

Supporting people with MND to make the decision about gastrostomy placement



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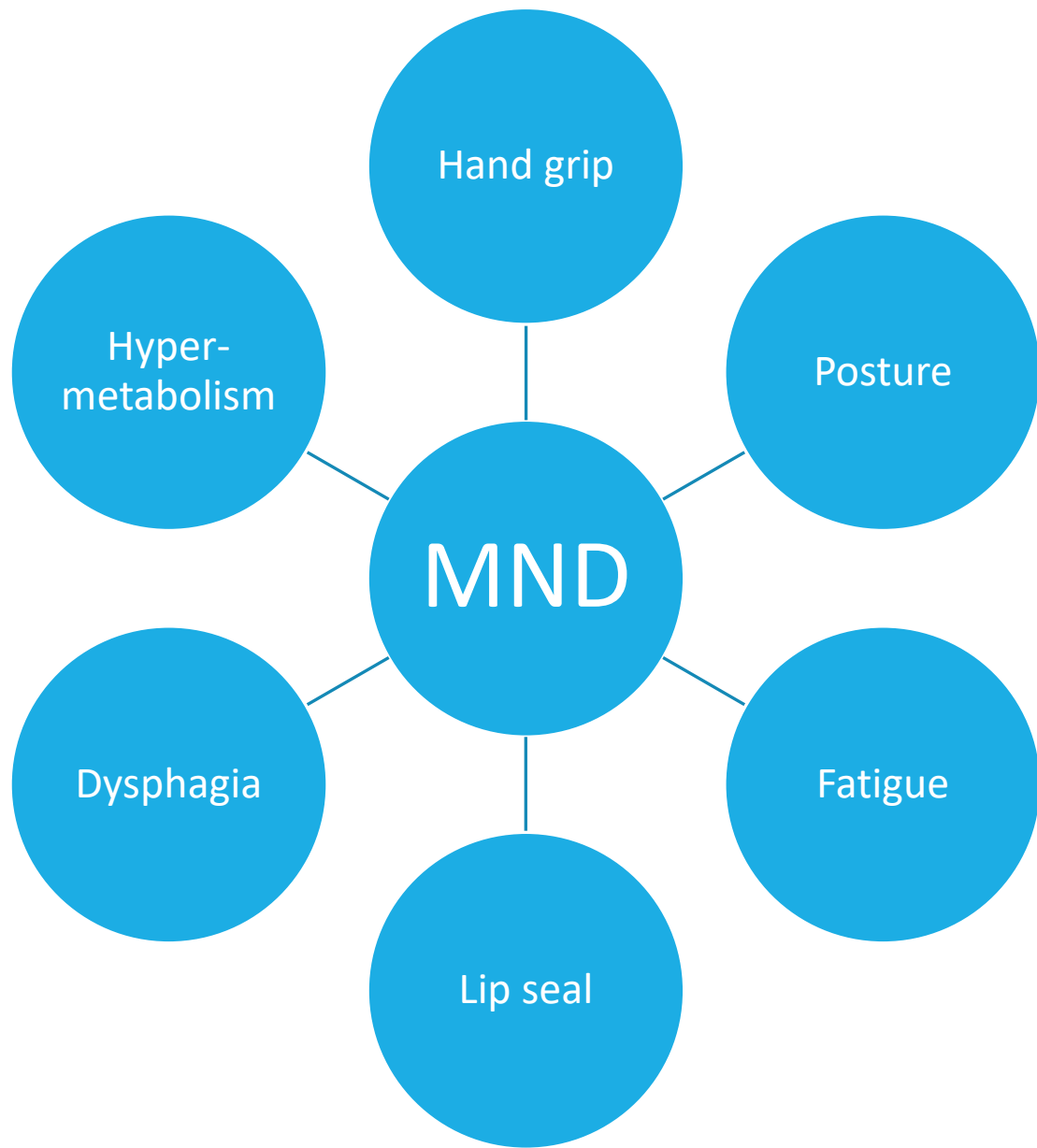


Image from google

Weight matters in MND

BMI

Ning et al 2019



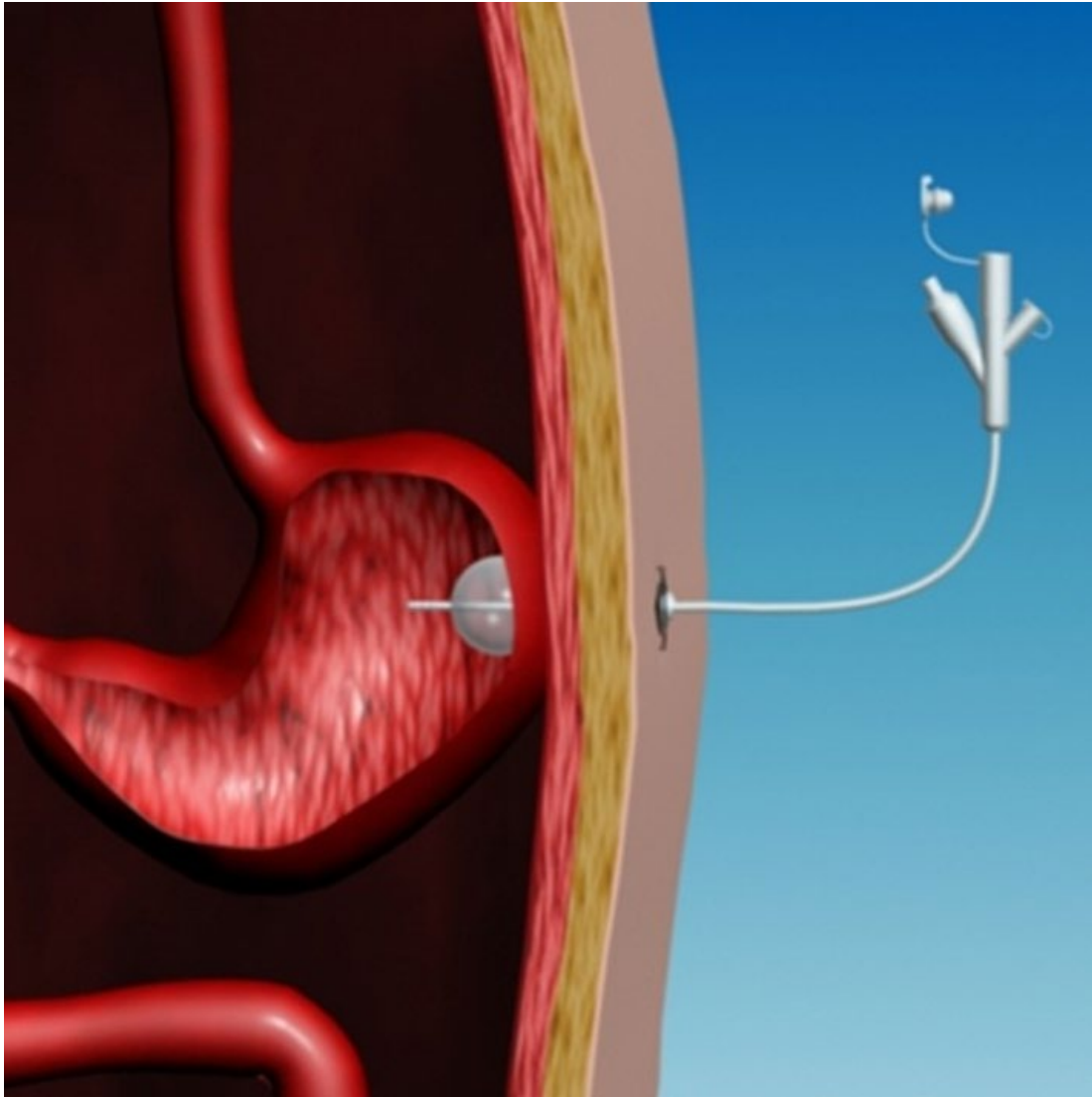
Weight
change

Shimizu et al 2019

...pre-diagnosis
...post -diagnosis
...pre-gastrostomy

 **HighCALs**





Simples?

Can't eat

Tell patient about
gastrostomy

Decision

“The absence of a cure, a small number of evidence-based treatment options and a rapidly progressive disease course generate a ‘**worst case’ decision-making context.**” (Hogden et al 2014)

Diagnosis → Decision making → End of life

↑ Symptom progression ↑

↻ Appraising and re-evaluating ↻

King et al 2009

Values based judgements

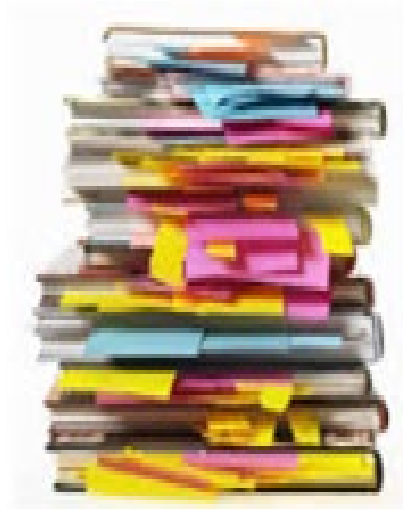


Qualitative Evidence Synthesis

Maintaining control



Tipping the balance



Sharing the burden



“To a large extent, I keep my head pretty well buried in the sand as far as the reality of all this is concerned. Because as soon as you lift your head up and start to think about all these things – you have to every now and then – it all gets a bit overwhelming.”
(Hogden et al 2012)



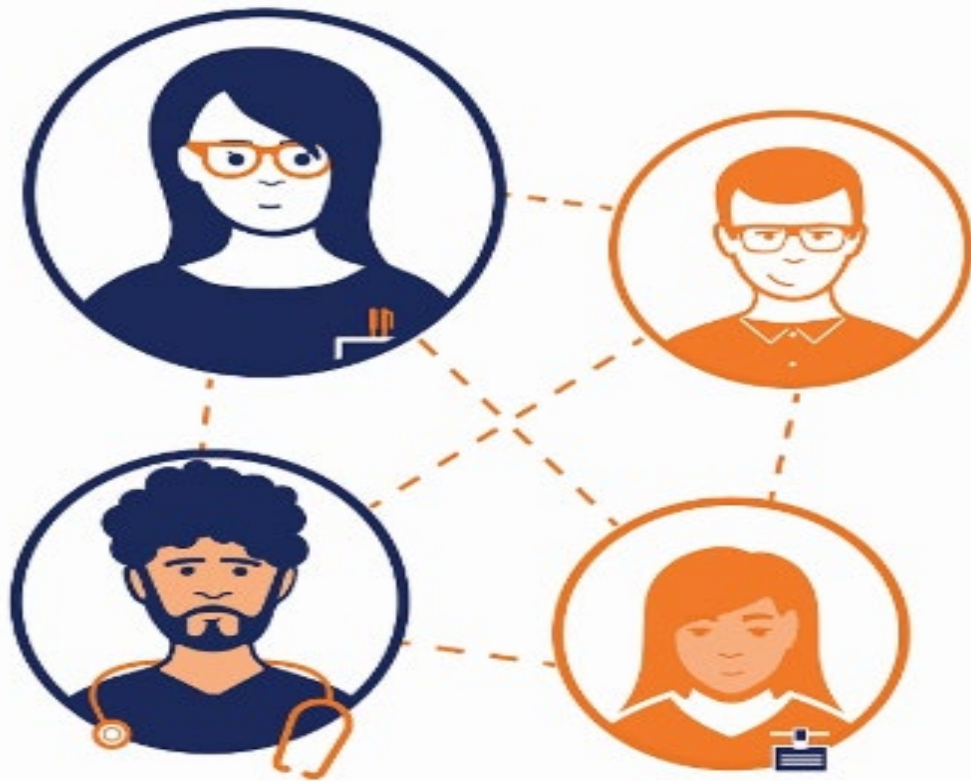
Multiple indicators...which one and when?

Table 1. Timing of gastrostomy indication.

Clinical indicators	Respondents, <i>n</i> (%)
Malnutrition/weight loss	29 (100)
Dysphagia	29 (100)
Prolonged and effortful meals	29 (100)
Recurrent chest infections	27 (93)
Insufficient intake of liquids	24 (83)
Low vital capacity	24 (83)
Decreased appetite	19 (65)
Dependency on others	10 (34)
Hypermetabolism	2 (7)
Oral hygiene	2 (7)
Criteria/cutoff values^a	
<i>Cutoff values for malnutrition/weight loss^b</i>	
≥ 10% weight loss in last 3-6 months	22 (76)
≥ 5% weight loss in last 3-6 months	11 (37)
≥ 10% premorbid weight loss	10 (34)
BMI ≤ 18,5	7 (24)
≥ 5% premorbid weight loss	5 (17)
BMI ≤ 20	4 (14)
No explicit cutoff value	2 (7)

Van Eenennaam et al 2021

MND MDT – a unit of decision support?



Involvement in decision-making process	
Family	29 (100)
<i>ALS care team members^a</i>	
Speech therapist	29 (100)
Dietician	29 (100)
Social worker	9 (31)
Occupational therapist	8 (28)
Physiotherapist	7 (24)
Psychologist	3 (10)
ALS care team during team meeting	3 (10)
<i>Other healthcare professionals^a</i>	
Gastroenterologist	15 (52)
Pulmonologist	13 (45)
General practitioner	7 (24)
Radiologist	6 (21)
Others (i.e. neurologist or nurse specialist, otorhinolaryngologist, anesthetist, case-manager palliative care team, homecare team)	8 (28)

Van Eenennaam et al 2021

Coordinating MDT decision support

'I think my...fear is you can get so many teams of people involved. You've got specialist palliative care, GP and primary care, respiratory care, gastroenterologist who's been involved with the PEG, the rehabilitation team, a neurologist who's saying – you know, and the possibilities of confusion and misinformation are enormous...I was going to say warfare' (Chapman et al 2021)

"I think often the structure of the clinic makes that difficult because Dr X saw her first, documented in the notes, which is great, but it really would have been nice to talk to Dr X verbally, before [the patient] came into our rooms. Sometimes it can be quite difficult. Sometimes the neurologist might write 'Not for PEG' in big writing, but they don't say why." (Hogden et al 2012)

Timing matters...

Diagnosis



Initiate discussion



Decision making

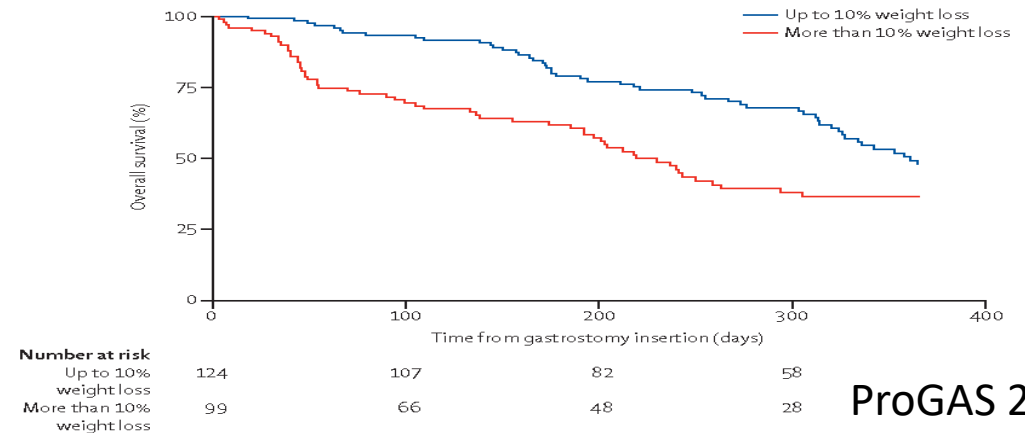


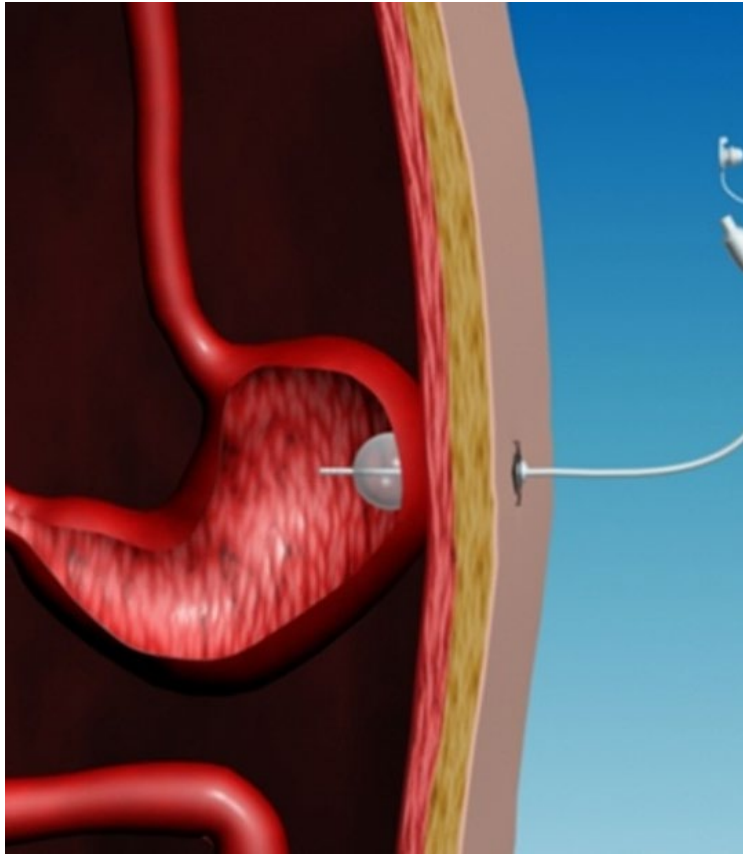
Decision/referral



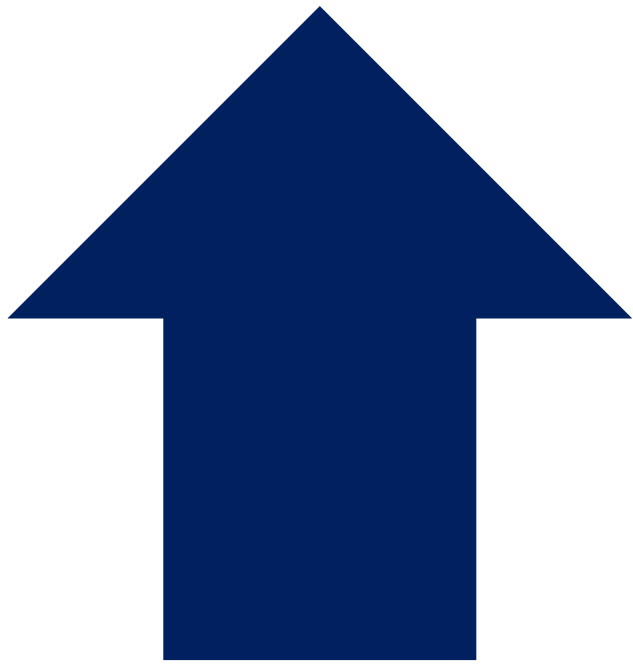
Gastrostomy placement

'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' (Greenaway et al 2015)





Picture of a PEG Salesman used for promotion



Benefits:

Prolong survival

Improve nutritional status

Reduce aspiration/choking risk

Reduce mealtime stress

Concerns:

Practical issues

Body image

Time taken to feed

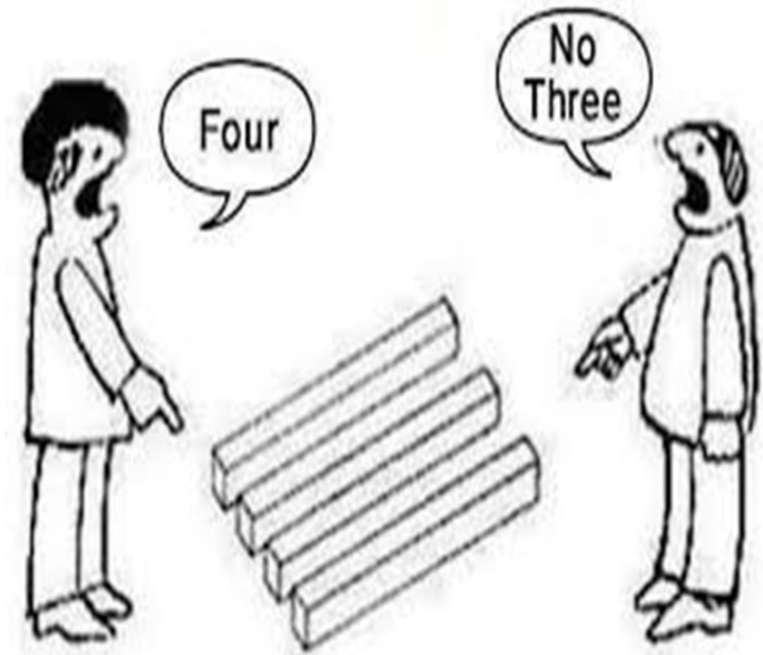
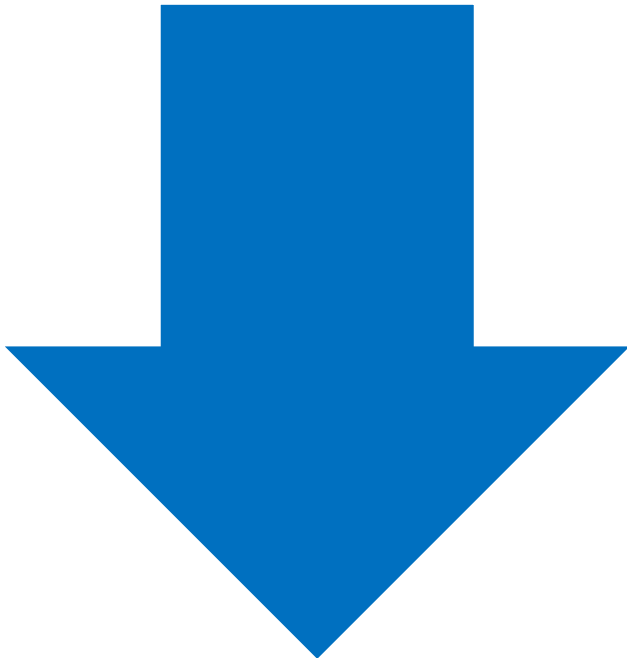
Tube/stoma complications

Missing oral diet

Social withdrawal

Disturbed sleep

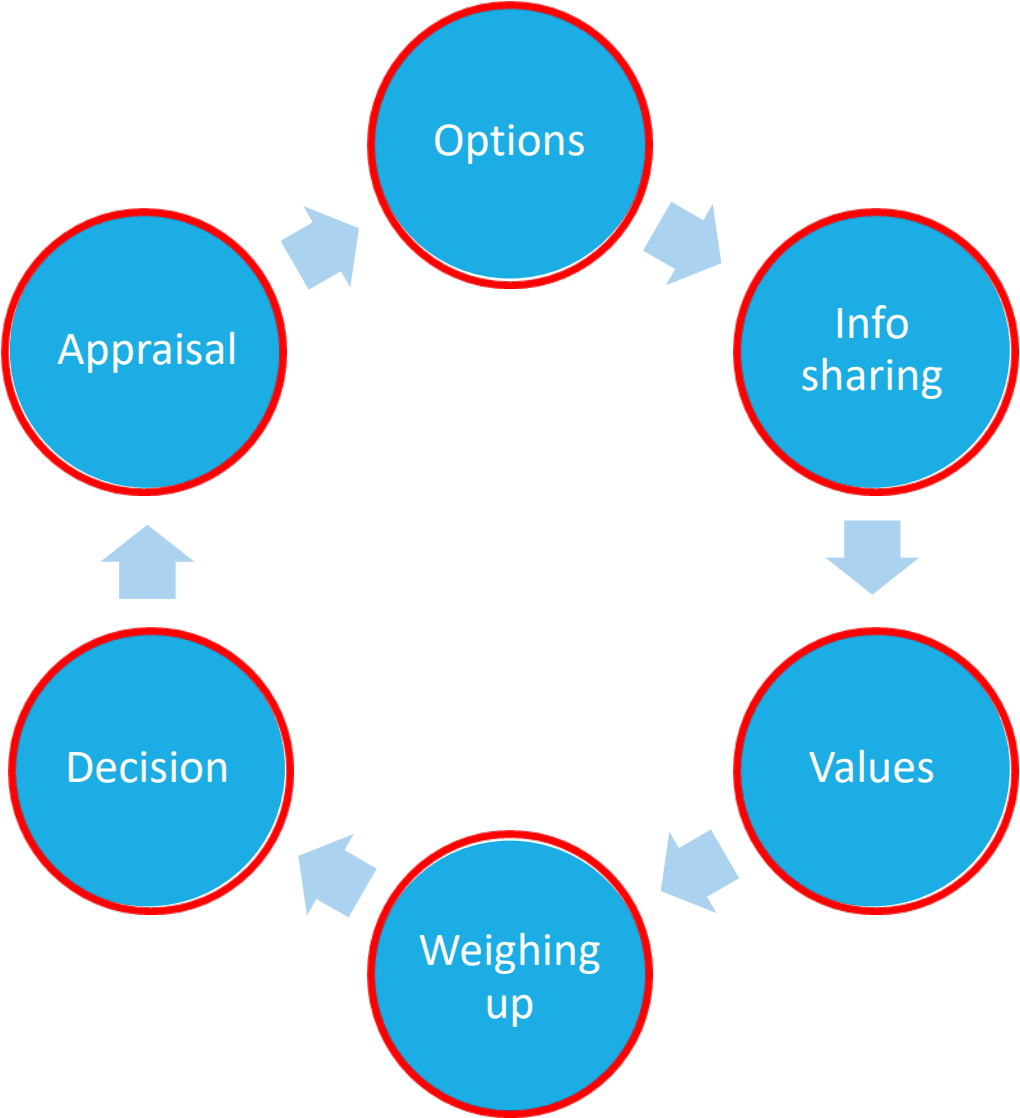
Caregiver burden



Yes.

No.

Maybe.






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THINKING about a tube >



FITTING a tube >

 Learn about tube feeding in MND/ALS
The Basics - Start Here >



LIVING with a tube >



CARING for someone >



Welcome to *Gastrostomy tube – Is it for me?*

What is a decision aid? ▼

Who is the decision aid for? ▼

What are my options now? ▼

How might the decision aid help me? ▼

Using the decision aid ▼

Meet the team 

Next 

UNIVERSITY OF
Southampton

mnda
motor neurone disease
association



Survey of HCP practice

Aim

Understand the practice and attitudes of HCPs who support pwMND to make decisions about gastrostomy placement

Takes 15-20 minutes to complete.

Link:

https://shef.qualtrics.com/jfe/form/SV_4NqBa3IN1zqFYiy

Please share far and wide...



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Are you interested in helping us understand how to best support people with motor neurone disease (MND) making decisions about gastrostomy feeding tube placement?



We are conducting a survey of healthcare professionals practice about how they support people with MND to make decisions about gastrostomy feeding tube placement.

The survey is open to any UK healthcare professional who has discussions about gastrostomy feeding tube placement with people with MND .

If you are interested in being involved please follow the link to the survey in the tweet or email you have received. Please forward the survey link to any of your healthcare professional colleagues who may be interested in being involved.



For more information please contact the principal researcher, Sean White, at smwhite1@sheffield.ac.uk or 0114 2222295

Summary

Decision making is:

Complex

Threatening

Support needs to be: supportive, compassionate, evidence based, well communicated, coordinated

Link:

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For more information please contact the principal researcher, Sean White, at smwhite1@sheffield.ac.uk or 0114 222295