



BUDGET 2022

Pre-budget submission

SEPTEMBER 2021





INTRODUCTION

Spinal Injuries Ireland (SII) is the only organisation dedicated to providing support services for the 2,200+ people in Ireland living with a Spinal Cord Injury (SCI), their family members, carers and health care professionals. We estimate that every week in this country, three people sustain a devastating SCI.

The World Health Organisation (WHO) has acknowledged that a SCI is one of the most devastating and life changing injuries that a person can sustain. However, with the right supports and services, a person can live a fulfilled life in the community. SII works in partnership with the Spinal Cord System of Care Programme at the National Rehabilitation Hospital (NRH) to bridge the gaps in the pathway of care to ensure full inclusion in the local community when a person with a new injury returns home.

Unfortunately, in Ireland, there are many obstacles placed in the pathway for people with a SCI, and their families. Regrettably, one of these greatest obstacles is created by the agencies of the State, in the manner in which eligibility for a medical card is determined and awarded. Without a doubt, a SCI is a permanent, life-long, and life changing, condition. In spite of this, the granting of medical cards for those with a SCI in Ireland is based on an assessment of ‘means’, which can be arbitrary, and the maximum period for any card is three years.

The UN Convention on the Rights of People with Disabilities commits state parties to “Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons”.

The core message for Budget 2022 from SII is for the Government to designate SCI as a long-term and permanent condition, and to extend eligibility for the medical card to all of those with SCI, on a permanent basis. We send this message to Government on the basis of extensive engagement with our Service Users, whose direct perspectives are quoted in this submission, as well as their families, the health care professionals supporting them and their families, as well as our own Board and Medical Advisers.

The ‘means not needs’ approach delays or denies treatment and the supply of necessary equipment to many with a SCI. It also contributes to significant stress, financial hardship, erosion of personal dignity and independence and additional physical and mental health challenges. It is an inhuman approach. It must change. Budget 2022 provides an opportunity for such change.

Fiona Bolger

CEO, Spinal Injuries Ireland

1. BACKGROUND

SPINAL INJURIES IRELAND (SII)

Spinal Injuries Ireland (SII) is the only organisation dedicated to providing support services for the 2,200 + people in Ireland living with a SCI.

Our mission is to engage people with a SCI, and their family members. Together, we address barriers to full participation in society and empower our 2,200 service users to work towards achieving personal, social and vocational goals once again.

SII provides a service that is supportive, goal-oriented and individual to the service user. We have a dedicated professional and volunteer team, who provide our key services. We are the only support agency in Ireland that provides a pathway of support, as follows:

- **Case Management:** One to one support and information from a SII Community Outreach Officer (COO). Provides on-going personalised support services for people with a SCI from the time of injury.
- **Community Education Programme:** Addressing the practical and health related needs of those living with a SCI and secondary health issues they encounter
- **Peer Support Programme:** Trained peer volunteers with lived experience of a SCI. They share their own recovery journey and perhaps, most importantly, engendering hope.
- **Psycho-educative Programme:** Addressing the psychological aspect of sustaining a SCI for Service Users and their family.
- **Vocational Programme:** Explore options for education, training and employment
- **Activities Programme¹ :** Supported activities with SII trained volunteers including a boat trip in Dublin Bay, shopping and cinema trips in our special adapted wheelchair bus.
- **SII Resource Centre:** Information and resources centre providing facilities for people with a SCI and their family adjacent to the NRH

¹Since March 2020, all of our activities have gravitated online, with the exceptions of the activities programme. We hope to presently resume this programme, subject to Public Health guidelines

2. INCIDENCE OF SPINAL CORD INJURY IN IRELAND

An extensive review of the epidemiology of SCI was carried out, through two studies, in 2016 and 2017². According to a retrospective study, the number of new cases of traumatic SCI remained consistent, from 53 in 2014 to 61 in 2013 and 2016. This equated to 11.5 and 12.8 per million of the population – one of the lowest incidences in the developed world. The research indicates that an increasing number of older people are sustaining traumatic SCI. On that basis, the mean age at onset is steadily rising – from 44.1 in 2010, to 47.9 in 2013 and 52.8 in 2016.

The primary cause of injury has changed from road collisions to falls less than 2 meters in those over the age of 55. Consistent with the change in age profile and cause of injury, the patterns of injury are also changing. The most common pattern of injury is now incomplete tetraplegia (an injury to the spinal cord in the neck). This generally results in partial but not total paralysis of most or all of the muscles in the body, and usually accompanied by bladder and bowel difficulties.

Up to 2017, non-traumatic SCI had never been previously studied in Ireland. There were 128 new cases in 2017 – more than double those recorded for trauma in any previous year. There was a higher-than-average age onset, at 56.7 years. For the first time, there was a virtual equal gender split, with 50.8% of cases occurring in females.

The most common cause was degenerative conditions of the spine, such as a disc prolapse or arthritic changes in the vertebrae compressing the spinal cord. Tumours were the second most common cause (26%), most of which were from metastatic spinal cord compression or secondary tumours from cancer.

3. IMPACTS OF LIVING WITH A SCI IN IRELAND

“Of the many forms of disability which can beset mankind, a severe injury or disease of the spinal cord undoubtedly constitutes one of the most devastating calamities in human life”

Sir Ludwig Guttman, Founder of the Paralympic Games

In consultation with our service users and other key stakeholders, SII has identified three core priorities, which, if implemented, would make a material improvement to their quality of life.

These are:

- Provision of medical cards, based on need and on a permanent basis
- Implementation of the National Strategy for Neuro-rehabilitative services, including “A National Trauma System for Ireland”
- Automatic approval of funding for home care packages for patients with the most complex needs

Of these, the core priority is the provision of medical cards, based on need and on a permanent basis. In 2019, Dr. Pádraig McNeela³ a Senior Lecturer at the School of Psychology, NUI Galway, published an analysis of a qualitative survey of 272 SII service users.

²Smith, Dr. Emer, “Prospective Epidemiological Update on Traumatic Spinal Cord Injury in Ireland, 2018.

³Spinal Injuries Ireland – Medical Card Survey : Analysis of Qualitative Survey Responses’, Dr. Pádraig MacNeela, Senior Lecturer, School of Psychology, NUI Galway, 2019

The survey was conducted in June and July 2019. The responses are grouped by survey respondents who do have a medical card, and those who do not have a medical card.

Across both groups, there were common perspectives and shared experiences on the challenges of living with a SCI in Ireland. These included:

- Their sense that a SCI is a life-long condition, with complex and varied associated burdens. It should therefore be classified as a life-long condition, similar to diabetes or epilepsy
- Medical challenges as a result of a SCI remain life-long, regardless of the case of injury, and associated with a risk of developing secondary conditions that can be debilitating and even life-threatening.
- In many cases people with a SCI are unable to return to their former employment. In addition, it is common for a spouse or family member/partner to give up their employment in order to care for their family member at home, once they have been discharged from an acute care or rehabilitation setting. As a result, both the individual's and family income can be seriously depleted as a result of the loss of one or more income. It is estimated that 25% of those with a SCI live below the poverty line. ⁴
- Work and employment emerge as a key issue – the role that work could have in improving quality of life and fulfillment, yet people are worried that if they earn too much or work too many hours they may lose their medical card.

We also wish to support a move towards the automatic approval of funding for home care packages for patients with the most complex needs, regardless of age, arising from their SCI. We endorse a centralized approach to the management of home care funding for people with SCI so as to ensure they are not “competing” with patients with less complex conditions, to gain funding from small local budgets. Prompt approval of home care packages (triggered by early clinical assessment of patients with SCI) will ensure that patients can return home once their rehabilitation is complete and avoid excessive time in hospital away from family and loved ones. By avoiding delays in discharge back to their communities, rehabilitation beds become available more promptly for newly injured patients, ensuring more rapid access to rehabilitation.

Finally, we would welcome greater collaboration between disability services and the Department of Housing, Local Government & Heritage, to explore the possibility of local authority housing being made available for shared supported living or as interim discharge destinations.

⁴Spinal Injuries Ireland –Service User Survey, Dr. Pdraig MacNeela, Senior Lecturer, School of Psychology, NUI Galway, 2018



4. NEED NOT MEANS – SCI CALLS FOR MEDICAL CARDS FOR ALL PEOPLE WITH A SERIOUS SPINAL CORD INJURY (SCI)

The vision of Sláintecare is to achieve a universal single-tier health and social care system, where everyone has equitable access to services based on need, and not ability to pay.”

(Sláintecare Implementation Strategy & Action Plan 2021 – 2023, Government of Ireland, 2020)

“Ever since Ireland ratified the UN Convention on the Rights of Persons with Disabilities, we have signaled to those with a disability that we are now serious about making a difference – a difference that will make things better. The ratification raised awareness of the lived experience of people with disabilities, but we have much more to do.

In doing more, we now need to improve the services available through better implementation and by working together across Government in a better way. We want to empower and give those with a disability the ability to choose the supports that most meet their needs.”

(Programme for Government, June 2020)

On the basis of the research, we have undertaken amongst our service users, as well as the ongoing feedback through our stakeholder network, there is a very deep chasm between the aspirations referenced in both of the recent Government documents above, and the everyday experiences of those living with a Spinal Cord Injury in Ireland in 2021.

Dr McNeela’s analysis reveals real difficulties for both those with a medical card, and those who have been deemed to be ineligible for a medical card.

4.1 MEDICAL CARD HOLDERS

Many of the medical card holders outlined the efforts and difficulties inherent in securing and retaining a card, and many write in stark terms about their worries and concerns about losing a card:

- Firstly, in terms of the burdens they are facing which would be insurmountable without a medical card, and;
- Secondly, they feel vulnerable to losing the card – having lost it before, being granted a card on a temporary basis, or they can visualize other circumstances, such as means testing, spousal income or their own employment that would jeopardise their position in the current position (See Appendix 1) The testimonies in Appendix 1 illustrate the constant state of fear and uncertainty which exists for those with a SCI, even when they are granted a medical card. This is due to the arbitrary and opaque process through which an application is considered, as well as the fact that the intervention of a public representative may be necessary in order to reverse a rejection of an application. In addition, it underlines how the current criteria for being awarded and granted a medical card can hamper those with a SCI from seeking to return to work, or to seek to fulfill their true potential in a work environment.

“There is a real requirement for the Government to provide permanent certainty for people with a Spinal Cord Injury. There is an irrefutable need for both a permanent medical card, as well as an adapted protocol to be introduced. This one change in Budget 2022 would make an immeasurable improvement to the lives and welfare of those with a Spinal Cord Injury, and their families “ (Health Care Professionals)

4.2 NON-MEDICAL CARD HOLDERS

While those with a medical card expressed their concerns about its temporary nature, non-medical card holders experience an even deeper level of fear and financial stress. Issues include the sense that there is an invisible disability if one is not in a wheelchair, as well as the impact on a family. There is also an ongoing financial struggle, due to a lack of access of essential care and supports, as well as sometimes dealing with the struggle of rehabilitation. (See Appendix 2 for testimonials)

4.3 COSTS

Each person with a SCI has individual requirements, and it is therefore not possible to identify an 'average' or 'optimum' monthly or annual cost for medical care, equipment, bowel and bladder care, pressure relieving equipment, etc.

The types of additional and specialist requirements for those with a Spinal Cord Injury include:

- Equipment – motorized chair, bed hoist, adaptations to car
- Home adaptations
- Bowel and bladder care – catheters, pads, wipes, specialist bowel/bladder care nurses
- Skin and pressure relieving care – creams, pressure relieving cushions, dressings
- Pain Management
- Foot/leg supports, orthotics



CONCLUSION

Quite simply, the current situation where Irish citizens, with a life-long condition, do not have the basic resources, to provide for items essential for their personal hygiene, mobility, pain management and dignity is absolutely unacceptable and in breach of the UN Convention on the Rights of People with Disabilities.

A Spinal Cord Injury is a permanent condition. SII call on the Government to acknowledge this fact, and to include SCI on the list of long-term conditions in Budget 2022. We also call on the Government to extend the medical card to those with a Spinal Cord Injury, based on need, in Budget 2022.

Appendix 1.

Spinal Injuries Ireland – Medical Card Survey : Analysis of Qualitative Survey Responses’, Dr. Pdraig MacNeela, Senior Lecturer, School of Psychology, NUI Galway, 2019

QUALITATIVE FINDINGS Medical card holders

These are:

- **Spinal Cord Injury should be a recognized illness for medical cards**

“A spinal cord injury is a life long injury”

- **The cost of medical cards would balance out economically, and confer dignity**

“We do not want to be part of a ‘hand out’ culture, but deserve a hand up that will allow us contribute actively to the economic and social system’

- **The scale of the loss associated with Spinal Cord Injuries**

“I am classified as a walker. I have no feeling in my legs and feet. Both feet have collapsed in so I wear handmade boots with leg supports and orthotics and a walking stick. I drive with hand controls, self catheterise, bowel manage etc. I rely on the medical card for pain meds, catheters, bowel meds, specialised foot wear etc.”

- **Medical cards are a necessary support to cope with the challenges involved in having a Spinal Cord Injury**

“Life with a spinal cord injury is very unpredictable. Employment is difficult to secure and our health can change or fluctuate. None of us know what our future can hold, especially as we age..”

- **Compensation and Claims – negative impact on medical card**

“We lost our medical card straight away on receipt of compensation – we were not informed – just could not use it. Others in the same situation didn’t lose theirs.. When appealed .. unsuccessful.. as compensation is classed as means..”

- **Difficulty of getting a medical card – stressful process, repeated applications, not receiving full Medical Card**

“I was refused a Medical Card when first applied. I suffered lots of medical issues re bowel and bladder. I reapplied and contacted (public representative).

Also got my daughter to outline my situation. I am now in receipt of a Medical Card”

- **Repeated applications for medical card over 20 years, unreasonable financial costs and unfairness of economic assessment**

“For the first 20 years post-injury, I did not have a medical card. Over this time my medical costs were significant. I had to pay the full drugs payment scheme costs but this did not cover non-prescription cost for items like examination gloves, suppositories, dressings and bandages for pressure sores, wipes etc. Pressure revealing cushions cost €500 every two years. I bought three wheelchairs in 20 years at a cost of approximately €24,000. I also had to pay for replacement parts which could have been an additional €7,000 over the years. ... Because I had no medical card, I had no access to services and had only recently learnt that the wheelchair I have been using is not appropriate and has been the cause of worsening my condition. ... I applied for a medical card on two occasions ... I was rejected due to my "income" (I failed the means test), notwithstanding my application was on medical need. The means test concluded that I was receiving an income from money I had in the bank ... their assessment calculated that the money in the bank was equivalent to a regular income sum that bore no resemblance to reality. “

- **Uncertainty and fear about the medical card being withdrawn – concern about meeting the high level of ongoing medical and health care need**

“My medical card was granted on hardship grounds, not an entitlement, so I live in fear each year whether it will be renewed or not. I really need it for incontinence pads, chiropody service, public nurse for dressings etc. and walking aids.”

- **Overwhelming fear and concern about the possibility of losing the medical card**

“My first medical card was rejected twice before I finally got approved ... I was penniless at the time and the medical card dept knew this the card I got was a three year card, when it came for renewal this year I received one for 12 months this time. It feels

like a hangman's noose around my neck ... the negative effect this has on my mental health is tremendous. Every time I sit in my chair put on my calipers, slip in a pad or put in a catheter I worry about losing my medical card because I need it for all these things and I can't afford them myself. I'm a dead man if I lose my card plain and simple ... it's inhuman to make disabled people jump through hoops like this for a constitutional right."

- **Difficult experiences of losing the medical card and negotiating the appeals system**

"Medical card was withdrawn for over a year. To the point I couldn't even buy my catheters my partner battled every day to get it back leaving me reusing catheters. I had become unwell and couldn't even afford to go to my GP."

- **Employment and medical cards – Fear of losing the card and not being able to develop full potential**

"This is such a pivotal topic. I have spent years studying, developing myself to get back to a baseline where I can have a successful life. Going back to work and the future possibility of starting my own company put my medical card in jeopardy. I am currently appealing after a failed medical card review. This would have a huge financial impact and set me back so far after all my progress."

"I have been prevented from taking higher grade roles within the public service due to the fear of losing my medical card"

Appendix 2.

Spinal Injuries Ireland – Medical Card Survey : Analysis of Qualitative Survey Responses', Dr. Pdraig MacNeela, Senior Lecturer, School of Psychology, NUI Galway, 2019

QUALITATIVE FINDINGS Non-medical card holders

- **The expenses of medical care, GP visits, prescriptions, mobility aids, professional services and home adjustments**

"A medical card would help me replace medical equipment such as electric wheelchair, bed, hoist, etc. I also have to pay fully for glasses, dental and other items. As a quadriplegic I cannot even get a quote for private health insurance. This means I have to wait on the public waiting lists to see consultants and procedures. I had to wait 18 months to have surgery (had I been seen private it could have been done in two weeks)."

"I am in no receipt of any social welfare assistance it ended on my long term illness benefit after two years. We are a one-income family. State says I'm entitled to nothing I attend doctor and chemist regularly with no support or medical card to help. My GP has started only charging me 20 euros to help me"

"After a spinal cord injury, if one is walking with an aid, no one cares. You are better. People think you

have a sprained ankle. You are NOT. Life is completely changed for you and your whole family. There are huge personal, psychological and financial implications afterwards for the individual and their families. It really feels that no one cares. We are stuck in the middle and it's very, very hard."

- **Barriers to getting a medical card – employment status, family income, pensions, claims, age, uncertainty about entitlement. Self-employment, spousal income, insurance claims, age, or being on pension are also cited by the HSE as reasons for not granting a medical card.**

"I am over 70 and a medical card would greatly ease my situation. I am told I am ineligible because I have a Pension"

"Because of my husband's earnings I'm not entitled to a medical card. I can't apply for disability because of my husband's earnings"

"Medical card withdrawn in the last month due to turning 18 so the impact has not yet been felt."