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7th June 2023

Deputy John Lahart,
Dáil Eireann,
Leinster House,
Kildare Street,
Dublin 2.

Dear Deputy Lahart,

The Health Service Executive (HSE) 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 Number: 24918/23

To ask the Minister for Health his plans to develop a specialist service for Huntington's disease; and if he will make a statement on the matter

The HSE funds a range of community services and supports to enable each individual with a disability, including persons with Huntington's disease, 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 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.

There are over 400 subtypes of dementia, with the most common form being Alzheimer's disease, followed by vascular dementia and mixed Alzheimer and vascular dementia. Other common forms of dementia include Dementia with Lewy Bodies (DLB), Fronto-temporal Dementias and less common types such as Huntington's disease, Parkinson's disease dementia and Creutzfeldt-Jakob disease (O'Shea et al. 2018). However, there is a large number of rarer types of dementias including Huntington's disease, identified in people under the age of 65. There is a challenge from the point of view of accurate diagnosis (Fadil et al., 2009). The Clinical Care Programme is working on the development of a pathway for Huntington's disease. This is focused on the clinical design aspect of a pathway of care for Huntington's disease and not on a National Working Group for Huntington's disease.

In addition, the National Dementia Office commissioned a review of pathways of diagnosis and post-diagnostic support for people with young onset dementia, which was published in 2020. This has informed the development of a Dementia Model of Care which was published on May 31st, 2023. The model outlines pathways of care for all people living with dementia; from identification of symptoms/signs, through to assessment, diagnosis, and communication of a diagnosis, care planning and post-diagnostic support. The model sets out a range of targets and practice recommendations to advance the treatment, care and support for those living with dementia in Ireland. Within the Dementia Model of Care where dementia is part of an established neurodegenerative or neurological condition such as Huntington's disease, coordination of care usually rests with the respective neurology service.

Kind Regards,

A handwritten signature in black ink, appearing to read 'Janette Dwyer', written in a cursive style.

Ms Janette Dwyer
Assistant National Director,
Services for Older People, Change & Innovation