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News Features

Fulfilling a duty of rehabilitative care

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It is said that a society can be judged by how it treats its most vulnerable members. The Medical Independent reports that when it comes to providing appropriate rehabilitation services, Ireland is neglecting its duty of care.

Almost 20 per cent of the Irish population have some form of disability and it is estimated that thousands are suffering in silence with a neuro-disability. Despite this, Ireland has the lowest number of consultants in rehabilitation medicine in Europe and just one specialist rehabilitation centre, which is 50 years old.

The National Rehabilitation Hospital (NRH) in Dunlaoghaire has 150 patients on its waiting list, some of whom have been waiting for up to a year. Because of a lack of specialists and in-patient beds, those with the most complex needs are often forced to wait the longest. Perhaps even more telling is that despite the granting of planning permission three years ago for a new 235-bed purpose-designed rehabilitation hospital on the NRH site, the Department of Health and the HSE have yet to sanction the build.

Ireland currently has the lowest number of physical and rehabilitation specialists in Europe. While the European average is approximately 3.3 consultants per 100,000 population, Ireland has languished at the bottom of the table for quite some time with just 0.17 per 100,000 citizens. Croatia has the highest number of specialists in the field in Europe, followed by Latvia and the Czech Republic.

Our nearest neighbours the UK, against which Ireland's health service is regularly pitted, has the second worst ratio of rehab consultants to population in Europe.

Dr Áine Carroll was recently appointed National Clinical Lead for the HSE's rehabilitation medicine programme and is also a former Chair of

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the Medical Board at the NRH in Dunlaoghaire.

A consultant in rehabilitation medicine at the NRH and St Vincent's University Hospital in Dublin, Dr Carroll is one of just six consultants working in rehabilitation medicine in Ireland today, one of whom is in a temporary position.

According to Dr Carroll, when discussing the need for more consultants and beds in rehabilitation medicine, Ireland regularly quotes from the British Society of Rehabilitation Medicine guidelines. However given that our consultant staffing levels are second only to the UK, this means that Ireland is aspiring to be the second worst in Europe.

Targets

"Even when we make recommendations about staffing levels and numbers of in-patient beds we are told that we are reaching for the stars and we are not; we are actually reaching for the bottom," Dr Carroll remarked.

She advised that we should be reaching for the stars. However that would mean increasing the number of consultants from 0.17 to approximately seven per 100,000 and Dr Carroll feels that the cost of such a rapid expansion would be prohibitive.

In fact, with just six consultants – five of whom are based in Dublin – Ireland does not even have the recommended minimum 27 posts which would be required to provide an effective rehabilitation service.

The chronic lack of services throughout the country means that all six of the consultants in rehabilitation medicine here are forced to split their time between acute hospital attachments, community-based sessions and their own specialist areas.

"Each of us has an acute hospital attachment and some of us have community-based sessions. Two of my colleagues do sessions with Enable Ireland, for example, but all of us are split three ways. Another consultant is involved with disabled drivers; each of us has got an area of special interest. I would be one of four brain injury consultants. I have one spinal injuries colleagues and one prosthetic, orthotic and limb absence colleague," Dr Carroll explained.

As five of the six consultants are based in Dublin, Dr Carroll and her colleagues also try to provide as many outreach clinics as possible around the country. However limited manpower makes this extremely difficult.

"There is only so much that one can do. I think we have to be very realistic about that. Six specialist consultants for an entire country is not just inadequate, it is ridiculous," she said.

Dr Carroll said there is a need to develop acute neurological rehabilitation services on site at the two neuroscience centres in Beaumont Hospital in Dublin and at Cork University Hospital. She predicted that Beaumont would see two-thirds of all neurosurgical cases and a third of cases would be seen at the Cork unit.

"In the States they talk about Trauma 1. You can't be a Trauma 1 centre



Dr Anthony O'Connor
Patients deserve the truth

Dr Christine O'Malley
Inanimate aggression

Dr Paul Heslin
HSE's '1984' move on GPs

Dr Sara Burke
Stand-off on free GP care

without on-site acute rehabilitation so in this country we don't have any Trauma 1 centres. For that matter we don't have any major trauma networks in this country. What happens if you have a head injury and a spinal cord injury? Who is going to make the call? Do you go to Beaumont or the Mater? You could end up going to a district general hospital with no in-house expertise."

This is not rocket science. We know that the outcomes are much better when you have centres with appropriate expertise, she added.

Dr Carroll's view is supported by the findings of a recent UK study published in the Journal of Neurosurgical Anesthesiology. The study on the effect of specialist neurosciences care on outcome in adult severe head injury has shown that following severe head injury, mortality rates are higher when the patient is not treated in a specialist neuroscience unit.

According to the researchers, the "data support current national [UK] guidelines and suggest that increasing transfer rates to NSUs [Neuroscience Units] represents an important strategy in improving outcomes in patients with severe head injury".

In Ireland today if someone suffers an Acquired Brain Injury (ABI) in Donegal or Sligo, they are transferred to Dublin for treatment. Dr Carroll said the time taken to transfer the patient results in "a significant delay" before they can be assessed by a rehabilitation medicine consultant.

Dr Carroll said there is also a requirement to develop regional centres and a hub-and-spoke model for rehabilitation services in Ireland, which is something that both she and her colleagues at the NRH have been advocating for some time.

Like so many medical emergencies, time is of the essence following an ABI and any delay can have a detrimental effect on the long-term outcome for the patient.

According to Dr Carroll, one of the most important roles consultants in rehabilitation medicine have in an acute setting is in assessing the patient as soon as possible post injury. This is particularly vital to avoid further complications. Consultants like Dr Carroll can advise on issues such as fracture, spasticity and pressure sore avoidance as well as the management of neuro-behavioural complications.

"Patients, mainly with traumatic brain injuries, are agitated and in a state of, what we call, post-traumatic amnesia. We can give advice about how to manage these cases."

There can also be continence and quality-of-life issues. The patient may also be subject to the inappropriate prescribing of sedating medication. Apart from the very obvious human costs for individual patients and their families, a delay in accessing specialist treatment can also have financial consequences, which manifest in an increased length of stay.

It is estimated that up to 18 per cent of people in Ireland have a disability of some kind, with the main ones being cardiovascular or musculoskeletal. While neurological disabilities are less prevalent, they tend to be more severe and affect a larger proportion of young people. However a dearth of any real Irish data means that the prevalence of neurological disabilities in Ireland is almost impossible to quantify.

“Acquired brain injury really is a silent epidemic in this country. Most of those individuals with ABI will never have access to rehabilitation medicine expertise because they simply never get referred. A lot of ABIs would go to casualty and never be admitted in the first place,” Dr Carroll stated.

Epidemic

The lack of any real Irish data also makes it impossible to quantify how many people with ABI have not received adequate care. However Dr Carroll said it was likely to be in the 1,000's.

“If you think that there are approximately 11,000 strokes in the country every year, you can multiply that by two to include all causes of ABI. It is probably going to be higher than that but we don't know because our data collection is so poor.”

Dr Carroll explained that while the most complex cases are appropriately referred to specialists like herself and her colleagues, the lack of manpower means that they simply cannot access the 1,000s who may be suffering in silence.

“If there was a critical mass of us to screen, ideally we would like to be hearing about the people who haven't been admitted from ED, to have a follow-up clinic just to make sure that none of these people are having any difficulties.”

Dr Carroll said that the hidden disabilities following mild traumatic brain injuries can lead to ongoing difficulties for many years. These can include cognitive deficits, problems with attention, concentration, memory and personality changes. A sufferer can also have difficulty in planning, organising and sustaining relationships. Issues such as fatigue and depression are also common.

Mr Kieran Loughran has been CEO of Headway for the last five years. The charity provides support and services to people affected by ABI.

According to Mr Loughran, in that time, services for those affected and their families have “stood still” and the lack of any real data on the exact number of people affected in Ireland serves to further hamper developments.

He said it has been recognised that services for brain injured people in this country are “inadequate” and he pointed to a dearth of community-based services as another example of how the needs of these most vulnerable people are being ignored.

Mr Loughran explained that, in general, there is a four- to five-year gap between the onset of injury and the time those affected approach organisations like Headway seeking support.

He explained that the reason for this time lapse is multifactorial and includes the fact that, for seriously ill patients and their families, surviving and recovering from the initial brain injury obviously take priority.

“Very often they have to recover from the first trauma of the accident. At one stage we had a hospital-based service and when we heard of head

trauma cases, we would go to the family and they wouldn't want to know, understandably... they didn't want to talk about brain injury and ongoing life with brain injury, [they] just wanted to make sure that the person survived," Mr Loughran said.

Headway provides a range of community-based services for all those affected by ABI, from counselling for the client and their loved ones, to rehabilitation and therapeutic supports to help the sufferer return to work. The charity also provides day rehabilitation services for those more profoundly affected by brain injury.

We provide counselling and support for both the family and the person. The consequences of that person not knowing or recognising their family has a profound impact on the family, children, wife or husband of the person affected, Mr Loughran explained.

According to Mr Loughran, for some ABI sufferers, it is a matter of "learning the whole process of living all over again".

Mr Loughran said "the lucky ones" are admitted to the NRH in Dunlaoghaire, while the "unlucky ones" are those treated in an acute hospital and discharged back into the community once their visible wounds have healed.

Like Dr Carroll, Mr Loughran said that ABI has been dubbed the "silent epidemic" as, for some, the consequences of an injury may not manifest for weeks or months. According to the Headway CEO, those sufferers who are discharged from an acute setting once the immediate acute stage of their illness has passed, are in real danger of being simply "forgotten" or "lost to the system".

"If you are in hospital, you are in the system. When you leave hospital you are out of the system. The injury can manifest itself in many ways – by violence, drug addiction, inappropriate behaviour, the whole brain has been scrambled."

"I could bang my head doing some DIY at home and just continue on as if nothing has happened. Then a month later something might happen and I start behaving strangely or odd. People brought into A&E are not always scanned for brain injury, it may manifest itself later," he added.

Again the lack of epidemiological studies in this area makes it impossible to know just how many ABI sufferers are lost to the system in this way, and Mr Loughran said that this information gap desperately needs to be addressed.

Like most voluntary agencies fighting for survival in the current economic climate, Headway's budget has reduced by approximately 10 per cent over the last three years.

Funding for disability services was somewhat spared in Budget 2011, being cut by just 1.8 per cent, a relatively lower reduction compared to other areas in the health budget. However the overall budget was cut from €1,582 million in 2010 to €1,554 million in 2011 and the amount spent by the HSE in the voluntary sector was cut from €411 million in 2010 to €391 million in 2011.

The exact figure spent on rehabilitation services for individuals with ABI is

not specified in the HSE's 2011 Service Plan. However Mr Loughran said that even if the figure has quadrupled, it would still not be enough to provide the level of services that people need.

He said that in the current economic environment where funds are limited, it was important to encourage those within the sector to find a smarter way of working i.e. make the most of what little resources they do have.

"Or as the Government are saying, do more with less," he stated.

Mr Loughran added that as brain injury affects "every part" of a person's life, inter-departmental working at Government level is also important

NRH

The NRH in Dunlaoghaire, which this year celebrates its 50th anniversary, is the only specialist rehabilitation hospital in the country.

The Sisters of Mercy originally purchased the current building in 1916 and opened it on February 11th 1918 as a TB sanatorium. In the 1950's, with the demand for TB services on the wane, the Order, together with a number of visionary doctors including Dr Thomas Gregg, established a hospital for the provision of rehabilitation services. The hospital was, and still is, a unique self-contained rehabilitation unit, the only hospital of its kind in Ireland.

Before the advent of the NRH, Irish patients suffering from spinal cord injury were sent to Stoke Mandeville in the UK for treatment. The first paraplegic patient, a victim of a road accident, was admitted to the NRH in 1961.

In 2008 the NRH received full planning permission for a new 235-bed purpose-designed rehabilitation hospital but three years later, funding has still not been made available.

"The hospital continues to advocate for the new hospital which is in line with its recommendation for the development of a hub-and-spoke model for rehabilitation services in Ireland, as outlined in the hospital's submission to the Working Group for a National Strategy for Rehabilitation," the NRH stated.

The pre-tender estimate in 2008 for the new project was €124 million, which in today's economic climate could arguably be less, and the completion time was three to four years.

The NRH has said that planning approval has been granted for the new hospital to be built on a greenfield site within the existing hospital campus. This allows the NRH to remain fully operational and continue service provision to patients with minimal disruption while the new hospital is being constructed.

So why, three years after full planning permission has been granted and the need for more in-patient rehabilitation beds is so painfully clear, has the HSE or the Department of Health not sanctioned the build?

The Medical Independent put this question to HSE Dublin Mid-Leinster and was told that "such developments were put on hold pending the

completion of a review entitled the National Policy and Strategy for the Provision of Neuro Rehabilitation Services in Ireland 2011-2015. The report was commissioned jointly by the Department of Health and the HSE.”

The Medical Independent then asked the HSE Dublin Mid Leinster for more detail on this review and if the Executive could explain why the redevelopment of the NRH is dependent on its publication. However, at the time of going to print, this publication had not received a response to this query.

Dr Carroll said that, with the go ahead from the HSE, work could begin on the new hospital in less than a month.

Consultant-led rehabilitation programmes at the NRH are tailored to meet the individual needs of adult and paediatric patients in the following areas: Brain injury (including traumatic and non-traumatic brain injury, stroke, and other neurological conditions); spinal cord system of care (including traumatic and non-traumatic spinal cord injury); Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) and paediatric-family centred rehabilitation.

There are currently 110 beds available for in-patient admissions: 47 beds for patients with ABI, including stroke and 38 dedicated to those with spinal injury. Seventeen beds are reserved for amputee and limb absence patients and the hospital also has eight paediatric beds.

Waiting times

The waiting times for the hospital's four care programmes vary and while the overall wait time is not excessive, the low volume and high care needs of the most dependent patients mean that they are the ones who face the longest wait.

Dr Carroll explained that the waiting time for admission to the NRH's neuro-behavioural unit for patients with complex needs can be longer than other programmes and is currently approximately 18 weeks.

Even more striking however, waiting times for admission to the hospital's disorder of consciousness service for individuals who have suffered very severe brain injuries, is up to a year Dr Carroll explained that those waiting to access the disorder of consciousness service at the NRH are very severely compromised and it is very unlikely that they would ever recover to a point where they would regain independence in their activities.

However she said there is a lot that the hospital can do in terms of providing appropriate 24-hour positioning programmes and advice on management to avoid contractures and pressure sores. Medication can also be revised to ensure that clients are not overly sedated and the NRH can also give advice on appropriate stimulation programmes.

“The other thing is that we can assess these people objectively to say how much of them is still inside, which is very reassuring for family members because for the family members, the biggest fear is that these individuals have locked-in syndrome that they are inside but because of their physical

disability they can't communicate. That is their biggest fear. So a lot of what we do in these circumstances is in reassuring them that they are not locked in and that they have got a very severe disorder of consciousness. The amount of peace that that brings to family members is enormous and it is very frustrating that we can not bring them that sort of peace earlier," Dr Carroll stated.

The reason why this invaluable peace of mind cannot be provided sooner is that there are currently just three beds allocated to the disorder of consciousness programme at the NRH.

"It is very labour intensive because we have such a shortage of beds. We can't justify anymore beds because you can make the argument that it is a much better investment of resources to invest that time and effort into individuals who are going to increase their functionality, reduce care costs, hopefully get them home, get them back to work. These are individuals who will never get to that point, so we have to limit the number of beds for that service to three."

"We need to raise the profile of rehabilitation medicine. We have gone through the Celtic Tiger years with no investment and no strategies being funded...and here we are, the Celtic Tiger is gone and we are still waiting. These are the most vulnerable people in our society and our society really owes a duty of care to these individuals. They have long been ignored and it really is time for a revolution in rehabilitation. This has got to change," she concluded.

National Rehabilitation Hospital (NRH) fact file

Over the last 50 years the NRH has cared for more than 35,000 in-patients from throughout Ireland and has reviewed in excess of 250,000 persons in its out-patient services.

Currently there are 110 in-patient beds available at the NRH: –

- 47 beds for patients with ABI, including stroke
- 38 beds dedicated to those with spinal injury
- 17 beds for amputee/ limb absence
- 8 paediatric beds

There are 150 patients (all age categories) on the waiting list for in-patient rehabilitation within the following diagnostic categories:

- Brain injury programme (including stroke)
- Spinal cord system of care
- Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR)
- Other neurological conditions

The average regional HSE % distribution of in-patient admissions is:

- 33 per cent HSE Dublin Mid Leinster

- 24 per cent HSE West
- 24 per cent HSE South
- 19 per cent HSE Dublin North East

The average length of in-patient stay per programme is:

- Brain injury programme: 57 days
- Stroke: 91 days
- Spinal cord system of care: 111 days
- POLAR: 49 days

The average discharge destination for patients who have completed their rehabilitation programme is:

- Discharged home: 80 per cent
- Back to acute hospital for non-medical reasons: 10 per cent
- To residential /nursing care: 10 per cent

90 per cent of in-patient admissions come from the acute hospital sector and 10 per cent come from primary care services.

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