**Briefing on: Risk, vulnerability and Coronavirus for SCI people**

**Latest Update:** **1st May 2020**

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**Purpose**

Spinal cord injured people, their families and carers have been contacting SIA to question whether they should be considered as ‘at risk’ or ‘vulnerable’ in light of the Coronavirus epidemic and the guidance published by the Government and NHS England.

**Should spinal cord injured people be considered as ‘vulnerable’ and if so, what are we meant to do differently?**

**Background**

This document aims to provide clarity around the issue of risk, vulnerability and Coronavirus for spinal cord injured people (adults and children), and to ensure you get the expert care and support you may need.

Everyone's situation is different and therefore providing the same advice to everyone is not practical. However, we hope that this guidance is helpful and reassuring.

**Is a spinal cord injured (SCI) person more likely to get Coronavirus than others?**

There are no indicators that SCI adults or children are more likely ***to catch*** Coronavirus, but as many SCI people have suppressed immune systems or respiratory issues, and all SCI people face the risk of additional infections and conditions related to bowel, bladder and skin, often through lack of knowledge of SCI care requirements in a hospital setting, ***the impact*** of contracting Coronavirus may be more severe.

**Do NHS England know this, and do they therefore consider SCI people to be more at risk?**

At the end of February 2020 SIA informed the NHS’s ‘Clinical Reference Group for Spinal Services’ of our view of the risk to SCI people if they were to contract Coronavirus:

**SIA’s position is that many** **SCI people have severe respiratory issues and/or a compromised immune system, either of which put them at an increased risk of serious illness from Coronavirus.**

This information was communicated to NHS England, who accepted the advice provided.

**How do I interpret the official guidance from the Government on all this?**

The information published by the Government and NHS England refers to people considered to be at “increased risk of severe illness from Coronavirus.” This was published as part of the ‘social distancing’ guidance and can be found here: <https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

This was followed up by guidance on ‘shielding’ for those considered “at very high risk of severe illness from coronavirus (COVID-19) because of an underlying health condition, and for their family, friends and carers.” The full guidance can be found here: <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

It's important to note that the health conditions highlighted in the two sets of guidance above were examples, rather than a prescriptive list. It wouldn’t be feasible for the advice to cover every type of health condition. So, although SCI isn’t specifically mentioned, it has been accepted by NHS England that some SCI adults or children have severe respiratory issues and/or a compromised immune system, either of which will put them at an increased risk of serious illness from Coronavirus.

**So, what are the particular risks to SCI people in relation to Coronavirus?**

Coronavirus is a potentially serious condition for anyone, but SCI people may face a particular risk specifically because of:

1. **A compromised immune system**

If for example you acquired your SCI through Transverse Myelitis, Guillain-Barre Syndrome, Metastatic Spinal Cord Compression or Spinal Tumour, you may have an impaired or compromised immune system and therefore be at greater risk of serious infection.

1. **Tetraplegia or high-level paraplegia and a weakened cough reflex**

If you have a higher level of SCI then your respiratory function may be compromised, resulting in a weakened cough reflex. SCI people who contract COVID-19 are more likely to require acute care, as the consequences of this virus on an already compromised respiratory function could prove critical.

1. **Additional health risks for all SCI people**

All SCI people are acutely aware that any illness, particularly those that lead to a hospital visit can risk the emergence of a variety of other health challenges related to bowel, bladder and skin. As well as opportunistic infections, the risk exacerbated by the wrong care from non-specialist health professionals in acute settings where the focus is the treatment of COVID-19, is significant.

**So, what should I do next?**

1. **Stay at home and avoid the chances of contracting virus if you possibly can**

Given the risk of serious illness from contracting Coronavirus, it’s important to reduce as much as possible the chances of becoming ill from the virus. Each person will have to make their own judgement about how far they want to go with ‘isolating’ or ‘shielding’, but asking family, friends and neighbours to support you and using online services whenever possible is a good start.

1. **Register for preferential local services**

Local government, business, charities and the general public are now geared up to help those advised to stay at home. For example, many supermarkets are offering preferential food delivery slots to elderly, disabled and vulnerable customers – partly by interrogating their own records to identify who those customers are, and partly by being given access to the Government’s own database. You may also find that small business, for example a local farm shop, have developed the way they deal with their customers to fit with people’s circumstances in the current climate.

1. **Sign up for support**

Any SCI adult or child with the vulnerabilities to Coronavirus as described – with tetraplegia or high-level paraplegia and a weakened cough reflex, or who have an impaired or compromised immune system, can go to: [www.gov.uk/coronavirus-extremely-vulnerable](http://www.gov.uk/coronavirus-extremely-vulnerable) to sign up for additional support. This can include help with food, shopping deliveries and additional care.

1. **NHS Volunteer Responders**

Hundreds of thousands of volunteers have joined the NHS Volunteer Responders programme, and are available to support people in England at risk from the Coronavirus.  The help on offer ranges from support with grocery shopping and collecting prescriptions to ‘check in and chat’ phone calls.

To get this support, or if you are a carer and want to secure support for someone you care for, ring **0808 196 3646** (8am to 8pm) or have a look at the website for more information: <https://volunteering.royalvoluntaryservice.org.uk/nhs-volunteer-responders-portal/isolating>

Volunteer Responders is being delivered by Royal Voluntary Service, who are one of the UK’s largest and longest-standing volunteering charities.

1. **Complete a Care Plan**

An Emergency Care Plan is a form to ensure you receive the right care if admitted as an emergency to your local hospital. To request the support of a SCI Nurse Specialist to complete one for you please [fill in a referral form](https://www.spinal.co.uk/how-we-help/nurse-specialists/contact-nurse-specialists/) or call 0800 980 0501**.** See also a brief you can print off for any non-SCI specialist nurses or doctors – [Advice for Healthcare professionals](https://www.spinal.co.uk/wp-content/uploads/2020/03/Considerations-for-healthcare-professionals-.pdf). You can see more about all this in [a short video from one of our Specialist Nurses](https://youtu.be/LzAH2_6UJVk).

1. **Register yourself with your Local Authority, CCG and GP**

Make sure that your Local Authority, CCG and/or GP are aware of your needs as a SCI person.

**What support can I get from SIA and its partner charities?**

SIA has re-deployed its entire workforce and its volunteers to support you, in particular its Specialist Nursing, Advocacy and support network teams. We have set up a triage system – a quasi-111 service dedicated to responding to SCI people’s needs during the epidemic.

If you get in touch with SIA via the dedicated phone line and email – set out at the bottom of every one of our advice briefs – we can link you via one of three areas:

* **Information and Advice** – we will talk you through any concerns and link you to our latest briefs, advice and videos as well as updated government advice at [www.spinal.co.uk/Coronavirus](http://www.spinal.co.uk/Coronavirus) and on Social Media.
* **Advocate** – We have an Advocacy Team ready to take up your case with you to help you ensure proper care at home and/or in hospital whilst managing the impact of Coronavirus.
* **Support** – We are building a network of partners to support you with all elements of your health and wellbeing during this time of isolation and concern. We will refer, link and triage SCI people to other services, charities and advice as needed. We have also set up an online meeting place to meet each other, and talk to experts across a range of health and wellbeing areas. Again, use our advice line and web links, and follow #CoronavirusSCI and #TogetherInIsolation on Social Media.

SIA’s Advice Line is: **0800 980 0501** for advice, or look at the information published on our website at [www.spinal.co.uk](http://www.spinal.co.uk)

**If you think you have Coronavirus**

If you think you may have been exposed to Coronavirus or are displaying symptoms, you should immediately:

* Call NHS 111 and clearly state that you are SCI and therefore considered to be ‘at risk’. Explain that your care support is essential in meeting your SCI needs.
* If appropriate, inform your care provider - either the Care Agency that supplies your carers, or your local Clinical Commissioning Group or Local Authority.
* Inform your local specialist Spinal Cord Injuries Centre and/or your GP.
* Make sure you have completed the [SIA Care Plan](https://www.spinal.co.uk/wp-content/uploads/2020/03/My-usual-SCI-Care-interventions.docx) – see earlier advice.

**Further information**

For further SIA information, please:

* Call our Support Line on **0800 980 0501** for further information and guidance.
* Visit the [Coronavirus landing page](http://www.spinal.co.uk/coronavirus/) on our website.
* Follow us on Social Media:
  + Facebook: [Spinal Injuries Association](https://www.facebook.com/SpinalInjuriesAssociation)
  + Twitter[: @spinalinjuries](https://twitter.com/spinalinjuries) – if possible, please use the hashtag #CoronavirusSCI
  + Instagram: [@spinal\_injuries](https://www.instagram.com/spinal_injuries/?hl=en)
  + YouTube: [Spinal Injuries](https://www.youtube.com/user/SpinalTV)
* NHS guidance on Coronavirus: <https://www.nhs.uk/conditions/coronavirus-covid-19/>
* The Government’s Coronavirus information is here: <https://www.gov.uk/coronavirus>

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