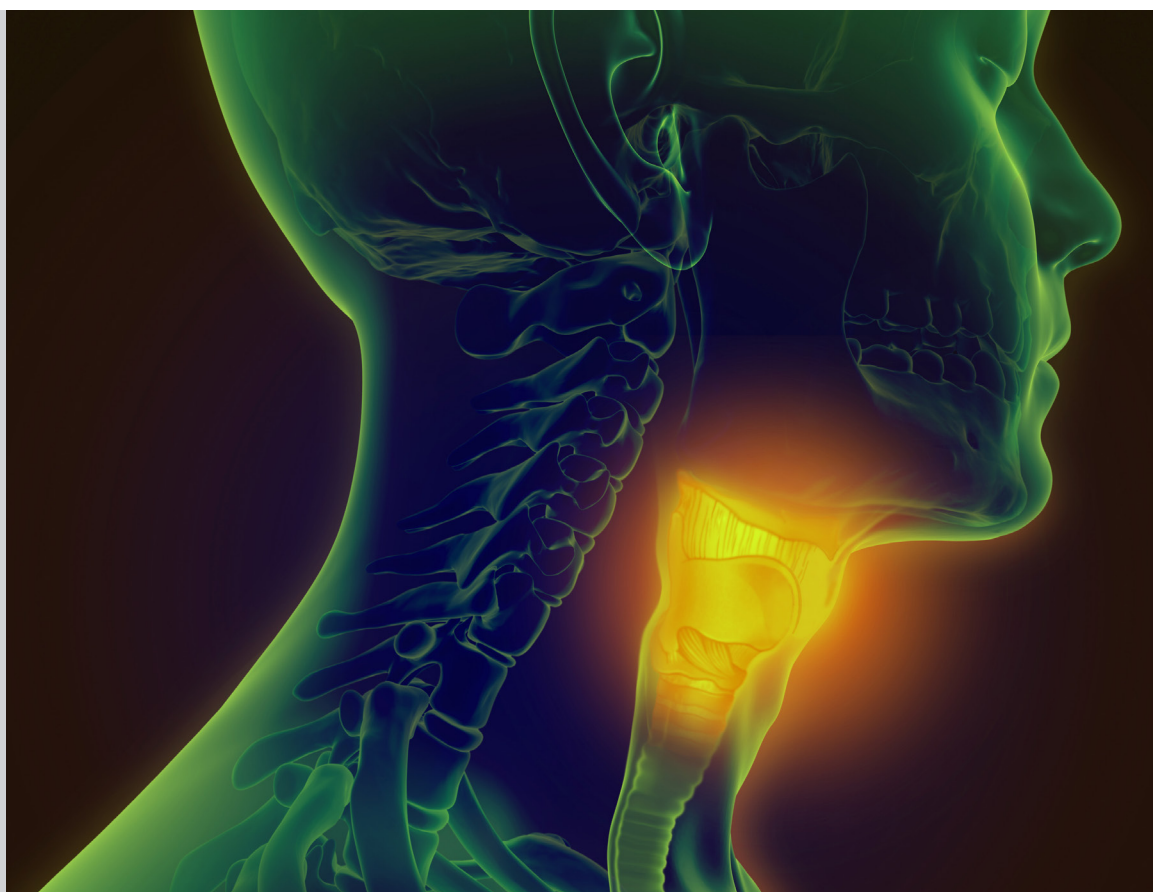


Hard to Swallow?

A review of the quality of dysphagia care provided to patients with Parkinson's disease aged 16 years and over who were admitted to hospital when acutely unwell



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A review of the quality of dysphagia care provided to patients with Parkinson's disease aged 16 years and over who were admitted to hospital when acutely unwell

A report published by the National Confidential Enquiry into Patient Outcome and Death (2021)

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Foreword

This study was conceived with the main intention of examining the quality of care for patients with dysphagia. In order to try and focus on the specific issues of relevance to dysphagia, it was decided that it would be best to take dysphagia in the context of one diagnostic group. Given the reportedly high prevalence of dysphagia affecting patients with Parkinson's disease (PD) and parkinsonism, patients were selected for sampling if they were admitted acutely to hospital and had a diagnosis of PD. So, when reading this report, bear in mind that it was not intended to give a comprehensive overview of the care of PD patients, but rather to allow an in-depth review of dysphagia recognition and care. It also stands that the learning from this report should be transferable, and systematic improvements in identifying and managing dysphagia should be relevant for all diagnoses associated with dysphagia, not just PD.

The other important factor to be aware of is that sampling for this study was undertaken prior to the COVID-19 pandemic, which will almost certainly lead, in the fullness of time, to substantial changes in the infrastructure and operation of the NHS.

In addition to the clinical and organisational sources of information gathered, this study has also included a sample of opinions from patients and carers about the dysphagia care which they received while in hospital. Patients and carers are a valuable source of information, and this brief insight into their views serves to confirm that patients and carers know much more about their own chronic conditions than us as clinicians. This was demonstrated by the comments that some perceived that their problems with swallowing were not really taken seriously by healthcare staff.

As is so often the case with NCEPOD reports, this study highlights the importance of paying attention to some of the basics in care, such as good oral hygiene, hydration, nutrition, feeding position and availability of specialist advice from speech and language therapists, dietitians, nutrition team members and housekeeping to ensure that the texture of food and liquids is tailored to the individual needs of the patient. Having to wait more than 48 hours often with prolonged periods 'nil by mouth' because you are admitted after 5pm on Friday and these essential services stop at the weekend should not be the accepted norm in our modern healthcare system.

As ever I, and my fellow trustees, are most grateful to all the advisors, case reviewers, patients, local reporters, clinicians and ambassadors, together with the NCEPOD clinical co-ordinators, and staff who have made this report possible. I hope that any healthcare staff who see patients with dysphagia, from whatever cause, no matter how infrequently, will find the recommendations in this report of assistance when caring for them.



Ian C Martin
Chair

Key messages aimed at improving the care of people with Parkinson's disease and swallowing difficulties whilst in hospital

MESSAGE 1. DOCUMENT THE SWALLOW STATUS OF ALL PATIENTS WITH PARKINSON'S DISEASE AT THE POINT OF REFERRAL TO HOSPITAL



12/25 respondents to the online patient survey indicated that **problems with eating, drinking or swallowing medication**, while in hospital, were **not taken seriously by the healthcare team**

83/277 (30%) patients had **dysphagia when presenting to hospital**

20/79 sets of notes of patients who were **known to have dysphagia did not contain information relating to dysphagia**

MESSAGE 2. SCREEN PATIENTS WITH PARKINSON'S DISEASE FOR SWALLOWING DIFFICULTIES AT ADMISSION



30/409 (7.3%) patients had a **history of aspiration pneumonia** prior to their admission

96/449 (21.4%) patients had **indicators of dysphagia on admission**. The most common indicators were difficult or slow chewing and swallowing and coughing or choking

287/479 (59.9%) patients had their ability to continue with normal diet and fluid intake, which is an **indicator of dysphagia**, assessed at admission.

MESSAGE 3. REFER PATIENTS WITH PARKINSON'S DISEASE WHO HAVE SWALLOWING DIFFICULTIES (OR WHO HAVE PROBLEMS WITH COMMUNICATION) TO SPEECH AND LANGUAGE THERAPY



51/209 (24.4%) patients were referred to **speech and language therapy** following swallow screening **on arrival** at hospital. The case reviewers were of the opinion that **a further 36/132 (27.3%) patients should have been referred**

96/377 (25.5%) patients were referred to **speech and language therapy on admission**, and in 87 patients this was for dysphagia

Case reviewers indicated there was **a delay in referral to speech and language therapy in 25/96 patients**

MESSAGE 4. NOTIFY THE SPECIALIST PARKINSON'S DISEASE SERVICE (HOSPITAL AND/OR COMMUNITY) WHEN A PATIENT WITH PARKINSON'S DISEASE IS ADMITTED, IF THERE IS ANY INDICATION THAT THERE HAS BEEN A DETERIORATION OR PROGRESSION OF THEIR CLINICAL STATE



307/397 (77.3%) patients were under the care of a **Parkinson's disease service** prior to their admission

180/316 (57%) sets of case notes contained **no evidence** that patients with Parkinson's disease had a **named contact with their Parkinson's disease service**

Parkinson's disease consultants and/or specialist nurses were involved for **160/497 (32.2%) patients**

MESSAGE 5. PROVIDE WRITTEN INFORMATION AT DISCHARGE ON HOW TO MANAGE SWALLOWING DIFFICULTIES



168/292 (57.5%) patients/carers were provided with **information on the administration of medicines prior to discharge**. The information was more likely to be provided if the patient's Parkinson's disease medication had been altered during the admission

There was **no evidence** in the case notes of **communication at discharge** with those responsible for the care of the patient in the community in **90/275 (32.7%) cases reviewed**

There was evidence in the case notes that the **patient's level of swallowing/aspiration risk in the community was considered prior to discharge** for **61/210 (29.0%) patients**

Executive summary

Aim

To examine the pathway of care for patients with Parkinson's disease (PD) who were admitted to hospital when unwell, and to explore multidisciplinary care and organisational factors in the process of identifying, screening, assessing, treating and monitoring of their ability to swallow.

Method

Adult patients aged 16 and over with PD who were acutely unwell and admitted to hospital for at least one day, between 7th January and 3rd March 2019. From the whole group a maximum of four patients per hospital were randomly selected for inclusion. The treating clinician was asked to complete a questionnaire and case notes were requested for peer review.

Key messages

Five key messages listed here, have been agreed as the primary focus for action, based on the report findings and recommendations (see pages 9-11 and Appendix 1).

1. Document the swallow status of all patients with PD at the point of referral to hospital

Since dysphagia can occur at every stage of PD it is important to assess and communicate its presence in a referral letter. Information relating to dysphagia was not available in the referral letter of 20/79 patients who were known to have dysphagia at the point of referral.

2. Screen patients with PD for swallowing difficulties at admission

Patients admitted to hospital may have swallowing difficulties, not recorded as 'dysphagia'. Other indicators should be considered, such as the patient's ability to swallow food, fluids or medication, whether they have control of saliva or have a history of pneumonia.

3. Refer patients with PD who have swallowing difficulties (or who have problems with communication) to speech and language therapy

Early input, as needed, from speech and language therapy (SLT) is fundamental to improving swallowing difficulties and communication for many patients with dysphagia. In this study referral to SLT was made following a swallowing screen on arrival for 51/209 (24.4%) patients and case reviewers were of the opinion that a further 36/132 (27.3%) patients should have been referred.

4. Notify the specialist PD service (hospital and/or community) when a patient with PD is admitted, if there is any indication from the notes, or following discussion with the patient or their relatives/carers, that there has been a deterioration or progression of their clinical state

For any team caring for a patient with PD it is important to know if there has been any unexpected change in the patient's clinical status or care plan. While a majority of patients in this study were under the care of a PD service prior to their admission, there was no evidence of contact with their PD service, on admission, documented in 180/316 (57%) sets of notes.

5. Provide written information at discharge on how to manage swallowing difficulties

At the point of discharge from hospital any changes in care or medication, as well as swallowing status (including the ability to take oral medication), nutrition plan or level of future risk of dysphagia should be provided to care providers as well as the patient and family members.

Recommendations

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. Please see Appendix 1 for how the key findings in the report support the recommendations. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives by those providing care to this group of patients.

The result of local clinical audits or quality improvement initiatives should be presented at quality or governance meetings and action plans to improve care should be shared with executive boards.

Executive boards are ultimately responsible for supporting the implementation of these recommendations. Suggested target audiences to action recommendations are listed in italics under each recommendation. The primary target audience/audiences are in bold.

The term 'healthcare professionals' includes, all specialties and grades who would be involved in the care of this group of patients

1	Document the swallow status of all patients with Parkinson's disease at the point of referral to hospital. Target audiences: Primary care and community Parkinson's disease teams
2	Notify the specialist Parkinson's disease service (hospital and/or community) when a patient with Parkinson's disease is admitted, if there is any indication from the notes, or following discussion with the patient of their relatives/carers, that there has been a deterioration or progression of their clinical state. Target audiences: Healthcare professionals who see patients at admission, clinical and medical directors
3	Screen patients with Parkinson's disease for swallowing difficulties at admission, irrespective of the reason for admission. This should include: <ul style="list-style-type: none"> • Ability to swallow food, fluids and medication • Control of saliva • A history of pneumonia Target audiences: Healthcare professionals who see patients at admission and clinical directors
4	Refer patients with Parkinson's disease who have swallowing difficulties* (or who have problems with communication) to speech and language therapy. Target audiences: Healthcare professionals who see patients throughout their admission and clinical directors

*See Figure 4.3 in the report for a list of indicators of swallowing difficulties

RECOMMENDATIONS

5	<p>Ensure patients are able to take the medication they have been prescribed at, and throughout, their admission. If there are concerns about whether or not the patient can swallow safely consider other formulations of medication (e.g. liquid rather than a tablet) or ways of administering them.</p> <p>Target audiences: Healthcare professionals who see patients at, and throughout, their admission, pharmacists, and clinical directors</p> <p><i>NB: Levodopa should be administered within 30 minutes of the prescribed administration time. This is in line with NICE Quality Standard 164. See also the Parkinson's UK medication optimisation consensus statement</i></p>
6	<p>Ensure there is a hospital policy for the different ways of administering medication and the review of medications at the point of patient discharge. This includes the use of rotigotine patches.</p> <p>Target audiences: Clinical directors, medical directors, hospital pharmacists, specialist Parkinson's disease teams and quality improvement leads</p>
7	<p>Screen the nutritional status of patients admitted to hospital with Parkinson's disease and act on the findings.</p> <p>Target audiences: Clinical directors, dietitians, nutrition team members and healthcare professionals who see patients at, and throughout, their admission</p> <p><i>NB: All patients admitted to hospital should undergo a nutritional screen using a validated screening tool such as the BAPEN Malnutrition Universal Screening Tool (MUST) this in line with NICE Quality Standard 24</i></p>
8	<p>Involve speech and language therapists, pharmacists, dietitians and nutrition team members in any multidisciplinary (MDT) discussion of patients with Parkinson's disease and swallowing difficulties.</p> <p>Target audiences: Clinical directors, speech and language therapists, pharmacists, dietitians and nutrition team members</p>
9	<p>Formalise pathways for the provision of modified texture diet and fluids to include input from:</p> <ul style="list-style-type: none"> • Speech and language therapists • Pharmacists • Dietitians or other nutrition team members • Hospital housekeeping and catering services • Community care <p><i>This is in line with the International Dysphagia Diet Standardisation Initiative (IDDSI)</i></p> <p>Target audiences: Medical directors, clinical directors, clinical teams caring for patients with dysphagia. This includes speech and language therapists, pharmacists, dietitians, hospital housekeeping and catering services, community Parkinson's disease teams and quality improvement leads</p>

RECOMMENDATIONS

10	<p>Ensure there is a hospital policy for 'risk feeding' which includes the assessment or re-assessment (if already undertaken at admission) of mental capacity regarding this decision. The policy should state that discussion should involve:</p> <ul style="list-style-type: none">• Patients• Family members and/or carers• Speech and language therapists• Dietitians/nutrition team members• Pharmacists <p><i>Target audiences: Clinical directors, medical directors, speech and language therapists, pharmacists, dietitians and nutrition team members and quality improvement leads</i></p>
11	<p>Provide written information at discharge on how to manage swallowing difficulties, including:</p> <ul style="list-style-type: none">• Swallow status• Ability to take oral medication• Changes to medication including any new ways of administering them• Nutrition screening tool score and care plan including any texture modifications to food and/or fluids• Positioning• Level of dysphagia risk in the community <p>To:</p> <ul style="list-style-type: none">• The patient• Family members and/or carers• Community healthcare professionals (e.g. GP, community Parkinson's disease team, community pharmacist, care home staff) <p>A proforma could be used for this discharge summary.</p> <p><i>Target audiences: Clinical directors, healthcare professionals who see patients throughout their admission, quality improvement leads</i></p>

Introduction

Dysphagia is a difficulty in moving food from the mouth to the stomach. Well established risk factors for dysphagia include advanced age, head and neck cancer, pulmonary disease and neurological disease, such as Parkinson's disease (PD). PD is a neurodegenerative disease which is increasingly prevalent, and also more common with increasing age.¹

Estimates of the prevalence of dysphagia in PD vary across the literature.² Reasons for this include patients being unaware of their dysphagia, and so not seeking medical advice, as well as dysphagia not being recognised or documented by healthcare professionals.

Lack of recognition of dysphagia can lead to serious complications. Attempting to take food or drink can result in choking or aspiration pneumonia.³ Furthermore, patients with dysphagia may be drooling saliva, indicating their lack of ability to swallow safely. Assessment of these indicators is important, as the inability to swallow can lead to dehydration, malnutrition and weight loss.^{4,5}

Patients with PD have a high rate of admission to hospital,⁶ and the most common reason for this is pneumonia. As dysphagia is an independent predictor of poor outcome in acute care,⁷ is common in PD and can occur at any stage of PD, screening for it at the point of admission to hospital would provide an opportunity for earlier intervention.

In addition to eating and drinking, difficulty swallowing can also lead to problems taking oral medication. Timely administration of medications for PD helps with symptom control, as outlined in the Parkinson's disease UK Medicines Optimisation Consensus Statement.⁸ The NICE Quality Standard for Parkinson's disease (QS 164) also highlights that missed doses of levodopa can lead to worsening symptoms and serious complications, leading to a negative impact on quality of life and prolonged hospital stay.⁹

There are a number of national guidelines written for the care of patients with PD, in addition to NICE QS 164. NICE Guideline 71¹⁰ states that patients with PD should have a PD nurse specialist as a point of contact with specialist services to facilitate continuity of care, information sharing, advice and support. NICE Guideline 71¹⁰ and NICE QS 164⁹ state that patients with PD should be referred to speech and language therapy if problems are identified with communication, swallowing or saliva control. Speech and language therapists can provide effective assessment, care and advice for patients with dysphagia.¹¹

The NICE Quality Standard on nutrition support in adults (QS24) also recommends that all patients should be screened for the presence (or risk) of malnutrition on admission.¹² Screening should be repeated weekly for inpatients. A validated screening tool, such as the Malnutrition Universal Screening Tool (MUST) can aid with this.¹³

Discharge planning should start as early as possible during an admission. For people with PD, plans for discharge should be co-ordinated across the different groups of professionals who are involved in their care during the hospital admission and their ongoing care in the community. As well as speech and language therapists and the specialist PD team, this also includes dietitians, pharmacists, physiotherapists, occupational therapists, and the patient's family where appropriate. Any change in PD medication and/or specific dietary modifications while in hospital should be communicated to the patient's GP or specialist PD team.⁹

This study was developed and designed with multidisciplinary clinical input as well as patient and lay input, to examine the process of recognition and dysphagia care provided to patients with PD who were admitted to hospital when acutely unwell. Organisational and clinical aspects of care were reviewed, and recommendations have been made to drive quality improvement in the care provided to future patients with dysphagia and PD.

Method and data returns

Study Advisory Group

A multidisciplinary group of clinicians was convened to identify the objectives of the study and advise on the key questions to be asked of their peers. The Study Advisory Group (SAG) comprised physicians in acute medicine, neurology, palliative and geriatric medicine, speech and language therapists, physiotherapists, dietitians, pharmacists, specialist nurses, otolaryngology and gastrointestinal surgeons, rehabilitation specialists and lay and patient representatives.

Study aim

To examine the pathway of care for patients with Parkinson's disease (PD) who were admitted to hospital when unwell, and to explore multidisciplinary care and organisational factors in the process of identifying, screening, assessing, treating and monitoring of their ability to swallow.

Objectives

The SAG identified specific objectives that would address the aim of the study.

These included:

- Initial assessment and recognition of dysphagia, including risk assessment and any delays in diagnosis
- Assessment of swallowing
- Ongoing management of dysphagia with regard to food, drink and medications
- Decision-making, including multidisciplinary input and clinician seniority
- Treatment planning, including continuity of care and communication
- Dietary modifications, including modified textures and diets, nutritional screening and 'risk feeding'

- Medication management, including pharmacological and non-pharmacological care of patients, and the availability of PD medications
- End of life care, where appropriate
- Discharge/follow-up arrangements, including communication with relevant healthcare professionals
- Organisational factors that impacted on patient outcomes

Study population and sampling criteria

Inclusion criteria

Adult patients aged 16 and over with PD who were acutely unwell and admitted to hospital between 7th January and 3rd March 2019. Patients were identified by ICD10 codes for PD in any position:

- G20 Parkinson's disease
- G21.1 Other drug-induced secondary parkinsonism
- G21.2 Secondary parkinsonism due to other external agents
- G21.3 Postencephalitic parkinsonism
- G21.4 Vascular parkinsonism
- G21.8 Other secondary parkinsonism
- G21.9 Secondary parkinsonism, unspecified

Exclusions

- Patients admitted as a day case, as not enough data would be available for a review
- Patients who were admitted to Level 3 (ICU/ITU) critical care, as they may have been intubated
- Patients who were admitted to independent hospitals, as this group of patients were unlikely to be acutely unwell.

Sampling criteria

From the whole group a maximum of four patients per hospital were randomly selected for inclusion, and a request was made to the treating clinician to complete a questionnaire.

Hospital participation

NHS hospitals in England, Scotland, Wales and Northern Ireland were expected to participate as well as public hospitals in the Isle of Man, Guernsey and Jersey.

Data collection

Patient/carer online survey

An open-access, anonymous survey was circulated online to allow patients with PD who were admitted to hospital with dysphagia, or their carers, to provide their views on the care received as an inpatient. A link was sent to a wide group of stakeholders to disseminate via their local and national service user and carer networks.

Spreadsheet

A pre-set spreadsheet was provided to every local reporter to identify all patients meeting the study criteria during the study time period. From this initial cohort sampling for inclusion in the study took place.

Questionnaires

Two questionnaires were used to collect data for this study: a clinician questionnaire relevant to each patient and an organisational questionnaire for each participating hospital.

Clinician questionnaire

This questionnaire was sent electronically to the consultant responsible for the care of the patient at the time of their hospital admission. Information was requested on the patient's initial clerking, assessment of swallowing, ongoing care, dietary modifications, medicine optimisation, 'risk feeding' decisions, end of life care and discharge/death (if applicable).

Organisational questionnaire

This questionnaire was disseminated to each hospital with patients in the study and included questions on pathway/protocols and the provision of services relating to dysphagia.

Case notes

Copies of case note extracts were requested for each case that was to be peer reviewed. These included:

- General Practitioner (or other) referral letter
- Ambulance service patient report form/notes
- All inpatient annotations/medical notes/nursing notes/allied health professional notes
- Any operation notes/anaesthetic records/consent forms
- Fluid balance/weight/food/drug/observation and oral care charts
- Malnutrition Universal Screening Tool (MUST)
- Mental capacity assessment forms
- Advance care plans or do not attempt cardiopulmonary resuscitation (DNACPR) forms/treatment escalation forms
- Discharge summary
- Clinic letters for one year prior to the index admission

As the number of patients identified as experiencing dysphagia was lower than expected, following receipt of the first 350 sets of notes, the case note request was amended to focus on those patients where the clinician indicated that the patient had any (or all) of the following:

- Indicators of dysphagia at some point during the admission
- Required modified diet/fluids
- Missed/had altered medication

Peer review of the case notes and questionnaires

A multidisciplinary group of case reviewers was recruited to peer review case notes. The group of case reviewers comprised consultants, clinical nurse specialists and allied healthcare professionals from the following specialties: speech and language therapy, geriatric medicine, acute medicine, palliative care, neurology, nursing, dietetics, physiotherapy, pharmacy and surgery.

Questionnaires and case notes were anonymised by non-clinical staff at NCEPOD. All patient identifiers were removed. Neither the clinical co-ordinators at NCEPOD, nor the case reviewers had access to patient identifiable information.

After being anonymised, each set of case notes was reviewed by at least one reviewer within a multidisciplinary group. At regular intervals throughout each case review meeting, the chair allowed a period of discussion for each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for discussion.

Case reviewers answered a number of specific questions using a semi-structured electronic questionnaire and were encouraged to enter free-text commentary at various points.

The grading system below was used by the case reviewers to grade the overall care each patient received:

Good practice: A standard that you would accept from yourself, your trainees and your institution

Room for improvement: Aspects of **clinical** care that could have been better

Room for improvement: Aspects of **organisational** care that could have been better

Room for improvement: Aspects of both **clinical and organisational** care that could have been better

Less than satisfactory: Several aspects of clinical and/or organisational care that were well below the standard that you would accept from yourself, your trainees and your institution

Insufficient data: Insufficient information submitted to NCEPOD to assess the quality of care

Information governance

All data received and handled by NCEPOD complied with all relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006 (PIAG 4-08(b)/2003, App No 007), PBPP (1718-0328) and the Code of Practice on Confidential Information.

Each patient was given a unique NCEPOD number. All electronic questionnaires were submitted through a dedicated online application. Prior to any analysis taking place, the data were cleaned to ensure that there were no duplicate records and that erroneous data had not been entered. Any fields that contained data that could not be validated were removed.

Data analysis

Following cleaning of the quantitative data, descriptive data summaries were produced. Qualitative data collected from the case reviewers' opinions and free-text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis. The data were reviewed by NCEPOD clinical co-ordinators, a clinical researcher and researcher to identify the nature and frequency of recurring themes.

Data analysis rules

- Small numbers were suppressed if they risked identifying an individual
- Any percentage under 1% has been presented as <1%
- Percentages were not calculated if the denominator was less than 100 except for comparison of percentage across a group
- Anonymised case studies have been used to illustrate particular themes

The findings of the report were reviewed by the SAG, case reviewers, and the NCEPOD Steering Group including clinical co-ordinators, trustees and lay representatives prior to publication. In addition, the recommendations were independently edited, and the report proofread, by two external proof-readers.

Data returns

Clinical data

In total 11,584 patients were identified as meeting the study inclusion criteria (Figure 1). Subsequently 227 were excluded, including 94 patients who were identified as not having PD. Up to four patients per hospital were randomly selected for review of their care, which resulted in a sample of 878 patients. Clinician questionnaires were sent for completion for all this sample. An initial request was made for the case notes to be returned for all 878 patients however, this was subsequently streamlined to request case notes for just those patients where the clinician completing the clinician questionnaire indicated that the patient experienced dysphagia during the admission. This resulted a total of 562 sets of case notes being requested.

In total, 505/878 (57.5%) clinician questionnaires were included in the analysis and 344/562 (61.2%) sets of case notes were peer reviewed by the case reviewers; this included 126 patients with dysphagia.

Patients were identified for inclusion using the ICD10 codes G20 (Parkinson’s disease) and G21 (secondary parkinsonism). Of the 878 patients sampled for clinician questionnaire completion, 50 had an ICD10 code of G21. While patients with both Parkinson’s disease and secondary parkinsonism were included in the study, the term Parkinson’s disease is used throughout the report.

Organisational data

Organisational questionnaires were returned from 177/283 (62.5%) hospitals.

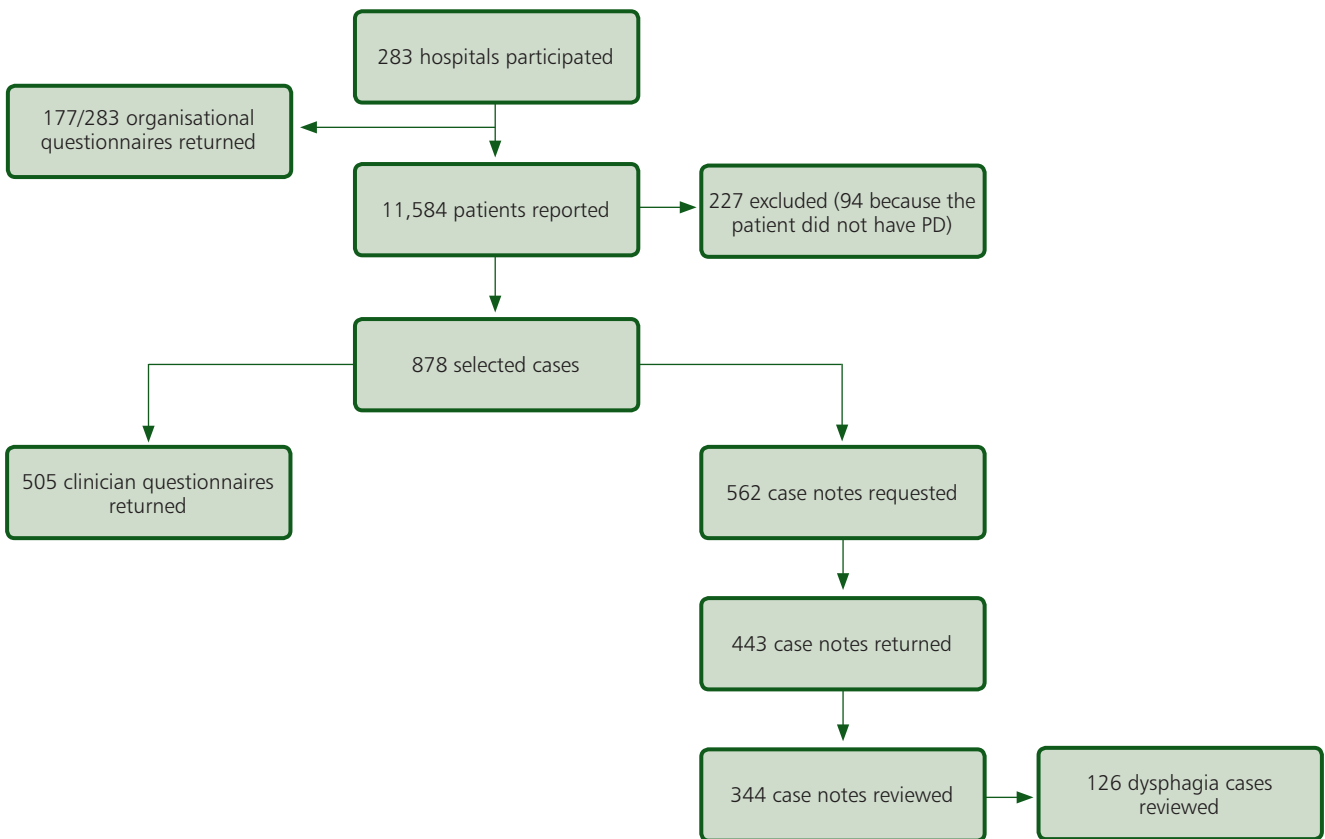


Figure 1.1. Data returns and study inclusion for questionnaires and case note review

Patient survey data

This chapter describes the data collected from patients with Parkinson's disease (PD) and carers via the online survey and gives their views on the provision of services for patients with dysphagia.

Fifty-seven respondents stated that they had been admitted to hospital during the previous year, 45 of whom also indicated that they had swallowing difficulties. Of these, 26 people completed the remainder of the survey with 18/26 surveys completed by a relative or carer and 7/26 by a person with PD. The age of the person with PD ranged between 52-89 years, and the length of time since diagnosis ranged between a "very recent" diagnosis to 17 years.

The management of inpatient swallowing difficulties was rated as 'good' or 'adequate' by 10/25 respondents and as 'poor' or 'unsatisfactory' by 15/25 respondents (Figure 2.1). Seventeen respondents highlighted issues related to food provision: six commented that it was either inedible or there was limited

help and three commented that there was no assessment/lack of knowledge, in so far as no one asked what food would be acceptable or about whether they could swallow foods or medications.

Seventeen patients saw a speech and language therapist while in hospital. For 10/17 people this was for swallowing, for 4/17 for both speech and swallowing, and for three people, for speech alone.

In order to maintain a 'safe swallow', patients should sit upright at 90 degrees when eating and drinking, and not eat when slouching or lying down.¹⁴ Eleven respondents reported that food, drink or medication was given while the patient was lying down.

Problems with eating, drinking or swallowing medication while in hospital were not taken seriously by the healthcare team in the view of half the respondents (12/25).

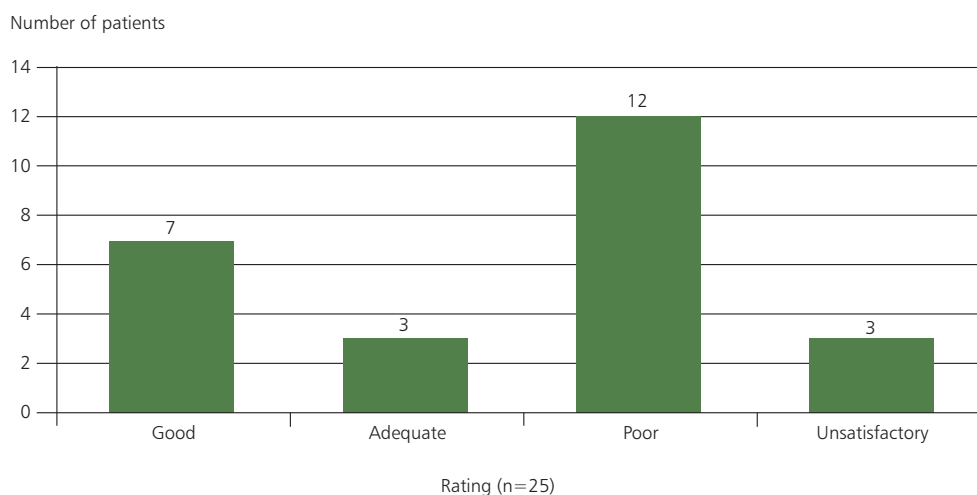


Figure 2.1. Rating of the management of the swallowing problems while in hospital

Patient and carer survey data

Key Findings

1. 10/25 respondents to the online survey rated the management of swallowing difficulties as 'good' or 'adequate' and 15/25 respondents rated the management as 'poor' or 'unsatisfactory'
2. 11 patient/carer respondents to the online survey reported that food, drink or medication was given while the patient was lying down
3. 12/25 respondents to the online survey indicated that problems with eating, drinking or swallowing medication while in hospital were not taken seriously by the healthcare team

Study population

This chapter provides an overview of the sampled study population from the data collected from hospitals.

Figure 3.1 shows the age and gender distribution of patients included in this study population. The average age of men was 78.3 years and of women 79.9 years. In total, 312/504 (61.9%) of the study sample were men and 191/504 (37.9%) were women.

Identification of dysphagia in the sample population

Clinicians completing a questionnaire indicated that 83/412 (20.1%) patients had dysphagia at some point during their hospital admission (Table 3.1).

In addition, there were several questions in the clinician questionnaire relating to indicators of, or the presence of, dysphagia during the admission:

- Did the patient have indicators of dysphagia on admission?
- On reflection, did the patient experience dysphagia during the admission?

Table 3.1 Clinician reported that the patient had dysphagia at some point during the admission

	Number of patients	%
Yes	83	20.1
No	329	79.9
Subtotal	412	
Unknown	59	
Not answered	34	
Total	505	

Clinician questionnaire data

- Was medication altered during the admission due to swallowing difficulties?
- Was a modified diet indicated at some point during the admission?
- Were modified fluids indicated at some point during the admission?
- Was the patient 'risk feeding' prior to admission?

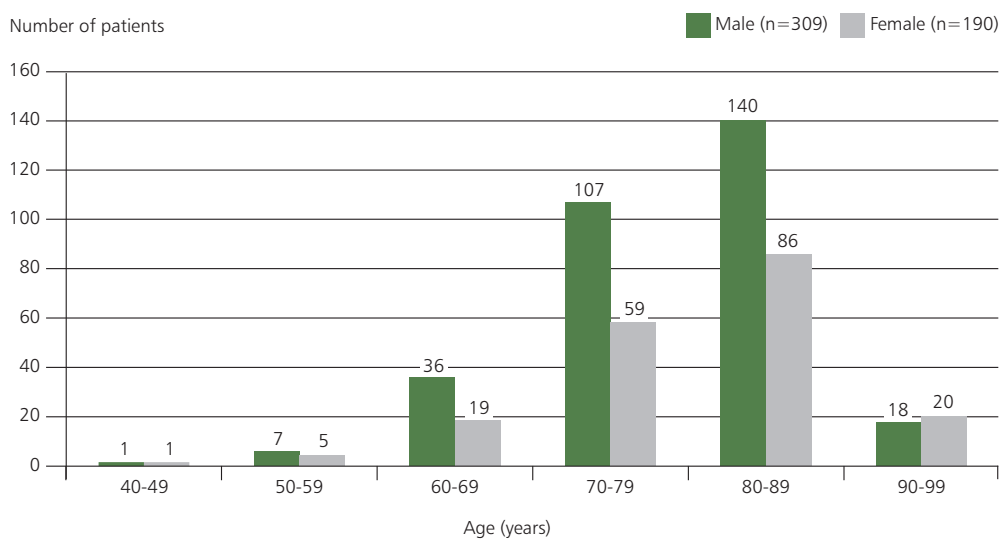


Figure 3.1. Age and gender of the study population

There were 154/505 (30.5%) patients where the answer to at least one of these questions was 'yes', indicating dysphagia was present during the admission, perhaps more commonly than was initially recognised (Table 3.2).

Table 3.2. Indicators or presence of dysphagia during the admission

	Number of patients	%
Yes	154	30.5
No	351	69.5
Total	505	

Clinician questionnaire data

A similar percentage of patients were identified from their case notes, assessed by the case reviewers, as having dysphagia when presenting to hospital (83/277; 30%) (Table 3.3). It should be noted that the 344 case notes selected for peer review were skewed towards patients who either had indicators of dysphagia at or during the admission or required modified diet/fluids or missed/altered their medications.

Table 3.3 Dysphagia was present in this patient on arrival at hospital

	Number of patients	%
Yes	83	30.0
No	194	70.0
Subtotal	277	
Unable to answer	48	
Not answered	19	
Total	344	

Case reviewer data

Following peer review of the notes, the case reviewers indicated that overall 126/312 (40.4%) patients had dysphagia at some point during the admission (Table 3.4).

Table 3.4 The patient had dysphagia at some point during the admission

	Number of patients	%
Yes	126	40.4
No	186	59.6
Subtotal	312	
Unable to answer	32	
Total	344	

Case reviewer data

Stage of Parkinson's disease

At the time of admission, the mean time since diagnosis of PD in this study population was 6.7 years (range 0-27 years). A clinical scale for staging PD has been recommended as a pragmatic method to plan for care throughout the disease process.¹⁵ The Hoehn and Yahr Scale was one of the first tools to measure the extent of disability in, and monitor progression of, PD¹⁶ and the Movement Disorder Society - Unified Parkinson's Disease Rating Scale (MDS-UPDRS) combines elements from multiple scales to provide a more comprehensive understanding of the disease, including its non-motor features¹⁷ (Appendix 2). Admitting clinicians were asked to retrospectively indicate the severity of PD in this study population. The 'Stages of Care' rating was most frequently completed (417/505; 82.6%) with most patients in the 'maintenance' or 'complex' stage at the time of admission (Table 3.5).

Table 3.5 Stage of Parkinson's disease at the time of admission

	Number of patients	%
Diagnosis	36	8.6
Maintenance	165	39.6
Complex	136	32.6
End stage	80	19.2
Subtotal	417	
Unknown	88	
Total	505	

Clinician questionnaire data

Table 3.6 Hoehn and Yahr Scale at the time of admission

	Number of patients	%
Stage 1	18	9.0
Stage 2	23	11.6
Stage 3	39	19.6
Stage 4	71	35.7
Stage 5	48	24.1
Subtotal	199	
Unknown	306	
Total	505	

Clinician questionnaire data

Table 3.6 shows the Hoehn and Yahr Scale at the time of admission. The MDS-UPDRS score appeared to be of limited use (10/505; 2.0% responses – data not shown).

Dysphagia can occur at any stage of PD although is more likely as the disease progresses. In this study, indicators of dysphagia during the admission occurred each stage of PD with 30/76 (40.5%) in stage 5 compared with 18/123 (14.4%) of those with no indicators of dysphagia (Figure 3.2). Similarly, 49/133 (36.8%) of patients with indicators of dysphagia during the admission were in the end stage of Parkinson’s disease compared with 31/284 (10.9%) of those with no indicators of dysphagia (Figure 3.3).

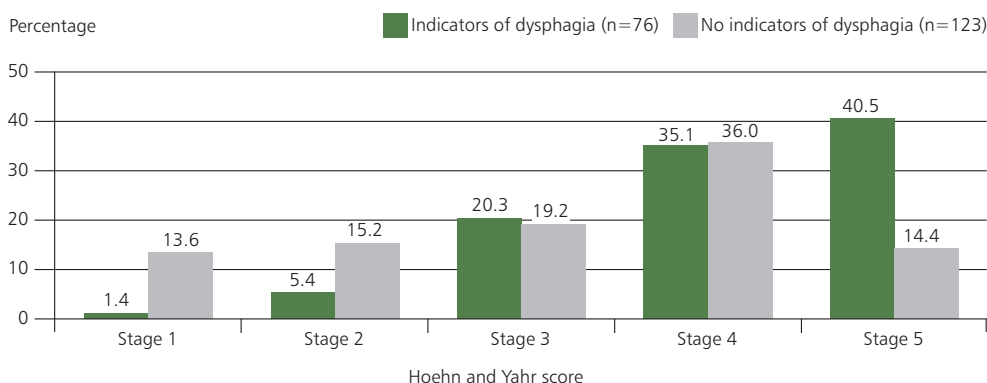


Figure 3.2. Hoehn and Yahr Scale by the presence of dysphagia during the admission
Clinician questionnaire data

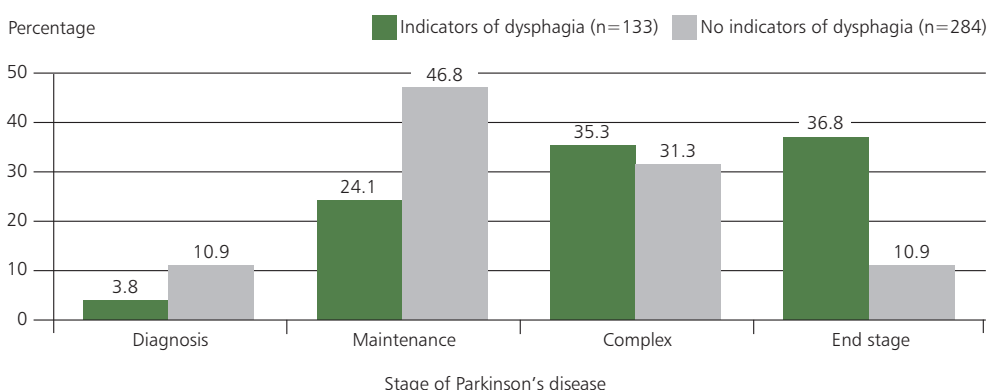


Figure 3.3. Stage of Parkinson's disease by the presence of dysphagia during the admission
Clinician questionnaire data

Care under a Parkinson's disease service

NICE Quality Standard 164⁹ stipulates that patients should have a PD nurse specialist as a point of contact with specialist services to facilitate continuity of care, information sharing, advice and support. This contact also ensures patient needs are proactively reviewed and addressed.

Consultants completing the clinician questionnaire reported that 307/397 (77.3%) patients were under the care of a PD service prior to their admission. However, case reviewers found no evidence of documentation of this information in 180/316 (57.0%) cases reviewed. Lack of such documentation could lead to incomplete discharge planning and handover back to the Parkinson's disease service at the end of the hospital stay.

According to a recent systematic review, patients with PD are about 1.5 times more likely to be admitted to hospital compared with age matched healthy peers.¹⁸ Common reasons for acute admission to hospital are respiratory and urinary tract infections (22%), worsening motor features of PD (19%) and falls (13%). Aspiration pneumonia is also common in those presenting with respiratory infection, primarily due to dysphagia. Urgent or emergency admissions from residential and care homes are usually due to falls. The most common reason for admission to hospital in this study population was falls (142/505; 28.1%) and frailty (63/505; 12.5%), followed by symptoms suggestive of cardiorespiratory involvement (with cough and shortness of breath). Some patients were admitted with multiple symptoms (Table 3.7).

While most patients were admitted from home (368/495; 74.3%), 52/495 (10.5%) were admitted from a nursing home and 48/495 (9.7%) a residential home (Table 3.8). Most patients in this study were admitted as an emergency (445/500; 89.0%) reflecting the presenting features listed.

Table 3.7 Presenting feature

	Number of patients	%
Fall	142	28.1
Frailty	63	12.5
Shortness of breath	57	11.3
Confusion/delirium	56	11.1
Cough	54	10.7
Fever	54	10.7
Elective admission	27	5.3
Abdominal pain	26	5.1
Vomiting	19	3.8
Drowsiness	18	3.6
Chest pain	17	3.4
Constipation/diarrhoea	17	3.4
Cerebrovascular disease	15	3.0
Other	54	10.7

Answers may be multiple; n=505
Clinician questionnaire data

Table 3.8 Where the patient was admitted from

	Number of patients	%
Home	368	74.3
Nursing home	52	10.5
Residential care home	48	9.7
Another hospital	17	3.4
Other	10	2.0
Subtotal	495	
Unknown	10	
Total	505	

Clinician questionnaire data

In keeping with the presenting features listed in Table 3.7, most patients required admission to a medical specialty (383/505; 75.8%) and were placed either in a medical assessment unit or a medical ward (Table 3.9). The medical specialties receiving these patients were general medicine (137/505; 27.1%) and geriatric medicine (106/505; 21.0%). Surgery requiring sedation, general or regional anaesthesia was undertaken in 79/493 (16.0%) patients.

Most patients had additional comorbidities (453/495; 91.5%); with dementia, cerebrovascular disease, diabetes and chronic pulmonary disease being most frequent (Figure 3.4) and 362/451 (80.3%) patients had more than one comorbidity.

Table 3.9. Type of ward to which the patient was first admitted

	Number of patients	%
Medical assessment unit	273	54.7
Medical ward	92	18.4
Surgical ward	82	16.4
Surgical assessment unit	21	4.2
High dependency care	4	<1
Other	27	5.4
Subtotal	499	
Unknown	6	
Total	505	

Clinician questionnaire data

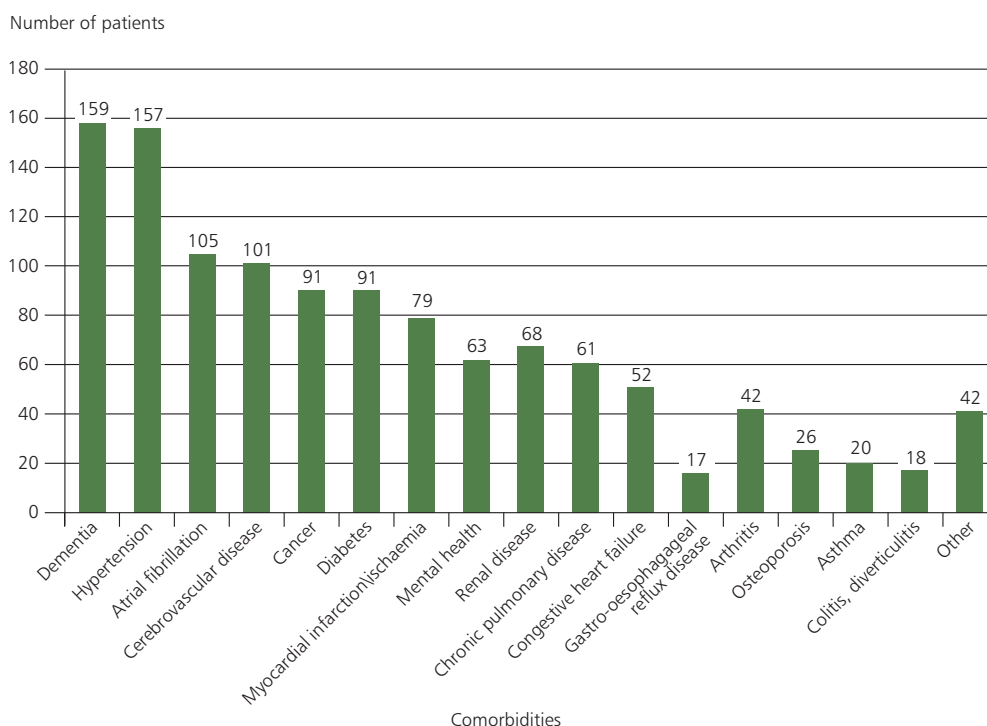


Figure 3.4 Comorbidities
Answers may be multiple; n=451
Clinician questionnaire data

Table 3.10 History of aspiration pneumonia by the presence of dysphagia during the admission

	Dysphagia		No dysphagia		Subtotal	Not answered	Total
	Number of patients	%	Number of patients	%	Number of patients	Number of patients	Number of patients
Yes	18	27.3	6	2.2	24	6	30
No	48	72.7	272	97.8	320	59	379
Subtotal	66		278		344	65	409
Unknown	17		51		68	28	96
Total	83		329		412	93	505

Clinician questionnaire data

There were 30/409 (7.3%) patients who had a history of aspiration pneumonia prior to their admission. Of these 30 patients, 18/24 patients had dysphagia. Of those without aspiration pneumonia, 48/320 (15%) had dysphagia. (Table 3.10)

Key Findings

4. 83/412 (20.1%) patients had dysphagia at some point during their hospital admission, in the view of clinicians completing the questionnaire
5. 154/505 (30.5%) patients had indicators of dysphagia during the admission, when data from multiple questions in the clinician questionnaire were combined
6. 83/277 (30%) patients had dysphagia when presenting to hospital documented in the case notes
7. 307/397 (77.3%) patients were under the care of a Parkinson's disease service prior to their admission
8. 180/316 (57%) sets of case notes contained no evidence that patients with Parkinson's disease had a named contact with their Parkinson's disease service
9. 30/409 (7.3%) patients had a history of aspiration pneumonia prior to their index admission. Of these 30 patients, 18/24 patients had dysphagia. Of those without aspiration pneumonia, 48/320 (15%) had dysphagia

Referral, initial assessment and admission

This chapter presents data on the recognition of and dysphagia care provided from referral to the point of admission.

Referral

A referral letter was available for 77/386 (19.9%) patients. The referral letter commonly included information about the patient's medical care history (64/72), comorbidities (55/72) and current medications (51/72). However, information that

was not shared as often included details of the level of dysphagia risk (7/72), action plans in the community (8/72) and advance decision planning (3/72) (Figure 4.1).

Since dysphagia can occur at every stage of PD it is important to assess and communicate its presence in a referral letter. Case reviewers found that information relating to dysphagia was not available in 20/79 sets of notes of patients who were known to have dysphagia at the time of arrival (Table 4.1).

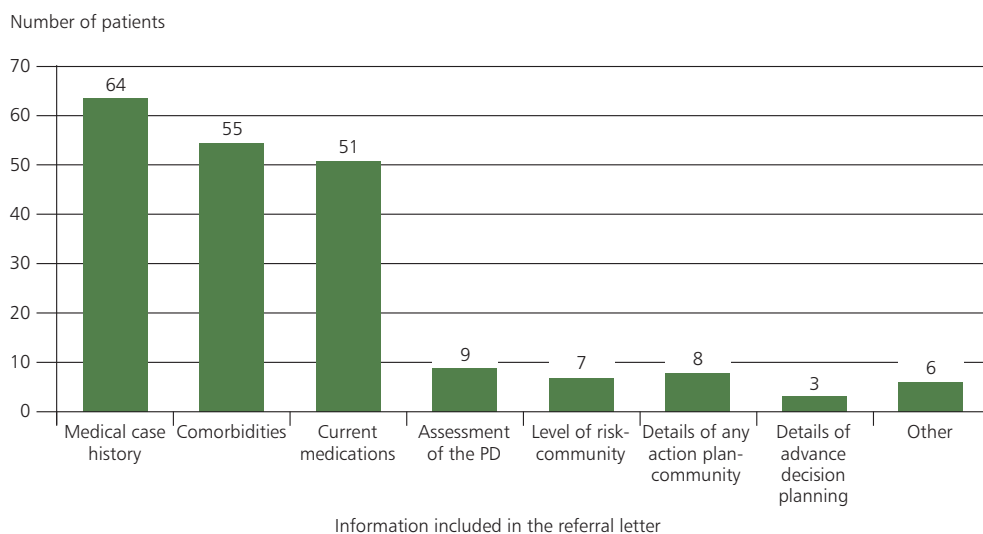


Figure 4.1
Information included in the referral letter
Answers may be multiple; n=72
Clinician questionnaire data

Table 4.1 Information relating to dysphagia was available with the patient on arrival

	Dysphagia on admission	No dysphagia on admission	Subtotal	Not answered	Total
	Number of patients	Number of patients	Number of patients	Number of patients	Number of patients
Yes	59	12	71	7	78
No	20	72	92	35	127
Subtotal	79	84	163	42	205
Unable to answer	3	1	4	14	18
NA – no dysphagia on arrival	1	109	110	11	121
Total	83	194	277	67	344

Case reviewer data

Initial assessment

Activities of daily living

Patients with PD can have a variety of symptoms that interfere with activities of daily living and their ability to live independently. It is therefore important to identify deterioration in motor function and co-ordination early and at every opportunity. Similarly, dysphagia is an important contributor to the deterioration in quality of life.

Clinicians returning a questionnaire reported that an assessment was made on arrival of how the person was managing at home for 388/479 (81.0%) patients, and the patient's medication history, and their ability to take it, for 363/479 (75.8%) patients. However, an assessment of whether the patient had symptoms of dysphagia was made for only 179/479 (37.4%) patients. The ability to continue with normal diet and fluid intake, which is an indicator of dysphagia, was assessed for 287/479 (59.9%) patients. Similarly, assessment of dehydration and difficulty in controlling saliva, were assessed in 222/479 (46.3%) and 62/479 (12.9%) patients respectively (Table 4.2).

Presence of dysphagia

There was evidence in the case notes that 78 patients presented with information relating to their current level of dysphagia (Table 4.3). In the opinion of case reviewers 58/78 patients had their dysphagia managed appropriately.

There was evidence in the case notes relating to the initial assessment of the presence of dysphagia in only 123/312 (39.4%) patients, while a similar number of patients (133/335; 39.7%) reported difficulty with speech. All were more likely to be assessed when dysphagia was recognised to be present during the admission (Figure 4.2 overleaf).

Table 4.2 Assessments undertaken

	Number of patients	%
How the patient was managing at home	388	81.0
Medication history and compliance	363	75.8
Whether the patient was eating and drinking a normal diet prior to admission	287	59.9
Whether the patient had difficulty with speech/communication	255	53.2
Whether the patient was admitted with dehydration	222	46.3
Mental capacity	218	45.5
Whether the patient had symptoms of dysphagia on admission	179	37.4
Any side effects associated with medications	114	23.8
Whether the patient had difficulty with controlling saliva	62	12.9
None of the above	46	9.6
Subtotal	479	
Unknown	26	
Total	505	

Answers may be multiple; n=479
Clinician questionnaire data

Table 4.3 Evidence in the case notes that the patient arrived with information relating to their current level of dysphagia

	Number of patients	%
Yes	78	38.0
No	127	62.0
Subtotal	205	
Unable to answer	18	
NA - dysphagia not present on arrival	121	
Total	344	

Case reviewer data

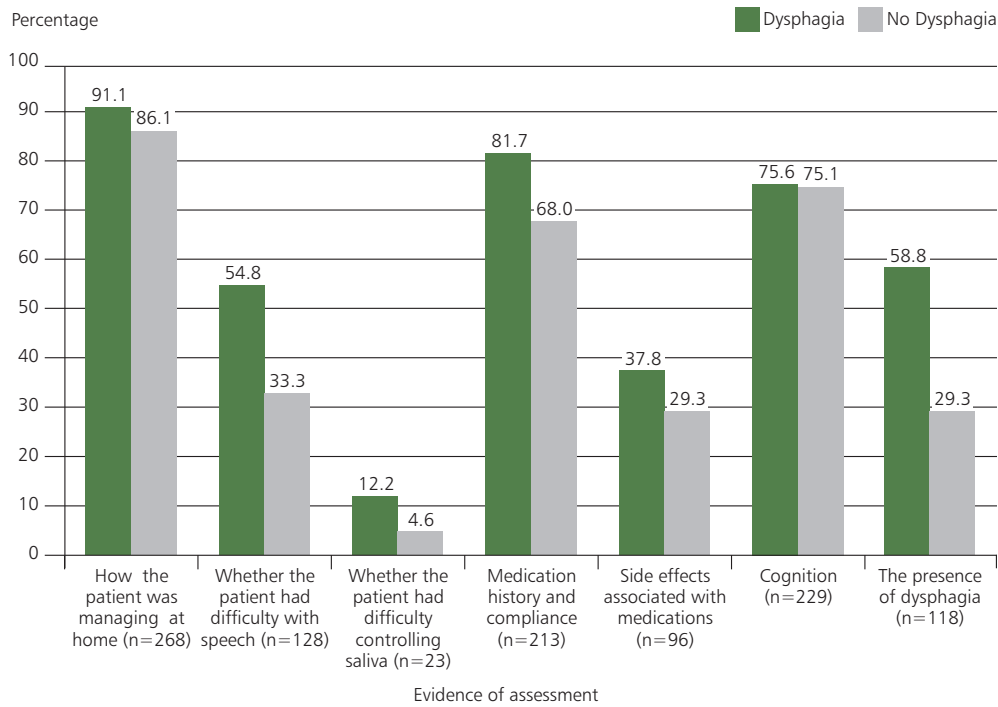


Figure 4.2 Assessments made at the initial assessment
Case reviewer data

Case note reviewers indicated there was a delay in recognising dysphagia at initial assessment in 28/141 (19.9%) of the cases reviewed (Table 4.4). Where there was a delay, this affected the outcome in 6/19 patients, most commonly manifesting as lower respiratory infection or aspiration pneumonia.

Table 4.4 A delay in recognising dysphagia at the initial assessment

	Number of patients	%
Yes	28	19.9
No	113	80.1
Subtotal	141	
Unable to answer	39	
NA - dysphagia not present on arrival	164	
Total	344	

Case reviewer data

Screening for dysphagia

Early screening for dysphagia helps in establishing the need for further assessment of risk of complications, including dehydration and malnutrition. NICE Quality Standard 2¹⁹ for the care of adults following a stroke stated that swallow screening should be undertaken within four hours of admission. Even though it does not appear in the 2016 update, it is still supported by NICE at local level. Although not specific to patients with PD, this quality standard was adopted into the study. There was evidence in the case notes that a swallowing screen was undertaken within four hours of arrival for 44/316 (13.9%) patients. These included 24/75 patients who were known to have dysphagia at admission but missed in a further 51/75 patients who were assessed to have dysphagia on arrival (Table 4.5 overleaf).

Table 4.5 Dysphagia on arrival and swallow screening undertaken within four hours

	Dysphagia on admission	No dysphagia on admission	Subtotal	Unable to answer	Not answered	Total
	Number of patients	Number of patients	Number of patients	Number of patients	Number of patients	Number of patients
Yes	24	18	42	1	1	44
No	51	161	212	43	17	272
Subtotal	75	179	254	44	18	316
Unable to answer	8	15	23	4	1	28
Total	83	194	277	48	19	344

Case reviewer data

Reviewers found evidence in the case notes that referral to speech and language therapy was made following a swallow screen on arrival for 51/209 (24.4%) patients (Table 4.6). They were of the opinion that a further 36/132 (27.3%) patients should have been referred at this stage.

Table 4.6 The patient was referred to speech and language therapy following a swallow screening on arrival

	Number of patients	%
Yes	51	24.4
No	158	75.6
Subtotal	209	
Unable to answer	11	
NA	124	
Total	344	

Case reviewer data

In the opinion of the case reviewers, the initial assessment of patients was satisfactory in 206/287 (71.8%) cases reviewed. The main reason case reviewers rated the initial assessment as not satisfactory, was that the swallow assessment was incomplete or not undertaken at all in 60/81 patients, or not actioned when the patient had difficulty swallowing in 23/81 cases reviewed. For three patients both these steps were not undertaken satisfactorily even after dysphagia was recognised.

Admission

Indicators of dysphagia at admission

Based on data from the clinician questionnaire, 96/449 (21.4%) patients had indicators of dysphagia on admission. The most common indicators were difficult or slow chewing and swallowing and coughing or choking (Figure 4.3 overleaf).

CASE STUDY 1

A 64-year-old patient was admitted with inability to cope at home. The patient was noted to be coughing on water and medicines. However, no swallow screening was performed at admission and the patient was made 'nil by mouth' by the clerking doctor who suggested referral to speech and language therapy. By the next day the patient was drowsy and confused due to a combination of dehydration, missed oral medications and lack of any alternative medications administered.

Case reviewers were of the opinion that these complications could have been avoided by undertaking prompt swallow screening, referral to speech and language therapy and prescription of intravenous fluids and suitable medications in liaison with the Parkinson's disease specialist team and pharmacy.

Indicators of dysphagia

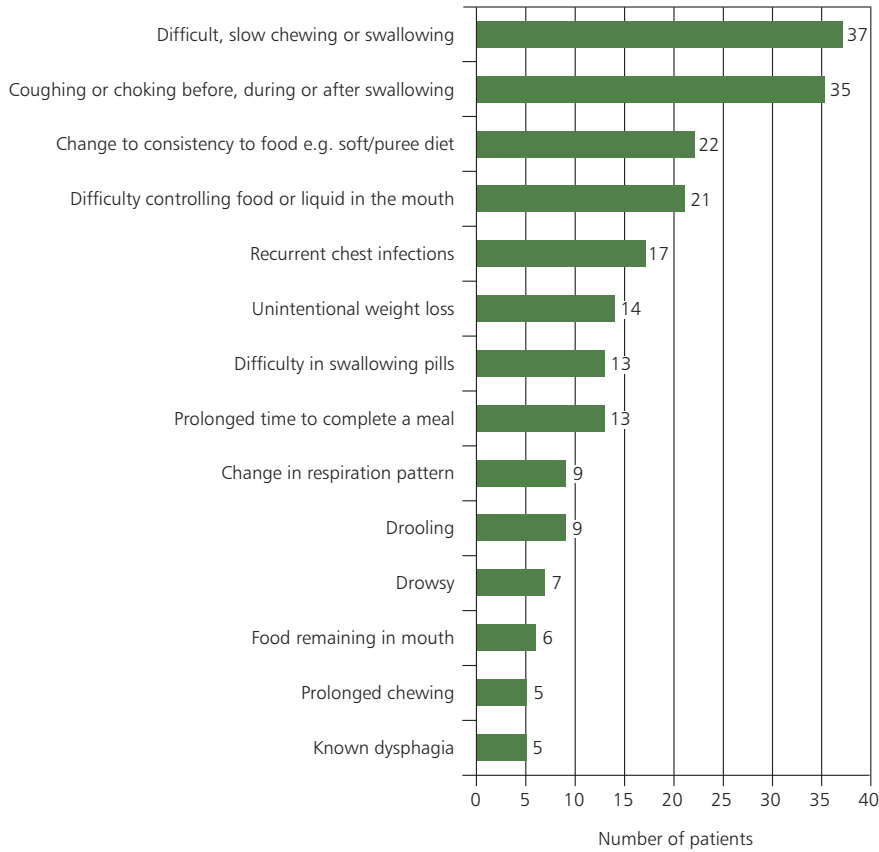


Figure 4.3. Indicators of dysphagia on admission

Answers may be multiple; n=96
Clinician questionnaire data

* Other responses provided – Wet voice quality, unexplained temperature spikes, food sticking in throat, hoarse voice, feeling of obstruction, avoiding particular foods e.g. dry/hard, heartburn, regurgitation of undigested food, avoiding social occasions, frequent throat clearing all <5 patients

History of coughing/choking

Frequent coughing, choking or nasal regurgitation of food when swallowing are important symptoms of dysphagia and dehydration is common in patients with dysphagia. A history of choking was present in 33/406 (8.1%) patients

and signs of dehydration assessed in 299/443 (67.5%) patients, primarily by monitoring fluid balance (191/443, 43.1%) and urine output (105/443, 23.7%) (data not shown), although there was no documentation for 144/443 (32.5%) patients (Table 4.7).

Table 4.7 A history of choking and hydration assessment

	History of choking		Hydration assessed	
	Number of patients	%	Number of patients	%
Yes	33	8.1	299	67.5
No	373	91.9	144	32.5
Subtotal	406		443	
Unknown	99		62	
Total	505		505	

Clinician questionnaire data

Referral to speech and language therapy (covered in further detail in Chapter 5)

NICE Quality Standard 164⁹ for patients with PD includes a referral to the speech and language therapy (SLT) team if problems are identified with communication, swallowing or saliva. Consultants completing the clinician questionnaire reported that on admission 96/377 (25.5%) patients were referred to SLT, and in 87 patients this was for dysphagia (Table 4.8).

Table 4.8 The patient was referred to speech and language therapy on admission

	Number of patients	%
No	281	74.5
Yes – for dysphagia	72	19.1
Yes – for both dysphagia and communication	15	4.0
Yes – for communication	9	2.4
Subtotal	377	
Not applicable	97	
Unknown	31	
Total	505	

Clinician questionnaire data

Non-motor assessments

While the motor manifestations of PD are most obvious from early disease and form an important part of its diagnostic criteria, other features collectively called non-motor symptoms, can be obscure but still have a significant impact. These comprise dementia related to PD, orthostatic

Table 4.9 Non-motor assessments at admission

	Mental health history		Cognition		Hallucinations, dementia or depression	
	Number of patients	%	Number of patients	%	Number of patients	%
Yes	139	32.3	322	70.0	196	46.3
No	292	67.7	138	30.0	227	53.7
Subtotal	431		460		423	
Unknown	74		45		82	
Total	505		505		505	

Clinician questionnaire data

CASE STUDY 2

A 76-year-old patient with Parkinson's disease was admitted with clinical suspicion of aspiration pneumonia. The patient was not assessed for dysphagia and swallow screening was missed at admission. Over the next 48 hours, the patient became less responsive and was transferred to critical care with sepsis.

Case reviewers were of the opinion that timely swallow screening, referral to speech and language therapy and an appropriate plan for nutrition, hydration and administering medications could have prevented these complications.

hypotension, drooling of saliva, depression, impulse control disorder, psychotic symptoms and sleep disorders. Medications given for PD can produce or aggravate some of these features, such as orthostatic hypotension, impulse control disorder, hallucinations and delusions. In patients with PD and dementia up to 20% have been noted to have dysphagia.²⁰ Since many of these non-motor symptoms can compromise swallowing and nutrition, they require prompt identification and multi-professional collaboration to achieve optimal control.

Cognitive assessment was most often completed at admission (322/460; 70%), while mental health history and assessment were completed in 139/431 (32.3%) patients and 196/423 (46.3%) patients respectively (Table 4.9).

Carers can be an important source of information in the assessment and ongoing care of patients, especially for those patients with cognitive impairment. Case reviewers found evidence in the case notes that family members and/or carers provided information relevant to a patient's admission in 208/330 (63.0%) cases.

Medication (covered in further detail in Chapter 8)

Timely administration of medications for PD helps with symptom control. The Parkinson's disease UK Medicines Optimisation Consensus Statement⁸ and NICE Quality Standard 164⁹ recommend that patients in hospital should take levodopa within 30 minutes of their individually prescribed administration time, as missed doses can lead to worsening symptoms and serious complications, resulting in a negative impact on quality of life and prolonged hospital stay. Missed doses could also exacerbate dysphagia, which may impair the ability to take subsequent doses, leading to progressive deterioration.

Consultants completing the clinician questionnaire reported that 81/283 (28.6%) patients admitted via the emergency department missed one or more doses of medication. In addition, for a further 158/505 (31.3%) patients it was unclear whether they had missed a dose, highlighting the importance of good documentation (Table 4.10).

Table 4.10 Doses of medication were missed, for those patients admitted via the emergency department (ED) or an acute admission unit

	Number of patients	%
Yes	81	28.6
No	202	71.4
Subtotal	283	
Unknown	158	
Not applicable – not admitted via ED/acute admission unit	64	
Total	505	

Clinician questionnaire data

When a patient is unable to swallow, or it is considered unsafe to allow oral medication, alternative routes or drugs should be considered. Any substantial changes to medications should be done in consultation with the PD

specialist team, pharmacist, patient, family and/or carers. Of the 114 responses recorded as to why medication was not given, 21/114 (18.4%) were due to a clinical suspicion of dysphagia and 20/114 (17.5%) were due to a decision to keep the patient 'nil by mouth' (Table 4.11).

Table 4.11 Reason that medications were not given

	Number of patients	%
Concerns about dysphagia/ known dysphagia	21	18.4
Patient 'nil by mouth'	20	17.5
Clinical decision to not administer (details not noted)	20	17.5
Drug not prescribed/prescribed late	13	11.4
Drug was not available on ward	13	11.4
Patient arrived out of hours	10	8.8
Patient refused	7	6.1
Other	10	8.8
Total	114	

Clinician questionnaire data

Medication history was most often verified on admission via the hospital pharmacist (253/423; 59.8%) or via a family member or carer (152/423; 35.9%) (Table 4.12). There was evidence in the case notes that 291/329 (88.4%) patients that they presented with information relating to their present drug dose and mode of administration (Table 4.13 overleaf).

Table 4.12 How the medication history was verified

	Number of patients	%
Hospital pharmacist	253	59.8
Family member/carer	152	35.9
GP referral letter	53	12.5
Blister pack	11	2.6
Other	129	30.5
Subtotal	423	
Unknown	82	
Total	505	

*Answers may be multiple; n=423
Clinician questionnaire data*

Table 4.13 Evidence in the case notes that the patient presented with information relating to their drug dosage and mode of administration

	Number of patients	%
Yes	291	88.4
No	38	11.6
Subtotal	329	
Unable to answer	15	
Total	344	

Case reviewer data

Nutritional screening

NICE Clinical Guideline 32 on nutritional support for adults recommends that all hospital inpatients should be screened for the presence (or risk) of malnutrition on admission.⁵ Screening should be repeated weekly for inpatients. Such screening should be undertaken with the aid of a validated screening tool. The Malnutrition Universal Screening Tool (MUST) was introduced in 2003 by the British Association of Parenteral and Enteral Nutrition (BAPEN) and supported by multiple organisations like the Royal College of Nursing and British Dietetic Association.¹³ It is also mentioned in NICE Quality Standard 24, which covers the care for adults who are malnourished or at risk of malnutrition in hospital or in the community.¹²

There were 69/152 (45.4%) hospitals in which there was no policy for the nutritional assessment of patients admitted with PD (Table 4.14).

Table 4.14 Policy on nutritional assessment for all patients admitted with Parkinson's disease

	Number of hospitals	%
Yes	83	54.6
No	69	45.4
Subtotal	152	
Unknown	25	
Total	177	

Organisational data

Data from the clinician questionnaire indicated there was a record of nutritional screening undertaken on admission for 295/434 (68.0%) patients. The most commonly used method of nutritional screening was the MUST (226/287; 78.7%) (Table 4.15).

Table 4.15 Method of nutritional screening was used

	Number of patients	%
Malnutrition Universal Screening Tool (MUST)	226	78.7
Estimated weight	69	24.0
Family/carers	37	12.9
Other	44	15.3
Subtotal	287	
Unknown	8	
Total	295	

Answers may be multiple; n=287
Clinician questionnaire data

Case note reviewers found a record in the case notes of a nutritional screening being undertaken on admission in 162/336 (48.2%) cases reviewed. Where this was undertaken the case note reviewers indicated this was adequate in 136/157 (86.6%) patients. There was evidence in the case notes that a MUST score was calculated on arrival for 119/316 (37.7%) patients. In the opinion of the case reviewers the correct score was calculated for 102/111 (91.9%) patients, and the correct action to be taken identified as a result of MUST screening for 100/109 (91.7%) patients (Table 4.16).

Table 4.16 A MUST score calculated on arrival

	Number of patients	%
Yes	119	37.7
No	197	62.3
Subtotal	316	
Unable to answer	28	
Total	344	

Case reviewer data

Key Findings

10. 20/79 sets of notes of patients who were known to have dysphagia at the time of arrival did not contain information relating to dysphagia
11. An assessment of whether the patient had symptoms of dysphagia was made for 179/479 (37.4%) patients
12. 287/479 (59.9%) patients had their ability to continue with normal diet and fluid intake, which is an indicator of dysphagia, assessed at admission. Similarly, assessment of dehydration and difficulty in controlling saliva, were assessed in 222/479 (46.3%) and 62/479 (12.9%) patients respectively
13. 123/312 (39.4%) patients had documented assessments of dysphagia at the initial assessment, while a similar number of patients (133/335; 39.7%) reported difficulty with speech
14. 44/316 (13.9%) patients had swallow screening undertaken within 4 hours of arrival. This missed 51/75 patients who were known to have dysphagia on arrival
15. 51/209 (24.4%) patients were referred to speech and language therapy following swallow screening on arrival at hospital. The case reviewers were of the opinion that a further 36/132 (27.3%) patients should have been referred
16. 96/449 (21.4%) patients had indicators of dysphagia on admission. The most common indicators were difficult or slow chewing and swallowing and coughing or choking
17. 96/377 (25.5%) patients were referred to speech and language therapy on admission, and in 87 patients this was for dysphagia
18. 81/283 (28.6%) patients admitted via the emergency department missed one or more doses of medication. For a further 158/505 (31.3%) patients it was unclear whether they had missed a dose. Of the 114 responses recorded as to why medication was not given, 21/114 (18.4%) were due to a clinical suspicion of dysphagia and 20/114 (17.5%) were due to a decision to keep the patient 'nil by mouth'
19. 69/152 (45.4%) hospitals did not have a policy for the nutritional assessment of patients admitted with Parkinson's disease
20. 295/434 (68.0%) patients had a nutrition screen undertaken on admission as recorded in the clinician questionnaire. This was documented in the case notes of 162/336 (48.2%) patients
21. There was evidence in the case notes that a Malnutrition Universal Screening Tool (MUST) score was calculated on arrival for 119/316 (37.7%) patients

Formal swallowing assessment after admission

On admission to hospital, if there are concerns about a patient's ability to swallow safely or if they are unable to complete a swallow screening test, they should be promptly referred to the speech and language therapy (SLT) service for formal assessment and care of their dysphagia.

While a ward-based clinical assessment of swallowing may be performed by SLT in patients with Parkinson's disease (PD), there may be a need to make an instrumental assessment. Fiberoptic endoscopic evaluation of swallowing (FEES) uses a flexible endoscope to directly visualise the process of swallowing for different food consistencies and liquids. A videofluoroscopic swallowing study (VFSS) uses modified barium swallows with foods and fluids of different consistency to study the processes of swallowing.

In this study, it was reported that there was a protocol for the screening for dysphagia in 88/161 (54.7%) hospitals, and 105/163 (64.4%) hospitals in which there was a protocol for the assessment of dysphagia (Table 5.1).

Table 5.1 A protocol for the screening for and/or the assessment of dysphagia

	The screening for dysphagia		The assessment of dysphagia	
	Number of hospitals	%	Number of hospitals	%
Yes	88	54.7	105	64.4
No	73	45.3	58	35.6
Subtotal	161		163	
Unknown	16		14	
Total	177		177	

Organisational data

Data from the clinician questionnaire showed a formal assessment of swallowing was undertaken during the admission for 117/457 (25.6%) patients. A formal assessment of swallowing was more likely to be undertaken in patients with indicators of dysphagia on admission (indicators of dysphagia on admission 67/93;

72.0% vs. no indicators of dysphagia on admission 42/325; 12.9%). Patients who, on review of the case notes were identified as experiencing dysphagia during the admission, were also more likely to have a formal assessment of swallowing (dysphagia during the admission 60/82; 73.2% vs. no dysphagia during the admission 33/300; 11.0%).

For a majority of patients this assessment was undertaken as a clinical assessment of swallowing (111/115; 96.5%) and VFSS or FEES was used for just 8/115 (7.0%) patients. Data from the organisational questionnaire indicated VFSS was available and could be used for assessment of dysphagia in 157/170 (92.4%) hospitals, the average waiting time to access this service ranged between 1-105 days with a mean waiting time of 14 days.

Similar data from the case reviewers showed that there was evidence in the case notes of a formal assessment of swallowing undertaken during the admission for 100/335 (29.9%) patients. Where such an assessment was not undertaken the case reviewers were of the opinion that one should have been undertaken for a further 51/200 (25.5%) patients.

Based on the case notes, the reviewers indicated the presence of dysphagia was not assessed adequately during the admission for 93/218 (42.7%) patients (Table 5.2).

Table 5.2 The presence of dysphagia assessed adequately during the admission

	Number of patients	%
Yes	125	57.3
No	93	42.7
Subtotal	218	
Unable to answer	33	
NA	93	
Total	344	

Case reviewer data

CASE STUDY 3

A 77-year-old patient was admitted with episodes of choking and “difficulty in swallowing fluids and medications”. After initial screening and assessment by speech and language therapy services a feeding plan was put in place that included using nasogastric (NG) tube feeding. No mention was made of engaging with the patient, their family or carers about NG tube insertion or including them in the decision-making process.

Case reviewers were of the opinion that this patient would have benefited from a formal assessment using videofluoroscopy (VFSS) or fiberoptic endoscopy (FEES) depending on local resources. This would have helped in developing a robust long-term plan for managing dysphagia and its effects.

Documentation of dysphagia

Dysphagia was documented as a symptom at some point during the admission in 118/343 (34.4%) sets of case notes.

Where dysphagia was documented in the case notes as a symptom during the admission, the case reviewers indicated this was cared for appropriately throughout the admission for 71/114 (62.3%) patients. The most common reasons for inappropriate dysphagia care related to poor documentation (11/43); a lack of SLT review (10/43); dysphagia not being assessed at all (8/43) or a delay in assessment (7/43).

Where it was documented as a symptom, in the opinion of the case reviewers there had been a delay in recognising dysphagia in 23/114 (20.2%) patients. The most common reason was a delay in or the lack of initial swallow screening for 13/23 patients or lack of recognition of the presence of signs and symptoms prior to admission for 10/23 patients.

Where there was a delay in recognising dysphagia, the reviewers were of the opinion that this affected the outcome for 6/18 patients. Four patients developed pneumonia and two patients were discharged with incomplete plans for community care.

Where dysphagia was not documented as a symptom, case reviewers found evidence that a diagnosis of dysphagia was missed for 16/209 (7.7%) patients.

Key Findings

22. 88/161 (54.7%) hospitals had a protocol for the screening of dysphagia, and 105/163 (64.4%) had a protocol for the assessment of dysphagia
23. 117/457 (25.6%) patients had a formal assessment of swallowing undertaken during the admission as recorded in the clinician questionnaire
24. There was evidence in the notes that a formal assessment of swallowing was undertaken during the admission for 100/335 (29.9%) patients. Where such an assessment was not undertaken the case reviewers were of the opinion that one should have been undertaken for a further 51/200 (25.5%) patients
25. Videofluoroscopic swallowing study was available in 157/170 (92.4%) hospitals but only used in 5/115 (4.3%) patients
26. Case reviewers indicated the presence of dysphagia was not assessed adequately during the hospital admission for 93/218 (42.7%) patients
27. Case reviewers found that there was a delay in recognising dysphagia in 23/114 (20.2%) of patients while they were in hospital
28. Where there was a delay in recognising dysphagia, case reviewers were of the opinion that this affected the outcome for 6/18 patients

Multidisciplinary team involvement during the admission

Patients with Parkinson's disease (PD) manifest a combination of symptoms requiring the support of multiple professional groups and services. Issues with mobility and function should be addressed by physiotherapists and occupational therapists (OTs). Difficulties with communication and the consumption of food and drink require help from speech and language therapists (SLTs) and dietitians. This multidisciplinary input is supported by NICE Quality Standard 164.⁹ The Parkinson's UK website lists the following professionals as being of help in an individual's care: GPs, Parkinson's specialists, Parkinson's nurse specialists, SLTs, OTs, dietitians, physiotherapists, pharmacists, psychologists and counsellors.²¹

Parkinson's disease service

A specialist PD service was reported to be available in 146/171 (85.4%) hospitals. Where a PD service was in place, a consultant led the service in 129/145 (89.0%) hospitals; this was either a geriatrician (74/128; 57.8%) or a neurologist (52/128; 40.6%). A PD specialist nurse led the service in 13/145 (9.0%) hospitals and a specialist PD nurse was employed in 123/171 (71.9%) hospitals from which a response was received.

Availability of the multidisciplinary team members

On-site access to OT and physiotherapy was available in all hospitals from which an organisational questionnaire was received (177/177; 100.0%), SLT, dietetics and pharmacy services were available in 176/177 (99.4%) hospitals. A nutrition team was available in 143/177 (80.8%) hospitals.

SLT services were available during the normal weekday working hours (Monday to Friday, 8:00 to 18:00) in 140/172 (81.4%) hospitals, and available seven days a week in a further 12/172 (7.0%) hospitals. In the remaining hospitals (20/172; 11.6%) services were

provided for various durations of time and none had a 24/7 service. A 24/7, on-site access to services was available for pharmacy in 58/168 (34.5%) hospitals, physiotherapy in 21/171 (12.3%) and OT in 2/171 (1.2%) hospitals (Figures 6.1-6.5 overleaf). All but two hospitals had an on-call pharmacist to help with medications when the pharmacy was closed.

Consultants who completed the clinician questionnaire reported that physiotherapists were involved in the care of 373/497 (75.1%) patients and SLTs for 119/497 (23.9%) patients. Specialist PD consultants and/or specialist nurses were involved for 160/497 (32.2%) patients. Other clinicians who contributed to the care of 132/497 (26.6%) patients included acute care, elderly care, neurology, palliative care physicians, surgical teams and allied healthcare professionals (Table 6.1).

Table 6.1 Healthcare professionals involved in the patient's care during the admission

	Number of patients	%
Nurse	399	80.3
Pharmacy	380	76.5
Physiotherapy	373	75.1
Occupational therapy	262	52.7
Speech and language therapy	119	23.9
Specialist Parkinson's disease consultant	106	21.3
Dietitian	98	19.7
Specialist Parkinson's disease nurse	83	16.7
Nutrition team	16	3.2
None	7	1.4
Other	132	26.6
Subtotal	497	
Unknown	8	
Total	505	

Answers may be multiple; n=497
Clinician questionnaire data

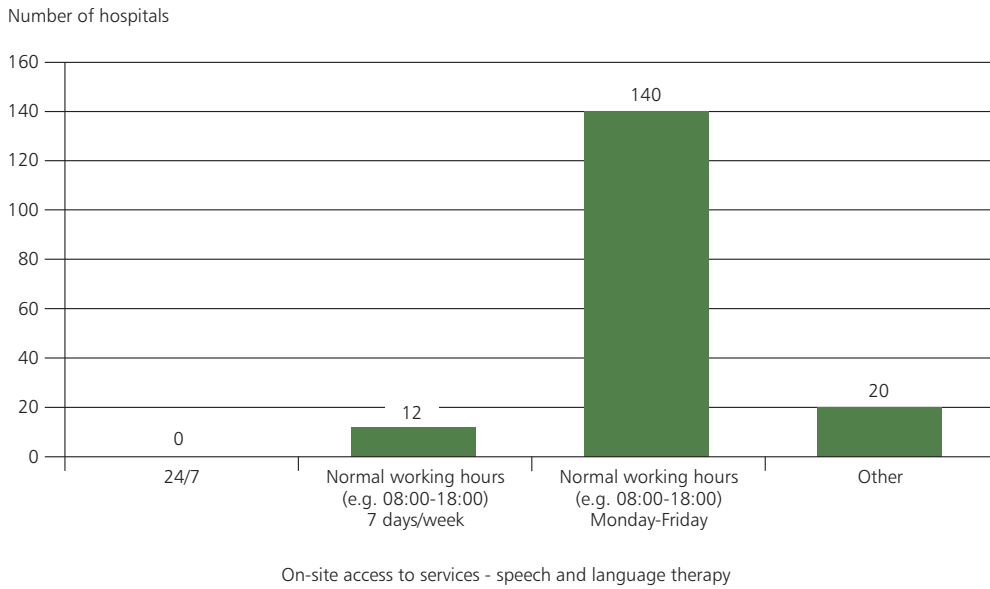


Figure 6.1 On-site access to speech and language therapy
Organisational data

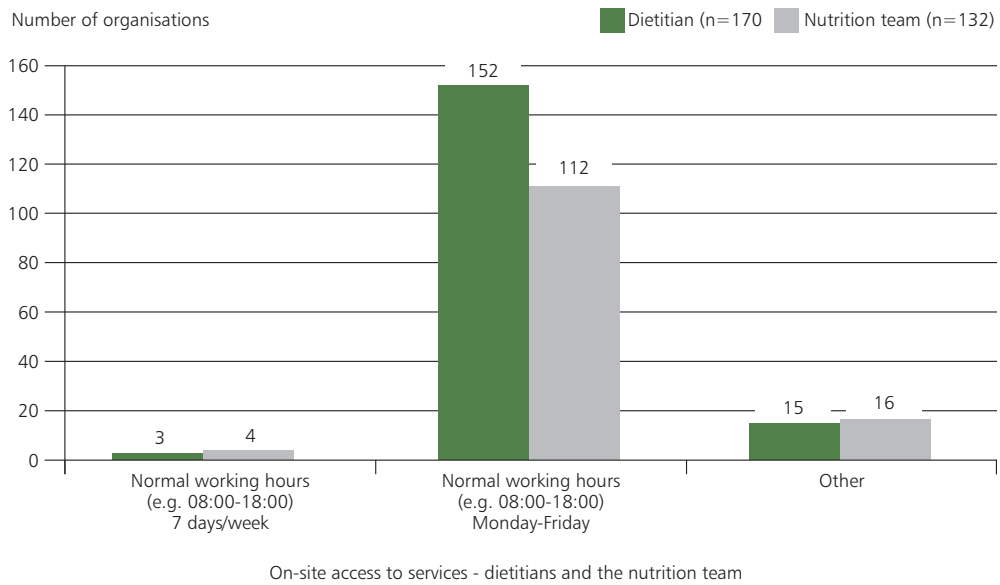


Figure 6.2 On-site access to dietitians and the nutrition team
Organisational data

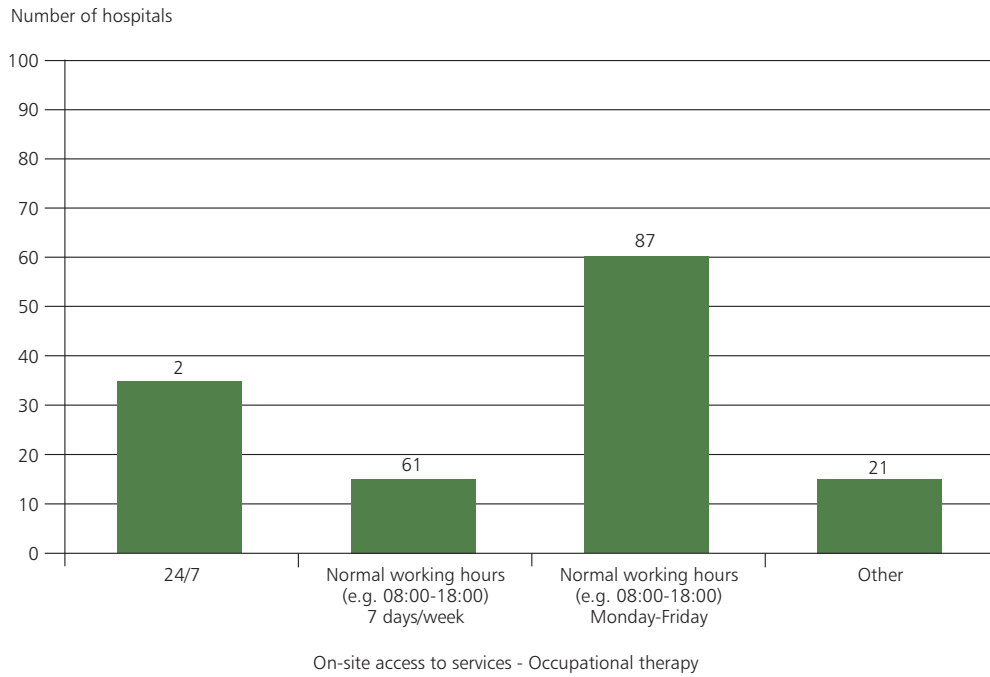


Figure 6.3. On-site access to occupational therapy
Organisational data

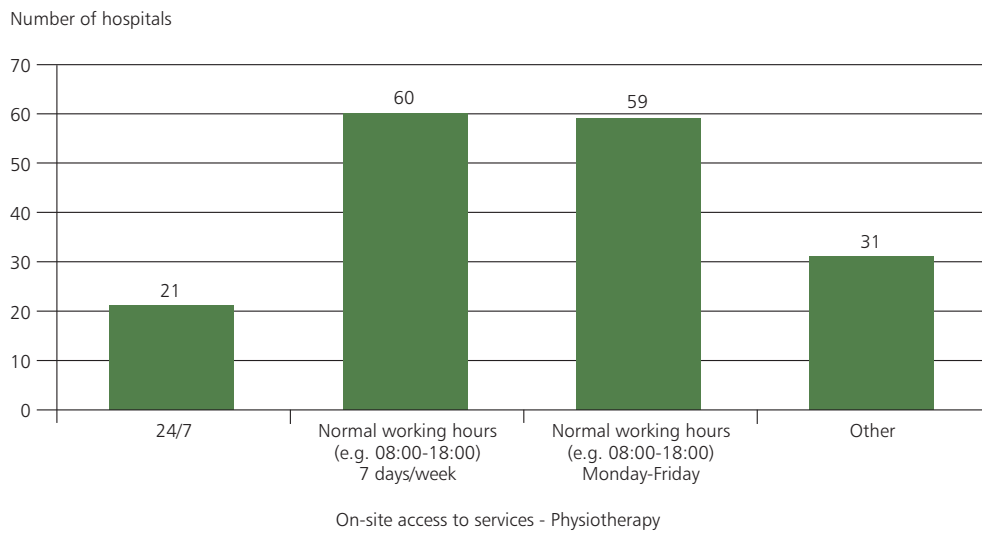


Figure 6.4. On-site access to physiotherapy
Organisational data

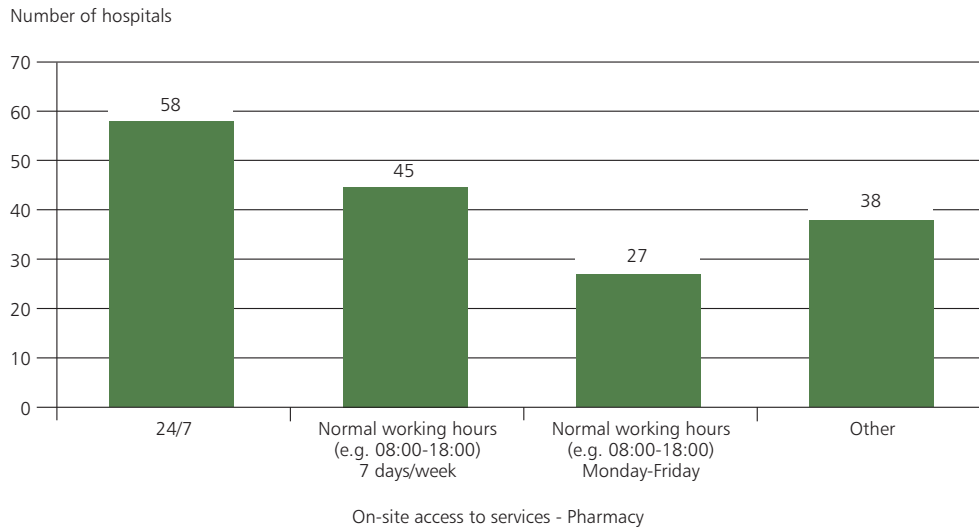


Figure 6.5. On-site access to pharmacy
Organisational data

Referral to other healthcare professionals during the admission

A referral for physiotherapy was made for 240/323 (74.3%) patients, while 108/317 (34.1%) patients were referred to SLT and 97/324 (29.9%) patients were referred to the PD team (Table 6.2). Case reviewers considered that a further 46/187

(24.6%) patients should have been referred to SLT and 67/195 (34.4%) patients to the PD team (Table 6.3 overleaf).

Analysing instances of multiple omitted referrals highlighted 45 patients for whom a total of 114 referrals were not made: 27 patients had two missed referrals and a further 13 patients had three missed referrals.

Table 6.2 Specialties to which the patient was referred to during the admission

	Speech and language therapy		Dietetics		Nutrition team		Occupational therapy		Physiotherapy		Parkinson’s disease team	
	n	%	n	%	n	%	n	%	n	%	n	%
Yes	108	34.1	73	22.6	10	3.2	169	53.0	240	74.3	97	29.9
No	209	65.9	250	77.4	303	96.8	150	47.0	83	25.7	227	70.1
Subtotal	317		323		313		319		323		324	
NA	23		13		26		7		7		3	
Unable to answer	4		8		5		18		14		17	
Total	344		344		344		344		344		344	

n=number of patients
Case reviewer data

Table 6.3 Specialties to which the patient should have been referred to during the admission

	Speech and language therapy		Dietetics		Nutrition team		Occupational therapy		Physiotherapy		Parkinson’s disease team	
	n	%	n	%	n	%	n	%	n	%	n	%
Yes	46	24.6	38	18.4	21	8.1	20	15.7	11	15.9	67	34.4
No	141	75.4	168	81.6	237	91.9	107	84.3	58	84.1	128	65.6
Subtotal	187		206		258		127		69		195	
Unable to answer	22		44		45		23		14		32	
Total	209		250		303		150		83		227	

n=number of patients
Case reviewer data

Timing of referrals

Details of the point at which the patient was referred to other specialties, following admission, is shown in Figure 6.6.

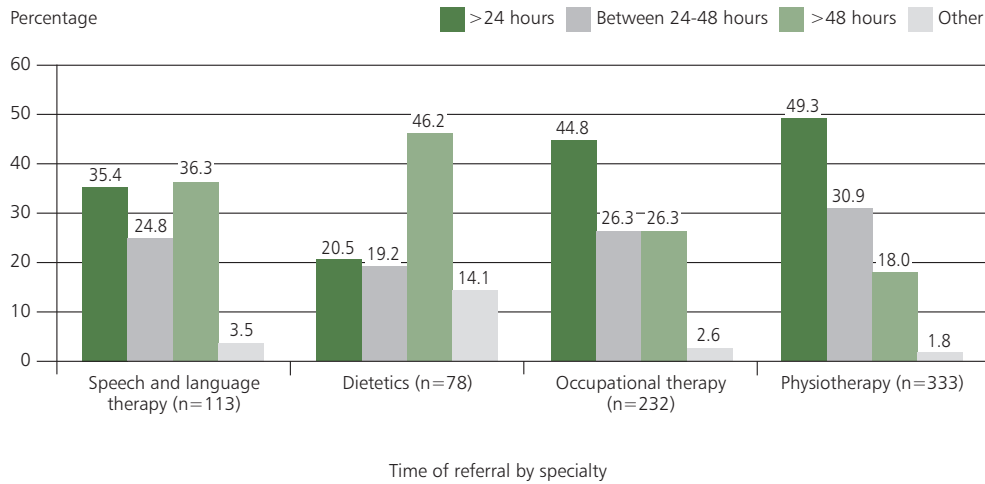


Figure 6.6 Timing of referral to different specialties, following admission
Clinician questionnaire data

Table 6.4 A delay in referral to other specialties

	Speech and language therapy	Dietetics	Nutrition team	Occupational therapy	Physiotherapy	Parkinson's disease team
	n	n	n	n	n	n
Yes	25	16	2	8 (5.2%)	18 (8.3%)	10
No	71	48	8	146 (94.8%)	200 (91.7%)	82
Subtotal	96	64	10	154	218	92
NA	10	0	0	1	1	0
Unable to answer	1	9	0	14	21	5
Total	107	73	10	169	240	97

n=number of patients

Case reviewer data

Table 6.5 A delay in assessment by other specialties

	Speech and language therapy	Dietetics	Nutrition team	Occupational therapy	Physiotherapy	Parkinson's disease team
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Yes	27 (26.5%)	18 (27.3%)	3 (33.3%)	16 (10.3%)	20 (8.9%)	19 (21.8%)
No	75 (73.5%)	48 (72.7%)	6 (66.7%)	139 (89.7%)	204 (91.1%)	68 (78.2%)
Subtotal	102	66	9	155	224	87
NA	0	0	0	1	1	2
Unable to answer	6	7	1	13	15	8
Total	108	73	10	169	240	97

n=number of patients

Case reviewer data

Case reviewers indicated that there was a delay in referral to SLT in 25/96 patients, and a similar proportion in referral to dietetics (16/64 patients) (Table 6.4). Review of multiple delays in referral highlighted that 18 patients had a delay in referral to two or more specialties.

There was evidence of a delay in assessment following a referral to SLT for 27/102 (26.5%) patients and to dietetics in 18/66 (27.3%) (Table 6.5). Additionally, 24 patients had delays in 51 assessments, with three patients experiencing delays in assessment by three separate specialties.

Eating and drinking

Data from the clinician questionnaire indicated that a decision to keep the patient ‘nil by mouth’, was made for 108/490 (22%) patients following admission.

This decision was made because of impending surgery, investigation or procedure for 51/104 (49.0%) patients. In the remaining 66 patients, the most common reason was that they had difficulty swallowing (22/66) or were too drowsy to have their swallow screened (19/66). There were also patients who had evidence of complications of dysphagia such as aspiration pneumonia (10/66) or choking (2/66) (Table 6.6). Nine patients had multiple reasons for being ‘nil by mouth’.

Table 6.6 Reason the patient made ‘nil by mouth’

	Number of patients	%
Surgery, investigation or procedure needed	51	49.0
Difficulty swallowing	22	21.2
Drowsy	19	18.3
Aspiration pneumonia	10	9.6
Clinical decision	8	7.7
Choking	2	1.9
Subtotal	104	
Unknown	4	
Total	108	

Answers may be multiple; n=104
Clinician questionnaire data

Of the 108 patients made ‘nil by mouth’, 23/108 (21.3%) had support with eating and drinking (either a nasogastric, nasojejunal or gastrostomy tube insertion) during the admission. A modified texture diet was indicated at any point during the admission for 41/95 patients, and thickened fluids for 30/96 patients. Fourteen patients made ‘nil by mouth’ on admission were ‘risk feeding’ prior to admission, and this was considered for a further 12/52 patients on or following admission.

Case reviewers were of the opinion that for patients kept ‘nil by mouth’ (n=83), medications were managed appropriately for 55/71 patients where it could be assessed (Table 6.7).

Table 6.7 Medication managed appropriately for patients ‘nil by mouth’

	Number of patients
Yes	55
No	16
Subtotal	71
Unable to answer	12
Total	83

Case reviewer data

A policy for assisting patients with eating and drinking who are unable to do so by themselves was in place in 121/154 (78.6%) hospitals. Where a policy was in place, a staff member was identified who would be responsible for assisting patients in 95/114 (83.3%) hospitals.

There were 145/433 (33.5%) patients who required assistance with eating and drinking. Where help was required, it was available at all times for 80/135 (59.3%) patients, and someone was available to help sometimes for 33/135 (24.4%) patients. No information was recorded for the remaining patients (22/135; 16.3%) (Table 6.8).

Table 6.8 Someone available to help with eating and drinking

	Number of patients	%
Yes - all the time	80	59.3
Yes – sometimes	33	24.4
Not recorded	22	16.3
Subtotal	135	
Unknown	10	
Total	145	

Clinician questionnaire data

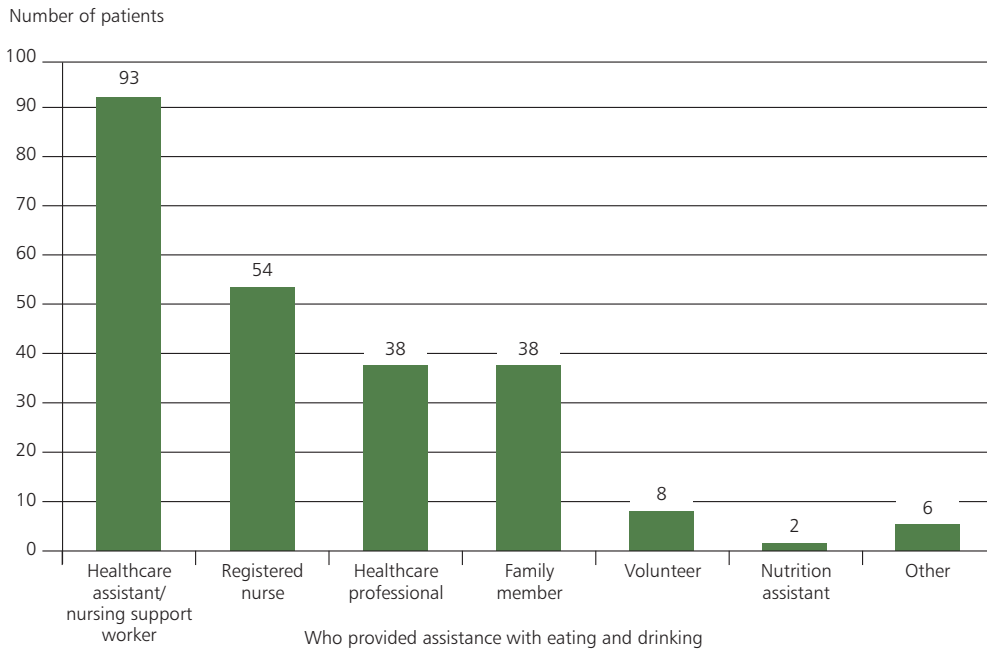


Figure 6.7 People assisting the patient to eat or drink
 Answers may be multiple; n=111
 Clinician questionnaire data

Where assistance with eating and drinking was available, it was most often provided by a healthcare assistant/nursing support worker (93/111; 83.8%), by family members (38/111; 34.2%) or other healthcare professionals (38/111; 34.2%) (Figure 6.7).

The risk of malnutrition and its impact was assessed and documented for 180/399 (45.1%) patients. Action following this included the regular use of food/nutrition charts (58/180; 32.2%), dietitian referral (38/180; 21.1%), and the use of oral nutritional supplements (14/180; 7.8%). No action was indicated (including as a result of end of life/palliative care) for 33/180 (18.3%) patients.

Tube feeding

To provide support with nutrition and hydration, patients who cannot swallow may be considered for insertion of a feeding tube (nasogastric (NG), nasojejunal (NJ) or gastrostomy tube).

Case reviewers found that 25/344 (7.3%) patients had a feeding tube inserted for the purpose of feeding to improve nutrition and hydration. Four patients had multiple tubes inserted. There was a delay in 8/29 of these procedures being undertaken.

Oral hygiene and care

A protocol for the care of oral hygiene was reported to be in place in 107/148 (72.3%) hospitals. Where this was in place, it designated who was responsible for oral hygiene in 78/99 hospitals.

Data from the clinician questionnaire indicated that 216/354 (61.0%) patients had their oral hygiene assessed by nursing staff.

Case reviewers indicated that for 160/298 (53.7%) patients there was no evidence in the notes that the patient’s oral hygiene was cared for during the admission (Table 6.16). Where there was evidence, case reviewers were of the opinion that this was appropriate for 114/120 (95.0%) patients.

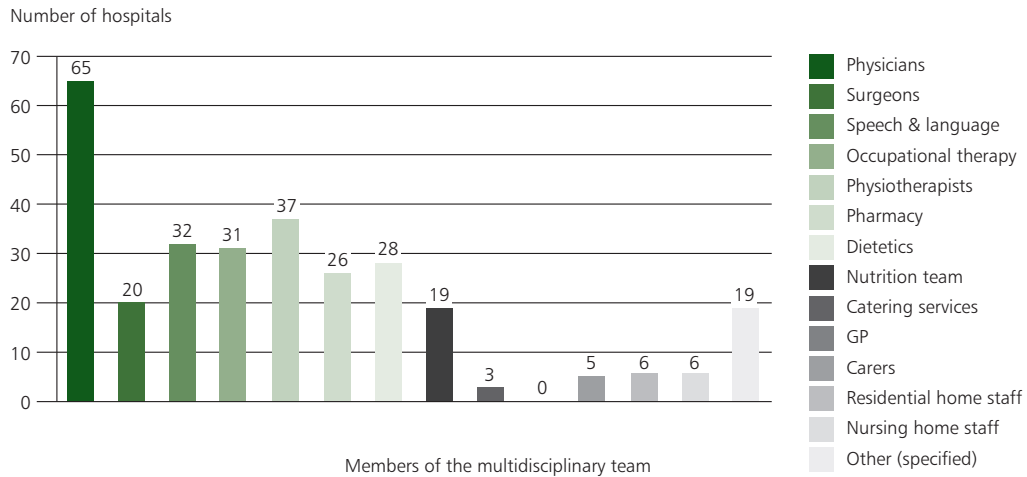


Figure 6.8 Members of the multidisciplinary team for patients with Parkinson’s disease
 Answers may be multiple; n=73
 Organisational data

Multidisciplinary team (MDT) meetings

It was reported from 75/168 (44.6%) hospitals that specialist MDT reviews took place for patients admitted with PD. In these hospitals there was also variation in membership of the MDT with 32/73 reporting presence of SLT, 28/73 presence of dietetics and 19/73 nutrition team members. (Figure 6.8).

CASE STUDY 4

A 79-year-old patient was admitted with urosepsis. The GP referral letter commented on their ongoing dysphagia and clearly documented their medication. Following admission, the patient was seen on the first day by the Parkinson’s disease team, speech and language therapy and physiotherapy. The following day a multidisciplinary team meeting was undertaken, and the specialty registrar documented that the patient’s relatives had been informed of the ongoing management plan with respect to the patient’s care and were in agreement with the plan.

The reviewers considered this to be excellent care and what should be expected with regard to multidisciplinary team input.

The patient’s care was reviewed at an MDT meeting during the admission for 221/426 (51.9%) patients (Table 6.9). The SLT team were represented at 43/221 (19.5%) meetings, of which 22/33 were when the patient was known to have dysphagia (Figure 6.9 overleaf). A record of this review was documented in the case notes of 144/214 (67.3%) patients.

Table 6.9 The patient’s care was reviewed at an MDT meeting during the admission

	Number of patients	%
Yes	221	51.9
No	205	48.1
Subtotal	426	
Unknown	50	
NA – elective surgical admission	29	
Total	505	

Clinician questionnaire data

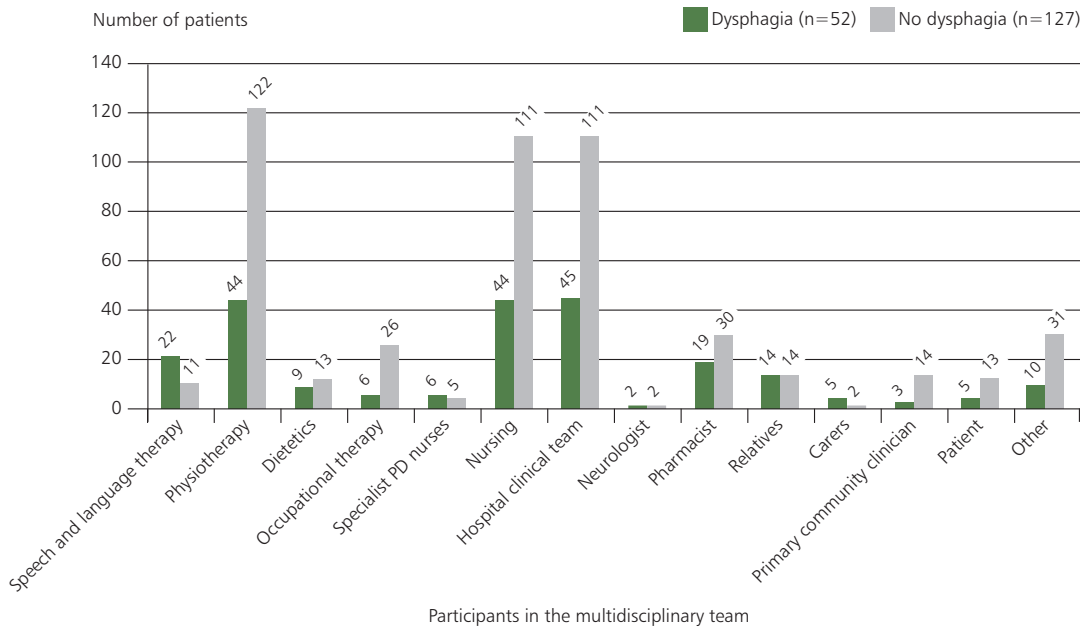


Figure 6.9 MDT attendance and evidence of dysphagia at any stage
Clinician questionnaire data

The case reviewers reported that an appropriate MDT discussion was undertaken during the patient’s admission for 158/246 (64.2%) patients (Table 6.10). There was little difference in whether an appropriate MDT discussion was undertaken between patients with dysphagia (62/100; 62.0%) or without dysphagia (91/130; 70.0%).

Table 6.10 An appropriate MDT discussion was undertaken during the admission

	Number of patients	%
Yes	158	64.2
No	88	35.8
Subtotal	246	
NA	22	
Unable to answer	76	
Total	344	

Case reviewer data

Care planning for a complex condition such as PD requires close collaboration with the patient, their family, carers and the hospital teams. In 245/273 (89.7%) sets of case notes reviewed, the case reviewers were of the opinion that there was adequate shared decision-making between the patient and healthcare professionals; and in 229/251 (91.2%) cases between the patient’s family and healthcare professionals (Table 6.11).

Table 6.11 Adequate shared decision-making between the patient, the patient’s family and healthcare professionals

	Patient and professionals		Patient’s family and professionals	
	Number of patients	%	Number of patients	%
Yes	245	89.7	229	91.2
No	28	10.3	22	8.8
Subtotal	273		251	
Unable to answer	71		93	
Total	344		344	

Case reviewer data

Key Findings

29. On-site access to occupational therapy and physiotherapy was available in all hospitals from which an organisational questionnaire was received (177/177; 100.0%)
30. Speech and language therapy, dietetics and pharmacy services were available in 176/177 (99.4%) hospitals
31. A nutrition team was available in 143/177 (80.8%) hospitals
32. Parkinson's disease consultants and/or specialist nurses were involved for 160/497 (32.2%) patients
33. Referral for physiotherapy was made for 240/323 (74.3%) patients, while 108/317 (34.1%) were referred to speech and language therapy and 97/324 (29.9%) patients were referred to the Parkinson's disease team
34. The reviewers were of the opinion that a further 46/187 (24.6%) patients should have been referred to speech and language therapy and 67/195 (34.4%) patients to the Parkinson's disease team
35. Analysing instances of multiple omitted referrals highlighted 45 patients for whom a total of 114 referrals were not made: 27 patients had two missed referrals and a further 13 patients had three missed referrals
36. Where patients were referred, case reviewers indicated there was a delay in referral to speech and language therapy in 25/96 patients and delay in referral to dietetics in 16/64 patients
37. A policy for assisting patients with eating and drinking who are unable to do so by themselves was in place in 121/154 (78.6%) hospitals
38. 160/298 (53.7%) patients had documented evidence in the case notes that oral hygiene was managed during their admission
39. Specialist multidisciplinary team (MDT) reviews took place for patients admitted with Parkinson's disease in 75/168 (44.6%) hospitals, with 32/73 reporting the presence of speech and language therapy, 28/73 dietetics and 19/73 nutrition team members
40. 221/426 (51.9%) patients had their care reviewed at an MDT meeting during their admission
41. 158/246 (64.2%) patients had an appropriate MDT discussion undertaken during their admission in the opinion of the case reviewers

Texture modifications (food and drink)

Texture modified meals may be provided to people who have chewing and swallowing difficulties, such as those with dysphagia. Food texture may be altered to reduce the likelihood of aspiration or choking. Equally, texture modification might enhance comfort and modified consistencies may help the patient to eat sufficient food to reduce the risk of malnutrition. There are international standards for the modification of food consistency set by the International Dysphagia Diet Standardisation Initiative (IDDSI) (see Appendix 2).²²

Modified texture diet (food)

Data from the clinician questionnaire highlighted that a modified texture diet was indicated at some point during the admission for 108/462 (23.4%) patients. Where it was indicated, a modified texture diet was provided for all 103 patients, where the data were available (there were five patients where this was unknown). In the opinion of the case reviewers, 101/314 (32.2%) patients required a modified texture diet while they were an inpatient (Table 7.1).

Table 7.1 A modified texture diet was indicated at some point during the admission

	Clinician view		Case reviewer view	
	Number of patients	%	Number of patients	%
Yes	108	23.4	101	32.2
No	354	76.6	213	67.8
Subtotal	462		314	
Unknown	43		30	
Total	505		344	

Clinician questionnaire and case reviewer data

There was evidence in the case notes that a modified texture diet was advised for 95/278 (34.2%) patients, and in the majority (80/95) this was advised by the speech and language therapy (SLT) team (Table 7.2). Where a modified texture diet was advised, there was evidence in the case notes that this was provided for 72/88 patients, and that dietary instructions were followed for 61/66 patients, where the data were available.

Table 7.2 Evidence in the case notes that a modified texture diet was advised

	Number of patients	%
Yes – by speech and language therapy	80	28.8
Yes – by someone else	15	5.4
No	183	65.8
Subtotal	278	
NA	60	
Unable to answer	6	
Total	344	

Case reviewer data

CASE STUDY 5

A 59-year-old patient was admitted with cellulitis involving a superficial leg wound requiring intravenous antibiotics. The patient's dysphagia was noted on admission. On the morning of the admission the patient was assessed by the speech and language team and then received regular reassessments until discharge.

The reviewers commented on the excellence of the speech and language input and the documented involvement of other healthcare professionals, all coordinated by the admitting medical team.

A multidisciplinary approach to meal planning, to ensure the menu was nutritionally analysed and compliant with modified texture meals, was present in 100/138 (72.5%) hospitals. Where this occurred, dietitians were involved in 100/100 (100.0%) hospitals; SLTs in 97/100 (97.0%) hospitals and catering in 86/100 (86.0%) hospitals (data not shown).

Thickened fluids

Thin liquids, such as water, pose safety challenges for patients with dysphagia because they flow too quickly. Therefore, thickened liquids are frequently recommended with the goal of slowing down the flow to allow more time for airway closure. Thickened liquids can also increase sensory awareness/feedback which may contribute to improvements in swallow function.

Data from the clinician questionnaire reported that thickened fluids were indicated at some point during the admission for 80/464 (17.2%) patients. From this group, the clinician completing the questionnaire reported that 52/68 patients, where it could be assessed, had indicators of dysphagia during the admission. Thickened fluids were used for 71/76 patients (Table 7.3). This was communicated to pharmacy for 52/53 patients and was unknown for an additional 18 patients. Medication was modified appropriately for 64/66 patients.

The case reviewers considered there was evidence in the notes that a thickener was advised for 59/268 (22.0%) patients (Table 7.4). Where a thickener was advised, there was evidence in the notes that catering/housekeeping were notified in only 17/44 instances, and this was communicated to pharmacy in 17/45 instances. There was evidence in the case notes that thickener was provided to 40/50 patients, and medication was modified appropriately for 25/36 of these patients.

Table 7.3 Thickened fluids were indicated at some point during the admission

	Thickener indicated		Thickener advised	Thickener used
	Number of patients	%	Number of patients	Number of patients
Yes	80	17.2	72	71
No	384	82.8	6	5
Subtotal	464		78	76
Unknown	41		2	4
Total	505		80	80

Clinician questionnaire data

Table 7.4 Evidence in the case notes that a thickener was advised for addition to fluids

	Number of patients	%
Yes – by speech and language therapy	50	18.7
Yes – by someone else	9	3.4
No	209	78.0
Subtotal	268	
NA	70	
Unable to answer	6	
Total	344	

Case reviewer data

A hospital policy for the prescribing and use of thickeners was in place in 99/148 (66.9%) hospitals.

In 101/135 (74.8%) hospitals the thickeners used in hospital were the same as those used in the community.

Key Findings

42. 101/314 (32.2%) patients required a modified texture diet whilst they were an inpatient in the opinion of the case reviewers
43. There was evidence in the case notes that a modified texture diet was advised for 95/278 (34.2%) patients; in 80/95 patients this was advised by speech and language therapy
44. Where advised, a modified texture diet was provided for 72/88 patients
45. 100/138 (72.5%) hospitals had a multidisciplinary approach to meal planning
46. Where a thickener was advised, there was evidence in the notes that catering/housekeeping were notified in only 17/44 instances, and this was communicated to pharmacy in 17/45 instances
47. An organisational policy for the prescribing and use of thickeners was in place in 99/148 (66.9%) hospitals

Medication management during the admission

Medication at arrival and admission was covered in Chapter 4 where it was noted that complications can develop if medication for Parkinson's disease (PD), particularly levodopa, is not taken on time, or medications are not provided via a suitable route. Options that have been suggested for taking medication include:²³

- "Whole tablets or capsules, crushed tablets or opened capsules taken with a spoonful of food at the appropriate IDDSI Level for the patient. This is likely to be the best option for most patients
- Whole tablets or capsules, crushed tablets or opened capsules taken with a spoonful of thickened fluid at the appropriate IDDSI Level for the patient
- Liquid medicine mixed with a thickening agent"

Missed medications

Medication was missed during the admission for 121/416 (29.1%) patients (Table 8.1) and was more likely to be missed in patients with dysphagia (dysphagia 45/76; 59.2%; no dysphagia 54/271; 19.9%) The principal reasons for missing medication were as a result of the patient being made 'nil by mouth' (33/110; 30.0%), the patient being unable to

CASE STUDY 6

A 76-year-old patient was found collapsed at home and brought into the emergency department (ED) by ambulance. In the ED the staff found medication for the patient's Parkinson's disease (PD) in their personal effects. The PD team were called to the ED to advise on the patient's medication. The patient was admitted with a urinary tract infection and while an inpatient was seen regularly by the PD team and speech and language therapy (SLT).

The reviewers commented on the promptness of both the PD team involvement and SLT. They remarked that this demonstrated good practice in minimising delays in patients receiving PD medication.

take the medication (32/110; 29.1%) or the patient refusing medication (22/110; 20.0%) (Table 8.2) overleaf. Of the 22 patients where refusal was given as a reason for missing their medication, 11 had dementia listed as a comorbidity.

Table 8.1 Medication was missed during the patient's admission by presence of dysphagia

	Dysphagia		No dysphagia		Subtotal	Not answered	Total
	Number of patients	%	Number of patients	%	Number of patients	Number of patients	Number of patients
Yes – once	13	17.1	26	9.6	39	11	50
Yes – more than once	32	42.1	28	10.3	60	11	71
No	31	40.8	217	80.1	248	47	295
Subtotal	76		271		347	69	416
Unknown	7		58		65	24	89
Total	83		329		412	93	505

Clinician questionnaire data

Table 8.2 The reasons for medications being missed

	Number of patients	%
Patient 'nil by mouth'	33	30.0
Patient unable to take	32	29.1
Patient refused	22	20.0
Not available on the ward	18	16.4
Awaiting medication review	10	9.1
Not suitable medication for a feeding tube	6	5.5
Awaiting confirmation of feeding tube placement	5	4.5
Not available in the pharmacy	3	2.7
Patient away from the ward	3	2.7
Other	3	2.7
Subtotal	110	
Unknown	11	
Total	121	

Answers may be multiple; n=110
Organisational data

Availability of medicines

A policy for the administration of medication to patients who have dysphagia or who develop it in hospital was in place in 113/156 (72.4%) hospitals. Where this policy was in place, this complied with the Parkinson’s UK Medicines Optimisation Consensus Statement⁸ in 75/81 hospitals (there were a further 32 hospitals where this was unknown).

Access to medication should be maintained and medication for PD should be on the critical medicines list so that supplies can be accessed at all times.^{8,24} Data from the organisational questionnaire indicated there were differences in the medications available in different ward areas in 94/141 (66.7%) hospitals.

Data from the clinician questionnaire indicated that, on admission, there was no check for 96/257 (37.4%) patients that their last scheduled dose of PD medication had been taken.

Changes to medication

Medication for PD was altered during the admission for 114/458 (24.9%) patients. This was more likely to occur in patients who experienced dysphagia during the admission (dysphagia 46/81; 56.8% vs. no dysphagia 46/302; 15.2%). The main reason for medication to be altered was as a result of swallowing difficulties (46/111; 41.4%) (Table 8.3).

Table 8.3 The reason for the patient’s Parkinson’s disease medication to be altered

	Number of patients	%
Swallowing difficulties	46	41.4
Patient experiencing confusion/agitation/hallucinations/altered level of consciousness	35	31.5
Worsening of condition	24	21.6
Progression of disease	15	13.5
Patient experiencing nausea/vomiting	3	2.7
Non-availability of medicines	0	0.0
Other	36	32.4
Subtotal	111	
Unknown	3	
Total	114	

Answers may be multiple; n=111
Clinician questionnaire data

Management of medications

There was evidence in the case notes that medicines management was appropriately undertaken for 210/263 (79.8%) patients. Where medications management was not appropriately undertaken, case reviewers thought this affected the outcome for 12/39 patients.

There was evidence in the case notes that the mode of provision of medication was considered if dysphagia was present for 82/166 (49.4%) patients (Table 8.4). The case reviewers also found evidence that the mode of provision of medication was determined for 71/107 (66.4%) patients who experienced dysphagia during the admission.

Table 8.4 Evidence in the case notes that the method of provision of medication was considered if dysphagia was present

	Number of patients	%
Yes	82	49.4
No	84	50.6
Subtotal	166	
NA	167	
Unable to answer	11	
Total	344	

Case reviewer data

Delay in administration of medication

In the opinion of the case reviewers, there was a delay in the administration of medication following admission for 57/263 (21.7%) patients. The main reasons for delay

were the absence of medications on the ward (13/52) or the patient was 'nil by mouth' (13/52) (Table 8.5). Where the reason was recorded 'other' the most common reason related to patient refusal (5/21); there were four instances where the reason for delay was not recorded in the case notes nor the medication chart returned. Delay occurred more frequently in patients identified by case reviewers as experiencing dysphagia during the admission (Table 8.6).

Table 8.5 Reasons for the delay in administering medications

	Number of patients	%
Not available on the ward	13	13.3
Patient 'nil by mouth'	13	86.7
Patient unable to swallow	10	
Non-availability in the emergency department	5	
Non-availability in the pharmacy	1	
Other	19	
Subtotal	52	
Unable to answer	5	
Total	57	

Case reviewer data

Table 8.6 Delay in the administration of medication by presence of dysphagia during the admission

	Dysphagia during admission		No dysphagia during admission		Subtotal	Unable to answer	Total
	Number of patients	%	Number of patients	%	Number of patients	Number of patients	Number of patients
Yes	28	28.6	22	16.2	50	7	57
No	75	76.5	114	83.8	189	17	206
Subtotal	98		136		234	24	258
Unable to answer	23		50		73	8	81
Total	126		186		312	32	344

Case reviewer data

Table 8.7 Changes to the patient’s Parkinson’s disease medication by referral to the Parkinson’s disease team during the admission

	Parkinson’s disease medication changed during the admission				
	Yes	No	Subtotal	Unknown	Total
	Number of patients	Number of patients	Number of patients	Number of patients	Number of patients
Yes	32	35	67	6	73
No	28	117	145	13	158
Subtotal	60	152	212	19	231
Not applicable	0	1	1	0	0
Unable to answer	6	6	12	0	12
Total	66	159	225	19	244

Clinician questionnaire data and case reviewer data

The presence of a PD team was associated with more frequent changes in the patient’s medication (Table 8.7).

Rotigotine patches

While levodopa is considered the most effective drug for managing PD symptoms it may not always be possible for patients to take it orally. Rotigotine, another PD medication can be delivered via skin patches and a once-daily patch provides stable concentrations of the drug over 24 hours. This route of rotigotine delivery is useful in patients scheduled for surgery or in those with dysphagia. It is important to note that specialist advice should be sought before modifying any drug therapy.

A policy for the use of rotigotine patches in patients with PD was in place in 127/158 (80.4%) hospitals (Table 8.14). The presence of a policy was not affected by the presence of a specialist PD team.

Data from the clinician questionnaire showed that 88/468 (18.8%) patients were prescribed a rotigotine patch while in hospital (Table 8.15). Where a rotigotine patch was prescribed, alternative forms of medication had been considered for 42/68 patients; the Parkinson’s UK Medicines Optimisation Consensus Statement⁸ consulted for 21/50 patients, and there was a clear plan in place to review the patch before discharge for 44/75 patients. Clinicians were of the opinion that a patch should have been prescribed for only 37/69 patients (Table 8.8).

Table 8.8 Consideration of patch use

	Alternative forms of medication considered	Parkinson’s UK Medicines Optimisation Consensus Statement consulted	Clear plan to review patch before discharge	A patch should have been prescribed
	Number of patients	Number of patients	Number of patients	Number of patients
Yes	42	21	44	37
No	26	29	31	32
Subtotal	68	50	75	69
Unknown	20	38	13	19
Total	88	88	88	88

Clinician questionnaire data

The case reviewers found evidence that the patient was prescribed a rotigotine patch while in hospital in 80/339 (23.6%) sets of case notes. Where a patch had been prescribed, in the opinion of the case reviewers this was appropriate for 67/70 patients. There was evidence in the notes that there was a clear plan to review the patch prior to discharge in 25/45 patients. There was no evidence in the case notes that 38/72 patients who had a rotigotine patch prescribed were referred to the PD team during this admission.

CASE STUDY 7

An 82-year-old patient with Parkinson’s disease (PD) was admitted following a fall at home and sustaining a fractured neck of femur. Prior to surgery the patient remained ‘nil by mouth’ for a significant period of time, which led to them not receiving their normal PD medication. An anaesthetist liaised with the PD team who visited the patient and considered treatment options and prescribed a rotigotine patch. The patient had surgery to fix the fracture and, with continuing input from the PD team and speech and language therapy, returned to their care home 14 days post-operatively.

The case reviewers recognised the importance of involvement of the PD team and the recognition of the need for an alternative route of administration. However, they commented on the extensive ‘nil by mouth’ period and the effect it had on the patient.

Medication at discharge

Data from the clinician questionnaire highlighted that information on the administration of medicines prior to discharge was provided to 168/292 (57.5%) patients/ carers and that information was more likely to be provided if the patients’ PD medication had been altered during the admission (Table 8.9).

Almost all patients (431/442; 97.5%) had a discharge summary provided on discharge from hospital (see Chapter 10). The discharge summary mentioned the administration of medication in 262/416 (63.0%) and information about the treatment period and frequencies in 190/416 (45.7%).

Table 8.9 The patient/carer received information on the administration of medicines prior to discharge by Parkinson’s disease medication alterations

	Was the patient’s PD medication altered during this admission?						
	Yes		No		Subtotal	Unknown	Total
	Number of patients	%	Number of patients	%	Number of patients	Number of patients	Number of patients
Yes	47	64.4	114	54.5	161	7	168
No	26	35.6	95	45.5	121	3	124
Subtotal	73		209		282	10	292
Unknown	41		135		176	37	213
Total	114		344		458	47	505

Clinician questionnaire data

Key Findings

- 48. 121/416 (29.1%) patients missed medication during their hospital stay. The principal reasons for this were the patient being 'nil by mouth' (33/110; 30.0%) and being unable to take the medication (32/110; 29.1%)
- 49. 113/156 (72.4%) hospitals reported a policy for the administration of medication to patients who have dysphagia or who develop it in hospital in place. Where this policy was in place, it complied with the Parkinson's UK Medicines Optimisation Consensus Statement in 75/81 hospitals
- 50. On admission, there was no check for 96/257 (37.4%) patients that their last scheduled dose of PD medication had been taken
- 51. Where medication management was not appropriately undertaken, case reviewers thought this affected the outcome for 12/39 patients
- 52. 82/166 (49.4%) patients with dysphagia had their mode of provision of medication considered
- 53. The mode of provision of medication was determined for 71/107 (66.4%) patients who experienced dysphagia during the admission in the opinion of the case reviewers
- 54. 127/158 (80.4%) hospitals had a policy for the use of rotigotine patches in patients with Parkinson's disease
- 55. 88/468 (18.8%) patients were prescribed a rotigotine patch while in hospital
- 56. Where a rotigotine patch was prescribed, alternative forms of medication had been considered for 42/68 patients; the Parkinson's UK Medicines Optimisation Consensus Statement consulted for 21/50 patients, and there was a clear plan in place to review the patch before discharge for 44/75 patients
- 57. 168/292 (57.5%) patients/carers were provided with information on the administration of medicines prior to discharge. The information was more likely to be provided if the patient's Parkinson's disease medication had been altered during the admission

'Risk feeding'

'Risk feeding'

When swallowing difficulties (dysphagia) become severe, it is often considered unsafe for patients to continue eating and drinking due to the risk of aspiration and choking.⁴ The term 'risk feeding' is used when a patient continues to eat and drink orally despite the associated risks. 'Risk feeding' may be deemed appropriate for a number of reasons:²⁵

- Alternative feeding options (via a feeding tube) may not be feasible due to the patient's medical condition
- The risks of alternative feeding options may be too high
- The patient may be at the end of their life and a palliative approach deemed more appropriate by the patient, their family or the medical team
- Alternative feeding may not prolong or improve the patient's quality of life
- An informed patient who retains mental capacity may not be prepared to give up the pleasure of eating and drinking, nor may they wish to have an invasive procedure such as insertion of a feeding tube.

The decision-making process around 'risk feeding' is complex and decisions should always be made and actioned following discussion with the patient, their family and the multidisciplinary team. If such a discussion does not take place it could lead to patients being kept 'nil by mouth', without an alternative means of feeding, to the detriment of their comfort and nutrition.^{25,26}

Organisational data showed that 104/160 (65.0%) hospitals were reported as having a policy for 'risk feeding'. The policy covered the interface between primary and secondary care in 60/78 hospitals. The policy met the Plain English standards recommended for patients²⁷ in 42/45 hospitals and was unknown in a further 59/104 hospitals.

The clinician questionnaire data showed that 38/421 (9.0%) patients were 'risk feeding' prior to admission to hospital. Of this group, 30/38 had a re-evaluation of 'risk feeding' on admission. Within the 383 patients not already 'risk feeding' at admission, a further 29 patients were considered for 'risk feeding' on, or following, admission. Within this group, an assessment was undertaken prior to 'risk feeding' for 26/27 patients, and this included an assessment of mental capacity, to make the decision at the time, for 17/22 patients.

The reviewers found evidence in the case notes that 'risk feeding' was considered in 49/292 (16.8%) patients assessed. Speech and language therapists were involved in the discussions for 41/110 (37.3%) patients. 'Risk feeding' was subsequently undertaken in 36/46 patients (Table 9.1). Case reviewers indicated 'risk feeding' had been undertaken appropriately in the majority of patients (30/36).

Table 9.1 Evidence of 'risk feeding' in the case notes

	'Risk feeding' was considered		Speech and language therapy involved in the discussion		'Risk feeding' undertaken
	Number of patients	%	Number of patients	%	Number of patients
Yes	49	16.8	41	37.3	36
No	243	83.2	69	62.7	10
Subtotal	292		110		46
NA	47		219		-
Unable to answer	5		15		3
Total	344		344		49

Case reviewer data

Key Findings

58. 104/160 (65.0%) hospitals were reported as having a policy for 'risk feeding'
59. An assessment of mental capacity was undertaken in 17/22 patients who were being assessed for 'risk feeding'
60. Speech and language therapists were involved in the discussions related to 'risk feeding' for 41/110 (37.3%) patients. 'Risk feeding' was subsequently undertaken in 36/46 patients

Advance care planning, palliative and end of life care

People with Parkinson's disease (PD) and their family members should be offered the opportunity to develop an Advance Care Plan, by discussing the prognosis of the condition. This discussion should establish priorities centred around the patient's wishes which are then recorded in the Advance Care Plan. The options considered might include 'Advance Decisions to Refuse Treatment' (ADRT), 'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision, 'Recommended Summary Plan for Emergency Care and Treatment' (ReSPECT) process and lasting powers of attorney for finance and property and/or health and welfare. End of life care may also need to be considered. This is likely to be a difficult area to discuss but should not be ignored. All discussions are likely to be informed by the patient's ability to make specific decisions, and this should be aided by mental capacity assessments specific to each decision.

Markers of advanced disease were present in 183/432 (42.4%) patients and 52/383 (13.6%) patients had an Advance Care Plan or similar plan in place, which was more likely to be in place as the severity of the disease increased (Table 10.1).

Table 10.1 Advance Care Plan in place by stage of Parkinson's disease

	Number of patients
Diagnosis	0
Maintenance	11
Complex	13
End stage	18
Subtotal	42
Unknown	10
Total	52

Clinician questionnaire data

Responses to the clinician questionnaire indicated end of life care was discussed with 114/472 (24.2%) patients during the admission. Most frequently this was with family members (95/110; 86.4%) and the patient (48/110; 43.6%) (Table 10.2).

Table 10.2 People involved in end of life discussions

	Number of patients	%
Other family members	95	86.4
Patient	48	43.6
Carers	10	9.1
Usual Parkinson's disease specialist	5	4.5
GP	3	2.7
Community team	3	2.7
Other	21	19.1
Subtotal	110	
Unknown	4	
Total	114	

Answers may be multiple; n=110

The reviewers reported that 61/340 (17.9%) patients were 'not for active treatment' as they were nearing the end of their life. For the majority of these patients (49/59) the end of life care provided during the admission was assessed by the reviewers to be satisfactory.

Care at the point of discharge from hospital

Discharge planning should start as early as possible during a hospital admission. For people with Parkinson's disease (PD), plans for discharge should be co-ordinated across the different groups of professionals who are involved in their care during the hospital admission and their ongoing care in the community.

It is well-established practice that the patient's GP or community clinical team should receive a written discharge letter.²⁷ The letter should also meet the standards for outpatient letters set by the Professional Record Standards Body.²⁸

The discharge letter should do three main things:

- Record relevant facts about the patient's health and wellbeing
- Present information in a way that improves understanding
- Communicate a management plan to the patient, GP and any other professional groups.

In the context of patients with PD, any change in medication and/or specific dietary modifications should also be communicated to the patient's GP.⁸ Consideration should also be given to the role community pharmacists play in the care of patients with PD.

Discharge process

The majority of patients (454/502; 90.4%) were discharged alive from this admission.

At discharge, the clinicians caring for the patient in hospital involved the home carers of 211/267 (79.0%) patients in discharge planning for (Table 11.1).

Table 11.1 The patient's home carers were involved in discharge planning

	Number of patients	%
Yes	211	79.0
No	56	21.0
Subtotal	267	
Unknown	76	
Not applicable	111	
Total	454	

Clinician questionnaire data

Case reviewers found evidence of the patient being referred to colleagues in the community, in 209/281 (74.4%) sets of case notes. There was no evidence in the case notes of communication at discharge with those caring for the patient in the community in 90/275 (32.7%) cases reviewed.

Risk assessment

Data from the organisational questionnaire showed that patients with PD were routinely assessed for their level of risk of dysphagia in the community prior to discharge in 108/148 (73.0%) hospitals.

There was evidence in the case notes that the patient's level of swallowing/aspiration risk in the community was considered prior to discharge for 61/210 (29.0%) patients. This was more likely to be considered where dysphagia was present during the admission (Table 11.2 overleaf). Where it was considered, an action plan was put into place for 52/60 patients assessed, and this was considered to be adequate by the case reviewers in 49/51 instances.

Table 11.2 Evidence in the case notes that the patient’s level of swallowing/aspiration risk in the community was considered prior to discharge by presence of dysphagia.

	Dysphagia during admission		No dysphagia during admission		Subtotal	Unable to answer	Total
	Number of patients	%	Number of patients	%	Number of patients	Number of patients	Number of patients
Yes	52	61.2	7	7.1	59	2	61
No	33	38.8	92	92.9	125	24	149
Subtotal	85		99		184	26	210
Unable to answer	3		7		10	2	12
NA	5		70		75	1	76
Total	93		176		269	29	298

Case reviewer data

Prescription of thickened fluids

Thickened fluids were prescribed to 37/336 (11.0%) patients at discharge. Where the patient was prescribed thickeners, the discharge was considered to be inadequate for 13/23 patients and in 17/37 cases the patient and/or carer did not receive a copy of the discharge summary. The patient’s home carers were involved in discharge planning for 21/25 patients who were prescribed thickened fluids. Where thickened fluids were indicated at some point during the admission 35/53 patients were prescribed thickeners at discharge.

Discharge summary

Almost all patients (431/442; 97.5%) had a written discharge summary on leaving hospital. Most commonly this included information about implemented interventions (294/416; 70.7%), the administration of medication (262/416; 63.0%) and information about the treatment period and frequencies (190/416; 45.7%) (Figure 11.1).

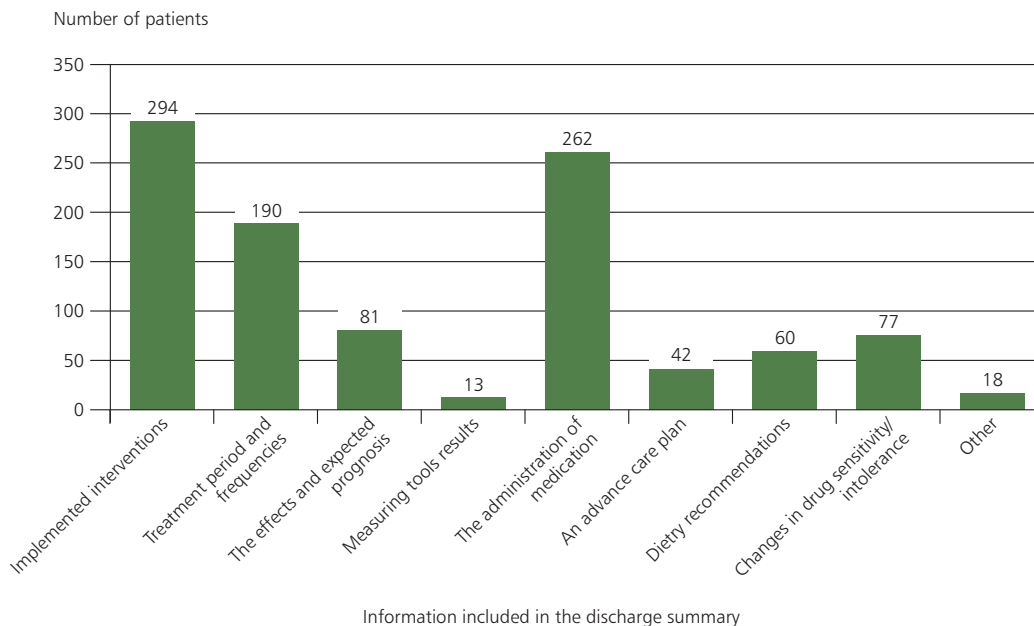


Figure 11.1 Information included in the discharge summary

Answers may be multiple; n=416
Clinician questionnaire data

Where a modified texture diet or fluids had been indicated during the admission, information on dietary recommendations was not included in the discharge summary for 52/88 patients. There was also variation in who received a copy of the discharge summary; most commonly this was the GP (422/425; 99.3%) and the patient and carers (208/425; 48.9%). The community-based team only received a copy for 28/425 (6.6%) patients, and the community pharmacist for 5/425 (1.2%) patients. Where the patient experienced dysphagia during the admission, the community team was given a copy of the discharge summary for 6/56 patients.

A discharge summary was available in 237/296 (80.1%) sets of case notes reviewed. Where a summary was provided, in the opinion of the case reviewers this was adequate in 175/236 (74.2%) cases assessed.

The areas in which the summary was not considered adequate included documentation of medication management (9/61), documentation of allied health professional (AHP) involvement (9/61), documentation of advance care planning (8/61) and documentation of dietary advice (7/61).

Death

Responses to the clinician questionnaire indicated that 23/48 patients who died experienced dysphagia during the admission (Table 11.3). The most common primary causes of death were bronchopneumonia/pneumonia (15/48) and aspiration pneumonia (10/48).

Table 11.3 Outcome by presence of dysphagia

	Dysphagia		No dysphagia		Subtotal	Unknown/ Not answered	Total
	Number of patients	%	Number of patients	%	Number of patients	Number of patients	Number of patients
Discharged alive	60	72.3	317	96.6	377	77	454
Died	23	27.7	11	3.4	34	14	48
Subtotal	83		328		411	91	502
Unknown	0		1		1	2	3
Total	83		329		412	93	505

Clinician questionnaire data

Key Findings

61. At discharge, the clinicians caring for the patient in hospital involved the home carers in discharge planning for 211/267 (79.0%) patients
62. There was no evidence in the case notes of communication at discharge with those responsible for the care of the patient in the community in 90/275 (32.7%) cases reviewed
63. There was evidence in the case notes that the patient's level of swallowing/aspiration risk in the community was considered prior to discharge for 61/210 (29.0%) patients
64. There was variation in who received a copy of the discharge summary; most commonly this was the GP (422/425; 99.3%) and the patient and carers (208/425; 48.9%). The community-based team only received a copy for 28/425 (6.6%) patients, and the community pharmacist for 5/425 (1.2%) patients
65. Where a summary was provided, in the opinion of the case reviewers this was adequate in 175/236 (74.2%) cases assessed

Overall assessment and quality of dysphagia care

Overall assessment of dysphagia care during the admission

The case reviewers assessed the overall dysphagia care the patient received during the admission. This was assessed to be good for 48/116 (41.4%) patients, adequate for 40/116 (34.5%) patients, and either poor or unsatisfactory for 28/116 (24.1%) patients (Figure 12.1). There were a further seven cases reviewed where dysphagia had been unrecognised as a symptom during the admission, and three cases where the reviewer was unable to grade the quality of dysphagia care provided.

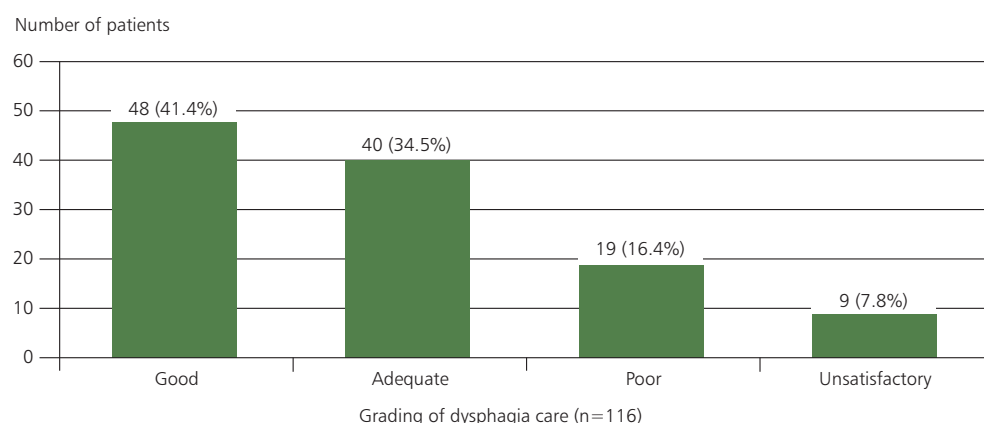


Figure 12.1
Assessment of the overall dysphagia care the patient received during the admission
Case reviewer data

Overall quality of care

The case reviewers were also asked to grade the overall quality of care the patient received during the admission. They considered this to be good for 159/336 (47.3%) patients. There was room for improvement for clinical care for 105/336 (31.3%) patients, in organisational care for 15/336 (4.5%) patients, and in clinical and organisational care for 48/336 (14.3%) patients. Care was graded to be less than satisfactory for 9/336 (2.7%) patients (Figure 12.2).

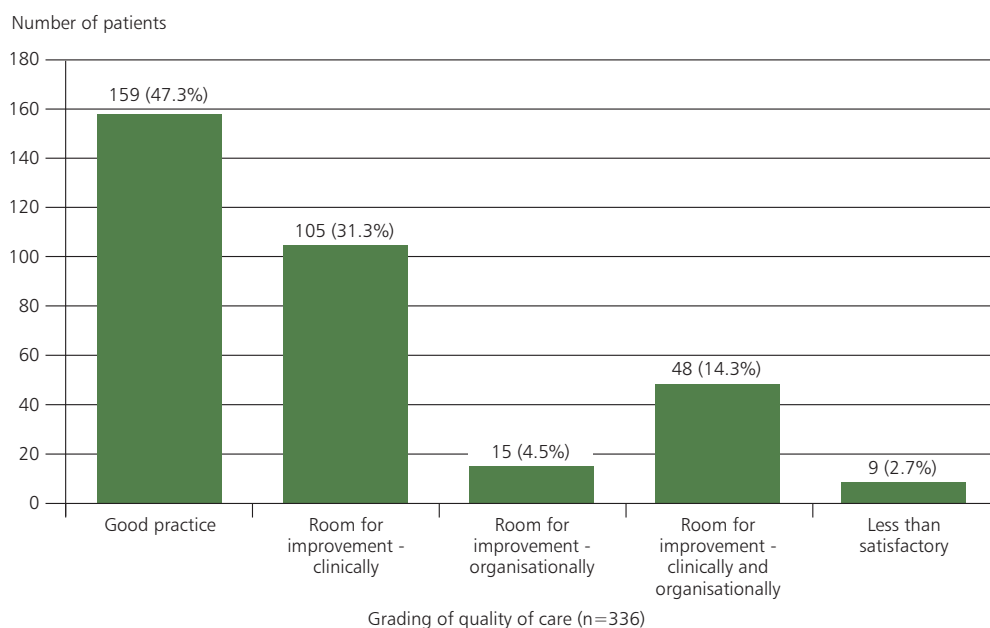


Figure 12.2
Assessment of the overall quality of care the patient received while in hospital
Case reviewer data

Presence of dysphagia and assessment of care

The overall quality of care was also analysed by the presence of dysphagia during the admission. The data seemed to describe that patients with dysphagia were less likely to experience good care than those without dysphagia (dysphagia 49/124; 39.5% vs. no dysphagia 106/182; 58.2%) (Figure 12.3). However, these data should be considered with caution as the numbers are low.

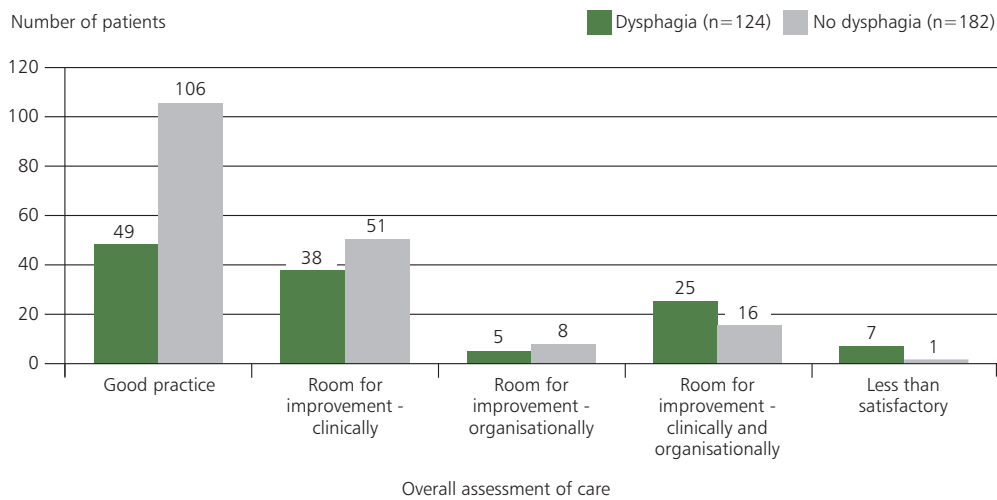


Figure 12.3 Overall assessment of care by presence of dysphagia during the admission

Case reviewer data

Key Finding

66. Dysphagia care was graded as good for 48/116 (41.4%) patients and adequate for 40/116 (34.5%) patients

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Glossary

Term	Abbreviation	Definition
Advance Care Plan		An opportunity for people to be involved in planning their future care, including medical treatment, while they have the capacity to do so
Advance Decisions to Refuse Treatment	ADRT	This lets a person, while they have mental capacity, to choose and explain which medical treatments they do not want doctors to give them, if a time comes when they lack capacity and cannot make the decision or communicate their wishes
Do not attempt cardiopulmonary resuscitation	DNACPR	A decision made by a person and/or their healthcare team not to attempt to restart their heart if the heart or breathing stops
Dysphagia		This is the medical term for swallowing difficulties. Some people with dysphagia have problems swallowing certain foods or liquids, while others can't swallow at all.
Fibreoptic endoscopic evaluation of swallowing	FEES	This a procedure in which a fibreoptic endoscope is inserted through the nose and into the throat to obtain a direct view of what happens when someone swallows
Impulse control disorder		This is a condition in which a person has trouble controlling emotions or behaviours
Levodopa		This is the most effective and commonly used drug in the treatment of Parkinson's disease
Malnutrition universal screening tool	MUST	This is a five-step screening tool to identify adults, who are malnourished, at risk of malnutrition (undernutrition), or obese. It also includes management guidelines which can be used to develop a care plan. It is for use in hospitals, community and other care settings and can be used by all care workers.
Modified texture diet		E.g. minced, chopped or pureed food
Nasogastric tube		This is a thin tube passed into the stomach via the nose. It is used for short- or medium-term nutritional support
Nasojejunal tube	NJ	This is a thin tube passed into the small intestine, through into the stomach via the nose. It is used for short- or medium-term nutritional support
Orthostatic hypotension		This is a sudden drop in blood pressure when someone stands from a seated or lying down position
Parkinson's disease	PD	This is a brain disorder that leads to shaking, stiffness, and difficulty with walking, balance, and coordination. Parkinson's symptoms usually begin gradually and get worse over time. As the disease progresses, people may have difficulty walking and talking.

GLOSSARY

Term	Abbreviation	Definition
Parkinsonism		This relates to any condition that causes a combination of the movement abnormalities seen in Parkinson's disease — such as tremor, slow movement, impaired speech or muscle stiffness
Postencephalitic parkinsonism		This is a disease believed to be caused by a viral illness causing changes in the brain
Recommended summary plan for emergency care and treatment	ReSPECT	This is a process that creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices
Risk feeding		This is when a person continues to eat and drink despite a significant risk of aspiration and or choking. This option is often appropriate when ensuring quality of life is the highest priority. It allows continued enjoyment, comfort, pleasure and social interaction associated with eating and drinking
Rotigotine		This medication is given using skin patches to treat the signs and symptoms of Parkinson's disease
Thickened fluids		Thicker liquids may help people with dysphagia to improve the control of the movement of a food bolus
Urosepsis		This is a type of sepsis that is caused by an infection in the urinary tract. It is a complication often caused by urinary tract infections that are not treated quickly or properly
Vascular parkinsonism		This affects people with restricted blood supply to the brain.
Videofluoroscopic swallowing study	VFSS	This is also known as modified barium swallow, is a radiographic procedure that provides a direct, dynamic view of someone swallowing

Appendices

Appendix 1: Line of sight between the recommendations, key findings and existing supporting evidence

Suggested groups to action the recommendation are shown in italics after each one, this is a guide only, not exhaustive. <i>The term 'healthcare professionals' includes all specialties and grades who would be involved in the care of this group of patients</i>	# represents the number of the supporting key finding	Associated guidelines and other related evidence
<p>1 Document the swallow status of all patients with Parkinson's disease at the point of referral to hospital.</p> <p><i>Document the swallow status of all patients with Parkinson's disease at the point of referral to hospital.</i></p>	<p>CHAPTER 2: PAGE 17 #3. 12/25 respondents to the online survey indicated that problems with eating, drinking or swallowing medication while in hospital were not taken seriously by the healthcare team CHAPTER 3: PAGE 20 #6. 83/277 (30%) patients had dysphagia when presenting to hospital documented in the case notes CHAPTER 4: PAGE 25 #10. 20/79 sets of notes of patients who were known to have dysphagia at the time of arrival did not contain information relating to dysphagia</p>	<p>NICE QS 164</p>
<p>2 Notify the specialist Parkinson's disease service (hospital and/or community) when a patient with Parkinson's disease is admitted, if there is any indication from the notes, or following discussion with the patient or their relatives/carers, that there has been a deterioration or progression of their clinical state.</p> <p><i>Target audiences: Healthcare professionals who see patients at admission, clinical and medical directors</i></p>	<p>CHAPTER 3: PAGE 22 #7. 307/397 (77.3%) patients were under the care of a Parkinson's disease service prior to their admission #8. 180/316 (57%) sets of case notes contained no evidence that patients with Parkinson's disease had a named contact with their Parkinson's disease service CHAPTER 6: PAGE 36 #32. Parkinson's disease consultants and/or specialist nurses were involved for 160/497 (32.2%) patients</p>	<p>NICE QS 164 NICE GUIDELINE 71</p>
<p>3 Screen patients with Parkinson's disease for swallowing difficulties at admission, irrespective of the reason for admission. This should include:</p> <ul style="list-style-type: none"> • Ability to swallow food, fluids and medication • Control of saliva • A history of pneumonia <p><i>Target audiences: Healthcare professionals who see patients at admission and clinical directors</i></p>	<p>CHAPTER 3: PAGE 24 #9. 30/409 (7.3%) patients had a history of aspiration pneumonia prior to their index admission. Of these 30 patients, 18/24 patients had dysphagia. Of those without aspiration pneumonia, 48/320 (15%) had dysphagia</p> <p><i>continued over</i></p>	<p>NICE QS 2</p>

	<p>CHAPTER 4: PAGE 26</p> <p>#11. An assessment of whether the patient had symptoms of dysphagia was made for 179/479 (37.4%) patients</p> <p>#12. 287/479 (59.9%) patients had their ability to continue with normal diet and fluid intake, which is an indicator of dysphagia, assessed at admission. Similarly, assessment of dehydration and difficulty in controlling saliva, were assessed in 222/479 (46.3%) and 62/479 (12.9%) patients respectively</p> <p>#13. 123/312 (39.4%) patients had documented assessments of dysphagia at the initial assessment, while a similar number of patients (133/335; 39.7%) reported difficulty with speech</p> <p>CHAPTER 4: PAGE 27</p> <p>#14. 44/316 (13.9%) patients had swallow screening undertaken within 4 hours of arrival. This missed 51/75 patients who were known to have dysphagia on arrival</p> <p>CHAPTER 4: PAGE 28</p> <p>#16. 96/449 (21.4%) patients had indicators of dysphagia on admission. The most common indicators were difficult or slow chewing and swallowing and coughing or choking</p> <p>CHAPTER 5: PAGE 34</p> <p>#22. 88/161 (54.7%) hospitals had a protocol for the screening of dysphagia, and 105/163 (64.4%) had a protocol for the assessment of dysphagia</p> <p>#23. 117/457 (25.6%) patients had a formal assessment of swallowing undertaken during the admission as recorded in the clinician questionnaire</p> <p>#24. There was evidence in the notes that a formal assessment of swallowing was undertaken during the admission for 100/335 (29.9%) patients. Where such an assessment was not undertaken the case reviewers were of the opinion that one should have been undertaken for a further 51/200 (25.5%) patients</p> <p>#26. Case reviewers indicated the presence of dysphagia was not assessed adequately during the hospital admission for 93/218 (42.7%) patients</p> <p>CHAPTER 5: PAGE 35</p> <p>#27. Case reviewers found that there was a delay in recognising dysphagia in 23/114 (20.2%) of patients while they were in hospital</p> <p>#28. Where there was a delay in recognising dysphagia, case reviewers were of the opinion that this affected the outcome for 6/18 patients</p> <p>CHAPTER 12: PAGE 62</p> <p>#66. Dysphagia care was graded as good for 48/116 (41.4%) patients and adequate for 40/116 (34.5%) patients</p>	
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<p>4</p>	<p>Refer patients with Parkinson’s disease who have swallowing difficulties* (or who have problems with communication) to speech and language therapy.</p> <p>Target audiences: Healthcare professionals who see patients throughout their admission and clinical directors</p> <p><i>*See Figure 4.3 in the report for a list of indicators of swallowing difficulties</i></p>	<p>CHAPTER 4: PAGE 26 #11. An assessment of whether the patient had symptoms of dysphagia was made for 179/479 (37.4%) patients CHAPTER 4: PAGE 28 #15. 51/209 (24.4%) patients were referred to speech and language therapy following swallow screening on arrival at hospital. The case reviewers were of the opinion that a further 36/132 (27.3%) patients should have been referred #16. 96/449 (21.4%) patients had indicators of dysphagia on admission. The most common indicators were difficult or slow chewing and swallowing and coughing or choking CHAPTER 4: PAGE 30 #17. 96/377 (25.5%) patients were referred to speech and language therapy on admission, and in 87 patients this was for dysphagia CHAPTER 6: PAGE 39 #34. The reviewers were of the opinion that a further 46/187 (24.6%) patients should have been referred to speech and language therapy and 67/195 (34.4%) patients to the Parkinson’s disease team CHAPTER 6: PAGE 41 #36. Where patients were referred, case reviewers indicated there was a delay in referral to speech and language therapy in 25/96 patients and delay in referral to dietetics in 16/64 patients</p>	<p>NICE QS 164</p> <p>NICE GUIDELINE 71</p>
<p>5</p>	<p>Ensure patients are able to take the medication they have been prescribed at, and throughout, their admission. If there are concerns about whether or not the patient can swallow safely consider other formulations of medication (e.g. liquid rather than a tablet) or ways of administering them.</p> <p>Target audiences: Healthcare professionals who see patients at, and throughout, their admission, pharmacists, and clinical directors</p> <p><i>NB: Levodopa should be administered within 30 minutes of the prescribed administration time. This is in line with NICE Quality Standard 164. See also the Parkinson’s UK medication optimisation consensus statement</i></p>	<p>CHAPTER 4: PAGE 31 #18. 81/283 (28.6%) patients admitted via the emergency department missed one or more doses of medication. For a further 158/505 (31.3%) patients it was unclear whether they had missed a dose. Of the 114 responses recorded as to why medication was not given, 21/114 (18.4%) were due to a clinical suspicion of dysphagia and 20/114 (17.5%) were due to a decision to keep the patient ‘nil by mouth’ CHAPTER 8: PAGE 50 #48. 121/416 (29.1%) patients missed medication during their hospital stay. The principal reasons for this were the patient being ‘nil by mouth’ (33/110; (30.0%) and being unable to take the medication (32/110; 29.1%) CHAPTER 8: PAGE 51 #49. 113/156 (72.4%) hospitals reported a policy for the administration of medication to patients who have dysphagia or who develop it in hospital in place. Where this policy was in place, it complied with the Parkinson’s UK Medicines Optimisation Consensus Statement in 75/81 hospitals #50. On admission, there was no check for 96/257 (37.4%) patients that their last scheduled dose of PD medication had been taken</p>	<p>NICE QS 164</p> <p>https://www.parkinsons.org.uk/professionals/resources/medicines-optimisation-consensus-statement</p> <p>https://www.sps.nhs.uk/articles/how-can-people-who-need-thickened-fluids-take-medicines/</p>

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6	<p>Ensure there is a hospital policy for the different ways of administering medication and the review of medications at the point of patient discharge. This includes the use of rotigotine patches.</p> <p>Target audiences: Clinical directors, medical directors, hospital pharmacists, specialist Parkinson’s disease teams and quality improvement leads</p>	<p>CHAPTER 8: PAGE 53 #54. 127/158 (80.4%) hospitals had a policy for the use of rotigotine patches in patients with Parkinson’s disease #55. 88/468 (18.8%) patients were prescribed a rotigotine patch while in hospital #56. Where a rotigotine patch was prescribed, alternative forms of medication had been considered for 42/68 patients; the Parkinson’s UK Medicines Optimisation Consensus Statement consulted for 21/50 patients, and there was a clear plan in place to review the patch before discharge for 44/75 patients</p>	<p>https://www.parkinsons.org.uk/professionals/resources/medicines-optimisation-consensus-statement</p>
7	<p>Screen the nutritional status of patients admitted to hospital with Parkinson’s disease and act on the findings.</p> <p>Target audiences: Clinical directors, dietitians, nutrition team members and healthcare professionals who see patients at, and throughout, their admission</p> <p><i>NB: All patients admitted to hospital should undergo a nutritional screen using a validated screening tool such as the BAPEN Malnutrition Universal Screening Tool (MUST) this in line with NICE Quality Standard 24</i></p>	<p>CHAPTER 4: PAGE 32 #19. 69/152 (45.4%) hospitals did not have a policy for the nutritional assessment of patients admitted with Parkinson’s disease #20. 295/434 (68.0%) patients had a nutrition screen undertaken on admission as recorded in the clinician questionnaire. This was documented in the case notes of 162/336 (48.2%) patients #21. There was evidence in the case notes that a Malnutrition Universal Screening Tool (MUST) score was calculated on arrival for 119/316 (37.7%) patients</p>	<p><i>Malnutrition Universal Screening Tool (MUST)</i> <i>NICE QS 24</i></p>
8	<p>Involve speech and language therapists, pharmacists, dietitians and nutrition team members in any multidisciplinary (MDT) discussion of patients with Parkinson’s disease and swallowing difficulties.</p> <p>Target audiences: Clinical directors, speech and language therapists, pharmacists, dietitians and nutrition team members</p>	<p>CHAPTER 6: PAGE 39 #34. The reviewers were of the opinion that a further 46/187 (24.6%) patients should have been referred to speech and language therapy and 67/195 (34.4%) patients to the Parkinson’s disease team CHAPTER 6: PAGE 41 #36. Where patients were referred, case reviewers indicated there was a delay in referral to speech and language therapy in 25/96 patients and delay in referral to dietetics in 16/64 patients CHAPTER 6: PAGE 44 #39. Specialist multidisciplinary team (MDT) reviews took place for patients admitted with Parkinson’s disease in 75/168 (44.6%) hospitals, with 32/73 reporting the presence of speech and language therapy, 28/73 dietetics and 19/73 nutrition team members #40. 221/426 (51.9%) patients had their care reviewed at an MDT meeting during their admission CHAPTER 6: PAGE 45 #41. 158/246 (64.2%) patients had an appropriate MDT discussion undertaken during their admission in the opinion of the case reviewers</p>	<p><i>NICE QS 164</i> <i>NICE GUIDELINE 71</i></p>

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<p>9</p>	<p>Formalise pathways for the provision of modified texture diet and fluids to include input from:</p> <ul style="list-style-type: none"> • Speech and language therapists • Pharmacists • Dietitians or other nutrition team members • Hospital housekeeping and catering services • Community care <p><i>This is in line with the International Dysphagia Diet Standardisation Initiative (IDDSI)</i></p> <p>Target audiences: Medical directors, clinical directors, clinical teams caring for patients with dysphagia. This includes speech and language therapists, pharmacists, dietitians, hospital housekeeping and catering services, community Parkinson’s disease teams and quality improvement leads</p>	<p>CHAPTER 4: PAGE 32 #19. 69/152 (45.4%) hospitals did not have a policy for the nutritional assessment of patients admitted with Parkinson’s disease CHAPTER 7: PAGE 47 #42. 101/314 (32.2%) patients required a modified texture diet whilst they were an inpatient in the opinion of the case reviewers #43. Where was evidence in the case notes that a modified texture diet was advised for 95/278 (34.2%) patients; in 80/95 patients this was advised by speech and language therapy CHAPTER 7: PAGE 48 #45. 100/138 (72.5%) hospitals had a multidisciplinary approach to meal planning #46. Where a thickener was advised, there was evidence in the notes that catering/housekeeping were notified in only 17/44 instances, and this was communicated to pharmacy in 17/45 instances #47. A hospital policy for the prescribing and use of thickeners was in place in 99/148 (66.9%) hospitals</p>	<p><i>International Dysphagia Diet Standardisation Initiative (IDDSI)</i></p>
<p>10</p>	<p>Ensure there is a hospital policy for ‘risk feeding’ which includes the assessment or re-assessment (if already undertaken at admission) of mental capacity regarding this decision. The policy should state that discussion should involve:</p> <ul style="list-style-type: none"> • Patients • Family members and/or carers • Speech and language therapists • Dietitians/nutrition team members • Pharmacists <p>Target audiences: Clinical directors, medical directors, speech and language therapists, pharmacists, dietitians and nutrition team members and quality improvement leads</p>	<p>CHAPTER 9: PAGE 56 #58. 104/160 (65.0%) hospitals were reported as having a policy for ‘risk feeding’ #59. The assessment of mental capacity undertaken in 17/22 patients who were being assessed for ‘risk feeding’ #60. Speech and language therapists were involved in the discussions related to ‘risk feeding’ for 41/110 (37.3%) patients. ‘Risk feeding’ was subsequently undertaken in 36/46 patients</p>	

APPENDICES

<p>11</p>	<p>Provide written information at discharge on how to manage swallowing difficulties, including:</p> <ul style="list-style-type: none"> • Swallow status • Ability to take oral medication • Changes to medication including any new ways of administering them • Nutrition screening tool score and care plan including any texture modifications to food and/or fluids • Positioning • Level of dysphagia risk in the community <p>To:</p> <ul style="list-style-type: none"> • The patient • Family members and/or carers • Community healthcare professionals (e.g. GP, community Parkinson’s disease team, community pharmacist, care home staff) <p>A proforma could be used for this discharge summary.</p> <p>Target audiences: Clinical directors, healthcare professionals who see patients throughout their admission, quality improvement leads</p>	<p>CHAPTER 2: PAGE 17</p> <p>#2. 11 patient/carer respondents to the online survey reported that food, drink or medication was given while the patient was lying down</p> <p>CHAPTER 8: PAGE 54</p> <p>#57. 168/292 (57.5%) patients/carers were provided with information on the administration of medicines prior to discharge. The information was more likely to be provided if the patient’s Parkinson’s disease medication had been altered during the admission</p> <p>CHAPTER 11: PAGE 59</p> <p>#61. At discharge, the clinicians caring for the patient in hospital involved the home carers in discharge planning for 211/267 (79.0%) patients</p> <p>#62. There was no evidence in the case notes of communication at discharge with those responsible for the care of the patient in the community in 90/275 (32.7%) cases reviewed</p> <p>#63. There was evidence in the case notes that the patient’s level of swallowing/aspiration risk in the community was considered prior to discharge for 61/210 (29.0%) patients</p> <p>CHAPTER 11: PAGE 61</p> <p>#64. There was variation in who received a copy of the discharge summary; most commonly this was the GP (422/425; 99.3%) and the patient and carers (208/425; 48.9%). The community-based team only received a copy for 28/425 (6.6%) patients, and the community pharmacist for 5/425 (1.2%) patients</p> <p>#65. Where a summary was provided, in the opinion of the case reviewers this was adequate in 175/236 (74.2%) cases assessed</p>	<p><i>NICE Guideline 5</i></p>
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Appendix 2: Useful links

PARKINSON'S UK

<https://www.parkinsons.org.uk/>

PARKINSON'S UK HELPLINE 0808 800 0303

The Parkinson's UK helpline is a free and confidential service providing support to anyone affected by Parkinson's.

hello@parkinsons.org.uk

Emails answered within 5 working days.

Text relay: 18001 0808 800 0303

Textphone number for textphone users only.

HOEHN and YAHR SCALE

Stage	Hoehn and Yahr Scale	Modified Hoehn and Yahr Scale
1	Unilateral involvement only usually with minimal or no functional disability	Unilateral involvement only
1.5	-	Unilateral and axial involvement
2	Bilateral or midline involvement without impairment of balance	Bilateral involvement without impairment of balance
2.5	-	Mild bilateral disease with recovery on pull test
3	Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent	Mild to moderate bilateral disease; some postural instability; physically independent
4	Severely disabling disease; still able to walk or stand unassisted	Severe disability; still able to walk or stand unassisted
5	Confinement to bed or wheelchair unless aided	Wheelchair bound or bedridden unless aided

Hoehn MM, Yahr MD. *Parkinsonism: onset, progression and mortality. Neurology* 1967;17:427– 442

STAGES OF PARKINSON'S DISEASE

Stage	
Early or diagnosis stage	The time when someone is first experiencing symptoms, being diagnosed and then coming to terms with this
Maintenance stage	When symptoms are controlled, perhaps by medication
Advanced stage	Often called the 'complex phase'
Palliative stage	Providing relief from the symptoms, stress and pain of the condition

MacMahon DG and Thomas S. (1998). *Practical approach to quality of life in Parkinson's disease: the nurse's role. J Neurol.* 1998 May;245 Suppl 1:519-22 (doi: 10.1007/pl00007732)

MOVEMENT DISORDER SOCIETY - UNIFIED PARKINSON'S DISEASE RATING SCALE (MDS-UPDRS)

<https://www.movementdisorders.org/MDS/MDS-Rating-Scales/MDS-Unified-Parkinsons-Disease-Rating-Scale-MDS-UPDRS.htm>

INTERNATIONAL DYSPHAGIA DIET STANDARDISATION INITIATIVE (IDDSI) FRAMEWORK

https://iddsi.org/IDDSI/media/images/Complete_IDDSI_Framework_Final_31July2019.pdf (<https://iddsi.org/>)



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@ <https://iddsi.org/framework/> Licensed under the Creative Commons Attribution Sharealike 4.0 License <https://creativecommons.org/licenses/by-sa/4.0/legalcode>. Derivative works extending beyond language translation are NOT PERMITTED.

GUIDELINES

- National Institute for Health and Care Excellence. 2018. Parkinson's Disease. Quality Standard [QS 164]
- National Institute for Health and Care Excellence. 2017. Parkinson's disease in adults. NICE guideline [NG 71]
- Parkinson's UK. 2017. Consensus statement for the optimisation of Parkinson's medicines in hospital. UK Parkinson's Excellence Network
- National Institute for Health and Care Excellence. 2006. Nutrition Support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition [CG 32]
- National Institute for Health and Care Excellence. 2012. Nutrition support in adults. Quality Standard [QS24]

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