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10th May, 2022

Deputy David Cullinane, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 19213/22

To ask the Minister for Health the steps that are being taken by the HSE and his Department to improve engagement with persons with Huntington's disease, their families and support staff; and if he will make a statement on the matter.

Dear Deputy Cullinane,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary questions, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Programme for Neurology (NCPN) on your question and have been informed that the following outlines the position.

The overarching aim of the National Clinical Programme for Neurology (NCPN) is that the patients should have equitable access to a high quality responsive and multidisciplinary service which provides accurate diagnosis and appropriate management for all neurological conditions, including those with neurological manifestations of Huntington's Disease (HD).

Huntington's Disease is a life-limiting genetic neurodegenerative and neuropsychiatric condition that leads to progressive physical, cognitive and psychiatric 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.

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 meet 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

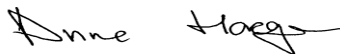
the psychiatric burden in this population, provide education and support to caregivers and family members and to support colleagues in the general adult services who may be struggling to care for these individuals.

The National Clinical Programme for Neurology (NCPN) 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).

It is not possible, in advance of full consultation, to quantify the investment required, but it is anticipated that the pathway and accompanying costed proposed implementation plan will be agreed in the coming months and submitted through the 2023 HSE national service planning process.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely



Anne Horgan
General Manager