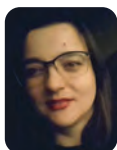


# Parkinson's

## Nutritional considerations & multidisciplinary team working



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In 1817, James Parkinson, a London-based surgeon and apothecary wrote a pamphlet '*An Essay on the Shaking Palsy*', which is the first medical description of the progressive neurological condition we now refer to as Parkinson's or Parkinson's Disease (PD).<sup>1</sup> Parkinson's UK states that it prefers the term Parkinson's to Parkinson's disease due to possible negative connotations of the word disease.<sup>2</sup>

There are an estimated 145,000 people living with Parkinson's in the UK.<sup>3</sup> The majority are over 50 years old, with only 1.3 % of people with Parkinson's under 50 years of age.<sup>4</sup> Parkinson's is more common in men (1.4-1.5 times) than women,<sup>4</sup> and is described by Parkinson's UK as the fastest growing neurological condition in the world.<sup>3</sup>

### Parkinson's symptoms

Parkinson's is a collection of 40 or more symptoms, divided into motor and non-motor symptoms.<sup>5</sup> It is the motor symptoms of tremor and bradykinesia (slowness of movement and rigidity) that are most associated with the condition.<sup>6</sup> However, there are many non-motor symptoms that can significantly affect those living with Parkinson's and lead to adverse outcomes and deterioration in quality of life, including:<sup>7</sup>

- Anxiety
- Depression
- Sleep disturbance
- Pain
- Constipation
- Hyposmia (loss of smell)
- Hypogeusia (loss of taste)
- Sialorrhoea (hypersalivation/excessive drooling)
- Dysphagia (swallowing problems).

### The impact on nutritional status

#### Risk of malnutrition

People with Parkinson's are at high risk of malnutrition; a systematic review and meta-analysis of 49 studies conducted in 21 countries across Asia, Australia, Europe and North and South America, involving 5,727 patients, found that 23.9% were at risk of malnutrition and 11.1% were malnourished.<sup>8</sup> A variety of malnutrition screening tools were used in these studies, including the 'Malnutrition Universal Screening Tool' ('MUST'), Subjective Global Assessment (SGA) and Mini Nutritional Assessment (MNA).<sup>8</sup> An earlier review by Sheard *et al.* put the rate of malnutrition in those with Parkinson's at 0-24% and risk of malnutrition at 3-60%.<sup>9</sup>

There are many reasons for the increased risk of malnutrition in people with Parkinson's. Increased age, severity of disease and depressive symptoms were most associated

with higher levels of malnutrition in people with Parkinson's.<sup>10</sup> The motor symptoms of Parkinson's, tremor and rigidity, may increase energy expenditure<sup>8</sup> and, if compensatory increases in energy intake do not take place, this can lead to weight loss. In addition, motor symptoms may make it more difficult for those with Parkinson's to shop, cook or feed themselves. Non-motor neuropsychological symptoms, such as anxiety and depression, may impair appetite and the desire to participate in self-care activities, including eating and drinking. Other non-motor symptoms, such as decreased gastrointestinal transit time, hyposmia and dysphagia, may also significantly interfere with oral intake and lead to weight loss.<sup>9</sup>

ESPEN Guidelines<sup>11</sup> state: "*Recommendation 23: We recommend that PD patients should undergo regular monitoring of nutritional and vitamin status during the course of the disease. Particularly, attention should be focused on changes in body weight, and the need of supplementing vitamin D, folic acid and vitamin B12. Grade of recommendation B - strong consensus (91% agreement)*".

#### Constipation

Constipation is one of the most common gastrointestinal dysfunctions, effecting 50-80% of people with Parkinson's.<sup>12</sup> Yu *et al.* (2018) noted that 24.5% of patients reported having constipation before the development of motor symptoms<sup>13</sup> and that has led to the theory that constipation may be a prodromal feature of Parkinson's and that constipation may indicate an increased risk of developing Parkinson's.<sup>14</sup> Yao *et al.* found that patients with constipation had a 2.36-fold increased risk of developing Parkinson's than those without constipation.<sup>12</sup> To help in the prediction of the development of Parkinson's, Yao and colleagues recommended looking for the presence of other non-motor symptoms, such as anosmia and rapid eye movement sleep disorder in combination with constipation.<sup>12</sup>

The full mechanism by which constipation occurs in people with Parkinson's is not yet fully understood, but Xu *et al.* describes how colonic transit time is prolonged in people with Parkinson's and that changes in the intestinal gut flora have been noted, including less *Bacteroidetes* and *Prevotellaceae* and more *Enterobacteriaceae*.<sup>15</sup> This in turn may affect neurotransmitter and microbial metabolite synthesis, resulting in poor gastrointestinal motility.<sup>15</sup> In addition, medication used to treat Parkinson's may further exacerbate constipation. Treatment with the dopamine agonist, levodopa, has been found to increase constipation within one year by delaying gastric emptying.<sup>15</sup> Constipation is a side effect of ropinirole, bromocriptine, and piribedil.<sup>15</sup> The poor mobility and increased sedentary lifestyle of those with Parkinson's may contribute to worsening gut motility, as would dehydration often associated with another non-motor symptoms of Parkinson's, such as dysphagia.<sup>15</sup>

Yu *et al.* found that the presence of constipation significantly impacted on the quality of life and activities of daily living of people with Parkinson's.<sup>13</sup> It has even been postulated that the early development of constipation in those with PD is associated with an increased likelihood of developing dementia.<sup>16</sup> Camacho *et al.* describe a hypothesis where changes in gut motility in patients with Parkinson's could result in a chronic immune response that alters in the gut microbiome leading to low-grade inflammation and degenerative neurological changes.<sup>16</sup>

In a systematic review by Pedrosa Carrasco *et al.* they describe good evidence for dietetic advice around diet and lifestyle changes.<sup>17</sup> These include advising increasing fluid and fibre intake as beneficial in the treatment of constipation in Parkinson's.<sup>17</sup> Also, they discuss two randomised control trials (RCT) that showed that taking the probiotic *Lactobacillus casei shortha* improved stool consistency and frequency and possibly increase colon transit time.<sup>17</sup> This systematic review reports that macrogol (commercial preparations are known by brand names: Laxido, Movicol, CosmoCol, Molaxole)<sup>18</sup> probably is the preferred laxative to use in patients with Parkinson's who have constipation; it was shown in RCTs to be safe and more effective than lactulose, improving stool frequency and consistency.<sup>17</sup>

### Loss of taste & smell

Oppo *et al.* state that hyposmia (smell dysfunction) occurs very early in the

development of Parkinson's.<sup>19</sup> Olfactory impairment is associated with a 10% increased risk of developing Parkinson's in the future.<sup>19</sup> Impairment of smell sensation is very common in people with Parkinson's, ranging from 75-95%, and is more common in men with Parkinson's.<sup>19</sup> A prospective study of 105 patients with Parkinson's and hyposmia and 59 patients with Parkinson's and anosmia showed that those with hyposmia have a worsening clinical course. He *et al.* proposed that the presence of olfactory dysfunction may be used to predict disease progression.<sup>20</sup> Losing the sense of smell can have a negative impact on quality of life and may contribute to depressive symptoms linked with decreased pleasure from food, drink and socialising.<sup>19</sup> Unlike hyposmia, ageusia (loss of taste) is much more commonly seen in advanced Parkinson's and is associated with cognitive impairment.<sup>19</sup>

### Dysphagia

Swallowing problems in people with Parkinson's are common, Suttrup & Warnecke report that more than 80% of patients develop dysphagia during the course of the disease.<sup>21</sup> Whilst Kwon & Lee found that oropharyngeal dysphagia can occur in 18.5-100% of patients with Parkinson's, depending on study parameters.<sup>22</sup> In the more advanced stages of Parkinson's dysphagia is more likely to be a prominent feature, and 68% of patients will have dysphagia 10-11 years after the motor symptoms of Parkinson's appear.<sup>22</sup> Patients may be unaware of their dysphagia. Kwon & Lee (2019) describe studies where 35% of patients self-report dysphagia but in studies where objective measures, such as the water swallow test, fiberoptic endoscopic evaluation of swallowing (FEES) or videofluoroscopy, are used the rate of dysphagia in patients with Parkinson's rises to 82%.<sup>22</sup> Thus, early detection by appropriately trained healthcare professionals, such as a speech & Language therapist (SLT), is crucial to identifying dysphagia in patients with Parkinson's. In addition, Kwon & Lee recommend multidisciplinary collaboration in managing dysphagia in patients with Parkinson's.<sup>22</sup>

Suttrup & Warnecke report that dysphagia reduces quality of life of those with Parkinson's.<sup>21</sup> In addition, it can make taking medication more difficult, contribute to the risk of malnutrition and increase the risk of aspiration pneumonia.<sup>21</sup> Aspiration pneumonia is the leading cause of death in people with Parkinson's.<sup>21</sup>

### Risk of osteoporosis, falls & fractures

People with Parkinson's are at increased risk of osteoporosis, low bone density and a three-fold increased risk of falls.<sup>23</sup> A study of 186 patients with Parkinson's and 802 controls, using dual-energy X-ray absorptiometry, found osteoporosis in 11.8% and osteopenia in 41.1% of those with Parkinson's.<sup>24</sup> They found that low body mass index and low 25-OH vitamin D levels correlated with low bone mineral density at both hip and lumbar spine.<sup>24</sup> Schini *et al.* found a more than two-fold increase in the risk of hip fracture and nearly two-fold increase in non-vertebral fracture in patients with Parkinson's compared to controls.<sup>23</sup> Feng *et al.* propose that the mechanisms that increase the risk of osteoporosis in people with Parkinson's are lack of physical activity, neuroinflammation mediated by TNF $\alpha$ , excessive MMP-9 production and vitamin D deficiency.<sup>25</sup>

### Multidisciplinary care

The National Institute for Health and Care Excellence (NICE) guidance recommends that people with Parkinson's should have access to a wide variety of healthcare professionals throughout their patient journey, including a Parkinson's specialist nurse (PD SN), physiotherapist (PT), occupational therapist (OT), SLT and dietitian to manage motor and non-motor symptoms.<sup>26</sup>

In 2010, the Scottish Intercollegiate Guidelines Network (SIGN) guidelines stated that multidisciplinary working is best practice.<sup>27</sup> However, there continues to be a lack of evidence to show consistent benefits of multidisciplinary team (MDT) working.<sup>28</sup> This is most likely due to the difficulty of conducting randomised controlled trials in diverse healthcare settings and using multiple outcome measures, rather than an actual lack of benefit of MDT working.<sup>28</sup>

For those with Parkinson's, in practice, having access to an MDT throughout their disease process can ensure that new and worsening conditions are picked up early and appropriate support is provided to those with Parkinson's and their carers.

Good nutrition and management of nutritional challenges is an important part of maintaining good quality of life,<sup>11</sup> and may in turn lead to reducing the risk of serious complications, such as falls, osteoporotic fractures, and bowel obstruction, in people with Parkinson's.

In practice, dietitians can work with SLTs to identify those with swallowing problems (dysphagia) and providing appropriate dietary advice on texture modification of food and thickening of fluids. Physiotherapists working with patients on improving balance, strength and resilience may identify patients who would benefit from dietetic advice to support their exercise programmes. As optimising bone health is important for the ongoing maintenance of good health, the dietitian may be key to identifying patients at risk of vitamin D deficiency and ensuring that this is addressed by appropriate supplementation.<sup>11</sup>

Healthcare professionals involved in the care of people with Parkinson's are detailed in **Figure 1**.<sup>29</sup>

### The Parkinson's Multidisciplinary Team (PD MDT) Clinic

#### Background

A Buckinghamshire NHS Trust Parkinson's Specialist Nurse (PDSN) confirmed that back in 1995 there were monthly PD MDTs held in a day hospital. Patients were able to attend for the whole day, with the morning devoted to assessment, then attendees could have lunch together and in the afternoon there was a more social focus with games, exercises, talks and input from the local branch of the Parkinson's Disease Society. At these original PD MDT days, patients were seen by a neurology specialist doctor, PDSN, physiotherapist, occupational therapist (OT) and OT assistant. Also in attendance were three nurses, a healthcare assistant (HCA) and volunteer. This clinic was popular with patients and healthcare professionals. However, when the day hospital was closed due to funding cuts, the PD MDT clinics ceased.

The reinstatement of a Buckinghamshire NHS Trust PD MDT Clinic began in March 2018. The current clinics run once a month, and we invite 6-8 patients to attend. Currently, the core members of the PD MDT are: PDSN, Physiotherapist, Therapy Assistant, SLT, Dietitian and

**Figure 1: Healthcare professionals involved in the care of those with Parkinson's<sup>29</sup>**



Adapted from Bloem B, Okun M, Klein C. (2021). Parkinson's Disease. *Lancet*; 397(10291): 2284-2303

Administrator. Initially, when the clinic was restarted in 2018, we also had an OT and OT assistant in place. Although, since 2020, we refer patients to an OT should they need support.

#### The Clinic

When the patient attends the PD MDT Clinic, they have the opportunity to:

- Be assessed by the physiotherapist for any mobility issues. This may lead to them being referred on to an exercise programme and/or referred to OT, who can assess if there are any equipment and adaptations that may support a patient's independence.
- See the PDNS for a symptoms and medication review.
- See the SLT and dietitian to review both communication and nutritional issues, such as swallowing difficulties, assessments of malnutrition, advice on micronutrient levels, such as vitamin D, and bowel function.

The SLT and dietitian have opted to perform joint reviews, as the management of dysphagia benefits from their complementary expertise on texture modification, thickening fluids, food fortification and recommending nutritional supplements. As we see patients on an annual basis, we are able to keep track of weight and may pick up signs of malnutrition developing through routine 'MUST' screening. In these cases, I provide initial dietetic advice to combat malnutrition and then refer directly to the Community

Nutrition and Dietetic Department for further follow-up to ensure individualised dietetic care plans are developed for the patient.

In addition, I aim to identify patients with constipation so they can receive information about increasing fluid, fibre and probiotic intake, as well as those that may benefit from medical interventions such as macrogol. This can be discussed directly with the PDSN, who can either prescribe or refer to the GP for prescription.

As already discussed, people with Parkinson's are at increased risk of osteoporosis, falls and fractures. Thus, a dietitian can play a crucial role in identifying patients who would benefit from advice to optimise their bone health through good nutrition and hydration. Other areas I may advise might be helping patients who take multiple doses of levodopa, multiple times a day, balance the possibility of an interaction between their medication and protein, and ensuring total protein intake is not compromised, which might put them at risk of malnutrition and sarcopenia.

In addition to these PD MDT Clinics, the Physiotherapists run a 6-week exercise programme for patients with Parkinson's. At the end of these sessions, members of the PD MDT are invited to give a short presentation to the attendees on a relevant topic. I discuss the key areas of concern around nutrition for patients with Parkinson's.



## Challenges

The biggest challenge for the PD MDT since restarting the Clinic in 2018 is finding a suitable venue with a large enough space for a physiotherapy assessment area, height measurement and weighing scales facilities, and consultation spaces for the PDSN, Dietitian and SLT. The original plans for the PD MDT Clinic were to rotate the clinic around different community sites across the Trust to bring the MDT closer to patients. However, this proved too difficult as there were insufficient sites with the correct type of facilities and space available on a monthly basis. In Spring 2018, we started off in a section of a ward on the top floor of Wycombe Hospital, but this had very limited space. The SLT and I had to choose between an area cordoned off by screens or in a storeroom for our consultations, which was less than ideal and did not provide good patient confidentiality. Thankfully, now we have access to a suite of rooms on the ground floor of Amersham Hospital, which ensures that all the members of the MDT have sufficient and appropriate spaces to carry out their assessments of patients.

Another limitation we frequently encounter is that many of our patients with Parkinson's have significant mobility problems that require them to attend our clinic via hospital transport. Sometimes the transport does not arrive at the correct time for the patient, so they are unable to attend their appointment and need to be rebooked, in some cases on numerous occasions.

### The future of the PD MDT Clinic

As stated by the Parkinson's UK, the number of people affected by Parkinson's

is growing and thus our PD MDT would aim to increase the capacity of the clinic to see more patients and review these patients at least annually in line with recommendations.<sup>30</sup> We would want to re-establish the OT and OT assistant as part of our core team, as their input is recommended by NICE.<sup>26</sup> In addition, considering the neuropsychological symptoms of Parkinson's, including access for patients to mental health support would be a key improvement to what the PD MDT can offer.<sup>29</sup>

Whilst anecdotally we believe that the PD MDT Clinic is providing benefits to the patient, we need to put in place mechanisms that would allow us to evaluate our outcomes more objectively and form a medium for patients to provide feedback routinely.

## Conclusion

Parkinson's is a condition with a heavy symptom burden for patients and their loved ones. In addition, people with Parkinson's have a high rate of utilisation of healthcare services, which results in associated costs to the NHS, particularly as a result of emergency admissions. Thus, a dietitian working as part of a MDT can be instrumental in helping these patients manage their condition and limit some of the risk by providing appropriate dietetic assessments and advice. By taking action to reduce the risk of malnutrition, appropriately manage constipation, detect early and help mitigate the effects of dysphagia, and support good bone health, the dietitian may prevent hospital admissions for those with Parkinson's.

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World Parkinson's Day takes place on 11 April 2023. Our PD MDT are planning on providing a training session via our Allied Healthcare Professionals (AHP) network to raise awareness of this condition and how MDT working can support people with Parkinson's.

For further information, or to see how you could get involved, visit: [www.parkinsons.org.uk/get-involved/world-parkinsons-day](http://www.parkinsons.org.uk/get-involved/world-parkinsons-day).

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