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8<sup>th</sup> March, 2022

Deputy Ruairí Ó Murchú  
Dáil Eireann,  
Leinster House,  
Kildare Street,  
Dublin 2.

Dear Deputy Ó Murchú,

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 9950\_22**

**To ask the Minister for Health if consideration has been given to establishing a working group under the joint auspices of the National Dementia Office and the integrated care programme to determine the needs and solutions to provide persons with Huntington's disease and their families a good standard of care; the engagements that have taken place; 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 is 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 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 (draft), which outlines pathways of care for all people living with dementia, including those who have a co-morbidity. This draft model outlines care pathways within the Irish health and social care system for people living with dementia; from identification of symptoms/signs, through to assessment, diagnosis, and disclosure, 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 draft

dementia 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.

Regards,



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**Janette Dwyer**  
**Assistant National Director,**  
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