

SPINAL NEWS

WINTER 2022

Menopause with a SCI

How to protect yourself online

Lester's Mammoth Challenge

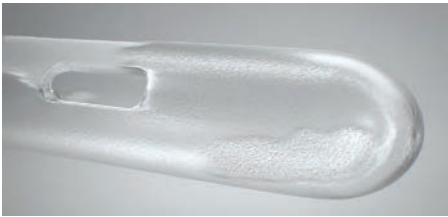
Healthy Eating for the Festive Season



The truth is:

Not all coatings are the same

Patients need a coating that protects the mucosa from the risks of damage, complications* and UTIs. **Some of the common pitfalls can be:**



Dry spots: Where the coating doesn't adhere to the catheter during insertion or withdrawal.



Short dry-out time: Insufficient hydration may cause the coating to dry out over time and become rough or sticky.

*Urethral bleeding (haematuria) and strictures

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Stays smooth

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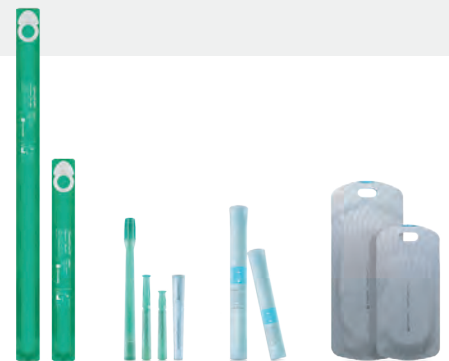


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WELCOME

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

There is a sense of normality returning as 2022 comes to a close although we all know that Covid is still in the community and we need to be vigilant.

One of the best things about 2022 was getting out and about to meet our service users, donors and supporters.

In particular, engaging with service users at the Out Patient Department in the NRH and at pizza evenings in the NRH was a welcome return to normality for our Outreach Team. In September, we ran a roadshow around the country in 8 different venues and thank you to all who attended to give voice to our campaign for medical cards and for sharing your stories with our team of researchers from University of Limerick. We hope to receive their final report in January and will use all the evidence gathered to help us design service provision for the next five years. Thank you to our sponsor Coloplast for providing the funding for the Roadshow and to the Coloplast nursing team who provided advice to our service users.

The good news is that for 2023 we are hoping to expand our peer meetings around the country and particularly in venues that we did not get to in 2022 and in Dublin we will be re-introducing peer lunches at our Resource Centre at the back of the NRH grounds so that if you are in the NRH for an appointment or you are an in-patient you can join in these events, facilitated by our trained peer mentors to whom we are very grateful.

Our events such as the Cork Jazz Ball, the Q Ball and the Barbecue in the Royal St George Yacht Club were back up and running this year and a huge thank you to Philip Quinlan and to all our volunteers who helped out at these events. A special thank you too to all the people who undertook a challenge or fundraised for us. In particular, you will enjoy Lester Cassidy's story in this magazine. I was lucky enough to be at Croagh Patrick on the day he did the climb and I cannot explain to you the warmth & emotional support that Lester received on the day. SII thanks Lester and all the citizens of Kilcock for their support.

Funding continues to be an issue for us. We receive 30% of our operational funding from the HSE and need to fundraise the remaining 70%. We are forecasting a loss for 2022 and although we wish to expand services in 2023, we need to bring in more funds. You may have noticed our Christmas appeal to raise funds for our free counselling service in 2023. If you or someone you know can contribute to this we would very much appreciate it.

Finally a huge thank you to all our staff and volunteers (administration, peer mentors, Board Directors, bus drivers, powerboat crew and fundraisers). To our service users and supporters thank you for all you do.

As a community we could not exist without one another and we wish you all a very happy Christmas and best wishes for 2023.

Kind Regards

Fiona Bolger CEO

SERVICES UPDATE



Roadshow

Autumn 2022 has been very busy for the team at Spinal Injuries Ireland. We started it with the launch of our pre budget submission which was distributed to Ministers prior to the budget. This year we had one clear ask and it was for medical cards for all people with a SCI based on needs not means.

We followed up our submission with a roadshow to 8 different venues hosting townhall meetings and delivering our message on radio and in the press. Thank you to all our service users, Emma Golding, John Finn, Nicholas Murray, Paul Fitzhenry, Richard Murray, Suzanne Winters, Anne Marie Weir & Olivia Shiel who worked on this campaign and amplified the story in the media.

The roadshow got underway in September with townhall meetings in counties Dublin, Laois, Galway, Limerick, Cork, Waterford, Donegal and Louth and thank you to Coloplast who enabled us to hold this roadshow with their sponsorship. It also gave service users an opportunity to meet with the Coloplast nursing team if they wanted to discuss any of their needs.

It was great to meet everyone in person after the Covid-19 lockdowns but more importantly everyone enjoyed meeting one another again and it was especially significant for newly injured patients who had not had an opportunity to meet their peers face to face. We are planning further peer meetings around

the country in 2023 and we hope that if you could not make these meetings that there will be a meeting more convenient to your home next year.

Guest speakers, Eva Wallace (retired NRH Bowel/Bladder Nurse Specialist) Olivia Shiel (service user and Patient and Disability Activist), Sonia McGarvey (family member), and Jack Kavanagh (service user and motivational speaker) joined the roadshows connecting with the audience through their empowering presentations.

National and local politicians attended the roadshows and gave SII an opportunity to campaign for improved services for those living with Spinal Cord Injury and to advocate for medical cards based on needs not means for all people living with a spinal cord injury.

Research

SII is funding and facilitating researchers from the School of Allied Health in the University of Limerick to carry out a study to understand the national situation for people living with Spinal Cord Injury (SCI) in the Republic of Ireland and to establish a clear direction for Spinal Injuries Ireland's Strategic Plan for 2023-2028.

The first phase in the research took place in September when we sent out a national online survey. This gave us an opportunity to take a snapshot of the current experiences of those living with a SCI. The second phase of the research through focus groups took part during the townhall meetings where the researchers

carried out in-person conversations with service users. We are very grateful to all service users who shared their stories and opinions with the researchers. It is essential that we receive all your opinions so that we can advocate on your behalf but more importantly so that we can design services that best suit our service users.

The next stage will involve stakeholder workshops with healthcare professionals, families, carers, staff & the Board of Directors to focus discussion on individual experiences and perspectives of what matters most.

As well as the primary research, literature reviews have been undertaken which will provide context and gain an understanding of the existing research and debates relevant to SCI.

The results will be published in early 2023 and will provide strong evidence, produced by participants, which will influence strategic planning, advocacy policy and practice development to build sustainable health and social care support services for people with SCI in Ireland.

Advocacy

All through the year SII has been advocating for people with a SCI with our membership organisations such as the Disability Federation of Ireland and the Neurological Alliance of Ireland. In addition, we published our pre budget submission and invited all local and government politicians to our Roadshow. We are very thankful to all politicians who either attended the roadshow or contacted SII to show their support. We are in the process of following up with everyone and planning our 2023 advocacy campaign. 'A Day in My Wheels' is our corporate awareness and funding programme. This year



we partnered with Cork County Council and Cork Chamber of Commerce to raise awareness of SCI and to offer a glimpse of how life is in Ireland for people with a SCI. Thank you to all our ambassadors; - John Twomey, Nathan Kirwan, Mary McGrath, Paul McCarthy, Gene O'Keefe and Mark Dalton who shared their stories on the day. Also, a huge thank you to the participants, including Councillor Deirdre O'Brien, Colin Ross, Conor Healy, Dr Anita Geary, Siobhan Kennedy and William O'Brien. Thank you to Kevin Dempsey from the Disability Federation of Ireland who provided the Inclusion & Diversity training. And finally we could not have hosted this event without the incredible support of Cork County Council & staff.

We have also run 'A Day in My Wheels' in a number of businesses such as Hollister and Google and we would like to thank both of these organisations for being willing to learn more and to help support SII who relies on funding for 70% of our operational costs annually. In 2023 we are hoping to expand this awareness & funding programme so if you are working with an organisation who would like to participate, please let us know.



SII VOLUNTEERS SHARE THEIR TIME & EXPERIENCES

The SII Pizza Evenings commenced in October in the NRH Spinal Unit Dining Room. Patients had an opportunity to spend some time together, enjoy pizza and meet with our peer volunteers and outreach officers. Our thanks to Clodagh Cogley, Karen Farrar, Bernard Healy and Conor McGinn who joined us on the evenings. We are continuing with these events in the NRH into 2023 so if there are any peer volunteers who would like to join us please let Hilary know.

Gemma Willis spoke to nursing managers, regional managers, members of the HSE and complex care nursing teams about the importance of the SII peer mentoring programme at the Resilience Symposium on 6th October. Gemma's real life experiences highlighted the importance of having someone to talk to who has experienced similar challenges and how she is motivated to help others who are going through the trauma of a recent SCI. Her infectious positivity had an impact on everyone in the room!

Our **Peer Roadshow representatives** gave voice to those living with SCI through the many local radio interviews undertaken throughout the country over the duration of the Roadshows.

Jack Kavanagh worked his usual magic with his motivational talks at our Galway and Waterford Roadshows. Jack talked about the different stages of grief and many of those who participated fed back how they had connected with a lot of what was discussed.

Olivia Shiel talked about her journey as someone living



with a SCI as a walker and the challenges that arise from this invisible condition. Discussing the power of peer support Susan McKeever's art classes provided an outlet for creativity but also built powerful life long friendships.

As a parent and advocate to her daughter Noirin, **Sonia McGarvey's** talk provided insight into the fight that people have to undertake in order to get necessary rehabilitation and basic care services.

Our peer volunteers continue to facilitate the Zoom

catchup's which came to a close on 16th November. Thanks to Ollie Hickey, Frank Lawlor, Gemma Willis, Conor McGinn and Julie Barnett for facilitating. The catchups will be back in January so watch out for dates on our social media.

Our Activities Volunteers are delighted to be back up and running with the activities programme. Huge thanks to our super, good humoured bus drivers Frank Lawlor and David Sparrow and to our crack team of RIB volunteers Philip Scallan, Eugene Power, Sue McGrath, Keith Thompson, Orna Turbidity and Glenn Heron. We were unable to take patients out of the NRH this year due to the Covid restrictions but were delighted to welcome many of the NRH staff on board. They can regale patients with their experiences and whet the appetites for next spring when our programme will start up again.

We would also like to give a special mention to Paal Janson, Jenny Needham and the fantastic team at Dun Laoghaire Marina who accommodated our RIB, shared the cost of the new hoist and looked after us so well.

Gerry Salmon and his team at MGM Boats were incredibly generous in sponsoring our fuel for the season and lifting the RIB out for us and washing her down on several occasions. We are incredibly grateful for their support and friendship.

Killen Marine in Dalkey and Tom Whelan of Solas Marine were also incredibly generous to us. We are so lucky to have such a supportive marine community.

Also as part of the Let's Go Programme we contacted all our new service users who had sustained their spinal cord injuries during the pandemic. This was a particularly difficult time for them as they were isolated from both family and friends and support services. Many have signed up for a RIB trip next spring, while others availed of family days out to the Wild Lights at Dublin Zoo, Christmas Pantomimes and Tayto Park. We also secured tickets to some sporting clashes so they could cheer on their favourite teams.

The Let's Go Programme will be extended to all service users in the New Year subject to adequate funding.



AN INTERVIEW WITH STEVEN MCGOWAN

Q. What was life like before your injury?

Steven: I was a very outgoing young man with big ambitions to move abroad to Australia. I was near the end of a 4 year apprenticeship in Metal Fabrication, about to go into the last phase of college just a week before my accident. I was working in an engineering company while living at home with my mother and younger brother. The plan was to move to Oz after completing my apprenticeship with my girlfriend at the time. My weekends were spent going out with mates, clubbing and socialising. My hobbies included going to music, comedy and car events. I was just a normal 20 year old without a worry in the world.

Q. Can you tell us a bit about your injury?

Steven: On 02/09/2017 I had a car accident which left me with a spinal cord injury. It was a single car collision and I was the only one in the car thankfully. I was airlifted to Galway General Hospital where they performed a spinal fusion surgery. I spent about 4 months in Galway before being transferred to the NRH in Dun Laoghaire. I spent a few months there before

leaving to get another operation on my knee that was stopping me from getting the full benefits of the rehab. I then returned after another few months. My time there was mostly spent trying to get as much power back as possible. My level of injury is T10 and I have an incomplete fracture. This left me paralysed from the waist down. At the start I had no feeling or power in both legs. The feeling was the first to come back slowly followed by small movements in my right foot. Now today I have near full feeling back, good movement in my right leg and never got power back in the left. I use a wheelchair but can also walk with a splint on my lower right leg and a brace on the full left leg aided. After my accident I spent 2 full years doing rehab continuing privately after leaving the NRH. I exhausted every avenue possible that may have helped my recovery. It got to a point where recovery plateaued and I was happy with the progress made knowing I gave it my all and hadn't left any door unopened.

At this point I was well ready to get back to work and did a CAD course in Solidworks and got a job in Modular Home company as a draftsman, creating 2D and 3D drawings of houses for customers as well as the manufacturing for the floor in the factory.





The first 2 years after my accident were the hardest mentally, coming to terms with being in a chair for the rest of life. In my head I was going to walk again with enough rehab and physio which prolonged coming to terms with it all. Once I accepted it and got back to work and a normal life it didn't take me long to get my mojo back and live a happy life. A huge thing for me also was getting back on the road driving, which didn't take me long as I was back within 7 months of the crash. The independence that it gave me was a game changer. All the other cons that came with a SCI were also extremely hard with the biggest being bladder control. I am lucky enough to have feeling and control of my bowels, but the bladder still isn't right and this affects me today. Spasms and sexual activity being some of the other problematic areas.

Q. At what stage did you encounter Spinal Injuries Ireland?

It was in the NRH I first encountered SII with one of their representatives visiting patients weekly, who was also a wheelchair user with a SCI. It was also my Community Outreach Officer, David Fitzgerald, who contacted me first about the rowing as Katie O'Brien was looking for a new partner.



Q. What are/were the biggest challenges when adapting to life with your SCI?

Steven: A huge one for me was dancing, not being able to boogie the way I did before. The body change and learning to be ok with being in a chair and not standing tall like I used to (even though I'm lucky enough to have the power to stand and walk with crutches sometimes). Bowel and bladder issues had to be addressed. Learning to get my confidence back in this new way of life. Sexual activity. I was depressed for some time afterwards and getting a handle on that was essential. So removing the negatives from my life and focusing on myself, talking to a professional or family member/friend (I did both of these) and looking after myself all helped. Training/working out has also had huge advantages.



Q. What is life like now?

Life right now is brilliant. I am very happy. This doesn't mean I don't have bad days, everyone has their ups and downs.

I am currently a full-time para rower on the Irish team. I started rowing in January 2021. There are 3 different para rowing categories PR1, PR2 and PR3. I'm PR2 which is arms/shoulders/trunk. It took me a while to get into it like anything but I took to it like a duck to water. After my accident I started doing a few gym bits and lifting weights, nothing serious but found it hugely beneficial both physically as a wheelchair user but, more importantly, mentally. I needed to find a sport I had an interest in and was half good at and rowing just fit the bill. I had tried some sports in the NRH but nothing excited me.

My rowing partner, Katie O'Brien, and I compete in the mixed double sculls event. I went to my first regatta in Italy in May 2022 and since then have been at a World Cup in Poland, Europeans in Germany and, most recently, the World Championships in Czech Republic. We managed to get to the A Final and finished 5th



there. Rowing has changed my life really, living a far healthier lifestyle now both physically and mentally. The training is tough going but I love the grind of it all, it's so good for the head. I left my job to go rowing full time. This was a huge decision to make but I'm so glad I made the right choice now. We are currently recruiting new para rowing athletes to add to the squad. If you think you would enjoy it or want to try something new do not hesitate to contact Rowing Ireland or myself to be given a shot of a lifetime. Being out on the water, training or racing, is just amazing. It just lets you forget about everything else and leave the wheelchair and everything that goes with it on land.

Q. What are you most proud of?

My strength of overcoming this life changing accident and pushing on to live this exciting life I currently have.

Q. Tell us about a goal, big or small, that you would like to accomplish

The main goal at the moment is the Paralympics games in Paris 2024 but first we need to qualify at the upcoming World Championships in Belgrade.

Q. Any quotes that resonate with you?

A saying everyone said to me while in hospital and rehab was 'Rome wasn't built in a day'. I hated this quote/saying so much at the time but have come to learn that unfortunately this couldn't be more true, as good things come to those who wait.

A quote I loved so much that I got tattooed on my chest is *'Accept what is, let go of what was, have faith in what will be.'*

One of my favourites that I came across lately is *'It isn't the mountains ahead to climb that wear you out; it's the pebble in your shoe'* from the great Muhammad Ali.

Q. How important a role did family play in your recovery?

I don't think I would be here today doing what I'm doing if it wasn't for my family pushing me on, day after day when times were hard lying in a hospital bed. Family is everything to me and I'm blessed to have them.

The team at Spinal Injuries Ireland wish Steven and Katie the very best of luck with their paralympic campaign. We have no doubt that great success lies ahead for this formidable pair.



CYBER SECURITY

A new Text-Checker service to verify if text messages are legitimate has been launched for Bank of Ireland customers.

The new services come as fraudsters are targeting the Irish population with increasing frequency. 74% of adults surveyed by Red C say they have received fraudulent text messages that appeared to be from their bank – an increase of 37% on 2021 figures. 43% received a fraudulent telephone call from a fraudster saying they were from their bank (up 25% since 2021) and 52% received a fraudulent email, an increase of 8%. Bank of Ireland's new text checking service is for customers who are in any doubt about a text they received saying it's from the bank.

Customers simply send the word 'Check' followed by the text message they wish to verify, to 50365 and they will receive confirmation within 60 seconds.



Bank of Ireland has also partnered with Prof Mary Aiken, a world-leading expert in Cyberpsychology, the study of the impact of technology on human behaviour.

Commenting during Fraud Awareness Week, Edel McDermott, Head of Fraud, Bank of Ireland said: "Our customers' financial wellbeing and peace of mind around their accounts is a top priority for Bank of Ireland. Despite warnings and increased awareness, the threat of fraud, most notably via text messages, is rising."

Bank of Ireland gave this advice:

- We'll never send you a text message with a link to a website that asks for your card number, your 365Online PIN, or for any one-time passcodes that we've sent to you.
- Be very careful with any phone number sent to you in a text. It could be fake.
- If you get a text that claims to be from Bank of Ireland but you are not sure if it's genuine, here's how to verify it:

BOI : We have temporarily restricted access on your BOI account due to suspicious activity, to re-authenticate visit : <https://bankofireland-online.com/>

"Through our new Text-Checker service, customers can have any text that looks like it's coming from Bank of Ireland verified in 60 seconds. We're also partnering with Professor Mary Aiken, to help our customers understand the ways that fraudsters will target them. Professor Aiken's insights and the Bank's simple message of Stop, Think, Check, will help customers protect themselves against fraud".

Prof Aiken has analysed some common examples of fraudulent texts and, in a series of videos, will break down what a fraudster will do, why that might catch people out and what people can do to protect themselves.

"We all know someone who has been targeted or become a victim of fraud," Prof Aiken said.

"There is a cybercrime epidemic, which is why we need to become aware of how we are being targeted, and most importantly, what we should do to protect ourselves. We simply cannot trust texts, emails or phone calls that look like they are coming from a business or official body in the first instance. It's difficult: trust is a very human trait but in an age of technology we have to adapt."

"I'm delighted to work with Bank of Ireland on this initiative – which is a first, in that it decodes the behaviours of fraudsters and the tactics that they use, making this real for people. The most important part of our advice though is to remind people to, simply – stop, think and check before reacting or responding to any communication they get in text, email or on the phone"

- Copy the text you wish to verify.
- Paste into a new message.
- Add the word CHECK before the text. (In the same text).
- Send to 50365.
- Alternatively email it to 365security@boi.com and we'll let you know if it was really from us. Remember to forward a screenshot of the text if possible.
- If you think you may have given away any of your banking details, please call our 24/7 Freephone line 1800 946 764 immediately.

HEALTHY EATING FOR THE FESTIVE SEASON

Written by Zoe Reichental,
CORU registered Dietitian

Healthy eating during the festive season can seem tricky! Most of us will gain a few pounds over the holidays. Following a spinal injury, the likelihood of weight gain is increased further due to adjustments in your body composition. As a result of inactivity, your body changes, leading to a loss of muscle and a potential increase in body fat. These changes mean you need less energy (calories) to be a healthy weight.

Excess weight gain can have consequences to your health, like diabetes and may also lead to difficulties when using a wheelchair, such as pushing or transferring, as well as muscle strain. Usually your energy (calorie) requirements are at least 10% lower than estimated. It is always best to avoid unnecessary weight gain, as it is harder to lose weight than maintain it!

On Christmas day, individuals can eat and drink up to 6,000 calories. This is up to 4 times the amount you would need on average per day. By making a few simple healthy choices during the festive season you can avoid additional weight gain.

Plan Ahead

- Don't try to lose weight during the holidays, aim to maintain your weight.
- Check your weight weekly at the same time, under the same conditions to catch any changes early (go to your local health centre if you are unable to check your weight at home)
- Be involved in making your shopping list – have the trolley filled with lots of healthy convenient options so they are accessible to you whenever you want a quick meal or snack at home (try beans on toast or fresh soup cartons)
- Pick one or two occasions in advance to indulge so you have something to look forward to with no worries

Here's some tips to help you to have a healthy and happy festive season!

1. Have three meals a day. By skipping a meal, it can increase your snacking later in the day.
2. Don't leave long gaps between meals as you may end up overcompensating at your next meal
3. Have 2-3 healthier snacks in between meals
4. If having a 3-course meal, try to choose a healthier starter like soup or a salad. Avoid anything deep fried!
5. Have your main meal with sauces on the side so you can control how much you add
6. Have a portion of fruit salad with your dessert to bulk it up
7. Always have a glass of water with your meal to quench your thirst and reduce your intake of other high calorie drinks
8. Fill your dinner plate with extra vegetables (at least ½ of the plate)
9. Think about your portion size – you can go back for seconds if the hunger is still there (it can take at least 20 minutes before your body realises that you are full)
10. Remember to enjoy your meal!

Healthier Snacking

Seasonal fresh fruit like apples, oranges and pomegranate

Dried fruit like sultanas, figs and dates

Popcorn or pretzels

Crackers or breadsticks with salsa or a small portion of nut butter

Crudités (raw vegetables) like carrot & peppers with hummus or reduced fat yoghurt dips

Unsalted nuts, particularly chestnuts for the time of year!

Low fat yoghurts



HEALTHIER WINTER DELIGHTS

Salmon Paté

Try out this dish as a tasty lunch option or dinner starter

Adapted from the British Heart Foundation

Servings: 4

Ingredients

225g cooked salmon fillets

6 tbsp of low-fat cream cheese or greek style yoghurt

1 tbsp horseradish sauce

1 tsp finely grated lemon zest

Fresh lemon juice, to taste

small bunch of dill or chives, chopped

Ground black pepper, to taste

Wholegrain bread or crackers, to serve

Green leaf mix, to serve

Method

Flake salmon into a bowl and combine with cream cheese/yoghurt.

Mix in horseradish sauce, lemon juice & zest, dill or chives and black pepper.

Serve with wholegrain toast and a side of mixed leaves.

Baked Apples

Try out this dish as a healthier alternative to apple pie

Adapted from Irish Nutrition and Dietetic Institute

Servings: 4

Ingredients

4 eating apples

40mls water

2 tbsp brown sugar

Handful of sultanas

A sprinkle of cinnamon (optional)

4 tsp butter

8 tbsp Low fat natural yoghurt

Method

Preheat the oven to 180°C / 350°F / Gas Mark 4.

Remove the core of the apples and place them standing up in a baking dish

Mix sultanas, brown sugar and cinnamon (if using) in a bowl.

Place the sultana mixture evenly into each apple. Add a tsp of butter onto each apple once filled.

Pour water around the apples and bake until soft (about 20 minutes)

Remove from the baking dish and serve with a drizzle of low fat natural yogurt





14th - 20th May 2023

Join us in Quinta do Lago next May for a week of cycling and socialising in the sun. All abilities catered for.



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PROPERTIES.COM

visit spinalinjuries.ie/cycle/
or scan the QR code to find out more



Find Out More

"Such a magic trip. Can't thank you all enough, the organisers, the outriders, the new friends. Looking forward to next year!" Jane Evans

A MAMMOTH CHALLENGE

A STORY OF RESILIENCE, DETERMINATION AND SHEER BLOODY MINDEDNESS BY LESTER CASSIDY

The 23rd July 1998, just four days after my 19th birthday, was just another Thursday at work as an apprentice carpenter, or so I thought. Little did I know, in the blink of an eye, my life would be turned upside down and changed forever.

Shortly after lunchtime, as I was working on a roof of a two-story house, the scaffolding gave way from underneath me and I fell about 24ft. I'll never forget trying to grab scaffolding bars mid fall trying to save myself or break my fall, but unlike you see in the movies, it's near impossible. I hit the ground with tremendous force and landed on a scaffolding plank on its side. I'll never forget the sound of hearing my back snap and the pain that followed. Immediately I knew I was in serious trouble. My legs were all pins and needles and I couldn't move them. It seemed like an age waiting on the emergency services to arrive, but it probably only took about half an hour. I was rushed straight to the Mater hospital where I underwent a 5 hour operation.

The next day, surrounded by very upset and concerned family members and my girlfriend Rachel, a doctor explained to me that I had sustained a double fractured broken back and, more importantly, inoperable damage had been done to my spinal cord. I was paralysed from the waist down and I might never walk again!

During the next two weeks in the spinal ward, I was bed bound. You have all day for things to play on your mind. Maybe I was in denial but paralysis long term never really crossed my mind. I have always been a very positive guy and just presumed I was going to make a full recovery and be back on my feet in no time. A specialist from the





NRH came to assess me and it was decided that I would be going there in a couple of weeks to learn to be independent again.

Before being a patient in the NRH I never even knew it existed, and wow what an amazing place it is. There's no feeling sorry for yourself there as there is always someone much worse off than you. All the staff from nurses, doctors, physios and occupational therapists do the most amazing job with one goal in mind; - to get the patient back to being as independent and healthy as possible. They are inspirational.

Being put into a wheelchair for the first time was very traumatic! It was a strange and scary feeling; I think myself, Rachel and the whole family cried for most of that day. I have to say it was one of the toughest days of my life. I never looked back from that day on. I am a very positive person and I was ready to move forward. That was my only "bad" day.

After I had my back brace removed I worked very hard, learning how to dress myself again, go to the toilet and I built up strength in the physio department each day so that I could push about in the wheelchair. I was determined to make the best of my situation. I even learned how to drive. Spinal Injuries Ireland (SII) set up a driving programme for patients. I signed up and on my first lesson I was out on the busy Dublin roads. I nearly had a heart attack.

One of SII's peer volunteers came to see me. He had fallen 120ft off a mountain and walked away. He gave me great encouragement and inspired me to keep on going.

Apart from the amazing support I received during this time from Rachel and my family, I also was blessed with a super network of friends and a very warm community spirit of my home town Kilcock. Nobody treated me any differently when I returned home in a wheelchair. This made my transition so much easier to just move on with my life and not dwell on the past.

Shortly after my release from the NRH myself and Rachel went travelling for a few months to see the world. We visited places like Australia and New Zealand and it was a truly amazing experience. Then we settled down, built a house and got married.

We have been truly blessed with three amazing kids. I am a stay-at-home dad and I have to say I love it. It's the most rewarding job in the world. My kids are everything to me.





A part of me always felt like I owed something to those amazing people who looked after me when I was down and at my lowest. I don't know why I waited almost 22 years to fundraise, maybe I was having a midlife crisis but in early 2020 I decided now was the right time.

Anyone who knows me knows I don't do things by half so if I'm going to do a fundraiser it's going to be a big one and there's not much bigger than a mountain. I spend a lot of time in the west of Ireland salmon fishing and it was always a dream of mine to get to the top of Croagh Patrick. After discussing it with Rachel and my friends we decided to give it a shot, but there was one big problem; - I know nothing about mountain climbing. So, I had to put a team together.

I enlisted the help of a friend David Walsh who is an expert in that department as my new team leader. I contacted Keith Dunne, an old school buddy of mine, who is brilliant with his hands and he was given the task of designing and fabricating my mountain buggy. Now all I needed was about 100 lads to lift me up!

Luckily Rachel and I are blessed with a wonderful number of friends. Both Rachel's mother and my mother are natives of Kilcock. My mum is one of 12 siblings and Rachel's is one of 13 so family alone could probably make up the numbers.

I think we raised almost €9,000 the first weekend I announced our intentions on social media, I was floored. There was an amazing buzz around the town about it and we were getting very excited. Then a little thing called Covid reared its ugly head.

It brought the country, the world and my little fundraiser to a halt and we had to re-schedule for the following year. Unfortunately, the following year we were hit with another obstacle. It turned out I actually had a different sort of mountain to climb when I was diagnosed with a brain tumour. We were in total shock. I had gotten a lump on the back of my head which doctors thought was a cyst at first but an MRI scan confirmed our worst fears. I was determined to overcome this, I had too much to lose. I was ready to fight. I come from a long line of fighters, it's in my blood. My grandad on my father's side lost his leg and returned to work driving diggers and machines on site shortly afterwards. My granny had terrible arthritis and her hands and bones were all distorted and really painful. She was a real warrior. They taught me to never give up on yourself.



On the 1st of April last year Professor Donncha O'Brien operated on me in Beaumont hospital and removed 100% of the tumour. I spent a week on my own in hospital because of Covid. It was a lonely time. I'm very thankful to Donncha and all the staff there. It turns out the type of tumour I had was Langerhans Cell Histiocytosis and is found in 1 in every million adults. I always knew myself I was one in a million but now it was official. Thankfully there was no cancer detected so I didn't need any treatment. And, apart from a big scar on the back of my head, I am fully recovered. I have had two 6-month scans since and both have been clear. I guess it really is hard to kill a bad thing!

I was more determined now than ever to complete the fundraiser.

Keith made the buggy and we organised a practise run in the Dublin mountains. I was worried my mates wouldn't all turn up but they turned out in their droves and we easily got to the top of Cruagh mountain. It was a magical day and we all felt like we were part of something very special. I have the best friends in the world. A few weeks later we took on the Sugarloaf mountains and more than 50 people turned up that day. Again we smashed it easily reaching the top

I visited schools, was in every newspaper, radio station in Ireland and even made the odd TV appearance, just trying to get the word out about my climb. It worked and the donations were rolling in. I was never off the phone, writing emails and giving interviews. I think I got every business in Kilcock and the surrounding areas to send a corporate donation. There was nowhere to hide from me. I really gave it my all.

When the big day finally arrived unfortunately so did a yellow wind and rain warning but hey nothing in my life has been easy up to this point, so I probably should have expected it. But my team were determined to get me to the top and nothing was going to stop us. My guess is about 400 people turned out that day and I am so thankful to each and every one of them. I think what we achieved that day will go down in history and we will be talking about it in my little town for years to come.

We all felt like we were 21 again after successfully completing our mission. We had a great party afterwards and celebrated into the early hours. We didn't feel 21 the next morning I can tell you.

I truly am thankful to everyone who supported me on this project. We raised €147,000 with the funds being divided equally between the NRH Foundation and SII. I am overwhelmed and overjoyed by this figure. It's amazing what can be achieved when a community pull together.



I'd like to finish up by thanking my wife Rachel. We have been together since we were 16. She has always been there for me when I needed her. Right beside me after my accident in '98 and all through my rehabilitation process, right beside me when I was recovering from my brain tumour, and right beside me at the top of Croagh Patrick, even though she twisted her ankle two weeks previously. Nothing was going to stop her being at the top of that mountain with me. Thank you darling I love you very much.

So, I might not have got the power back in my legs but I certainly recovered to have a powerful life. If anyone knows any disabled person looking to go mountain climbing, there's a buggy for sale on DoneDeal.

To anyone who has recently sustained a spinal cord injury I would say to you:

"Your life is not over. It's just the beginning of a new journey".

MENOPAUSE IN WOMEN WITH SPINAL CORD INJURY

BY SUCHETA IYENGAR



I am a Consultant in Obstetrics; Gynaecology and Menopause specialist at Buckinghamshire Healthcare Trust. For this article I will use the noun women to include all that have/ will experience the menopause.

In 2021 I was invited to speak to a group of women with Spinal Cord Injury (SCI) about the Menopause; and I was interested to know if and how the menopause may affect this group of women? Would they be affected any differently to able-bodied women, can they have the treatment options available and is the risk benefit ratio any different?

This was the first time that I reviewed the research in this group of women, and realised this is scanty. Most data is observational, and a significant proportion is from the USA, in the 1990s.

I would like to briefly mention the different ovarian hormones. The main hormones Estrogen, Progesterone and Testosterone, and are secreted cyclically, resulting in a regular menstrual cycle. Using hormones, for example, will alter this cycle. Menopause occurs when the ovary does not produce these hormones, and it is the lack of these hormones that cause symptoms, both in the short and long term.

Menopause is defined as the 'Last Menstrual Period', and the average age is 51y. Earlier studies suggested that women with SCI may become menopausal earlier, around 43y, but a more recent study has not found this. Further studies have found no difference in the symptoms in women with paraplegia/ tetraplegia; whilst some have suggested completeness of injury or level of injury may

cause more sweats/ worsening menstrual pattern. Women may also confuse menopausal symptoms with those due to the injury, rather than menopause and may not seek help as a result.

A woman is considered to be menopausal one year after her last period and therefore it is only retrospectively after this year that one can say she is now menopausal. The peri-menopause can be for a few years before this and may start from 45, or sometimes before. Periods are usually irregular, and associated with menopausal symptoms. These symptoms correlate with fluctuations in the levels of the hormones, eventually leading to a deficiency of estrogen, progesterone and testosterone.

Studies have suggested that women with SCI find hot flushes, night sweats cause less bother than in able-bodied women. An explanation is they may have had similar problems following their SCI and are able to cope with them. They may struggle more with increased spasticity, mood swings, depression and lack of sleep. Bladder spasms, vaginal dryness are pronounced, skin may be more friable, with an increase in pressure sores and slower wound healing. Lack of estrogen in the vulval, vaginal area, around the urethra can result in recurrent urine infections, difficulties in bladder management and incontinence. Sexual intercourse can become less pleasurable, with reduced libido, pain with

intercourse and risk of injury due to vaginal dryness and this may go unnoticed. In studies, women were more troubled with diminished sexual arousal, but there was no difference in sexual activity. Weight gain is also experienced in the menopause and managing this can be challenging, especially with reduced physical activity and limited access to sports facilities and equipment.

Receptors to estrogen are present all over the body, from the brain, eyes, hair and nails, skin, bones, breast, fat cells in the abdomen and genital area.

The long term effects include risk of osteoporosis and heart disease. Following the injury, there is an increase in re-absorption of the bone, resulting in the loss of bone density. In women with SCI, this is more so in the bones that are not weight-bearing, such as the hip/ thigh; whilst the bones in the spine are affected less. Estrogen deficiency in the menopause results in rapid loss of bone density, making the bone porous and more likely to fracture.

An increase in cardiovascular diseases including heart attacks and stroke is seen in the menopause, this may occur sooner in the women SCI; due to both limited mobility and less aerobic activity.

The history behind the use of HRT is interesting, it was given in the 1960s when Estrogen alone was used, and it was observed that they had less heart disease which was the leading cause of death at that time. However, the use of only Estrogen in women with a uterus resulted in an increase in cancer of the lining of the womb. Progesterone was added, and this benefit to the heart was reduced on this combination. The Women's Health Initiative (WHI) study was commenced in the 1990s, where women were either given Estrogen only (if they did not have a uterus), Estrogen and Progesterone or Placebo. The aim of this study was to see if HRT would prevent long term health conditions and the women were well beyond the menopause and not newly menopausal. It was stopped early as these women were found to have an increase in breast cancer and blood clots.

The study has been criticised for many reasons, the main one being that the findings of the study were on older women, in their 60s and these were applied to newly post-menopausal women who have a different risk profile. A 'window of opportunity' has since been suggested; that HRT should be given as close to the last menstrual period as possible, to help with menopausal symptoms, and not to prevent long term conditions.

Following the publication of this study, there was a reduction in women being prescribed HRT and also in

the research in this area; both in able-bodied women and those with SCI along with lack of experience and understanding of these issues in their healthcare providers.

Managing menopausal symptoms in both women with and without SCI begins with modification of lifestyle. There are incontrovertible health benefits of stopping smoking, reducing alcohol and caffeine intake, staying as mobile as possible as this helps in both reducing bothersome symptoms, improving bone and muscle strength and also preventing heart disease and stroke.

There is evidence of benefit with therapies including Cognitive Behavioural Therapy (CBT), this has been found to help mood, anxiety, sleep, and fatigue. Exercises such as yoga also help with joint aches and pains and to build strength. Non-hormonal medication such as Soy Isoflavones, Black Cohosh, St John's Wort may be used, with caution, as they are not regulated, and may interact with prescribed medication. Also, their benefit could be by action on the Estrogen receptor, so women should know this before using, especially if they wish to avoid hormones.

Other non-hormonal prescribed medication includes small doses of anti-depressants or medication used to prevent urinary urgency. These can help with menopausal symptoms and the treatment given would depend on what symptom is most bothersome. These have been studied extensively in women with breast cancer, who are unable to take hormones and can relieve symptoms by upto 60%.

Hormone replacement therapy (HRT) can be 80-90% effective in managing these symptoms. Estrogen (estradiol) can be given either through the skin or as a tablet and women who have a uterus need progesterone to prevent an abnormal thickening of the lining of the womb.

Estradiol is a body-identical, standardised and regulated medication. It is available as a patch (used twice a week), gel or spray (used daily). The progesterone is used either daily (post-menopause) or for 12 days per month (sequentially) in the peri-menopause. Estradiol is started at a low dose and changed (increased or decreased, based on how well the woman feels), usually after 3 months. HRT can be started after the age of 45 without the blood tests as the hormone levels fluctuate, so are not useful in either diagnosing or ruling out the menopause. The dose of estrogen also depends on the woman's age; younger women may need more and older women need less to get benefit. Progesterone is formulated in a patch combined with estrogen or as an oral tablet; equally can be had as an intrauterine device (coil).



Estradiol as a tablet is metabolized in the liver and can transiently increase the risk of getting blood clots, so is given if a preparation through the skin is not effective. This risk is already raised in women with SCI in the first few months, but this returns to normal over time.

Estradiol alone may help the vagina become moist, lubricated and supple, so preventing soreness and dryness; but if it does not, then they can be given additional vaginal estrogen, in the form of pessaries/creams. Using vaginal medication, however, can be challenging in women with tetraplegia. A vaginal estradiol ring that can be changed every three months is also available, but insertion and removal may not be straightforward.

Breast cancer is considered to be one of the risks of HRT. Lifestyle factors such as increased weight (BMI >30), excessive alcohol intake and smoking >5/day confers more of a risk than HRT and adequate daily exercise reduces the risk; so it is a balance.

The risks and benefits of HRT are very individual, and can be affected by personal and family history of breast cancer also what the woman prefers. Some are very keen to avoid any hormones, whilst some are happy to take them.

HRT is known to maintain and improve bone mineral density, and protect from fractures. However, the evidence for this is in able-bodied women and there is scanty data in women with SCI. The evidence of

protection to the heart is less definitive and HRT if taken in the early post-menopausal period/ in the perimenopause may protect against heart disease. The current thinking is if women start HRT late, then there is little risk of harm, but it may not benefit their cardiovascular system.

Testosterone is produced in very small quantities as compared to men. The production reduces in the peri and post-menopause and using testosterone externally has evidence of benefit in improving libido and sexual satisfaction. In the UK, the preparation available on the NHS is unlicensed for women, and they have to use about one eighth to one tenth of the dose that is given to men. Used at this dose, the risk of significant side-effects is negligible. As it is unlicensed, though, it needs regular monitoring by a health-care professional.

In conclusion, women with SCI are living many years after the menopause and should have a good quality of life. Some women have no bother, whilst some struggle as the symptoms can affect all aspects of their life.

Modifying lifestyle factors where possible is the cornerstone for all women in managing their health. Women with SCI can take HRT, of course other co-morbidities may need to be considered.

There is a significant need for research into this group of women, to help them and also disseminate information and increase awareness in their care-providers.

FUNDRAISING NEWS



Una Lynch and Tim Hurley on their Paris2Nice adventure

Community Fundraising

As usual you have been fantastic in challenging yourselves and raising funds to help us support those with a SCI and their families. Huge congratulations and thanks to Una Lynch and Tim Hurley who cycled the 750km from Paris2Nice raising €7,870 for SII. Neil Norton took on a gruelling 20 week training regime before facing his opponent in his first ever cage fight. While we think he's a bit mad we are hugely impressed and grateful. Thank you to Neil and everyone who supported him on this unusual but impressive challenge. Neil has now decided to take on the Half Marathon des Sables in Fuerteventura in 2023 and then the toughest ultra marathon in the world, the Marathon des Sables in the Sahara in 2024; 250 km over 7 days in the Sahara, again carrying food, rationed water in over 50 degrees of heat. A total "lunatic" to whom we are eternally grateful.

Monthly Prize Draw

Our monthly prize draw continued this year with over 350 tickets sold and raising over €2,500 every month. This sort of consistent regular fundraising is essential for us in planning future services and we desperately need to increase the number of regular donations through this channel. If you haven't signed up, for as little as €7 per month you have the chance of winning cash prizes of €1,000, €500 or €250 which are awarded to our lucky winners each month. Some have been lucky enough to win more than once! Please encourage friends and family to sign up and support our service users whilst giving themselves a real chance of a cash injection. Sign up at spinalinjuries.ie/raffle/.

Events

After a long hiatus it has been fantastic to have the opportunity to host in person fundraising events once again and so nice to meet many of our supporters face to face.

Our summer BBQ took place on the 10th September in the Royal St George Yacht Club in Dun Laoghaire. Following a gin reception, kindly sponsored by the Kinsale Spirit Company, guests were treated to a delicious meal with a wide selection of barbecued meats and salads. The amazing Lester Cassidy told his incredible story of how he sustained his spinal cord injury, overcame a brain tumour and went on to climb Croagh Patrick this year with the help of his friends raising an incredible €146,000 for ourselves and the NRH Foundation (you can read this story on pages 14 – 17). The guests then hit the dancefloor and boogied the night away to the fabulous Heebie BeeGees. The event raised over €10,000.

The following weekend SII hosted our inaugural London Lunch in the prestigious Queen's Club. Despite the air of mourning that hung over the capital city due to the Queen's death and impending funeral, the sun shone as 120 guests joined us for a drinks reception on the balcony followed by a delicious lunch in the President's Room. The beautiful Jenna Fitzgerald then shared her personal story of sustaining a spinal cord injury at a friend's wedding eight years ago. Her openness and honesty touched many hearts as she related the turbulent journey of her recovery. She is a remarkable lady and we are so grateful both to her and to all the guests who supported our first foray into the UK. Our generously donated prizes were raffled and auctioned off and the event proved a great success



Neil Norton and his children Alexander and Emelia presenting a cheque to Phil O'Kelly for his cage fight.

raising over £30,000. It's safe to say, like Arnold Schwarzenegger, we'll be back!

The next fundraising event to return to the calendar was the popular Cork Jazz Ball on the 29th of October. This took place in a new venue this year, the Cork International Hotel. 160 guests turned up to enjoy an evening of delicious food, fabulous music provided by the Underscore Orkestra and Gemma and the Jets and it raised an incredible €30,000. Also, a massive thanks to our sponsors Christy's Wine and Spirits, Classic Drinks, Kinsale Spirit Company and FADO for the delicious espresso martinis.

Next up was the now infamous Q Ball which took place on the 26th November in the Radisson Blu Royal in Dublin. Hosted by the equally infamous Philly Quinlan, the ball was a fun filled evening full of glamour and generosity. Bernard Healy shared his story of his spinal cord injury and guests generously donated to the raffle and auction that ensued before dancing the night away to the incredible Spring Break. The event raised €35,000.

GALLERY



Dancing to Heebie BeeGees at the Summer BBQ



Guests enjoying a drink in the sun at the Queen's Club at the London Lunch



A family enjoying their time on our RIB at the Inclusion Games



The crew of our Tall Ships Adventure from Poole to Dublin



Our dashing volunteers at the Q Ball



The Lipsett sisters bring the glamour as always to the Q Ball



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Christmas Appeal

This year we are fundraising to extend our free counselling service.

If you or a family member wish to avail of this service please contact us on 01 6532180 or spinalinjuries.ie/get-in-touch/.

If you can donate to provide free counselling to our service users and their families please visit spinalinjuries.ie or scan the QR code below.

Thank you and Happy Christmas!

