

**SUBMISSION ON
NEUROLOGICAL CARE
SERVICES IN IRELAND**

**A SECTOR IN CRISIS
DUE TO PRE-PANDEMIC
UNDERINVESTMENT AND
THE IMPACT OF COVID19**

NOVEMBER 2021

SUMMARY POINTS

1. Over 40,000 Irish people are diagnosed with neurological conditions each year¹ including stroke, acquired brain injury, epilepsy, multiple sclerosis and Parkinson's disease as well as a range of rare and genetic neurological conditions
2. Neurological care services worldwide have been significantly impacted by the COVID19 pandemic^{2,3}. In Ireland, COVID19 has precipitated an already looming crisis in neurological care as an overwhelming lack of capacity is coupled with pent up demand and additional needs following the pandemic. Neurological Care services in Ireland are facing:
 - i. Spiralling waiting lists in neurology with almost a 50% increase in outpatient waiting lists in neurology from August 2015 to August 2021⁴
 - ii. Pent up demand for neurorehabilitation services, including for long COVID patients with only 50% of the inpatient specialist rehabilitation beds required and a lack of community neurorehabilitation services throughout the country
 - iii. Critical threat to long term neurological care services due to the challenges facing the not-for-profit sector
3. A nationwide patient experience survey carried out by the Neurological Alliance of Ireland in June 2021 showed that **one fifth of patients with neurological conditions were still experiencing significant delays in accessing vital services due to the impact of COVID19**, this rose to almost 40% for access to their consultant neurologist
4. **Outpatient waiting lists for neurology now stand at nearly 24,000: approaching a 50% increase since 2015.** The number of people waiting more than 18 months has climbed from 355 in 2015 to 8,601 in 2021. Nurse specialists represent a vital tool in tackling neurology waiting lists.
5. **The dearth of neurorehabilitation services in Ireland represents a systemic weakness in our health system: acting as a barrier to effective trauma and stroke care as well as the effective use of acute hospital beds.** The Neurological Alliance is calling for investment to implement the National Neurorehabilitation Strategy⁵: a key commitment within the current Programme for Government⁶. The 2019-2021 Implementation Framework⁷ comes to an end this December with little or no progress on implementation. Only 2 of 9 community neurorehabilitation teams and less than thirty neurorehabilitation beds (out of a recommended additional one hundred and fifty) have been introduced in over a decade since the original Strategy was published.
6. There is an overwhelming dependence on the not-for-profit sector to provide the only long-term care and supports in the community for people with neurological conditions. These services are critically vulnerable due to long standing funding cuts, increasing costs and the impact of COVID19 on public fundraising. The Neurological Alliance seeks to highlight to the committee the urgent need to protect and resource this sector to prevent the loss of vital services.
7. Long COVID patients will require significant support from neurological care services. Resourcing of these services must take into account the capacity requirements within existing neurological care services to respond to the needs of this group.

¹ Model of Care for Neurology Services in Ireland (2016) Clinical Strategy and Programmes Division. Health Services Executive

² Lessons Learned from the COVID19 Pandemic: Priorities in care for people with neurological conditions after the pandemic (April 2021) National Neurosciences Advisory Group UK

³ Chahnez Charfi Triki et al (2021) Global Survey on Disruption and Mitigation of Neurological Services During COVID19. Journal of Neurology (2021) June 11: 1-13

⁴ Outpatient Waiting Lists by Speciality. National Treatment Purchase Fund Website www.ntpf.ie

⁵ National Policy & Strategy for the Provision of Neurorehabilitation Services in Ireland (December 2011) Department of Health

⁶ Our Shared Future: Programme for Government (October 2020) Government Publications (Ireland)

⁷ National Policy & Strategy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Action Implementation Framework 2019-2021 (2019) Health Services Executive

RECOMMENDATIONS

1. Immediate action to reduce neurology waiting lists through priority investment in neurology services including addressing the critical shortfall of neurology nurse specialists
2. A commitment to implement the National Neurorehabilitation Strategy by putting community neurorehabilitation teams in place in each Community Health Organisation (CHO) by the end of 2022
3. Funding the not-for-profit sector to the true cost of providing services in order to protect the only long-term services in the community for people with neurological conditions

NEUROLOGICAL ALLIANCE OF IRELAND

The Neurological Alliance of Ireland (NAI) brings together over thirty non-profit organisations to advocate for the rights of 800,000 people in Ireland living with a neurological condition. Founded in 2003, the NAI advocates for the development of quality services for people with neurological conditions and their families. Our campaigns are rooted

in the experience of our members and the individuals and families with whom they work. We provide a united and expert voice on neurological care through research, advocacy, policy development and education. Further information is available at

www.nai.ie and
www.loveyourbrain.ie

FURTHER INFORMATION

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EVIDENCE OF THE IMPACT OF COVID19 ON ACCESS TO NEUROLOGICAL CARE

The Neurological Alliance of Ireland carried out a nationwide patient experience survey of people living with neurological conditions in June 2021, more than a year on from the onset of the pandemic. Respondents were questioned about their access to a range of essential services over the past six months. The findings indicate the impact of COVID19 on access to neurological care with access to

consultant neurology, physiotherapy, imaging and diagnostic tests and nurse specialists most significantly affected. Of serious concern is the extent to which the survey findings highlight the continued impact on access to services with almost 40% of patients still experiencing significant delays in accessing their consultant and over a fifth in accessing physiotherapy/ nurse specialists/diagnostic tests

and changing or commencing new medications. The June 2020 Consensus Statement⁸ issued by the Clinical Advisory Group for Neurology (Ireland) warned that extra resources would be needed for neurology services to cope with the backlog due to COVID19 and highlighted the significant capacity issues pre-COVID19 that would have to be addressed in order to enable services to address the backlog post-pandemic.

Table 1: NAI survey: Self report of 170 respondents May 2021

	Significant Impact of COVID19 on access to this service over the past year	Still currently (May 2021) experiencing very significant delays due to COVID19
Access to Consultant Neurologist	33%	38%
Access to Physiotherapy	18%	18%
Access to Diagnostic tests/Scans including MRI	21%	27%
Commencing a new medication or changing medication for your neurological condition	9%	21%
Access to a Nurse Specialist	19%	21%

⁸ Consensus Statement on Neurological Care Post COVID19 Lockdown (June 2020) Clinical Advisory Group on Neurology, Neurology Clinical Programme HSE/RCPI

CRITICAL ISSUE 1: GROWING OUTPATIENT WAITING LISTS IN NEUROLOGY

NEUROLOGY WAITING LISTS HAVE ALMOST DOUBLED OVER THE PAST FIVE YEARS AND CONTINUE TO INCREASE

Neurology services, hospital-based services for the diagnosis and treatment of neurological conditions, had one of the highest OPD waiting lists pre-pandemic with waiting times of up to two years to see a neurologist becoming an all too frequent characteristic of the service.

Neurology waiting lists now stand at almost 24,000 in contrast to 13,517 in 2015 when the Neurological Alliance of Ireland carried out its first national survey of neurology resourcing. The number of people waiting more than 18 months has climbed from 355 in 2015 to 8,601 in 2021.

The spiralling growth in neurology waiting lists is of concern for two reasons:

1. The COVID19 pandemic is only partially responsible for the increase in neurology waiting lists. Neurology already had one of the highest waiting lists of any specialty pre-

pandemic and waiting lists were already at 22,260 in January 2020 before the onset of the pandemic with 5,928 people waiting for more than 18 months.

2. Neurology services simply do not have the capacity to address pent-up demand resulting from the pandemic. Without significant intervention, waiting lists will continue to remain unacceptably high.

The Neurological Alliance of Ireland are calling for targeted investment in neurology services to tackle waiting lists. Investing in more nurse specialists in neurology is a cost-efficient way of addressing these challenges. Evidence from the UK demonstrates that nurse specialists in neurology can reduce consultant neurologist outpatient time by 40% assuming responsibility for monitoring and adjusting medication, and reducing (re)admission rates by 50%⁹.

Nurse specialists in neurology have a very significant impact on patients, increasing accessibility of healthcare and improving condition management. Services provided by nurse specialists in neurology include nurse-led clinics, rapid access clinics, telephone advisory services and outreach services. Significantly improving the quality of care at lower cost, mainly by preventing unnecessary admissions, through advice, information, support, counselling and – with appropriate safeguards – adjustments in medication.

Additional nurse specialists in neurology will free up capacity, reduce waiting times and ensure that patients have access to the specialist support they need to manage their conditions. It will also improve the coordination and continuity of care, reduce attendance at A&E, benefiting both patients and the wider health system.

A national survey of neurology services carried out by the Neurological Alliance of Ireland in late 2020¹⁰ showed a shortfall of up to one hundred neurology nurses across Ireland. This is based on the recommended caseload for nurses supporting patients with epilepsy, multiple sclerosis, Parkinson's disease and migraine as well as rare neurological conditions such as Huntington's disease and motor neurone disease.

⁹ Royal College of Physicians. *Local adult neurology services for the next decade. Report of a working party.* London: RCP, 2011

¹⁰ *Resourcing of Neurology Services in Ireland Five Years On 2015-2020: Key Findings From the Neurological Alliance of Ireland 2020 Survey of Neurology Services (March 2021)* Neurological Alliance of Ireland

CRITICAL ISSUE 2: THE DEARTH OF NEUROREHABILITATION SERVICES IN IRELAND: THE BARRIER TO EFFECTIVE TRAUMA, STROKE CARE AND EFFECTIVE USE OF ACUTE BEDS WITHIN THE HOSPITAL SYSTEM

Neurorehabilitation services represent a continuum of care from specialist inpatient rehabilitation to long term community supports aimed at preventing further disability and promoting recovery for people with neurological conditions.

Ireland has less than half the 288 specialist inpatient beds required for its population¹¹: all of which are concentrated in a single national centre resulting in long waiting lists and lengthy stays in acute hospitals for patients requiring neurorehabilitation as a result of trauma, stroke and other neurological conditions.

An analysis of HIPE data from 2017 showed that of the over 18,000 patients were admitted to acute hospital with neurological conditions only 1.5% of these people were discharged from hospital to a rehabilitation facility. Only 9% of major trauma patients in 2017 were discharged to specialist rehabilitation services¹².

Community neurorehabilitation services are critically underdeveloped: an issue that came to the fore during the pandemic when it became clear that there were huge gaps in community supports for patients being discharged from hospital.

The publication of the National Neurorehabilitation Strategy in 2011 and the release of a three-year Implementation Framework (2019-2021) almost a decade later, has seen little improvement in service provision:

- Less than thirty new specialist rehabilitation beds have been introduced since the Strategy was first published in 2011.
- Only two additional community neurorehabilitation teams have been funded despite a commitment in the 2019-2021 implementation framework to provide a minimum of one team in each of the nine CHO (Community Health Organisation) areas nationwide

- There has been no investment to develop new community neurorehabilitation services in response to the huge gaps in areas such as day services, vocational services and transitional and long-term care.

Neurorehabilitation services will be required to meet the backlog of new and existing patients who were unable to access neurorehabilitation services during lockdown. This was due to a combination of factors (i) patients discharged early from acute hospitals and who didn't get access to post-acute rehabilitation in the acute setting due to the COVID-19 outbreak, (ii) patients who did not get access to rehabilitation because of early discharge home (rehabilitation facilities were only admitting from acute hospitals) and (iii) patients with neurorehabilitation needs who had limited or no services in the community due to the redeployment of health and social care professionals.

The Clinical Advisory Group for Neurology in their 2020 consensus statement¹³ outlined that: *“Neurorehabilitation services have been curtailed within both hospital and community settings. The COVID19 epidemic will also place additional pressure on existing services, as those hospitalised will require extensive rehabilitation. Neurological consequences of COVID19 are also anticipated. Additional resourcing of rehabilitation services will be essential to maintain services”*.

¹¹ Model of Care for Specialist Rehabilitation Medicine (2018) Clinical Strategy & Programmes Division. Health Services Executive

¹² Major Trauma Audit National Report (2018) National Office of Clinical Audit

¹³ Consensus Statement on Neurological Care Post COVID19 Lockdown (June 2020) Clinical Advisory Group on Neurology, Neurology Clinical Programme HSE/RCPI

CRITICAL ISSUE 3: OVERWHELMING DEPENDENCE ON NOT-FOR-PROFIT ORGANISATIONS STRUGGLING WITH SUSTAINABILITY

Long term neurological care services in Ireland are critically dependent on a network of patient organisations which provide the only long-term care in the community for people with neurological conditions. These are extremely wide ranging but include services such as specialist helplines, self-management programmes, key worker and case manager roles, vocational, respite and residential care services as well as information and training for healthcare staff in the community.

Successive funding cuts and an ongoing shortfall in statutory funding in order to fund the true cost of providing services mean that the not-for-profit neurological sector is struggling to survive year on year. Demand for the services provided by patient organisations continues to grow but the cost of providing these services has increased: including because of increased insurance costs, increased costs involved in complying with regulations/standards etc. In 2020, not for profit organisations faced

a further increase in demand for their supports with the onset of COVID19 and the closure/curtailment of other services.

“The vital importance of not-for-profit organisations in the delivery of everyday care for neurological illness in this country cannot be overstated. They contribute millions each year from fundraised income without which neurological care in this country could not be sustained”

(Professor Orla Hardiman: National Clinical Lead for Neurology¹⁴)

The threat to the sustainability of not-for-profit neurological patient organisations has serious implications for neurological care in Ireland with these organisations providing the crucial infrastructure of community and long-term specialist support for people living with neurological conditions. Any closure/curtailment of service provision by even a single patient organisation in this sector has a devastating subsequent impact on the care and treatment available to patients with that condition.

The Neurological Alliance of Ireland is calling for Section 39 organisations to be protected from any cuts in 2022 and that sustainability supports for the community and voluntary sector introduced in the wake of COVID19 are continued for as long as restrictions continue to impact on public fundraising. A report published by the National Economic and Social Council¹⁵ has highlighted the overwhelming response of voluntary sector health and

social care providers to the COVID19 pandemic. It acknowledges that this response should provide a catalyst for a new relationship with the voluntary sector.

For the Neurological Alliance of Ireland, implementation of the recommendations of the Independent Review Group on the Role of Voluntary Organisations¹⁶ is critical to addressing the systemic challenges facing not for profit organisations providing vital health and social care services for people with neurological conditions and their families.

¹⁴ M Submission to the Special Oireachtas Committee on COVID19 response (July 2020) Neurological Alliance of Ireland

¹⁵ Building a New Relationship Between Voluntary Organisations and the State in the Health and Social Care Sectors: Paper from the Dialogue Forum with Voluntary Organisations (June 2021) National

Economic and Social Forum

¹⁶ Report of the Independent Review Group established to examine the Role of Voluntary Organisations in Publicly Funded Health and Personal Social Care Services (October 2018) Government Publications

LONG COVID PATIENTS AND NEUROLOGICAL CARE

“Evidence strongly suggests that patients surviving COVID-19 are at high risk for the subsequent development of neurological disease”

(Journal of Alzheimer’s Research & Therapy June 2020¹⁷)

“We are facing a secondary pandemic of neurological disease”

(Robert Stevens, Associate Professor of Anaesthesiology and Critical Care Johns Hopkins Medicine, Baltimore¹⁸)

There is increase worrying evidence of the emergence of a significant cohort of patients with neurological needs as a consequence of COVID19¹⁹. Evidence is increasingly emerging that COVID-19 is a disease with significant neurological consequences with research suggesting that over a third of patients may suffer neurological sequelae^{20,21}. Neurological consequences with a long-term impact include cerebrovascular events (stroke), hypoxia, extreme fatigue and cognitive impairment.

Long-term neurological complications arising from COVID-19 will present to already overstretched neurology services with long waiting lists. These patients will also require access to specialist neurorehabilitation services which were already completely inadequate to meet demand pre COVID and in no position

to address additional demand. It is estimated that 5% of COVID19 patients will need focused, ongoing, intensive specialist rehabilitation²². This does not include patients in the community who missed out on rehabilitation due to COVID19 and those deconditioned due to long periods of cocooning. Planning for supports for long COVID patients must take into account the additional demand on neurological care services already struggling with the capacity issues highlighted throughout this submission.

¹⁷ Heneka et al (2020) “Individual and long-term consequences of COVID-19 infections for the development of neurological disease. *Alzheimer’s Research & Therapy*: 12: Article 69 (June 2020)

¹⁸ How COVID-19 can damage the brain <https://www.bbc.com/future/article/20200622-the-long-term-effects-of-covid-19-infection>

¹⁹ Neurological Associations of COVID19 (2020) *The Lancet*: Sept (1) Volume 19, Issue 9 p.767-783

²⁰ Henecka et al (2020) Immediate and Long-term consequences of COVID-19 infections for the development of neurological disease. *Alzheimer Research & Therapy* (12) 69 (April 2020)

²¹ Lancet Editorial: The Neurological Implications of COVID-19. June 2020 (19)

²² Rehabilitation in the Wake of COVID-19: A phoenix from the ashes. *British Society of Rehabilitation Medicine (BSRM)* April 2020

NAI MEMBER ORGANISATIONS

Acquired Brain Injury Ireland

Alzheimer Society of Ireland

An Saol

Aphasia Ireland

Ataxia Foundation 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

National Council for the Blind

Neurofibromatosis Association of Ireland

Neurology Support Centre

North West MS Therapy Centre

Parkinson's Association of Ireland

Peamount Healthcare

Polio Survivors Ireland

PSPA Ireland

Slanu Stroke Rehab

Spinal Injuries Ireland

Spina Bifida Hydrocephalus Ireland

The Rehab Group

Associate Members

Brain Tumour Ireland

*Syringomyelia Chiara Malformation
Support Group*

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