Research on carers of people with neurological conditions

At least 700,000 people in Ireland have a neurological condition.\(^1\)

The Neurological Alliance (UK) report estimates that 1.5% of the population cares for someone with a neurological condition. According to this estimate, this represents over 60,000 people in this country.

Carers of those with neurological conditions have been found to experience significant stress and burden as a result of their caring role. Comparisons have been made in research studies both between neurological conditions and between these conditions and other chronic illnesses in terms of the burden placed on the caregiver. In many cases, there is an increased perceived burden of care associated with the cognitive and behavioural changes in some neurological conditions such as acquired brain injury, stroke and dementia.\(^2\) Physical care, associated with disabling conditions like spinal cord injury, is associated with less perceived burden by carers than the impact of behavioural and cognitive changes associated with conditions such as acquired brain injury.\(^3\) However, all aspects of care contribute significantly to the burden on the carer and the effects on their health and wellbeing.

Isolation and stigma are factors associated with neurological conditions that impact significantly on carers of these individuals. Isolation has been shown to be a significant problem affecting carers of people with dementia and acquired brain injury.\(^4\)

The pattern of physical, cognitive and emotional/psychological effects of neurological conditions on the individual can present a bewildering complexity for carers, most of whom will be dealing with the effects of a neurological condition for the first time in their lives. In particular, personality and behaviour changes, loss of intellectual functioning and depression can lead to a perception that the person they once knew is no longer the same. This “loss” of selfhood is a distinctive aspect of some neurological conditions and can represent a significant difficulty for carers.


\(^3\) Carers Perspective on respite for persons with acquired brain injury. Chan J (2007) International Journal of Rehabilitation Research: 30(2) 137-146

\(^4\) Quality of life and well being issues for people with traumatically acquired brain injury and spinal cord injury, and their unpaid carers (Gething et al.2000) Australian Ageing Research Directory

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The situation facing Irish carers

Carers of people with neurological conditions in Ireland face the lack of specialised personnel crucial to enabling them to understand and manage the impact of the condition. There are acute shortages of all personnel involved in the multidisciplinary management of neurological conditions, from consultant neurologists to clinical nurse specialists, occupational, speech and language and physiotherapists. Critically, specialist teams based in the main neuroscience centres are not properly resourced to manage the workload of ensuring long term care and management of people with neurological conditions, and the specialised community teams which should ensure this long-term follow up are not in place for the majority of neurological conditions.

Many neurological conditions are chronic conditions which require long term care and treatment. The co-ordination of such long term care presents a difficulty, particularly when the condition is complex, requiring multiple specialities to be involved. Physical, intellectual and psychological effects of neurological conditions require specialised care that should be integrated throughout all stages of diagnosis and treatment. Unfortunately, such specialised multidisciplinary teams are not in place for many neurological conditions and the result is that carers face difficulty accessing and co-ordinating services. Particular difficulties are experienced at key transition points, such as when a child enters adult services, or when a progressive neurological condition deteriorates so that the person requires residential care. The lack of integrated care pathways and a single key worker to co-ordinate this transfer means that the person and their carer risk falling between the gaps in service delivery.

The recently published National Stroke Audit\(^5\) pointed to the lack of a range of services for the management of the acute, intermediate and long term effects of stroke. These include multidisciplinary management in an acute hospital stroke unit, intermediate access to rehabilitation and long term follow up in the community through the work of specialist stroke rehabilitation teams. Many of these findings are equally relevant for a range of neurological conditions.

While most people with neurological conditions can be accommodated with adequate support in their own homes, the lack of specialised residential care is a significant problem for many carers. Appropriate residential care for late-stage progressive neurological conditions and severe acquired brain injuries is a key component of the treatment pathway for people with neurological conditions. There is a significant lack of such specialised facilities in Ireland.\(^6\)

In the previous section, it was pointed out that the complex range of consequences of a neurological condition can present a very difficult challenge for carers who lack information and training on dealing with the effects of the condition. Specific coping

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\(^5\) National Audit of Stroke Care (April 2008) Irish Heart Foundation in Association with the Department of Health and Children, Ireland

\(^6\) Report of the working group on the needs of people with significant disabilities, Unpublished report, Department of Health and Children, Ireland.
strategies and management techniques can greatly assist carers in their role of caring for someone with a neurological condition. Voluntary organisations play a key role in this regard, but input is required from neuropsychologists, behavioural specialists and rehabilitation consultants. The numbers of these health professionals in Ireland is significantly below what is required for a population of our size⁷.

Many carers of people with neurological conditions face resource issues in sourcing treatment. The lack of community occupational, speech and language and physiotherapy means that private treatment sometimes has to paid for to supplement the service available in the community. This is often critical to prevent the deterioration of the condition from lack of appropriate intervention. In many cases, this specialised treatment is simply not available. There is also significant geographical inequity in relation to the provision of services for people with neurological conditions with many services, including the only specialised inpatient centre for neurorehabilitation, based on the East coast.

Transport presents particular difficulties for people with neurological conditions and their carers. Accessible, quality public transport is not available in most parts of the country and only a limited transport service is provided by the health services. The location of neurology services in large population centres means that people have to travel long distances, not only for diagnosis but for long term treatment of their condition. The location of a single centre for specialised rehabilitation of neurological conditions in Dun Laoghaire means that carers are faced with long journeys or even relocating for weeks or months at a time to be near to their family member.

To summarise, carers of people with neurological conditions in Ireland are faced with a number of difficulties:

- Lack of specialised personnel to diagnosis and manage neurological conditions, both in the hospital and community
- Lack of integrated care pathways for the management of long term chronic neurological conditions
- Geographical inequity and difficulty in accessing neurology services
- Complex physical, intellectual and psychological effects associated with many neurological conditions creating a burden for many carers
- Social isolation and stigma associated with many neurological conditions
- Lack of specialised services at different parts of the care pathway, including the

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⁷ White book on Physical and Rehabilitation Medicine In Europe (Sept 2006), European Board of Physical and Rehabilitation Medicine
The Neurological Alliance of Ireland

The Neurological Alliance of Ireland represents over 20 voluntary organisations working with people with neurological conditions and their families. The NAI has produced a series of three documents, outlining Standards of Care for People with Neurological Conditions. The documents are unique in achieving the input of all the specialists involved in the provision of services to people with neurological conditions, together with voluntary organisations, in a partnership approach. The documents outline in detail a number of issues facing people with neurological conditions and their families and carers. Dealing with the diagnosis of a condition, managing the physical, intellectual and psychological consequences and issues such as relationships and stigma are discussed in detail. Specific recommendations are provided as to how services can be better designed and resourced to meet the range of needs of individuals and their families. The Standards of Care provided a blueprint for the design and delivery of services for people with neurological conditions which is person and family centred in its approach.

The publication of the Standard of Care documents led to the commissioning of a review of neurology services by Comhairle na nOspideal (now the National Hospitals Office) in 2003. This report recommended the development and resourcing of neurology services in Ireland, most importantly the appointment of more consultant neurologists, the development of multidisciplinary teams and a review of neurorehabilitation services.

The recommendations of the Standards of Care and the National Hospital’s Office (Comhairle na nOspideal) report are also reiterated in the Strategic Review of Neurology and Clinical Neurophysiology Services carried out by the HSE in partnership with stakeholder groups involved in the provision of neurology services, including the Neurological Alliance of Ireland. This review was completed in December 2007 and submitted to the National Hospitals Office. The Neurological Alliance is calling for this report to be published and implemented in full.

Recommendations

Significant investment and development of services for people with neurological conditions in Ireland are crucial to ensuring the wellbeing of carers of people with these conditions. At present, they face significant difficulties in accessing specialised care and co-ordinating the different services required. Neurological conditions are unique in the range of physical, intellectual and psychological effects associated with them. As such, they present a significant challenge to carers and their families.

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8 Standards of Care for People with Neurological Conditions (1999-2002), Vol I to III, Neurological Alliance of Ireland
The Neurological Alliance of Ireland makes a series of recommendations for carers of people with neurological conditions whom research has shown to be at significant risk for increased burden and anxiety associated with their role.

These include:

- The implementation of the recommendations of key reports in this area, including the Strategic Review of Neurology and Clinical Neurophysiology Services, the Comhairle na nOspideal report on Neurology and Neurophysiology Services and the National Stroke Audit, will be crucial to improving the welfare and quality of life of people with neurological conditions and their carers in Ireland.
- Appointment of specialist multidisciplinary teams, both in the hospital and community, to manage the long term care of people with neurological conditions.
- Appointment of a specialist keyworker to liaise with the family and ensure coordination of the range of services required.
- Key personnel such as clinical nurse specialists, rehabilitation assistants and neuropsychologists are crucial to inform and support carers in the management of neurological conditions.
- Voluntary organisations need to be developed and resourced in their unique role of providing specialised support and training for carers of people with neurological conditions.
- The training, support and provision of information to carers must be seen as a key aspect of the delivery of services to people with neurological conditions.
- The carer should be consulted at each stage in the planning and delivery of services to the individual with a neurological condition and be involved in any decisions about their care.

Submitted by the Neurological Alliance of Ireland, April 2008