

Supporting people with MND to make the decision about gastrostomy placement

Background

People with motor neuron disease (MND) face many challenges to be able to take adequate oral diet. Weight loss is associated with poor outcomes for people with MND, including shorter prognosis. Gastrostomy placement is routinely offered to manage the risks of aspiration and malnutrition. The qualitative literature describes challenges faced by all stakeholders during decision making about gastrostomy. This poster summarises the complexity of the decision-making process and the role healthcare professionals (HCPs) have supporting informed decisions.

Conclusion

There are multiple opportunities for delay in placing gastrostomy tubes in MND care; delays that may limited the potential benefit of the intervention. HCPs play an important role in collaborating with people with MND and their caregivers and coordinating with their MDT colleagues, to navigate the myriad of clinical, interactional and psychosocial factors that influence how, what and when decisions are made.

The decision-making process

Introducing the option

People with MND can adopt avoidant strategies e.g. denial, to cope with the diagnosis, disease progression and in response to intervention options that can represent a stark reminder of disease progression. Such responses can present a barrier to initiating discussions about gastrostomy placement. HCPs make decisions about when to introduce the gastrostomy option, based on a range of clinical indicators and a subjective assessment of whether an individual with MND is 'ready' to have this discussion. Clinical guidance recommends early discussions about gastrostomy, recognising the time it can take to make decisions and the risk of negative outcomes if gastrostomy is placed too late in the disease process.

Gastrostomy: a complex decision

Informed decision making about gastrostomy requires an understanding of the risks and benefits of: 1. the procedure to place a gastrostomy, and 2. home enteral feeding. While clinical and nutritional outcomes are relevant to people with MND, preferences in relation to the impact enteral feeding will have on their independence, sense of self, autonomy and on their caregivers, play a significant role in decision making. People with MND can have differing goals with regards extending life, which may inform preferences for gastrostomy which is often perceived to improve

prognosis even if the evidence for this is effect is inconclusive.

Evidence and detailed guidance on optimal timing of gastrostomy is lacking, which is a source of decisional conflict for HCPs and people with MND. There are multiple indications for gastrostomy placement that are progressive and need to be monitored for, including the role respiratory failure plays in the procedural risks. People with MND require more robust guidance about gastrostomy timing, communicated in a manner that can allow understanding of the issues and acceptance of the uncertainties.

Healthcare professionals play an important role in supporting people with MND to make decisions about if, and when, to have a gastrostomy placed. This includes presenting the available choices, addressing avoidant coping strategies facilitating an understanding of predicted outcomes with or without gastrostomy, providing guidance about timing and assist with the evaluation of the risks and benefits in the construction of a values-based decision. Multiple different HCP roles are involved in supporting an individual person with MND about the decision to have a gastrostomy placed. Qualitative literature has found that there is potential for mixed messages to be given, which may contribute to decisional conflict.