

DIETETIC GUIDELINE FOR PARKINSON'S DISEASE

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Colophon

Dietetic guideline for Parkinson's disease

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1 Introduction

1.1 Reason for development of the guideline

Many patients with Parkinson's disease (PD) are or will be confronted with diet related problems. A study carried out in 2008 showed that there was a need for a Parkinson specific guideline describing the treatment of these problems.

This guideline describes the diagnosis and treatment of patients with PD and highlights the dietary approach to the treatment of PD.

The guideline is made up of four parts:

1. The guideline 'Nutrition in Parkinson's Disease' which is intended for all care providers involved in the recognition, diagnosis and treatment of diet related problems in Parkinson's Disease: General practitioners, Neurologists, Geriatricians, Rehabilitation Specialists, Parkinson's Specialist Nurses and Therapists;
2. The Dietetic guideline in Parkinson's disease', describing the diagnosis and dietetic treatment;
3. The patient version, in which patients are given advice on how to manage nutrition and diet related problems;
4. The justification and explanation of the guidelines, including evidence from the literature.

1.2 Procedure

The guideline is based on key questions formulated through bottleneck analysis carried out among dietitians associated with ParkinsonNet. During the first meeting with the Dietitians from the primary study group, those key questions were discussed and formulated. The first author (MvA) conducted a systematic literature search appraised the literature found. Next, the first author (MvA) wrote the draft texts with the support of the second author (HD). During the meetings with the primary study group, the draft texts were discussed and consensus was reached on the content and recommendations. Several draft texts were emailed to the group and commented on. The draft version of the guideline was then put to the primary as well as the secondary study group of dietitians with specialist experience. All experts were asked to judge the guideline on relevance, comprehensiveness and usefulness from the perspective of their profession. The comments were incorporated in the final version of the guideline.

1.3 Patient population

The guideline focusses on patients with PD encountering food-related problems as presented in primary, secondary and tertiary health care settings at all stages of PD.

The guideline recommendations are aimed at the diagnosis and treatment of idiopathic PD in particular. However, the hypokinetic-rigid syndrome may also be caused by the various types of atypical parkinson, including vascular parkinson, progressive supranuclear palsy (PSP), multiple system atrophy (MSA) and drug-induced parkinson. The guideline will probably be applicable to these cases as well. Not all food-related problems described in this guideline will occur in atypical parkinson, and problems may occur at an earlier or a later stage. However, the treatment will not be different.

1.4 Target group

The guideline is primarily aimed at dietitians looking after patients with Parkinson's disease in primary health care, free lance dietitians, dietitians working in the community, secondary health care (dietitians working in a hospital setting), and tertiary health care settings (dietitians in Parkinson's disease specialist centers and nursing homes). Furthermore, the guideline is a tool for carers referring patients with PD to a Dietitian: Neurologists, General Practitioners, Specialists in Geriatric Medicine, Rehabilitation Specialists, Clinical Geriatricians and Parkinson's Nurses. The guideline is also instructive for care providers working together with a dietitian, such as Occupational Therapists, Physiotherapists, Speech Therapists, Nurses and Health Care Assistants.

2 Parkinson's disease

2.1 Epidemiology

Currently, approximately 50,000 people in the Netherlands suffer from PD. The incidence of the disease increases with age. Due to ageing, the prevalence is expected to rise to 90,000 by 2025. Although the diagnosis is most often made after the age of sixty years, in approximately 5% of the patients the diagnosis is made before the age of forty.

2.2 Pathogenesis, development and prognosis

PD is a progressive neurodegenerative disease largely caused by a loss of dopamine-producing neurons in the substantia nigra, particularly in the first stage of the disease. In the later stages of the disease, lesions of non-dopaminergic systems play an increasing role.

However, some of these non-dopaminergic lesions may also play a role during the premotor stage of PD. Relevant to this guideline is the early development of autonomic dysfunction (as this may result in constipation) as well as olfactory disorders (as hyposmia may result in a loss of appetite).

PD is a very complex disease accompanied by impairments and disabilities with regards to many areas:

- the locomotor system and motion-related functions, such as bradykinesia, tremor and gait abnormalities;
- mentally, such as a reduced motivation and cognitive flexibility, anxiety, hallucinations and depression;
- sensory, such as a reduced sense of smell;
- pain;
- voice and speech, such as a reduced volume and problems with articulation;
- autonomic nervous system, such as orthostatic hypotension, constipation and a reduced exercise tolerance;
- urogenital and reproductive, such as incontinence and sexual dysfunction;
- skin, such as an excessive production of sweat;
- sleep, such as insomnia, REM sleep behavior disorder and excessive daytime sleepiness.

As a result, patients experience many limitations in daily life activities and huge engagement problems.

PD is a progressive disease, but the exact development of health problems largely varies. Patients in whom a rest tremor is prominent, the development of the process is more favourable (slower progression, less frequently and delayed occurrence of postural instability and cognitive decline) compared to patients in whom bradykinesia and rigidity are prominent. A later age of onset and cognitive decline are associated with a more rapid disease progression. Due to current medical counselling, the total life expectancy has almost normalised.

2.3 Drug treatment

The moment at which drug treatment is initiated depends on functional impairments and/or the impact of symptoms (such as a severe tremor) experienced by the patient due to motor symptoms of the disease. Non-motor symptoms such as depression and dementia may also be a reason to initiate drug treatment.

The most common drugs used in PD and their actions are listed in appendix 2: 'Account and Explanation'. The food-related side effects of the drugs are added as well. In the early stages of PD, levodopa and dopamine agonists are equally effective in treating motor symptoms. Which of these drugs is chosen depends primarily on the individual patient and his or her pattern of symptoms. The effect of levodopa may be influenced by proteins in food. Proteins can compete with levodopa uptake both from the gut and across the blood-brain barrier and may therefore inhibit the effect of levodopa¹. The effect of dopamine agonists is not influenced by proteins.

2.4 Limitations in skills and activities

Due to motor and cognitive problems, movements are slow and have slowed down and activities take much more effort and energy. This may also affect the ability to eat and drink.

Eating and drinking

Patients with PD may have difficulties with eating and drinking due to slow arm and hand movements or tremors affecting one hand. As a result, it is difficult for them to hold their cutlery properly and eating and drinking takes much more time and is more ineffective due to food and/or drink spillage. Chewing and swallowing difficulties may lead not only to a longer meal duration, but also to forced alterations to food consistency. Tough food, for example, takes too much effort to chew or may get stuck in the throat. In other cases, eating and drinking without choking is only possible if he or she is not distracted or has learned not to speak at the same time.

Difficulties with eating and drinking and a risk of choking may also lead to engagement problems. The patient may prefer to only dine with familiar people and avoid social events or parties.

Cognitive problems and learning abilities

Cognitive problems may affect the treatment of patients with PD. The patients' abilities to process information as well as their attention and memory functions may be changed. Although patients with PD are able to process new information and learn new skills, they need more time and a quiet environment to do so. Offering too much information at the same time may be confusing. Furthermore, it is important that information is repeated frequently and discussed with the carer as well.

¹ The literature refers to the competition between proteins and levodopa. From a biochemical point of view, this is not entirely correct as it concerns the competition between amino acids and levodopa. To ensure the readability of the guideline and to be in keeping with the use of words in scientific literature, it was decided to refer to the competition between proteins and levodopa instead of the competition between amino acids and levodopa.

3 Diet related problems

The most common diet related problems in PD stated in the guideline are described here in short. From chapter 5 onwards, the key questions and recommendations are discussed for each of the problems.

1. Unintentional weight loss/malnutrition

Weight loss often develops several years before the diagnosis of PD is made. Patients lose more weight when the disease progresses, motor fluctuations occur and a poor response to treatment is observed.¹⁻² Weight loss increases the risk of the development of malnutrition. Three to sixty per cent of the patients are at risk of malnutrition and two to twenty-four per cent of patients actually suffer from malnutrition.³ These figures vary considerably as different criteria for defining malnutrition/risk of malnutrition have been used and study populations vary in age and stage of PD.

2. Constipation

Constipation occurs in 30-35% of patients with PD.⁴⁻⁶ The pathophysiology is partly determined by the occurrence of neurodegeneration in the plexus myentericus.⁷ Immobility and a reduced fluid and/or fiber intake may also contribute. Constipation may develop even before the diagnosis of PD is made. The occurrence is also high in patients with MSA.⁷ Constipation may lead to unpredictable absorption of medication for Parkinson's disease. As a result, response fluctuations may develop or worsen and the patient may also be greatly inconvenienced by constipation itself.

3. Medication intake and response fluctuations in relation to food

Up until now, levodopa has been the most effective drug for the treatment of Parkinson's disease. Proteins can compete with levodopa uptake both from the gut and across the blood-brain barrier and may therefore inhibit the effect of levodopa.⁸ The clinical relevance of the competition between proteins and levodopa is not yet clear.

4. Unwanted weight gain/extra weight

Weight gain occurs when there is an imbalance between energy intake and energy expenditure. Unwanted weight gain may result from a change in lifestyle, physical activity and dietary patterns. Furthermore, unwanted weight gain may be a side effect of dopamine agonist therapy, which may cause compulsive eating behaviour⁹⁻¹⁰, or deep brain stimulation (DBS).¹¹ Unwanted weight gain can lead to an increased risk of the development of metabolic syndrome, diabetes mellitus and cardiovascular disease.

5. Chewing and swallowing difficulties

In general, chewing and swallowing difficulties are late symptoms of PD. In MSA and PSP, swallowing difficulties occur at an earlier stage.¹² Approximately 35% of the patients with PD perceive swallowing difficulties. However, in no fewer than 82% of the patients a swallowing difficulty is identified when objective parameters are being used.¹³ Oral hypokinesia and rigidity may lead to chewing and swallowing difficulties. As a result, patients may experience difficulties with certain food and drink consistencies, which may lead to dietary deficiencies and/or weight loss.

6. Slowed gastric emptying

Although slowed gastric emptying occurs frequently in patients with PD, the exact prevalence is unknown.¹⁴ Right from the onset of the disease, gastric emptying may be affected.¹⁵ Slowed gastric emptying may lead to unpredictable absorption of levodopa, reduced effectiveness of levodopa and symptoms such as bloating, rapid satiety and nausea.¹⁶ Slowed gastric emptying may occur in MSA as well.

Not many studies have been conducted into the effect of food on gastric emptying. Liquidised food seems to improve gastric emptying, whereas more solid food has shown to reduce gastric emptying. Furthermore, the digestion time is delayed by the use of high-fat and/or high-fiber food, which may therefore affect gastric emptying.

7. Orthostatic hypotension

Orthostatic hypotension occurs in approximately fifty per cent of the patients and is usually seen in advanced stages of PD.¹⁷ MSA is accompanied by severe autonomic dysfunction, whereby orthostatic hypotension may develop at an early stage. Although dietary intervention only play a small part in the treatment of orthostatic hypotension, this condition has been included in the guideline to be complete.

8. The role of vitamins and minerals

Patients frequently ask questions about the potentially beneficial effects of vitamin and mineral supplements and in particular antioxidants such as vitamin E and coenzyme Q10.¹⁸⁻¹⁹

Furthermore, patients with PD are at an increased risk of vitamin D deficiency, which increases the risk of reduced bone density, osteoporosis, falls and hip fractures.²⁰⁻²¹

There also appears to be a correlation between long-term use of high doses of levodopa and the development of polyneuropathy, which may be caused by vitamin B12 deficiency.²²

Perioperative nutritional management

In the multidisciplinary guideline, recommendations have been made towards the development of a protocol for perioperative care by a multidisciplinary study group. This protocol will also include perioperative nutritional management. Therefore, it was decided to wait for this protocol and not to include perioperative nutrition in this guideline.

4 Collaboration between the care providers involved

4.1 Introduction

Many health professionals may be involved in the recognition, diagnosis and treatment of diet related problems (Fig 4.1). Each health professional has his or her own duties and responsibilities.

The patient plays an important role as well. The role of each of the health professionals is discussed in the guideline 'Nutrition in Parkinson's Disease'.²³

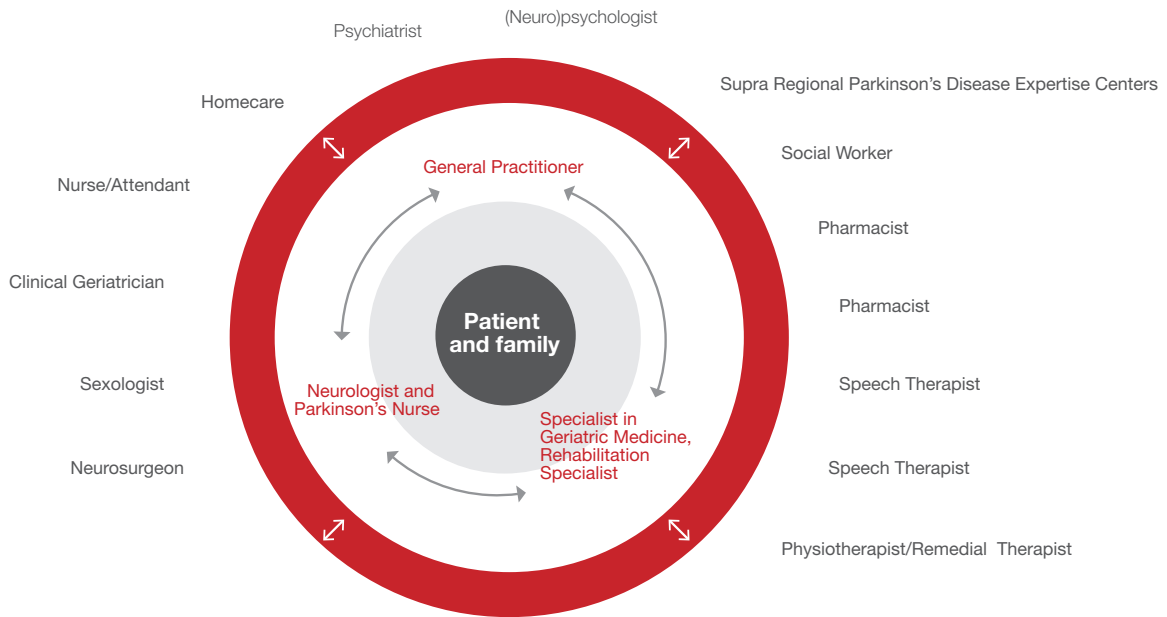


Fig 4.1

Health professionals involved in the care for patients with PD. This figure was copied from the 'Multidisciplinary guideline for Parkinson's disease'.²⁴ Health professionals involved in the recognition, diagnosis and treatment of diet related problems in PD are placed in the shaded boxes.

4.2 The role of the patient

The patient plays an important role in the self management of dietary problems by:

- following their weight by weighing themselves regularly and recording their weight;
- taking their medication in the right way and at the right time;
- discussing constipation, difficulties chewing and swallowing, weight changes or response fluctuations with the attending Consultant or Parkinson's Specialist Nurse;
- discussing general questions about nutrition with the attending Consultant or Parkinson's Specialist Nurse;

If patients are not able (anymore) to carry out self management tasks (e.g. because of advanced age, cognitive decline or depression), the role of the carer or relative becomes (even) more important (see the following section).

4.3 The role of the carer

Due to the chronic and degenerative character of PD, patients become more and more dependent on the support of others. Carers such as partners, children and neighbours play an important role in supporting the patient both from a psychosocial and practical point of view. They also play a key role in the treatment of diet related problems, amongst other things as preparing meals and helping the patient to follow nutrition and dietary advice.

4.4 Multidisciplinary collaboration

It is important to communicate effectively and coordinate care properly. In order to enhance collaboration, ParkinsonNet has been developed. ParkinsonNet consists of regional networks of health professionals specialised in treating and counselling patients with PD or Parkinson-like disorders (the so-called atypical parkinsonisms). Patients with PD should preferably be referred to health professionals associated with a regional ParkinsonNet (www.parkinsonnet.nl).

Referral criteria as described in this guideline should be known to all health professionals involved, allowing each health professional to signpost to other health professionals where and when required.

4.5 Referral

4.5.1 Referral criteria

The criteria for referral to a dietitian have been described for each of the diet related problems.

These criteria have also been described in the guideline 'Nutrition in Parkinson's Disease'.²³

1. Unintentional weight loss/malnutrition:

- Unintentional weight loss of >5% within 1 month or >10% within 6 months and/or a low body weight (age 18-65: BMI <18,5 kg/m² and >age 65: BMI <20 kg/m²);
- A high risk of malnutrition assessed by a validated screening tool (SNAQ (for the various target groups), MUST, MNS-SF);
- Permanent unintentional weight loss over a period of 1-2 years.

2. Constipation

- Patients with the diagnosis of constipation who have difficulties following plain dietary advice given by the attending Consultant or Parkinson's Specialist Nurse about fluid and fibre, and who need further specific advice for this.

3. Medication intake and response fluctuations in relation to food

- The presence of response fluctuations presumably associated with eating patterns and not improving after plain dietary advice given by the Consultant Neurologist or Parkinson's Specialist Nurse.

4. Unwanted weight gain and extra weight

- Unwanted weight gain resulting from a change in eating and/or physical activity patterns;
- Unwanted weight gain resulting from compulsive eating behaviour, and treatment for the compulsive eating behaviour is initiated as well;
- Unwanted weight gain after the use of clozapine;
- Unwanted weight gain after DBS.
- Obesity (BMI ≥ 30 kg/m²) or extra weight (BMI ≥ 25 kg/m² and/ or a waist circumference ≥ 102 cm for men and ≥ 88 cm for women), and if it is the patient's own wish to loose weight.

5. Chewing and swallowing difficulties

- Dietary problems as a result of chewing and swallowing difficulties, which are expected to last more than a week;
- Unintentional weight loss of $>5\%$ within 1 month or $>10\%$ within 6 months and/or a low body weight (age 18-65: BMI $<18,5$ kg/m² and $>age 65$: BMI <20 kg/m²);
- A high risk of malnutrition assessed by a validated screening tool.

6. Slowed gastric emptying

- In case of slowed gastric emptying where treatment by the Consultant Neurologist has achieved insufficient results (see guideline 'Nutrition in Parkinson's disease') or where unintentional weight loss occurs.

7. Orthostatic hypotension

- Dietary measures only play a small role in the treatment of orthostatic hypotension. Therefore, dietary advice is given by the doctor in charge. The dietitian is not involved in the treatment of orthostatic hypotension.

8. The role of vitamins and minerals

- If the patient has questions about (alternative) nutrition and whether there is a need to take additional vitamin and mineral supplements;
- If the patient has questions about additional Calcium and vitamin D intake in osteopenia and osteoporosis;
- In case assessment of the vitamin and mineral status is required.

The patient may also contact the dietitian on his or her own initiative via the so-called directly accessible dietetics (directe toegankelijkheid diëtetiek, DTD).

4.5.2 Referral data

When the patient is referred by a General Practitioner or a Consultant in Medicine, it is important that the referral contains the following information:

- Reason for referral;
- Diagnosis: Parkinson's disease and any comorbidity;
- Symptoms: chewing and swallowing difficulties, nausea, constipation, weight loss, excessive eating, weight gain, tremors, dyskinesias;
- Medication: list of current medication used and time of medication intake;
- Other information: cognitive problems, height, weight, development of weight, result of any screening for malnutrition.

4.6 Duration and frequency of treatment

The duration and frequency of treatment has to be tailored to the individual needs of the patient and needs to be assessed by the dietitian. It is dependent on the dietary problems encountered, the patient's ability to follow the advice given and the goals which have been set. In some cases, one or two consultations may suffice, in other cases more are needed.

5 Summary of recommendations

The guideline consists of 32 key questions and 43 recommendations in total. An overview of the key questions and recommendations for each diet related problem is given below:

1. Unintentional weight loss/malnutrition
2. Constipation
3. Medication intake and response fluctuations in relation to food
4. Unwanted weight gain and extra weight
5. Chewing and swallowing difficulties
6. Slowed gastric emptying / gastroparesis
7. Orthostatic hypotension
8. The role of vitamins and minerals

5.1 Unintentional weight loss/malnutrition

1. *Which screening tools can be used for the screening for malnutrition in patients with PD?*

Recommendation 1

The screening tools which have already been implemented (MUST, MNA, SNAQ for the various target groups) can be used for screening for malnutrition in patients with PD in the various settings.

For the screening frequency, it is advisable to at least follow the guideline 'Screening and treatment for malnutrition', see table 3.2, page 16 of 'Account and explanation'.

At outpatient clinics where the screening of patients with PD has not yet been introduced, it is advisable to choose a screening tool with an indicator for unintentional weight loss and BMI. The following tools are suitable for this purpose: MUST, SNAQ+BMI and MNA for older patients with PD. It is advisable to screen patients with PD for (the risk of) malnutrition at the outpatient clinic on a yearly basis. This screening can be carried out by the Consultant Neurologist or the Parkinson's Specialist Nurse.

5.1.1 Examination

2. Which subjects need to be addressed in any case during dietary history taking regarding symptoms of unintentional weight loss/risk of malnutrition in patients with PD?

Recommendation 2

The diet history for patients with PD who are referred because of unintentional weight loss/risk or malnutrition, should be aimed at obtaining following information:

| | |
|----------------------------|---|
| Anthropometric data | <ul style="list-style-type: none"> current weight, usual weight, development of weight, height % weight loss BMI result of screening for malnutrition |
|----------------------------|---|

| | |
|-----------------------|--|
| Dietary Intake | <ul style="list-style-type: none"> energy, protein, macro- and micronutrient intake appetite duration of meals taste and smell chewing abilities gastric emptying swallowing difficulties |
|-----------------------|--|

| | |
|----------------|---|
| General | <ul style="list-style-type: none"> tremors, rigidity, dyskinesias ADL/DADL defaecation problems use of medication + time schedule cognition depression quality of life comorbidity change in living and physical activity patterns influence of and dependence on environment pain other health professionals involved in treatment |
|----------------|---|

3. *What standard diagnostic investigation must be done and what additional diagnostic test(s) could be done in addition to diagnose malnutrition in patients with PD?*

Recommendation 3

A set of criteria is used to assess the degree of malnutrition. It is advisable to always determine the percentage of unintentional weight loss, BMI and dietary intake. Additional measurements can be done to determine the fat mass and fat-free mass.

Malnutrition is present in case of:

- Unintentional weight loss >5% within 1 month and/or >10% within 6 months
- BMI < 18,5 kg/m² and BMI < 20 kg/m² in patients aged over 65

Muscle mass depletion is present in case of:

- Fat-free mass falling below the fifth percentile of the reference values (see for reference values www.nutritionalassessment.azm.nl).

4. *Are the resting energy expenditure and daily energy expenditure increased in patients with PD? How can the resting energy expenditure be assessed, and is there a difference between the measured and estimated resting energy expenditure?*

Recommendation 4

Although indirect calorimetry is the most accurate method for determining the individual's resting energy expenditure, this method may often not be practical.

If it is not possible to measure the resting energy expenditure (REE), the REE is determined by using the Harris Benedict formula. In patients with dyskinesias or muscle rigidity, it may be necessary to assume an increased REE. However, based on the available literature it is not possible to give an indication of how much the calculated REE should be increased by. This greatly depends on individual factors as well.

In case of underweight or extra weight, there is no need to make a recalculation in terms of a healthy BMI when using this formula.

In order to calculate the total daily energy requirements, additional calories are being added to the REE to account for physical activity. If the aim is to increase the patient's body weight, an extra 30% will be added.

The energy requirements calculated by formulas is an estimation. Therefore, it is important to monitor the weight and to gradually increase the energy intake in case of unwanted weight loss.

5.1.2 Treatment

5. *What are the protein requirements for patients with PD suffering from malnutrition?*

Recommendation 5

In case of malnutrition, 1.2-1.5 grams of protein per kg body weight is recommended (in case of a BMI > 27 kg/m², this formula uses the body weight associated with a BMI of 27 kg/m²).

In order to make use of the extra proteins, it is also important that the energy intake is sufficient and the patient is encouraged to exercise.

In light of the competition between proteins and levodopa, it is important to check whether the patient develops more symptoms when the protein intake is being increased. If this is the case, it is advisable to discuss a dosage adjustment of levodopa with the neurologist. If it is not possible to adjust the dosage, a reduction in protein intake should be considered to a level at which symptoms, if any, are acceptable to the patient.

6. *What dietary interventions are necessary when treating malnutrition in patients with PD?*

Recommendation 6

Based on the calculated energy and protein requirements, it is determined in the consultation with the patient and/or his or her carer whether changes in the current dietary pattern will result in an adequate intake.

If an adequate intake cannot be achieved by making adjustments to the current dietary pattern, nutritional supplements and/or enteral feeds may be recommended.

7. *When should nutritional supplements be opted for? Which type is preferred?*

Recommendation 7

If it is not possible to achieve an adequate energy and protein intake with normal food, it is advisable to use nutritional supplements.

When determining the type and amount of supplements, the calculated energy and protein requirements serve as a starting point.

If the patient follows a diet based on 0.8 grams of protein/kg actual body weight (see chapter 5.3 medication intake and response fluctuations in relation to food), nutritional supplements with reduced protein levels should be chosen such as juice based supplements, modular supplements e.g. maltodextrin or specially developed supplements for patients suffering from kidney failure. If there are no gastric emptying abnormalities, a fat emulsion may be considered as well.

In patients who keep losing weight gradually despite an adequate intake of normal food, a modular supplement e.g. maltodextrin may be considered.

8. *When should (additional) enteral feeds be opted for? What is the preferred moment to place a PEG tube?*

Recommendation 8

Enteral feeds are recommended for patients with PD who are not able to meet their nutritional intake despite individual dietary advice and dietary adjustments.

A PEG tube may be considered if enteral feeds are required for more than 6-8 weeks. The current situation, prognosis, ethical matters, expected effect on quality of life and the wishes of the patient with PD should be taken into consideration when deciding whether or not to place a PEG tube.

In order to limit the competition between enteral feed proteins and levodopa, the enteral feed should be administered via boluses. In that scenario, the medication is taken or administered half an hour before the boluses are given. Another option is to give additional enteral feed during the night.

When enteral feeds are administered continuously, competition may occur between the feed proteins and levodopa. When the feed is administered continuously over the course of 24 hours, the competition between proteins and levodopa is probably limited as the amount of protein administered per hour is low. Competition occurring between levodopa and enteral feed when the feed is administered continuously can be limited by stopping the pump half an hour before levodopa is taken, then taking the levodopa and restarting the pump half an hour after taking

levodopa. If the patient does not use levodopa during the night, another option is to administer a higher protein feed during the night and lower protein feed during the day, in which case the total daily protein requirements are being met.

If a high protein enteral feed is used in the treatment of malnutrition and this leads to a poorer response, the amount of levodopa should be adjusted in consultation with the Consultant Neurologist. If this is not possible, the total protein intake may be limited by choosing a low protein enteral feed.

5.2 Constipation

5.2.1 Examination

9. *What subjects should be discussed during diet history regarding symptoms of constipation?*

Recommendation 9

At the diet history, the dietitian asks information about the following:

- Defaecation frequency per week;
- Stool consistency, in which the Bristol Stool Scale may be used as a practical tool;
- Duration constipation and contributing symptoms caused by constipation;
- Fluid and fibre intake with a focus on changes to the diet already made by the patient;
- Changes in lifestyle, diet or physical activity patterns;
- Use of medication which may cause constipation (e.g. morphine or anticholinergics);
- Use of medication to stimulate defaecation (e.g. fibre supplements or laxatives);
- Use of and experiences with probiotics;
- Chewing and swallowing, duration of meal times;
- Feeling that the bowels are empty after going to the toilet or still feeling an urge;
- In case the patient has a strong urge accompanied by faecal incontinence or defaecation difficulties despite soft stools, he or she is more likely to have anorectal dysfunction than constipation; refer the patient back to the doctor in charge.

5.2.2 Treatment

10. *Do dietary fibres have a favourable effect on the treatment of constipation in PD? If so, what is the recommended daily intake?*

Recommendation 10

The treatment of constipation is based on the 'Guidelines for a healthy diet' ('Richtlijn goede voeding'). These guidelines advise 3.4 grams of dietary fibre per megajoule, which amounts to 30-40 grams of dietary fibre per day. A higher fibre intake than recommended in these guidelines is not necessary.

11. *Does fluid have a positive effect on the treatment of constipation? If so, what is the recommended daily intake?*

Recommendation 11

The treatment of constipation is based on the 'Guidelines for Food Choice 2011' ('Richtlijnen voedselkeuze 2011') from the Netherlands Nutrition Centre ('Voedingscentrum'), i.e. 1.5-2.0 liters of fluid for adults. A higher fluid intake than recommended in this guideline is not necessary.

12. *Do probiotics have an effect on the treatment of constipation in PD?*

Recommendation 12

The use of probiotics in the treatment of constipation in patients with PD has not yet been researched sufficiently to recommend the use of probiotics. The study group has no problem advising a trial of probiotics, but recommends evaluation of the effects after four weeks. If there is no effect, the treatment with probiotics can be stopped.

13. What (dietary) interventions are necessary when treating constipation in PD?

Recommendation 12

The treatment consists of two phases:

1. Non-drug related advice

If there has been no improvement after two weeks of non-drug treatment or if the patient is very much troubled by constipation, drug treatment can be started.

2. Drug related advice

1. *Non-drug related advice*

- Dietary fibres: 3.4 grams per MJ, i.e. 30-40 grams of dietary fibres per day;
- Fluid: 1.5-2.0 liters of fluid for adults;
- 'Guidelines for a healthy diet 2006' and 'Guidelines for Food Choice 2011' are taken as reference;
- Regular meals including breakfast, no skipping of meals;
- Fibre supplements such as psyllium and methylcellulose are only recommended if the patient is not able to take a sufficient amount of fibre with his or her meals;
- Exercise: 30 minutes of moderate intensity exercise per day;
- The use of probiotics may be considered, although there is a lack of sufficient scientific evidence;
- Not to suppress the defaecation reflex.

2. *Drug related advice*

- Lactulose or Macrogol are recommended as first choice of treatment;
- Contact laxatives and other osmotic laxatives such as Bisacodyl or magnesium oxide, if the first choice drug has no effect or is not tolerated;
- An enema should be considered in case of faecal impaction or in case defaecation has not occurred after three days of oral therapy in a patient with severe symptoms.

5.3 Medication intake and response fluctuations in relation to food

5.3.1 Examination

14. *What subjects should be addressed during diet history regarding symptoms of response fluctuations when levodopa is used?*

Recommendation 14

At the diet history, it is advisable that in case of response fluctuations the dietitian asks information about:

- How levodopa is being taken;
- At what time levodopa is being taken;
- At what time meals are being taken;
- On and off phases during the day;
- The protein intake and distribution.

In order to gain insight into these matters, the patient may be asked to fill out a food and symptom diary to record response fluctuations, time of medication intake and time of taking meals. It is important that clear instructions are being given to the patient by the Parkinson's Specialist Nurse or dietitian on how to fill in the different categories in the diary, such as on, off and dyskinesias. The diary should be kept for at least three days in order to provide good insight into response fluctuations. An example of such diary can be obtained from appendix 6 of 'Account and explanation'.

5.3.2 Treatment

15. *What is the best way to take levodopa?*

Recommendation 15

Levodopa should preferably be taken half an hour before meals with some water, juice (no grapefruit juice) or fruit puree. If it is not possible to take it before meals, levodopa can be taken at least 1 hour after meals. When levodopa is prescribed, the doctor in charge or Parkinson's Specialist Nurse should discuss this advice with the patient.

16. *What is the recommended protein intake for patients with PD using levodopa?*

Recommendation 16

The recommended protein intake for patients with PD who use levodopa and do not suffer from malnutrition is equal to the recommended protein intake for healthy adults, i.e. 0.8 grams of protein/kg actual body weight. (In case of a BMI>27 kg/m², this formula makes use of the body weight associated with a BMI of 27 kg/m²).

17. *Is a low protein diet effective in case of response fluctuations when levodopa is used?*

Recommendation 17

In patients with PD experiencing response fluctuations, a protein intake of 0.8 grams of protein/kg actual body weight is advised in order to improve levodopa absorption. (In case of a BMI>27 kg/m², this formula makes use of the body weight associated with a BMI of 27 kg/m²).

Protein intake is distributed throughout the day. In order to put together a diet plan, use a diary filled out by the patient to record response fluctuations.

If a patient experiences off moments after a meal, the amount of protein in this meal could be restricted in consultation with the patient.

The diet should be evaluated after one week. If the diet has no effect, it does not need to be continued. If the diet does have an effect, the patient is taught how to vary his or her diet.

18. *Is a diet with an adjusted protein distribution throughout the day effective in patients with response fluctuations?*

Recommendation 18

For patients experiencing an insufficient response to levodopa a diet with an adjusted protein distribution (protein redistribution diet, PRD) could be advised. However, this type of diet is difficult to maintain and may result in nutrient deficiencies.

A diet with an adjusted protein distribution will look as follows: 10-15 grams of protein until dinner and from dinner onwards, an unrestricted protein intake is allowed. However, it should be assessed per patient what protein restriction could be achieved during the day. Patients who prefer more on time in the evening should take more protein during the day and fewer in the evening.

If a patient is willing to follow a diet with an adjusted protein distribution, the diet should be evaluated after one week. If the diet has no effect, it does not need to be continued.

19. *Is it allowed to advise a high protein diet and products high in protein such as nutritional supplements and/or enteral feeds when levodopa is used?*

Recommendation 19

See question and recommendation 8 and 9, chapter 3 unintentional weight loss/malnutrition

20. *Should enteral feeds be administered by bolus or continuously when levodopa is used?*

Recommendation 20

See question and recommendation 8 and 9, chapter 3 unintentional weight loss/malnutrition

21. *Is dietary intervention required in case of intraduodenal infusion?*

Recommendation 21a

In case of intraduodenal infusion of levodopa ('duodopa'), the same protein recommendations can be applied as the protein recommendations for oral levodopa use.

Recommendation 21b

If the patient is dependent on enteral feeds, the duodenal port on the PEG tube can be used for the administration of levodopa.

The recommendations given for oral levodopa can also be applied when deciding what type of enteral feed should be used (see recommendation 9).

It appears to be best to administer enteral feeds continuously as in this way levodopa as well as the enteral feed are being administered gradually and thus peaks in protein intake are avoided. If continuous administration of enteral feed is not preferred for other reasons, bolus feeding may be considered.

5.4 Unwanted weight gain/extra weight

5.4.1 Examination

22. *What subjects should be addressed during dietary history-taking regarding symptoms of weight gain in PD?*

Recommendation 22

During history-taking, the dietitian asks information about the following subjects:

- Usual weight, current weight, course of the weight, height, waist circumference;
- Change in living, eating and physical activity patterns after the disease has begun;
- Treatment of PD:
 - has the patient undergone deep brain stimulation?
 - has the patient developed compulsive eating behavior due to the drug treatment?
- Dietary history: energy, protein, macro- and micronutrient intake

5.4.2 Treatment

23. When is an energy-restricted diet indicated in patients with PD?

Recommendation 23a

An energy-restricted diet is indicated in case of:

- Unwanted weight gain as a result of a change in eating and/or physical activity patterns; Unwanted weight gain as a result of compulsive eating behavior, in which case intervention for the compulsive eating behavior is initiated as well;
- Unwanted weight gain after DBS;
- Obesity: a BMI of ≥ 30 kg/m²;
- Extra weight: a BMI of ≥ 25 kg/m² and/or a waist circumference of ≥ 102 cm for men and ≥ 88 cm for women), and it is the patient's own wish to lose weight. There is no active screening for extra weight. However, if the presence of extra weight is assessed, it is important to give advice on how to prevent further weight gain.

Recommendation 23b

If patients undergo DBS, it is advisable to screen them prior to DBS with a focus on the course of the weight and current intake. For patients in whom weight gain is not desirable, it is important to give advice aimed at the prevention of weight gain. In addition, these patients are advised to closely monitor the course of their weight after DBS and discuss unwanted weight gain with the attending doctor or Parkinson's nurse.

24. What (dietary) interventions may result in weight loss achieved in a responsible way in patients with PD?

Recommendation 24a

For patients with unwanted weight gain or extra weight, an energy-restricted diet (600 kcal less per day) based on the 'Guidelines for a healthy diet' is advisable in combination with exercise advice on having 60 minutes a day of moderate-intensity physical activity.

Assistance of a physiotherapist with regard to the advice on exercise may be advisable. The patient may also be informed of special exercise groups for patients with PD.

Recommendation 24b

The treatment of obesity in patients with PD is based on the guideline 'Diagnosis and treatment of obesity in children and adults' ('Diagnostiek en behandeling van obesitas bij kinderen en volwassenen') CBO 2008.

5.5 Chewing and swallowing difficulties

5.5.1 Collaboration

1. *How do the speech therapist and dietitian collaborate with regards to the treatment of chewing and swallowing difficulties in PD?*

Recommendation 25

During the treatment of chewing and swallowing difficulties, the speech therapist will decide which consistencies the patient can safely and effectively swallow. The dietitian will then draw up a treatment plan based on this advice aimed at maintaining or achieving an adequate intake.

2. *Which techniques will the speech therapist apply throughout the treatment of chewing and swallowing difficulties in patients with PD?*

Recommendation 26a

Techniques to reduce the risk of choking on fluids

It is recommended that patients with PD who complain about choking but don't show signs of choking/aspiration during swallowing tests and provocation tests:

1. are informed that choking/aspiration may occur as a result of performing dual tasks, and:
2. are made aware of exercises aimed at focusing on achieving a safe swallow.

Only if the above mentioned recommendations do not result in sufficient/adequate improvements, should the speech therapist consider other interventions.

It is recommended that the speech therapist assesses whether in patients with PD who easily choke/aspirate on fluids, neck flexion is sufficient/adequate and whether this can be maintained in order to solve the problem.

For patients with PD who easily choke/aspirate on fluids, it is recommended that the speech therapist assesses whether smaller volumes or consistent use of thicker fluids are sufficient in order to prevent them from choking/aspirating.

Recommendation 26b

Techniques to improve prolonged chewing and delayed swallowing response

The speech therapist may consider assessing the result of activation exercises on the swallowing response prior to each meal.

For patients with PD who are chewing too long (hypokinesia) and/or holding food in their mouth without swallowing (akinesia), it may be useful to assess whether they can be taught the process of eating consciously and gradually and with the use of specific cues.

If it is difficult to influence behavior in order to improve prolonged chewing and a delayed swallow response, it is recommended to advise food with modified consistency.

Recommendation 26c

Techniques to reduce pharyngeal residue

It is advisable for the speech therapist to teach patients with PD suffering from pharyngeal passage problems how to consciously and consistently create a more forceful swallow.

If it is difficult to influence behavior in order to improve pharyngeal passage problems, it is recommended to advise food with modified consistency..

If the speech therapist advises the patient to modify food consistency, it is recommended to ask a dietitian to advise the patient on how to maintain the nutritional adequacy of the food.

5.5.2 Examination

3. *What subjects should be addressed during dietary history-taking regarding chewing and swallowing problems?*

Recommendation 27

During dietary history in patients with chewing and swallowing problems, the dietitian should obtain information about:

- The advice given by the speech therapist regarding desirable food consistency.
- Anthropometric data
 - current weight, usual weight
 - Weight development, height
 - % weight loss
 - BMI
- Intake
 - fluid intake
 - energy, protein, micronutrient intake
 - length of meal times

5.5.3 Treatment

4. *Which dietary interventions are required when treating chewing and swallowing difficulties in patients with PD?*

Recommendation 28

The main chewing and swallowing problems and the advice on adjusting consistencies

| Problem | Consistency | Try to avoid |
|--|---|---|
| difficulty with chewing | soft and grinded food | tough and hard food: tough meat, hard fruits, crust |
| difficulty with manipulating food in the mouth | soft food | hard, granular or crumbly food, thin liquids |
| too little saliva | soft and liquid food; more use of fluids during meals | dry food |
| easily choking on liquids | <ul style="list-style-type: none"> • thick liquids; thickening of thin liquids | thin liquids |
| difficulty with swallowing | <ul style="list-style-type: none"> • Liquid and soft food | tough and hard food |

(from 'Swallowing disorders in adults' 'Slikstoornissen bij volwassenen')²⁵

When food with modified consistency is used (liquidised food in particular), it may be necessary to add a vitamin and mineral supplement, nutritional supplements or enteral feed. For patients who choke/aspirate on thin liquids, nutritional supplements may need to be thickened or pre-thickened dietary supplements may be used.

For dietary interventions necessary to deal with malnutrition, see recommendations 5-8.

If the patient is at risk of developing dehydration, it is important that he or she is frequently reminded to drink. It is important that patients who are not able to drink on their own are given assistance. If he or she is not able to take enough fluid orally, enteral or parenteral fluid replacement should be considered.

For the practical implementation of the advice, please refer to the dietary treatment guideline 'Swallowing difficulties in neurological disorders' ('Slikstoornissen door neurologische aandoeningen') or the book 'Swallowing difficulties in adults' ('Slikstoornissen bij volwassenen').25-26

5.6 Slowed gastric emptying

5. *What does the treatment of slowed gastric emptying in patients with PD consist of?*

Recommendation 29

If nausea is caused by levodopa usage, the patient may be advised to take levodopa with drinking or a snack low in protein.

Medication treatment for slowed gastric emptying consists of a prokineticum which is not able to cross the blood-brain barrier, such as domperidone. Metoclopramide is contraindicated.

The following dietary advice is given for slowed gastric emptying:

- Take several small meals per day;
- Reduce the amount of fat in food;
- Take enough fluids to drink, but avoid carbonated drinks and drinks with a high osmolarity;
- Use liquid food instead of solid food;
- Reduce the amount of fiber in case of a high fiber intake.

5.7 Orthostatic hypotension

6. Which dietary interventions are necessary when treating orthostatic hypotension in patients with PD?

Recommendation 30

Ensuring a high fluid and salt intake is just one of the instructions given when treating orthostatic hypotension. The attending doctor is, therefore, the right person to give advice and evaluate the advice. The dietitian is not involved in the treatment of orthostatic hypotension.

5.8 The role of vitamins and minerals

7. Differs the recommended daily intake of vitamins, minerals and trace elements for patients with PD from the recommended daily intake of vitamins, minerals and trace elements for healthy adults?

Recommendation 31a

The recommended daily intake (RDI) of vitamins and minerals for healthy adults (see appendix 7) is also applicable to patients with PD.

When treating patients with Parkinson's disease, several nutrients should be focused on, as explained further below:

Antioxidants

- Vitamin E (tocopherol)
- Coenzyme Q10

Recommendation 31b

There is no indication for prescribing vitamin E and Coenzyme Q10 in order to reduce the progression of the disease.

Vitamin B12

Recommendation 31c

In case of a diagnosed vitamin B12 deficiency associated with polyneuropathy, replacement therapy for vitamin B12 should be given by the attending doctor.

Levodopa, vitamin B12 and folic acid in relation to homocysteine

Recommendation 31d

No recommendations can be made yet with regard to replacement of folic acid and vitamin B12 when treating patients with PD and elevated homocysteine levels.

Vitamin D

Recommendation 31e

The patient is given advice on vitamin D replacement by the general practitioner, specialist in geriatric medicine or clinical geriatrician in accordance with the recommendation of the Health Council of the Netherlands (Gezondheidsraad):

An additional 10 µg per day of vitamin D is advised to:

- Women aged ≥ 50 and men aged ≥ 70 with a light skin who come outside frequently enough;
- Women aged < 50 and men aged < 70 with a dark skin or who do not come outside frequently enough (less than 15 minutes per day);
- Women aged < 50 wearing a veil.

An additional 20 µg per day of vitamin D is advised to:

- People with osteoporosis;
- People living in a rest home or nursing home;
- Women aged ≥ 50 or men aged ≥ 70 with a dark skin or who do not come outside frequently enough (less than 15 minutes per day);
- Women aged > 50 wearing a veil.

Do not use more than 50 µg per day of vitamin D in the form of supplements.

The dietitian will give advice on vitamin D replacement, if it is shown during a consultation that the patient has not yet been advised on this topic by the attending doctor or Parkinson's nurse.

Calcium

Recommendation 31f

The recommended daily intake (RDI) for healthy adults is applied, i.e. 1000 mg (age 19-50), 1100 mg (age 50-70) and 1200 mg (> 70).

If it is not possible to achieve an adequate calcium intake through diet, calcium replacement is necessary to at least reach the recommended daily amount.

Iron

Recommendation 31g

Iron supplements have the ability to limit levodopa absorption. Therefore, iron supplements and levodopa should not be taken simultaneously. The times the patient takes iron supplements and levodopa should be separated by as long as possible.

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Appendix

Used abbreviations

| <i>Abbreviation</i> | <i>Explanation</i> |
|---------------------|--|
| ADL | Activities of Daily Living |
| RDI | Recommended Daily Intake |
| BMI | Body Mass Index |
| DBS-STN | Deep Brain Stimulation subthalamic nucleus |
| DEE | Daily energy expenditure |
| DADL | Domestic Activities of Daily Living |
| LESA | National Primary Health Care Collaborative Agreement (Landelijke Eerstelijns Samenwerkings Afspraak) |
| MC | Multidisciplinary consultation |
| MDR ZvP | Multidisciplinary guideline for Parkinson's disease |
| MNA-(SF) | Mini Nutritional Assessment (Short Form) |
| MSA | Multiple System Atrophy |
| MUST | Malnutrition Universal Screening Tool |
| NVD | Dutch Association of Dietitians |
| OH | Orthostatic hypotension |
| PSP | Progressive Supranuclear Palsy |
| PV | Dutch Parkinson's Disease Association |
| PEG | Percutaneous Endoscopic Gastrostomy |
| REE | Resting energy expenditure |
| SNAQ | Short Nutritional Assessment Questionnaire |
| SNAQRC | Short Nutritional Assessment Questionnaire, residential care |
| PD | Parkinson's disease |