



We are at **Dementia Research Centre**, 8-11 Queen Square, London WC1N 3BG

Nearest mainline train stations: London Euston and King's Cross St Pancras

Nearest tube stations: London Euston, King's Cross, Russell Square, Euston Square, and Holborn

Getting involved...

If you are interested in participating in our research, please email our recruitment team at **drctrialenquiries@ucl.ac.uk**

The DRC also actively supports <u>Join Dementia Research</u>, which matches participants to appropriate research studies throughout the UK.



www.ucl.ac.uk/drc/research-2

DEMENTIA RESEARCH CENTRE

Contact us...

If you have any questions or would like more information, please get in touch with our research recruitment team by emailing us at <u>drctrialenquiries@ucl.ac.uk</u>

You can also contact us by telephone during office hours (9-5, Mon-Fri) on **020 3448 3105**

DISCLAIMER: We aim to ensure that all information is as accurate as possible, but we accept no responsibility for any errors, omissions or inaccuracies. Please see the clinician responsible for your care, a social services representative, or your GP if you have specific needs which require attention. Any medical decisions should be taken in discussion with an appropriate health care professional.

Brain Signatures

We are recruiting!

Official title

Brain Signatures of Auditory Information Processing in the Degenerative Dementias

Purpose of the study

Many people with dementia have difficulty understanding or responding to speech and other complex sounds in daily life, and this can be a major source of distress and disability. This study investigates the ways in which the brain's processing of complex sounds (such as speech, music and environmental noises) and other information from the senses changes in different dementia diseases. We will assess hearing abilities and brain activity when listening to sounds, and compare this in patients and healthy volunteers. This comparison will allow a better understanding of the brain changes in different forms of dementia, and may be used in future to aid diagnosis, and help develop and assess treatments.

Participants

Patients with a diagnosis of Alzheimer's disease, frontotemporal dementia, or primary progressive aphasia, and cognitively-healthy volunteers (>50 years old). Information from cognitively well study partners is very important to the study.

What is involved?

Participation in this study is completely voluntary. This study ideally involves a two-day **in-person** visit to the Dementia Research Centre (8-11 Queen Square), however flexible **remote** (home-based video) or **hybrid** (part in-person, part remote) options are also available. Participants will be asked to take part in a number of different activities: (1) experimental and standardised psychology tasks, (2) hearing tasks, (3) interview sessions with questionnaires, and (4) a brain MRI scan.

Sleep Physiology Study

We are recruiting!

Official title

Brain Signatures of Auditory Information Processing in the Degenerative Dementias: Sleep Physiology Sub-Study

Purpose of the study

This study is an extension to the Brain Signatures study, and is in collaboration with the UK Dementia Research Institute. Sleep has recently been linked to dementia, however how the relationship works is currently unknown. This pilot study aims to evaluate how sleep is affected in different forms of dementia and how this impacts the person's functioning and care in daily life. The main aim of this study is to see how sleep is or is not disrupted with a dementia diagnosis, but also, whether this study is feasible and allow us to plan for larger studies in the future.

Participants

Patients with a diagnosis of Alzheimer's disease, frontotemporal dementia, or primary progressive aphasia, and cognitively-healthy volunteers (>50 years old). This study requires a study partner who preferably lives in the same house.

What is involved?

Participation in this study is completely voluntary. This study takes place **remotely** (i.e. from your own home) over 7 days. Participants will first go through an initial screening to assess eligibility (questionnaires and oximeter readings). For the study, participants will (1) complete a daily sleep diary for 7 days, (2) wear an overnight 'sleep headband' for three nights to measure sleep activity, and (3) 30-minutes of psychological tasks (looking at memory, learning, etc.) conducted before and after sleep.

We are recruiting!

Official title

Genetic Frontotemporal Dementia Initiative

Purpose of the study

The study purposes are to improve our understanding about frontotemporal dementia (FTD) and help measure effectiveness of future treatments. The specific aims are to identify the earliest features of genetic FTD and to understand how it progresses over a period of several years.

Participants

We are inviting people who have received a diagnosis of genetic FTD and their first degree relatives.

What is involved?

This study involves annual visits to the Dementia Research Centre. The research visit will take place over 1 to 2 days where we will complete neuropsychology assessments, take blood and urine samples, perform an MRI scan and sometimes people will choose to have a lumbar puncture. We will cover the costs of travel and accommodation for the visit. You will be asked to nominate someone who knows you very well to act as your informant. They will be asked to provide information on your general health and wellbeing throughout the study.

EDoF-S

We are recruiting!

Official title

Early Detection of FTD/MND using digital biomarkers: an observational study of Symptomatic frontotemporal dementia and motor neurone disease (EDoF-S)

Purpose of the study

The aim is to understand how digital biomarkers are altered within symptomatic FTD and MND and assess their utility as early markers of disease and disease progression biomarkers. This study will run alongside two parallel studies of the same digital devices and computerised tests in a predominantly presymptomatic cohort (EDoF-GENFI) and a control population (EDoF-Normative).

Participants

100 participants with a diagnosis of a genetic or sporadic FTDspectrum disorder (including bvFTD, svPPA, nfvPPA, PSP, CBS) and/or MND will be recruited via specialist clinics at NHNN.

What is involved?

- Baseline visit: neurological history and examination, brief assessments of thinking, memory, language and behaviour. Non-invasive muscle tests: high density surface EMG and muscle ultrasound.
- Remote collection for 4 weeks: Fitbit for 4 weeks to collect data on activity levels, heart rate, and sleep; IMU worn on the lower back for 1 week to assess gait and activity; Ignite cognitive test on the iPad and BRAIN keyboard tapping task at baseline, 1 week, 2 weeks and 4 weeks.
- Feedback will be collected via online survey to assess feasibility and acceptability of the protocol.

Local FAD study

Seeking volunteers

Official title

Longitudinal Study of familial Alzheimer's disease

Purpose of the study

To improve the diagnosis of Alzheimer's disease, particularly aiming to identify the earliest features of the condition and understand how these change over time.

Participants

We are inviting healthy people who have a family history of familial Alzheimer's disease, or people who have received a diagnosis of Alzheimer's disease, particularly familial Alzheimer's disease due to identified genetic mutations.

What is involved?

This study involves annual research activities, which may involve visiting the Dementia Research Centre or review via telephone or video calls (depending on your customised visit schedule). Inperson research visits will take place over 1 to 2 days and involve medical and neuropsychology assessments, a small blood sample, and an MRI scan. We will ask you to nominate someone who knows you well to be your study partner and we will ask them to provide information on your general health and wellbeing. We will cover travel and accommodation costs (for in-person visits) and also make a small payment as a thank you gesture. We may invite you to participate in additional research activities, such as an additional scan, at other times and according to your interest.

If you are interested in participating, please reach out to us at: drc-fadresearch@ucl.ac.uk

Improving detection of dementiarelated visual loss

We are recruiting!

Official title

Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy

Purpose of the study

When dementia affects the back of the brain, it can cause dementia-related visual impairment. For some people, visual loss is the earliest sign of dementia. People with dementia-related visual impairment are usually seen first by eye health professionals. They frequently receive eye or psychiatric misdiagnoses, delaying diagnosis and treatment for years.

This study aims to improve detection of dementia-related visual impairment in different settings- from highstreet opticians to specialist hospital clinics. This involves developing a rapid test we have made for the UK BioBank study.

Participants

People with a diagnosis of posterior cortical atrophy. People with a diagnosis of Alzheimer's disease experiencing prominent memory difficulties.

What is involved?

Participation in this study is completely voluntary. This study involves a one-off visit which can be **in-person** at the Dementia Research Centre (8-11 Queen Square) or **remote** (via home-based video). All participants will be asked to complete a rapid (5 minute) visual test. Participants will also be asked to complete additional visual, memory and language tasks taking a total of 60-90 minutes.