






## End of Life Care Planning and Information Handover Amongst Dementia Patients Awaiting Long Term Care

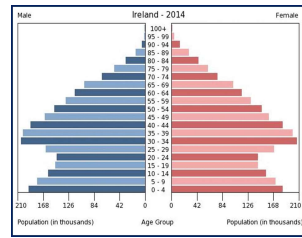
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## Background

- Ireland's population is ageing
- 47,000 people living with dementia  
→ expected to treble in coming 3 decades




Ireland - 2014  
Male (left), Female (right)  
Age Group (95-99 to 0-4)  
Population (in thousands)

**The majority will die in either acute hospitals or long-term care facilities**

de Siun 2014, Dempsey, Dowling et al. 2015, Reyniers, Delliens et al. 2015

## Background



- Needs unrecognised
- At risk of inappropriate prescription of antipsychotics
- Vulnerable to burdensome interventions at end of life
  - ? Increased mortality

## Background

Needs in advanced dementia include

- Impaired speech and swallow
- Gait impairment
- Incontinence
- Loss of appetite, weight, muscle mass
- Pain
- Dyspnoea
- Behavioural and Psychological Symptoms of Dementia (BPSD)

McCarthy, Addington-Hall et al. 1997, Mitchell, Teno et al. 2009, Hughes, Jolley et al. 2007, Birch and Draper 2008


## Background

At end of life people with dementia receive different care

- Pain under-treated
- More likely to have invasive procedures
- Spiritual concerns neglected
- High levels of unmet needs amongst carers
- Less likely to be referred for specialist palliative care input

Lloyd-Williams 1996, Everett 1999, Morrison and Siu 2000, Sampson, Gould et al. 2006, Hennings, Froggatt et al. 2010

## Background

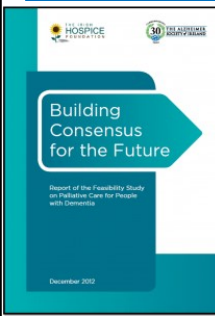


Culture  
Cognitive disability

Difficulty knowing when end of life is near  
Poor awareness among carers and clinicians of the life-limiting nature of dementia

Hughes, Jolley et al. 2007, Birch and Draper 2008, Ryan, Gardiner et al. 2012, Regan, Kearney et al. 2013, Brecher and West 2016

## Background




**THE IRISH NATIONAL DEMENTIA STRATEGY**

"Palliative Care should...be considered as having a role...from point of diagnosis through the trajectory of illness, to end of life and bereavement support for family members"

"Regular assessments of palliative care needs should be conducted by staff providing care to people with dementia"


## End of Life Care Planning and Information Handover Amongst Dementia Patients Awaiting Long Term Care



## Objectives

- Identify whether a palliative approach to EOLC planning is considered amongst dementia patients awaiting nursing home care
- Assess the quality of handover information on diagnosis and EOLC plan at key clinical transition points

## Methods

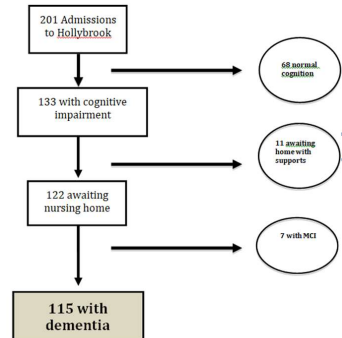


**Retrospective case note review**

**All patients with dementia admitted to HL from SJH to await nursing home care x 1 year**

**Palliative Care Needs Assessment Guidance and 2004 NICE guideline**

## Results

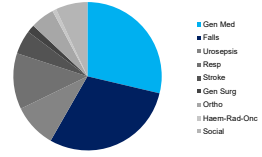
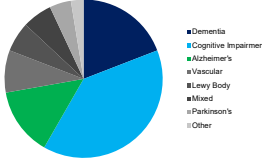


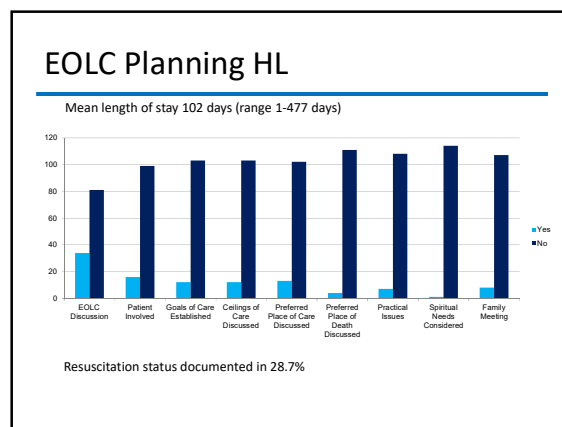
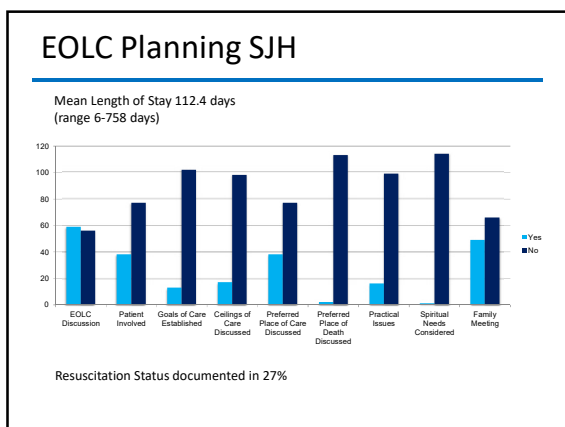
## Results

**Female 70%**  
**Male 30%**

**Mean age 83.7 years (range 62-98)**

**94% admitted from home**

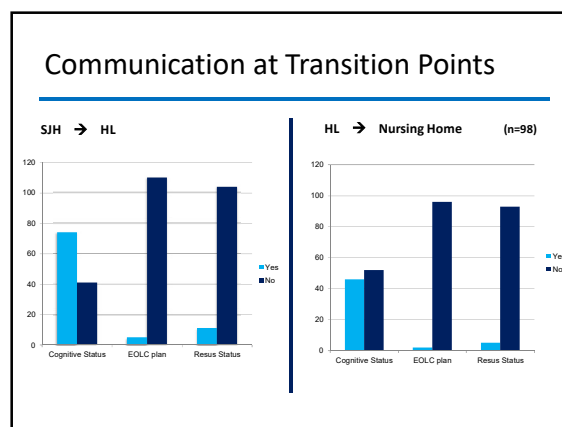


### Results

24 patients (21%) were re-admitted to SJH from HL:

- Falls 30%
- Respiratory Failure 30%
- General Medical 21%
- Others 19%

13 patients (11%) died following admission to HL



### Discussion

Among this group of people with dementia awaiting nursing home care, a palliative approach to end of life care planning was rare

- Inadequate communication between clinicians, patients and carers
- Limited involvement of the patient in decision-making
- A failure to hand over critical clinical information

### 1. Inadequate Communication

- EOLC discussion documented for 51% before discharge to HL
- Preferred place of death noted for just 2%
- 'Closed Awareness'

Costello 2001, Casey, Murphy et al. 2011

## 1. Inadequate Communication

- Goals and ceilings of care generally established over the phone with families following an acute deterioration in clinical condition
- Reactive rather than proactive approach

Dying well with dementia: qualitative examination of end-of-life care†

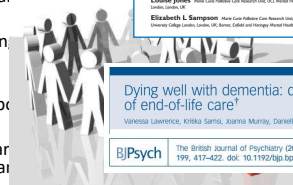
Vanessa Lawrence, Kritika Samsi, Joanna Murray, Danielle Harari and Sube Banerjee

BJPsych The British Journal of Psychiatry (2011) 199, 417-422. doi: 10.1192/bjp.bp.111.093989

## 2. Poor patient involvement

- One third of patients had direct input into their care while in SJH
- Decision-making
- Care planning diagnosis
- Concerns about
- Poor familial palliative fra

Original Article  
**Preferences for end-of-life care: A nominal group study of people with dementia and their family carers**  
 Karen H Denzil, Vanessa Lawrence, Kritika Samsi, Joanna Murray, Danielle Harari and Sube Banerjee  
 Louise Jones, Elizabeth L Sampson



Dying well with dementia: qualitative examination of end-of-life care†  
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## 3. Poor clinical handover

SJH → HL	HL → NH
<ul style="list-style-type: none"> <li>• No cognitive dx for one third</li> <li>• EOLC plan handed over for 4%</li> <li>• Resus status documented for 10% (available for 27%)</li> </ul>	<ul style="list-style-type: none"> <li>• No cognitive dx for more than half</li> <li>• EOLC plan handed over for 2%</li> <li>• Resus status documented for 5%</li> </ul>

## 3. Poor clinical handover

The underdetection of cognitive impairment in nursing homes in the Dublin area. The need for on-going cognitive assessment  
 Suzanne Cahill, Ana M. Diaz-Ponce, Robert F. Coen, Cathal Walsh  
 Age and Ageing, Volume 39, Issue 1, 1 January 2010, Pages 128-131, https://doi.org/10.1093/ageing/afp198  
 Published: 20 November 2009

Prevalence of dementia 89%  
 32% had a diagnosis of dementia  
 65% of those nurses considered cognitively intact had dementia

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY  
 An International Journal of Geriatric Psychiatry  
 Published online in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/gps.779  
 The recognition of dementia in 'non-EMI' nursing home residents in South East England  
 A. J. D. Macdonald\* and G. I. Carpenter<sup>2,3</sup>

Prevalence of dementia 65%  
 35% of these were recognised by nurses as having dementia

## Conclusions

- Specific challenges associated with EOLC in dementia
- The shift toward a palliative approach to dementia care has yet to occur in Ireland
- Opportunities to provide the best quality of care are being missed
- Critical need for staff training

## Limitations

- Small numbers
- Single site
- Indirect method of determining dementia dx
- Case note review

## Strengths

- Real world view
- First study of its kind in Irish setting
- First in international literature to look at quality of clinical handover

THANK YOU



**QUESTIONS**