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***This Medicines Information Leaflet is produced locally to optimise the use of medicines by encouraging prescribing that is safe, clinically appropriate and cost-effective to the NHS.***

# Care at the end of life: Dying with Parkinson's disease

## Parkinson's disease and related Parkinsonian syndromes

This document sets out guidance for symptom management of a patient when a diagnosis of dying has been established by the multidisciplinary team.

## Introduction

This guidance applies to patients who have been recognised to be dying with a likely prognosis of hours /short number of days. Patients are likely to be bed bound, sleeping for long periods and unable to take oral medications.

## Background information

Patients may have a diagnosis of Parkinson's Disease (PD) or related Parkinsonian syndromes (Multiple System Atrophy, Progressive Supranuclear Palsy, Corticobasal Degeneration, and Lewy Body Dementia).

As patients approach the end of their lives the goal of care is symptom management rather than the maintenance of mobility. Therefore, lower doses of dopaminergic medications may be needed. The aim of dopamine therapy is to ensure that the patient is pain free and is not rigid, both at rest and on receiving nursing care. 52% of patients experience pain as they are dying[1]. Other common symptoms are excess respiratory secretions (58%), delirium/agitation (51%), fever (23%), and nausea /vomiting[1].

**Medications to be avoided where possible** are antipsychotics: both typical (e.g., haloperidol) and atypical (e.g., risperidone, olanzapine), antiemetics: (e.g., metoclopramide), and other medications with anti-dopaminergic activity.

## Medication for management of PD

Amantadine, MAO-B inhibitors, COMT inhibitors and anticholinergic medication should be deprescribed in the last week or two of life.

1. Continue levodopa (L-dopa) and dopamine agonists for as long as possible. Consider switching L-dopa to equivalent dose of orodispersible preparations (Madopar) if the patient can swallow (Dissolve in water or squash). If the patient has a nasogastric tube (NGT) in place orodispersible preparations (Madopar) may be given via the NGT.
2. Regular and modified release L-dopa should be converted to the identical doses of orodispersible preparations (Madopar) see MIL Guidelines for the use of Parkinson's medication in patients who are NBM or dysphagic
   If the patient is taking combination Levodopa/entacapone, switch to

equivalent dose of orodispersible Madopar and do not replace entacapone.
3. Remember GI function is impaired in the last days of life and medication may not be reliably absorbed.
4. If the patient is on low dose dopamine therapy (e.g., L-dopa 62.5mg tds or rotigotine patch 2mg od) and it was started in the last four weeks, you may stop medications. Review clinically (at least daily), checking for signs of increasing rigidity.
5. Where the enteral route is not possible / reliable commence a rotigotine patch. See MIL Guidelines for the use of Parkinson's medication in patients who are NBM or dysphagic
6. Too little dopamine replacement: There is a risk of neuroleptic malignant-like syndrome, resulting in rigidity and fever. This can also occur with sudden cessation of deep brain stimulation (DBS). If this happens, seek urgent advice from the PD team (nurse during routine clinical hours or the on-call neurology registrar).

### Patients on a Duodopa infusion

Continue the intestinal infusion of Duodopa. Seek advice from the PD team during routine clinical hours or neurology team on call.

### Patients on an apomorphine infusion

Continue the infusion. Seek advice from the PD team during routine clinical hours or neurology team on call.

## Symptom management at the end of life

### Management of excessive secretions

Continue hyoscine hydrobromide patches where they have been helpful prior to this end-of-life care phase.

50% of patients who are dying have a column of fluid in their upper airways that oscillates with respiration. Though noisy, it is not troublesome to unconscious patients.

1. Explain the reason for noisy breathing to those at the bedside.
2. Position patients on their sides allowing gravity to help secretions drain from the oral cavity.
3. Administer PRN hyoscine butylbromide 20mg SC hourly, with maximum dose of 120 mg/24 h (does not cross blood brain barrier) – it appears to work in 2/3 of patients.
4. If the PRN was helpful, add 40−60 mg hyoscine butylbromide/24 hours to continuous subcutaneous infusion (CSCI).
5. Where secretions remain troublesome, escalate to palliative or PD care team. They may advise dose escalation or a trial of glycopyrronium.

### Management of Pain

1. Assess the cause of pain (e.g., rigidity, urinary retention, constipation) and treat where possible
2. Trial 2.5mg morphine SC to see if the patient settles as pain eases. If helpful prescribe 2.5mg four hourly PRN.
3. If more than 3 PRNs are needed in 24 hours, commence a CSCI via a T34 syringe pump. The usual starting dose is 10mg morphine/24 h.
4. If the patient has an eGFR of less than 30 mL/min, use oxycodone 1–2 mg SC every 4 hours. If more than 3 PRNs are needed in 24 hours, please discuss with the palliative care team.
5. Please seek advice from the palliative care team if the patient has abnormal hepatic and /or renal impairment.

## Management of delirium and agitation

Patients may be agitated/delirious and experience more troublesome hallucinations and delusions than usual. Consider reversible causes (e.g., constipation, pain, urinary retention, high dose of dopamine agonists e.g., rotigotine patch). Provide a quiet environment for the patient.

a. If on a rotigotine patch or dopamine agonist, reduce the dose of the drug or patch size if possible.
b. Explain what is happening to the patient and/or their family.
c. Use midazolam 2.5mg 4 hourly PRN.
d. If more than 3 PRN doses are needed in 24 hours, commence a CSCI via a T34 syringe pump. Usual starting doses, midazolam 10 mg/24 hours. If needed, increase by 50% after 24 hours and then to 20mg/24 hours.
e. Seek the advice of the palliative care team if more than 30 mg/24 h is required (CSCI and PRNs).
f. Where hepatic function is abnormal (LFTs greater than 4 times upper limit of normal) please discuss with the palliative care team.

## Management of rigidity

1. Review the dose of dopamine (dispersible Madopar or rotigotine patch). If needed discuss with PD team during routine clinical hours or neurology team on call.
2. Use midazolam as for delirium/agitation.

## Management of nausea and vomiting

This symptom is less troublesome in the last days of life. Always assess for constipation.

1. If a patient has an enteral route domperidone 10–20 mg tds (tablets/oral solution) is the antiemetic of choice
2. Otherwise, prescribe PRN cyclizine 25 mg SC/IV tds. If 3 PRNs are needed in a 24-hour period, consider a CSCI with 75 mg/24 hours.
3. Review after 24–48 hours and if needed, increase to 100 /24 hours
4. Where nausea/vomiting remain troublesome, escalate to palliative care team
5. With exception of domperidone, all antiemetics may increase rigidity. Review the patient daily.

## Management of Dyspnoea

This is unlikely to be a troublesome symptom at the end of life. Ensure PRNs of an opioid (see pain) and a benzodiazepine (see agitation / delirium) are prescribed.

## Mouthcare

Continue to offer sips of fluid where safe to do so, alternatively a single use green sponge may be used to moisten the patient's mouth. If insufficient to maintain a moist oral mucosa prescribe biotene 4 hourly regularly.

## Deep brain stimulation (DBS)

Deep brain stimulation (DBS) uses an implantable pulse generator (battery), usually placed in the infraclavicular area, connected to leads within the brain. Patient/family may also have access to a remote programmer, and a charging unit in the case of a rechargeable device. Seek advice from the patient's DBS team if they have a rechargeable battery in place for instructions on how to re-charge the system as appropriate.
Deactivation of DBS may lead to increased symptoms burden, so it should be left on. After death, the DBS device does not need to be switched off. If the patient is to be cremated, alert the bereavement team as the funeral directors need to be informed that a DBS is in situ.

## Use of EOLC PowerPlan on EPR

Please modify your prescribing in light of the advice above – prescribing an opioid, benzodiazepine and an antiemetic (domperidone or cyclizine). Please ensure SC medications are prescribed as dying patients will lose their oral route.

## Brain donation

Where possible, ask the patient and family to have the details and contact numbers for the site accepting the patient's donation to hand in advance. Tissue needs to be collected within 48 hours so please note the intent to donate on EPR and inform the bereavement office as soon as possible after the patient dies.

***References***


1. Hindmarsh J, Hindmarsh S, Lee M. Idiopathic Parkinson's Disease at the End of Life: A Retrospective Evaluation of Symptom Prevalence, Pharmacological Symptom Management and Transdermal Rotigotine Dosing. Clin Drug Investig. 2021 Jul 2. doi: 10.1007/s40261-021-01054-1. Epub ahead of print. PMID: 34213758.
2. International Parkinson and Movement Disorder Society. Task Force on Palliative Care. Available online: https://www.movementdisorders.org/MDS/About/Committees--Other-Groups/MDS-Task-Forces/Task-Force-on-Palliative-Care.htm
3. Palliative Care Formulary (OUH staff licence) – log in details on http://ouh.oxnet.nhs.uk/PalliativeCare/Pages/Default.aspx


**Contact details for advice for inpatients:**
**Palliative Care Team:**
http://ouh.oxnet.nhs.uk/PalliativeCare

**Parkinson's Specialist Nurse at Oxford** University Hospitals Mabel Eghaghe, Advanced Nurse Practitioner
Tel: 01865 234048
Secretary: 01865 231295 / 24848 Email: mabel.eghaghe@ouh.nhs.uk
Inpatient advice available Monday, Tuesday, Wednesday & Friday 9-5pm

**Neurology specialty registrar on call: via JR switchboard**

**Contact details for outpatients:**

**Oxfordshire Community Neurology Specialist Nurses** (Jo Bromley, Nic Findlay, Louise Ludlow)
Tel: 01865 737465 Mon to Friday (excluding BHs) 8.30am to 4.30pm
*For outpatients in the community in Oxford City please contact Mabel Eghaghe (OUH hospital PD Nurse) 9am – 5pm*

Further information can also be obtained from the OUH Parkinson's Disease Information intranet site:
http://ouh.oxnet.nhs.uk/Parkinsons/Pages/Default.aspx


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