

Personal Information collected:

- Your name and address
- Telephone number
- Email (if you use one)
- 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



Dementias and Neurodegeneration

Please telephone

0191 246 7388

or write to us at:

Clinical Research Network
North East and North Cumbria
Dementias and Neurodegeneration
(DeNDRoN)
St Nicholas Hospital
Jubilee Road
Gosforth
Newcastle upon Tyne
NE3 3XT

or email:

dendron@ntw.nhs.uk

NHS

*National Institute for
Health Research*

**Clinical Research Network
North East and North Cumbria**

Dementias and Neurodegeneration

Case Register Information Leaflet for Patients and their Relatives or Friends

Dementias and Neurodegeneration Case Register

The Clinical Research Network: North East and North Cumbria delivers research in 30 medical specialties, including Dementias and Neurodegeneration (DeNDRoN). We are part of the NHS.

We help carry out clinical research studies for all types of **dementia, mild cognitive impairment**, and neurodegenerative diseases such as **Parkinson's disease, multiple system atrophy** and **progressive supranuclear palsy**.

Our research can be to improve treatment, diagnosis, care or management of dementias and neurodegenerative diseases. The Case Register holds the names of patients interested in research. When there is a suitable study, people on the Case Register may be asked if they would like to take part.

We invite you to join the Dementias and Neurodegeneration (DeNDRoN) Case Register

Telephone: 0191 246 7388

Dementias and Neurodegeneration
DeNDRoN, St Nicholas Hospital
Jubilee Road, Gosforth,
Newcastle-upon-Tyne NE3 3XT



Joining the Case Register

We ask you to sign a consent form so we can hold information about you. The consent form can be signed when we visit you at home, or you can return it to us in the post.

You do not have to join the Case Register and it will not affect the quality of your medical care at all if you decide not to join.

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 be on the Case Register.
- You are free to leave the Case Register at any time without giving a reason. Withdrawing from the Case Register does not change your medical care in any way at all.
- If you wish to talk about your or your relative's participation in the Case Register, please contact us.

What happens after you sign 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 research 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 a research study or not.

There is unlikely to be a suitable study for all Case Register members.

We send out regular newsletters updating you about our research.

What happens to the information

The information on the Case Register is stored on a secure computer and is only used by authorised Clinical Research Network staff. Your contact information is passed to research teams 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 neurodegeneration exists. If the network should cease to exist, all information would be destroyed.