

Saint Mary's Hospital
Manchester Centre for Genomic Medicine

Information for Patients

Huntington's Disease Multi-disciplinary Clinic

Huntington's Disease (HD) Multi-disciplinary Clinic

Our specialist clinic is for people who have Huntington's disease, and their family and carers. At the clinic we can give advice on the treatment and management of symptoms, and offer social and emotional support. We can also provide information about Huntington's Disease and current research, including the opportunity to participate in clinical trials if appropriate.

What should I bring to the appointment?

It is very helpful to try and come with a family member, friend or carer who knows you well. Please also bring:

- A full list of your current medication.
- Reading glasses, if you use them.

Who will I see at the clinic?

Our team includes specialist doctors, psychologists, clinical researchers and Huntington's Disease Association (HDA) care advisors. Together, we aim to provide the best care possible and address your needs.

During your appointment you will see several members of the team to discuss any current symptoms. This will include a physical examination, some brief tasks of cognition (thinking) and some questions about how you have been feeling. You and your family or carers will be able to ask questions and discuss any problems you may have.

You will also have the opportunity to talk to a Regional Care Advisor from the HDA, who can offer support and advice on access to benefits, respite, specialist equipment and care.

Depending on your current needs, we may refer you to your local speech and language therapist and/or dietitian, physiotherapist or occupational therapist.

If you have consented to participate in the REGISTRY research study you may also see a research nurse to collect blood and urine samples.

How long will my appointment last?

Your annual review appointment will last most of the afternoon (about 3 hours). If we recently changed your medication at a clinic visit, you may come back for a brief medication review which will last about 15-30 minutes.

What is the REGISTRY research study?

REGISTRY is a study run by the European Huntington's Disease Network (EHDN) that aims to collect information about HD patients throughout Europe. This information will help us to better understand HD, find new treatments and help recruit suitable candidates for future trials. We are the largest REGISTRY site in the UK. If you are interested in participating you will be able to talk to one of the team about it in more detail.

How often will my appointments be?

Usually once a year for your annual appointment. If we have made any changes to your medication, we may ask to see you again after 2 or 3 months for a brief medication review. However, if you need to you can request an appointment at any time.

For more information

If you have any more questions please contact Isobel Atkinson, our clinic secretary, and she will refer you to the appropriate member of the team.

Manchester Centre for Genomic Medicine

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