

Understanding Palliative Care

17 March 2021

CONVERSATIONS: Interpreting & Translating

SMRPCC

Centre for Cultural Diversity in Ageing

POWERED BY All Graduates

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Centre for Cultural Diversity in Ageing

**Our Vision**

All aged care consumers in Australia experience inclusive and accessible care

**Our Purpose**

To build the capacity and capabilities of Australian aged-care providers to deliver services that are welcoming, inclusive and accessible.

**Our Service Areas**

- Inclusive practice training and workshops
- Capacity building to promote cultural inclusion and equity
- Diversity advice and consulting

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Partners in Culturally Appropriate Care (PICAC) program

The Centre for Cultural Diversity in Ageing is funded through the Department of Health, PICAC program.

The Centre forms part of the PICAC Alliance, a national body comprising PICAC funded organisations across Australia.

The Alliance aims to be a voice and discussion conduit into information, training and resources to inform aged and community care services.

PICAC alliance

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Introduction to Palliative Care in Aged Care

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- ▶ 0433414011

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What is Palliative Care?

- ▶ Care provided to an individual diagnosed with a life limiting illness. It includes physical, emotional and spiritual care that is provided to relieve the suffering and enhance the quality of life.

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What is Palliative Care?

- ▶ It is not just "end of life" care. (also known as "terminal care")
- ▶ End of Life care is about the last days or weeks of the persons life.
- ▶ Palliative care can be provided for years.
- ▶ It can be provided even when the individual is receiving active treatment of their condition

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### Palliative Approach to Care

- ▶ Principle of all aged care provided.
- ▶ Recognition that the condition can't be cured but care can be provided.
- ▶ Responsive to the individuals needs – different for every person
- ▶ Might be symptom management, social care/ support, psychological care or spiritual support.



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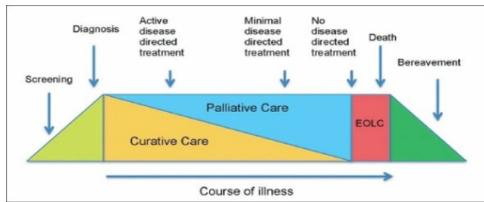
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### Model of care



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### Where is Palliative Care Provided?

- ▶ Palliative care is provided in hospitals, a person's home or in residential services (think aged care, disability services, other supportive residential services)



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Who Provides Palliative Care

- ▶ The largest provider are the family and friends of the individual
- ▶ GPs
- ▶ Residential In\_Reach services (Victoria)
- ▶ Aged care facilities/ residential services
- ▶ Community based palliative care services
- ▶ Hospitals



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Who Provides Palliative Care

- ▶ Community Based – service based in the community employing Drs, nurses, allied health staff who visit the person in their own home
- ▶ Hospitals – palliative care units provide support to manage distressing symptoms and where possible discharge the individual home



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What Do People Die Of

- ▶ Lets look at the main disease trajectories
  - ▶ Cancer
  - ▶ Organ Failure
  - ▶ Frailty/ Dementia



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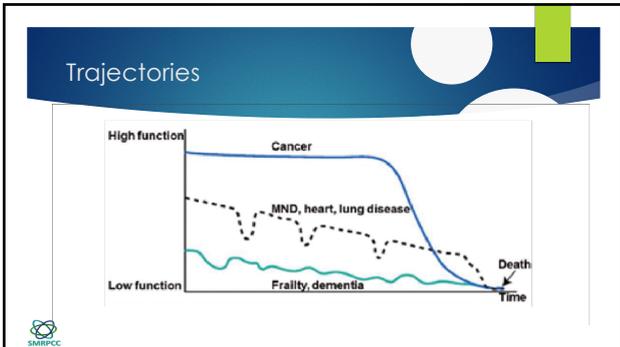
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### Dementia Trajectory

- ▶ Disease that is the biggest cause of death for women in Australia is.... Dementia. It is the second largest cause of death in Australia (behind cardiovascular disease) and is about to overtake it.
- ▶ Lets look at the separate handout

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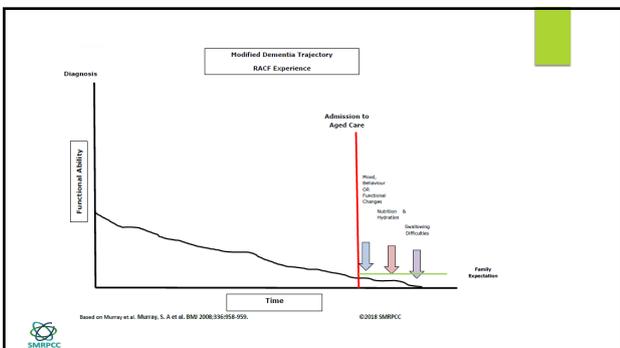
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### When Do We Know That Someone is Going To Die?

- ▶ Person may have a sudden deterioration/ decline – cardiovascular event (heart attack or stroke)
- ▶ No longer responds to usual medications
- ▶ Serious infection (pneumonia, septicæmia)
- ▶ Become very lethargic (sleep most of the day)
- ▶ Refusing food and drinks – dehydrated or losing weight
- ▶ Altered conscious state
- ▶ Discoloration of the extremities (cold, blue or mottled arms/ legs)
- ▶ Over time a change in their functional ability
- ▶ Increase in symptoms – breathlessness, pain, oedema, bowel/ urine problems, delirium/ agitation
- ▶ Evidence of organ failure



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### Symptoms Associated With Dying

- ▶ Pain
- ▶ Dyspnoea/ Shortness of Breath/ Noisy Breathing
- ▶ Restlessness/ Agitation
- ▶ Nausea & Vomiting



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### Pain

Pain

- ▶ An unpleasant sensory experience
- ▶ Every person experiences pain differently
- ▶ Not all people will experience pain when they are dying
- ▶ May experience pain/ discomfort from being in bed and unable to move (think arthritis etc)
- ▶ Severe pain may come from heart failure, cancer, bowel obstruction, urinary retention



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**Pain**

- ▶ Opiates are the drug of choice, usually Morphine, Hydromorphone and Fentanyl
- ▶ Myths of Morphine
  - ▶ People associate Morphine with dying
  - ▶ See handout from Palliative Care Australia
- ▶ Very strong medication but small doses are given and increased as needed (titrating)
- ▶ Side effects – nausea/ vomiting, constipation, drowsiness
- ▶ Morphine does not hasten death if used appropriately. The person is dying from their disease.



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**Shortness of Breath/ Dyspnoea/ Noisy**

Shortness of breath (dyspnoea)

- ▶ Often associated with heart or lung disease (COPD, CCF)
- ▶ Exacerbated by anxiety
- ▶ First line treatment – Morphine (or other opiate), anti anxiety medication
- ▶ "Death Rattles" prior to death – may need medication to dry up secretions



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**Shortness of Breath/ Dyspnoea**

- ▶ Medication
- ▶ Repositioning
- ▶ Use of fans or open windows – hand held fans
- ▶ Cool face cloths
- ▶ Reassurance and staying with the resident



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**Agitation/ Restlessness**

Agitation/ Restlessness

- ▶ Can be caused by low oxygen levels, changes in body chemistry (caused by organ failure), infection (delirium), pain
- ▶ Oxygen may not be effective at this stage
- ▶ Medications (Clonazepam/ Midazolam +/- pain medication)
- ▶ Stay with the person, hold their hand, reassurance. Sometimes the person may be scared.



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**Nausea & Vomiting**

- ▶ Might be a side effect of other medications, might be as a result of a slow/ blocked bowel, infection, pain
- ▶ Administer medication (anti emetic medication such as Maxalon/ Ondansetron)
- ▶ Positioning
- ▶ Mouth care



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**Basic Care Needs**

- ▶ Assessment and management of any symptoms
- ▶ Mouth care and skin care - critical
- ▶ Continence care – bowel and kidneys may slow right down but will still be functioning
- ▶ Food and fluids- whatever the person wants!
- ▶ **MOST IMPORTANT – talk to the person. Hearing is the last sense we lose!**



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**Family Engagement During Residence**

- ▶ Residents or their representatives need to be involved in all aspects of decision making.
- ▶ Families can be complex and interesting
- ▶ Often can be long histories of challenging relationships
- ▶ Some families withhold information from the resident
- ▶ Complex decision making when the person in question "lacks capacity" for decision making
- ▶ Often meetings are held at the last minute..



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**Family Engagement During Residence**

- ▶ What does the resident/ representative know about their condition, what do they want to know and how do they want that information..



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**Case Conferences**

**The Briefing:**

- ▶ The purpose of the briefing is for the Healthcare Professional and the Interpreter to have a shared understanding of the process of the interpreted communication, respective roles and the goal of the discussion with the CaLD client.
- ▶ Terminology and what is to be covered in the session can also be discussed to help the interpreter's preparation.  
(AUSIT Code of Ethics - 7.4 Interpreters and translators request briefing and access to reference material and background information before their work commences)



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Case Conferences

- ▶ Remember.. Not all health professionals are skilled at communication. Some are brilliant, some aren't.
- ▶ Your guidance and support with the approach to communication may be required.
- ▶ General culturally specific information may be needed to ensure open lines of communication are enabled



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Case Conferences

- ▶ Aged care is different to other healthcare settings because we often have long term and established relationships
- ▶ Might be to develop a "Goals of Care" form
- ▶ Might be an Advance Care Directive
- ▶ Might be because the resident is entering the end of life phase
- ▶ Might be to ascertain the residents understanding/ capacity
- ▶ Might be a general care plan review



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Case Conferences

- ▶ Medical decision maker laws, Goals of Care or Advance Care Directives are different in every state/ territory in Australia
- ▶ Its not just about resuscitation!
- ▶ ELDAC (End of Life Directions for Aged Care)- Legal Toolkit
  - ▶ <https://www.eldac.com.au/tabid/4902/Default.aspx>



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Case Conferences

- ▶ Are an opportunity to for health professionals, residents and their representatives to sit down and have a discussion about the residents condition, diagnoses, prognosis and to identify their preferences with regard to end of life decision making
- ▶ It's about "being on the same page". Improving understanding and developing an agreed plan.



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Case Conferences

- ▶ Honest, gentle and compassionate communication is critical
- ▶ Allow time for the resident/ representative to express their emotions (cry, be angry etc)
- ▶ Allow the resident/ representative to ask questions



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Case Conferences

- ▶ Acknowledge the difficulty of this situation
- ▶ Sometimes asking questions such as the following can help
  - ▶ What if the hospital can't fix the problem, what would you like us to do.
  - ▶ If you weren't able to talk to us and tell us what you wanted, who should we talk to. Have you spoken with them and explained what you might want
  - ▶ Specific scenario's - stroke, unable to walk, unable to feed yourself, unable to talk. What is happening for the resident at the moment?
  - ▶ Find out, if possible, who and what is important to the person (physical, emotional, spiritual and cultural needs)
  - ▶ Where would they want care provided (hospital or the aged care home)



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**Case Conferences**

- ▶ Families may be reluctant to accept the "decision maker" role and want the Dr to make decisions.
- ▶ Often will say they want "everything" for their loved one.
  - ▶ NO UNDERSTANDING THAT EVERYTHING MAY NOT BE ON OFFER
  - ▶ What does everything mean to them



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**A Few Suggestions Before the Session Starts**

- ▶ Take every opportunity to "educate" the HPs.
- ▶ If the communication is causing distress to the resident, advise the HP.
- ▶ Acknowledge and respect your own response to the situation



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**You Are a Critical Part of the Team**

- ▶ Remember how important you are as part of the team that is trying to enable the residents voice
- ▶ Remember this is about what the resident wants... not the family and not you.
- ▶ What are your beliefs about death and dying? Does this impact on how you communicate?
- ▶ Use every opportunity to guide the health professionals about cultural differences (they need a lot of guidance sometimes!). Help build the cultural bridge to effective communication



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**You Are a Critical Part of the Team**

- ▶ Debriefing is an opportunity for the interpreter and the Healthcare Professional to give feedback on the interpreted session and to ask for feedback from each other. This is a mutual learning process and contributes to a higher quality of service delivery.



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**Looking After Yourself**

Self care is critical so think about the following

- ▶ Debrief or discuss with family, friends or colleagues. **TALK** about your feelings
- ▶ Eat well, sleep well (limit alcohol, recreational drugs)
- ▶ Exercise – go for walks to clear your head
- ▶ Recognise that some people do not react well to difficult news. Their anger or frustration may be directed at you because they don't know how to respond to their emotions
- ▶ If you are experiencing emotional distress see a counsellor (mental health care plan, Employee Assistance Program etc)
- ▶ Challenge your own belief systems and understand what you believe and why. Don't impose on others what your perception of good care, good death are



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