‘It starts cognitive and ends physical’

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- Late palliative care - ?missed opportunities

Dementia staging

Functional based

-Functional Assessment Staging Test

Stage 3 – problems in work

Stage 4 – problems planning

Stage 5 - needs help choosing clothes

Stage 6 – needs help with ADL

Stage 7 – loss of ability to sit, walk

Cognition based

-Global Deterioration Scale (Reisberg)

Stage 1-4 - cognitive

Stage 5 - problems with ADL

Stage 6 – incontinence, personality change, delusions, compulsion

Stage 7 – loss of motor function

Prognostication

Ability of tools to predict mortality are modest at best

‘prognosis’ based service provision vs ‘needs’ based

Prognostication

Six month mortality in nursing home residents with advanced dementia

- Pneumonia - 46%
- Febrile episode -44%
- Eating problems -38%

- Mitchell et al N Engl J Med 2009;361:1529-38

THE IRISH NATIONAL DEMENTIA STRATEGY

The Irish National Dementia Strategy
Section 3 – Guiding Principles and Priority Actions

Regular assessments of palliative care need should be conducted by staff providing care to people with dementia. Staff should have the training in the principles of palliative care needed to assess palliative care need, and referral should be made to specialist palliative care services to support care provision where required. People with dementia should be supported to be cared for in the place of their choice, as far as is possible, including at the end of life.

The Irish National Dementia Strategy
Section 6 - Integrated Services

- Better availability of a range of person-centred, flexible and responsive services that encourage people with dementia to make decisions around their care and that respect their will and preferences from diagnosis through to end-of-life care.
- Better co-ordination, integration and smoother transitions between primary, secondary, mental health, community care, acute, long term and palliative care services.
- Hospitals should be dementia-friendly from admission to discharge/death. This includes environmental aspects as well as clinical support.

The Irish National Dementia Strategy
Section 6 - Integrated Services

- Staff in all care settings should have the necessary training for treating and supporting a person with dementia, including training in palliative approaches that are appropriate for people with dementia.
- People with dementia should be facilitated and supported to live and die well in their chosen environment including their own home or nursing home if that is their choice. Specialist palliative care should be available to all people with dementia and their families in all care settings and at home, if required, to optimise quality of life and support a comfortable and dignified death

Palliative care is..

the active, total care of patients whose disease is no longer responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care the achievement of the best possible quality of life for the patients and their families.

WHO 2002

Levels of Palliative Care Specialisation

Level One – Palliative Care Approach

- Palliative care principles should be practised by all health professionals.
- Should be a core skill of every clinician at hospital and community level.
- Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.

Level Two – General Palliative Care

- A proportion of patients and families will benefit from the expertise of healthcare professionals who have had some additional training and experience in palliative care, perhaps to diploma level.
- Should be available in hospital or community settings.

Level three – Specialist Palliative Care

- Core activity is limited to the provision of palliative care.
- More complex and demanding care needs
- Analogous to secondary or tertiary health care services.

Palliative Care Competence Framework

MEDICINE | NURSING | MIDWIFERY | HEALTH CARE ASSISTANTS
SOCIAL WORK | OCCUPATIONAL THERAPY | PHYSIOTHERAPY
SPEECH AND LANGUAGE THERAPY | DIETETICS / CLINICAL NUTRITION
PHARMACY | PSYCHOLOGY | CHAPLAINCY/PASTORAL CARE

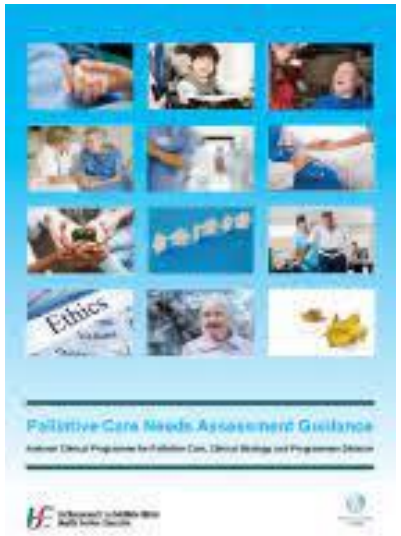
HSE PALLIATIVE CARE

FORUM OF IRISH POSTGRADUATE MEDICAL TRAINING BODIES

Specific Challenges in Dementia

- Prognosis
- Diagnosis of the dying or terminal phase
- Symptom assessment
- Social, psychological or spiritual assessment
- Treatment decisions
- Ethics
- The family: role and support

Palliative Care Needs Assessment



Palliative Care Needs Assessment

- When?
- Where?
- Who?
- How?
- What next?

When?

- at diagnosis of a life-limiting condition,
- at episodes of significant progression/exacerbation of disease,
- a significant change in the patient's family/social support,
- a significant change in functional status,
- at patient or family request,
- at end of life.

Palliative Care Needs Assessment (HSE)

- Diagnosis - early – advance care planning
  - moderate/late – care planning; symptom assessment
- ‘sentinel events’ – require care at home; require nursing home care; aspiration pneumonia; acute event requiring hospitalization

Four domains of Palliative Care Needs Assessment

- Physical
- Social/occupational
- Psychological
- Spiritual

Treatment Decisions Challenges in Dementia

- Goal of treatment
- Competence
- Ethics
- Legal
- Family

Symptoms

Management

- Diagnose cause
- Treat cause
- Treat symptom

Symptoms

Management

- Diagnose cause
- Treat cause
- Treat symptom

Assessment

- History
- Examination
- Appropriate investigation
- Effect of intervention

Consider

- Verbal Rating Scale - patient

  - proxy
- Observe and document behaviour (note most scales/assessment tools for non-verbal patients, even those called pain scales, are behaviour observation tools)
  - Facial expression
  - Rubbing / guarding / bracing
  - Vocalization
  - Restlessness
- Observe and document effect of interventions (differentiate sedation, as distress may settle if patient is sedated with an opioid or other drug)
- Familiarity – enlist knowledge of formal / informal carers

Assessment Tools

- Non-verbal patients
- Short term memory
- Behaviour assessment

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- Behaviour assessment – distress observation, not just pain
  - Pain
  - Toileting
  - Fear
  - Anxiety
  - Nausea

Eating and drinking in Dementia

- Ability to swallow reduces
- Feeding, including self-feeding (Irish National Audit Dementia recommends a full menu of finger food)
- Reduction in oral intake may be temporary and reversible; may be associated with anorexia, nausea, dyspepsia, sore mouth, constipation, infection (including simple viral infection)
- A time-limited or purpose-limited trial of artificial nutrition and hydration may be warranted

Dysphagia

- 13-57% incidence; earlier onset in Alzheimer type than in frontotemporal dementia
- Limited evidence of the value of altered consistency of food/fluids
- No evidence to support use of gastrostomies
- Greater rates of swallowing problems in patients associated with more advanced dementia
- Swallowing difficulties associated with reduced skeletal muscle mass

Takagi et al https://doi.org/10.1111/ggi.12728

Flynn et al https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011077.pub2/full

Algiakrishnan et al systematic review https://doi.org/10.1016/j.archger.2012.04.011

Challenges

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- ‘Orphan’ patients

Challenges

- ‘Orphan’ patients - ? A medical diagnosis ? A psychiatric diagnosis
- ‘Orphan’ symptoms - BPSD – very difficult to manage at home, or in acute hospital setting

Challenges

- ‘Orphan’ patients
- ‘Orphan’ symptoms –BPSD
- Prognostic uncertainty – acute deteriorations because of intercurrent problems e.g. infection, causing delirium, reduced oral intake, renal impairment

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- Lack of knowledge

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- Prognostic uncertainty
- Lack of knowledge
- Lack of integration

Palliative Care resources

- Palliative Care Clinical Programme – includes Model of Care, Competence Framework, Palliative Care Needs Assessment https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/
- All Ireland Institute for Hospice and Palliative Care – on-line education on the Palliative Hub https://aiihpc.org/our_work/the-palliative-hub/
- RCPI – on line course about communication and advance care planning https://courses.rcpi.ie/product?catalog=Advance-Care-Planning
- European Certificate for Essential Palliative Care, Our Lady's Hospice https://olh.ie/education-research/european-certificate-in-essential-palliative-care/
- Irish Hospice Foundation https://hospicefoundation.ie/
- Advance Care Planning for patients - Let Me Decide http://www.letmedecide.org/about-us

Thank you