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Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,  
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Dear Deputy Burke

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary questions, which were submitted to this department for response. I wish to apologise for the slight delay in response,

**PQ 21362/22**

*To ask the Minister for Health the way that the National Rehabilitation Strategy addresses the needs of young persons with paediatric Huntington's disease and juvenile onset Huntington's disease; the way that it addresses the needs of young carers of a family member with Huntington's disease; and if he will make a statement on the matter.*

**PQ 21363/22**

*To ask the Minister for Health his plans to increase access to long-term care for patients with Huntington's disease; and if he will make a statement on the matter.*

**21365/22**

*To ask the Minister for Health his plans to increase the number of facilities with the capacity to provide multi-disciplinary care for people with Huntington's disease considering that Bloomfield Hospital is the only facility in Ireland that does so which is not accessible to persons living in many parts of Ireland; and if he will make a statement on the matter.*

**21366/22**

*To ask the Minister for Health the actions his Department or the HSE are taking to improve access to Bloomfield Hospital's Huntington's disease service for patients considering that it only has the capacity to care for 2% of the persons with Huntington's disease in Ireland at present; and if he will make a statement on the matter.*

**PQ 21367/22**

*To ask the Minister for Health his plans to improve engagement with persons with Huntington's disease, their families and the staff who support them; and if he will make a statement on the matter.*



## **HSE Response**

Huntingtons Disease (HD) is a complex disorder and those affected have complex neurological, genetic counselling, psychological, psychiatric, palliative, social and longer term care needs. It is a degenerative life limiting neurological condition and leads to progressive deterioration of the physical, cognitive and emotional self. It is multifaceted and can cause a wide variety of symptoms

Each child of a parent with the HD gene has a 50% chance of inheriting the condition. Symptoms usually present between the ages of 30 – 50 years. Juvenile onset HD may occur in 10% of those affected, with onset before 20 years of age. It is estimated that there at least 1,000 people with HD in the Republic of Ireland.

The HSE acknowledges the difficulties faced by people who have disabilities due to Huntington's Disease and is providing services with the intention of enabling each individual to achieve his or her full potential and maximise independence, including living as independently as possible. Disability services are provided based on the presenting needs of an individual. Services are provided following individual assessment according to the person's individual requirements and care needs.

As Huntingtons disease is a progressive disease, the needs and requirements of the individual with this disease will change as the disease progresses.

## **National Neuro-Rehabilitation Strategy**

The Implementation Framework for the Neurorehabilitation Strategy was launched on the 20th February 2019, and provides guidance for the development of specialist neurorehabilitation services across the continuum of care – from acute, to post-acute and community services.

Neuro-rehabilitation services play a critical role in supporting recovery and/or maximising ability of those with neurological conditions. We know from our own mapping exercises, that there is a dearth of neuro-rehabilitation services in both inpatient and community levels.

The plan to address this is described within the implementation framework for the Neuro-Rehabilitation Strategy. It outlines a 10-step approach which will see each CHO introducing local implementation teams to oversee and guide the implementation process. It also describes a managed clinical rehabilitation network demonstrator project which is currently progressing through the development of post-acute and community neuro-rehabilitation services across CHO 6 & 7, with full year funding of €2.29m available from 2021. This funding included the establishment of 10 additional in-patient beds on the Peamount Healthcare campus with a complement of 26 staff which is now fully operational. Disability Services Community Healthcare Area 6 are currently working on the recruitment of five therapy posts, capital funding for the service has already been received and the location for the Community Neurorehabilitation Team (CNRT) has been identified. Disability Services Community Healthcare Area 7 are working with Primary Care to identify the location & governance for the Community Neurorehabilitation Team in this area and will progress to the recruitment of five therapy posts.

### **Key Messages:**

- The introduction of the first Managed Clinical Rehabilitation Network in Ireland is hoped to be the exemplar for the national roll-out of the Neuro-rehabilitation Strategy.
- The project, funded by the SláinteCare Redesign Fund, involves the commissioning of 10 new beds at Peamount Healthcare and introducing Multi-disciplinary teams for CHOs 6 & CHO 7, serving patients with complex presentations who do not require inpatient facilities and those who need to transition from hospital to home.
- These new beds introduce some 3,500 additional specialist rehab bed days per annum into the system.
- With average length of stay of approx. 90 days, this means that 40 patients per annum will have their rehabilitation needs met in an appropriate setting outside of acute hospitals.
- The beds are expected to reduce the NRH waiting list by over 30%, and take direct referrals from AMNCH, SJH, SVUH, Beaumont & the Mater for patients with neurological conditions.



The multidisciplinary teams will take referrals from hospitals and the NRH and ensure improved inpatient flow and reduced length of stay in the acute setting.

What we want to achieve through this demonstration pilot site MCRN:

- Person centred coordinated approach to patient care
- Development of appropriately resourced interdisciplinary inpatient, outpatient and home and community based specialist rehabilitation teams supported by education and training
- Introduction of the three-tier model of complexity-of-need
- Reduction in Waiting times for assessment and access to inpatient & community rehabilitation services
- Improved patients outcomes and experience
- Standardised pathway for people who require neuro rehabilitation
- Enhanced communication between inpatient and community services to support to delivery of the right care, in the right place, at the right time
- Build up a supporting infrastructure for the demonstration project to deliver neuro rehabilitation to patients as required across the continuum of care
- Develop a model of care that can be rolled out nationally

The learning from this will inform the roll out of the strategy nationally. Implementation of the strategy will lead to improved patient experience and improved patient outcomes for all with neurological conditions including Huntingtons Disease.

Paediatric Huntingtons disease is exceedingly rare and care of affected children/adolescents is by the small number of paediatric neurologists. The care plan is as determined by the child's individual needs and would include a multidisciplinary and holistic approach. Paediatricians and paediatric neurologists would be happy to work with the NCP for neurology to map out requirements for affected children.

### **Long Term care**

The HSE is fully committed to the UN Convention on the Rights of People with a Disability and the implementation of Sláintecare which is ultimately about delivering the right care in the right place at the right time. The establishment of a statutory home support scheme, underway in the HSE, that enables people to live as independently as possible in their home is a fundamental sought after requirement that has the potential to develop greater choice and options to suit need.

Current policies in Disability services are based on the principles of person-centredness to ensure insofar as possible that the supports for a person are based on individual assessed need, will and preference and to support people to remain as close to home and connected to their community as possible.

The key focus of the *Transforming Lives Programme* is to support people with disabilities to 'live ordinary lives in ordinary places' and to reconfigure disability services and supports to achieve this critical aim.

Notwithstanding this, residential services make up the largest part of the Disability funding disbursed by the HSE – over 60% of the total budget of €2.2 billion in 2021. In the absence of multi-annual funding to increase capacity, decisions in respect of allocation of residential placements is based on greatest presenting need, potential associated risk/safeguarding and the suitability of the service to meet the needs and requirements of the individual.

The Nursing Home Support Scheme provides the funding for long term placements in nursing homes and while it is mainly utilised by people over 65 years, there are younger people living in nursing homes satisfied with this arrangement as for many, this may be the appropriate setting based on their clinical and support needs. The HSE acknowledges that this must be the subject of a care and case management approach that facilitates structured reviews and where the will and preference of the individual is of paramount importance.



Bloomfield Hospital is an approved centre that specialises in the care and treatment of long term psychiatric illness and has a particular focus on care of the elderly and Huntington's Disease. Residents are mainly elderly, however, the age range of residents, which includes younger persons owing to the increased number of admissions of people with Huntington's Disease, is from mid-twenties to 80 plus years of age. Bloomfield provides long-stay residential care to mental health service patients from CHO areas and not necessarily exclusively those with Huntington's Disease.

Bloomfield Hospital may not be the appropriate setting for all persons with the varying stages of Huntingtons Disease. It is reported that the needs and requirements of people with disabilities are being met settings such as the community and in other healthcare settings, for example; Nursing Homes

Specialist care should be provided by a multidisciplinary team, spanning hospital and community services. The team should comprise a Consultant Neurologist with expertise in HD, a Consultant Psychiatrist, specialist nurses and health and social care professionals – HSCPs (including genetic counsellors, psychologists, dietitians, medical social workers, occupational therapists, speech and language therapists, and physiotherapists). Interfaces with other related services should include community-led dementia services, neuro-rehabilitation, community disability, services community psychiatry services, community social care, child protection and palliative care.

This type of integrated care is essential for those with Huntington's Disease. High quality management requires integrated care that meets genetic counselling, psychological, psychiatric, palliative, social and long-term care needs. Access to specialist psychiatry services with multidisciplinary team members for those with early onset cognitive disorders is vital to decrease the psychiatric burden in this population, provide education and support to caregivers and family members and to support colleagues in the general adult services who may be struggling to care for these individuals.

#### **Engagement with persons with Huntington's disease**

The role of the HSE is to provide a multi-disciplinary team approach, which includes the provision of health and personal supports required by people with Huntington's disease incorporating hospital, primary care and community services.

The National Clinical Programme for Neurology (NCPN) informs that it has been working in conjunction with Scheduled Care Transformation Programme (SCTP), within the Strategy and Planning Division of HSE, and the HSE Clinical Design and Innovation team, who lead the NCPs overall, on the development of an integrated care pathway for Huntington's Disease. Mapping out the broad ranges of services and establishing an evidence-based care pathway that serves HD needs will require extensive consultation and planning with all stakeholders. This process is currently underway in finalising the evidence-based pathway and consultation has commenced with care provision stakeholders. As Huntington's Disease is a complex condition that requires support across all aspects of the healthcare system, including the voluntary sector, development of an integrated pathway will require a fully integrated approach and detailed engagement with all stakeholders including Huntington's Disease Association of Ireland (HDAI).

Yours sincerely



**Bernard O'Regan**  
**Head of Operations - Disability Services,**  
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