

Dysphagia in people with Parkinson's Disease: Organisational questionnaire

A. INTRODUCTION

Please complete one organisational questionnaire for each hospital in your Trust/Health Board that admits patients with Parkinson's Disease.

What is this study about:

The aim of this study is to examine the pathway of care of patients with Parkinson's Disease (PD) who are admitted to hospital when unwell. In particular, to identify and explore multidisciplinary care and review organisational factors in the process of identifying, screening, assessing, treating and monitoring the ability to swallow.

Who should complete this questionnaire:

This questionnaire has been designed to collect data on the organisational structures surrounding the care provided to patients with Parkinson's Disease who are admitted to hospital for any reason.

One questionnaire should be completed for every hospital within this Trust/Health Board where patients with Parkinson's Disease might be cared for/ treated.

This questionnaire should be completed by a clinician responsible for providing care to this group of patients. This may be the lead clinician (neurologist/care of the elderly), speech & language therapist or specialist Parkinson's Disease nurse.

Questions or help:

A list of definitions can be found here: <https://www.ncepod.org.uk/Dysphagia.html>

If you have any queries about this study or this questionnaire, please contact: dysphagia@ncepod.org.uk or telephone 020 7251 9060.

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical & Surgical care.

B. THE HOSPITAL

1. B1. Please indicate what type of hospital this is:

- DGH <500 beds DGH ≥500 beds University Teaching Hospital
 Unknown

If not listed above, please specify here...

2a. B2a. Does this hospital have onsite access to the following services? (Please tick all that apply)

- Occupational therapy Physiotherapy Speech & language therapy
 Dietitians Nutrition team Pharmacy
 Unknown

Please specify any additional options here...

2b. If answered "Occupational therapy" to [2a] then:

B2b. If YES to occupational therapy, when is this service available?

- 24/7
 Normal working hours (e.g. 8am-6pm) 7days/week
 Normal working hours (e.g. 8am-6pm) Mon-Fri Unknown

If not listed above, please specify here...

2c. If answered "Physiotherapy" to [2a] then:

B2c. If YES to physiotherapy, when is this service available?

- 24/7
 Normal working hours (e.g. 8am-6pm) 7days/week
 Normal working hours (e.g. 8am-6pm) Mon-Fri Unknown

If not listed above, please specify here...

2d. If answered "Speech & language therapy" to [2a] then:

B2d. If YES to speech & language therapy, when is this service available?

- 24/7
 Normal working hours (e.g. 8am-6pm) 7days/week
 Normal working hours (e.g. 8am-6pm) Mon-Fri Unknown

If not listed above, please specify here...

2e. If answered "Dietitians" to [2a] then:

B2e. If YES to dietitians, when is this service available?

- 24/7
 Normal working hours (e.g. 8am-6pm) 7days/week
 Normal working hours (e.g. 8am-6pm) Mon-Fri Unknown

If not listed above, please specify here...

2f. If answered "Nutrition team" to [2a] then:

B2f. If YES to nutrition team, when is this service available?

- 24/7
- Normal working hours (e.g. 8am-6pm) 7days/week
- Normal working hours (e.g. 8am-6pm) Mon-Fri Unknown

If not listed above, please specify here...

2g. If answered "Pharmacy" to [2a] then:

B2g. If YES to pharmacy, when is this service available?

- 24/7
- Normal working hours (e.g. 8am-6pm) 7days/week
- Normal working hours (e.g. 8am-6pm) Mon-Fri Unknown

If not listed above, please specify here...

3a. B3a. Does this hospital have a specialist Parkinson's Disease (PD) service ?

- Yes
- No
- Unknown

3b. If answered "Yes" to [3a] then:

B3b. If YES to 3a, who is responsible for running/leading this service?

- Consultant
- Nurse
- Unknown

If not listed above, please specify here...

3c. If answered "Yes" to [3a] and "Consultant" to [3b] then:

B3c. If a CONSULTANT, what is their specialty?

- Neurologist
- Geriatric medicine
- Unknown

If not listed above, please specify here...

3d. If answered "Yes" to [3a] then:

B3d. If YES to 3a, who is responsible for reviewing Parkinson's Disease patients when admitted to hospital? (Please tick all that apply)

- The PD Service lead
- Other PD service professional
- On-call general physician
- Unknown

Please specify any additional options here...

1a. C1a. Is there a protocol for the screening of dysphagia?

Yes No Unknown

1b. C1b. Is there a protocol for the assessment of dysphagia?

Yes No Unknown

1c. If answered "Yes" to [1b] then:**C1c. If YES, does it give deadline(s) by which time a patient should have been assessed?**

Yes No Unknown

1d. If answered "Yes" to [1b] then:**C1d. If YES, does it contain: (Please tick all that apply)**

- Who will screen the patient
- Who will assess the patient
- Criteria for referral to the SLT team
- Time limit by which the assessment needs to be completed
- Time by which assessment by SLT team should be completed
- The role of the dietitian
- Plan for nutrition after hospital discharge
- Unknown

Please specify any additional options here...

2a. C2a. Does this hospital have a formalised scoring tool for dysphagia?

Yes No Unknown

2b. If answered "Yes" to [2a] then:**C2b. Does the tool specify actions that need to be taken if the patient has dysphagia?**

Yes No Unknown

2c. If answered "Yes" to [2a] then:**C2c. If YES, what do these actions include?**

- Referral to speech & language therapy
- Referral to dietitians
- Referral to ENT
- Referral to gastroenterology
- Referral to pharmacy
- Local protocol/nutrition care plan (based on MUST score) followed
- Unknown

Please specify any additional options here...

3. C3. Which staff members are trained to undertake dysphagia assessments? (Please tick all that apply)

Speech & language therapists Nursing staff Unknown

Please specify any additional options here...

4a. C4a. Does this hospital use a scale for assessing drooling in patients with Parkinson's Disease?

Yes No Unknown

**4b. If answered "Yes" to [4a] then:
C4b. If YES, please specify which scale:**

5a. C5a. Is there a protocol for managing oral hygiene?

Yes No Unknown

5b. If answered "Yes" to [5a] then:

C5b. If YES, does it designate who is responsible for oral hygiene?

Yes No Unknown

5c. If answered "Yes" to [5a] then:

C5c. If YES, what does the protocol include? (Please tick all that apply)

- Assessing oral hygiene on admission
- Education and support for oral hygiene
- Regular reminders about oral hygiene
- Providing physical support for oral hygiene
- Monitoring oral hygiene
- Assessing the ability of patient to access drinking water
- Unknown

Please specify any additional options here...

6a. C6a. Is there a policy for assisting patients with eating and drinking who are unable to do so themselves?

Yes No Unknown

6b. If answered "Yes" to [6a] then:

C6b. If YES, does it identify a staff member responsible for assisting patients?

Yes No Unknown

7a. C7a. Is there a policy for assisted drinking/fluid intake?

Yes No Unknown

7b. If answered "Yes" to [7a] then:

C7b. If YES, does it identify a staff member responsible for assisting patients?

Yes No Unknown

8a. C8a. Is there a policy on nutritional assessment of all patients admitted with PD?

Yes No Unknown

8b. If answered "Yes" to [8a] then:

C8b. If YES, does it give deadline(s) by which time a patient should have been assessed?

Yes No Unknown

8c. If answered "Yes" to [8a] then:

C8c. Does it specify actions that need to be taken if the patient's nutritional status is compromised?

- Yes No Unknown

8d. If answered "Yes" to [8a] and "Yes" to [8c] then:

C8d. If YES, what do these actions include?

- Positioning Modified diet
 Supplements Nasogastric (NG) tube
 Percutaneous endoscopic gastrostomy (PEG) feeding
 Modified meal times supported by HCA/ nurse Unknown

Please specify any additional options here...

8e. If answered "Yes" to [8a] then:

C8e. Does it specify actions that need to be taken if the patient's fluid intake is compromised?

- Yes No Unknown

9. C9. Are there hospital guidelines for initiating parenteral nutrition?

- Yes No Unknown

10a.C10a. Is there an MDT approach to menu planning to ensure the menu is nutritionally analysed and compliant with modified texture meals for patients admitted to this hospital with Parkinson's Disease?

- Yes No Unknown

10b.If answered "Yes" to [10a] then:

C10b. If YES, which specialties are involved? (Please tick all that apply)

- Dietitians Speech & language therapists The patients clinical team
 Nursing team Catering Unknown

Please specify any additional options here...

11. C11. Is there a nil by mouth policy/protocol for patients with dysphagia/suspected dysphagia?

- Yes No Unknown

12. C12. Is there a policy for the insertion of NG tubes in patients with Parkinson's Disease?

- Yes No Unknown

13a.C13a. Is there an organisational policy for the prescribing and use of thickeners?

- Yes No Unknown

13b.If answered "Yes" to [13a] then:

C13b. If YES, does this include information on how thickeners are prescribed?

- Yes No Unknown

13c.If answered "Yes" to [13a] and "Yes" to [13b] then:

C13c. If YES, are these prescribed: (Please tick all that apply)

- Through catering Through pharmacy Unknown

Please specify any additional options here...

14a.C14a. Is there a policy for administration of medications to patients who have dysphagia or who develop it whilst in hospital?

- Yes No Unknown

14b.If answered "Yes" to [14a] then:

C14b. If YES, does this comply with the Parkinson's UK Medicines Optimisation Consensus Statement?

<https://www.parkinsons.org.uk/professionals/resources/medicines-optimisation-consensus-statement>

- Yes No Unknown
-

15. C15. Does the hospital have a policy for the use of Rotigotine patches in patient's with Parkinson's Disease whilst in hospital?

- Yes No Unknown
-

16a.C16a. Does the hospital have an organisational policy for at-risk feeding?

- Yes No Unknown

16b.If answered "Yes" to [16a] then:

C16b. If YES, does this cover the interface between primary and secondary care?

- Yes No Unknown

16c.If answered "Yes" to [16a] then:

C16c. If YES, does it meet the Plain English standards recommended for patients?

- Yes No Unknown
-

17a.C17a. Are patients with PD assessed for their level of risk of dysphagia in the community before discharge from hospital?

- Yes No Unknown

17b.If answered "Yes" to [17a] then:

C17b. If YES, does it include guidance on whom to refer to before discharge?

- Yes No Unknown

17c.If answered "Yes" to [17a] then:

C17c. If YES, does it involve the family, carers and social care workers?

- Yes No Unknown

17d.If answered "Yes" to [17a] then:

C17d. If YES, does this include information about the handover of care to the community at discharge ?

- Yes No Unknown

17e.If answered "Yes" to [17a] then:

C17e. Is the community team always sent a copy of the discharge summary?

- Yes No Unknown

D. FACILITIES

1. D1. Does the hospital have a facility to insert PEG tubes?

- Yes No Unknown

2a. D2a. Does the hospital have video fluoroscopy available and used to assess dysphagia?

- Yes No Unknown

2b. If answered "Yes" to [2a] then:

D2b. If YES, what is the average waiting time to access this service?

Days Unknown

2c. If answered "No" to [2a] then:

D2c. If NO, how is this dealt with?

3. D3. Does the hospital have facilities to undertake fiberoptic endoscopic evaluation of swallowing (FEES)

- Yes No Unknown

4. D4. Does the hospital have the facilities to make audio or video recordings of patient's spontaneous speech?

- Yes No Unknown

5. D5. Does the hospital use:

- In-house caterer Meals bought in Unknown

Please specify any additional options here...

E. STAFFING

1a. E1a. Does the hospital have specialist multidisciplinary team reviews for patients admitted with Parkinson's Disease?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

E1b. If YES, which specialties are a member of this team? (Please tick all that apply)

- | | |
|-------------------------------------------------------|------------------------------------------------------------------------|
| <input type="checkbox"/> Physicians | <input type="checkbox"/> Surgeons Specialist Parkinson's Disease nurse |
| <input type="checkbox"/> Speech & language therapists | <input type="checkbox"/> Occupational therapists |
| <input type="checkbox"/> Physiotherapists | <input type="checkbox"/> Pharmacy |
| <input type="checkbox"/> Dietetics | <input type="checkbox"/> Nutrition team |
| <input type="checkbox"/> Catering services | <input type="checkbox"/> GP |
| <input type="checkbox"/> Carers | <input type="checkbox"/> Residential home staff |
| <input type="checkbox"/> Nursing home staff | <input type="checkbox"/> Unknown |

Please specify any additional options here...

2. E2. Does the hospital have a clinical lead for Parkinson's Disease?

- Yes No Unknown

3. E3. Does the hospital have a specialist Parkinson's Disease nurse?

- Yes No Unknown

4. E4. Does the hospital have a lead/champion for mouth care/oral hygiene?

- Yes No Unknown

5. E5. What access to community teams/services is available? (Please tick all that apply)

- Community dietitian
- Oral hygiene
- Community physiotherapists
- Community speech & language therapists
- Community occupational therapists
- Parkinson's Disease nurse
- District nurse
- Advanced and practice nurse teams
- Community rehabilitation nurses
- Residential home/nursing home staff
- Social workers
- 3rd sector Parkinson's Disease support
- Mental health team
- Carer support provision
- Carers from NHS and Independent providers and the Health and Social care team
- Unknown

Please specify any additional options here...

6. E6. Are patients admitted to this hospital able to be referred to dietitians in the community at the point of discharge for ongoing advice and support?

- Yes No Unknown

7a. E7a. Does this hospital have a nutrition team for adult patients?

- Yes No Unknown

7b. If answered "Yes" to [7a] then:

E7b. If YES, who is in this team? (Please tick all that apply)

- | | |
|----------------------------------------------------------------|-------------------------------------------------------|
| <input type="checkbox"/> Clinicians | <input type="checkbox"/> Dietitians |
| <input type="checkbox"/> Pharmacists | <input type="checkbox"/> Nutrition nurse specialists |
| <input type="checkbox"/> Specialist Parkinson's Disease nurses | <input type="checkbox"/> Speech & language therapists |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

7c. If answered "Yes" to [7a] and "Clinicians" to [7b] then:

E7c. If CLINICIANS, please specify the specialty(ies)

- | | | |
|-------------------------------------------|--------------------------------------------------|-------------------------------------------|
| <input type="checkbox"/> General medicine | <input type="checkbox"/> Acute internal medicine | <input type="checkbox"/> Gastroenterology |
| <input type="checkbox"/> General surgery | <input type="checkbox"/> Geriatric medicine | <input type="checkbox"/> Unknown |

Please specify any additional options here...

7d. If answered "Yes" to [7a] and "Clinicians" to [7b] then:

E7d. If CLINICIANS, please specify the grade(s)

- Consultant
- Staff grade/Associate specialist
- Trainee with CCT
- Senior specialist trainee (ST3+ or equivalent)
- Junior specialist trainee (ST1&ST2 or CT equivalent)
- Basic grade (HO/FY1 or SHO/FY2 or equivalent)
- Specialist Nurse (Nurse consultant, nurse practitioner, clinical nurse specialist)
- Senior staff nurse, enrolled nurse (EN) etc)
- 1st Level nurse, staff nurse (RGN)
- Non-registered staff (HCA etc.)
- Unknown

Please specify any additional options here...

7e. If answered "Yes" to [7a] then:

E7e. How often does the nutrition team have an MDT meeting?

- Weekly Fortnightly Monthly Unknown

If not listed above, please specify here...

7f. If answered "Yes" to [7a] then:

E7f. How often does the nutrition team undertake rounds?

- Daily (7days/week) Daily (5 days/week) Weekly Unknown

If not listed above, please specify here...

7g. If answered "Yes" to [7a] then:

E7g. What responsibilities do the nutrition team undertake?

- | | |
|-----------------------------------------------------------------------|---------------------------------------------------------------------|
| <input type="checkbox"/> Review only enteral nutrition referrals | <input type="checkbox"/> Review only parenteral nutrition referrals |
| <input type="checkbox"/> Review both enteral and parenteral referrals | <input type="checkbox"/> Review of at risk feeding |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

7h. If answered "Yes" to [7a] then:

E7h. With respect to ordering and administering parenteral nutrition (PN), does the nutrition team have:

- Complete autonomy (i.e. can say no to PN) Advisory role only
 Unknown

Please specify any additional options here...

8a. E8a. Are the catering team involved in the wider care of patients admitted with PD?

- Yes No Unknown Not applicable

8b. If answered "Yes" to [8a] then:

E8b. If YES, what is their role?

8c. If answered "Yes" to [8a] then:

E8c. If YES, are they able to provide appropriate meals at a time that meets such patient's medication schedule?

- Yes No Unknown

9. E9. Is there an overarching nutrition team, steering group/forum involved in the development and ratification of local guidelines?

- Yes No Unknown

10. E10. Are there specialist nutrition nurses within your hospital?

- Yes No Unknown

11. E11. Are the ward nurses given specific training in the care of patients who have dysphagia?

- Yes No Unknown

F. MEDICATION MANAGEMENT

1a. F1a. Does this hospital have a medicines reconciliations policy?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

F1b. If YES, does it provide guidance on situations where liquid versions of medications may or may not be appropriate?

- Yes No Unknown
-

2. F2. Does the hospital pharmacy have ready availability of Parkinson's disease medications in their dispersible or liquid version?

- Yes No Unknown
-

3a. F3a. Are medications for Parkinson's Disease available in the Emergency Department?

- Yes No Unknown

3b. If answered "Yes" to [3a] then:

F3b. If YES, please specify which medications are available:

3c. If answered "Yes" to [3a] then:

F3c. If YES, is there a policy/ protocol to ensure that PD patients do not miss their dopaminergic medication?

- Yes No Unknown

3d. F3d. Do hospital staff have access to an on-call pharmacist to help with medications when the pharmacy is closed?

- Yes No Unknown
-

4a. F4a. Once admitted, within this hospital are there any differences in the medications available in different ward areas?

- Yes No Unknown

4b. If answered "Yes" to [4a] then:

F4b. If YES, please give further details:

5a. F5a. Are thickeners used in the hospital the same as those used in the community?

Yes

No

Unknown

5b. If answered "No" to [5a] then:

F5b. If NO, is the same type of product used in the hospital and community? (i.e. gum or starch based)

Yes

No

Unknown

5c. If answered "No" to [5a] then:

F5c. Please give any further details about any disparity between thickeners used in hospital and the community:

G. INFORMATION FOR PATIENTS/ CARERS

1a. G1a. Does this hospital have information and resources relating to dysphagia available for patients and carers?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

G1b. If YES, does this include post discharge information regarding access to support?

- Yes No Unknown

1c. If answered "Yes" to [1a] then:

G1c. If YES, does this information comply with the use of Plain English standards recommended for patients?

- Yes No Unknown
-

2. G2. Does this hospital provide printed information on the swallowing process to patients and carers ?

- Yes No Unknown

1. H1. Is there an audit of dysphagia practice within your hospital?

Yes

No

Unknown

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

By doing so you have contributed to the data set that will form the report and recommendations due for release in December 2020