

**Adult Speech and Language Therapy**

**EATING AND DRINKING WITH ACKNOWLEDGED RISK**

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| **Multi Professional Team Guidance for the Shared Decision Making Process in Adults with Oropharyngeal Dysphagia** |

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| **Applies To** | Adults with diagnosed oropharyngeal dysphagia being treated by health professionals working in Somerset Foundation Trust | **Exclusions** | Adults with eating and drinking difficulties associated with oesophageal impairmentsChildren under the age of 18 |

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1. **FLOW DIAGRAM**

 **Stage 1: Identification -** **Is the Patient A Candidate For Eating And Drinking With Acknowledged Risks?**

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| Shared decision making context relating to eating and drinking with risk identified\* (see 5.3). |

**Stage 2: Gather more information**

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| Establish the goal of intervention / care, for example active treatment, or end of life care etc. |

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| Establish whether an advanced care plan or eating and drinking with risk care plan is already in place. |

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| Document consent and capacity relating to understanding of the current difficulty / concern and capacity to consent to formal swallowing assessment. |

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| Referral to Speech and Language Therapy (SLT) if appropriate to carry out formal assessment of swallowing with consent (if person has capacity or in Best Interests if they don’t have capacity. SLT will document risks associated with eating and drinking and feed back to person with dysphagia and the wider MDT / appropriate colleagues. |

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| Determine whether CANH is appropriate – see Trust guidance on Supporting Decision Making Regarding Clinically Assisted Nutrition and Hydration(CANH). |

**Stage 3: Decision Making**

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| Person with dysphagia has capacity and makes their decision to be nil by mouth with CANH or to eat and drink with acknowledged risks, or a combination of both. |

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| Person’s capacity to consent to these recommendations is assessed and documented. |

**OR**

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| The patient lacks capacity, but a best interests MDT discussion has taken place that has concluded that the person will be nil by mouth with CAHN or they should eat and drink with acknowledged risks |

All decisions to be fully documented in person’s records, and fully communicated with relevant family, carers and health professionals.

**Stage 4: Implementation and Communication**

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| Document agreed recommendations and strategies to support oral intake with acknowledged risk. If SLT involved, they will produce a written eating and drinking with risk care plan. Medical team or GP to document suggested management strategies in the event of deterioration, e.g. chest physiotherapy; parenteral fluids; antibiotics; symptom control measures. |

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| Whoever is involved in the process needs to ensure the plan is communicated with all relevant health professionals across community and acute based care. |

**2.0 INTRODUCTION**

2.1Oropharyngeal dysphagia can affect people of all ages, genders, race, economic backgrounds and protected groups. This guidance document is intended to ensure that people with oropharyngeal dysphagia who are at risk from continuing to eat and drink orally are treated equitably with due regard to Best Practice as outlined within this guidance document.

2.2 Oropharyngeal Dysphagia (difficulty swallowing) frequently occurs in adults as a result of an acquired medical condition (such as stroke, neurological disease, head injury, cancer, dementia, spinal surgery) (*Clave and Shaker 2015*).

2.3 Dysphagia is prevalent in the older person, particularly when cooccurring with frailty and is frequently associated with end of life (*Smithard, 2016; Chen et al, 2010; Marik et al, 2003*).

2.4 The well documented consequences or risks of eating and drinking with dysphagia are malnutrition, dehydration, aspiration pneumonia, distress, social isolation choking and even death (*Leder & Suiter, 2009*).

2.5 With individuals living longer and living with more complex health conditions, the need for multi professional teams to support decisions around eating and drinking with risks is increasing.

2.6 The decision-making and management of dysphagia is complex; involving assessment of nutritional options and recommendations, weighing up benefits and risks, prognosis and capacity to consent (*Dibartlo, 2006; 10; Sommerville, 2019*).

2.7 The aim of this document is to assist and guide professionals in applying a consistent and unified approach to supporting a person with dysphagia in the decision making process around eating and drinking when there are known and acknowledged risks involved.

2.8 This guidance is written with the aim of putting individuals with oropharyngeal dysphagia at the centre of the decision making process, allowing them to have ownership of the decision. It is acknowledged that risk cannot be avoided or denied and that understanding how risk is caused and influenced can help to support individuals to be empowered to understand the risk and make their own decisions.

2.9 The processes outlined in this document should be followed when there are known, persisting or deteriorating swallowing difficulties and where the outcome of the oropharyngeal swallowing assessment may identify significant health risks associated with continued eating and drinking.

2.10 This guidance has been very closely based on a recently published paper ‘Eating And Drinking With Acknowledged Risks: Multidisciplinary Team Guidance For The Shared Decision-Making Process (Adults)’ (*RCSLT et al 2021*).

2.11 This guidance should also be read in conjunction with the Trust’s Dysphagia Policy (work in progress) and the Trust’s guidance document entitled ‘Supporting Decision Making Regarding Clinically-Assisted Nutrition and Hydration (CANH) (if appropriate).

2.12 The Mental Capacity Act (2005) must be applied at all times when supporting individuals and their families / carers to make decisions relating to eating and drinking with acknowledged risk.

**3.0 DEFINITIONS**

3.1 **Oropharyngeal Dysphagia**

A swallowing disorder resulting from a neurological or physical impairment of the oral or pharyngeal mechanisms (*RCSLT 2014*).

3.2 **CANH**

 Clinically-Assisted Nutrition and Hydration is legally viewed as a medical treatment. It refers to all forms of tube feeding, e.g. nasogastric tube, percutaneous endoscopic gastrostomy (PEG) or parenteral nutrition (PN). It doesn’t include oral feeding, by cup, spoon or other method for delivering nutrition into the patient’s mouth.

3.3 **Advanced Care Plan (ACP)**

 A process of discussion between an individual and their care providers to make clear a person’s wishes, often in the context of anticipated deterioration. In the instance of an individual lacking capacity, the ACP is compiled with involvement from relatives/carers or an Advocate.

3.4 **Aspiration**

 When food or drink passes the vocal folds and enters the lungs.

3.5 **Aspiration Pneumonia**

 Results from inhalation of oropharyngeal contents into the lower airways that leads to lung injury and resultant bacterial infection.

3.6 **Capacity**

 Mental capacity is the ability to make your own decisions.

3.7 **Dehydration**

 A state in which a relative deficiency of fluid causes adverse effects on function and clinical outcome.

3.8 **Eating and Drinking with Acknowledged Risks**

 Continuing to eat and drink despite the associated risks from having dysphagia.

3.9 **Malnutrition**

 Malnutrition is a state of nutrition in which a deficiency or excess (or imbalance) of energy, protein and other nutrients causes measurable adverse effects on tissue/body form (body shape, size and composition) and function and clinical outcome.

3.10 **MDT**

 Multidisciplinary Team

3.11 **SLT**

 Speech and Language Therapist

**4.0** **ROLES AND RESPONSIBILITIES**

**Trust Responsibilities**

4.1 The Trust Chief Executive has overall accountability for the effective and safe operation of the Trust, ensuring the safety and well-being of service users and others are taken fully into account at all times.

 **Consultant / GPs Responsibilities**

4.2Consultants / GPs have overriding responsibility of individuals under their care and therefore often make the decision, particularly within an inpatient setting (for those individuals lacking capacity), taking fully into account the individual’s wishes and the rest of the MDT’s views.

The Consultant or GP should consider the appropriateness for treatment escalation in the event of an anticipated decline in the person’s condition, whether they are in hospital or in their own home / care home.

**Medical Practitioner Responsibilities**

4.3Medical Practitioners are responsible for identifying risks relating to eating and drinking and making appropriate referrals to Speech and Language Therapy. Medical Practitioners will assess a person’s capacity to understand the identified risks and whether they have capacity to consent to a formal swallowing assessment. Medical Practitioners are responsible for communicating decisions relating to eating and drinking with acknowledged risk in letters / correspondence.

 **Speech And Language Therapy Responsibilities**

4.4 Speech and Language Therapists are responsible for carrying out a formal assessment of swallowing, which could include a bedside swallowing assessment and / or an objective assessment such as videofluoroscopy or FEES. Speech and Language Therapists advise the person with dysphagia (and the multi professional team involved in their care) on the safety of their swallowing, level of risk associated with eating and drinking and with recommendations to minimise the risks associated with continued eating and drinking. Speech and Language Therapists discuss Clinically-assisted nutrition and hydration (CANH) options with the individual if appropriate. Speech and Language Therapists have a shared responsibility with the medical team and / or other relevant professionals for assessing capacity to understand and follow swallowing recommendations and assessing capacity to consent to CANH.

 **Dietitians Responsibilities**

4.5 Dietitians are responsible for supporting the individual to optimise their nutritional intake, regardless of whether an individual has made an informed decision (or a Best Interest Decision has been documented) to continue eating and drinking orally with acknowledged risk. Dietitians are responsible for assessing the candidacy of the person for alternative nutrition and hydration options.

Dietitians support other members of the MDT regarding the development and implementation of the individual’s nutrition and hydration care plan.

 **Nurses Responsibilities**

4.6 Nurses use professional judgement to identify if an individual is likely to be a candidate for eating and drinking with acknowledged risks and highlight to the medical professional and / or Speech and Language Therapist. Nurses are responsible for ensuring the eating and drinking with acknowledged risk care plan is followed including scrupulous mouth care and optimal positioning.

Nurses act as the person’s advocate, evaluating care and risk managing situations in conjunction with medical colleagues, the person and their family.

Nurses are responsible for escalating any concerns back to the medical team / MDT / GP as appropriate.

 **Health Care Assistants Responsibilities**

4.7 Health Care Assistants support the individual to follow eating and drinking recommendations as much as possible. They will document and escalate issues as appropriate.

 **Palliative Care Team Responsibilities**

4.8 The Palliative Care Team are responsible for informing the MDT if an individual has been placed on the end-of-life pathway. They will provide support the individual (or to family carers in the individual lacks capacity) on eating and drinking at the end of life. The Palliative Care Team will ensure individuals have a plan of care including symptom control, psychological, social and spiritual support.

 **Pharmacists Responsibilities**

4.9 Pharmacists are responsible for ensuring medications are in a form which are easier to swallow and will provide advice on whether medications can be altered (e.g. crushed) to make them easier to swallow, and / or whether they can be taken with thickened fluids or food.

**5.0 PROCESS DESCRIPTION**

 **Shared Decision Making Context Relating To Eating And Drinking With Risk Identified**

5.1 All health professionals involved in working with or caring for individuals with oropharyngeal dysphagia, should be aware of the potential risks, and be able to identify scenarios when eating and drinking with acknowledged risk guidance needs to be applied.

5.2 When a potential eating and drinking with risk scenario is identified by a health professional it should be documented in the individual’s medical records, discussed with the individual (or family / carers if the individual lacks capacity), and discussed with the relevant MDT members jointly responsible for the care of the individual.

5.3 Eating and drinking with acknowledged risks can be applicable to various scenarios / contexts as follows:

* An individual with capacity who fully understands the resulting risks of eating and drinking and wishes to continue to eat and drink despite the risks.
* An individual who has capacity and declines Clinically Assisted Nutrition and Hydration (CANH) or modified diet / fluids.
* An individual who is nearing the end of their life where the focus moves away from medicalisation to maximising quality of life.
* An individual who is meeting their nutritional requirements via CANH and chooses to eat and drink with acknowledged risks for pleasure.
* MDT discussions with the individual and / or their significant others to determine if the procedure risks of long term CANH (e.g. percutaneous gastrostomy) outweighs the benefits.
* An individual who lacks capacity where CANH may not be suitable, as the enjoyment of eating and drinking and the enhanced quality of life this brings outweighs the risks associated with developing aspiration pneumonia.

 **Establish The Goal Of Intervention Or Care**

5.4Prior to the initiation of a plan to eat and drink with acknowledges risks, health care professionals involved in the care of the individual with oropharyngeal dysphagia need to gather detailed information regarding the nature of the dysphagia and associated prognosis. This includes identifying whether the individual’s clinical condition is transient or unlikely to change in spite of intervention. Consideration of how future management will impact on quality of life is key taking account the principles of dignity and non-maleficence.

 **Establish Whether An Advanced Care Plan Or Eating And Drinking With Risk Care Plan Is Already In Place**

5.5 The MDT should establish whether there is any existing guidance or documentation regarding management of the risks associated with continued eating and drinking. Where this is identified, teams should ensure that the information is shared with all relevant people promptly. Such existing information might include written guidance on the recommended foods to try, the best times of day for the individual to eat and drink to minimise risks, or advice on how to offer food and drink more effectively to improve safe swallowing such as the rate of intake or the need to allow additional time to ensure food has fully cleared. Where such information is identified, members of the MDT should aim to establish where and when the plan was put in place and whether it remains relevant. In addition, the MDT should seek to liaise with the person who agreed the care plan wherever possible.

 **Document Consent And Capacity Relating To Understanding Of The Current Difficulty / Concern And Capacity To Consent To Formal Swallowing Assessment**

5.6 Individual’s have the right to decline a formal assessment of their swallowing. If an individual with capacity who is experiencing oropharyngeal dysphagia (despite having the risks fully explained to them) declines to have their swallowing assessed this should be documented in their medical notes. In such cases Speech and Language Therapists are unable to provide any recommendations or care plan and the individual should be allowed to continue to eat and drink as they choose. Individuals making this choice should still be supported by Dietitians to maximise their nutritional intake, provided they have consented to input from a Dietitian.

5.7 When an individual is unable to consent to a referral to Speech and Language Therapy or to a formal assessment of their swallowing, a decision will be made in their Best Interests in accordance with the Mental Capacity Act (2005).

 **Formal Swallowing Assessment Carried Out By SLT**

5.8 The SLT will conduct a formal swallowing assessment in order to determine any interventions and support that may help to reduce risks associated with the individual’s dysphagia. For example risks may be reduced by appropriate mouth care routines, advice on optimal textures, positioning, equipment, the environment, level of assistance and supervision as well as facilitated eating and drinking.

5.9 The SLT will determine whether further objective assessments such as videofluoroscopy or FEES are required to support the decision making process.

5.10 The SLT will have discussions with the individual and those closest to them in relation to individual beliefs and preferences associated with eating and drinking, such as food preferences, mealtime routines and cultural, religious and spiritual beliefs.

5.11 The SLT will give consideration to the psychosocial impact of dysphagia and its associated interventions on a person's wellbeing. These are necessary components to factor into a supportive framework of decision-making around eating and drinking with acknowledged risks.

5.12 The SLT will document and discuss with the individual whether the dysphagia risks can be mitigated with various strategies (as outlined in 5.8) or whether the swallowing is unsafe and CANH needs to be considered. The SLT will document the outcome of the discussion with the patient (or their family member / carer if they lack capacity) and the initial thoughts / decision of the patient.

5.13 In the instance where an SLT is unavailable, local guidelines should be followed.

 **Determine Whether CANH Is Appropriate**

5.14 Healthcare professionals should work together when considering whether CANH is appropriate. Healthcare professionals should refer to the Trust’s guidance document Supporting Decision Making Regarding Clinically Assisted Nutrition and Hydration(CANH).

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 **Conducting A Capacity Assessment**

5.15 It is every individual’s basic human right to be included in decisions about their care. There is a presumption that adults have capacity to make decisions about their care and treatment, unless there is valid reason to suggest the contrary. Healthcare professionals should apply the principles of the Mental Capacity Act (2005) throughout the decision making process.

5.16 All discussions and decisions relating to Mental Capacity should be fully documented in the person’s medical records.

**6.0 TRAINING / COMPETENCE REQUIREMENTS**

6.1 Mental Capacity Training on OWL.

6.2 IDDSI Bite-Sized.

6.3 Having difficult conversations.

**7.0 MONITORING** *Outline the process to monitor compliance to the document. This should relate back to the process description and make clear how the effectiveness of the document will be monitored and measured (e.g. through audit.*

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| **Element of policy for monitoring** | **Section** | **Monitoring method -** **Information source (e.g. audit)/ Measure / performance standard** | **Item Lead** | **Monitoring frequency /****reporting frequency and route** | **Arrangements for responding to shortcomings and tracking delivery of planned actions** |
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**8.0 REFERENCES**

8.1 Eating And Drinking With Acknowledged Risks: Multidisciplinary Team Guidance For The Shared Decision-Making Process (Adults) (RCSLT 2021). <https://rcslt.org>.

8.2 Eating, Drinking Swallowing Competency Framework (RCSLT 2019). <https://www.rcslt.org/speech-and-language-therapy/clinical-information/dysphagia#section-4>

8.3 Prevalence Of Perceived Dysphagia And Quality-Of-Life Impairment In A Geriatric Population (Dysphagia. 24, 1-6) (Chen, PH, Golub, JS, Hapner, ER and Johns, MM - 2009)

 <https://pubmed.ncbi.nlm.nih.gov/18368451/>

8.4 Dysphagia: Current Reality And Scope Of The Problem (Nature Reviews Gastroenterology & Hepatology 12(5), 259) (Clavé, P and Shaker, R (2015))

8.5 Careful Hand Feeding: A Reasonable Alternative To PEG Tube Placement In Individuals With Dementia (Journal Of Gerontological Nursing. 32(5), 25-33) (Dibartolo, MC (2006))

8.6 Aspiration Pneumonia And Dysphagia In The Elderly (Chest. 124, 328-336) (Marik, PE and Kaplan, D (2003))

<https://pubmed.ncbi.nlm.nih.gov/12853541/>

8.7 Dysphagia: A Geriatric Giant (Med Clin Rev. 2(1), 1-7) (Smithard, DG (2016))

**9. APPENDIX A**