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29th April, 2022

Deputy David Cullinane
Dáil Eireann,
Leinster House,
Kildare Street,
Dublin 2.

Dear Deputy Cullinane,

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 19210_22

To ask the Minister for Health if the National Dementia Strategy will include operational details to address the needs of persons with Huntington's disease; if the detailed plan will be published; and if he will make a statement on the matter.

Ireland's National Dementia Strategy was published by the Department of Health in December 2014. The Strategy seeks to progress the dual and overarching principles of personhood and citizenship by enabling people with dementia to maintain their identity, resilience and dignity and by recognising that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society. A mid-term review of the Strategy was published in 2018 and an independent evaluation completed in 2019.

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.

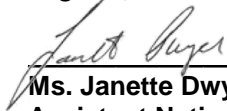
There are a large number of rarer types of dementias for example Huntington's disease, identified in people under the age of 65. There is a challenge from the point of view of accurate diagnosis (Fadil et al., 2009). The Clinical Care Programme is working on the development of a pathway for Huntington's disease. This is focused on the clinical design aspect of a pathway of care.

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 (draft), which outlines pathways of care for all people living with dementia, including those who have a co-morbidity, rarer forms of dementia and

people with young onset dementia. This draft model outlines care pathways within the Irish health and social care system from identification of symptoms/signs, through to assessment, diagnosis, being told 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 people living with dementia in Ireland.

Within the draft model of care where dementia is part of an established neurodegenerative or neurological conditions such as Huntington's disease, coordination of care usually rests with neurology service. The draft model went out for public consultation in 2021 and workshops were held with relevant interest groups as part of the consultation process. It is expected to be published later this year.

Regards,



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