

WHAT MATTERS REPORT 2023



What really matters to spinal cord
injured people in the UK today

Introduction

We believe every spinal cord injured (SCI) person has the right to a fulfilled life and should be treated fairly and with respect. But how exactly does that life look for you? And what kinds of things get in the way of you living the life of your choosing?

Your voices – your stories and experiences - are at the heart of our work here at SIA and through our annual ‘What Matters?’ survey, we are privileged to hear them loudly and clearly.

And why is this important? Through your responses, we gather stories and statistics which help provide a snapshot of the reality of living with SCI. **We see the things you need us to help change.** Most importantly, your responses directly shape our work – from the campaigns we decide to run, to the research we focus on and to the front-line services we work hard to provide.

Year on year, more of you are taking part in this sector-leading survey, with this year’s having the greatest response yet – 994 people took the time to get in touch, the vast majority who have SCI. This is truly transformative for us as we plan our work as an organisation. This on-going conversation with the SCI community means so much and we know the responsibility that comes with it and the part we must play in amplifying your voices as we fight for change.



SCI people completed an extensive survey

REPORT FINDINGS

The ‘What Matters?’ survey findings do not make an easy read. Your stories are often heart breaking, your experiences shocking. But we don’t have to tell you that. By sharing them, you’ve lent your voice to a movement for change, joining others to be louder and bolder and so making it harder for society to look away.



Executive Summary

Thank you once again for the overwhelming response we have had to this year's 'What Matters?' survey. We had almost double the number of people get in touch to share their stories and experiences with us, making this the greatest response we've ever had to this survey. We are so grateful. Your responses help in so many ways, not least of all in helping shape our programmes and campaigns moving forward.



Simply put, this survey exists so we can identify what barriers prevent you and your loved ones from living a fulfilled life. It remains clear from your responses that too often too many spinal cord injured people are failed; failed by a health and social care system in crisis, failed by lack of coordination of

support and perhaps worst of all failed by a lack of expertise when you need it.

We've read each one of your comments and we're shocked and saddened by what we've learnt. It's clear too many live in fear of even the most fundamental services: visiting general hospitals and other care settings because you feel staff are ill equipped to deal with SCI patients... over two thirds of those who had been in hospital were unable to receive decent bowel care! We were heartbroken to read that after being admitted to hospital with a leg broken in four places, one of you received no bowel care at all. That person told us they "ate very little for the nearly four days I was in hospital and discharged myself so I could go home and manage my own bowels."

This cannot continue. Proper bowel care and bladder management are essential to living well with a SCI.

Meanwhile, almost half of all respondents - 47% of you - shared that you experience anxiety and/or depression. Lack of specialised mental health services for SCI people remains a serious concern as you work to rebuild your lives after injury with one respondent telling us that their "weakened mental health has removed me from any kind of personal life" and that "more needs to be understood" by health and mental health professionals.

"It's clear too many live in fear of even the most fundamental services: visiting general hospitals and other care settings because you feel staff are ill equipped to deal with SCI patients."

An emerging concern is how many shared your fears on the impact the cost-of-living crisis on your daily lives... 8 out of 10 of you are concerned at how you'll manage financially next winter.

As you will know, 2023 marks the launch of our new strategy. So, what does this mean for you? Thanks to what we've learned from your continued conversations with us, we are setting out not just ambitious goals, but goals aimed at transformation of the systems. We are going to double our reach, insist on referral of every spinal cord injured person to their association, so we can fight your corner from the outset, and we are launching an academy to work within the health and care system to ensure there is the necessary expertise for proper care and support. And we will continue to campaign with our partners and please most of all with you, our members. Please do join our **#SeriousSh1t campaign** and look out for more campaigns and policy work to push for better coordinated support from injury to home.

We know this is ambitious, but we are driven by your stories and experiences to ensure this change happens. By sharing with us you play a vital role in supporting our work and campaigns. Thank you.

**Nik Hartley OBE,
Chief executive officer**

Key Findings

The survey considered three key areas: body, mind and life. We have asked What Matters?

Body



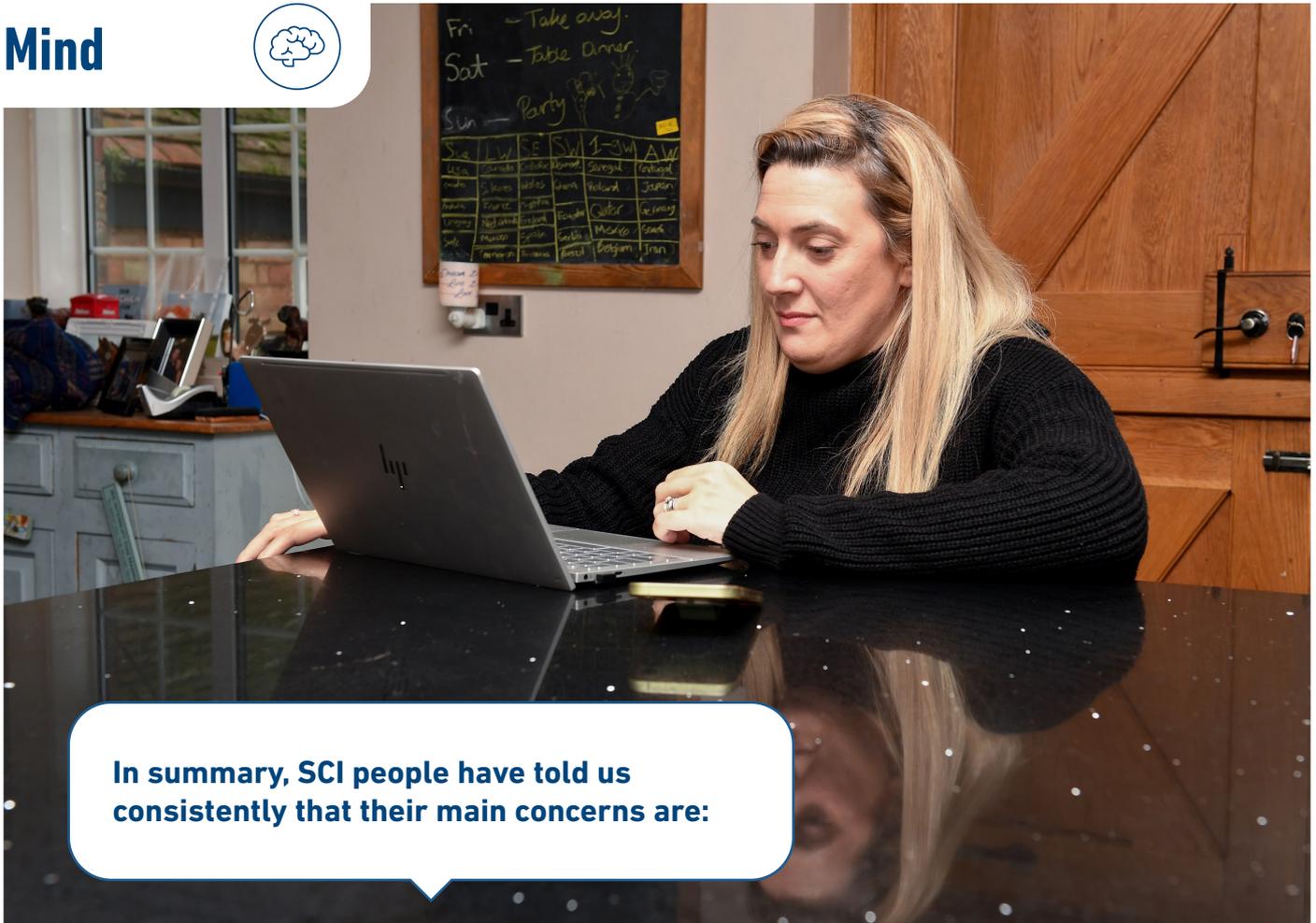
In summary, SCI people have told us consistently that their main concerns are:

1. Bowel management (50%)
2. Bladder management (47%)
3. Pain management (42%)
4. General medical access (37%)
5. Ageing with an SCI (35%)
6. Wheelchair provision (35%)
7. Fitness and exercise (30%)
8. Skin care and management, including accessing information about pressure ulcers (22%)

Key Findings

The survey considered three key areas: body, mind and life. We have asked What Matters?

Mind



In summary, SCI people have told us consistently that their main concerns are:

1. Anxiety or depression has affected them (47%)
2. Friends, family and intimate relationships has been affected (41%)
3. A lack of specialist rehabilitation support (41%)
4. Access to counsellors and therapists who understand SCI (36%)
5. Isolation or loneliness (36%)
6. Self-confidence affects them (36%)
7. Expressed concerns around a lack of availability of services, such as wheelchairs or housing adaptations (30%)
8. Self-image (27%)
9. Feeling disconnected from other SCI people (20%)

Key Findings

The survey considered three key areas: body, mind and life. We have asked What Matters?

Daily Life



In summary, SCI people have told us consistently that their main concerns are:

1. Accessing the outdoors and countryside (90%)
2. Society's attitude towards disabled people (89%)
3. Accessible parking (84%)
4. Adapting their home to their needs (82%)
5. Finding accessible housing (80%)
6. Access to vocational activities (70%)
7. Accessing social care (64%)
8. Funding their care needs (61%)
9. Accessing care in their own home (57%)
10. Standards of care (50%)
11. Access to wheelchairs and mobility equipment (35%)

Body



MAKING YOUR VOICE HEARD

“General hospitals better understanding the needs of people with SCI especially bowel and bladder management. I fear having to go into hospital.”

“For me to be able to access places/professional people to keep myself to a healthy level is imperative.”

“My family, friends and carers are the most important things. After that it's access to medical services.”

“More easily available medical support both locally and at spinal centres. I don't feel that they are there for me in the same way that they were in the past. I find help hard to get in this specialised area.”



50%

Said the lack of general healthcare professionals' knowledge of bowel management was a concern



Body



More than a third (36%) of our survey respondents had reported a stay in hospital during the last two years, and of them, 69% didn't receive a good standard of bowel management care. The lack of knowledge and expertise around SCI-specific bowel care can put the community at risk of further complications. We are working to highlight the issue this year with our **#SeriousSh1t campaign**.

Below are quotes to illustrate what a lack of bowel care means for spinal cord injured (SCI) people:

"The ward had problems finding someone who could manually evacuate my bowel, so my wife had to come in to do it."

"They hadn't the first idea what to do to help me when my bowels were severely compacted. They wouldn't liaise with the National Spinal Injuries Centre (NSIC) for help and advice; the info I got them from NSIC, they refused to look at. I spent two weeks as an inpatient in severe discomfort when I was already three weeks impacted on admission. This triggered many bouts of autonomic dysreflexia! Disgusting experience!"

"I use Peristeen (an anal irrigation system), and not one staff member knew how to use it. I had a broken hip and had to struggle myself to do my bowel care and passed out twice in the bathroom."

General hospital ward staff and GPs come across few SCI patients during their careers. That means some doctors and healthcare professionals have never had the experience of caring for someone with an SCI before or have an awareness of the specialist medical and social care needs of SCI people.

Many of the people we asked said they feared being cared for in a general hospital or care home. Staff in these settings are often not sufficiently trained or experienced enough to provide adequate or appropriate care for SCI people.

⇌ URGENT CHANGE IS NEEDED

To improve the long-term physical health of SCI people, we need:

- Access to appropriate health care from suitably qualified and trained health care professionals.
- GPs and hospital medical staff to have a greater awareness of the clinical implications of SCI.
- Access to regular physiotherapy and rehabilitation post-injury.
- Access to good educational resources to help with self-management.
- Health care professionals to listen and recognise that SCI patients can be experts in their own condition.



Are concerned about pain management



Mind



MAKING YOUR VOICE HEARD

"My pain is awful ... and I have lots of issues with pain and numbness, bladder and bowel problems and depression. It's vile."

"My mental health and physical health have suffered. I don't see friends anymore. I feel like a burden."

"My weakened mental health has removed me from any kind of personal life, with a lack of friendships, sexual relationships and employment. More needs to be understood by medical and mental health professionals."

"The ability to be as independent as possible matters the most to me. I fight hard to live a normalish life but my mental health has gotten worse and like everyone I struggle. My friends who still call don't understand my pains and frustrations. I can be irritable due to my condition which doesn't help with friends and family."



36%

Said having access to counsellors who understand spinal cord injuries from the point of injury and beyond is crucial



Mind



Previous years' survey findings and our work on our It's Not Just Physical report have highlighted the need for a greater focus on mental health and wellbeing. This year's survey delved deeper into this area to establish the degree to which mental health problems affect the SCI community.

The results show that some of the feelings that arose during the Covid pandemic and lockdowns continue as more than a third (36%) of respondents said they still experienced isolation or loneliness. Last year, 34% answered that they felt this way.

Last year, almost half of our respondents told us mental health was among the biggest challenges preventing them from leading a fulfilled life, with many saying they could not access mental health support. We saw a similar picture again this year.

Specific problems included a lack of self-confidence, poor self-image, post-traumatic stress disorder (PTSD), inadequate access to SCI-specific and general mental health services and relationship troubles. Little support for the loved ones of SCI people was also reported.

⇌ URGENT CHANGE IS NEEDED

To help improve the mental health of SCI people, we need:

- Access to psychological support at the point of injury and rehabilitation.
- Ongoing counselling and mental health support for all after hospital or spinal centre discharge.
- Mental health support for the families of SCI people.
- Mental health and general medical services to better understand the psychological issues SCI people face.



Said that anxiety or depression has affected them

Daily Life



MAKING YOUR VOICE HEARD

"SCI people are viewed as people with bad backs, with no consideration about what else SCI has brought with it – even from medical professionals. [We also experience] pain, mental problems, lack of sleep, anxiety, etc."

"In so many ways, I've lost independence. My social life is so impacted, and I'm reliant on people coming to see me because I can't get out to them. I can no longer do my favourite hobbies, go to the gym, or just pop out to the shops. Cauda Equina Syndrome (CES) dominates my entire life and every decision I make. It's no longer, "Would I like to do this?" and instead just, "Am I capable?" It cuts across everything in my entire life."

"I feel good any time someone comments that they view disabled people differently after meeting me; my hands and brain still work."

"What matters to me is feeling purposeful. I want to make a difference in others' lives, and express and share all my experiences. I hate the loneliness, invisibility, avoidance and being misunderstood. I want to see laws brought out, all to be accepted and inclusive workplaces. We are all human and are of use."



89%

Said society's attitude to disabled people has an impact on their daily lives



Daily Life



The cost-of-living crisis is having an enormous impact on the daily lives of those in the SCI community. 8 out of 10 survey respondents told us they were concerned about how they will manage financially next winter, having already been impacted this winter. Poor access to vocational activities, accessible parking, home adaptations and appropriate wheelchairs also continue to affect our community.

Other concerns reported covered many elements, including access to benefits, NHS continuing healthcare and care eligibility, the cost of living when there is a need for wheelchairs and other equipment, getting out and about, and poor access to shops, leisure activities and even hospital visits.

Simply getting out of home remains as challenging as ever. Between 64% and 90% of survey respondents highlighted difficulties with all related aspects, including access to the outdoors and countryside, parking, shopping, hotels, leisure, public transport, air travel and blue badge schemes.

Many respondents spoke of dropped kerbs not being opposite each other and how simple changes to planning would make a considerable difference to their daily lives. Non-enforcement of the appropriate use of accessible parking spaces continues to be a concern and affects many of our respondents' ability to access facilities.

Care in the home, care standards and accessing carers from abroad remain challenging for our community, as do financial concerns about paying for home adaptations, funding care needs and the lack of accessible housing.

⇒ URGENT CHANGE IS NEEDED

To help SCI people have access to everything needed to level the playing field with non-disabled people and enable them to lead fulfilled and happy lives, we need:

- Health and social care that provides for SCI people's ongoing needs.
- Care support that is built around and reflects the needs of SCI people.
- Adapted houses to provide safe and comfortable homes.
- Fit for purpose wheelchairs and mobility aids.
- Job opportunities that reflect skills, experience and aspirations.
- Health and leisure opportunities and access to outdoor spaces.
- A decent standard of living and a valued place in society.



The Report

Appendix

Core Survey Questions

- Q1. To help us understand what really matters to those in the SCI community, please select FIVE key issues from the list. Please put these in the order of priority to you, from one to five, with one being the most important.
- Q2. Have you had a pressure ulcer in the last 12 months?
- Q3. Thinking back to your last hospital admission, how well managed was your bowel function by the hospital-based health care professionals?
- Q4. Again, thinking back to your last hospital admission, how long did it take for your bowel function to return to normal after discharge? Please tell us how many days, weeks or months it took.
- Q5. To help us understand what really matters to those in the SCI community, please choose FIVE issues that have directly affected your mental health and wellbeing. Please put these in the order of priority to you, from one to five, with one being the most important.
- Q6. Employment, education, and vocational activities. Please say below how much having an SCI has affected access to the following:
- Q7. Finance, benefits and legal services. Please say below how much having an SCI has affected access to the following:
- Q8. Housing matters. Please say below how much having an SCI has affected access to the following:
- Q9. Getting around. Please say below how much having an SCI has affected access to the following:
- Q10. Care and support. Please say below how much having an SCI has affected access to the following:
- Q11. Attitudes towards disabled people. Please say below how much having an SCI has affected access to the following:
- Q12. Buildings, services and leisure. Please say below how much having an SCI has affected access to the following:
- Q13. Have the increased costs of essentials such as heating bills, transport and food affected your health over the last year? You may choose more than one answer.
- Q14. Have these increased costs meant that you have needed additional support such as a food bank, a warm space or something else?
- Q15. How concerned are you that your life will become more difficult next winter due to the increased cost of living?
- Q16. Body, mind and life. Please expand or clarify any of your answers to explain in more detail what matters to you most and what changes or improvements you would like to happen.
- Q17. How has having an SCI affected your life in terms of work, relationships with family and friends, hobbies and interests, general health, and mental health and wellbeing?
- Q18. To better serve you, we want to know what SCI people would like from us. So, how can we help you and other SCI people lead a fulfilled life?
- Q19. Would you be happy to be contacted by a member of our communications team? We would love to hear about your experiences in more detail. If so, please provide a contact email below:

Acknowledgements

The data and comments included in this report were collated from the 994 qualitative and quantitative responses we received to our What Matters? survey. Of the respondents, 876 were SCI people. We would like to thank everyone who completed the survey and contributed their time and thoughts so generously.

What Matters? is an ongoing conversation with the SCI community. We remain dedicated to listening to everyone affected by spinal cord injury to understand the issues faced so that we can continue to give our support in the best way possible.



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injuries
association
for life after spinal cord injury

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