



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
31-33 Sráid Chaitríona, Luimneach.

Office of the Head of Operations,
Disability Services/Social Care Division,
31-33 Catherine Street, Limerick.

T: 00353 (0) 61 483369

Suíomh Gréasáin/Website: <http://www.hse.ie>

26th June 2020

Deputy Cathal Crowe
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: cathal.crowe@oireachtas.ie

Dear Deputy Crowe,

The Health Service Executive 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 12265/20

To ask the Minister for Health the supports being considered for those living with Parkinson's disease in view of the extraordinarily low number of dedicated nurses for such patients nationwide; and if he will make a statement on the matter.

HSE Response

Community Supports to People with Parkinson's Disease

The objective of the HSE is to provide a multi-disciplinary team approach which includes the provision of health and personal supports required by people with Parkinson's disease and incorporates hospital and primary care and community services.

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

It must be noted that we are currently experiencing the effects of the COVID-19 pandemic. In preparing for and responding to COVID-19 and to fully align with Public Health guidance as recommended via the NPHET, the HSE and its partner service providers put in place a range of measures, which included the prioritisation of vital residential and home support services whilst curtailing or closing certain services such as day services, respite services, and certain clinical supports in order to; a) prioritise essential public health services at CHO level and b) ensure continued delivery of the referenced residential and home supports provision. As a result, some services and facilities available for persons with Parkinson's disease may have been effected over the last few months.

Notwithstanding this, under the Roadmap for Reopening, processes are now underway in order to plan for the reintroduction of non-Covid services. In that regard the HSE has now developed a number of important guidance documents to assist disability services. These are now also available on the website below and include the following:



Building a Better Health Service

CARE COMPASSION TRUST LEARNING

1. Framework for Resumption of Adult Day Services;
2. Reshaping Disability Services From 2020 & Beyond

Available at: <https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/>

It is important to note that the above guidance is interim and subject to change in line with the overall management of the Covid-19 pandemic and in accordance with contemporary Public Health Guidance;

CHOs and S38/39 agencies continue to work together at a regional level in order to plan and co-ordinate efforts.

The HSE continues to plan the re-establishment of vital non-covid supports and services including therapy services. This includes very careful and detailed work on the part of the Disability Sector with national guidance and will result in directing how all funded agencies can deliver services on a medium to long-term basis. Plans have to comply with guidance as set out by the National Public Health Emergency Team as well as Public Health specialists in the HSE.

In addition the Disability Sector is re-establishing a number of structures including the National Consultative Forum as well as other operational structures that will co-ordinate and support the sector as we continue to navigate this pandemic and make every effort to deliver supports and services in line with Public Health Guidance.

The facilities and options available for persons with Parkinson's disease which will be delivered in line with Public Health Guidance are outlined below.

Assisted Living Services

The HSE provides a range of assisted living services including Personal Assistant (PA) and Home Support services to support individuals to maximise their capacity to live full and independent lives. These are related but separate services and each is funded separately. While the resources for the provision of assisted living services available are substantial they are finite.

PA and Home Support Services are provided either directly by the HSE or through a range of voluntary service providers. The majority of specialised disability provision (80%) is delivered through non-statutory sector service providers.

PA Services

The role of a Personal Assistant (PA) is to assist a person with a disability to maximise their independence through supporting them to live in integrated settings and to access community facilities. The PA works on a one to one basis, in the home and /or in the community, with a person with a physical or sensory disability. A vital element of this personalised support is the full involvement of the individual (service user) in planning and agreeing the type and the times when support is provided to them; supporting independent living must enhance the person's control over their own life.

Home Support Services

The Home Support service provides domestic and or personal care inputs at regular intervals on a weekly basis. Temporary relief is offered to the carer by providing a trained reliable care attendant to look after the needs of the person with the disability. The service provides support to the parents to enable them to spend quality time with the other siblings in the family: it also supports the individual with the disability in terms of their care plan with particular attention in the personal needs of the individual. Home supports can be provided through a dedicated home support service or through the generic home help service. Home supports can be an alternative to residential care, where support to individuals in daily living can avoid the need for full time residential services.

Accessing Services

Services are accessed through an application process or through referrals from public health nurses or other community based staff. Individual's needs are evaluated against the criteria for prioritisation for the particular services and then decisions are made in relation to the allocation of resources. Resource allocation is determined by the needs of the individual, compliance with prioritisation criteria, and the level of resources available. As with every service there is not a limitless resource available for the provision of home support services and while the resources available are substantial they are finite. In this context, services are discretionary and the number of hours granted is determined by other support services already provided to the person/family.

The HSE is committed to protecting the level of Personal Assistant (PA) services and Home Support services available to persons with disabilities including those who have disability as a result of Parkinson's disease.

Therapy Services

People with disability as a result of Parkinson's Disease can benefit from therapeutic assistance, including Physiotherapy, Occupational Therapy and Speech and Language therapy as well as a range of medical interventions.

Therapy services for adults are generally delivered through Primary Care Teams, community therapy services and through specialist adult disability providers.

The HSE has prioritised the development of therapy services in recent years with a range of multi-disciplinary supports, including Speech and Language Therapy, Occupational Therapy, Physiotherapy and Psychology, put in place from 2005 to 2009. In 2013, additional funding of €20m was provided to strengthen Primary Care services. This comprised over €18.5m for the recruitment of over 260 Primary Care team posts and over €1.4m to support community intervention team development. There was also a €4m allocation within the 2016 Service Plan to facilitate the recruitment of Speech and Language Therapists to address waiting lists as part of the overall Speech and Language Therapy waiting list initiative within Primary Care and Social Care. The allocation provides for an additional 83 posts.

There will be improvement in access to Primary Care Occupational Therapy Services with a focus on addressing patients waiting over 52 weeks, through the appointment of 40 Occupational Therapists.

Aids and Appliances

People with disability as a result of Parkinson's Disease may be eligible for Medical/surgical aids and appliances that facilitate and/or maintain mobility and/or functional independence and are responsive to a person's presenting needs at any given time. These assistive devices enable people with a disability to maintain their health and to optimise functional ability.

The Parkinson's Association of Ireland

The Parkinson's Association of Ireland is largely funded through voluntary contributions and was allocated Grant Aid Agreement in 2020 of €60,000 from HSE Primary Care Services, Community Healthcare Organisation Area 2, (Galway / Mayo / Roscommon) under Section 39 of the Health Act.

National Services include:

- The National Parkinson's Helpline (Freephone 1800 358 359)
- Parkinson's Nurse Specialist education & outreach programme
- Branch network of community volunteers throughout Ireland
- Parkinson's Publications including the quarterly magazine and website www.parkinsons.ie

The HSE liaises with the Parkinson's Association of Ireland through its membership of the Neurological Alliance of Ireland, which is a national umbrella organisation for voluntary groups, professionals and

interested parties representing the views and concerns of those whose lives are affected by neurological conditions.

National Neuro-Rehabilitation Strategy

The Neuro-rehabilitation Strategy Implementation Framework (IF) was launched in February 2019. The overarching aim of the Strategy is the development of neuro-rehabilitation services to improve patient outcomes by providing safe, high quality, person-centred neuro-rehabilitation at the lowest appropriate level of complexity. This must be integrated across the care pathway, and provided as close to home as possible or in specialist centres where necessary.

These services should be configured into population based managed clinical rehabilitation networks (MCRNs). The MCRN, while an effective model in a number of European countries, is a new concept in Ireland. MCRNs are recognised as having the potential to bring together an appropriate range of primary, secondary and tertiary services to ensure equitable provision of high quality and clinically effective services. Considering the scale of fundamental change proposed it was decided to advance a demonstrator project across CHO 6 & 7 (which includes Peamount Healthcare, the Royal Hospital in Donnybrook and the National Rehabilitation Hospital) ahead of National roll-out.

The learning from the demonstrator project will inform implementation of the Neuro-rehabilitation Strategy across each CHO.

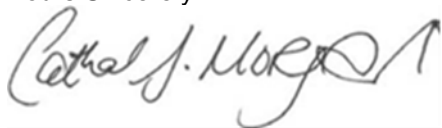
Work on developing the necessary operational structures to support Network Functioning across the demonstrator area continues and the 'design phase' of the model is at an advanced stage. Funding for a 10-bed Neurorehabilitation Unit at Peamount Hospital has also been approved. Recruitment for this unit is currently underway and it is hoped that the unit will be operational by Q3 2020.

The capital project at the National Rehabilitation Hospital is also nearing completion and will be operational within in the coming weeks. The new building has capacity for 120 patients which is an uplift of approx. 20 beds. Funding has also been approved for staffing to support this increased capacity.

The 2019 target for Neurorehabilitation, as outlined in the HSE Service Plan was to 'Commence a pilot project in CHO 6 and 7 to support the roll-out of the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015'. As such, the 2019 target agreed in the Service Plan has been met as work on the demonstrator is progressing.

With respect to targets proposed in the Implementation Framework itself, targets have not all been met however progress is being made across the CHO's with respect to identifying Leads and establishing Local Implementation Teams.

Yours Sincerely



**Dr. Cathal Morgan,
Head of Operations - Disability Services,
Community Operations**