What matters to families participating in end of life discussions for relatives living in aged care facilities
Presentation overview

• The PA Toolkit for Residential Aged Care Facilities
• Palliative Care Case Conferences (PCCCs)
• Family involvement in PCCCs
The PA Toolkit

An evidence-based knowledge translation product that uses an integrated framework of care that relies upon three key processes:

1. Advance care planning
2. Palliative care case conferences
3. End of life care pathway
Components of the PA Toolkit

- Workplace Implementation Guide
- Training Support Guide
- Guide to the Pharmacological Management of EOL (Terminal) Symptoms in RAC Residents
- Therapeutic Guidelines for Palliative Care, Version 3
- Resident and Family Resources
- Bereavement Support Booklet for RACF Staff
- 3 Learning Modules
- 3 Self Directed Learning Packages
- 3 DVDs
  - ‘Suiting the Needs’
  - ‘All on the Same Page’
  - ‘Using the RAC EoLCP’
- 2 Educational Flipcharts
  - Introduction to a Palliative Approach
  - Clinical domains
When would a palliative care case conference be indicated?

- Obvious signs of deterioration in a resident who has advanced progressive disease:
  - Multiple readmissions to hospital
  - Recurrent infections
  - Increasing weakness and fatigue
  - Decreasing oral intake / weight loss
  - Increasing care needs
  - Increased family support

- The ‘surprise question’ – Would you be surprised if this resident died within the next six months?\(^6\)
Palliative Care Case Conference:

• **Planned meeting using a structured process** held between a resident (and / or their family) and the health care team

• **Share** health information and identify goals of care

• **Aim for consensus** in relation to treatment and care

• **Document case conference** outcomes and write up care plan
Pre-planning is essential!

- Identify a facilitator/coordinator
- Who should attend?
  - Resident (if capable/competent)
  - Legal decision maker/Family members
  - Aged care team (link nurse, careworker, GP, allied health, clergy, specialist palliative care nurse)
- Invitations
- Collect information
  - Clinical records
  - Medication charts
  - Advance planning documentation
  - Family questionnaire
Planning Checklist

- Track invitations
- Track documentation
- Possible case conference goals

### Form 4: Palliative care case conference: planning checklist

<table>
<thead>
<tr>
<th>Participants: Name and contact details</th>
<th>Invitation sent? (Date)</th>
<th>Accepted (A) or declined (D)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<table>
<thead>
<tr>
<th>Document</th>
<th>Required</th>
<th>Obtained</th>
<th>N/A</th>
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<tbody>
<tr>
<td>Family questionnaire</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff communication sheet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical record (including most recent medication chart)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advance care planning documentation (legal or non-legal)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Other (specify)</td>
<td></td>
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</table>

Goals of case conference:

_________________________________________________________________________________
_________________________________________________________________________________
Family Invitation and Questionnaire

- Invitation provides:
  - Date, time, location
  - Staff contact

- Invitation includes responses to FAQ
  - What is palliative care?
  - Is my family member dying very soon?
  - What is a palliative care case conference?
  - Who from my family should attend?
Family Invitation and Questionnaire cont

- Family are able to think through their questions/ concerns
- Questionnaire asks:
  - What are your main issues/concerns?
  - What questions would you like answered?
  - For a rating of distress

2. How upset / worried are you about these concerns?
   (Place a cross on the line)

   1
   ________________________________
   Not at all

   10
   As worried as I could possibly be
Palliative Care Case Conference: Conducting the Meeting

• Introductions

• What does the resident/family already know?

• Review the family questionnaire

• Review current status, prognosis and treatment options

• Review advance care plan
Palliative Care Case Conference: After the Meeting

- Document key issues and actions using the Palliative Care Case Conference Summary Sheet
- Amend the Care Plan to reflect goals and actions
- Ensure there is review dates and people assigned
- Order or cease medication as required
- Ensure the resident and family have no other issues
- Provide a copy of the summary to the family and GP
### Form 5: Palliative care case conference summary

#### Name of Resident

#### Date of Birth

#### Purpose of Case Conference

#### Participants:
- Resident in attendance?  
  - Yes  
  - No

#### Health Professional

<table>
<thead>
<tr>
<th>Name</th>
<th>Discipline/Position</th>
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<tbody>
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<td></td>
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</table>

#### Family Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship</th>
</tr>
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<tbody>
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<td></td>
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</table>
Family Palliative Care Case Conference Study

32 dyads (resident and family) where the following information was available:

- Family Questionnaire prior to attending the PCCC
- Palliative Care Case Conference Summary Sheet
- Follow up phone interviews (n=29)
Family Palliative Care Case Conference Study

Data analysis

-Attendees at the PCCCs
-Thematic analysis of verbatim texts of the Family Questionnaire
-Text from Palliative Care Case Conference Summary Sheets matched to Family Questionnaire themes
-Thematic analysis of phone interviews with family
## Attendance - Staff

<table>
<thead>
<tr>
<th>Who attended the PCCC?</th>
<th>N</th>
<th>(%)</th>
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<tbody>
<tr>
<td>General Practitioner</td>
<td>22</td>
<td>(68.8)</td>
</tr>
<tr>
<td>Specialist Palliative Care Nurse</td>
<td>22</td>
<td>(68.8)</td>
</tr>
<tr>
<td>RACF nursing staff</td>
<td>32</td>
<td>(100.0)</td>
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<tr>
<td>Allied health</td>
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<td>(6.3)</td>
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</table>
Attendance – Family/Resident

- Six residents (18%)
- One family member – 34.4%
- Two family members – 40.6%
- Various combinations of family members (spouse, daughters and grand daughters common)
<table>
<thead>
<tr>
<th>Issue identified</th>
<th>N</th>
<th>(%)</th>
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<tr>
<td>Physical and medical needs</td>
<td>22</td>
<td>(68.8)</td>
</tr>
<tr>
<td>Pain/ comfort</td>
<td>18</td>
<td>(56.3)</td>
</tr>
<tr>
<td>End of life/ care planning</td>
<td>17</td>
<td>(53.1)</td>
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<tr>
<td>Nutrition and hydration</td>
<td>13</td>
<td>(40.6)</td>
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<tr>
<td>Care processes</td>
<td>12</td>
<td>(37.5)</td>
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<tr>
<td>Psychological needs</td>
<td>11</td>
<td>(34.4)</td>
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<tr>
<td>Family role</td>
<td>8</td>
<td>(25.0)</td>
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<tr>
<td>Quality of life</td>
<td>7</td>
<td>(21.9)</td>
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<tr>
<td>Pastoral care</td>
<td>2</td>
<td>(6.3)</td>
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</table>
Physical and medical needs

- She is continually having TIA's - mini seizure? Diabetes levels spike for no apparent reasons. Skin irritations that she will pick at until sore/bleeding.
- As she has been severely anaemic over the past two years and required blood transfusions, does she have regular blood tests to keep a check on this.
- What were the results of the gastroscopy? What other health concerns does he have?
- Lack of use of her left arm in recent weeks.
- Personal hygiene needs to be considered more.
End of Life / Care Planning

• I would prefer her not to go to hospital if this can be avoided...What are the next stages in the decline and how long are these likely to last? What happens when she can't eat?

• What is actually considered palliative? Are antibiotics palliative? I hope so as I've seen them help mum's symptoms.

• Will his pacemaker prolong his life beyond its natural time?... What drugs are likely to be used? Standard drugs used in palliative care for dementia? ...Will he be kept very sedated? Is this best for him? Would he have better care in a dedicated hospice?

• Expectations - what is normal, what will happen in the future (eg facing realities)... What does the future hold?

• What is available to me in grief counselling?
Nutrition and Hydration

• What happens when she can't eat?
• Adequate fluid intake
• [Resident is] very thin - seems to be starving...what is best food at this time?
• Meals - mum is quite often losing interest in eating (morning tea and lunches). Not sure about dinner.
• Also knowing that he is not eating is a concern but I understand that this cannot be forced upon him.
Care Processes

• I want mum to be...well cared for, treated with dignity....
• He needs gentle reminding of how a to carry out simple instructions.
• Timing of medication, timing for change of pads...
• Are enough staff available for optimal care? Will the staff's English be adequate?...Will particular carers/nurses be in charge or random staff?
• At times more gentle with her when turning her over.
Psychological Needs

- I'd like to be summoned to give support and reassurance if she became frightened and tormented in her confusion.
- Emotional condition of her, particularly re crying and possible depressive state of mind...are there any antidepressant medications which would benefit her?
- She keeps saying that she wishes just to not wake up.
- I am distressed not being able to know what awareness he has of what is happening to him...is it possible to assess his awareness of what is happening to him?
- Depression, anxiety
- Panic attacks
Family Role

• What am I to do to help her? How do I involve other family members?

• Can't continue to participate hands on in her care as she progresses to the palliative stage.

• How are we as family involved to ensure Mums wishes/wants are met?
Quality of Life

- I hope she will be able to have some stimulation for as long as possible and not be left in bed...
- That there is no quality of life for him.
- Social contact...Does Mum qualify for any social visits?
- Meeting her simple pleasures (music and chocolate)
# Issues documented against themes raised

<table>
<thead>
<tr>
<th>Theme</th>
<th>N</th>
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<tr>
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<td>(86.4)</td>
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<tr>
<td>Pain/ comfort</td>
<td>17/18</td>
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<td>Nutrition and hydration</td>
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<td>(92.3)</td>
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<tr>
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<td>Psychological needs</td>
<td>7/11</td>
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<td>(37.5)</td>
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<tr>
<td>Quality of life</td>
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<td>(71.4)</td>
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<td>Pastoral care</td>
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<td>(100.0)</td>
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Value of the family questionnaire

- Appreciate the open communication
- Very good idea – because if you go to the doctor you like to think about beforehand and jot down things because sometimes you forget.
- It allows you to get your thoughts together.
- An opportunity to write our thoughts and manage a plan. And an opportunity to cover a broad range of care questions.
- Family got together and looked at what family wanted to get out of it.
Value of Palliative Care Case Conference

- All at the same level and understanding what the families want.
- Good to know what staff would do in caring for Dad.
- Everybody there, nursing staff, GP – discussed issues and answers given, left feeling good and informed for once.
- Enlightened on what was occurring and what was to occur and how to attend to these needs.
- Discussed mum’s wishes – no resuscitation or hospital transfer. They’d never asked about this before and it’s very important.
- Getting to know who was caring for mother.
- Confidence he would receive good personal medical supervision and care.
Conclusion

- Palliative care case conferences are valued by family members
- Use of the family questionnaire provided the opportunity for family to express very sensitive and personal issues that may not have been identified previously
- Most family issues raised were addressed using the structured processes involved in the case conference
- There is a great value in involving family in the care planning needs of residents at the end of life to ensure we know What Matters
Palliative care case conferences in long-term care: views of family members

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