

## MND Register

Full name of the person  
who has MND:

---

Maiden name

---

Date of Birth

\_\_\_\_\_

day      month      year

current address  
of the person with MND:

---

---

---

Postcode

---

Telephone

---

Hospital attended:

---

Consultant Name:

---

Who is the GP of the person named above?

Name:

---

Address:

---

I would like to be on the Register and receive information on research studies:

Please tick one

I would like to be on the Register but NOT receive information on research studies:

I do not wish to be on the Register:

Thank you for taking the time to complete this form. Please return this along with the consent form in the envelope provided. Please keep the information sheet provided.

For more information please contact:

Judy Newton  
National Nursing Lead for MND  
Euan MacDonald Centre  
University of Edinburgh  
Chancellor's Building  
49 Little France Crescent  
Edinburgh  
EH16 4SB

Shuna Colville  
Research Project Manager  
Anne Rowling Clinic  
University of Edinburgh  
Chancellor's Building  
49 Little France Crescent  
Edinburgh

Tel: 0131-242-7985

0131-465-9520

Email: [info@care-mnd.org.uk](mailto:info@care-mnd.org.uk)

Website: [www.care-mnd.org.uk](http://www.care-mnd.org.uk)

## MND Register - Consent form

Name of Researchers: Prof Siddharthan Chandran, Dr Suvankar Pal, Shuna Colville

Please initial box

- 1) I confirm that I have read and understood the information sheet (V4.1, 09/10/2017) for the above study and have the opportunity to ask members of the Research Team questions at any time.
- 2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. Should I withdraw, my medical care or legal rights will not be affected.
- 3) I understand that my medical notes will be examined over time, information processed and stored securely by responsible individuals from the research team or their regulators.   
**No identifiable information will be given to third parties.**
- 4) I understand that I will not benefit financially from taking part in this study.
- 5) I agree to take part in the above study.
- 6) I agree that my health care team can be informed that I am taking part in this study.
- 7) I agree to receiving information about future research projects which may include clinical trials. This does not commit you to participating in future research.

### OR Complete only if you do not wish research information

- 8) I agree to my name being placed on the Register but do not wish to be contacted regarding research studies.

Name of Patient: \_\_\_\_\_

Date:

Signature: \_\_\_\_\_

Where the patient is physically unable to sign a proxy can complete the form and sign on their behalf as long as the proxy is satisfied that the patient has understood the information sheet and the consent form.

Name of witness: \_\_\_\_\_

Date:

Signature of witness: \_\_\_\_\_

Name of Care Team member: \_\_\_\_\_

Date:

\*(if present)

Signature \_\_\_\_\_