

THE NEUROLOGICAL ALLIANCE OF IRELAND (NAI) IS CALLING FOR PRIORITY INVESTMENT IN NEUROLOGICAL CARE IN THE UPCOMING BUDGET

INVESTMENT IN NEUROREHABILITATION SERVICES

€4.5m to implement the demonstrator project in CHOs 6 & 7 as the first step in delivery of the Implementation Framework for the National Neurorehabilitation Strategy 2019-2021

INVESTMENT IN NEUROLOGY SERVICES

€1.3m investment in neurology services to address growing waiting lists and unacceptable waiting times for neurology services

INVESTMENT IN SPECIALIST SERVICE PROVISION BY VOLUNTARY NEUROLOGICAL ORGANISATIONS

NAI is calling for the implementation of the recommendations of the Independent Review Group on the role of voluntary organisations in the provision of publicly funded health and personal social services



THE NEUROLOGICAL ALLIANCE OF IRELAND IS THE NATIONAL COALITION ON NEUROLOGICAL CARE

Contact Us:

-  nai.ie
-  [@naiireland](https://twitter.com/naiireland)
-  facebook.com/nai
-  01 8724120

NAI IS SUPPORTING CALLS FOR INVESTMENT IN CONDITION SPECIFIC SERVICES AND OTHER SUPPORTS AS FOLLOWS:

Stroke

€7.7m to roll out Early Supported Discharge teams for stroke patients nationwide and develop thrombectomy services to ensure access for all suitable stroke patients, regardless of location

Epilepsy

€1.13m to fully implement the National Epilepsy Programme's Women's Health in Epilepsy project and provide additional nurse specialists to achieve the recommended level of staffing for the Irish population

Dementia

€18.4m to support investment in dementia advisors, home care support, dementia key workers and promote dementia inclusive communities as well as to address the gaps in dementia services

MS Care centre

€600,00 additional funding in 2020, to restore the MS Care Centre 365 days a year

Home Care Support

€110 million increase in the Home Supports budget to begin to meet unmet need in 2020, while the statutory Home Care scheme is being developed

LIVING WITH A NEUROLOGICAL CONDITION IN IRELAND:

Over 800,000 Irish people live with neurological conditions including dementia, stroke, epilepsy, acquired brain injury, Parkinson's disease and multiple sclerosis as well as rare and genetic conditions.

Research published by the Neurological Alliance of Ireland earlier this year¹ highlighted the enormous challenges faced by these individuals and their families in accessing healthcare and other supports.

Our nationwide survey based on over 600 responses showed that:

- 30% waited more than 12 months to see a neurologist to have their condition diagnosed
- One in five could not access vital services including counselling (22%) physiotherapy (18%) and psychology (18%). More than one in ten could not access neuropsychology (12%), neurorehabilitation, home care support or case management services (11%)
- One in ten patients were paying more than €100 a month out of their own pocket for supports such as physiotherapy and medications
- One third of carers reported that home care support was insufficient or inappropriate for their needs

¹ Living with a Neurological Condition in Ireland (2019) Neurological Alliance of Ireland https://www.nai.ie/assets/81/48AD1F31-5BE3-41B4-8EF879708BF2F621_document/Final_Survey_report_.pdf

² Neurology Commissioning Toolkit (2016) Association of British Neurologists

NEUROLOGICAL CONDITIONS ACCOUNT FOR:

- 17% OF GP VISITS
- 10% PRESENTATIONS TO A & E
- 19% OF ALL HOSPITAL ADMISSIONS
- 33% OF PEOPLE LIVING IN RESIDENTIAL CARE

2019, OVER 21,000 PEOPLE WERE WAITING TO SEE A NEUROLOGIST, 8,202 HAVE BEEN WAITING FOR MORE THAN A YEAR

INVESTMENT IN NEUROLOGY SERVICES

In January 2010, 9,217 people were waiting on an OPD appointment for a neurologist³. By January 2019 this number had risen to 20,950, an increase of over 120% over nine years. This increasing demand for neurology services is not being matched by investment in the service. An audit of neurology services nationwide carried out by the Neurological Alliance in partnership with the National Neurology Clinical Programme⁴ showed that no neurology centre had access to a full multidisciplinary team while regional centres in Sligo, Limerick and Waterford had no dedicated physio-therapy, speech and language or occupational therapy services.

The NAI is calling for €1.3 investment in neurology services in 2020

The NAI is calling for investment in neurology services to support a number of initiatives aimed at reducing waiting lists, improving outcomes and addressing critical staffing shortages that threaten the safe delivery of services.

- €500,000 to begin the rollout of the national headache pathway, headache is responsible for over a third of referrals to neurology services
- €500,000 to address the issue of neurologists working in isolation and ensure the safe delivery of services
- €100,000 to begin to address critical shortages in Clinical Nurse Specialists for conditions such as multiple sclerosis, Huntington's disease, Parkinson's disease and muscular dystrophy
- €200,000 as part of a 5 year plan to develop a specialist national centre for motor neurone disease

The three year implementation framework for the National Neurorehabilitation Strategy (2019-2021⁶), published earlier this year, is a key action within the Slaintecare implementation plan but it will completely fail to deliver without dedicated investment. Despite a clear commitment to community neurorehabilitation in the current Programme for Government, there has been NO investment in new community services since the Neurorehabilitation Strategy was published in 2011

INVESTMENT IN NEUROREHABILITATION SERVICES

Neurorehabilitation services are vital to support recovery and prevent disability. Neurorehabilitation services in Ireland are critically underdeveloped with only 9% of major trauma patients being discharged to neurorehabilitation services⁵. The National Rehabilitation Hospital in Dun Laoghaire continues to struggle to provide for the needs of the country with less than half the recommended number of beds for a population of our size.

The NAI is calling for €4.5m investment in neurorehabilitation services in 2020

A neurorehabilitation demonstrator project was established in September 2018 in CHOs 6 & 7 to provide critically needed access to specialist rehabilitation services and address growing waiting lists in the National Rehabilitation Hospital.

The NAI is calling for investment of €4.5m in 2020 to enable the implementation of the demonstrator project in CHO's 6 & 7 as the first step in the delivery of the three year implementation framework for the National Neurorehabilitation Strategy 2019-2021.

³ Outpatient Waiting List Data by Speciality (2019) National Treatment Purchase Fund

⁴ Report on National Survey of Neurology Services (2016) Neurological Alliance of Ireland https://www.nai.ie/assets/22/E622B527-41E1-4471-9EFDAE484E1745B2_document/NAI_Report_on_National_Services_2015_C.pdf

⁵ Major Trauma Audit National Report (2017) National Office of Clinical Audit

⁶ National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Action: Implementation Framework 2019-2021 (2019) Health Services Executive

INVESTMENT IN SPECIALIST SERVICE PROVISION BY VOLUNTARY NEUROLOGICAL ORGANISATIONS

The recently published report of the Independent Review Group⁷ recognises the valuable role of the voluntary sector in providing flexible, responsive and innovative responses to health and social care needs. Ireland is strongly reliant on neurological organisations within the voluntary sector in order to provide neurorehabilitative and other supports in the community given the dearth of specialist services available in the statutory health sector.

Many voluntary providers are struggling to continue to meet the cost of providing services in the context of successive cutbacks in funding from the HSE. This issue was highlighted in a series of presentations to the Joint Oireachtas Committee on Health on June 19th 2019 where the cumulative deficits among voluntary disability providers were estimated to be in excess of €40m. The NAI supports the calls from this hearing for a review of these deficits and the relationship between the HSE and voluntary providers in the context of the full implementation of the recommendations of the Independent Review Group.

FUNDING FOR CONDITION - SPECIFIC SERVICES AND OTHER SUPPORTS

Stroke

- €6.4m to ensure that endovascular stroke centres providing thrombectomy are developed in conjunction with emergency services to provide access for all suitable stroke patients regardless of location
- The 3 year incremental plan for the new and replacement equipment from 2020-2022 inclusive to be expedited, making the remaining €6.4m available in the Capital Plan for 2020
- €1,290,481 to roll out Early Supported Discharge programmes nationally for stroke patients

The national roll out of ESD for stroke patients, beginning with Year 1 of the phased roll out, including addressing staffing deficits in the six existing teams, at a cost of €1,290,481 in 2020

⁷ Report of the Independent Review Group Established to Examine the Role of Voluntary Organisations in Publicly Funded Health and Personal Social Services (2019) Department of Health

Epilepsy

€1.13m to (a) meet the specialist nursing targets outlined in the National Epilepsy Care Programme's Model of Care of 1 nurse per population of 140,000. Research⁸ has shown that epilepsy specialist nurse posts improve patient care across a number of indicators while remaining cost-neutral. An investment in six additional posts in 2020 at a cost of €460,000, specifically targeting the existing regional imbalance in epilepsy services and underserved populations such as adolescents and people with epilepsy and intellectual disability, would improve the quality of epilepsy care and deliver savings in other areas such as the use of emergency/acute services.

(b) Ensure that all commitments made in 2018 to resource and implement the National Epilepsy Programme's 'Women's Health in Epilepsy' project are fulfilled in their entirety. Resources required include a consultant post, six adult ANPs and one paediatric ANP, a data manager, administrative support and funding to develop the Epilepsy Patient Portal and the Epilepsy & Pregnancy Register, at a total cost of €1m per annum. The consultant post and five ANP posts remain outstanding (€670,000).

Dementia

Invest €18.4m in dementia services as follows:

- Invest €7.415m in service gap
- Invest €1.68m in dementia advisory service
- Invest €6m in home care
- Invest €2.31m in dementia key workers
- Invest €1m in dementia inclusive communities

MS Care Centre

The Multiple Sclerosis (MS) Care Centre is a 12 bedded unit which provides respite care for people with MS (PwMS) and other progressive neurological conditions. MS Ireland are seeking full cost recovery to enable the MS Care Centre to open 50 weeks a year in order to meet the demand for this specialist type of respite for people living with MS and other progressive neurological conditions.

- Cost: Additional funding of €600,000 in 2020

Home Support

The Neurological Alliance of Ireland, as a member of the **Home Care Coalition**, is supporting the call for increased investment in home care in 2020

- €110 million increase in the Home Supports budget to begin to meet unmet need in 2020, while the statutory Home Care scheme, committed to in the Programme for Government, is being developed

⁸ SENSE study: Higgins, et al. (2018)
Epilepsy & Behaviour, Volume 85, 85-94

NEUROLOGICAL ALLIANCE OF IRELAND MEMBER ORGANISATIONS

Acquired Brain injury Ireland
Alzheimer Society of Ireland
An Saol
Aphasia Ireland
Ataxia Ireland
Aware
Bloomfield Health Services
Cheshire Ireland
Chronic Pain Ireland
Dystonia Ireland
Enable Ireland
Epilepsy Ireland

Headway
Huntington's Disease Association of Ireland
Irish Heart Foundation
Irish Hospice Foundation
Irish Motor Neurone Disease Association
Migraine Association of Ireland
Move4Parkinsons
Multiple Sclerosis Society of Ireland
Muscular Dystrophy Ireland
Neurofibromatosis Association of Ireland
North West MS Therapy Centre
Parkinson's Association of Ireland

Polio Survivors Ireland
PSPA Ireland
Syringomyelia Support group of Ireland
Spinal Injuries Ireland
Spina Bifida Hydrocephalus Ireland
The Rehab Group

Associate Members

Irish Association of Speech and Language
Therapists
Myaware