INTRODUCTION

Scope of guideline
This guideline has been produced to support health professionals when working with patients and their whānau where risk feeding is considered.

Risk feeding
When swallowing disorders (dysphagia) become severe, it is often deemed unsafe to continue eating and drinking due to the high risk of aspiration pneumonia and/or choking. Risk feeding is the term used when a patient continues to eat and drink orally despite risk. This may be considered instead of non-oral feeding options such as nasogastric tube or gastrostomy tube feeding. In some cases, small quantities of risk feeding may be chosen in combination with alternative feeding. This is often called ‘tastes for pleasure.’

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

- Non-oral feeding options (nasogastric, gastrostomy, TPN) may be limited due to the patient’s medical condition or the risks of non-oral feeding options (such as gastrostomy placement) may be too high.
- The person may be at the end of their life and a palliative approach deemed more appropriate by the team, patient and/or whānau.
- The team may not believe alternative feeding will prolong or improve quality of life.
- An informed, competent person may not be prepared to give up the pleasure of eating and drinking, or they may not wish to have an invasive procedure such as tube feeding.

Background
This guideline acknowledges that risk feeding is ethically and medically complex and that feeding decisions can impact on patient well-being as well as health. It is important that a shared decision-making approach is used. Personal and cultural beliefs, values and needs must to be considered and whānau are frequently involved in helping the patient make decisions. There can be conflicting opinions between a patient and their whānau, and there can be multiple clinical opinions from the health professionals working with the patient. Patients may have different levels of decision-making capacity, communication needs and health literacy. Logistics of providing timely information can impact on the quality of the communication and the opportunity for the patient and their whānau to fully consider the information provided. Complex feeding decisions can be associated with high health risks. As feeding plans are often passed on to different carers or whānau, decisions need to be carefully documented by the treating team to safeguard the role of the carer, respect the patient’s choice to accept risk, and put in place an agreed plan for the future including how to best support patient and carer, and how to manage possible health complications.

Use of the guideline
This guideline provides explicit evidence-based statements to support consistent interprofessional practice. The guideline provides a flow chart relating to the key themes of: ASSESSMENT, COMMUNICATION, MANAGEMENT PLANS AND DOCUMENTATION. For each theme, there is further guidance for the interprofessional team including links to related literature and resources to support best practice in the decision-making process.
Context
This guideline should be interpreted with the unique New Zealand context in mind. As health professionals working in New Zealand, we are committed to upholding the Treaty of Waitangi and to reducing health inequities. Clinicians utilising this guideline should ensure their practices are culturally appropriate and demonstrate the importance of holistic views of health and wellbeing that include physical, mental, social and spiritual elements, especially with persons who identify as Māori.

Definitions
For the purpose of this guideline, the definition we have used to best describe Whānau is:

A whānau is a Māori social structure incorporating all age ranges, interests and experience. It is a form of extended family but does not necessarily comprise blood-relatives\(^1\). In this guideline, whānau will be used to describe a patient’s social supports of any ethnicity.

Methodology
Twenty-nine staff members, three patients and three whānau participated in semistructured interviews. Staff included: one nurse manager, one stroke ward nurse specialist, one palliative care clinical nurse specialist, one social worker, six registered nurses, three dietitians, four speech-language therapists, three house officers, four registrars, and five consultants. Interviews were transcribed and analysed for themes (Miles, Watt, Wong, McHutchison, Friary, 2016; http://ggm.sagepub.com/content/2/233721416665523.full.pdf+html).

Fifty consecutive clinical cases were audited. Data regarding length of stay, documentation of feeding decisions, length of time nil-by-mouth, nutritional screening and nutritional support, documented communication with the patient and whānau and professionals involved were recorded and analysed (McHutchison, Miles, Spriggs, Jayathissa in preparation).

Louise McHutchison and Dr Anna Miles established a working group of specialist clinicians at Hutt Valley District Health Board. Members varied in locality, service and experience. Specialists external to the Hutt Valley District Health Board were asked to form a consultation group. The aim was to gain advice on draft guidelines from experienced professionals who worked across the variety of different client groups where risk feeding is common as well as across the variety of contexts of New Zealand (e.g. academic, healthcare services).

A structured review of the literature was carried out. The working group devised a list of key words for the database search, guided by the global themes that emerged from the staff, patient and whānau interviews and audit. Search databases included Medline, Embase, Cochrane, Scopus, CINAHL, Google scholar and relevant national and international professional association sites e.g. Ministry of Health NZ, Medical Council of New Zealand, British Geriatric Society, Royal College of Physicians, and American Speech-Language-Hearing Association (ASHA). Hand searching through reference lists and bibliographies of relevant reviews and research was carried out. Best practice guidelines were researched and included, relating to feeding decisions, shared decision making in healthcare, and the ethical and legal rights of patients and their advocates. Literature was read and appraised by the working group using the Scottish Guidelines Group (http://www.sign.ac.uk/methodology/checklists.html). Literature that did not meet the requirements set by the Scottish Guidelines Group was rejected.
Acknowledgments
This guideline has been developed by Hutt Valley District Health Board and The University of Auckland. Thank you to the patients, whānau and clinicians who agreed to be interviewed regarding their experience of complex feeding decisions. The experiences and perspectives that were shared have been considered throughout the development of this guideline.

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Endorsements
- New Zealand Speech-language Therapists’ Association (NZSTA) approved
- Special Interest /group Nutrition in Gerontology (SING), Dietitians New Zealand approved
- Hospice New Zealand Clinical Advisors approved
- Spectrum Care Trust, New Zealand approved
- New Zealand Speech-language Therapist Health Leaders Group, approved
SUMMARY OF RECOMMENDATIONS

Assessment

Recommendation 1: A full medical assessment is the first priority, preferably by a doctor experienced in nutrition support.

Recommendation 2: Although the lead doctor holds the final responsibility for the decisions regarding a patient’s swallowing and nutritional management, they should work closely with the interprofessional team, where available, to optimally manage feeding.

Recommendation 3: A ‘nil by mouth’ decision must be made in consultation with the patient, taking into consideration the amount of risk to the patient, and the patient or whānau preferences, values and beliefs.

Communication

Recommendation 4: Discussions with patient and whānau should take place as early as possible after identifying the risk of oral feeding.

Recommendation 5: Where possible, patients / whānau should be given notice that there will be a meeting about a patient’s feeding difficulty.

Recommendation 6: Clinicians should make it their responsibility to ask patients how they like information to be presented, any specific cultural beliefs, needs and values that need to be considered, and who they would like to be present at any meetings.

Recommendation 7: Communication should also take into account the health literacy of the patient and whānau, and be in a language that is clear and non-ambiguous.

Recommendation 8: The interprofessional team should ensure that appropriate measures have been taken to enable participation in discussions and decision making.

Recommendation 9: All appropriate feeding options should be discussed, including their risks, benefits and viability.

Management

Recommendation 10: The management plan should include:

- The feeding decision made, e.g. risk feeding, non-oral feeding, combined oral and non-oral routes.
- Why the feeding decision was made, and any reasons why other feeding options were not pursued.
- Who was involved in the final feeding decision? If an EPOA rather than the patient was involved, this needs to be clarified in the management plan.

Documentation

Recommendation 11: Decisions made during an episode of care must be easily accessible so that all those involved in the patient’s care (within the hospital and in the community) are aware of the plan.
Interprofessional assessment

An interprofessional approach to dysphagia management is well established, and recognised as best practice to optimise nutrition, hydration, safety and well-being for patients. Teams should be collaborative in nature, with the patient at the centre of their efforts.

The Royal College of Physicians (2010) suggest four key questions should be answered:
1. what is the underlying diagnosis?
2. what is the mechanism of the oral feeding problem?
3. can the person eat and drink, and, if so, at what risk?
4. what are we trying to achieve?

These questions should underpin the shared goals of the team and patient, ensuring that all members of the interprofessional team are working towards the same outcome. The team should firstly consider what is medically indicated and then consider:
- whether a palliative versus active treatment approach (prolonging, curative, or life-saving) is indicated
- the values and preferences of the patient / whānau
- have feeding decisions been made in the past?
- what support is needed to achieve the goal?

A validated nutritional screening including the patient’s current weight (such as the Malnutrition Universal Screening Tool – MUST http://www.bapen.org.uk/pdfs/must/must_full.pdf), should take place within the first 24 hours of admission.

Recommendation 1: A full medical assessment is the first priority, preferably by a doctor experienced in nutrition support.

Recommendation 2: Although the lead doctor holds the final responsibility for the decisions regarding a patient’s swallowing and nutritional management, they should work closely with the interdisciplinary team, where available, to optimally manage dysphagia.

The doctor will request information from specific team members as appropriate to the patients’ condition and presenting health difficulties.

**Dietitians:** provide information about current nutritional status and nutritional requirements. Dietitians develop enteral and parenteral nutrition feeding plans, when appropriate, and nutrition-related discharge plans.

**Gastroenterologists:** are able to provide pre-assessment of the viability and risks of gastrostomy placement

**Nurses:** play a significant role in feeding and identifying vulnerable patients. Nurses provide daily hands-on assistance for those patients who have swallowing difficulties and need to be supported, and should be engaged in the process as part of the team.

**Occupational therapists and Physiotherapists:** can also help with regards to respiratory management, positioning, and optimal feeding strategies (British Geriatric Society, 2012), and this adds to the overall assessment of risk.

**Palliative care teams:** provide information and support to patients and whānau living with life-limiting conditions. They advise on symptom management for physical symptoms associated with dysphagia and feeding at risk and on advance care planning as required. They can support ethical decision making at the end of life; managing uncertainty particularly in a hospital setting

**Social workers and whānau liaison:** facilitate better care, assisting the patient and their whānau by identifying the patient’s goals, concerns, psychosocial and spiritual needs and varying daily needs.

**Speech-language therapists:** provide information about swallowing physiology and safety. Instrumental assessment should be completed if a feeding decision is dependent on oro-pharyngeal swallow function. They can provide strategies to reduce risk.

Risk feeding in the palliative patient

Where a patient is deemed palliative, interprofessional team involvement does not automatically cease. Palliative care for dysphagia is aimed at maximising swallowing function, maintaining pulmonary health, and facilitating nutrition choices which take into account the patient’s food preferences and ethnic and religious backgrounds despite the impaired swallowing. It is recommended that the same holistic assessment principles be used for patients at all stages of the life continuum.

“At the end of life, even if deemed to have an ‘unsafe swallow,’ a risk management approach may offer the patient the best quality of life” and “nil-by-mouth should be a last resort, not the initial default option”
**Patient’s perspective**

An integral part of assessment is obtaining the patient’s perspective and/or the perspectives of whānau.

**Recommendation 3:** A ‘nil by mouth’ decision must be made in consultation with the patient, taking into consideration the amount of risk to the patient, and the patient or whānau preferences, values and beliefs.

The patient or whānau must be given all of the information about the risks and benefits of risk feeding or nil-by-mouth in order to make an informed choice. If short-term non-oral feeding is considered, then consultation with the patient and whānau must take place.

“An assessment taken in isolation that designates the patient as ‘nil by mouth’ without considering the patient holistically or offering oral fluids is bad practice.”

It is recommended that the following areas be included when assessing risk and determining the most appropriate feeding approach:

- Distress to the patient caused by feeding method, discomfort, hunger or thirst and impact on social well-being of the patient
- Respiratory status including the ability to cough effectively, tolerate chest infections and the impact of breath support on swallowing function
- Mobility including independence with feeding, positioning and the impact of restricted mobility on chest status
- Severity of the dysphagia including aspiration risk and risk of nutritional insufficiency
- Risks associated with invasive procedures
- Practicality including the ability of the patient and/or carer to maintain oral hygiene, carry out a feeding regimen, the need for supports or education and ability to put these in place
- Capacity of the patient in order to establish patient’s capacity to make decisions and whether there is a need for an EPOA
COMMUNICATION

Clinician-led individualised discussions with patient and whānau, with the support of the interprofessional team

**Timing of the communication**

**Recommendation 4:** Discussions with patient and whānau should take place as early as possible after identifying the risk of oral feeding.

Right 6 (10) of the Code of Rights outlines that informed consent requires time for the patient and their whānau to digest the information given, formulate further questions in order to make the most appropriate decision for themselves or their whānau. For many cultures, decisions require additional time to consult with the wider whānau or community, and so this also needs to be taken into consideration.

**Recommendation 5:** Where possible, patients / whānau should be given notice that there will be a meeting about their feeding difficulty.

Ensure the patient/whānau have the opportunity to invite appropriate support persons (e.g. key whānau members, pastoral support, Social Worker, Pacific Health Liaison, Māori Health Whānau Liaison). Ensure you know who the nominated spokesperson for the patient/whānau is. This cannot be assumed and needs to be asked.

It is important to identify if there is an EPOA. If so, has it been activated? If not, does it need to be? If there is an EPOA and the patient is not competent, that individual is the person who should contribute to the feeding decision. That decision, then needs to be communicated to the rest of the whānau.

There should be further opportunity to meet with the team, should the patient and their whānau have further questions or uncertainties that need clarification.
Tailoring the communication to the needs of the patient

Although there is broad diversity within all cultures, clinicians should ensure they have an understanding of the needs of Maori and Pacific peoples when providing information. The Medical Council of New Zealand \textsuperscript{2,15} states that health professionals should "make it a standard part of practice to ask every patient what their ethnic background is and not make assumptions based upon skin colour or appearance. By asking the question, you not only reveal your respect for the patient’s individual heritage, but you also have an opening to discuss cultural preferences."

Recommendation 6: Clinicians should make it their responsibility to ask patients how they like information to be presented, any specific cultural beliefs, needs and values that need to be considered, and who they would like to be present at any meetings.

Recommendation 7: Communication should also take into account the health literacy of the patient and whānau, and be in a language that is clear and non-ambiguous \textsuperscript{6}.

It should also take into account any special communication needs of the patient or whānau. Many patients with oral feeding difficulties have communication or cognitive disabilities which affect understanding, retention and processing of verbal and written information.

Recommendation 8: "The interprofessional team should ensure that appropriate measures have been taken to enable participation in discussions and decision making \textsuperscript{6}.”

Measures include:
- using appropriately trained staff to speak to patients and their support people
- having awareness of any communication and cognitive impairments, e.g. aphasia, language barriers
- finding out strategies used to support communication
- using communication aids, e.g. alphabet charts, hearing aids, written support, drawing, gesture
- providing interpreters including for whose patients who are deaf/blind and who may use sign or other means of communication.

Capacity of the patient must be considered, which can be partial and this needs to be established. Refer to Right 7 (4) of the Code of Rights \textsuperscript{16}. If the patient has been assessed as not having capacity, there is a need to establish if the patient has a formal EPOA, Welfare Guardian or Advance Directive in place.

If there is no formal agreement in place, then there needs be consultation with the patient’s social worker and managing doctor who will provide further guidance around process. Further legal advice may be required.

Whether or not the patient has capacity, they should be included in discussions as much as possible and their views should be included in the decision making process.

The right information

The treating clinician, or most appropriate interprofessional team member, must lead the meeting and all staff involved in the patient’s care may not need to present. The meeting should be tailored to the needs of the patient. It is essential, however, that all of the information has been gathered from the team prior to the meeting and that it is given in a consistent and cohesive manner.

There should be consistency of information given by the interprofessional team, and specifically this should include:
- dysphagia diagnosis
- nutritional diagnosis
- prognosis
- feeding options
- provision of both written and verbal information

Recommendation 9: All appropriate feeding options should be discussed, including their risks, benefits and viability.

Ethical principles must be adhered to, and the Royal College of Physicians (2010) \textsuperscript{6} clearly states that “clinicians should not support an intervention that has no benefit.”
Feeding plan
The Royal College of Physicians (2010) outlines that patients with oral feeding difficulties “deserve special care, which should be tailored to their requirements, and not to the needs of others”. They further add that “If (a decision to provide an appropriate method of feeding) is equivocal then consideration of other factors surrounding the condition can be helpful to enable all parties to arrive at a decision.”

- Recommendation 10: The management plan should include:
  - The feeding decision made, e.g. risk feeding, non-oral feeding, combined oral and non-oral routes.
  - Why the feeding decision was made, and any reasons why other feeding options were not pursued.
  - Who was involved in the final feeding decision? If an EPOA rather than the patient was involved, this needs to be clarified in the management plan.

Where oral feeding will continue, strategies should be put in place to promote and preserve the ability to eat and drink.

The management plan should include any strategies to help limit risk such as:
- Oral hygiene advice
- Mobility
- Texture modification
- Feeding techniques
- Positioning
- Fatigue management
- Respiratory strategies e.g. supported coughing techniques

Future planning
Ceiling of treatment needs to be considered in the context of acute-on-chronic conditions. If a patient who is nearing end of life is readmitted to hospital, there needs to be a clear documented agreement about what should be offered.

Future treatment and aims should be discussed and agreed with the patient and their chosen whānau support in terms of:
- Future hospital admissions
- Invasive treatments
- Non-invasive treatments
- Symptom control

Advance Care Plan (ACP): if the patient has an ACP this should be mentioned in the management plan. If the patient does not have an ACP, and the patient has capacity to put this in place, then this option should be discussed. A generic Advanced Care Plan is available from the Advanced Care Co-operative: http://www.advancecareplanning.org.nz/assets/My_Plan_2016.pdf.

Discharge-care
A discharge care plan should outline:
- Signs and symptoms of aspiration related health complications
- Where to seek advice and support, including contact details of any patient or whānau supports within the hospital
- The right to review decisions - if possible, dependent on patient’s prognosis and options available to them
- How primary care can support the patient in the community
- Any package of care or community nursing plan
Clear documentation made readily available to the patient and treating team concurrently and retrospectively.

**Recommendation 11:** Decisions made during an episode of care must be easily accessible so that all those involved in the patient’s care (within the hospital and in the community) are aware of the plan.

All interprofessional team assessments and discussions with the patient should be clearly documented to include:
- How the information was provided
- What options were discussed
- Risks and benefits of each option discussed
- Who was present at the discussion
- The opinion of the patient and family
- The reason for the risk feeding decision

The management plan should be readily available on the patient’s electronic records (discharge summary, transfer to care facility, care plans etc.)

Patient (or their EPOA, Welfare Guardian, Whānau support) should receive a printed copy of their management plan. Where a risk feeding decision has been made, documentation should clearly outline that the patient is continuing to eat and drink, and that they (or their support person) are aware of the risks associated with this.

Regular health-care providers for each patient (GP, Long term care facilities, community speech-language therapist, community dietitian) should receive copies of the management plan.

Health passports are available to all patients. Patients with communication disabilities in particular should be offered a communication passport, and this should contain a copy of their management plan.

References:


