

**28 December 2023**

## **HUNTINGTON'S DISEASE**

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

This can be found on our website, see the link below

[About the Trust | Belfast Health & Social Care Trust website \(hscni.net\)](https://www.hscni.net/about-the-trust)

### **2. How many people living within the Trust have either a predictive or symptomatic diagnosis of Huntington's disease?**

There is no data base within the trust that has numbers of those people who get tested for HD, so therefore it is impossible to determine who has been tested and who is at risk.

We only have a caseload for the Belfast S/E area and they are just the affected individuals that have been referred to us.

There are many more positive people but not engaging with services, as well as those who have been tested but not symptomatic at present.

All we can go by is the prevalence of HD in NI which is currently 10/12: per 100'000 of the population.

Genetics would see patients for diagnostic (sometimes) and predictive testing to see whether they have the gene; usual management is either through Neurology or the specialist Neurology Movement Disorder Clinic.

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**People Residing in Northern Ireland Who Have Received a Predictive Diagnosis or a Diagnosis of Huntington Disease Based on Symptom Presentation and Subsequent Blood Test**

**Diagnostic Testing**

<u>Year</u>	<u>No. Patients Tested</u>	<u>No. Positive* Patients</u>
2011:	29	5
2012:	41	8
2013:	40	6
2014:	24	5
2015:	34	7
2016:	39	15
2017:	36	4
2018:	32	5
2019:	22	6
2020:	23	6
2021:	22	6
2022:	27	9
2023:	28	7

**Predictive Testing**

<u>Year</u>	<u>No. Patients Tested</u>	<u>No. Positive* Patients</u>
2011:	15	7
2012:	17	8
2013:	6	2
2014:	13	3
2015:	13	5
2016:	17	7
2017:	16	7
2018:	19	11
2019:	18	10
2020:	15	8
2021:	14	6
2022:	14	4
2023:	10	5

\*At least one *HTT* allele in Reduced Penetrance or Complete (Full) Expansion range

Normal Range	6 - 26 repeats
Intermediate Range	27 - 35 repeats
Reduced Penetrance Range	36 - 39 repeats
Complete Penetrance Range	> 39 repeats

Approximate Error Rate: 6 – 39 CAG repeats: +/- 1 repeat  
 40 – 49 CAG repeats: +/- 2 repeats  
 ≥ 50 CAG repeats: +/- 3 repeats

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

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There is no way of answering how many patients are at 25% or 50% or 75% risk of HD - this dataset can only be estimated from prevalence figures.

**4. How many people within the Trust have received funding for PGD within the last 5 years?**

We are only aware of 1 person that has been funded for PGD within our Belfast Trust remit in the last 5 years.

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

People with HD attend consultants with expertise in managing HD at neurology outpatient clinics. The previous dedicated HD clinic is planned to restart, however at present there is no neuropsychiatry service in Northern Ireland.

People with HD and psychiatric or cognitive symptoms access their local Community mental health team for management of these symptoms like all other patient with similar problems.

Patients in the BHSCT and SET have access to the HD nurse specialist. A second HD nurse has been appointed, but hasn't taken up post yet. When the second HD nurse is in place, the neurology service will consider how the two nurse can cover other areas in Northern Ireland.

There is no dedicated bed space for people with HD. There are no beds dedicated for other neurodegenerative conditions. However, people with HD can access inpatient management if required at the regional neurology ward, RVH, 4E. Respite and rehabilitation beds are also available for people with HD in the neurology unit in Musgrave Park Hospital. Mental health services would be in a better position to comment on access to psychiatric inpatient beds.

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

None at present

**7. In the past 5 years has the Trust funded anyone with Huntingtons' Disease to access special services, other than PGD, in**  
**a) Another Trust**  
**b) An area outside of Northern Ireland**

Not that we are aware of.

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**8. How many neurologists are currently employed by the Trust?**

There are currently 14 Neurologists employed by the Belfast Trust

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

The average waiting time for routine first appointment is 167 weeks

**10. How many neuropsychologists are currently employed by the Trust?**

There are currently 10.88 WTE Practitioner Psychologists employed by the Belfast Trust within Neuropsychology specialisms. This includes staff across inpatient and outpatient acute, and post-acute services for Neurology, Neurosurgery, and Brain Injury related teams, and community teams related to Older Adult and Dementia Services, Community Stroke Team, and Community Acquired Brain Injury Services.

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

The average waiting time for a first appointment across current neuropsychology service waiting list related to Neurology and Neurosurgery services pathway is 166 weeks. There is very significant variation in waiting times across differing services areas, which is influenced by demand and commissioned capacity.

**12. How many neuropsychiatrists are currently employed by the Trust?**

There is 1 neuropsychiatrist employed by the Trust (0.825 WTE). A proportion of this psychiatrist's time is currently spent additional specialist neuropsychiatry training.

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

There is no waiting list

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

There are a total of 10.8 WTE neurology physiotherapists in BHSCT.

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

The current waiting time is 27 weeks

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

There are 44 Occupational Therapists employed in the adult community service

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

On 1st December 2023, the waiting time is 29 weeks

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

**Funded SLT = 67.01 wte** This included staff across all adult services acute and community services i.e. District General hospital in and outpatient services, Regional in and outpatient services, Adult community services including adult learning disability.

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

We do not collect the average waiting times for first appointment.

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

There are 96 adult dietitians employed by the trust. The average waiting time is 25 weeks as of the end of November

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

The average waiting time is 25 weeks as of the end of November

**22. Under which directorate(s)/service area(s) does Huntington's disease sit within the Trust?**

Neurology services, Acute and Unscheduled care

**23. Who are the HD relevant service leads within the Trust?**

Lead Nurse Neurology Services- Sarah Toner  
Huntington's Disease Nurse specialist – Majella McConville

**In an effort to build condition specific awareness and help reach affected family members we would like to establish links with front line staff via their team leads;**

**Could you provide the name and email address for relevant team/service leads**

**1. Adult social work**

Grove SW Team: (028) 95046191  
Mount Oriel SW Team : (028) 9504 2367

**2. Occupational therapy**

02895040311

**3. Physiotherapy Department**

02896158800

**4. Primary health care (GP surgeries/health centres)**

The information requested is not held by Belfast Trust and is exempt under Section 21: Information reasonably accessible to the applicant by other means

GP surgeries fall outside the jurisdiction of the Trusts. GP practices in Northern Ireland fall under the remit of the SPPG at Department of Health.

You will find their details on the website

[Home - DOH/HSCNI Strategic Planning and Performance Group \(SPPG\) – formerly HSCB](#)

**5. Speech and language therapy**

02895040553

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**6. Community mental health**

CMHT - Mental Health Triage Team (referral Management) 02895042920

**7. Community pharmacy**

Same as No 4 this would fall under Primary health care

**8. Dieticians**

02895 040201

**9. Palliative care**

Call management Centres

N&W 08456066596

S&E 02890 565565

**10. District nursing**

As above

**11. Neurology**

Lead Nurse Neurology Services

028 96 155291

**12. Genetics**

Contact the Genetics Dept, BCH on:

- Postal address: Clinical Genetics, A floor, Belfast City Hospital, BT9 7A
- E-mail: [genetic.medicine@belfasttrust.hscni.net](mailto:genetic.medicine@belfasttrust.hscni.net)
- 028 9504 8022

**13. Carer Support**

Same as Qu1. Adult SW and Qu 6. CMHT