British Association of Clinicians in ME/CFS

ME/CFS Tube Feeding Survey Report

Survey Conducted August-October 2025

Report published September 2026

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Introduction

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is a complex multisystem illness. The hallmark feature of ME/CFS is Post-Exertional Malaise (PEM). This is the worsening of symptoms following even minor physical, cognitive, sensory or emotional exertion. The symptom exacerbation is disproportionate to the energy expended. It can happen immediately or have a delayed onset and it can take days, weeks or even months for someone to return to their baseline (1,2).

Anyone with ME/CFS can develop nutrition related problems and people with severe and very severe ME/CFS are at high risk of malnutrition due to eating and drinking difficulties, severe fatigue and high symptom burden which can lead to significant unintended weight loss.

If oral nutrition support strategies are not effective, consideration may be given to delivering a liquid formula through a tube directly into the gut (enteral feeding) or delivering feed directly into the blood stream (parenteral feeding). Different types of tube may be considered depending on the clinical issues present and include nasogastric (NG), nasojejunal (NJ), percutaneous endoscopic gastrostomy (PEG) and percutaneous endoscopic jejunostomy (PEJ).

There are many complex and inter-related problems that can lead to someone living with ME/CFS not being able to maintain adequate oral nutrition and hydration therefore necessitating tube feeding. ME/CFS is a multisystem condition which can mean adaptions may be required to standard procedures and decision-making tools to accommodate the physiological problems that occur in ME/CFS.

BACME is aware this aspect of ME/CFS treatment and care is not well resourced within the NHS. This means there are very few ME/CFS specialist dietitians and insufficient medical staff with a good understanding of ME/CFS, leading to people with ME/CFS struggling to access good quality, safe and timely care (3).

There is no ME/CFS specific nutrition guidance available for clinicians. This is an area of treatment and care that BACME is hoping to develop in collaboration with nutrition specialist organisations.

As we do not have robust evidence from research studies to base guidance on, the experiences of those who have lived experience of needing tube feeding will be invaluable to help inform the development of a clinical guideline. This was the motivation to conduct a survey looking at the current and past provision of tube feeding for people with ME/CFS.

To understand the difficulties and achievements from all perspectives we have also explored the experiences of carers (paid and unpaid) and clinical staff from a wide spectrum of backgrounds.

People with ME/CFS (pwME/CFS) have been involved through all stages of the project and we are very grateful for their time, energy and expertise. Their contributions to this report can be used to improve care for others.

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Methods

Survey Design

An initial set of questions was drafted with 3 sections:

- Questions for pwME/CFS
- Questions for carers
- Questions for clinicians

The initial draft was shared with a small group which included people with ME/CFS with experience of tube feeding, BACME Patient and Carer representative and a few clinicians with specialist dietetic and ME/CFS experience.

Revisions were made in response to the feedback, and the second draft was then circulated to a wider group which included additional people with severe ME/CFS, advocates of people with severe ME/CFS and several ME/CFS charity representatives.

We received a lot of valuable feedback and suggestions, and further revisions were made before finalising the survey design.

It was recognised that tube feeding is only one aspect of nutrition support but for the purposes of keeping the survey as manageable as possible and to focus on the highest priority issues for guideline development, questions were restricted to exploring experiences of tube feeding. There are some questions that capture information about people who have required parenteral feeding, but it was beyond the scope of this survey to fully explore the issues related to it.

We also allowed lots of opportunities on the survey for free-text narrative responses which provide additional valuable insights.

Survey Distribution

We asked several organisations to support with raising awareness of the survey:

- Information about the survey was posted on the BACME website
- BACME members were informed and encouraged to complete the survey and share with any patients or colleagues whom it would be relevant for
- Advocates of people with severe ME/CFS shared it amongst their support networks
- ME/CFS Charities informed their members and encouraged participation

It was recognised that for pwME/CFS the cognitive and emotional demand of completing the survey would be significant, so we aimed to acknowledge this in the survey messages and provided support with completion where possible.

The Survey was open to complete for 8 weeks between August and October 2025

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Survey Report development

The numerical data from the survey responses were entered into the report. Due to the small number of respondents, percentages have not been used for most questions in order to avoid giving a misleading impression of precision or generalisability.

A large volume of free-text comments was received. Key themes have been identified and summarised within the report. In addition, a selection of anonymised direct quotes have been included to illustrate the experiences of different respondent groups. These quotes have been colour coded as follows:

- quotes from pwME/CFS in blue
- quotes from carers in amber
- quotes from clinicians in green

The survey comments were reviewed by multiple members of the report team, allowing for a range of perspectives when selecting content for inclusion. Some quotes were chosen to reflect commonly reported themes, while others highlight individual experiences. Given the complexity of the issues and the relatively small number of people with direct experience, these individual accounts are included as they may provide valuable insights for others encountering similar situations.

Once the survey data and comments had been compiled a BACME subgroup met including clinicians from medical, dietetic, nursing and therapy backgrounds and patient and carer representatives. They provided reflections on the data collected for each section of the report along with conclusions and key recommendations for future guideline development.

The whole survey team were able to provide feedback on the report prior to publication.

Survey Participants

105 survey responses were started by

- 41 pwME/CFS
- 29 carers
- 35 clinicians

Some people started the survey but did not complete or save any responses

The maximum number of responses to questions in each section was:

- **28** pwME/CFS responses
- **21** carer responses
- **26** clinician responses

Maximum **75** responses overall had completed questions.

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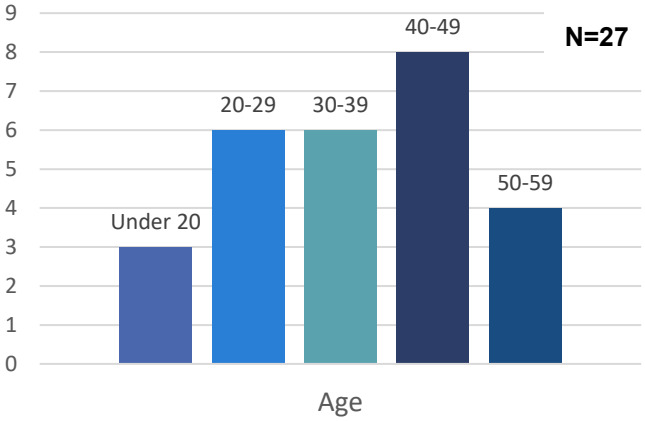
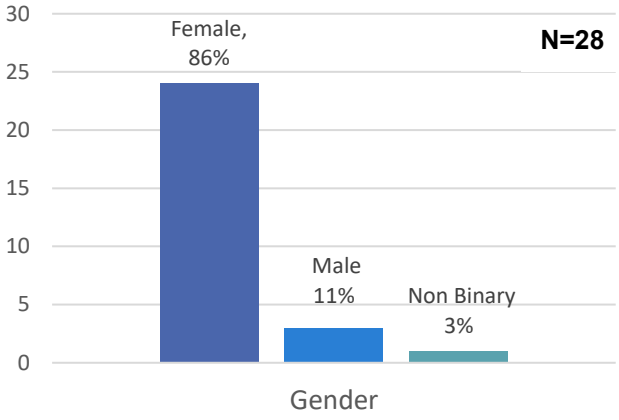
Demographics

People with ME/CFS

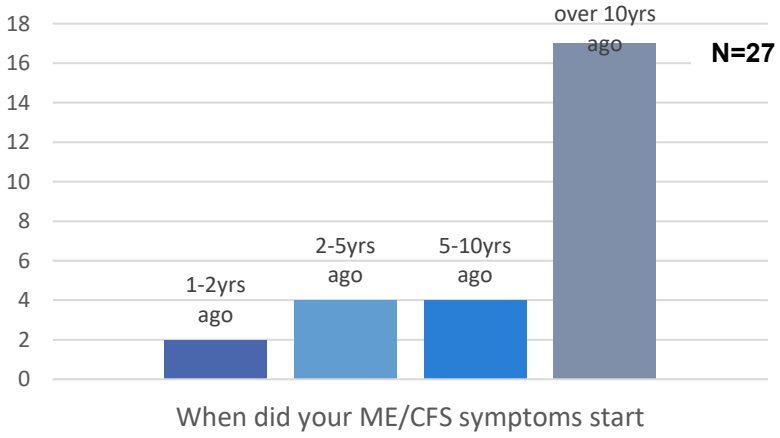
Age range of 27 pwME/CFS completing the survey was **17** to **56** with 86% female

(One response was age 3 which we presumed was an error so discounted it)

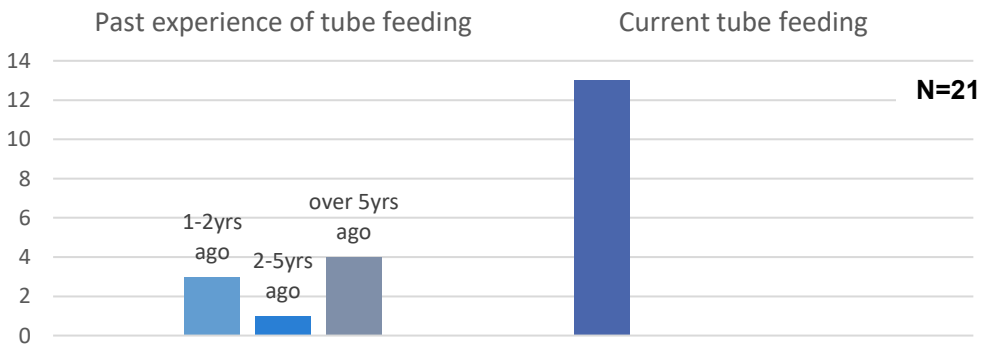




63% of respondents have had ME/CFS symptoms for over 10 years



62% of pwME/CFS completing the survey are currently receiving tube feeding



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Associated Health problems

16 pwME/CFS indicated they had additional medical problems impacting their ability to maintain adequate nutrition at the time they received tube feeding (some respondents indicated more than 1 additional problem).

These included:

- **5** with food allergies/intolerance
- **1** abdominal surgery
- **2** with an eating disorder (including anorexia nervosa, bulimia and avoidant restrictive food intake disorder (ARFID))
- **12** with other conditions

Other conditions reported included:

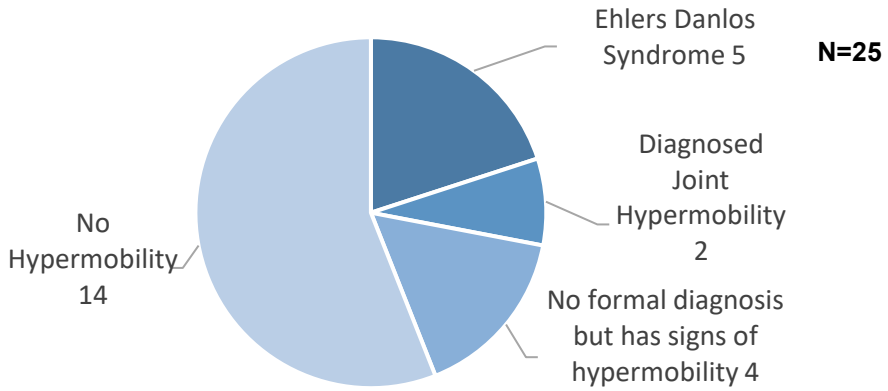
- Lactose and fructose intolerance
- Coeliac Disease
- Gut motility problems
- Irritable Bowel Syndrome
- Gastroparesis
- Small Intestinal Bacterial Overgrowth (SIBO)
- Pancreatitis/Pancreatic Insufficiency
- Gallbladder and appendix surgery
- Covid infection
- Dysautonomia/POTS
- Mast Cell Activation Syndrome (MCAS)/Histamine intolerance
- Ehlers-Danlos Syndrome

8 pwME/CFS indicated they had experienced nutrition related problems prior to developing ME/CFS. These included:

- Food Intolerances including lactose and fructose intolerance
- Irritable Bowel Syndrome
- Binge eating
- Weight loss due to overwork
- Tube feeding in infancy

Joint Hypermobility

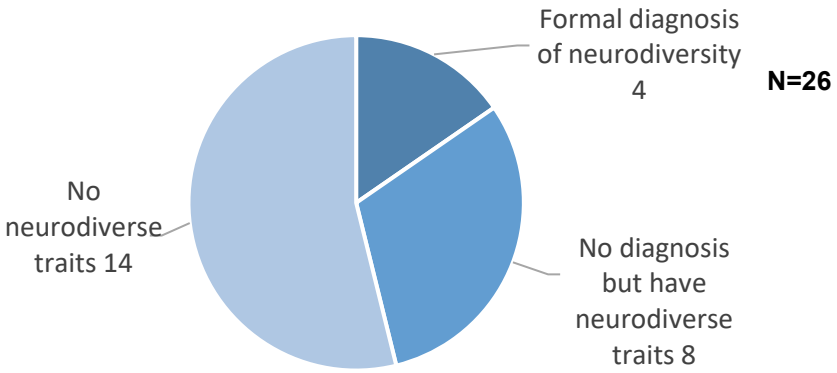
11 out of 25 (44%) pwME/CFS indicated they have some form of Joint Hypermobility



Comments included diagnosis being given by various practitioners including a genetics service and a chiropractor and several people awaiting assessment.

Neurodiversity

12 out of 26 (46%) pwME/CFS indicated they have been diagnosed as Neurodiverse or have Neurodiverse traits



Comments included self-diagnosed autism, dyslexia and dyspraxia and comments regarding developing sensory sensitivity as part of the ME/CFS illness.

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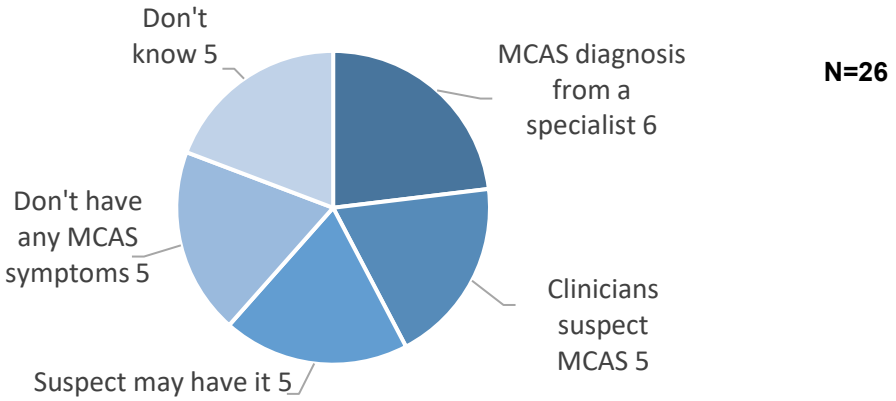
Mast Cell Activation Syndrome

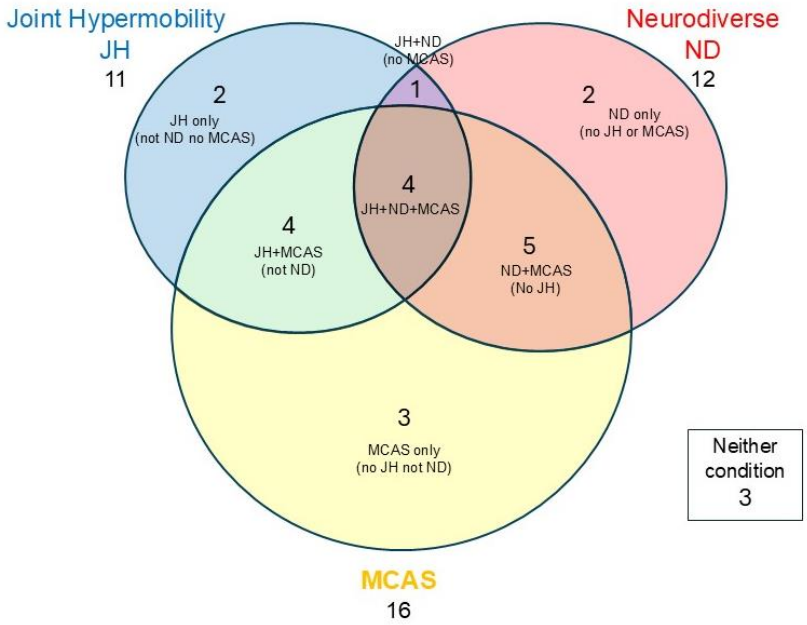
16 out of 26 (62%) pwME/CFS have a diagnosis of MCAS or suspect they have it



Comments referenced MCAS diagnosis being made by an ME doctor, cardiologist with dysautonomia interest and private dietitian.

Some comments reflected on the MCAS diagnosis being taken seriously by their GP and gastroenterologist but there are also comments reporting other doctors and specialists in the NHS not taking it seriously and symptoms being psychologised or believed to be psychosomatic.

Overlaps between Joint Hypermobility, Neurodiversity and MCAS:



Carers

20 out of 21 carers are a family member of the pwME/CFS

1 carer is a paid carer not related to the pwME/CFS

Comments indicated 6 are parents, 1 is a spouse

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Clinicians

Job Roles

Job roles of survey participants:

6 Acute hospital dietitians

5 ME/CFS specialist therapists

3 Home Enteral Nutrition Service dietitian

2 ME/CFS specialist doctors

2 Gastroenterologists

2 Community dietitians

1 Dietitian within an ME/CFS service

1 GP

1 Consultant nurse

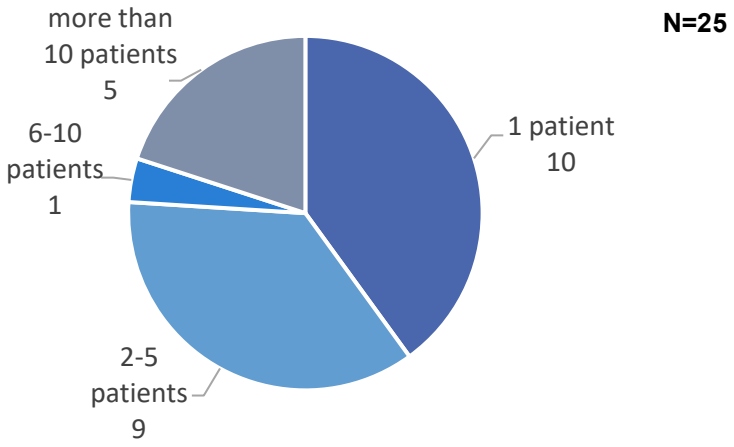
1 Long Covid specialist doctor

1 Nutrition specialist nurse for enteral feeding

1 General medicine outpatient dietitian

Clinical experience of tube feeding

Number of patients requiring tube feeding that you had direct involvement with



Comments reported that ME/CFS was not always the primary diagnosis leading to requiring tube feeding with Ehlers Danlos Syndrome, gastroparesis and IBS being common primary factors.

One respondent shared their extensive experience in secondary and tertiary care and private practice spanning many years.

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Reflections on demographic data

The age and gender distribution of respondents was broadly consistent with that reported in UK ME/CFS populations (4) and the data collected in this survey does not indicate any specific age group being at higher risk of nutritional issues. Gastrointestinal symptoms are common in ME/CFS, making it difficult to distinguish between pre-existing medical co-morbidities, ME/CFS related symptoms, and unrelated health issues. This highlights the complexity and heterogeneity of nutritional challenges and underscores the importance of individualised care.

Clinicians in NHS specialist ME/CFS services report an over-representation of people with joint hypermobility and neurodiversity compared to background incidences, suggesting these may be risk factors for ME/CFS (5,6). Limited access to diagnostic specialists often leads to self-diagnosis or underdiagnosis. These conditions can co-occur and both are associated with gastrointestinal issues (7,8,9,10), which may contribute to nutritional difficulties and implementing targeted treatment may improve nutritional intake (11).

Mast Cell Activation Syndrome (MCAS) is an emerging focus in ME/CFS clinical care (12), though there are significant knowledge gaps and diagnostic criteria remain unclear (13) leading to conflicting opinions and inconsistent approaches. It is possible that MCAS may represent more than one disease entity with symptoms that overlap with the immune dysregulation that occurs in ME/CFS. Over half of respondents reported MCAS diagnoses or suggestive symptoms, which may indicate immune mediated problems are a risk factor for more significant nutritional problems. This is important to recognise as targeted treatments may be identified if mast cell dysfunction is contributing to gastrointestinal symptoms (14,15). It is also important that pwME/CFS have access to specialist professional support with diagnosing and managing MCAS-type problems as prolonged and unnecessarily strict exclusion diets can be counterproductive and aggravate nutritional compromise.

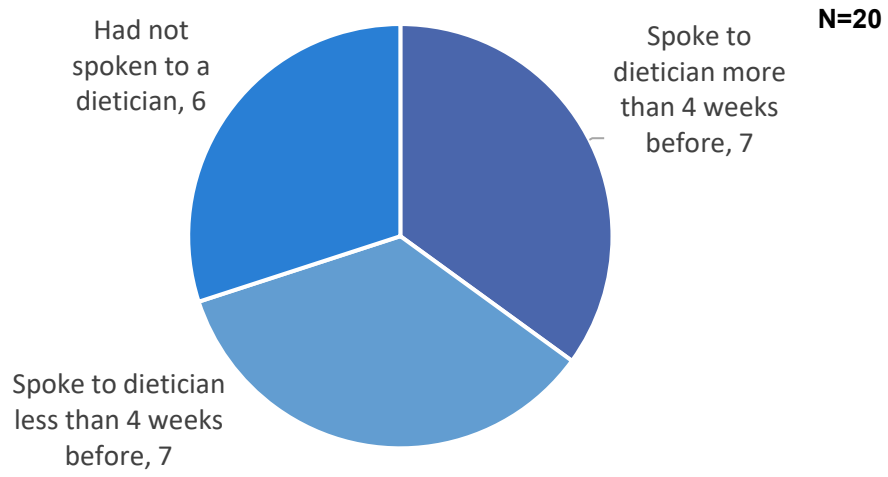
The survey did not explore incidence of Dysautonomia, such as Postural Tachycardia Syndrome (POTS), as it is already recognised to have a high prevalence in ME/CFS, particularly in severely affected individuals (16). Autonomic dysfunction commonly results in gastrointestinal problems and therefore will likely contribute to nutritional issues (17,18,19,20) and malnutrition can cause and aggravate autonomic dysfunction.

The carers demographic data demonstrates that nearly all carers completing the survey were unpaid, highlighting the substantial family caregiving burden (21).

Participating clinicians were from a range of backgrounds but predominantly dietetic staff from different clinical settings. Most clinicians have limited experience of tube-feeding for people with ME/CFS; only six clinicians had experience with more than five patients. Gastroenterologists, who play a key role in tube-feeding decisions, were underrepresented (n=2) which may be reflective of the fragmented multidisciplinary care for people with ME/CFS.

Nutrition Support prior to commencing Tube Feeding

14 out of 20 pwME/CFS had spoken to an NHS dietitian prior to commencing tube-feeding. Only half of them had been under the care of a dietitian more than 4 weeks before tube feeding was started.



Comments described variable experiences with dietetic input prior to tube feeding ranging from long term support to sporadic involvement. In one case, referral to a dietitian only came after the NG tube was inserted. Some common themes were long waiting time after referral and their health deteriorating whilst waiting for dietetic review.

> Yes, I was receiving support via Ensure drinks. However it got to a point were I was unable to swallow the ensure drinks, this is were i was hospitalised and a feeding tube was put in place

> I had spoken with a dietitian to try and find a way forwards to supply me with nutrition that didn't flare up symptoms earlier in 2023. It had taken a considerable period from when this was first requested by my physio/OT/paediatric consultant, however, for an appointment to be available, and during that time, my condition had deteriorated.

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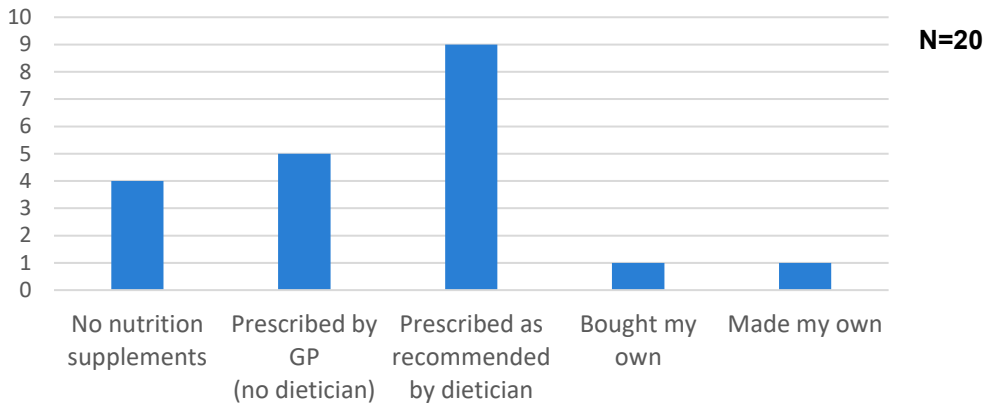
16 out of 20 pwME/CFS had trialled oral supplements prior to starting tube feeding

Almost half of them had accessed them without dietitian recommendation



Comments suggest that most individuals did try oral nutrition supplements prior to tube feeding, however these were often not well tolerated. Issues reported were dislike of taste and/or texture, food intolerances, post-prandial symptom exacerbation, and fatigue.

> We were trying to supplement my diet with drinks but it was unsustainable and straining to do so for too long as well as take In fluid led to eating ability collapsing entirely

> As I had struggled with eating for a few months before I got a tube, my parents had bought smoothies, milkshakes which met the nutritional needs for a meal … and made me soups. We also focused on healthy high quality foods with high calories such as chia pudding or olive oil. This was all found out through our own research.

> I had tried many supplements before I had ME and could only tolerate one but could not manage this once I had ME because of sugar sensitivity

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Reflections on nutrition support prior to commencing tube feeding

There is a significant and concerning lack of dietetic input and nutritional support prior to starting tube feeding. Nutritional assessment by a dietitian and establishing a treatment plan to optimise oral intake needs to start months before the need for tube feeding is reached in line with the malnutrition pathway. Only 7 of 20 pwME/CFS spoke with a dietitian more than 4 weeks prior to starting tube feeding. This means more than half of pwME/CFS completing this survey only had access to a dietitian at the point that their nutritional compromise had got to a critical stage. This indicates that nutritional issues are not being identified early and referrals to dietitians are delayed. It is also possible that referrals are rejected if the standard criteria are not met e.g. evidence of weight loss or malnutrition risk score. Comments reflect that long waiting times and lack of access to specialist dietitians also contributes to the deficiencies in this aspect of ME/CFS care.

Oral nutritional supplement (ONS) drinks are reported to be poorly tolerated for a variety of reasons including factors related to ME/CFS such as food intolerances, post-prandial symptom exacerbation and fatigue. There are many different ONS products available and it may take some time to work through different products to find which suits that individual person and also for the pwME/CFS to build trust in the dietitian advising them. This needs to be done early as the physiological and emotional stress related to deteriorating nutritional intake will also exacerbate ME/CFS symptoms resulting in a downward spiral which could include escalating difficulties with tolerance and reduced capacity to engage in appointments to discuss trialling other products. It also requires dietitians to have an awareness of the complexity and heterogenicity of ME/CFS and a willingness and adequate resources to provide this level of clinical care. Delayed access to dietitian support may lead people with ME/CFS to seek information online or through discussion forums, where they may encounter unhelpful or harmful advice, or information that is not relevant to their individual circumstances, increasing anxiety about specific foods or ingredients.

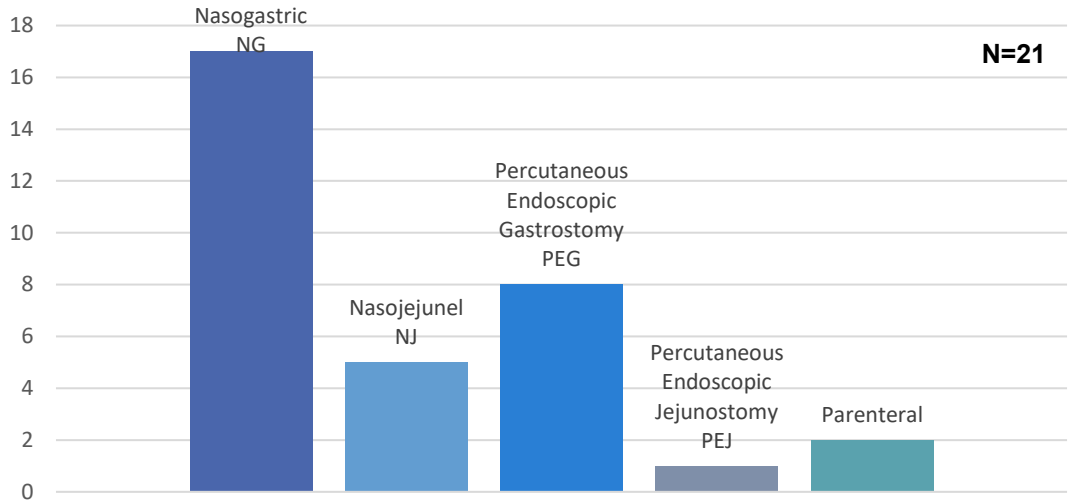
It is essential that when an oral supplement is not tolerated that the reasons for this are fully explored as there are a wide range of options which can be tried. The feeds that are used for tube feeding commonly contain the same ingredients used in oral nutritional supplements so if they are not tolerated when taken orally, then using the same product via a tube may still not be of any benefit depending on the reason for the poor tolerance.

Another aspect of early intervention that could be overlooked is care provision. Many pwME/CFS develop nutritional compromise due to the severity of their fatigue as they are too fatigued to prepare meals and can become too fatigued to chew and swallow food. Providing adequate care support and occupational therapy assessment early could support someone with severe ME/CFS by minimising their energy demands across all domains and that could protect against escalating fatigue that can be a key contributor to nutritional issues.

Provision of Tube Feeding

pwME/CFS Data

Types of feeding used



Comments included explanation of move from PEJ to parenteral feeding due to being unable to tolerate the feed and was a joint decision made by the pwME/CFS and their gastro team and felt to be the right decision.

Number of feeding support episodes

17 out of 20 pwME/CFS have had one episode of tube feeding with **3** people having experience of 3 or more episodes of feeding support.

Length of feeding episodes

13 pwME/CFS indicated they are currently receiving tube feeding with the time ranges given:

- 8 weeks
- 6 months
- 1 year (2)
- 2 years (3)
- 3.5 years- expected to be long term
- 5 years NG then PEG-J, 2 years parenteral
- 7 years
- 8 years
- 20-25 years

For those who had tube feeding in the past

- 1 pwME/CFS had it less than a month
- 1 pwME/CFS had it 1-3 months
- 2 pwME/CFS had it 3-6 months
- 2 pwME/CFS had it 1-2 years

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Where feeding is delivered

- **4** out of 21 pwME/CFS received all of their tube feeding in hospital
- **15** out of 21 pwME/CFS started the tube feeding in hospital and then continued at home
- **1** out of 21 pwME/CFS started in hospital then transferred to another care setting
- **1** out of 21 pwME/CFS had the feed all delivered at home

Comments described starting tube feeding in hospital but encountering significant barriers when trying to continue feeds at home. Some pwME/CFS were eventually allowed home feeding, usually only after external specialist input or the support of an individuals' GP, while others were refused or faced restrictive conditions such as signing liability waivers or threats of tube removal if they self-discharged. Comments reflected that decisions appeared inconsistent and influenced by clinician attitudes rather than clinical need, with some respondents describing coercive dynamics, lack of understanding of ME/CFS, and a reluctance from hospital teams to support home feeding.

I didn't have one time that tube feeding was considered to be continued at home. However, I wasn't allowed to leave hospital WITH the NG tube unless it was for a specific time frame that it would then be stopped. My dad had to sign a slip to say if anything were to happen to me With the tube (as in aspiration or tube moving) if my health were to decline or I died from it then it would be our fault rather than the hospital.

My feed was continued at home but only because my GP at the time agreed to it…I self discharged when I turned 16 my parents had been threatened that if I left they would remove my NG tube (I was being subjective to graded exercise and bullied by staff, when I was bedbound with my ME). Thankfully my GP agreed to support me having my tube at home and it was him who continued to prescribe the feeds.

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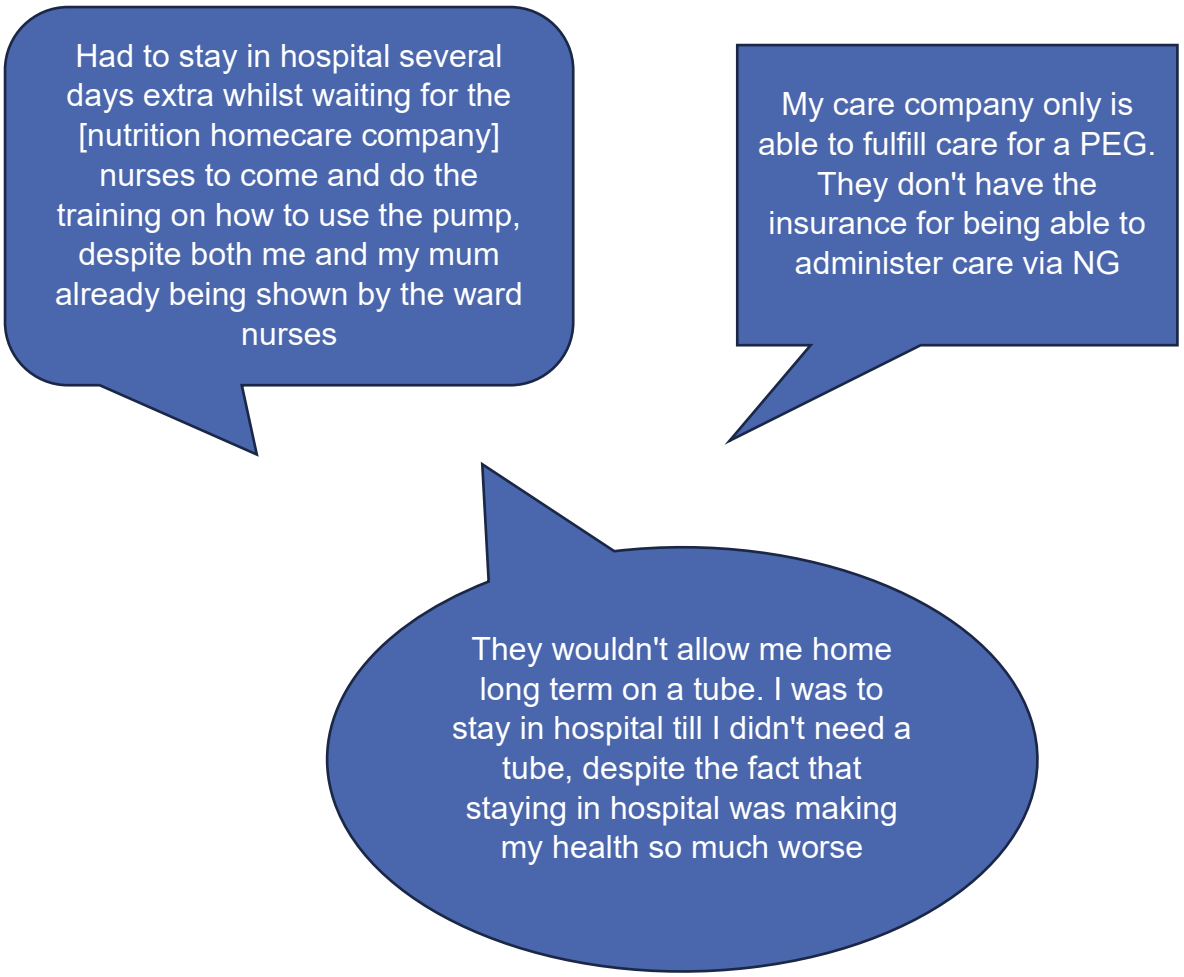
9 out of 20 pwME/CFS reported challenges related to arranging their feeds to be delivered at home which delayed their discharge from hospital.

Difficulties included:

- Hospital staff refusing discharge to have feeding delivered at home
- Hospital dietitians opposing tube feeding
- Waiting for nutrition homecare company nurses to provide training to family members
- Family having to buy an appropriate bed/equipment
- Delays waiting for specialist feed to be delivered
- Care companies not having enough adequately trained staff or relevant insurance to deliver the feed (these difficulties were encountered with NG and parenteral feeding)
- Withdrawal/lack of care home places



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Continuing Health Care Funding

- **2** out of 18 pwME/CFS had Continuing Health Care (CHC) funding already in place at the time of commencing tube feeding
- **10** out of 18 pwME/CFS did not have CHC funding
- **6** out of 18 pwME/CFS were either not eligible due to being under 18 or weren't sure (Children and Young People's Continuing Care (CYPCC) is available for those under 18)

3 pwME/CFS commented that their application was refused or they were not felt to meet the threshold for CHC funding.

Specialist feeds

9 out of 19 pwME/CFS needed a specialist feed

Specialist feeds listed by pwME/CFS included:

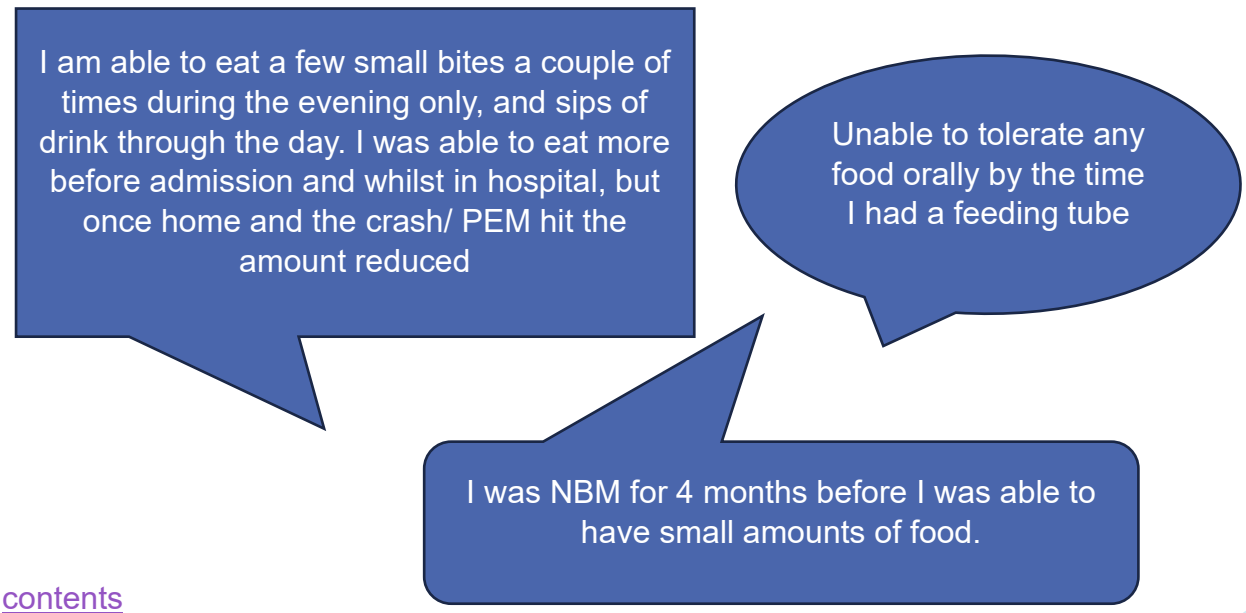
- Gluten Free (3)
- Other exclusions including soya, lactose, eggs, casein, dairy (2), vegan
- Low Enzyme feed
- Pre-digested/elemental formula (3)
- High protein or fibre
- Ketogenic feed

(We did not specify the definition of specialist feed and dietitians may not class some of these as specialist feeds)

Oral intake while receiving tube feeding

14 out of 20 pwME/CFS had some oral intake (food or supplements) while receiving tube feeding

Comments reported that except for one individual who was able to consume an 'almost normal amount of food' alongside their tube feed, most pwME/CFS report being unable to tolerate any oral nutrition, or very minimal. Several pwME/CFS reported being unable to swallow, and others described not being able to tolerate the food or nutrition supplements.



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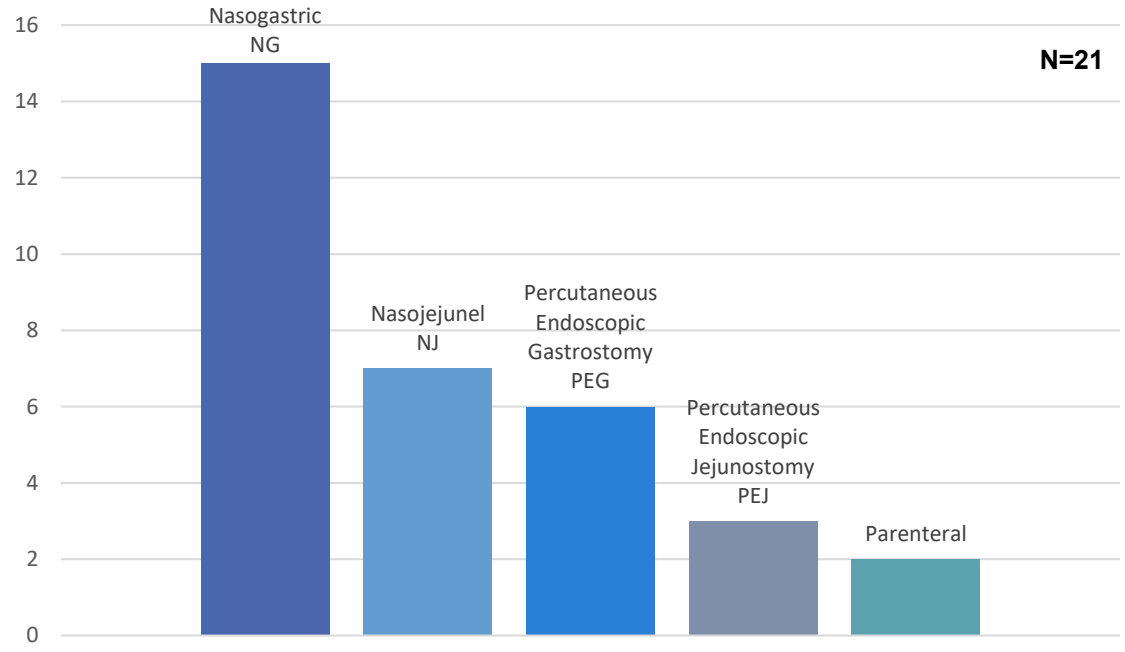
Carers data

Types of feeding used



17 out of 21 carers are supporting someone with current ongoing tube feeding

Length of feeding episodes:

4 carers reported Up to 1 year

10 carers reported 1-3 years

3 carers reported 4-10years

1 carer reported over 20years

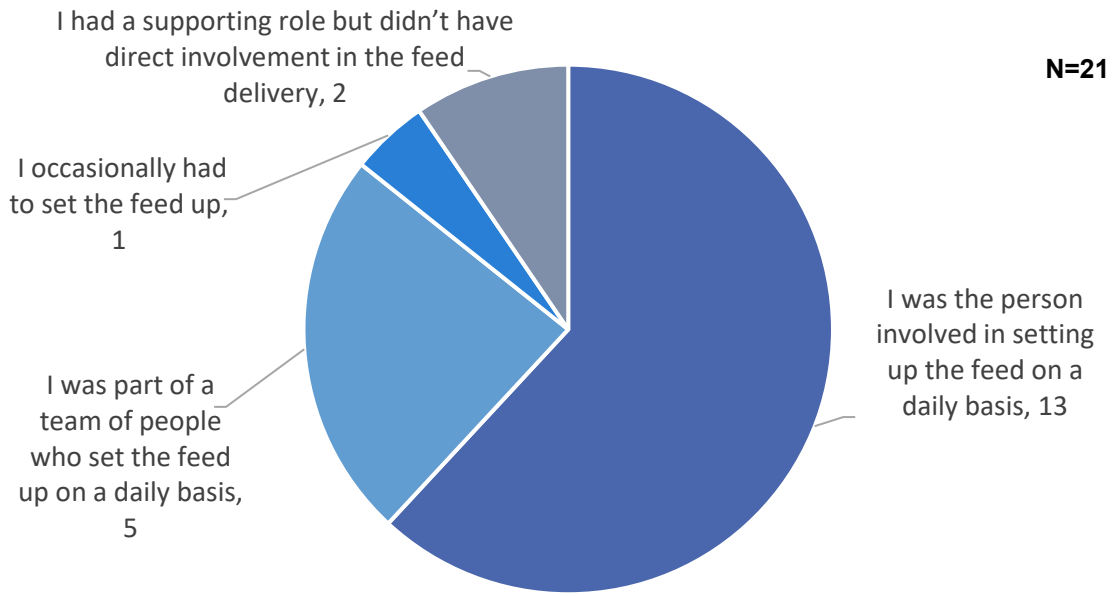
Past experience of tube feeding:

2 carers reported the pwME/CFS needing the tube feed for 1-2years,

1 carer reported the pwME/CFS needing the tube feed for 3-6months

1 carer reported the pwME/CFS needing the tube feed for less than 1 month

Carer's role in administering the feed



There is no provider in our area for the change of NG tubes in the community, or any training provided for the placing of the tube even for the very severe patients that are completely bedridden and unable to attend hospital. Hence I have had to do this without any training.

This is ongoing. I set up the feed and connect the pumps daily and administer regular water flushes throughout the day. She has 2 pumps. One administers the feed and the other administers water. These are connected together and feed slowly 24 hours a day.

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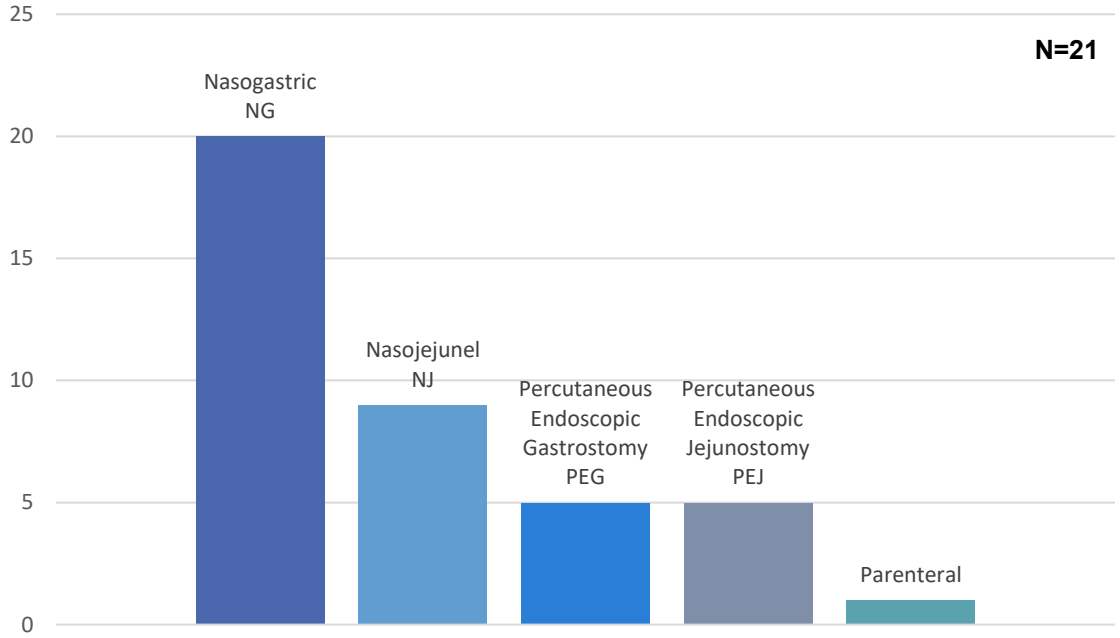
Clinician data

Types of feeding used



Comments referenced using a RIG-J tube (Radiologically Inserted Gastrostomy) and a PEG-J (with jejunal extension).

Length of feeding episodes:

2 clinicians reported less than 1 month

4 clinicians reported 3-6 months

4 clinicians reported 6-12 months

2 clinicians reported 1-2 years

7 clinicians reported over 2 years

Clinicians with experience of more than one pwME/CFS requiring tube feeding commented on a wide time range from days to months to years with the longest reported as 7 years.

I have had partial success with all the above. PEJ feeding offers least hope of success and should in my view be avoided. Peg-J always falls back into the stomach…I have never seen it lead to meaningful improvement in patient outcome, contrary to other modalities.

The services available to address these are in my view wholly inadequate.

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Where feeding is delivered

- **2** out of 23 clinicians reported feeding being delivered in hospital
- **20** out of 23 clinicians reported starting the tube feeding in hospital and then continued at home
- **1** out of 23 clinicians reported starting in hospital then transferred to another care setting

Reflections on the provision of tube feeding

The majority of pwME/CFS completing the survey have had tube feeding for at least 1 year or more, with some receiving it for over 5 years. It is possible that the methods for advertising the survey will not have captured those who received tube feeding for shorter periods of time so they may be under-represented in this data.

There is experience of several different types of feeding tube with nasogastric feeding being the most common in all 3 groups completing the survey. Comments indicate the type of feeding tube was sometimes changed due to tolerance issues and one clinician reported in their experience PEG-J tube was the least likely to be beneficial, but this contrasts with a pwME/CFS reporting switching to PEG-J led to better stability and tolerability. It is beyond the scope of this survey to determine if any particular type of feeding tube is preferable over another. There may be some factors specific to ME/CFS that need to be incorporated into this decision. Nasogastric tubes require regular changing and the energy demands involved can hinder progress with regard to stabilising ME/CFS symptoms, in which case a longer-term tube that doesn't require regular changes such as a PEG may be a better choice for some people. Jejunal extension tubes have higher mechanical failure/displacement rates, which is often the reason for poor outcomes. There are also geographical variations regarding having access to staff with training to allow tube changes to be done at home or the distance to travel to the hospital where a tube can be changed. Tubes can sometimes become displaced or block and if this occurs 'out of hours' it may require a hospital assessment.

This survey did not explore parenteral feeding; however, 2 pwME/CFS and 1 clinician reported having experience with it. There are different risks involved in the delivery of parenteral feeding with infection risk, blood clots and liver damage being key concerns (22). It can be challenging to deliver parenteral feeding at home meaning this decision may come with the additional detriment of trying to manage ME/CFS in a hospital environment. In the UK parenteral feeding services are funded differently to tube feeding services (centrally vs primary care budgets) and there are very strict criteria that need to be met to consider this route of feeding.

Although the majority of pwME/CFS and clinicians report that feeding was eventually delivered at home, there were multiple significant barriers to this happening. Some of these challenges related to care provision and equipment and feed supplies. However it is concerning to read how many pwME/CFS experienced distressing situations related to conflicting opinions and attitudes and the burden of risk being

placed on pwME/CFS and their families rather than there being a shared decision process with equal parity given to all perspectives.

Continuing Health Care (CHC) funding means medical care needs are paid for through NHS healthcare funding (rather than social care funding). This is available for people who have a primary health need which is severe, complex and unpredictable. There are specific criteria that need to be met to be eligible for it and requiring tube feeding would not automatically mean a person meets the criteria. The majority of pwME/CFS completing the survey did not have CHC funding in place and a few had applied but been declined. This demonstrates that the provision of care for people with severe ME/CFS and those requiring tube feeding would need to come through social care and is very often being provided by unpaid family members.

Managing tube feeding at home places a significant burden on carers, and this should always be carefully considered when making decisions about initiating tube feeding. Carers require specialist training to safely manage feeding and associated care needs. It is also important to have contingency plans in place should the primary caregiver become unwell or otherwise be unable to provide care.

For those pwME/CFS who live alone discussions would need to take place with social care providers prior to the tube feeding being started. It can often be challenging to get adequate care in place in advance and many standard care packages may not be able to extend to managing tube feeding and their insurance may not cover for managing tube feeds. Intermittent care visits would not be suitable for someone receiving continuous feeding and using bolus feeds can often be more problematic regarding tolerance issues. If the care provision is not in place it could lead to the pwME/CFS remaining trapped in hospital, unable to be discharged due to this deficit in care provision. For family members providing care, they should be included in the decision-making process given the significant burden that will be placed on them to manage the feeds at home.

The survey data demonstrates pwME/CFS can require a range of feed types to meet their needs. A variety of polymeric feeds were used such as with or without fibre and high protein versions. These feeds are generally gluten and lactose free but depending on the need for other dietary exclusions such milk protein or soya other options needed consideration. The other types of specialist feeds reportedly used included pre-digested feeds (peptide/elemental) and disease specific such as keto feed. There is insufficient data gathered in this survey to provide any commentary on whether pwME/CFS may benefit from any specific type of feed but likely represents the need to have an individualised trial and error approach to find the most suitable product.

The survey showed that pwME/CFS were often unable to tolerate oral intake alongside the feed for a variety of reasons. The option to be supported with oral intake should form part of the care plan when commencing tube feeding but without the pwME/CFS feeling pressurised to do so. The tube feed should safely meet their nutritional needs until such time as oral nutrition can resume. Small amounts of oral intake can add quality of life for some but cause stresses for others and this should be assessed on an individual basis.

Factors contributing to decisions about Tube Feeding

pwME/CFS reported reasons for needing tube feeding

18 out of 19 pwME/CFS indicated they had a clear understanding of why they needed tube feeding.

Comments reported:

- Unable to tolerate sufficient food and fluid intake
- Malnourishment and dehydration
- Difficulty swallowing
- Nausea, fullness, pain and fatigue
- Energy demands of chewing, swallowing and digestion resulting in exhaustion
- “My life was at risk”

Carer perspectives on care planning

12 out of 18 carers felt their knowledge of the pwME/CFS was taken into consideration when planning their care

6 out of 18 carers did not feel their knowledge of the pwME/CFS was taken into consideration

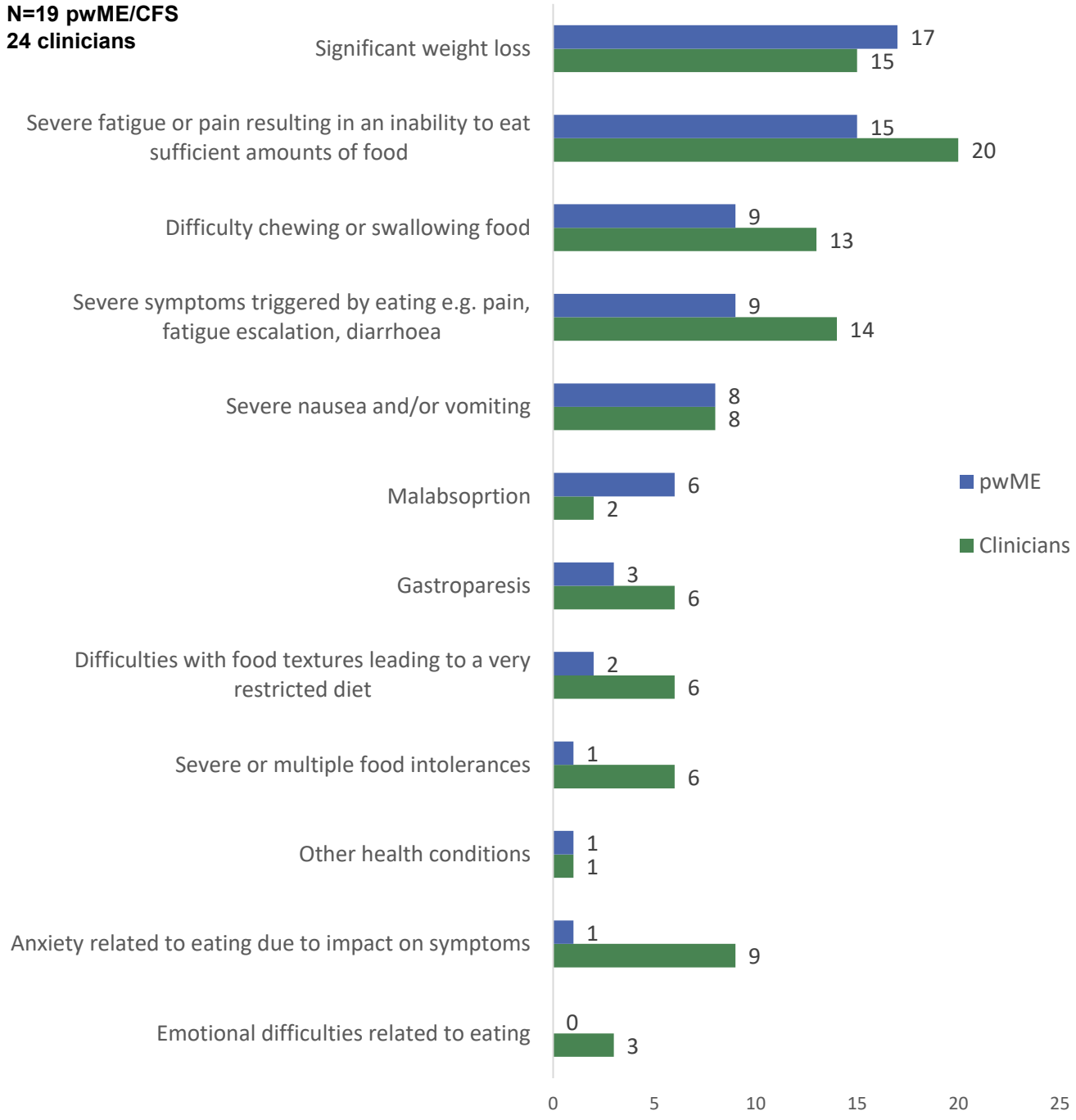
Comments reflected difficulties getting consistent approaches with conflicts between health professionals and hospital protocols and management obstructing access to care. 1 carer reported having to create a petition to facilitate appropriate care provision for their relative.

As her mother, I know all the problems and sensitivities she has, so we have planned all interaction to take these into account. Light and sound sensitivity mean working in subdued lighting and as quietly as possible. Her time in hospital last year was traumatic, as the nursing staff and doctors did not take these problems into account, causing her ME to worsen.

Planning around the timing of the feed, their difficulties with tolerating flushes and the noise produced by the pump

Symptoms contributing to the need for tube feeding

(pwME/CFS and Clinician responses are not necessarily about the same patients)



Additional comments from pwME/CFS included:

- Oesophageal and bowel dysmotility
- Severe constipation/ no motility
- Pancreas issues due to malnutrition and starvation

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Additional comments from clinicians included:

- Swallowing difficulties possibly related to a primary endocrine problem
- Multiple factors occurring at the same time
- Abdominal pain and nausea not being investigated

One comment highlighted the complexity of multiple inter-related factors that can impact on nutritional intake and how simplistic terms such as gastroparesis and intolerance can lead to a failure to explore some of the correctable factors driving symptoms.

> …we are at risk of doing a disservice to people if we do not explore the pathophysiology of their "intolerance"

Clinician reported problems related to initiating feeding

Clinicians' comments reported difficulties with feed tolerance, particularly discomfort and intolerance in young patients, sometimes leading to requests for alternative feeding methods without clear clinical indication. System-level challenges were also prominent, including delays due to investigations, differing opinions between teams, supply issues, and limited understanding of ME/CFS among non-specialist staff. Some comments indicated an eating disorder was considered when there was no evidence of it and another comment highlighted that there are often co-morbidities

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alongside the ME/CFS which can lead to disordered eating including neurodiversity, EDS and psychological issues. Other difficulties mentioned included communication and coordination issues across teams, access to suitable feeds and logistical challenges with ongoing care.

Patients wanting NJ tubes where as clinicians did not think this was appropriate. Community dietitians with potentially less experience in these conditions wanting to rely on feed more than acute clinicians/dietitians whos focus is on building oral intake.

Very difficult experience due to the lack of understanding (and preconceptions) of non-specialist ward staff and teams

Reported difficulties tolerating feed, and patient requesting switch to PN despite no clinical indication

We have been having feed supply issues. We have had some complaints from 1-2 patients who feel the consultants looking after them in gastro are not 'sympathetic'

…A liaison psychiatrist had been asked to review patient on the ward and there was an opportunity for some email dialogue between myself as an ME specialist, the gastroenterologist and the Liaison psychiatrist which was helpful to a degree. The liaison psychiatrist did not feel the patient had any significant mental health issues but some of the email dialogue hinted at the suspicion the patient had some form of eating disorder despite there being no evidence of this

…the community team and the consultant felt that NG feeding would improve patient's overall symptoms which were largely related to fatigue however the hospital team did have concerns about aspiration risk as she could not tolerate being upright for feeding for long periods of time. I do however feel there was very good communication between the patient, family, nutrition team, consultant and dietitians

…Despite the gastroenterologist agreeing to commence feeding the ward dietician refused to write up the prescription for the feed as there wasn't evidence of significant weight loss…

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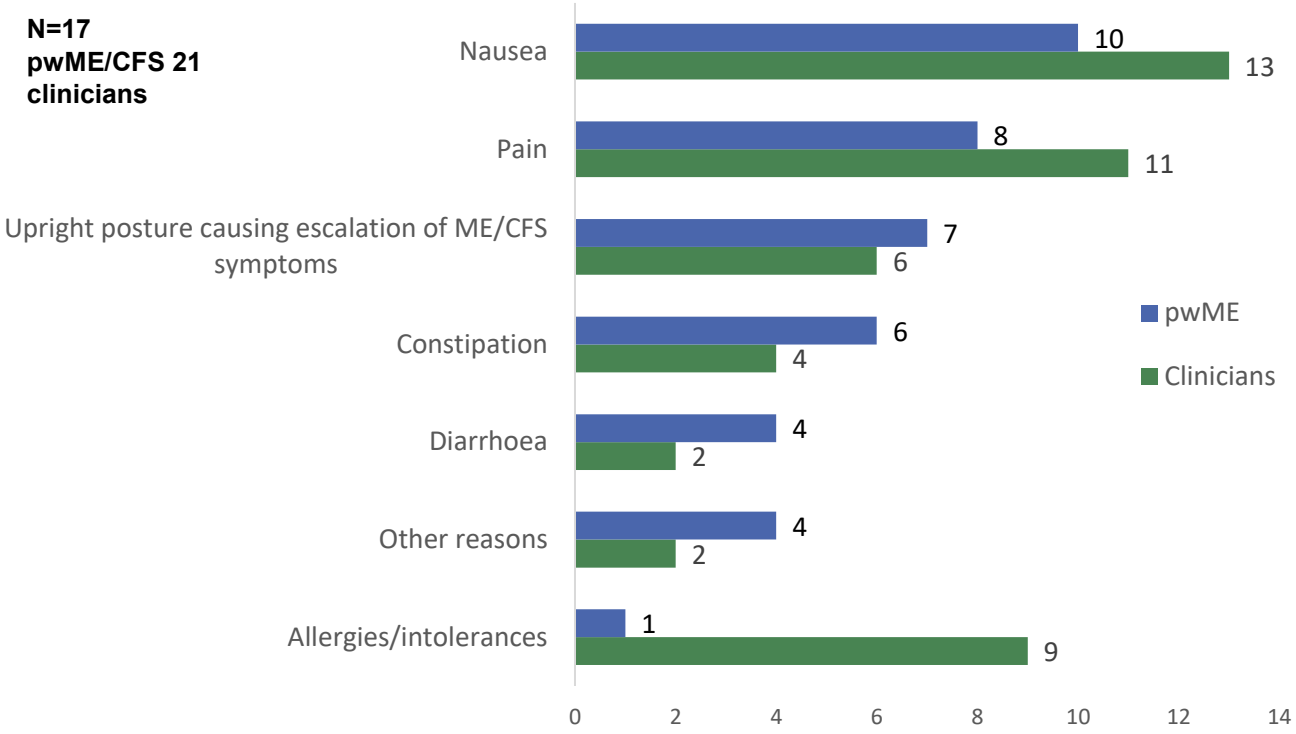
Tolerance of Tube Feeding

15 out of 17 pwME/CFS experienced difficulties tolerating the tube feeding

14 out of 21 clinicians had experience of patients not tolerating the tube feeding



pwME/CFS additional reasons given included:

- Difficulty tolerating the rate of feed advised by the dietitian
- Difficulty tolerating the interaction of the medics – energy draining
- Feed escalating fatigue/energy crashes
- Refeeding syndrome
- Concerns about the low fibre content not supporting a healthy gut microbiome

Only able to tolerate it in an upright/seated position

I've had no issues with choking or aspiration… decades of being fed semi flat

I had issues at the beginning due to re feeding syndrome due to being left for over a year with little support

Full body crashes after every feed increase too, very low BP (in 70's and 80's systolic) low body temperature, shaking, turning incredibly pale, feeling absolutely horrendous, unable to hold a conversation etc.

This was harder to explain to them than the nausea

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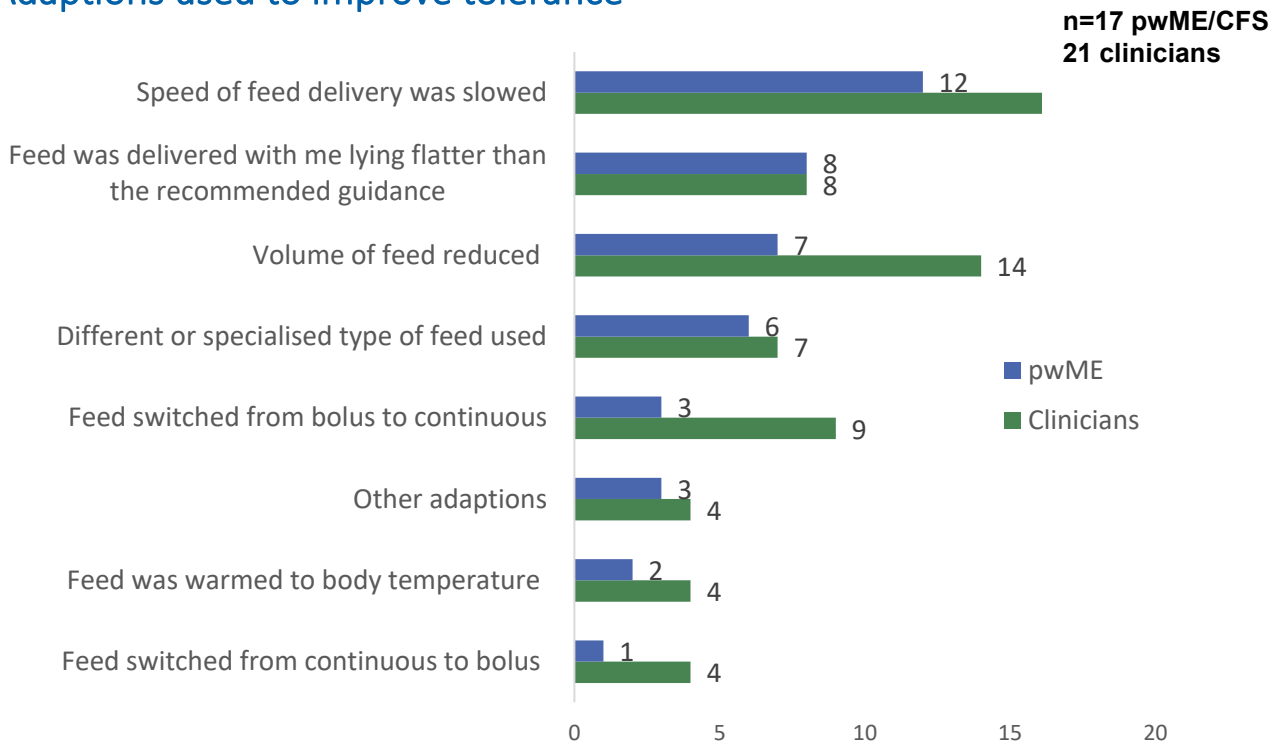
Clinician additional reasons given included:

- Difficulty tolerating flushes
- Non-specific symptoms that were difficult to pinpoint
- Bloating
- Headache
- Psychological difficulties with the tube
- Symptoms unrelated to feed including pain and nausea

Remains jejunely fed due to postural intolerance making gastro feeding harder

Adaptions used to improve tolerance



Alternative feeds included gluten free, keto feed and pre-digested formulas
pwME/CFS comments included:

- e.g. Peptamen,
- Calorific value increased to compensate for slow delivery
- Changing route of feeding (NG to NJ then some parenteral)

Clinician comments included:

- Alternative feed included elemental, partially hydrolysed, ketogenic, peptide, soya based,
- Bolus feeds being used due to difficulty tolerating the noise of the pump
- Time of feed amended to work with patient's awake period

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I realise that I am atypical in how relatively easily I can be tube fed

I wasn't laying completely flat but was lower than the recommended.

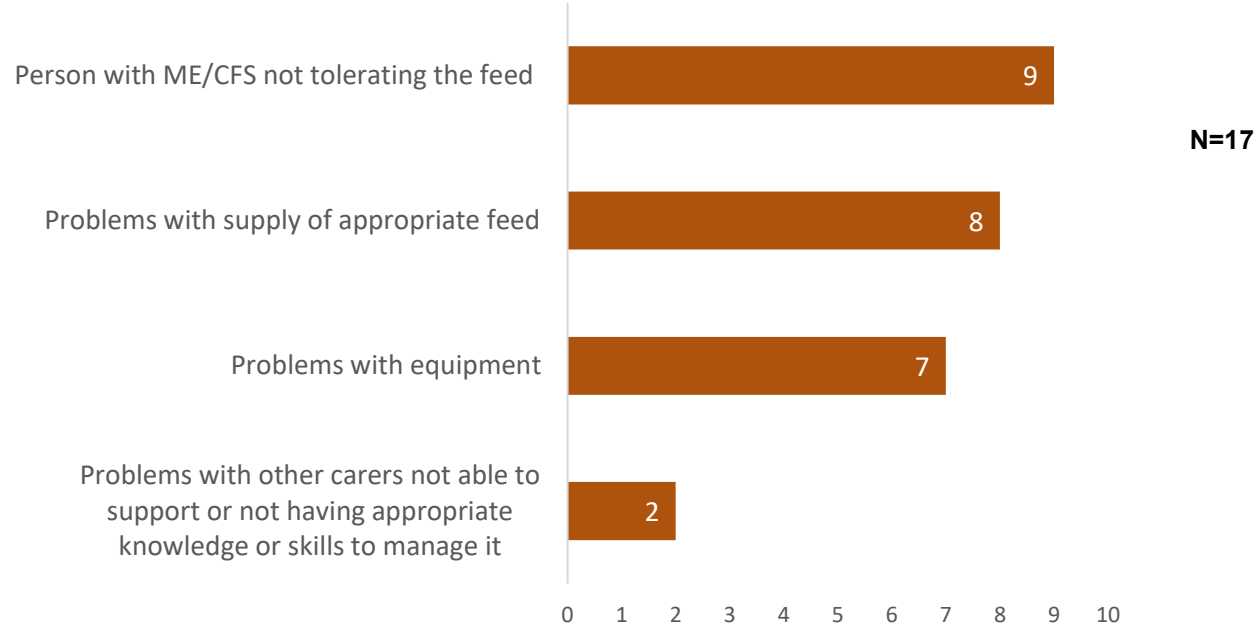
I had to be quite vocal and strong about needing to go at my pace instead of a pressured pace.

My patient adjusts the rate of her feed over a 24 hour period. It runs faster in the morning, slower in the afternoon and even slower overnight.

the psychological co-morbidities often contribute to the challenges of managing the nutrition - would be great to have psychology, dietetics and gastrointestinal all in one place...

Allowing ad hoc breaks in feeding to promote feelings of control and autonomy.

Carers experience of feeding related problems



Other problems reported included:

- Tube failures requiring re-admission
- Tube becoming embedded requiring surgery
- Tube blockage with medication
- Granuloma at PEG site
- School nurse refusing to be trained
- Tolerance issues related to MCAS, gastroparesis, POTS, severe orthostatic intolerance
- Noisy pumps, alarms and vibrations negatively impacting ME/CFS symptoms

Feeds not being started until hours after they should have due to staff being to busy. Which resulted in me being accused of turning off the pump as the amount of food had not been administered by the time expected. Patient requests to have a break being ignored resulting in vomiting and further distress/relapse. No understanding that PEM can be triggered in severe patients by simply feeding. …No understanding that the patient couldn't feed at a 30' angle, due to autonomic disfunction(POTS). Resulting in further relapse as patient was unable to sleep at all for 5 nights due to distress/discomfort. Who by this point could not vocalise her distress as PEM resulted in the loss of speech.

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20 out of 21 carers were given training on how to administer feeds

1 carer did not receive any training as it wasn't applicable

Comments reported training being delivered by hospital staff or by nutrition homecare company nurses, often prior to discharge. Some report receiving good support from supply companies, others report very minimal levels of training and inconsistencies in knowledge of hospital staff.

Reflections on factors contributing to decisions about Tube Feeding

ME/CFS is a complex multisystem condition, and many people with severe or very severe disease have comorbidities (23) that contribute to nutritional difficulties. Despite this complexity, there was strong agreement between pwME/CFS and clinicians regarding the main reasons for initiating tube feeding: weight loss, severe fatigue or pain, difficulty chewing or swallowing, and symptoms triggered by eating.

Clinicians were more likely than pwME/CFS to report that their patients had anxiety or emotional difficulties related to eating. This may reflect differences in the populations represented, different perspectives or a tendency for clinicians to focus more on psychological explanations. Comments from both groups highlighted that conflicting opinions can hinder safe, timely and appropriate care, with incorrect assumptions about psychological causes being a major issue. This mirrors narratives reported in published case studies (24,25). Often these issues are assumed or implied without clear evidence which emphasises the importance of using validated screening tools if an eating disorder is suspected such as those referenced on the NICE Clinical Knowledge Summary (26) whilst also recognising their limitations for screening for other types of disordered eating e.g. Avoidant or Restrictive Food Intake Disorder (ARFID). Identifying that a person has an eating disorder should lead to them having access to appropriate support and treatment for it. Clear documentation when there is no evidence of an eating disorder may help reduce conflict and distress and improve care.

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Clinician comments also stressed the need to look beyond symptoms and labels such as “gastroparesis” or “food intolerance” to better understand the underlying pathophysiology. Sometimes a pwME/CFS may be described as not tolerating food when it may be more related to them not being able to manage eating as a result of severe fatigue. Early identification of mechanisms driving symptoms may allow more targeted management and potentially prevent progression to the point where tube feeding is required. As symptoms triggered by eating were among the most common reasons for tube feeding, exploring whether these relate to dysautonomia, immune dysregulation e.g. MCAS, or other mechanisms may identify additional treatment strategies (14,15,17,18,19,20). Also looking at the wider picture of energy demands and reducing these where possible may increase a pwME/CFS’ energy capacity for eating. Reviewing medications, excipients and supplements of all types may also reveal products that could be aggravating digestive symptoms.

Tolerance of tube feeding was a major issue reported by both pwME/CFS and clinicians, with nausea and pain being the most common difficulties. A further challenge, more specific to ME/CFS, is that prolonged upright positioning can worsen symptoms because of orthostatic intolerance associated with autonomic dysfunction. Research has shown that around 90% of pwME/CFS demonstrate abnormal reductions in brain blood flow during tilt testing, even those without significant changes in heart rate or blood pressure (27). In people with severe ME/CFS, a 15-minute 20° head-up tilt resulted in a mean 27% reduction in cerebral blood flow (28), demonstrating that even sitting up in bed can result in altered circulatory responses.

This has important implications for tube feeding, as most hospital trusts have enteral feeding guidance that recommends maintaining a semi-upright position of approximately 30–45° during feeding and for a period afterwards to reduce the risk of reflux, regurgitation, and aspiration. For pwME/CFS prolonged upright positioning may worsen physical and cognitive fatigue and can trigger post-exertional malaise (29). The autonomic nervous system also plays a key role in regulating gut motility and blood glucose regulation (30,31,32), meaning orthostatic stress may contribute to other symptoms of intolerance caused by delayed gastric emptying or rapid gut transit leading to symptoms of nausea, pain, diarrhoea and constipation along with escalation in fatigue or energy ‘crashes’. Different types of feed and feed volume can also trigger autonomic responses leading to symptom escalation.

This demonstrates a specific difficulty for pwME/CFS which should be incorporated into decision making regarding the potential benefits and risks of starting or delaying tube feeding. Guidance on positioning during feed delivery is not based on a robust evidence base so it should not be seen as a non-negotiable barrier. It may be appropriate to operate outside the standard tube feeding guidance if this is deemed necessary to manage ME/CFS symptoms and if it leads to improved tolerance of the feed, whilst recognising there are potential risks associated with delivering feeds with the person laying flat. This will require assessment by a senior clinician or specialist MDT on an individual patient basis.

Other adjustments reported to improve tolerance included reducing feed speed or volume, trialling different feed types, switching from bolus to continuous feeding, warming the feed, and separating fluids and feed.

Logistical difficulties were also prominent. Clinicians described challenges in providing conditions and care practices that help to minimise the worsening of ME/CFS symptoms in a hospital environment, along with difficulties encountered due to staff not having a good understanding of ME/CFS. Carers reported that their expertise was not always recognised and described distressing situations requiring significant advocacy. Additional issues highlighted included pump and alarm noise, feed supply problems, inconsistent staff training, and the substantial burden placed on unpaid carers and family members.

Tube Changes

pwME/CFS experiences

14 out of 17 pwME/CFS needed their tube changed more than once

Location of Tube change:

12 out of 17 pwME/CFS always had tube changes done in hospital

2 out of 17 pwME/CFS started having changes done at hospital then moved to changing it at home

1 out of 17 pwME/CFS always had tube changes done at home

Comments from pwME/CFS related to tube changes demonstrate there is some variation in the timings between changes (which may relate to different types of tubes) and it is often needed due to problems such as blockages or tube damage.

There is also variation in the accessibility of staff and/or training to conduct tube changes at home which can also vary dependant on type of tube used.

It's changed every 90 days approximately

Changed every few weeks or if there was a problem

I throw up my NG now and again

Hospital still make me go in to change tube, even though I do the change myself.

Attending every 3 months takes a huge amount of energy, but thankfully they book me in in advance and no longer make me go via A&E

My tube was changed every month or so. It often got blocked and would have to be changed again.

Always in hospital for NJ but at home for NG

The xxxx nurses in our area … are not trained to place NG tubes in the home and there is no community option so changes have to be done at the hospital which is around 50 minutes away.

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Clinician experiences

14 out of 23 clinicians indicated tube changes always done in hospital

5 out of 23 clinicians indicated started with changes done at hospital then moved to changing it at home

2 out of 23 clinicians indicated had tube changes always done at home

2 out of 23 clinicians didn't know

Comments reference how it may be dependent on type of tube as some can only be changed in hospital (e.g. RIG-J and jejunal extensions).

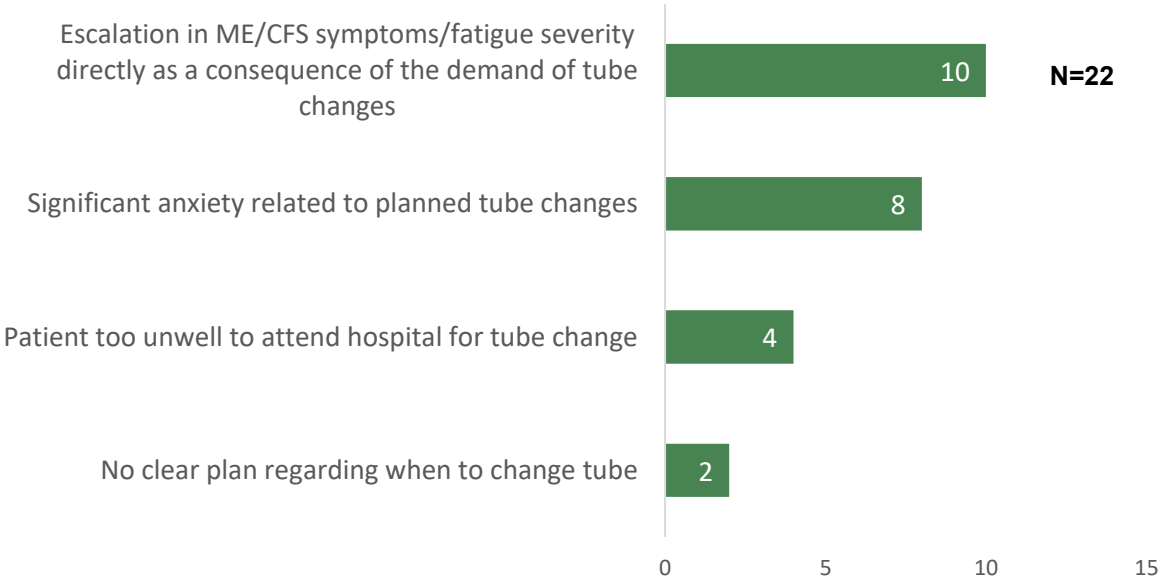
these days current guidance makes home change very tricky as correct placement is a big issue.

This has now changed and some hospital at home team will do this

Impact of tube changes

10 out of 17 pwME/CFS reported that the hospital admission and/or tube change caused an escalation in ME/CFS symptoms and/or a post-exertional malaise flare

17 out of 22 clinicians reported difficulties related to tube changes



Other reasons given included:

- Difficulties with hospital transport
- Short notice appointment cancellations
- Significant distance to travel
- Sedation required for the procedure exacerbating fatigue

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I have had hospital admissions that I never recovered from

Every time I have to go to the hospital it causes a worsening of my ME. The crash gets worse and lasts longer each time.

It is the hospital admission that for me was the problem / harm because of lack of expertise and no informed drs managing my care , unaccommodating rigid hospital routines & horrifically inappropriate ward environments that could not be substituted by a private room

2 out of 3 times we have the had to wait nearly 2 hours for the patient transport to take us home, despite requesting each time for them to wait as it is only a 10 minutes away appointment, if that.

We have asked each time for there to be a bed at the hospital as I need to lay down, the first time there wasn't one at all … the 2nd time there was a bed in a nice dark quiet room, but a nurse kept popping in to check on us and disturbing my rest, and the 3rd time there was only a very hard uncomfortable examination table/ couch which I was laid on for 2 hours with people coming in and out and a lot of noise around

Change of route in delivery of feed

pwME/CFS responses

8 out 17 of pwME/CFS needed a change in the route of delivery of their feed

Reasons for needing a change included:

- NG to PEG due to NG causing throat irritation and discomfort
- NG to PEG as a long-term plan
- NG to NJ as unable to tolerate feed then converted to PEG-J giving better stability and tolerance
- NG to NJ due to difficulty tolerating feed but not much better with NJ so switched to parenteral feed. Regained weight with that which led to NG being reinstated and then symptoms and oral intake improved enough to stop parenteral feeds.
- NJ for nearly 3 years. Then moved to PEG-J for 2 years. Then moved to a PICC line but had a number of blood clots so moved to Hickman after 7 months.

Clinician responses

10 out of 23 clinicians had experience of the route of feeding being changed

Reasons for needing a change included:

- Need for long-term feeding (6)
- In-experienced clinicians thinking PEJ tube will work when it usually doesn't (1)
- Need for long-term nutrition support due to mental health issues rather than ME/CFS (1)
- Improve security of the tube to reduce need for hospital trips (1)
- NG not sufficient so switched to PEG (1)

NJ to PEG-J for longer term security at home- NJ had become dislodged several times as an inpatient, requiring interventional radiology to re-site. If this happened at home would require a trip back to hospital which would be extremely challenging

Reflections on tube changes

Tube changes can have a significant impact on people living with severe and very severe ME/CFS. The need for tube changes should be factored in and discussed with the pwME/CFS, and their carers who carry out most or all of their care, from the outset, when deciding whether or not to tube feed.

Clarity should be sought as to the likely duration of tube feeding and community care options to help devise and plan for the most appropriate type of tube. Nasogastric tubes were the most commonly used but these require more frequent changes and may not be easily managed in the community. Gastrostomy tubes rarely need changing for several years at a time and may be more easily managed in the community but require a more invasive insertion method with the necessary hospitalisation, sedation and observation etc which will exacerbate ME/CFS symptoms and consequentially slow recovery. Some tubes require daily or weekly maintenance.

For most pwME/CFS in this survey, tube changes occurred in hospital. The journey to and from hospital, and being in a hospital environment, potentially cause significant post exertional malaise (PEM). This an important consideration for a pwME/CFS who is already severely or very severely affected. Hospital staff need to be informed of ways to meet ME/CFS specific patient safety needs as covered in the guidance produced by the Royal Devon University Health Care Trust (33).

As well as factoring in the environment where tube changes take place, the expertise of available staff, and frequency of tube changes, partly determined by the type of tube in situ, needs careful consideration. Staff need to be knowledgeable about ME/CS and have guidance to follow. Multiple hospital visits caused by the need for tube changes can have a long lasting, detrimental effect on a pwME/CFS.

Most pwME/CFS, carers and clinicians in this survey indicated difficulties occurred in relation to tube changes. While the type of difficulty varied, these mostly related to the healthcare system including difficulties with hospital transport, cancelled appointments at short notice and the distance to the hospital.

Changing the route of feed delivery affected almost half of respondents. Reasons for changing the route varied. These included mechanical difficulties (throat irritation), inexperience of clinicians, change in the body weight of the pwME, the need for improved stability of the tube at home, and the need for longer term feeding when ME/CFS was superseded by a mental health difficulty.

When making a decision about tube feeding, potential impact of tube changes and tube maintenance needs to be factored in and planned for as early as possible. The pwME/CFS and their carers should be included in all discussions and decisions from the start (34).

Stopping feeding

Expectations of duration of tube feeding

pwME/CFS perspectives

11 out of 16 pwME/CFS knew what factors would influence how long they needed the tube feeding

5 out of 16 pwME/CFS did not know what would influence how long they needed tube feeding

Comments included:

- Regaining swallow
- Regaining ability to tolerate oral food and fluids
- Weight improving
- Improved function

I'm always terrified they will take it away while I still need it.

My weight is stable and much better now and there has been no mention of removing the tube

Clinicians' perspectives

10 out of 21 clinicians have experience of patients needing tube feeding significantly longer than anticipated.

Comments reported not having any specific expectation or anticipating that it could be for a long time.

2 comments referred to it being patient choice including once person keeping the tube even when it wasn't being used for feeding. One comment reflected that the influence of social media might be driving ongoing tube use.

enteral feeding did not solve the problem which was impacting intake

Had hoped improving nutrition would lead to stability and then improvement in ME/CFS symptoms and energy capacity but the demand of managing the feed and especially attending hospital for tube changes meant it took a lot longer to achieve stability

Planning an exit before you start or at least a strategy of how you might reach an exit is important, That needs to be discussed with the patient - and often is not

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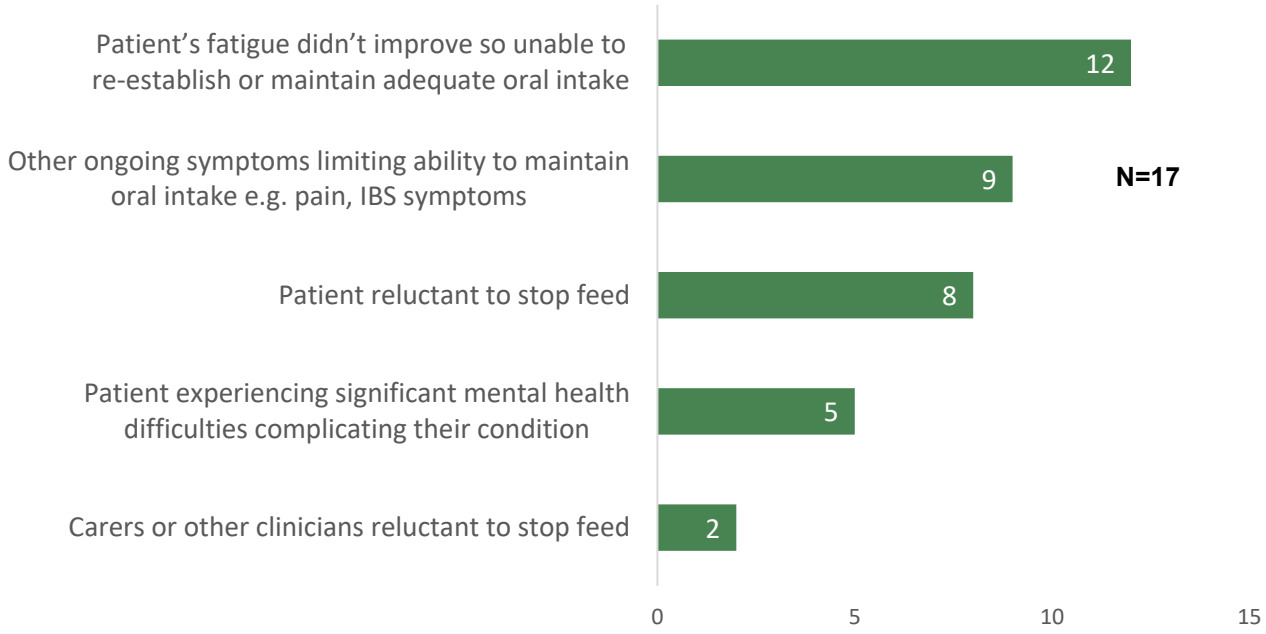
Difficulties stopping feeding

14 out of 17 clinicians reported difficulties related to stopping tube feeding



I am not aware that any patient I have seen has been able to transition off of tube feeding

Reflections on stopping tube feeding

The majority of pwME/CFS knew what factors would need to improve in order to stop tube feeding, but the comments also demonstrate that they didn't always feel an equal partner in the decision making.

Almost half of clinicians reported that tube feeding was needed longer than they anticipated and the majority had experience of difficulties stopping tube feeding. This may be for several reasons including lack of prior clinical experience of tube feeding, lack of data or guidelines specific to ME/CFS and expectations that improving nutritional intake would lead to improvement in gastrointestinal symptoms, capacity for oral intake and an improvement in ME/CFS symptom severity.

The data in this survey reflects a more complex reality where tube feeding often doesn't result in rapid improvement in symptoms or fatigue severity and it is more common for pwME/CFS to require tube feeding for years rather than months.

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Timing, planning and delivery of tube feeding

Initiation of feeding

pwME/CFS responses

13 out of 15 pwME/CFS felt their tube feeding had been started too late

2 out of 15 pwME/CFS felt their tube feeding was started at the right time

Many comments described significant deterioration in health including weight loss, malnutrition and dehydration before tube feeding was commenced. A common theme was community clinicians e.g. dietitian or GP recommending referral for tube feeding but hospital clinicians disagreeing and insisting on other approaches. Several comments reported lack of understanding of how ME/CFS can impact nutrition intake and pushing psychological or psychiatric explanations.

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Carers responses

14 out of 20 carers felt the tube feeding had been started too late

6 out of 20 carers felt their tube feeding was started at the right time

Carer's comments reported that tube feeding was often only started after severe malnutrition, dehydration, or life-threatening deterioration had already occurred. Delays were commonly attributed to clinical reluctance, disagreement between professionals, and barriers to hospital admission. Many felt that earlier intervention could have prevented significant decline or long-term harm.

3rd admission for investigation due to NG tube issues, refused admission by 4 hospitals, resulting in patient having no feed for over 2 weeks and considerable further deterioration.

My daughter stopped being able to eat and drink in January and got tube feeding at the end of April. She and we believe she became very close to dying.

Finally agreed when she was still losing weight whilst under their care in hospital.

By the time an NGT was placed daughter was severely dehydrated and had lost a lot of weight due to the inability to swallow safely

NG feeding was introduced too late. My 14 year old daughter was barely able to swallow water by the time they finally agreed to admit her despite countless requests from us. She was needing to be transferred using a PAT slide by the time they inserted an NG tube. The consultant radiologist and some of the team assisting were visibly moved by my daughter's determination to comply with the swallow assessment despite the challenges. He spoke gently to her and said 'I hope one day your physical strength matches your mental strength' I wished some of his colleagues and especially those with decision making power could have observed this and the countless other examples of my daughter's resilience, determination and perseverance.

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Clinician responses

9 out of 20 clinicians felt the tube feeding had been started too late

11 out of 20 clinicians felt their tube feeding was started at the right time

Clinician's comments described the timing of tube feeding as variable, with some cases started appropriately but others too late, often at crisis point, or occasionally too early. Delays were linked to clinical concerns e.g. aspiration risk, service barriers, and difficulty accessing appropriate inpatient care. Several also noted uncertainties about benefit, with feeding often initiated as a last resort when oral intake failed.

I think in some cases, started too late and patients had reached a crisis/hospital admission

Mixed, sometimes too soon sometimes too late sometimes about right.

in all cases far to late - despite firm debate and recommendations from the specialist ME/CFS team.

It was not easy to get my patient admitted and her feeding issues addressed- it felt like no-one in secondary care felt a patient with ME needed their input and should be admitted under their care

I do not think that there was a ever a right time to start enteral feeding in these patients. Majority started due to inability to meet nutritional requirements orally, in most cases this did not improve with enteral feeding. Started as last dietetic resort. Potentially could be avoided with earlier and specific psychological input.

It took a long time to agree for the patient to be NG fed, the main concerns were that she could not sit up right for long enough so the hospital were very concerned about the patient's aspiration risk and reluctant to insert the tube. The patient was very fatigued so we did suggest that with better nutrition her tolerance to sitting up may improve.

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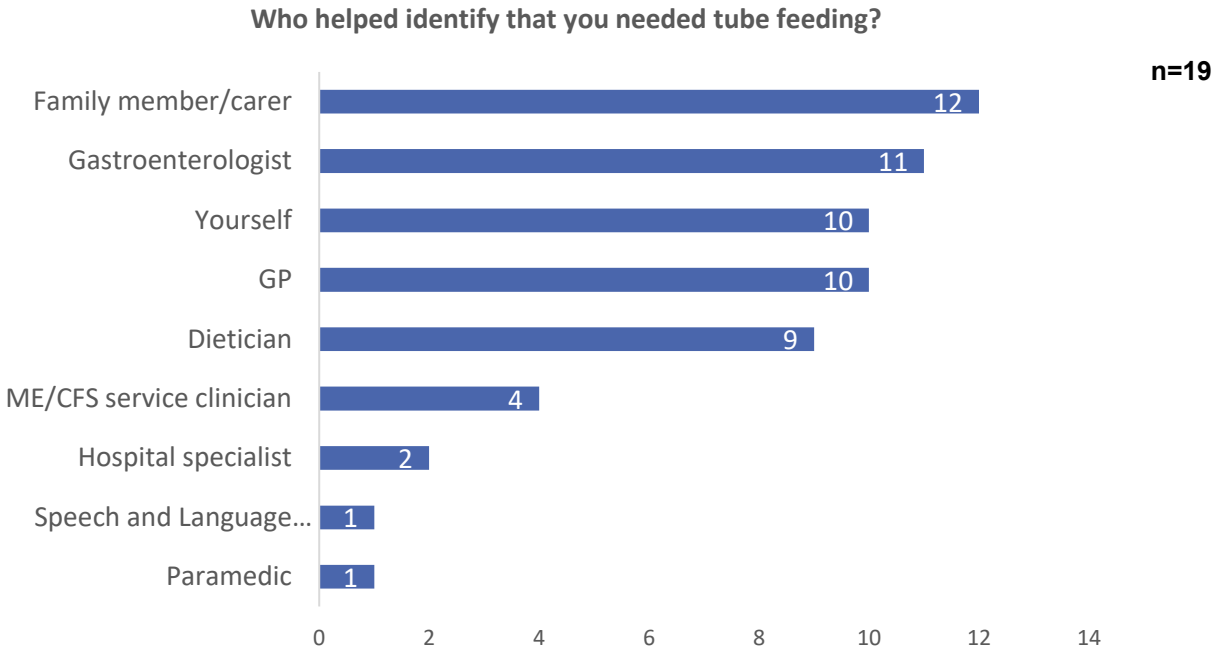
Identifying the need for tube feeding



Others included a paramedic, physio from Action for ME and a liaison psychiatrist

Comments reported there often being differing opinions between different clinicians and between clinicians and pwME/CFS and family members

It wasnt until the hospital contacted my ME specialist, until they actually believed that I wasnt making my symptoms up and admitted me for an NG

Mainly my ME/CFS specialist, who liaised with everyone else and fought very hard for me.

GP initially …The community dietitian then got involved… by which point things were a lot worse and she was very concerned so referred me for admission for tube feeding in hospital. The ME service I am under had also suggested that tube feeding could help. Once admitted the doctor was very against it and refused. The hospital dietitians…all recommended tube feeding…

contents

Feeding plan and monitoring

pwME/CFS responses

4 out of 17 pwME/CFS had a written plan for their tube feeding

10 out of 17 pwME/CFS did not have a written plan

3 out of 17 pwME/CFS were unsure if they had a written plan

pwME/CFS comments referred to there being documentation in their hospital notes. One person commented on initially having a clear plan written by their dietitian but over time the plan and their medical team changed and the guidance became 'looser'.

Some people reported having no ongoing ME/CFS support and conflicting discussions regarding gastroenterology follow-up.

Clinician responses

8 out of 23 clinicians indicated there was a written plan including review dates and factors relevant for review

7 out of 23 clinicians indicated there was a written plan regarding the feed but no structured plan regarding monitoring or review

6 out of 23 clinicians indicated there was no written plan in place

2 out of 23 clinicians were unsure if there was a written plan

Clinician comments reference plans not being adhered to with reasons including change of hospital staff with differing views and one comment referenced the patient not complying with reviews.

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It is very hard for a specialist therapist with nearly 25 years experience to stand up to a locum or consultant doctor who says dismissive comments.. such as they will eat if they get hungry enough etc.

Clinical responsibility

13 out of 23 clinicians indicated there was a clear agreement as to who was clinically responsible for decisions relating to the tube feeding

10 out of 23 clinicians indicated it was not clear who held clinical responsibility for decisions related to tube feeding

Comments reported that clinical responsibility for prescribing, administering, and reviewing the provision of tube feeding was held by gastroenterology/medical teams, GP's, Dietitians, and ME/CFS services or combinations of the above. This differed significantly between respondents to the survey. Often respondents felt like there was confusion over who was supposed to hold responsibility or that they were left with clinical responsibility without fully understanding the complexities of the condition. There was a general consensus amongst respondents that MDT involvement was most appropriate for decision making.

Very little MDT discussion. Often hospital thought ME team holding responsibility which wasn't the case. Aware community team had little experience of ME management

Sat between gastro and MECFS team- gastro not experienced in this situation, needed a lot of advice around adaptations needed for this procedure and didn't always believe/listen

Decisions being made by multiple medical teams with dietitian supporting inside these decisions.

Dietetic plan clear. Medical plan not clear

All decision making seems to lie with me as the dietitian looking after the patient at home.

contents

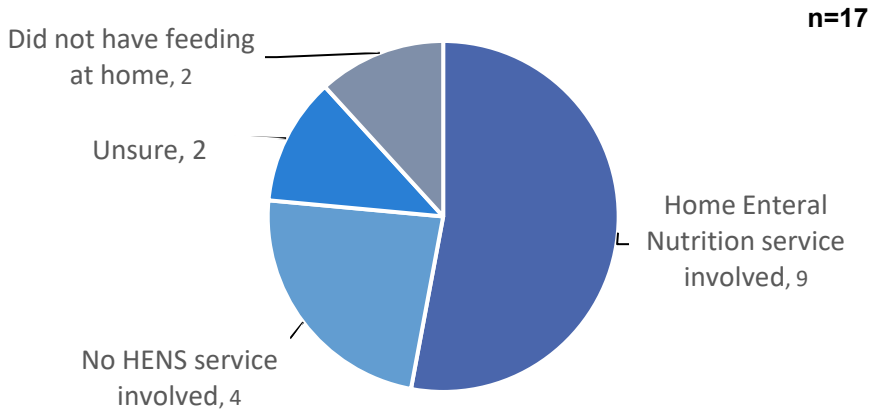
Contact details

Comments reference being in hospital the whole time or responsibilities being deferred to the nursing home doctor or dietitian. Some comments reflected a lack of confidence in the advice given by hospital staff.

HMS & [nutrition homecare company] once we were home were amazing. Hospital was much less well managed

[nutrition homecare company] supplied numbers and allocated a nurse to us, who has contacted us occasionally to check in. Also spoken to her with queries and got helpful answers

Home Enteral Nutrition Service (HENS)

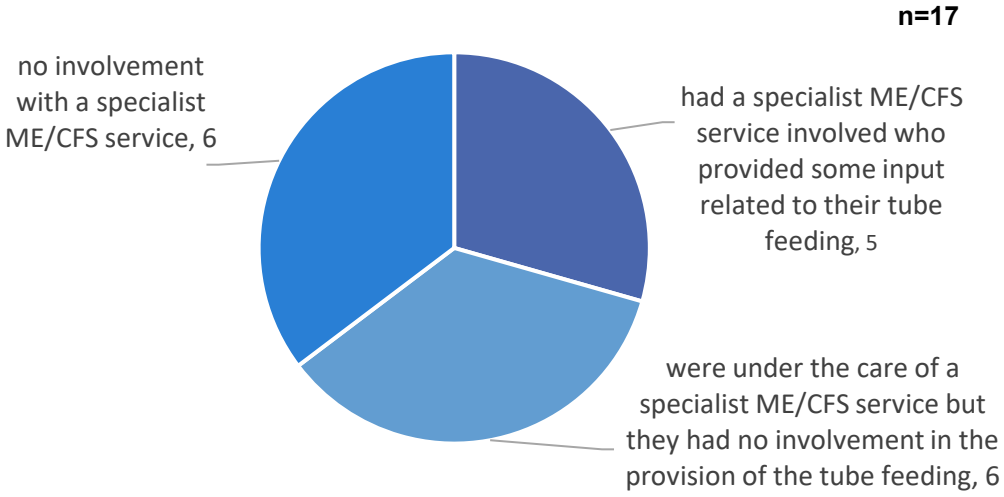


Comments referenced having access to nutrition homecare company nurses and dietitians.

contents

Specialist ME/CFS service involvement

pwME/CFS responses regarding involvement of specialist ME/CFS service



No-one reported having an ME/CFS service independently advising their tube feeding team

Comments reflected both positive and negative experiences of specialist ME/CFS services. Positives were related to staff from Specialist ME/CFS services reaching out and passing on information to other services.

When the experience was less positive, comments were based around:

- Services not meeting the needs of people severely affected by ME/CFS
- Lack of adequate experience of tube feeding
- Failure to recognise that feeding difficulties were part of ME/CFS
- Being unable to draw on other services that may have had more tube feeding specific experience

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I am under the XXXX ME/CFS service. The doctor who works there was contacted by the psychiatrist (!) at the hospital and she gave a lot of information to both him and the consultant and was very helpful with providing them with a bit of understanding about ME and what was needed. I think it would have been a lot more of a struggle without her input. The occupational therapist at the service has also provided information to the dietitian and have had contact to try and make things work as well as possible for me. I think they also arranged an MDT.

Yes, they've been pretty useless, including stating in a letter "There was nothing else to discuss regarding management of her ME/CFS, as the main problem is the gastric disorder" totally missing that the two are very much linked if not totally linked… so they just left me to it to fight with my family on our own.

The local m.e Service was not really fit for purpose as it had a policy whereby the OT's were only trained to be able to come in when you're feeling better again to help you pace your activities but that didn't apply to me and they showed real lack of knowledge and understanding about what they should be doing to help people with severe anything at all… Neurological services have been closed for me because of my diagnostic label, yet the nhs opted out of developing severe ME expertise too.

I would say "specialist" in a loose fitting way. They were considering specialist but they didn't have a lot of experience about tube feeding and the consultant had a tendency to blame me for needing tube feeding so they weren't helpful. I did get some support from the dietitian of the specialists but a lot of it was my parents having to fight to get me the care and support I needed. The second and third time I needed a tube, I wasn't under a specialist M.E. service.

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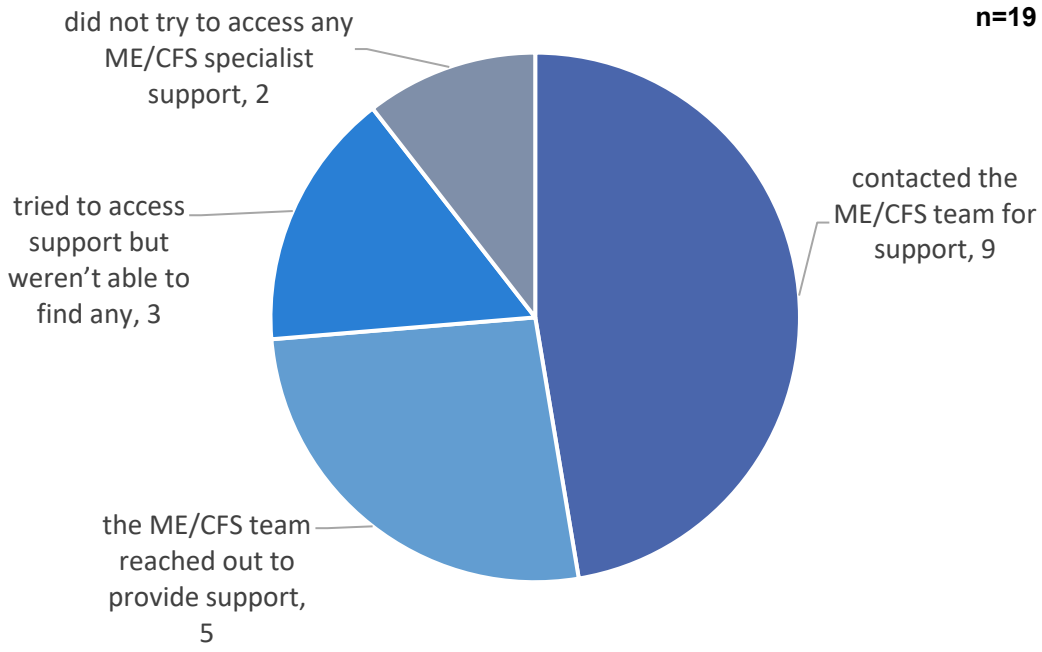
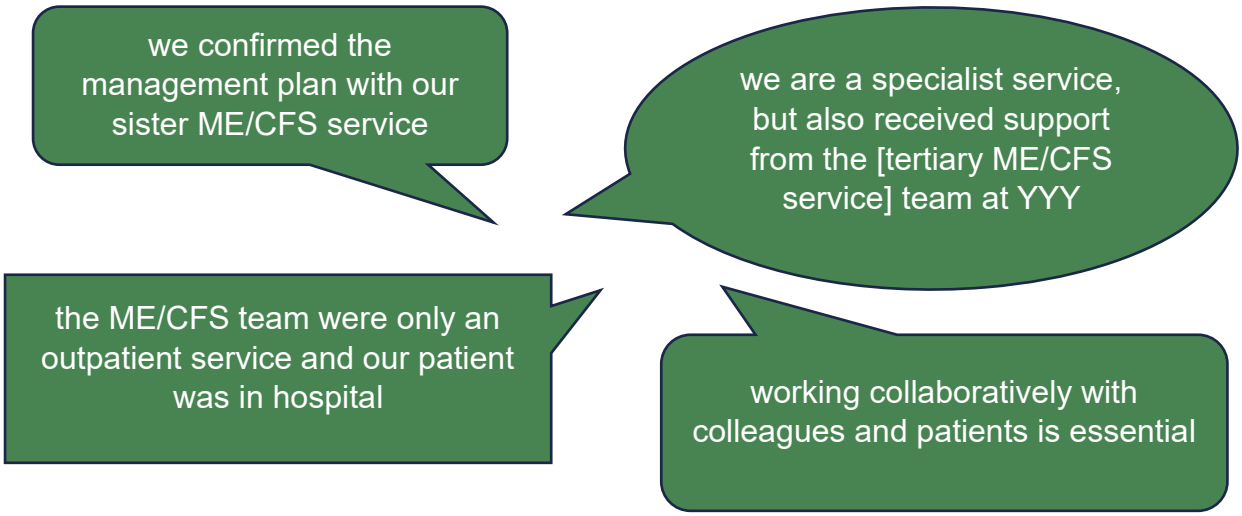
Clinician responses regarding accessing specialist ME/CFS support

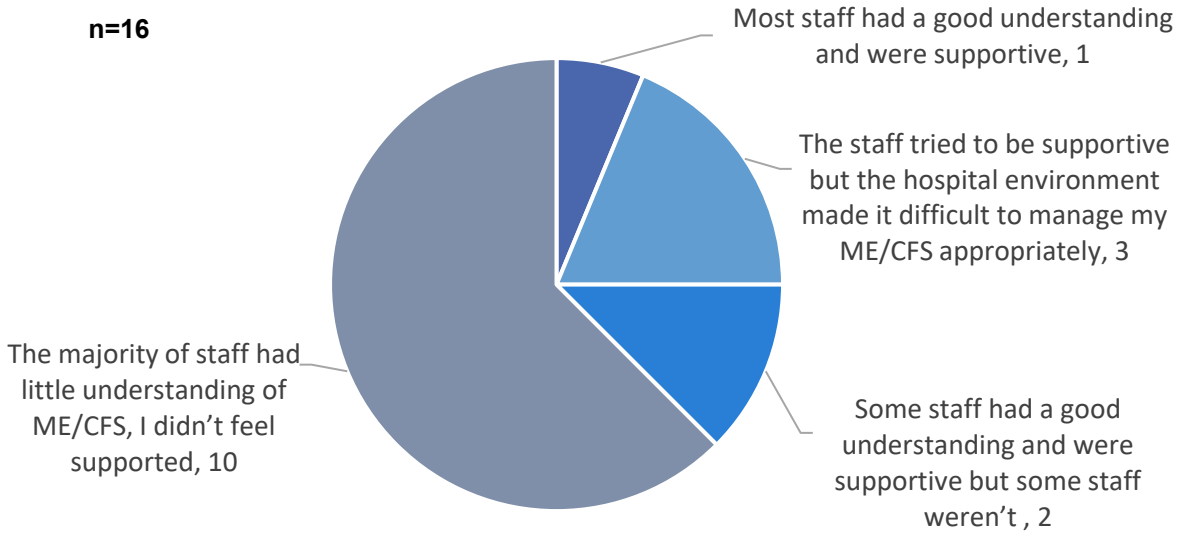


Comments reflected that there was variation in clinicians being able to access support from specialist ME/CFS services. Some clinicians already based in specialist ME/CFS services were able to provide support to colleagues based within gastroenterology services and dietetics. Comments showed that sometimes this was initiated by the specialist ME/CFS services reaching out to other departments, whilst for some respondents it was initiated by the service requiring specialist input.

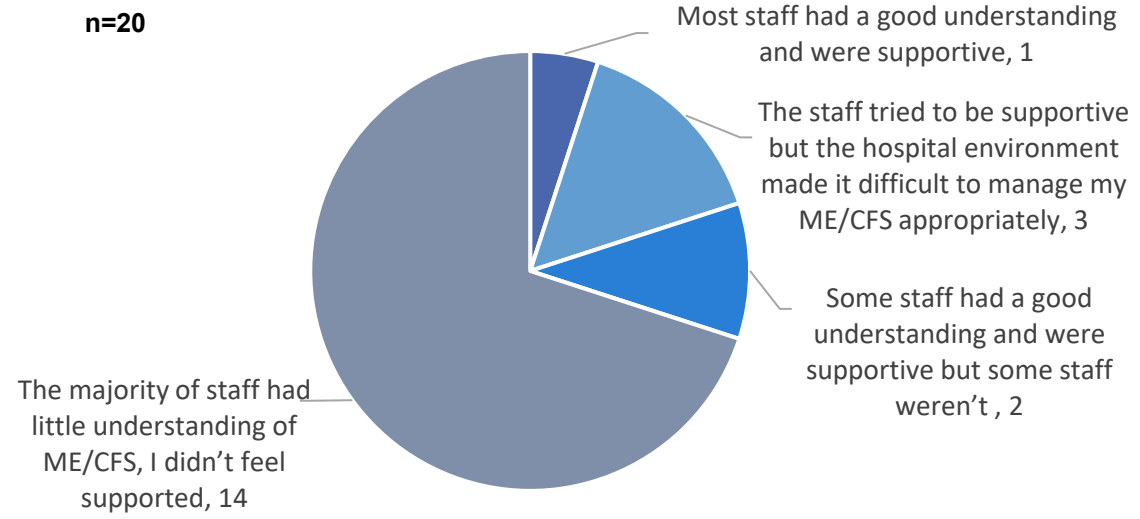


Hospital Care

Hospital's level of understanding ME/CFS pwME/CFS responses



Carers responses



5 out of 16 pwME/CFS had a pre-written document to help explain their care needs in hospital

11 out of 16 pwME/CFS did not have a pre-written hospital care plan document

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Comments reported that pwME/CFS and their families felt there was a lack of understanding of severe ME and the reasonable adjustments required by people with severe ME/CFS. This was noted particularly around the need to manage sensory hypersensitivities. The healthcare professionals failed to understand the need for quiet, low lighting and absence of chemicals.

Respondents reported that some clinicians thought ME/CFS was psychological or that the symptoms, including gastric, could not be due to ME/CFS. In one instance this led to a safeguarding referral and accusations of Munchausen's by Proxy.

It was noted by some pwME/CFS that individual healthcare professionals did try to understand however none reported this being hospital wide.

Where the patient had a hospital passport respondents felt it was ignored; typically put in the file and not read.

doctors at the hospital wasn't educated in how ME affects digestion and put it down as a "non-organic" issue that "wasn't medical". I been told that I had a "non organic overlay of symptoms". That i was making my symptoms up for medical attention. And that ME was not a severe enough condition to cause my symptoms.

Some staff certainly tried to understand, for which I was grateful.

I was treated as having eating disorder little belief for my ME except for one consultant I had had but he wasn't available for my last admission

I was very lucky that my ME specialist and GP both fought very hard for me, but hospitals are not good places for severe ME, and none of the hospital staff seemed to have any idea of how to support me.

We printed and filled in the supporting people with ME/CFS in hospital pack produced by the 25% ME group, action for ME, brame and ME association. This was put straight into my file and didn't appear to have been looked at by anyone as they didn't seem to know any of the information that was included in it.

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She has been accused of being lazy, refusing to walk, not wanting to eat, not making enough effort. Repeated safeguarding, refusal to read consultants letters, accused of providing false letters, and of munchhowsens by proxy.

We had to educate the staff, fight for a side room, limited observations, for us to provide most the care, for us to advocate for xxx's needs

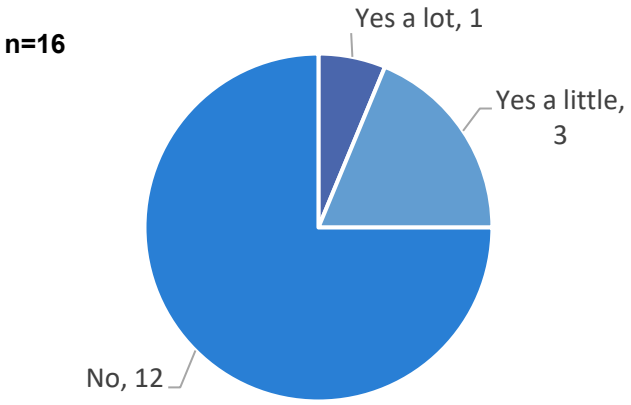
Doctors seemed to have little understanding of the ME symptoms and how they may affect the digestive system. Many tests came back normal, so they suggested it was psychological

Family assistance to speak for her was taken as interference and an emotional need to be a carer. I watched my loved one try to speak and struggling knowing that I had to stay silent

The environment of the hospital was very difficult. Eventually we moved to a cubicle on a quiet ward. The staff were given education on ME/CFS and made adjustments which they clearly felt uncomfortable about and every decision had to be escalated to the head of nursing.

Dietitian's knowledge of ME/CFS

Did the dietitian involved in your care have knowledge or experience of ME/CFS that made you feel confident in their advice?



Comments from pwME/CFS showed a clear consensus that the dietitians involved in their care were not adequately knowledgeable or experienced in managing ME/CFS. Despite this, most respondents also felt they were well supported by dietitians and felt confident in the care and advice provided by them.

I saw several different dietitians whilst in hospital, none of which seemed to know anything about ME but were very understanding when I explained, and they were all very much of the opinion that tube feeding would be best given my circumstances. I felt that even though they didn't have much knowledge of ME, they knew what I needed and were supportive of that even when the doctors weren't so I trusted their advice.

Although she didn't have experience in M.E I still felt confident with her advice.

They were good but didn't have knowledge of ME.

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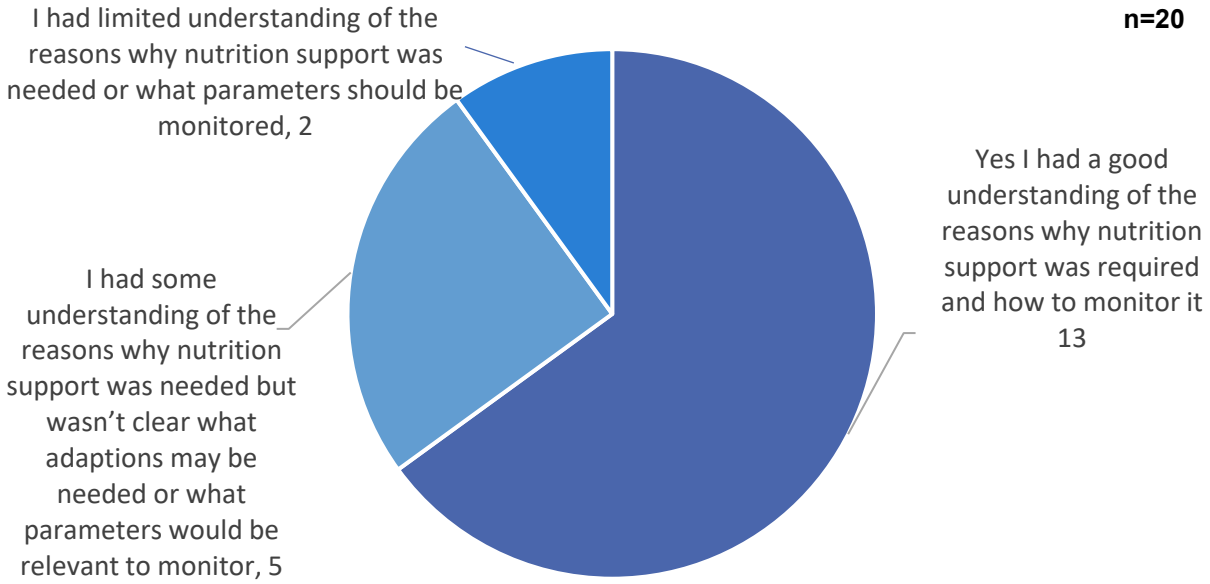
Clinicians level of knowledge

Do you feel you have a good understanding of the reasons why the person with ME/CFS required tube feeding and what parameters should be used for monitoring and informing decisions to stop nutrition support



Comments reflected on developing a better understanding over time and the lack of training or prior experience in the delivery of this level of nutritional support.

I feel I had a good understanding that the patient was malnourished and this was likely exacerbating her symptoms of fatigue, the challenge was as there is no clear guidance about when and how to monitor / any special recommendations for this patient group then it was challenging when different professionals had different view points about initiating feeding

in a patient with a very low BMI, even though we had agreed to trial tube feeding for 3 weeks and stop if no weight gain achieved, everyone was nervous to stop the feed after 3 weeks as the patient still had a low BMI and there were no further options

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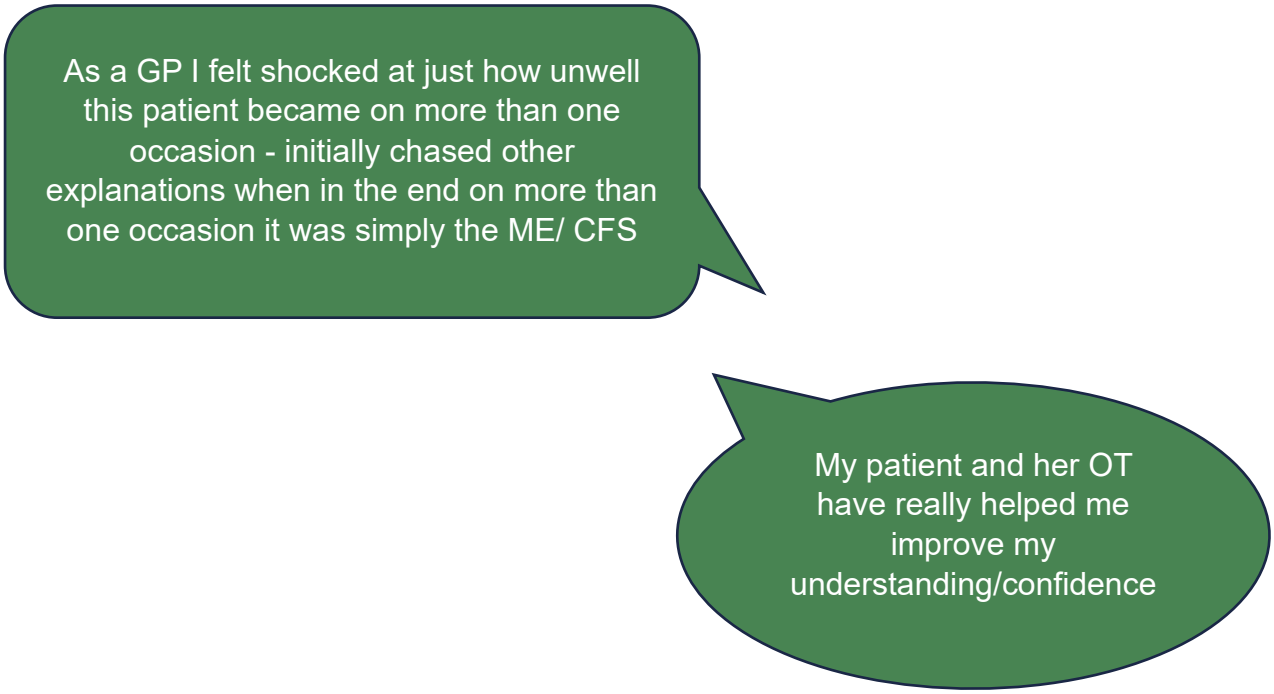
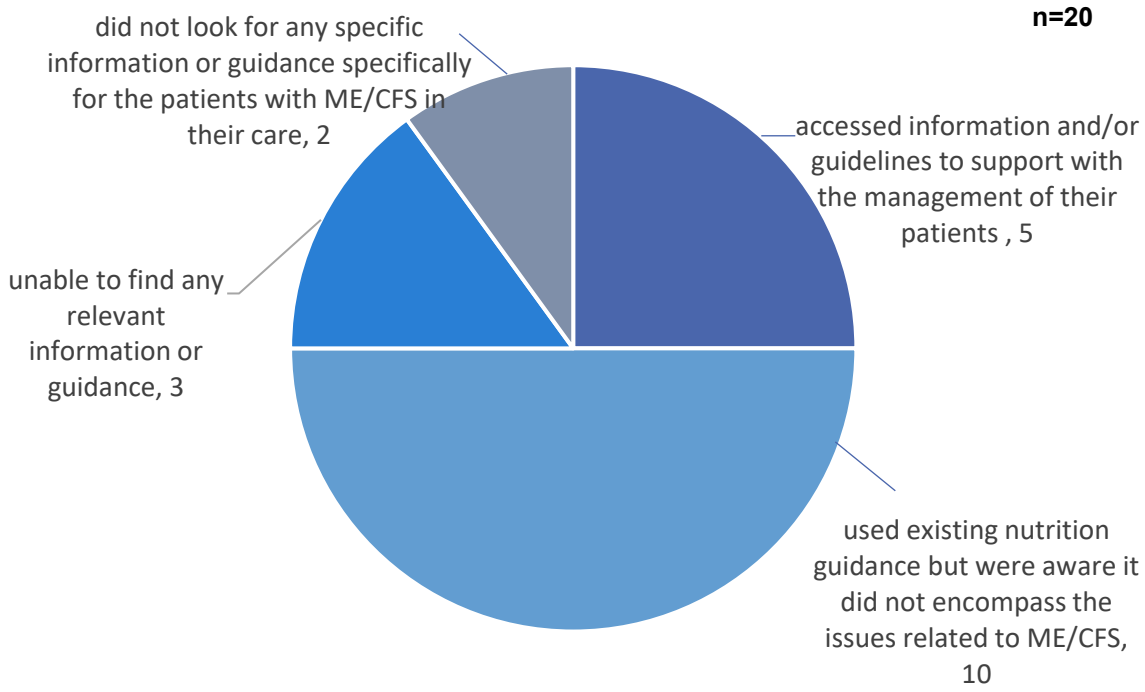
20 Clinicians responded to a question related to their understanding of the physiology of ME/CFS:

- **14** out of 20 clinicians felt confident in their understanding of ME/CFS and what strategies are needed for management and minimising symptom exacerbations
- **5** out of 20 clinicians have some understanding of ME/CFS but do not feel confident in what adaptations are needed in a hospital environment
- **3** out of 20 clinicians have some understanding of ME/CFS but do not feel confident in how to assess and make decisions relating to nutritional issues in people with ME/CFS



Access to ME/CFS and Nutrition guidelines

Clinicians were asked if they accessed any information and/or guidelines to support with the management of their patients



Examples of sources of information included:

- Medical Emergencies in Eating Disorders (MEED)
- BAPEN
- British Dietetic Association
- BACME
- Peer groups

Comments indicated information sources lacked information relating to complex care.

Reflections on timing, planning and delivery of tube feeding

While the majority of pwME/CFS and carers felt that their tube feeding had been started too late, only 9 out of 20 clinicians felt it had been started too late. The only reference to tube feeding being started too soon was in a clinician's comments. This difference may reflect the delays in recognising the severity of nutritional compromise and how it impacts ME/CFS symptoms and the failure to provide access to comprehensive dietetic support early. Clinicians are aware of the risks involved in delivering feeding via a tube and hence would always want to have exhausted less risky and less demanding options first. Our data points towards this action being taken too late and hence leading to pwME/CFS and carers feeling they had already reached a critical point when action was taken.

Refeeding syndrome can occur when nutrition is increased rapidly after prolonged malnutrition and may cause life-threatening complications so requires hospital monitoring. Prolonged nutritional compromise and very low BMI increase the risk; therefore, early nutritional intervention may help prevent further deterioration and reduce the risk of refeeding problems.

Comments from pwME/CFS and carers highlight substantial barriers to timely, appropriate, and safe care, resulting in significant emotional distress alongside deteriorating physical health. Clinicians also expressed frustration when their recommendations were not respected or acted on.

The data suggest that the need for tube feeding is most often identified by pwME/CFS and their carers, gastroenterologists, GPs, and dietitians. Only a small number of respondents reported involvement from an ME/CFS clinician. This likely reflects limited access to specialist ME/CFS services, particularly for those with severe ME/CFS, as many services are either not commissioned to support this group or focus on rehabilitation for medically stable patients (35). Limited resources and clinical staffing often prevent ME/CFS services from supporting patients who are medically deteriorating and may also result in less experience and confidence among ME/CFS clinicians in assessing the need for tube feeding. Nevertheless, some comments highlighted the valuable role of ME/CFS services in advocating for patients and providing education and support to other clinical teams.

The responses relating to written plans and ongoing monitoring demonstrate wide variation and lack of clarity. Written plans may be in place regarding the logistics of the feed type, speed, volume etc but broader clinical plans detailing the reasons for tube feeding, the goals, monitoring plans and who holds clinical responsibility appear to be lacking.

Home Enteral Nutrition Services (HENS) or the Home Enteral Tube feeding Service (HETF) are multidisciplinary teams, typically led by specialist dietitians and often including nutrition nurses and other healthcare professionals. They provide assessment, education and ongoing support for people requiring tube feeding at home. They undertake comprehensive nutritional and hydration assessments, develop and monitor individualised feeding regimens, prescribe or recommend appropriate enteral feeds and supplements, and provide training to patients and carers on tube care, feed administration and managing complications. HENS review patients in a range of settings, including at home, outpatient clinics and by telephone

or video consultation, and act as a central point of contact for patients, carers and healthcare professionals regarding home enteral feeding. These services are managed locally so there is likely to be variation in the structure and names of the of the teams. Four pwME/CFS reported not having a HENS team involved and it is difficult to know if this is due to it having a different name in their area or whether they did not have access to a specialist tube feeding team to guide their care.

The NICE guideline on nutrition support for adults states that all people having enteral tube feeding in the community should be supported by a coordinated multidisciplinary team, receive an individualised care plan, and receive training and information on feed delivery and emergency contact numbers (36). This survey data demonstrates that this is not being consistently provided to pwME/CFS.

The data relating to hospital care demonstrates that the majority of pwME/CFS and their carers had experienced hospital staff having little understanding of ME/CFS and this led to a failure to implement appropriate adjustments such as with managing hypersensitivities safely. There were also experiences of their condition being psychologised or inappropriate safeguarding concerns being raised and pre-written hospital care plans being ignored. Even in situations where staff were supportive, the hospital environment had a negative impact on pwME/CFS.

The pwME/CFS' experience of dietetic staff was that they often lacked any specialist knowledge or experience of ME/CFS but were on the whole supportive and were able to provide appropriate advice and advocacy.

Clinicians indicated that most had a reasonable understanding of ME/CFS and recognised factors that could lead to malnutrition. However, they also expressed difficulties related to lack of clinical guidance and lack of confidence managing situations where their patient was seriously underweight.

Collectively, these comments point to recurring problems with conflicting clinical opinions, unclear responsibility for decision-making, and decisions being made by clinicians with limited understanding of ME/CFS and nutritional issues.

Conflicting opinions about tube feeding may partly arise from differing expectations of its goals and expected outcomes:

- If tube feeding is viewed as a treatment for ME/CFS, this may lead either to it being dismissed as ineffective or continued longer than necessary.
- Expectations that it will improve gastrointestinal symptoms or oral intake tolerance may also be misplaced, as survey data suggest these problems often persist and can sometimes worsen with tube feeding.
- Clinicians may base decisions on their experience or awareness of other chronic conditions such as hypermobile Ehlers-Danlos and disorders of the gut brain axis where some studies have shown that tube feeding may not offer much benefit or may be inferior to continuing with oral feeding strategies (37,38).
- Goals for tube feeding typically focus on improving BMI but this can be challenging for pwME/CFS who may be too severely ill to be weighed and if they are unable to tolerate full feed volumes this may not be an achievable

short-term goal. They may also have different fluid and sodium requirements to aid with the management of dysautonomia conditions such as PoTS.

- There may be a hope that tube feeding will reduce anxieties arising from weight loss and malnutrition, but these anxieties may be replaced by others relating to difficulties with the feed regime and delivery, all the additional demands it creates for pwME/CFS and the psychological impact of becoming dependant on artificial feeding.
- Clinical goals such as improving quality of life are inherently subjective and may be viewed differently by pwME/CFS, their families, and clinicians.
- In most cases, the primary aim is to prevent further deterioration or death from malnutrition, and achieving this may require tube feeding to be maintained much longer than is usual.

The survey findings suggest that these goals are often not explicitly discussed, leading to a lack of shared understanding and to pwME/CFS and carers feeling that their views are not adequately considered.

All ME/CFS care is compromised by the absence of a clear medical home. As a multisystem condition, it does not sit within a single specialty, and no medical Royal College has overall responsibility for developing guidelines or overseeing clinical services. Consequently, ME/CFS services vary widely; some have no medical input, while others rely on clinicians from diverse specialties who often work part-time within the service and may lack access to investigations or prescribing (35).

For patients whose nutritional problems arise from a primary gastrointestinal condition, responsibility for nutrition support usually falls to gastroenterology services. However, when nutritional difficulties develop directly as a consequence of ME/CFS, severe fatigue, or associated comorbidities, responsibility for decisions regarding nutrition support is often unclear. In contrast, for conditions such as Motor Neurone Disease or stroke, where tube feeding may be required for non-gastrointestinal reasons, established clinical pathways clearly define clinical responsibility and support decision-making.

For children and young people(CYP) there may be some tertiary settings where multidisciplinary care is already well established leading to better co-ordination and access to different clinicians. However, outside tertiary settings, care for CYP can also be very fragmented if opinions are needed from multiple specialists, potentially in different hospitals, such as gastroenterology, cardiology, endocrinology, neurology, pain team etc.

The lack of established clinical pathways for pwME/CFS contributes to conflicting opinions, fragmented care, and uncertainty around nutrition support. Addressing this requires improved multidisciplinary working, improved education about the physiology of ME/CFS, greater clarity regarding clinical responsibility, and accessible ME/CFS-specific guidance for pwME/CFS and clinicians from all professional backgrounds in every region.
It may be that one way to address these difficulties is to establish more robust clinical networks in regions or at a national level where expertise can be developed and tapped into more rapidly and effectively.

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Thoughts on provision of tube feeding

pwME/CFS responses

Do you feel tube feeding was beneficial for your health and management of your ME/CFS?

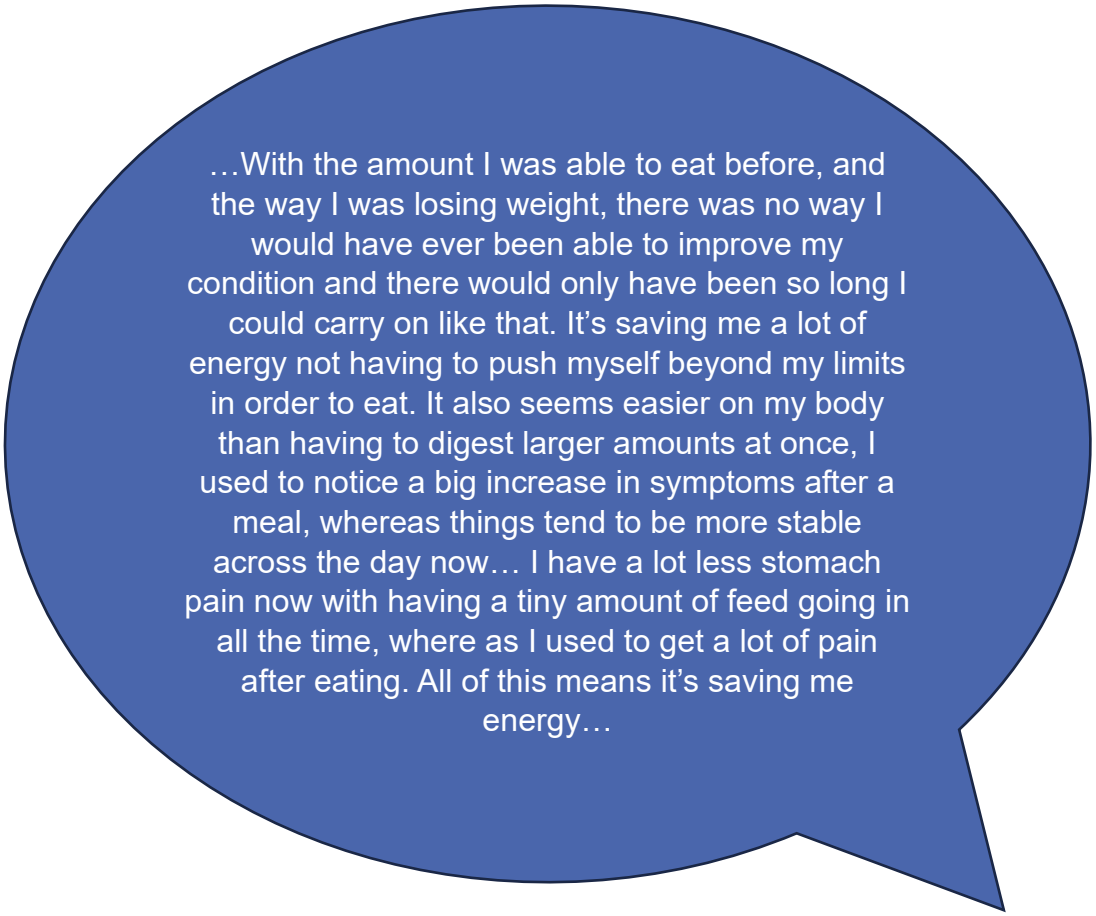
100% (16 pwME/CFS) answered Yes

Overall, do you feel having tube feeding was the right option for you?

100% (16 pwME/CFS) answered Yes - there are/were definite benefits from having it

Comments demonstrated:

- All participants felt tube feeding was beneficial,
- Benefits included with energy conservation and enabling them to restart food It ameliorated nausea and pain in 2 participants.
- 4 stated it stopped them from dying



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Before tube feeding, nearly all my energy in a day was revolved around chewing and swallowing me food. And having to be led down while it digested, as otherwise I'd throw it up. All my active hours were spent trying to get enough calories in. I now how that period of energy to put toward something else…

…I was on an NJ and once I was settled with it, the nausea and pain was pretty much non-existent…

…I otherwise was not able to consume enough nutrition to survive. I believe there have also been other longer-term benefits, too, given the improvement I've experienced over the last 2 years following being on tube feeding…

Tube feeding stopped me from dying. It was absolutely essential. It meant that I didn't have to use my extremely limited energy to eat a full main meal which would've taken hours, but I could have the nutrition fed to me and build my energy back up.

My health was spiralling downwards prior to tube feeding as I was become very malnourished, not absorbing meds, etc. Things have stabilised since I've been tube fed.

I definitely had a lot more energy when I had my tube and I kind of miss it as the nausea and pain weren't there.

It's absolutely not easy, but yes it was the right decision

I don't think it's an exaggeration to say it was life saving…

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Clinician responses

17 out of 20 clinicians felt there were identifiable benefits of tube feeding for the patients with ME/CFS they have seen

Clinician's comments reported that the main benefits of tube feeding were preventing or reversing malnutrition, stabilising or increasing weight, and in some cases prolonging life, with a few patients experiencing modest improvements in energy or quality of life. For some individuals, it enabled small functional gains or reduced anxiety for everyone involved by ensuring consistent nutritional intake. However, benefits were variable, with several clinicians noting limited or no improvement in fatigue or overall ME/CFS symptoms, and in one case ongoing dependence on feeding despite minimal clinical improvement.

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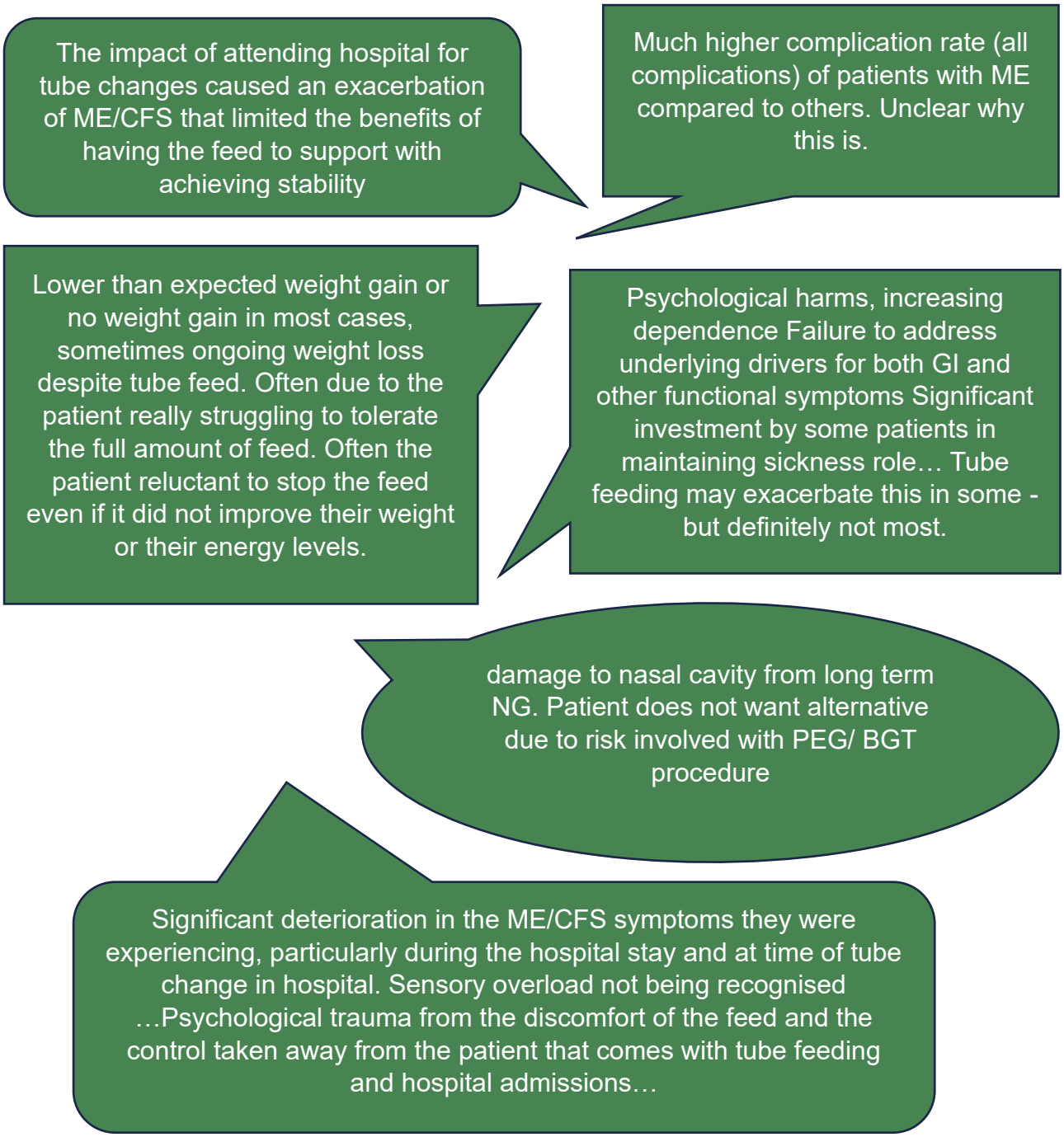
10 out of 21 clinicians felt there were identifiable harms related to the delivery of tube feeding

Comments highlighted several potential harms, most notably worsening of ME/CFS symptoms, particularly due to hospital admissions, sensory overload, and the physical and logistical burden of tube changes. There were also concerns about psychological impacts, including increased dependence, over-medicalisation, loss of autonomy, and in some cases, trauma associated with treatment. Additional issues included physical complications e.g. nasal damage, higher-than-expected complication rates and the risk of long-term reliance on tube-feeding without clear overall benefit.



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Additional Information

At the end of the survey, respondents were able to submit further thoughts and reflections.

Common themes reported by pwME/CFS were:

- Life-saving but difficult intervention
- Lack of clinician knowledge and understanding of ME/CFS
- Need for earlier intervention
- Impact of hospital environments
- Importance of specialist support and advocacy
- Variability in care and access
- Practical challenges with feeding and equipment
- Psychological impact and feeling misunderstood

Enteral & Parenteral feeding has literally saved my life. The times in hospital are always tough on my ME (I have major crashes every time I'm discharged) but the ward I'm admitted to know me and are kind, caring and supportive…

…It would also be so much better if someone could invent a pump where the alarm can be sent as a notification to a phone, rather than a loud alarm right next to me. The alert could then be sent to my mum's phone, rather than me having to turn the alarm off and then send her a message asking her to come and help!...

I think it was very beneficial for me having the involvement of the ME service that I am under. If it hadn't been for them I would have felt very alone (other than my mum), and I think we would have had to really fight to get the help I needed… I think there needs to be a lot better education for doctors about ME, and in particular about severe and very severe ME and the impact it can have on being able to eat. I think there also needs to be more education and focus on the importance and benefit of early intervention when it comes to feeding tubes and for doctors to start seeing it as a way of helping a struggling patient, rather than an absolute last resort once they have deteriorated past the point of it causing long term worsening and harm. Earlier intervention would have been so much better for me and would have prevented my ME getting as bad as it did…I think if they had guidance that was specific to ME, taking these things into consideration it might have made it easier and they might have had a better idea of what to do. The actual tube feeding is absolutely fine. I'm tolerating it well and it's helping me…

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I think that it all remains a huge postcode lottery - having an excellent GP and a wonderful ME/CFS specialist who have fought for me and advocated for me, and who have been confident to go 'against' protocols (eg 30 degrees head elevation) has meant that I have had a relatively 'easy' time compared to many others…Nobody ever wants tube feeding, but despite this, for me, it was definitely the right thing to do and has given me back a little bit of quality of life.

One of the major issues for me with tube feeding, which led to me having to be on parenteral nutrition to supplement the feed, was the issue of rate. I could not go above around 80 without triggering almost immediate diarrhoea, which severely restricted the amount of feed I could obtain each day…I also noted that there was also a lack of knowledge around recommended concentration for the feed I was on

Options are so important, options of how to increase feed slower, or in stages, or at the patients own pace regarding their symptoms. Also, scare mongering that there is no good options and everything will lead to decline and death is not helpful. Neither is leaving things so long you have to have lost basically all function before they decide to do it.

From NG to PEG. Was also heavily warned of the risks of tube feeding or PN feeding almost to the point where they didn't acknowledge the risks of doing nothing… I was told I had very limited options and all were likely to lead to escalation to the next, and death. It's been terrifying. Once the NG was placed, the support finally kicked in and it's saved my life. I just wish they had listened to me sooner.

Common themes reported by carers were:

- lack of understanding of ME/CFS among healthcare professionals
- Inadequate or inconsistent access to appropriate care
- Negative and sometimes traumatic hospital experiences
- Delays and poor care pathways
- Practical and logistical challenges of tube feeding
- Need for more personalised, flexible care
- Emotional burden on patients and families
- Need for ME-specific guidance and specialist support

Our experience of support from multiple hospitals in different areas regarding ME/CFS has been devastating and completely unbelievable It has proved impossible to get support for NG changes in the community or to have been offered the training for me to be able to change the tube at home… Over a period of 10 years, we have only met 1 consultant who had limited understanding of the condition and treated us with respect…

Our dietitian has been really supportive but is very aware he has no knowledge/experience of working with ME/CFS patients. He would have appreciated professional dietetic support himself. NICE guidelines talk about specialist dietitians - is this a realistic expectation? Could expertise be centrally collated and available for NG tube experts with limited ME/CFS experience

It has been frustrating to see the lack of understanding that the frequent tube changes needed (currently on tube number 12 in as many months) have a big negative impact on the wider health of the person in my care. There is a lack of defined care pathway when the NJ tube fails - it requires going to A&E…being admitted for IV fluids (very hit and miss) and then awaiting a slot in endoscopy for the tube to be replaced. Along the way there is much misunderstanding about the impact of being left on a trolley in a corridor for up to 18 hours etc…

Knowing what help is available and…if using other things could improve the experience would be good. We have had to find out or stumble across information to enhance the tube feeding experience.

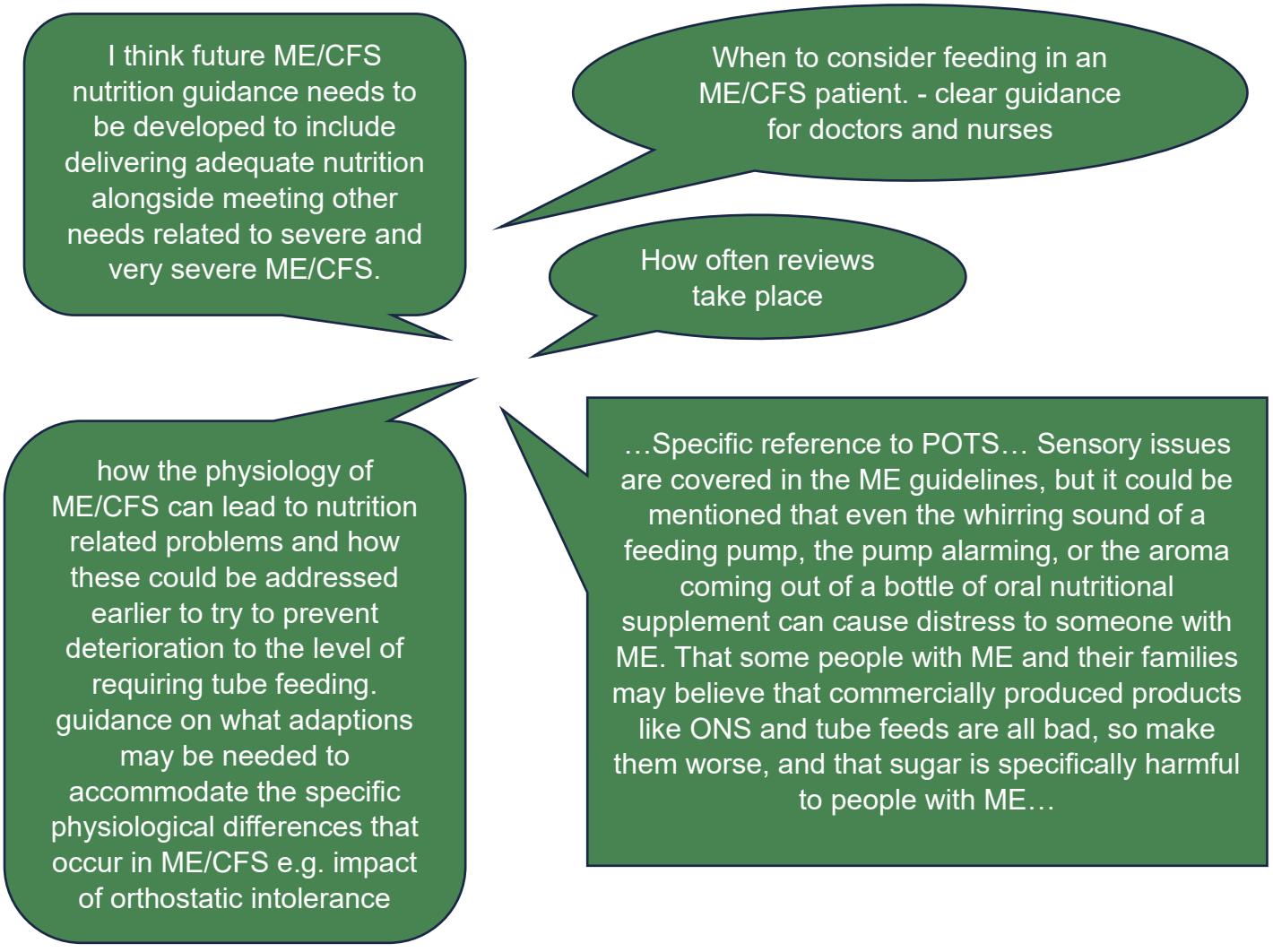
During her time in hospital she lost a lot of weight, the ability to swallow, she could not talk or tolerate us in her room, all her symptoms got worse. We feel that she got PTSD from the hospital admission.

Clinician's suggestions for guideline development

16 Clinicians provided suggestions for what needs to be included in future ME/CFS nutrition guidelines.

Comments showed that there is a clear need for clinical guidance on tube feeding in severe ME/CFS. Suggestions for areas the guidance should cover include:

- considerations in severe ME/CFS of benefit versus risk
- when and how to start, for how long, monitoring and how and when to stop
- different tube feeding approaches NG/NJ/PEG/PEG-J
- types of tube feeding formulas to meet nutritional requirements and dispelling the myth that these are harmful e.g. because they contain sugar
- overlapping conditions that may also be present such as POTS and the recommendations relating to additional fluid, salt and electrolytes
- addressing concerns such as positioning for tube feeding
- consideration of the specific needs of children and young people



contents

…As a result of our experiences we have started writing a local pathway for the nutritional management paediatric patients with severe and very severe MECFS, whilst this is still rare we have learnt a lot from our experience that we would be keen to use to change practice. I believe that such guidelines are important, and that CYP need to be considered more within existing ones

clear evidence based guideline of the benefits vs risks of tube feeding, when to escalate and how to manage the patients expectations that it may not help things as much as they might have hoped. guidelines need to link with BSG and NICE guidelines about when longer term tube types are indicated- i.e PEGs as it is difficult for the gastroenterologists to demonstrate that the risk outweighs the benefits in a patient who does not have a malabsorptive condition or dysphagia

Reflections on respondents' thoughts on provision of tube feeding

Given the multisystem nature of ME/CFS, where gastrointestinal symptoms such as nausea, reflux, abdominal pain, bloating and IBS-type symptoms are common (39), alongside profound fatigue, post-exertional malaise, sleep disturbance and cognitive dysfunction (40), it is unsurprising that respondents with severe and very severe ME/CFS reported tube feeding as beneficial. Reported benefits ranged from energy conservation, symptom improvement, improved quality of life and in some cases preventing death.

Clinicians also identified important benefits of tube feeding, including reversal of malnutrition, weight stabilisation or gain, improved quality of life, increased energy, and prevention of life-threatening nutritional compromise. However, around half also reported potential harms, including worsening symptoms, physical complications, increased dependence, and treatment-related trauma.

These findings highlight the need for careful individualised assessment of the benefits and risks of tube feeding, with pwME/CFS and their carers fully involved in decision-making and offered choices wherever possible (34). Decisions may include when to start and stop tube feeding, type of feeding tube, feed formulation, feeding rate, and positioning during feeding.

Respondents consistently emphasised the importance of timely intervention. Delays in initiating tube feeding, particularly where hospital admission is required, were identified as a significant barrier. Where admission is necessary, care should be delivered by clinicians experienced in ME/CFS where possible, with appropriate

environmental adaptations and management strategies for severe and very severe ME/CFS (33,41).

Clinicians highlighted the need for dedicated guidance on tube feeding for pwME/CFS. Suggested areas for inclusion were indications for tube feeding, assessment of risks and benefits, choice of feeding method (e.g. NG, NJ, PEG), when to start tube feeding, feeding protocols, positioning requirements, and consideration of co-existing conditions, which are common in severe and very severe ME/CFS (23).

Keeping the individual needs of each pwME/CFS, including consideration of the specific needs of children and young people, is of paramount importance in the provision of accessible, effective and quality treatment and care for pwME/CFS, particularly where they are severely or very severely affected.

Conclusions

This survey has several limitations, including a small sample size and the potential for selection bias associated with the recruitment methods used. However, in an area where published research remains extremely scarce, the findings provide valuable insight into the experiences of people with ME/CFS, their carers, and the clinicians involved in their care. They should help inform future clinical practice, service development and further research.

A notable finding was the volume and strength of the personal accounts submitted. The emotive responses illustrate the considerable distress that nutritional compromise and tube feeding decisions can cause for pwME/CFS, their families and clinicians. They also highlight the potential for serious and life-threatening consequences when nutritional needs are not adequately recognised or addressed. In the most tragic circumstances, this has contributed to loss of life, as illustrated by the premature death of Maeve Boothby O'Neill at the age of 27 (3).

- **Nutritional problems are common, serious and often recognised too late.**

A consistent finding across pwME/CFS, carers and clinicians was that nutritional problems were often recognised and acted upon late, with many respondents describing a prolonged period of deterioration before appropriate assessment or intervention was provided.

Early assessment is essential to identify and address nutritional problems promptly, allowing a range of interventions to be explored and trialled with the aim of preventing deterioration wherever possible.

Achieving this requires greater awareness of ME/CFS across all medical specialties, enhanced training for dietitians, increased access to specialist ME/CFS dietetic support, and stronger medical provision within ME/CFS services.

- **Nutritional compromise in ME/CFS is multifactorial and requires comprehensive assessment.**

Symptoms and nutritional difficulties may be influenced by autonomic, immune, gastrointestinal, endocrine, neurodevelopmental and environmental factors. While some contributing factors are shared with other conditions, others may be more specific to ME/CFS. The profound energy limitation and risk of escalating Post-Exertional Malaise can mean a pwME/CFS can struggle to maintain adequate nutritional intake as a direct result of having insufficient energy to chew and swallow a complete meal. The fluctuating nature of the condition in response to any physiological, mental or social demand can contribute to symptoms which result in difficulties digesting food, oral supplements and tube feeds.

Early comprehensive assessment is therefore essential to identify treatable contributors and prevent deterioration.

Survey responses highlighted problems with inappropriate psychological attribution of nutritional difficulties, which causes distress and can delay assessment, treatment and access to appropriate support.

- **Tube feeding can be lifesaving but is complex and requires individualised decision-making.**

Survey findings suggest that tube feeding can be lifesaving for some people with ME/CFS, and it may improve quality of life if it reduces symptoms and the energy demands of maintaining adequate hydration and nutrition, but it is neither a simple nor low-risk intervention.

Differences between pwME/CFS and clinician perspectives may reflect differing expectations regarding its benefits and duration. In many cases, tube feeding is a supportive intervention and may not improve ME/CFS severity or address the underlying causes of nutritional compromise.

Tube feeding presents unique challenges for pwME/CFS and often requires adaptations to standard feeding protocols to improve tolerability. Some of these are issues that can occur in other conditions but there are specific considerations for pwME/CFS including:

- Orthostatic intolerance and the standard requirement for feed to be delivered in a head elevated position
- Demand of attending hospital for tube fitting and changes
- Noise of the pump and alarms and vibrations in the tube
- Need to adjust feed volumes, speed, temperature etc
- Volume of fluid required to manage dysautonomia
- Demand of managing healthcare appointments, care providers, feed and equipment suppliers and repairs etc.

For many pwME/CFS gastrointestinal symptoms like nausea and pain can be triggered by digesting and these issues are likely to persist when the feed is delivered by a tube and in some cases may be exacerbated by the requirement to have a large volume of feed delivered within a specific time frame. If adaptions to feed types, volume and speed are needed it may lead to the tube feeding not providing adequate nutrition support and thereby not effectively addressing the nutrition risks immediately.

Tube feeding can also increase the medicalisation of daily life without guaranteeing substantial medium-term improvement which can negatively impact on management of their ME/CFS. For others, addressing nutritional deficiencies can improve energy capacity and quality of life.

These findings highlight the need for individualised risk–benefit assessment. Decisions should consider the causes of nutritional compromise, ongoing

contributing factors, available care and support, previous interventions, the impact of hospital admissions and tube changes, realistic expectations of benefit, and the wellbeing of the pwME/CFS.

- **Unpaid carers provide a substantial proportion of support and must be included in decisions.**

All forms of activity place demands on the limited energy available to pwME/CFS. Nutritional problems may begin when a pwME/CFS lacks the energy to shop for, prepare, or cook food and can progress to difficulties eating due to severe fatigue. Comprehensive supportive care can reduce these energy demands, improve access to nutritious food, and play an important role in managing and stabilising ME/CFS.

It is clear from the responses in this survey that this care burden is falling heavily on unpaid family members. Improving access to funded care could be an effective way to reduce the nutritional risks and help prevent deterioration.

When tube feeding is being considered, the availability and sustainability of care at home should form part of the decision-making process. Tube feeding often places substantial long-term demands on carers, including coordinating with healthcare teams and suppliers, managing equipment, and undertaking daily feeding-related tasks. Standard social care packages may be insufficient or unable to support these needs and cannot be arranged in advance, potentially delaying hospital discharge.

Family members and carers frequently have extensive knowledge of the individual's symptoms, triggers, and effective management strategies. Tube feeding may reduce the concerns and responsibilities of carers to ensure the pwME/CFS is meeting all their nutrition and hydration requirements. With the person's consent, carers views should be sought, valued, and incorporated into decision-making and admission and discharge planning wherever possible.

- **Current service provision and clinical pathways are inadequate and responsibility is often unclear.**

The majority of clinicians who completed the survey were dietitians, reflecting the significant responsibility often assumed by dietetic services despite limited access to coordinated medical support.

Survey comments frequently highlighted how conflicting professional opinions can delay care, hinder decision-making, and add to the distress experienced by pwME/CFS and their families.

Many clinicians reported limited experience or confidence making these complex and difficult decisions and in the absence of clear clinical guidance or specialist networks, this can contribute to delays in treatment and poor communication.

As a result, people with ME/CFS may not receive sufficiently personalised information to make informed decisions or feel fully involved as equal partners in their care.

The survey also highlights significant gaps in specialist ME/CFS service provision. Many services lack the resources and capacity to support people with very severe ME/CFS or those experiencing deterioration. Limited availability of home visits can further hinder early identification of nutritional problems and increasing care needs, reducing opportunities for timely intervention and support. Contact with pwME/CFS may also be limited by the severity of their fatigue and capacity for conversations. Positive survey responses suggest that ME/CFS specialists can play a valuable role in identifying problems, educating other healthcare professionals, coordinating care, and advocating for people with ME/CFS. However, the ability to provide this support is dependent on adequate service commissioning and resources.

These findings demonstrate the need for stronger multidisciplinary working, greater efforts to identify and address treatable contributing factors, and improved resources to support clinical decision-making. A standardised care pathway is also needed, including clear arrangements for clinical responsibility, agreed treatment goals, appropriate monitoring and outcome measures, and defined criteria and timescales for reviewing and discontinuing tube feeding.

- **Improved education, research, clinical guidance and specialist services are urgently needed.**

Despite the challenges highlighted in this survey, all respondents with ME/CFS felt tube feeding had been the right decision for them.

A key priority for the future should be the earlier identification and management of nutritional problems, with the aim of preventing deterioration to the point where tube feeding becomes necessary. However, there remain significant gaps in our understanding of the causes and management of nutritional compromise in ME/CFS, and further research is urgently needed.

Our aim is for pwME/CFS and clinicians involved in their care to be provided with clear, evidence-informed guidance to support shared decision-making. Greater education about ME/CFS across health and care settings is also essential to address persistent misunderstandings of the condition, which continue to contribute to delays in care and inequitable access to appropriate support.

Key recommendations for the future

- **Embed routine nutritional screening within ME/CFS care**, including in primary care and in ME/CFS services at initial assessment, during therapy programmes, throughout disease progression, and during relapses.
- **Promote early identification and intervention in meeting nutritional needs,** with timely referral to dietetic services for assessment and support to reduce the risk of deterioration and the need for tube feeding.
- **Recognise the need to adapt usual assessment tools** to account for ME/CFS factors including difficulties measuring weight/BMI, not relying on blood markers as the only indicator of risk, slowness of eating needing to be observed over a prolonged period to evaluate nutritional intake accurately
- **Develop standardised clinical guidance and decision-support tools** to assist clinicians in assessing nutritional compromise, evaluating treatment options, and making decisions regarding tube feeding.
- **Provide structured assessment of factors contributing to reduced nutritional intake**, including ME/CFS-related symptoms, dysautonomia, gastrointestinal symptoms, immune-mediated reactions, pain, neurodiversity, sensory hypersensitivities, emotional factors, and social care related barriers.
- **Promote treatment of underlying causes of nutritional compromise**, including appropriate medical review of gastrointestinal, autonomic and immune factors and medication management to optimise symptom control while minimising ineffective or excessive prescribing.
- **Optimise oral nutritional intake,** through comprehensive assessment including exploring food and oral nutritional supplement options, making adaptations for preferences, intolerances and sensory sensitivities, and addressing practical challenges such as access to food, meal preparation, and care support.
- **Recognise the need for an individualised management plan** using a problem-solving approach that involves a degree of flexibility and may require empirical prescribing.
- **Support informed, shared decision-making** by providing clear information on the potential benefits, risks, and limitations of different feeding methods before the plan is formulated and consent obtained.
- **Implement written care plans,** including agreed tube feeding goals, monitoring requirements, review schedules, criteria for adapting treatment, and clear indicators for when tube feeding should be reduced or discontinued.
- **Implement ME/CFS-informed approaches to enteral feeding,** recognising that standard tube feeding protocols may require modification to improve nutritional

support. Adaptations may include adjustments to positioning, feed volume, delivery rate, feeding schedules, and feed type, particularly where symptoms such as orthostatic intolerance, gastrointestinal dysfunction, or post-exertional symptom exacerbation affect the ability to tolerate feeding.

- **Clarify clinical responsibility and accountability** for ongoing review, management of feeding regimens, decisions regarding tube changes, and discontinuation of tube feeding where appropriate.
- **Increase investment in specialist ME/CFS services**, including all services having access to ME/CFS trained dietitians and medical input and able to provide support for people with very severe ME/CFS including home-based assessment.
- **Reduce waiting times** for access to specialist ME/CFS services and dietetic assessment.
- **Improve education and training** on ME/CFS for primary care clinicians, hospital teams, and non-specialist dietitians to support earlier recognition and more appropriate management of nutritional issues.
- **Develop stronger clinical networks and collaboration**, including multidisciplinary regional and national networks linking ME/CFS specialists, dietitians, gastroenterologists, neurogastroenterologists and other relevant professionals.
- **Strengthen multidisciplinary working**, ensuring coordinated care, effective communication, and clear allocation of clinical responsibilities across relevant healthcare professionals and medical specialities.
- **Improve data collection, service evaluation, and research collaboration** to strengthen the evidence base and improve future care for pwME/CFS experiencing nutritional compromise.
- **Undertake further research** into the causes of nutritional compromise in ME/CFS, the effectiveness and tolerability of oral nutritional supplements and enteral feeding, and factors associated with successful outcomes.

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Glossary

ARFID	Avoidant Restrictive Food Intake Disorder
BACME	British Association of Clinicians in ME/CFS
BAPEN	British Association for Parenteral and Enteral Nutrition
BSG	British Society of Gastroenterology
CHC	Continuing Health Care
CYP	Children and Young people
EDS	Ehlers-Danlos Syndrome
GP	General Practitioner
GPwSI	GP with a specialist interest
HENS	Home Enteral Nutrition Service
HETF	Home Enteral Tube Feeding Service
HMS	Home Management Service
MCAS	Mast Cell Activation Syndrome
MDT	Multidisciplinary Team
NG	Nasogastric tube (tube inserted through nose into stomach)
NJ	Nasojejunal tube (tube inserted through nose into the small bowel (jejunum))
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
ME/CFS	Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
ONS	Oral Nutritional Supplement
PEG	Percutaneous endoscopic gastrostomy (tube inserted through the abdominal wall into the stomach)
PEJ	Percutaneous endoscopic jejunostomy (tube inserted through the abdominal wall into the small bowel (jejunum))
PEM	Post-Exertional Malaise
pwME/CFS	Person with ME/CFS
OT	Occupational Therapist
PoTS	Postural Tachycardia Syndrome

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