

## Position Statement

# **The Role of the Speech Pathologist in Supporting Informed Choice and Shared Decision Making in Dysphagia**

## **Working with ‘Risk Feeding’**

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# 1. Background

## Origin and Scope

Speech pathologists are tertiary trained allied health professionals who have a critical role to play in the multidisciplinary assessment and management of oropharyngeal dysphagia (Speech Pathology Australia (SPA), 2004). Within this field, speech pathologists frequently work with people who choose not to follow speech pathology recommendations and to instead manage the risks associated with their dysphagia. Often this can lead to speech pathologists feeling challenged by ethical and professional considerations and seeking clarity about their role in these situations. Furthermore, other members of the treating or support team for that person may benefit from guidance around the role of the speech pathologist in these scenarios.

This Position Statement has been developed to reflect the position of Speech Pathology Australia regarding the role of the speech pathologist in supporting informed decision making with people choosing not to follow dysphagia recommendations. This Position Statement is relevant for speech pathologists working with people across the lifespan, encompassing infants, children, adolescents, adults, and older people. Throughout the Position Statement when referencing people who receive speech pathology services, this may include the person themselves, their family, carers, and legal decision makers.

This Position Statement may provide a framework for consistency of practice for speech pathologists working with people with dysphagia who choose not to follow speech pathology recommendations for the management of their dysphagia. This Position Statement also acts as a means of providing education and advocacy to external stakeholders, including multidisciplinary team members, management, facilities, government and funding bodies, as well as consumers and their carers / families.

## Terminology

The appropriate terminology to use when a person does not wish to follow dysphagia recommendations is both contentious and inconsistent across the profession. The term 'risk feeding' is one commonly used within organisations and the literature, and there are a number of organisations developing internal policies and guidelines in this area of clinical practice.

In development of this Position Statement, a common theme emerged both from the Working Party and the literature review; overall, many clinicians and researchers dislike both the terms 'risk' and 'feeding' in this context. Individually, 'risk' as a term in healthcare has become synonymous with danger or workplace compliance, and as such can place unnecessary guilt and burden on people with dysphagia and their carers/families. 'Feeding' can be considered a demeaning term for use in relation to adults who instead eat and drink (Murray, Mulkerrin, & O'Keeffe, 2019). Overall, it was considered that 'risk feeding' as a label has negative connotations and does not reflect a person-centred approach to dysphagia management.

Although the Working Party agreed with the concerns outlined above in relation to the term 'risk feeding,' it was acknowledged that the term is used broadly both within the profession of speech pathology and by members of the multidisciplinary healthcare team. As such, although it was not considered feasible or within the scope of this paper to endeavour to change the term or introduce a new term, it was considered a key priority of this Position Statement to acknowledge and represent the broader and overarching principles related to 'risk feeding.' For this reason, the Position Statement has been titled ***"The Role of the Speech Pathologist in Supporting Informed Choice and Shared Decision Making in Dysphagia,"*** to reflect the focus of the role of the speech pathologist in this situation.

In discussions with people living with dysphagia and their carers/families, speech pathologists should consider minimising or avoiding use of the term 'risk feeding' due to the potentially negative connotations of the term. Speech pathologists should provide education and information in a clear, non-biased manner that enables a person with dysphagia to make informed choices regarding their own healthcare. Furthermore, speech pathologists have a responsibility to ensure that decisions relating to a person choosing to eat / drink at risk are made within a shared decision-making framework.

## **Reasons for Making an Informed Choice to Eat and Drink against Recommendations ('Risk Feed')**

In developing this Position Statement, a thorough literature review was conducted which revealed that speech pathologists working across a variety of clinical areas throughout the world find managing clients who eat / drink at risk to be a very complex area of clinical practice. Although there is limited evidence specifically regarding the number of adults who elect to eat / drink at risk, some studies suggest that only between 21.9% and 52% of people adhere to dysphagia recommendations (Krekeler, Broadfoot, Johnson, Connor, & Rogus-Pulia, 2018).

The literature notes that adults who live at home are twice as likely not to follow speech pathology recommendations for dysphagia management than those living in residential aged care facilities, and that in the adult population younger people are more likely to not follow speech pathology recommendations than older people (Colodny, 2005; Kaizer, Spiridigliozzi, & Hunt, 2012).

Overall, reasons for choosing not to follow speech pathology recommendations for texture modified food, thickened fluids and/or management strategies include:

Dislike of the texture and taste of modified foods / fluids;

- Social implications, such as exclusion from social events, and cultural and religious considerations;
- Denial of a swallowing problem;
- Desire to continue to have particular foods;
- Difficulty implementing recommendations, such as difficulty preparing modified food and/or thickened fluids;
- Nearing the end of life and/or being managed within a palliative approach, and therefore electing to comfort feed (Krekeler et al., 2018; Colodny, 2005; Kenny, 2015).

In some cases, the severity of a person's dysphagia may mean that they are unable to safely swallow any fluid consistencies or diet textures, and for various reasons they may also not be considered appropriate for enteral feeding. In these cases, the only option for a person who elects not to accept enteral feeding may be to eat / drink at risk.

Additionally, recent shifts in policy directions towards person-centred health care models are empowering people to more actively participate in decision making around their healthcare decisions, which may include considering not following dysphagia recommendations. Using a shared decision-making framework as discussed below may support speech pathologists when navigating this scenario.

## **Risk Management and Dysphagia**

When a person is diagnosed with dysphagia, their treating speech pathologist will work with them to develop a multi-faceted management plan that meets their individual needs. As per the Clinical Guideline: Dysphagia (SPA, 2012), the aims of dysphagia intervention are to maximise the safety, efficiency and effectiveness of a person's swallow, and should involve specific intervention(s) that optimise clinical outcomes and target the underlying impaired function(s).

A risk management approach in dysphagia involves the treating speech pathologist, as a member of the multidisciplinary team, considering the risks and benefits of oral intake for each person while also identifying ways to maximise health, wellbeing, and quality of life. The multidisciplinary team also needs to consider other factors and co-morbidities that place a person at risk of adverse events such as developing aspiration pneumonia as part of the risk management plan.

## **Person-Centred Health Care**

Healthcare in Australia is evolving, with an increasing move away from traditional “medical models” with people as passive recipients of health care to a more person-centred approach (Delaney, 2015). Within a person-centred approach to health care, people are considered active participants in the decision-making process, with a focus on greater collaboration, respect, and communication between health care professionals and the people who are the recipients of health care (Delaney, 2015). Research has shown that the move towards person-centred care results not only in improved patient outcomes, but also in improved adherence to treatment plans and improved satisfaction with health care services (Delaney, 2015).

A further increasing focus of person-centred health care in recent years, especially in the aged care and disability sectors, has been the concept of dignity of risk. The Aged Care Quality Standards have as their foundation “Standard 1: Consumer Dignity and Choice,” which reiterates the focus on this concept of dignity of risk (Aged Care Quality and Safety Commission, 2019). Dignity of risk refers to the right of health care consumers to make their own decisions about their care and services, including their right to take risks (Aged Care Quality and Safety Commission, 2019). Health care organisations and providers therefore need to consider both risk management and their duty of care in provision of services, as well as respecting a person’s rights to make their own decisions. Ultimately, if a person makes a health care decision that is potentially harmful, the health care provider has a responsibility to ensure the person understand the risk(s) associated with their decision, as well as how these risks could potentially be managed (Aged Care Quality and Safety Commission, 2019). Ultimately, the focus is on collaborative health care and supporting people to make decisions which help them live their life the way they choose (Aged Care Quality and Safety Commission, 2019).

These considerations have led to the increasing use of shared decision-making frameworks when working with people making decisions which pose a higher than expected risk to their health.

## **Shared Decision-Making Frameworks**

Shared decision-making frameworks can be a useful tool to consider the many factors involved in decisions around eating and drinking against speech pathology recommendations. Decisions around eating and drinking can impact on a person’s well-being and health, and be influenced by someone’s personal, religious and cultural beliefs, values and needs. The treating team need to consider these factors in the context of a person’s decision-making capacity and any individual circumstances such as the likely severity of risk to a person’s health when developing a plan to implement a decision to eat / drink at risk.

Shared decision making occurs when health care providers and recipients of health care work together to make a health care decision that is best for the individual. Shared decision making involves discussion of a person’s current medical condition and illness trajectory and discussing options for treatment and care with consideration of their potential benefits and limitations. This information is informed by evidence-based practice and the professional’s knowledge and experience. The person’s individual circumstances, including their values and priorities, are also a key component of this discussion and should underpin an agreed care plan. People have the right to change their mind about a previously agreed plan, including withdrawing or withholding medical interventions that they perceive to be burdensome or non-beneficial (Elwyn et al., 2017; Australian Commission on Safety and Quality in Health Care, 2019b).

Shared decision making has become an increasing focus of health care providers due to research indicating that:

- People are less informed and involved in making decisions about their health care than they would like to be;
- Shared decision making can improve satisfaction with care and leads to better quality decisions;
- People using evidence-based decision aids have improved knowledge of the options, more accurate expectations of possible benefits and harms, and feel that they had greater participation in decision making than people receiving usual care;
- Better-informed people make different, often more conservative and less costly choices about their treatment, because the information provides a realistic appreciation of likely benefits and risks of treatment, and therefore enables decisions about the potential outcomes in a more considered way (Australian Commission on Safety and Quality in Health Care, 2019b, paragraph 2).

## 2. Definitions

**Risk** is the effect of uncertainty on objectives, and is usually expressed in terms of risk sources, potential events, their consequences, and their likelihood (International Organization for Standardization, 2018). In this case, maintaining health, wellbeing and safety in those people who present with dysphagia and associated complications.

**Risk management** helps reduce the variability of outcomes (International Organization for Standardization, 2018).

**Risk feeding (or eating / drinking at risk)** describes situations where a person makes an informed decision to continue oral intake that has been deemed unsafe by the treating speech pathologist and/or medical team. Ideally, the person has engaged in shared decision making where there is an understanding of the potential swallowing related health complications, whilst accepting the risk of swallowing related health complications which may be associated with this decision. When risk feeding, the goals of medical care are active ongoing treatment.

It may also describe situations where a person with dysphagia is not considered appropriate for enteral feeding by their treating team, but also presents with dysphagia and risk of associated complications. Reasons a person may not be appropriate for enteral feeding include not tolerating enteral feeding and general anaesthetic risk for surgical placement.

**Comfort feeding** refers to a person's decision to continue oral intake for quality of life purposes, typically at the end of life where the goals of care are of a palliative / comfort care nature rather than curative treatment.

**Person-centred care** is respectful of and responsive to the preferences, needs and values of patients and consumers. Key dimensions include respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, access to care, and partnerships with patients, carers and family in the design and delivery of care (Australian Commission on Safety and Quality in Health Care, 2019a).

**Substitute decision makers** are legally appointed to make decisions on behalf of another person. These decisions may be about financial, lifestyle or medical issues (State of Victoria, 2018).

**Supported decision making** emerged from disability and human rights-related activity that promotes the idea that people with a disability are entitled to exercise choices about their lives. Supported decision making involves the provision of decision-making support which enables people with communication and cognitive disabilities to exercise their legal decision making rights (Simmons & Gooding, 2017; Office of the Public Advocate, 2017).

**Informed decision making** is the two-way communication process between a person and their treating health professionals. It is central to person-centred health care. Informed decision making reflects the ethical principle that a person has the right to decide what is appropriate for them, considering their personal circumstances, beliefs and priorities. This includes the right to accept or to decline certain health interventions, and the right to change that decision. To ensure a person can exercise their right to decide, they need to receive information that is relevant to them (Patient Safety and Quality Improvement Service, 2017).

**Duty of care** is the obligation to provide professional services in accordance with what other speech pathologists working in the same field would have done in the same circumstance. Consequently, it is the duty of the speech pathologist to be aware of recent literature in their field, current practices carried out by peers, adhering to workplace policies and procedures, and being conversant with the Speech Pathology Australia documents.



When considering if duty of care has been met, speech pathologists should consider what clinical interventions another speech pathologist with a similar level of experience and knowledge in the area would have offered, and subsequently what recommendations would have been made in the same situation. For example, would the same person seen by a different speech pathologist have received the same advice and treatment?

**Capacity** refers to an adult's ability to make their own decisions.

### 3. The Position of Speech Pathology Australia

The following statements articulate the position of Speech Pathology Australia regarding the role of the speech pathologist in supporting informed choice and decision making of people with dysphagia - working with risk feeding, and are informed by current best evidence.

#### **3.1 It is the position of Speech Pathology Australia that it is within the scope of practice of speech pathologists to assess, diagnose and treat swallowing difficulties, including with people who elect to eat / drink at risk.**

Speech pathologists are tertiary trained allied health professionals with expertise in the assessment, treatment, and management of oropharyngeal swallowing disorders (dysphagia). As such, speech pathologists have a fundamental role in working with this clinical population. Specifically, speech pathologists are responsible for providing assessment, direct intervention (including recommendations for modification of food and fluid texture, or strategies to manage the dysphagia), education, and advocacy regarding a person's swallowing function and mealtime assistance needs. Speech pathologists may continue to provide professional services to a person who elects to eat / drink at risk where those services continue to provide benefit. For example, education on and implementation of safe swallowing strategies to reduce the risks associated with the chosen oral intake.

While speech pathologists at entry level to the profession have the competency required to work with people with dysphagia, including those who elect to 'risk feed,' the Association recognises that this is a complex area of clinical practice. As such, Speech Pathology Australia recommends that speech pathologists working with people who elect to eat / drink at risk who have limited experience in this area should engage the support of experienced speech pathologists while developing knowledge and confidence in this area of clinical practice.

#### **3.2 Speech pathologists working with people who elect to eat / drink at risk are bound by professional standards practice documents, organisation-specific policies and procedures, and legislative requirements as per all other areas of clinical practice.**

As in all other areas of clinical practice, speech pathologists working with people who elect to eat / drink at risk are bound by professional standards and practice documents, including the Speech Pathology Australia Code of Ethics (SPA, 2010), Competency-based Occupational Standards for Speech Pathologists (SPA, 2011), Scope of Practice in Speech Pathology (SPA, 2015), and the Dysphagia Clinical Guideline (SPA, 2012). They are also bound by national, state / territory, and organisation-specific legislation and policies / procedures.

Speech pathologists working with people who elect to eat / drink at risk have a responsibility to offer services and information for the purpose of minimising the harm people and their families / carers may experience. In order to execute professional duty of care related to information provision, it is the role of the speech pathologist to:

1. Provide clear information to the person and/or their legal substitute decision maker (parent, guardian or enduring power of attorney (EPOA)) on the person's condition, providing a clear summary and explanation of their assessment results (including the severity of the person's condition).

This information may need to be provided to the person and/or their legal substitute decision maker on more than one occasion as required. The information should be presented in a language or format appropriate for the person to ensure accessibility of the information.

2. Describe all treatment options available to the person as part of a process of shared decision making.
3. Discuss all known risks and possible / potential consequences associated with each treatment option.
4. Act on new information as it comes to hand; for example, if the person changes their mind. This may mean the treating speech pathologist needs to revisit and have these discussions with people and their legal substitute decision makers (if applicable) on more than one occasion.

### **3.3 Speech pathologists working with people who elect to eat / drink at risk are required to clearly document all aspects of intervention for which they are professionally responsible.**

As in all other areas of clinical practice, it is the role of speech pathologists to clearly document all relevant information related to the results of their speech pathology assessment, as well as any recommendations that would minimise any identified risks. This information should be documented in the person's official medico-legal record, as relevant to the organisation in which they work (for example, medical chart or client management system). Documentation should be completed even in the context of a person who subsequently indicates a wish to continue oral intake against speech pathology advice.

Multidisciplinary discussions regarding the person's decisions should be documented and include:

1. Who was present for the discussion, including all members of the health care team;
2. Who was the decision maker or legal substitute decision maker present for the conversation;
3. What information (as described above) was provided to the person or their substitute decision maker, and in what format(s);
4. What was discussed in relation to the person's priorities and preferences;
5. The final decision and outcome of the discussion, including a management plan to implement the decision to 'risk feed.'

It is important to note that signing a waiver does **not** mean that informed consent was obtained and does not replace the need for discussions and documentation as described above.

### **3.4 It is the position of Speech Pathology Australia that the role of the speech pathologist is to work collaboratively with the multidisciplinary team in responding to and managing a person's decision to eat / drink at risk**

A person's decision to eat / drink at risk should be managed collaboratively by the multidisciplinary team. Although speech pathologists have expertise in the assessment, diagnosis and management of dysphagia, they are not solely responsible for the healthcare management of people who elect to eat / drink at risk. They therefore should engage with relevant members of the multidisciplinary team for areas outside of their scope of practice as required.

The multidisciplinary team in these situations will depend on the clinical context and the complexity of the clinical presentation. This may include members of the health workforce (medical, nursing and allied health staff), teaching workforce (teachers and assistants), and community and/or home-based care staff (including disability services officer, support workers and personal care providers). Family members should be considered a key part of the team.

The multidisciplinary team should consider whether the person who elects to eat / drink at risk has the capacity for legal consent and is therefore able to give informed consent. It is within the scope of practice of speech pathologists to work with the multidisciplinary team to contribute to determination of a person's legal capacity to make a decision to eat / drink at risk. Where this is deemed to not be the case, the discussion regarding eating / drinking at risk should be held with the person's nominated substitute decision maker or a process of supported decision making should be undertaken. There may be some situations in which the multidisciplinary team needs to consider a range of other factors, considering a person's individual circumstances.

Furthermore, speech pathologists need to ensure that all relevant people (person with dysphagia, parents/guardians, substitute legal decision makers, those involved in supported decision making, multidisciplinary team members) are informed of the type and extent of the risk associated with a decision to eat / drink at risk, and that the person and/or their legal substitute decision maker is provided with all available relevant information in order to make an informed decision. This should include but is not limited to information related to additional medical issues which may arise as a result of the decision to eat / drink at risk, and nursing/care/support staff's capacity to assist with eating and drinking.

A management plan to implement the decisions made around eating / drinking at risk should be documented by the speech pathologist. This may be in the context of organisational / team-based documentation referring to a 'risk feeding' management plan.

**3.5 It is the position of Speech Pathology Australia that speech pathologists should continue to provide professional services to a person who elects to eat / drink at risk where those services continue to provide benefit.**

Speech pathologists may provide further support to someone who has elected to eat / drink at risk where there is clinical benefit, such as the implementation of safe swallowing strategies to minimise risk ('risk mitigation'). A person who exercises their autonomy in making an informed decision to eat / drink at risk should not be denied ongoing treatment for other medical conditions, nor should they be denied ongoing speech pathology services for continued provision of education and support.

As in all other areas of clinical practice, speech pathologists should engage in person-centred care when supporting people who elect to eat / drink at risk. Decision making around eating / drinking at risk and dysphagia management can be highly emotive for people and their families, and it is imperative that people who elect to eat / drink at risk and their families are respected and valued as partners in their receipt of speech pathology services.

An informed decision to eat / drink at risk is not necessarily a permanent one, and may need to be re-evaluated in the future. Speech pathologists should support people and their families to review this decision as their circumstances change. People who elect to eat / drink at risk have the right to revisit and revise their decision at any time, and to make different or additional informed choices regarding their ongoing care.

**3.6 Speech pathologists working with people who elect to eat /drink at risk should be involved in the development of organisational policies and protocols.**

Speech Pathology Australia acknowledges that individual organisations and workplaces may need to develop site-specific policies and procedures to support implementation of this Position Statement. It is appropriate for and within the role of speech pathologists with experience in this area of clinical practice to be involved in the development of such documents as a member of the broader healthcare team.

In the development of site-specific policies and procedures, services and facilities should endeavour to have consistent use of terminology when describing scenarios where people elect to eat / drink at risk in order to minimise confusion.

## **4. Conclusion**

Speech pathologists play a critical role, as a member of the multidisciplinary team, in the management of people who make an informed decision to eat and drink at risk, or 'risk feed'. This is a complex area of clinical practice which has become an increasing focus of service delivery due to moves away from traditional and didactic healthcare models to inclusive, collaborative decision making within a person-centred model.

When working with people who elect to eat / drink at risk, speech pathologists should be aware of their professional requirements in relation to documentation and execution of their professional duty of care. They should work closely with members of the multidisciplinary team, including the person and their significant others, and be an active participant in the development of organisation-specific policies and procedures.

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