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of UK Dietitians

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**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
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***Best practice guidance for dietitians on  
the nutritional  
management of Parkinson's***

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## Introduction

People living with Parkinson's are particularly susceptible to weight loss and malnutrition. Involuntary movements associated with Parkinson's result in increased energy expenditure, while disease symptoms and medication side effects can limit food intake and alter metabolism. They may also choose to follow unconventional nutritional therapies that consequently exacerbate malnutrition. Dietitians play a key role in helping people with Parkinson's to optimise their nutritional status and manage various nutrition-related symptoms and medication side effects. To assume this role, dietitians need to have up-to-date knowledge about the nutritional consequences of Parkinson's, as well as strategies for managing a variety of nutrition-related symptoms.

For an overview of Parkinson's Disease, including symptoms and treatments, we recommend accessing the Parkinson's UK website<sup>1</sup> for up-to-date information, and signposting to other learning content and programmes. In order to help establish any learning needs you may have, it is recommended you utilise the AHP Competency Framework for Progressive Neurological Conditions<sup>2</sup>, which also includes a section dedicated to Parkinson's Disease

## Nutritional management at different stages of Parkinson's

### Diagnosis and early disease

Parkinson's can be a challenging diagnosis to make in its early stages. It is a diagnosis based on clinical observation and exclusion of other conditions<sup>3</sup>.

NICE recommend considering referring people with Parkinson's Disease to a dietitian for specialist advice<sup>4</sup>.

#### *Dietetic assessment*

The initial assessment could be facilitated by another healthcare professional as well as a dietitian e.g. Parkinson's Nurse, GP or practice nurse. Examples of assessments that could be undertaken are: weight; height; body mass index (BMI); and/or using a validated nutrition screening tool e.g. the Malnutrition Universal Screening Tool (MUST)<sup>5</sup>, or the Patients Association Nutrition Checklist<sup>6</sup>.

## *Dietary intervention*

### Healthy eating

There is no specific diet required; however, people newly diagnosed with Parkinson's should be advised to eat a healthy and well-balanced diet. Good nutrition is essential to the wellbeing of this client group. It is imperative to establish and maintain good eating habits throughout the course of the condition<sup>7</sup>.

Written and verbal information should be provided on how to adopt the Healthy Eating Guidelines set out by the Food Standards Agency (FSA) and are incorporated into the Parkinson's UK resource *Diet and Parkinson's*<sup>8</sup>.

### Weight maintenance

Being underweight, something commonly experienced by those living with Parkinson's, as well as being overweight can lead to adverse health effects. In overweight individuals, it is advised that an agreed goal for ideal body weight should be established. This is especially significant in those who have co-morbidities e.g. hypertriglyceridaemia, diabetes, CVD etc.<sup>9</sup>. Unintentional weight loss is common; people with Parkinson's are at increased risk of malnutrition and nutritional status should be monitored routinely regularly throughout the course of the disease<sup>10</sup>. Malnutrition in Parkinson's is probably under-reported, and several predictors of malnutrition have been found: older age at diagnosis, higher levodopa equivalent daily dose/body weight, anxiety and depression and living alone<sup>10</sup>. Dysphagia is also frequently seen, especially in the advanced phases of the disease, although it can be present at any stage<sup>10</sup>.

Body weight should be monitored throughout the course of the disease, and steps taken to ensure nutritional needs are met – this may include a food first approach, supplementation including individual vitamins and oral nutrition support when deemed appropriate, as well as consideration of artificial nutrition support where indicated (i.e. Nasogastric feeding, gastrostomy and in very rare cases, if the enteral route is ruled out, parenteral nutrition). However, it should always be remembered, as with many neurological conditions, this client group is particularly unique and must be treated as individuals; it is well known that this condition does not affect one person in the same way as the next.

### High fibre diet with good fluid intake

Constipation is one of the most common problems experienced by Parkinson's patients.

About 60-80% of patients with Parkinson's complain of constipation, which usually appears about 10 to 20 years before motor symptoms become evident<sup>11</sup>.

It is thought to be caused by damage to the peripheral or central nervous system<sup>11</sup>.

Other causes of constipation in Parkinson's patients are lack of fibre intake, a lack of fluid intake – often associated with dysphagia, decreased mobility and as a result of some Parkinson's medications.

Dietary advice on how to prevent constipation by following a high fibre/fluid intake should be provided, and supporting written information is available in the Parkinson's UK resource *Looking after your bladder and bowels when you have Parkinson's*<sup>12</sup>.

In addition to advising on a high fibre and fluid intake, ESPEN suggest people with Parkinson's experiencing constipation can benefit from the use of fermented milk containing probiotics and prebiotic fibre<sup>10</sup>.

### Antioxidants

There is no evidence to support that taking supplemental doses of antioxidants slows the progression of the condition or enhances the effects of Parkinson's drugs.

NICE explicitly state that Vitamin E should not be used as a neuroprotective therapy<sup>4</sup>, and ESPEN state that supplementation of antioxidants are not recommended<sup>10</sup>.

For those who are concerned about their intake of antioxidants, they should be reassured that a well-balanced diet will meet their antioxidant needs. Signposting them to the section on Antioxidants in the Parkinsons UK '*Diet and Parkinsons*' resource will help reinforce your advice and guidance<sup>8</sup>.

### Co-enzyme Q10

It was previously thought that taking supplementary co-enzyme Q10 could delay the progression. However, evidence remains inconclusive and NICE guidance recommends that co-enzyme Q10 should not be used as a

neuroprotective therapy, except in the context of clinical trials<sup>4</sup>. Co-enzyme Q10 can be found naturally in offal, beef, soya oil, oily fish and small amounts in peanuts.

## B Vitamins

ESPEN states that during regular monitoring of nutrition and vitamin status, particular attention should be focused on folic acid, vitamin B12 and vitamin D<sup>10</sup>.

Treatment with levodopa has shown an elevation of homocysteine. This is greater in patients on higher doses of levodopa and is due to levodopa methylation by catechol-O-methyltransferase (COMT). Concomitant use of COMT inhibitors may limit the raising of plasma levels, although the regulation is closely linked to vitamin B12 and folate status. Studies have shown that levodopa-treated Parkinson's patients have also lower circulating levels of folate and vitamin B12. Administration of these vitamins is effective in reducing homocysteine levels and should be considered to prevent neuropathy and other complications associated with hyper-homocysteinaemia<sup>10</sup> – the indication for supplementation should be considered and discussed with the multi-disciplinary team.

## Vitamin D

NICE advises people with Parkinson's to take a Vitamin D supplement<sup>4</sup>. See NICE guidance on Vitamin D for recommendations on vitamin D testing<sup>13</sup>, and the NICE quality standards on Falls in Older people<sup>14</sup> and Osteoporosis<sup>15</sup>.

All at risk groups are currently advised to take a supplement that meets 100% of the reference nutrient intake (RNI) for their age group. At the time of publication, the RNI is 10 micrograms/day for all the general population over 4 years old, and in population groups at increased risk of vitamin D deficiency<sup>13</sup>.

## Monitoring

Dietitians that specialise in progressive neurological conditions agree that people newly diagnosed with, or in the early stages of Parkinson's, should have a nutritional assessment and/or their nutritional status reviewed at least on an annual basis if there are no indications for a more frequent review (e.g. clinical changes), or at the patients' and/or multidisciplinary team's request (this may be by a dietitian, or another health/care professional) - this is supported by ESPEN<sup>10</sup>.

## Advanced disease

### *Dietetic assessment*

Assessment is similar to the early stages of the condition paying particular attention to:

- unintentional weight-loss
- decreased oral intake
- swallowing difficulties
- poor dentition, dry mouth
- changes to taste and smell
- increased frequency of dyskinesias (abnormal involuntary movements)
- early satiety
- gastrointestinal problems: Nausea, vomiting, gastroparesis, reflux, diarrhoea
- constipation
- side effects of medication (see Table 1 below)
- physical difficulties impairing eating and drinking and preparing meals
- bone health
- weight-gain after deep brain stimulator (DBS) insertion
- mental health problems, including impulse control disorders (e.g. binge eating)
- frequency of 'on' (increased involuntary movements) and 'off' (increased muscle tone) periods
- orthostatic hypotension (OH) – characterised by a sudden fall in blood pressure that occurs when a person assumes a standing position

Name of drug	Mode of action	Side effects
<b>Levodopa</b> (Co-beneldopa, co-careldopa)	The most effective drug in the treatment of Parkinson's. It is a larger neutral amino acid – tyrosine derivative – and is absorbed in the small intestine. Once absorbed it crosses the blood-brain barrier where it is converted to	Prolonged use can result in nausea, vomiting and hypotension. Associated with hyper-homocysteinaemia. A decarboxylase inhibitor, Benserazide, is combined with levodopa to minimise these side effects.

	dopamine.	Weight loss.
<b>Dopamine agonists</b> (pramipexole, ropinirole)	These are a class of drugs that provide antiparkinsonian effects while avoiding some of the problems associated with levodopa.	Acute side effects of these drugs include nausea, vomiting, postural hypotension and psychiatric problems. Increased risk of developing impulse control disorders.  They tend to occur with the initiation of treatment and as intolerance develops over several days to weeks.
<b>MAO-B inhibitors</b> (rasagiline, selegiline, safinamide)	This is used in the early stages of Parkinson's to delay the use of levodopa. It provides reduced motor fluctuations and increased 'on' time.	It has amphetamine and metamphetamine metabolites which can cause insomnia, therefore could induce daytime sleeping.
<b>Anticholinergics</b> (procyclidine, trihexyphenidyl)	This is typically used in younger Parkinson's patients (<60 years) in whom resting tremor is the dominant clinical feature and cognitive function is preserved.	Side effects may include dry mouth, constipation and nausea
<b>Amantidine</b>	This is an antiviral agent that is believed to increase dopamine release by blocking dopamine re-	Side effects include confusion, hallucinations, insomnia, nightmares and dry mouth.

	<p>uptake by stimulating receptors and possibly by anticholinergic effects.</p>	
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**Table 1:** Medication side effects: the following medications are commonly used in the management of Parkinson's

Antiemetics are usually used in conjunction with these medications to ease the symptoms of nausea and vomiting.

### *Dietary intervention*

#### Oral nutrition support (ONS)

ONS should be provided when the patient can no longer maintain their body weight through oral diet/intake alone<sup>16</sup>.

A food first approach should be explored first, with suggestions such as food fortification, high energy/protein advice, and regular small energy-dense meals.

The use of oral nutrition support products, including sip feeds, should be considered for those who are unable to maintain an adequate intake with food alone, or are unable to adhere to food fortification due to, for example, anxiety at meal times, early satiety or lack of sufficient help to prepare the fortified meals and snacks.

Imaginative use of these products will help reduce taste fatigue and increase adherence to recommendations.

Particular attention should be paid to those on a texture modified diet (TMD), especially puree diets. Puree diets are known to provide varying nutritional adequacy and can be unpalatable, if not prepared imaginatively. Some fortification techniques and suggestions may need to be amended. All patients on texture modified diets should have their intake assessed by a dietitian for nutritional adequacy<sup>17</sup>.

It is recommended that the dietitian and speech and language therapist work closely to

ensure the patient receives appropriate and optimal nutrition and hydration, and consideration should be given to the use of pre-thickened ONS.

People with Parkinson's should be advised not to take over-the-counter dietary supplements without first consulting their pharmacist or other healthcare professional<sup>4</sup>.

### Artificial Nutrition Support (ANS)

In Parkinson's it often helps to anticipate artificial feeding, or the placement of a feeding tube to support hydration, at an early stage through discussions with the patient and/or carer, supported by the multidisciplinary team<sup>18</sup>.

Swallowing difficulties need to be addressed promptly to prevent weight loss and malnutrition. About 95% of Parkinson's patients experience swallowing difficulties at some stage of the condition<sup>19</sup>.

Silent aspiration can occur, and many people with Parkinson's may be unaware they have a problem. When assessing and monitoring, always look out for red flags that indicate silent aspiration could be happening.

Dysphagia occurs in the later stages of Parkinson's compared to atypical parkinsonian syndromes e.g. progressive supranuclear palsy (PSP) or multiple system atrophy (MSA)<sup>20</sup>.

Significant problems with swallowing require expert assessment from a speech and language therapist and guidance regarding appropriate food texture modification. Since texture modified diets e.g. puree, may be nutritionally diluted and not energy dense enough to prevent weight loss, additional supplementary enteral nutrition support may be indicated.

Tube feeding may be given alongside oral intake, or as the main source of nutrition. Short-term feeding via nasogastric tube is likely appropriate to manage an acute event impacting swallow or nutritional intake. For longer term, a gastrostomy (for example a PEG or RIG) should be considered<sup>16</sup>.

Gastrostomies are being used increasingly in the treatment of patients with neurogenic dysphagia to prevent or reverse nutritional deficits<sup>21</sup> and this can improve fitness and quality of life for those patients unable to take sufficient supplements orally.

Reassurance should be given that gastrostomies can be placed before food intake has fallen or weight loss has occurred, in order to support optimal hydration.

### *Bone health/Osteoporosis*

People with Parkinson's have been found to have a lower bone mineral density (BMD) and increased risk of osteoporotic fracture<sup>10</sup>. The reasons are multi-factorial and include low mobility, decreased muscle strength, low body weight, deficiency in Vitamin D, B12, folic acid and hyperhomocysteinaemia<sup>22</sup>. As discussed earlier (page 4), Vitamin D supplementation is recommended for a large proportion of the general population – if a person is not already on a Vitamin D supplement when they are diagnosed, then they should be re-assessed as their risk level will be greater.

If BMD is lower, then in line with usual treatment for osteoporosis, calcium requirements are likely to be increased, and greater than the 700mg/day reference nutrient intake for the general population over 19yrs old. A supplement may be required to meet requirements, and this should be discussed with the MDT.

### *Orthostatic hypotension (OH)*

OH (also known as postural hypotension) is a sudden fall in blood pressure that occurs when a person assumes a standing position.

The prevalence of symptomatic orthostatic hypotension (OH) may be as high as 60% in people living with Parkinson's<sup>23</sup>.

This could be caused by: a) dopaminergic drugs which induce or worsen orthostatic hypotension and/or b) primary autonomic failure with an involvement of the peripheral autonomic system caused by Parkinson's.

OH sufferers may also experience post-prandial hypotension (PPH), resulting in blurred vision and dizziness after meals. These symptoms can occur any time from ingestion to 90 minutes post meal. Studies from long-term care facilities have shown that 24-36% were diagnosed with PPH<sup>24,25</sup>. It has been suggested that the nutrient composition of meals affect the magnitude of the decrease in postprandial hypotension.

The intestines require a large amount of blood for digestion. When blood flows to the intestines after a meal, the heart rate increases and blood vessels in other parts of the body constrict to help maintain blood pressure. However, with this patient group, such mechanisms may be inadequate. Blood flows normally to the intestines, but the heart rate does not increase adequately and blood vessels do not constrict enough to maintain blood pressure. As a result, blood pressure falls.

Symptoms include:

- feeling dizzy and light-headed
- changes in vision such as blurring, greying or blacking vision
- feeling vague or muddled
- losing consciousness with or without warning – a 'blackout' or 'faint' as a result of hypotension
- pain across the back of shoulders or neck – 'coat hanger' pain
- pain in lower back or buttocks
- angina-type pain in the chest
- weakness
- fatigue

The symptoms are typically worse when standing and improve on lying down.

### Dietary management of OH

The main aim of the dietary management is to assist in the alleviation of the symptoms of hypotension, by focusing on the factors that affect blood pressure.

The goals of treatment are improving functional capacity and quality of life, and preventing injury, rather than achieving a target blood pressure<sup>26</sup>. Dietary changes aim to alleviate the symptoms of postural and postprandial hypotension and assist with fatigue management.

The skills of the dietitian are required when advising on ways to manipulate the diet, to ensure the nutritional adequacy of the diet is not compromised. It should also be ensured that restrictive diets are not followed, which would lead to further risk of malnutrition in an already nutritionally vulnerable group of patients.

Advice for people with OH:

- Avoid large meals<sup>27</sup> - aim for smaller, evenly distributed meals
- Reduce carbohydrate intake, especially simple sugars<sup>28,29</sup>. It has been hypothesised that carbohydrates induce hypotension in autonomic failure through the vasodilating properties of insulin<sup>30</sup>
- Increase intake of salt
- Increase fluid intake<sup>31</sup>
- Decrease or omit alcohol intake<sup>32</sup>

### PPH accompanied by weight loss

As the OH progresses, many patients experience weight loss, the reason being multifactorial. Patients may restrict intake as they associate meals or a certain food with post-prandial symptoms, or as a consequence of dysphagia.

Deciding upon which oral supplement to use can become a challenge if you are trying to get your patient to avoid/decrease glucose intake. Some patients can tolerate energy-dense oral sip feeds without experiencing symptoms, especially if sipped slowly. However, for those that do experience PPH symptoms, a lipid-based solution such as Calogen/Procal shots, can be useful. The provision of innovative recipes and suggestions on how to incorporate these supplements into meals will be helpful to the person living with PPH.

It is important to liaise with the MDT regarding treatments, as it may be preferred to manage OH/PPH pharmacologically, allowing nutritional intake to be maximised. If the patient's autonomic failure is so severe, dietary intervention may not offer any benefit.

### *Weight gain post-chronic bilateral subthalamic or deep brain stimulation (CDBS)*

Deep Brain Stimulation (DBS) is a procedure in which stimulating electrodes are placed stereo-tactically into the deep structures of the brain. DBS in selected patients has provided significant therapeutic benefits. Successful DBS allows a decrease in medication or makes a medication regimen more tolerable. There are gains in movement and control. Consequently, the intervention is used for patients who cannot be adequately controlled with medications or whose medications have severe side effects. Only a very small subgroup of people (~1-10%) diagnosed with Parkinson's are eligible for DBS<sup>33</sup>.

It has been shown that weight gain can occur in 87% of patient's post DBS surgery. Around 38% of these patients were found to be overweight (BMI>26–29.9) six-months post-operatively. This is thought to be due to improvement in motor fluctuations, rather than an increase in oral intake<sup>34</sup>.

Dietary intervention (using ideal body weight to calculate energy requirements) at time of surgery has been advocated by researchers in Portugal<sup>35</sup> to enhance the benefit of the surgery and prevent metabolic disorders. It is thought that excessive weight gain could exacerbate motor function impairment in Parkinson's.

It is suggested that clinicians actively monitor weight changes in these patients<sup>10</sup>.

Discussion of, and encouraging adoption of the Healthy Eating Guidelines as set out

by the Food Standards Agency (FSA) and incorporated into the *Diet and Parkinson's* resources<sup>8</sup> available from Parkinson's UK can be a useful to prevent rapid weight gain in those who are undergoing or have undergone DBS surgery.

### *Dietary protein manipulation*

Levodopa is the standard, and often initial, therapy for patients with this condition; however, with continued treatment and as the condition progresses, up to 80% of patients experience 'wearing off' symptoms, dyskinesias and other motor complications.

It was believed in the late 1980s and early 1990s that dietary protein manipulation would help control motor fluctuations<sup>36,37,38,39,40,41</sup>. Levodopa (L-dopa) disappears from the blood very quickly, usually about 60–90 minutes after administering the drug.

Protein can delay gastric emptying and competes with the absorption of L-dopa, and the manipulation of dietary protein may reduce fluctuations in some patients.

Current recommendations<sup>4</sup> are to advise people with Parkinson's disease on levodopa who experience motor fluctuations, to;

- avoid a reduction in their total daily protein consumption, and
- discuss a diet in which most of the protein is eaten in the final main meal of the day (a protein redistribution diet)

There is no evidence to support low protein diets<sup>10</sup>.

Do not offer creatine supplements to people with Parkinson's disease<sup>4</sup>.

Dietary management of any gastro-intestinal symptoms, e.g. delayed gastric emptying, constipation, may also be beneficial, as these can impair L-dopa efficacy<sup>10</sup>.

People with Parkinson's treated with continuous duodenal duodopa should follow similar recommendations, and should be advised to distribute food intake throughout the day and to divide the protein intake<sup>10</sup>.

In cases of continuous enteral tube feeding (low-infusion-rate), there are no restrictions but it is advisable to concentrate feeding during the night hours if possible, in order to limit interactions<sup>10</sup>.

Finally, in tube-fed patients still treated with oral formulations of levodopa-containing medications it is suggested the pausing of feeding for at least 1 h before and 30-40 min after drug administration<sup>10</sup>.

## *Monitoring*

Every four to six weeks if there have been any changes to medications or treatment plan, with particular focus on the swallowing recommendations.

Every three months if the patient's condition is stable.

For oral nutrition support, regular review of ONS prescriptions every three months is advisable, to ensure the appropriateness of the intervention. Samples of ONS can be trialed before any changes are requested to the GP prescription.

Some centres offer one-day holistic reviews to re-assess mobility, swallow, speech and nutritional status; if you do not have access to these, it is important to liaise with other members of the MDT to ensure you are keeping in line with the patient's overall management plan.

## **Palliative Care**

Palliative care is about helping to keep quality of life through managing symptoms, relieving pain and managing any other distressing aspects of advanced Parkinson's. The management of Parkinson's remains largely palliative, despite huge advances in the medical field. As Parkinson's progresses, many people will need some element of care and support alongside their treatment. Palliative care isn't just for 'end of life'. It relies on healthcare professionals making people with Parkinson's aware of, and directing them towards, services and support at an early stage.

NICE recommend that consideration is given to referring people at any stage of Parkinson's disease to the palliative care team to give them and their family members or carers (as appropriate) the opportunity to discuss palliative care and care at the end of life<sup>4</sup>.

There is no set time for how long the palliative phase lasts. It can potentially be a long time, and Parkinson's can still change and develop further within this time<sup>42</sup>.

It has been documented that a patient can spend on average 2.2 years in the palliative care stage<sup>43</sup>. During this stage there may be a need to withdraw dopaminergic medications due to lack of drug efficiency. Decreased mobility and being bed-bound can result in the risk of pressure ulcer development.

Decisions may need to be made about the nutritional management and treatment in the future to give the person with Parkinson's an opportunity to state their preferences in

case they lose capacity for making decisions in the future<sup>44</sup>.

### ***Dietetic assessment***

Assessment will be similar to the early stage taking into special consideration:

- suitability of active +/- aggressive nutrition support
- prognosis
- palliative care team advice
- multidisciplinary team opinion
- patient's wishes
- any advanced care planning

### ***Dietary intervention***

Artificial nutrition support may be withdrawn if it is causing discomfort or distress, or not deemed to be in patient's best interest. You may be asked to reduce the volume of enteral feeds to prevent fluid overload.

Oral nutrition should always be offered but not forced upon those who decline it or when there is risk of aspiration or choking. If a patient chooses to maintain an oral intake despite being advised it is unsafe, it should be ensured that the patient is fully informed of the consequence of their decision, and they should be continued to be supported.

### ***Monitoring***

Monthly reviews may be more appropriate or as agreed with/at the request of the MDT or palliative care team.

## Summary

The risk of malnutrition and body weight must be routinely monitored from diagnosis, and as the condition progresses<sup>10,45,46</sup>. Worsening motor symptoms e.g. dyskinesias should also be monitored to prevent or reverse weight loss in people living with Parkinson's<sup>10,47</sup>.

As highlighted throughout this document the nutritional management of a person living with Parkinson's may change and evolve throughout the progression of the condition.

Dietitians have the skills to help people living with Parkinson's to optimise their

nutritional status and manage nutrition-related symptoms at all stages of the condition<sup>48</sup>.

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