Study No:

**Assessment Toolkit for Dementia with Lewy Bodies**

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| 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 the core and suggestive features of DLB.

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| **DLB Diagnostic Criteria Tick** | | |
| 1 | Clinician diagnosis of dementia (cognitive decline sufficient to interfere with | |
| social/occupational function). |  |
| 2 | Use screening questions below to cover the four domains of: cognitive fluctuation, visual hallucinations, RBD and parkinsonism. | |
|  | Using your experience identify how many core and biomarker features of DLB are present (see below): | |
| 3 | **Core clinical features** | |
| * Fluctuation in cognition * Recurrent visual hallucinations * REM sleep behaviour disorder * One or more features of spontaneous parkinsonism |  |
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| 4 | **Indicative Biomarkers** | |
| * Dopaminergic abnormalities in basal ganglia on SPECT/PET * Low uptake on MIBG myocardial scintigraphy * Polysomnography (PSG) confirmation of REM sleep without atonia |  |
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| Diagnose **Probable DLB** if either 2 core features are identified or 1 core and 1 indicative biomarker feature. |  |
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| 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. |  |

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| **Other Diagnoses** | | | | | |
| Parkinson’s Disease Dementia (PDD) (PD >1 yr before cognitive symptoms) Alzheimer’s Disease  Other Dementia  MCI | | | |  | |
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|  | |
| Patient informed of diagnosis. | **Yes** |  | **No** | |  |

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| **Questions to Identify Symptoms of DLB** |
| Please respond to each of the questions below, asking carer or patient as appropriate. |

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| **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** |  | **No** |  |
| 2 | Between getting up in the morning and going to bed at night, does the  patient spend more than one hour sleeping? | **Yes** |  | **No** |  |
| 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** |  | **No** |  |
| 4 | Is it moderately difficult to arouse the patient so they maintain  attention through the day? | **Yes** |  | **No** |  |

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| **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. | | | | |

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| **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** |  |

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| **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** |  | **No** |  |
| 2 | Have you ever seen something (or things) that other people could not see? | **Yes** |  | **No** |  |
| **For the carer:** | | | | | |
| 1 | Does the patient have hallucinations such as seeing false visions? | **Yes** |  | **No** |  |
| 2 | Does he / she seem to see things that are not present? | **Yes** |  | **No** |  |

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.

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| **Assessment of Parkinsonism (5-item UPDRS)** |
| Parkinsonism in DLB requires the presence of at least one of bradykinesia, rest tremor or rigidity. The 5-item UPDRS is a brief and validated scale for identifying parkinsonism in DLB  (See below for further details) |

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| **POSTURAL TREMOR OF THE HANDS** | | | |
| Normal | No tremor. | 0 |  |
| Slight | Tremor is present but less than 1 cm in amplitude. | 1 |  |
| Mild | Tremor is at least 1 but less than 3 cm in amplitude. | 2 |  |
| Moderate | Tremor is at least 3 but less than 10 cm in amplitude. | 3 |  |
| Severe | Tremor is at least 10 cm in amplitude. | 4 |  |
| **KINETIC TREMOR OF THE HANDS** | | | |
| Normal | No tremor. | 0 |  |
| Slight | Tremor is present but less than 1 cm in amplitude. | 1 |  |
| Mild | Tremor is at least 1 but less than 3 cm in amplitude. | 2 |  |
| Moderate | Tremor is at least 3 but less than 10 cm in amplitude. | 3 |  |
| Severe | Tremor is at least 10 cm in amplitude. | 4 |  |
| **FACIAL EXPRESSION** | | | |
| Normal | Normal facial expression. | 0 |  |
| Slight | Minimal masked facies manifested only by decreased frequency of blinking. | 1 |  |
| Mild | In addition to decreased eye-blink frequency, masked facies present in the lower face as well, namely fewer movements around the mouth, such as less spontaneous smiling, but lips not parted. | 2 |  |
| Moderate | Masked facies with lips parted some of the time when the mouth is at rest. | 3 |  |
| Severe | Masked facies with lips parted most of the time when the mouth is at rest. | 4 |  |
| **GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)** | | | |
| Normal | No problems. | 0 |  |
| Slight | Slight global slowness and poverty of spontaneous movements. | 1 |  |
| Mild | Mild global slowness and poverty of spontaneous movements. | 2 |  |
| Moderate | Moderate global slowness and poverty of spontaneous movements. | 3 |  |
| Severe | Severe global slowness and poverty of spontaneous movements. | 4 |  |
| **RIGIDITY** | | | |
| Normal | No rigidity. | 0 |  |
| Slight | Rigidity only detected with activation manoeuvre. | 1 |  |
| Mild | Rigidity detected without the activation manoeuvre, but full range of motion is easily achieved. | 2 |  |
| Moderate | Rigidity detected without the activation manoeuvre; full range of motion is achieved with effort. | 3 |  |
| Severe | Rigidity detected without the activation manoeuvre and full range of motion not achieved. | 4 |  |

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| Total 5-item UPDRS Score = | | | |  | |
| Is Parkinsonism present? (Use clinical judgement but for guidance a score >7 suggests significant parkinsonism is present, though a high score (>2) in a single domain may be sufficient to meet criteria) | **Yes** |  | **No** | |  |

# Appendix: Instructions for Assessing Parkinsonism (from UPDRS) POSTURAL TREMOR OF THE HANDS

Rate each hand separately. Rate the highest amplitude seen. Instruct the patient to stretch the arms out in front of the body with palms down. The wrist should be straight and the fingers comfortably separated so that they do not touch each other. Observe this posture for 10 seconds.

# KINETIC TREMOR OF THE HANDS

This is tested by the finger-to-nose maneuver. With the arm starting from the outstretched position, have the patient perform at least three finger-to-nose maneuvers with each hand reaching as far as possible to touch the examiner’s finger. The finger-to-nose maneuver should be performed slowly enough not to hide any tremor that could occur with very fast arm movements.

Repeat with the other hand, rating each hand separately. The tremor can be present throughout the movement or as the tremor reaches either target (nose or finger). Rate the highest amplitude seen.

# FACIAL EXPRESSION

Observe the patient sitting at rest for 10 seconds, without talking and also while talking. Observe eye-blink frequency, masked facies or loss of facial expression, spontaneous smiling and parting of lips.

# GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)

This global rating combines all observations on slowness, hesitancy, and small amplitude and poverty of movement in general, including a reduction of gesturing and of crossing the legs. This assessment is based on the examiner’s global impression after observing for spontaneous gestures while sitting, and the nature of arising and walking.

# RIGIDITY

Instructions to examiner: Rigidity is judged on slow passive movement of major joints with the patient in a relaxed position and the examiner manipulating the limbs and neck. First, test without an activation maneuver. Test and rate neck and each limb separately. For arms, test the wrist and elbow joints simultaneously. For legs, test the hip and knee joints simultaneously. If no rigidity is detected, use an activation maneuver such as tapping fingers, fist opening/closing, or heel tapping in a limb not being tested. Explain to the patient to go as limp as possible as you test for rigidity.

**Assessment Toolkits for Lewy Body Dementia**

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| 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. |

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| **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). |

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| **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). |

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**Assessment Toolkit for**

**Parkinson’s Disease Dementia**

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

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

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| **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** |  |

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| **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** |  |

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| **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).** |

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| **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.** |

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

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

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| 1 | Clinician diagnosis of Parkinson’s Disease. |  |
| 2 | Onset of cognitive decline >1 year after onset of Parkinson’s disease. |  |
| 3 | Represents a decline from premorbid level. |  |
| 4 | Deficits are severe enough to impair daily life (social, occupational, or personal care), independent of the impairment due to motor or autonomic symptoms. |  |
| 5 | MOCA <21 or impaired on other cognitive test (if MOCA <26, diagnose PD-MCI if impairments in daily living are mild). |  |
| 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: | |
|  | * 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. |  |
| 7 | Absence of delirium, depression, systemic illness or drug intoxication sufficient to the cause cognitive impairment. |  |
| 8 | Absence of other plausible cause of dementia, especially severe cerebrovascular disease. |  |

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| **Please go to page 6 to confirm your clinical diagnosis.** |

**Assessment Toolkit for**

**Dementia with Lewy Bodies**

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| 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. |

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| **DLB Diagnostic Criteria Tick** | | | |
| 1 | Clinician diagnosis of dementia (cognitive decline sufficient to interfere with social/occupational function). | |  |
|  |
| 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** |  | |
|  | * Fluctuation in cognition * Recurrent visual hallucinations * REM sleep behaviour disorder * One or more features of spontaneous parkinsonism |  |  | |
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|  |  | |
|  |  | |
| 4 | **Indicative Biomarkers** |  | |
|  | * Dopaminergic abnormalities in basal ganglia on SPECT/PET * Low uptake on MIBG myocardial scintigraphy * Polysomnography (PSG) confirmation of REM sleep without atonia |  |  |
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| Diagnose **Probable DLB** if either 2 core features are identified or 1 core and 1 indicative biomarker feature. |  |
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| 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. |  |

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| **Please go to page 6 to confirm your clinical diagnosis.** |

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| **Questions to Identify Symptoms of DLB Tick** |
| Please respond to each of the questions below, asking carer or patient as appropriate. |

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| --- | --- | --- | --- | --- | --- |
| **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** |  | **No** |  |
| 2 | Between getting up in the morning and going to bed at night, does the patient spend more than one hour sleeping? | **Yes** |  | **No** |  |
| 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** |  | **No** |  |
| 4 | Is it moderately difficult to arouse the patient so they maintain attention through the day? | **Yes** |  | **No** |  |

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| --- | --- | --- | --- | --- |
| **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** |  |

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| **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** |  | **No** |  |
| 2 | Have you ever seen something (or things) that other people could not see? | **Yes** |  | **No** |  |
| **For the carer:** | | | | | |
| 1 | Does the patient have hallucinations such as seeing false visions? | **Yes** |  | **No** |  |
| 2 | Does he / she seem to see things that are not present? | **Yes** |  | **No** |  |

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| 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. |

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| **What is your clinical diagnosis? Tick** |

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| --- | --- |
| Parkinson’s Disease Dementia |  |
| Parkinson’s Disease MCI |  |
| Parkinson’s Disease |  |
| Probable DLB |  |
| Possible DLB |  |
| Alzheimer’s Disease |  |
| Other Dementia |  |

**Tick**

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| **Patient Informed of Diagnosis?** |  |