



# Providing care and support towards the end of life death and dying

Professor Jennifer Tieman  
Flinders University  
CHSP Conference, November 2021



CARESEARCH®  
palliative care knowledge network

CareSearch is funded by the Australian Government Department of Health

[caresearch.com.au](http://caresearch.com.au)



## Ageing, caring, and end of life

Older Australians are all of Australia and so are very diverse

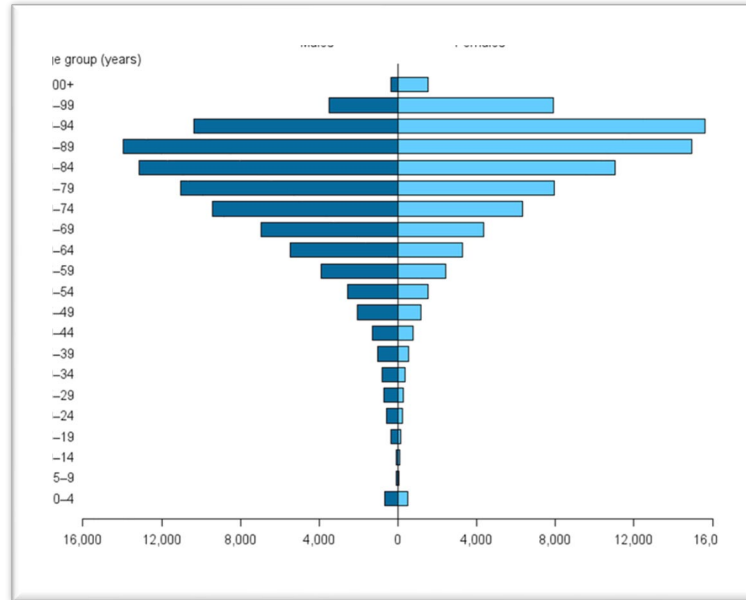
Older people want to live in their own homes and as independently as possible for as long as possible

Older people living in their home often rely on the support of family and friends

As people age, they are more likely to use aged care services.

Increasingly intersect between ageing, caring, dying and grieving

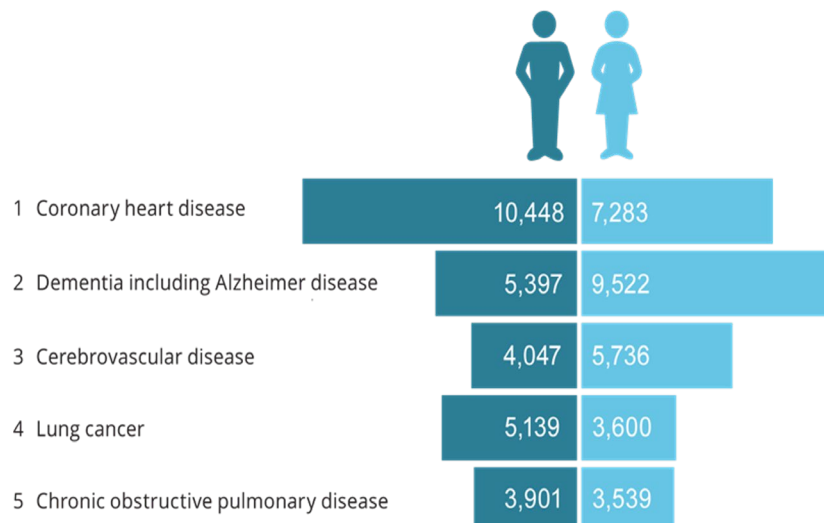
## Living longer and dying older



Source: AIHW National Mortality Database (Table S2.1).

*Compassionate, respectful, and individualised support for older people approaching the end of their lives is a necessary component of aged care services.*

## How we die is changing



Source: AIHW National Mortality Database (Table S3.1).

People have different deaths. Some will die in their sleep, some will get cancer, many may have dementia, and many will have heart problems

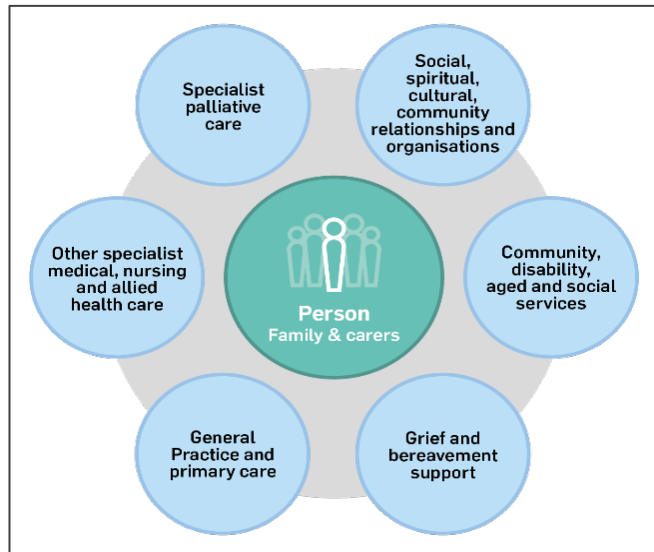
We all have a part to play

Recognise and acknowledge what is happening

Be able to talk about dying, grief and loss

Respect the individual and take the lead from them

Take care of yourself



# Learning about death and dying

www.caresearch.com.au

**CARESEARCH**  
palliative care knowledge network

Providing evidence-based information about palliative care for everyone because death and dying will affect all of us.

Books to help kids understand death and grief

These are some recommended favourite books and resources from CareSearch staff for children. You can use them as starting point when talking to children about death and dying, how to cope with grief and the importance of remembering loved ones who have died.

#### Babies and Toddlers (0 - 4 years)

##### Todd Parr (2015). The Goodbye Book

Told through the eyes of a pet fish who has lost his companion, this brightly illustrated book tells a moving story about saying goodbye and the big feelings that children can have.

##### Caron Lewis (2016). Ma, Always

This is a touching story of death and the importance of remembering as told through the eyes of Gus and Ma, two polar bears living in a city zoo.

##### Margaret Wise Brown (2016). The Dead Bird

An uncomplicated story of friends finding a bird lying motionless on the ground. After discovering that the bird had died, the children sing their farewells and bury the bird in the park.

##### Jon Crowley (2015). Grandpa's Hat

Grandpa's Hat is the story of a boy and all his favourite animals, who help him discover that although his Grandpa is gone, he doesn't have to be forgotten. Currently used as a resource for [Julian of Assisi for Little and Great \(JAG\)](#)

##### Brita Teckentrup (2014). The Memory Tree

A moving tale celebrating the memories left behind when someone dies. When Fie dies, his friends continue to celebrate his life by remembering all of the things that they did together when he was alive.

##### [Remembering and Endings episode on PlaySchool](#)

(ABC iView)

This Play School episode celebrates new life, and reflects on the love we have for those who have died. There are times to play and have fun, and there are also times to be sad and treasure memories of people and pets that are missed.

##### [Sesame Street in Communities - Heloise's Fish Garden](#)

This episode is full of interactive activities and videos specifically designed for children aged 2 to 5 to help explore and express their emotions after someone has died. Resources include a Great Toolkit providing tips, stories and guides to help families to move forward through stages of grief.



CARESEARCH  
palliative care knowledge network

CONTRAST: ■ A A A A Search Q Login

Home Community Health Professionals Evidence About Us News

## Dying2Learn



Home / Community / Dying2Learn

### Finding answers to questions about death and dying

Birth and death - these are something we will all have to cope with. But when it comes to the latter, we seem reluctant to think about, talk about, and plan for it. This is your chance to find out more.



I'm curious - about death and dying  
Explore what influences our views.



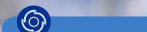
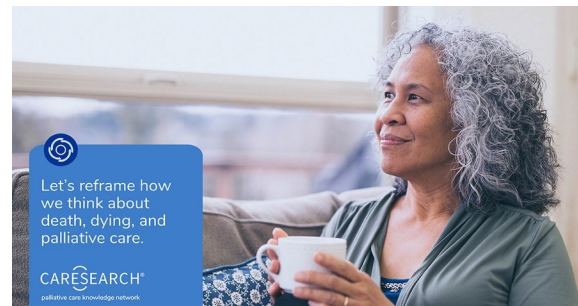
Tell me about palliative care  
Palliative care supports people living with a life.



What about our digital world?  
Online is changing how we learn things and



Rethinking death and dying  
So, what do we think about death and dying?



Let's reframe how we think about death, dying, and palliative care.

CARESEARCH  
palliative care knowledge network

CARESEARCH®

# Advance care planning

[www.caresearch.com.au](http://www.caresearch.com.au)

CARESEARCH<sup>®</sup>  
palliative care knowledge network

Providing evidence-based information about palliative care for everyone because death and dying will affect all of us.

We all need a plan

## What is advance care planning?

Advance care planning is about documenting your wishes to speak for you when you no longer can.

This will help your family and friends to make decisions about your care if you cannot. Advance care planning generally covers three things:

- Thinking and talking about your healthcare values and preferences.
- Appointing a substitute decision-maker.
- Completing a document such as an Advance Care Directive.

How many of us have taken the time to stop and think about what we would want to happen if we became seriously ill or if someone close to us was seriously ill what they would want?



CARESEARCH<sup>®</sup>  
palliative care knowledge network



Advance Care Planning  
in Five Easy Steps

CARESEARCH<sup>®</sup>



# What is palliative care?

[www.caresearch.com.au](http://www.caresearch.com.au)

**CARESEARCH®**  
palliative care knowledge network

Providing evidence-based information about palliative care for everyone because death and dying will affect all of us.

### What is palliative care?

Palliative care is person-centred care and support for people with a life-limiting illness. This includes support for their family and carers. The aim is to help people live their life comfortably and as fully as possible by supporting their physical, emotional, social, and spiritual needs.

Examples of the care required might include:

- Relief from distressing symptoms including
  - Pain
  - Depression
  - Fatigue (tiredness)
  - Nausea
  - Breathlessness (dyspnoea)
  - Anxiety
- Psychological and spiritual support
- A support system to help patients and family live as actively as possible until death
- Support to help the family cope during the person's illness and in their own bereavement.



## Palliative Care Support for Patients, Carers, and Families

CareSearch provides trustworthy information about palliative care for patients, carers, and families as well as for health professionals



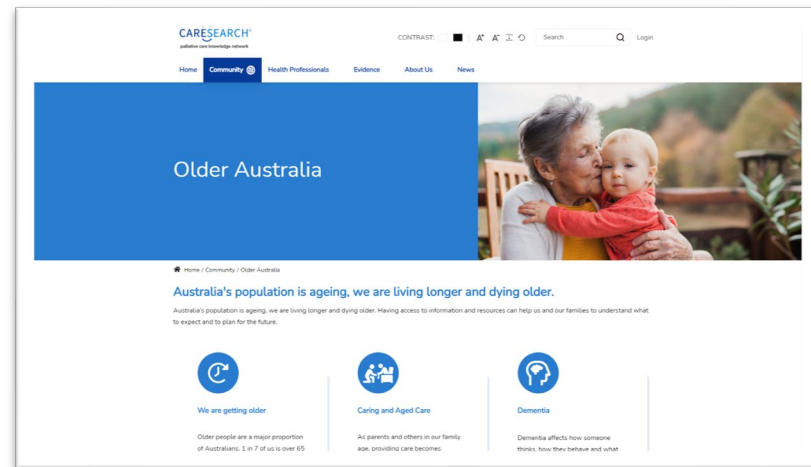
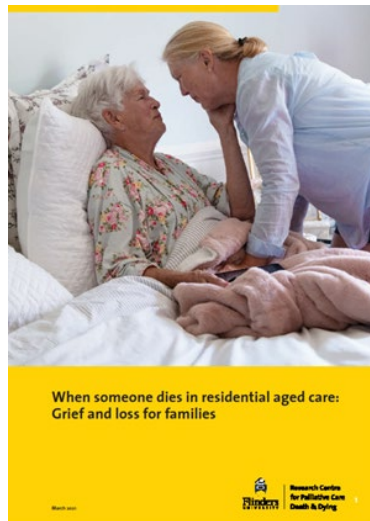
CareSearch is funded by the Australian Government Department of Health.  
Printed June 2021





# Supporting families and carers

[www.caresearch.com.au](http://www.caresearch.com.au)  
[www.carerhelp.com.au](http://www.carerhelp.com.au)  
<https://www.flinders.edu.au/research-centre-palliative-care-death-dying>



**carerhelp**

## Information Pack for Family Carers

CarerHelp presents a new printed resource for specialist palliative care services.



Strengthen your support for family carers who are caring for a dying person.

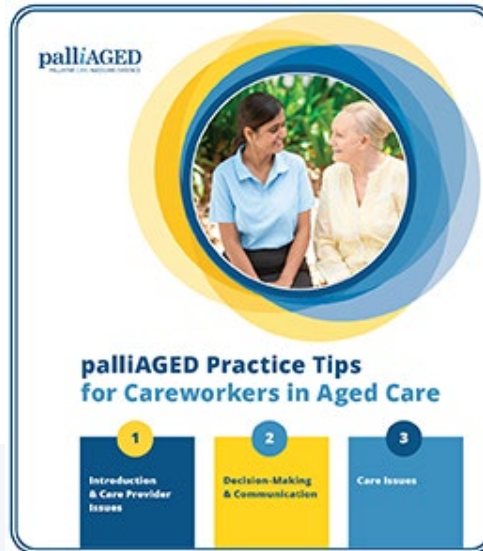
To order free packs, visit [bit.ly/CarerHelpInfoPack](http://bit.ly/CarerHelpInfoPack)



**CARESEARCH®**

# Aged care resources

[www.palliaged.com.au](http://www.palliaged.com.au)



## My Emergency Contact List: Helping you keep track of your team

Insert name of your organisation

My name: \_\_\_\_\_

**Reminder:**  
Put this list on your fridge or somewhere where it can be easily found.

Relationship/ Role	Name	Phone Number	Contact at time of death? (Y/N)
Partner/friend/family			
Substitute decision-maker			
Specialist			
General Practitioner (GP)			
Nurse			
Pharmacist			

palliAGED Practice Resources [www.palliaged.com.au](http://www.palliaged.com.au)

# Taking care of yourself

[www.palliated.com.au](http://www.palliated.com.au)  
[www.eldac.com.au](http://www.eldac.com.au)

Page 1 of 3

## Self-Care Plan: Aged Care Team

Insert your name

Caring for others can be rewarding. However, staff working in aged care look after many people who die. You might find this loss hard to accept. You might find it hard to sleep, no longer enjoy your work, or feel tired. This can affect you and your family. Self-care is what we do to maintain balance in our life.

A self-care plan based on what you like to do can help. We have suggested a few things that you could try, but what you choose will depend on you.

### Workplace self-care - Activities to help you at work

Some examples

Regular meetings with supervisors or a more experienced colleague  
Join a support group with the people you work with  
Attend training programs

My Activities:

### Physical self-care - Activities that help you to stay fit and healthy

Some examples

Develop a regular sleep routine  
Aim for a healthy diet  
Take lunch breaks and go for a walk  
Get some exercise before/after work regularly

My Activities:

Self Care  
COMES FIRST

Coming soon ELDAC  
self care resources

## Trustworthy resources

All of the resources are backed by quality processes in terms of evidence assessment and review by Australian health professionals

The CareSearch, CarerHelp, ELDAC and palliAGED websites meet the requirements for registration with HonCODE and Health Direct

These projects have been funded by the Department of Health to support aged care and health care with information about palliative care and end of life.

[www.caresearch.com.au](http://www.caresearch.com.au)

Twitter: @CareSearch

Facebook: CareSearch Project