

# Living Life with Dementia:

## Practical approaches to care



Enabling the mealtime experience for a person with  
Intellectual Disability and Dementia

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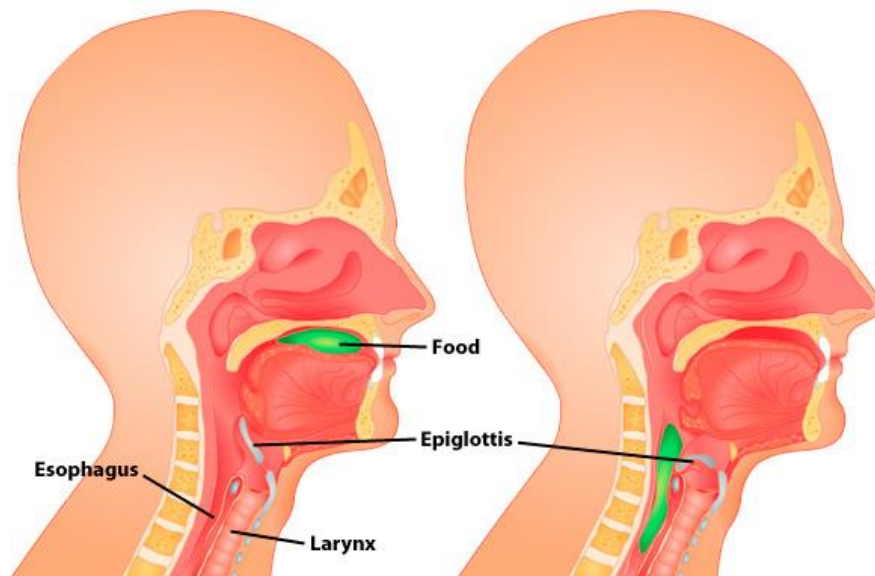
Speech and Language Therapist

Cathy Wyer

Occupational Therapist

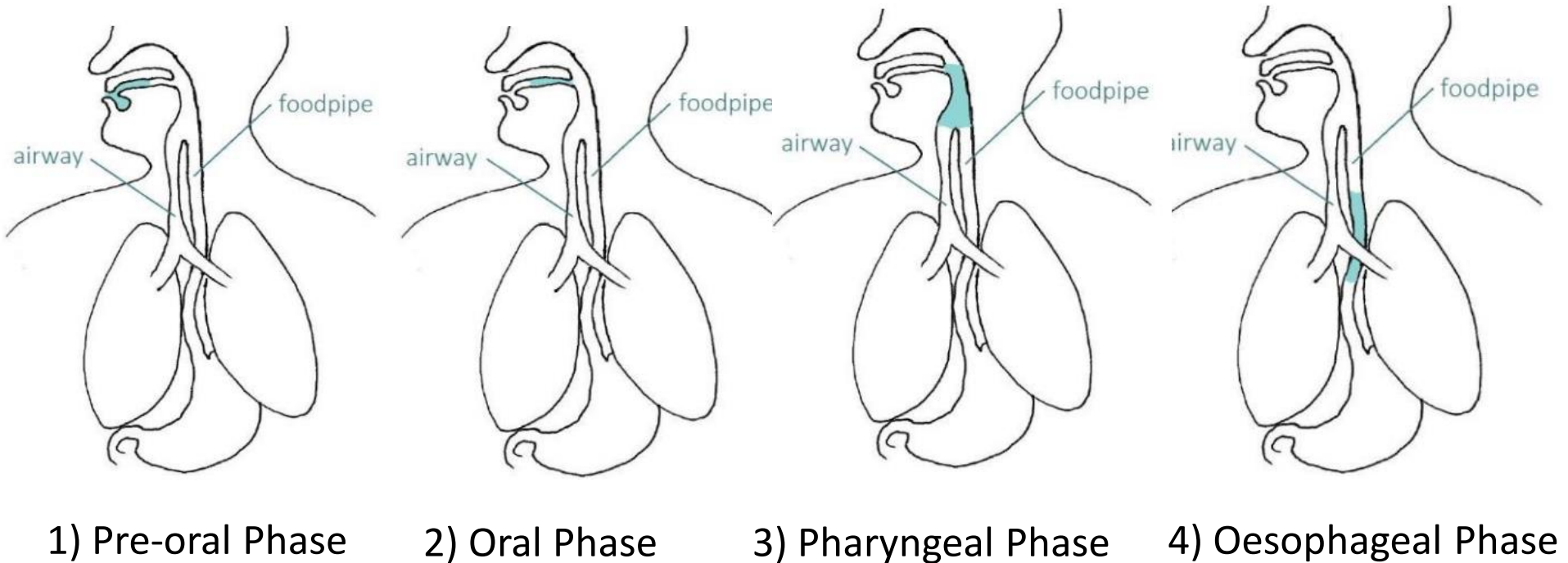
# What is feeding, eating, drinking and swallowing (FEDS)?

- **Feeding:** the physical act of bringing food/fluid to the mouth
- **Eating, drinking and swallowing:** process includes preparing food for swallow, moving it to the back of the mouth, triggering the swallow and getting the food safely past the airway



# Normal Swallow

Four main stages in the eating, drinking and swallowing process:



# What is Dysphagia?

- Dysphagia is described as difficulty moving food from mouth to stomach. (Logemann, 1998)
- Dysphagia can occur at any of the different stages of the swallowing process.
- Higher prevalence rates than within typical population. Prevalence of dysphagia is increased with severity of cognitive and physical disability. (Cichero, 2006)

# Common causes of dysphagia in ID and Dementia

Oral function

Physical

Sensory

Environment

Oral hygiene

Medication

Communication

Cognition

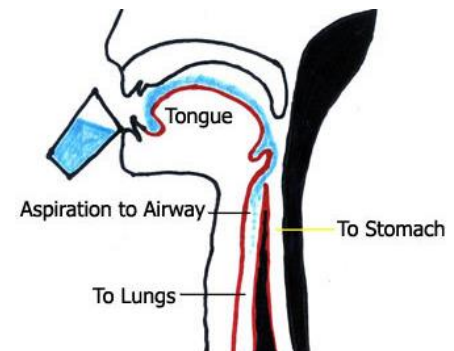
Swallow  
problems

Ageing

Poor feeding  
technique

# Risks of Dysphagia

- **Aspiration:** The accidental movement of food/fluid through the air passages and into the lungs
- **Asphyxiation:** Severely deficient supply of oxygen to the body due to abnormal breathing (e.g. choking)
- **Respiratory disease (recurrent chest infections)**, in particular aspiration pneumonia and asphyxia, have been identified as common causes of **death** in people with intellectual disability (Chadwick and Joliffe, 2009)
- **Dehydration/Malnutrition** - may lead to secondary issues such as infection, impaired wound healing, immune deficiency, dehydration
- Negative impact on a person's **quality of life** associated with dysphagia can include loss of personal dignity and reduced opportunity for choice making and communication around mealtimes (Chadwick 2006)
- Hospital admissions
- Increased **cost of care**
- Increased **Morbidity/Mortality**



# Signs and Symptoms of Dysphagia

## Overt

- ☐ Coughing before, during or after food/fluid
- ☐ Choking
- ☐ Throat clearing during/after food/fluid
- ☐ Runny/watery eyes and nose
- ☐ Gurgly or “wet” voice
- ☐ Multiple swallows
- ☐ Regurgitation
- ☐ Difficulty in placing food in mouth
- ☐ Difficulty chewing or preparing food to swallow
- ☐ Inability to control food or saliva in the mouth: spillage / drooling / spitting
- ☐ Oral residue after swallowing
- ☐ Holding food/fluid in mouth (pooling)
- ☐ Fatigue
- ☐ Food avoidance and/or fear of swallowing
- ☐ Fatigue
- ☐ Altered breathing during/after meals (rapid, gurgly or shortness of breath)

## Covert

- ☐ Weight Loss with no other reason identified
- ☐ Temperature changes
- ☐ Respiratory changes
- ☐ Dehydration



Chest infections/pneumonia

# Swallow assessment

- A swallowing assessment as part of the baseline measure of dementia would be best practice.
- Need for monitoring.

British Psychological Society (2015)





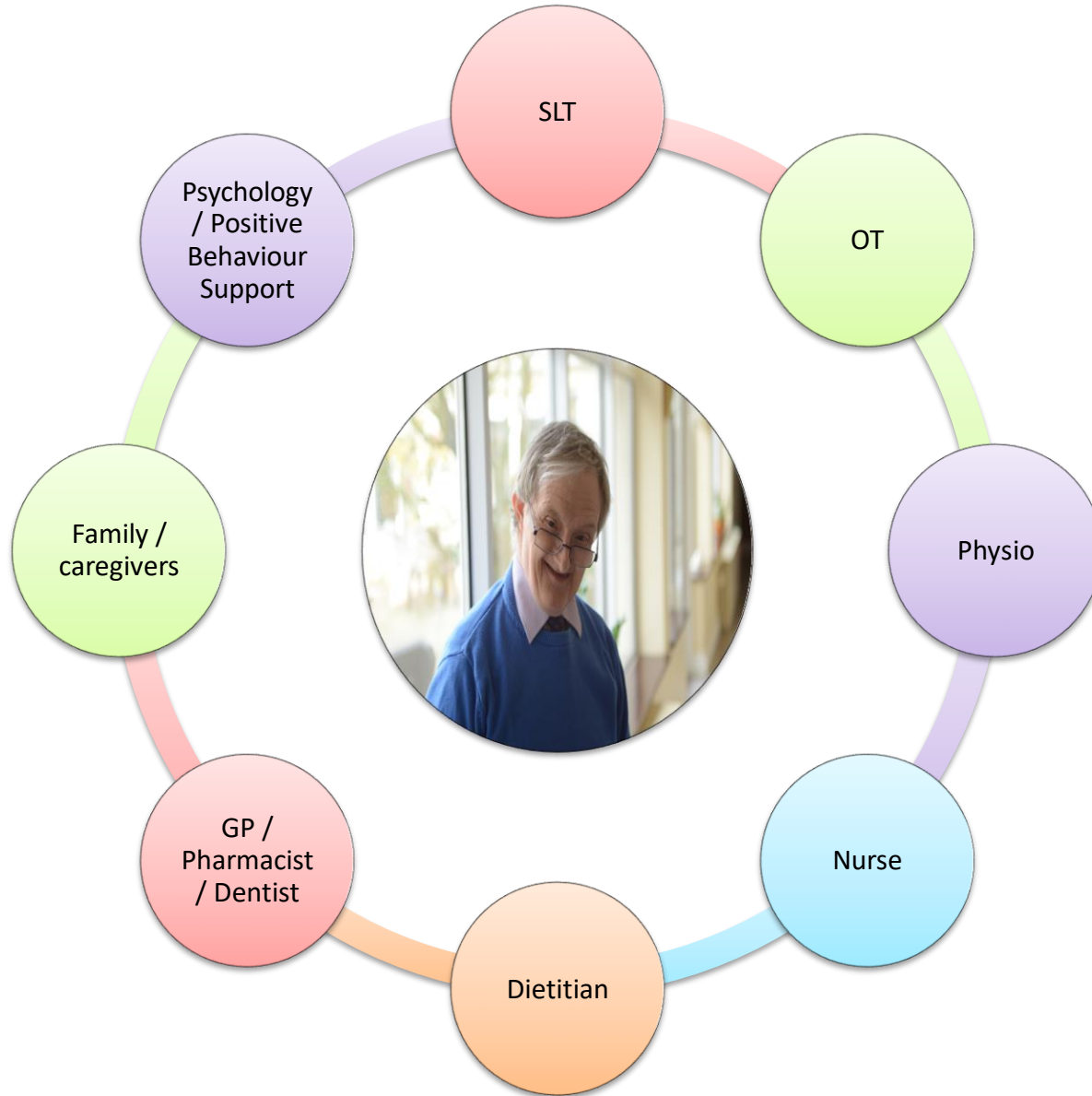
# Role of SLT in Dysphagia

- **Assess/diagnose** the person's dysphagia looking at the oral mechanism and swallow function for feeding
- **Make recommendations** to minimise the extent and effects of dysphagia for the individual i.e swallow care plan
  - Facilitate **safe** eating and drinking
  - **Minimise** risk of aspiration
  - **Maximise** quality of life
    - Least restrictive diet and fluids
    - Postural changes and equipment
- Consider communication supports at mealtimes
- Educate person, family/carers and staff

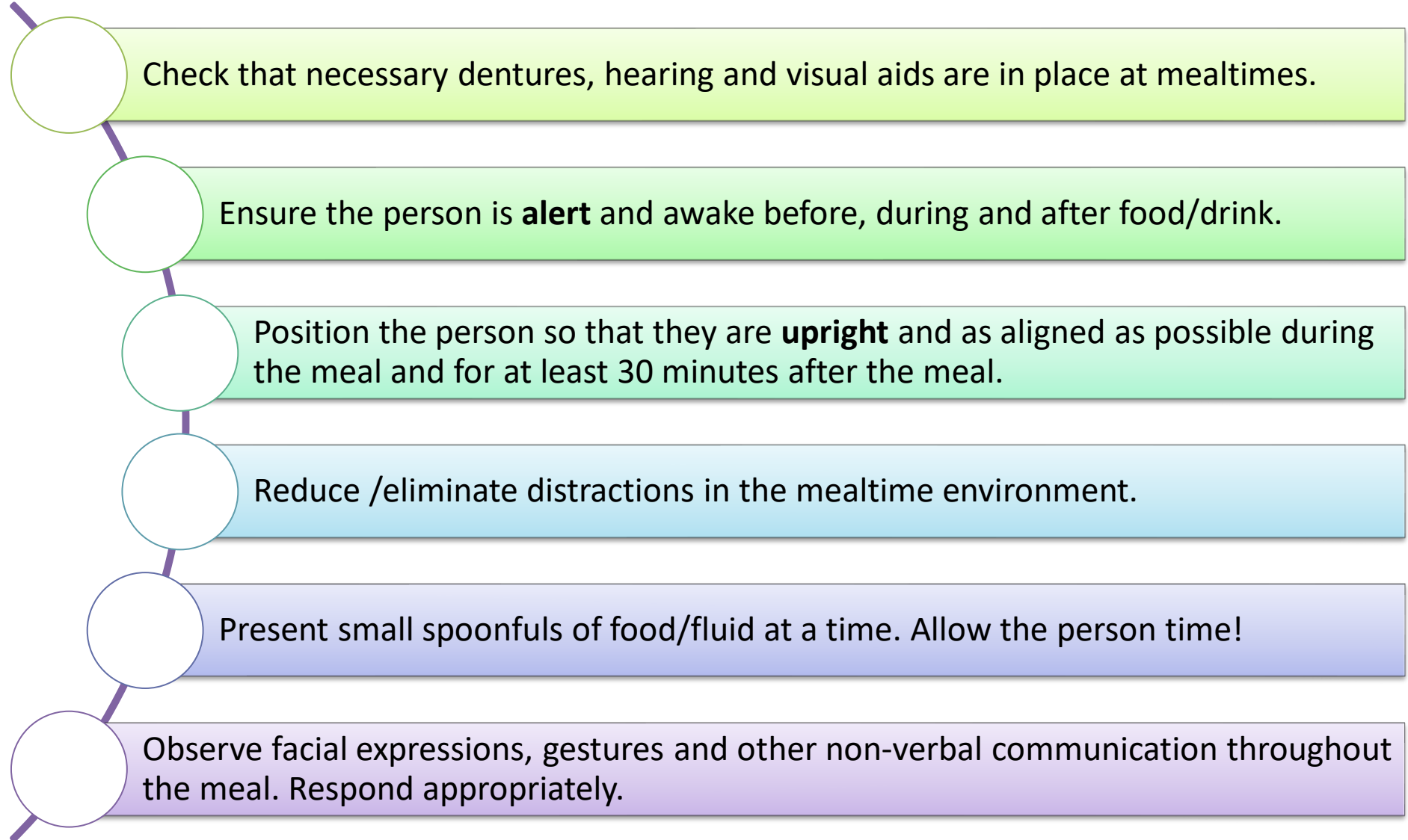


Often in collaboration with MDT, in line with best practice.

# Team Approach



# Safe feeding, eating, drinking and swallowing checklist



Check that necessary dentures, hearing and visual aids are in place at mealtimes.

Ensure the person is **alert** and awake before, during and after food/drink.

Position the person so that they are **upright** and as aligned as possible during the meal and for at least 30 minutes after the meal.

Reduce /eliminate distractions in the mealtime environment.

Present small spoonfuls of food/fluid at a time. Allow the person time!

Observe facial expressions, gestures and other non-verbal communication throughout the meal. Respond appropriately.

# Safe feeding, eating, drinking and swallowing checklist

**Little and often** over the course of the day rather than three large meals.

Suitable finger foods/snacks should be made available across the day for individuals who engage in physical activity e.g. pacing/ wandering.

Offer foods and drinks with high **flavours**.

Check for any food/drink left in the mouth.



Discontinue feeding if you observe coughing, choking, shortness of breath, watery eyes or a wet/'gurgly' voice.

Monitor the person's intake of food and drink.

# Things to consider

Environment

Independence  
vs assistance

Baseline skills

Positioning

Supervision

SLT guidelines:  
Food/fluid  
modification

Adaptive  
equipment

Cues: Verbal /  
visual / tactile

Pacing

Communication

Preference

Appearance/  
presentation of  
meals

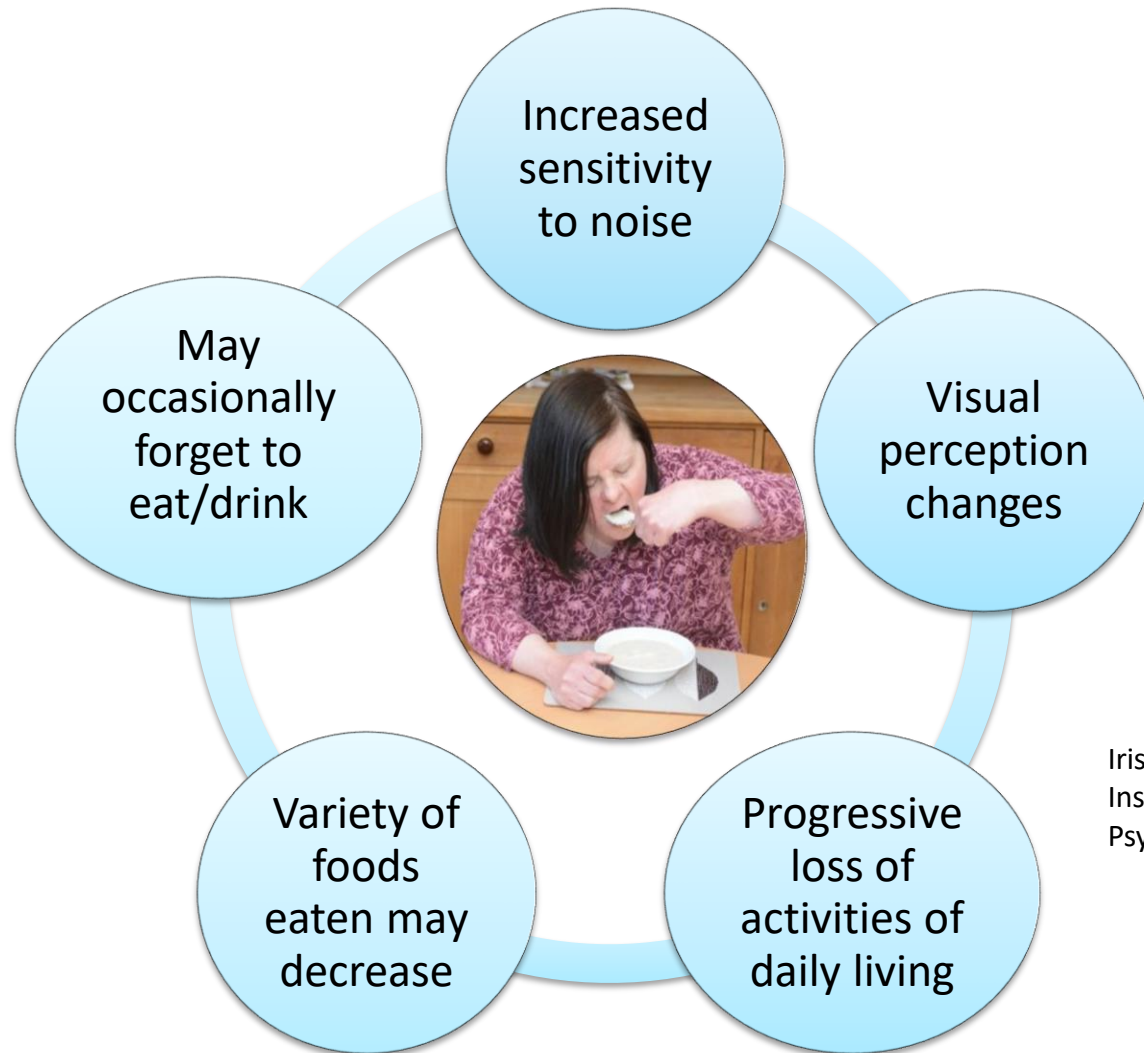
# Things to consider







# Early Stage: Enabling the mealtime experience for a person with Dementia, DS and ID



Irish Nutrition & Dietetic  
Institute 2015, British  
Psychological Society, 2015



# Early Stage: Supportive Mealtime Environment - Vision

## ISSUE:



## SOLUTION:

One block colour e.g. red/blue to contrast against tableware to minimise visual confusion

Avoid busy patterns on table cloths and aprons/bibs



# Early Stage: Supportive Mealtime Environment - Vision

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## ISSUE:

Unable to distinguish chair from table and floor



## SOLUTION:



Contrasting block colour cushion on chair



Contrasting block colour table cloth

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# Early Stage: Supportive Mealtime Environment - Noise

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## ISSUE:

Plates/cups/utensils on wooden table tops creates increased background noise

## SOLUTION:

Table mat/oil tablecloths that absorb noise

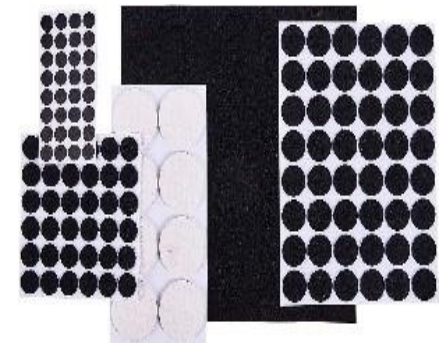
One block colour e.g. red/blue to contrast against tableware to minimise visual confusion



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Chair/table legs scraping on the floor when being moved

Fit felt pads under all chair legs/table legs



# Early Stage: Supportive Mealtime Environment - Noise

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**ISSUE:**

Background noise of TV/Radio

Multiple conversations going on/chatter etc.

Sounds reflect off hard surfaces, like walls, floors and ceilings

**SOLUTION:**

Turn off TV/Radio

Where possible, minimise conversations with others at mealtimes

Consider an alternative dining area or having staggered mealtimes

Consider low calming background music

Dampen down sound reverberation using pictures/art/wall hangings on the walls. This can help with sound absorption

Ensure all equipment is regularly serviced to minimise noise from wheels etc.

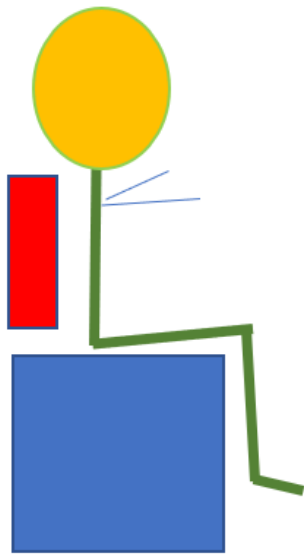
Use signage to remind staff/carers to keep noise levels down



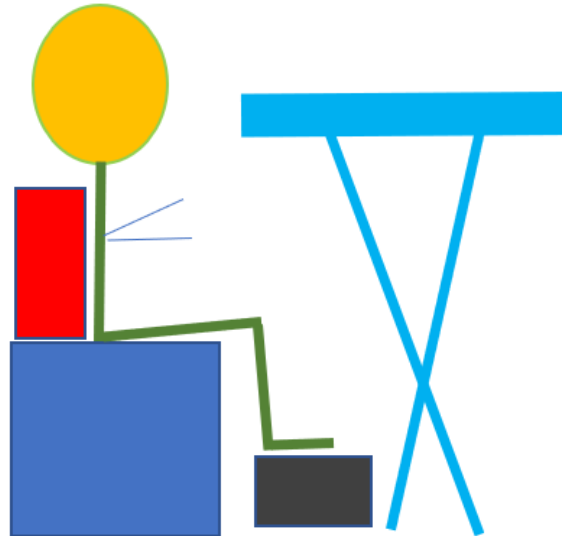
# Early Stage: Supportive Mealtime Environment - Posture



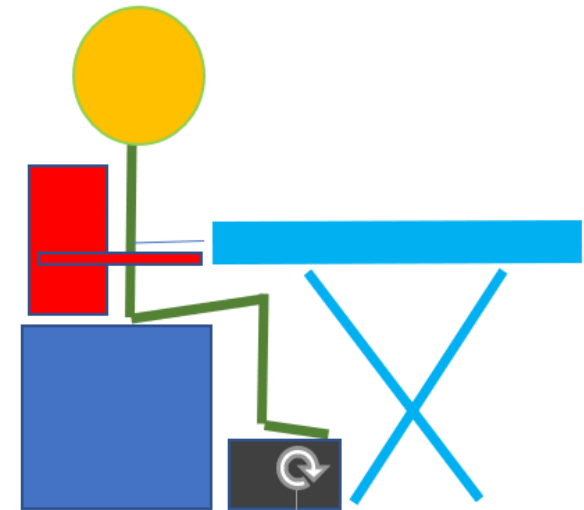
# Early Stage: Supportive Mealtime Environment - Positioning



- Feet are unsupported
- Back is unsupported

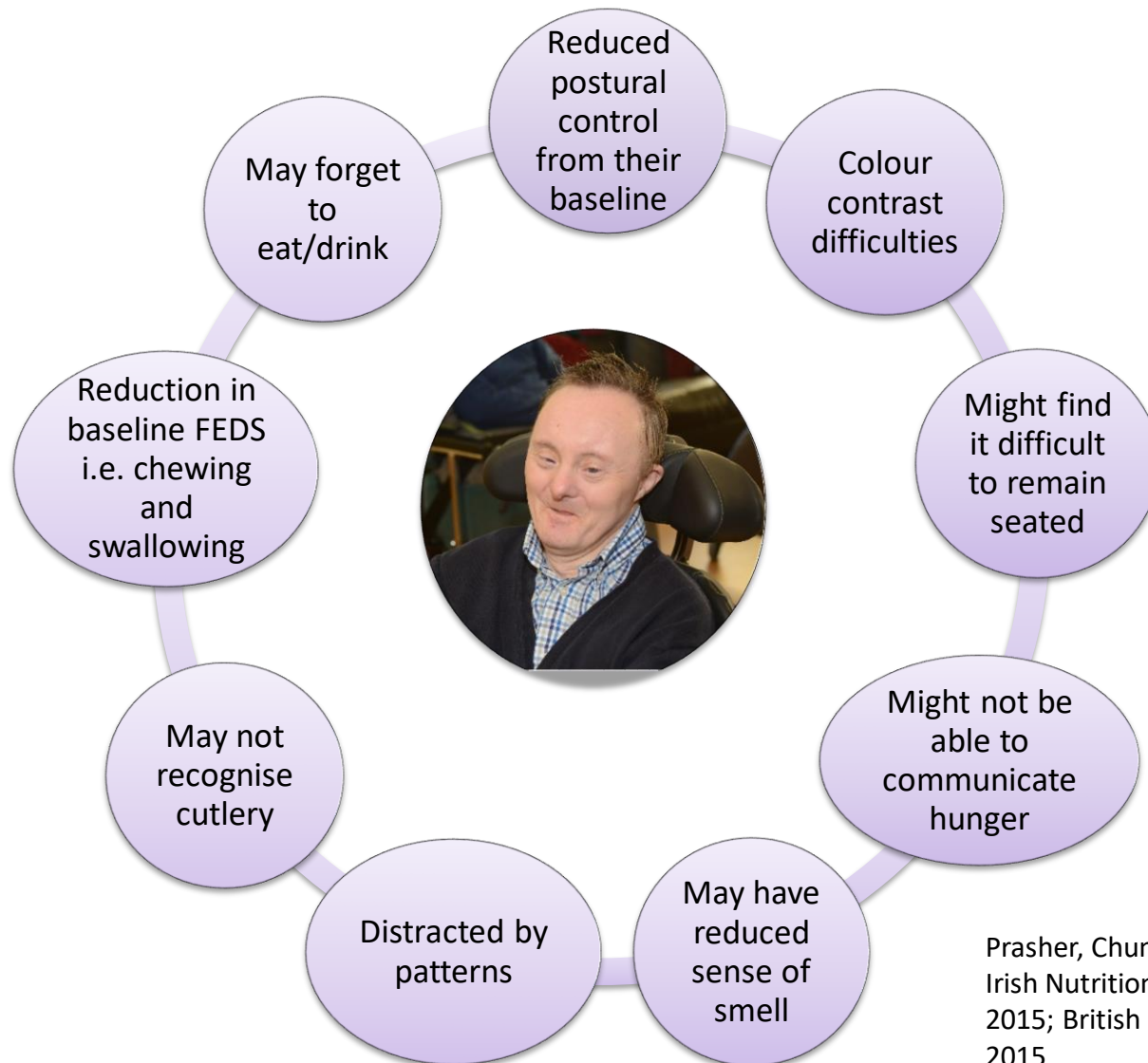


- Table is too high
- No armrests for those who need trunk support



- ✓ Stable base of support for the feet
- ✓ Back supported by backrest
- ✓ Armrests to provide arm and side support where required
- ✓ Table at correct height to promote access to mealtime equipment

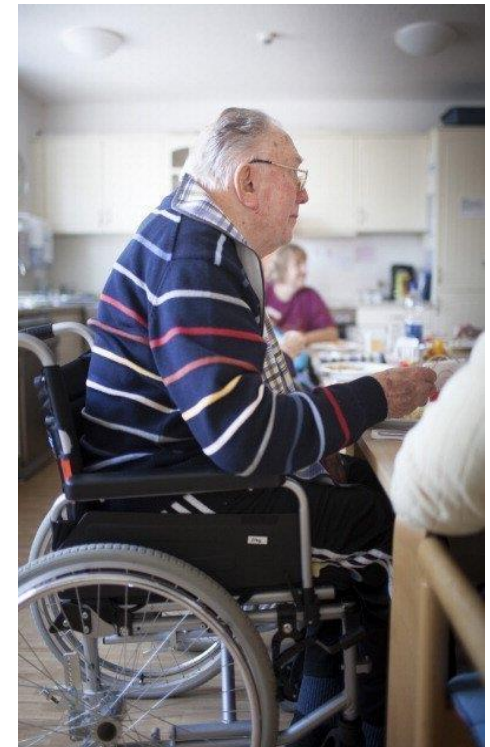
# Middle Stage: Enabling the mealtime experience for a person with Dementia, DS and ID



Prasher, Chung and Haque 1998,  
Irish Nutrition & Dietetic Institute  
2015; British Psychological Society,  
2015



# Middle Stage: Seating to promote maintenance of skills and safe feeding





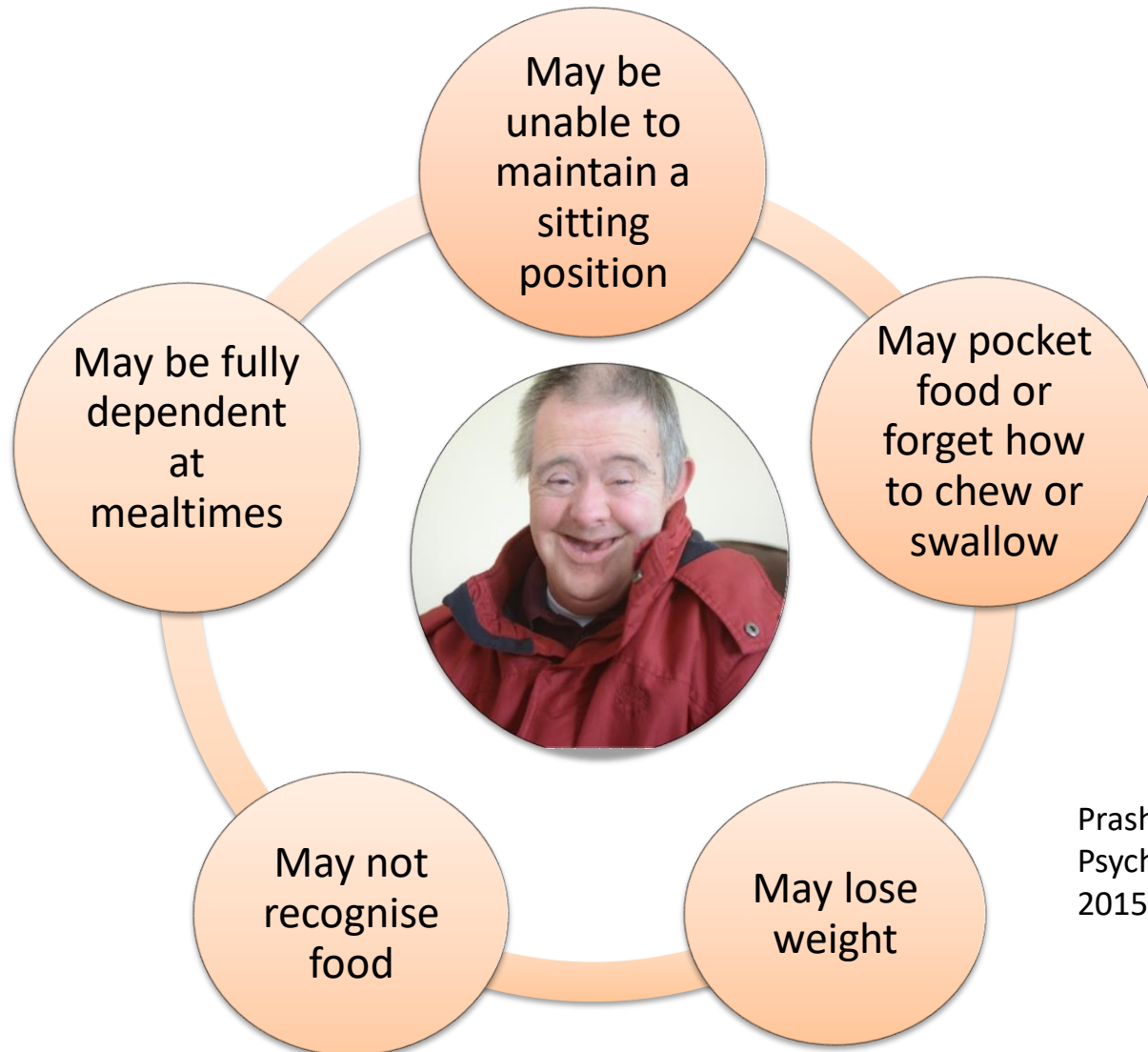
# Middle Stage: Adaptive Equipment

In the early to mid stages adaptive equipment may be appropriate, examples include:

- Foam handle spoon to support someone's grasp
- Plate/bowl with built up sides to help someone scoop food
- Dycem mat to stabilise a bowl



# Late Stage: Enabling the mealtime experience for a person with Dementia, DS and ID



Prasher, 1995; British Psychological Society, 2015

# Late Stage: Promoting fully supported safe feeding - Positioning

Tilt in space seating



Profiling bed:



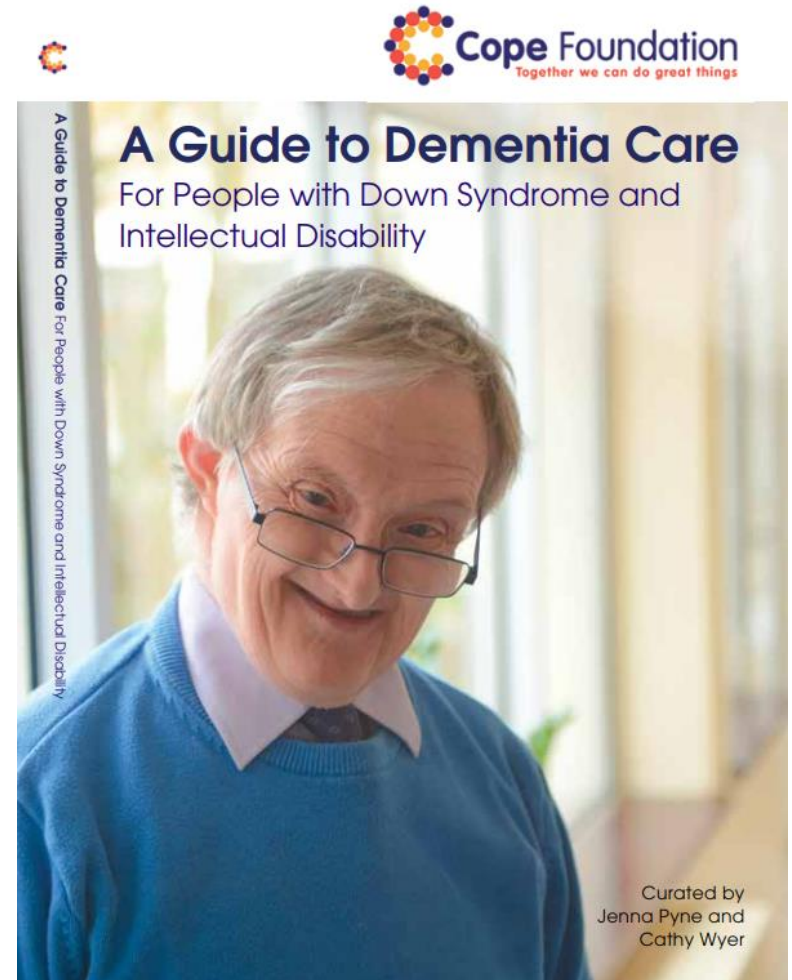
# Food for thought...

- Supporting someone with Down Syndrome or Intellectual Disability who has dysphagia and dementia presents a set of unique and difficult challenges.
- Remember to monitor for changes:
  - Deterioration in chest status
  - Signs or symptoms of aspiration
  - Unusual eating and drinking patterns
  - Weight loss
- Consult with medical and clinical therapy team as appropriate to discuss the best and safest dysphagia management, nutrition, and environmental supports.
- Acknowledge and respect the person's journey, in particular at late stage dementia.
- With the right training, knowledge, and support; caregivers and staff can significantly enhance the quality of life of someone with DS or ID with dementia.



# Thank you for listening!

*We hope our book proves to be a useful resource with practical approaches to support those who care for people with Down Syndrome or Intellectual Disability at risk of or who have Dementia.*





# References

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