SJOG Hospitaller Services

Respecting Choice and Managing Risk

Supporting individuals with learning disabilities who decline adapted diets despite choking hazards

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For Paul

Contents

Introduction

People with learning disabilities often face unique challenges in managing their health, particularly when it comes to conditions like dysphagia, which is characterised by difficulty in swallowing. Dysphagia plans are tailored to mitigate risks associated with choking and aspiration, and to ensure safe and adequate nutrition. However, there are cases where individuals with learning disabilities, who have the capacity to consent, choose to refuse adherence to these plans.

The core issue at hand here involves balancing autonomy with safety. People who refuse to follow dysphagia plans often cite quality of life as a primary reason for their decision. They may argue that strict adherence to such plans can lead to a reduction in their enjoyment of food and overall life satisfaction. This raises important ethical considerations about respecting the choices of individuals with learning disabilities while ensuring their health and safety.

Care providers, and support teams must navigate these situations carefully, respecting the individual's autonomy and right to make informed decisions, while also providing education and support to help them understand the potential risks and benefits. This delicate balance requires a compassionate, person-centred approach that honours the individual's values and preferences, aiming to enhance their quality of life without compromising their well-being and rights.

When individuals with learning disabilities refuse to adhere to a dysphagia plan, care providers face significant risks and challenges.

Dysphagia plans are designed to prevent serious complications such as choking, aspiration, and malnutrition, which can have severe, even life-threatening, consequences. The refusal to follow these plans can therefore place individuals at heightened risk of harm. Care providers therefore face legal and ethical risks to ensure the safety and wellbeing of the people they support. Failure to prevent harm can result in legal and regulatory consequences.

Care providers also have a responsibility for the health and safety of support staff who may present with emotional and psychological stress due to understanding the implications of individuals they are supporting not adhering to professional guidance. This can be emotionally taxing for staff, who may be fearful of the consequences of injury to their reputation and that of the care provider.

Navigating these risks requires a delicate balance of respecting individual autonomy while fulfilling duty of care. Care providers must engage in thorough documentation, communication, and collaboration with the individual, their families, and multidisciplinary teams to mitigate risks and ensure informed decision-making. This approach helps in managing the ethical complexities and legal responsibilities inherent in providing care to individuals with learning disabilities who refuse to adhere to dysphagia plans.

This paper explores the complex connection of legal, ethical, and good practice guidance in supporting individuals with learning disabilities who do not consent to adhering to a dysphagia plan. Current guidance provides toolkits for providing support to individuals who do not have capacity; less so for people who do have capacity.

This paper presents a synthesis of good practice guidance for supporting people who do have capacity, offering an actionable toolkit for care providers.

Prevalence of dysphagia in the learning disability community

According to Mencap (2021) there are approximately 1.5 million people in the UK with a learning disability. There are thought to be about 350,000 with a severe learning disability alone (Public Health England, 2016). There has been limited historic research in learning disabilities and dysphagia until recently.

Smith et al., 2020, estimated 58% of people with learning disabilities have difficulties with communication. Moreover, eating, drinking and dysphagia potentially affects between 8.1% and 11.15% of people with a learning disability (Robertson et al, 2017). 15% are known to require support to eat and drink (Public Health England, 2016).

Speech and Language Therapy caseloads have seen significant increases in people with learning disabilities requiring support with eating and drinking. This is estimated between 36% to over 70%.

There is a higher prevalence of dysphagia in people with severe learning disabilities. This is due to:

- hypotonia (poor muscle tone causing muscle weakness), or
- hypertonia (too much muscle tone causing stiffness) and
- poor coordination.

People with a severe learning disability have a significant intellectual disability with an IQ level between 20-25. This can be linked with a reduced perception and acquisition of independence skills such as eating and drinking. As a result, people may be unaware that certain foods can be a risk e.g. tough meats, dried food such as bread etc. These foods require masticatory preparation (chewing) before swallowing (Public Health England, 2016).

People with learning disabilities face significant health inequalities and often have a higher prevalence of difficulties with eating, drinking and swallowing. This is often impacted further by a range of coexisting conditions, i.e., autism, sensory difficulties and even mental health. It is estimated that 89% of people will require speech and language intervention (Bradshaw, 2007).

In 2004, the National Patient Safety Agency (NPSA) identified dysphagia as a significant health risk for people with learning disabilities. In a cross-sectional study in Greater Glasgow the prevalence of dysphagia in severe learning disabilities was 14% (Kinnear et al., 2018). The study illuminated data from 47% of GP practices in England, identifying 5% of people with mild to moderate learning disabilities with dysphagia. This increased to 11.7% in people aged 75 years and over.

The trend in data and research indicates this population continues to be at significant risk of choking and more likely to be at risk of dysphagia than the rest of the population.

Despite these worrying trends, the requirement to use evidence-based practice (EBP), many gaps exist in the literature regarding approaches to SLT for individuals with learning disabilities. Research into communication-based interventions for individuals with learning disabilities are often underpowered and of poor quality (Wood and Standen, 2021). Additionally, interventions pertaining to dysphagia specifically for the population of people with learning disabilities are not well-explored, with most studies investigating enteral feeding only, of which also lack robustness (Manduchi et al., 2020).

The impact of this leaves people with learning disabilities, care providers and their staff vulnerable to the risk of poor practice and even fatalities. There are gaps in good practice tools for those choosing to opt out of following dysphagia plans in the UK.

Our research helps to close this gap by translating the research into useful good practice.

What are dysphagia and aspiration?

According to the Royal College of Speech & Language Therapists (2018):

Dysphagia describes eating and drinking disorders in children and adults that may occur in the oral, pharyngeal and oesophageal stages of deglutition. This includes problems positioning food in the mouth and in oral movements, including sucking, chewing (mastication) and the process of swallowing. The 'normal' swallow needs the respiratory, oral, pharyngeal, laryngeal and oesophageal anatomical structures to function in synchrony, which is dependent upon the motor and sensory nervous system being intact.

Aspiration is the inhalation of either oropharyngeal or gastric contents into the lower airways, that is, the act of taking foreign material into the lungs.

What are the signs of dysphagia?

The main characteristics of dysphagia (RCSLT 2024) are:

Oesophageal Dysphagia - Oesophageal dysphagia affects the food pipe (oesophagus), meaning food does not move smoothly into/through the oesophagus to the stomach. Symptoms include:

- Choking
- Coughing
- Difficulty initiating a swallow
- Diminished cough reflex
- Dysarthria (slurred speech/weakness is speech muscles)
- Nasal regurgitation

Oropharyngeal Dysphagia - Oropharyngeal dysphagia is the inability to swallow food or drink. The condition can also cause breathing difficulties, choking, and drooling.

- Absent protective reflexes
- Delayed initiation of swallow
- Gagging and vomiting
- Gurgling voice
- Nasal regurgitation
- Poor bolus formation (chewing food before swallowing)
- Tongue pumping (back and forward movements of the tongue as the person tries to get their swallow going)
- Wet respiration (respiratory distress)

Mortality rates associated to dysphagia within the learning disability population

Dysphagia is a distressing and dangerous condition that in some people can lead to death. Thacker et al (2008) states that 'feeding and swallowing impairments are key predictors of increased morbidity and mortality in adults with learning disabilities', while Chadwick and Jolliffe (2009) show that dysphagia is a significant issue for people with learning disabilities and those who care for them.

The Learning Disabilities Mortality Review (LeDeR) Programme 2019 UK annual report highlighted people with learning disabilities are prematurely at risk of death to a treatable cause. Alongside preventable health inequalities, mortality is on average 15-20 years sooner than neuro-typical people.

Approximately 40% of people with a learning disability and dysphagia will experience reoccurring respiratory tract infections. In some cases, this has been known to go unnoticed due to people being unable to communicate their needs. The review highlighted people are at risk of premature death identifying aspiration pneumonia as a signature cause of death.

The Foundation for People with Learning Disabilities UK suggests people with learning disabilities are 58 times more likely to die before the age of 50. They cite respiratory conditions being one of the leading reasons for death.

In 2012, Hampshire Safeguarding Adults Board Multi Agency Partnership produced guidance *'Reducing the risk of choking for people with a learning disability – A multi-disciplinary agency review in Hampshire'* due to five cases of choking resulting in death.

This review illuminated the difficulty of acquiring national figures for the premature deaths of people with learning disabilities due to choking in the UK. The review highlighted that dysphagia in learning disabilities lacked research and even consideration within the field. Furthermore, the guidance suggests that choking incidents in this population are often missed, posing the possibility that choking deaths are higher than reported.

This research did, however, review the prevalence of choking incidents in the wider population to illuminate the scale of the problem. Patterson et al (2021) researched newly-developed suction devices to improve the outcome of foreign body airway obstruction (FBAO). Their findings reported that FBAO was responsible for nearly 2,000 ambulance calls in London alone, and 250 deaths by choking in the UK.

ONS data between 2018 and 2022 identified 681 deaths in care homes, and 589 deaths in hospitals with choking as the main cause of death. These mortality rates lack accuracy, and research suggests the figure is likely to be much higher due to the condition being masked by people's learning disabilities.

A report by the Welsh Government - *An overview of mortality amongst people with a learning disability, 2012-2022* was published in 2024 examining learning disability and choking in more detail.

Between this timeline, 3299 deaths were recorded for people with learning disabilities. The most common age at death was 67 years. This report examined three areas of causal mortality in more detail:

Table 1: Number of deaths in Wales involving people with learning disabilities (2012 – 2022)

Cause of death	Death mentions cause	No of deaths where dysphagia was the underlying cause	Median Age
Respiratory infections	(n=1138)	(n=499)	66 years old
Intestinal obstruction and/or constipation	(n=77)	(n=36)	62 years old
Dysphagia, aspiration pneumonia and choking on food or vomiting	(n=342)	(n=70)	63 years old

The report also highlighted that most of the learning disability group were identified as Downs Syndrome as the underlying cause of death.

Is quality of life a legitimate factor to refusing to adhere to a dysphagia plan?

In addition to the significant health risks posed by dysphagia, there is also a huge impact on quality of life for individuals. Eating and drinking are fundamental aspects of people's lives. Dysphagia may prevent people from being able to enjoy the taste and textures of food they like, as well as the social aspect of shared meals.

Modified meals and eating/drinking apparatus can make people feel different and excluded at mealtimes. It can be deeply distressing for some people. Being able to independently choose what to eat and drink is an important contributory factor to some people's quality of life. These choices may be limited by the impact of dysphagia itself but may be further curtailed if the person is living in a hospital or social care setting due to staffs' concern for the 'vulnerable' person.

Social interaction during mealtimes is important for many people. Dysphagia can impede the person's ability to enjoy the mealtime experience. It can result in a lack of choice and control, and safety overrides a pleasurable experience.

The Royal College of Speech and Language Therapists, 2024 reported several other key factors in why people refuse to follow a safety plan:

- **Embarrassment:** People report embarrassment when following modified diets, or needing to depend on others, especially when coughing or needing assistance when choking.
- **Dependency:** The increased need to rely on others such as mashing up food or being supported with specialist equipment e.g. modified cutlery can be a sense of losing independence for people. This can also lead to frustration of needing others to support them.
- **Depressing:** Not being able to eat and drink what they want can cause depression. People report a sense of impairment of following a modified diet which can be upsetting and distressing.

This report exposes that people who have capacity, would rather accept the risk of choking to maintain a good quality of life as their non-negotiable preference. This, of course, is their right to do so, however when supported by registered services, places greater risk on care providers to demonstrate they have mitigated potential harm.

Mental Capacity

One of the major barriers often experienced in social care practice is the fear amongst care providers (and consequently their staff). Fear comes from the responsibility for keeping those they care for safe; they must ensure that all risks are eliminated. This feeds a risk-adverse culture, which is exacerbated by the fear of culpability and safeguarding litigation.

The Mental Capacity Act (MCA) 2005 has helped to move this attitude away from risk, by establishing the most 'proportionate response' and the least 'restrictive approach', as well as considering the benefits and burdens of a decision. Sir Judge Munby puts forward the notion of positive risk taking into a much more comprehensible light.

Justice Mumby (Court of Protection, 2007) said:

> "The fact is that all life involves risk and the young, the elderly and the vulnerable, are exposed to additional risks and to risks they are less well equipped than others to cope with. But just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation to always put the physical health and safety of the elderly and vulnerable before everything else. Often it will be appropriate to do so, but not always.
>
> Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safer if it merely makes them miserable?"

The MCA in the UK therefore provides a framework for making decisions on behalf of individuals who lack the capacity to make certain decisions for themselves. However, when an individual with a learning disability has capacity and refuses to adhere to a dysphagia plan, the MCA's principles still provide crucial guidance for ensuring their rights and autonomy are respected while addressing safety concerns.

It is worth noting that practitioners and family members often see the reduction of risk as the critical factor, whereas the person may feel their quality of life is more important than reducing the risk e.g. of choking. The MCA highlights an adult taking this view is not necessarily lacking capacity and may not be making an 'wise decision'. It may be a reasonable decision depending on their personal circumstances and preferences.

During this study SJOG identified 5 good practice areas in relation to dysphagia from the MCA guidance that would help care providers. These five areas have been developed by SJOG into a workable solution consistent with good practice:

1. Assessment of Understanding

Ensure Informed Decision-Making: Verify that the individual fully understands the risks and consequences of not following the dysphagia plan. This involves clear, accessible communication and repeated discussions if necessary.

Documenting the Process: Keep detailed records of all discussions and assessments to ensure that the individual's decision is well-documented and informed.

2. Risk Management

Collaborative Approach: Engage with the individual, their family, and a multi-disciplinary team to explore alternative strategies that might make adherence more acceptable while still mitigating risks.

Regular Reviews: Continuously review the individual's decision and their health status. If their capacity changes, the approach may need to be adjusted.

3. Respecting Autonomy

Support and Respect: Respect the individual's right to make their own choices. This includes acknowledging their values and preferences, even if these differ from the medical advice given.

Quality of Life Considerations: Weigh the importance of quality of life in the decision-making process. The individual's perception of their quality of life should be a significant factor in the care plan.

4. Legal Safeguards

Advanced Care Planning: Encourage the creation of advanced care plans or directives that outline the individual's wishes regarding their care. This can provide clarity and guidance in future situations where their capacity might be in question.

Legal Advice: In complex cases, seek legal advice to ensure that the individual's rights are fully protected and that the care provider's responsibilities are clearly understood.

5. Practical Implementation

Care providers should incorporate the following practices to align with the MCA when a person with capacity refuses to adhere to a dysphagia plan:

Training and Awareness: Ensure that all staff are trained in the principles of the MCA and understand how to apply them in everyday care settings.

Person-Centred Care: Focus on person-centred care approaches that prioritise the individual's preferences and values. This may include finding acceptable compromises or alternative methods to manage dysphagia risks.

Communication Strategies: Use communication aids and strategies to enhance understanding and decision-making capacity. This includes visual aids, simplified language, and other tools suited to the individual's needs.

By following these guidelines, care providers can navigate the complex situations where individuals with capacity refuse to adhere to dysphagia plans, balancing respect for autonomy and professional responsibility.

The fundamental standards and dysphagia

The Care Quality Commission (CQC) has drawn up a series of essential standards, including involving quality and safety. If healthcare professionals fail to meet these standards, they can receive warnings or fines, and the services in which they work may be closed. The CQC also passes on evidence of poor practice to the relevant regulators, which can prompt investigations into professionals' and organisations' fitness for practice.

In September 2022, CQC published Issue 6: *Caring for people at risk of choking*, a lesson learning review. Although this review involved a vulnerable person who had been deemed as lacking capacity, the review highlighted a lack of 'reasonable due care and attention' to the adherence of speech and language therapist advice and guidance. Providers need to demonstrate they have responded to this guidance and make every effort to explain it to people.

All care providers are required to practice within the 14 Fundamental Standards of Care in the UK. The review from 2022 showed this was seriously lacking in the care home supporting the person which resulted in a large fine and closure of the home.

Where due care and attention is taken by following regulatory compliance, the management of dysphagia according to people's wishes and preferences can be achieved within a window of tolerance. Table 1 has been developed by SJOG to provide analysis of regulatory relevance to dysphagia.

Table 2: Cross referencing of fundamental standards to the management of dysphagia

Fundamental Standard	Descriptor	Relevant to dysphagia?	Regulation Ref
Person Centred	You must have care or treatment that is tailored to you and meets your needs and preferences.		Reg 9
Visiting and accompanying	If you're in hospital, a care home or a hospice, you should be able to have visitors. If you're living in a care home, you should be able to go out on visits without difficulty. And if you need to go to hospital or a hospice for an appointment, you should be allowed to have someone with you.		Reg 9A
Dignity and respect	You must be treated with dignity and respect at all times while you're receiving care and treatment. This includes making sure: • You have privacy when you need and want it. • Everybody is treated as equals. • You're given any support you need to help you remain independent and involved in your local community.		Reg 10

Fundamental Standard	Descriptor	Relevant to dysphagia?	Regulation Ref
Consent	You (or anybody legally acting on your behalf) must give your consent before any care or treatment is given to you.		Reg 11
Safety	You must not be given unsafe care or treatment or be put at risk of harm that could be avoided. Providers must assess the risks to your health and safety during any care or treatment and make sure their staff have the qualifications, competence, skills and experience to keep you safe.		Reg 12
Safeguarding from abuse	You must not suffer any form of abuse or improper treatment while receiving care. This includes: • Neglect • Degrading treatment • Unnecessary or disproportionate restraint • Inappropriate limits on your freedom.		Reg 13
Food and drink	You must have enough to eat and drink to keep you in good health while you receive care and treatment.		Reg 14
Premises and equipment	The places where you receive care and treatment, and the equipment used in it must be clean, suitable and looked after properly. The equipment used in your care and treatment must also be secure and used properly.		Reg 15
Complaints	You must be able to complain about your care and treatment. The provider of your care must have a system in place so they can handle and respond to your complaint. They must investigate it thoroughly and take action if problems are identified.		Reg 16

Fundamental Standard	Descriptor	Relevant to dysphagia?	Regulation Ref
Good Governance	The provider of your care must have plans that ensure they can meet these standards. They must have effective governance and systems to check on the quality and safety of care. These must help the service improve and reduce any risks to your health, safety and welfare.		Reg 17
Staffing	The provider of your care must have enough suitably qualified, competent and experienced staff to make sure they can meet these standards. Their staff must be given the support, training and supervision they need to help them do their job.		Reg 18
Fit and proper staff	The provider of your care must only employ people who can provide care and treatment appropriate to their role. They must have strong recruitment procedures in place and carry out relevant checks such as on applicants' criminal records and work history.		Reg 19
Duty of candour	The provider of your care must be open and transparent with you about your care and treatment. Should something go wrong, they must tell you what has happened, provide support and apologise.		Reg 20
Display of ratings	The provider of your care must display their CQC rating in a place where you can see it. They must also include this information on their website and make our latest report on their service available to you.		Reg 20A

The table demonstrates that fundamental standards span various regulations within the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. By cross-referencing these fundamental standards, we propose that care providers can ensure a comprehensive, person-centred approach to the management of dysphagia.

Training

Training staff who support people with learning disabilities and dysphagia is essential to ensure safety. Training usually consists of identifying the signs of dysphagia, including texture modification, understanding SLT plans, posture, and how to use specially adapted equipment. A large proportion of time is spent training staff on the written guidelines to ensure the team remain consistent with professional guidance.

Chadwick et al., 2003 reported the distinct lack of research into dysphagia in community settings, and the level of training of non-compliance dysphagia management strategies. This remains relevant to this day.

There is an abundance of training on the Mental Capacity Act, first aid, person-centred planning etc, however there is no such training on the management of dysphagia where people with learning disabilities do not consent to their treatment. There is a need to bring dysphagia and non-adherence best practice together in one place due to each person's complexities and decisions. Taking a holistic person-centred approach by looking at all these areas within a workable procedure will close this gap.

As a minimum, this research has identified the following holistic training requirements as mandatory to balance best practice for dysphagia and non-adherence:

- Dysphagia – Level 2 certification
- Nutrition and Hydration
- Emergency First Aid – practical course
- Emergency First Aid – theory course
- Duty of Care & Duty of Candour
- Person centred approaches
- Consent
- Oral Care
- Postural Support
- Reporting and Recording
- Safeguarding
- Mental Capacity Act
- Dignity in Care
- Health & Safety
- Emergency contingencies e.g. LifeVac
- DNACPR Decisions

The lack of ongoing reflective practice once a skill has been learned is one of the significant flaws in current training models. Many courses in social care are e-learning based which means the ability to continually test competency is not available, unless providers develop their own tools.

Girzadas et al. (2007) researched the use of competency tools in clinical environments. The findings of this research highlights competency tools are greatly challenged when it comes to validity. The challenge is not only involving a technical skill, but the ability to critically think and factor in the multiplicity of person-centred approaches. Our research would add an additional factor; the lack of procedural guidance in one place affects good practice and may even hamper it. Competency tools require 'practice educators' to not only develop good competency assessment but also monitor their usage and visually observe practice.

Furthermore competency-based practice should be an ongoing practice but is often overlooked due to time constraints on social care staff. Competency-based practice in dysphagia management, however, is crucial for ensuring safety, enhancing the quality of care of people, maintaining professional accountability, and improving outcomes. It supports effective interdisciplinary collaboration, meets legal and ethical standards, and promotes continuous professional development. By embedding this into practice, care providers can deliver more effective, reliable, and person-centred care in the management of dysphagia.

SJOG has brought together the latest research and guidance and developed a competency-based assessment. This actively tests and observes competency, whilst audits from a quality assurance perspective against dysphagia policy, risk and practice.

Development of the toolkit

One of the most effective ways to improve quality of care and transform the delivery of practice is by adopting the Knowledge to Action (KTA) Framework. Formerly developed in 2006 by Dr Ian Graham and colleagues in Canada, this model incorporates more than 30 change theory approaches.

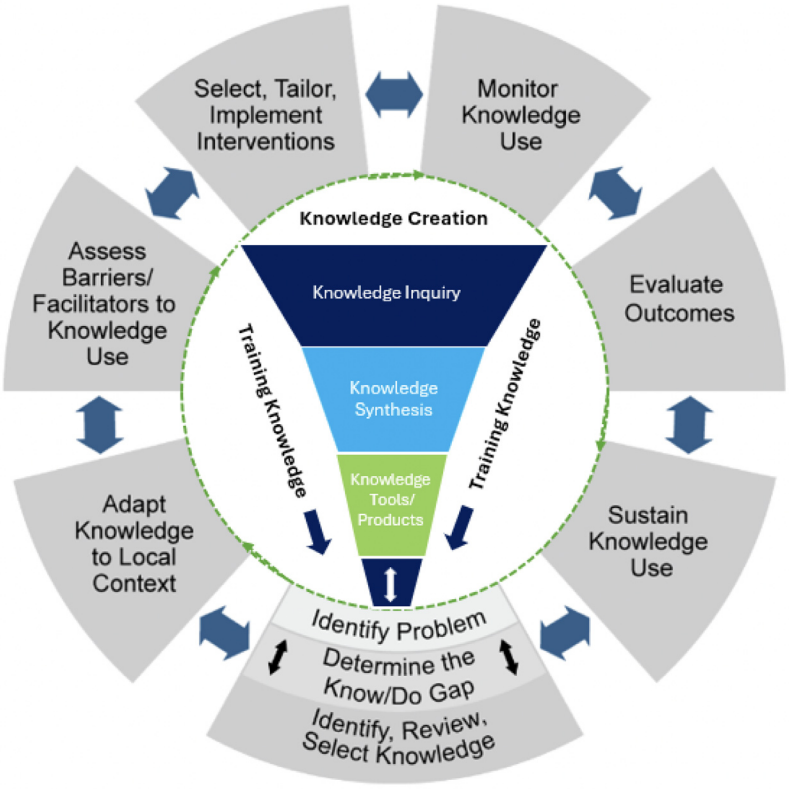
KTA is a structured approach with a seven-stage action cycle that health and social care professionals are using to review complex (and changeable) challenging practices. KTA is rooted in evidence-based research to help the translation of knowledge into sustainable practice. Knowledge translation from research has been defined as a process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve practice and provide more effective provision to strengthen the social care system.

Figure 1 offers an overview of the stages:

1. Knowledge creation represented in the funnel.
2. Action cycle – the stages of identifying the problem and adapting knowledge to the local context, the barriers, developing new interventions etc and monitoring and evaluation the actions.

This process is iterative in nature and allows for multiple co-production. The involvement of people with learning disabilities, families and professionals was crucial to understand how to improve practice.

Figure 1: The Knowledge to Action Framework (Graham, et.al, 2006)



The development of our toolkit was undertaken by a comprehensive review of legislation and good practice dysphagia literature. This helped to inform the essential components required to ensure both people with learning disabilities and care providers remain legally and ethically safe in practice.

The knowledge we have gathered from research and good practice helped identified the salient components of the toolkit. Mental capacity good practice guidance outlined in this research assisted structuring the procedure to ensure people's rights were not only protected but firmly placed at the start of this procedure. Implementing a KTA approach ensures people's rights were the golden thread throughout the research.

Overall, the reason we chose KTA was:

- Grounded in evidence-based research
- Promoted involvement from various stakeholders and is co-produced
- Iterative process that allows for changing situations in people's needs
- Helps to make sense of multiple complex situations
- Helps to establish sustainable best practice
- Identifies the barriers and uses knowledge as the catalyse for solutions
- Helps to identify outcomes

The KTA approach assisted in structuring the toolkit into the following:

1. The dysphagia management procedure (Appendix 1)

- General information
- Care planning
- Mental capacity
- Mental capacity assessment
- Mental capacity outcome
- Legitimate decision making – quality of life
- General health
- Oral health
- Professional involvement
- Support team
- Business continuity
- Risk assessment
- Family members
- Right to change mind
- DNACPR
- Final decision
- Management sign off
- Nominated Person sign off

2. Dysphagia/Choking – Audit/Competency Assessment Tool (Appendix 2)

- The person
- Training (LifeVac © training of the equipment)
- Environment
- Food/preparation
- Feeding safety routines

3. Risk Assessment for Staff Teams (Appendix 3)

- Centralising all risk mitigation together
- Supporting teams and their wellbeing

Adopting Knowledge for Action helped to close the practice gap and ensure people with learning disabilities remain safe, with a sound and effective risk mitigation procedure and risk plan.

Adopting knowledge translation into a toolkit

We chose knowledge translation (KT) and adapted this into a toolkit as it helped to synthesise research into best practice (Yamada et al., 2015). This synthesis helped improve the fidelity of dissemination, practice exchange and the sound ethic application of knowledge to improve outcomes for people. The drive of this research and toolkit was to strengthen regulated social care activity in the management of dysphagia where people have capacity.

Evidence-based toolkits can be used to facilitate practice change, and can include strategies for guideline implementation, informing policy, practitioner training, and provide quality audit materials to support transparency of practice. To be effective, toolkits should also provide high-quality evidence to guide their use or implementation (Thoele, et al. 2020).

Developing a toolkit on dysphagia that encapsulates both capacity and no capacity has significantly benefitted our community of practice by providing a centralised resource that incorporates the latest research, guidelines, and best practices.

This toolkit can serve as a comprehensive guide to the wider social care professional community by enhancing the safety, quality and consistency of care.

Conclusions

We can conclude in this research that dysphagia can negatively impact on people's quality of life to a significant degree. The loss the independence, control in decision-making and frustration being of more importance than the risk of choking. The balance of what is acceptable demonstrating that quality of life is a legitimate reason for not adhering to a dysphagia plan.

There is an abundance of regulation and good practice guidance in protecting the rights of people with learning disabilities. This focuses more on those who do not have capacity to consent to professional advice and treatment. The tension between respecting and maintaining a person's right to not adhere to an adapted diet versus the fear and culpability risks to providers, can unduly pressurise and influence people's decisions.

With the support of the Knowledge to Action Framework, adopting the five good practice areas of the Mental Capacity Act, 2005 and synthesising this with evidence-based research, has offered SJOG's community of practice a newly created procedure that respects people's rights, whilst safeguards the provider. It offers a training aid in the management of non-adherence of adapted diet.

SJOG's research listened to the voices of people with learning disabilities and co-produced a procedure through the translation of knowledge into a workable procedure. The procedure was extended to ensure safe practices were promoted through a competency-based assessment and risk assessment for colleagues to offer additional reassurance.

The toolkit has provided people with learning disabilities control over their quality-of-life decisions and promoted enjoyment over mealtimes as opposed to the fear of choking. The toolkit has readdressed the balance of risk, personal autonomy and safe practical personalised intervention.

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Dysphagia Procedure – Appendix 1

For people to make decisions about their dysphagia treatment and provide valid consent, health and social care professionals need to provide them with sufficient, clear and accurate information about any proposed course of action or treatment. Professionals need to ensure a procedure where 'reasonable care' has been taken so the person understands the level of risk they are making with regards to their decision.

This procedure considers research and good practice guidance where a person has the capacity to consent to their treatment, and particularly where they may refuse treatment.

General Information

Name of person	
Date of birth	
National Health No	
Date commenced	
Lead person completing procedure	

People involved in this procedure

Name	Role/Position

Care Planning

As a provider your organisation is required to have robust processes to ensure that appropriate eating and drinking care plans are in place for any person who is at risk of choking. This must be undertaken regardless of the person's capacity to understand. If the person is making an unwise

decision to eat high risk foods or drink, the provider should ensure they understand the risks they are taking and have a documented mental capacity assessment to support their decision.

Before starting this procedure consider this good practice guidance below to support any referral to a speech and language therapist: : Guidance on how to manage a choking and or aspiration risk

Mental Capacity

The Mental Capacity Act (2005) supports adults to make their own choices. If a decision needs to be made by the adult in relation to their diet, then in line with best practice and legal requirements, the adult has a right to be supported to make their decision.

The Mental Capacity Act 2005 and Code of Practice set out the practices to be followed, including the statutory best interests checklist (section 4, MCA 2005). Please use the link below:

https://www.gov.uk/government/uploads/system/uploads/attachment_da ta/file/497253/Mental-capacity-act-code-of-practice.pdf

For those adults where there may be diminished mental capacity and where a choking risk exists, eating and drinking will be a complex area to navigate for these adults and associated staff members who are supporting them. The Mental Capacity Act (2005) seeks to ensure that people who lack capacity to make specific decisions for themselves are protected from harm that may arise from their lack of capacity, by allowing others to make decisions in their 'best interests'.

There may be circumstances when a staff member or carer may need to assess an adult's capacity in relation to their choking risk, for example, where an adult likes a particular kind of food which has the potential to raise their risk of choking, and they want to eat that food but the staff member is unsure whether they have the mental capacity to understand the potential dangers that would bring.

Deciding if an assessment of capacity is needed is not always obvious. The staff member should always start by assuming the adult has capacity to make the specific decision (in line with principal 1 in the Mental Capacity Act, 2005).

Consider these questions:

Does the staff member or carer have any evidence to make them think that capacity may be impaired?	

Is there evidence of a mental impairment or disorder?	
Does the person admit to any problems in relation to choking risk? If so, does he/she seek appropriate assistance?	
Can the person recognise risky situations and respond accordingly?	
Could the person ask others for help in an emergency?	
Would the person encounter safety or physical health risks because of memory problems?	

If the answers to any of these questions leave a staff member with concerns, they should undertake an assessment of capacity in relation to the adult's decision making in relation to their choking risk.

Mental Capacity Assessment

Date of mental capacity assessment	
Name of assessor	
Role of assessor	
Specific question to be assessed	Is _____ capable of making an informed decision of whether to follow the professional guidance of a dysphagia plan?
Outline the choices/reasons the person has and share information to inform decision making	**Option 1 Follow the SALT plan** – explain exact detail from the plan **Reason:** Or **Option 2 Not follow the advice in the SALT plan** – explain the risks and consequences of not following professional advice **Reason:**

Accessible forms of communication used (if appropriate)		
Outline the risks that have been discussed with the person. Include sharing of information, probabilities and outcome(s)		
Repeat the information and ask the person to repeat this back		
Outline the questions and responses to the questions	Questions by assessor	Responses by person
Outline the persons choice and the reason for this choice. Take into consideration their person-centred preferences, wishes and values whether these are wise or unwise		

Mental Capacity Outcome

Outcome of mental capacity assessment. A clear rationale behind the decision must be set out showing the evidence that have been considered	
The person **HAS** capacity	
The person **DOES NOT** have capacity	

Important practice point: If the adult is assessed as being unable to make an informed decision about their own care, a best interest meeting must be held in line with the Mental Capacity Act, 2005.

Option 2 – Decision not to follow the dysphagia plan – legitimate decision?

Important practice point: Recognising the adult's wish for a quality of life is a legitimate factor. To practitioners and family members the reduction of risk is usually of critical importance, whereas the adult may feel their quality of life is more important than reducing their risk of choking. An adult taking this view is not necessarily lacking capacity and may not be making an 'unwise decision'. It may be a reasonable decision depending on their circumstances, priorities, history and preferences.

The following section must be completed with the person to ensure they are fully aware and educated about the consequences and risks of not following the SALT guidance.

General Health

Has the person received a health check with the GP?	
The GP has been made aware of the person's decision to not follow SALT guidance. The GP discusses and checks this with the person	
Are there any known medications that cause drowsiness at certain times of the day when eating should be avoided?	
Does the person have dry mouth?	
Does the person have increased saliva?	
Does the person have relaxed muscle tone?	
Has the person choked within the last 12 month?	
Has the person aspirated in the last 12 month?	
Health passport has been reviewed and up to date.	

Oral Health

The person's oral hygiene has been reviewed and checked by a dentist. Include date and any actions.	
If the person has dentures, have these been checked as fitting correctly.	
If the person refuses to wear dentures, ensure the risks are explained and understood. Record exact conversation and responses.	

Professionals

The speech and language therapist has been informed the person has refused to follow guidance.	
Any further advice offered by the Speech & Language Therapist regarding offering support to the person.	
Proactively inform Adult Safeguarding Team of the risks involved and evidence of how the person has been involved, including their decision.	
Proactively informed Care Quality Commission of all actions taken to avoid risks.	

Support Team

The support team have completed dysphagia training within the last 12 months.	
The support team have completed emergency first aid within the last 12 months.	

The support team have completed bespoke training (where person is in a wheelchair / bed bound / physical conditions) within the last 12 months. The support team can execute the first aid plan well.	
The support team can identify the signs of dysphagia and understand their duty of care to report.	
The support team understand the need to ensure the person has good posture when eating	
The support team understand the behavioural presentation of people with learning disabilities e.g. eating fast, gulping food, over filling mouth. The team can talk confidently and consistently on mitigating these risks	
Dysphagia competency assessment completed for each member of the support team. (See appendix 2)	

Business Continuity

There is a regular procedure in place to undertake emergency testing of the person's first aid procedures, to test support team responses and consistency of the risk assessment.	
There is evidence of testing reports in place.	
There is evidence of checking the testing report against the person's risk assessment.	

Risk Assessment

The person has been involved in developing their own risk assessment – identify person has capacity	

Describe the person's posture and how to reduce the risk of choking	
How to support the person to eat	
Details of the choking/aspiration in last 12 months	
Document annual health check and dental check	
Any medicines that cause drowsiness – certain medications can cause suppression of the gag reflex	
Signs and symptoms of choking	
Any utensils used	
Use of dentures (if applicable)	
Level of supervision and support	
Consider dysphagia devices e.g., LifeVac etc	
Level of support team training and frequency – HIGH RISK include 6 monthly refresher training	
Recording of eating/drinking (describe in daily notes and where possible include photo all mealtimes)	
Business continuity emergency testing procedures and frequency	
Contingency plan in event of choking e.g., first aid treatment	
All incidents of choking MUST be fully recorded	
Information on when to call emergency services	
Consider a place mat that identifies good eating habits the person can refer to (useful	

reminder) – need to gain consent from the person to use this	
The person has consented to sharing this procedure and risk assessment with GP, health & social care professionals e.g. social worker, safeguarding, police etc	

Family Members

Where there are living family members, it is advised the person should inform them of their decision not to follow the SALT treatment. The person must consent to this information being disclosed.

Consent given by the person	
Name of people informed	
Date informed	
Family comments	

Right to Change Mind

The person has a right to change their mind, and this should be regularly asked and recorded clearly. This includes after the decision has been reached.

Date	Question/Discussion	Decision

Do Not Attempt Cardiopulmonary Resuscitation

Important practice point: If the person stops breathing following a choking incident, this is a potentially reversible event and cardiac pulmonary respiratory resuscitation (CPR) should be commenced immediately regardless of a valid 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) in place.

Date document created/reviewed.	
Signed by medical professional – include name.	

Or:

The decision to NOT undertake cardiac pulmonary respiratory resuscitation requires explanation here.	

Final Decision

Important practice point: People are not required to justify their decision to refuse consent, but healthcare professionals should seek to ensure that people base their decisions on accurate information and have corrected any misunderstandings.

Final decision reached by the person (record here the decision reached in the person's own words where possible).	

Management Only Section

Management is required to prepare their colleagues for this decision to take effect. Preparing support colleagues is an important part of this process, so they are fully aware of the decision and how to support the person. The following section are considered good practice.

Date of team meeting	
Attendance list and roles.	

Review this dysphagia procedure and risk assessment. Encourage discussions and document all concerns and how these are being mitigated.	
Training has been checked for all colleagues.	

Name of registered manager.	
Registered manager signature.	

Nominated Individual

The nominated individual has responsibilities under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. The registered manager must ensure the nominated individual receives this completed document and to verify that all quality and safety compliance standards have been followed.

Comments and review of documentation.	

Print name	
Role	
Signature	

Dysphagia/Choking – Audit/Competency Assessment Tool – Appendix 2

Name of person being observed: **Time: Breakfast _____ Lunch _____ Dinner _____ Snacks _____ Date: _____**

Observation	Comment	Action
The Person:		
Has the person had any choking incidents in the last 12 months?		
Has the person had involvement from the SALT Team? ***(Record date of last communication)***		
What level SALT plan is in place? ***In-line with SALT descriptors.***		
Has the person got **Informed Refusal** to follow the SALT plan in place? ***(Record date of communication with health professional)***		
Is the information from the SALT team recorded in the person's eating /drinking care plan on Access [care planning system]? ***(Record date of last review)***		
Is the information detailing the person's **Informed Refusal** recorded in the person's eating/drinking plan on Access? ***(Record date of last review)***		
Has the person got an up-to-date risk assessment in place detailing the risk of choking? ***(Record date of last review)***		
Training		
Have colleagues completed face-to-face first aid training?		
Have colleagues completed additional face-to-face first aid training (choking)?		
Has the person living in the service attended first aid training (choking) ***(Record the date attended)***		

Have colleagues completed the on-line LifeVac training?		
Have colleagues familarised themselves with the LifeVac device?		
Is the LifeVac poster displayed near to the device?		
Is there a LifeVac risk assessment and is it in date?		
Have all colleagues read and understood all LifeVac information?		
Environment		
Is the room (kitchen/dining room homely and attractive to stimulate the senses?		
Is the room well lit?		
Are there contrasting colours? ***(Contrasting colours give definition between table, plate, and tools).***		
Food Preparation		
What equipment is used to prepare the food in line with person's requirements? ***(Document observation)***		
Are the correct utensils used by the person, to facilitate a safer swallow and improve sensory awareness? ***(Document observation)***		
What food is being served?		
Has the food been prepared in line with the SALT guidelines?		
Has the food been prepared in line with the person's wishes? (***Review documented conversation between person/support colleague and photographic evidence)***		

Does the food being served look appealing? Are foods separated on the plate? Are foods colorful and vibrant? ***(Food should be appealing in presentation and smell in order to stimulate the appetite and salivary flow. Document descriptive overview or alternatively upload a photograph and attach to audit)***		
Is the food being served at the correct temperature?		
Does the food have a good nutritional balance?		
Has the food been seasoned? ***(Taste a sample)***		
Feeding Safety Routines		
Conscious level of person?		
Is the room free from distractions, i.e. loud music, lots of people talking?		
Was the person given adequate time to eat and drink? ***(Were insulated containers used to maintain the temperature of the food for the person who may take a prolonged time to eat)?***		
Positioning - Is the person positioned upright?		
Is the person encouraged to remain sitting up right for approx. 30 minutes after finishing their meal to avoid reflux?		
Is the person's support positioned at eye level, so that signs of difficulty can be observed, as well as providing verbal prompts and encouragement. ***(Sitting beside a person may lead them to turn their head, which may make swallowing more difficult)***		
Oral hygiene – was the persons mouth clean and free from residue at the end of the meal?		

Is the person encouraged to complete a 'clearing swallow', a 'saliva swallow' or a drink of water to assist in clearing residue from the mouth?		
Is the person wearing their glasses/hearing aids during the meal? ***(Swallowing requires multi-sensory stimulation)***		
Are the person's dentures in place whilst eating?		
Has the person enjoyed the meal? ***(Document observations of person's presentation or verbal feedback when questioned)***		

Action Log

Action	By Whom	By When	Completed

Risk Assessment – Appendix 3

Activities/areas being assessed: colleague welfare supporting in difficult circumstances – health & safety versus mental capacity (choice)

Summary overview of risk and decision(s) taken:

Activity	Person at Risk	Significant Hazards	Risk*			Risk Control Measures – examples below	Residual** Risk		
			L	C	DR		L	C	DR
Supporting Eating & Drinking	Person Colleagues	Choking Aspiration Repeated chest infections Bruising – back/ chest/shoulders Broken bones (ribs) Stress/anxiety Consider posture and ability to hold head/neck up straight. Trauma Increased stress/anxiety Fear				✓ All colleagues have received first aid training, and additional first aid training (choking when positioned in a wheelchair). ✓ First aid training (choking when positioned in a wheelchair) is repeated twice a year. ✓ Colleagues are supported to practise safe first aid techniques for individuals in wheelchairs monthly using role play in emergency scenarios, in-line with the BCP. ✓ The risk of choking is on the agenda at all team meetings to discuss concerns and learning outcomes. ✓ Colleagues have successfully administered emergency first aid on several occasions following serious choking incidents, in the service. ✓ Observation confirms colleagues are competent in this area risk and required emergency response. ✓ Colleagues have received training on the safe use of LifeVac (anti choking device) ✓ All colleagues have read and understood the Anti-LifeVac risk assessment. ✓ All colleagues aware that any use of the LifeVac must be reported to LifeVac. ✓ LifeVac device positioned in the service in the case of emergency in main office/reception area. ✓ The service has a nurse call system in situ, in the case of an emergency. ✓ Colleagues are competent in calling external emergency services. ✓ The service operates an open-door policy. ✓ Colleagues have access to senior management and on-call. ✓ Colleagues receive regular supervisions, using elements of the trauma informed care documentation. ✓ Colleagues will receive de-briefings following any episodes of choking. ✓ Colleagues to proactively request 1-1 support or supervision immediately if concerned.			

						✓ Colleagues can request additional training. ✓ Colleagues have access to the employee assistance programme. ✓ Colleagues have access to Bright Line (mental health support) ✓ Colleagues can be referred to occupational health. ✓ Colleagues have wellness plans. ✓ The PCN will be invited into the service to talk with colleagues about choking risks v's choice. ✓ CQC and Safeguarding have been notified of increased risk to life in the service. All documentation has been shared to ensure a management plan is in place and to evidence transparency. Following all attempts to sustain life, resulting in _____ [name] going into cardiac arrest, colleagues must make _____ comfortable, two colleagues to remain with _____ until the emergency services arrive. All other colleagues assisting in the emergency should remove themselves. Colleagues must escalate the incident to the senior manager on call.			

Likelihood (**L**) = Very likely (5) -Likely (4) –Fairly likely (3) – unlikely (2) very unlikely (1)

Consequence (**C**) = Catastrophic (5) – Major (4) – Moderate (3) – Minor (2) – Insignificant (1)

Degree of Risk* (DR) = LIKELIHOOD x CONSEQUENCE

** Residual risk is the level of risk that remains after suitable and sufficient control measures are introduced.

Service:	

Service manager:		Date:

Consequence of hazardous event taking place	▯	5	5	10	15	20	25
1. Insignificant – no injury	**Consequence**	4	4	8	12	16	20
2. Minor – minor injuries needing first aid		3	3	6	9	12	15
3. Moderate – up to three days' absence		2	2	4	6	8	10
4. Major – more than three days' absence		1	1	2	3	4	5
5. Catastrophic – death			1	2	3	4	5
			Likelihood ▯				

Likelihood of hazardous event taking place
1. Very unlikely
2. Unlikely
3. Fairly likely
4. Likely
5. Very likely

17 – 25	**Unacceptable** – Stop activity and make immediate improvements
10 – 16	**Tolerable** – Look to improve within specified timescale
5 – 9	**Adequate** – Look to improve at next review
1 – 4	**Acceptable** – No further action, but ensure controls are maintained

Name of individual undertaking assessment review	
Signature of individual undertaking assessment review	
Position of individual undertaking assessment review	
Review interval period	
The next scheduled review date:	Comments/Actions: