

Progress Report for The October Club

SCI Nurse Specialist Project

Partnership Aims

- To ensure that spinal cord injured (SCI) people receive good quality care and have the best chance to reach their potential and achieve a fulfilled life after injury.
- To enhance the SCI expertise of healthcare practitioners caring for SCI people nationwide.
- To build the capacity of SIA through the implementation of a hub and spoke model.
- To demonstrate the efficacy and cost-effectiveness of our model.
- To strengthen our visibility, connections and voice to influence policy and practice.
- To augment our public affairs, advocacy and peer support activities.

Intended Outputs and Activities

- An expanded SCI Nurse Specialist team
- 1,000 SCI people reached and supported each year
- 1,000 healthcare professionals trained each year
- A monitoring and evaluation process designed and implemented
- A hub and spoke support network established

Key achievements to date

We have expanded our SCI Nurse Specialist team.

We now have a team of five nurses (four full-time specialist nurses and one part-time triage nurse). Latest recruits include Darren Bracken who joined SIA in December 2019 and is a specialist in spinal cord injury having worked previously at the Spinal Injury Centre in Sheffield and, even more recently, Karen Biggs who joined SIA in January 2020, with a background in neuro-nursing. The impact of this expanded team has been transformative already; not only in our expanded work for spinal cord injured people but, as you will read in the second half of the report, in our ability to mobilise a response to the coronavirus pandemic.



Karen Biggs

“My passion is for the best possible care for SCI people – because I know from a professional and personal perspective what a huge difference the right care and support can make to someone being able to lead a fulfilled life with SCI.”



Darren Bracken

“I am very excited to take up this role within the SCI Nurse Specialist team and relish the opportunity to increase knowledge and understanding of SCI across the wider community. I have always been passionate about SCI and being able to join SIA at a time of expansion, excites and inspires me.”

We have reached and supported over 400 people affected by spinal cord injury.

Since October 2019, our SCI Nurse Specialists have supported more than 400 spinal cord injured people. This includes at least 200 people who have been supported since March 2020, during the Coronavirus pandemic. Referrals to our SCI Nurse Specialist team have doubled in recent months.

Our expanded Nurse Specialist team has played a crucial role in helping to keep spinal cord injured people safe and well during the Coronavirus crisis.

SCI people are a high-risk group when considering the impact of COVID-19. Many have respiratory conditions, reduced immunity and rely on carers for everyday tasks, so the prospect of illness and/or isolation is terrifying. In addition, there is a risk that some SCI people are being discharged from hospital too soon, as NHS resources have been redirected to support Coronavirus patients.

In response, SIA has redeployed its entire team of specialists to support spinal cord injured people during these challenging times, to meet an increased demand for our services.

Despite facing a £1m shortfall in fundraising income this year, we are doing more, with less, and delivering a programme of support around the following three pillars:



Specifically, our SCI Nurse Specialists are:

- Responding to calls to our 111-style emergency support line – 0800 980 0501.
- Contributing to our dedicated online resources at <https://www.spinal.co.uk/coronavirus/>
- Providing virtual support sessions for those whose require clinical guidance.
- Attending SIA's virtual drop-in cafes, to help answer queries relating to clinical care.
- Helping SCI people create Emergency Care Plans, should they be admitted to hospital.
- Providing online training for healthcare professionals.
- Creating and sharing videos on topics which help SCI people manage their condition.
- Overseeing the delivery of our new counselling and wellbeing service.

Please click the links below to see some of the advice videos from our SCI Nurse Specialists.

[Karen Biggs, SCI Nurse Specialist, offers her tips for skincare health](#)

[Karen Biggs, SCI Nurse Specialist, offers tips on fever and respiratory infection](#)

Supporting the SCI Community
Join one of our daily cafes!

Monday SIA Drop-In Clinic Speak directly to our SCI Nurse Specialists, Advocacy and Support Network teams so we can answer your questions.	Tuesday This Is Spinal Crap Podcast Covering a new topic with guest speakers each week.	 Virtual Cafes Monday to Friday Live @ 3pm every day
Wednesday SIA Drop-In Clinic Speak directly to our SCI Nurse Specialists, Advocacy and Support Network teams so we can answer your questions.	Thursday This Is Spinal Crap Cafe Join us as we talk about the week's podcast subject.	

In collaboration with others, we are providing daily virtual cafes at which SCI people can seek support, speak directly to our SCI Nurse Specialist and other experts, ask questions, meet the team and interact with others.

"Spinal cord injury is life changing but it doesn't have to be devastating, there is support out there and people doing incredible things! I've learned a lot and made great friends. Thanks for your support."

CASE STUDY: [Click to hear more about how our SCI Nurse Specialists are reaching and supporting spinal cord injured people during the Coronavirus pandemic.](#)

We have trained more than 200 healthcare professionals.

In line with our project plans, we have enhanced the knowledge and skills of hundreds of healthcare professionals on vital topics such as bladder and bowel management.

Between October 2019 and March 2020, more than 200 healthcare professionals attended a training course delivered by SIA, including:

- 42 who attended one of six training courses on Managing a Neurogenic Bowel, which took place in Newcastle, Manchester, Worthing, Liverpool, Birmingham and Milton Keynes.
- 80 who have been trained through the delivery of four courses on Good Clinical Practice in Spinal Cord Injury, which took place in Cumbria, Newcastle, Kent and London.
- 23 who attended bespoke training courses delivered for healthcare organisations including Emma Way Associates, NFC Health and Seahorse Associates.
- More than 55 delegates who attended a Study Day held in Manchester.

In addition, our Peer Support team have delivered six workshops for healthcare professionals, providing information about spinal cord injury from a personal perspective.

We know that our training is making a difference to clinical practice and policy, from the feedback we receive from those who have attended our training courses. For example:

“We have developed an updated bowel management guidance and step-by-step in line with the SIA training.”

“We now have a policy relating to neurogenic bowel care for all patients with an injury or disease process that causes them to have a neurogenic bowel. We have purchased 'Bertie the bottom' so we can teach neurogenic bowel care and teach the difference between a reflexic and flaccid bowel and appropriate management.”

“When looking at care packages for patients with spinal injury I am able to use the information I have learnt when considering care needs.”

“I've passed on knowledge, and now personally used the training and experience whilst delivering bowel care to a client. The information is also incorporated into our training for support staff.”

We have established a Hub and Spoke Support Network.

Alongside the expansion of our SCI Nurse Specialist programme, we have established a regionalised support network, to meet the holistic needs of SCI people.

Our frontline teams are now organised as a hub and spoke model, working from two main hubs - north and south. Through each hub, we are delivering SIA's vital services (clinical support, peer support, counselling, information and advocacy) as well as signposting people to other organisations for specialist help on issues such as mental health, housing and wheelchair skills.

The development of this network model positions us well to meet all the needs of SCI people, not only immediately after injury but also throughout their lives.

Alongside this exciting development, we are designing and implementing a new monitoring and evaluation framework which will enable us to build the evidence for the provision of specialist support for SCI people. This will give us greater opportunities to influence policy, practice and attract additional investment.

We have built SIA's capacity to achieve greater visibility, networks and influence.

A key element of our partnership with The October Club was to build SIA's capacity for the future through greater connections with service providers, policy makers and potential funders. Some examples of progress to date are below:

- In December 2019, alongside two other UK leading spinal cord injuries charities, we published ["More than a number"](#). This landmark report, calls for urgent action to address serious concerns in how the NHS funds care for severely disabled people.
- When the Coronavirus was taking hold, we wrote to Matt Hancock, Secretary of State for Health, a number of Government ministers, members of Parliament and contacts within the NHS to raise our concerns for SCI people. In the light of this advice, the NHSE Clinical Reference Group for Spinal Services advised the NHSE Covid-19 team that **SCI should be considered "high risk" in their planning**.
- A number of SIA staff attended a strategic NHS England workshop on the future of SCI services. We are **now working directly with the NHS Covid-19 team** and Commissioners to support specialist SCI services in these challenging times.
- We have launched our [Together in Isolation](#) fundraising campaign, which includes a direct appeal for donations and grants, as well as a programme of virtual fundraising events and activities. SIA is facing a £1m loss of income in the 2020/21 year due to Coronavirus.
- In April, we **recognised Spinal Cord Injury Awareness day**, alongside our partner charities Aspire and Back Up. The day was all about raising awareness and understanding of the impact and effect of spinal cord injury, told through the personal stories of people affected.
- In addition, with your support, **our team now has up-to-date IT equipment** which is much more efficient and accessible for our SCI colleagues. This has greatly improved our overall effectiveness.

Thank You and Next Steps

Thank you to The October Club for your wonderful support of our SCI Nurse Specialist project.

Next steps will include:

- Continuing to provide our programme of Information, Advocacy and Support to SCI people, as the lockdown restrictions are lifted.
- Developing and delivering online training for healthcare professionals, until we can resume face-to-face training.
- Working with the NHS and other service providers and policy makers, to continue to keep SCI people safe and well.
- Implementing a monitoring and evaluation framework that will build the evidence we need to help raise national standards in the care of SCI people, as well as build SCI expertise nationally amongst healthcare professionals.
- Extending and promoting our Together in Isolation fundraising campaign, so that we can continue to meet the increased demand for our services, in light of a £1m fall in income.
- Continuing to strengthen our networks with other charities, statutory bodies, funding partners and key decision-makers – building on the momentum created through our partnership with The October Club and SCI Nurse Specialist project.



We're also delighted to share with you the following message from our Patron, HRH The Princess Royal.



As Patron of the Spinal Injuries Association, I understand the many challenges that you experience in your daily lives as well as the grit and determination needed to rebuild your lives after injury or diagnosis. Many rely on carers to meet basic life sustaining needs. Some are more susceptible to infections and are at greater risk of severe complications if they develop symptoms. Self-isolation and social distancing away from loved ones can be hard, painful even, for all of us.

I want to let you know that you are not forgotten. Charitable organisations from across the country are united in their commitment and determination to support vulnerable people. Spinal Injuries Association's ambition is nothing less than to ensure that no injured person is left to face this crisis alone. Their determination that every SCI person gets the information, advocacy and support they need to stay safe and well, and out of hospital – thereby saving lives and protecting the NHS – is to be applauded. Their work is a great example of those who are working so tirelessly to support other vulnerable people in our communities across the country.

Thank you once again.

For more information, please contact:

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