



Oifig an Stiúrthóra Cúnta Náisiúnta  
Clár Cúraim Pobail Feabhsaithe &  
Conarthaí Príomhchúraim  
Feidhmeannacht na Seirbhíse Sláinte  
Urlár 2, Páirc Ghnó Bhóthar na Modhfheirme,  
Bóthar na Modhfheirme, Corcaigh, T12 HT02

Office of the Assistant National Director  
Enhanced Community Care Programme &  
Primary Care Contracts  
Health Service Executive  
Floor 2, Model Business Park,  
Model Farm Road, Cork, T12 HT02

[www.hse.ie](http://www.hse.ie)  
T: 021-4928512  
E: [primarycare.strategy@hse.ie](mailto:primarycare.strategy@hse.ie)

**Minister Sean Fleming**  
**Dáil Eireann,**  
**Leinster House,**  
**Kildare Street,**  
**Dublin 2.**

**Date 29/01/24**

**PQ 57188/23 - To ask the Minister for Health what services are available for people who are in their late 50's who require the majority of services for people with dementia/Alzheimer's such as psychiatry for later life and day services as they are not disabled and too young for this service; the supports that are available; and if he will make a statement on the matter**

Dear Minister Fleming

I refer to your parliamentary question, which was passed to the HSE for response.

Dementia is typically diagnosed in people over 65 years of age, but there is a growing awareness of the prevalence and impact of dementia diagnosed in people aged 65 or under. This is referred to as 'young onset dementia'. People with Young Onset Dementia (YOD) has been reported to account for up to 10% of all cases (Pierce et al. 2014) with Alzheimer's disease being the most common subtype. However, rarer dementia types such as fronto-temporal dementia are disproportionately higher in those under 65 and in general in this age group, early symptoms can be more challenging to identify and lead to longer paths to accurate diagnosis. People with an intellectual disability (ID) require particular consideration, as they have a significantly higher risk of developing dementia when compared to the general population (Strydom et al. 2013). For people with intellectual disability and Down syndrome living with dementia, 50–75% are under the age of 65 years.

### **Under 65 Dementia Care Pathways**

The National Dementia Strategy was published in December 2014 and identified a number of priorities in relation to care pathways. The Strategy recommended that the Health Service Executive develop National and Local Dementia Care Pathways to describe and clearly



signpost the optimal journey through the system from initial presentation with worrying symptoms, through to diagnosis, including levels of intervention appropriate to need at any given time.

The Dementia Model of Care is due to be published on May 31st, 2023 and builds on the work of the National Dementia Strategy (2014), the HSE Corporate Plan 2021 - 2024 and has been developed within the context of Sláintecare (2020–2023) and the health reform agenda, where delivering the right care, in the right place, at the right time, given by the right team, is a central principle. The aim of the Dementia Model of Care is to provide earlier recognition and intervention for those living with dementia as well as their support networks. The Dementia Model of Care offers in-depth guidance which is presented across a series of targets and practice recommendations to advance the treatment, care and support for the thousands of people living with dementia in Ireland (including those under 65) and outlines best practice for:

- a) Pathways to diagnosis and guidance on assessment for clinicians
- b) Communication of a diagnosis using best international practice
- c) Care planning/personalised care planning-inclusive of the person with dementia and their supporter/carer
- d) Post-diagnostic support across five strands which include understanding and planning, staying connected, staying healthy, supporting cognition and emotional wellbeing

People 65 years and under with a suspected dementia or those with atypical or unclear presentations that require a more detailed assessment will predominantly be assessed and supported in a Regional Specialist Memory Clinic (RSMC). These highly specialised services will incorporate a broad skillset of clinical specialties such as Neurology and Psychiatry, as well as enhanced neuropsychology and medical social work services, in recognition of the complexity of these cases. However, these patients may utilise the post diagnostic support services that are local to where they live, which will be provided by a network of Memory Assessment and Support Services (MASS). Each person under 65 diagnosed with dementia will have a named contact person in the RSMC and/or local MASS, to ensure that they and their families have guidance and support through the post-diagnostic phase. As of January 2024; four RSMCs have been funded to date, they are located in the Mercy University Hospital, Cork, Galway University Hospital, Tallaght University Hospital and St James's Hospital, Dublin. As part of the implementation programme of the Model of Care, care pathways have been devised to ensure that all those with suspected or confirmed dementia under 65 are afforded optimal care, leveraging both regional expertise and local wrap-around services as appropriate.



The recently established National Intellectual Disability Memory Service (NIDMS) in Tallaght University Hospital will follow the pathway outlined above but also possess the unique MDT skill-mix required to assess and diagnose the more complex and often unmet needs of people with an intellectual disability.

From a community perspective, there are many post diagnostic supports available. The Alzheimer's Society of Ireland (ASI) has appointed 29 Dementia Advisors that offer national coverage who will provide information and advice throughout the person's journey with dementia, help connect them with dementia supports, services, and local groups and help the local community to become more dementia friendly. The ASI also published Harnessing community information and support for people with young onset dementia and their families: Guidance for community groups and healthcare professionals in September 2022. It includes practical recommendations which may be utilised by community groups or healthcare professionals to consider the needs of people with young onset dementia.

### **Home Support Services for People with Dementia**

The Home Support Service is funded by Government to deliver a volume of service each year as approved in the HSE National Service Plan. It is a non-statutory service and access to the current service is based on an assessment of the person's needs by the HSE and having regard to the available resources and the competing demands for the service.

The HSEs Older People Operations Office (OPO) and the National Dementia Services (NDS) have collaborated on the development of an enhanced model of service delivery for Home Support clients with a mild cognitive impairment (MCI) or clients with Dementia.

To respond to the growing and increasing need around the provision of care in the home, a system of support is required, one that centres on the personalised needs of the person living with dementia as well as providing needed respite for family carers. This approach builds on current person centred services already in place but provides scope and flexibility to provide a broader more holistic range of support to people living with dementia that includes both personal care and psychosocial support. The current model of home support provision is heavily weighted towards personal care. This can disproportionately impact people living with dementia who may be able to get up and dressed each day but who may have difficulties with other aspects of everyday life as a result of impairment with their cognition.



Evidence has shown that providing low levels of service/number of hours per week can improve quality of life for the person with dementia and their family carer and help maintain them at home for longer. Providing supports that are personalised to the person living with dementia focuses on addressing both their personal and/or functional needs (ADLs) and well as their psychosocial needs. Psychosocial interventions as part of a client's Home Support Plan such as supporting ability, social engagement and participation in meaningful activities (such as hobbies, household tasks and chores) can improve cognitive ability, enhance emotional well-being and reduce behavioural symptoms.

The desire for the vast majority for people with dementia is to remain at home, however this is a chronic and progressive disease and there may come a time in the person's life where their specific care needs can no longer be met in their own home and they will require residential care. This decision will be made through consultation with the person with dementia and often their family members.

I trust this is of assistance.

**Yours sincerely,**

A handwritten signature in blue ink, appearing to read 'G. Crowley', with a horizontal line underneath.

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**Geraldine Crowley,  
Assistant National Director,  
Enhanced Community Care Programme &  
Primary Care Contracts**