

A decision aid for Gastrostomy in MND

BACKGROUND

- Choosing if and when to have a gastrostomy tube fitted is difficult for people living with MND
- There is little evidence of increased survival, quality of life outcomes are mixed and there are risks associated with the procedure
- Patient decision aids are designed to support people to make difficult decisions

Aim: To develop and test a web-based patient decision aid to support people with MND to decide whether to have a gastrostomy tube fitted

METHOD

DiAMoND was a three phase study. Patients, carers and healthcare professionals contributed throughout as both study advisory committee members and research participants



Content and design: Literature reviews, in-depth semi-structured interviews and prioritisation surveys informed what to include in the decision aid and functionality



Develop and test: A prototype web-based decision aid was created, tested with users and improved iteratively.



Evaluation in practice: Healthcare professionals were invited to offer the decision aid to patients to test whether it is acceptable, practical and useful

KEY FEATURES OF:

Gastrostomy tube: Is it for me?

Presents evidence-based information

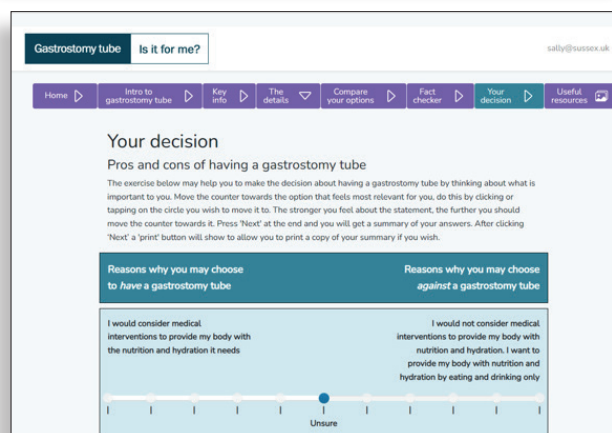
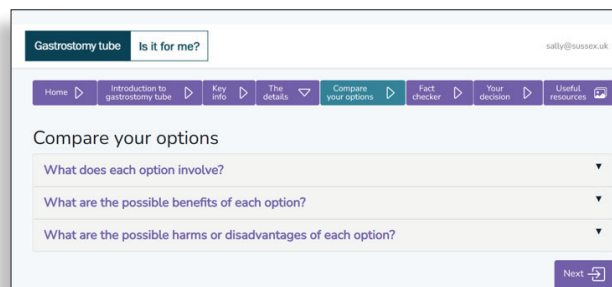
Basic information presented first with option to click through to more detail

Communicates risks and benefits associated with each option

Helps people clarify their own personal values and preferences

Checks understanding

Provides links to useful resources



DISCUSSION AND RECOMMENDATIONS

- *Gastrostomy tube: Is it for me?* (see www.gastrostomychoice.co.uk) is a co-designed web-based app which conforms to International Patient Decision Aid Standards
- It provides all the information stakeholders consider important for decision-making
- Health care professionals can use the app to support conversations around gastrostomy
- Patients and carers can use the app to support decision making and communicate their decision

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