SHORE-C

Sussex Health Outcomes Research & Education in Cancer

UNIVERSITY OF SUSSEX

brighton and sussex medical school

When should health care professionals start talking about gastrostomy tubes to people diagnosed with motor neurone disease?*

Dr Sally Wheelwright

s.wheelwright@sussex.ac.uk

𝕏 @SallyWheel

*I don't have a simple answer

Last year…

DiAMoND

A study to support decision making in MND

Aim

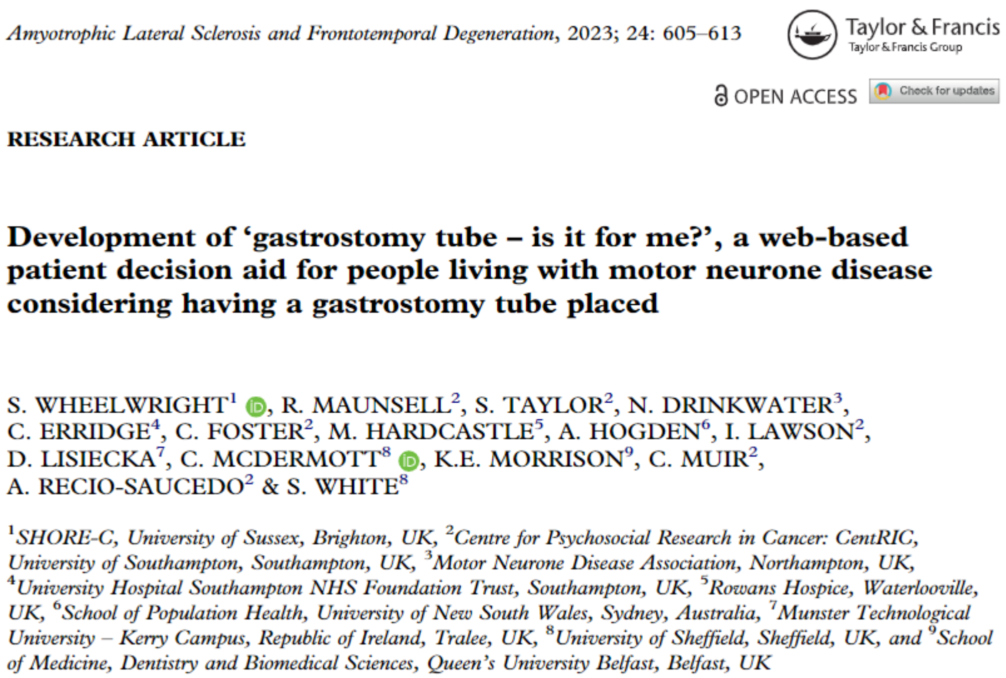
To **develop** and **test** a web-based patient decision aid to support people with MND to decide whether to have a gastrostomy tube fitted

DiAMoND

A decision aid to support people living with MND

Gastrostomy tube

Is it for me?



Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2023; 24: 605–613

Taylor & Francis
Taylor & Francis Group

OPEN ACCESS
Check for updates

RESEARCH ARTICLE

Development of 'gastrostomy tube – is it for me?', a web-based patient decision aid for people living with motor neurone disease considering having a gastrostomy tube placed

S. WHEELWRIGHT[1], R. MAUNSELL[2], S. TAYLOR[2], N. DRINKWATER[3], C. ERRIDGE[4], C. FOSTER[2], M. HARDCASTLE[5], A. HOGDEN[6], I. LAWSON[2], D. LISIECKA[7], C. MCDERMOTT[8], K.E. MORRISON[9], C. MUIR[2], A. RECIO-SAUCEDO[2] & S. WHITE[8]

[1]SHORE-C, University of Sussex, Brighton, UK, [2]Centre for Psychosocial Research in Cancer: CentRIC, University of Southampton, Southampton, UK, [3]Motor Neurone Disease Association, Northampton, UK, [4]University Hospital Southampton NHS Foundation Trust, Southampton, UK, [5]Rowans Hospice, Waterlooville, UK, [6]School of Population Health, University of New South Wales, Sydney, Australia, [7]Munster Technological University – Kerry Campus, Republic of Ireland, Tralee, UK, [8]University of Sheffield, Sheffield, UK, and [9]School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast, Belfast, UK

Academic paper in *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*[1]

Link for health care professionals (HCPs)

www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/dysphagia/

Link for patients

www.mndassociation.org/support-and-information/living-with-mnd/eating-and-drinking/

Direct link

gastrostomychoice.co.uk

Compensating

↑Weight loss
↑Aspiration risk
↑Procedure risk
↑Mealtime burden

I'll have it
when I need it

They say n
done sooner ra
later but what is sooner
rather than later?

When should HCPs start talking about gastrostomy tubes? The patient view

When should HCPs start talking about gastrostomy tubes? The carer’s view

The earlier that anybody makes mention of this the better

ths you are in
mation you get
n you are still
trying to process somebody having a progressive terminal condition. You really want the information in bite size pieces rather than all at once.

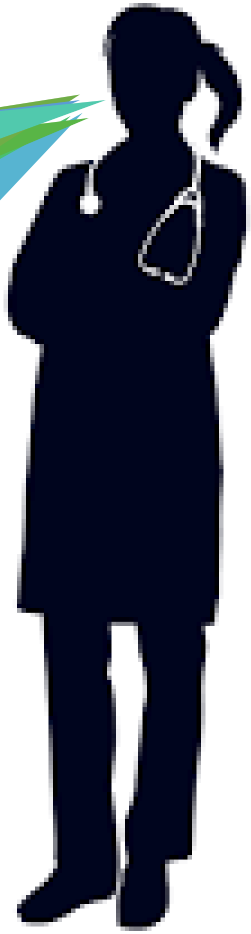
you are telling somebody. Early enough so we don’t have the hassle that we went through but you are not doing it too early that you create psychological worry too soon.

When should HCPs start talking about gastrostomy tubes? The HCP view

So my personal opinion is that I’d like to get in there relatively early, certainly within, even if they are asymptomatic within maybe three to four months of diagnosis… My consultant would probably say later on and we would wait until someone was symptomatic

people
any
at the
ot that
their
hat.

tandard
protocol in my book



From the literature

On average, discussion held around 7 months after diagnosis

(US[2], Australia[3])

50:50 split between HCPs who introduced the topic very soon after diagnosis and those who waited until there was an indication for gastrostomy

(The Netherlands[4])

Stepwise approach to providing information. Detailed information only welcomed if it fitted with own experience

(The Netherlands[5])

From the literature (2)

Providing information too early has a detrimental effect on QoL for some but for others, allowed more time for quality decision making

(Australia[6])

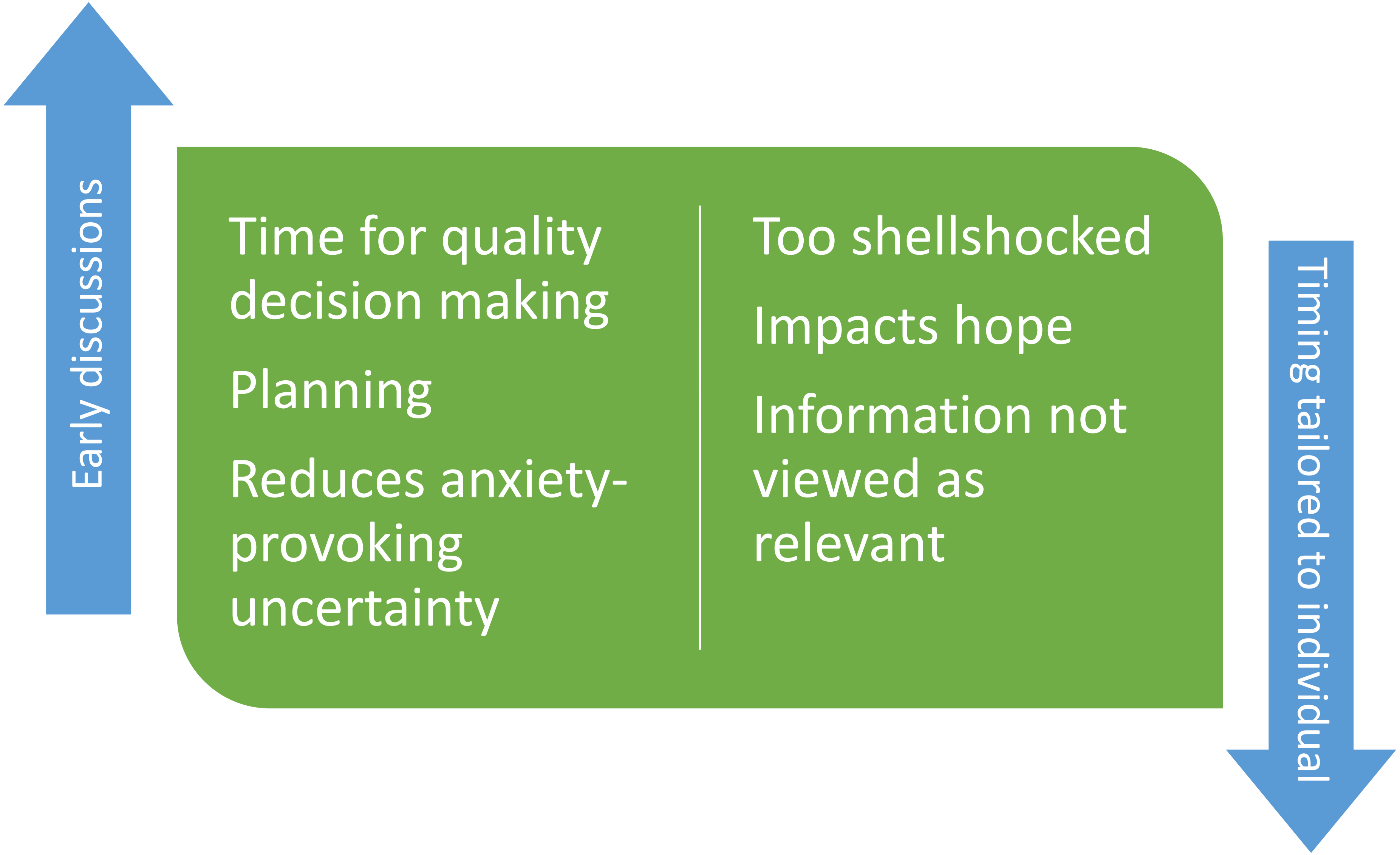
More medical HCPs (76%) compared with allied health professionals (52%) were in favour of early discussion of gastrostomy

(UK[7])

Some HCPs in favour of early discussion, others thought factors like disease progression, social factors, emotional coping and acceptance should be taken into consideration

(UK[8])

Summary



Early discussions

Time for quality decision making

Planning

Reduces anxiety-provoking uncertainty

Too shellshocked

Impacts hope

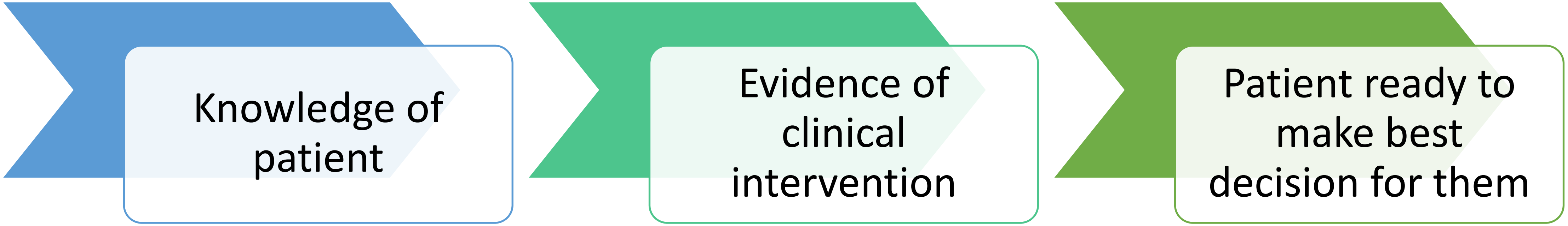
Information not viewed as relevant

Timing tailored to individual

MND is “perfect storm” for decision making

- Delayed diagnosis
- Diagnosis bombshell
- Average survival time 2-4 years
- No cure
- Limited evidence-based treatment options
- May progress rapidly
- Communication may be affected
- Cognitive decline possible
- Uncertainty

Ethically focused clinical cost benefit analysis



Knowledge of patient

Evidence of clinical intervention

Patient ready to make best decision for them

Some challenges

HCPs aware of issues that need to be considered ahead of plwMND raising them or even wanting to know

Conversations around advance care planning can be difficult for all

How can this be mitigated so that there can be an opening conversation at the right time?

Reframing the idea of early and late discussions

Well-timed conversations

Mis-timed conversations

Well-timed conversations

Provides opportunity to share knowledge & understanding, and to correct misunderstandings

Allows service delivery to be planned effectively

Occurs before pressing need to start enteral feeding

Mis-timed conversations

Too soon

- plwMND may not be ready to hear information
- Threat to ‘here and now’ coping strategy
- Loss of hope
- Damage the caring relationship

Too late

- May not be possible to care for plwMND because wishes are unknown
- May be too late to arrange a gastrostomy
- May not gain significant benefit from feeding tube
- Missed opportunities to initiate advance care planning

Four summary points and a question

- The DiAMoND patient decision aid is freely available at gastrostomychoice.co.uk
- Gastrostomy decision making is a process, rather than an event
- Getting the timing right on when to start the conversation is difficult
- Having gastrostomy conversations may be difficult, but it is an essential component of shared decision making

Would more communication skills training be helpful?

References

1. Wheelwright S, et al., Development of ‘gastrostomy tube – is it for me?’, a web-based patient decision aid for people living with motor neurone disease considering having a gastrostomy tube placed. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2023. 24(7-8): p. 605-613.

2. Astrow AB, et al., Decision-making in patients with advanced cancer compared with amyotrophic lateral sclerosis. Journal of Medical Ethics: Journal of the Institute of Medical Ethics. 2008;34(9):664-8.

3. Labra J, et al., Gastrostomy uptake in motor neurone disease: a mixed-methods study of patients' decision making. BMJ Open. 2020;10(2):e034751.

4. Van Eenennaam RM, et al., Current practices and barriers in gastrostomy indication in amyotrophic lateral sclerosis: a survey of ALS care teams in The Netherlands. Amyotrophic Lateral sclerosis & Frontotemporal Degeneration. 2022;23(3):242-51.

5. Seeber A et al., Advance care planning in progressive neurological diseases: Lessons from ALS. BMC Palliative Care. 2019;18.

6. Paynter C, et al., How people living with motor neurone disease and their carers experience healthcare decision making: a qualitative exploration. Disability & Rehabilitation. 2022;44(13):3095-103.

7. Ruffell TO, et al., Healthcare professionals’ views on the provision of gastrostomy and noninvasive ventilation to Amyotrophic Lateral Sclerosis patients in England, Wales, and Northern Ireland. Journal of palliative care. 2013;29(4):225-31.

8. Martin NH, et al., Decision Making About Gastrostomy and Noninvasive Ventilation in Amyotrophic Lateral Sclerosis. Qualitative Health Research. 2016;26(10):1366-81.

Student project survey

Please consider completing this anonymous survey which asks for your view on whether a gastrostomy patient decision aid for people with other neurodegenerative conditions would be useful.

https://forms.office.com/e/Z29u2cME33

It takes less than 5 minutes.

Please share with colleagues.