

What we learned:

7 media interviews (articles published or radio interviews).

The total social media reach for these Conversations was 15,011.

Was the Conversation Series considered a useful approach?

What we did:

To determine if the local, in-person Conversations workshop methodology was a success for those who attended, we asked participants to rate their level of satisfaction with the event.

What we learned:

We received 79 responses to this question and 97.46% responded Excellent or Good.



97% Excellent or Good satisfaction rating

Overwhelmingly, the participants rated their level of satisfaction as excellent or good, which suggests that the format and methodology of the Conversations events were successful from the community's perspective. This is consistent with the final comments in the evaluation survey that participants were invited to share, which included comments such as "fantastic", "thought provoking" and "wonderful session".

PALLIATIVE CARE SOUTH AUSTRALIA'S POLICY GUIDING PRINCIPLES

Palliative
Care is...

about the
whole person



for
every age &
every stage



about the
community
of care



about
choice, autonomy
& dignity



not
'one-size
fits all'



Everyone's
business



care for
the carer



a human
right



Palliative Care.
It's more than
you think.



