

# Feeding Tubes in Parkinson's

## Why, when, what, and how?



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One in 37 people alive today in the UK will be diagnosed with Parkinson's in their lifetime.<sup>1</sup> Parkinson's affects everyone differently and not everyone will experience all the symptoms.<sup>2</sup> It is suspected that due to the underuse of validated tools and objective instruments for assessment in Parkinson's and related movement disorders, alongside poor self-awareness of the conditions, dysphagia (difficulty swallowing) is under-diagnosed.<sup>3</sup> But it has been found that more than 80% of people with Parkinson's develop dysphagia at some point during the course of their condition.<sup>4</sup> Dysphagia may initially present as a mild symptom with eating or drinking becoming more effortful or time consuming, or coughing at mealtimes, but can progress over time. Discomfort during, or not being able to eat and drink the things you enjoy, can lead to a decreased quality of life.<sup>5</sup> Worsening dysphagia could ultimately lead to malnutrition, dehydration and aspiration.<sup>5</sup> Parkinson's patients have a four times higher risk of developing aspiration pneumonia during the 10-year period after diagnosis, and two-thirds of patients die within a year after the first occurrence of aspiration pneumonia.<sup>6</sup> WHY consider a feeding tube in Parkinson's? Although use of an enteral feeding tube, such as a percutaneous endoscopic gastrostomy (PEG), does not eliminate the risk of aspiration, enteral access could facilitate nutrition, fluid and medication administration in those individuals who may have otherwise not been able to manage these safely.<sup>7</sup>

It should be noted that Parkinson's is sometimes referred to within the umbrella terms 'Parkinsonism' or 'Parkinsonian syndromes' in the available literature. These terms are used to group several similar conditions on the basis of their shared clinical features. The conditions included are idiopathic Parkinson's, vascular Parkinsonism, drug-induced Parkinsonism, progressive supranuclear palsy (PSP), multiple system atrophy (MSA), cortico-basal degeneration (CBD), and other rarer causes of Parkinsonism.<sup>8,9</sup>

### Healthcare professionals (HCPs) views on tube feeding

A 2020 study conducted in Egypt<sup>10</sup> looked at the attitude and experience of neurologists towards PEG tubes. Although 98% of the interviewed neurologists (n = 100)

stated that they would recommend PEG for patients with prolonged need of nasogastric feeding, only 88% referred patients for a PEG. A 2015 study conducted in Malaysia<sup>11</sup> found that most HCPs involved in the care of geriatric patients would advocate PEG feeding. A 2016 systematic review<sup>12</sup> on the attitudes and barriers to PEG feeding found that only half of the reviewed studies reported positive perceptions towards PEG feeding. The main barriers for offering PEG were identified as lack of choice (poor knowledge, inadequate competency and skills, insufficient time given, not enough information given, lack of guidelines or protocol, resource constraints), confronting mortality (choosing life or death, risk of procedure) and weighing alternatives (adapting lifestyle, family influences, attitudes of HCPs, fear and anxiety).

## WHEN to discuss a feeding tube

Disease progression should prompt discussions around consent, advance care planning (ACP) and advance decision to refuse treatment (ADRT) to allow people the opportunity to plan for a time when they may lose capacity. Some identifiable stages of disease progression could be the onset of swallowing problems, care need changes including care home placement, frequent admissions for aspiration pneumonia, or unplanned weight loss.<sup>7</sup> Because artificial nutrition and hydration (ANH) has been recognised as a form of medical treatment, and an advance decision can refuse ANH,<sup>13</sup> the ADRT discussions should include preference with regard to tube feeding.

Brown *et al.*<sup>7</sup> advise that it is essential that feeding tube options are discussed at the first markers of advanced disease. Tuck *et al.*<sup>14</sup> investigated the preferences regarding timing of conversations related to prognosis and ACP/end of life (EOL) care options in people with Parkinson's. They found that 12% of respondents would discuss EOL options at the time of diagnosis, half desired to talk about advanced directives early in the course of their Parkinson's, and 25% preferred to postpone discussions on life expectancy and practical aspects of EOL care until their condition worsened. Although the majority of respondents (69%) had signed an ACP document,<sup>14</sup> other published data reports that only 37% of individuals with markers of advanced disease have had discussions about advanced care plans,<sup>7</sup> and generally awareness and understanding of ACP in people with Parkinson's is low.<sup>15</sup> Churm *et al.*<sup>15</sup> explained that: *"While there is desire to be better informed about ACP, this did not translate into desire to engage in ACP."* Early involvement of palliative care teams may have a positive influence on ACP initiation.<sup>16</sup>

## WHAT to consider when assessing for a feeding tube

### Input from the MDT

The Parkinson's disease in adults National Institute for Health and Care Excellence (NICE) guideline (NG71)<sup>17</sup> recommends referring people with Parkinson's to a dietitian for specialist advice. However, the responsibility of assessing which individuals are suitable for feeding tube insertion does not lie with the dietitian alone and should be performed as a multidisciplinary team (MDT), alongside a complete clinical evaluation of the

swallow conducted by speech and language therapy (SLT), advanced care planning, and the planning and coordination of future treatment and home care prior to tube insertion.<sup>7,18,19,20</sup>

### Risk of feeding tube complications

Brown *et al.*<sup>7</sup> advise that the risk of complications should be discussed with the individual. These would vary depending on co-morbidities, age, gender, body mass index, antibiotic prophylaxis, concurrent medications, biochemical values including platelet count and clotting time/factors, admission type (elective or nonelective), and stage of their medical condition.<sup>7,21,22</sup> Immediate risks may include aspiration pneumonia, ileus, infection, haemorrhage, pain, perforation of an internal organ, and the need for a step-up in care on discharge.<sup>7,21,22</sup> There may also be delayed risks to consider, such as peristomal leakage or infection, skin or gastric ulceration, buried bumper syndrome, tubes becoming dislodged or blocked, and granulation around the stoma site.<sup>18</sup> Further consideration should also be given to the cognitive influence of the condition. Irrespective of motor symptoms, marked cognitive impairment may render an individual unable to function independently. This could result in behavioural symptoms that risk harm, such as pulling at the tube which may result in a dislodged tube, trauma or peritonitis.<sup>23</sup>

### Risk of post-insertion mortality

Post-insertion survival rates should also be discussed. Morbidity and mortality would be expected to be higher in the context of progressive neurological disease.<sup>19</sup> Brown *et al.*<sup>7</sup> report a 7-day mortality rate of 0% and a 30-day mortality of 6.0% following PEG insertion in individuals with Parkinsonian disorders. Although quality of life was not surveyed in their study, the median survival in people with Parkinson's and dementia was found to be 344 days, which suggests that PEG placement in carefully selected individuals is not futile. Shintani<sup>24</sup> also reported that PEG feeding may lead to longer survival than oral feeding in home care residents with neurological impairments. Brown *et al.*<sup>7</sup> express that: *"If dysphagia leads to significant problems taking oral dopaminergic medication, and if giving that medication by [short-term] nasogastric tube leads to significant, worthwhile clinical improvements, then [long-term] PEG tube insertion should be considered."*

### Available care support

Available care support needs to be assessed to determine whether the current care provision is adequate to support with tube care, or to consider what the safest and most appropriate alternative(s) may be. Increased care needs may require a move into a nursing or care home (NH/CH). Brown *et al.*<sup>7</sup> reviewed how often individuals with Parkinsonian conditions are discharged to institutions (NH/CH) after PEG insertion. In their study, nearly a third of individuals admitted from home were discharged to institutional care, even though many reported their preferred place of care for final illness is their own home. Jensen *et al.*<sup>25</sup> found that the transition into institutional care takes part mainly in advanced stages of Parkinson's, due to advanced symptoms being associated with high caregiver burden and moderate depression of informal caregivers. The trend toward shorter survival in institutionalised (NH) individuals likely reflects their greater frailty.<sup>7</sup>

### Nutritional status & factors that may affect nutritional interventions

It's important that a nutritional assessment is conducted before a decision around tube insertion is made. This allows for early optimisation of nutrition regardless of whether a feeding tube is appropriate or not.<sup>19</sup> Within the Gloucestershire Home Enteral Feeding (HEF) Team a Neurology Dietitian is funded to support PEG assessments for all Gloucestershire patients with neurological conditions. The dietitian would conduct a domiciliary visit to establish nutritional status and required intervention(s), but will also use this opportunity to assess if there are any additional factors that may affect their nutritional plan. These factors may include medications, daily routine, available care support, home environment, current motor function, and whether there have been any changes to the individual's mobility and/or dexterity. See **Table 1** for details.

### Disadvantages vs advantages

Food is social, and eating together or offering food can help family and friends feel that they nourish their loved ones. Offering food can be used to show affection to loved ones, to show hospitality to strangers, or to adhere to or express religious beliefs.<sup>31</sup> Tube feeding may result in the lessening of this social interaction. Feeding tubes and enteral feeding can also be burdensome, leading to logistical challenges and a negative impact on comfort, dignity, body image, and quality of life.<sup>32,33</sup>

**Table 1: Factors potentially affecting nutritional interventions in Parkinson's**

Factors to consider	Reasoning
Medication(s)	<p>Symptomatic treatment of Parkinson's is based on the dopamine precursor levodopa.<sup>26</sup> Dietary amino acids can interfere with the absorption of levodopa,<sup>26</sup> which is why the NG71<sup>17</sup> recommends individuals on levodopa who experience motor fluctuations ensure a diet in which most of the protein is eaten in the final main meal of the day (a protein redistribution diet [PRD]). Alternatively, in those with motor fluctuations, a low-protein diet (LPD) has also been found to be an effective and economical approach to improve fluctuating response to levodopa. As the disease progresses and motor fluctuations become more severe, PRD may be more efficacious and lines up with the NG71 which recommends individuals with Parkinson's avoid a reduction in their total daily protein consumption.<sup>17,26</sup></p> <p>In addition, higher abundance of specific gut bacteria that restrict levodopa absorption also plays a significant role in motor fluctuations.<sup>27</sup> In healthy conditions, small intestinal bacterial overgrowth (SIBO) is prevented by the ileocecal valve, pancreatic enzyme activity, gut motility and gastric acid. However, those individuals likely to require levodopa often struggle with gut motility dysfunction and are also often on proton pump inhibitors (PPI) which are associated with SIBO, and in turn results in inhibited levodopa absorption.<sup>27</sup></p> <p>Interactions with some medications therefore make it logistically challenging to fit oral meals or tube feeds into the day without compromising on calorie or protein intake and symptom management.</p>
Gastrointestinal symptoms	<p>Levodopa is only absorbed in the small intestine. Therefore, gastric emptying is a major determining factor for onset of symptom relief.<sup>28</sup> However, many individuals with Parkinson's struggle with gastric dysmotility and constipation which can affect their motor response to levodopa. It is important that this is managed. Often prokinetic agents may be of particular benefit.<sup>7</sup> Prokinetics may also help relieve reflux which, if left untreated, could result in aspiration.</p>
Biochemical values	<p>Assess whether there are any underlying micronutrient deficiencies that may require supplementation. The NG71<sup>17</sup> recommends individuals with Parkinson's take a vitamin D supplement. The format of this may require adjusting depending on their ability to swallow.</p>
Daily routine	<p>The individual's daily routine may dictate method or timing of tube use. They should ideally be at a 30-45° angle when using the tube (to reduce aspiration risk);<sup>7</sup> depending on their daily routine/sleeping hours tube use may need to be limited to certain times. Oral meals (whether the individual has a safe swallow or is eating at risk) as well as medications, personal care, work/school, travel, and exercise, all need to be considered in method or timing of tube use.</p>
Dietary preferences, intolerances, and changes to oral intake	<p>Depending on the individual's need or preference for bolus or pump feeding, they may require training to get this in place as soon as possible. Feeding plans should be amended as suitable in relation to reported intolerances. A reduction in oral intake, deteriorating swallow, and frequent chest infections may all contribute to earlier feeding tube insertion to prevent further decline.</p> <p>Consider discussing that, just because enteral access is available, there may need to be a decision made around ANH withdrawal at EOL if there is no longer the possibility that it will benefit the patient, to mirror the natural decline that would've happened with oral intake.<sup>29, 30</sup></p>
Available care support	<p>Care support may dictate method or timing of tube use if the individual requires support; for example, they may not be able to pump feed if they live alone and are unable to use the pump without support, or they may only be able to feed via bolus at times when their friends/family/carers are available to support with this.</p>
Motor function and changes to their mobility and/or dexterity	<p>Dyskinesia (uncontrolled, involuntary movement that may occur with long-term levodopa use or progression of Parkinson's)<sup>31</sup> may dictate method or timing of tube use. This is due to involuntary movements potentially increasing the risk of displacement or entanglement of the feeding tube or extension tubing making some methods or timing of tube use impractical and unsafe.</p> <p>A decline in mobility may make daily activities such as mobilising to the toilet challenging, so night-time feeding may not be helpful if it would result in more frequent urination and therefore an increase in the need to mobilise overnight.</p> <p>A decline in dexterity may make using syringes or performing day-to-day feeding and tube care tasks more challenging, so alternatives such as pump feeding or care support may need to be considered.</p>
Declining respiratory function	<p>A decline in respiratory function may result in earlier feeding tube insertion to prevent respiratory decline beyond which the procedure would no longer be safe.</p>

However, feeding tubes may improve symptom control by allowing the administration of essential medication.<sup>7</sup> It has also been shown to improve nutritional markers by providing valuable access for nutrition and hydration in individuals who may otherwise struggle to manage this safely,<sup>7</sup> and, from experience, may allow for eating or drinking for pleasure rather than leaving the individual feeling pressured to meet their requirements through oral intake alone. In Gloucestershire some patients have reported that using the tube can be faster and easier than attempting an oral meal, which may have previously caused them a lot of distress.

## HOW to proceed towards feeding tube insertion

Sarkar *et al.*<sup>19</sup> advise that all patients should:

- Have a valid and written consent in place before tube insertion
- Ideally be monitored on a ward familiar with feeding tube care so any complications can be easily identified before the patient is safe to be discharged home, and
- Have biochemistry and other necessary investigations completed prior to admission to avoid potential discharge delays or anticipate failure to proceed with the procedure. Suggested biochemical tests include full blood count, renal function, platelet count

and clotting time/factors, liver function, bone profile, C-reactive protein, albumin, and glucose levels. In declining respiratory function, consider measuring FVC.

In Gloucestershire it's recommended all of the relevant tests are completed a maximum of 7 days prior to PEG insertion.

## After discharge with a feeding tube

Brown *et al.*<sup>7</sup> discovered that markers of improved nutrition were present in 83% of their patient group who were reviewed by a HEF team following discharge home with a feeding tube. They found that HEF follow-up was more likely in those discharged to their own home, and that survival was shorter for those discharged to a NH/CH, as well as in patients not followed up by a HEF team. The lower HEF follow-up rates of NH/CH patients may in part reflect a perception that the NH/CH staff have all the necessary expertise and require no further support.<sup>7</sup> However anecdotally, and based on the data from Brown *et al.*<sup>7</sup> it is recommended that HEF teams follow up all patients discharged with a feeding tube regardless of discharge location.

It can be helpful if the dietitian who conducted the PEG assessment remains involved or works closely with the follow up (HEF) care of the individual to allow for continuity of care. In Gloucestershire the

Neurology Dietitian role allows for dietetic assessment pre-PEG, support during admission for the tube insertion, and follow-up after discharge with a feeding tube (either directly or by one of the colleagues they work closely with within the HEF service).

## Conclusion

Dysphagia can affect more than 80% of people with Parkinson's. Enteral tube access can facilitate administration of nutrition, fluid, and medication in those individuals who may have otherwise not been able to manage these safely. However, feeding tubes do not eliminate the risk of aspiration and can have a negative impact on quality of life. Assessment of patient suitability for feeding tube insertion should be approached as a multidisciplinary team. The risks of complications and mortality should be discussed with the individual and the advantages and disadvantages weighed up. Changes to care needs and potential institutionalisation need to be considered. An assessment of nutritional status and factors that may affect nutritional interventions needs to be done prior to tube insertion. HEF follow-up has been shown to improve nutritional markers and should be considered regardless of discharge location.

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