

TOGETHER IN ISOLATION

Helping spinal cord injured people stay safe and well

The 50,000+ people in the UK who live with spinal cord injury (SCI) are one of the highest risk groups in any planning for the Coronavirus pandemic.

- SCI people are at much greater risk of developing life-threatening respiratory infections, as those with high-level injuries are less able to cough.
- Many SCI people have impaired immune systems.
- Many SCI people depend on carers for essential day-to-day care such as showering, eating and taking medication.
- There are life-threatening risks for SCI people who are attending or being admitted to General Hospitals, for example, pressure ulcers, or inappropriate bladder and bowel care.
- Hospitals are being asked to redirect resources to treat Coronavirus patients, which will limit specialist care for SCI people. This could lead to serious health complications and, in some cases, preventable deaths amongst SCI people.

SCI people need information, advocacy and support now.

Despite the challenges of isolation, cancelled fundraising events and protecting its own staff and volunteers, SIA is re-deploying its entire efforts to a programme of expert support for this vulnerable population.

We are helping spinal cord injured people stay safe and well during these challenging times. **TOGETHER IN ISOLATION.**

sia spinal
injuries
association
FOR LIFE AFTER SPINAL CORD INJURY

Registered Charity No. 1054097
Registered Company No. 3175203



What we're doing to help

If you are spinal cord injured, a common cold can cause pneumonia; a hospital visit often leads to ulcerated skin or bowel and bladder infections; one carer with suspected infection can mean isolation and potential health risks within days.

That is a normal month.

The exponentially increased risks of Coronavirus to spinal cord injured people has the potential to be devastating to a huge number of people, who are already facing the challenge of a life paralysed by spinal cord injury.

SIA, the national charity representing all 50,000 SCI people, has quickly responded by launching a programme of interventions that can save lives, prevent infections and relieve what is a growing capacity crisis for the NHS.

It is a simple, virtual response by our clinical experts and national teams of expert peers (spinal cord injured people), based on three core needs: clinical and relevant **information** and advice; representation and **advocacy** to ensure health professionals know how to support a person paralysed with a spinal cord injury who is being treated for Covid-19; and **support** to manage isolation while paralysed with a spinal cord injury, focusing on health and wellbeing.

INFORMATION

- A freephone advice line **0800 980 0501** to speak to our expanded nurse specialist service.
- Regularly updated advice and support on SCI related to the Coronavirus and Covid-19, through briefings, videos and social media links – all being captured at [SCI and Coronavirus](#)
- Regular updates to the SCI community on anything that is advised by statutory bodies relevant to them.

ADVOCACY

- Increased advocacy service available through our advice line to address availability of care and appropriate SCI-health management if admitted to hospital.
- Representation of all SCI people to government, NHS and the wider care systems to ensure the priority needs of SCI people are being considered at every step.

SUPPORT

- Opportunities for SCI people and their families to speak to a Peer Support Officer via telephone or video conferencing.
- Expert staff and volunteers to refer, link and triage SCI people to other support services, charities and advice as needed.

Some of the work we have already undertaken

- Communicating with the Department of Health and Social Care, NHS England and the Chief Medical Officer to ensure that they are aware of the particular vulnerabilities of SCI people and seeking assurances that they are putting appropriate plans in place to mitigate risks.
- Liaising with NHS 111 to ensure that all SCI people, given their increased vulnerability, are treated as priority cases.
- Working with Clinical Commissioning Groups to establish protocols for SCI people who may need to self-isolate but also require carers or personal assistants.
- Re-deploying elements of our peer support, nursing and advocacy teams to offer telephone-based support to all SCI people who have concerns related to their spinal cord injury, because of the Coronavirus.
- Publishing and constantly updating detailed briefings on Coronavirus and how SCI people, their families, friends and carers can respond – on a dedicated landing page [SCI and Coronavirus](#)
- Creating a nurse expert film to help every SCI person build a care plan so that if they are admitted to hospital their unique care needs can be met.
- Planning with our home delivery partner, SIA Healthcare, to ensure that SCI people can continue to get their essential medicines and other supplies and looking into sanitation-based supply options for all SCI people regardless of their being a member of SIA Healthcare.
- Communicating with leading NHS decision makers to ensure that SCI people who may have been exposed to Coronavirus or who are diagnosed with Coronavirus will have a care pathway that takes into consideration all of their health and care needs.

WORKING REMOTELY THROUGHOUT

- We are prioritising the safety of our staff and volunteers, many of whom are spinal cord injured, enabling them to work safely and with confidence.
- We are continuing to provide essential support at this difficult time, but are doing so in different ways.
 - All face to face meetings are being replaced with telephone or video meetings.
 - Where our SCI Nurse Specialists need to visit SCI people to advise on urgent and sometimes life-threatening care issues, we are undertaking risk assessments and adopting additional protective measures where appropriate.
 - Meetings involving non-service users are, where practical, being held remotely rather than face to face.

TOGETHER IN ISOLATION: Thank you for your support

Thank you so much for supporting our work. We are truly grateful for your help during what is a very frightening and challenging time for spinal cord injured people and their families.

Inevitably, we are having to cancel many fundraising events and activities, resulting in a shortage in funds to deliver our vital services upon which many SCI people and their families depend - just when they need us most. We estimate lost income of up to £500,000 over the next six months. Your support at this difficult time means so much to us.

If you can, please help us to help spinal cord injured people stay safe and well.

- Please share our freephone number **0800 980 0501** and encourage spinal cord injured people and their families to contact us if they need our help.
- Please direct people and organisations to our online information resources at [SCI and Coronavirus](#), if you feel they would benefit from the advice and guidance we can offer.
- Please share a link to our urgent fundraising appeal [Together in Isolation Appeal](#), if you know of anyone who might be able to support us financially.
- Please keep an eye on our website and social media sites for information about our virtual fundraising events and activities taking place over the next six months.



“Be in no doubt we are the 1%. We have to fight for the lives of every spinal cord injured person out there. The situation is critical. So we have unanimously agreed we will not stop.”

Jamie Rhind, SIA Head of Services, Tetraplegic C5/6

We understand that the Coronavirus pandemic is having an impact on everyone. Your support at this challenging time is greatly appreciated by us all at SIA, as we strive to protect and support one of the most vulnerable groups at risk of the virus itself, as well as its implications on the availability of health and care services.

Thank you.