

Dementias and Neurodegenerative Diseases Research Network

Please telephone:
0191 223 2740

or write to us at:

North East DeNDRoN
St Nicholas Hospital
Jubilee Road, Gosforth
Newcastle upon Tyne
NE3 3XT

or email:
dendron@ntw.nhs.uk

or contact us through the website

www.dendron.nihr.ac.uk/northeast

Dementias and Neurodegenerative Diseases Research Network

**Patient List
Information
Leaflet for
Patients and
their Relatives
or Friends**

Personal Information collected:

- Your name and address
- Telephone number
- Whether you live alone
- Date of birth
- Gender
- Diagnosis
- Date of diagnosis
- GP's name and address
- Hospital consultant's name
- NHS number
- Hospital number
- Medication
- MMSE Score if appropriate
- Next of kin/carer name and address



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Welcome to DeNDRoN

The Dementias and Neurodegenerative Disease Research Network is part of the NHS through the National Institute for Health Research. DeNDRoN helps with clinical research studies for all types of **dementia, mild cognitive impairment**, and neurodegenerative diseases such as **Parkinson's disease, progressive supranuclear palsy** and **multiple system atrophy**.

DeNDRoN carries out research to improve diagnosis and management of dementias and neurodegenerative diseases, testing new treatments, and investigating how to support patients and their families.

The Patient List holds the names of people interested in taking part in research. People on the List can be matched to studies and may be asked if they would like to take part.

We invite you to join the North East DeNDRoN Patient List. Please contact us with any questions

Telephone 0191 223 2740

**NE DeNDRoN,
St Nicholas Hospital
Jubilee Road, Gosforth
Newcastle-upon-Tyne NE3 3XT**



Joining the Patient List

We telephone you to arrange a home visit to answer your questions about the Patient List. We ask you to sign a consent form agreeing to us holding information about you. You do not have to join the Patient List and it will not affect the quality of your clinical care at all if you decide not to.

Key points to remember:

- **You do not have to take part in any studies we tell you about.**
- We will contact you from time to time to check that you still want to take part.
- **You are free to leave the Patient List at any time without giving a reason. Withdrawing from the Patient List does not change your clinical care in any way at all.**
- If you wish to talk about your or your relative's participation, then please contact us.

What happens after signing the consent form

We send a copy of your consent form to your GP and hospital doctor, and return one to you.

We may contact you about new studies that might be suitable for you. These could involve different tests such as medical examinations, questionnaires, scans or blood samples. It is completely your choice to join in a study or not. There is unlikely to be a suitable study for all Patient List members.

We send out regular newsletters updating you about our research.

What happens to the information

The information on the Patient List is stored on a secure computer and is used only by DeNDRoN staff. It is passed to research staff outside DeNDRoN only if you tell us that you wish to be involved in their research. Your information will be held by us for as long as a research network for dementias and neurodegenerative diseases exists. If the network should cease to exist, all information would be destroyed.