

# The role of the death industry in Compassionate Communities

**Professor Samar Aoun**

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



## “Compassionate Communities” IS

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

# 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



Aspiration

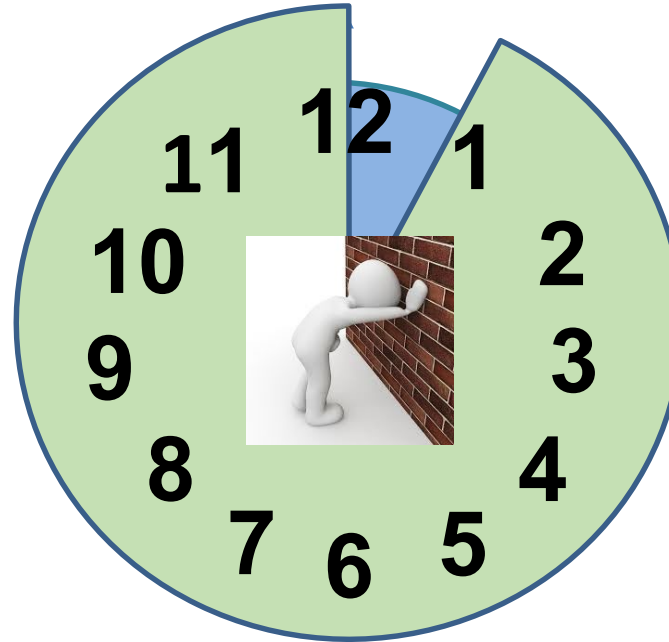


Evidence



Practice

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



## Formal Care <5% of the Day

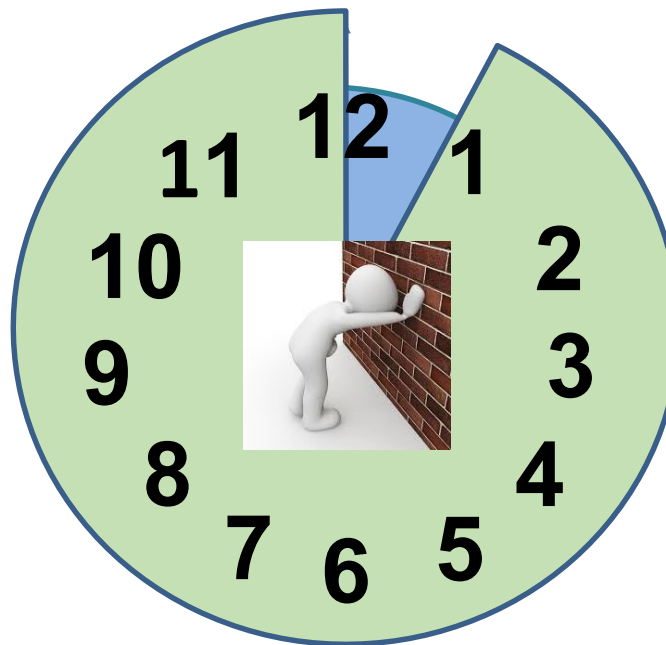
- ✓ Doctor
- ✓ Nurse
- ✓ Nurse Practitioner
- ✓ Personal Support Worker
- ✓ Social Worker
- ✓ Pharmacist



# 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



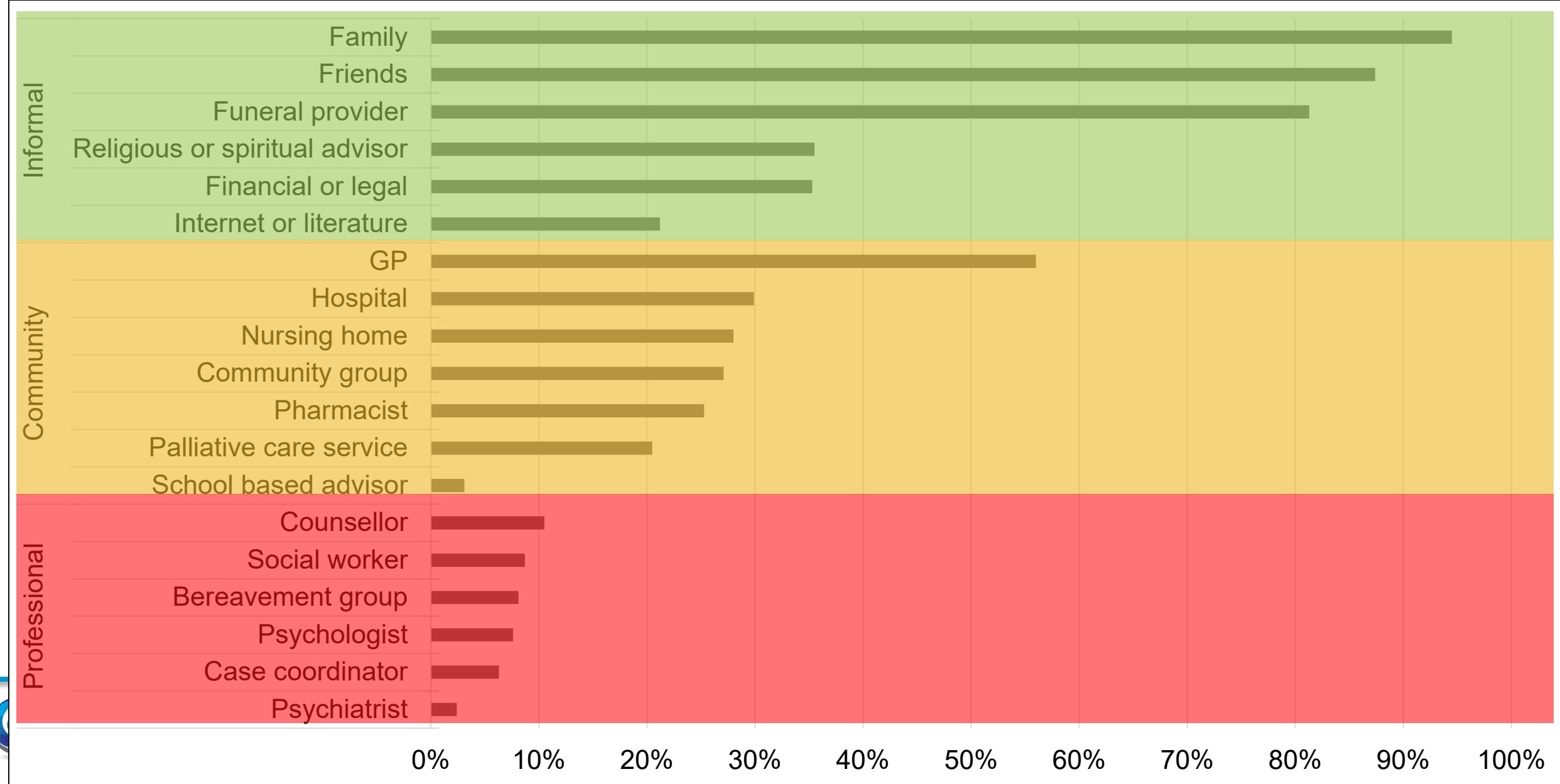
Adapted from Carpenter House model developed by r



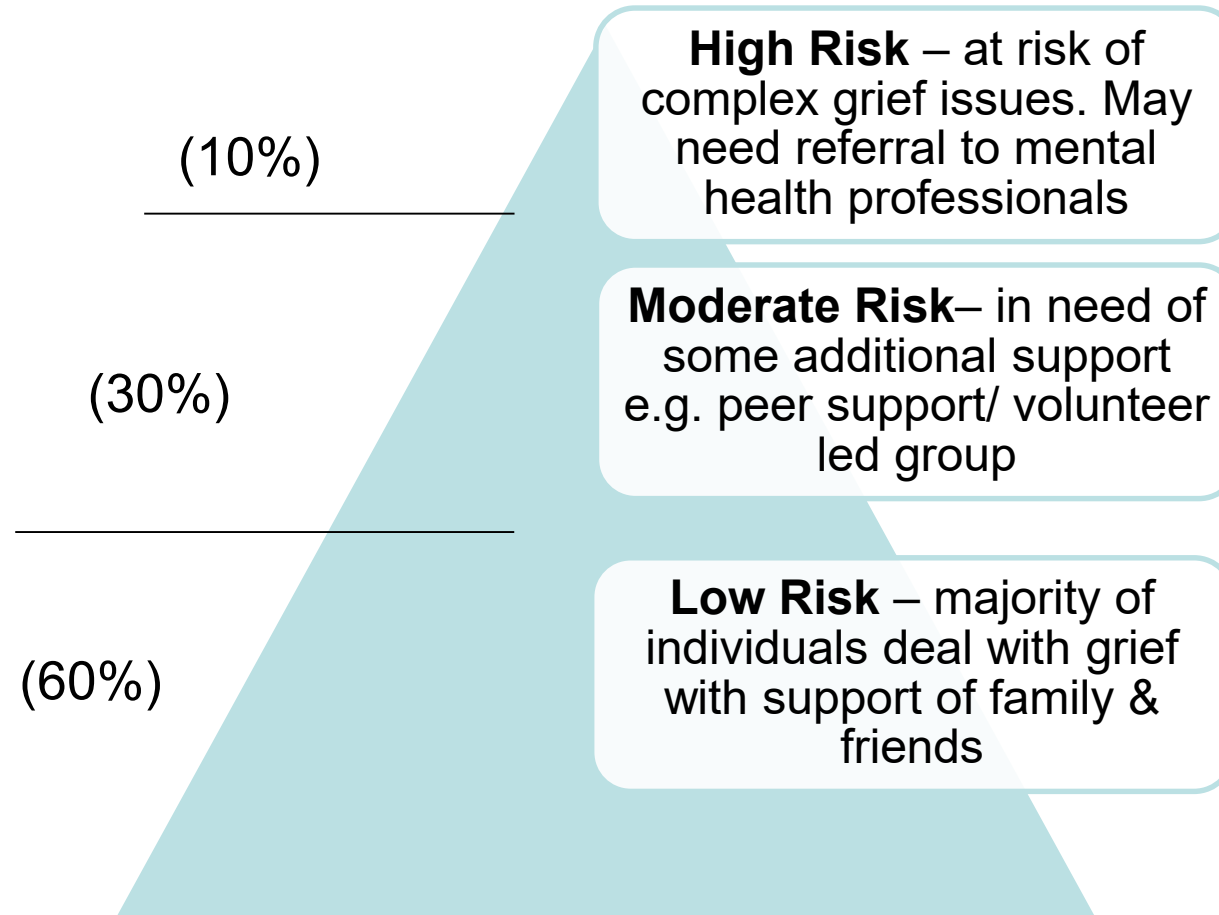
## Formal Care *<5% of the Day*

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

# Where people get bereavement support-National survey n=1,000 (Aoun et al, 2018)

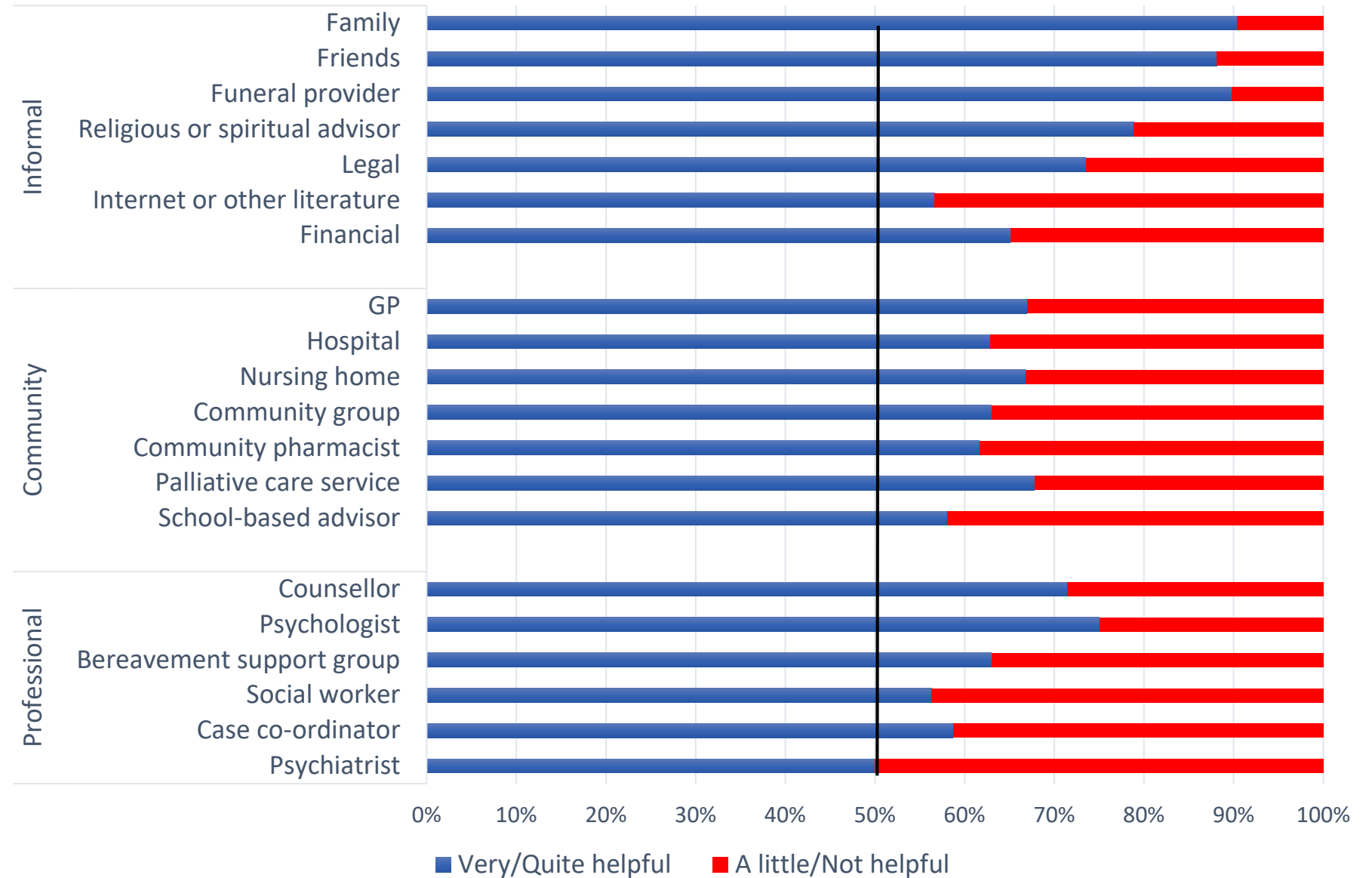


# The Public Health Model of Bereavement Support (Aoun et al, 2015)





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



# 'GROWING AROUND GRIEF'

(LOIS TONKIN, 1996)

WHATSYOURGRIEF.COM

PEOPLE  
THINK THAT  
GRIEF

SLOWLY  
GETS  
SMALLER

WITH

TIME

IN  
REALITY,  
GRIEF  
STAYS

THE  
SAME  
SIZE

BUT  
SLOWLY  
LIFE  
BEGINS

TO GROW  
BIGGER  
AROUND  
IT

# Key Learnings

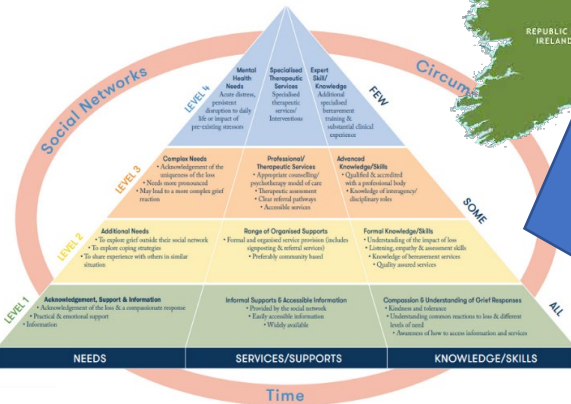
- The community needs to own its **central role** in end of life and bereavement care, with formal professionals **advising, supporting** and contributing as required.
- We need to support the '**everyday assets**' in the community who care for the bereaved and who are already involved in the everyday lives of those who were caring and recently bereaved. These assets are family, friends, neighbours, work colleagues and funeral providers to name a few.





# 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.

Sources: Swerissen H, Duckett, S. Dying Well, 2014.  
Productivity Commission Report, 2017



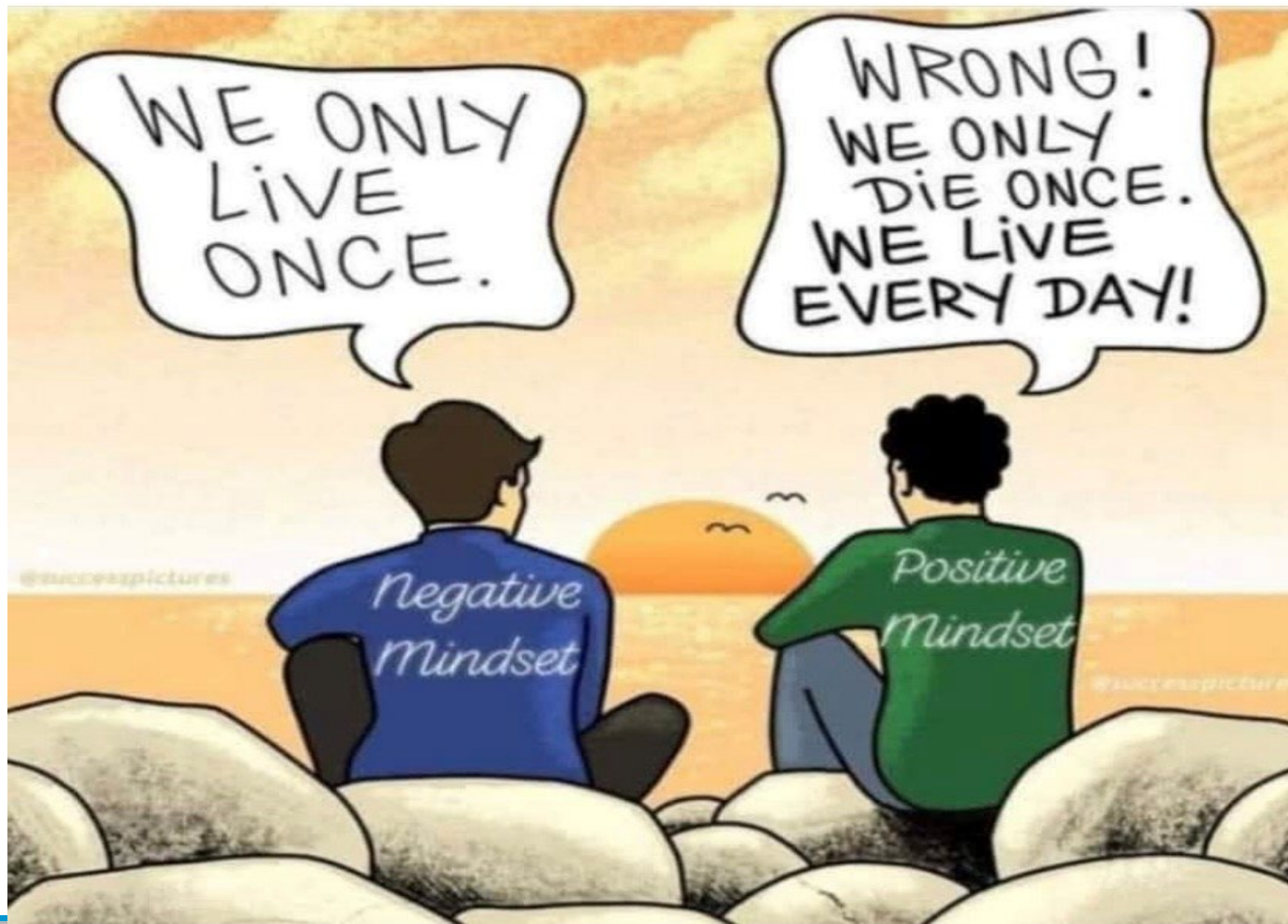
Photo by [Isaac Quesada](#) on [Unsplash](#)



# A freight train heading downhill towards us

(Demographer Bernard Salt- 2024)

- In just six years, the first of Australia's baby boomers will turn 85.
  - The number of Australians aged 85 and over will be growing at 60,000 per year by the end of the decade, up from about 20,000 in 2024.
  - A 2020 KPMG report found that by 2050, national demand for palliative care services will increase by 200%.
- Hopeful a "calamity" can be avoided by a change in approach.



*Death is a social event with a  
medical component,  
not a medical event with a social  
component.*



Professor Allan Kellehear



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

**SAMAR  
AOUN**



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

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

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

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

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

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

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

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

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

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

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

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

Let's connect formal care with informal care.

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

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

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

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

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

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

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

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

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

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

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

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



# RESEARCH WITH FUNERAL PROVIDERS

- Funeral providers were the most prevalent source of bereavement support after family and friends.
- Develop and implement a proactive and personalised approach to bereavement support for all clients.
- Offer activities that serve to build community capacity and skills around death, dying and bereavement.

DEATH STUDIES  
2019, VOL. 43, NO. 10, 619–628  
<https://doi.org/10.1080/07481187.2018.1506835>

Routledge  
Taylor & Francis Group

Check for updates

## Is there a role for the funeral service provider in bereavement support within the context of compassionate communities?

2018

Samar M. Aoun<sup>a,b</sup>, Jennifer Lowe<sup>a</sup>, Kim M. Christian<sup>c</sup>, and Bruce Rumbold<sup>a</sup>

<sup>a</sup>Palliative Care Unit, Department of Public Health, School of Psychology and Public Health, La Trobe University, Melbourne, Victoria, Australia; <sup>b</sup>Institute for Health Research, Notre Dame University, Fremantle, Western Australia, Australia; <sup>c</sup>School of Psychology, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia

### ABSTRACT

This is the first study to explore bereaved individuals' experiences of funeral service providers using these services' databases. A total of 839 Australians participated in a postal survey, 6–24 months into their bereavement. Funeral providers were reported to be the third most prevalent form of bereavement support after friends and family. Analysis found six themes related to perceived helpful or unhelpful support: instrumental support, professionalism, informational support, financial tension, communication, and emotional support. Funeral providers could improve their support by adopting a proactive approach to bereavement needs and offering personalized and ongoing support. We develop these suggestions by exploring their potential contributions to building community capacity around death, dying and bereavement.

### Introduction

Bereavement can be one of the most stressful and difficult times in an individual's life (Bottomley, Burke, & Neimeyer, 2017; Castle & Phillips, 2003).

Funeral directors as primary caregivers (Parsons, 2003) offer support and comfort to the bereaved in several ways (Hyland & Morse, 1995; Lensing, 2001). They assume responsibility for smooth service delivery





## RESEARCH WITH ACCA

### AIM

To better understand the influence of memorialisation on bereavement so that cemeteries, crematoria and the funeral industry can achieve better services and outcomes when discussing memorialisation with bereaved families.

### METHODOLOGY


- Phase 1: Scoping Literature review
- Phase 2: Consultations with the sector

# Memorialization Practices Are Changing: An Industry Perspective on Improving Service Outcomes for the Bereaved

Jennifer Lowe<sup>1</sup> , Bruce Rumbold<sup>1</sup>, and Samar M. Aoun<sup>1,2</sup>

## Abstract

Although considerable research efforts have focused on bereavement outcomes following loss, there are few studies which address the role of memorialization, particularly as it relates to formal service provision. Currently the funeral, cemetery, and crematorium industries are observing a steady decline in traditional and formal memorialization practices. This study aims to identify current memorialization practices and emerging trends, highlight key priorities for improving service outcomes for the bereaved, and understand the implications of changing consumer preferences for service provision. The study's qualitative research design incorporates two phases, a scoping literature review followed by in-depth interviews with eight service providers from the funeral, cemetery, and crematorium industries. A key finding is that the trend toward contemporary and informal memorialization practices blurs the lines between the role of consumers and service providers. There is a clear opportunity for service providers to engage in community education as a means of building supportive relationships with and improving service outcomes for the bereaved.

OMEGA—Journal of Death and Dying  
2021, Vol. 84(1) 69–90  
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DOI: 10.1177/0030222819873769  
journals.sagepub.com/home/ome  


# Memorialisation during COVID-19: implications for the bereaved, service providers and policy makers

Jennifer Lowe<sup>1</sup> , Bruce Rumbold and Samar M. Aoun

## Abstract

**Background:** The aim of this rapid perspective review is to capture key changes to memorialisation practices resulting from social distancing rules implemented due to the ongoing COVID-19 pandemic.

**Method:** As published peer-reviewed research pertaining to memorialisation practices during the COVID-19 pandemic is lacking, this rapid review includes academic literature from the pre-COVID-19 period and international media reports during the pandemic.

**Findings:** Changes to memorialisation practices were under way before COVID-19, as consumer preferences shifted towards secularisation and personalisation of ritual and ceremony. However, several key changes to memorialisation practices connected with body preparation, funerals, cremation, burials and rituals have taken place as a consequence of the COVID-19 pandemic.

**Discussion:** Although boundaries between public and private memorialisation practices were already blurred, the COVID-19 pandemic has accelerated this process. Without access to public memorialisation, practices are increasingly private in nature. A number of implications are considered for the bereaved, service providers and policy makers.

**Conclusion:** Forms of memorialisation and bereavement support emerging during the pandemic that blend the public and the private are likely to persist in a post-pandemic world.

**Keywords:** bereavement, COVID-19, funeral, grief, memorialisation, pandemic

Received: 14 May 2020; revised manuscript accepted: 19 November 2020.

Palliative Care & Social Practice

2020, Vol. 14: 1–9

DOI: 10.1177/  
2632352420980456

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# Service Provider Perspectives

*"We get people who run, ride, walk their dogs, every morning, every night through our park, they use it as open space. I think that more and more we'll see councils and urban planning identifying cemeteries as open space environments."*

*"You often see families coming all together here on birthdays and special days for them, they all spend time and have food and just be together."*

*"I think more education would benefit everybody... if people don't know what their options are, then they don't know what they should do... it's up to us to educate our communities on how different options might suit their situation."*

# Variables Influencing Consumer Decision-Making

## 1. Access

- (a) Geographical Location
- (b) Place of Death
- (c) Death Literacy
- (d) Digital Literacy

## 2. Tradition, Ritual, Ceremony

- (a) Cultural Heritage
- (b) Belief System

## 3. Grief Response

- (a) Cause of Death
- (b) Relationship to Deceased

## 4. Body Disposal

- (a) State-Based Legislation
- (b) Environmental Values
- (c) Religious Values

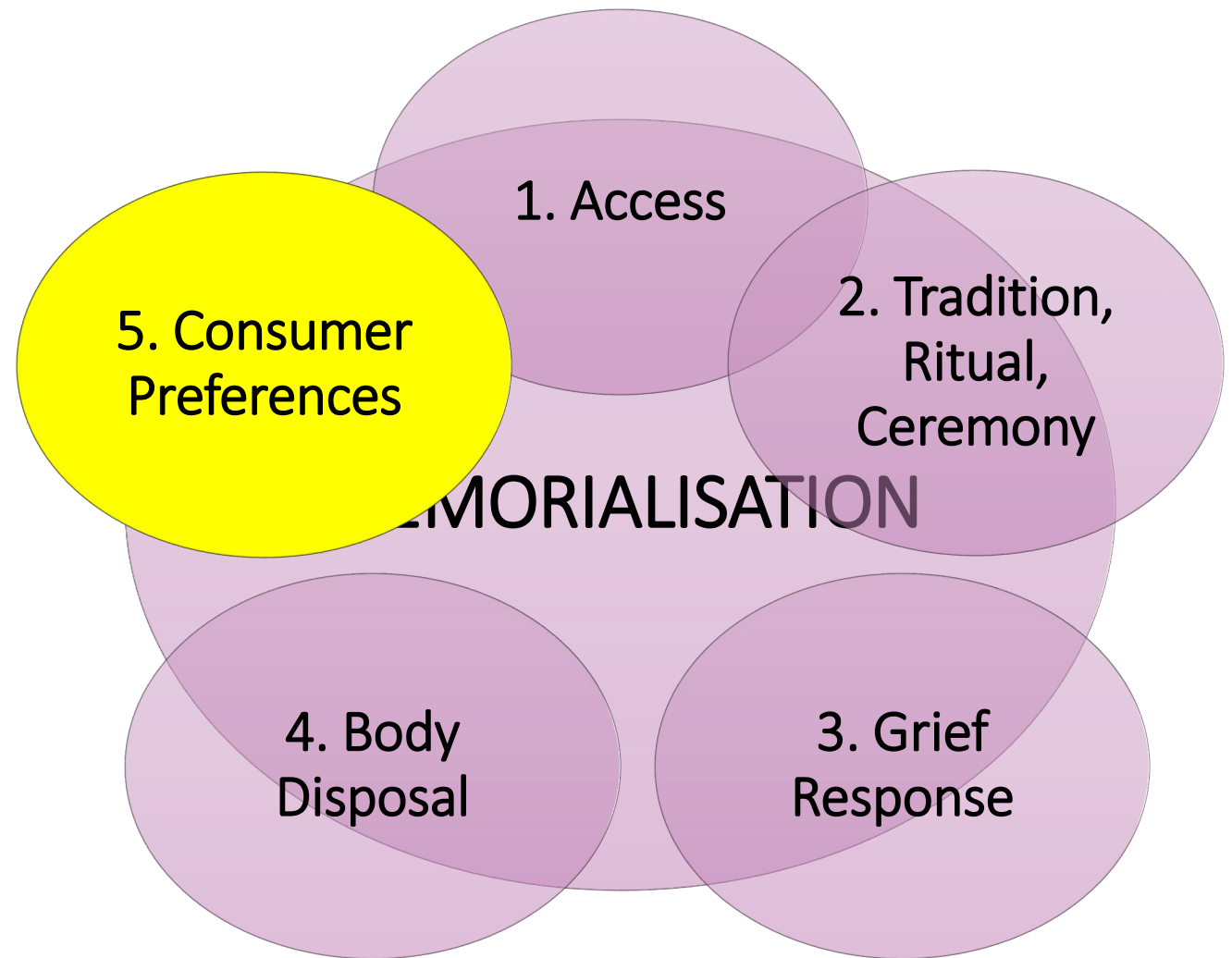
## 5. Consumer Preferences

- (a) Age
- (b) Gender
- (c) Family Dynamics
- (d) Socio-Economic Status
- (e) Relationship with Provider



Focus where you have **control**, your relationships with the consumers, create and maintain meaningful relationships within your communities.

Increase contributions to the wider communities through strategic activities with a key focus on relationship-building.





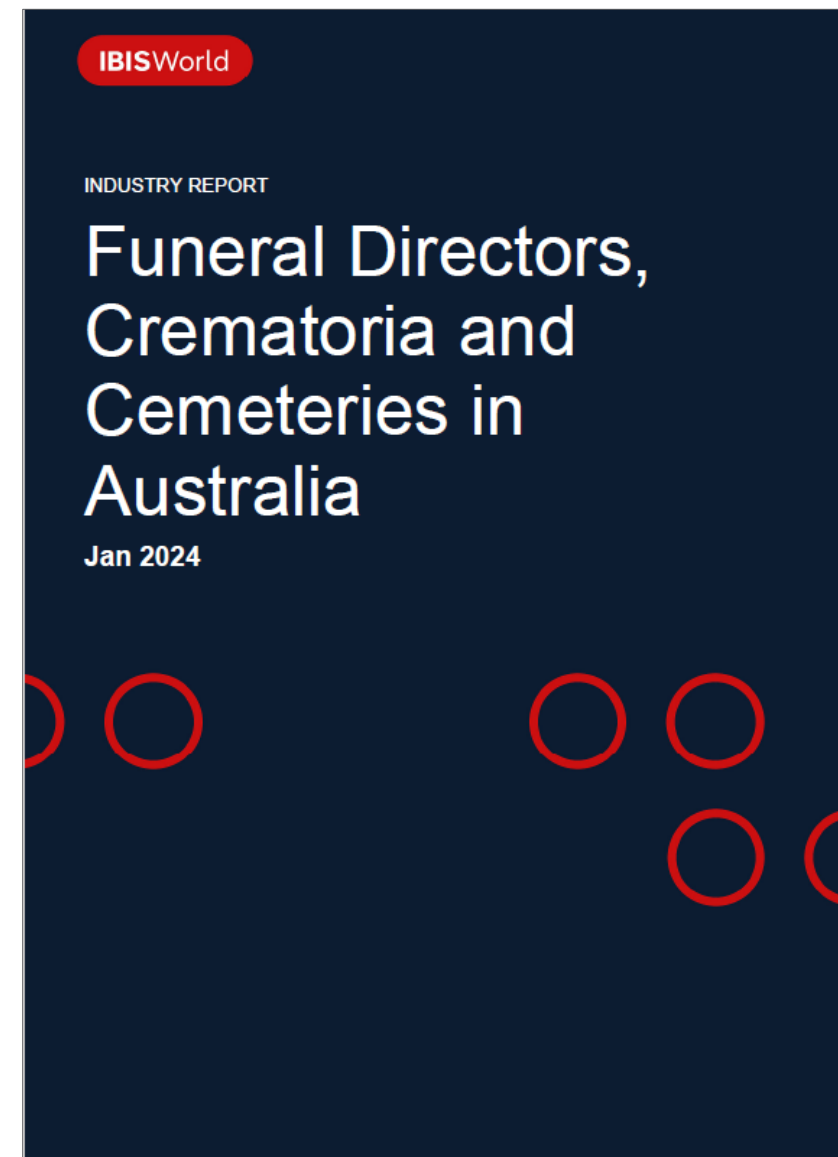
## Community-Based Relationship- Building Activities

| Strategy     | Objective                | Activity   |
|--------------|--------------------------|--|
| Partnerships | Community Integration    | <ul style="list-style-type: none"><li>-University body donation programs</li><li>-Local library historical repositories</li><li>-Primary and secondary schools</li><li>-Aged care and palliative care services</li></ul> |
| Education    | Disseminate Information  | <ul style="list-style-type: none"><li>-Special interest community groups</li><li>-Hold book clubs or trivia nights</li><li>-Community forums or focus groups</li><li>-Short courses or free info nights</li></ul>        |
| Facilitation | Offer Goods and Services | <ul style="list-style-type: none"><li>-Local small business expos</li><li>-Obligation free consultations</li><li>-Offer gardens for alternate use</li></ul>  |

# IBISWorld's (January 2024) industry report

Recognises service providers relationships with members of their local communities as central to the potential success and longevity of their operations.

Industry players can benefit from developing a local reputation for providing quality service. Word-of-mouth recommendations are important to obtain repeat family business.



## TAKE AWAY MESSAGE

The community is 're-claiming' death, dying and bereavement.

Reframing the role of the industry within such community-based approaches may help it respond more adequately to the cultural and market changes currently affecting the industry and the changing role of service providers.

# BE PART OF OUR WORK

What can we do as a community?

Improving death literacy and grief literacy



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



## 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





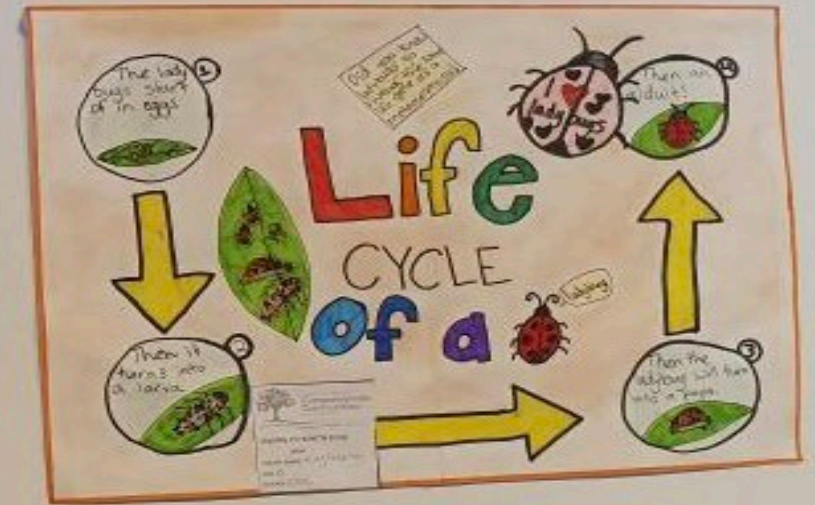




# Death Festival in Bunbury 2018



# 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 Wright 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 Wright 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 Wright (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 Wright 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."

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"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 Wright 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](mailto: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](http://www.facebook.com/Deathcafe) or visit [www.facebook.com/Deathcafe](http://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](http://swcommnetwork@gmail.com) or phone 0483 802 915





# 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





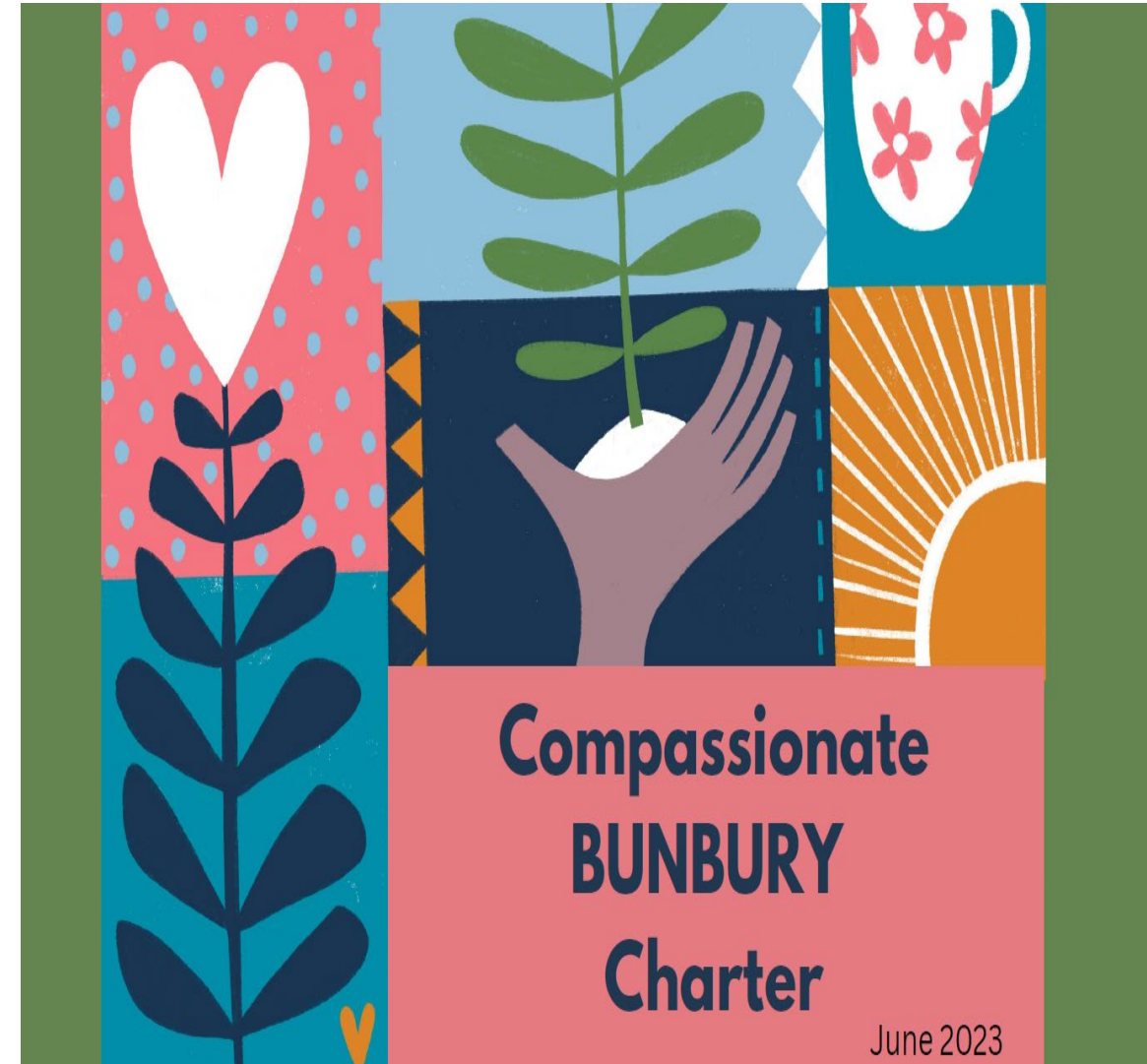


## Concert at Cemetery- Bunbury 5 Aug 2023



# 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.*

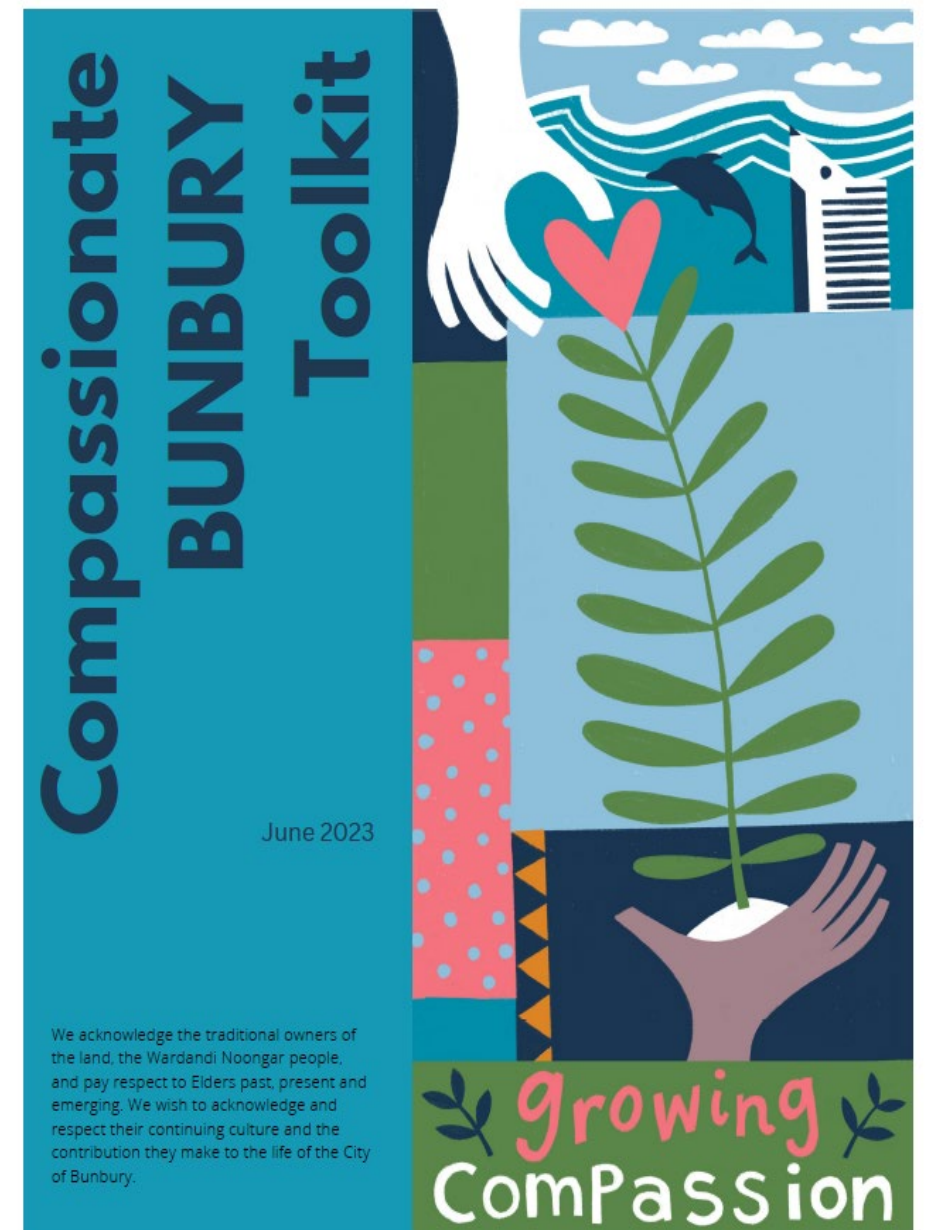


# Toolkit: Set of Actions & pledges

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







## 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



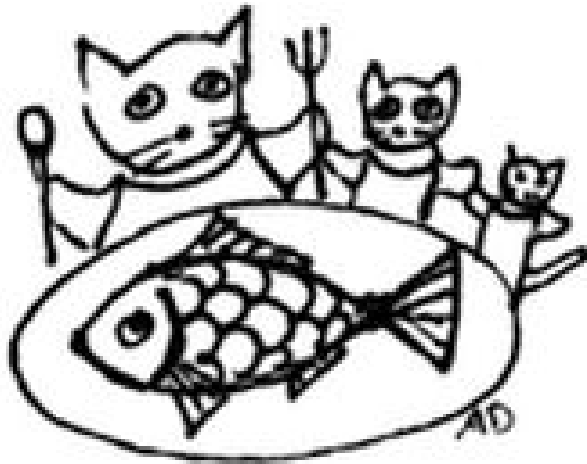




## Compassionate Bunbury Mayoral Award to Compassionate Connectors



Give a Family  
a Fish



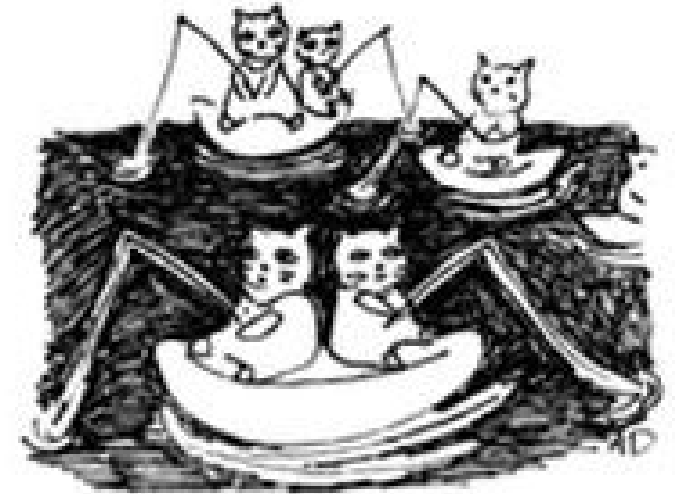
= Charitable Act

Teach a Family  
to Fish



= Sustainability

Organize a Community-  
Based, Intergenerational  
Fishing Collective



= Social Change

Artwork: Alyce Dedge

# Compassionate Communities Australia



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





As a peak body we have a role in:

1

**Advocacy and policy** development to shape dialogue that fosters a shared responsibility approach to end of life care.



2

Conducting **research** and sharing evidence-based public health approaches for example, palliative care, end of life care and community development



3

Building **partnerships** and opportunities for the community and formal services to work together.



4

**Education and development** of resources focusing on death and grief literacy.



5

Supporting **community led programs** including the Compassionate Connector program, Compassionate Workplaces, Compassionate City Charter & Toolkit.



# The Final Outcome!

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.





# END OF LIFE CARE IS ABSOLUTELY EVERYBODY'S RESPONSIBILITY