

OUR COVID 19 EDITION

# SPINAL NEWS

**Autonomic  
Dysreflexia**

**FIRST EVER ONLINE  
MY LIFE & WELLBEING  
CONFERENCE**

**New  
Monthly Prize  
Draw for 2021**




**Spinal  
Injuries  
Ireland**

Support at every stage

# Spinal Injuries Ireland in conjunction with Coloplast have produced two new cards



The first is a No Waiting Card for service users and can be easily carried around in your wallet and produced when required.

## No Waiting Card



The holder of this card has a medical condition which means they need to use your toilet **URGENTLY**

Thank you for your assistance

The second is an information card illustrating the warning signs of Cauda Equina Syndrome. This is for service users and healthcare professionals.

## Cauda Equina Syndrome (CES)

### YOUR 5 RED FLAGS TO SAVE YOUR SPINE

<b>S</b>	SADDLE ANAESTHESIA
<b>P</b>	PAIN
<b>I</b>	INCONTINENCE
<b>N</b>	NUMBNESS
<b>E</b>	EMERGENCY

**What is CES?**  
CES occurs when a bundle of nerves below the end of the spinal cord is damaged. Without fast treatment, permanent nerve problems and even paralysis can happen.

**What causes it?**

- Back / spine problems such as a slipped disc
- Tumours near the spine
- Injuries

Symptoms can develop slowly over months or suddenly – within a few hours.

If you would like either of these cards sent out to you please email [info@spinalinjuries.ie](mailto:info@spinalinjuries.ie) with your name and address and the card/cards you require or phone us on 01 6532180.



## WELCOME

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As we celebrated on New Year's Eve 2019, who could possibly have imagined the year that 2020 would be.

In early March we immediately ceased face to face services to people with a spinal cord injury to protect our service users and staff from contagion of the virus.

We continued the year providing all our services online and we hope that you have managed to stay connected with SII by phone, email, social media or website.

The Community Team worked tirelessly to develop online health & wellbeing content, particularly exercise, including chair yoga, healthy food and mental health. And of course, there was a little bit of fun too with music provided by service users.

We also launched our first virtual conference sponsored by Coloplast in October with speakers from Ireland and the UK covering subjects such as autonomic dysreflexia, pressure ulcers, sexuality & relationships and mental health. We also held a family day where our trained family peer mentors discussed the family aspect of spinal cord injury.

The last quarter of 2020, SII has been incredibly busy developing a new website which will go live in mid-December. It will be a more user-friendly portal for service users and we look forward to engaging further with you on [www.spinalinjuries.ie](http://www.spinalinjuries.ie)

Unfortunately, the only service we were not able to provide is the activities programme for patients in the NRH including trips on the powerboat in Dun Laoghaire. Hopefully we will be able to resume these activities later in 2021.

Alongside adapting and evolving our services, our fundraising was completely decimated especially in relation to the cancellation of our Spring Lunch, Q Ball & Cork Jazz Ball and challenges such as the Tall Ships Challenge and the Algarve Cycle. However, we were overwhelmed by the support that the organisation received from the Spinal Cord Injury community and supporters through the emergency appeal, individual challenges, and donations. As an organisation we were able to avail of the Temporary Wage Subsidy and the Employment Wage Subsidy and in September we were very grateful to receive a State stability fund of €134,000 which strengthened our financial position for the year end.

Our focus is now on 2021 which is very uncertain. We are concerned that we will not be able to run our events next year on which we rely for funding. As a result, you will note the raffle pack that is included with the magazine and if you can we would appreciate if you would consider signing up to our new monthly raffle.

Please stay in touch and if there is any additional service we can provide to you during these difficult times, please let us know.

May I take this opportunity to wish all our service users and supporters a very Happy Christmas and health and happiness for 2021.

**Kind Regards**

**Fiona Bolger CEO**

# COMMUNITY AND FUNDRAISING NEWS

In a year in which the world was turned upside down and life, as we knew it, was altered unimaginably the Spinal Injuries Community showed incredible resilience, tenacity, ambition, solidarity and generosity and we at Spinal Injuries Ireland are both sincerely proud and appreciative of everything you achieved. So many of our service users, family members and supporters took it upon themselves to do something extraordinary for the benefit of people living in Ireland with a spinal cord injury. In a year where all of our fundraising events were cancelled you took it upon yourselves to create personal events and challenges, start projects or join our virtual events and help us raise the funds required to continue to support our service users and their families. We would love to thank everyone individually here in the magazine but it would leave little room for anything else. We have included some of the highlights below to give you a flavour of what this amazing community came up with.

**We would like to thank you all for everything you have done this year. Collectively your support has been phenomenal. Thank you for being part of our SII community. #strongerthanever**

## ROWING ACROSS THE ATLANTIC

During the first lockdown period the Graiguenamanagh rowing club members decided it would be interesting to see if they could combine all of their distances to row the width of the Atlantic Ocean. The Atlantic challenge to raise money for Spinal Injuries Ireland was the brainchild of rower Dan Walsh whose girlfriend works as a nurse on the Spinal Unit in the Mater Hospital. After 3 weeks of teamwork, motivation, determination and commitment they had 50 participants, with their total journey amounting to 4,600KM or 3,000 miles from La Gomera in the Canary Islands to English Harbour in Antigua. They raised a fantastic €2,600 of much needed funds. Well done and thank you to all who took part.



## Marathons

In May of this year, in the middle of lockdown, Jonathan Ranson set himself a goal of completing a marathon using a hybrid hand-bike. It was a massive achievement and Jonathan raised an amazing €17,250.



Aengus Burke felt very curtailed in what he could do with Covid restrictions. But on the 21st June, he found a way around the limitations when he ran 21 miles. The route took him back to Rossleigh approximately every 22 minutes. The Portlaoise AFC U/16 team that Aengus coaches met at the same time to kick around a ball and join him on a relay basis for the duration of the run.

“I know the consequences of a spinal injury and appreciate the work done by Spinal Injuries Ireland. I suffered a spinal injury in 1984 but luckily made a full recovery, others are not so lucky,” said Aengus.

“I’m inspired by the work of Spinal Injuries Ireland and wanted to support them by raising money. The more people that know about Spinal Injuries Ireland, the greater their impact.”

Huge thanks to Aengus and Portlaoise AFC for raising over €2,700.

In November, Graham Whelan did his first ever marathon, having just recovered from Covid. Graham’s Mum Paula suffered a spinal injury in 2011 (see page 13). Graham said that SII helped his Mum and he wanted to return the favour. Thank you so much Graham, an amazing achievement.

In June we launched our Runners and Rollers Virtual Marathon and you all did your own versions of it. Our fantastic supporters Mary Healy and her brother in law Mark Nugent cycled and hand-cycled respectively 165km in the week. Ronan O'Keefe rolled 42km for us while his brother Donal ran alongside him and they raised over €1,500.

Not content with one marathon, Jim Clancy actually completed three including virtually travelling up Carrauntoohil twice in the same week of the eighth anniversary of becoming quadriplegic due to a high level spinal cord injury. An amazing result and Jim raised €600.



Kyle McCarthy also decided to set himself an almighty challenge and ran 400km in June, raising a fantastic €4,725. Kyle is a relation of Sr Aileen McCarthy, one of the founders of Spinal Injuries Ireland and the McCarthy family continue to be great supporters.

Rosie Gowran and her daughter Nora, aged 13, also ran a virtual marathon and raised over €1,200 while Community Outreach Officer, Philippa O'Leary did her mini marathon of 10km in Killarney and service user Paul Fitzhenry did his virtual Great Limerick Walk 10km in May.



## VIRTUAL PORTUGAL CYCLE

When Covid hit and we were forced to cancel our planned mixed ability cycle in the Algarve in collaboration with the IRFU Charitable Trust, Irish Paralympian Medallist, Mark Rohan, who was helping organise the event in Portugal, stepped into the breach and agreed to hand cycle from Porto to the Algarve, posting video footage as he went. Thanks to his efforts, where he raised over €8,000 personally, we were encouraged to set the challenge to lots of other brave cyclists in Ireland. A total of 32 people cycled or hand cycled the 220kms or 650kms virtual Algarve routes we set. One lady, Carmel Hughes, did it on her exercise bike and wheelchair user Birgit Tol used her therapy bike!

Senan Corry's father Diarmuid has a spinal cord injury and together they took part in our virtual cycle. Senan is only 13 years of age and cycled 294km, raising a whopping €995!

In total our cyclists raised an incredible €32,598.



# COMMUNITY AND FUNDRAISING NEWS

## A QUICK CHANGE OF TACK

Hazel Wilson in South Wickow put together a crack team of volunteers who are turning out the most colourful eye-catching facemasks which they are providing through local pharmacies and taking personal orders by phone with all proceeds going to Spinal Injuries Ireland (SII). Hazel is a former primary school teacher of Spinal Injuries Ireland service user Gemma Willis and it is Gemma's fantastic positivity that inspired Hazel and her team to raise money for SII. They have raised over €6,650 so far and the money is still coming in!



## Other fundraisers

Pop Artist Orla Walsh, whose husband has a SCI, kindly donated 50% of the proceeds of the sale of her Limited Edition Barry's Tea Prints, netting an incredible €6,574.37. The Barry Group also added a donation of €2,500 for which we are very grateful. Thank you so much Orla.

We are extremely grateful to Gonzaga College, St. Columcille's Community School and St Andrew's College who all ran jersey/non uniform days in aid of SII.



Our thanks to Eisner Amper who hosted a pre-match BBQ for the Ireland v Scotland Six Nations Rugby International. The event included a charity raffle in aid of SII and featured a great Q&A session with Scotland rugby legend Scott Hastings. Over €1,500 was raised and our own Philip Quinlan was there to tell his story and explain how vital these funds are to SII and how we spend them. Well done all. Much appreciated.

Thank you to everyone who did Facebook Birthday Fundraisers. This is an easy way to raise funds for your chosen charity and we really appreciate all those who selected SII as their charity of choice.

And finally, our own Robert Kenny took the drastic decision to shave his head last May. Robert sustained his spinal cord injury in a car accident in 1984 and is the longest serving team member of SII having joined the staff in 1998. He is the joker on the team and has kept us all entertained with his jokes on WhatsApp as we all work remotely. But fundraising is no joke to Rob. He works tirelessly organising collections in shopping centres and supermarkets all over Dublin. Since Covid 19 has put a halt to his gallop Rob decided to shave his head in an attempt to make up for his cancelled collections.

## Other Fundraising News

Many of you attend one or more of our annual fundraising events, organised by the inimitable Philip Quinlan. This year all of them were sadly cancelled. We organised an exclusive raffle amongst our regular events goers and raised an incredible €28,350. Your support is so vital to us and we really look forward to hopefully getting together with you all again in 2021.

A special thanks to Michael Lynam, of O'Brien Lynam Solicitors (OBL), for all his continued support. He personally ran several marathons for SII and then when celebrations for OBL's 20 years in business had to be put on hold due to Covid, himself and his partner Jack, very kindly decided to donate the funds that would have been spent on the night to SII.

We would also like to thank Neal McGroarty and Brindley Health care who donated generously to our Emergency Appeal and offered us whatever practical support they could provide to our service users through their 6 HIQA registered residential care homes in Donegal, Galway, Mayo and Kildare.

And finally, a big thank you to Neil Cauldwell of Neil Cauldwell Quantity Surveyors, for his consistent generosity in 2020.

**To all our supporters, donors, sponsors and service users – a massive THANK YOU.**

# SERVICES UPDATE - KEEPING IN TOUCH DURING COVID 19

We never saw this coming but, on the 14th March, we had to change the way we provide support and information to you overnight. Like so many other organisations we were unsure how best to adjust, but we all pulled together as a team and got on with it. Our first option was to phone all our service users individually and ensure you knew we were, (and still are), here for you at every stage of your injury.

We quickly replaced our face-to-face meetings with online options and transferred all our events online via our new best friend ZOOM!



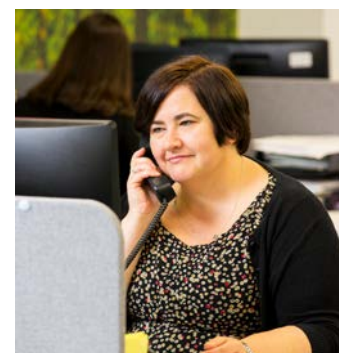
It was not long before we reached out to you to see what you needed most during these strange times and started to arrange a series of online activities. We asked you to get involved and share how you were dealing with living in the COVID – 19 world. We were overwhelmed by your support and, by sharing your experiences and coping skills during this time, your stories motivated others to keep engaged, supported and active.

In September and October SII hosted the first series of virtual education sessions via Zoom on Relationships, Intimacy and Sexuality facilitated by Michelle Donald PGDip.PST a qualified Psychosexual Therapist based in the UK.

“My expertise lies in the areas of sexual issues related to spinal cord injury and the issues that a SCI may bring with it. I feel it is necessary to address the issue of how important sexuality is after a spinal cord injury in that this aspect of the relationship shared by a couple is often neglected, with the focus being on the physical dysfunction.” - Michelle Donald

The webinar series was well received with over 200 of our service users attending the various talks over the 7 weeks. Topics covered a broad range of issues from what is psychosexual therapy, dating with a spinal injury & communicating your relationship needs.

We were also fortunate to have Pauline Shiels, Clinical Nurse Specialist in Relationships and Sexuality based in the National Rehabilitation Hospital join some of



our sessions. Pauline was able to answer the medical aspects of the conversation such as the impact of various medicines and appliances that may assist with function. Pauline encourages anyone with a spinal injury looking to discuss this area more to contact her on 01-2355288 or pauline.sheils@nrh.ie. Individuals who did not come through the NRH can also avail of the service, they will simply need to have a referral letter from a GP.

We also ran many webinars on a variety of topics including: Returning to work with a SCI, Healthy Bladder and Bowel Management, and Pressure Care Awareness.

We know how important it is to talk to someone who truly understands what it is like to have a spinal cord injury, so we moved our peer training online. We trained 7 more peer volunteers to make sure you can speak to people who have similar experiences to you. (See Peer Support Update)

Unfortunately, we were unable to meet you all at the ‘My Life and Wellbeing Conference’ which was planned for April. Moving online was the only way forward and we held our first online conference in October. Thank you for all your feedback and see our conference review on page 9.

We have been working in the background to bring you a new and interactive website which will launch very soon. Please let us know what you think and share any ideas you have to improve it.

The services we had to put on hold altogether were our activities programme and our Great Day Out Programme. These programmes aren’t just an effective way for people with a SCI to forget about their worries for a day. For many, it is the first bold step to integrating their lives back into society. The Great Day Out is often the first opportunity a person with a SCI gets to go outside the hospital gates. For many, it is a pivotal moment in overcoming both the psychological and physical barriers of returning to a normal life. We look forward to re-instating these services as soon as this pandemic allows.

Thank you for all your feedback and engagement this year and we wish you a peaceful Christmas and New Year.

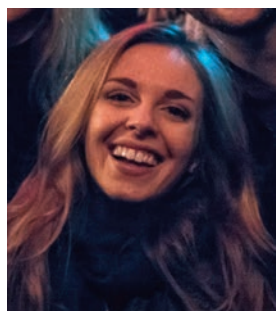
**Naomi and the Services Team.**

## Proudly supported by the Baxter International Foundation



A 2 day in person training was held in January 2020 with 19 attendees in total (14 peer and family volunteers and 5 activity volunteers).

These were a mixture of existing and new volunteers. The first day was for all attendees and covered an overview of Spinal injuries Ireland; strategy, organisational chart, governance code, fundraising, rationale for training and SCI causes and types. The specifics of volunteering and motivation for the role were explored. A psychotherapist presented on trauma, boundaries and listening and communication skills.



The second day of training was for the peer and family volunteers only and covered policies and procedures around engaging with service users both face to face and over the phone. This training also included telephone call skills, communication skills, awareness of boundaries, dealing with emotional distress and how to impart appropriate advice and information. Issues with confidentiality and reporting concerns were also covered.

All volunteers are Garda vetted and undergo Children First training, sign a code of conduct and a volunteer agreement before undertaking their volunteer role. Peer and family volunteer profiles were uploaded to the SII website so services users and family members can see who's available for them to speak with.



The training moved online due to Covid 19 and was held over 2 mornings in May over Zoom with 5 peer and 1 family volunteers. We now have completed training with 17 peer and 3 family volunteers who are available to provide support to other service users and their families.

One to one referrals for peer and family support are ongoing



From July 15th – August 19th we facilitated weekly Zoom Peer support coffee mornings. There were 6 sessions in total each Wednesday covering 6 groups; Transverse Myelitis & Guillain Barre, Cauda Equina Syndrome, manual wheelchair users, walkers, power chair users and walkers using an aid. The rationale behind dividing into these groups was in order to gauge the specific needs and topics of discussion of each group for future information sessions. It also allowed for people with similar issues to find a safe place to discuss them.

Peer volunteers from each group logged on to co-facilitate and deal with any queries that arose. The peer volunteers led the sessions they participated in which worked very well. Topics discussed included the following; recovery, acceptance, misdiagnosis, pain, sleep, fatigue, medication, treatment, trauma, pressure care, autonomic dysreflexia, wheelchair accessibility in hospitals, bowel/ bladder management, coping skills, resilience, equipment, managing expectations, communication with family and friends, and how to talk about your condition.



To link in with a trained peer volunteer please email [info@spinalinjuries.ie](mailto:info@spinalinjuries.ie) or phone 016532180

## Some Feedback from the Peer Support Coffee Mornings.

- “I might not get a solution here but there’s comfort in knowing I’m not the only one with this problem”. “
- These people understood, so weren’t afraid to talk about different topics.”
- “I found it very interesting to listen to everyone and realise that we may be broken but we are normal and what we are going through is normal for us”
- “I felt a great sense of belonging and understanding from meeting my peers.”



# MY LIFE & WELLBEING DURING COVID ONLINE CONFERENCE

A lot of planning had gone into our bi-annual conference scheduled for April this year and then postponed due to Covid. We were devastated to have to cancel it altogether and, as we had no idea what lay ahead with the pandemic and when we would get to run it, we decided to host a virtual conference. Our good friends in Coloplast who were sponsoring our planned conference were happy to come on board and so, from the 19th to the 23rd October, we hosted our first ever online conference.

With almost 250 engaging with the conference over the week, we were happy that it was the right decision and many of you have followed up looking for recordings and handouts. We would like to say a massive thank you to all our speakers who presented on a wide variety of topics. We really appreciate your experience, expertise and support.

We would also like to thank all of you who attended the conference. For those of you who couldn't make it recordings of some of the sessions are available online to watch on our YouTube Channel at: <https://bit.ly/MyLifeandWellebeingConference2020>

Finally thank you Coloplast for supporting the conference once again.

## CONFERENCE REVIEWS:

### ● Day 1: 19th October

#### Intro and welcome: Fiona Bolger

Our first webinar began with an overall introduction to the SII My Life and Wellbeing conference by Spinal Injuries Ireland CEO, Fiona Bolger. Fiona updated attendees on SII services and the adaptations in SII's work approach throughout 2020, due to Covid-19 restrictions. Fiona gave an overview of the week's online conference and thanked our speakers for promoting a diverse range of topics for our first virtual event.

#### An overview of the implementation of A Trauma System for Ireland: Mr Keith Synnott

Keith Synnott is the National Clinical Lead for Trauma services in Ireland and Consultant Orthopedic and Spine Surgeon working in the National Spinal Injuries Unit, Mater Misericordiae University Hospital, the National Orthopedic Hospital Cappagh and the National Rehabilitation Hospital.

Keith gave an overview of Trauma from an Irish perspective and looked nationally at the Irish system of Trauma, the developments from its implementation and how it has progressed and hopefully will continue to progress into the future.

#### NRH Update: Dr. Eimear Smith

Dr. Eimear Smith is a Consultant in Rehabilitation Medicine and Medical Director of the Spinal Cord System of Care Program at the National Rehabilitation Hospital and Mater Hospital, Dublin. Eimear shared a power point presentation with photos of the new NRH building and talked the viewers through the state-of-the-art new facilities and amenities it has to offer.

#### Meet the Team

This webinar focused on our service users & health care professionals getting to know the Spinal Injuries Ireland team. Our webinar started with a brief overview of everyone on the team and their varying roles. The webinar then provided the opportunity for people to put questions, queries and suggestions to the team for future events.



### ● Day 2: 20th October

#### Introduction to peer support volunteers

We met 7 of our peer volunteers on Tuesday morning. Brian Lawlor, who coordinates our peer support in the NRH, spoke about the support that had been happening prior to Covid 19. Gemma, Cathy, Bernard, Julie, Noreen and Sandra then all shared their experiences with spinal cord injuries and their reasons for becoming peer support volunteers. The importance of peer support was echoed in their stories as they are shared by so many other people.

#### Peer support work session

Conor McGinn, one of our peer support volunteers, talked about his experiences working in the public and private sector; firstly, in the civil service and then with a long career in AIB until his retirement in early 2020. He spoke about the physical accommodations his employers made even before any of these were mandatory and how support from his colleagues was key to success in his working life.

## Looking after your mental health: Ann Marie Flanagan

Ann Marie is a Regional Development Officer with Shine: supporting people affected by mental ill health. Ann Marie spoke about several topics that can impact on everyone's mental health and techniques to deal with mental health issues. Everyone has the potential to set and achieve personal & life goals, enhanced with support and new skills.

Ann Marie discussed the topic of resilience and characteristics of a resilient person which included some of the below.

Resilience - the capacity to recover from difficult life events. Resilience can help protect our mental health and recover from mental health issues, such as depression and anxiety. Resilience can also help offset factors that increase the risk of mental health issues, such as a previous trauma.

In order to manage feelings, it is essential to understand what is causing them and why. By remaining aware, resilient people can maintain control of the situation and think of new ways to tackle problems.

In danger situations people sometimes develop tunnel vision preventing them from noticing important details or taking advantage of opportunities. Resilient individuals can calmly and rationally look at the problem and envision a successful solution.

## ● Day 3: 21st October

### Psychosexual Therapy – What is it and how can it help those with a SCI? Michelle Donald

Michelle Donald PGDip.PST recently facilitated SII's first series of webinars on the topic of relationships, intimacy and sexuality over a 7-part series. Michelle is a fully qualified and accredited Psychosexual Therapist, registered with the College of Sexual and Relationship Therapists (COSRT). Michelle is a specialist working within Spinal Centres across the UK and also has a spinal cord injury.

Michelle gave a broad overview of what Psychosexual Therapy is and how it can be beneficial for not only people with a spinal injury but their partners as well.

#### Some of the topics discussed included:

- How this therapy is focused on specifically tailored education and cognitive behavioural therapy for each individual and help with people's reactions to changes in functioning.
- How psychosexual therapy can address couple communication and issues of adjustment and loss.

- Client goals are many and varied and approaches for each person/couple are always unique.

- Body mapping technique - This exercise emphasises intimacy and differences in sensuality.

The process helps people rediscover their own bodies and their partners bodies. This exercise enables people to better understand what has changed for themselves and for their partner in knowing which areas can now be comfortably touched.

### Are You Listening? How to communicate your needs. - Mary Scarff

Mary is a member of the Irish Association of Humanistic and Integrative Psychotherapy. She is a psychotherapist specialising in areas of Trauma and Relationship Counselling.

#### Mary's talk covered:

- What boundaries are and how they can promote a healthy relationship.
- How boundaries are abused and can result in co-dependency.
- Conflict and how it can be managed.
- Different styles of Conflict Management.
- Active Listening, what it is.
- Anger, when anger can have positive or a negative outcome for an individual.

## ● Day 4: 22nd October

### How the body deals with Trauma. Brid Keenan

Brid is a Gestalt Psychotherapist, Supervisor and trainer and a Somatic Experiencing Practitioner, working with the impact of Trauma of individuals, families and communities.

#### Brid's talk covered:

- What is Trauma and what happens in the aftermath of Trauma.
- Trauma is not a mental health condition, although it can become one if left unintegrated. Trauma is not a disorder, it is an injury.
- The body experiences trauma first, how we act out of trauma, will be influenced by our cultural context and family style.
- How Trauma affects our nervous system.
- Survival Strategy
- Behavioural patterns that develop through experience of Trauma.

- The Nervous System, Sympathetic and Parasympathetic.
- Somatic Experiencing: The River of Life – healing Trauma.
- Unintegrated Trauma, how the nervous system gets stuck in overdrive or underdrive.
- The Polyvagal System.
- Functional Immobility.
- Capacity and Regulation: supporting the capacity of the client, finding a way for them to be in the world that feels good for them. Enabling the person, the ability to live a better life.

### Autonomic Dysreflexia - Paula Keane

Paula is the Spinal Liaison Nurse in the National Rehabilitation Hospital.

#### Paula's talk covered:

- What is Autonomic Dysreflexia (AD).
- Causes of AD.
- Signs and Symptoms of AD.
- AD is a medical emergency, if not treated can lead to life threatening symptoms or even death.
- What to do in the event of AD.
- Emergency Treatment for AD.
- Prevention of AD, promoting knowledge as early recognition and prompt treatment can minimise complications.

### Pressure Wound Care – An Overview: Eimear Daly

Eimear Daly is the Programme Manager (Health and Continence) in the Crann Centre, Cork. Eimear has a wealth of knowledge and nursing experience having previously worked with Cope Foundation, Temple Street Children's Hospital Dublin and The Mercy University Hospital, Cork before joining the team in Crann Centre Cork. Crann Centre work with all age groups and their families living with a neuro physical disability.

During this webinar Eimear discussed topics such as

- Terminology used for various types of pressure wounds and importance of checking skin on a regular basis
- Pressure ulcers are preventable in 95% Cases and they can happen to anyone at any age, awareness is key.
- If you are immobile you are at greater risk as pressure cannot be relieved over bony prominences

### Risk Factors for Skin Breakdown & Pressure Ulcer Development in SCI such as

- Immobility, Inactivity
- Paralysis and Sensory loss/impairment
- Excessive moisture (wet skin is fragile)
- Bowel incontinence
- Bladder incontinence
- Perspiration
- Not drying skin fully post washing
- Muscle Atrophy (shrinking) reduces padding over bony prominences
- Nutrition: Risk malnutrition
- Altered circulation/blood supply
- Delayed wound healing
- Pre-existing or history of pressure ulcers

## ● Day 5: 23rd October

### Family support volunteers

We met Gabrielle and Mary, family members of two of our service users. Gabrielle spoke of “trying to hold it all together” when her daughter sustained a SCI abroad. Mary's husband sustained a SCI several years ago and she spoke of juggling this with family life with two young children. We are so grateful to these two ladies for being so honest and eloquent in sharing their lived experiences and they are more than willing to support others who may find themselves in a similar situation

### Wellness and Meditation - Karen Stokes

Karen is a wellness facilitator trained in child and adult wellness education. Karen specialises in gentle but effective wellness techniques designed to deal with stress, anxiety, depression, fears, anger, and trauma.

During this webinar Karen discussed topics such as

- Importance of self-care -Looking after ourselves as well as those we may support
- Awareness of stressors in our life and how to manage them
- Practical Techniques for coping with stress and anxiety.
- Relaxation and meditation

This session was an opportunity for people to relax and focus on their own self care needs. Karen went through a variety of techniques from visualisation/meditation and body & face mapping techniques to help individuals to enhance calm and reduce stress factors in their daily lives.

# COVID CONTRIBUTORS

As the Corona Virus launched its attack and we found ourselves in lockdown with all services moving to an online platform we tried to come up with a varied range of topics to keep you all entertained and occupied. From weekly quizzes to webinars and videos of Pilates and Yoga for you to do at home we did our best to keep interesting content coming your way. We could not have done this without the help and support of some of our service users and colleagues and friends who were happy to share their time and expertise with you.

We would like to particularly thank Rob O'Byrne of **What's Your Excuse Fitness** who provided us with some fantastic exercise options for you including his Upper Body Workout with Weights, his Sweeping Brush Routine and his Exercises at Home Routines. Rob is always willing to put something together for us to share with our service users and as a wheelchair user himself he fully understands the limitations many of you are experiencing. Thank you Rob.

Gemma Willis, another SII legend, shared some lovely videos with us telling us what she was getting up to, introducing us to her lovely puppy and most importantly sharing some of her delicious recipes with us. While we do promote healthy eating, it is really important to treat yourself during this pandemic and Gemma shared some gorgeous recipes with us and demonstrated how to make her favourite treats. She has kindly given us a festive recipe to share with you. Thank you Gemma. You always make us smile and your videos are a firm favourite on our Facebook and Instagram.



Bernard Healy also shared his Covid diary with us, giving us an insight into how he was coping and spending his time. Bernard is one of our peer support volunteers and is always willing to help when he can. Thank you Bernard.

Another group that pulled together to lift our spirits were the fabulous TKMex. This is a band of volunteers who get together to entertain patients in the NRH. Unfortunately, they haven't been allowed to do that during the pandemic but individually they recorded some lovely songs for us which we shared with you and the NRH. Huge thanks to Tim Rice, Kevin McCourt and Michael Swaine. We've cheekily asked for a few Christmas numbers so we're keeping our fingers crossed.

We would also like to thank physiotherapists John Lynch from the NRH and Ronan Langan for the videos they sent through which we shared with you. Also huge thanks to Jack Kavanagh, service user, pharmacist and life coach for putting together his video on how to look after yourselves during the pandemic. Your contributions were all greatly appreciated.

Our Yoga and Pilates videos for you to practice at home were very popular. Thank you to Justin Feddis and Denise Coughlan of Resolute Pilates and Wellness for putting these together specifically for our service users. Ali Dorgan, Nutritional Therapist also provided some great recipes and advice on healthy eating. Thank you all.

Finally, Q102 were our radio partners for 2020. Some of you recorded soundbites for us which were aired earlier this year. Thank you so much to Jennifer Hester, Rogerio Ribeiro, Kieran Fitzgerald, Aisling Kennedy, Barry McLoughlin, Tim Rice, Vicky Hayes, Paula McCormack and Joanne Jacob.



## Gemma Willis' Terrys Chocolate Orange Cheesecake

### Ingredients

- 300g chocolate cookies
- 100g butter (melted)
- Zest of 2 oranges
- 250g cream cheese
- 150g icing sugar
- 200g Terry's chocolate orange, plus extra slices for decorating
- 150g double cream



You will need a 21cm loose bottomed cake tin  
Crush the biscuits into crumbs.  
Mix in the melted butter and zest of 1 orange. Combine and press into the bottom of the tin.  
Mix together the cream cheese and icing sugar until smooth. Set aside.  
Melt the 200g of chocolate orange in a bowl over a pan of simmering water, making sure the bottom of the bowl isn't touching the water.  
Once melted, whip the cream until it forms soft peaks, then mix the melted chocolate and cream cheese mixture. Mix until smooth and well combined.  
Pour onto the biscuit base and smooth out. Chill in the fridge for at least 2 hours.  
To decorate use the remaining chocolate orange slices and orange zest.

# SERVICE USER STORY

Paula McCormack



**My name is Paula McCormack. Before my spinal injury I was a single Mum, a playschool teacher and a very active woman. My boys joined our local GAA club and I joined the management team in 1999 and continued with them until my accident in 2011.**

It was at a GAA training session that I had my accident. I had gone over early to get everything ready and while walking down a metal staircase with a bag of footballs in one hand and water bottles in the other I slipped on a flogpole that had been left on the stairs.

I was rushed to A&E in Tallaght hospital where I discovered I had dislocated my right ankle. One nurse was concerned about my back but nothing was done at that time. As I spent the next 5 months in casts and boots it kept me off work and resting a lot.

In November I had just finished physio on my foot and was beginning to get out and about a bit. One night a friend dropped me home and when I got out of the car my legs went from under me. I was like Bambi on ice. Somehow the boys managed to get me into the house but I could not move as my back was in excruciating pain. My son ran and got a neighbour who phoned the on-call doctor and stayed with me until the doctor came 4 hours later at 3 am. Straight away I was told that I had

slipped a disc and I received a morphine injection to relieve the pain to help me get into bed.

I got more injections over the weekend and my GP called out on Monday. He said to wait until after Christmas to have an MRI as the disc could slip back in, and this could take up to six weeks. In the meantime, he gave me morphine.

There are so many things about the next few weeks that I will never forget; - how well my two sons looked after me, doing things that boys shouldn't have to do for their Mum, like bringing in a bowl or bucket for me to use to pee into, lifting me and holding me while I peed, buying me sanitary items, and helping me shower. My bowel didn't work for weeks. The boys also looked after the housework and cooking. I will never forget the pain even though I was on a lot of morphine and other pain medicine.

In Jan 2012, I had my first MRI. I was told physiotherapy and surgery weren't the answer for me and injections were the way to go. I got about 3 months pain relief with the first cordial spinal injection, but it returned with a bang. I had a nerve root block, a further 7 cordial injections, a spinal cord stimulator trial and another MRI over the next 2 years but they all failed.

I was left in a lot of pain wearing a morphine patch and a tens machine continuously. I did a pain management course, had another MRI and opinion but 4 years after my fall I was no better off and getting no help.

Then one morning in November 2015 I lost control of my bladder. After another MRI I had an appointment with a Neurosurgeon who admitted me to hospital immediately and performed a discectomy on the Sunday morning. On Monday morning I was put sitting on a commode, I felt like I was going to fall off it, because my left leg and butt cheek was numb. After a while one of the nurses came into me and asked if I had gone to the toilet I told her that I didn't know. I realised I could not feel anything and my left leg was paralyzed. I spent 3 weeks in Tallaght hospital, was allowed home for Christmas and spent January waiting for a bed in the NRH.

I went to the NRH in February 2016 until the end of April. It was there that I was introduced to SII. There was something arranged most evenings by SII and this is where a lot of patients met up with each other from different areas of the hospital. I made some lifelong friends thanks to SII and we helped each other with our life changing situations.

**I had become very depressed and I suppose due to so many things going against me, I found myself going deeper and deeper into depression.**

Oh, I could laugh and joke but behind that smile I hid my depression. But I had a plan, I would manage for as long as I could but as soon as I became a burden to my sons I would do away with myself, I had plenty of drugs to do so.....today I can't believe I am even writing this.

From 2016, I had very little physio. I got into an 8-week program for people who had had a stroke, which was not much help to me but better than nothing. I was writing everywhere trying to get help. My SII community outreach officer got me into a hydrotherapy course in Tallaght hospital. Everything I did had to be timed around my bladder and bowel not being able to go out unless I had a bowel movement and having to self-catheterize myself 6/8 times a day which led to very bad infections.

**Because my house was not wheelchair friendly, I had to try to walk around the house and I would fall 20+ times a day.**

I really wanted to try to improve my core strength, but everyone I asked refused once they heard the words spinal injury.

Then one day I passed the Flyfit gym in Tallaght. It was very near my home and I noticed that they had

wheelchair ramps, so I rang the doorbell. It was there I met Brian Flaherty. I gave him the details of my spinal injury and he said he would look it up and see what he could do for me. 2 weeks later he had prepared a programme for me.

**Brian explains, "Paula was paralysed in her left leg. She arrived at the gym with the most positive attitude and enthusiasm to train. Who was I to stand in her way? We set about implementing a plan to improve her strength, body composition and overall health and wellness."**

"After a month or so Paula began to be able to lift her leg from the hip which improved her gait. We were both delighted. She also developed some sensation in the leg, and a few weeks later she began to get some movement. In August she fully extended her leg for the first time in 4 years. From September she started to perform sets and reps of leg extensions, leg curls and toe taps."



Brian left Flyfit to set up his own business (PerformanceDynamics.ie) but recorded videos of exercises for Paula to continue with on his personal training app. The two have remained firm friends.

Brian also introduced me to a book 'The power of the subconscious mind' by Dr. Joseph Murphy. When we started physically training I began to train my subconscious mind too. I imagined myself moving my leg. After I moved my leg I began to imagine myself walking my dog and I succeeded in doing that. I imagined myself going back to my doctor in



the hospital and him saying to me **'this is a miracle you are walking again'**. This happened this year. The power of a positive outlook is incredible.

I went to a family wedding at the end of September 2019. My goal had been to get to the wedding without my wheelchair and I did that. I used my leg splint and a crutch and, even if I say so myself, I looked and felt great.

At the wedding I met a lovely man named John from Tipperary, a place I had always loved because my Mother was from there. I had spent every summer of my childhood down there and John had lived around the corner from my Granny's house but I never met him until the wedding.

**I am now living my best life in Tipperary with John, my dog Oscar and 2 chickens Penny and Amber loving life, and being positive.**

I joined a gym in Tipperary, Xtreme Gym, which is a very modern gym, with great equipment and lots of space, and I follow Brian's app.

I still have a spinal injury and pain. I am still on morphine as well as other medication and I have continued problems with my bladder and bowel. Hopefully thanks to SII again and Debbie the Coloplast Nurse I will sort my bladder problems. I did come off my bowel medication, I use liquorice instead.

This year people have had to deal with Covid-19, cocooning, staying at home and missing out on family outings and social gatherings. I had to live like that for years. The Corona Virus may have given people some idea of what it is like for people living with spinal injuries and what they have to go through.

If I had private health insurance my disc would have been pared back at the start of my problem with a 3 day stay in hospital and a 3/5 week recovery, whereas I was left waiting and struck off waiting lists and left to my own devices. This is something that I feel very angry about still, and something I feel really needs to change.

I very much hope that this story can help at least one person to help themselves either mentally or physically....

**Believe to Achieve.....**

**Paula**



**Paula's son Graham has just undertaken his first marathon raising funds for Spinal Injuries Ireland having just recovered from Covid 19.**

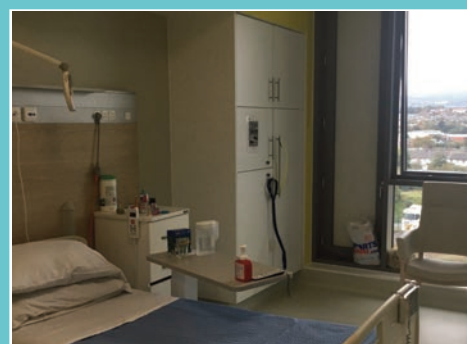
**A remarkable family all around.**

**If you would like to support Graham visit his page**

**[https://ie.gofundme.com/f/marathon-for-spinal-injuries-ireland.](https://ie.gofundme.com/f/marathon-for-spinal-injuries-ireland)**

# NRH UPDATE

As many of you know, the NRH moved to 'The New Hospital' during the summer. The move went very well and the patients are enjoying the new space, which is bright and light with many communal spaces for patients to meet and socialise. Unfortunately, our peer volunteers and community outreach team have been unable to visit, but we are in regular contact with the staff on the spinal team. Dr Eimear Smith sent some pictures of Phase 1 of the hospital. We hope to visit very soon.





# UPDATE ON “A TRAUMA SYSTEM FOR IRELAND”

by Mr. Keith Synnott, National Clinical Lead for Trauma Services



**The report “A Trauma System for Ireland” was published in 2018 and recommended the implementation of an inclusive trauma system. These systems have been shown to improve outcomes for trauma elsewhere.**

An inclusive trauma system is one where all components work together as part of a network so that patients are treated in the most appropriate location that is closest to where their injury occurs. This may mean that a minor injury is managed in a local injury unit nearby while patients with severe injuries are transferred to centres of excellence where all their injuries can be managed in one location to a high standard. The overriding philosophy is that the right patient is treated in the right place at the right time.

Another concept of the inclusive trauma system is that the network addresses all aspects of a care for trauma. This includes been involved in injury prevention, ensuring adequate prehospital care and transport, providing timely resuscitative care and definitive management and most importantly ensuring that rehabilitation services are provided and planned to allow patients get back to their highest possible level of function in the shortest time.

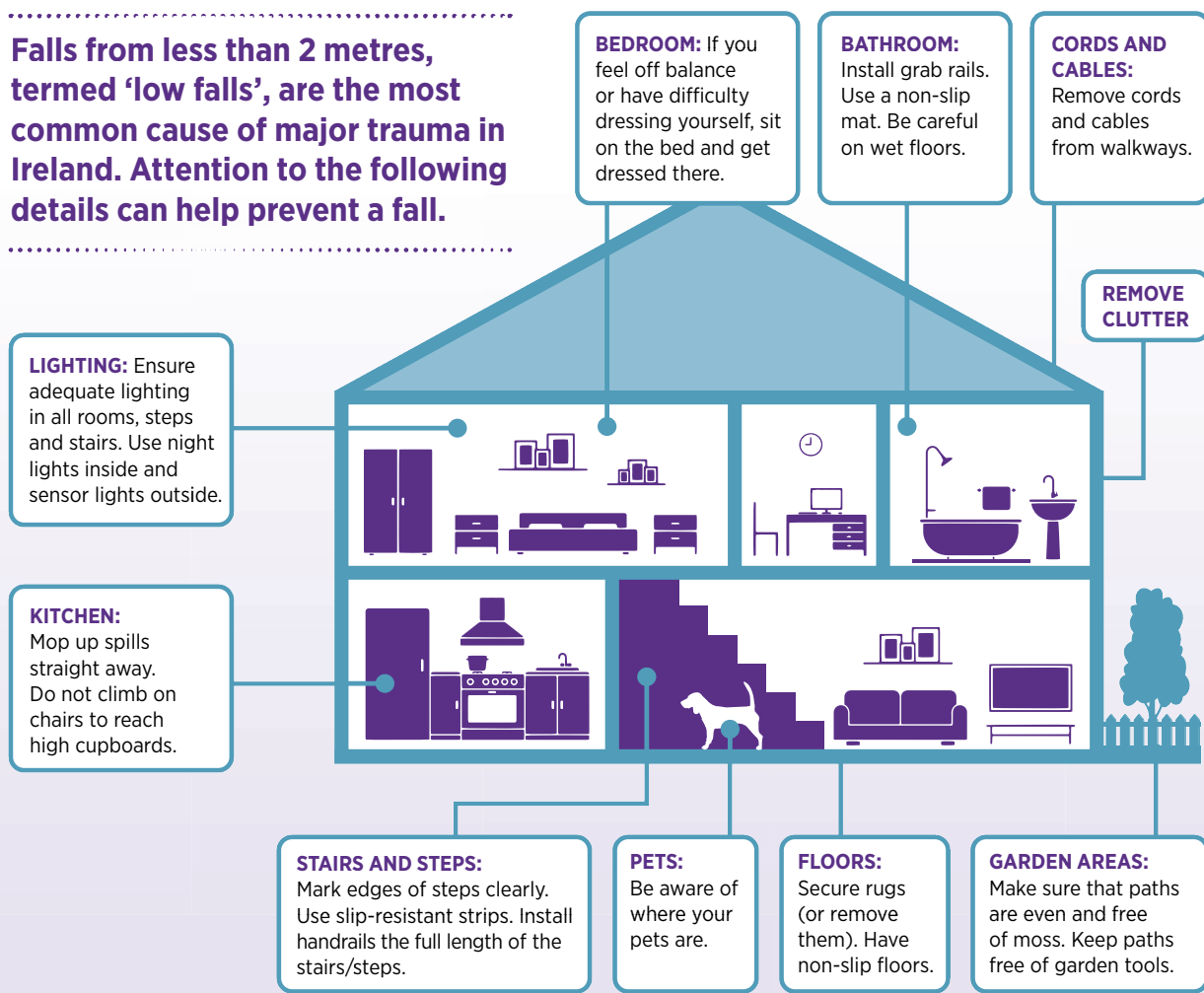
In Ireland it is envisaged that the trauma system will comprise of two networks centred around a major trauma centre in Cork and Dublin. Care will be delivered in a hold and spoke fashion in the major trauma centres, affiliated trauma units and injury units. Complex specialist rehabilitation will be provided in the National Rehabilitation Hospital and the major trauma centres with affiliated post-acute and community rehabilitation facilities.

The ambulance service will have triage and bypass protocols in place ensuring that patients are brought to the most appropriate facility. Depending on the distances involved this will either be to a major trauma centre or a trauma unit. Major trauma centres will be able to deal with all the injuries a patient may sustain. Trauma units will be able to provide initial resuscitation and stabilisation and often all subsequent care. If the patients injuries require a higher level of care they will be transferred to major trauma centres immediately. More minor injuries do not require Ireland’s transport may be managed in injury units.

Just as the system will endeavour to provide initial management on a timely basis it is envisaged that rehabilitation will begin as soon as possible. The aim is for a rehabilitation needs assessment to be completed within 48 hours so that further rehab can be planned and instituted on a timely basis minimising delays. The aim is for rehabilitation to be provided at the most appropriate level closest to patients home in the same fashion as initial management.

The national trauma office have completed a comprehensive implementation plan for the trauma system. The programme for government and budget 2021 have confirmed the commitment to developing an inclusive trauma system for Ireland. It is hoped that we can move from the planning to the implementation phase in 2021 and would hope to have a nascent trauma system in place by the end of the year. There are many challenges towards achieving what we hope will be a world-class comprehensive trauma system but this is a very exciting development which will hopefully benefit anybody who sustains a traumatic injury. The degree of enthusiasm surrounding this project is very encouraging and any support from any interested parties will help move the process along. While a project of this scale is challenging ultimately the potential benefits to patients make it worthwhile.

**Falls from less than 2 metres, termed 'low falls', are the most common cause of major trauma in Ireland. Attention to the following details can help prevent a fall.**



The National Office of Clinical Audit (NOCA) manages audits with the aim to measure patient care against defined clinical standards. The main purpose of clinical audit is to improve patient outcomes. The data collected by the different audits helps to support hospitals to identify areas for improvement. NOCA manages a suite of audits measuring the care of patients within areas such as stroke, hip fracture, major trauma, heart attack, intensive care patients and those having elective hip and knee replacements.

The importance of including the patient perspective is a key focus of the work within NOCA and each of the audits has a committee with a patient and public interest (PPI) representative(s). The PPI representative contributes towards the planning, design and implementation of audits. They help to develop guidance relevant to the audit, participate in the development of national reports and conferences. PPI representatives are also core members of the NOCA Governance Board.

One of the NOCA PPI representatives, Naomi Fitzgibbon is a member of the Major Trauma Audit and has recently worked on a home safety message derived from the data within the audit. Being Head of Services for Spinal Injuries Ireland Naomi understands how accidents leading to life changing injuries can impact on a person or family. Naomi provided her experience to better understand findings from the audit and provided input on how best to guide the healthcare system in achieving quality improvement and the wider public on injury prevention. The MTA 2018 report showed that falls at home are the leading cause major trauma injuries. The details of falls at home were used to design a home safety infographic which was featured in the report, on social media, online by falls groups and advocacy agencies such as Spinal Injuries Ireland.

For more details visit [www.noca.ie](http://www.noca.ie)  
 Louise Brent  
 Irish hip Fracture Database and Major Trauma Audit Manager  
 National Office of Clinical Audit

# AUTONOMIC DYSREFLEXIA

Autonomic Dysreflexia is a medical emergency which occurs in individuals with a spinal cord injury at or above the level of the 6th thoracic vertebrae. It is characterised by a sudden rise in blood pressure and a low heart rate, although very occasionally a fast heart rate can occur. Autonomic Dysreflexia is a condition unique to spinal cord injuries and is caused by an over-activity of the autonomic nervous system

## Causes of Autonomic Dysreflexia

**Bladder distension** (the most common cause) - examples include urinary retention due to a blocked catheter or failure to empty bladder, urinary tract infection, bladder/kidney stones, diagnostic interventions, and bladder instillations like washouts/flushes

**Bowel distension** (second most common cause) - examples include bowel impaction, digital rectal stimulation, suppository insertion/ enemas, haemorrhoids, and anal fissure/ tears

## Other Causes include

- Acute abdominal conditions
- Skeletal fractures
- Skin related disorders, pressure sores, ingrown toenails and burns
- Sexual activity
- Labour and delivery

## Signs and Symptoms of Autonomic Dysreflexia

- Severe throbbing headache
- Flushing or blotching of the skin
- Profuse sweating above the level of the lesion/ injury
- Goosebumps
- Blurred vision
- Nasal congestion
- Shortness of breath
- Apprehension or anxiety
- High Blood Pressure
- Slow heart rate  
(Very Occasionally a high heart rate can be experienced)

## On examination

Blood pressure of 20-40mmHg above the baseline or Systolic blood pressure (Upper reading) greater than 150 mmHg

It is a good idea for those with cord injuries above T6 to know their base line blood pressure, portable BP monitors are available in most pharmacies are relatively inexpensive

Note: Normal blood pressure in a cervical or thoracic spinal cord injury is approx. 15-20mmHg lower than in the non- spinal cord injured individual , the tip here is to know your own baseline blood pressure.

**AUTONOMIC DYSREFLEXIA IS A MEDICAL EMERGENCY IF LEFT UNTREATED**

## If not treated it may lead to:

- Assist the person to sit up if possible
- Call for help
- Loosen tight clothing, leg bag straps, abdominal binders and shoes
- Put on portable blood pressure monitor if available and note the reading
- Look for the cause
- Catheter is the first to check
- Check for bowel problems if bladder distension has been ruled out
- Do rectal check: if there is stool, remove it gently
- Use a numbing gel (instillagel) to decrease potential stimulation which could cause your blood pressure to increase even more
- If symptoms persist and cause is unknown take Nifedipine 10mg capsule 'bite and swallow capsule'
- If BP not settling and cause not identified contact medical team for further assistance

## Prevention:

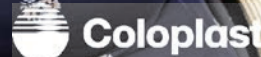
- Do regularly scheduled bladder and bowel programs
- Do routine skin care and nail care
- Avoid extreme hot or cold
- Take prescribed medications
- Autonomic dysreflexia is recognised as a medical emergency.
- Early recognition and prompt treatment minimise complications

**BE AWARE BE PREPARED & IF YOU HAVE CONCERNS CONSULT YOUR GP/NRH  
THE KEY IS KNOWING YOUR BASELINE BLOOD PRESSURE, TRIGGERS, AND SYMPTOMS.**

Contact details: • Paula Keane, Spinal Liaison Nurse NRH • 01-2355315 • paula.keane@nrh.ie

# Keep a look out for the Bladder and Bowel Health Check Take part and enter into a prize draw

Making life easier



Spinal Injuries Ireland are working with Coloplast Ltd, to reach out to our members to ask some real-life questions about their bladder and bowel and the impact on their daily life. If you are experiencing challenges, we may be able to help.

When you receive your survey (via email or post), please take time to complete it whether you are comfortable with your bladder and bowel management or not. By taking part it will provide us with the opportunity to understand where services to bladder and bowel management can be improved. If you are struggling or require some support and advice, working with Coloplast Nursing Service they will be able to provide initial help via video consultations, and also face to face appointments if required.

## Complete the survey and enter into a prize draw

By completing the survey you will be entered into a prize draw for a chance to win 1 of 5 vouchers for One4All worth €50. Look out for your Bladder and Bowel health check to enter.

*(If you have completed your survey already please email [info@spinalinjuries.ie](mailto:info@spinalinjuries.ie) to be entered).*

## What is the Coloplast Nursing Service?

Coloplast<sup>®</sup>  
Nursing Service

The Coloplast Nursing Service provide free nursing reviews to anyone requiring support or have questions about their bladder and bowel management. Provided by experienced bladder and bowel nurse specialists.

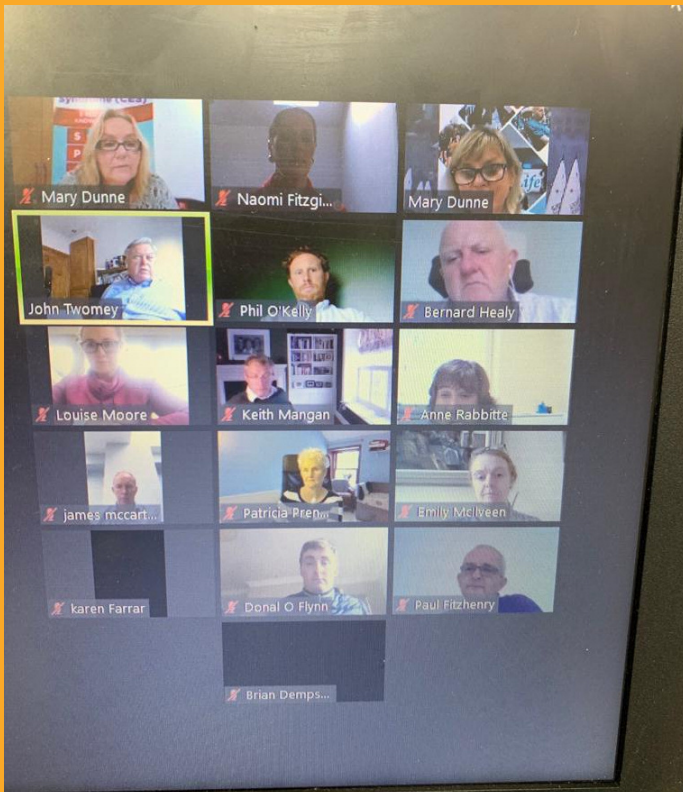
*Services include:*

- *Expert assessment and guidance on Intermittent Self Catheterisation, Trans-Anal Irrigation and Stoma care.*
- *Advice on diet and lifestyle in relation to optimal bladder or bowel management.*
- *Extra support and advice to those new to bladder and bowel management.*

## Video consultations now available

*Reviews can be requested by completing the Bladder and Bowel health check - look out for yours.*

On Wednesday 16th September SII held their Annual General Meeting and for this year it was held virtually due to Covid 19. We were honoured that Anne Rabbitte TD, Minister of State with responsibility for Disability addressed the AGM prior to the meeting. She outlined the investment that the state was making in rehabilitation and in particular with the new development at the NRH. Fiona Bolger, SII CEO responded to the Minister's address and she took the opportunity to detail the major issues that people with a spinal cord injury face and offered recommendations to the Minister as follows:



## RECOMMENDATIONS

1. Implement the National Strategy and Policy for Neuro Rehabilitation services in Ireland
2. Increased and ring-fenced budget for homecare packages for complex cases to clear the pathway of care and free up beds at acute and rehabilitation stages. An additional €2m cumulatively annually allocated centrally to the Spinal Cord programme would clear the pathway and decrease waiting times.
3. Grant medical cards based on medical need, not income, to people with a SCI.
4. Investment to address staff shortages and training for healthcare professionals in both inpatient and community settings.



Minister Anne Rabbitte thanked SII for giving her the opportunity to hear first hand all the issues and she looked forward to working with Spinal Injuries Ireland.

The Minister then left the meeting and the AGM began with Fiona Bolger outlining the work of the organisation during 2019 which was a very important year for SII as the year started with the launch of the strategic plan 2019-2022. She also reiterated that a person with a spinal cord injury is at the core of everything SII does and that each new service and support is based on research with the service users.

Fiona also took the opportunity to acknowledge the following groups for their support during 2019.

- Staff
- Volunteers, (peer, activities, fundraising and the Board of Directors)
- Spinal cord community nationwide
- Public funding from the HSE & Pobal
- Corporate partnerships with Windsor & Coloplast
- The staff of the NRH & Mater hospitals

Good governance is at the core of the organisation and Fiona also took the opportunity to thank Operations Manager, Mary Dunne who ensures that SII maintains the highest standard of governance.

Finally, Fiona remembered Sr Aileen McCarthy who passed away in May 2019. Aileen was one of the founders of the NRH and Spinal Injuries Ireland and she dedicated her life to improving services for people with a spinal cord injury. Fiona reiterated that SII is committed to ensuring that Sr Aileen's work continues to provide the best pathway of support for people with a SCI.

# MARY'S STORY

When your loved one suffers a spinal cord injury your life changes overnight. All the focus and attention, understandably, tends to be on the injured partner. Often their partner needs as much support. Mary O'Farrell is one of our family peer support volunteers. Her husband John sustained a spinal cord injury in 2005.

It was a lovely June day and the family were looking forward to their holiday the following week. By 10am their lives changed and they were plunged into a new reality that felt like a rollercoaster. John had sustained an incomplete spinal cord injury between C3 and T6 in a car accident and they still haven't really got a proper prognosis.

While John was being treated for his injuries Mary was left struggling, trying to keep some sort of normality for their young sons, aged 7 and 11. Not knowing what lay ahead she felt very scared and lonely. She began to suffer high levels of anxiety and even a couple of panic attacks.

John had gone from a job he loved as a psychiatric nurse and a great love of the outdoors to dealing with his new injuries and limitations. She felt John withdrew a little from her and the boys. Mary felt angry at this and their relationship went through a rocky time.

Often there was resentment and frustration with each other, neither of them realising how much the other was struggling.

John got accepted to the NRH where he was getting proper treatment and was focused on his recovery. Mary was trying to hold down a full-time job, manage the family and home and go up and down to John. The boys would be excited when their Dad was coming home for weekends, and even though things were enjoyable, she noticed that John wasn't fully engaged and appeared to be more relaxed when the time came to return to the NRH. Mary felt he was happier when he was in the hospital and she found it easier too as if she wanted to take the boys out, she could. When John was at home, they were very curtailed in what they could do.

Mary felt like she had lost her best friend, her soulmate and her partner and she got the impression that he appeared to be in a bubble that included him and the rehab but didn't include the rest of the family. She wasn't prepared for all the changes that John's injuries had forced upon them. Their future plans had completely changed.



When John was home she found it very stressful when they went anywhere. His bowel and bladder complications restricted what they could and couldn't do and often his pain dictated how long they could be out.

Mary explains that friends move on. They don't understand that you can't drop everything and go off spontaneously with them as you did before, so they stop asking. She talks about a sense that society and life have just left you behind.

Mary experienced a huge sense of grief – she grieved for her partner who she felt had withdrawn from her; for the life they had planned, the travel and their retirement; for her children losing that father figure and worried about the consequences. There was no-one to advise her that although one particular path may have closed, she would find another one. “There is a happy future there but you can't see it when you're in the middle of this turmoil.”

Life is just one adjustment after another. When John returned home permanently from the NRH they both took time to adjust to him living at home again and Mary looking after him. When John's condition deteriorated and he required carers, Mary felt guilty that she couldn't look after him properly. She felt she had let John down. She used to stay out of the way to avoid the carers in her own home. Now, she is very comfortable with them.

Communication is key. Mary and John have always communicated. Often it wasn't pleasant but they always talked. Things are good now. You learn to adapt and she is so glad to have John and for her boys to have their father.

Mary's advice is to take one day at a time. Hopefully tomorrow will be better and, for the most part, it is. Acknowledge your feelings and the grief of what you have lost.

To link in with a trained peer volunteer please email [info@spinalinjuries.ie](mailto:info@spinalinjuries.ie) or phone 01 6532180

# MONTHLY PRIZE DRAW

We're asking you to do something extraordinary this Christmas. Rather than a once-off donation, we're asking you to sign up to our Monthly Prize Draw by committing to donate just €7 per month throughout the year in 2021. This type of regular donation is essential to see us safely through the ongoing Corona Virus crisis. It means we can plan ahead; it makes us sustainable as an organisation and we can guarantee each and every one of our service users that we will be there when they need us.



## How it works:

1. Tickets cost €7 each per month.
2. There is no limit to the number of tickets you can purchase.
3. You can buy a ticket either by visiting [www.spinalinjuries.ie/raffle](http://www.spinalinjuries.ie/raffle) or by filling out a remit form and sending it in to us. Phone us on 01 6532180 if you don't have a remit form and would prefer to do it this way.
4. Once you have bought a ticket, we will email you confirmation of your purchase along with your ticket number/s. (Please note, this confirmation can take up to 24 hours as our system waits to receive confirmation from the respective bank).
5. Tickets can be bought on either a once-off ticket basis or a monthly ticket, which is the best way to support. With this monthly ticket, you will be issued a new ticket number by email on a monthly basis.

## The Prizes:

- 1st Prize: €1,000
- 2nd Prize: €500
- 3rd Prize: €250

The 3 cash prizes are available every month!

## The Draw:

The first draw will take place on Friday the 29th of January 2021, which is the last weekday of January 2021 and monthly from then.



# WEBSITE REVAMP

We're delighted to announce that we have completed the redesign of our website, [www.spinalinjuries.ie](http://www.spinalinjuries.ie).

The new site will be a far more user-friendly site to use, with a whole host of new features, including:

- A live chat feature so you can chat with one of our Community Outreach Officers directly through the site in real time. If you have a question about, well, anything SCI related, we'd be happy to help so log on and give it a go!
- A Community Forum - This is a space for people living with a spinal cord injury to chat amongst themselves about all things SCI. The Community Forum is going live in January 2021 and we'd love it if you gave it a try. The more we can bring the SCI community of Ireland together, the better.
- A new, improved Resources section. Want to find out about the ins and outs of accessing social welfare payments, international travel, the latest research? This is the place for you.
- The site is translatable into 6 other languages other than English: Irish, Spanish, Chinese, Polish, Portuguese and Romanian. This way we can support as many people in Ireland with a SCI as possible, whether English is their first language or not.
- There is a Text-to-Speech option for anyone who is visually impaired. If you double click on a block of text, a speaker icon will appear. Simply click on the speaker icon and the text will be read out aloud.

The site isn't just for people living with a SCI though. Whether you're a family member looking for some guidance, a medical practitioner, or someone looking to engage with our Peer Volunteers, log on and have a browse.

Also, we'd love to hear your feedback. If there's anything you think we should add to the site, get in touch with us via the Get In Touch button and let us know your thoughts!

We really wanted some updated photographs for our new website and we have to extend a huge thank you to our models who you will see scattered through the new site looking fabulous. Thank you to Jenny Needham, Rogerio Ribeiro, Philip Quinlan, Julia Thurmann, Paula McCormack, Barry McLoughlin, Rob O'Byrne, Kieran Fitzgerald and Jack Shannon Cole.

# SpeediCath - designed for you

## For gentle insertion and withdrawal

For more than 20 years, SpeediCath has made a difference to users with its pre-lubricated unique hydrophilic coating, smooth heat-polished eyelets and ease of use.



Read on to see why these users choose Speedicath catheters

**SpeediCath®**  
designed for you

*“It looks great, but that is not why I use it”*

Eva, SpeediCath Compact Eve user

SpeediCath Compact Eve combines easy handling with discretion in a compact design and is easy to integrate into your daily life.



*“I was afraid of hurting myself”*

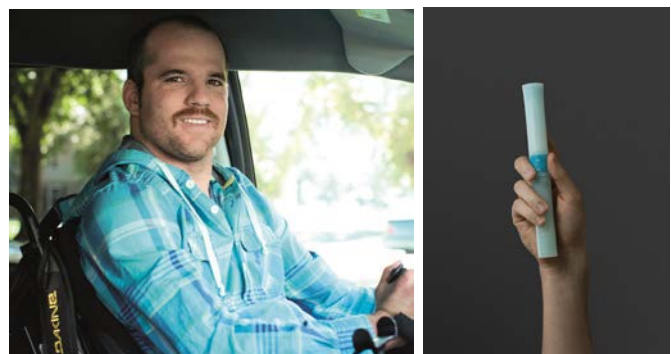
Jason, SpeediCath Flex user

SpeediCath Flex is a soft catheter with a dry-sleeve and a flexible tip that enables easy navigation through curves and bends of the urethra. SpeediCath Flex makes it easy to catheterise the right way.

*“You’re good to go”*

Thomas, SpeediCath Set user

SpeediCath Set is a simple and convenient all-in-one catheter and bag solution. With its easy-grip handle, there’s no need to touch the catheter and simple open and re-seal for discreet disposal.



For more information and to try SpeediCath catheters visit [Coloplast.ie](http://Coloplast.ie)