

# Supporting Nutrition in the Later Stages of Dementia

National  
Intellectual Disability  
Memory Service

18<sup>th</sup> May, 2021



## Speakers:

**Michelle Hurley, Senior Dietitian, Cope Foundation, Cork**

**Jenna Pyne, Senior Speech and Language Therapist, Cope Foundation, Cork**

# Format of Presentation

National  
Intellectual Disability  
Memory Service

1. Importance of Good Nutrition
2. Nutritional Challenges in the Early and Middle Stages of Dementia
3. Strategies to support Good Nutrition during these stages
4. Nutritional Challenges in Later Stages
5. Assistance with Eating/Comfort Care
6. Tube Feeding
7. End of Life care



# Importance of Good Nutrition

National  
Intellectual Disability  
Memory Service



Good nutrition means that your body gets all the nutrients it requires to work at its best.



It requires a varied diet with recommended portions from the different food groups represented on the food pyramid.



Required to maintain a healthy weight.  
Prevent illness  
Prevent malnutrition

# Consequences of Malnutrition

National  
Intellectual Disability  
Memory Service

- Increased risk of infection
- Increased hospitalisations and delayed recovery
- Increased mortality
- Poor wound healing
- Respiratory and cardiac difficulties
- Musculo-skeletal difficulties
- Depression, confusion & memory loss



# Nutritional Issues in Early Stage Dementia

National  
Intellectual Disability  
Memory Service



Reduction in the variety  
of foods eaten & changes  
in food preferences

Forgetting to eat or  
drink

## Goals:

**Maintain independence**  
**Maintain nutritional status**

Weight loss

Trouble with meal &  
snack preparation /  
reduction in feeding skills

# Advice for Carers

National  
Intellectual Disability  
Memory Service



Monthly weights  
and nutrition  
screening

Encouragement  
and assistance

3 balanced meals  
and snacks

Variety of foods

Fluids

Food First  
approach

Food fortification  
/ Oral Nutritional  
Supplements

Management of  
Overweight

Referral to  
Dietitian if  
necessary

FEDS +  
Communication

Environment

Positioning +  
Adaptive  
equipment



# The Food Pyramid

National  
Intellectual Disability  
Memory Service

Healthy Food for Life

www.healthyireland.ie



## The Food Pyramid

For adults, teenagers and children aged five and over

Not needed for good health.

Foods and drinks high in fat, sugar and salt



NOT every day



Maximum once or twice a week

Needed for good health. Enjoy a variety every day.

Fats, spreads and oils



In very small amounts

Meat, poultry, fish, eggs, beans and nuts



2 Servings a day

Milk, yogurt and cheese



3 Servings a day  
5 for children age 9-12 and teenagers age 13-18

Wholemeal cereals and breads, potatoes, pasta and rice



3-5\* Servings a day  
Up to 7\* for teenage boys and men age 19-50

Vegetables, salad and fruit



5-7 Servings a day

\*Daily Servings Guide – wholemeal cereals and breads, potatoes, pasta and rice

Active	Child (5-12)	Teenager (13-18)	Adult (19-50)	Adult (51+)	Inactive	Teenager (13-18)	Adult (19-50)	Adult (51+)
	3-4	4	4-5	3-4		3	3-4	3
	3-5	5-7	5-7	4-5		4-5	4-6	4

There is no guideline for inactive children as it is essential that all children are active.

Drink at least 8 cups of fluid a day – water is best



Get Active!

To maintain a healthy weight adults need at least 30 minutes a day of moderate activity on 5 days a week (or 150 minutes a week); children need to be active at a moderate to vigorous level for at least 60 minutes every day.

# Nutritional Issues as Dementia progresses – middle stage

National  
Intellectual Disability  
Memory Service

Forgetting to eat and drink  
Reduced attention span at mealtimes  
Distracted by patterns

Loss of interest in food  
Reduced sense of smell  
Taste changes

**Goal: Keep the person  
nourished and hydrated**

Loss of ability to use cutlery  
Unable to communicate  
hunger

Increase/decrease in activity  
levels; positioning difficulties  
FEDS difficulties  
Weight loss / malnutrition



# Managing Poor Intake / Weight Loss

National  
Intellectual Disability  
Memory Service

Monthly weights  
and nutrition  
screening

Little & often

Time of day that  
suits the person

Adequate fluids  
with focus on  
nourishing fluids

Protein  
twice daily

Carbohydrate  
sources for  
energy

Deserts/puddings  
twice daily

Finger foods /  
snacks

Favourite foods

Food fortification

Oral Nutritional  
Supplements

MDT involvement

# Changes in Taste and Food Preferences

National  
Intellectual Disability  
Memory Service

## **Taste changes occur for a number of reasons:**

- Part of brain responsible for taste / food preference may be affected
- Taste buds weaken as we get older

## **Preference for Sweet foods**

- Offer naturally sweet foods
- Sauces (eg. sweet and sour sauce, tomato sauce, cranberry sauce, etc), chutneys
- Fruit can be added to savoury foods
- Milk based deserts with jam/honey



# Nutritional Issues at Late Stage Dementia

National  
Intellectual Disability  
Memory Service

Unable to recognise food  
Holding food in the mouth

Food refusal

Inability to open mouth and  
turning head away when food  
is offered

## Goals:

To keep the person comfortable

To support the carer


Feeding, eating, drinking and  
swallowing difficulties

Dehydration  
Weight loss

Constipation  
Malnutrition

# Assistance with Eating / Comfort Care

National  
Intellectual Disability  
Memory Service



The person should be supported to eat and drink for as long as they show an interest and can do so safely.

MDT involvement to address changes to the environment; safety recommendations; etc.

Maintaining the person's dignity is a priority.

Ensure that the person assisting is well known to the person.

Present small spoonfuls of food/fluid. Allow the person lots of time.

# Assistance with Eating / Comfort Care

National  
Intellectual Disability  
Memory Service

Fatigue is common in late stage dementia, often resulting in very limited intake.

Offer favourite foods /fluids during periods of alertness.

Avoid low calorie, reduced fat or reduced sugar options. Instead include high fat, high sugar foods if accepted.

Oral nutritional supplements may be useful.

Recognise when the person does not want to eat or drink and honour this.

Remember that the goal is comfort care. Continued weight loss does not mean that you're not doing a great job.

# Tube Feeding

- When feeding problems and weight loss persist, a discussion re: artificial hydration and nutrition is often initiated by family or carers. \*\*\*\*\*Advance Care Planning
- At late stage Dementia, tube feeding has not been shown to extend life, improve nutritional status, reduce pressure sores or aspiration and may have some negative effects on quality of life.
- A person with dementia should not be tube fed (NG/PEG) if it is felt it would do more harm than good.



# End of Life

National  
Intellectual Disability  
Memory Service

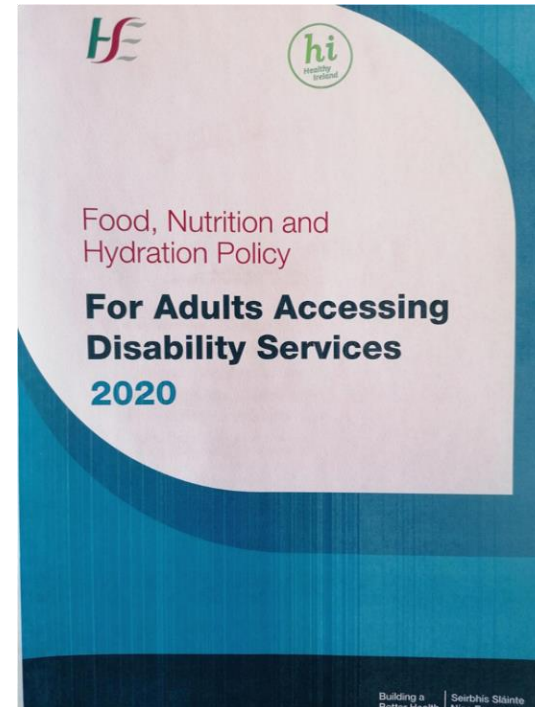
- As Dementia progresses, priority is quality of life and comfort, as well as the person's wishes (if previously stated).
- At this stage, the person will not meet their nutrition and hydration requirements - normal at end of life.
- As people with Dementia approach end of life, the body adapts physiologically and this prevents people from suffering.





# Resources

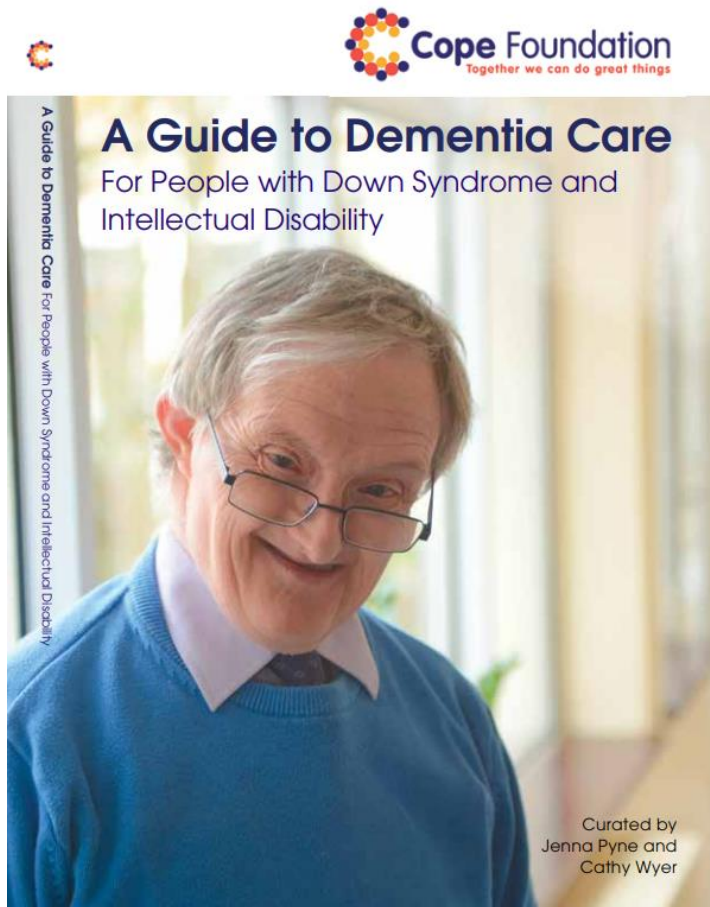
National  
Intellectual Disability  
Memory Service



- [Nutrition and Dementia Booklet March 2021 Update.pdf \(indi.ie\)](https://indi.ie/Nutrition%20and%20Dementia%20Booklet%20March%202021%20Update.pdf)
- [food-nutrition-and-hydration-policy-for-adults-accessing-disability-services1.pdf \(hse.ie\)](https://hse.ie/food-nutrition-and-hydration-policy-for-adults-accessing-disability-services1.pdf)

# Resources

National  
Intellectual Disability  
Memory Service



[Guide to Dementia Care \(cope-foundation.ie\)](http://cope-foundation.ie)



National  
Intellectual Disability  
Memory Service

# Supporting Nutrition in the Later Stages of Dementia

**Jenna Pyne**

Senior Speech and Language Therapist  
Cope Foundation

**Michelle Hurley**

Senior Dietitian  
Cope Foundation

# Common Causes of Eating and Drinking Issues in Dementia

National  
Intellectual Disability  
Memory Service

Dysphagia is described as difficulty moving food from mouth to stomach!

Physical

Sensory

Environmental

Poor oral hygiene

Medication

Communication and cognitive problems

# Risks of Eating and Drinking Issues in Dementia

National  
Intellectual Disability  
Memory Service



Dehydration

Poor appetite

Forgetting to eat

Weight loss and malnutrition

Swallowing difficulties

Aspiration pneumonia

Increased morbidity/mortality

# Difficulty Eating and Drinking in the Later Stages of Dementia: Signs

National  
Intellectual Disability  
Memory Service

## During/after meals

- Coughing or throat clearing
- Wet or gurgly voice
- Physically struggling with eating:
  - Difficulty placing food in mouth
  - Spilling food from mouth
  - Spitting out lumps
  - Holding food
  - Chewing for too long
  - Choking
  - Fatigue
- Food refusal

## Over time

- Avoiding certain foods
- Weight loss
- Dehydration
- Recurrent chest infections



# Case Example

- 61 year old woman with Down syndrome and late stage dementia
- LOMEDS
- Attended day service prior to changing needs
- Attended residential service Monday to Friday prior to COVID19, stayed with sister at weekends
- Lived with sister fulltime due to residential home closing
- Increased risk of falls due to seizure activity
- Challenging behaviours due to anxiety and agitation
- Change and loss of skills e.g. standing, mobility, difficulty processing information, change in swallow and feeding (dysphagia)



# Case Example

- Refusing food and fluids
- Weight loss
- Family anxiety
- Hospital admissions
  - Aspiration pneumonia
- Rapid deterioration over 6 months prior to death
- Continuously changing needs
- On-going input from MDT
  - To support client's changing profile
  - Offer family guidance and support
- End of life planning with GP and family

# Video

National  
Intellectual Disability  
Memory Service



# Strategies to support dementia and eating Issues

National  
Intellectual Disability  
Memory Service

The dining  
environment

Food to  
encourage

Flexibility

Food/fluid  
modification

WAITING

Modelling

Positive,  
simple  
language

Stop!



# Caregiver's experience in the later stages

National  
Intellectual Disability  
Memory Service

Guilt

Hopelessness

Frustration

Anxiety

Expectation

Grief

# Dementia and Eating Issues: Role of the Caregiver

National  
Intellectual Disability  
Memory Service



- Reduce distractions and facilitate a calm, safe, mealtime environment.
- Provide safe foods and drinks to the person, in line with MDT recommendations.
- Allow the individual to do as much self feeding as they can but provide assistance as appropriate.
- Offer cues and reassurance.
- Monitor food intake, note any food related changes or signs/symptoms of concern.

# Remember!

- Keep in mind the limitations of your role in feeding.

*The caregiver  
determines what foods  
are provided BUT the  
individual  
determines how much,  
when, and whether to  
eat what the caregiver  
provides.*

# Food for thought...

National  
Intellectual Disability  
Memory Service

- Monitor for changes:
  - Unusual eating and drinking patterns
  - Changes/concerns
  - Unplanned weight loss
- Consult with MDT or GP as appropriate to discuss the best and safest nutritional and feeding supports.
- Keep in mind the limitations of your role!



**Thank you for listening!**