A Longitudinal Cohort Study of Dementia with Lewy bodies

Unravelling the confounding influences of Alzheimer's disease and cerebrovascular disease in dementia with Lewy bodies

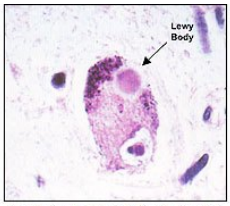
What is dementia with Lewy bodies?

Dementia with Lewy bodies (DLB) is a relatively common form of dementia in older age. People with DLB often have similar symptoms to people with Alzheimer's disease (AD) and Parkinson's disease dementia (PDD). Lewy bodies are tiny deposits of alpha-synuclein (a protein) in the nerve cells of the brain. It is not known exactly what causes the abnormal build-up of Lewy bodies in the brain.

Lewy bodies may affect movement and/or cognitive abilities. Approximately 50% of people with DLB also have an abnormal accumulation of the proteins found in Alzheimer's disease (amyloid and tau) however it is not yet understood what effect these have on the disease.

Symptoms of dementia with Lewy bodies may include:

- Changes in memory and thinking
- Fluctuations in attention or alertness
- Movement problems (eg slow and stiff movement, stooped posture, shuffling)
- Visual hallucinations
- Delusions
- REM sleep behaviour disorder (acting out dreams)



A Lewy body, pictured above, contains a mass of proteins, including synuclein, and is a characteristic feature of Parkinson's disease neural tissue.

Image courtesy of InVivo, Columbia University Health Sciences, Vol 1 No 19, 20 Nov 02

What is the Lewy Body Study?

In order to find an effective treatment or cure in the future, we first need to understand the changes that occur in the body and brain of people with DLB.

There have been very few longitudinal studies looking at the underlying causes and impact these have on disease symptoms and outcomes.

This study will be the first Australian longitudinal cohort of 100 people, aged 50+ years, diagnosed with DLB; 20 people aged 50+ years, diagnosed with PDD; 20 people aged 50+ years, diagnosed with AD; and 20 people aged 50+ years, with no reported memory concerns (healthy controls).

There will be up to 10 study visits over a 3 year period (or 2 study visits over 3 months for participants in the AD and healthy control groups). At the baseline visits participants will undergo:

- clinical and cognitive tests
- a blood test
- Brain MRI scan
- Brain PET scans (Amyloid, Tau and dopaminergic) *(optional)*
- cerebrospinal fluid donation via lumbar puncture *(optional)*.

Study participants will then be seen annually for follow up clinical and cognitive assessments and contacted by telephone in the intervening 6 months.

We hope that our research will lead to effective treatments in the future.

To be Eligible for the Study:

- **Diagnosed with DLB or PDD, or AD**
- **Age 50+ years**
- **Able to complete cognitive testing in English**
- **No past history of alcohol or drug dependence**
- **Have a close family member or caregiver who can provide collateral information.**

This study is being conducted by the Walter and Eliza Hall Institute (WEHI)

CHIEF INVESTIGATOR: A/Professor Rosie Watson (WEHI)

PRINCIPAL INVESTIGATOR/S: A/Professor Nawaf Yassi (WEHI)

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Frequently Asked Questions

IS THIS A DRUG TRIAL?

No. This is an observational study. This means that we will be assessing health outcomes in participants identified with DLB. Participants will undergo some tests that are not routinely available in clinical practice (for example PET scans) however these are to help us understand the underlying disease process and may not be of clinical benefit to participants.

WILL I RECEIVE THE RESULTS FROM MY TESTS?

You will receive the amyloid and VMAT2/F-DOPA PET scan results in consultation with your specialist. The TAU PET scan, MRI scan and genetic blood test results are for research purposes only and will not be disclosed to you. Any incidental findings of medical importance will be discussed with your doctor.

HOW LONG WILL I BE IN THE TRIAL?

You will be in the study for up to 3 years. Participation in the study is voluntary and you may withdraw at any time.

WHAT IS A MRI SCAN?

Magnetic Resonance Imaging uses a powerful magnetic field to take pictures of the structures inside your brain.

WHAT IS A PET SCAN?

PET stands for Positron Emission Tomography. A radioactive dye (tracer) is injected into a vein in your arm which can be detected via the PET machine and gives 3-dimensional images of the protein levels in your brain.

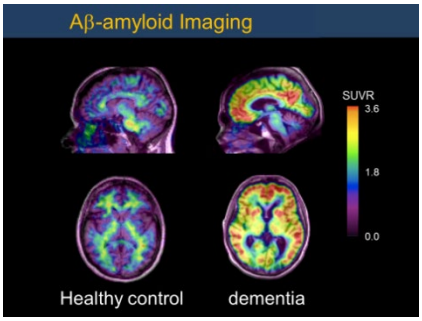

Figure courtesy of A/Prof Victor L. Villemagne.

WHAT IS A LUMBAR PUNCTURE?

Cerebrospinal Fluid (CSF) is the fluid surrounding the brain and spinal cord and can provide very important information for understanding the changes that occur in the brain of people with DLB. The lumbar puncture enables analysis of this fluid. A small amount of local anaesthetic is injected into the lower back. A small needle is then inserted to remove a sample of CSF for analysis. The lumbar puncture is an optional procedure in this study.

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED ABOUT ME?

To protect your confidentiality, any information collected about you will be de-identified and replaced with a study ID number. Your identity will remain confidential to the study team and will not be shared outside of the research team.

For more information about taking part please contact: **dementiaresearch@wehi.edu.au**

OR: Study Coordinator: **Lesley Vidaurre Ph: 03 9345 2177** Email: **Vidaurre.l@wehi.edu.au**

Study Doctor: **Dr Paula Loveland** Email: **Loveland.p@wehi.edu.au**

This study is registered on the Australian New Zealand Clinical Trial Registry https://www.anzctr.org.au
Trial ID: ACTRN12618000212257

Further information is also available on the Dementia Australia website under the "Dementia Research Foundation" tab www.dementia.org.au/research/participate/study/the-lewy-body-study

This study is approved by the Melbourne Health Human Research Ethics Committee (HREC/17/MH/89)