



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

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Introduction

Across the healthcare spectrum, individuals are surviving longer and with multiple comorbidities (Stafford, 2018). Dysphagia is more prevalent in older people and increases with the degree of frailty present and the degree of dependence irrespective of ethnicity (Smithard, 2016; Chen et al, 2010; Marik et al, 2003). Dysphagia is highly prevalent in a number of neurological or neurodegenerative diseases as well as head and neck diseases (Clave & Shaker, 2015). Included in the high prevalence group are adults with learning disability (Heslop et al, 2014). Malnutrition, dehydration, aspiration pneumonia, compromised general health, chronic lung disease, choking and even death may all be consequences of having dysphagia (Leder & Suiter, 2009). It is essential to note, however, that there is no linear relationship between dysphagia resulting in aspiration pneumonia. The complex adaptive system of our respiratory tract cannot be reduced to such a simplistic model (Dickson et al, 2016). The development of aspiration pneumonia may occur due to a combination of swallowing impairment and contributory factors such as poor oral hygiene, being dependent on others for assistance when eating and drinking, and high support needs for positioning during mealtimes (Langmore, 2002; Hibberd et al, 2013).

With individuals surviving longer with increasingly complex health needs, it is anticipated that the need to consider eating and drinking decisions in the presence of risk is only likely to increase with time (Chakalader, 2012). These risks can include aspiration of food and fluids into the airway, choking, malnutrition, dehydration, distress, and social isolation. 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).

Purpose and scope

The purpose of this document is to guide healthcare professionals through the complex decision-making process to support adults when eating and drinking with acknowledged risks. The aim is to provide a framework to facilitate a swift, consistent decision-making process respecting individual wishes and maximising quality of life. The guidance aims to clarify the assessment, decision-making and documentation processes required in order to achieve person-centred, multidisciplinary and multi-agency care planning with clear methods of review for individuals. It is in no way prescriptive but seeks to serve as guidance for adults with dysphagia across care settings.

While the Royal College of Physicians (RCP) document 'Supporting people who have eating and drinking difficulties' (2021) is the primary guidance for care and clinical assistance towards the end of life, this document will serve as an adjunct referring to the nuances within the decision-making process for adults eating and drinking with acknowledged risks irrespective of the stage or progression of their illness.

The decision-making process requires a person-centred problem-solving approach from the range of professionals involved in the individual's nutritional management and care. This document was therefore compiled in consultation with an expert working group. The names and roles are listed below:

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With thanks to everyone who took the time to contribute to this guidance by responding to the consultation and providing feedback to the working group.

While this document is aimed at enhancing the process of complex decision-making around eating and drinking across the UK, it is important to draw attention to the differences in legislation. The Mental Capacity Act 2005 applies in England and Wales. The equivalent legislation in Scotland is the Adults with Incapacity (Scotland) Act 2000. A Mental Capacity Act for Northern Ireland has been passed but is not yet fully in force; currently decisions about medical treatment take place under the common law. This guidance does not consider Scottish or Northern Irish legislation and readers are recommended to seek expert legal advice in those devolved parts of the UK about legal matters, but the general clinical principles will still apply. A summary of the main differences in the legal frameworks for decision-making in relation to those lacking capacity in England and Wales and those in Scotland, Northern Ireland (NI) and the Republic of Ireland can be found in [appendix 1](#) of the Association of Anaesthetists of Great Britain & Ireland's guideline '[Consent for anaesthesia](#)'.

The guidance around eating and drinking with acknowledged risks is predominantly a synthesis of existing information and evidence from across the UK and further afield. The authors would therefore like to thank colleagues across the speech and language therapy workforce and other healthcare professions for sharing good practice, web pages and publications.

Terminology

There are a number of terms used to describe the decision to eat and drink despite the associated risks of dysphagia. These risks may refer to aspiration, malnutrition, dehydration and choking. Terms such as 'risk feeding', 'eating and drinking with accepted risk', and 'feeding at risk' remain contentious among some groups as they may contain the words 'risk' and/or 'feeding'.

This guidance does not aim to be prescriptive regarding the use of any one particular term; instead it focuses on the principles for an effective decision-making process, rather than how to refer to it. After extensive consultation the term agreed for use within this document is 'eating and drinking with acknowledged risks'. The working group recognises that, in practice, professionals will need to use language and terminology appropriate for the individual and for the context but encourages the use of this agreed term.

Context and indications

Evidence-based practice is the "integration of best research evidence with clinical expertise and service user values" (Akobeng, 2005). It means that when health professionals make a treatment decision with a service user, they base it on their clinical expertise, the preferences of the individual, and the best available evidence.

For the purposes of this document, shared decision-making in dysphagia (SDMD) will be used to describe the decision-making process which occurs when an individual is eating and drinking with

acknowledged risks and follows the best practice and legal frameworks of evidence-based practice and the law associated with mental capacity and consent. The SDMD process will involve the person and/or relatives, and various members of the multidisciplinary team (MDT) such as the registered nurse, dietitian, speech and language therapist (SLT), physiotherapist, pharmacist and consultant or GP. These are examples of MDT members who may be involved but is in no way an exhaustive list of members who could be involved in the decision-making process.

In the past, risk has been regarded solely as a negative concept that should be avoided. It is, however, now recognised that risk is simply a fact of life; it may change dynamically and cannot be avoided or denied. If we understand risk and how it is caused and influenced, we can modify it so that we are more likely to achieve person-centred goals of care. Having a shared decision-making process in place enables us to do this more swiftly and efficiently with improved results (Somerville et al, 2019; Hansjee, 2018). It allows the person, at the centre of the decision-making process, to have ownership of the decision.

The SDMD process for individuals who are eating and drinking with acknowledged risks advises understanding the interests and wishes of the person and the individuals involved in their care, engaging in appropriate assessments and taking steps to minimise risks that exist. According to the Centre for Adults' Social Care (2003), the assessment must be properly documented and lead to protocols which cover all situations, including foreseeable emergencies. The SDMD process in this context ensures that all aspects of care and outcomes are considered. This approach results in a respectful and dignified person-centred decision which is made with considered thought and over a reasonable timeframe.

The care team should consider implementing SDMD where 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.

Eating and drinking with acknowledged risks can be applicable to various scenarios. Outlined below are some examples of instances where an individual may eat and drink with acknowledged risks:

- 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 (eg 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.

Steps in the decision-making process

The steps in the process of decision-making may differ according to the setting, but ensuring all aspects of care are included makes the decision-making process more robust. For hospital settings where the medical or nursing teams are likely to conduct an initial general assessment of the individual's health during out-of-hours periods, establishing the medical goal of intervention may be necessary for the pathway to be initiated. In the community however, it is more likely that the process would commence with an initial assessment of swallowing, thereafter a capacity assessment, followed by a discussion on the goal of intervention.



Conduct a clinical evaluation of the swallow

A complete clinical evaluation of the swallow should be conducted by an SLT, complementing the MDT assessment, in order to determine interventions and support that may reduce risk (see [SLT eating, drinking and swallowing competency framework](#)). Risks may be reduced by a range of interventions and support including appropriate mouth care routines, advice on optimal textures, positioning, equipment, the environment, level of assistance and supervision as well as facilitated eating and drinking (Hibberd et al, 2013; Hansjee, 2019).

Discussions with the individual and those closest to them should occur about what is important in relation to eating and drinking for the individual themselves. For example, food preferences, mealtime routines, and cultural, religious and spiritual beliefs associated with food are essential to assessment

but also to understanding 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.

In the instance where an SLT is unavailable, local guidelines should be followed. The [Eating, Drinking and Swallowing Competency Framework](#) also provides suggestions on management within these scenarios until a specialist assessment can occur.

Capacity assessment

One of the principles discussed in the Ethical Framework for Health and Social Care (2020) is that of respect. 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 proper reason to suggest the contrary. If there is such a reason, then a capacity assessment should be carried out. A decision should be made based on local legal frameworks within the respective nations. No further expansion detailing components of capacity assessments will be included in this document due to the respective regional variations.

As with all capacity assessments, the decision should be presented in an accessible format/language to make every attempt to support the individual to understand the issues involved in the decision-making process and be able to express their acknowledgement of the risks involved. This includes the principles of care set out in NICE guidelines NG108 (2018) 'Enabling the person to actively participate in their care'.

Where an individual lacks capacity to make a decision regarding their nutrition and/or hydration, a best interests multidisciplinary decision must be taken. It is essential that those engaged in caring for the person or those closest to them, or a designated advocate, are involved in determining whether the person had previously expressed wishes regarding eating and drinking decisions, and to help advocate for the individual's best interests.

If 'unbefriended', an independent mental capacity advocate should be involved to support decision-making on the person's behalf. If there is no agreement reached, the NHS body with responsibility for the person's care should present the case at court (further legal information is available in this guidance on [serious medical treatment](#)). All discussions should be documented in the case notes/care plan/reports and shared with the individual, relatives and professionals involved in their nutritional management and care, for the purposes of information handover and continuity of care.

The overall goal of this document is to support the decision-making process irrespective of the person having the capacity to accept the risks involved. As emphasised in the RCP guidance (2021), a person with capacity can choose to make a decision which appears to others to be unwise. That could include a decision that they wish to receive nutrition in a way that heightens risk to their general health. There may also be circumstances in which it is clear that an individual lacking capacity to make decisions wishes to receive nutrition in a specific fashion which appears to pose a risk to them. If there is a proper consideration of whether this is in their best interests, then those who act upon that known wish will be protected from liability, again so long as they have acted with due care.

Professional colleagues should agree who will discuss the outcomes and management plan with all concerned. Information should be presented in an accessible way whereby service users and those

closest to them, wherever possible, are provided with written information on eating and drinking with acknowledged risks, allowing time for reflection and questions (the General Medical Council has published some tips for [handling difficult conversations](#) and the Royal College of Physicians has published a framework on [conversations for ethically complex care](#)).

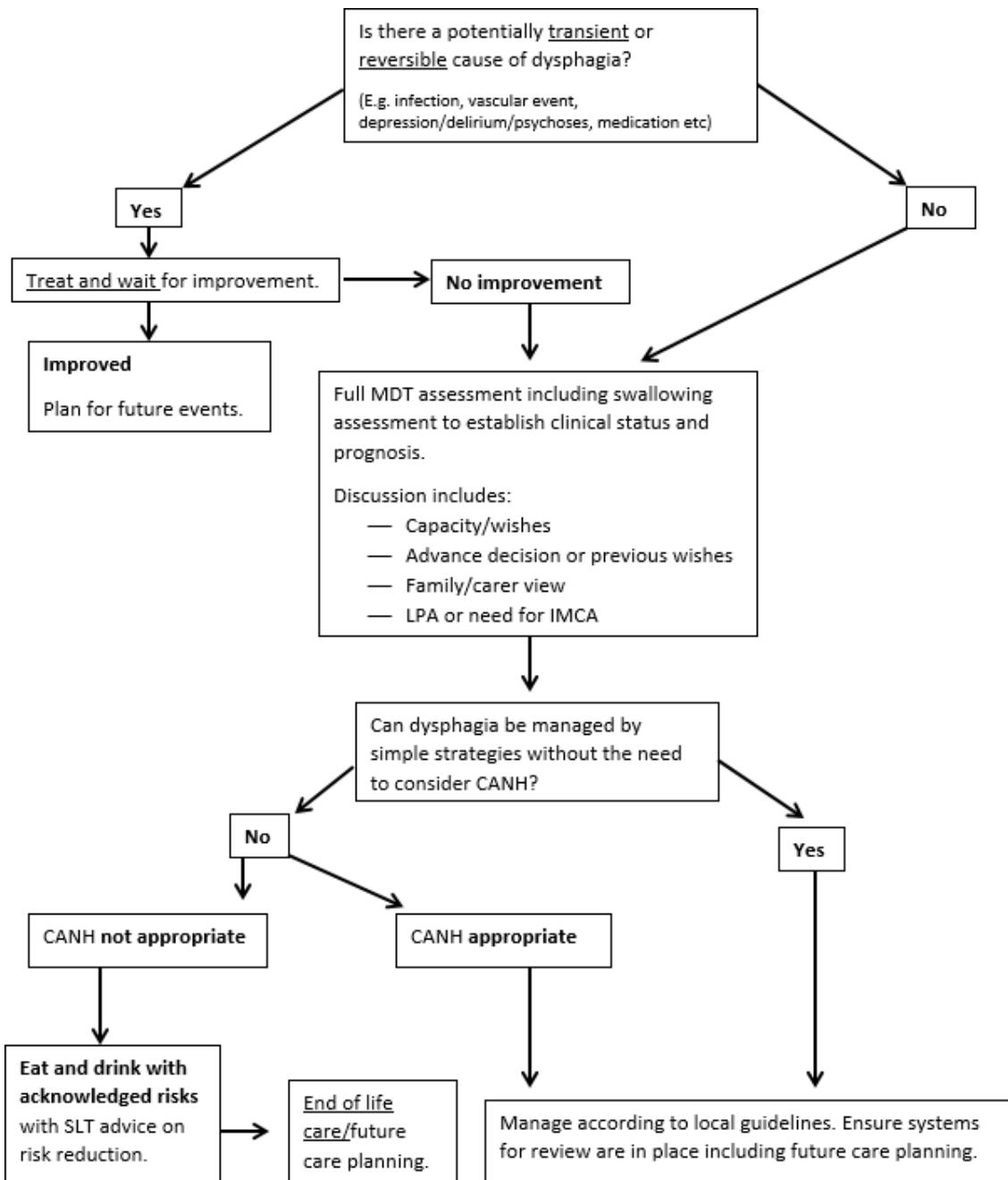
Establish the primary goal of intervention/care

When determining the nutritional plan, it is the responsibility of the clinicians involved in the individual's nutrition and hydration needs to prioritise the wishes and assess the burden and benefit of nutritional options, from a perspective of beneficence. It is essential therefore that the initiation of a plan to eat and drink with acknowledged risks is preceded by detailed information gathering to establish the nature of the dysphagia and associated prognosis. This includes identifying whether the individual's clinical picture is transient in nature or unlikely to change in spite of intervention. Consideration of how future management will impact on the quality of life for that individual is central to the process, particularly taking into account the ethical principles of dignity and nonmaleficence (RCP, 2021).

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.

Figure 1 shows a flowchart adapted from Smith et al (2009), which guides professionals through the early processes of clinical decision-making with respect to eating and drinking with acknowledged risks.

Figure 1



See [appendix 1](#) for a plain text version of the flowchart.

Communicate with the multidisciplinary team

Examples of the roles and responsibilities of the MDT within the decision-making process for individuals eating and drinking with acknowledged risks are outlined in Table 1 below. There is overlap between and amongst roles and what is relevant for one team member may equally apply to others. The roles listed in Table 1 are not exhaustive but examples of how team members may be involved in the decision-making process in various care settings.

Table 1

Roles	Responsibilities within SDMD for individuals eating and drinking with acknowledged risks
Individual/ family/carer (those closest to the individual)	<p>Be consulted on wishes/interests/beliefs.</p> <p>Provide information on eating and drinking preferences, mealtime routines, cultural, religious and spiritual beliefs associated with food.</p>
Medical practitioner	<p>Initiate the dialogue regarding the risks involved and if there are grounds to doubt whether the individual has capacity to make a decision about their nutrition, undertake a capacity assessment (particularly applicable during weekends/evenings in hospital settings).</p> <p>Refer to SLT for a swallowing assessment.</p> <p>Ensure anticipatory/advance health care plans are completed when needed.</p> <p>Include eating and drinking with acknowledged risks recommendations in letters/correspondence.</p>
Speech and language therapist	<p>Conduct a clinical assessment of swallowing.</p> <p>Conduct or facilitate a capacity assessment for nutritional options if needed.</p> <p>Discuss findings of the swallow assessment with the MDT, including the individual and their significant others. If possible, provide written information on eating and drinking with acknowledged risks (see General Medical Council tips for handling difficult conversations and RCP framework for conversations for ethically complex care).</p> <p>Make intervention person-centred and support recommendations that form the basis of how individuals will eat and drink with acknowledged risks.</p>

Consultant/GP	<p>Has overriding responsibility of individuals under their care and therefore often makes 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.</p> <p>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.</p>
Dietitian	<p>Support the individual to optimise their nutritional intake.</p> <p>Evaluate candidacy of the person for alternative nutrition and hydration options.</p> <p>Support other members of the MDT regarding the development and implementation of the individual's nutrition and hydration care plan.</p> <p>Support palliative care regarding eating and drinking at the end of life.</p>
Physiotherapist	<p>Discuss chest management with the medical team and ceiling of care with regard to respiratory needs.</p> <p>Provide assessment and recommendations about optimal positioning and postural support for eating and drinking.</p>
Nurse	<p>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/SLT.</p> <p>Appropriate nursing handover should take place to ensure that risks are acknowledged and minimised with scrupulous mouth care and optimum seating position.</p> <p>Support the individual to follow eating and drinking recommendations as much as is possible. Document and escalate issues.</p> <p>Act as the person's advocate, evaluating care and risk managing situations when SLT advice is not available, in conjunction with medical colleagues, the person and their family.</p> <p>Reviewing general physical health in community settings. Escalate concerns back to the MDT/GP as appropriate.</p>
Healthcare assistant	Support the individual to follow eating and drinking recommendations as much as is possible. Document and escalate issues if needed.

Palliative care	Inform the MDT if an individual has been placed on the end-of-life pathway. Provide support to the individual or those close to them on eating and drinking at the end-of-life. Ensure individuals identified as 'actively dying' have a plan of care including symptom control and psychological, social and spiritual support for the individual and family.
Pharmacy	Coordinate medication with medical professional and SLT to ensure medication is in a form which is easier to swallow (UK Medicines Information on thickening agents ; Cichero, 2013; Manrique et al, 2016).

Set out an advance care plan where appropriate

Collaboration of hospital and community services with GP practices is essential within this pathway of care. When appropriate, Advance Care Plans (ACP) should be implemented and reinforced with the individual's wishes being fully supported.

It is the responsibility of all MDT members to ensure a comprehensive summary of the decision and overview of the agreed advance care plan is communicated across healthcare settings for continuity of care (NICE, 2015). Advance care planning must always be done in conjunction with the person, be guided by their wishes, and should never be done by reference to blanket policies about categories of people (RCP, 2021).

Documentation

Having a protocol for the SDMD process can be beneficial in practice (Hansjee, 2018). In this way, the various processes of indications for eating and drinking with acknowledged risks, the capacity assessment for nutrition, eating and drinking recommendations, considerations for medication and advance care planning can all be captured in one document. Although this process may vary for different organisations, it is crucial to ensure all discussions are documented in care plans, medical notes and electronic records.

For care support staff who are usually assisting individuals with their eating and drinking, having a document which reflects the discussions and includes the decision to eat and drink with acknowledged risks is needed for governance, assurance and reassurance. There may also be circumstances in which it is clear that an individual lacking capacity to make decisions wishes to receive nutrition in a specific fashion which appears to pose a risk to them. If there is consideration of whether this is in their best interests, then those who act upon that known wish will be protected from liability, again so long as they have acted with due care. The possible resolutions to disagreements are not detailed in this document due to regional legal differences.

Once SDMD is complete for the individual eating and drinking with acknowledged risks, the decision should be added to care plans/discharge reports so that the receiving, admitting and/or supporting teams are aware of nutrition plans and future care. As swallowing abilities and preferences fluctuate, the individual still has the right to change their mind about the decision at a later stage, assuming they have capacity. If the individual does not have capacity to make a decision about their nutrition, a review of the current plan using best interests frameworks can be locally agreed within respective care settings. Communication and information sharing will ensure services achieve the overarching principles of care and support during times of transition (NICE, 2015).

Hospital settings

For hospital settings, where individuals can rapidly change in presentation due to the acute nature of the illness, it is suggested that SLTs monitor individuals who are eating and drinking with acknowledged risks regularly (weekly if possible, unless a review is requested sooner). This could involve an indirect check of food/fluid charts and speaking to the nurses or healthcare assistants to establish if there have been any concerns or changes to eating and drinking.

Recommendations may need to be amended during this episode of care. If, during their hospital admission, the individual is medically stable but is awaiting a care home with/without nursing, it is essential that the reports are disseminated to the GP and referral on to the community SLT (if needed) is completed when discharged. Not all individuals who are eating and drinking with acknowledged risks will require referral to the community SLT, but a referral may be required for support and advice with recommendations for the individual or significant other, as well as for psychosocial support. Thereafter if an individual who is eating and drinking with acknowledged risks is admitted to hospital, a review will still be required to establish if the diet/fluid recommendations in their care plan are indeed the most comfortable for this individual, taking into account their medical condition at the time of admission. This approach fosters personalised care and respective organisations can set up systems such as electronic alerts to enhance a prompt referral to an SLT for a review of swallowing on admission.

Community settings

For the individual in their own home or within community care settings, documentation in care plans, 'hospital passports', advance care plans (if needed) and correspondence with the GP is integral, not only in setting out a smooth transition of care, but also to ensure that the individual's wishes are being met along the care pathway. Once the SDMD process for eating and drinking with acknowledged risks is complete, it is suggested that the GP should include an anticipatory plan for the future management of any resultant chest infections.

Care home staff should receive training regarding care involved for individuals who are eating and drinking with acknowledged risks. The [Eating, Drinking and Swallowing Competency Framework](#) provides a framework for such training. Robust pathways should be set up locally to confirm that these individuals are managed in the most appropriate care setting (NHS Long term plan, 2019).

Outcome measures

At whatever stage in their care pathway an individual commences eating and drinking with acknowledged risks, it may be beneficial to establish if the individual or those closest to them (in the instance of the individual not having capacity) felt included in the decision-making process around their eating and drinking. Aspects of care such as establishing if their nutritional wishes/choices were met, and whether information was provided in an accessible format to aid understanding and involvement in decision-making, may be important to consider.

Obtaining outcome measures for those individuals who are approaching the end of their life can be challenging. Key information shared in a timely, compassionate, accessible manner has been associated with positive perspectives of end-of-life care (Royak-Schaler et al, 2006). Regardless of the condition, individuals and/or those closest to them consider receiving key information as being important to quality care, including discussions about prognosis and future treatment options (Heyland et al, 2003; Royak-Schaler et al, 2006). The national End of Life Care Strategy for England (2008) defines 'a good death' as treating an individual with dignity and respect. It is pertinent to recognise that for this eating and drinking with acknowledged risks framework the key focus is to maximise the quality of life of an individual, through the shared decision-making process, ensuring their wishes are respected as they approach the end of life.

Outcome measurement in this area is evolving and is an area which requires further research.

Glossary

Table 2 offers definitions for the terms of reference used throughout this guidance.

Table 2

Terms of reference	Definition
Advance 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.
Aspiration	When food or drink passes the vocal folds and enters the lungs
Aspiration pneumonia	Aspiration pneumonia results from inhalation of oropharyngeal contents into the lower airways that leads to lung injury and resultant bacterial infection.
Clinically Assisted Nutrition and Hydration (CANH)	Clinically Assisted Nutrition and Hydration refers to alternative means of receiving nutrition enterally.
Capacity	Mental capacity means you have the ability to make your own decisions
Dehydration	A state in which a relative deficiency of fluid causes adverse effects on function and clinical outcome
Eating and drinking with acknowledged risks	Continuing to eat and drink despite the associated risks from having dysphagia
Independent Mental Capacity Advocate (IMCA)	An IMCA is a legal safeguard who is appointed for people who lack the capacity to make specific important decisions, including making decisions about where they live and about serious medical treatment options (Mental Capacity Act 2005)
Lasting Power of Attorney (LPA)	An LPA is a way of giving an attorney the legal authority to make health and welfare decisions on a person's behalf if they lose the mental capacity to do so in the future, or if the person no longer wants to make decisions for themselves

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
MDT	Multidisciplinary team
Mouth care routines	The daily routine of keeping an individual's mouth clean
Optimal positioning	Where the individual is well positioned, upright with feet/trunk supported
Shared Decision Making in Dysphagia (SDMD)	An inclusive, multidisciplinary decision-making process regarding whether to introduce CANH and/or continue to eat and drink orally when the ability to swallow deteriorates with full acknowledgement of the resulting risks
SLT	Speech and language therapist
Unbefriended	Individuals who lack the capacity to make their own medical decisions but who have no family members or other surrogates to speak on their behalf

Appendix 1

Figure 1: Flowchart plain text

Top of chart begins Q: "Is there a potentially transient or reversible cause of dysphagia? (Eg infection, vascular event, depression/delirium/psychoses, medication etc)"

1. If "No" to transient or reversible cause, then: "Full MDT assessment including swallowing assessment to establish clinical status and prognosis. Discussion includes: capacity/wishes, advance decision or previous wishes, family/carer view, LPA or need for IMCA"
 - a. Then Q: "Can dysphagia be managed by simple strategies without the need to consider CANH?"
 - i. If "No" and CANH is appropriate, then: "Manage according to local guidelines. Ensure systems for review are in place including future care planning."
 - ii. If "No" and CANH is not appropriate, then "Eat and drink with acknowledged risks with SLT advice on risk reduction."
 1. Then End of life care/future
2. If "Yes" to transient or reversible cause, then "Treat and wait for improvement"
 - a. If "Improved", then "Plan for future events".
 - b. If "No improvement" then follow steps from 1, ie "No to transient or reversible cause".

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