



The DiAMoND Study

Development and pilot testing of a web-based decision aid for people with motor neurone disease considering a gastrostomy tube

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Motor neurone disease (MND) is a progressive neurodegenerative disease that results in the loss of multiple physiological functions, including the ability to swallow. People with MND are faced with numerous complex healthcare decisions. One such decision is whether to have a gastrostomy tube placed to administer fluid, nutrition, and medication as their swallow function declines. Due to the ethical challenges of conducting research in this area, the evidence for the benefits of tube feeding on survival and quality of life in MND is lacking and what evidence there is remains equivocal.^{1,2} Shared decision-making is a joint process in which healthcare professionals (HCPs) and a person work together to reach a decision about care.³ Interventions to support people with MND with shared decision-making are currently lacking in the UK. This article outlines new research to develop and pilot test a web-based patient decision aid to support individuals with MND to decide whether to have a gastrostomy tube fitted.

Why are people with MND offered a gastrostomy & what's the evidence base?

MND is a progressive disease affecting the nerves in the brain and the spinal cord. There is currently no cure. It is estimated that up to 5,000 people are living with MND at any one time in the UK,⁴ and the typical life expectancy from symptom onset is 3 years.⁵ Patients will experience a decline in physical function over the disease course, which may be accompanied by cognitive and behavioural change,⁶ requiring them to navigate a challenging care pathway with many complex decisions.

Dysphagia (difficulty swallowing) can affect up to two-thirds of people with MND in the late stages of the disease.⁷ It may cause distressing coughing and choking, lengthy mealtimes and aspiration, which in turn can lead to recurrent chest infections, malnutrition and weight loss.⁸

Low body weight and weight loss are independent predictors of a shorter survival.^{9,10} As well as the impact on the person with MND, increasing disability, requiring help to eat, and the need to modify the texture of oral diet and fluids can increase burden on caregivers. People with MND are routinely offered a gastrostomy tube to manage the challenges and negative outcomes associated with dysphagia and resulting malnutrition on the assumption it can provide nutrients, reduce the risk of aspiration, and potentially improve survival and quality of life.^{11,12} Gastrostomy refers to a small opening made in the abdomen, through which the feeding tube enters the stomach. However, there are no randomised controlled trials (RCTs) that explore the efficacy of tube feeding in MND and results from observational studies have not been able to provide definitive answers with respect to survival, nutritional outcome, or quality of life.¹

Gastrostomy placement in MND: a complex decision

Gastrostomy feeding can impact significantly on people's everyday life, with both positive and negative effects.^{13,14} Risks and burdens associated with gastrostomy feeding include complications arising from tube insertion, difficulties with feed administration, gastrointestinal complications, and the psychological impact, such as the tube acting as a reminder of physical decline. Potential benefits may include reduced anxiety associated with prolonged mealtimes by removing the necessity to eat and drink, weight stabilisation and perceived survival benefit. From the patient, carer, and healthcare professional (HCP) perspective, the decision about whether to have a gastrostomy is complex.¹⁵

HCPs can find it challenging to discuss gastrostomy tubes due to the limited evidence base for their benefit. In addition, there is a time sensitivity to this decision, with some patients becoming medically unfit for the procedure later in the disease trajectory due to frailty or respiratory failure. Earlier placement of a gastrostomy tube may reduce procedural risks and increase the likelihood of observing positive outcomes. However, some people may not be ready to undergo the procedure earlier in their disease trajectory, particularly when they do not perceive there is a physical need.² HCPs use their professional judgement to determine when a person with MND may be ready to discuss gastrostomy feeding, and how they present information about gastrostomy tubes. Some clinicians may struggle to present the information in a neutral way.

How a decision aid can help

Decision aids are developed to support complex, preference-based decisions.¹⁶ These decisions will often have multiple options, in this case: choosing to go ahead with gastrostomy placement, not having a gastrostomy tube now but planning to revisit the decision later, and deciding never to have a gastrostomy tube. There is currently no published patient decision aid for this patient group in the UK. By presenting evidence-based information, outlining the risks and benefits associated with each option,

checking understanding, and clarifying personal values and preferences, a decision aid may help people with MND make a decision about whether a gastrostomy is appropriate for them.¹⁷ Decision aids can also support conversations with family members and HCPs and encourage shared decision-making.¹⁸

Development & pilot testing of a web-based decision aid

The DiAMoND study, led by Dr Sally Wheelwright, and funded by Marie Curie and the Motor Neurone Disease Association, developed a web-based decision aid to support individuals living with MND to make the decision about whether to have a gastrostomy tube placed.¹⁹ The study was conducted in three phases as shown in **Figure 1**. People living with MND, their carers, and HCPs were involved in all three phases of the study as participants. In addition, a study advisory committee consisting of clinical experts, experienced researchers, individuals with MND and their carers supported the design of the study and all stages of the development of the decision aid.

DiAMoND study participants provided positive feedback on the decision aid. People with MND found the decision aid useful and would recommend it to others in their position.

"I knew a little bit about gastrostomy tubes before, but the aid provided me with much more information – very detailed but easy to understand."

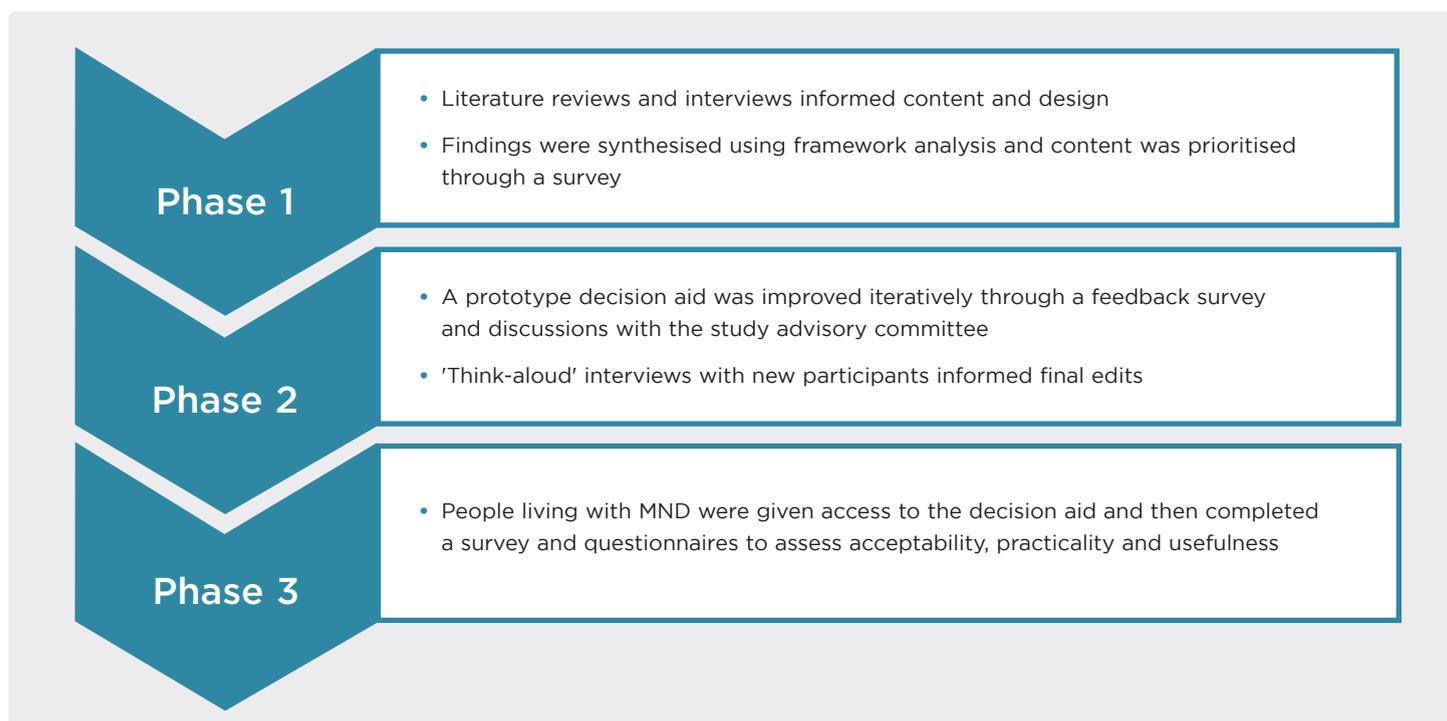
Person living with MND who used the decision aid

HCPs also thought the tool was a useful resource to help in their discussions with people with MND and their carers.

"This tool is amazing. It facilitates the decision; it makes them feel prepared as to what's coming. They will understand what it is, what the nuances are, what the disadvantages are and for them it will feel like an informed decision."

Dietitian, Focus Group 2

Figure 1: Development of the decision aid



Decision aid contents

The final version of the decision aid (see **Figure 2**), was developed in line with International Patient Decision Aid Standards.¹⁶ It presents evidence-based information, explains risks and benefits, checks the user's understanding of the information presented and helps clarify values and preferences. Users can choose to work through the decision aid in order or move around the different topics using the menu that appears at the top of each page, as seen in **Figure 3**. In each section, basic information is presented first. Potentially sensitive information and images are hidden unless users decide to access them, allowing control over the information seen. The definition for any technical terms used can be accessed easily by hovering the cursor over the relevant word.

The decision aid is designed to help people understand what is important to them (see **Figure 4**), so they reach a decision that is aligned with their values and preferences. The decision aid can also be used by carers and HCPs to assist or supplement existing discussions between the individual with MND, their family or carer and the multidisciplinary team.

Summary & how to access the decision aid

This evidence-based decision aid is the first in the UK to support people living with MND in gastrostomy tube decision-making. It was co-produced with stakeholders and conforms to international standards. The decision aid can be used flexibly by HCPs to best support their own clinical practice. Evaluation of the decision aid with people living with MND indicates they found it acceptable, practical and useful. The decision aid can be freely accessed on the MND Association website:

www.mndassociation.org.

Figure 2: Homepage of the decision aid

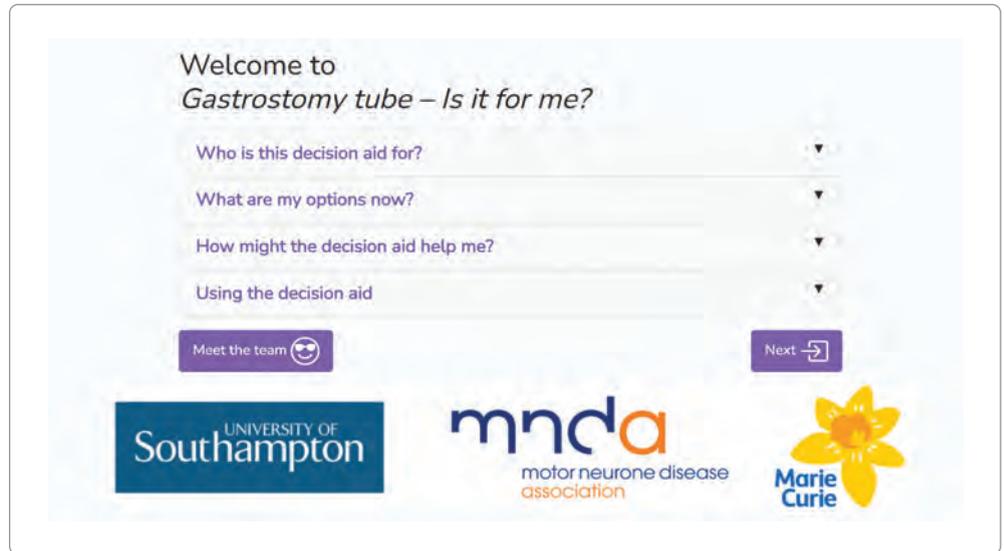


Figure 3: Decision aid layout

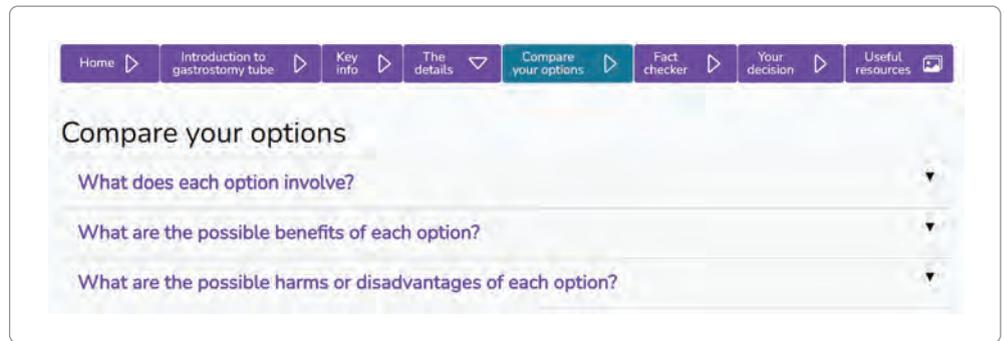
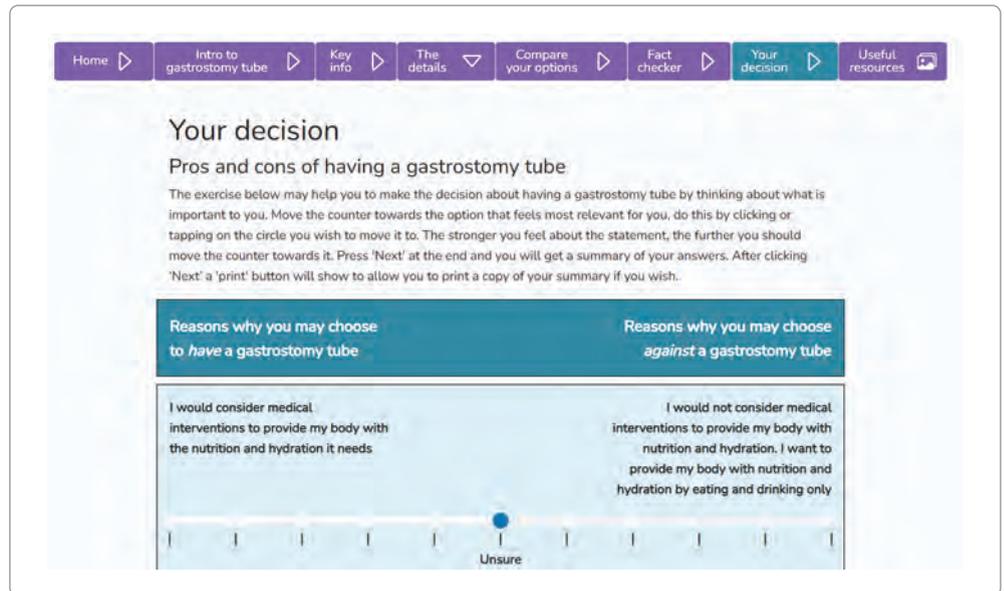


Figure 4: Helping to make a decision



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