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Deputy Aengus O'Snodaigh
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Dear Deputy Ó Snodaigh

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

PQ 11540/22

To ask the Minister for Health the reason that persons with Huntington's disease with the exception of a small number of persons in the late stages of the condition have no specialist services in Ireland; and if he will commit to establishing a working group within six months under the joint auspices of the National Dementia Office and the integrated care programme as a necessary first step to improving care for those suffering.

HSE Response

Huntington's Disease is a rare and complex hereditary neurological condition with an estimated 1,000 persons suffering from the disease in Ireland. 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.

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. Services are provided in a variety of community and residential settings in partnership with service users, their families and carers and a range of statutory, non-statutory, voluntary and community groups. Services, in the main, are provided either directly by the HSE or through a range of voluntary service providers. Voluntary agencies provide the majority of services in partnership with and on behalf of the Health Service Executive.

The National Clinical Programme for Neurology (NCPN) have been working in conjunction with HSE Scheduled Care Transformation Programme (SCTP), Strategy and Planning, throughout 2021/2022 on a proposed development of an integrated pathway for Huntington's Disease

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 detailed engagement with all stakeholders.

There is no dedicated national service for Huntington's Disease (HD) at present, although patients are seen regularly through the ENROL-HD research programme at Beaumont Hospital. The ENROL HD Centre at Beaumont hospital already participates in the development of international guidelines for Huntington's Disease and has laid the groundwork for the provision of multidisciplinary care to HD patients in Ireland.



A weekly clinic for HD patients has also been initiated in Beaumont, with limited administrative support. The objective of this clinic is to share best practice and mirror the existing successful national Motor Neuron Disease (MND) service in providing multidisciplinary care.

NCPN is currently developing a business case to support a five-year incremental development of a Huntington's Disease service, in keeping with the objectives of Sláintecare.

While there is no cure for Huntington's disease at this time, rehabilitative therapies such as physiotherapy, occupational therapy, speech and language therapy and diet and nutrition expertise can help manage physical symptoms. Support and information, neuropsychological and psychiatric services can help with cognitive and emotional changes.

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

The implementation framework is based on a 10-step approach pioneered by the Integrated Care Programme for Older People. This is a scientific approach based on data including population needs assessment, mapping of existing services, analysis of gaps in current services in line with benchmarked best practice. The ultimate goal of this approach is to put in place a national framework of acute, inpatient and specialist community neuro-rehabilitation service to meet the rehabilitative needs of those with Neurological Conditions.

National Neuro-Rehabilitation Strategy

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 at 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 for 2021. The learning from the demonstrator project will inform the implementation of the Neuro-rehabilitation Strategy across each CHO and implementation of strategy will roll-out from 2022. This funding included the establishment of 10 additional in-patient beds on Peamount which are now fully operational.

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.

The National Dementia Office (NDO)

The implementation of The Irish National Dementia Strategy (NDS) progresses with a focus on developing care pathways across all care settings, implementing flexible and personalised approaches to care. The Strategy was published at the end of 2014, and the following year the National Dementia Office (NDO) was established within the HSE, to oversee the implementation of the Strategy's actions. The NDO became fully staffed in 2017.

In total there are 35 actions (14 priority actions and 26 additional actions] within the Strategy. A full breakdown of progress was published in 2018 by the Department of Health in the NDS mid-term review.

Information obtained from the National Dementia Strategy informs that the National Dementia Office (NDO) is working with the Acute Hospital Division and other key HSE groups to progress a number of initiatives which aim to improve the care of a person with dementia in acute hospitals, where it is necessary for the person with dementia to attend and/or be admitted to hospital.

These current initiatives include:

- On-going acute hospital staff training in dementia care –A range of training in dementia and delirium care suitable for staff in acute hospitals, including 4 hour intensive, and 2-day detailed training programmes, are available for all staff in the acute hospital settings. These programmes are available through practice development and the centres for Nurse Education locally.
- Enhanced highly dementia-skilled staff capacity– this includes the development of new Nurse Specialist posts in dementia, including a national job description to standardise the expertise required for this post, and a business case template to aid local services to make a case for additional funding to secure the financing for a CNSp Dementia post.; in addition, some candidate Advanced Nurse Practitioners (ANP) in Older Persons posts has a specific focus on dementia. Further development of such posts is contingent on funding being provided by the Department of Health for a further round of applications for cANP in Older Person (Dementia) posts.
- Funding was secured in the 2021 budget for 6 new acute hospital dementia specialist posts (one per hospital group); to support person-centred care via dementia/delirium pathway implementation, staff training frameworks, and direct support for complex cases. All groups have chosen the most strategic site, based on INAD-2 data and their knowledge of the local context. A national job description was updated in Q4 2020 by the National Dementia Office, and the recruitment of these posts will begin shortly. We hope for funding for a second post per hospital group in 2022.
- The NDO have had several meetings with the Acute Hospital Division, and some hospital group and individual hospitals, to align dementia/delirium care to existing frailty, older persons or unscheduled care initiatives, thereby utilising the resource of existing multidisciplinary teams who can support good dementia/delirium care.

Huntington's Disease Association of Ireland

The Huntington's Disease Association of Ireland (HDAI) is a national S 39 non-statutory organisation established by Huntington's Disease family members to provide consultation, information and individualised support to those diagnosed with Huntington's disease, as well as to their families and their healthcare teams. HDAI is receiving a grant aid from the HSE Disability Services via Community Healthcare Area 9 (CHO 9) totalling €68,294 for 2021.

This organisation, a Registered Charity CHY 10130, was formally launched in 1985 and incorporated in 1998. HDAI provides support and specific information to Huntington's Disease (HD) patients, those at risk, carers and to health and social care professionals. HDAI is a niche organisation with experience in responding to issues arising from the complexities of HD and the impact it has on the core and extended family.



Services provided by HDAl include:

- A Family Support Officer is available to meet those with HD and their family members in crisis.
- Access to counselling Support group meetings / carers workshops in Dublin, Cork, Mayo / Roscommon and Limerick
- An annual information meeting /peer support network and respite weekend available to people with HD, those at risk and their families.
- Publications including leaflets, booklets and articles covering the many issues specific to HD.
- A quarterly newsletter and an annual magazine.
- Assistance with aids and the loan of specialised HD seating which helps protect against injury related to involuntary movements and debilitation.
- Talks and information seminars on request. HD ID cards provided on request. Support for Young people impacted by HD

Bloomfield Hospital

Bloomfield Hospital is an independent service run by the Society of Friends. This approved centre 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 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 comprises five units each with a different focus of care.

This hospital receives funding from both HSE Mental Health and Disability Services and currently all CHO areas with the exception of CHO 2 and CHO 4 are providing funding to this service. This service is received €10,875,115 euro in funding in 2021. Mental Health Service is the highest funder

Supports being provided for 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 HSE funds a range of community services to people with a disability, including persons with Huntington's disease. These include Assisted Living Services, Therapy Services, Respite Care and the provision of Medical/surgical Aids and Appliances. In addition to the Huntington's Disease Association of Ireland, the following agencies and services provide support to those diagnosed with Huntington's disease.

Therapy Services

People with Huntington's Disease can benefit from therapeutic assistance, including Physiotherapy, Occupational Therapy and Speech and Language therapy as well as a range of medical interventions. Therapy services for adults are generally delivered through Primary Care Teams, Community Therapy Services and through specialist adult disability providers.

Aids and Appliances

People with disabilities may be eligible for Medical/surgical aids and appliances that facilitate and/or maintain mobility and/or functional independence and are responsive to a person's presenting needs at any given time. These assistive devices enable people with a disability to maintain their health and to optimise functional ability.

Respite Services

The HSE and its funded Agencies provide respite care to children and adults with disabilities. Respite can occur in a variety of settings for various lengths of time, depending on the needs of the individual service user and their family or carer, and according to available resources. Respite is not always centre-based and can be provided in a number of ways, e.g. Centre based; In-Home; Home-to-Home; Family Support, etc. As a vital part of the continuum of services for families, respite potentially helps prevent out-of-home full-time residential placements, preserves the family unit, and supports family stability.

Assisted Living Services



The HSE provides a range of assisted living services including Personal Assistant and Home Support services to support individuals to maximise their capacity to live full and independent lives.

Personal Assistant Services

The role of a Personal Assistant (PA) is to assist a person with a disability to maximise their independence through supporting them to live in integrated settings and to access community facilities.

Services are accessed through an application process or through referrals from Public Health Nurses or other community based staff. Individuals' needs are evaluated against the criteria for prioritisation for the particular service and then decisions are made in relation to the allocation of resources. Resource

Home Support

The Home Support service provides domestic and or personal care inputs at regular intervals on a weekly basis. It differs from the role of a PA in that it focuses more on the necessary domestic and personal care inputs of those based mainly in the home but can occasionally include community activities. Temporary relief is offered to the carer by providing a trained reliable care attendant to look after the needs of the person with the disability.

PA and Home Support Services are provided either directly by the HSE or through a range of voluntary service providers and private for profit providers. The majority of specialised disability provision (80%) is delivered through non-statutory sector service providers.

As with every service there is not a limitless resource available for the provision of home support services and while the resources available are substantial they are finite. In this context, services are discretionary and the number of hours granted is determined by other support services already provided to the person/family.

Yours sincerely



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