PARKINSON'S
Excellence
Network

A toolkit for detecting and managing Parkinson's dementia

In partnership with

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London Hospitals
NHS Foundation Trust

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This project was funded through a Wellcome Enrichment Grant

ABOUT THIS TOOLKIT

What is this toolkit?

This toolkit aims to provide information on how to detect and manage Parkinson's dementia in clinic.

What information will it provide?

The toolkit gives an overview of Parkinson's dementia (risk factors, symptoms and assessments), treatment strategies, support and considerations to discuss with patients.

Who is it for?

This toolkit is aimed at movement disorder neurologists, geriatricians, Parkinson's nurses and other health professionals who care for people living with Parkinson's.

Although dementia is common in Parkinson's, it is not talked about enough, and people with the condition can be fearful of and reluctant to discuss the topic. Some healthcare professionals may also delay or feel unsure of how best to bring up the topic in clinic. This limits access to treatment and support, and makes it harder to carry out research into underlying causes. We hope that this toolkit will help to facilitate these conversations in the clinic.

There is a complementary patient-facing version of this toolkit, designed for people living with Parkinson's who have experienced or are worried about cognitive changes, and their families. This is freely available online or to order in print at: **parkinsons.org.uk/thinkingandmemory**

Why look for dementia in patients with Parkinson's?

- Dementia is common in Parkinson's: around 50% of people with Parkinson's will develop dementia within 10 years of their diagnosis[1].
- Making a positive diagnosis of dementia can mean that people access the right help and treatments.
- Dementia in Parkinson's and the associated symptoms can respond to treatment.
- A diagnosis of dementia can impact on the choice of treatment for motor symptoms.
- New disease-modifying treatments are emerging. In the near future, patients could be targeted for these.

RISK FACTORS, SYMPTOMS AND DIAGNOSIS

Which people with Parkinson's are at higher risk of Parkinson's dementia? [2,3]

- Older age at onset (~70), and older age in general
- Vascular disease (especially hypertension and diabetes)
- Depression
- Genetic risk groups: e.g. *GBA*-associated Parkinson's
- REM sleep behaviour disorder
- Orthostatic hypotension
- Presence of visual illusions or hallucinations
- Prior episodes of delirium (e.g. during episodes of infection)

How to make a positive diagnosis of Parkinson's dementia

- When patients experience difficulty doing everyday tasks and are losing independence due to cognitive deficits.
- More than one cognitive domain is affected on testing (e.g. visuospatial and executive deficits are particularly common in Parkinson's dementia) – see Table on page 6.
- If patients (or their family) are aware of cognitive changes, but they can manage day-to-day activities without significant functional impairment, this is termed **Parkinson's with mild cognitive impairment (PD-MCI)**.

What are the symptoms to look for?

Cognitive Domain	Symptom
Frontal / Executive	• Difficulty planning tasks (e.g. booking travel, shopping, following a recipe) • Difficulty managing finances • Difficulty multitasking
Attention	• Getting easily distracted • Losing train of thought
Visuospatial	• Difficulty finding objects in a cluttered scene (e.g. not seeing the salt cellar on a messy table) • Difficulty reading in general, words moving about on a page • Sustaining minor scrapes on driving • Confusion using a mobile phone or household appliances
Memory	• Repeating questions and conversations • Forgetting to take tablets on a regular basis • Leaving appliances turned on
Language	• This is usually well-preserved, but can have some issues (e.g. losing the thread of conversation, struggling in a group environment, lack of initiating conversation in a group)

Other important symptoms

- **Prominent fluctuations in thinking:** sometimes lucid, other times sleepier or confused/disorientated.
- **Visual hallucinations:** usually formed, of people or animals.
- **Delusions:** especially delusions of jealousy or of identification (e.g. thinking they are not home when they are, and Capgras delusions – thinking a family member has been replaced by a person who looks similar). There may also be general suspiciousness and paranoia.
- **Autonomic symptoms:** especially postural hypotension.
- **Daytime somnolence**

Find out more: The *Diamond Lewy Toolkits* are helpful to diagnose Parkinson's dementia and dementia with Lewy bodies.[4, 5]

How to assess?

If there is time, a Mini-ACE[6, 7], Mini Mental State Examination (MMSE), or Montreal Cognitive Assessment (MoCA) are useful to provide measures of severity and to assess change over time.

- For the Mini-ACE, a cut-off of ≤25/30 has high sensitivity and specificity for a diagnosis of dementia. A score of ≤21/30 is almost always diagnostic of dementia.[6, 8]
- To note: Cut-off scores are not absolute and should be considered in the context of educational background, and level of functional impairment. Dementia is still possible with a high score.

When time is limited, useful screens can be:

- **Animal fluency:** (name as many animals as you can in 90 seconds) < 16 in 90 seconds.[9]
- **Clock-drawing task:** ask the patient to draw a clock with all the numbers on and the hands pointing to ten past eleven.
- **Pentagon copying** or **copying a wire cube.**

What investigations to consider?

- Consider blood tests for reversible metabolic causes, e.g. FBC/U&E/B12/folate/thyroid function/calcium.
- Consider screening for constipation/infection.
- Structural imaging: MRI brain, or CT if not feasible.
- If available, refer for formal neuropsychological assessment.

Making a positive diagnosis of Parkinson's dementia can be a positive and helpful step

- Often the patient and family are aware that "something is not quite right".
- A positive diagnosis means that appropriate treatment can be started and current treatments reviewed.
- The patient and their family can access support and resources once a diagnosis of dementia is made.

Parkinson's dementia and dementia with Lewy bodies

Parkinson's dementia is diagnosed when dementia develops in the context of established Parkinson's, with onset of cognitive symptoms at least 12 months after the onset of motor symptoms.[10]

Dementia with Lewy bodies (DLB) is dementia with at least 2 of 4 possible core clinical symptoms: motor parkinsonism, recurrent visual hallucinations, cognitive fluctuations and a history of REM sleep behaviour disorder.

DLB can be diagnosed with 1 core symptom in the presence of specific indicative biomarkers (one of a positive: DAT (dopamine transporter) scan, MIBG (meta-iodo-benzyl-guanidine) scan or polysomnography-confirmed REM sleep without atonia).[11]

DLB is diagnosed when dementia occurs before, or within 12 months of the onset of motor Parkinsonism.

Lewy body dementia is an umbrella term including both dementia with Lewy bodies and Parkinson's dementia. It can be used to refer to people with either of these conditions. It can also be useful in patients where the precise onset of cognitive symptoms is not clear.

TREATMENT STRATEGIES FOR PARKINSON'S DEMENTIA

Please note: These treatment strategies are also suitable for people with dementia with Lewy bodies (DLB).

Rationalise drugs

- Withdraw anticholinergic medications
- Withdraw amantadine
- Reduce/withdraw dopamine agonists, slowly and looking out for dopamine agonist withdrawal syndrome
- Simplify Parkinson's drug regime – use levodopa-based therapies only, if possible
- May need to reduce total dopaminergic medication dose
- **When changing medications, use cautious up-titration, and make one change at a time**
- **When withdrawing medications, monitor for worsening motor symptoms**

Cholinesterase inhibitors (rivastigmine, donepezil, also galantamine) and memantine

- Check heart rate: [12, 13]
  - **Pulse over 60 and no cardiac history (e.g. heart block or unexplained syncope):** proceed.
  - **Pulse 50-60 and no history of funny turns, or syncope:** proceed, with pulse check ideally after 1 week. (If remain asymptomatic: continue, with pulse check after each dose increase).
  - **Pulse less than 50 or irregular:** arrange ECG to screen for cardiac conduction abnormalities.
  - Also do ECG if history of unexplained syncope, or patient is taking rate limiting medication (e.g. beta blockers).
  - If in doubt: seek cardiology advice and consider pacemaker.
  - Note that atrial fibrillation is not a contraindication to cholinesterase inhibitors.
- Rivastigmine patch is better tolerated than capsule[14]; alternative is donepezil
- Memantine can be used if donepezil or rivastigmine are not tolerated or if there are cardiac contraindications
- There is less evidence for efficacy of galantamine

Treat anxiety and depression

- Clinicians with expertise in psychiatric symptoms of Parkinson's recommend duloxetine; with mirtazapine, venlafaxine and sertraline as alternatives
- Consider cognitive behavioural therapy if available

Treat nocturia

- Avoid excess fluids, caffeine and alcohol in the evenings
- Mirabegron
- Avoid anticholinergics as these will worsen confusion
- Treat constipation which will worsen urinary symptoms
- Nocturnal Sinemet CR can help with night time mobility but may worsen hallucinations

Consider sleep

- Consider aggravating factors for poor sleep at night such as obstructive sleep apnoea
- If REM sleep behaviour disorder is affecting the sleep quality of the patient or partner, consider treatment with clonazepam or melatonin

Treat postural hypotension

- Check for postural drop and supine hypertension
- Increase in fluid and salt intake, compression stockings, elevate bed, advice on standing slowly
- Consider 24 hour blood pressure
- Consider midodrine or fludrocortisone

- GP or community nurses to check blood pressure between clinic visits, or patient to check with own blood pressure monitor

Preventing fractures[15] using the BONE-PARK algorithm

- Optimise Vitamin D and calcium intake
- Assess falls
- Quantify fracture risk using FRAX score[16]
- Consider Alendronate/Zoledronate if appropriate

General management

- Promote exercise[17]: combination of aerobic (e.g. brisk walking), and postural exercises[18] (e.g. yoga, Pilates); recommend half an hour 5 x per week
- Encourage social activities: seeing friends/social groups
- Control vascular risk factors
- Treat sensory impairment: cataracts and hearing loss
- Suggest balanced diet, stop smoking, reduce alcohol
- Physiotherapy assessment and intervention
- Consider cognitive stimulation therapy if available
- Interventions for carers (e.g. psychoeducation such as STrAtegies for RelaTives)[19]
- Regular follow-up and point of contact for carers and patients
- Refer to memory clinic if appropriate, or community mental health if psychosis prominent

PATHWAYS FOR SUPPORT FOR PATIENTS AND CARERS

- Encourage opening up to friends and family
- Request a carer's needs assessment (through GP or directly if appropriate)
- Ask GP to arrange an Occupational Therapy (OT) home assessment. OTs can also advise on routine management, apathy and carer strain
- Consider asking GP for Improving Access to Psychological Therapy (IAPT) for carer
- Check whether the patient and the people who care for them are linked to the local Parkinson's service and Parkinson's nurse
- Signpost to other resources through Parkinson's UK, The Lewy Body Society, Age UK, Alzheimer's Society, Rare Dementia Support
- Consider referring to Lewy Body Dementia nurse, or local admiral nurse
- Consider asking GP to refer to community psychiatry and mental health navigators or nurses

PRACTICAL THINGS TO THINK ABOUT

- **Driving:** Ask about driving – if in doubt, suggest a drivability test
- **Insurance:** Need to notify DVLA and travel/car/life insurance if dementia is diagnosed
- **Power of Attorney:** Advise lasting power of attorney for health and finances: should be done early while patient has capacity
- **GP follow up:** Ensure the new dementia diagnosis is documented on your clinic letter – this will prompt an annual review by GPs
- **Benefits:** A patient and/or their carer may be entitled to a range of benefits. To look for more information on what is available, patients can reach out to: **parkinsons.org.uk/benefits**
- **Advanced care planning:** consider the ReSPECT framework if appropriate: **www.resus.org.uk/respect**

HOW WE DEVELOPED THIS INFORMATION

This booklet was co-developed as part of a multidisciplinary project, led by **Dr Rimona Weil**. The project, Patterns of Perception in Parkinson's (PoP-PD), was co-developed with people living with Parkinson's and Parkinson's UK. Dr Weil is a Neurologist at the National Hospital for Neurology and Neurosurgery, and Neuroscientist at UCL.

The project involved a collaborative core team including:

- Public engagement experts (based at UCL)
  - » Joanne Thomas
  - » Cassie Hugill
  - » Sian Rose
- Researchers (based at UCL)
  - » Ivelina Dobreva
  - » Dr Moïse Roche
  - » Charlotte Dore
- Artists (based at Central Saint Martins)
  - » Anne Marr
  - » Ruairiadh O'Connell

We thank the many lived experts who contributed to the entire project, and particularly to the lived expert resource. Please refer to the lived expert resource for the list of lived expert contributors.

We are also grateful to the following experts who provided valuable input into this toolkit:

- Dr Duncan Alston, Geriatrician, London
- Dr Khaled Amar, Neurologist, Dorset
- Dr Neil Archibald, Neurologist, South Tees
- Dr Rohan Bhome, Psychiatrist, London
- Prof Camille Carroll, Neurologist, Plymouth
- Emma Edwards, Parkinson's Specialist Nurse, Plymouth
- Dr Jennifer Foley, Clinical Neuropsychologist, London
- Prof Tom Foltynie, Neurologist, London
- Dr Victoria Haunton, Geriatrician, Plymouth
- Prof Emily Henderson, Geriatrician, Bristol
- Dr Ashwani Jha, Neurologist, London
- Fiona Lindop, Specialist Physiotherapist, Derby
- Cathy Magee, Parkinson's Specialist Nurse, London
- Dr Luke Massey, Neurologist, Dorset
- Dr Biju Mohamed, Geriatrician, Cardiff
- Dr Katherine Patterson, Neurologist, London
- Dr Eladia Ruiz-Mendoza, Geriatrician, Peterborough
- Dr Bhanu Ramaswamy OBE, Physiotherapist, Sheffield
- Prof Anette Schrag, Neurologist, London
- Prof Monty Silverdale, Neurologist, Salford
- Dr Aida Suarez-Gonzalez, Clinical Neuropsychologist, London
- Dr Ajenthan Surendranathan, Neurologist, London
- Dr Caroline Williams-Gray, Neurologist, Cambridge
- Prof Alison Yarnall, Geriatrician, Newcastle

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The Parkinson's Excellence Network connects health and social care professionals to share best practice, access resources and education, and drive improvements to services for people with Parkinson's and their families.

Get involved at **parkinsons.org.uk/professionals**

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Last updated: June 2023. Next review date: 2026. Order code: EXCEL0010.