

# Palliative Care Approach in Community Care OT

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Occupational Therapist, Community Care Program

Canberra Health Services

Wednesday, 22<sup>nd</sup> March 2023

# WELCOME TO COUNTRY

*I wish to acknowledge the traditional custodians of the land we are meeting on, the Ngunnawal people. I wish to acknowledge and respect their continuing culture and connections to the land. I would also like to acknowledge and welcome other Aboriginal and Torres Strait Islander peoples who may be attending today's session.*



# OUTLINE

PEPA Clinical Placement  
Experience

Key messages from PEPA AH  
Workshop

Grief and Loss

OT and Palliative care

Reflections for CCOT

# PEPA Clinical Placement Experience Clare Holland House, Barton ACT 28-30 November 2022

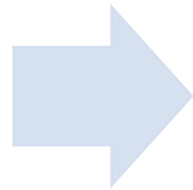


Link: <https://youtu.be/NZrX3FmM4VU>

# PEPA Clinical Placement Experience

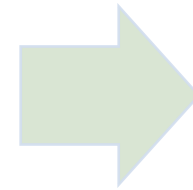
## DAY 1

- > Tour/orientation to CHH with Acting ACT PEPA Manager Rachel Bilton-Simek
- > Triage Nurse (Emma Warren) – home based vs outpatient Pal Care
- > Observe and sit in with Physiotherapist (Alicia Palmer) at outpatient gym



## DAY 2

- > Ward round with registrar, Dr Avard
- > Attended MDT
- > Observed outpatient clinic ran by registrar (Dr Dash)



## DAY 3

- > Buddy up with CHH OT Jenny Thorek
  - > Observed Interdisciplinary team meeting
- > Observed outpatient palliative care clinic with different registrar (new referral to service)
  - > Observed new admission procedure with registrar
- > Debriefed with PEPA manager; resource sharing

# QUIZ TIME!

Palliative care is provided in many places including hospital, hospice, RACF, and in the home.

Palliative Care is just for people with cancer

Palliative care hastens death; it is the beginning of the end

Palliative care means no more treatment

Pain is an inevitable part of dying

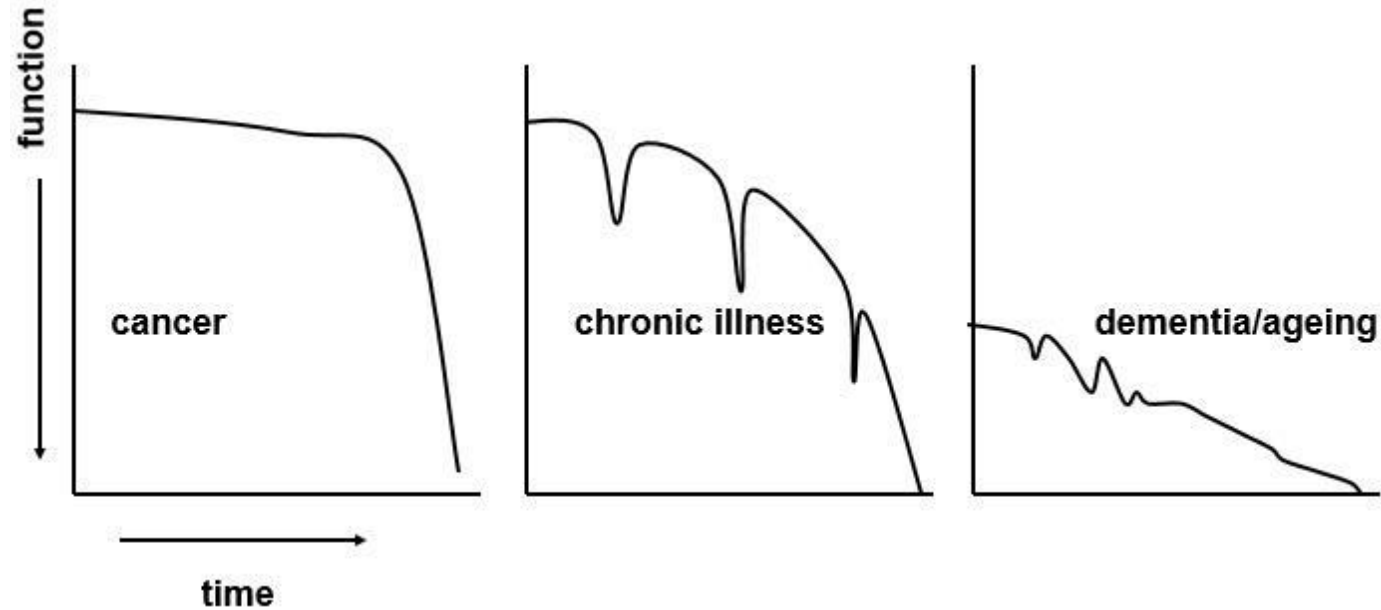
# Key Messages from PEPA AH Workshop

## What is Palliative Care?

*“Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”*

WHO (2020): [Palliative care \(who.int\)](https://www.who.int/palliative)

# Key Messages from PEPA AH Workshop



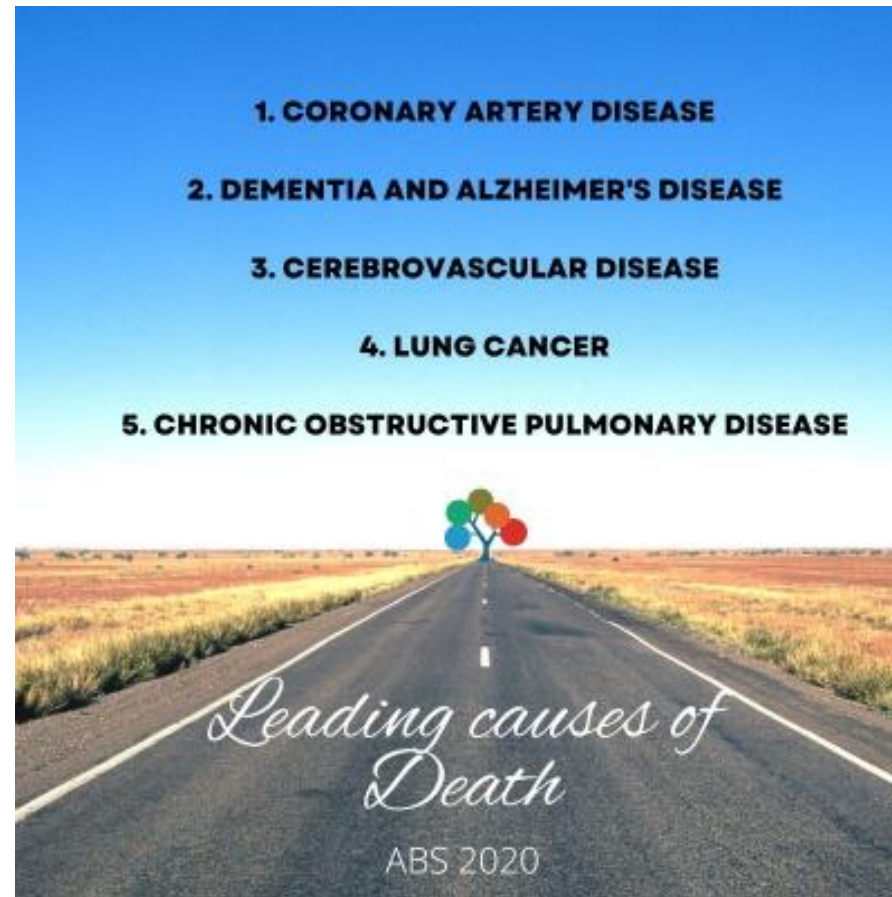
## Illness Trajectories

- Short period of evident decline – mostly cancer
- Long term limitations with intermittent serious episodes – mostly heart and lung failure
- Prolonged dwindling – mostly frailty & dementia

# Key Messages from PEPA AH Workshop



# Key Messages from PEPA AH Workshop



# Key Messages from PEPA AH Workshop

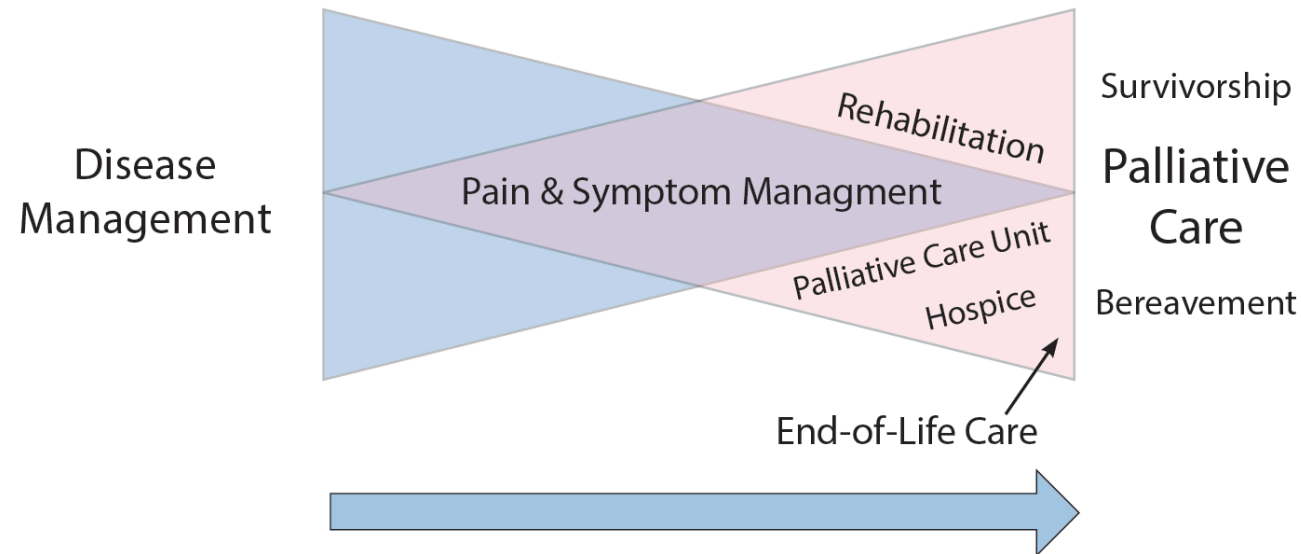
*The phrase 'palliative care is **everyone's business**' is a way of emphasising that people affected by life-limiting illness can be found in all healthcare contexts, and highlights that all members of the healthcare team have a role to play.*

*This is why it is important for all members of the healthcare team to have an understanding of the principles of palliative care and key aspects of the palliative approach to care.\**

Source: Palliative Care Australia. National Palliative Care Standards Canberra: Palliative Care Australia; 2018

# Key Messages from PEPA AH Workshop

Figure 1: The Bow Tie Model of 21<sup>st</sup> century palliative care<sup>2</sup>



Source: [Palliative Care for the Patient with Incurable Cancer or Advanced Disease - Part 1: Approach to Care - Province of British Columbia \(gov.bc.ca\)](https://www.gov.bc.ca/palliative-care/)

# Key Messages from PEPA AH Workshop

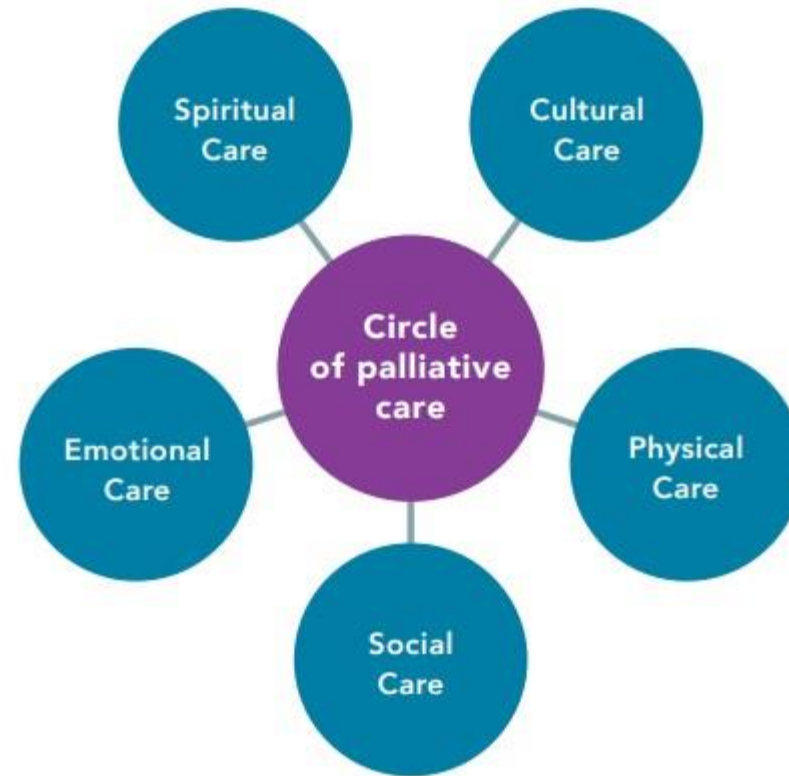
Key concepts of Palliative approach to care:

- Person and family-centred care
- Life-limiting illness
- Quality of life (activity)

# Key Messages from PEPA AH Workshop

## Holistic care

- Physical needs
- Spiritual needs
- Cultural needs
- Social needs
- Emotional needs



# Key Messages from PEPA AH Workshop

## **SYMPTOM MANAGEMENT**

- **Pain**
- **Breathlessness**
- **Fatigue**
- **Sleeping problems**
- **Nutrition and hydration concerns**
- **Confusion and delirium**
- **Suffering**

[Resource: Caresearch Clinical Evidence Summaries](#)



## Reflection Point

*Looking at my current or previous caseload, who among my patients have had a life limiting condition?*

*Who can benefit or could have benefitted from early palliative care?*


# Key Messages from PEPA AH Workshop



**National Advance Care Planning Week**  
20–26 March 2023

**The time is now  
to talk about what  
matters most to you.**

[acpweek.org.au](http://acpweek.org.au) #acpweek23



**ACT Government**

## ACP - Advance Care Planning

ACP is an important conversation about your future health and personal care.

*“If we know your choices for future health care, we can respect them.”*

**Advance Care Planning includes:**

- Thinking about your values, beliefs and health goals
- Choosing someone to speak on your behalf if ever you can't
- Making sure you have a say in your own healthcare
- Talking with your family, doctors and people you have chosen to speak for you

**ACP Quick Facts:**

- ACP is for everyone you can be fit or young
- ACP supports your loved ones during a medical crisis
- ACP helps your healthcare team to plan the best care for you
- ACP is more than an end of life conversation
- Your ACP can change as your life and health changes
- Your ACP choices can be kept in your medical record
- ACP is a conversation that matters
- ACP helps you get the care that is right for you

For more information contact [acp@act.gov.au](mailto:acp@act.gov.au) or (02) 5124 9274.

If you have difficulty reading a standard printed document and would like an alternative format, please phone 13 22 81. If English is not your first language and you need the Translating and Interpreting Service (TIS), please call 13 14 50. For further accessibility information, visit: [www.health.act.gov.au/accessibility](http://www.health.act.gov.au/accessibility)  
[www.health.act.gov.au](http://www.health.act.gov.au) | Phone: 132281  
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# Key Messages from PEPA AH Workshop

## THE SURPRISE QUESTION



# Key Messages from PEPA AH Workshop

## ADVANCE CARE PLANNING

- A voluntary process
- Things to consider:
  - Make sure the right people are involved
  - Ask open-ended questions
  - Clarify and check regularly
  - Ask questions about decision making
  - Reassure the person that their decisions will be respected.
- “Find your pitch”
- 3 elements:
  - EPOA, Statement of choices, Health Direction - [Advance Care Plan \(ACP\) Statement of Choices documents A4 V2.pdf \(act.gov.au\)](#)
- Self referral to CHI is ideal. If referring a client via DHR, create an “Ambulatory Order” for “ADVANCE CARE PLAN”
- Anne Knobel – Advance Care Planning Program Officer  
E: [acp@act.gov.au](mailto:acp@act.gov.au)  
Ph: 51249274

# Key Messages from PEPA AH Workshop



Link: <https://www.youtube.com/watch?v=hsZ287okl8c>



# Palliative Care Services in the ACT

## CHS (NOT HBPC)

- Outpatient specialist pal care MD, nurse and SW
- Rapid access
- Supportive renal care

Refer early via CHI to Primary Palliative Care CNC

## Calvary Care

- Triage nurse (O/P and HBPC)
- PEACE (aged care service)
- Inpatient unit

Referral forms found on website. Best for GP to refer.



## Key Messages: Grief and Loss Workshop

- Presenter: Sonia Fenwick
- Grief Centre Canberra
- [Canberragriefcentre.com.au](http://Canberragriefcentre.com.au)
- Ph: 0409966515

# Key Messages Grief and Loss Workshop

## OUTLINE

- Overview of grief
- Role of attachment theory in loss
- Finite and nonfinite loss, anticipatory grief
- Anticipated loss, sudden/unexpected loss
- Role and experience of hope in the midst of loss
- Supporting grief

# Key Messages Grief and Loss Workshop

***“It can only feel like a loss when that which is taken away is of value/importance to use. Therefore, we only grieve that for which we have an attachment.”***

Why do we attach?

What do we attach to?

# Key Messages Grief and Loss Workshop

## TYPES OF LOSS

- External
- Internal

## WHAT IS GRIEF?

- Normal human response to impending or actual loss/an attachment “wound”
- Gap between “having” and “not having”
- Individual and unique experience

# Key Messages Grief and Loss Workshop

## DEFINITIONS

### ***Grief***

- *The reaction and response to loss, and experience*

### ***Mourning***

- *The process of adaption following a death, the experience of grief continues when mourning has been attended to*

### ***Bereavement***

- *Term to describe grief following a loss by death*

# Key Messages Grief and Loss Workshop

## CONTEXT OF LOSS

- Non-finite loss
- Finite loss
  - Anticipated
  - Sudden/unexpected

## LOSS AS A THREAT

- Amygdala is activated – protective mechanism (fight/flight/freeze); overpowers rational thinking
- Whole body stress response – need to “calm the amygdala” first

# Key Messages Grief and Loss Workshop

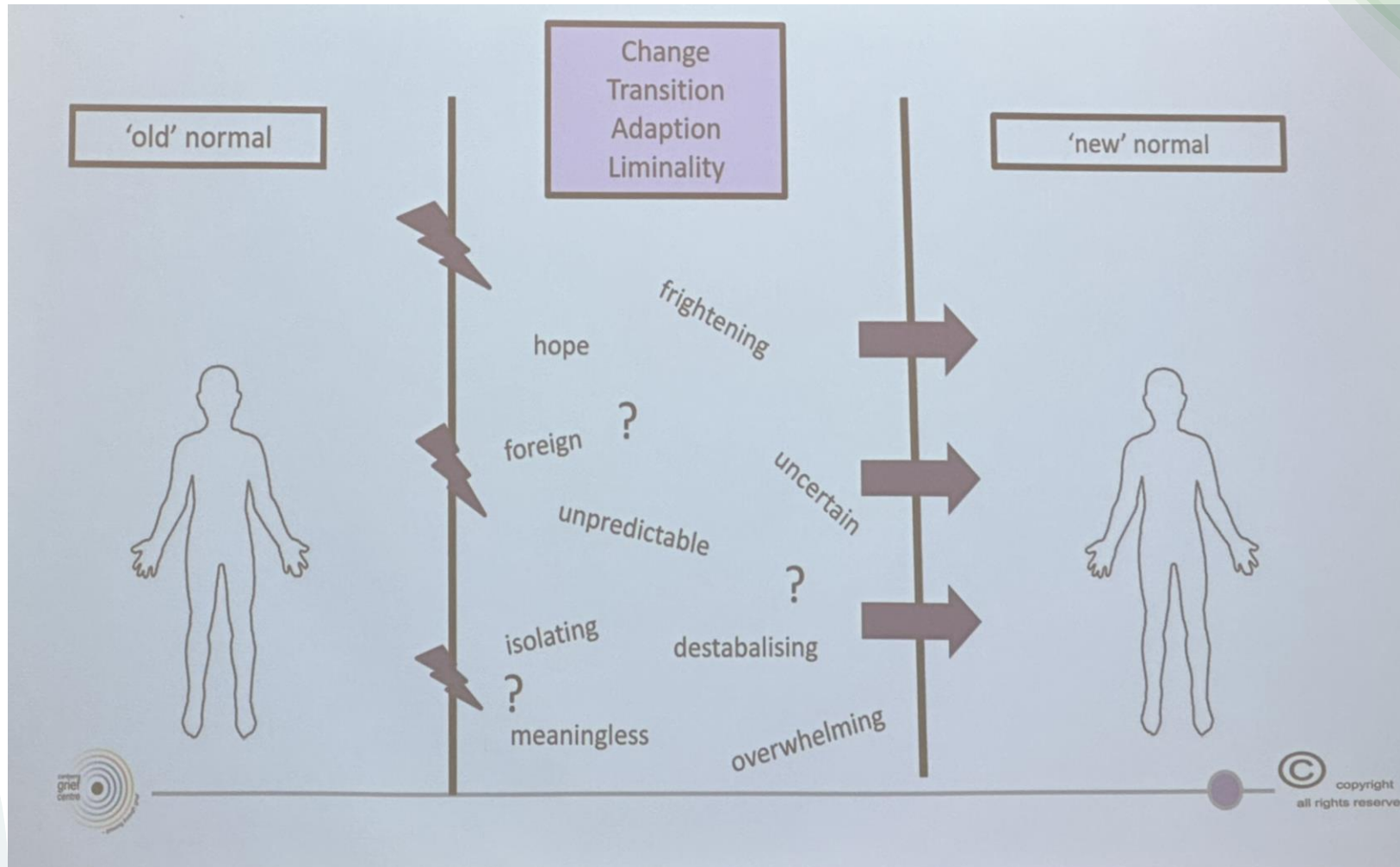
## MODELS & THEORIES

- William Worden's Task Model of Mourning
  - To accept the reality of the loss
  - To experience the pain of the loss
  - To adjust to a world in the wake of the loss
  - To find an enduring connection with the loss in the midst of embarking on a new life
- The Dual Process Model (Strobe and Schut)
- Robert Neimeyer: Grieving as a Meaning Reconstruction

Figure 3.3 Visual representation of the Dual Process Model of Grief<sup>22</sup>



# Key Messages Grief and Loss Workshop



# Key Messages: Grief and Loss Workshop

## INGREDIENTS FOR HEALTHY GRIEVING

- Survive (vs thrive)
- Time for pause
- Dual process
- Worden's tasks
- Hopeful and open to new possibilities

## NEW 'NORMAL'

- Attendance to Worden's tasks
- Self re-defined
- New sense of equilibrium, stability
- Living with loss, new relationship with loss

# Key Messages: Grief and Loss Workshop



Kubler-Ross' 5 Stages of Grief:  
<https://www.ncbi.nlm.nih.gov/books/NBK507885/>

Source:  
<https://youtu.be/4g8KeqjSyqg>



# OT in Palliative Care (OTA Position Statement)

This statement supports and underpins a range of occupational therapy roles in working with people and their circles of support living with life-limiting conditions:

- Optimises **quality of life** and promotes occupational performance over the course of disease progression through participation in meaningful occupations, via comprehensive assessment and intervention
- Promotes adaptation and coping with the challenges associated with **life limiting illness**, by reframing occupational goals and expectations in the face of impending death
- Supports capacity to attend to affairs and the development of legacy
- Assists with management of symptoms such as **fatigue, breathlessness and pain** through **assessment, education, counselling, task redesign and equipment prescription**
- Provides support to the person to remain in/return to the place of care of their choice through assessment, intervention and care co-ordination
- Provides expert assessment of the person's ability to manage safely within their own home. Targeted interventions, such as education and environmental modifications address identified goals. The occupational therapist's **understanding of the illness enables planning for future needs**
- Provides expert liaison within the care team to promote best outcomes
- Provides **support, education and training to informal caregivers to reduce risk of injury, negative experiences and complex bereavement**. The informal caregiver role can be challenging, generating anxiety and stress in an already uncertain situation.

[https://otaus.com.au/publicassets/6d5829df-2503-e911-a2c2-b75c2fd918c5/Occupational%20Therapy%20and%20Palliative%20Care%20\(August%202015\).pdf](https://otaus.com.au/publicassets/6d5829df-2503-e911-a2c2-b75c2fd918c5/Occupational%20Therapy%20and%20Palliative%20Care%20(August%202015).pdf)

# Living actively in the face of impending death: constantly adjusting to bodily decline at EOL

22 March 2023

Research

## Living actively in the face of impending death: constantly adjusting to bodily decline at the end-of-life



Deidre D Morgan <sup>1, 2</sup>, David C Currow <sup>3</sup>, Linda Denehy <sup>2</sup> and Sanchia A Aranda <sup>2, 4</sup>

Correspondence to Dr Deidre Morgan, Occupational Therapy, Flinders University, G.P.O. Box 2100, Adelaide SA 5001, Australia; [deidre.morgan@flinders.edu.au](mailto:deidre.morgan@flinders.edu.au)

### Abstract

**Context** People with advanced cancer experience bodily change resulting in debilitating functional decline. Although inability to participate in everyday activities (occupation) contributes to profound suffering, limited research has examined the relationship between altered bodily experience (embodiment) and functional ability.

**Objectives** The purpose of this study was to better understand the lived experience of functional decline for people with advanced cancer living at home.

**Methods** Indepth interviews were conducted with 10 community dwelling people with advanced cancer about their bodily experiences of functional decline. This study employed a pragmatic qualitative approach, informed by hermeneutic phenomenology.

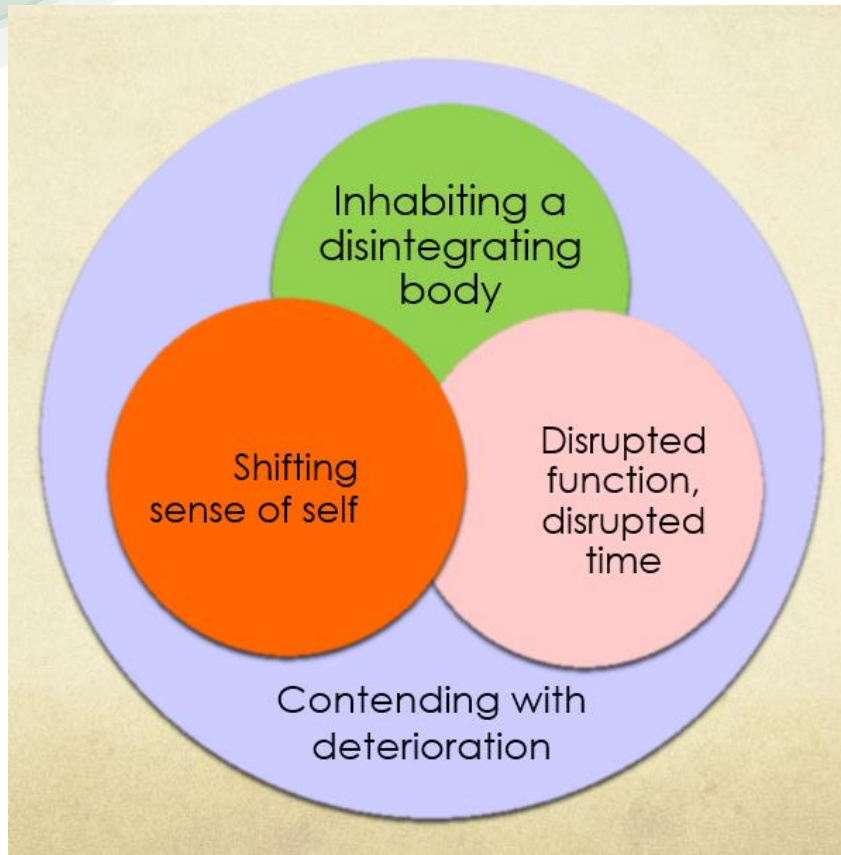
**Results** People described living with rapidly disintegrating bodies and how this affected their ability to participate in everyday activities. Analysis identified themes which were evaluated against conceptual frameworks of 'occupation' and 'embodiment'. People experienced a shifting sense of self. They had to continuously reinterpret changing bodies. Previously automatic movements became disjointed and effortful. Simple actions like standing or getting out of bed required increasing concentration. Relentless bodily breakdown disrupted peoples' relationship with time, hindering their ability, but not their desire, to participate in everyday activities. Contending with this deterioration is the work of adaptation to functional decline at the end-of-life.

**Conclusions** This study highlights the role active participation in everyday activities plays in mediating adjustment to functional decline. These findings challenge us to look beyond palliation of physical symptoms and psychospiritual care as ends in themselves. Symptom control and palliation should be viewed as mechanisms to optimise active participation in essential and valued activities.

<http://dx.doi.org/10.1136/bmjspcare-2014-000744>



# The Occupation of Living at EOL



Morgan et al 2015

1. “How do I inhabit a disintegrating body?” focuses on the altered embodiment/bodily experience that occurs with advanced cancer
2. The next two themes relate to the impact of this altered embodiment on every day activities. OTs in the room would call this everyday occupations. They are “Disrupted time, disrupted function’ and a “Shifting sense of self”
3. The last one explores the work of contending, the ways in which people work to adapt to rapid bodily deterioration & functional decline


# The Occupation of Living at EOL

The occupation of living at the end-of-life. Morgan 2012

Inhabiting a disintegrating body	Disrupted function, disrupted time	A shifting sense of self	Contending with deterioration: The work of occupational adaption
<b>Subtheme</b> <i>Living with my body</i> <i>Constructs</i> -An unfamiliar body -A vulnerable body: something is wrong -A disintegrating body -An intrusive body -An unreliable and unpredictable body	<b>Subtheme</b> <i>Disrupted function</i> <i>Constructs</i> -It just exhausts me -I was able to...but now I just can't	<b>Subtheme</b> <i>An innate desire to do</i> <i>Constructs</i> -The desire for purposeful doing -Less of this and more of that	<b>Subtheme</b> <i>Re-evaluating who I am and the expectations I have of myself and everyday life (Occupational identity)</i> <i>Constructs</i> -Reframing expectations and appraisal of one's abilities and opportunities
	<b>Subtheme</b> <i>Disrupted time</i> <i>Constructs</i> -A paradoxical relationship with time -Altered routines- a different normal	<b>Subtheme</b> <i>A yearning to be</i> <i>Constructs</i> -Being who I am	<b>Subtheme</b> <i>Strategies to manage bodily changes (Occupational competence)</i> <i>Constructs</i> -Thinking about moving before doing -New ways of doing
		<b>Subtheme</b> <i>The shifting relationship between doing and being</i> <i>Constructs</i> -Doing enables me to continue to be -Inability to do hinders my ability to be -Inability to do means everything falls on my family	<b>Subtheme</b> <i>Drawing support from others to manage physical and functional changes</i> <i>Constructs</i> -Receiving assistance is characterised by deep ambivalence -Interactions with health clinicians may hinder or aid the work of contending -How do others manage?


# SPICT4ALL

22 March 2023



THE UNIVERSITY  
of EDINBURGH

**Supportive and Palliative Care  
Indicators Tool (SPICT-4ALL™)**



CARESEARCH®  
palliative care knowledge network

**The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:**

**Does this person have signs of poor or worsening health?**

- Unplanned (emergency) admission(s) to hospital. ☐
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day) ☐
- Needs help from others for care due to increasing physical and/ or mental health problems. ☐
- The person's carer needs more help and support. ☐
- Has lost a noticeable amount of weight over the last few months; or stays underweight. ☐
- Has troublesome symptoms most of the time despite good treatment of their health problems. ☐
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life. ☐

**Does this person have any of these health problems?**

Cancer	Heart or circulation problems	Kidney problems
Less able to manage usual activities and getting worse. <input type="checkbox"/>	Heart failure or has had attacks of chest pain. Short of breath when resting, moving or walking a few steps. <input type="checkbox"/>	Kidneys are failing and general health is getting poorer. <input type="checkbox"/>
Not well enough for cancer treatment or treatment is to help with symptoms. <input type="checkbox"/>	Very poor circulation in the legs; surgery is not possible. <input type="checkbox"/>	Stopping kidney dialysis or choosing supportive care instead of starting dialysis. <input type="checkbox"/>
<b>Dementia/ frailty</b>	<b>Lung problems</b>	<b>Liver problems</b>
Unable to dress, walk or eat without help. <input type="checkbox"/>	Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best. <input type="checkbox"/>	Worsening liver problems in the past year with complications like: <ul style="list-style-type: none"> <li>fluid building up in the belly</li> <li>being confused at times</li> <li>kidneys not working well</li> <li>infections</li> <li>bleeding from the gullet</li> </ul> <input type="checkbox"/>
Eating and drinking less; difficulty with swallowing. <input type="checkbox"/>	Needs to use oxygen for most of the day and night. <input type="checkbox"/>	A liver transplant is not possible. <input type="checkbox"/>
Has lost control of bladder and bowel. <input type="checkbox"/>	Has needed treatment with a breathing machine in the hospital. <input type="checkbox"/>	
Not able to communicate by speaking; not responding much to other people. <input type="checkbox"/>	<b>Other conditions</b>	
Frequent falls; fractured hip. <input type="checkbox"/>	People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well. <input type="checkbox"/>	
Frequent infections; pneumonia. <input type="checkbox"/>	<b>What we can do to help this person and their family.</b>	
<b>Nervous system problems</b> (eg Parkinson's, MS, stroke, motor neurone disease)	Start talking with the person and their family about why making plans for care is important. <input type="checkbox"/>	
Physical and mental health are getting worse. <input type="checkbox"/>	Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care. <input type="checkbox"/>	
More problems with speaking and communicating; swallowing is getting worse. <input type="checkbox"/>	We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage. <input type="checkbox"/>	
Chest infections or pneumonia; breathing problems. <input type="checkbox"/>	We need to plan early if the person might not be able to decide things in the future. <input type="checkbox"/>	
Severe stroke with loss of movement and ongoing disability. <input type="checkbox"/>	We make a record of the care plan and share it with people who need to see it. <input type="checkbox"/>	

For more on palliative care visit [www.caresearch.com.au](http://www.caresearch.com.au)

Please register on the SPICT website ([www.spict.org.uk](http://www.spict.org.uk)) for information and updates.

SPICT-4ALL™, June 2017

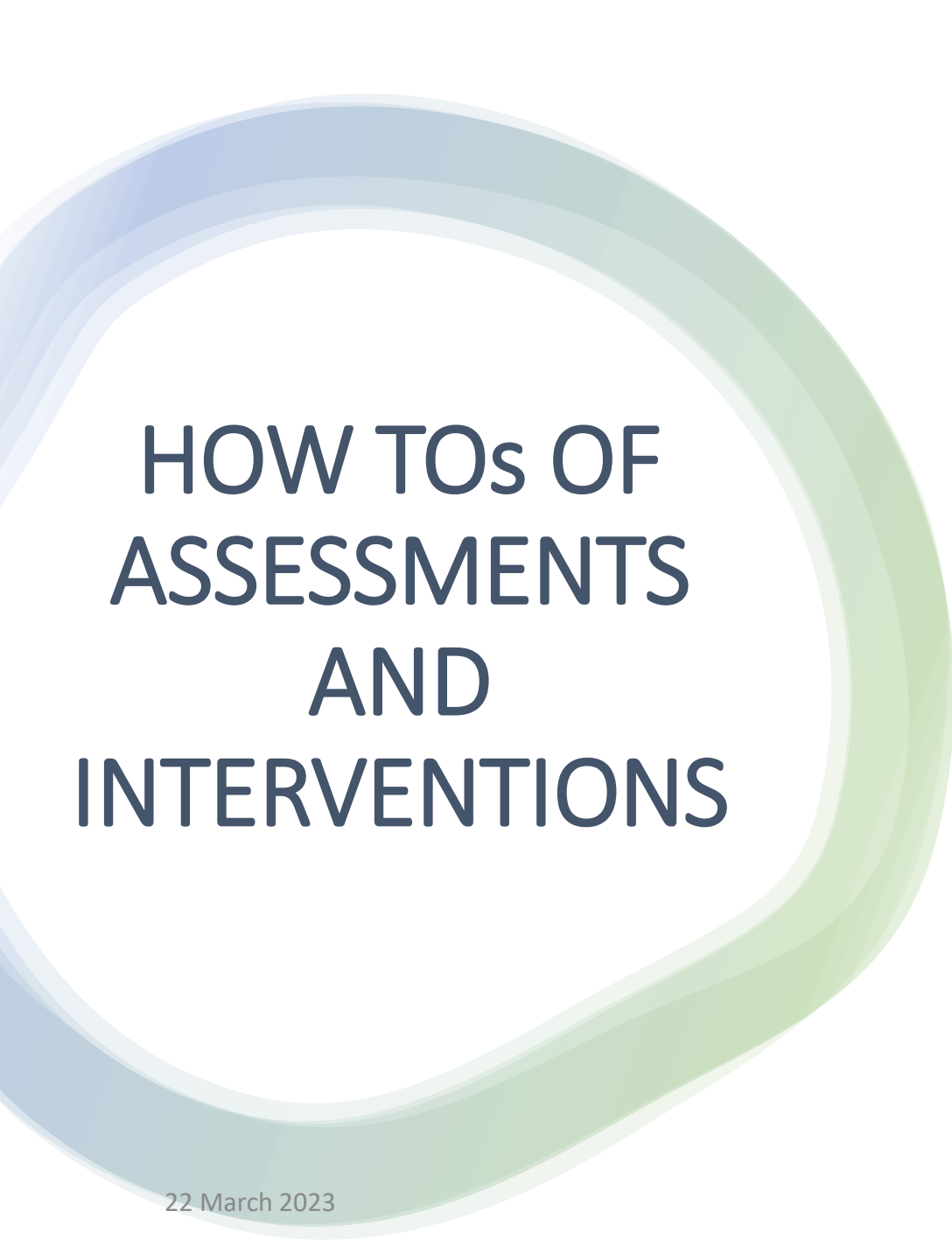
Source: [Caresearch](http://Caresearch)



# Reflection Point

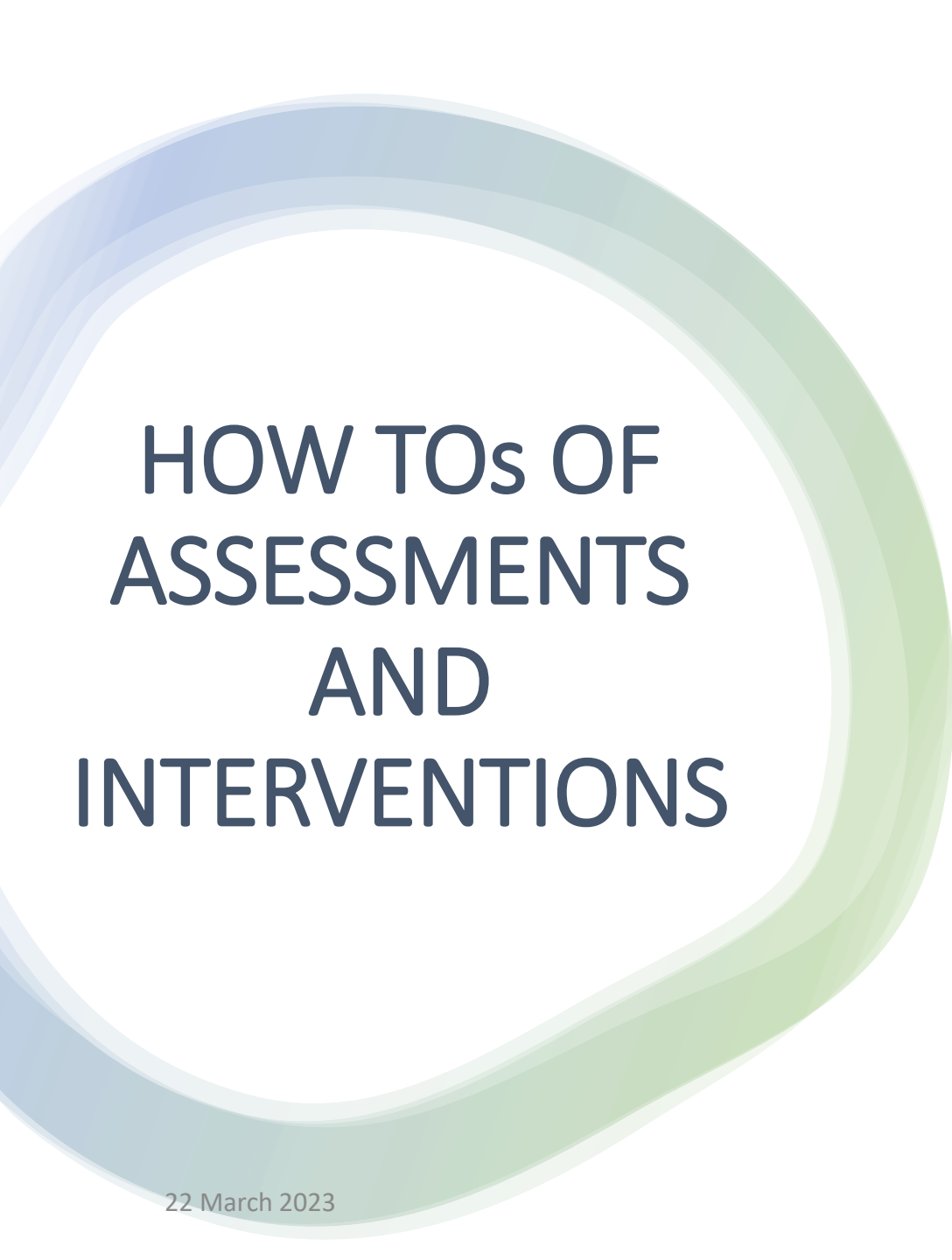
*Looking at my current/previous caseload, how could I have approached my assessment and interventions differently?*

*What are some of the ways that OT can provide a palliative care approach in within Community Care?*



# HOW TOs OF ASSESSMENTS AND INTERVENTIONS

- Client centered priority setting
- Don't assume you know what is important
- Develop own philosophy of care
- Need to be aware of own emotions
- Utilise coping strategies



# HOW TOs OF ASSESSMENTS AND INTERVENTIONS

- Brief interventions
- Relationship building
- Often confrontational even if OT is supportive
- Process vs outcome
- No intervention is “irrelevant” or a waste of time
- Patients don’t ‘refuse’, they decline



# Reflection Point

*Should we review our  
CCOT triage process?  
How can we work  
collaboratively with the  
existing specialist  
palliative care service in  
the ACT?*



# Reflection Point

*What can we do about  
self-care?*

# QUIZ TIME!

Busting Palliative Care Myths - Palliative Care Australia

**FACT:** Palliative care is provided in many places including hospital, hospice, RACF, and in the home.

**MYTH:** Palliative Care is just for people with cancer

**MYTH:** Palliative care hastens death; it is the beginning of the end

**MYTH:** Palliative care means no more treatment

**MYTH:** Pain is an inevitable part of dying

Thank you for  
your time!  
Any questions?

### REQUIEM

Lives are sacred; theirs and ours,  
Trees and creatures, birds and flowers  
Light a candle bright and small;  
Requiem for one and all.

Life is wondrous, so is death;  
Glorious the final breath.  
Let a flower be the prayer,  
Life and death be everywhere.



Credits: <https://www.leunig.com.au/works/recent-cartoons/225-requiem>



# RESOURCES

- [Palliative care assessment tools](#)
  - Supportive and Palliative Care Indicators Tool (SPICT)
  - Symptom Assessment Scale (SAS)
  - Australia Modified Karnofsky Performance Status (AKPS)
  - Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)
- [Gwandalan Palliative Care Education and Training](#)
- [Palliative Care Curriculum for Undergraduates \(PCC4U\)](#)
- [CareSearch \(OT\)](#)
- [Helping You to Live Until You Die Booklet \(OT Australia\)](#)
- [Routine Clinical Assessment of Psycho-Existential Symptoms in Supportive and Palliative care](#)
- [Home - PEPA \(pepaeducation.com\)](#)
- [Shift your Care to a Palliative Approach – YouTube](#)
- [Waiting Room Revolution | A Podcast for those facing serious illness.](#)
- [Occupational Therapy in Oncology and Palliative Care, 2nd Edition | Wiley](#)
- [PEPA Learning Guide for Allied Health Professionals](#)
- [Palliative Care Australia: Discussion Starters](#)
- [End of Life Law for Clinicians](#)
- [ELDAC Self-care resources](#)
- [More Good Days Wellness Wheel](#)
- [Healing After Loss \(Calvary Health Care\)](#)
- [When Someone Dies \(ACT Health\)](#)
- [End of Life Essentials Online Course](#)



# RESOURCES

- [The Gold Standards Framework: Proactive Identification Guidance](#)
- [Eating & Drinking video to help support a relative in palliative care](#)
- [Eating and Drinking at the End of Life \(dementia\)](#)
- [Managing Pain video to help support a relative in palliative care](#)
- [Morgan DD, Currow DC, Denehy L, \*et al.\* Living actively in the face of impending death: constantly adjusting to bodily decline at the end-of-life. \*BMJ Supportive & Palliative Care\* 2017;\*\*7\*\*:179-188.](#)
- [Palliative Care Curriculum for Undergraduates](#) (PCC4U)
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- Helen von Post & Petra Wagman (2019) What is important to patients in palliative care? A scoping review of the patient's perspective, *Scandinavian Journal of Occupational Therapy*, 26:1, 1-8, DOI: [10.1080/11038128.2017.1378715](https://doi.org/10.1080/11038128.2017.1378715)
- [PEPA Padlet - Clinician Toolbox](#)
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- Palliative care myths: [https://palliativecare.org.au/wp-content/uploads/dlm\\_uploads/2016/12/20151109\\_myths\\_updated.pdf](https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2016/12/20151109_myths_updated.pdf)
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# Photo from our CCOT PD Session 22/03/2023

