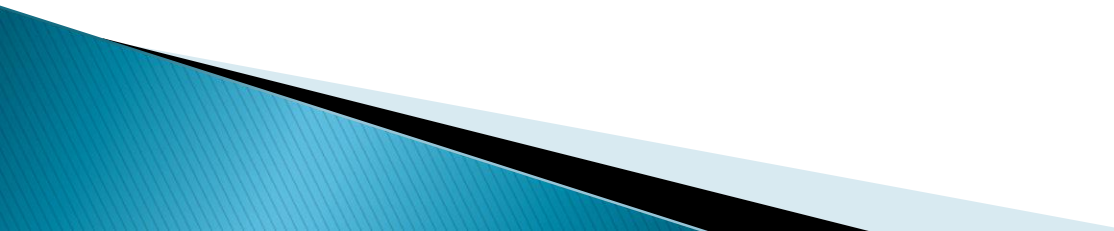


End of Life and Palliative Care for people with dementia in an Acute Hospital.

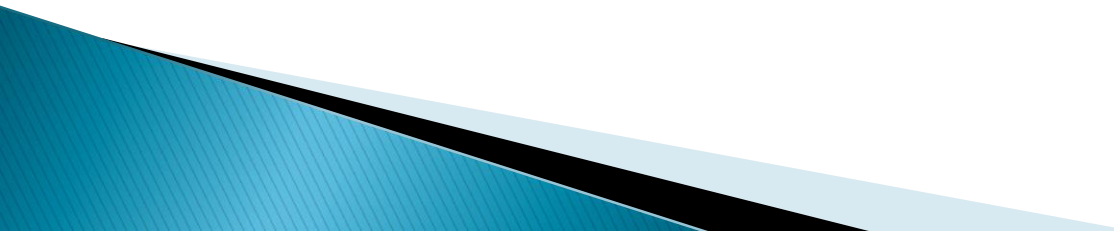
Jean Barber CNS Palliative Care
/ CNS Gerontology



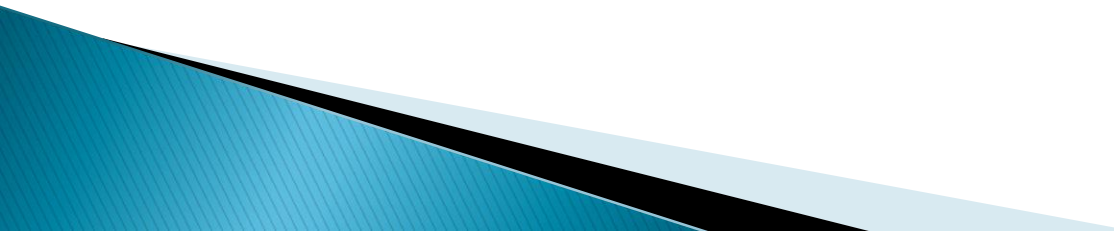
End of Life Care – Dementia.

- ▶ 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.
- 

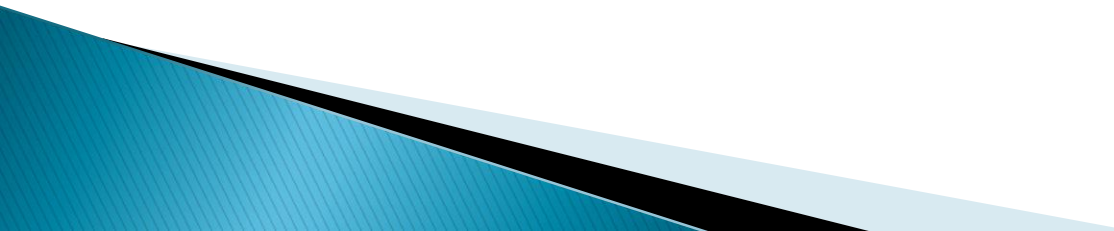
End of Life Care – Dementia.

- ▶ 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**)

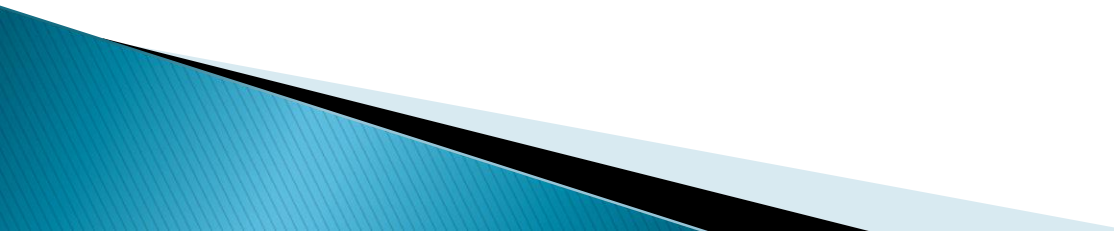
Physical Information

Mobility (<i>please circle</i>):	Independent	Stick	Frame	Assistance 1 or 2	Wheelchair	Immobile
Transfers (<i>please circle</i>):	Independent	Assistance 1 or 2		Standing Hoist	Full Hoist	
Falls risk (<i>please circle</i>):	Low	Medium		High		
Functional level (Barthel): <i>If unsure, please describe:</i>	___ / 20					
Skin Integrity (<i>please circle</i>):	Intact	Grade 1	Grade 2	Grade 3	Grade 4	
Location (if applicable):				Waterlow Score: ___ / 47		
Nutrition:	Weight ____ kgs			MUST Score:		
Diet Modification (<i>please circle</i>):	Diet: Normal	Texture A		Texture B	Texture C	Texture D
<i>If unsure please describe:</i>	Fluids: Normal	Grade 1		Grade 2	Grade 3	Grade 4
Continence (<i>please circle</i>):	Incontinent of urine:		Day	Night	Day & night	
	Incontinent of bowel:		Day	Night	Day & night	
	Urinary catheter:		Y / N	Next change date:		
	Type:		Size:			
Cognition: <i>If unsure please describe:</i>	MMSE ___ / 30			AMTS ___ / 10		
Communication (<i>please circle</i>):	Normal	Functional verbal communication		Limited verbal		
Accompanying patient (<i>please circle</i>):		Spectacles	Hearing Aid	Dentures		
Any other relevant information incl. (<i>please circle</i>) : Y / N (<i>Please attach separately</i>)						

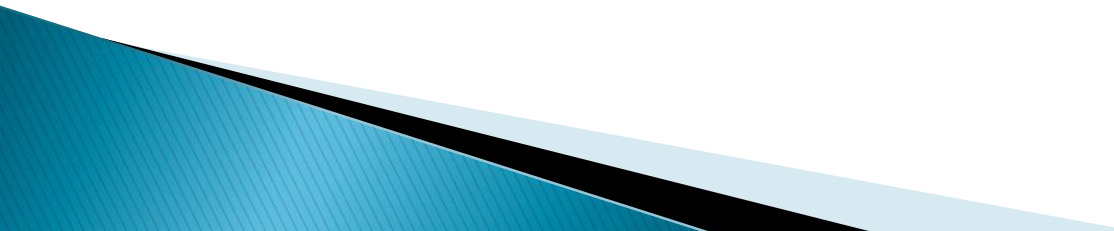
Signed: _____ Grade: _____ Date: _____

SVHG Nursing Home transfer letter July 2012

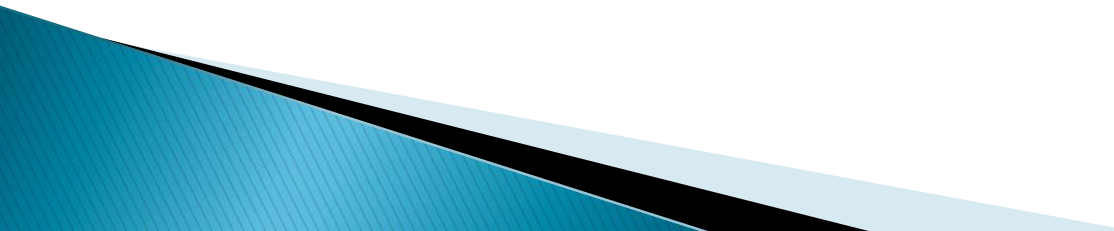
Dysphagia – difficulty in swallowing.

- ▶ 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.
- 

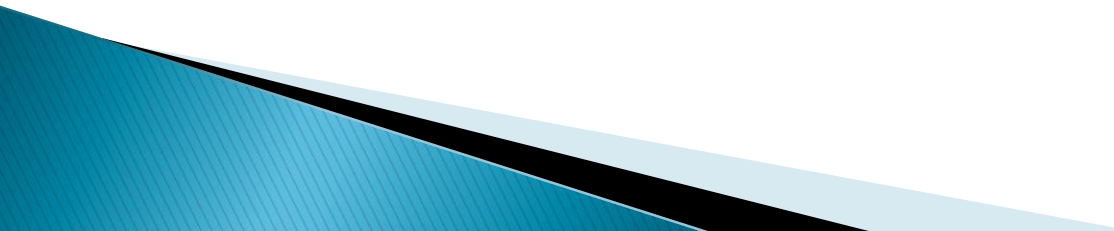
Nutrition and hydration.

- ▶ 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 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.		Negative vocalization.		Facial expression.		Body language.		Consolability.	
Normal	0	None.	0	Smiling or inexpressive.	0	Relaxed.	0	No need to console.	0
Occasional laboured breathing. Short periods of hyperventilation.	1	Occasional moan or groan. Low level speech with a negative or disapproving quality.	1	Sad. Frightened. Frown.	1	Tense. Distressed pacing. Fidgeting.	1	Distracted or reassured by voices or touch	1
Noisy laboured breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	2	Repeated troubled calling out. Loud moaning or groaning. Crying.	2	Facial grimacing.	2	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	2	Unable to console, distract or reassure.	2



PTO.

Pain assessment tool

PAIN SCALE.

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

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

Description of Pain: (1) Type: (A) Throbbing. (B) Shooting. (C) Stabbing. (D) Sharp. (E) Cramping. (F) Aching.
(D) Duration: (1) Continuous. (2) Intermediate.

[illegible]

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 ??
- 