



Palliative and end-of-life care for frail older people and those living with dementia: Research and Practice

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AMNF Professional Development



ELDAC is funded by the Australian Government Department of Health, Disability and Ageing

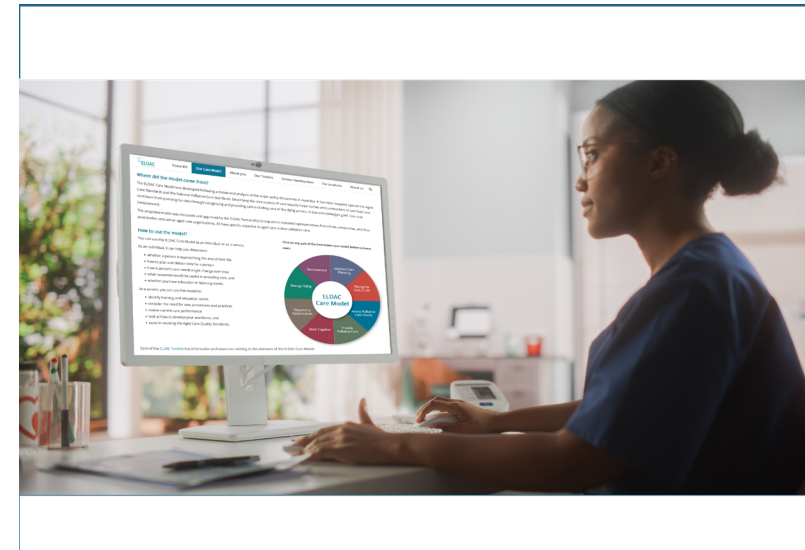
Acknowledgement of Country

ELDAC acknowledges the Kurna people, the Traditional Custodians of the land on which we meet, and the many custodians of ancestral lands and waters throughout Australia. We recognise the knowledge, strength and resilience of Aboriginal and Torres Strait Islander Peoples, and their continuing spiritual and cultural connections to land, water and community.

ELDAC pays respect to Elders past and present

Overview of Session

- ELDAC's role in Aged Care
- Evidence-based resources
- Current research in Dementia Palliative Care
- A palliative approach and good palliative care
- Key tools to help assess needs
- Feedback about resources
- Q&A session



What is ELDAC?

- National free online resource for aged care staff and health professionals
- Care for older people at the end of life
- Consortium of 3 universities and 4 peak bodies



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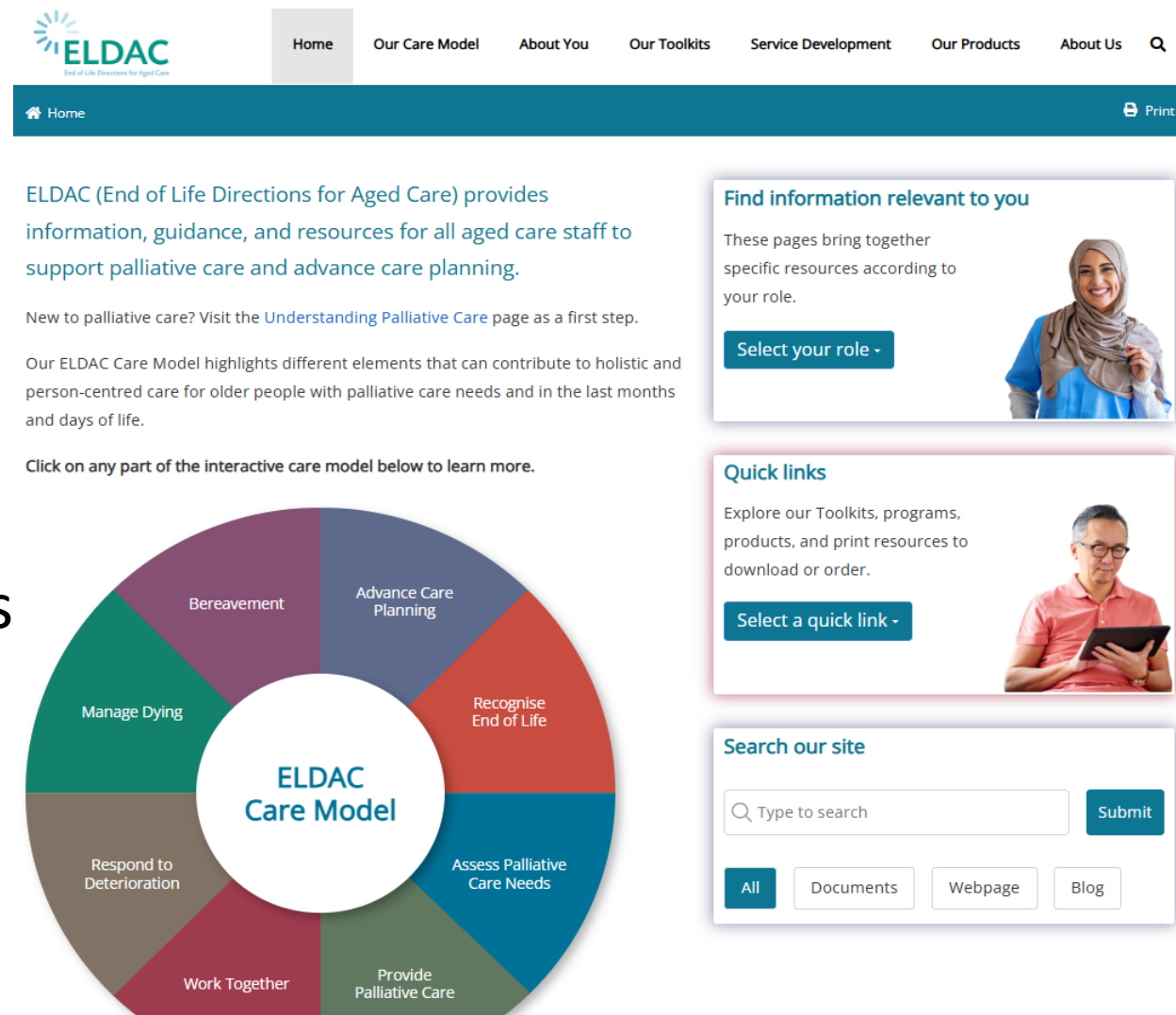
Educate, inform, improve quality of care, aligned with quality standards

How to engage with ELDAC?

- Explore the website

<https://www.eldac.com.au>

- Relevant to roles
- Quick links
- Search function
- Education modules and videos
- Equip and PaCE
- Linkages program



ELDAC (End of Life Directions for Aged Care) provides information, guidance, and resources for all aged care staff to support palliative care and advance care planning.

New to palliative care? Visit the [Understanding Palliative Care](#) page as a first step.

Our ELDAC Care Model highlights different elements that can contribute to holistic and person-centred care for older people with palliative care needs and in the last months and days of life.

Click on any part of the interactive care model below to learn more.

ELDAC Care Model

- Advance Care Planning
- Recognise End of Life
- Assess Palliative Care Needs
- Provide Palliative Care
- Work Together
- Respond to Deterioration
- Manage Dying
- Bereavement

Find information relevant to you

These pages bring together specific resources according to your role.

Select your role -

Quick links

Explore our Toolkits, programs, products, and print resources to download or order.

Select a quick link -

Search our site

Type to search

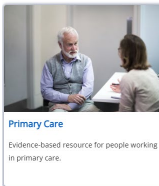
How to engage with ELDAC

ELDAC Toolkits

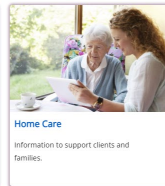
The ELDAC toolkits provide information, resources, and tools to help you provide palliative care and support advance care planning. They are evidence based and designed for use in Australian aged care services.



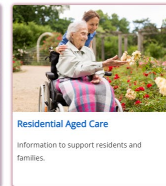
Toolkits are a collection of information, resources and tools around a particular topic or practice area. They provide users with meaningful and practical materials to care for older Australians at end of life. They can help users to develop a plan and organise their efforts to follow evidence-based recommendations or practices.



Primary Care
Evidence-based resource for people working in primary care.



Home Care
Information to support clients and families.



Residential Aged Care
Information to support residents and families.




Dementia
Information to support people with dementia and their families.



Service Development

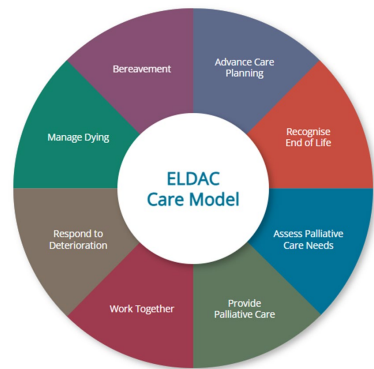
Aged care services have an important role in caring for older people at the end of life.

ELDAC provides resources and programs that develop service capability in providing palliative care.

Understanding Diversity

Understanding diversity in older people and specific end of life care needs.



Talking with Families

Self-care Resources



Aged care services provide access to the aged care workforce, enable linkages between different organisations providing services to older people, and can facilitate workforce development. The following ELDAC activities are supporting aged care services and workforce development.



Linkages Program

A team of facilitators support service development by building partnerships.



ELDAC Education

Explore ELDAC learning activities on palliative care and advance care planning.




PaCE Aged Care

Palliative Care Education Aged Care

Finding Education Options

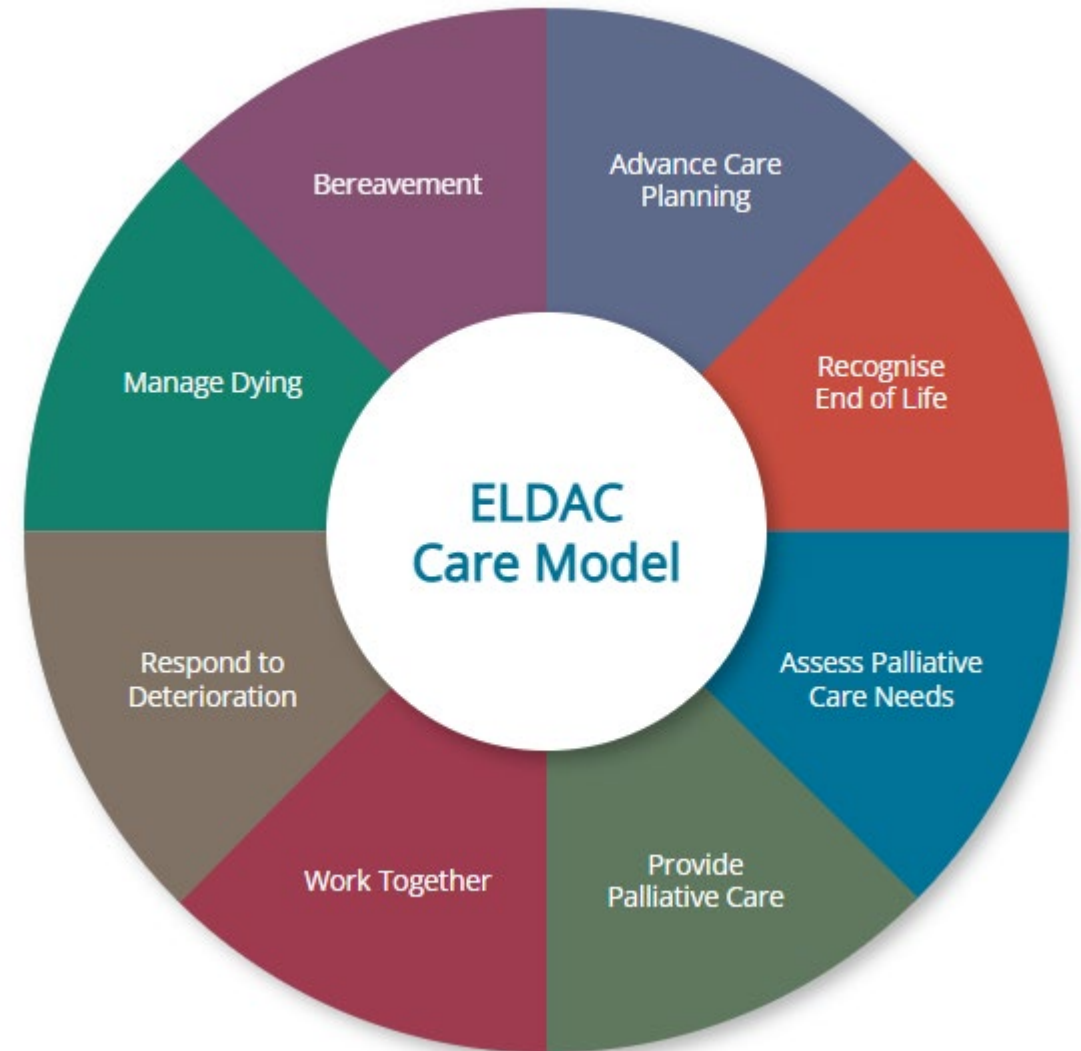
PaCE Aged Care is an online directory of palliative care education options suitable for aged care.



Common Clinical Tools

Access a range of clinical assessments and practice tools to support care across various care settings.

A framework for End-of-Life care



Evidence-based toolkits

ELDAC Toolkits

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Home Care

Information to support clients and families.



Residential Aged Care

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End of Life Law

The law at end of life for the aged care sector.



Linkages

Linkages between aged, primary and palliative care services.



Dementia

Information to support people with dementia and their families.



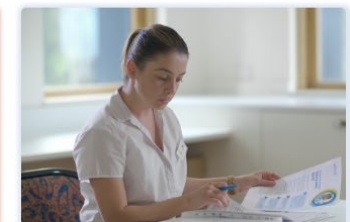
Allied Health

Practical resources and information to support allied health professionals.



Managing Risk

Information and guidance on effective governance and risk management.



Toolkit Educational Videos

Improve your skills in end-of-life care by learning from palliative care experts and clinicians.

Dementia Tool Kit

- Clinical tools to recognise end-of-life in people living with dementia
 - The Surprise Question:
 - The SPICT: identify indicators of deteriorating health for Palliative care
 - The FAST: progression of functional decline stages in dementia
 - The AKPS: performance across activities and self-care
(Score of 40 is an indicator of loss of function and need for palliative care)
- Responding to deterioration
 - Is the cause treatable or not? Consult with others
 - UTI, delirium, and infections are preventable and treatable
 - 4AT for screening for delirium and cognitive impairment

ELDAC products

Our Products

The ELDAC Project aims to support palliative care and advance care planning in the aged care sector.

As well as our ELDAC Toolkits and the Linkages Program, we have responded to identified needs in the sector with specific products and initiatives.

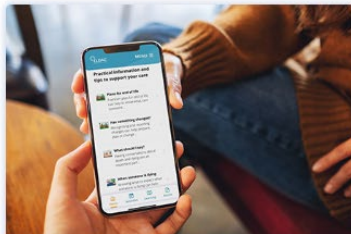


We use multiple practical strategies to build national capability in the palliative, primary and aged care sectors to support older people with palliative care needs and those who are coming to the end of their life. ELDAC initiatives cover awareness raising options, digital solutions, resources for project and quality improvement activities, and practical resources for residential aged care and home care services. All are free to access and to use.



Addressing the Standards

3 key steps to support aged care services prepare for and address Outcome 5.7: Palliative care and end-of-life care.



Home Care App

An app for care workers dealing with care issues at the end of life.



Self-care Room

Resources and ideas to support the wellbeing of aged care staff.



Talking with Families

Supports staff to have end of life conversations with families.



Understanding Diversity

Understanding diversity in older people and specific end of life care needs.



My Care Matters

Resources for aged care services highlighting the value of their care.



Digital Dashboard

A systems approach to tracking end of life care and reporting.



Home Care Search

One click PubMed searching that finds articles relating to home based aged care.



ProSeek

Database of palliative care projects and reports relevant to aged care.

Current research in palliative dementia care

- Gaps:
 - Not recognised as a life-limiting condition
 - Uncertain prognosis- difficult to identify the end-of-life stage
 - Poor symptom control
 - Confusion between behaviour management and pain relief
- Challenges:
 - Few dementia-specific end-of-life care models
 - Psycho-social and spiritual care needs over longer periods of time
 - Needs of caregivers
 - Complex co-morbidities and frailty

Current research in palliative dementia care



Ref: Lewis, S., Curryer, C., Triandifilidis, Z., Carr, S., Davis, D., Jeong, S. Y.-S., Goodwin, N. (2023). Rapid Review of Models of Palliative Care for People with Advanced Dementia: Report. Central Coast Research Institute for Integrated Care, Gosford NSW. <https://ccri.asn.au/>

Figure 1. Essential components (domains) of a model of palliative care for people with dementia.

People with dementia may die in:

1. Mild-advanced stages: and die from another illness (e.g., cancer, heart disease)
2. More likely in advanced stages: People may die with several problems. Dementia may not be the only cause of death, but interacts with other conditions to complicate identification and treatment
3. In Advanced stages: People may die from complications arising from end-stage dementia (e.g., pneumonia) or from organ failure.

10,900 women and 6,500 men die annually due to dementia

The second cause (after heart disease) of the burden of disease (AIHW, 2025).

Current research: Unanswered questions

priorities for palliative and end of life care 2025, guided by people with lived and/or professional experience, in order, starting with the highest priority.

1 How do **people with dementia** experience end of life? How can palliative and end of life care better meet their needs and those of their carers, friends and families?



2 How can NHS, social services and charities work more **collaboratively to provide joined-up** care that better meets the needs of people with a serious life-limiting illness and their carers, friends and families?



Ref: Hudson et al 2025
<https://healthopenresearch.org/documents/7-2>

3 What kinds of palliative and end of life care and support need to be in place to **enable people to die well at home**?

What skills do staff need?
What helps or hinders the delivery of care at home?



4 What are the best ways to provide **personalised palliative and end of life care** that meets all the physical, mental, practical, social and spiritual needs of a person with a serious life-limiting illness?



5 How can palliative and end of life care better meet the complex needs of people with **multiple health conditions**?



9 What are the best ways to provide palliative and end of life care, **support and advice at all hours** (24/7 or out of hours)?



6 How can **communication and care co-ordination** be improved across the teams of health and social

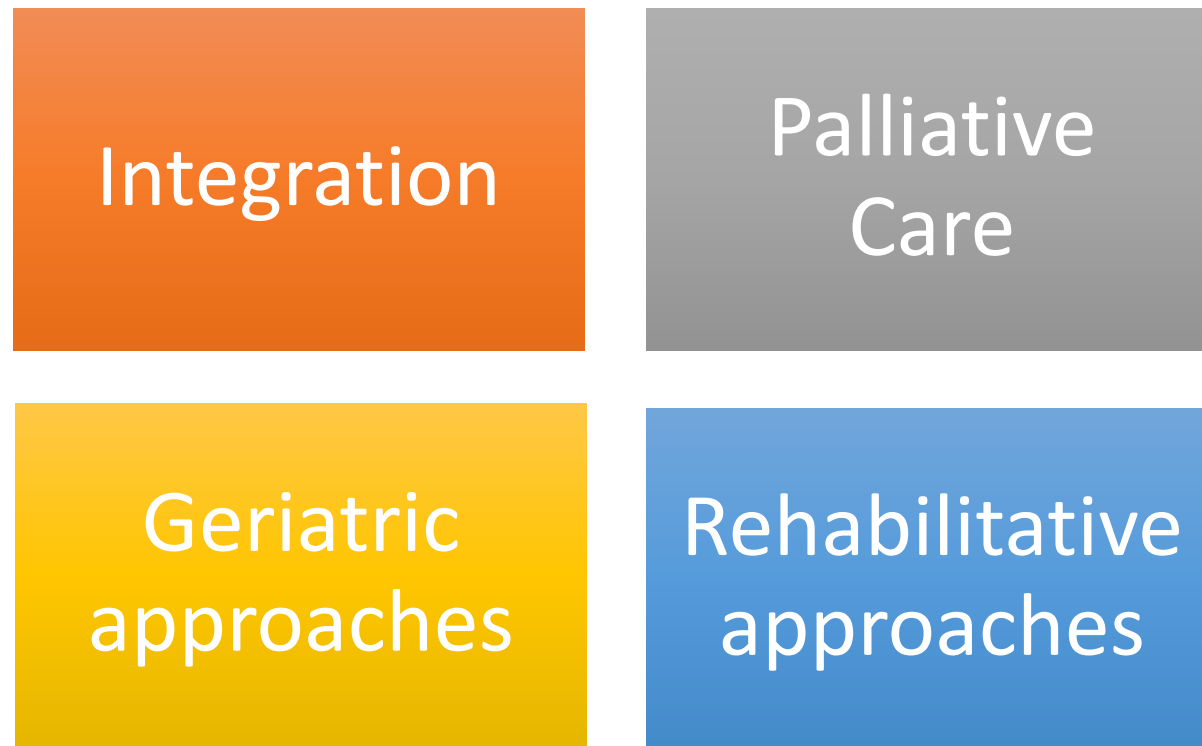
7 What **skills, training and information** do **carers, friends and family members** need to be able to care for someone who is dying

8 How can the **quality of palliative and end of life care in hospital** be improved? What helps or hinders improvement?

10 How can palliative and end of life care better meet the needs of people **who live alone, or are socially isolated**?

Current research: priorities

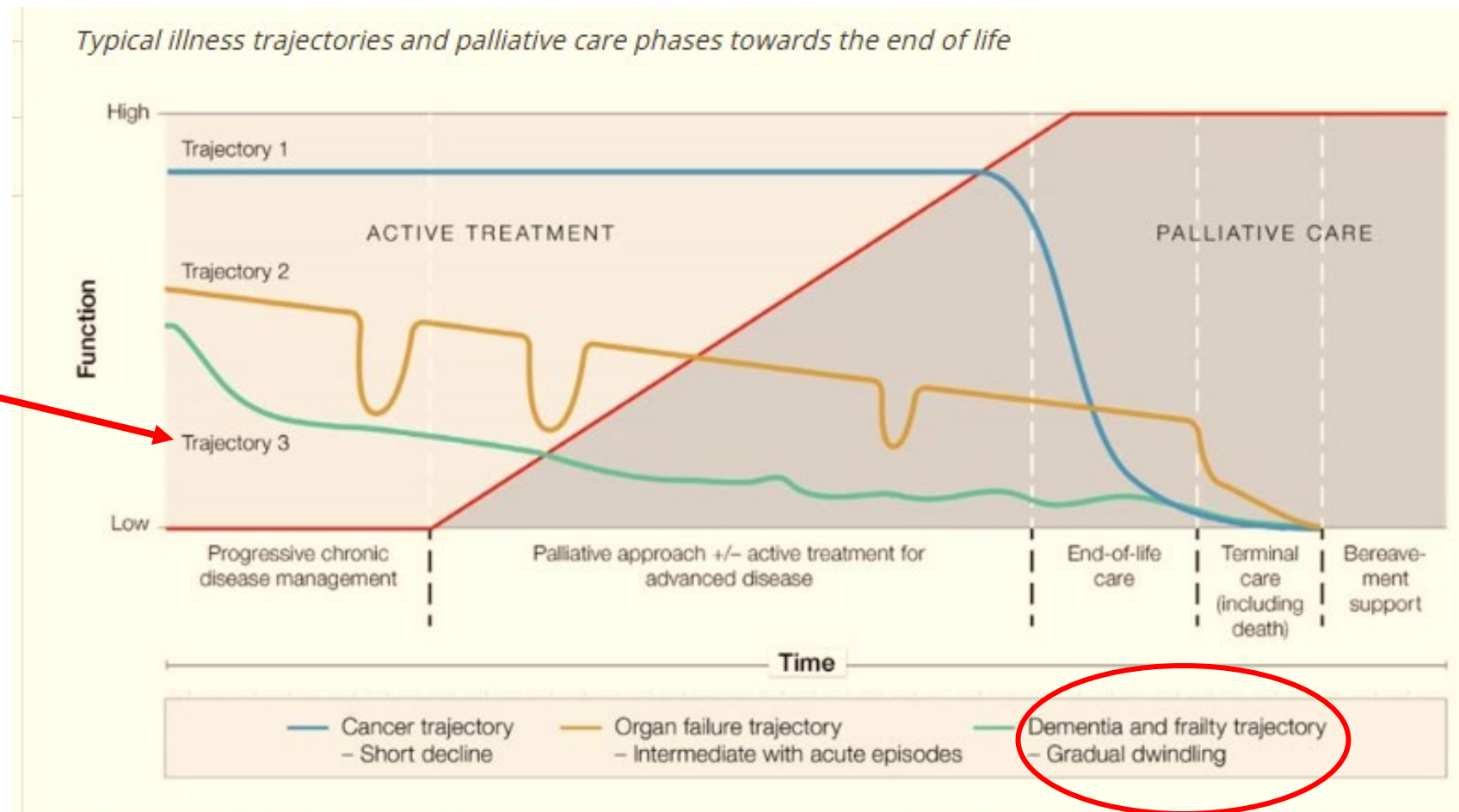
International Research priorities for palliative care of older people



Ref: Van den Block et al 2025, and
Davies et al 2025

Current research: Frailty

- 4 trajectories of decline
- Frailty and dementia require longest time in palliative care
- Acute deterioration and sudden death complicate trajectories



Ref: Cohen-Mansfield et. al., 2018;
Covinsky et. al., 2003

So what can we do?

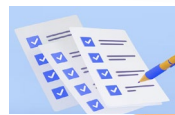
LET'S
RETHINK



Rethink palliative care over the last 12 months of life



Recognise that dementia and frailty are life-limiting conditions



Plan early for advance care needs with the person and family



Assess needs and monitor pain and distress regularly



Offer emotional and psycho-social supports regularly

Collaborate with others, allied health, psychosocial support,

Self-Care: Key to Palliative Dementia Care

Pause and reflect
Develop a plan
Raise your understanding
Coping with death and dying



<https://www.eldac.com.au/Our-Products/Self-care-Room>

Feedback to ELDAC

Brief anonymous survey

QR code



or

<https://tinyurl.com/ELDAC-survey>



Any questions?



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