

SPINAL NEWS

AUTUMN 2023

*Market Research
informs SII Strategy*

**Tall Ships Caribbean
Adventure**

**Meet Our New Peer
Outreach Officers**

Safe House – Ukrainian SCI Relief



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WELCOME

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This magazine contains real life features and SII does not endorse any products or services listed within.

I hope you have all had a good summer and are keeping well.

In this issue of Spinal News we are updating you on all that we have been doing over the last few months. I hope you have taken the time to join some of our peer catch ups and education programmes. If not please check out our calendar of events on www.spinalinjuries.ie for upcoming events.

As always, we are extremely grateful to everyone who helped fundraise for us. As you are aware we have to fundraise for 70% of our operational costs and we very much appreciate the support we receive.

This September, we are asking you to join with us in lobbying for change to medical cards for people with a SCI.

You should have received an email from us on this topic, requesting you to contact your local TDs and Senators to make them aware of the issues and to ask them to represent you as their constituent at a briefing in Leinster House on 21st September.

We have two asks for Budget 2024 and we really need your local representatives to support us.

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.

We have detailed the full submission on page 20 in this document so please contact your local representatives and ask for their support.

Let's all pull together to try to get this moving. If you have any questions or suggestions for this grass roots campaign, please email advocacy@spinalinjuries.ie or phone 01-6532180. If you have not received an email, please contact us to ensure we have your correct email address.

We will send you an update after the briefing so we can all continue to lobby for this essential support.

As autumn approaches stay warm and well, and don't forget to check out our upcoming events.

Kind Regards

Fiona Bolger CEO

GEMMA WILLIS – PEER OUTREACH OFFICER



In 2015 my life changed in ways I never would have expected. At the age of 21 I was involved in a car accident.

At an age where you learn so much about life, I went from training to be a pastry chef to being in a hospital bed in a coma. I came out of the coma after 6 weeks when I then started to learn the extent of my injuries. I was so bamboozled as every day I was learning new things about my injuries. I was injured from head to toe which is funny as I have an acquired brain injury and I have no toes as one of my legs is amputated and on the other leg my toes were amputated with loads of injuries in between, the main being spinal cord injury. I fractured C2 in my neck and I broke L4 where I now have metal rods in my back. Yet I've very patchy feeling from T3 down with the limited trunk control as the seat belt ripped all my tummy muscles and burst my bowel and the arteries going to my leg. At 21 you don't expect to hear words like catheter or stoma bag, let alone to have them. I spent 9 months in the Mater where I had 14 operations. We joked after my 13th op how unlucky it was and that maybe I should have another.

I went out to the NRH where I stayed 3 months on the brain injury ward then got transferred down to Our Ladies (spinal ward) and I stayed 4 months. I worked so hard to reach the goals I had set out for myself in the meetings with the teams, goals they didn't think I would reach; "simple things" yet such a change to me like turning in bed or learning to SIC and pulling up your trousers. I celebrated every small milestone over the 16 months and you helped to celebrate your peers' milestones too cheering each other on, learning to sit yourself up or lifting a heavier weight in the gym. I really relied on my peers while in the NRH as at 22, I was the baby of the two spinal wards.

My first memory of Spinal Injuries Ireland was when they were in the portacabin beside the NRH and one morning they were having a coffee morning and myself and one of the ladies went over to it and we chatted away to them. I then got linked in to David when I came home who was a great help to me especially in the early days, when looking for advice about getting back to "normal life".

Jump forward to the start of 2020, I got trained as a peer mentor which I was delighted and excited about, to share some of my positivity with people who needed it, yet we all know what actually happened in 2020, Covid hit. So instead of visiting the hospital as a peer mentor SII started Zoom meetings for everyone linked to SII to chat together. SII then asked me would I like to make some cooking videos with my knowledge for them to share on their socials, plus they showed people you can still cook/bake in a wheelchair.

In 2021 SII planned a trip sailing on a Tall Ship, something I knew I would love to do, yet I sadly had to miss it as I was at home with a pressure sore from the transfer board.

So when the opportunity came up in 2022 and 2023 I signed up straight away. The two trips were just fantastic, making amazing friendships and learning so much about life and myself.

I have loved going up every few months for the pizza nights SII hold in the NRH for the patients and getting to chat in a relaxed environment. SII approached me about interviewing for the position of Peer Outreach Officer which I was delighted to accept. I'm very excited to get started in the NRH and to start mixing with and getting to know the patients. As well as working with a team and helping to be the peer I know I needed and show them your life doesn't end when something tragic happens.

You can contact me on gemma@spinalinjuries.ie

JACK SHANNON COLE – PEER OUTREACH OFFICER

Before my life-changing injury in 2012, I was just an ordinary teenager—attending secondary school, playing sports, and worrying about the usual teenage dilemmas, like how to approach and talk to girls. Little did I know that everything would come crashing down in an instant after a fall, just two days after Christmas.

The accident left me paralyzed, with a broken T8 vertebrae in my thoracic spine. Being so young at the time, I couldn't immediately grasp the gravity of the situation. It took a few weeks to truly comprehend the reality of my new life and the challenges that lay ahead.

For about five weeks, I found myself in Temple Street Hospital, where the supportive staff helped me cope while I waited for a bed at the National Rehabilitation Hospital. Looking back, those days are somewhat of a blur, as denial often clouds the minds of people in our situation. I now realise that I was too hard on myself during that period of adjustment.

The transfer to the National Rehabilitation Hospital was a nerve-racking experience, but it also brought a sense of hope and determination. The paediatric unit, with its six beds, became my new home, and the atmosphere was all about progress and moving forward. From the moment I arrived, it was Go Go Go, and I soon discovered that staying active and engaged was a healthier distraction than passively lying in a hospital bed.

Unlike most people, I spent a significant amount of time—about 10 months—at the NRH. Throughout that period, I underwent various therapies and treatments aimed at helping me adapt to my new reality and regain as much independence as possible.

The journey was undoubtedly challenging, but the unwavering support from the hospital staff, coupled with my own determination, helped me push through. Though my life had taken an unexpected turn, I learned to embrace my new circumstances, and as time passes, you learn to adapt and with a good attitude you realise that there's not much that you can't do that you could before your injury.

Now, as a 25-year-old, I'm pursuing my dreams in the academic realm. I'm currently finishing up my Financial Advisory degree at the prestigious Institute of Banking in University College Dublin. While it may have taken me longer than anticipated, I've learned a valuable lesson about life: anything worthwhile requires time and patience.

Beyond academics, I've discovered a deep passion for sports and representing my country. Since 2017, I



have proudly represented Ireland in Wheelchair Basketball. Being part of the national team has been an absolute pleasure, and it has allowed me to achieve some of the most significant accomplishments of my life. With my teammates, we secured two bronze medals—the European Youth Para Games in Finland in 2021 and the European Division C Championships in the Czech Republic in 2017. These victories have filled me with immense pride and joy, and they remind me that dedication and hard work truly pay off.

My athletic journey continues, and this September, we are once again heading to Bosnia and Herzegovina to compete in a new challenge. I feel privileged to represent my country on an international stage and to have the opportunity to inspire others through my sporting achievements.

I'm excited to embark on a new chapter as I join the Spinal Injuries Ireland team alongside my colleague, Gemma. In this role, we will be facilitating as Peer Officers, providing valuable support and understanding to others who have experienced similar challenges as us. It's an honour to be part of a team that makes a positive impact on the lives of individuals with spinal cord injuries, and I look forward to being a source of strength and encouragement for those going through their own journeys of recovery and adaptation.

As I reflect on my life's journey, I can see the remarkable progress I've made, and I'm immensely grateful for the experiences that have shaped me into the person I am today. Though living with a spinal cord injury remains a challenge, I've learned to face it head-on and appreciate the strength and resilience I discovered within myself during this transformative journey.

You can contact me at jack@spinalinjuries.ie

MARKET RESEARCH

Spinal Injuries Ireland set out to gain a comprehensive understanding of the experiences of individuals living with Spinal Cord Injuries (SCI) in Ireland.

We invited Dr Rosie Gowran and her team in the University of Limerick to carry out the research, to gather and examine the insights from various stakeholders, including service users, families and carers, health professionals and the SII team, with the goal of informing the development of a five-year Strategic Plan (2024-2029) for Spinal Injuries Ireland.

The findings from this research initiative contribute to the existing body of knowledge on SCI in Ireland, providing evidence-based insights to improve the provision of care and support for individuals affected by SCI. The research is ethically approved and will be published in peer journals.

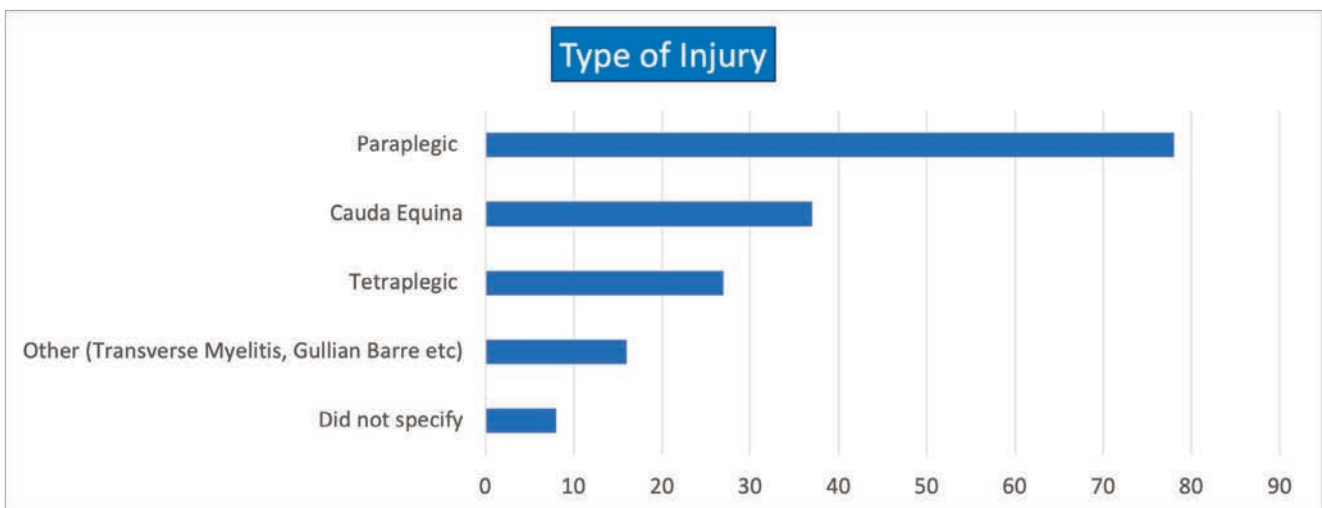
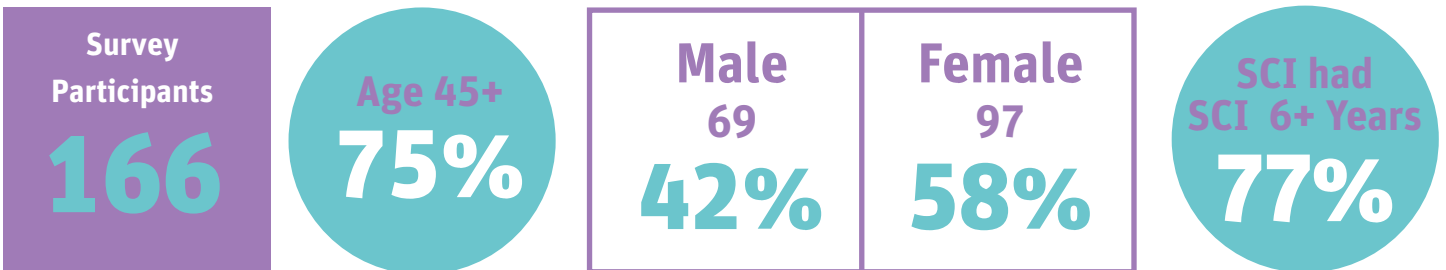
Methodology

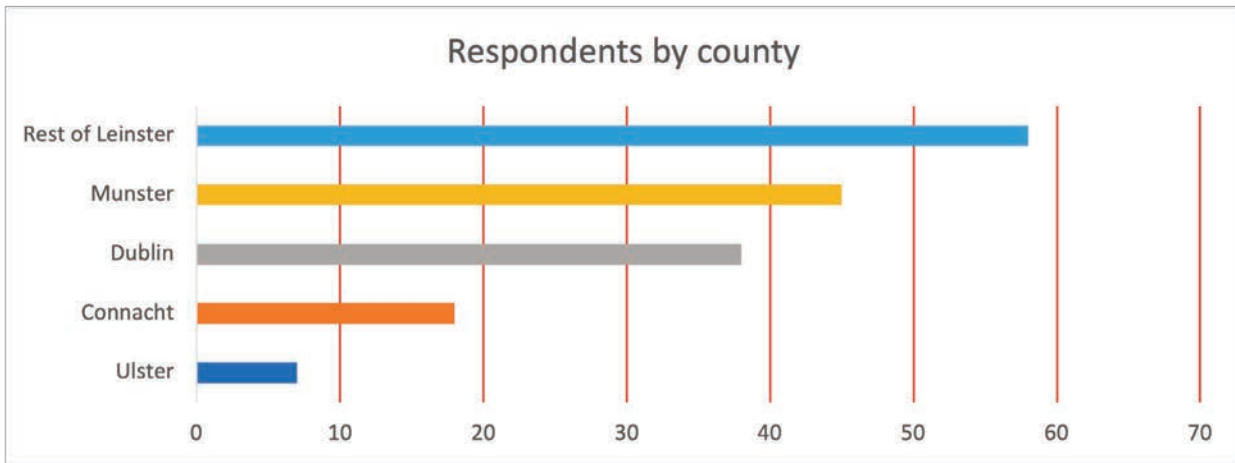
To achieve a comprehensive understanding of the current priorities, a research methodology was employed that embraced inclusivity. A rapid review of recent literature was initially carried out. This was followed by online surveys, interviews and focus groups where we engaged with individuals living with SCI, capturing a diverse range of perspectives. This research allowed us to access the SCI community and identify emerging needs and challenges.

Our National Survey

SII invited our service users to take part in an online survey.

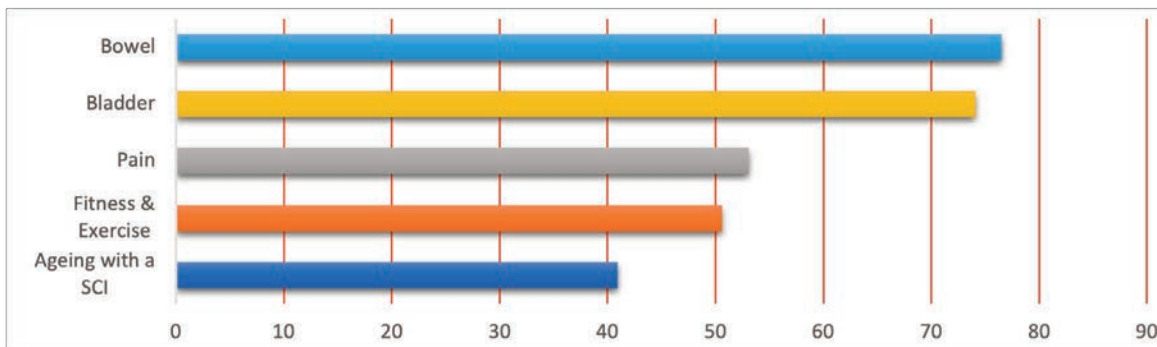
Respondents





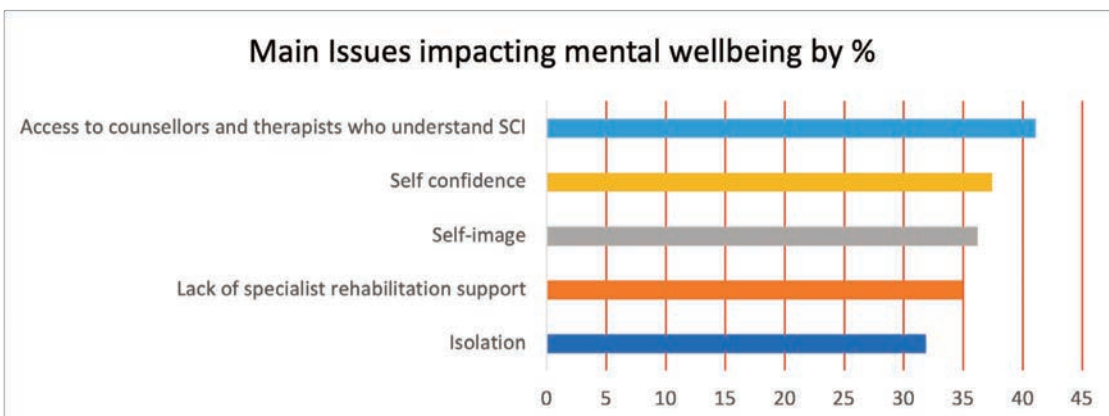
What Really Matters to people with SCI?

When asked what really matters to people with a SCI, bowel and bladder management were the top issues. However, this could equally be a result of ageing, or ageing with SCI, as opposed to simply having a SCI. Pain management (53.6%), fitness and exercise (50.6%), and ageing with SCI (41%) were also given importance as issues, as well as sexual issues (33.7%), skin management (31.9%), equipment/ living aids (20.5%) and wheelchair provision (16.3%).



What are the main issues that have the biggest impact on wellbeing and happiness?

The main issues identified as having the biggest impact on mental wellbeing and happiness were access to counsellors and therapists with understanding of SCI, self-image, a lack of specialist rehabilitation support, isolation, self-confidence and personal relationships. Attitudes towards disabled people were also acknowledged as an issue.



- Over 33% of people cited sexual issues were a concern
- 32% reported skin issues were a concern.
- 32% reported feeling isolated
- 59% cited funding care and benefits to be challenging.
- 25% have challenges accessing housing
- 13% see Covid as affecting their lives
- 60% believe that there needs to be a change in the attitude of the general public towards persons with a disability

Other areas identified as affecting everyday life

Financial

Access to benefits
 Planning future finances
 Funding care needs

Access

Availability of public transport
 Funding own mobility needs
 Personal transport
 Accessible parking
 Hotel rooms

Addressing key issues through this survey, focus groups and interviews with stakeholders were held nationally in September and October 2022.

Over 150 participants, people with SCI, their loved ones, healthcare workers, and the SII team were generous in sharing their experiences of living with or caring for a person with a spinal cord injury; identifying barriers and facilitators to enabling them to live their lives.

As well as individual interviews and group meetings, 8 Townhall meetings were held across Ireland (Dublin, Portlaoise, Galway, Limerick, Cork, Waterford, Donegal, Dundalk).

On Spinal Injuries Ireland:

“... Spinal Injuries Ireland have the perspective of a patient with a spinal cord injury and try to educate people on what is really important to people and is kind of a very useful thing...”

“ SII are important for peer support, linking, and signposting to local services. ”

On national services after being discharged from hospital

What participants said:

Participants living with SCI, whilst acknowledging the support they had received whilst in hospital, and from SII, they highlighted the positives and negatives of their experiences transitioning and living in their local communities.

“ The confidence of people working with people with spinal cord injuries in the community is a little bit limited. I think people maybe are a bit nervous working sometimes with people with spinal cord injuries. ”

“ From a public health service, I find there is very little or anyone I can refer onto when somebody finishes in the National Rehabilitation Hospital. ”

“ You’re often referred to see allied health professionals who have no training in managing people with spinal cord injuries. ”

“ Often feel forgotten about ‘fallen off a cliff’ as no follow up or support or checks. ”

Priorities for SII to focus on over the next five years.

Physical and Mental Wellbeing

Staying well when living with SCI is a key factor expressed by participants, of the townhall meetings, for the person, family, and friends. Looking after fitness, maintaining body strength, range of movement, bowel, bladder, skin care, nerves, and chronic pain management were issues raised throughout the focus group discussions. Access to mental health services; contact with others, both those with and without SCI, is seen as important to reduce social isolation and sense of loneliness.

What participants said:

Ageing with a SCI

Addressing issues in relation to ageing with a disability and acquiring other disabilities in addition to the SCI.

“ ... what they go through is just a lifelong learning about themselves, how they're different, how they need to be at the different stages of their life as they age and how their needs change. ”

Local Services

Access to local support services is seen as important, having supports when you need them, having ‘someone to call in an emergency’.

“ Maybe expert local rehab centres, even provincially as a starting point... so from the moment the person is discharged through the NRH they are aware of this person who is in the locale and they can start planning for supports for these people that would be a big big piece. ”

Pain

Access to pain specialists with an understanding of SCI was difficult to access for many.

“ ... people do need access to pain specialists with expertise in managing people with persistent pain following a spinal cord injury. ”

Exercise

People living with SCI understand the importance of exercise with a SCI but reported that they were unable to find suitable exercise classes and facilities that would cater to their needs.

“ Access to gym and fitness classes: live active lives, be well; also helps with pain management, and creates friends, a social outlet, and enjoyment. ”

Isolation

People living with a SCI report the isolation that their condition brings and how building a support system around them can prevent isolation

“ Importance of family and friends for staying mentally well, and to stay off isolation and loneliness. ”

Access to a Community

Accessibility which appears generally poor was raised throughout the discussions as an area that needs to be developed.

“Getting out so can look beyond the 4 walls of room/ home”

“Something to look forward to, being able to get out and enjoy things”

Advocacy:

SII plays an important role in national advocacy for persons with SCI which needs to be further strengthened. Various levels of need were highlighted, so targeting particular aspects within national, local, urban, or rural contexts.

What participants said:

“Role in advocating for there being a specific service providing arm of the HSE provision for people with spinal cord injury because we have met many people in the hospital who are waiting a very, very long time to go home because they cannot get carers to provide care for spinal cord injury.”

“The advocacy piece, the medical cards, seems to me would have the biggest ripple effects for our service users.”

Research

Research is seen as a key component to support an advocacy campaign.

What participants said:

“So, I think another thing that Spinal Injuries Ireland could do is advocate for more research funding in the field.”

“Having that research behind us, it's easier for us then to go and advocate to the other acute hospitals and so forth for representation and to have a presence there.”

Identifying access to timely supports nationally and locally

Access to supports is dependent on geographical area and is not quick enough. It is different depending on nationally/locally and is different depending on age/level of injury/economic status.

What participants said:

“Support was not timely enough. Ask for support and accept it. Nice to have people around. Don't be afraid to challenge your therapists – as they can learn too from your questions.”

Information

Providing useful information and updates on resources is important to participants, for example the SII magazine, online and in-person information sessions. Setting up a resource guide brought together from service user experiences of living and managing SCI was discussed.

What participants said:

“So, not just like providing information at a local level, but helping to collate the information as well, so that if you have people in every county or every collection of counties or whatever, actually pooling that information of what is

Education and training

The need for education and training for all was indicated throughout the discussions.

What participants said:

There is a need for a greater understanding of the complexity of living with SCI, locally and nationally about people living with SCI, building capacity and raising awareness.

“... people have to understand spinal cord injury in detail because a moment of carelessness as you know will lead to weeks in bed.””

“They train with us for maybe four to six weeks and by the time they've trained with us for four to six weeks, they're really good at spinal cord injury care and then something happens and maybe probably just start again. And it's embarrassing for X, she gets really embarrassed.””

Peer Support

What participants said:

Many participants identified peer support as being important for the person with SCI, families, and friends.

“And he was the same level as me. And I was thinking, my God, I didn't think, you know, I could get to that stage. And that's really what gave me the kind of motivation to get involved with spinal injuries.””

“If you can link people in with the right people. It's great, you know, and that's linking with our members, you know, just from time to time, people ask what do we do and you know, I suppose we prioritise the people who are struggling. But the more contact we have with our members, the better.””

“I think the family support is wonderful””

Accessibility to health services

What participants said:

“I think there's a massive shortage of vocational rehabilitation for these patients.””

“subsequent services available to people in the communities seem to be quite limited and quite restricted,””

“I think people have to fight tooth and nail for access to these things. That shouldn't be that way.””

Access

What participants said:

General community accessibility, transportation, access to assistive technology, suitable housing and, when required, transitional housing, hotels, holiday locations, and venues are inaccessible or difficult to access.

“... I think housing is a big issue and worry for people if they don't have their own permanent house, you know that will they be evicted, or will they ever be able to get accessible accommodation again if that happened ...””

Findings are not surprising and mirror much of the international literature and what appears in research conducted and previously reported by SII.

Evidence suggests that SII is highly valued in its role supporting persons with SCI and their families beyond rehabilitation. Findings indicate that SII provides a variety of supports through advocacy, information, peer support, counselling, activities, events and community outreach. Indicators suggest that SII should be more visible, increasing its profile publicly, taking a fresh approach to the services and supports they offer.

Recommendations for Spinal Injuries Ireland

Specific priorities should be considered in the context of the four overarching concepts:

A lifespan approach, inclusive of people with spinal injuries of all ages, and those who are ageing with spinal injuries.

A health and wellbeing approach addressing key issues to promote the general health and wellbeing of people living with spinal injuries.

A systems-based approach, with seamless and timely access to services, according to clear and transparent pathways to all providers serving people with SCI regardless of geography.

A partnership-based approach with leading disability organizations in Ireland, Europe, and Internationally.

Key Priorities

The priorities below are grouped according to three pillars: Operational Effectiveness, Awareness and Advocacy, and Education and Research.

Operational Effectiveness

Clarify mission, vision, values, and target population.

Evaluate existing service offerings to identify areas for improvement.

Align the peer mentorship programme with a clear mission and vision for the organisation.

Develop and implement an onboarding process.

Demonstrate effectiveness of the work of Spinal Injuries Ireland.

Increase awareness of spinal cord injuries among key stakeholder groups in Ireland.

Facilitate access to medical cards for all people with spinal cord injuries in Ireland.

Awareness and Advocacy

Advocate for access to skilled staffing for people with SCI across all health/social care.

Advocate for national guidelines on accessible public spaces/accessible public transport.

Advocate for increased access to accessible housing.

Education and Research

Develop and deliver educational programming for persons with spinal cord injuries.

Develop and deliver educational programming for carers/families of people with SCI.

Develop and deliver educational programming for non-spinal cord injury clinical staff.

Identify areas of further research development to support SII programmes.



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CLINIC LOCATION: Spinal Injuries Ireland SII, G3 The Pottery, Bakers Point, Pottery Road, Dun Laoghaire, Co. Dublin



FUNDRAISING NEWS



Spring Lunch

We kicked off our fundraising events with the glamorous Spring Lunch in the Intercontinental Hotel in Ballsbridge on Saturday 25th March. This is the largest of our annual fundraising events with 400 guests attending the lavish affair. Our sincere appreciation to the Institute of Education who sponsored the event again this year and to everyone who donated both raffle and auction prizes.

Following a delicious lunch, guests listened intently as Declan Naughton shared his own personal story of sustaining a spinal cord injury in 2018 and how our peer support programme really helped him in coming to terms with his injury and the changes to his life.

The raffle and auction then took place, expertly conducted by Eamonn O'Connor, with the auction raising a fantastic €32,000. Guests then took to the dancefloor as the fabulous Spring Break kept them entertained into the evening. The event was a great success raising an incredible €128,000. Our thanks to the organising committee comprising Philip Quinlan, Prof. Caitriona Ryan, Emmet Kilduff, Fiona McGouran, Una Kearns and Lizzie Burke. Also thank you to all our guests and those who donated prizes for their remarkable generosity.

Tall Ships Caribbean Adventure

In March of this year, 36 people, including 12 people with a spinal cord injury, joined us for the voyage of a lifetime. Spinal Injuries Ireland chartered the SV Tenacious, the only fully accessible tall ship in the world, and we sailed it from Antigua in the Caribbean to Guadeloupe and back. The weather was glorious, the scenery idyllic, but that didn't mean the ship would sail itself. Everyone on board was part of a working crew. Watch duty, mess duty, setting the sails, swabbing the decks, it didn't matter what the task, everyone got involved. We had an absolutely fabulous crew take part and we can't thank them enough for their amazing, and continued, support. Together the participants of our inaugural Caribbean Adventure raised almost €150,000, a fantastic achievement. To find out more about this voyage, please read the first hand accounts on page 16.

If you're interested in taking part in our next Caribbean Adventure in 2024, please visit:
<https://spinalinjuries.ie/tall-ships-challenge-2024/>

Summer BBQ

Thankfully the rain stopped just in time for our Summer BBQ which took place in Merrion Cricket Club on Saturday 10th June. Following the tasty barbecue the beautiful Jennifer Hester shared her story to a standing ovation from the guests. The very charitable Rob Hoban expertly conducted the auction before the fabulous Mundy entertained guests and kept the dance floor full. Our sincere thanks to Master Butcher Fintan Dunne in J. Collins and Sons Butchers who donated all the meat, to Dunnes Stores for donating the wine and to caterer Paul Quinlan for cooking up a storm. Thank you to everyone who attended and generously donated to the raffle. The event raised €43,000.

Monthly Prize Draw

Our Monthly Prize Draw continues to both raise much needed funds for Spinal Injuries Ireland whilst also making three people a lot richer each and every month! We are so grateful to the almost 400 people who support this campaign on a monthly basis. In 2022 the draw raised over €25,000 for people with spinal cord injuries and we are hoping to see the same again in 2023.

If you would like to get involved, please visit:
<https://spinalinjuries.ie/raffle/>



Women's Mini Marathon

On 4th June 6 fabulous ladies took on the VHI Women's Mini Marathon on behalf of SII, two of them with spinal cord injuries themselves. Well done ladies for completing the marathon and we hope you had fun along the way. They raised over €3,000 between them.

Rob's Collections

Our longest serving staff member, Robert Kenny, was only delighted to see the back of Covid and get back out to meet the public in various supermarkets and shopping centres around Dublin. Robert loves chatting to people and spreading the word about our work in SII. He's on a roll and, so far this year, has collected an amazing €30,000!



Business Partners

Spinal Injuries Ireland is delighted to announce the foundation of our Business Partnership Programme. This programme seeks to partner with companies who are pro-actively supportive of people with spinal cord injuries.

Each business partner not only works towards improving the lives of those with spinal cord injuries on a daily basis, but also generously supports Spinal Injuries Ireland. This financial commitment helps us to provide further support to people with spinal cord injuries via our Community Outreach, Peer Support, Let's Go, Counselling and Education programmes.

We are so grateful to our inaugural Business Partners. Below is a full list of our partners to date.

- Callan Tansey Solicitors
- Care to Comfort, Electric Adjustable Bed Specialist
- Gillen Markets
- Lavelle Partners
- McCarthy & Co Solicitors
- McMahon Goldrick Solicitors
- Moneywise, Financial Planning Advisory Specialists
- OBL Solicitors

Tall Ship's Caribbean Adventure



Peter O'Shea

So, where do I start? Well – EPIC – that's the word that comes to mind regarding my Tall Ships experience in 2023.

I was in the NRH in 2019 following a 'supposedly' routine back operation for a disc compression that didn't quite go to plan. That's where I met the SII guys and I registered with them. I subsequently heard of the trip planned for Lisbon to Cadiz and thought of going on that, but then the world fell apart with Covid. Fast forward to early 2023 and in February I got wind of the trip due for March. I thought I had missed the boat (pardon the pun) but contacted Phil nonetheless. Luckily for me he called the next day with two slots still available. I was certainly going to go for it and I contacted a mate of mine who jumped at the chance too – why not!

Quick as a flash it was early morning Saturday March 4th and we were in Dublin Airport meeting approx. 40 others. I knew nothing about sailing whatsoever so really had no clue what to expect. From those first encounters it was clear there was going to be plenty of craic to follow, regardless of any tall ships know how or not! It was an eclectic mix of people, 8 wheelchair users plus their buddies, 4 "walkers" with spinal cord injuries and a mix of others, friends and people who had just seen the trip on social media.

We arrived in Antigua on Saturday evening with excitement, but also a sense of – what lies ahead? Getting to the ship itself was very impressive, docked amongst some of the world's largest super yachts. On board we went, made very welcome by the crew and our team leaders, shown our bunks and a quick brief of the ship until a proper talk the next day and the hope of getting out to sea.

The following days were simply fantastic! What's what on a tall ship? Ropes – lots and lots of ropes – more than 6 miles apparently, and I'd well believe it. Sails, masts, yards, the bridge, crows nest, bunks, the mess, engine room, helming, and so many other terms I've forgotten. By the way – no Wi-Fi either, well, very basic, so that meant away from the world – great! And, can't forget the honesty bar (which we made great use of, and all very honestly too) – the source of so many get togethers, sing songs and chit chat during the week. Of course, there was also the small matter of the Caribbean. Sailing to Guadeloupe and back during the week. Swimming off the side of the ship – what an experience! Brings a new meaning to "man overboard" – just ask Lester. So many experiences, climbing the mast and going out on the yard arm, but also seeing so many conquer any fears or worries they had, and achieving goals that previously seemed impossible – very emotional to be part of.

Finally – the people – words can't express how truly great it was to meet each and every one of them. A real honour to be part of the 2023 Tall Ships Experience.

Aisling Leahy

Enter 2023. A new year, a new challenge!!

Pre Covid, and on an annual basis, I committed to annual charity challenges, invariably oriented around some sort of pain induced, endless hills and wrong direction winds type cycling challenges.

However, post covid, a different challenge was on my mind. Living on the west coast of Ireland, I thought something sea oriented would be amazing, one that would be an adventure, whilst also still challenging me. And then, some weeks later, the Spinal Injuries Ireland

Tall Ship popped into my Instagram feed. The pitch... sailing around THE Caribbean, volunteering with people of varying abilities, and no sailing experience required.

It all seemed too good to be true but “why not I thought” to myself. No less than a week or two later I get the call from SII, and before I know it, I’m a fully-fledged ‘never sailed before, solo going, member of a 40 strong volunteer crew’. No turning back then, and the same can be said to this day, some 4 months since the SII Tall Ship Challenge.

The Unknown Adventure

It all began at Dublin Airport, where a scattering of wheelchair users and fully abled volunteers, like me, met for the very first time. From the offset, it was very clear there was a common bond amongst this ‘stranger to one another’ group – not knowing each other’s names, we all gelled on the anticipation of the unknown adventure ahead of us. Two flights later, landing in Antigua, the volunteer crew were fully fledged friends already. Little did we know, even 5 months later, we would all still be a tight group, sharing stories to this day via our “Caribbean Crew” WhatsApp group chat.

The ‘Challenge(s)’

As part of the volunteer crew on the SV Tenacious Tall Ship – the only purpose-built tall ship in the world for less abled people- the only ‘challenge’ I would say I experienced, hand on heart, was actually leaving the ship and saying goodbye to my new found friends. The experience of the SII Adventure Challenge was all encompassing – it entailed bunkbed sharing, deck scrubbing, kitchen shenanigans over various ‘mess’ duties, night-time portside singing, beach bumming, sea dipping, mast climbing, sailing the ship, lengthy laughter – the list of experiences is endless, and some are hard to put into words. They simply don’t need words!

The Lessons and Legends

Whilst I speak of ‘challenges’ above, I remind myself of why I opted to embrace the SII Adventure Challenge. As a designer of the built environment, the design of spaces and places is an everyday task. We don’t always get the designing of spaces and places right, but by learning from ‘ALL’ users of the built environment, we can only learn to improve.

Witnessing first-hand the experience of everyday wheelchair users, and spinal cord injured persons, the SII Adventure Challenge on the SV Tenacious afforded me the opportunity to learn better, how we can, and should do better when it comes to placemaking. If wheelchair users can operate freely and ably on a ship on water for a week, why is it that everyday experiences in the built environment are far more challenging. Ever since the SII experience, when I put pen to paper designing our built environment, I constantly remind myself of how our environment should be for all, and for my fellow crew team, especially those who have been affected by lifechanging spinal cord injuries.

Ciara O’Mahony

“The sea, once it casts its spell, holds one in its net of wonder forever.”— Jacques Yves Cousteau.

In March 2023 I found myself back on familiar ground, the deck of the SV Tenacious, ready to embark on a Caribbean adventure. The next 10 days of sailing had too many highlights to possibly name, from spectacular sunsets to singing late night sea shanties. Being part of the crew on Tenacious is a special experience and I should know as this was my 2nd voyage having sailed in 2022 from Poole to Dublin. People often ask what is it that makes it so special and the answer isn’t easily put into words. To allow myself a clichéd moment to paraphrase a quote from Pirates of The Caribbean ***“Wherever we want to go, we’ll go. That’s what a ship is, you know. It’s not just a keel and a hull and a deck and sails, that’s what a ship needs but what a ship is... what Tenacious really is... is freedom”***

Aside from living out my pirate fantasy, I have found incredible freedom onboard both physically and mentally. In my normal life I go about my day in a world that unfortunately isn’t built for me as a T2 4paraplegic, you deal with steps, out of order lifts, inaccessible venues, poor pavements and numerous other barriers.



At times it takes its toll and you become tired and burnt out. Tenacious has the opposite effect as the only fully accessible tall ship in the world where nothing and nowhere is off limits. From helming the ship on the bridge deck, to the lower mess and bunks to going aloft up the masts. There’s nowhere you can’t go and no experience escapes you. This includes mess duty, night watches, hauling sails and everything in between. Part of the crew, part of the ship and you instantly feel that community and spirit onboard that puts everyone on an equal playing field. Voyages are filled with so many moments that I will treasure for years to come, and I’ve made lifelong friends. It’s difficult to do the experiences justice with words, it truly must be lived to be believed. Coming home after each voyage I’m renewed and empowered despite my exhaustion and it’s a testament to the power of real inclusivity and accessibility and the difference it can make in our lives.

Bookings Now Open for 2024, please visit <https://spinalinjuries.ie/tall-ships-challenge-2024/>

ESCIF Safe House



A transit home for disabled war refugees



The shelter of the European Spinal Cord Injury Federation (ESCIF) in Cyców, Poland provided care for disabled refugees from beginning of April until the end of September 2022 with logistical and financial support from the Swiss Paraplegic Foundation and the German Spinal Injuries Association (FGQ). The safe house within the aid project "Ukrainian SCI Relief" may be closed meanwhile, but the help for the SCI community in Ukraine continues.

Just a few days after the Russian invasion on Ukraine had begun end of February 2022, the first calls for help came from the Ukrainian Spinal Cord Injured community. Those who could set out on their own, fled the country or left Ukraine with the help of their contacts in Europe. After the first convoys of the German Spinal Injuries Association and the Maltese Cross arrived at the Polish-Ukrainian border to pick up refugees with a disability, it became apparent that the existing support for the disabled was quite inadequate. Helpers from European organisations were on site several times in March and experienced the situation in the Polish refugee camps. Everyone was deeply impressed by the helpfulness of the Polish people, the broad support and the relief supplies that were delivered within days. Nevertheless, one could not fail to see that there was no adequate help or facilities for people with special needs available.

Planning for the shelter

After initial discussions throughout the European paraplegic organisations, the European Spinal Cord Injury Federation (ESCIF) decided to set up a safe house so that refugees from Ukraine could find accessible accommodation and adequate care before being further distributed to other countries in Europe. After a short search an almost ideal property was found by a lucky coincidence in Cyców, Poland, barely 30 km from the Polish-Ukrainian border. The former care home was rented by ESCIF. The safe house opened at the beginning

of April 2022, operated by a small team of doctors, nurses and ESCIF board members. Medical problems could be treated adequately, the residents were equipped with the necessary aids and further transport organized.

With the support of the Active Rehabilitation Ukraine network and the Agape Rehabilitation Centre in Luzk, many people with disabilities could be brought to the shelter. By the end of May, more than 60 people with disabilities and their relatives had already been brought to Germany and Switzerland, where they were offered long-term accommodation and medical care where necessary. Gradually, accommodation also became available in other countries. With the help of the highly committed volunteers of the Maltese Cross, trips between the Polish-Ukrainian border region and the long-term shelters in Finland, the Netherlands, Austria, Czech Republic and England were made almost every week since end of March.



A sense of security

The people that arrived at the shelter had experienced terrible things at their home and on their flight. No clean water, no food, no electricity for weeks, freezing cold weather, endless heavy bombardments and finally dead bodies on the streets as they fled Mariupol, Charkiv, the suburbs of Kiev and other parts of the country. One young woman from Mariupol told the safe house team on her arrival, **"I finally feel safe, here the Russian missiles can't reach me."** Sara Muff, a qualified nurse at the Swiss Paraplegic Centre in Nottwil, who had already gained extensive experience in aid projects in Haiti and Lesbos, immediately agreed to support the ESCIF project and was one of the first helpers on site. She describes the feeling of security people feel when they arrived and often sleep through the night for the first time in weeks.

"After a few days, they were like transformed," she reported. "I only really noticed this when I looked at the photos some weeks later. The war refugees looked terribly emaciated on arrival, but they looked a lot better after just a few days' stay in the safe house."

Happiness and sorrow lie close together

Together with Susanna Meier, a senior consultant at the Swiss Paraplegic Centre in Nottwil, Sara organized care and a stock of the most important aids and medication. **"Besides caring as a nurse, my job was also relationship work. It was like a jigsaw puzzle; little by little, the refugees gained trust and revealed something about themselves,"** Sara told us. The new arrivals were often reluctant to talk about their problems at first. Most of them had severe pressure sores and chronic urinary tract infections, but they were afraid of being sent away again in case of complications. Even before the war, they have not always had good experiences with the health sector in their country. Some told us that they were treated like second-class patients because of the wheelchair. When a resident in Kiev sought help during her escape, the doctor told her that he would not waste his resources on her.

Quite surprisingly, the mood in the safe house was mostly good. Birthdays were celebrated, the table was festively set for public holidays and celebrations. When spending a good time together, the war trauma faded into the background for a few hours. Nevertheless, the residents often sat together in the evening, watching news and videos through tears. All of them had to leave friends and family behind. One resident waited weeks and weeks for a sign of life from her boyfriend, officially he was considered "missing." And then the terrible uncertainty. All of the refugees wanted to go back home as soon as possible, but they knew that this may not be possible for many years. Though all organisations involved had initially hoped that the shelter might not be needed for the full length of the projected six months, it soon became clear that the war in Ukraine and its aftermath will occupy us all for a long time to come.

From Cyców to Kronberg, Helsinki, Nottwil and Prague

All in all more than 200 refugees have received initial care and accessible shelter at the safe house. After an average stay of 10 -15 days, they moved on so that others could follow.

This fast and non-bureaucratic help was made possible by a large number of individual donations and the support of many sponsors and partners. Last but not least, the volunteers at the shelter, who were recruited through the German and Swiss Paraplegic organisations, did an outstanding job on site in Cyców. Their work has received the greatest recognition from all sides. The procurement of accessible accommodation proved to be



the greatest challenge throughout the project. A stroke of luck was the provision of a former training centre in Kronberg, barely 20 kilometers from Frankfurt in Germany. More than 30 people could be accommodated there in June 2022 and a real residential community with a great sense of togetherness developed within the first few weeks. Although there are many successes to report, it is also fair to mention the problems, not least of which was the provision of transport as well as medical services and aids to start with. It was only thanks to the financial and logistic support of partner organisations and individuals that supplies could be ensured when - which unfortunately was not quite uncommon - authorities played for time and many practicing doctors behaved uncooperatively.

Help continues

In September the operation of the safe house no longer made any sense due to the lack of resources for the accommodation and rehabilitation of spinal cord injured refugees in the European environs. In addition, the organisations involved in the aid project noticed a growing refusal on the part of the local authorities to accept and further support refugees with disabilities from Ukraine. Nevertheless, ESCIF and its members tried to look ahead in a constructive manner and to anticipate what kind of support could be offered in the most targeted and efficient way. The European paraplegic associations continue to be involved in the development of services in Ukraine and Poland. In addition, ESCIF, together with the Ukrainian partner organisations, project partners and sponsors, further support the SCI community in Ukraine. Care for the refugees in the individual countries is being provided by the ESCIF member organisations including e.g. legal advice, peer-counseling and online get-togethers for Ukrainian refugees in Germany.

The project would not have been possible without the support of a multitude of organisations, donors, sponsors and helpers. They offered amazing support in the form of donations of money and goods, the provision of living space and last but not least many helping hands. A heartfelt Thank You to everyone involved.

Kevin Schultes

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.

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)

KEEP YOUR BLADDER HEALTHY

It is important that you empty your bladder regularly as prescribed by your doctor or nurse. If you cannot empty your bladder naturally, intermittent self-catheterisation (ISC) is considered the gold standard.

Why do doctors – and Coloplast advisers – recommend ISC:

- has low risk of complications and infections.
- instils more freedom and independence.
- maintains a healthy bladder.
- improves quality of life.
- enables 'normal' sex life, thanks to less or no involuntary loss of urine, and more self-confidence.

Most people using intermittent self-catheterisation find it more comfortable and convenient than indwelling catheters. And when you find a method, which you think is good and you master it, it is easier to stick to the schedule and empty the bladder as prescribed.

Surveys suggest that catheters that have a special smooth and low friction coating (hydrophilic-coated), are more comfortable, convenient and easy to use. They have also been linked with lower rates of infection and urethral damage when compared to other catheters. Other benefits include giving you greater independence and a better overall quality of life.

You need to be patient – with training and practice you will most likely be able to empty your bladder in a few minutes and catheterisation will then become a routine you barely think about in your daily life. It is natural to feel slightly insecure and nervous about having to learn intermittent self-catheterisation (ISC). The thought of having to insert a tube into your body – not just once, but many times during the day – can seem overwhelming at first.

But you can take solace in the fact that 1000s of people like you do it every day, and while they may have had the same worries, now it has become part of their daily routine – just as it will for you.

Tips for intermittent self-catheterisation (ISC)

Where can I do ISC?

A suitable place for doing intermittent self-catheterisation is somewhere where you feel comfortable and at ease. It might help to map out places that you go to regularly so that you can plan ahead.

Privacy:

To have privacy when doing ISC is really important. Find out where the bathrooms are that give you the privacy you need. And plan your day so you can visit them as needed.

Cleanliness:

When ISC is performed, there is always a risk of infection, but your own bacteria are rarely the main reason for getting urinary tract infections – the risk actually increases when other people like your nurse or helper do it on you.

Whatever the location or circumstance, do not forget to wash your hands immediately before touching the catheter. If you need to touch anything (wheelchair rims, crutches, a bathroom door handle) after you've washed your hands, use hand sanitising gel or an antiseptic wipe before touching the catheter.

If you often suffer from urinary tract infections (UTIs) you might be concerned about doing catheterisation outside your home. Nevertheless, it is important that you empty your bladder regularly, as urine left in the bladder is one of the main reasons for getting UTIs. So when you are out and about it is not a good idea to skip catheterisation – even though it can be difficult to find a clean bathroom.

Diet

Make sure you stay well hydrated – you should aim to drink enough fluids so that your urine stays a pale colour; avoid constipation – staying hydrated can help with this, as can eating high-fibre foods, such as fruit and vegetables and wholegrain foods.

By Saragh Broe - Coloplast Urology Nurse Specialist

Ref: www.coloplast.ie

If you would like some support with ISC please contact our Clinical Coordinator at 01 9190190 to arrange a consultation with a member of our nursing team.



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**CLINICAL CASE MANAGEMENT FOR CATASTROPHIC INJURIES
SUPPORTING PEOPLE WITH SPINAL INJURIES TO LIVE AT HOME.**

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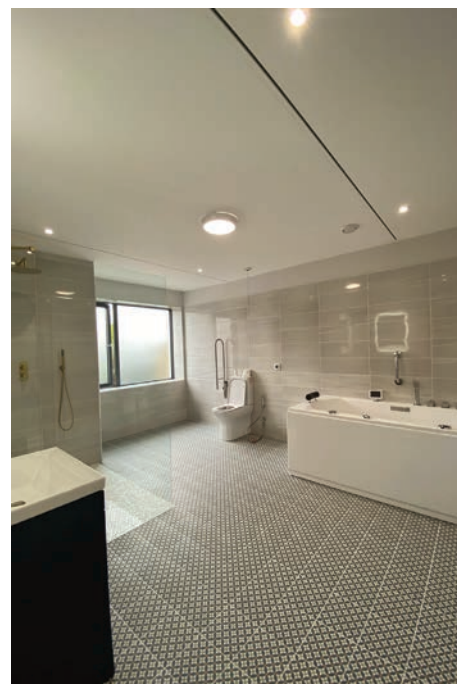
MCS provides a comprehensive case management service designed to maximise independence and quality of life for our clients. Creating bespoke care plans we ensure safe and exceptional supports. We have extensive experience in sourcing Personal Assistants and care teams, thereafter, monitoring the service to ensure the highest standards of care.

We recently completed an adapted build for a wheelchair user, client of ours in Dublin, which brought great joy to our Client and his family. This included a discrete overhead tracking system for a hoist, a large wet room and a fully accessible ground floor, leading seamlessly into the garden. More details available on our website.

<https://mcscasemanagement.ie/>

Call us on 01 493 6948

Email: info@mcscasemanagement.ie



OUR PROGRAMME

Grant Aid HSE National Lottery Funding

SII continues to pursue grant aid on behalf of service users. This year, individuals in South Dublin, Wicklow, Carlow, Waterford, and North Tipperary have secured grant aid for assistive technology projects. The continuous support from HSE National Lottery funding has enabled us to provide essential assistive technology to those in need across the country. Devices such as doorbell cameras, laptops, smartphones, tablets, smart fans, robot hoovers, smart security systems, and dragon computer software are enhancing safety, communication, employability, education, and daily activities for people with SCI.

Hospital Saturday Fund

Our Outreach Team can apply on your behalf for funding for specialist mobility equipment, medical appliances and aids, house adaptations, therapeutic equipment, and therapeutic treatments, up to a maximum of €2,250, through the Hospital Saturday Fund. For more information, please contact Hilary at hilary@spinalinjuries.ie or Denise at denise@spinalinjuries.ie. They will be pleased to provide you with up-to-date information about grant amounts and eligibility criteria.

Peer Volunteering

Our peer volunteers continue to support individuals with SCI through meetups, phone calls, and face-to-face meetings. The SII pizza evenings, hosted on the spinal ward of the NRH, have proven particularly successful, with an average of 20 patients attending these monthly Monday evenings. Our team of peer volunteers and staff are available to share experiences and provide guidance on leading a successful life with SCI. For patients unable to attend the pizza evenings, the SII lunches offer an opportunity to leave the hospital for a few hours and spend time with the SII team and some of our peer volunteers at the SII resource centre.

Interested in volunteering as a Peer Mentor? Contact one of our team members at info@spinalinjuries.ie.

Zoom Meetings: Connecting and Supporting through the SII Catchups

Throughout the year, our virtual Zoom catch-up chats have proven to be a valuable way of maintaining connections and fostering a sense of community among participants. These meetings occur on Wednesday evenings at 7pm. Check out the Events Calendar on our website to find out when they are coming up and how to join.

A Day In My Wheels

Roll with us October 2023



A DAY IN MY WHEELS



Call **01 653 2180**

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