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Sussex Health Outcomes Research & Education in Cancer

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DiAMoND

Decision Aid for gastrostomy in Motor Neurone Disease



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@DiAMoNDstudy_



Care and support
through terminal illness

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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

What does the medical evidence say about gastrostomy for people living with MND?

Little evidence
of increased
survival

Evidence on
impact on
QOL equivocal

Procedure
risks

Patient decision

My philosophy is to try to live as long as possible and I'm aware that MND patients die for two reasons: lack of nutrition and lack of air. So I was aware that I would need to tackle both of those things at some stage.

I used to like walking, sailing, photography, sewing. All those sort of things are either not possible or just so difficult that I can only do them in very small doses. Probably the one or two great pleasures that are still left in life for me are food and drink and I cannot see anywhere that for me would be a quality of life in having some liquid pumped in that I couldn't taste, couldn't enjoy the flavour, couldn't get the texture. Why would I do it?



Timing – when to have a gastrostomy?

Health care professionals may recommend having a gastrostomy sooner rather than later

- Fit enough for the procedure
- Some evidence that early placement more beneficial



Timing – patient view

They say make sure it's done sooner rather than later but what is sooner rather than later? They don't say we're talking next month, no definite time, it's down to you.

My opinion is I don't really want to put a hole in my body that I don't need just yet but I would like to do it before it's too late, so it's a question of deciding time.

We're dealing with things as we have to, and it's probably not a bad way of going about it. And just thinking I'll worry about it when it gets here. I can't worry about it before.

So I'm not saying never, but I don't want to decide yet, so my decision now is 'not at the moment'.

Timing: triggers

Weight loss

Difficulty swallowing

Prolonged mealtimes

Recurrent chest infections

Weakened breathing

Summary so far

- Deciding whether to have a gastrostomy tube fitted is a personal choice
- Most people find it a difficult decision to make
- Deciding the right time to have a tube fitted is also difficult

Decision aids



International Patient Decision Aid Standards (IPDAS)
Collaboration

Patient decision aids are designed to support people to make difficult decisions.

- Assist patients in making informed choices about treatment options that align with their personal preferences and values.
- Clarify personal values and preferences
- Present evidence-based information
- Communicate the risks and benefits associated with each option
- Check understanding

DiAMoND Study Method



Phase 1: Content and Design

- Literature review
- Semi-structured, in-depth interviews
- Prioritisation of information: MoSoCoW



Phase 2: Develop and Test

- Alpha-testing: feedback survey
- Beta-testing: 'Think-aloud' interviewing
- Final prototype developed



Phase 3: Evaluation in Practice

Assess the acceptability, practicality and usefulness to people living with MND, their carers, and the healthcare professionals working with them

Any burning questions before
we look at the decision aid?

DiAMoND

Decision Aid for gastrostomy

**Gastrostomy
tube**

Is it for me?

ease



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