End of Life and Palliative Care for people with dementia in an Acute Hospital.

Jean Barber CNS Palliative Care / CNS Gerontology
Patients with dementia receive the same end of life care as all other patients in an acute hospital.

We use a "End of Life Care Map" in St Michaels Hospital: includes initial assessment, ongoing assessment, nursing care, communication and anticipatory prescribing.
End of Life Care – Dementia.

Three main challenges exist:
1) Diagnosing dying,
2) Dysphagia,
3) Pain assessment and management.
Patient presents in an acute hospital with confusion and is acutely ill:

- Elderly, co morbidities++
- What is the patients baseline?
- Has the patient been officially diagnosed with dementia?
- How advanced is the disease?
Major obstacle in an Acute Hospital.

- Transfer from Home – family supply information.
- Generic “Nursing Home to Acute Hospital” transfer letter – SVHG, South Dublin.
- Need accurate baseline information in order to make crucial medical decisions.
# Nursing Home to Acute Hospital (SVHG) Transfer Letter

## Personal Information
- **Name:**
- **DOB:**
- **Specified NOK:**
- **NOK Phone No.:**

## Primary Care Information
- **Nursing Home:**
- **Phone Number:**
- **Fax Number:**
- **GP Name:**
- **GP Phone No.:**

## Medical Information
### Referral reason:
- Medicines list attached *(please circle)*: Y / N
- Medical History attached *(please circle)*: Y / N
- DNR order attached *(please circle)*: Y / N
- Advanced Care Directive attached *(please circle)*: Y / N
- Infection Risk e.g. MRSA *(please circle)*: Y / N *(Please attach eradication protocol and recent results)*

## Physical Information
### Mobility *(please circle):*
- Independent
- Stick
- Frame
- Assistance 1 or 2
- Wheelchair
- Immobile

### Transfers *(please circle):*
- Independent
- Assistance 1 or 2
- Standing Hoist
- Full Hoist

### Falls risk *(please circle):*
- Low
- Medium
- High

### Functional level (Barthel):
- If unsure, please describe:
- Score: / 20

### Skin Integrity *(please circle):*
- Intact
- Grade 1
- Grade 2
- Grade 3
- Grade 4

### Location (if applicable):
- Waterlow Score: / 47

### Nutrition:
- Weight: **___** kgs
- MUST Score:

### Diet Modification *(please circle):*
- Diet:
- Fluids:
- Texture A Grade 1
- Texture B Grade 2
- Texture C Grade 3
- Texture D Grade 4

### If unsure please describe:

### Continence *(please circle):*
- Incontinent of urine:
- Incontinent of bowel:
- Urinary catheter:
- Type:
- Day
- Night
- Day & night
- Next change date:
- Size:

### Cognition:
- If unsure please describe:
- MMSE / 30
- AMTS / 10

### Communication *(please circle):*
- Normal
- Functional verbal communication
- Limited verbal
- No verbal
- Accompanying patient *(please circle):*
- Spectacles
- Hearing Aid
- Dentures
- *(Please attach separately)*

## Signed:
- **Grade:**
- **Date:**

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*SVHG Nursing Home transfer letter July 2012*
Dysphagia – difficulty in swallowing.

- Part of the dying process.
- *But*
- Dysphagia also occurs in advanced dementia – does not always signify that the patient is dying.
Nutrition and hydration.

- Dysphagia – what should you do?
- Is it due to dementia or is the patient dying?
- Patient may also have had a poor oral intake over a long period of time.
- Malnutrition and weight loss.
Nutrition and hydration

- Recurrent aspiration pneumonia: may be the cause of admission to acute hospital.
- Family worried may die from malnutrition.
- Pressure to do something.
- Need to make a decision.
Nutrition and hydration.

- Is the dysphagia transient? Background of infection?
- Is dysphagia due to advanced dementia?
- Is the patient dying?
- Should you give artificial nutritional support?

- Each scenario is different and should be treated as such.
Nutrition and hydration

- NGT feeding in advanced dementia:
  - Does not prolong life,
  - Does not improve pressure sore outcomes,
  - Does not reduce infection,
  - Does not improve functional status,
  - Is a risk factor for aspiration.

- Comfort feeding. Review by SALT: thickened food and fluids.
Inadequate control – less analgesia than their cognitively intact counterparts.
Yet, may have pressure sores, leg ulcers, arthritis, back pain etc.
Present with challenging behaviour: e.g. aggressive, agitated.
Put down as part of their dementia and not a indication of pain.
Self report when mild to moderate dementia.

Family / carer report.

Objective assessment – PAINAD Tool.

Many tools available (Abbey Pain Scale, PACSLAC, DisDAT)

Observe current behaviour and non verbal communication.

Analgesic trial to validate the presence of pain.

Observe subsequent behaviour.
# Pain assessment tool – PAINAD

**Pain assessment for patients who cannot verbalise.**

Total score range from 0 to 10 (based on a scale of 0 to 2 for 5 items), with a higher score indicating more severe pain.

(0 = no pain to 10 = severe pain).

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<tbody>
<tr>
<td>Normal</td>
<td>None.</td>
<td>Smiling or inexpressive.</td>
<td>Relaxed.</td>
<td>No need to console.</td>
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<tr>
<td>Occasional laboured breathing.</td>
<td>Occasional moan or groan. Low level speech with a negative or disapproving quality.</td>
<td>Sad. Frightened. Frown.</td>
<td>Tense. Distressed pacing. Fidgeting.</td>
<td>Distracted or reassured by voices or touch</td>
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<td>Noisy laboured breathing.</td>
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<td>Facial grimacing.</td>
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<td>Long period of hyperventilation.</td>
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<td>Cheyne-Stokes respirations.</td>
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PTO.
# Pain assessment tool

## Pain Scale

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- **(0)** No Pain.
- **(1-4)** Mild Pain.
- **(5-6)** Moderate Pain.
- **(7-9)** Severe Pain.
- **(10)** Unbearable Pain.

## Description of Pain:

- **(T)** Type: (A) Throbbing, (B) Shooting, (C) Stabbing, (D) Sharp, (E) Cramping, (F) Aching.
- **(D)** Duration: (1) Continuous, (2) Intermediate.

## Pain Assessment Sheet

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Family /carers.

- Exhausted.
- Recurrent episodes of hospital admissions.
- Presented with difficult decisions.
Prognosis.

- Recurrent episodes of aspiration pneumonia can lead to numerous hospital admissions.
- Very difficult to decide if this particular admission is going to be the last one.
- Dying a longer process than for a person who does not have dementia??
- Advanced Directives??
- Physician Orders for Scope of Treatment – USA ??