

Saint Mary's Hospital
Manchester Centre for Genomic Medicine

Information for Patients

North West Regional Huntington's Disease Multi-Disciplinary Service

The Huntington's Disease Multi-Disciplinary Team is focused on providing the best care possible to people who have or are at risk of developing Huntington's Disease (HD), their families and carers.

We provide advice on genetic testing, the treatment and management of symptoms and access to support.

As one of the largest HD research sites in the UK we are able to offer information about current research and opportunities for participation.

Who are we?

Our team is made up of people with different skills, including:

- Specialist doctors.
- Genetic Counsellors.
- Psychologists and clinical researchers.
- Huntington's Disease Association (HDA) Care advisors.



We see people for any of the following reasons:

- To give advice and information.
- To provide help with coping and emotional support.
- For the treatment and management of symptoms.
- To discuss genetic testing and family planning.
- To explain HD risk to children/other family members.
- To offer information about HD related research and outline opportunities for participation in research, if appropriate.

Genetic counselling and testing

Family members at risk of HD, who would like more information, support or to discuss issues such as genetic testing, can be referred to one of our Genetic Counsellors via their GP.

Predictive test follow-up clinic

Individuals who are gene positive, but who are not yet showing symptoms of HD are invited once a year to a follow-up clinic. The appointment lasts approximately 2 hours and can include the following:

Support around coping with a predictive test result.
Opportunities for participation in research.

A physical examination, some questions about how you've been feeling and brief tasks of cognition (thinking).

HD management clinic

This clinic aims to provide a service to patients who have symptoms of HD, their family and carers. The appointment lasts approximately 3 hours and will include the following:

Assessment of symptoms and advice on their treatment and management.

Support and advice from a HDA Regional Care Advisor on access to benefits, respite, specialist equipment and care.

Information about research and opportunities to participate.

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.

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