Palliative Care in Paediatric Neurodisability

Dr Joanne Balfe
Consultant Paediatrician
The Children’s Sunshine Home
Paediatric Neuro-disability

- Assessment and management of children with complex neuro-developmental disorders including severe cerebral palsy and intellectual disability with co-morbidities
## Prevalence of Disability

<table>
<thead>
<tr>
<th>Disability</th>
<th>Prevalence (per 1000 children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral Palsy</td>
<td>3</td>
</tr>
<tr>
<td>Severe learning disability</td>
<td>3</td>
</tr>
<tr>
<td>Autism</td>
<td>~10</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>0.3</td>
</tr>
<tr>
<td>Metabolic Disorders</td>
<td>1</td>
</tr>
</tbody>
</table>
Prevalence of Life-limiting Conditions

• 14.5/10,000
• Approximately 1600 children with life-limiting conditions in Ireland
• ACT/RCPCH recommend ~50% will have active palliative care needs
Paediatric Mortality 2009

Total deaths: 363

Paediatric Mortality Register
Annual Report 2011
Causes of Death

- Neoplasms: 7%
- Respiratory Diseases: 7%
- Perinatal Period: 27%
- Infectious & Parasitic Diseases: 2%
- Congenital Malformations: 26%
- SIDS: 8%
- External Causes: 12%
- Others: 11%

Paediatric Mortality Register
Annual Report 2011
<table>
<thead>
<tr>
<th>Location of Death</th>
<th>Total No of Deaths</th>
<th>Deaths from all life-limiting Conditions</th>
<th>Deaths from Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>283</td>
<td>216</td>
<td>13</td>
</tr>
<tr>
<td>Home</td>
<td>66</td>
<td>40</td>
<td>26</td>
</tr>
<tr>
<td>Dublin Maternity Hospital</td>
<td>83</td>
<td>81</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>30</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>462</strong></td>
<td><strong>346</strong></td>
<td><strong>39</strong></td>
</tr>
</tbody>
</table>

Palliative Care for Children with life-limiting conditions in Ireland - A national Policy 2010
Paediatric Palliative Care

- Active and total approach to care, embracing physical, emotional, social and spiritual elements
- Enhancement of quality of life for the child and support for the family
- Management of distressing symptoms, provision of respite and care following death and bereavement

ACT and RCPCH 1997
“…for children with complex medical conditions, because of the emotional impact, the focus of Palliative Care is not about dying but about assistance with medical decision making, improving symptom control, and anticipatory guidance for episodes of worsening disease…services that even children who survive require.”

WHO Cancer Pain Release Vol 19, Nos 2+3, 2006
Paediatric v Adult Palliative Care

- Small number of children
- Large number of conditions, rarity
- Many illnesses familial
- Timescale
- Care of family
- Developmental needs
- 2/3 children with palliative care needs have disability
Table 2. Life-limiting conditions: the Association for Children’s Palliative Care (ACT)/Royal College of Paediatrics and Child Health (RCPCH) categories. Adapted from ACT/RCPCH¹

<table>
<thead>
<tr>
<th>ACT/category</th>
<th>Definition</th>
<th>Example conditions</th>
<th>Main characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Life-threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during phases of prognostic uncertainty and when treatment fails.</td>
<td>Cancer, cardiac anomalies</td>
<td>Possible cure</td>
</tr>
<tr>
<td>2</td>
<td>Conditions in which there may be long phases of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible.</td>
<td>Cystic Fibrosis, Muscular Dystrophy, HIV/AIDS with antiretroviral treatment</td>
<td>Normal phase following diagnosis</td>
</tr>
<tr>
<td>3</td>
<td>Progressive conditions without curative treatment options, in which treatment is exclusively palliative and may commonly extend over many years.</td>
<td>Batten’s disease, Mucopolysaccharidosis, HIV/AIDS without antiretroviral treatment</td>
<td>Relentless</td>
</tr>
<tr>
<td>4</td>
<td>Conditions with severe neurological disability, which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not considered progressive.</td>
<td>Severe Cerebral Palsy</td>
<td>Unpredictable</td>
</tr>
</tbody>
</table>
Illness trajectory

- Child’s Condition
- Years
- Death
Prognosis in Cerebral Palsy

• Strauss et al 1980-1995 Cohort
  – If unable to lift their head and NG fed – median survival of 7 years from time of 1st assessment
  – If fed orally but by others life expectancy 14 years
  – If unable to life head when prone 8 x risk of death

• By 2002 - Increase in survival in severe group to 20 years
National reports

- 2001- Report of the National Advisory Committee on Palliative Care
- 2005- A Palliative Care Needs Assessment for Children
- 2010- Palliative Care for Children with life-limiting conditions in Ireland- A National Policy
- 2011- Respite Services for Children with Life-limiting conditions and their families- A needs assessment for Dublin/Mid-Leinster and Dublin/North-East
Current Paediatric Provision

• Paediatric Specialist Palliative Care
• General and Community Paediatricians
• Community Services
  – Community Palliative Care Teams
  – Disability Services
  – Respite services including The Children’s Sunshine Home
  – Home Care
    • Jack and Jill Nursing
    • HSE nursing
The new name for ACT and Children’s Hospices UK

We are the UK voice for children and young people who are not expected to live to reach adulthood and their families. We are here to ensure that these families have the best quality care and support wherever they live and for as long as they need it.

We are developing a new Together for Short Lives website. For now you can find out more about our work by visiting the separate ACT and Children’s Hospices UK websites.
Challenging Symptom Profile of life-limiting conditions in children: A survey of Health Care Professionals and families

*Malcolm, C et al Palliative Medicine 25(4) 357-364 Jan 2011*

<table>
<thead>
<tr>
<th>Symptom</th>
<th>High</th>
<th>Medium</th>
<th>Low</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizure</td>
<td>9</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Drooling</td>
<td>8</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Muscle spasm</td>
<td>7</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Secretions</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Constipation</td>
<td>6</td>
<td>5</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Nausea/Vomiting</td>
<td>6</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Pain</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Breathing difficulties</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Pain in Infants

• “Even when there is sensitivity is it reasonable to assume that neural mediation does not extend above the level of the thalamus.”

McGraw 1941
Welcome to the official home of the Wong-Baker FACES Foundation, an organization created to support research and promote education in pain assessment and management in people of all ages.

**Wong-Baker FACES Pain Rating Scale**

0 No Hurt
2 Hurts Little Bit
4 Hurts Little More
6 Hurts Even More
8 Hurts Whole Lot
10 Hurts Worst

Explore our website and find information about the Wong-Baker FACES™ Pain Rating Scale, including guidelines for using the FACES, research articles, the history of the scale, a tribute to Dr. Donna Wong, and find out more about our foundation and board of directors.

Visit our store and purchase products featuring the Wong-Baker FACES™ Pain Rating Scale. All proceeds go toward the Foundation’s goals to elevate the importance of excellence in care for those experiencing pain.
Welcome to the PPP website

The Paediatric Pain Profile (PPP) is a behaviour rating scale for assessing pain in children with severe physical and learning impairments.

From this website you can

- Find out about the [development](#) of the Paediatric Pain Profile.
- Download the Paediatric Pain Profile with instructions for its use.
- Order bound paper copies of the Paediatric Pain Profile.
- Find [links](#) to other websites relevant to health care and to children's pain.

Background to the study:

Severe physical and learning impairment is a feature of many chronic and disabling conditions in children. These children have many potential sources of pain. Pains may arise from the disease process itself (e.g. neuropathic pain or muscle spasm), be secondary to the disease (e.g. musculo-skeletal pain or pain from reflux oesophagitis) or incidental (e.g. tooth ache or otitis media). However, because the children have difficulty in communicating their pain it can go unrecognized and untreated. It is the child’s behaviour often, rather than their verbal report, which has to be interpreted to determine if they have pain. Because it can be difficult sometimes for parents and for health care professionals to distinguish which behaviours do indicate pain and to follow the progress of pain relieving treatments, we have developed a pain assessment scale specifically for this population of children.
<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>4/6</td>
<td>2100</td>
<td>Birth</td>
</tr>
<tr>
<td>4/6</td>
<td>0430</td>
<td>ECG</td>
</tr>
<tr>
<td>4/6</td>
<td>1230</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>0100</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>0200</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>0500</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>0600</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>0630</td>
<td>ECG</td>
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<tr>
<td>11/6</td>
<td>0700</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>0800</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>0900</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1000</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1100</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1200</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1300</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1400</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1500</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1600</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1700</td>
<td>ECG</td>
</tr>
<tr>
<td>11/6</td>
<td>1800</td>
<td>ECG</td>
</tr>
</tbody>
</table>

*HR = 160, 160, 190*
**FLACC Score**

<table>
<thead>
<tr>
<th>Categories</th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face</td>
<td>No particular expression or smile</td>
<td>Occasional grimace or frown, withdrawn, disinterested</td>
<td>Frequent to constant frown, quivering chin, clenched jaw</td>
</tr>
<tr>
<td>Legs</td>
<td>Normal position or relaxed</td>
<td>Uneasy, restless, tense</td>
<td>Kicking or legs drawn up</td>
</tr>
<tr>
<td>Activity</td>
<td>Lying quietly, normal position, moves easily</td>
<td>Squirming, shifting back and forth, tense</td>
<td>Arched, rigid, or jerking</td>
</tr>
<tr>
<td>Cry</td>
<td>No cry (awake or asleep)</td>
<td>Moans or whimpers; occasional complaint</td>
<td>Crying steadily, screams or sobs, frequent complaints</td>
</tr>
<tr>
<td>Consolability</td>
<td>Content, relaxed</td>
<td>Reassured by occasional touching, hugging, or being talked to; distractible</td>
<td>Difficult to console or comfort</td>
</tr>
</tbody>
</table>

*Note:* Each of the five categories Face (F), Legs (L), Activity (A), Cry (C), and Consolability (C) is scored from 0-2, which results in a total score between 0 and 10.


Welcome

This site is intended for the benefit of families and health professionals involved in the care of children and adolescents who need long term mechanical ventilation.

By sharing information, this website aims to help such children and young people to move out of hospital into an environment more suited to long term care and rehabilitation - at home, if at all possible.

The site has been running for some years but is updated regularly.

Please feel free to contact stuart.novis@nhs.net with any comments you may have for improving the appearance and content on the site.
Symptom Control

• Rainbows Children’s Hospice: Basic Symptom Control in Children’s Palliative Care
  http://www.act.org.uk/page.asp?section=167&sectionTitle=Basic+symptom+control+for+children’s+palliative+care

• Children’s Palliative Care Handbook for GPs
  http://www.act.org.uk/page.asp?section=411&sectionTitle=Children's+palliative+care+handbook+for+GPs
Ethics in Paediatric Palliative Care
Ethical Issues

• Withholding and Withdrawing Care
  – Feeding
  – Ventilation
  – Intravenous therapy

• Autonomy of Parents v Best interests of Child
Witholding or Withdrawing
Life Sustaining Treatment
in Children:
A Framework for Practice

Second Edition

May 2004
Withholding and Withdrawing Life Sustaining Treatment

1. The Brain Dead Child
2. The “permanent Vegetative” State
3. The “no chance” situation
4. The “no purpose” situation
5. The “unbearable” situation
Edvard Munch, The Sick Child
End-of-life
What do parents want

• Honest and complete information
• Ready access to staff
• Co-ordination of communication and care
• Emotional expression by staff
• Parent-Child relationship
• Faith

Meyer; Pediatrics 2006
End of life planning

• Do Not Resuscitate forms can be unhelpful
  – Cardiovascular arrest rare
  – Do not address gradual deterioration
  – Perceived as negative by family
Personal resuscitation Plans

- Involve discussion between family, consultant paediatrician and nurse
- Informing families guidelines followed
- Provides choices and options
- Opens communication
Personal Resuscitation Plan for Child/Young Person in Residential Care

Please keep visible at the front of medical records at all times

1. Personal Details

Name: ___________________________    DOB: ___________________________

Address: ________________________________________________________________

Next of Kin Contact Details ______________________________________________

________________________________________________________________________

Ethnicity: _______________    Language spoken: _______________    Religion: _______________

Need for an interpreter: YES [ ] NO: [ ]

2. Background

Diagnosis/reason for plan

3. Resuscitation Plan

3.1 In the event of a sudden collapse with respiratory or cardiac arrest (carefully and clearly delete all options not needed):

Yes    No

1. Comfort and support child an family
2. Suction upper airway
3. Oxygen for comfort using mask or nasal prongs
4. Preserve airway using head tilt/chin lift
4. In the event of gradual life threatening deterioration:

**Symptoms/signs to expect:**

(please carefully and clearly delete all options not needed and complete boxes as necessary)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. comfort and support child and family</td>
<td>[ ]</td>
</tr>
<tr>
<td>b. suction upper airway</td>
<td>[ ]</td>
</tr>
<tr>
<td>c. oxygen for comfort face mask/nasal cannulae</td>
<td>[ ]</td>
</tr>
<tr>
<td>d. maintain airway if it helps</td>
<td>[ ]</td>
</tr>
<tr>
<td>e. oral antibiotics</td>
<td>[ ]</td>
</tr>
<tr>
<td>f. change feeds to clear fluids</td>
<td>[ ]</td>
</tr>
<tr>
<td>g. analgesia</td>
<td>[ ]</td>
</tr>
<tr>
<td>h. move to a quiet room</td>
<td>[ ]</td>
</tr>
<tr>
<td>i. other symptom relief</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

If ____________ continues to deteriorate despite the above care would you wish for transfer to an acute hospital?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. intravenous fluids</td>
<td>[ ]</td>
</tr>
<tr>
<td>b. intravenous antibiotics</td>
<td>[ ]</td>
</tr>
<tr>
<td>c. intubation and ventilation</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

If ____________ continued to deteriorate and it was decided that transfer to hospital was not in his/her best interest do you have any special wishes for his/her care?
The “Wishes” Document

- Advanced Care Planning in Children with life-limiting conditions- The Wishes Document. Fraser et al Arch Dis Child 2010
  - [http://adc.bmj.com/content/suppl/2010/03/16/95.2.79.DC1/Child_family_wishes_guidance_notes_(1).pdf](http://adc.bmj.com/content/suppl/2010/03/16/95.2.79.DC1/Child_family_wishes_guidance_notes_(1).pdf)
Issues at End-of-life

• Recognition
• Review medication
• Anticipate symptoms
• Review interventions
  – Sats monitors
  – Blood testing etc
• Allow discussion re care after death

ACT Best Practice. Prompts for care in last hours and days of a child’s life 2010
Key decisions at end-of-life

Health Problem

- What goal to prioritise?
  - Maximise quantity of life
    - More time in one's life
  - Maximise quality of life
    - More life in one's time
Bereavement Support

• Post death care plan
• Service
• Annual bereavement service
• Counselling
• Sibling workshops
The mention of my child's name may bring tears to my eyes,
But it never fails to bring music to my ears.
If you are really my friend,
let me hear the music of her name!
It soothes my broken heart and sings to my soul!
~Author Unknown ~
Thank you
Palliative Care and Neurological Disease: Ethical Reflections

25th November 2011

Prof. David Smith

Dept. General Practice
Introduction

• Different Ethical Issues arise with different neurological diseases
• Focus on Dementia and Alzheimer's
  – Advanced Care Planning
  – Nutrition and Hydration
  – Substituted Judgement
  – Best Interests
Introduction

• Major ethical principles in palliative care relate to:

1. **Autonomy** [respecting the values of the patient].
2. **Beneficence and non-maleficence** [applied to therapeutic strategy and decision making, such as truth-telling and choice of medication].
3. **Justice** [the balance between personal need and social resources, as in the selection of place of care].
Introduction

• Decision making in terminal care is a demanding and stressful duty for all involved.
• Truth telling and cultural differences.
• The situation is ethically complex, and the decisions have been shown to depend not only on patients’ preferences or clinical circumstances but also on the personal characteristics of the doctor.
Introduction

• Variation in the extent to which different specific life-supporting options were forgone -- in the case of both withholding and withdrawing decisions.

• The wishes of the patient’s family’s that “all be done” significantly increased the treatment activity of all doctors.

• In some instances advance directives can lead to fewer life-supporting decisions.
Advanced Care Planning

- Desire to improve the quality of care that patients with advanced dementia receive when they are dying.
- Understanding of the palliative care needs of these patients and the natural history of advanced disease is limited.
- Many people with advanced dementia have unplanned emergency admissions to the acute hospital; this is a critical event.
- These patients have complex needs but often lack capacity to express their wishes.
- Often carers are expected to make decisions.
• Advance care planning discussions are a means by which carers could plan for the future and feel more supported in making decisions regarding patient care.

• Benefits may include more consistent supportive care, fewer emergency hospital admissions of patients with dementia and better resolution of carer bereavement.
• One of the pre-eminent problems in caring for persons with dementia is deciding whether and how to provide food and water.
• It is unclear how many persons with advanced dementia are provided with artificial nutrition and hydration through long-term tube feeding, almost always in the form of a PEG.
• Cultural and Religious Influences:
  – Among Orthodox Jews, implementing tube feedings for a family member with progressive dementia is standard.
  – In Catholicism it is argued that a person with advanced dementia should not necessarily be supported by tube feeding, so long as nothing is done to hasten death.
The ethics of proportionality require that benefits outweigh risks and burdens.

There are, however, a number of significant burdens associated with tube feeding.
Nutrition and Hydration

• The Alzheimer's Association contends that refusing or withdrawing artificial nutrition and hydration are legitimate areas for choice.

• The American Academy of Neurology Ethics and Humanities Subcommittee has concluded that while oral hydration and nutrition should always be provided and encouraged, there should be no artificial nutrition and hydration by enteral or parenteral means unless chosen by the patient or proxy.

• This latter distinction can cause problems.
Substituted Judgement and Best Interests

• Medical ethics has traditionally been governed by two guiding, but sometimes conflicting, principles:
  – Autonomy
  – Benevolence.
• These principles provide the rationale for the two most commonly used standards for medical decision-making:
• In dealing with patients with Alzheimer’s Disease the Substituted Judgment Standard shows concern for patient autonomy,
• The Best Interest Standard shows commitment to benevolence.
Both standards are vulnerable to criticisms. The principles can seem to offer conflicting prescriptions for action. The criticisms and conflict figure prominently in discussion of advance directive decision-making and Alzheimer’s disease.
Substituted Judgement and Best Interests

• **Personal Identity**
• In a sense, the problems arise from our uncertainty about just what constitutes personal identity.
• “If certain things happened to me, the truth may not be that I become a very different person. The truth may be that I cease to exist, and the resulting person is someone else.”
• The changes in personality and behavior are so great, and the loss of memories of the so vast, in Alzheimer’s patients that it makes sense to question whether we are dealing with one person or with two. The two have been referred to in the literature as the “now” self and the “then” self.
Substituted Judgement and Best Interests

• The “now” self is the contemporary one, suffering from Alzheimer’s. The “then” self is the earlier one, the one existing before the radical memory loss of Alzheimer’s was complete.

• So, which self should make decisions about whether, how, and to what extent the Alzheimer’s patient should be treated?

• The two principles of medical ethics come into play at this point.
Suppose a patient is now incompetent in the general, overall sense . . . , but that, years ago, when perfectly competent, he executed a “living will” providing that he was not to be kept alive by expensive medical treatment if he became permanently demented.

Does autonomy now require that such provisions be respected, by those in charge of the patient?

Should we honor the autonomy of the “then” self by doing what the person has stipulated, for example, in an advance directive, or what we believe that the person would want if no explicit instructions have been provided?
Substituted Judgement and Best Interests

- Or should we honor our commitment to benevolence by doing what we take to be in the best interests of the patient?
- Which is the better standard for decision-making—Substituted Judgment or Best Interest?
Substituted Judgement and Best Interests

• The Substituted Judgment Standard
• A brief and simple way of stating the Substituted Judgment Standard for decision-making is that we should do for the patient what we believe the patient would want done if he or she was able to make the decision.
• It is our voice that is being substituted; the judgment itself should come, indirectly of course, from the patient.
• This done either by an Advance Directive or Proxy.
Substituted Judgement and Best Interests

• **Problems with Substituted Judgment/Advance Directives**
• The problems identified with the reliance on the Substituted Judgement or use of advance directives are all reducible to inadequate knowledge.
• The patient probably does not know enough about the empirical state of affairs concerning his/her disease; a patient certainly does not know what the state of affairs will be when her/she becomes demented.
Substituted Judgement and Best Interests

- The nature of decision-making is that it must respond to changing circumstances in the world and in the agent.
- But this is impossible for one who has lost the competence possessed when an original decision was made.
- A patient may have embodied in his or her advance directive a prospective judgment about life-support technology, but thinking ahead is not the same as an autonomous, concurrent judgment that considers changing, concrete interests.
Substituted Judgement and Best Interests

• **Best Interest Standard**
  • The Best Interest Standard state that we decide for the patient based on what we take to be in the patient’s best interest, regardless of what we think the patient might decide.
  • We determine that we will do whatever will result in the patient’s contemporary benefit.
  • This is, of course, a form of paternalism.
  • But we deem the paternalism to be justified, usually by reference to a claim that the patient is not capable, for whatever reason, of making a rational decision about his or her own best interest.
Substituted Judgement and Best Interests

- There are two kinds of interests that patients may have.
  1. They care about the felt quality of their future experiences. They dread future pain or discomfort. These are called their *experiential* interests.
  2. They care about the overall value or worth of the life that they are leading. These concerns describe their *evaluative* interests or critical interests.
Substituted Judgement and Best Interests

- Focus on experiential interests when concerned with what will be best for the patient’s life right now.
- Focus on evaluative, or critical interests, when concerned with what is best for patient’s life in an overall sense.
Substituted Judgement and Best Interests

- The Best Interest is motivated largely by our sympathetic imagination.
- We believe that we have an obligation to help others when we believe them unable to help themselves.
- The medical profession have a duty to compassion; that is, a duty to do what is best for a person when the person is unable—for whatever reason—to choose, and cause, the best to be done. So, a doctor should do what is best for the patient.
- If the patient disagrees, it is probably because the patient lacks the knowledge that the doctor possesses.
Substituted Judgement and Best Interests

• Problems with the Best Interest Standard
• Unfortunately, it is not as easy as it might sound to determine what is in a patient’s best interest.
• The determination is particularly difficult in cases (like the latter stages of Alzheimer’s disease) when the patient is unable to communicate.
Substituted Judgement and Best Interests

- **The Successor Standard**
- Given the problems with the Substituted Judgement and the Best Interest, there is a need for a better way of handling decision-making for Alzheimer’s patients.
- Suggest the Successor Standard from the successor self
- One of the strengths of this notion is that it enables us to limit the earlier self’s influence over the life of the successor self without resorting to a form of paternalism.
Substituted Judgement and Best Interests

- Advanced directives are occasions for communication, not a means of definitively settling treatment decisions.
- For the patient whose mental competence is irrevocably lost, advanced directives offer valuable pieces of evidence about a patient’s intentions.
- But, like all evidence, they are never beyond the need for interpretation, qualification, and negotiation as circumstances change.
Substituted Judgement and Best Interests

• In other words, advance directives should be thought of not as a command so much as it is the statement of preferences.

• If the successor self appears not to be well served by execution of the preferences, then we have grounds for acting against the preferences and for the best interest of the successor self.

• The relationship between the Substituted Judgement and the Best Interest should be seen as a dialectic—a conversation that functions to leave each better informed.
THANK YOU
Neurological disease – is everything all right?

Dr. Tony O’Brien
Marymount University Hospice & Cork University Hospital

I.A.P.C. Dublin
November 25, 2011
Question

• Should palliative care services care for neurological diseases?

• Answer:
Question

• Should palliative care services care for neurological diseases?

• Answer: No, absolutely not!
Question

• Should patients with palliative care needs as a direct and unavoidable consequence of neurological disease (or other pathologies) have access to palliative care, if they so choose?

• Answer:
Question

• Should patients with evident palliative care needs as a direct and unavoidable consequence of neurological disease (or other pathologies) have access to palliative care, if they so choose?

• Answer: Most certainly yes!
Principles

• Treat the patient, not the disease

• Manage the illness, not the pathology
Definition

• **Disease** – describes a specific pathology affecting an organ, tissue or system in the body

• **Illness** – describes the subjective experience of the disease in the unique context of an individual’s life – past, present and anticipated future

Lickiss JN, 2009
Assess the patient, not the disease

Assess the patient

Reassess the patient

Assess the patient again
Whole person care

Physical

Spiritual

Social

Emotional
National policy

• All patients should have access to specialist palliative care services when and where required

• Access based on need, and on need alone
  – Not based on pathology, financial status, postal address

• Patients should be enabled and encouraged to express their preferences about where they wish to be cared for and where they wish to die

• Services should be sufficiently integrated and flexible as to allow easy movement of patients from one care setting to another
Integrated SPCS

In-patient Unit

Spec. Palliative Care

Day Care OPD

Community

Hospital

Education / Training / Research / Resource Centre
Levels of specialisation

• Level one – palliative care approach
  – Basic principles practiced by all HCPs

• Level two – general palliative care
  – Intermediate level care
  – Sub-specialty interest

• Level three- specialist palliative care
Problems – actual / perceived

• Knowledge deficit
• Fear of being swamped / overwhelmed
• Funding concerns, including charitable funds
• Fear of being used to bridge gaps in service provision that is the responsibility of others
• Less certain prognostication
• Structure / ambience of facilities
• Blocked beds
‘Til death us do part?

• Persons with specialist palliative care needs, irrespective of the underlying pathology, need specialist palliative care

• Persons who NO LONGER have specialist palliative care needs must be discharged from the specialist palliative care service

• Specialist palliative care services cannot and should not attempt to plug the gap in all other services
Palliative care for all

• Disease based approach
  – Heart failure, dementia, COPD

• Excessive focus on death / dying
  – The rationale for disease selection was based on the following factors:
    • Mortality rates for these diseases

• Simplistic classification
  – Malignant
  – Non-malignant
Case study

• 78 year old man
• Carcinoma of oesophagus / stented
• Carcinoma of prostate / bone metastases
• Multiple myeloma
• Critical aortic stenosis
Service admission policies

• Most policies are:
  – designed to limit or delay access to services
  – designed primarily to meet the needs of the service providers
  – deficient in identifying and responding to the needs of service users
  – fail to adequately respond to need in an effective, efficient and timely fashion
  – fail to provide care where and when it is required
Referral Criteria

Referral criteria for access to xxx hospice services are as follows:

1. A patient with progressive, life-threatening, incurable illness and a limited prognosis, **AND**
2. The patient will also have difficult and/or complex needs which cannot be met by other teams, requiring specialist palliative care **OR**
3. The patient is in the last few days of life and seeks terminal care in their preferred place of dying
4. The patient consents to referral to the hospice

Published admission policy. UK hospice
Marymount referral policy

• On receipt of a referral, the team will endeavour to gather as much information as possible about the patient and family

• All patients referred will be assessed by a member of the specialist palliative care team

• If a patient is deemed not to have specialist palliative care needs, they are discharged

• Early referral is desirable
• Traditionally, hospice and palliative care was offered to patients only after all other treatments had failed.

Dr. Len Lichtenfeld, Deputy CMO, American Cancer Society
It is urgent that we move capacity to provide this kind of care upstream.

Palliative care needs to be available from the point of diagnosis.

Dr. Diane Meier, Mt. Sinai School of Medicine, New York.
Disease modifying Rx

Optimal pain & symptomatic Rx

Palliative care / end of life care, rehabilitation & bereavement care
Rehabilitation

A process aimed at restoring personal autonomy in those aspects of daily living considered most relevant by the patient and family

Standards of cancer care

- Access to palliative care from initial visit
- All patients routinely screened for palliative care needs
- Education of patients and families that palliative care is an integral part of comprehensive cancer care
- Education of all healthcare professionals in knowledge, skills and attitudes of palliative care
- Interdisciplinary specialist teams
- Measurement of palliative care outcomes
- Institutional quality programmes

National Comprehensive Cancer Network, 2011
Standards of patient care

• Access to palliative care from initial visit
• All patients routinely screened for palliative care needs
• Education of patients and families that palliative care is an integral part of comprehensive health care
• Education of all healthcare professionals in knowledge, skills and attitudes of palliative care
• Interdisciplinary specialist teams
• Measurement of palliative care outcomes
• Institutional quality programmes
Screening for palliative care needs

- Uncontrolled symptoms
- Distress related to diagnosis or therapy
- Serious co-morbid physical / psychosocial issues
- Life expectancy < 12 months
  - Poor performance status KPS < 50 or ECOG >3
  - Hypercalcaemia
  - Brain / leptomeningeal metastases
  - Delirium
  - Superior vena caval obstruction
  - Spinal cord compression
  - Significant hepato-renal dysfunction
- Patient and / or family request

National Comprehensive Cancer Network, 2011
Screening for palliative care needs

• Uncontrolled symptoms
• Distress related to diagnosis or therapy
• Serious co-morbid physical / psychosocial issues
• Life expectancy < 12 months
• Patient and / or family request

National Comprehensive Cancer Network, 2011
Assess the patient

• Disease status & symptom burden (total)
• Disease trajectory
• Current management / compliance
• Functional status
• Quality of life
• Psychosocial / emotional / spiritual wellbeing
• Support framework
• Accommodation
• Patient’s preferences & needs
It’s not about disease. ..it is about people