“We need our heads examined”

In March of 2014, we received a letter from our Taoiseach, Enda Kenny, TD (original in Irish) stating:



(English translation)

*The anger, dissatisfaction and frustration that you feel are clear and understood. You are right that Pádraig should be able to receive care here in his own country, the place where his parents and friends live. But, as your experiences show, the health system that we have here at the moment is unsatisfactory; it is not able to provide health care for its patients when they need it most.*

“We need our heads examined” because this country denies its most vulnerable citizens the most basic right to neuro-rehabilitation.

What does this mean? – For our family, and for other families like ours?

A well-known rehab consultant, when asked, how we could affect change and make neuro-rehabilitation a reality for all of those who need it in this country, as long as they need it, said: “Change will come when enough families agitate. It is the families who will be able to drive change.”

So here, today, is my opportunity to do exactly what the doctor ordered.

Three years ago, our son Pádraig had just finished his degree in Irish and History at Trinity College Dublin. He had been the Reachtaire of the Cumann Gaelach. He had been a broadcaster with several Irish language radio stations, he had edited a book and magazine in Irish, he was an Irish champion swimmer and had spent time swimming in a Division 1 college in the US.

The day after we celebrated his 23rd birthday, he went off to Cape Cod on a J1 visa, to take the summer off and to consider the many different options open to him, to plan the next few exciting years of his life.

Less than a month later, on 27 June 2013, on a bright Thursday morning, he cycled to work and was hit by a truck trying to overtake him. A few millimeters, a split second, changed his life forever.

He acquired a catastrophic brain injury.

After two and a half weeks in Cape Cod Hospital where doctors were telling us, his family, that his life would be intolerable and never be meaningful again, after a long protracted negotiation with the insurance company, and an appalling encounter with the local Sheriff, Pádraig was repatriated in an air ambulance, his head secured in a special head protector, strapped to a stretcher with duct tape, his mother squashed behind him, with a styropor box on her knees containing her son’s bone flap (from his skull) on dry ice.

We had decided that if he were to die, it should happen here in Ireland.

What followed was four months in Beaumont Hospital. We learned about something called ‘early neurological rehabilitation’. We learned that there was a waiting list of a year for one of only three beds suitable for our son in the country’s only rehabilitation hospital for a treatment period of just three month.

We were told by consultants in other countries that waiting that long would be irresponsible and grotesque.

We got approval to remortgage our house to pay for early neuro-rehabilitation for our son abroad, but then found out that, being Irish and German, our son would have access to the German health system if he moved there.

Just before Christmas 2013 when families were coming back home from all over the world to celebrate Christmas together, Pádraig went on his second air ambulance flight, this time to Hamburg in Germany to get access to the treatment not available to him here in his country. Our family was split up. Pádraig’s two sisters stayed in Dublin, I moved with Pádraig to Germany, and my wife commuted between the two countries.

Pádraig spent 14 month in a neuro-rehab clinic and was then discharged into our care. We rented an apartment in Hamburg for him, my wife and myself.

Pádraig was prescribed physio, OT, and SLT – about 9 hours per week in total. These were provided by therapists we could select ourselves and who came to our apartment for the sessions. Within weeks, Pádraig had received a therapy table, an extra-long stand-up bed, a MOTOMed with arm trainer, and other equipment – all for his exclusive use.

Pádraig improved so much that in May 2015, we were able to take him on a week-long pilgrimage to Lourdes, involving a 28-hours train journey in the company of 350 other pilgrims. It was the first of several journeys he has undertaken since his accident. Last months, he boarded his first commercial flight since the accident.

When Pádraig returned to Ireland last September, he had to be hospitalized to be assessed for a home care package. He spent four months in the National Rehabilitation Hospital (NRH) in Dun Laoghaire, from where he was discharged home in January – not a given in this country where most young persons with his kind of injury end up in nursing homes.

The home care package covers his care delivered by “Personal Assistants” employed by a service provider who are working in our home without any formal supervision but our own, and outside of any formal regulatory framework. There is no HIQA regulation for home care.

The NRH when compiling their recommendations did not even recommend ongoing neuro-rehabilitation to be delivered in the community – although we repeatedly asked for such a recommendation. While nursing homes receive a top up of around €300 per week for therapies, this is not the case in a home environment – as therapy is supposed to be provided by community therapists.

However, most therapists in the community are not qualified and have no experience to deal with neuro-rehabilitation, especially not in cases of severe acquired brain injury – even if they did have the time to deliver it, which they do not.

Pádraig’s community physio now visits us once a month.

Last week, we received a phone call from the HSE saying that they were going to collect the MOTOMed exercise bike he had received on loan just three months ago.

A recent outpatient appointment in the NRH, one that he had been waiting for for months, turned out to be a form-filling exercise, rather than the beginning of a structured block of neuro-rehab sessions, which is what we had expected.

We know that Pádraig is not alone. In fact, he is probably in a good place compared to many other young persons we have met along the way. Each time he is examined and seen by specialists, they are surprised to see his body in such good shape.

We are working with parents whose sons and daughters did not only NOT receive adequate neuro-rehabilitation – their physical and mental condition actually deteriorated dramatically because of, what I can only call, gross neglect:

* Some had dislocated shoulders because nurses had pulled them up by their arms.
* Some got bed sores because of inadequate care in acute hospital wards – where they had stayed for months and years because there was no adequate neuro-rehabilitation available to them
* Many had dropped feet meaning they would not be able to stand without the help of what they called ‘Garry Glitter’ boots.
* At least one person lost all of their teeth because of a lack of care.
* There is a case where a person with a severe acquired brain injury has never seen a neurologist in 26 years.
* The muscles of many locked up in spasms that can no longer be released leading to terrible wounds.
* One family was told by a consultant the only treatment their son required was nutrition, medication, and hydration.
* Another family was told not to ‘waste’ their hard earned fundraising money on their son, but, instead, to chill out on one of the Canary Islands.
* Yet another family found out that staff were scheduled to check on their son left alone in a nursing home room with closed doors once every hour – when the toilets in the same institution were checked once every 30 minutes.
* In another case, drugs were administered against the expressed wishes of the family.

And the list goes on.

Some time in the future, we will look back at this time of great prosperity and wonder how on earth did we allow the sons and daughters of our families to be left with what just about amounts to the equivalent of an ‘end of live’ treatment.

This scandal must stop.

We must treat people with neurological conditions with dignity and with respect. We must afford them the treatment they require and we must afford them every opportunity to live their lives in their communities.

This requires funding, but, even more importantly, it requires a change of hearts and minds.

We have to make sure that,

* never again will the State be allowed to decide that a citizen will not be afforded treatment and support – because it considers they’re not worth it.
* never again will young (or old) people be neglected to a point where their muscles spasm, their teeth fall out, their feet drop, and their bowel movements are regulated by medication to suit their carers;
* never again will our sick and most vulnerable people be considered by cold-blooded consultants as ‘a bad investment’ for scarce resources.

We will make sure that neuro-rehabilitation becomes a reality, not a strategy or a 5 or 10 year plan. We have had enough of plans and strategies. We cannot wait any longer while our family members suffer.

We ask you for your support for the An Saol Project launched last Saturday. (You can find out more about it on [www.ansaol.ie](http://www.ansaol.ie)) and we ask you, especially, for your support for the brilliant and timely campaign launched today by the NAI.

Because yes, we *do* need our heads examined if we continue our inaction in the light of the suffering of thousands of people with neurological conditions.