Eating and Drinking with Acknowledged Risks - Clinical considerations when supporting people living with MND

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Royal Hospital for Neuro-disability
A national medical charity

Royal Hospital for Neuro-disability (RHN)

We are an independent medical charity that provides rehabilitation and long-term care to people with complex neurological disabilities

- **Founded:** 1854
- **Location:** Putney, London
- **Services:** Brain Injury Service, Specialist Nursing Home, Specialist Services (Ventilator Unit, Huntington's Disease, Adults with PLD, Neuro-Behavioural Unit)

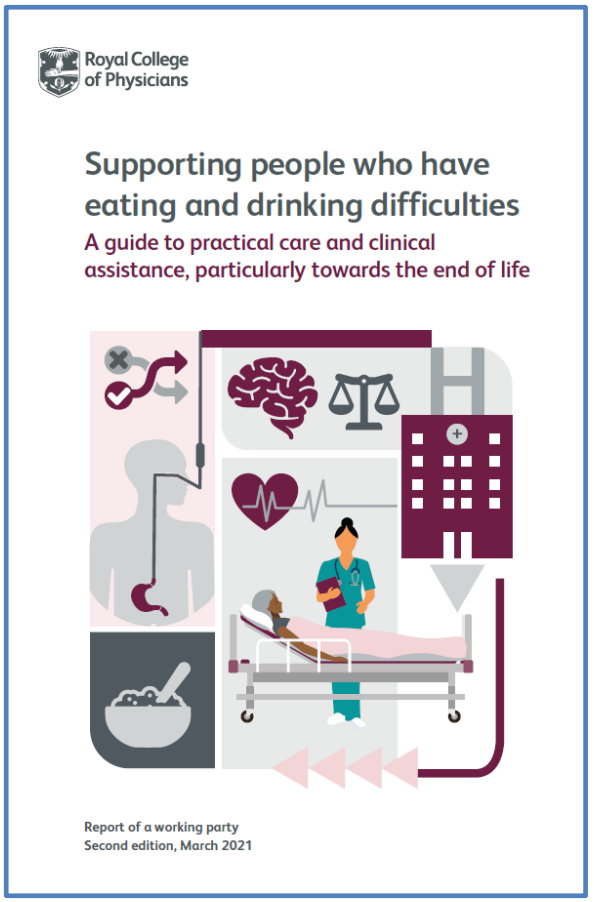
Definitions

“ Where swallowing difficulties are chronic or progressive, or a patient is palliative, tube feeding is often not deemed appropriate. Instead, patients continue to eat and drink despite the risks of pneumonia and death. There is currently little evidence to guide clinical practice in this field often termed “risk feeding.”” *Miles et al., 2016*

“The decision to eat and drink despite the associated risks of dysphagia. These risks may refer to aspiration, malnutrition, dehydration and choking” *RCSLT, 2021*

“Individuals who continue to eat and drink orally despite a perceived risk of choking or aspiration” *RCP, 2021*

NEW(ish) GUIDANCE



Challenges

- When does it become risk feeding/EDAR??
- What ‘risk’ are we talking about?

Principles of an EDAR Approach

- **Person centred**
- **MDT approach –** risks, benefits & burdens
- **Collaborative** working
- **Preserve oral intake**
- Tube feeding – **not either/or**
- **QOL** and **comfort** are priorities

The context - MND

- **Progressive** swallow deterioration, variable rate but can be rapid
- Ideally want to be making **pro-active advance decisions** with the person in advance about what they want re: gastrostomy vs EDAR as things progress.
- Put talking about this on the table **early on** - while person can still convey their wishes (if they want to)

Why develop an internal guideline?

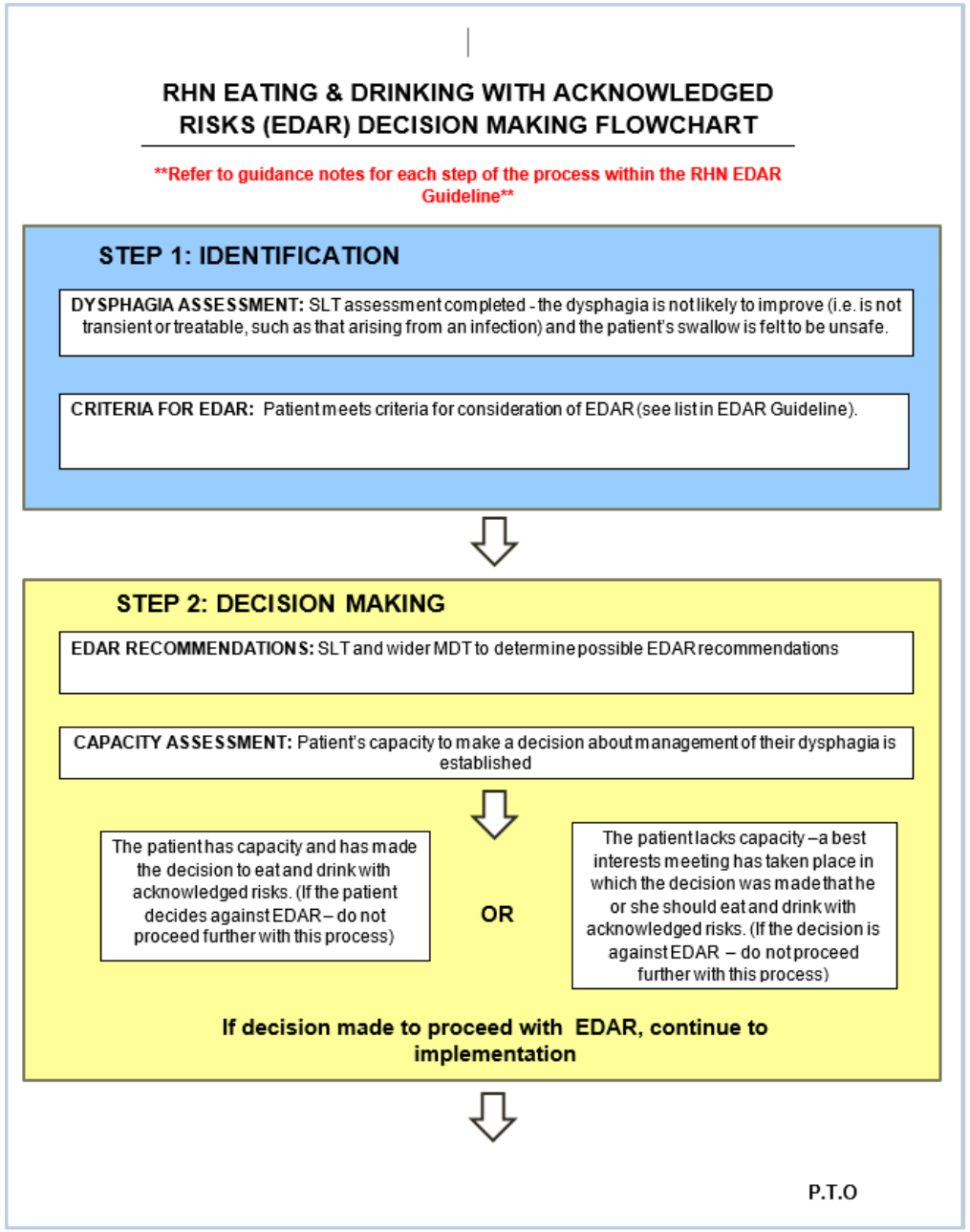
- To provide a **clear and consistent pathway** to **support clinical decision making** in the timely consideration and implementation of EDAR with a patient/resident.

- To ensure that the EDAR decision process **complies with relevant law and professional guidance**.

- To provide a framework for **clear and consistent documentation** of EDAR decisions and recommendations across the hospital

- To ensure that the **decision is fully person-centred**, whether or not the patient has capacity for this decision.

The Pathway



RHN EATING & DRINKING WITH ACKNOWLEDGED RISKS (EDAR) DECISION MAKING FLOWCHART

Refer to guidance notes for each step of the process within the RHN EDAR Guideline

STEP 1: IDENTIFICATION

DYSPHAGIA ASSESSMENT: SLT assessment completed - the dysphagia is not likely to improve (i.e. is not transient or treatable, such as that arising from an infection) and the patient's swallow is felt to be unsafe.

CRITERIA FOR EDAR: Patient meets criteria for consideration of EDAR (see list in EDAR Guideline).

STEP 2: DECISION MAKING

EDAR RECOMMENDATIONS: SLT and wider MDT to determine possible EDAR recommendations

CAPACITY ASSESSMENT: Patient's capacity to make a decision about management of their dysphagia is established

The patient has capacity and has made the decision to eat and drink with acknowledged risks. (If the patient decides against EDAR – do not proceed further with this process)

OR

The patient lacks capacity –a best interests meeting has taken place in which the decision was made that he or she should eat and drink with acknowledged risks. (If the decision is against EDAR – do not proceed further with this process)

If decision made to proceed with EDAR, continue to implementation

P.T.O

STEP 3: IMPLEMENTATION

DOCUMENTATION: SLT to document EDAR recommendations and summary of outcome of EDAR decision making process. See EDAR guideline for all documentation to be completed.

COMMUNICATION: SLT to ensure all relevant people are aware of EDAR recommendations with support given to staff/patient/family as appropriate.

STEP 4: ONGOING MANAGEMENT

ADVANCED CARE PLANNING: Consider advanced care planning and Treatment Escalation Plan including consideration of acute hospital admission; antibiotics; symptom control measures (e.g. suction/chest physio); resuscitation status.

REVIEW: For CC patients - EDAR decision and guidelines will be reviewed at least annually as part of annual Mealtime clinic or on referral. For BIS patients – responsibility to review should be passed to new treating team on discharge

DISCHARGE: Ensure clear communication of EDAR guidelines to discharge destination and GP, and make local SLT team aware.

RECONSIDER EDAR DECISION FLOWCHART IF:

- The patient's dysphagia improves and they are no longer considered to be at risk
- Risks, benefits or burdens change
- If the patient (with capacity) changes their mind and no longer wishes to continue EDAR

1. Identification

Dysphagia assessment

- Thorough SLT assessment.
- Is the dysphagia transient or treatable? … No
- Is the patient's swallow is felt to be unsafe? … Yes

… then consider EDAR as a management option.

1. Identification

Possible Criteria for risk feeding:

- Patient has expressed that they do not want CANH - with or without capacity.
- Patient is declining to follow SLT recommendations to manage risks associated with their dysphagia (e.g. refusing modified food or fluid) – with or without capacity.
- Patient without capacity for this decision and has an Advance Decision to Refuse Treatment (ADRT) or statement of wishes stating they do not want CANH.
- Patient who is meeting their nutrition and hydration needs through CANH and wants to have some oral intake with acknowledged risks for quality of life.
- Patient who is approaching the end of their life.
- Patient for whom the risks of placement of CANH outweigh benefits.
- Patient for whom CANH not possible/an option.

Partially adapted from RCSLT guidance, 2021

Questions we should be asking

RCP (2021) suggests that three key questions should be answered:

- What is underlying diagnosis?
- What is the mechanism of the eating and drinking problem?
- Can the person eat and drink, and if so, at what risk?

Also consider… **what are we trying to achieve?**

2. Decision-Making

EDAR recommendations

Includes consideration of food and fluid textures, positioning, equipment, environment, level of assistance and supervision.

Need to take into account for all the options:

- Risks
- Benefits
- Burdens

Based on SLT ax, evidence base, clinical experience, wishes of patient, info from their loved ones, context, and ethical principles

What are the options?

CONTEXT DEPENDENT – e.g…

- NBM, tube feeding
- Tastes for pleasure, plus tube feeding
- Full oral diet, nil tube feeding
- Mostly oral diet, tube feeding top up
- Free water protocol
- Other innovative options…

Person-centred

What does the patient want?

Consider:

- Preferences
- Wishes
- Culture
- Religion
- Lifestyle
- Past decisions
- Priorities

Other things to consider…

- Oral hygiene
- Saliva management
- Chest intervention
- Fatigue management
- Medications
- Environment
- Staff training and support

2. Decision-Making

Capacity assessment

- Specific to this decision.
- Explore risks and benefits of the different options.

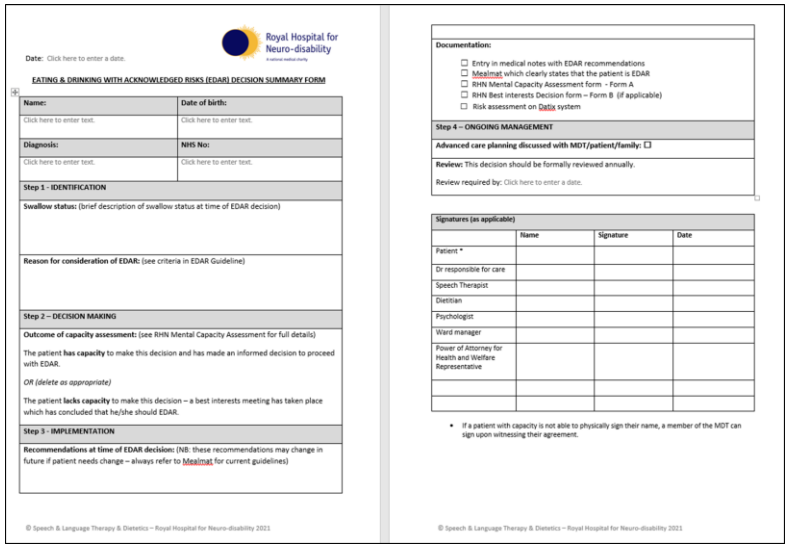
Best interests decision making

Considerations:

- Who is the decision maker?
- Getting everyone there
- Strong emotions/opinions

3. Implementation

Documentation & communication!



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Date: Click here to enter a date.

EATING & DRINKING WITH ACKNOWLEDGED RISKS (EDAR) DECISION SUMMARY FORM

Name:	Date of birth:
Click here to enter text.	Click here to enter text.
Diagnosis:	**NHS No:**
Click here to enter text.	Click here to enter text.

Step 1 - IDENTIFICATION

Swallow status: (brief description of swallow status at time of EDAR decision)

Reason for consideration of EDAR: (see criteria in EDAR Guideline)

Step 2 – DECISION MAKING

Outcome of capacity assessment: (see RHN Mental Capacity Assessment for full details)

The patient **has capacity** to make this decision and has made an informed decision to proceed with EDAR.

OR (delete as appropriate)

The patient **lacks capacity** to make this decision – a best interests meeting has taken place which has concluded that he/she should EDAR.

Step 3 - IMPLEMENTATION

Recommendations at time of EDAR decision: (NB: these recommendations may change in future if patient needs change – always refer to Mealmat for current guidelines)

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Documentation:

- ☐ Entry in medical notes with EDAR recommendations
- ☐ Mealmat which clearly states that the patient is EDAR
- ☐ RHN Mental Capacity Assessment form - Form A
- ☐ RHN Best interests Decision form – Form B (if applicable)
- ☐ Risk assessment on Datix system

Step 4 – ONGOING MANAGEMENT

Advanced care planning discussed with MDT/patient/family: ☐

Review: This decision should be formally reviewed annually.

Review required by: Click here to enter a date.

Signatures (as applicable)

	Name	Signature	Date
Patient *			
Dr responsible for care			
Speech Therapist			
Dietitian			
Psychologist			
Ward manager			
Power of Attorney for Health and Welfare Representative			

- If a patient with capacity is not able to physically sign their name, a member of the MDT can sign upon witnessing their agreement.

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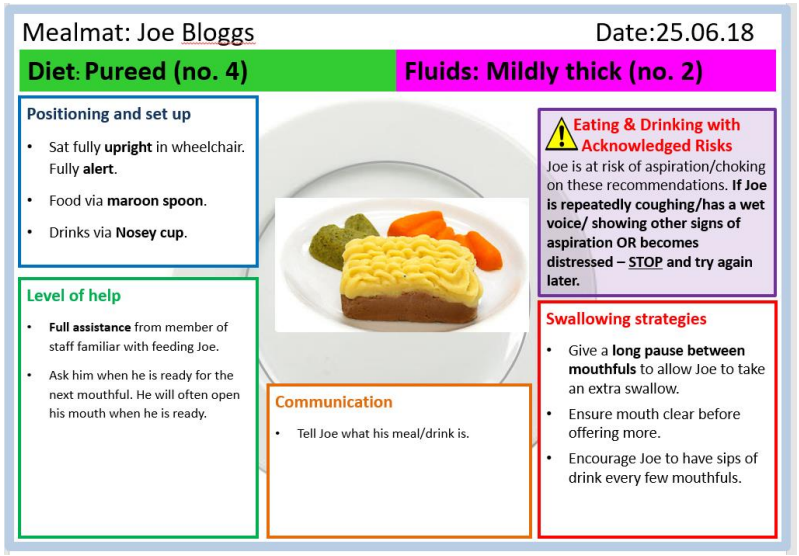

Mealmat: Joe Bloggs Date:25.06.18

Diet: Pureed (no. 4) **Fluids: Mildly thick (no. 2)**

Positioning and set up

- Sat fully **upright** in wheelchair. Fully **alert**.
- Food via **maroon spoon**.
- Drinks via **Nosey cup**.

Level of help

- **Full assistance** from member of staff familiar with feeding Joe.
- Ask him when he is ready for the next mouthful. He will often open his mouth when he is ready.

Communication

- Tell Joe what his meal/drink is.

⚠ Eating & Drinking with Acknowledged Risks

Joe is at risk of aspiration/choking on these recommendations. **If Joe is repeatedly coughing/has a wet voice/ showing other signs of aspiration OR becomes distressed – STOP and try again later.**

Swallowing strategies

- Give a **long pause between mouthfuls** to allow Joe to take an extra swallow.
- Ensure mouth clear before offering more.
- Encourage Joe to have sips of drink every few mouthfuls.

Supporting staff/family

It can be challenging supporting someone to eat and drink at risk –

- Distress
- Anxiety/fear of litigation

Need to ensure appropriate support -

- Promote understanding of rationale for decision
- Promote understanding of legal position regarding litigation
- Emotional support available?

4. Ongoing Management

- Treatment escalation plan/future care planning
- Review
- Communication of guidelines to relevant professionals

Case Study

- 51 year old gentleman with MND
- Mild-moderate deteriorating oropharyngeal dysphagia
- Handover on admission: ‘not for PEG’
- NIV

References

- Royal College of Physicians. Supporting people who have eating and drinking difficulties. Guide to practical care and clinical assistance, particularly towards the end of life. Report of a working party. London: RCP, 2021
- Royal College of Speech & Language Therapists. Eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process (adults). London: RCSLT, 2021
- Department for Constitutional Affairs. Mental Capacity Act. London, 2005.
- Mental capacity act 2005 , Code of Practice (2007). Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf
- Chakladar, E. (2012). British Geriatrics Society best practice guide: dysphagia management for older people towards the end of Life. Retrieved from http://www.bgs.org.uk/good-practice-guides/resources/goodpractice/bpgdysphagia
- General Medical Council, (2010). Treatment and care towards the end of life. Retrieved from http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf
- Right Care Progressive Neurological Conditions Tool Kit: https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf.

References

- Miles, A., Watt, T., Wong, W. Y., McHutchison, L., & Friary, P. (2016). Complex feeding decisions: perceptions of staff, patients, and their families in the inpatient hospital setting. *Gerontology and Geriatric Medicine*, 2, 2333721416665523.
- Sommerville, P., Lang, A., Harbert, L., Archer, S., Nightingale, S., & Birns, J. (2017). Improving the care of patients feeding at risk using a novel care bundle. Future Hospital Journal, 4(3), 202-206.
- Murray, A., Mulkerrin, S., & O'Keeffe, S. T. (2019). The perils of 'risk feeding'. *Age and ageing*, *48*(4), 478-481.
- Hansjee, D.,2018. Risk Feeding: From protocol to model of care. Royal College of Speech & Language Therapists Bulletin, Issue 789, Redactive, London.
- Finucane T. E., & Bynum J. P. (1996) Use of tube feeding to prevent aspiration pneumonia. Lancet. 348, 1421-1424.
- Soar, N., Birns, J., Sommerville, P. et al. Approaches to Eating and Drinking with Acknowledged Risk: A Systematic Review. Dysphagia 36, 54–66 (2020).
- Langmore, S. E., Skarupski, K. A., Park, P. S., & Fries, B. E. (2002). Predictors of aspiration pneumonia in nursing home residents. Dysphagia, 17(4), 298-307.
- Sommerville, P., Hayton, J., Soar, N., Archer, S., Fitzgerald, A., Lang, A., & Birns, J. (2022). Prognosis in dysphagic patients who are eating and drinking with acknowledged risk: results from the evaluation of the FORWARD project. Age and Ageing, 51(2)
- O'Keeffe, Shaun T. et al. 'Aspiration, Risk and Risk Feeding: A Critique of the Royal College of Physicians Guidance on Care of People with Eating and Drinking Difficulties'. 1 Jan. 2021 : 63 – 72.
- Hibberd, J., Fraser, J., Chapman, C., Mcqueen, H., Wilson, A., 2013. 'Can we use influencing factors to predict aspiration pneumonia in the United Kingdom'. Multidisciplinary Respiratory Medicine 8:39.

References

- Palecek, E. J., Teno, J. M., Casarett, D. J., Hanson, L. C., Rhodes, R. L., & Mitchell, S. L. (2010). Comfort Feeding Only: A Proposal to Bring Clarity to Decision-Making Regarding Difficulty with Eating for Persons with Advanced Dementia: (See Editorial Comments by Dr. Daniel J. Brauner, pp 599–601). Journal of the American Geriatrics Society, 58(3), 580-584.
- Daggett, A., Logemann, J., Rademaker, A., & Pauloski, B. (2006). Laryngeal penetration during deglutition in normal subjects of various ages. Dysphagia, 21(4), 270-274.
- Langmore, S. E., Terpenning, M. S., Schork, A., Chen, Y., Murray, J. T., Lopatin, D., & Loesche, W. J. (1998). Predictors of aspiration pneumonia: how important is dysphagia?. Dysphagia, 13(2), 69-81.
- Vesey, S., Leslie, P., & Exley, C. (2008). A pilot study exploring the factors that influence the decision to have PEG feeding in patients with progressive conditions. Dysphagia, 23(3), 310.
- Panther, K. (2005). The Frazier free water protocol. Perspectives on Swallowing and Swallowing Disorders (Dysphagia), 14(1), 4-9.
- Hansjee, D. (2018). An Acute Model of Care to Guide Eating & Drinking Decisions in the Frail Elderly with Dementia and Dysphagia. Geriatrics, 3(4), 65.
- Lisiecka, D., Kelly, H., & Jackson, J. (2021). How do people with Motor Neurone Disease experience dysphagia? A qualitative investigation of personal experiences. Disability and rehabilitation, 43(4), 479-488.
- NICE guideline NG42. Motor neurone disease: assessment and management. 2016