

Appendix 2 | Assessment Toolkits for Lewy Body Dementia

Assessment Toolkits for Lewy Body Dementia

There are two toolkits, depending on whether the patient is presenting with a primary cognitive problem or with cognitive decline in the context of established Parkinson's disease.

One toolkit is for assisting in the diagnosis of Parkinson's Disease Dementia

This is therefore recommended for people with cognitive decline who have established Parkinson's disease (diagnosis for more than one year before the cognitive problems began).

The other toolkit is for assisting in the diagnosis of Dementia with Lewy Bodies

This toolkit is designed for use with people whose primary presenting problem is cognitive decline and who may or may not have evidence of recent Parkinson's disease (parkinsonian symptoms beginning at the same time or within a year of the cognitive symptoms).

Assessment Toolkit for Parkinson's Disease Dementia

Name:	Date of testing:
Date of birth:	Tester's name:
NHS No:	Informant:

Step 1: Please ask the following questions to the patient and/or his/her informant/carer:

Memory		Tick	
Please ask the following questions about memory.			
1	Do you/does your relative have problems remembering things, e.g. what happened yesterday or what you were doing earlier?	Yes	No
2	Do you/does your relative have difficulty remembering names of people you know well?	Yes	No
3	When talking to people do you/does your relative often forget what had been said?	Yes	No

Executive Impairment/Function		Tick	
Please try to determine whether any difficulty is due to memory decline or physical impairment:			
1	Do you/does your relative have problems handling money or bank cards when paying for things?	Yes	No
2	Do you/does your relative have difficulty looking after your/their own tablets?	Yes	No
3	Are you/is your relative able to use household appliances on your own that you have used for a long-time, e.g. the TV or washing machine?	Yes	No

Step 2: If Yes to 1 or more questions on memory AND 1 or more questions on executive impairment/function in step 1 then please administer the MOCA (or any other preferred cognitive assessment instrument to more fully assess for cognitive impairment).

Step 3: If MOCA<26 (or below cut-off for other instrument) and problems with everyday activities are due to memory decline and not due to physical impairment then please discuss with patient and/or carer/relative.

1	Seek confirmation of memory decline and related impairments in daily living activity.	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Ask how long have these memory problems been present: Have they been present for >1 year before Parkinson's disease	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Did these changes or difficulties develop gradually or rather than coming on suddenly?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Do you think there was anything specific that caused these memory problems?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Step 4: Now determine if the patient meets each of the 8 criteria below:

1	Clinician diagnosis of Parkinson's Disease.	<input type="checkbox"/>
2	Onset of cognitive decline >1 year after onset of Parkinson's disease.	<input type="checkbox"/>
3	Represents a decline from premorbid level.	<input type="checkbox"/>
4	Deficits are severe enough to impair daily life (social, occupational, or personal care), independent of the impairment due to motor or autonomic symptoms.	<input type="checkbox"/>
5	MOCA <21 or impaired on other cognitive test (if MOCA <26, diagnose PD-MCI if impairments in daily living are mild).	<input type="checkbox"/>
6	A dementia syndrome with insidious onset and slow progression, developing within the context of established Parkinson's disease and diagnosed by history, clinical, and mental examination, defined as:	<input type="checkbox"/>
	• Impairment in more than one cognitive domain from the MOCA:	
	• Attention: Serial 7s	
	• Executive functions: Lexical fluency, trails	
	• Visuo-spatial functions: Clock drawing, wire cube	
	• Memory: Recall of 5 objects.	<input type="checkbox"/>
7	Absence of delirium, depression, systemic illness or drug intoxication sufficient to the cause cognitive impairment.	<input type="checkbox"/>
8	Absence of other plausible cause of dementia, especially severe cerebrovascular disease.	<input type="checkbox"/>

Please go to page 6 to confirm your clinical diagnosis.

Assessment Toolkit for Dementia with Lewy Bodies

Name:	Date of testing:
Date of birth:	Tester's name:
NHS No:	Informant:

Please use this Assessment toolkit in all people with cognitive decline. Below are the diagnostic features of dementia with Lewy bodies (DLB) at two levels of confidence (probable DLB and possible DLB) and on the following pages are specific questions to assist in the identification of core and suggestive features of DLB.

DLB Diagnostic Criteria		Tick
1	Clinician diagnosis of dementia (cognitive decline sufficient to interfere with social/occupational function).	<input type="checkbox"/>
2	Use screening questions below to cover the four domains of: cognitive fluctuation, visual hallucinations, RBD and parkinsonism.	
	Using your experience to identify how many core and biomarker features of DLB are present (see below and next page):	
3	Core clinical features <ul style="list-style-type: none"> • Fluctuation in cognition • Recurrent visual hallucinations • REM sleep behaviour disorder • One or more features of spontaneous parkinsonism 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
4	Indicative Biomarkers <ul style="list-style-type: none"> • Dopaminergic abnormalities in basal ganglia on SPECT/PET • Low uptake on MIBG myocardial scintigraphy • Polysomnography (PSG) confirmation of REM sleep without atonia 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Diagnose **Probable DLB** if either 2 core features are identified or 1 core and 1 indicative biomarker feature.

Diagnose **Possible DLB** if any one feature is present. In such circumstances consider whether to refer subject for a dopaminergic SPECT scan (DaTSCAN), or MIBG or PSG, depending on local availability.

Please go to page 6 to confirm your clinical diagnosis.

Questions to Identify Symptoms of DLB

Tick

Please respond to each of the questions below, asking carer or patient as appropriate.

Cognitive Fluctuation (to carer)

If two or more of these are answered 'Yes' the subject is highly likely to have cognitive fluctuation

1	Does the patient show moderate changes in their level of functioning during the day?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Between getting up in the morning and going to bed at night, does the patient spend more than one hour sleeping?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Is the patient drowsy and lethargic for more than one hour during the day, despite getting their usual amount of sleep the night before?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Is it moderately difficult to arouse the patient so they maintain attention through the day?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

REM Sleep Disorder**(to carer = bed partner)**

Have you ever seen the patient appear to "act out his/her dreams" while sleeping (punched or flailed arms in the air, shouted or screamed)?

Yes

No

If answered affirmatively, then RBD is highly likely to be present.

REM Sleep Disorder**(to patient only if no bed partner and they have sufficient cognitive ability to be confident their answer is reliable)**

Have you ever been told that you seem to "act out your dreams" while sleeping (punched or flailed arms in the air, shouted or screamed)?

Yes

No

Visual Hallucinations**For the participant: Some people see things that other people cannot see.**

1	Do you feel like your eyes ever play tricks on you?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Have you ever seen something (or things) that other people could not see?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

For the carer:

1	Does the patient have hallucinations such as seeing false visions?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Does he / she seem to see things that are not present?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

If, according to clinical judgement, visual hallucinations are present, determine as far as possible their frequency and recurrence. As a guide, visual hallucinations associated with DLB should not only occur during delirium, and are often recurrent over a period of months.

What is your clinical diagnosis? **Tick**

Parkinson's Disease Dementia	<input type="checkbox"/>
Parkinson's Disease MCI	<input type="checkbox"/>
Parkinson's Disease	<input type="checkbox"/>
Probable DLB	<input type="checkbox"/>
Possible DLB	<input type="checkbox"/>
Alzheimer's Disease	<input type="checkbox"/>
Other Dementia	<input type="checkbox"/>

Tick

Patient Informed of Diagnosis?