

CareSearch and palliAGED

putting evidence into everyday practice

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CareSearch is funded by the
Australian Government Department of Health.



- Increasing Ageing population –longevity revolution
- Despite all the advancements in modern medicine, the mortality rate remains at 100%
- The number of people dying is set to double over the next 25 years
- Leading causes of death -dementia, cardiac disease and cancer
- 21st C people live with chronic conditions for many years before dying

‘In this world, nothing can be said to be certain except death and taxes’ (B. Franklin)

THE AGED CARE PUZZLE

DEMAND

VS

SUPPLY

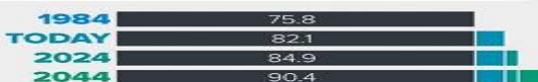
GROWING POPULATION AUSTRALIAN 65+ POPULATION



AGEING SOCIETY MEDIAN AGE



INCREASED LONGEVITY LIFE EXPECTANCY AT BIRTH



POPULATION PYRAMIDS AGE VS. POPULATION (THOUSANDS)



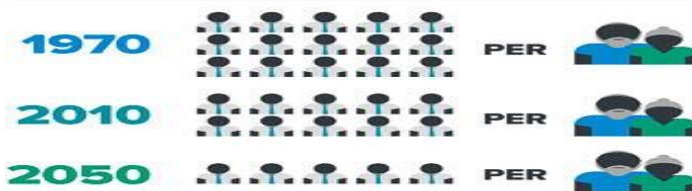
85+ POPULATION



LETTERS FROM THE QUEEN



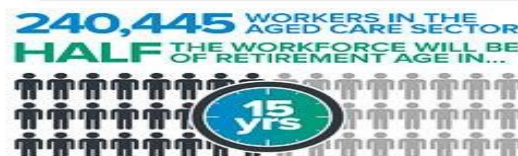
DECLINING WORKFORCE RATIO RATIO OF WORKERS : RETIRED COUPLE



AGEING WORKERS MEDIAN AGE IN WORKFORCE SECTORS



MASS RETIREMENT RETIRING AGED CARE WORKFORCE



MASS RECRUITMENT



GROWING NEED



- Ageing population-longevity revolution
- 15% of Australians (3.7 million) are aged 65 and over in 2016 with projected growth to 22% (8.7 million) by 2056
- 1 in 5 will be over 85 years



CareSearch is the online source for evidence on palliative care for all Australians.

- WHO recognises the need to improve access to end of life and palliative care as core component of health systems –across the life course and continuum of care
- All settings where people live and die -not just hospitals & specialist palliative care services
- Increasing emphasis on primary health care and community based care
- Death and dying will affect all of us at some time – so it's everyone's business
- Result is increasing pressure to provide end of life and palliative care and ensure its quality
- Department of Health funds range of programs to improve care planning, end of life and palliative care

What is palliative care?

A person and family-centred form of active and supportive care that seeks to maximise quality of life for people with a life-limiting illness.

End of life and Palliative care approach is ***holistic*** and addresses:

- physical symptoms
- emotional wellbeing
- cultural and spiritual needs
- social and family support
- ***Quality of Life***



> Longer and complex care needs

> Increased life expectancy



Males:
80.4 years

Females:
84.6 years

> Diverse population with different lived experiences

- **6.1 M** born overseas
- **787 K+** identified as Aboriginal and Torres Strait Islander
- **7 M** live in rural and remote areas
- **3.9 M** people aged 65+
- **4.3 M** with disability, **668 K+** with intellectual disability
- **11%** are of diverse sexual orientation or gender identity
- **436 K+** living with dementia
- **14 K** children under 15 have a life-limiting condition
- **2.7 M** unpaid carers

> 5.3 M have multimorbidity or 2 or more of the following:

- Cardiovascular disease
- Chronic obstructive pulmonary disease
- Diabetes
- Arthritis
- Cancer
- Asthma
- Cancer
- Mental health conditions



> Increase in ageing population



3.9 M in 2017
to
7.5 M in 2047



**Rise in demand of
aged care services**



**More expected to
choose to remain living
at home as they age**

> Workforce planning and capacity building to meet demand



> Education & training to meet requirements of providing quality, person-centred & evidence-based palliative care



In 2016, there were only

226
palliative
medicine
physicians



3,457
palliative
care nurses

employed nationally



> Aged care staff recruitment, training & retention

BENEFITS



► Offers a support system to help you live as well as possible



► Can help you get optimal care based on your needs, preferences, values and available resources



► Provides relief from pain and other physical and emotional distress



► Offers a support system to help you address the physical, emotional, financial, social and spiritual challenges brought by the patient's illness



► Prepares you for what to expect and to participate in making decisions



► Can help cope with grief and bereavement

For patients

For carers and families

For health and aged care providers

For health professionals

Benefits of quality palliative care



► Enables a multidisciplinary team approach to address the needs and preferences of patients and their families



► Helps manage symptoms to minimise impact on activities of daily living



► Helps manage acute deterioration



► Helps with anticipatory prescribing and care planning at end of life



► Can help support families and provide culturally respectful care



► Helps provide better care through improved symptom control, pain relief and comfort for both patients and their families



► Helps reduce stress from hospital admissions



CareSearch is the online source for evidence on palliative care for all Australians.

- Care search Celebrating 10 years- palliAGED 1 year anniversary
- Major resource for end of life and palliative care in Australia
- Valuable work of continuously identifying, evaluating, synthesising and disseminating trustworthy information and best available evidence
- Free online 24/7 access to the best available evidence
- Information and resources available for the whole community -health and aged care practitioners, patients, carers, families, friends
- Build awareness, capacity, understanding and knowledge
- Linking education, research and practice –'triple strand of care'



Why is evidence important?

- An evidence-based approach uses the best available evidence to answer clinical, care and service related questions
- Evidence is crucial in delivering the most appropriate and person centred quality end of life and palliative care for all
- Highlights the need for investment, research and improved service



Helps us understand the potential benefits and harms of a treatment or intervention



Provides insights to the most likely outcome of a treatment or intervention across a population



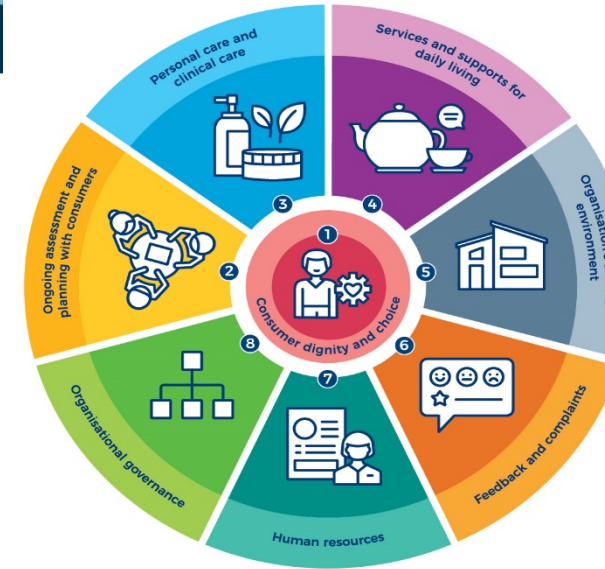
Empowers us to ask informed questions and make informed decisions



Serves as the basis to drive continuous quality and service improvement

Evidence is important in Aged care

- New Aged care Quality Standards stress the need for **evidence-based** care
- Deliver personal and clinical care that is **best practice** and focused on the consumers needs, goals and preferences optimises their health and well-being
- Support the **whole person's** well-being (emotional, psychological ,spiritual)
- Provide information that is up to date and accurate and easy to understand
- Assessment and planning identifies and addresses the consumer's current needs, goals and preferences, including **advance care planning** and **end of life planning**
- Deterioration or change of a consumer's condition is recognised
- Needs, goals and preferences of consumers nearing the **end of life** are recognised and addressed, comfort maximised and their dignity maximised



We jump the hurdles to make it easier for health and aged care practitioners to put evidence into practice / We provide access to the latest evidence, information and guidance to help providers and consumers / We provide tools to help you find and use evidence for yourself

ENSURING YOUR 24/7 ACCESS TO THE BEST AVAILABLE EVIDENCE

Palliative care covers many diseases and uses different treatments to address physical, emotional, social, spiritual and other needs.

Finding the best available evidence is difficult and time consuming because:

- ▶ The number of studies has grown exponentially in the past decade
- ▶ The literature covers numerous topics, journals and databases
- ▶ There is lack of consistent terminology and descriptions
- ▶ Relevant studies are not always listed as palliative care
- ▶ Some questions are difficult to answer

What we do:

- ▶ Identify and screen over 500 systematic reviews per month
- ▶ Add over 40 systematic review studies per month
- ▶ Update over 40 webpages per month
- ▶ Add over 40 reports, guidelines and conference abstracts to the grey literature per month
- ▶ Promote our website and resources

Why we do this:

- ▶ To highlight the latest findings
- ▶ To synthesise new implications of certain treatments and interventions to patients and services
- ▶ To provide access to current areas for further research

Translating Evidence into Practice

- Can help to bridge the 'theory into practice gap'
- CareSearch helps shorten the pathway to the latest and best quality research evidence
- Summarise research findings into practical guidelines about providing the best care.
- Translate research findings into easy-to-understand language ~~jargon~~
- Information is quality-checked and has
 - HonCode certification
 - Health Direct certification



Why Access to Quality Information Matters

Information can help us to:

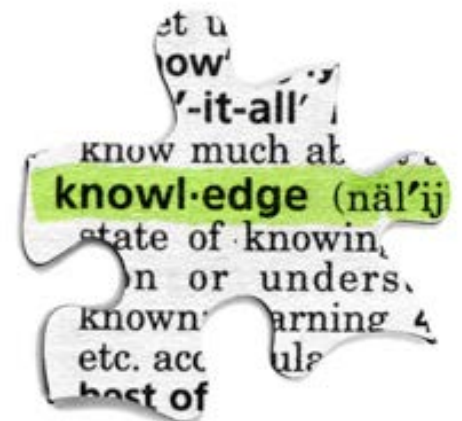
- Understand our options
- Feel more capable of making decisions
- Reduce fear and uncertainty
- Access to relevant, clear, trustworthy information helps us make informed choices
- Can be more confident of choices made when they are based on evidence
- Empowers us to ask informed questions and make informed decisions
- Information needs can change, so ongoing access to information is important



How information can help patients, carers, and families

Consumers and carers can be reluctant to ask questions.

- People may have trouble remembering everything they are told
- Printed information from a trustworthy website can support patients and families
- **My Information Kit** has a selection of factsheets on key topics to print out for patients or carers and family related to dying, loss and bereavement
- It includes a cover sheet that you can write your contact details on



CareSearch

Death and dying will affect all of us. CareSearch provides trustworthy information about palliative care for patients, carers and families as well as for the health professionals providing their care. Just as trustworthy information can help patients and families understand what is happening and make decisions, research evidence helps clinicians provide the best possible care.

CareSearch@10:
**Making palliative
care evidence
evident** [MORE >](#)



Patients, Carers and Families

[Find out more >](#)



For Health Professionals

- [GPs](#)
- [Allied Health](#)
- [Nurses](#)

Information For

- [Residential Aged Care](#)
- [Aboriginal and Torres Strait Islander](#)
- [Researchers](#)

Information For

Palliative care information is important for patients and their families and for the health workforce who provide their care. These sections provide access to resources and literature relevant to the practice of palliative care for different professional groups and for patients, carers and families. They have been developed either in association with peak bodies, professional organisations and individuals from that area.



**Patients, Carers and
Families**

GPs

Residential Aged Care

Researchers

Allied Health

Nurses

**Aboriginal and Torres
Strait Islander Care**

Related Sites



- ▶ Understand what palliative care is and isn't



- ▶ Understand, plan and manage issues when living with a life-limiting illness



- ▶ Feel confident to ask questions and make informed decisions



- ▶ Locate and access other palliative care resources and services



- ▶ Critically appraised and summarised clinical evidence for best practice



- ▶ The latest systematic reviews on 135 palliative care related topics



Information for specific community groups:

- ▶ Aboriginal and Torres Strait Islanders
- ▶ Rural and remote residents
- ▶ Children
- ▶ Lesbian, gay, bisexual, transgender and intersex patients
- ▶ Culturally and linguistically diverse patients
- ▶ People with disability
- ▶ Homeless
- ▶ Prisoners
- ▶ Dementia patients
- ▶ Young carers



- ▶ Tools and resources to help with clinical decisions



- ▶ Search filters to easily identify research findings within PubMed and grey literature



- ▶ Quality palliative care resources you can recommend to your patients and their carers



- ▶ Latest research findings and gaps for further studies



- ▶ Education and professional development resources



- ▶ Apps, tools and resources for health and aged care settings



- ▶ Critically appraised and summarised evidence for the aged care context



- ▶ Education and professional development resources to improve team and workforce capacity

BUILDING CAPACITY BY CONNECTING THE WORKFORCE TO EDUCATION

CareSearch helps to build capacity and understanding through palliative care education.

WE:



- ▶ Identify, develop and share information on education and training options



- ▶ Help the workforce navigate learning choices in the Education section



- ▶ Deliver online professional learning courses, including the award-winning Dying2Learn



- ▶ Host a range of national and local professional education programs

SUPPORTING THE PALLIATIVE CARE COMMUNITY

CareSearch works with many organisations and programs in Australia.

WE:



- ▶ Host and provide technical support to more than 20 palliative care initiatives through our website



- ▶ Contribute our expertise to national and local projects



- ▶ Link palliative care initiatives and professionals

STRENGTHENING PALLIATIVE CARE RESEARCH IN AUSTRALIA

Research is essential for improving the quality of palliative care.

WE:



- ▶ Enable researchers to share information, collaborate and prevent duplication through our research register



- ▶ Connect people to the latest, relevant research with search filters for PubMed



- ▶ Support new researchers to design and action their study



- ▶ Conduct research to build palliative care knowledge

CareSearch

- Powers **palliAGED** and has a range of related projects, programs and partnerships
- Dying2Learn, ELDAC, EOL Essentials, TEL, Advance, caring@home

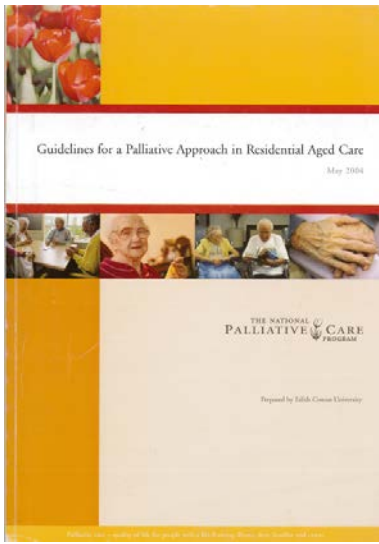


Dying2Learn

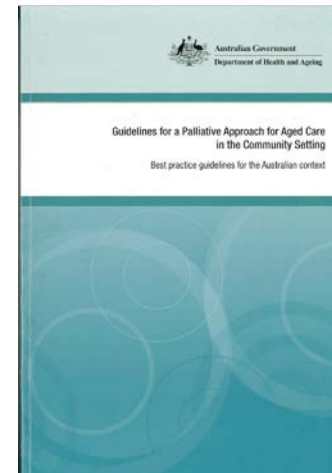
- Death and Dying , Loss and Grief
- Improving death literacy
- Over 4,000 participants in MOOC
- Sharing the Dying2learn
- Useful resources and information
- Publishing research findings



- palliAGED is an free online resource –available 24/7
- supporting quality end of life and palliative care-aged care focus
- Provides easy to find and use up to date evidence based guidance and resources about providing the best care
- Translate research findings into easy-to-understand language
- Launched in 2017 -updated revised APRAC and COMPAC guidelines



The Palliative Approach
in Residential Aged Care
(APRAC)



Palliative Approach for
Aged Care in the
Community (COMPAC)
Guidelines

palliAGED
PALLIATIVE CARE AGED CARE EVIDENCE

SUBSCRIBE CONTACT  

Home Australian Context Evidence Centre Practice Centre For the Community News 

Welcome to palliAGED

palliAGED makes it easy to find and use palliative care evidence and practice resources in aged care.

Older Australians, their families and friends are also welcome to use these trustworthy resources.



[Go to Evidence Centre](#) [Go to Practice Centre](#) [For the Community](#)

palliAGED apps

The palliAGED apps provide nurses and GPs with easy and convenient access to information to help them care for people approaching the end of their life.



Videos



The Impact of palliAGED on the aged care sector

What's New

Tweets by @palliAGED

  Lunched today: ELDAC (End of Life Directions for Aged Care) a new online resource providing palliative care and advanced care planning information, resources and services in the one place eldac.com.au @ELDAC_agedcare #CareSearchpartner

[Liked](#) [View on Twitter](#)

Follow palliAGED :   

   This site complies with the HONcode standard for trustworthy health information: [verify here](#).

palliAGED palliAGED is funded by the Australian Government Department of Health. palliAGED is managed by CareSearch, Flinders University.	About palliAGED About the Project Acknowledgements Project Team Terms and Conditions	Quick Links Family Resources Practice Points Evidence Topics Specific Needs palliAGED apps Site Map	Contact Us If you have any queries, please contact us:  Email - palliaged@flinders.edu.au  Twitter  Vimeo
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palliAGED
PALLIATIVE CARE AGED CARE EVIDENCE

palliAGED makes it easy to find and use palliative care evidence and practice in aged care

For health and aged care workers and older Australians, their carers and families

Evidence into everyday practice

Evidence Centre provides a single gateway to support fast and reliable access to evidence to inform good practice

- evidence summaries
- practical information for a large number of relevant symptoms, medicines, clinical issues and care practices
- guidance on how to find and use evidence

Practice Centre - complementary

- provides practical options to apply in practice
- What can I do, what can I learn, what can organisation do
- links to tools and practice resources

> Evidence Summaries

- > Advance Care Planning (ACP)
- > Advocacy
- > Bereavement
- > Care Coordination
- > Case Conferences
- > Cognitive Issues
- > Communication Skills
- > Communication at End-of-Life
 - > Communication at End-of-Life - Synthesis
- > Comorbidity
- > Costs and Economics
- > Deprescribing
- > Education Carer
- > Education Workforce
- > Elder Abuse
- > Emergency Planning
- > Environmental Modification
- > Family Carers
- > Family Conflict
- > Goals of Care
- > Managing Crises
- > Models of Care
- > Needs Assessment
- > Nutrition
- > Quality of Life
- > Referral
- > Resilience
- > Respite Care
- > Self Care
- > Social Support
- > Spiritual Care
- > Syringe Drivers

Communication at End-of-Life

Key Messages

- ➊ Good communication underpins the quality of palliative care [1] and is associated with better quality of life for older adults receiving palliative care. [2]
- ➋ Older adults would like the opportunity to discuss their end-of-life needs and often value frank conversations with health care professionals. [2-4]
- ➌ Older adults are more likely to wait for health professionals to raise the topic of end-of-life discussion than initiate the discussion [5,6]
- ➍ It is often not clear which health professional should lead end-of-life discussions. [1-3,5] Preferably, this should be someone with whom the person feels comfortable and with whom he or she will have regular contact. [1,3,5]
- ➎ The timing, content, pace and setting of conversations are important in helping people deal with difficult issues at or near end-of-life. [3,5]
- ➏ Older adults may want practical information on how their condition will affect activities of daily living and what to expect as health deteriorates, but may not want prognostic information. [5,6]

Search PubMed

EoL Comms: Palliative & Aged
EoL Comms: Palliative only
EoL Comms: Aged only
[About these searches](#)

Practice Points

Read Synthesis

Background

Recent years have seen significant improvement in the provision of palliative and end-of-life care, with communication between health professionals, the patient and their family at the core of a positive end-of-life experience. [2] There is concern that despite improvements in care, discussion of end-of-life planning is not always delivered in a timely manner, may be ineffective or of poor quality. [1,4,5]

This review aims to discuss the evidence for timely initiation of end-of-life discussion and how older adults would prefer to receive this information.

Evidence Summary

A significant number of older adults with non-malignant but progressive and life-limiting conditions receive palliative and end-of-life care. [7] The importance of good communication in the end-of-life phase has long been recognised by health care providers and has been shown to improve patient and family understanding, enhance therapeutic

Practice Points

pallAGED
Palliative Care Advanced Graduate Education

Home Australian Context Evidence Centre Practice Centre For the Community News Q

Practice Centre > Evidence in Practice > Communication at End-of-Life

Evidence in Practice

- Advance Care Planning (ACP)
- Advocacy
- Bereavement
- Care Coordination
- Care Conferences
- Cognitive Issues
- Communication Skills
- Communication at End-of-Life
- Comorbidity
- Costs and Economics
- Deprescribing
- Education Career
- Education Workforce
- Elder Abuse
- Emergency Planning
- Environmental Modification
- Family Carers
- Family Conflict
- Goals of Care
- Managing Chw
- Models of Care
- Needs Assessment
- Nutrition
- Quality of Life
- Referral
- Resilience
- Respite Care
- Self Care
- Social Support
- Spiritual Care
- Syringe Drivers
- Terminal Care
- Volunteers
- Workforce

For GPs

- pallAGED Apps
- Projects and Resources
- Telehealth Resources
- Training and Education
- Living Evidence

Communication at End-of-Life

What we know

Communication between a person receiving palliative care, their family, and health professionals is at the core of a positive end-of-life experience. Older adults would like the opportunity to discuss their end-of-life needs and often value frank conversations with health care professionals. The timing, content, pace and setting of conversations are important in helping people deal with difficult issues at or near end-of-life. Many older adults may wait for health professionals to raise the topic of end-of-life discussions and often it is not clear which health professional should lead end-of-life discussions.

[Go to Evidence Centre](#)

What can I do?

Communicating about end-of-life issues can be difficult. You may like to ask how you can help. Remember that listening and acknowledging concerns may be of great comfort.

Patient and families appreciate being listened to, being invited to ask questions. You may not know the answer to every question, but you can be of help by sharing information. "Here is a brochure, maybe you could talk to ... about ..."

Familiarise yourself with types of questions people may ask. Asking questions can help. An aid for people seeing the palliative care team (514k) pdf.

Checking a person's understanding of the current situation is a good way to start a discussion. You can use ask-tell-ask technique to structure these discussions.

Use Communication Cards to communicate with people in their preferred language. @from The Centre for Cultural Diversity in Ageing

What can I learn?

Read:

- about breaking news, helping people plan, supporting carers and identifying end of life patients from Dying Matters.
- about active listening (158k) pdf.
- a factsheet: Talking with Families (75k) pdf from the PA Toolkit.
- "Supporting a good end of life" (544k) pdf for tips on communication for staff of residential aged care facilities.
- Palliative Care Network of Wisconsin Fast Facts and Concepts (Responding to Patient Emotion).
- Clayton J, Hamlock K, Butow P, Tattersall M, Currow D. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. Med J Aust. 2007 Jun 18;186(12 Suppl):S7, S9, S83-S88.
- Therapeutic Guidelines: Communicating with the patient in palliative care (subscription required).
- Responding to Strong Emotions from CareSearch.
- The Vital Talk website has tips and even the VITAL Talk Tips app.

Check out these videos:

- Palliative Care and the Human Connection. Ten steps for what to say and do when talking about palliative care. It is primarily for doctors but can be of interest to many people.
- "Someone is dying. What do I say?": Care, compassion and communication at end of life (48 minutes) from the PA Toolkit.

Use the PCGJ online learning modules to learn about:

- Communicating with people with life-limiting illnesses.
- Communication principles.
- Responding to losses.
- End-of-life concerns.

What can my organisation do?

Have readily available to families Asking questions can help. An aid for people seeing the palliative care team.

Develop a list of flags to clearly identify the triggers for palliative care or end-of-life care discussions or review discussions.

Providing comfortable non-clinical meeting rooms for end-of-life discussions may offer a more nurturing environment for discussion, putting everyone at ease.

Have a member of staff or key health professional provide a telephone follow up after initial discussions to check how information has been received and understood. Offering the opportunity to clarify information may reduce stress and anxiety experienced by the person and their family.

What can I do?

What can I learn?

What can my organisation do?

> Finding Evidence
> Symptoms and Medicines
> Agitation > Delirium > Depression > Dyspnoea > Fatigue > Nausea > Noisy Secretions > Pain > Prescribing of Medicines > Administering of Medicines
> Quality Processes
> Research Gaps
> Specific Needs

Symptoms and Medicines

As high quality Australian materials exist, these links have been combined, creating a single gateway - supporting fast and reliable access to evidence to inform your clinical practice.

Symptoms

Agitation	Dyspnoea	Noisy Secretions
Delirium	Fatigue	Pain
Depression	Nausea	

Medicines Management

Prescribing of Medicines	Administering of Medicines
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Resources

While many of these resources are freely available, others require a subscription in order to access the link.

Open access

- > [CareSearch website](#)
- > [Caring Safely at Home Project - Queensland](#)
- > [Eastern Metropolitan Region Palliative Care Consortium](#)
- > [eviQ: Cancer Treatments Online](#)
- > [palliAGEDgp Smartphone application](#)
- > [Tasmanian Government Specialist Palliative Care Service](#)
- > [The Council of Australian Therapeutic Advisory Groups \(CATAG\)](#)

Subscription only

- > [Australian Medicines Handbook \(AMH\)](#)
- > [Therapeutic Guidelines \(Palliative Care\)](#)
- > [Palliative Care Formulary \(PCF\)](#)
- > [Australian Don't Rush to Crush Handbook](#)
- > [Australian Injectable Drugs Handbook](#)

For information on subscriptions, refer to [Australian Medicines Handbook](#), [Therapeutic Guidelines](#), [Palliative Care Formulary](#), [Australian Don't Rush to Crush Handbook](#), and the [Australian Injectable Drugs Handbook](#) websites for details.

For the Community

Older Australians are generally fit and well and most are living in their own home. Over time they may need more support and there are many different services that can help them remain independent. However, some because of cognitive issues such as dementia or specific conditions like breathlessness may need more care. Families are often involved in providing this support and care, directly or indirectly.

As an older person ages, they will become frailer and underlying conditions may worsen and they will enter the last phase of their life. Understanding how things will change as the older person moves towards death and by talking about what type of care will be needed is often helpful for both the person and the family.

These pages provide information on palliative care and end of life care and on services and resources that can help the person and their families.



palliAGED Apps

- Apps provide easy and convenient access to information anywhere anytime
- palliAGEDnurse and palliAGEDgp App
- Web based - updated as new evidence and resources are released
- Base on Palliative Approach Framework pathways of care
- Online-offline capacity - use with or without the internet

Download now via

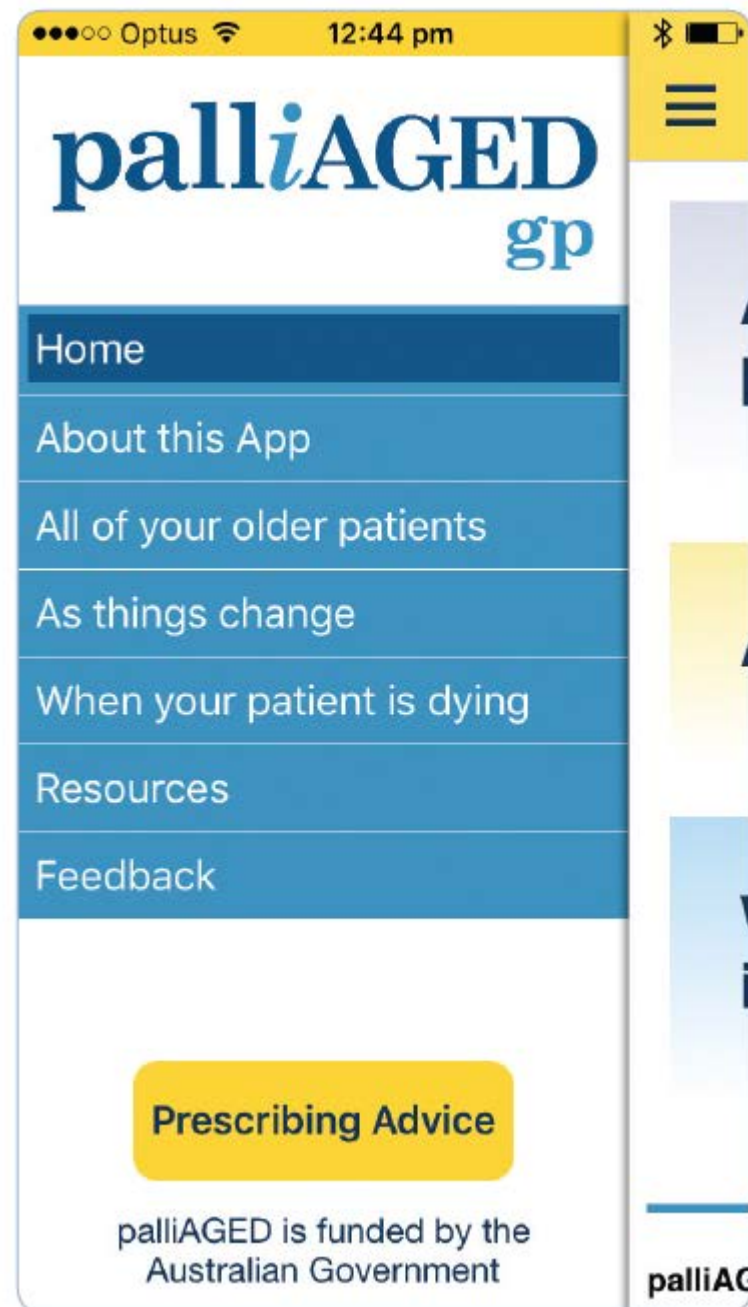
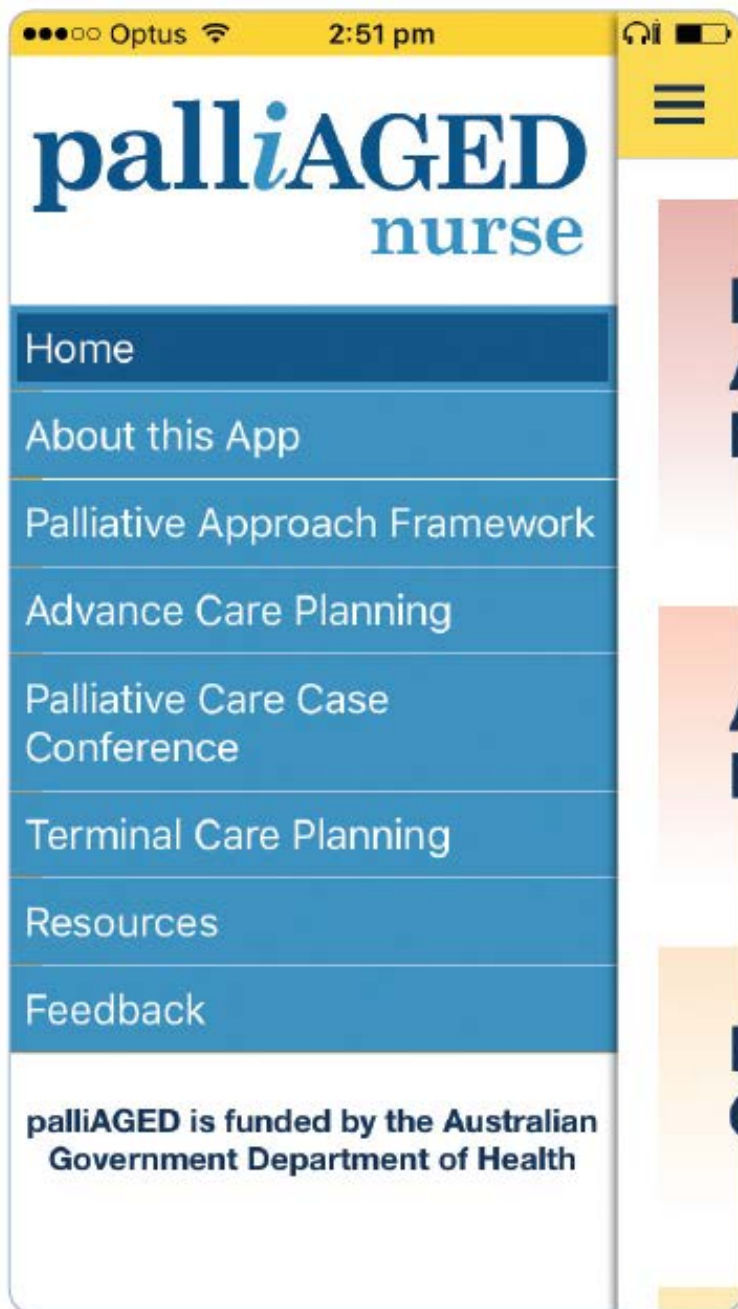


[Apple iTunes App Store™](#)



[Play Store for Android™](#)





CareSearch-palliAGED Engagement

- Building knowledge and awareness through sector engagement
- Engagement project – Aged, Allied Health and Patients, Carers, Families
- We welcome comments, feedback and involvement

‘A life well lived deserves a good ending ‘



palliAGED Practice Tip Sheets for Aged Care



- Developed to support people providing palliative care to older people –careworkers and nurses
- Key care issues are presented in a concise format, with companion sheets available for training and support

1

**Introduction to
palliative care
and care provider
issues**

2

**Decision-making
and communication
issues**

3

Care Issues

www.caresearch.com.au

www.palliaged.com.au



CareSearch recognises the many people who contribute their time and expertise including members of the CareSearch and palliAGED Advisory Groups.

We welcome your enquiries and feedback at anytime



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