# Dying in residential aged care – implementing an evidence-based model of palliative care

A/Prof Deborah Parker

UQ/Blue Care
Research & Practice Development Centre

cebparac

# Project members

- **Specialist Palliative Care Services**
  - Peter Jenkin, Southern Adelaide Palliative Care Services (SAPS)
  - Helen Walker, Cancer and Palliative Care Network – Department of Health – WA
  - Liz Reymond, Brisbane South Palliative Care Collaborative (BSPCC)
- **Aged Care Facilities**
  - QLD
    - Blue Care Amaroo
    - Blue Care Iona
    - Queensland Health – Moreton Bay Nursing Unit and Redland Residential Care
  - WA
    - Brightwater – The Oaks and The Cove
  - SA
    - Padman Health Care - Miroma and Skyline
    - Boandik Lodge
- **Internal Evaluator**
  - Desley Hegney, Professor (Honorary) School of Nursing and Midwifery, UQ; National University of Singapore

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Residential Aged Care

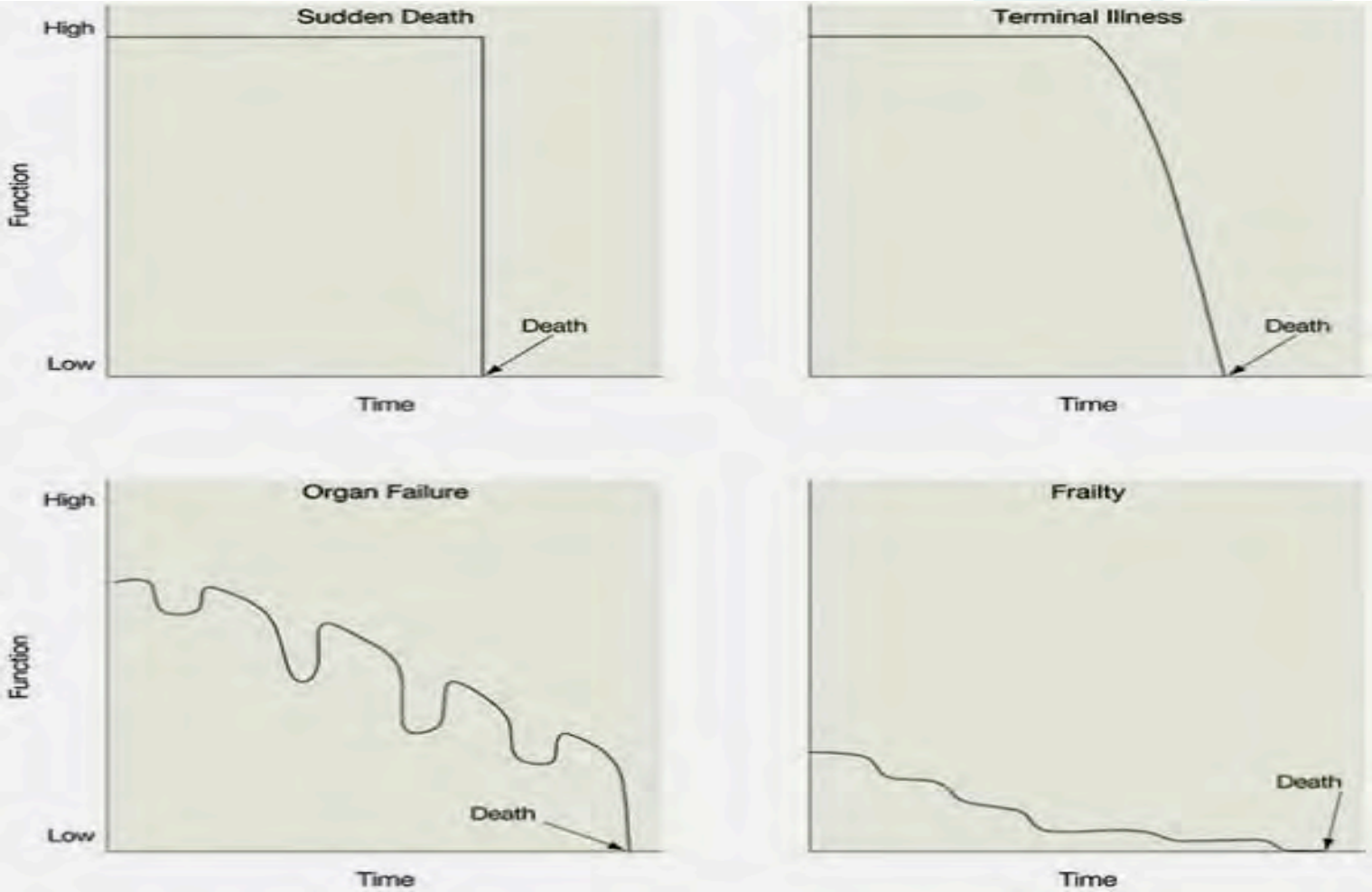
- June 2007 – 170,071 aged care places
- 70% of these are high care
- 88% of permanent separations are from death
- Length of stay for these residents
  - 17% < 3months
  - 19% 3-12 months
  - 45% 1-5 years
  - 19% > 5 years

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Dying trajectories

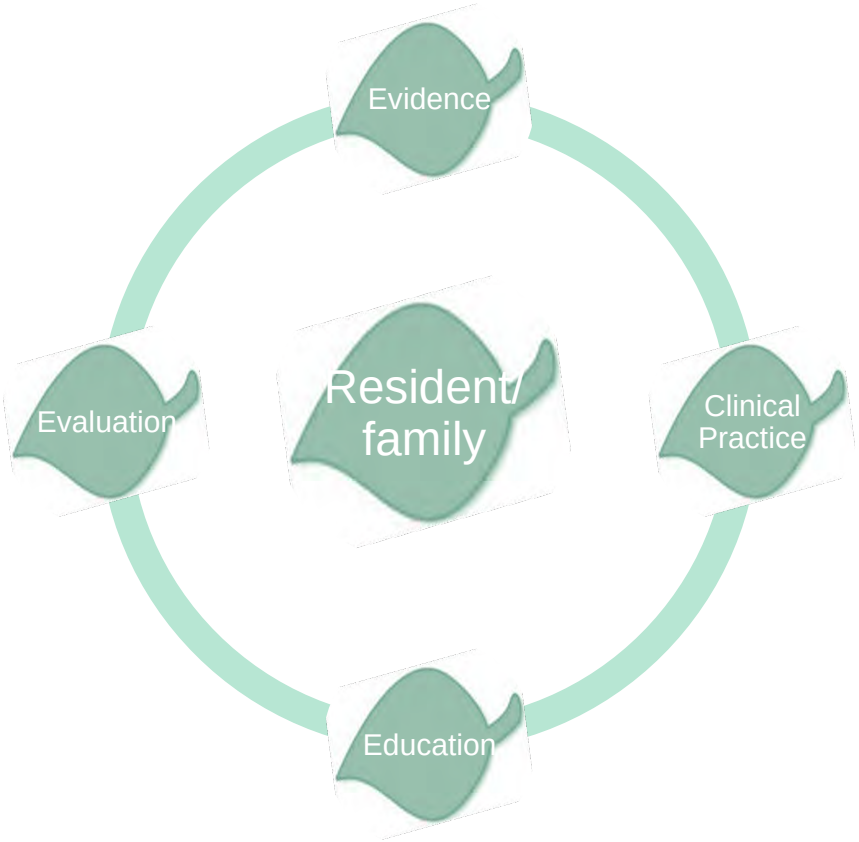
(Lunney JR et al 2002. Profiles of Older Medicare decedents JAGS 50, 1108-1112)




cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Aim of the Project




To implement and evaluate an evidence based model of care to address the palliative care needs of residents in residential aged care

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

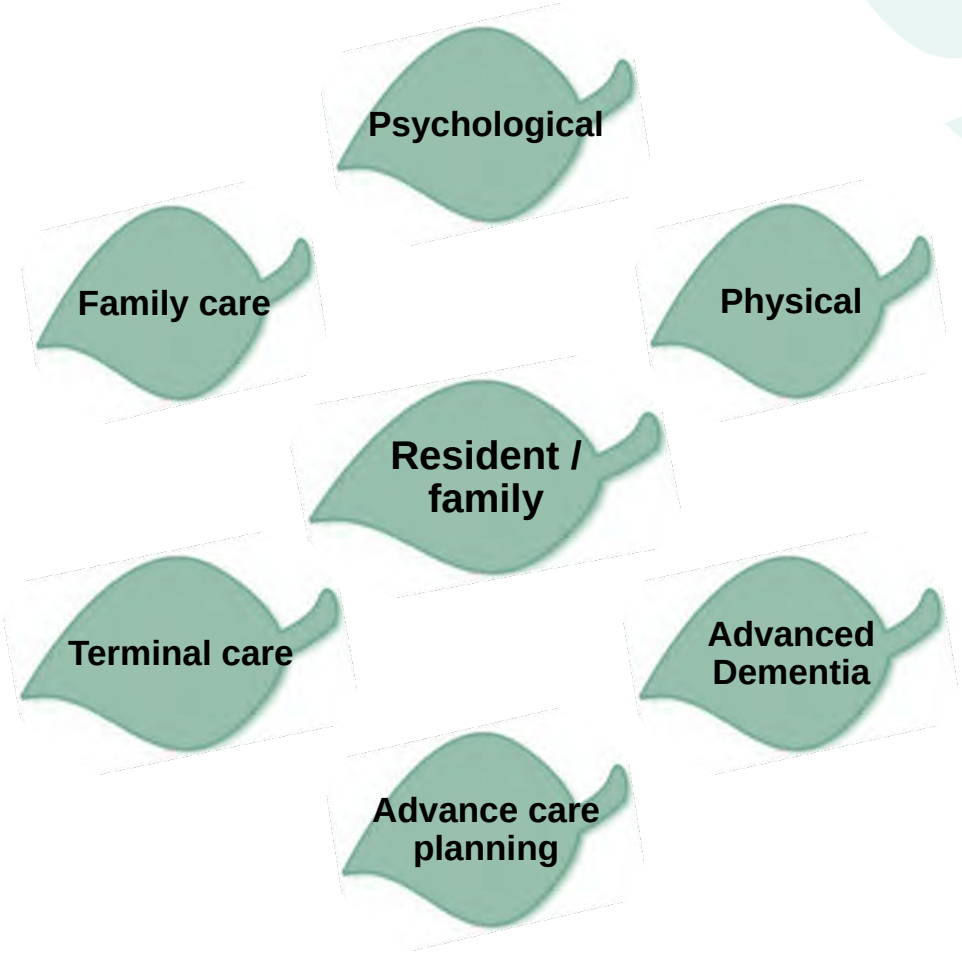
# Evidence

- Guidelines for a Palliative Approach in Residential Aged Care Facilities – NHMRC endorsed edition (APRAC)
- Australian Pain Society Guidelines (APS) and PMG Kit for Aged Care for pain management in residential aged care facilities
- Victorian Government Delirium Guidelines
- NICE Dementia Guidelines

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Six Domains of Clinical Practice




cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Clinical Practice

- Each domain will provide information and resources on the following
  - Guidelines
  - Policies/Standards
  - Assessment tools/Management strategies
  - Educational resources
  - Audit/outcomes

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Residential Aged Care

- ACFI – Funding instrument
  - This is how facilities receive the funding to provide care
  - There are 2 main items that are particularly relevant
    - Pain management which has 3 options depending on how much time and complexity.
      - This can be directed by an RN
    - Palliative care program involving end of life care where ongoing care will involve very intensive clinical nursing and/ or complex pain management in the residential care setting.
      - This must signed off by a CNC/ CNS with 5 years experience in pain or palliative care or a medical practitioner

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Advanced Dementia Domain

| Guideline | Policy/Standard | Assessment/ Management | Education/ Resources | Audit/Outcome |
|---|---|---|---|---|
| **Pain**<br>Assessment using dementia specific pain tools promotes alleviation of pain and discomfort (APRAC - 12)<br><br>The Abbey Pain Scale or PAINAD should be used to assess pain for residents with dementia (PMG - 5)<br><br>The treatment of pain in people with severe dementia should involve both pharmacological and non-pharmacological measures. (NICE). | **ACA Standards**<br>2.4 - Residents receive appropriate clinical care.<br>2.8 - All residents are as free as possible from pain.<br>2.9 - The comfort and dignity of terminally ill residents is maintained.<br><br>**ACFI Question 12**<br>Item 3 Simple pain management<br>OR<br>Item 4a – More complex pain management<br>OR<br>Item 4b –Complex and frequent<br><br>**PCA Standard 3**<br>Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregivers and family | **Assessment**<br>Abbey Pain Scale<br><br>**Management**<br>Pharmacological<br>Non-pharmacological | **Assessment**<br>How to use the Abbey Pain Scale (Pain toolkit )<br><br>**Management**<br>Pharmacological (Pain toolkit, Therapeutic guidelines)<br>Non-pharmacological (Pain toolkit)<br>Caresearch | **Pain**<br>Pain Audit (Pain toolkit) |



The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Advanced Dementia Domain

| Guideline | Policy/Standard | Assessment/ Management | Education/ Resources | Audit/Outcome |
|---|---|---|---|---|
| **Dysphagia**<br>People with dementia should be encouraged to eat and drink by mouth for as long as possible. Nutritional support, including artificial (tube) feeding, should be considered if dysphagia is thought to be a transient phenomenon, but artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity (NICE) | **ACA Standards**<br>2.4 - Residents receive appropriate clinical care.<br>2.9 - The comfort and dignity of terminally ill residents is maintained.<br><br>**ACFI Question 12**<br>Item 6 – Management of special feeding undertaken by an RN, on a one-to- one basis, for people with severe dysphagia, excluding tube feeding. Frequency at least daily<br>Item 17 – Management of ongoing tube feeding<br>**PCA Standard 3**<br>Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregivers and family | **Dysphagia Assessment**<br>Edinburgh Feeding evaluation in Dementia (EFED) Scale<br>Referral for speech/ dietician<br><br>**Management**<br>Nutritional support – modified diet<br>Positioning<br>Oral Care | **Assessment**<br>How to use the EFED Scale<br><br>**Management**<br>JBI review<br>APRAC guideline<br>Dysphagia guidelines<br>Caresearch | Dysphagia audit |

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

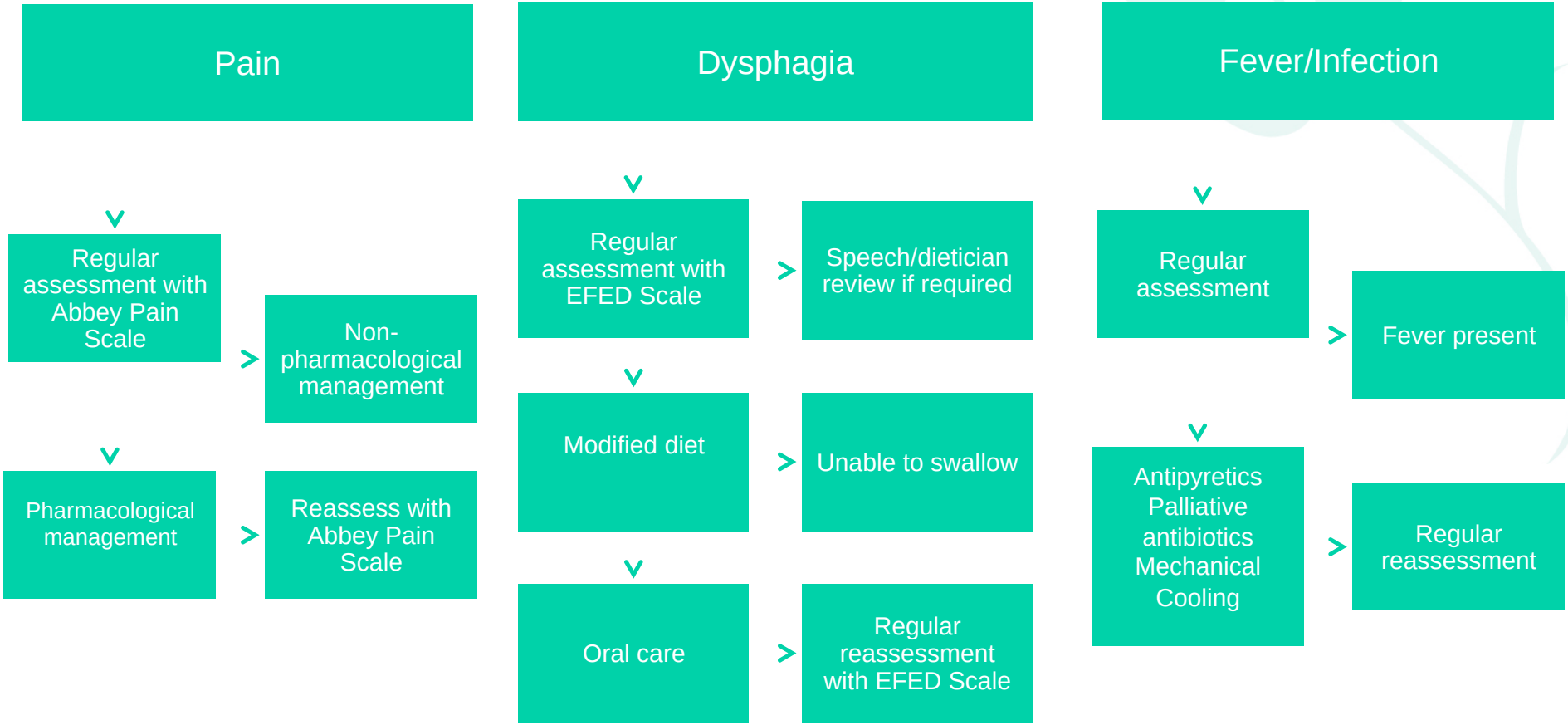
# Advanced Dementia Domain

| Guideline | Policy/Standard | Assessment/ Management | Education/ Resources | Audit/Outcome |
|---|---|---|---|---|
| **Fever/Infection**<br>Aggressive medical treatment of infections is not recommended, although short term antibiotic therapy may ease symptoms and improve QOL (APRAC – 13).<br><br>A clinical assessment should be undertaken. Simple analgesics, antipyretics and mechanical means of cooling the person may suffice. Antibiotics may be considered as a palliative measure in the terminal stages of dementia, but this needs an individual assessment (NICE) | **ACA Standards**<br>2.4 - Residents receive appropriate clinical care.<br>2.9 - The comfort and dignity of terminally ill residents is maintained.<br><br>**PCA Standard 3**<br>Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregivers and family | **Assessment**<br>Temperature as required<br>Assess and document signs of infection/fever<br><br>**Management**<br>Antipyretics<br>Mechanical cooling<br>Palliative use of antibiotics | APRAC guidelines<br>NICE guidelines<br>Caresearch | Audit questions related to whether symptoms assessed and managed appropriately |

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Advanced Dementia Flow chart




cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Domains of Clinical Practice

- Psychological
  - Delirium
  - Depression
  - Psychological distress (includes anxiety)
- Family care
  - Communication
  - Inclusion in care
  - Grief/bereavement

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Domains of Clinical Practice

- Physical
  - Pain
  - Nutrition/hydration
  - Mouth care
- Advanced Care Planning
  - Legal/non legal
  - Case conferences
- Terminal Care
  - End of life pathway

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Education

**Use of existing education resources**

- A Palliative Approach in Residential Aged Care
  - Self directed modules
  - DVD – Suiting the needs
  - GP online training modules
- Pain Management Guidelines and Toolkit
- Brisbane South Palliative Care Collaborative – Residential Aged Care End of Life Care Pathway

**Development of new education resources**

- DVD – How to conduct a palliative care case conference
- A self-directed learning module for Link nurses
- Power points for each clinical domain for use by project and ongoing by facility staff

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Implementing the Model of Care

- The model will be introduced for 10 residents within each RACF (total of 90 residents)
  - New residents admitted to the RACF (total of 45 residents)
  - Existing residents in each RACF (total of 45 residents)

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Entry points in the Model of Care

| | | | | |
|---|---|---|---|---|
| Expected prognosis >3 months | Nurse led care conference which includes ACP | Care plan where required refers to the six domains of care | Reassess every 6 months or earlier if required | If prognosis of < 3 months conduct Palliative care case conference |
| Expected prognosis < 3 months | Palliative care case conference (GP or spec pall care nurse | ACFI claim for palliative care and/or pain management | Palliative care plan (six domains of care) | If prognosis < 1 week commence End of life pathway |
| Expected prognosis < 1 week | Commence on end of life pathway | ACFI claim for palliative care and/or pain management | Reassess if death does not occur within 1 week | Palliative care plan (six domains) |

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Pre Implementation Evaluation

- Chart audit of 10 resident deaths within previous 12 months
- After death survey of 10 bereaved carers

  After Death Interview – Nursing Home Version (Teno et al)
- Provider data
  - Palliative care providers evaluation tool 2.1 (Eager et al 2003) – Assess staff knowledge and confidence in palliative care
  - Palliative care service assessment evaluation tool 3.1 (Eager et al 2003) – Assess RACF capacity to provide palliative care

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Post Implementation Evaluation

- Chart audit of residents
- After death survey of 10 carers of residents in implementation study
  - After Death Interview – Nursing Home Version (Teno et al)
  - Modified Interview for residents who did not die during implementation period
- Reassessment of provider data in each RACF
  - Palliative care providers evaluation tool 2.1 (Eager etal 2003) – Assess staff knowledge and confidence in palliative care
  - Palliative care service assessment evaluation tool 3.1 (Eager etal 2003) – Assess RACF capacity to provide palliative care

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program

# Sustainability/Generalisability

- **Final product is a Toolkit**
  - Key domains from evidence based guidelines
  - Use of current Standards
  - Linked to ACFI (funding instrument)
  - Generic templates
  - Self directed learning module
  - DVD resource

cebparac

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program