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

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End of Life Care – Dementia.

- 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.

Decision making – information.

- 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.
- Transfer from Nursing Home – quality of information sent. Varies – audit.
- Generic "Nursing Home to Acute Hospital" transfer letter – SVHG, South Dublin.
- Need accurate baseline information in order to make crucial medical decisions.

Nursing Home Transfer letter.

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): ___ / 20
If unsure, please describe:

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: Normal Texture A Texture B Texture C Texture D
Fluids: Normal Grade 1 Grade 2 Grade 3 Grade 4
If unsure please describe:

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

Cognition: MMSE __/ 30 AMTS __/ 10
If unsure please describe:

Communication *(please circle)*: Normal Functional verbal communication Limited verbal No verbal
Accompanying patient *(please circle)*: Spectacles Hearing Aid Dentures
Any other relevant information incl. *(please circle)* : Y / N (*Please attach separately*)

Signed: Grade: Date:

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 to 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.

Challenge – assessing pain

- 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.

Pain assessment tools.

- 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

St. Michael's Hospital

Addressograph.

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).

Breathing independent of vocalization.	
Normal	0
Occasional laboured breathing. Short periods of hyperventilation.	1
Noisy laboured breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	2

Negative vocalization.	
None.	0
Occasional moan or groan. Low level speech with a negative or disapproving quality.	1
Repeated troubled calling out. Loud moaning or groaning. Crying.	2

Facial expression.	
Smiling or inexpressive.	0
Sad. Frightened. Frown.	1
Facial grimacing.	2

Body language.	
Relaxed.	0
Tense. Distressed pacing. Fidgeting.	1
Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	2

Consolability.	
No need to console.	0
Distracted or reassured by voices or touch	1
Unable to console, distract or reassure.	2

0 1 2 3 4 5 6 7 8 9 10

PTO.

Pain assessment tool

PAIN SCALE.

0 1 2 3 4 5 6 7 8 9 10

(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.

Date.	Time.	Location Of Pain.	Pain Score	Description Of Pain.		Analgesia Used.	Evaluation of Pain Relief.		If Not Relieved Action Taken.	Sig.
			No Pain.	T.	D.		Time.	Score.		

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 ??