

The Multidisciplinary Huntington's Disease Clinic

What is the Multidisciplinary Huntington's Disease Clinic?

It is a specialist tertiary clinic for people who either have or are at risk of having Huntington's disease, and their families/carers.

We see people for the following reasons:

- For genetic counselling and testing
- For prenatal genetic counselling and testing
- For management of symptoms
- To give advice, information, social and emotional support
- To give information about research and the opportunity to take part in current research projects in Huntington's disease, if appropriate

How can I be referred to the clinic?

We can accept referrals from General Practitioners (GPs) and other Hospital based specialists including neurologists, psychiatrists and clinical geneticists.

GPs should refer via the Electronic Referral System (ERS) - the service details on ERS are: **Huntington's Disease Multidisciplinary Clinic – Department of Neurogenetics – NHNN – UCLH – RRV**

Other specialists should address referrals to:

Professor Sarah Tabrizi (Professor of Clinical Neurology)
Huntington's Disease Multidisciplinary Clinic
Box 104
The National Hospital for Neurology and Neurosurgery
Queen Square
London WC1N 3BG

Please note - we are not able to accept self referrals or see people outside the NHS

Who will I see in clinic?

There is a whole team of people who work as part of the clinic. You may see one or more of them at your appointment, depending on what your needs are, what the needs of your family/carers are and what the person who originally referred you said in their referring letter.

Consultant Neurologists:

Professor Sarah Tabrizi (Lead Clinician)
Professor Edward Wild
Dr Thomasin Andrews
Professor Thomas Warner
Dr Michael Flower
Dr Peter McColgan
Dr Davina Hensman

Consultant Neuropsychiatrists:

Dr Nadeem Mazi Kotwal
Dr Stefania Bruno

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| Consultant Clinical Geneticist: | Dr Shereen Tadros |
| Consultant Nurse: | Rachel Taylor |
| Clinical Nurse Specialist: | Desiree Salanio |
| Clinical Research Fellows: | Dr Mena Farag, Dr Michael Murphy, Dr Mitsuko Nakajima, Dr Sangeeth Rajagopal |
| Huntington's Disease Association Advisors: | Rachel Boothman, Tracey Hole, Anna Holmes, Dawn Stilwell |
| Research Co-ordinators: | Kate Fayer, Olivia Thackeray |
| Administration Team Leader: | Siham Ali |

We offer different types of clinic appointment including face to face (where people attend the hospital outpatient department), remote video appointments (where you see the clinician via MS Teams video link) and telephone. The type of appointment you are offered will depend on a number of different factors including whether we have seen you before, what your needs are and how difficult it is for you to travel to clinic.

How long will my appointment take?

The amount of time you spend in clinic will depend on who you see and what issues you need to discuss.

Who can come with me to my appointment?

This depends on you. You may choose to come with a family member, friend, carer, or health/social care professional such as a social worker or community nurse.

How often will I need to come back to clinic?

Again, this very much depends on you. Some people come back once a year, some people come more often. If you are started on a new medication in clinic, we may need to see you again fairly soon in order to see how the medication is working and check that it suits you. Also, if you are having difficulties, you may need to come back to clinic more frequently.

Will I be referred to anyone else?

There are a number of other services both within this hospital and externally that you may be referred to. These include local Mental Health Services, Speech and Language Therapy, Physiotherapy, Occupational Therapy, the Dietitian and Psychology.

As we are a tertiary service we are not able to provide day to day management or urgent/crisis support and so patients/carers should always contact their own GP, NHS 111 or 999 in an emergency situation. However we are always happy to provide advice and guidance to local health and social care professionals.

What if I have more questions before I come to clinic?

The team can be contacted at: uclh.huntingtonsdiseaseservice@nhs.net