

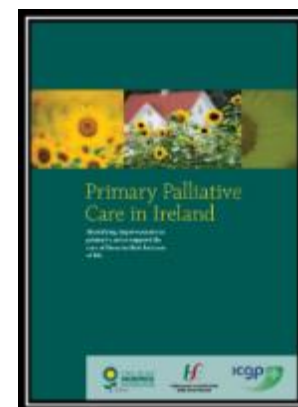
CHALLENGES OF END OF LIFE CARE IN A PROGRESSIVE NEUROLOGICAL POPULATION

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nurses for night care



Today:

- Background
- End of life care and Palliative Care
- Group work
- Discussion
- Going Forward

Policy:



- What is end of life care?



What is good end-of-life care?



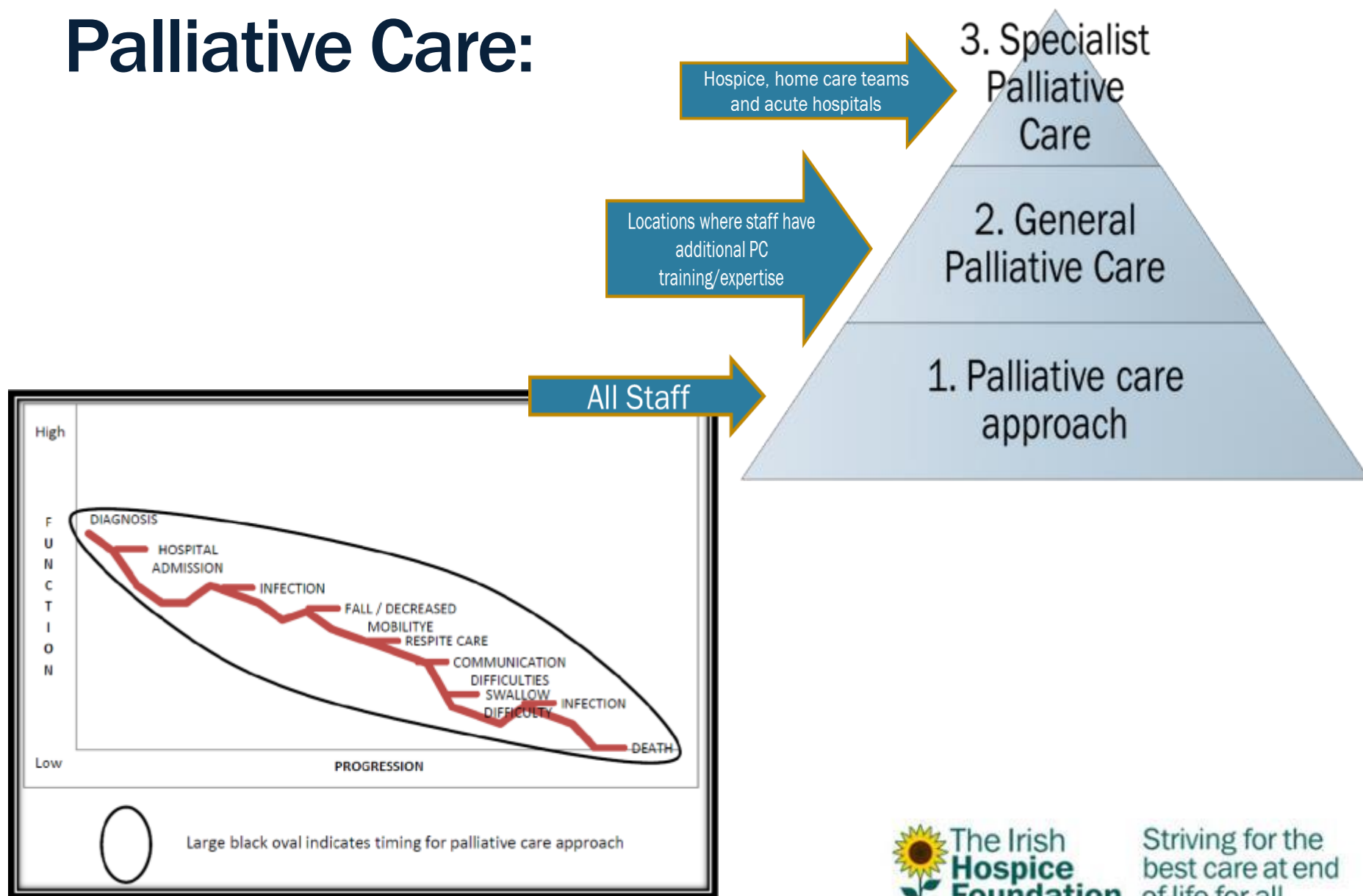
When I receive good end-of-life care...

- I will be respected for who I am, and I will be at the centre of all decisions about my care. I will have confidence in the quality of the care provided to me.
- I will be prepared for what lies ahead.
- I will have choice, where possible, in my preferred place of care and have the supports I need for a good death.
- I will have comfort and dignity in my care as death approaches.
- I will know that my family and those important to me will be supported and cared for after my death.

- What is palliative care?



Palliative Care:



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In Groups:



1. What are the needs of people with neurological illness?
2. What issues arise when care is discussed?
3. How do you identify and respond to care needs?

- What are the needs of people with neurological illness?



Palliative Care Needs	Description
1. Clinical input from neurologists and specialist staff.	Pain and symptom management; multi-disciplinary care of complex needs; clinical staff and research.
2. Psycho-social care of individuals and their carers (before and after the person dies).	<p>More concern with the person living rather than the disease. Multi-disciplinary care and holistic approach to the different non-physical needs of individuals and their carers e.g., emotional, social and spiritual.</p> <p>Awareness of possible anxiety and depression amongst patients and their carers.</p>
3. Availability of palliative care earlier in the disease trajectory.	<p>Acknowledgement of the relatively long duration and unpredictability of the disease, and the benefits that can result from the provision of different levels of palliative care at different stages of the disease.</p> <p>More timely referral of individuals to palliative services, especially with rapidly advancing conditions.</p>
4. Improve range and quality of palliative care services.	<p>Less fragmented and more coordinated services; more services nationwide; more resources for respite care, night nursing, nutritional advice, speech and language, equipment to help people communicate etc.</p> <p>Some individuals find access to services more difficult than others. Palliative care should be accessible for people with different conditions and people who do not live in the geographic area served by a palliative care team.</p>
5. Recognition of end-of-life phase.	Research to establish more accurate triggers of the end-of-life phase.

6. Acknowledge unpredictability of diseases.	Awareness of the potential for sudden and unexpected progression of the disease, and death.
7. Awareness and understanding of different neurological conditions	<p>Some medical staff are perceived to know little about rarer conditions.</p> <p>Some diseases require specialist treatments.</p>
8. Planning Ahead	<p>Cognitive and behaviour change can make planning ahead challenging, especially if left too late in the process. Individuals should be given every opportunity to make informed choices about their future care.</p> <p>IHF Think Ahead document or similar.</p>
9. Staff informed, confident and sensitive in anticipating people's needs	Training is required for carers and health professionals on understanding and responding to the needs of people with advancing neurological conditions.
10. Increasing focus on quality of life	Provide individuals with interventions and activities that impact positively on their quality of life.
11. Staff adopt approach that acknowledges respect and dignity of the person	Some health care professionals, carers and individuals lack an understanding of the condition e.g., cognitive and behavioural change, an awareness that resources are not 'wasted' on people who are dying of an incurable condition.
12. General information and support.	<p>Knowing where to get help and information</p> <p>Being present to the person, responding to questions.</p>



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- What issues arise when care is discussed?



Issues that arise when care is discussed:

1. Sensitive and challenging
2. Difficulty accessing specialist palliative care services
3. Services fragmented, lacking co-ordination,
4. Timing to initiate the conversation
5. Encouraging to plan ahead
6. Training and education

(IHF & NAI, 2014)

Neurology Palliative Care Challenges:

- Long duration of neurological illnesses
- Recognition of end of life phase
- Potential sudden death (MND)
- Lack of predictable course of illness
- Complex multidisciplinary care
- Specialist treatments (PD, deep brain stimulation)
- Neuro-psychiatric problems
- Rapidly advancing disease means that some may need palliative care early on
- Many die but not from the neurological condition
- Planning end of life care can be challenging
- Cognitive changes – need for planning early on in illness
- Communication
- Care environment

(National End of life Care Programme UK, 2010 & Skirton & Glendinning, 1997)

- How do you identify and respond to care needs?



Identify & Respond:

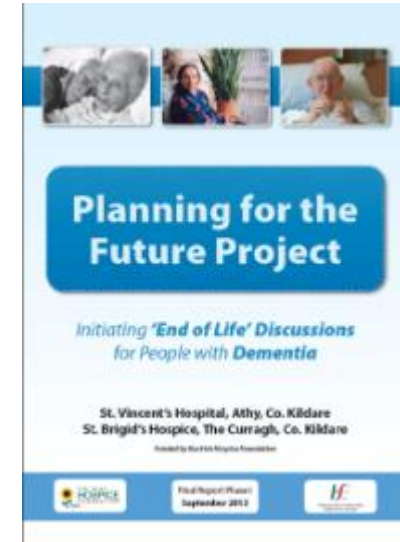
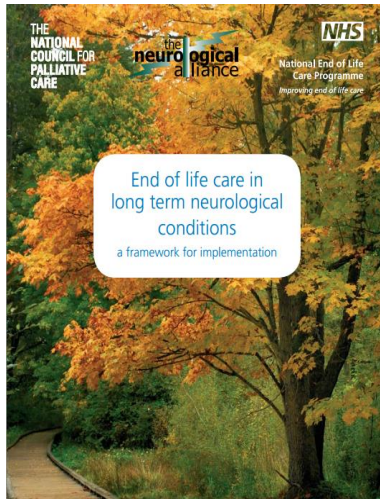
- Provide information
- Provide support
- Raise awareness
- Prompt conversations

Going Forward.....

- What one thing can you do differently within your practice or organisation with regard to providing palliative care?



Resources:



hospicefoundation.ie/healthcare-programmes/palliative-care/palliative-care-for-all/advancing-neurological-illness/

- ▶ DEMENTIA PALLIATIVE CARE
- ▶ RESIDENTIAL CARE
- ▶ PRIMARY PALLIATIVE CARE
- ▶ MEET THE TEAM

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[I'M A HEALTHCARE WORKER LOOKING AFTER SOMEONE WITH AN ADVANCING NEUROLOGICAL ILLNESS – READ ON >>>](#)



Irish Projects

- Guidelines for physiotherapy management of Motor Neuron Disease
- Palliative care needs in Parkinson's disease: an initiative to raise cultural awareness, educate healthcare workers and provide cohesive support to patients and their carers/families.
- A Qualitative Study of Psychological and Psychotherapeutic Approaches for Motor Neuron Disease (MND) Patients
- Dying with Dignity in Disability Services in Ireland
- Physiotherapy led palliative exercise programme for Parkinson's disease (PEP-PD) patients in an out-patient setting: a feasibility study
- Transition to adult services by young people with life-limiting conditions in Belfast and Dublin: a realist evaluation using mixed methods (TASYL study)

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- ✓ Neurological Alliance of Ireland
- ✓ Neurological Alliance of Ireland member organisations
- ✓ Project Advisory Group

Thank you and Questions

For more information:

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