

19 March 2026

Huntington's disease

Supporting people impacted by Huntington's disease, raising awareness of the condition, advocating for improved services and practices, and providing opportunities for the community to connect.

1. What is the population of people within the Trust?

The below information is taken from current caseloads and is only confirmed information. Belfast Trust do not know how many people have the gene. The Northern Trust and Western Trust numbers are slowly increasing as the Trusts become more aware of this service.

Belfast Trust & South Eastern Trust Total	71 + 8 Deceased	35	92	109 + 14 Deceased
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71 with Huntington's disease symptoms under care in the Belfast & South Eastern Trust.

35 known children 50:50 at risk therefore 50% chance of inheriting the Huntington's disease gene.

92 known grandchildren 25% chance of inheriting the gene currently.

109 known siblings who have 50:50 at risk.

Southern Trust Total	28 + <5 Deceased *	54	20	70+ <5 Deceased *
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Northern Trust Total	39 + <5 Deceased *	57	21	50
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Western Trust Total	38 + 6 Deceased	63	41	39
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1. How many people living within the Trust have either a predictive or symptomatic diagnosis of Huntington's disease?

There is no database with the complete numbers of individual diagnosed or at risk of Huntington's disease within Northern Ireland

2. How many people living within the Trust are at 25/50 or 75% risk of developing Huntington's disease?

See question 1 response.

3. How many people within the Trust have received funding for PGD/PGT within the last 5 years?

Belfast Trust does not maintain a referral list that can be searched by referral reason so it is possible that some referrals may not have been captured in this exercise as "reason for referral" is not universally coded on our system. The referral numbers provided below represent numbers on the basis of activity / access to funded services which has been collated from local records.

2021 x <5 referrals *

2022 x <5 referrals (<5 re-referrals from 2021) *

2023 x <5 referrals *

2024 x <5 referrals (<5 re-referrals referred 2023) *

2025 x 6 referrals (<5 re-referrals) *

4. Do you offer any services specific to people with Huntington's disease e.g. outpatient clinics, dedicated bed space, HD nurse specialist?

There are Huntington's disease nurse specialists covering the region and Huntington's disease symptomatic patients attend these nurses in outpatient clinics/home visits. There is no dedicated bed space for these patients.

5. Are there any business cases pending for the development of any services specific to people with Huntington's disease?

No business cases are pending for Huntington's disease services.

6. In the past 5 years has the Trust funded anyone with Huntington's Disease to access special services, other than PGD/PGT, in

a) Another Trust

b) An area outside of Northern Ireland

Belfast Trust do not hold a database for recording patients diagnosed with Huntington's disease who are referred/funded for access to specialist services. Extra-Contractual Referral team in Strategic Planning and

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Performance Group/Department of Health approve funding requests for treatment. Contact details on referrals funded ecrs@hscni.net.

7. How many neurologists are currently employed by the Trust?

There are currently 13.8 WTE Neurology Consultants employed in Belfast Health and Social Care Trust.

8. What is the average waiting time for a first appointment with a neurologist within the Trust?

NEUROLOGY

Priority	Average Wait (Weeks)
Urgent	90
Routine	195

This data is for the average for a general neurology appointment and is available on the My Waiting Times NI website. [Belfast HSC Trust - Outpatient - DOH/HSCNI Strategic Planning and Performance Group \(SPPG\)](#)

9. How many neuropsychologists are currently employed by the Trust?

Overall there are 10wte Psychologists employed within Neuro-focused services in Belfast Health and Social Care Trust

These Psychologists are commissioned to deliver services across a range of services including:

Regional Brain Injury Unit	2 wte
Neurology Inpatient Unit Musgrave Park	1 wte
CBIRT (Community Brain Injury Rehab)	1.4wte
Regional Neurology and Neurosurgery RVH	5.6wte

10. What is the average waiting time for a first appointment with a neuropsychologist within the Trust?

Waiting time across services are not collated on an average wait and differ depending on service area. Within the Royal Victoria Hospital the shortest waits are currently within Cognitive Assessment Clinic (11-12 weeks) and longest waits are in the Parkinson's disease service (52-58 weeks).

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11. How many neuropsychiatrists are currently employed by the Trust?

There is no specific funding for a Psychological Service to individuals or families living with a diagnosis or concerns regarding Huntington's disease. However, families may be identified if referred into our Cognitive Assessment or Adjustment Services for other concerns and will also be seen if they are referred during an inpatient admission to Musgrave Park Hospital. Such referrals to Neuropsychology are usually appropriate in earlier stages but with disease progression and associated features a referral to Community Mental Health and Psychiatry is more appropriate to meet their needs.

Neuropsychologists are Practitioner Psychologists, registered with HCPC (mostly Clinical Psychologists) with special interest and training in neurological conditions or neurosurgery psychological sequelae and impacts.

12. What is the average waiting time for a first appointment with a neuropsychiatrist within the Trust?

Neuropsychiatry provision, is 1 WTE Neuropsychiatrist with 6 programmed activities of Direct Clinical Care (one programmed activity equates to 4 hours of work), across all Belfast Health and Social Care Trust community neuropsychiatry and provision of neuropsychiatry liaison services.

There is no resident doctor.

13. How many neuro-physiotherapists are currently employed by the Trust?

There are 3 neuro-physiotherapists who have a service that manages Huntington's disease in an outpatient/community setting. A total of 22 neurophysiotherapists delivering to Inpatients and 7 neurophysiotherapists delivering to Outpatients – however all other services are Disease specific ie Spinal cord injury, Stroke, Acquired Brain Injury and Neurosurgery.

The average Outpatient wait time is 12 weeks

14. What is the average waiting time for a first appointment with a neuro-physiotherapist within the Trust?

Community setting (Home based) – 16 weeks
Outpatients where patients attends for their appointment - 3 months

15. How many adult occupational therapists are currently employed by the Trust?

Inpatient - Acute Neurosciences team – 6 OTs WTEs covering both neurology and neurosurgery.

Inpatient - Neurology Unit – 2.5 WTEs – Neurology only

Inpatient - Regional Acquired Brain Injury Unit – 8.8 WTEs – brain injury only.

Community Brain Injury Team – 2 WTE –Brain injury only.

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16. What is the average waiting time for a first appointment with an adult occupational therapist within the Trust?

Regional Acquired Brain Injury Unit do an outpatient service. This is consultant lead which has a low waiting list to see patients. This is brain injury only.

Belfast Trust do not have occupational therapists outside of the inpatient settings (Acute Neuro team and Neurology Unit) who provide neuro-specialist services for people with neurological conditions –no community Neuro occupational therapists or outpatient services.

17. How many adult speech and language therapists are currently employed by the Trust?

In total we have 1.5 wte neuro- speech and language therapists for Belfast Trust this includes the regional services in Royal Victoria Hospital and in and ward services in Musgrave Park Hospital.

18. What is the average waiting time for a first appointment with an adult speech and language therapist within the Trust?

Neurology patients In patient waiting time 2 days – in community 13 weeks

19. How many adult dieticians are currently employed by the Trust?

0.2 WTE band 5 neurology beds Royal Victoria Hospital
0.8 WTE band 7 neurology rehabilitation Musgrave Park Hospital

20. What is the average waiting time for a first appointment with an adult dietician within the Trust?

No dedicated community resource

***Use of <5 (less than five):** We are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act - Personal Information relating to a third party, as the small numbers involved could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.