‘Let Me Decide’
Advance Care Planning Programme

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Irish public’s awareness of end-of-life terms

<table>
<thead>
<tr>
<th>Terminology</th>
<th>Know a great deal (%)</th>
<th>Know a fair amount (%)</th>
<th>Know just a little (%)</th>
<th>Heard of but know nothing (%)</th>
<th>Never heard of (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance directive</td>
<td>1</td>
<td>2</td>
<td>13</td>
<td>13</td>
<td>71</td>
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<tr>
<td>Living Will</td>
<td>10</td>
<td>15</td>
<td>28</td>
<td>15</td>
<td>31</td>
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<tr>
<td>DNR order</td>
<td>13</td>
<td>16</td>
<td>32</td>
<td>13</td>
<td>25</td>
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<tr>
<td>CPR</td>
<td>17</td>
<td>34</td>
<td>49</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Post-mortem</td>
<td>23</td>
<td>33</td>
<td>33</td>
<td>6</td>
<td>4</td>
</tr>
</tbody>
</table>

‘Let Me Decide’ Programme

The systematic implementation of both
Advance Care Planning using the
‘Let Me Decide’ Advance Care Directive
and
a General Palliative Care Educational
Programme
in long-term care institutions in Ireland
Let Me Decide

• Originally developed by Prof Willie Molloy in 1988 in Canada
• Researched in community and long term care settings in Canada and elsewhere
• Had to be “Irishified”
  • Irish edition of ‘Let Me Decide’ book
  • Irish versions of the ACD forms
  • Different legislation here in relation to both
    – ACDs
    – Medical decision-making for people lacking capacity
Who legally makes decisions for someone in a coma?

If you were in a coma and in the final stages of a terminal illness, and you had not expressed any wishes as to how you would like to be treated, who would you most like to make decisions about starting or stopping treatments such as life support? (n=667)
Who do Irish Healthcare professionals want to decide for them? 2012

Only 26% of Irish HCPs correct as to who legally decides (n=474)
Of the doctors, only 35% of correct (n=165)
Let Me Decide - ACD training

• Introduction to Advance Care Directives
• Legal Issues
• Ethical Issues
• Practical Issues
• Measuring Capacity
• Completing an ACD
Why do Advance Care Planning?

- Mr Murphy is an 84 year old man
- He moved to a nursing home a month ago.
- He has Alzheimer’s disease for 7 years.
- He doesn’t recognise his children but smiles at his wife.
- He needs help getting in and out of bed and walks with help.
- He has urinary incontinence and occasional faecal incontinence
- He is vomiting bright red blood and his blood pressure is low (BP 80/40). He is seriously unwell.
- His family are not available
If this was your patient

Percentage choosing this level of care:

- Palliative
- Limited
- Surgical
- Intensive

Patient

- Limited has the highest percentage.
If this was your Father
If this was **your self**

![Bar chart showing percentage choosing different levels of care](image-url)

- **Palliative**: Highest percentage
- **Limited**: Moderate percentage
- **Surgical** and **Intensive**: Lowest percentages
Why do Advance Care Planning?

• More control over your future care if ever incapable.
• Promotes respect for patient’s wishes
  – 90% compliance with pts wishes in large US study (Teno)
• Evidence it improves end of life care*
• Reduces Family stress, anxiety & depression*
• Easier end of life decision making

*Detering et al. BMJ 2010;340:c1345
Why do Advance Care Planning?

• Older people want to be consulted themselves
  – Holland: 70% (VanMil, Med Dec Making 1997)
    94% (Cotter P., Age and Aging 2009)

• But...
Other reasons to do Advance Care Planning....

• Legislative / Funding reasons:
  – US: Obliged to ask if there’s an ACD and promote

• HCPs think they are a good idea: Our Survey
  – 91% HCPs felt ACDs a good idea,
  – 75% would recommend people to complete one

• Reduces transfer of dying patients to hospital
  – By 22.7% (Australia: Detering et al BMJ, 2010)
  – From 15% to 8% (UK: Hockley et al Pall Med 2010)
    • ACP and LCP
Older People in LTC

65-69 years
Older People in LTC

70-74 years
Older People in LTC

75-79 years
Older People in LTC

85-89 years
Older People in LTC

90-94 years
Older People in LTC

≥ 95 years
≥ 95 years
If 25% of all deaths are in LTC......
then highly important to empower LTC staff to provide good palliative care
Palliative care needs in long term care

Evidence of unmet palliative care needs of residents in long-term care

Evidence of unmet palliative care educational needs of staff in long-term care
Satisfaction with training in end-of-life care by occupation

Adequate Training
Neutral
Inadequate Training

Percentage

Doctor
Nurse
AHP
Student
Baseline Staff Questionnaire

• 80* completed surveys, 98% female
• Mean age 45 years with mean experience of 20 years
• Only 34 of 80 (43%) had any PC training
  – 37 didn’t answer the question
  – So potentially 58% had no PC training
• Only 4 had experience of working in Specialist Palliative care (3 for 6 mnths, 1 for 1 yr)
Baseline Staff Questionnaire

• Discussing EOL issues:
  – 43% felt unconfident (30-80%)
  – 41% felt confident (20-67%)

• Dealing with bereaved families:
  – 31% unconfident (17-43%)
  – 47% confident (36-67%)

• Setting up a syringe driver
  – 37% unconfident (20-100%)
  – 48% confident (0-61%)
Let Me Decide – Palliative Care Education

• General palliative care education
• Aimed at LTC staff
  – First 3 sessions for nurses & Healthcare assistants
  – Last 3 sessions for nurses
• Five core topics
  – Informed by Staff Learning Needs Questionnaire
    (to build on knowledge & experience of staff)
  – Informed also by the Proposed Palliative Care Competency Framework
Let Me Decide – Palliative Care
Education Topics

1. Principles of Palliative Care
2. Communication at the End-of-Life *
3. Loss, Grief & Bereavement **
4. Optimising Comfort – Symptom Assessment and Management (Double session) ***
5. Advance Care Directives, Care Planning & Ethical Issues **
Let Me Decide – Progress

All 3 Pilot Study homes have:

• Agreed policies & procedures for using ‘Let Me Decide’
• Completed ‘Let Me Decide’ and Palliative Care training for staff
• Have started Advance Care Planning with residents using ‘Let Me Decide’
## Progress in 3 Pilot Study Homes

<table>
<thead>
<tr>
<th>Nursing Home</th>
<th>ACDs/EOL Care Plans completed (%)</th>
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<tbody>
<tr>
<td>1. 112 Beds</td>
<td>N = 65/112 (58%)</td>
</tr>
<tr>
<td>2. 92 Beds</td>
<td>N = 64/92 (69%)</td>
</tr>
<tr>
<td>3. 72 Beds</td>
<td>N = 29/72 (40%)</td>
</tr>
<tr>
<td>Overall</td>
<td>N = 158/276 (57%)</td>
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Distress ......for who?

Only 8% of older Irish in-patients found discussing CPR distressing .....but most of them still wanted to discuss it

Challenges Encountered/Solutions

• Difficulty for homes in releasing staff for training (both ACP and Palliative Care components)
  *Online learning for staff will address this*

• Non-management staff who received LMD training are NOT taking ownership of process
  *Live ‘Demos’ have commenced for the benefit of these staff*

• High % of Residents with some level of cognitive impairment – Education step and Capacity assessment step are very time-consuming
  *Refinement of Educational Aids & Capacity Assessment Tool;*
Challenges Encountered/Solutions

• Staff have little spare time to fit in discussions about end-of-life care with residents

• Need to choose the right time to initiate such discussions with residents due to the sensitivity of the topic

• Logistical difficulties where several family members want to be involved in discussions about EOL care for their incapacitated relative

Advance Care Planning Facilitator
Outcome Measures

Primary

To determine the program's effect on

• how a person dies

  – *Quality of Dying and Death (QODD) questionnaire* (last 7 day version) administered to relatives of deceased residents

  – Chart review
Outcome Measures

Secondary:

– Feasibility of implementing both programmes
– Study participation rate, compliance with AC Directives/AC Plans
– Mortality rates
– Place of death, transfers to hospital
– Symptom control in the last week
– Healthcare utilisation and costs
– Staff confidence in providing quality end-of-life care
Baseline Data

• Suggests high satisfaction with care received
  – Some really good initiatives (easily copied)
• Low level of advance care planning
  – Usually left until person is dying
• Of those who died in LTC
  – 8-11% were transferred in last 3/12,
    • Of these 56% died within 2/52 of return to LTC
• 6-22% died in hospital
  – Local study suggests 14-37% of transfers inappropriate or avoidable
  – Potentially burdensome or unwanted ….. plan ahead!
Thank you