

APPG on SCI – Issues and Solutions (November 2021)

The Issues:

- **Access to life-long mental health services.**
- **Access to appropriate social care support.**
- **Access to specialist spinal cord injury services.**
- **Knowledge and understanding of spinal cord injury in the NHS.**

Too many people with spinal cord injury (SCI) are not being given the chance to live fulfilled lives and contribute to society. SIA's work addressing serious health conditions like pressure ulcers and urinary tract infections, and emerging mental health challenges, repeatedly lead back to the issues caused by a lack of access and availability of specialist and holistic support post-injury.

It's these issues of access and availability that the 'All-Party Parliamentary Group (APPG) on SCI' are actively working to change, and in doing so enable SCI people and their families to successfully adjust to their injury and ultimately resuming a fulfilled and productive life.

There are crucial gaps in services that can be addressed, and in doing so transform the landscape for all SCI people and their families. This document sets out the key issues and also the solutions the APPG and SIA are committed to achieve.

Access to life-long mental health services

- Spinal cord injury is so much more than a raft of physical conditions; in very many cases, sustaining a SCI causes mental health problems too. The psychological damage caused by a SCI is significant and very concerning, as research undertaken by SIA, the University of Reading and the University of Buckingham in 2021 clearly demonstrates.
- SCI people must have life-long access to mental health services that will give them the support they need when necessary. The APPG wants to see investment in increased capacity to serve all SCI people with counselling and mental health support as they rehabilitate and for the rest of their lives.
- SIA and the APPG are calling for the NHS and mental health bodies to provide:
 - Access to much more, and more appropriate, psychological support for SCI people at *all* stages of their post injury journey: immediately following injury; when they are discharged from hospital to another care setting or to their home; and for the rest of their lives.
 - Newly injured people must be screened for pre-existing mental health issues.
 - A full risk assessment must be conducted before a SCI person moves from a care setting (hospital, nursing home, care home) into their own home.
 - Medical staff supporting SCI people with their mental health must also understand how their physical problems can impact their mental health, and be trained accordingly in bladder, bowel, skin and pain management.

Access to appropriate social care support

- If SCI people are unable to get the best care support possible, they risk ending up in hospital; care can be a matter of life and death for many SCI people.
- SCI people have already faced considerable stress throughout the pandemic, with many forced to protect their health by shielding throughout. Many now face the significant additional stress of no longer being able to get the high-quality, skilled and experienced Personal Assistants (PAs) they require, and who are essential to help them manage their daily care needs.
- The end of freedom of movement has resulted in a dramatic limiting of the choice that SCI people have when it comes to employing the carers, as they can no longer directly employ new PAs from Europe.
- Comprehensive reform of the care sector, including more funding for care workers, is desperately needed, but until that it is done, SCI people should not pay the price by having an increasingly difficult (and sometimes impossible) job to find the care they need to live dignified and fulfilled lives.
- SIA and the APPG are seeking Ministerial support for a new and distinct immigration route, so that individual SCI people can continue to have the option of directly employing their PAs from abroad. This would not lead to a meaningful change to migration levels, but would make a dramatic difference to SCI people.

Access to specialist SCI services

- The evidence is clear. SCI people have better outcomes if they can access a specialist Spinal Cord Injury Centre. Without specialist care, the likelihood of dangerous bowel, bladder and skin issues are significantly higher, causing distress and risk to individuals and unnecessary cost to the NHS.
- The APPG understands there are enormous pressures on the NHS, but it is not right that many SCI people are unable to access optimal care in the right place and the right time. The consequences of this failure are lifelong; the current position is not cost effective and financial resources are wasted. Access to specialist care and support provides value for money and significantly better outcomes for a SCI person.
- We are seeking Ministerial commitment to support the existing NHS recommendation of an increase in the capacity of the Spinal Centre network. In addition, no beds within the current Spinal Centre network should be given over for general medical patients.

Knowledge and understanding of SCI in the NHS.

- SIA and the APPG are seeking a commitment to raise the knowledge of specialist staff in major trauma centres (MTCs) and general medical settings, so they can provide higher quality and more appropriate care for SCI people in those environments.
- SIA is already supporting this by delivering education and training via the SIA Academy, and are very keen to address the desperately urgent upskilling need across the NHS.

For more information, please contact SIA's Campaigns Manager:

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