

## **BUDGET 2024**

### **Pre-budget submission**

Spinal Injuries Ireland (SII) is the only organisation dedicated to providing an evidence-based support service 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 an SCI. The World Health Organisation (WHO) has described it as one of the most devastating and life changing injuries that a person can sustain. However, with the right supports and services, a person with a SCI 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.

**[www.spinalinjuries.ie](http://www.spinalinjuries.ie)**

**Spinal Injuries Ireland (SII) is a support service for people who have been medically certified as having suffered a life changing spinal cord injury. SII is seeking two things:**

- That the provision of medical cards to people with spinal cord injury be based on certified medical needs and not means.
- That the review cycle for medical card holders with a spinal cord injury be on a 10-year basis.

### **What is a spinal cord injury?**

SII supports 2,200 people who live with the ongoing consequences of an injury to their spinal cord.

The spinal cord runs from the base of the skull down to the lower back. A spinal cord injury can occur at any of these levels, with effects corresponding to the level of the injury. Typically, a spinal cord injury leads to diminished function or complete loss of function below the level of the injury.

The diminished function that occurs includes paralysis, loss of bowel and bladder control, chronic pain, muscle weakness and psychological distress. While the levels of injury vary from person to person, it is typical that a person can't walk or has difficulty walking; needs life preserving drugs on an ongoing basis; requires specialist equipment to manage bladder and bowel functions; and is acutely vulnerable to infections and pressure injuries because of their condition. Many need essential equipment like a wheelchair and some need physical support to do simple daily things like getting out of bed and getting dressed.

Despite these difficulties, the vast majority of people with spinal cord injury want to work. They want to participate as effectively as they can and to contribute as much as they can to society.

In preparation for this submission, SII carried out a survey of its service users in July 2023 of whom 70% have a medical card; 30% do not. SII believes that this means that there are approximately 700 people who are deserving of a medical card so that they can access the right care at the right time.

The vast majority (80%) of respondents are of working age but only 33% are working. Almost half (47%) of the people with a medical card said the need to hold onto their medical card prevented them from working.

***“As a rehabilitation physician, the ultimate goal for many of my patients affected by SCI is a return to work. This brings them enormous social, psychological and intellectual fulfilment and a true sense of achievement in the aftermath of life changing injuries. Fear of loss of the medical card is a substantial barrier to return to work and therefore a barrier to achieving their optimal outcome from their rehabilitation.”***

Dr. Eimear Smith, Consultant in Rehabilitation Medicine at the Mater University Hospital and the National Rehabilitation Hospital.

## Ask 1: The automatic provision of medical cards to people with a Spinal Cord Injury based on certified medical needs rather than means.

When someone suffers a spinal cord injury and is medically certified as having a lifelong condition which needs medical support, the first consideration of the health service is that person's financial situation. In the immediate aftermath of learning that one might, for example, never walk again or that one might have to adapt a home or move house to accommodate a wheelchair and that a suite of unforeseen expenses has just been introduced to one's life, the means test is very distressing.

One of the chief considerations of a person with spinal cord injury when it comes to taking up employment is the potential loss of a medical card. The thresholds are low: €164 per week if you are living with your family or €184 if you are living alone. In that context, the application of the means test to a person with a spinal cord injury acts as a disincentive to them being part of the workforce.

A typical response to the July 2023 survey was:

*'The biggest challenge I had engaging in the workforce was the risk of losing my medical card as a result. It is a serious concern for a lot of people as the benefit often does not outweigh the risk.'*

For those whose situations don't allow them to work, the means test is distressing and frightening. These people have practically no chance to improve their financial situation in the event that they are not granted a medical card.

*"This is an arbitrary and inhuman approach which is delaying or denying treatment and the supply of necessary equipment to many people living with a spinal cord injury," said Fiona Bolger, CEO of Spinal Injuries Ireland.*

Distress is not isolated to the injured person. The means test can include examination of the household income thereby involving the whole family in an already stressful situation. This distress recurs every time there is a review.



## **Ask 2: To extend the review cycle for medical card holders with a Spinal Cord Injury to 10 years.**

Medical cards are granted to persons with a spinal cord injury on the basis, firstly of means and secondly as a matter of discretion. That discretion considers the level of a person's injury and their overall circumstances.

70% of spinal cord injury sufferers do have a medical card, which is welcome, many of these are granted on a discretionary basis. Regardless of the basis on which they are granted, all are subject to review. Typically, the reviews occur annually or every three years. In many cases, the review does not involve the cardholder who simply receives the reissued card in the post. In other cases, the cardholder is subject to a rigorous review. SII carried out a survey of all people with a SCI in Ireland in July 2023, 54% of people have been subject to a medical card review. Most find this to be a very daunting experience, especially when the consequences of losing the card can be devastating. Younger people live in fear of losing access to medical services and often only earn to the salary threshold, impacting on their opportunities to develop careers.

In addition, people ageing with a SCI are concerned about the future and what their medical needs may be and as a result this causes undue stress and worry.

It is extremely difficult to make any viable long-term life plans when one is faced with the possibility of a massive, perhaps unbearable, increase in expenses. It is particularly unsettling when this possibility arises annually or, at best, every three years.

SII does not understand any rationale behind the current review cycle. It appears to be an unnecessary burden to place on people whose lives are already very compromised. The sad reality is that the quality of life and the financial circumstances of people with a spinal cord injury tend to deteriorate over time. At minimum, the review cycle is a source of huge stress. At maximum, it is a barrier to full participation in society, be it in the community or the workplace.

**In these circumstances, SII is appealing to Government to immediately extend the review cycle for medical card holders with a spinal cord injury to 10 years.**

### **What does a medical card mean to someone with a Spinal Cord Injury?**

In reality a medical card offers someone with a spinal cord injury 4 essential areas of access to healthcare:

1. Pharmacy – life preserving drugs such as pain killers, spasm control, bowel & bladder supplies
2. Equipment – wheelchair, bed mattress, hoist, shower chair, standing frame, transfer boards
3. Homecare – out of bed support, washing, dressing, help with food preparation and shopping
4. GP/PHN – bowel support, GP visits, dressings, treatment for UTIs and pressure injuries  
(People with a SCI have a higher incidence of UTIs and pressure injuries)

Spinal Injuries Ireland

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