

A CALL FOR ACTION



Seeking to address health inequalities for the spinal cord injured population, working in collaboration with the NHS and other key partners.

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Inequalities experienced by disabled people are well-documented. This call for action seeks to address health inequalities for the spinal cord injured population, working in collaboration with the NHS and other key partners, and in doing so improve the life outcomes for patients and their families whilst saving resources. It recognises that a person-centred approach to care is paramount and foundational to any meaningful change.

Need

In post war Britain, pioneered by Sir Ludwig Guttmann, the UK led the world in the development of integrated, life-long rehabilitation. The outcomes were as game-changing as the development of vaccines: from a life-limiting and ultimately fatal condition, people with spinal cord injury were able not just to live but, **achieve a fulfilled life for themselves and their families.**

That has been the vision of the Spinal Injuries Association (SIA) ever since. But it is at risk. SIA's number one goal in its national [Strategy 2030](#) is a **health and care system that works for people with spinal cord injury.**

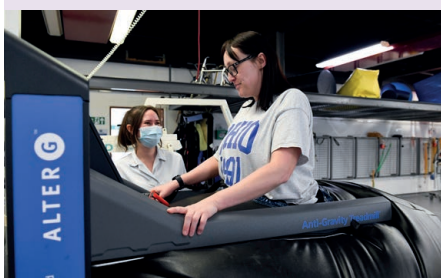
Across too many metrics this is simply not the case for people who live with spinal cord injury.

As the national patient representative body, through its frontline work, research and member-feedback, we are seeing increasingly debilitating and unnecessary challenges faced by tens of thousands of our members.

Much is about investment and funding. But it is also about inconsistent and uncoordinated services, creating holes across the health and care system through which people with spinal cord injury and their families are falling.

In 2024, we are convening our sector through a network of partners to address:

Inconsistent rehabilitation pathways that are too dependent on geography, socio-economic factors and overly diversified approaches



Almost universal fear of health and care settings outside of the specialist centres. In non-specialist settings there is a lack of capacity and/or knowledge to care for someone paralysed with spinal cord injury



Barriers to accessing appropriate expert care that is shattering health and life outcomes for too many



THE CALL FOR ACTION

This is a **call for action** agreed by people affected by spinal cord injury in collaboration with experts in the spinal cord injury sector. We are calling for a **spinal cord injury national strategy**, that establishes consistent, long-term and holistic rehabilitation and support as the expectation for all.

The call proposes **five systemic changes** that will transform physical and mental health outcomes, save money through efficiencies and innovation, and address health inequalities.

- 1** **Defined expectations for any rehabilitation pathway anywhere in the country**, whether through a spinal centre or not, including:
 - i. **Who is admitted** to which pathway and why
 - ii. **Minimum rehabilitation expectations** for level of injury, condition and pathway
 - iii. **Waiting time expectations** for key pillars of rehabilitation
 - iv. **Minimum multi-disciplinary staffing levels** per patient

- 2** **Agreed standards and training-requirements for general health and care settings** targeting:
 - i. **Training to competency** for care of skin, bowel, bladder, breathing and other special requirements wherever a person with spinal cord injury accesses NHS services - major trauma centres, district general hospitals or general practices
 - ii. **National policies on standards** of care that are implemented universally, eg bowel care and cauda equina syndrome pathway
 - iii. **Agreed rehabilitation and spinal cord injury care course content** for health care professional, medical and nursing training

- 3** **A framework of support for Continuing Healthcare (CHC) decision-making** including:
 - i. **Specialist representation** available at each assessment/ re-assessment
 - ii. **Every assessment carried out face-to-face**
 - iii. **NHSE National Framework applied** consistently with accountability and enforcement

- 4** **A coordinated national programme of research, modelling and testing** to create an evidence base of best practice in:
 - i. **Rehabilitation**
 - ii. **Treatment**
 - iii. **Reintegration into society**
 - iv. **The costs associated with inadequate provision**

- 5** **A nationwide patient representative network** including:
 - i. **Connected from first day** of diagnosis
 - ii. **Representation to support patient voice**, and that of their friends, families and carers, at every decision-making step
 - iii. **Coordination of links** to specialist and community support services
 - iv. **Patient voice** at centre of systems, design and delivery



APPENDIX OF NEED, IMPACT AND EVIDENCE

A national strategy would present a coherent vision to government, media and the general public, the opportunities and the challenges. It would allow the health and care system to plan services nationally, regionally, and locally and justify the need and allocation of resource. It would ultimately lead to:

- Improved patient outcomes and safety
- Address health inequalities and inequity in service provision
- Enhanced research and innovation
- Optimised resource allocation
- Holistic healthcare system integration
- Standardisation of care
- Increased access to specialised services
- Prevention and education initiatives
- Quality of life enhancement
- International collaboration and leadership



In What Matters 24 report **only 10%** of respondents answered yes to the question:

“Do you think the health and care system works for people with spinal cord injury?”

compared to the **24%** NHS satisfaction in the wider population.

1 THE NEED FOR:

Defined expectations for any rehabilitation pathway anywhere in the country whether through a spinal centre or not.

The spinal cord injury centres aspire to provide the gold standard of rehabilitation and the promise of lifetime ongoing care. However, there are severe challenges in capacity and marked regional variations in quality and provision, which have led to deterioration over the last 15 years. Examples would be outreach, psychology, patient ratios to consultants and therapists. Funding mechanisms need to be transparent and accountable to ensure equity and value for money and the delivery of the service specification. Post graduate education and standards for staff working within spinal cord injury specialist care settings would increase the status of the profession and improve recruitment and retention.

Many with a spinal cord injury are not admitted onto the spinal pathway of care, for example those with cognitive impairment or comorbidities (cancer). They still have a spinal cord injury with its associated impacts on skin, bladder, bowel, respiration and mental health. They still need appropriate and safe care. There is a need for policy to support delivery of spinal cord injury specialist care needs both within and without the spinal pathway.

A coherent vision of spinal cord injury care needs to be mandated nationally so that it is deployed consistently across all Integrated Care Boards (ICBs) and thence to local health care settings. It needs to incorporate physical and mental health needs in the face of the changing demographic of the spinal cord injury population.

A vision of the long term care pathway is required, including mental health and therapy needs in addition to medical needs such as urology. An example would be the availability of ongoing accessible rehabilitation post discharge. There are specific groups of people who will deteriorate from their initial rehab if they can not or do not access further rehab / wellness or fitness programmes built into their lives. Similarly with the equitable and timely provision of wheelchairs. It is a great waste of resources having invested in specialist rehabilitation only for this to be lost through a disconnect with the care and provision in the community. Not only is there a cost in lost human potential but there is a direct cost to the NHS in readmitting people with pressure sores, sometimes for months, for the want of physiotherapy, wheelchair or mental health provision.

“Spinal centres provide the ‘a’ class of rehabilitation and treatment but not everyone is lucky enough to go to one so what happens to those patients when they come home. Without the guidance and expertise it is too easy for them to fall into cycles of poor health involving bowel, bladder and skin.”

SIA member

“Dad was suicidal – on a cocktail of chemo drugs, feeling sick and desperate. I was in meltdown. Every day, we had district nurses, social workers, hospice staff – the house was like Piccadilly Circus. But no-one understood his spinal cord injury. No-one could help with his bowel care. No-one warned us about the dangers of autonomic dysreflexia (AD). No-one explained how good skin care could prevent life-limiting pressure ulcers. So, nothing got any better.”

Tina SIA member

2 THE NEED FOR:

Agreed standards and training-requirements for general health and care settings:

Still people with a spinal cord injury fear being admitted into non specialist settings due to a lack of capacity and knowledge. Those with the expertise and/or experience are often prevented from patients with spinal cord injury (eg carers). Standards for care exist, for example the RCN's guidance on bowel care, but yet most trusts have no policy, where one exists it is inconsistently applied, and fewer still have the trained staff or capacity to deliver it.

Physical factors are creating barriers to accessing preventative screening (for example physical access to mammograms and womens' health screening) which is decreasing life expectancy in the spinal cord injury population.

Agreed course content on spinal cord injury care included in all health care professional training would create greater awareness, skill and capacity in health care settings for immediate prevention of harm and knowledge of availability of specialist support.

Standardisation of spinal cord injury care plans adhered to as people transition between health and care settings (patient passport) would increase patient safety and save money. A patient that acquires a pressure sore in hospital or complications resulting from poor bowel care can result in treatments and bed stays measured in months. Prevention is cheaper than treatment.

“Clearly there is much to be learned within general hospitals in regard to medical understanding of those people with a spinal cord injury. I found the experience of staying on the ward extremely distressing: virtually every aspect of my health deteriorated except for the cyst for which I was admitted. This was particularly distressing as the methods of avoiding or treating these other problems have been well established by specialist medical practice and have been part of my daily life for many years. “

Tim Clare SIA member



3 THE NEED FOR:

A standardised framework of support for Continuing Healthcare (CHC) decision-making:

Based on the NHS England 'Model of Rehabilitation Services' (NHS England, 2016), NHS needs to work closely with community health services and local authorities for a more joined up approach to care, housing and wheelchair and equipment provision. This principal is enshrined in the Health and Care Act and the creation of Integrated Care Systems. However practice lags behind ambition with massive variations in levels of service. The Kings Fund and others highlight that care services are massively underfunded and that there are enormous regional variations. Consistent training and resources need to be available for care workers. A nationally consistent approach to CHC decision making is needed and to deliver this a central patient voice is required.

The case of Tom Lazarides debated in Parliament (hansard helen hayes) illustrates the problems faced.

"Tom Lazarides and his family encountered a system that seemed incapable of delivering the safe, appropriate, high-quality care and support that he needed and was entitled to. As a consequence, they spent the two years from Tom's discharge from Stoke Mandeville Hospital in the autumn of 2021 to his untimely death in the autumn of 2023 constantly fighting a system that ultimately failed them"

Helen Hayes,
House of Commons, 29/2/24

For Lynda Hoskings the stress of finding appropriate care has become overwhelming: "It keeps me awake at night and I have to rely on sleeping pills which I have been on for three years. How am I supposed to live this life when I can't afford to get the care I need? People don't realise how hard it is to access decent care and the danger if you don't receive any help."



4 THE NEED FOR:

A coordinated national programme of research, modelling and testing of best practice

Innovation, and improvements in patient outcomes and experience are to be encouraged, but if these innovations are not widely adopted when found to be best practice, then their impact is limited. A way of quickly achieving consensus and adoption needs to be found. The existing structures of information exchange and change management are not overcoming the barriers to change that are needed and are in part contributing to the regional variations referred to above. For example the CES pathway developed by GIRFT has not yet been nationally mandated and thus not consistently implemented.

“My friend told the doctor she was worried it was cauda equina syndrome. The doctor reassured us that it wasn't, but she would refer me for an MRI however it wasn't urgent and I was sent home in the meantime. Three days later I went back to A&E as in addition to the pain and numbness I woke up in the night incontinent. An urgent MRI was then completed confirming I have cauda equina syndrome and if they did not operate within the next 24 hours, I would be paralysed from the waist down.

I cannot walk unaided and continue to have no feeling in my leg or groin. Daily tasks are a struggle, and the nerve damage has also affected my bowels and bladder, so I now have to self-catheterise.

I feel like my voice has been completely ignored for the last 9 months by health professionals and now it is very hard to come to terms with what has happened and my new way of life. I wish someone would have listened to my worries sooner so that this could have been prevented but I'm grateful that I still have the feeling and use of one of my legs.”

SIA member



5 THE NEED FOR: A nationwide patient representative network

A fulfilled life is defined by the interplay of body, mind and life needs, and an over medicalised focus on narrow aspects of the treatment of the injury will hinder rehabilitation and the rebuilding of lives. The third sector should be the natural and automatic partner of the health and care system, not only because through membership it can help access and articulate the patient voice, but also because it connects a patient to a network of advice, support and care that will be essential for the rest of that person's life. This is a network that is not the remit, or within the capacity, of the health and care system to provide.

Disabled people's voices need to be valued and prioritised in the planning and delivery of health and care services.

[Towards A Partnership Between Disabled People And Health Care Services | The King's Fund \(kingsfund.org.uk\)](#)

It is interesting to note that the Richmond Group's key 5 themes ([Areas of work richmondgroupofcharities.org.uk](#)) necessary "to ensure patients have access to high quality, compassionate and sustainable care."

Are:

1. Coordinated care
2. Patients engaged in decisions about their care
3. Supported self management
4. Prevention and early intervention
5. Emotional, psychological and practical support

"I was the only disabled person I knew, the only spinal cord injury person I knew, the only one who was going through the incontinence, lack of independence. I still felt really alone, which was strange being around family and friends again. But it felt like no one understood what I was going through. I think this was where I reached my lowest point."

SIA member on leaving the spinal unit

"Knowledge is power and we support many to become an expert in their own condition. Simple specialist knowledge can save lives and mental trauma."

SIA specialist nurse

"Given the pressures the NHS is under, there is help here that has got some potential to be unlocked and cascaded more widely."

**Former disability minister
Tom Pursglove MP**





1974 - 2024

sia 50

for life after spinal cord injury

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