North West Anglia
NHS Foundation Trust

CHOICES: Guideline for Supporting and Documenting Complex Decisions in those with Eating, Drinking and/or swallowing difficulties. Version 1

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VERSION CONTROL SUMMARY

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2023 Version 1		New guideline	N/A	20/4/2023	26/4/2023

CONTENTS

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CHOICES: Guideline for Supporting and Documenting Complex Decisions in those with Eating, Drinking and/or Swallowing Difficulties.

1. INTRODUCTION

1.1 **CHOICES** was developed as a tool to guide through the principles of decision making and aid documentation of decisions in situations where there is a risk associated with continued oral intake in cases of eating, drinking and/or swallowing (EDS) difficulties and a risk feeding approach is being considered.

1.2 **Risk Feeding Definition**

A "risk feeding" approach may be appropriate for a number of reasons:

1) Benefits of eating and drinking orally (such as enjoyment and quality of life) are deemed to outweigh the risks (such as chest infections, choking, weight loss)
2) Clinically assisted nutrition and hydration (CANH) options may be limited by a person's medical condition or risk of CANH options may be too high.
3) The person may be approaching the end of their life and a palliative approach may be more appropriate.
4) CANH will not prolong or improve quality of life.
5) A person may not wish to give up the pleasure of eating and drinking, either to be nil by mouth or take modified foods and/or fluids.
6) A person may not wish to have an invasive procedure such as tube feeding.

1.3 **Move Away From Term "Risk Feeding"**

More recently there has been criticism of the term "Risk Feeding" (Murray et al, 2019). There are several reasons this term is falling from favour:

1) "Risk Feeding" has negative connotations, with it having the potential to portray an unbalanced risk/benefit of potential treatment options and encourages a risk averse approach that may ultimately be detrimental to the person with EDS difficulties wellbeing.

2) It is unfair to label a patient as "risk feeding" when a patient is palliative/ approaching the end of their life. There are often no other alternative options and it can place an unnecessary burden of risk on carers / family members wanting to support a patient's comfort and quality of life.

3) The concept of risk from aspiration can be difficult to quantify, with there being a body of evidence that aspiration of food and/or drink does not always lead to aspiration pneumonia and that aspiration pneumonia is not always due to aspiration of food and/or drink (Langmore et al. 2002, RCP 2021).

4) There are risks from treatments considered to prevent aspiration:

Thickened fluids may increase risks of dehydration and urinary tract infections (Robbins et al., 2008), have significant impact on quality of life (Lim et al. 2016) and cause more serious chest infections if aspirated (Robbins et al. 2000).

Being nil by mouth can worsen oral hygiene, thus increasing risk of aspiration pneumonia (Pace and McCullough, 2010), can be further detrimental to swallow function and can significantly impact on a person's wellbeing, even if for a short period of time.

2. PURPOSE

2.1 The following documents are available to support ethical decision making. This tool is based on the best practice principles from these documents. It does not aim to be a substitute for the information contained within them. It is good practice for those supporting complex decisions in those with EDS difficulties to read and be familiar with their contents.

- Mental Capacity Act (2005)
- Supporting people who have eating and drinking difficulties**:** A guide to practical care and clinical assistance, particularly towards the end of life. RCP (2021)
- Clinically assisted nutrition and hydration (CANH) and adults who lack the capacity to consent. Guidance for decision making in England and wales. BMA/RCP (2018)
- Treatment and care towards the end of life; good practice in decision making'. GMA (2010)
- Eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process –adults (RCSLT 2021)

3. PATIENT GROUP COVERED

3.1 CHOICES focuses on supporting adults with eating, drinking and/or swallowing (EDS) difficulties. A wide range of conditions can cause EDS difficulties, such as Dementia, Stroke, Progressive neurological conditions and Cerebral Palsy.

3.2 CHOICES should not be used with those that are at risk of imminently dying, as pursuing oral intake that is comfortable and maintains quality of life should be the priority (see *Appendix 1*), but may be applicable to those approaching the end of life in certain circumstances.

3.3 **Approaching End of Life**

The General Medical Council (GMC) defines that patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

1. advanced, progressive, incurable conditions
2. general frailty and co-existing conditions that mean they are expected to die within 12 months of existing conditions
3. if they are at risk of dying from a sudden acute crisis in their condition
4. life-threatening acute conditions caused by sudden catastrophic events

4. CHOICES EXPLAINED

4.1 CHOICES is an acronym for the main factors that need to be considered when making a decision with or for a person with risks associated with continued oral intake in the context of EDS difficulties. It aims to provide positive terminology and encourage a balanced approach to decision making and to reinforce that people with EDS problems have a choice. It is a flexible document to support a range of potential decisions and option scenarios.

CHOICES stands for:

Centred around the person
Holistic
Options
In best interests
Communicated
Evidenced
Shared

5. CENTRED AROUND THE PERSON

5.1 Safe and efficient EDS skills are not only necessary to maintain adequate nutrition and hydration but are also essential to participating in a range of socio-cultural experiences (Kenny, 2015). Dietary restrictions that are unduly onerous or do not consider the range of implication for that individual on their cultural identity, social opportunities, quality of life and pleasure are likely to put a strain on professional relationships and reduce compliance and satisfaction (Colody, 2005).

It is therefore essential that when making a choice about oral intake with or for a person with dysphagia it is centred around them as an individual and that risks of potential treatment options are presented as well as potential risks of continued oral intake.

If a person is unable to make choices for themselves it is important that information is gathered from the patient's behaviour, family, friends and carers in order to build a picture of what the person might have wanted and/or what they want now.

The following questions may be helpful to consider:

- Has the person expressed any past/present wishes?
- What is the quality of his/her life at present (from his or her perspective)?
- What is his/her awareness of the world around him/her?
- Is there any (or any significant) enjoyment in his/her life? If so, how can this be maximised? Is food/drink a source of enjoyment?
- Is there any real prospect of recovery of any functions or improvement to a quality of life that he/she would value?
- What are the implication of any of the options on the individual, e.g. care/placement implications if CANH is pursued?

This information should be listed in the "Centred around the person" section on the CHOICES form.

6. HOLISTIC

6.1 It is important that risk associated with EDS problems is considered in the context of other co-morbidities so that undue weight is not given to risk of deterioration from oral intake versus other illnesses.

The following should be considered so that a balanced decision around oral intake is made:

1. Is the person "approaching the end of their life" (GMC)?
2. What is their frailty score?
3. What are the other co-morbidities / risks to life?
4. Are there any reversible causes of EDS difficulties?
5. What were previous levels of functioning?
6. What is the prognosis if CANH were to be started / continued/ discontinued?

Other relevant co-morbidities, prognosis and reversible causes should be listed in the "Holistic" section on the CHOICES form.

7. OPTIONS

7.1 It is important that the viability of oral intake methods +/- CANH options are explored and discussed as an MDT (see Appendix 6) before being presented to the person with EDS difficulties or other decision making partners. This encourages a consistent message to be presented by all health care professionals involved and avoids unnecessary confusion about the risks and options (see *Appendix 7*).

Examples of things to consider are:

- Can oral intake be modified/supported?
- Would the person with EDS difficulties be a candidate for CANH, e.g. PEG?
- Would they medically be able to tolerate this procedure?
- Is there evidence that this patient group would benefit?
- Would the person be a candidate for a trial of NG feeding?
- What advance care planning needs to be considered (e.g. preferred place of death, avoiding further admissions?
- How will future infections be managed (e.g. ceilings of care, oral versus IV antibiotics)?

Appendix 2 provides an expanded table to list pros and cons of options in more complex cases or to provide a written summary to the person with dysphagia or their proxy to support memory and aid contemplation of options. *Appendix 3* provides an example of supporting someone with communication problems to make a choice.

A list of relevant options should be listed here with an outline of pros/cons for that individual in the "Options" section on the CHOICES form.

8. IN BEST INTERESTS

8.1 If the person with EDS difficulties mental capacity is in doubt then a mental capacity assessment needs to be completed.

8.2 If the person has communication difficulties, it is important to facilitate communication so lack of capacity is not presumed. A speech and language therapist may be needed to support with this.

8.3 It needs to be established whether an Advance Directive is in place or whether anyone holds Lasting Power of Attorney (LPA) for Health and Welfare.

8.4 An IMCA (independent mental capacity advocate) should be requested when there is no next of kin or anyone other than a paid carer or any other 'appropriate representative' to advocate on the patients behalf. IMCAs are required when they have lost capacity for decisions regarding change of accommodation/ serious medical treatment (e.g. PEG insertion) / accommodation review/ Safeguarding of Adults at Risk (with a protective measure). Other advocacy options are available. Please see Peterborough and Cambridgeshire – Total Voice www.voiceability.org for further information/referral process.

8.5 The Mental Capacity Act (2005) states that if making a decision in someone's best interests "treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms". This is important when considering restrictions such as NBM.

Whether a person has capacity or whether a trust MCA form has been completed should be listed here in the "In best interests" section on the CHOICES form.

If there is an Advance Directive or Lasting Power of Attorney for Health and Welfare, this should be listed in the "In best interests" section on the CHOICES form. Copies should be put in the medical notes. Whether an IMCA is required should be listed here.

9. COMMUNICATED

9.1 It is important to communicate effectively (a) as a group of professionals (b) with the person with EDS difficulties or family/other representatives and (c) when transferring to another ward/ on discharge to avoid confusion and mixed messages.

9.2 It is important to give explanations, back up discussions with written information, repeat information and give time to understand information and make choices (Miles 2016).

9.3 Sometimes rapid decisions may need to be made, however, in cases where delaying a decision can cause further harm/distress/ medical interventions that are not in the persons best interests, e.g. keeping someone nil by mouth in cases of advanced dementia/frailty.

9.4 Any decisions should be communicated effectively to those caring for the individual e.g. nursing staff, to prevent unnecessary concerns around coughing or perceived risk of aspiration impacting on the patient's continuity of care.

9.5 The decision must be shared with those professionals responsible for the future care of the patient e.g. GP, district nursing team, care home staff. Advance care planning discussions should be documented appropriately on the CHOICES form and ReSPECT document and communicated via the hospital discharge summary.

9.6 *Who* has been communicated with (full name, title, relationship to person with EDS difficulties), *how* choices have been communicated (e.g. best interest meeting) and *when* (date) should be listed in the "Communicated" section on the CHOICES form.

The CHOICES form can be transferred with the patient on discharge to aid continuity of care and should be referenced in the hospital discharge summary.

10. EVIDENCED

10.1 It is important that a risk of aspiration/choking of food and/or drink is evidenced and not presumed. Aspiration pneumonia is not always due to aspiration of food and drink.

10.2 "It is important to distinguish between the effects of oral intake on the patient's symptoms and experiences and risk to life" (Murray et al, 2019).

10.3 Evidence may be in the form of:

- A speech and language therapy clinical assessment
- Instrumental assessments such aS video fluoroscopies
- Case-history information correlating EDS problems with the clinical presentation
- Dietetic assessments
- Weight loss history

Evidence of risks including nature, frequency and severity where possible, should be listed in the "Evidenced" section of the CHOICES form.

11. SHARED

11.1 The professionals most appropriate to the decision should be part of the CHOICES process. For example, in cases where options for alternative nutrition and hydration are being explored or discounted, a Consultant or senior doctor would need to lead the process. However, in cases where a person with mental capacity is choosing between possible SLT treatments, e.g. whether to take thickener, an SLT may be the most appropriate professional to lead the process. *Appendix 6*. Provides a list of possible MDT members.

12. APPROVAL

12.1 This guideline will be approved by the Nutrition Steering Group, Rehabilitation Services Quality & Governance Meeting, Patient Safety Insight & Involvement Committee, FISS Divisional Leadership Board and the Quality Governance & Operational Committee.

13. DISTRIBUTION

13.1 This guideline will be available on SharePoint.

14. ACKNOWLEDGEMENTS

14.1 Thank you to the following for reviewing and supporting this piece of work:

Dr S. Carding (Palliative Care Consultant)
Dr L. Ellis (Geriatrician)
Dr. Bashford (Ortho-Geriatrician)
N. Craner (Adult Safeguarding Lead Practitioner)
NWAngliaFT Speech and Language Therapy Department
Nutrition Steering Group

15. REFERENCES

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RCSLT (2021) Eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process (adults)

Robbins, Joanne (2000). Protocol 201: A NIDCD-Funded MultiSite Clinical Trial in Swallowing. Perspectives on Swallowing and Swallowing Disorders (dysphagia). 9. 2-3. 10.1044/sasd9.2.2.

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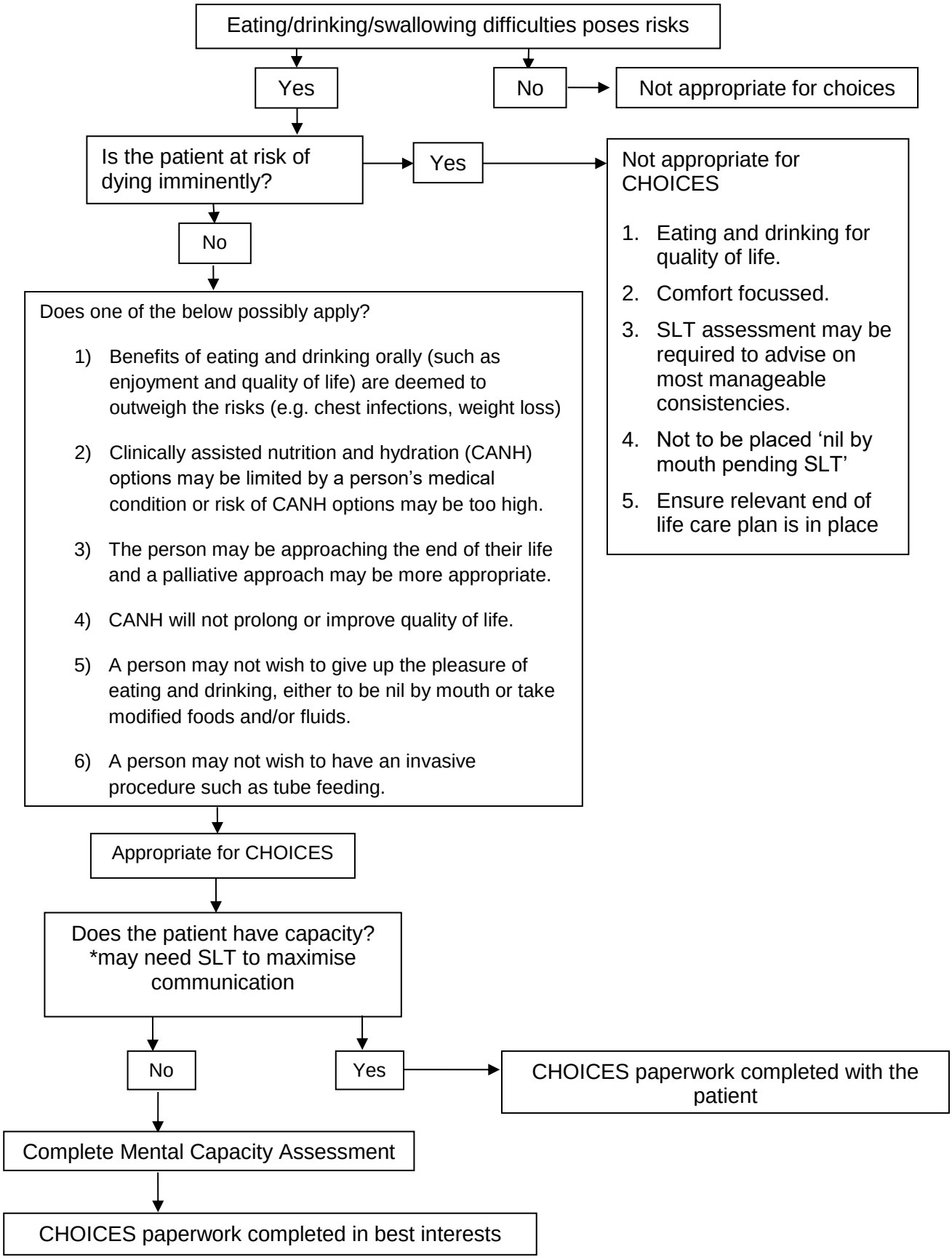
APPENDIX 1: HOW TO USE CHOICES



APPENDIX 2: CHOICES - OPTIONS FORM

Options	Pros	Cons
Choice 1		
Choice 2		
Choice 3		

APPENDIX 3: EXAMPLE OPTIONS FORM – SUPPORTING COMMUNICATION IMPAIRMENT

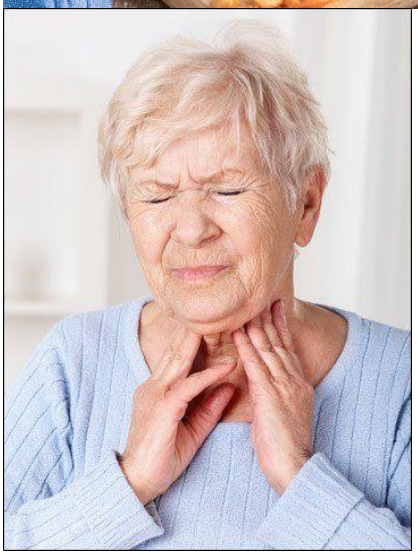
We are going to talk about **swallowing difficulties** and **alternative ways of feeding**

You have **swallowing difficulties** due to your **stroke**.

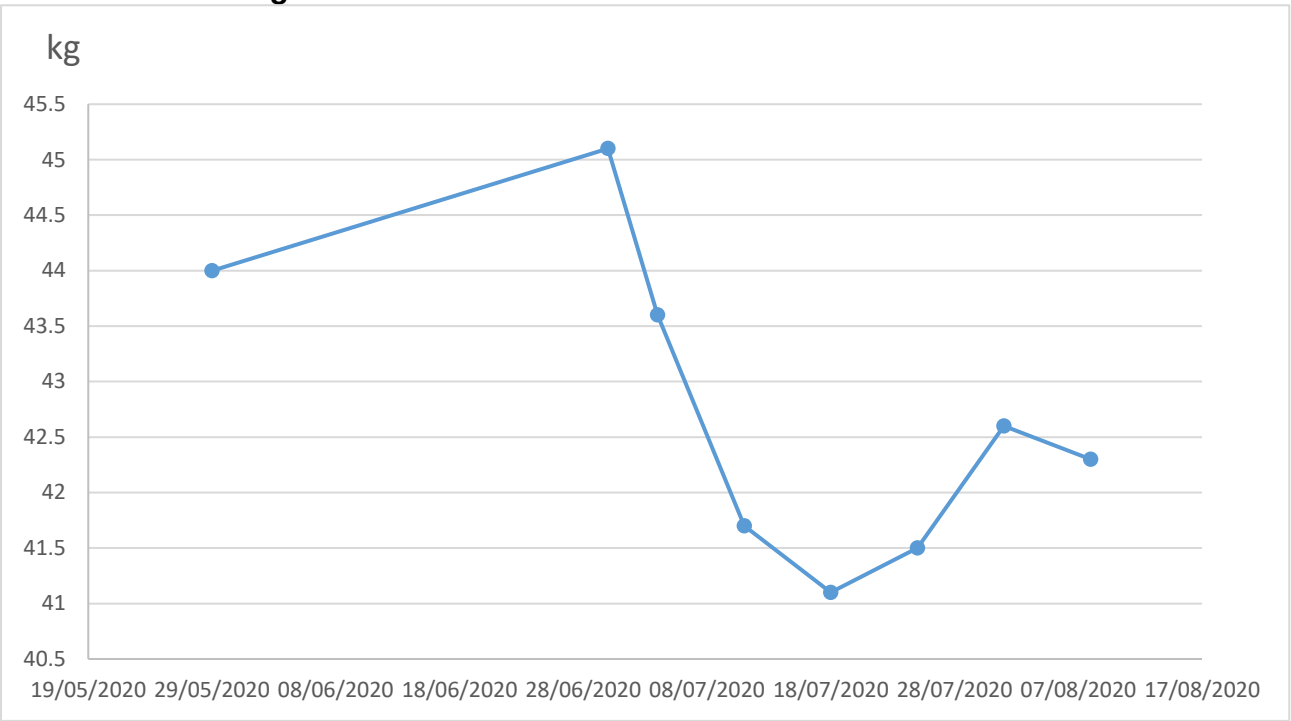
You are having:

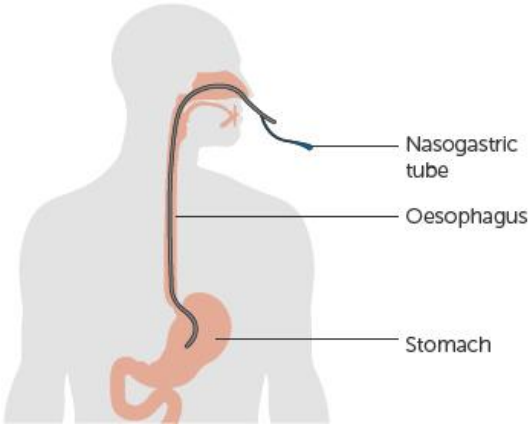
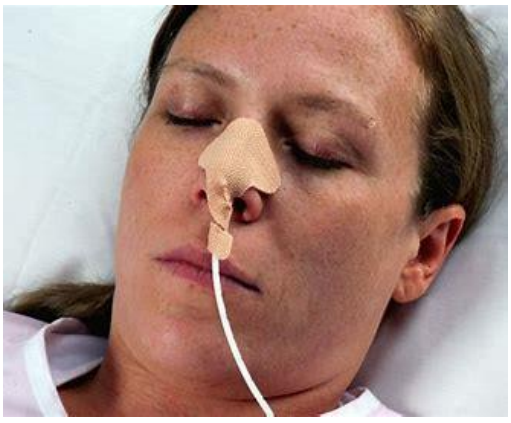
Thickened drinks

Pureed diet



You have lost weight



At the moment, you have a **feeding tube in your nose** **This is for:** **Tablets** **Water** **Feed** **You can't go home with a tube in your nose** **But** You **are Not eating and drinking enough** **It is difficult to swallow** Your weight is low	 

Option 1

Tube in your nose out

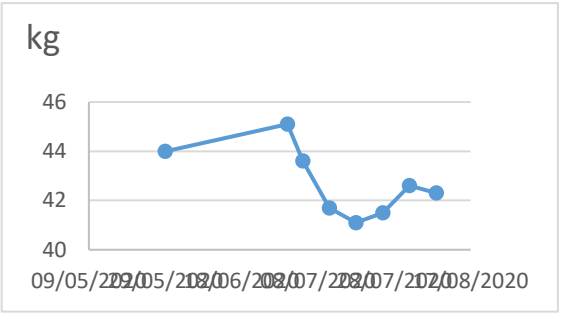
You can go home

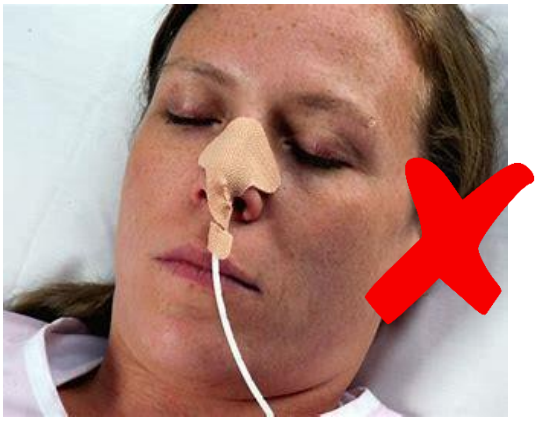
And eat and drink

Level 3 thickened drink

Pureed diet

You may lose more weight





Option 2

A **feeding tube** that goes **directly into your stomach.**

You can go home with a feeding tube

For:

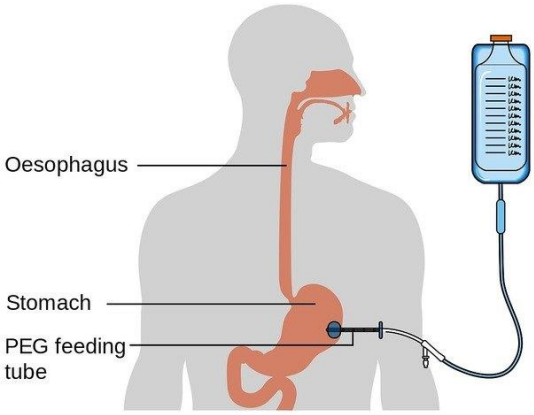
Tablets
Water
Feed

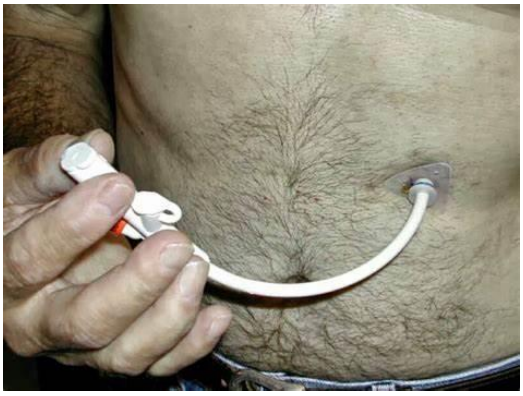
It is **hidden** under your clothes.

And

You can still eat and drink

Level 3 thickened drink and puree





Option 3

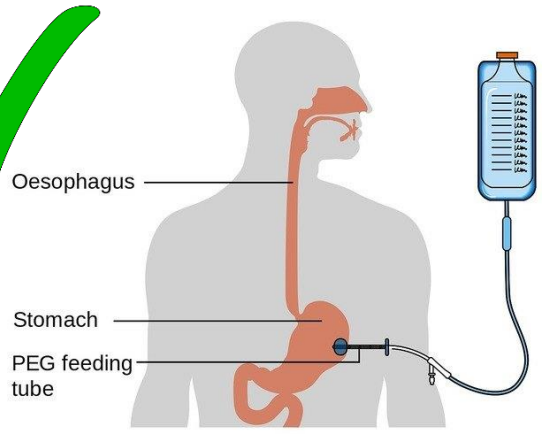
A **feeding tube** that goes **directly into your stomach.**

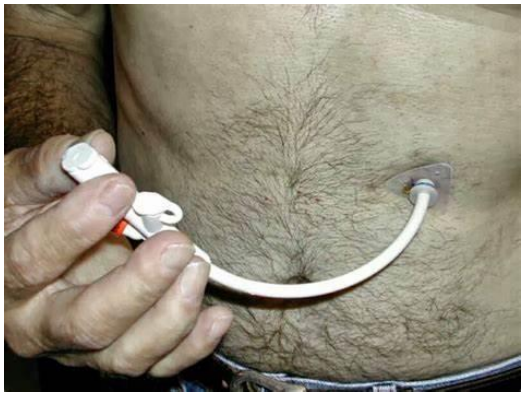
You can go home with a feeding tub

For:

Tablets
Water
Feed

It is **hidden** under your clothes.





NO eating and drinking

I don't enjoy

Thickened drinks

Pureed diet

APPENDIX 4: CHOICES FORM. MAKING DECISIONS WITH OR FOR PEOPLE WITH EATING AND DRINKING DIFFICULTIES

Name		DOB		NHS/DIS		Date	

Centred around the Person: (Past/present wishes and beliefs, implications for the individual)

Holistic: (Consider in context of other co-morbidities, prognosis, reversible causes.)

Options: (List the choices in this case? Pros and cons of options? Advanced care planning options?)

In best Interests:

Presumed mental capacity? Yes ☐ No ☐ If no =Trust MCA ☐ IMCA needed? Yes ☐ No ☐
LPA Health & Welfare? Yes ☐ No ☐ (if yes- who. Place copy in notes).
Advance Directive? Yes ☐ No ☐ (if yes- Place copy in notes).

Communicated: Who have the choices been discussed with (name, relationship to person), how and when?

When (date): How:
Who:

Evidenced: (What are the risks? How do we know they exist? How frequent /severe are they?)

Shared: (Which professionals have been involved in this decision making process? Name and profession):

Who needs to know for the future?

CHOICE: (including wishes for future management of infections +/- hospital readmission)

APPENDIX 5: CHOICES EXAMPLE FORM 1

Name	Example 1	DOB	58yrs	NHS		DIS	

Centred around the Person: No formally expressed previous wishes. Staff at Care Home told IMCA that X has been much less interactive over the past months Son concerned that if X is fed via the PEG that she will lose interaction opportunities at meal times. X's friend told IMCA about X's previous suicide attempt when she became more dependent and was having little interaction with people except for visits for care. IMCA asked whether a PEG would enable a more peaceful death. Palliative care Dr explained that X symptoms could be managed without a PEG. IMCA raised the issue that X may need to move to a different part of care home if had a PEG and therefore would not be able to return to "home" as she knew it and to staff that were familiar to her.
Holistic: End stage MS. Fully dependent on care and nutrition needs. Prognosis likely to be weeks to a small number of months. PEG unlikely to extend prognosis.
Options: PEG – High risk in this case. Continue oral intake with acknowledgement that full nutrition and hydration needs are not met and that end of life is supported.
In best Interest: Does person have presumed mental capacity: Yes ☐ No X If no =Trust MCA - YES LPA Health & Welfare – no Advance Directive - no X is unable to communicate due to both physical and cognitive disability. IMCA as has no next of kin and family have not been in contact with X for some years.
Communicated: (Son), (sister), Mother, Sister (x/x/2021- best interest meeting).
Evidenced: There is no evidence that X is at risk of aspiration. She has not had repeated chest infections. Her chest has remained clear during the admission. There is, however, a reduced efficiency which results in her not meeting her hydration and nutrition needs orally
Shared: Dr S. (Gastroenterology Consultant), Speech and Language Therapist, community dietitian, hospital dietitian, IMCA, Dr C (Palliative Medicine consultant).

CHOICE:

All agreed PEG not in x's best interests. To continue oral intake as able of thin fluids and puree diet.

Not for future admission – for end of life care including management of X's epilepsy which would need to be managed to ensure she did not have a seizure. She is currently still taking her anti-epileptic medication orally.

APPENDIX 6: CHOICES EXAMPLE FORM 2

Name	Example 2	DOB	70yrs	NHS		DIS		Date	

Centred around the Person: Lives with wife. Requires prompting with certain ADLs. Independently mobile. Reduced enjoyment from meal times due to length of time taken to eat a meal and dysphagia. Concerns about increasing frailty and weight loss. Concerns around ability to take PD medication and impact on symptom control
Holistic: Early stage dementia Parkinson's Disease (Hoehn and Yahr Scale Stage 3) Dysphagia secondary to PD. Possible level of decompensation to dysphagia impairment secondary to weight loss and recent aspiration pneumonia.
Options: Trial of NG feeding with/ without oral intake - to assess if any functional improvement in dysphagia secondary to decompensation from recent aspiration pneumonia. PEG feeding with/without oral intake for QOL Continued Oral Intake Only with acknowledged risk of deterioration.
In best Interest: Does person have presumed mental capacity: Yes X No ☐ If no =Trust MCA ☐ LPA Health & Welfare Yes ☐ No X (if yes- who. Copy in notes). Advance Directive Yes ☐ No X (if yes- copy in notes). Has capacity to make decisions around nutrition and hydration, though requires more time to process information and benefits from key information being written down.
Communicated: Discussion with Y and Y's wife on (date) during a meeting.
Evidenced: Videofluoroscopy showed moderately-severe dysphagia due to PD with aspiration of all consistencies. Recent admission with aspiration pneumonia. 2 stone weight loss in 6 months. Increasing difficulties swallowing medication. Reduced enjoyment of meal times due to length it takes.
Shared: Geriatrician, Gastroenterologist, Speech and Language Therapist, Dietitian.

CHOICE:

Trial of NG feeding with swallow therapy programme.
Referral for PEG.

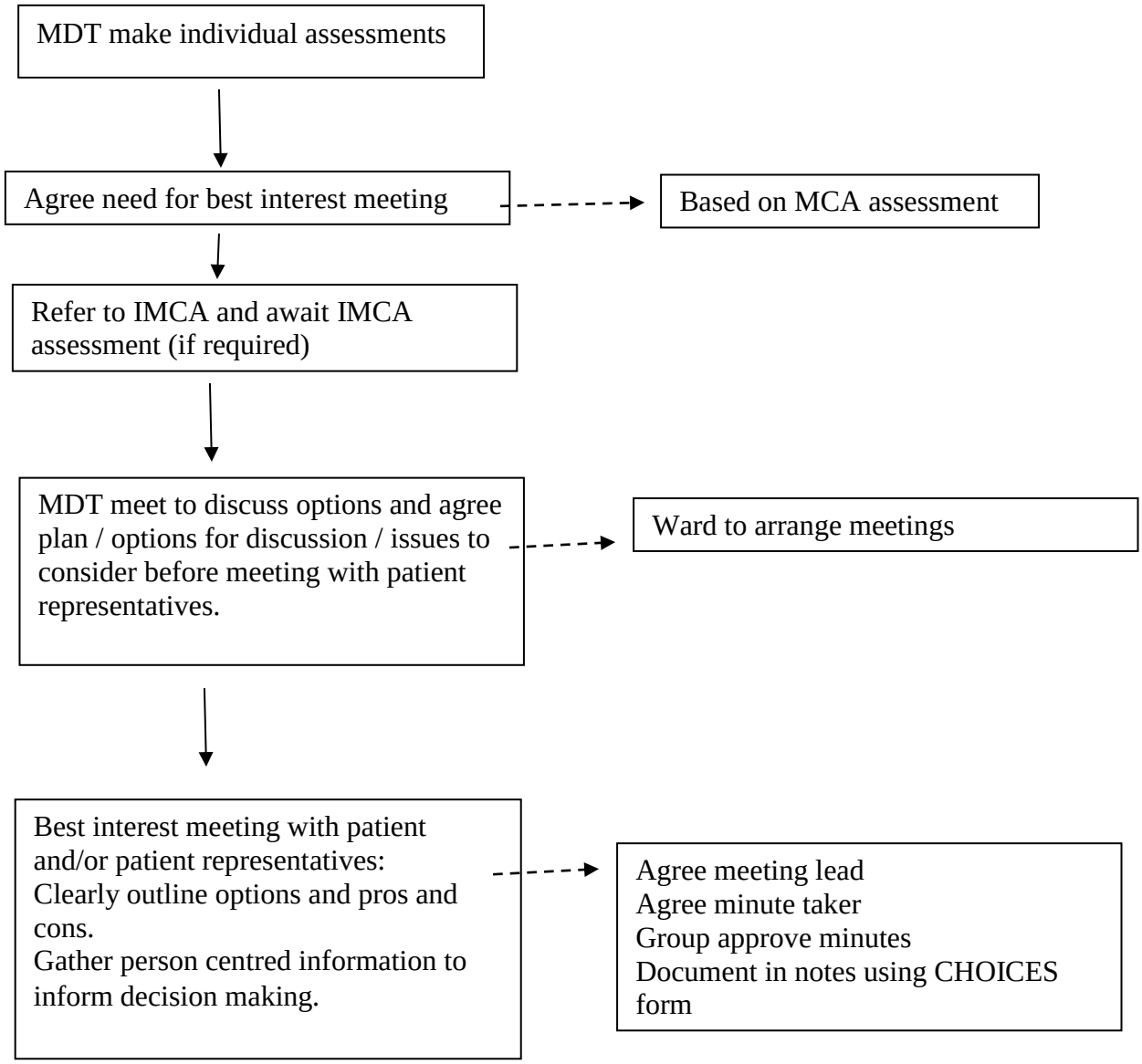
Re-assessment of swallow function in 4 weeks to advise re potential improvements to guide oral intake for quality of life alongside CANH.

APPENDIX 7: MULTI DISCIPLINARY TEAM MEMBERS

Lead Consultant*
Ward Nurse*
Speech and Language Therapist *
Dietitian*
Nutrition Nurse*
Pharmacist
Palliative Care Nurse / Consultant
Gastroenterologist
Physiotherapist
Safeguarding Team
Learning Difficulties Specialist Nurse
Other Specialist Nurses, e.g. MS
IMCA

*Core members

APPENDIX 8: GUIDANCE ON BEST INTEREST DECISION MEETINGS



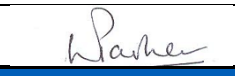
APPENDIX 9: QUALITY ASSURANCE CHECKLIST

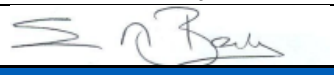
		Y/N/ n/a	COMMENTS (to author for amendments)
1	**Title of document**		
	Is the title clear and unambiguous	Y	
2	**Type of document (e.g. procedure, guidance)**	**Guideline**	
	Is it clear whether the document is a procedure, guideline, standard operating procedure?	Y	
3	**Introduction**		
	Are reasons for the development of the document clearly stated?	Y	
4	**Content**		
	Is the standard model template used?	Y	
	Are all sections of the front cover completed?	Y	
	Is the document in the correct format?	Y	
	• Paragraphs numbered consecutively	Y	
	• Headers: only on front page to contain logo	Y	
	• Footers: on every page except front page	Y	
	Are the Version Control numbers correct in the panel and the footer	Y	
	Are the objectives/aims clearly stated?	Y	
	Does this document concern the handling, moving or storage of personal identifiable or commercially sensitive information? If yes, has a Summary Privacy Impact Assessment been completed?	NA	
	Does the document meet the criteria for Second Level approval?	Y	
5	**Evidence Base**		
	Is the type of evidence to support the document explicitly identified?	Y	
	Are associated documents referenced?	Y	
6	**Approval Route**		
	Does the document identify which committee/group will approve it?	Y	
7	**Review Date**		
	Is the review date identified?	Y	

If answers to any of the above questions is 'no', then this document is not ready for approval, it needs further review.

COMPLIANCE TEAM:		
1.	Date Comments returned to author by Compliance Lead	
2.	Date of Compliance Team approval	07.11.22
3.	Name of Compliance Lead	Louisa Scoggins

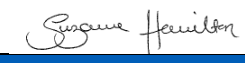
Please do not delete any of the below approval sections.
If certain sections are not applicable to the document's journey please enter 'N/A'

SPECIALTY APPROVAL MEETING: Nutrition Steering Group			
If the committee/group is happy to approve this document would the chair please sign below and send the document and the minutes from the approval committee to the Corporate Governance Team. **To aid distribution all documentation should use electronic signatures and be sent electronically wherever possible.**			
Name	Linda Parker	**Date**	08/04/2021
Signature			

CBU APPROVAL MEETING: FISS - Rehabilitation Services Quality and Governance Meeting			
If the committee/group is happy to approve this document would the chair please sign below and send the document and the minutes from the approval committee to the Corporate Governance Team. **To aid distribution all documentation should use electronic signatures and be sent electronically wherever possible.**			
Name	Susan M Bentley	**Date**	28/11/2022
Signature			

ADDITIONAL APPROVAL MEETINGS: Complete all that apply

If the committee/group is happy to approve this document would the chair please sign below and send the document and the minutes from the approval committee to the Corporate Governance Team. **To aid distribution all documentation should use electronic signatures and be sent electronically wherever possible.**

Patient Insight, Involvement and Improvement Committee		Drugs & Therapeutics Committee	
Name	SUZANNE HAMILTON	**Name**	***Not Applicable***
Date	25/11/2022	**Date**	Enter date
Signature		**Signature**	
Trust Infection and Prevention Control Committee		**Safeguarding Committee**	
Name	***Not Applicable***	**Name**	***Not Applicable***
Date	Enter date	**Date**	Enter date
Signature		**Signature**	

FIRST-LEVEL APPROVAL: FISS Divisional Leadership Board			
If the committee/group is happy to approve this document would the chair please sign below and send the document and the minutes from the approval committee to the Corporate Governance Team. **To aid distribution all documentation should use electronic signatures and be sent electronically wherever possible.**			
Name	James Hender	**Date**	08/03/2023
Signature			

SECOND-LEVEL APPROVAL COMMITTEE: Quality Governance & Operational Committee			
If the committee/group is happy to approve this document would the chair please sign below and send the document and the minutes from the approval committee to the Corporate Governance Team. **To aid distribution all documentation should use electronic signatures and be sent electronically wherever possible.**			
Name	Dr Suzanne Hamilton	**Date**	20/04/2023
Signature