

WHAT MATTERS REPORT 2024



What's important to people with
spinal cord injury in the UK today

Introduction

Every two hours, a person's life changes forever when they sustain a spinal cord injury. Their world – and that of those close to them – is turned upside down. Previously insignificant matters become considerable challenges, and people face barriers they've never had to consider.

More than 80% of respondents to our survey said having a spinal cord injury had affected all areas of their life – from work to relationships and hobbies to health and wellbeing.

Understanding these obstacles and amplifying the voices of the spinal cord injury community is at the heart of what we do. That's because we believe every person with spinal cord injury has the right to a fulfilled life, one in which they are treated fairly and with respect.

What Matters? is our sector-leading survey that we carry out each year to better understand the issues people with spinal cord injury face. This report provides a snapshot of our findings and compares them with last year's survey results.

This year, 913 people shared their stories, of them, 723 live with a spinal cord injury. Their responses highlight what's important to them across our key areas: body, mind and life. The data and lived experiences our respondents shared give us the insight needed to further refine our services, research and campaigns. The findings will also drive our delivery plans on the front line and allow us to better support people living with a spinal cord injury across the UK.

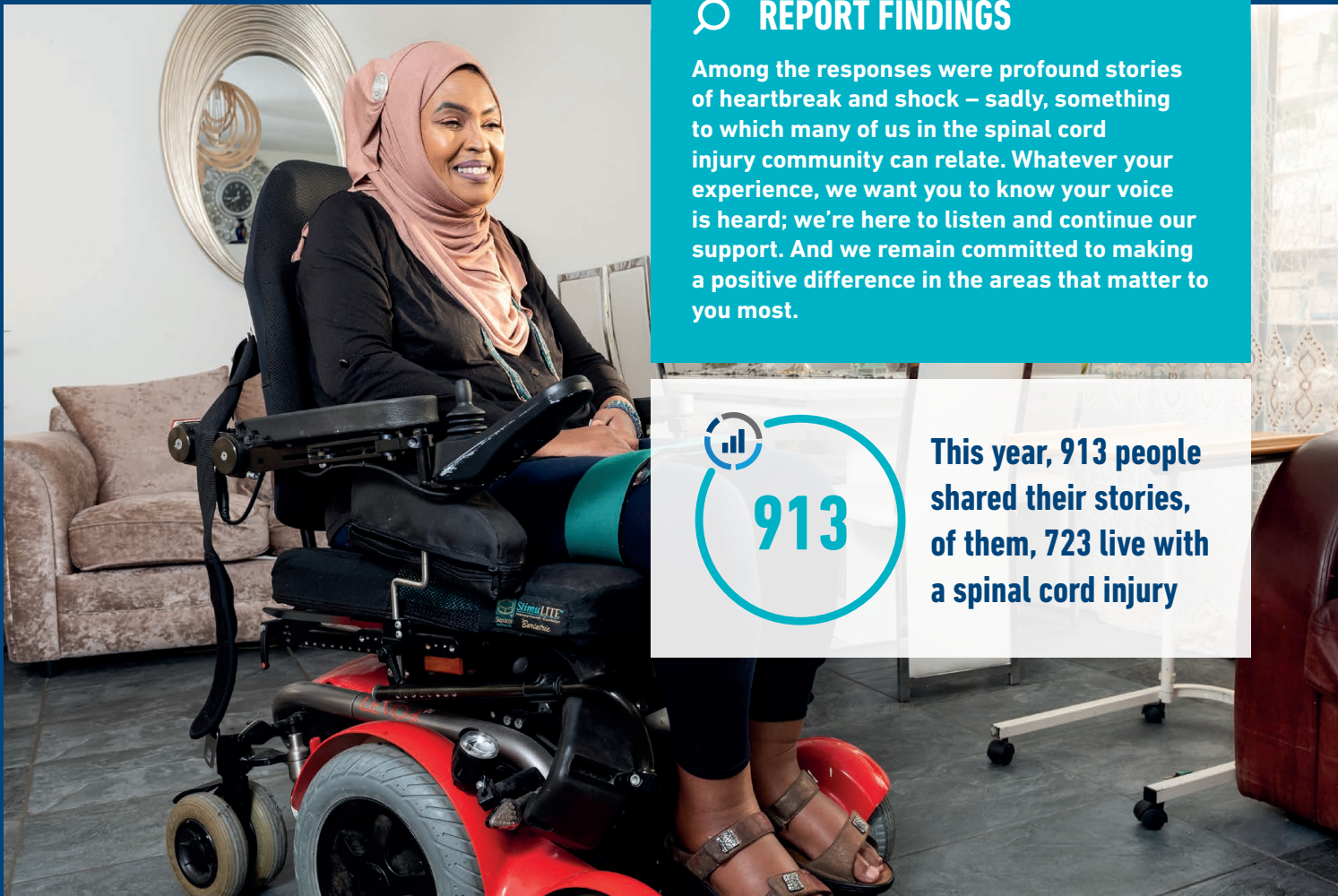
REPORT FINDINGS

Among the responses were profound stories of heartbreak and shock – sadly, something to which many of us in the spinal cord injury community can relate. Whatever your experience, we want you to know your voice is heard; we're here to listen and continue our support. And we remain committed to making a positive difference in the areas that matter to you most.



913

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Executive Summary

This year is one of particular significance for us as we mark the formation of SIA half a century ago. In September 1974, the late Baroness Masham founded the charity with a vision to create the first organisation to support and guide people with spinal cord injury and their loved ones. Fifty years on, and we continue to ensure her legacy thrives by working to help everyone affected by spinal cord injury lead fulfilling lives.



Central to our work is listening to the spinal cord injury community to learn about the barriers that block people from easily accessing the help and support needed to live a life of their choosing. That is where What Matters? comes in.

This collaborative project is our ongoing conversation with people affected by spinal cord injury, and it evolves with each year. **More than 900 of you shared your compelling stories and experiences with us this year.** For your time and openness, we are truly grateful. **Thank you.**

Your responses have painted a picture of a world in which too many people with spinal cord injury still have to fight for the support they deserve and need, or risk going without.

More than half of you said the health and care system does not work for people with spinal cord injury and a staggering **42% said that accessing routine and diagnostic tests has been challenging.** That such a considerable proportion of our community faces barriers to vital health and care services is appalling.

We also heard how more than half of people with spinal cord injury continue to be worried about their **bowel management needs going unmet, especially in general healthcare settings,** and how more than a third of people who said they'd had a **pressure ulcer in the past year felt it wasn't diagnosed correctly.** We know only too well that delayed or incorrect diagnoses can result in grave and long-lasting repercussions. Worst of all, **this is an entirely preventable problem.**

Besides the physical impact of substandard care and support, you told us about the state of your psychological wellbeing. **The findings of the survey are sobering.** Nearly 70% of respondents shared that they had experienced mental health challenges, and 39% said they'd had suicidal thoughts. Yet, despite the high prevalence of mental health problems,

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there continues to be a lack of access to counselling and therapists who understand spinal cord injury. More than three-quarters of you agree with that, which is a far greater proportion than a year ago.

Poor public awareness of spinal cord injury was also highlighted in the survey's findings. Three-quarters of you felt media representation of this life-long condition was either negative, insufficient or completely absent. Meanwhile, **46% of people had experienced negativity in public opinion towards spinal cord injury.** No one should ever be "spoken to like a toddler" – yet this is the experience for some people with spinal cord injury.

Society's failure to ensure inclusivity and equality for all disabled people – even when it is needed most – is stark. This cannot go on.

Your input leads to action. It helps us to shape our existing and future programmes and campaigns to create a better future for the spinal cord injury community. We will continue to amplify your voices where they need to be heard most and be ambitious in our drive for a fulfilled life for everyone affected by spinal cord injury.

So, thank you again for continuing this frank conversation with us. We will continue to call for real action to ensure positive change for our community over the next half-century and beyond.

Nik Hartley OBE,
chief executive officer

Key Findings

The What Matters? survey considered the impact of spinal cord injuries on three key areas: body, mind, and life.

Body



People with spinal cord injury have told us consistently that their main concerns in each area are:

1. Bowel management (51%)
2. Bladder management (46%)
3. Ageing with a spinal cord injury (44%)
4. Specialist spinal cord injury centres (42%)
5. Wheelchair provision (40%)
6. General medical access (38%)
7. Pain management (37%)
8. Availability of community medical services (26%)
9. Fitness and exercise (25%)
10. GP services (24%)
11. Equipment and living aids (20%)
12. Skin care and management, including accessing information about pressure ulcers (19%)

Key Findings

Mind



People with spinal cord injury have experienced challenges across the following areas:

1. Relationships with friends and family (91%)
2. Isolation and loneliness (81%)
3. Self-confidence (87%)
4. Self-image (76%)
5. Anxiety (80%)
6. Depression (78%)
7. Suicidal thoughts (39%)
8. Lack of access to counsellors and therapists who understand spinal cord injury (74%)
9. Lack of specialist rehabilitation support (52%)
10. Lack of access to general mental health and wellbeing services and support (46%)
11. Access to counsellors and therapists who understand spinal cord injury (85%)
12. Access to specialist rehabilitation support (76%)

Key Findings

Daily Life



People with spinal cord injury have experienced difficulties accessing the following areas:

1. Access to hobbies (93%)
2. Accessing the outdoors and countryside (92%)
3. Accessing public transport (91%)
4. Accessing air travel (91%)
5. Accessing shops (91%)
6. Accessible parking (88%)
7. Employment issues (87%)
8. Home adaptations (83%)
9. Funding care needs (84%)
10. Availability of accessible housing (81%)
11. Accessing social care (80%)
12. Accessing benefits (77%)

Body



HAVING YOUR VOICE HEARD

"Bowel incontinence, they stopped my regular medication which left me with no control. Very embarrassed and tearful".

"My PA had to stay with me 24/7 as meds were not given on time and bowel care was atrocious".

"Terrible! Nobody acknowledged my needs or understood even when I explained, I felt petrified of how I would cope".

"They didn't really understand my needs until SIA contacted them".

"Horrendous. No bowel care knowledge, lack of knowledge on protecting the skin and poor pain management due to a lack of understanding of how nerves work in spinal patients".

"Poor, no one knew about dysreflexia or what to do about it".

"Multiple admissions with sepsis because of pyelonephritis (kidney infection). Each time, the pathway from contact with a GP to receiving appropriate medical care was horrendous".

"Poor bowel care, poor understanding of spinal cord injury".



51%

Said they were worried about bowel care management



Body



Almost half (43%) of our survey respondents said they had been admitted to hospital in the last two years as an in-patient, and of them, 54% received substandard bowel care. This was found to have lasting repercussions because 40% of respondents said it took three or more months for their bowel function to return to normal after being discharged. Even more worrying is the response from more than a third (34%) of people who said bowel function was still a problem after being in hospital. The lack of knowledge about spinal cord injury-specific bowel care in general medical settings can put the community at real risk of further complications. Our #SeriousShit campaign remains among our key priorities. We have launched a petition that calls on the government to ensure that every NHS hospital has a bowel care policy and specialist bowel care. At the time of publishing this report, we have 5916 petition signatures.

"Staff did not understand transanal washout. Eventually, they gave me three enemas in bed. Despite me having no control, they left me in my faeces. I finally removed the smell and bits of faeces when I took myself to the shower under the cover of the night. (I feel) so degraded".

Many respondents to this year's What Matters? survey still feel extremely concerned about the poor standard of bowel care, as well as access to trained healthcare professionals and the lack of knowledge around the specialist medical and social care needs of people with spinal cord injury.

Almost one in five (19%) survey respondents said they had experienced a pressure ulcer in the last 12 months but more than a third of them (36%) said they didn't feel that their pressure ulcer was correctly diagnosed.

"It was a stage four ulcer, and I was finally referred to community nursing. After a month, they treated the ulcer, but it took five months to heal".

"(I was lying on an) inappropriate mattress for eight hours when admitted to A&E".

"Not enough support available".

The fear of being admitted to a general hospital remains high across the spinal cord injury community.

↔ URGENT CHANGE IS NEEDED

To improve the long-term physical health of people with spinal cord injury, we are campaigning for:

- Access to appropriate treatment from suitably qualified and trained healthcare professionals.
- For all healthcare professionals to have a better awareness of spinal cord injury and the clinical implications.
- Healthcare professionals to listen and recognise that patients with spinal cord injury can be experts in their own condition.
- Accessible education and resources to support self-management.
- Access to appropriate ongoing treatment post-injury, such as physiotherapy and rehabilitation.
- Access to appropriate NHS care, routine screening, and diagnostic testing relevant to ageing.



44%

Said they were concerned about aging with a spinal cord injury



Mind



HAVING YOUR VOICE HEARD

"Grief, grief, grief. Loss of identity, changed dynamics, loss of role and purpose. Feelings of doom and abandonment and constantly retelling the story leave a person as a shell".

"I am depressed and suffer from anxiety. I have low self-esteem and poor self-image. I don't feel like a woman anymore. I'm not attractive or pretty, I am just disabled".

"Sometimes life doesn't seem worth living. It's such a struggle to manage day-to-day living with everything you need to arrange and remember. The expectations from everyone are too much".

"My mental health is severe and very delicate since my injury. I tried to keep low stress, but I battle with anxiety and have depression".

"Twenty years later, I still have struggles with my mental health".

"I get depressed all the time and wonder if it's worth living like this".



40%

More than two-thirds of survey respondents told us they had experienced mental health problems and 40% said they'd had suicidal thoughts



Mind



This year, our What Matters? survey asked more specific questions about mental health, focusing on the particular challenges the spinal cord injury community faces. Mental wellbeing is an important topic that isn't spoken about enough, and our findings revealed that **40%** of people hadn't discussed their mental health support needs with anyone.

Respondents told us they lived with anxiety, depression, and suicidal ideation. Some said they had experienced post-traumatic stress disorder, addiction issues and substance misuse. Without support or proper treatment, these problems can have catastrophic, long-lasting consequences on a person's recovery and life going forward.

Your responses to the survey continue to highlight the struggles and challenges that prevent the spinal cord injury community from leading a fulfilled life. More than three-quarters of people (**76%**) said there was a lack of access to counselling and therapists who understood spinal cord injury – an increase of **40%** from the previous year.

Relationship problems and poor self-confidence and self-image were among the other issues our community reported.

Connections with family and friends remain a key priority for almost all people with spinal cord injury (**91%**), our survey found. Almost two-thirds of people (**62%**) also said they want to feel connected to other people in the spinal cord injury community, with many recognising the benefits of peer support or mentoring.

Maintaining intimate and sexual relations was also important to many of our respondents (**47%**), but access to spinal cord injury-specific sexual advice or support has proved difficult (**30%**).

⇌ URGENT CHANGE IS NEEDED

To help improve the mental health of people with spinal cord injury, we are campaigning for:

- Access to psychological support at the point of injury and throughout rehabilitation.
- Ongoing counselling and mental health support for all after discharge from hospital or spinal centres.
- Mental health support for the wider spinal cord injury community, including families and friends.
- Training and support for healthcare professionals to enable them to better understand the psychological issues people with spinal cord injury face.



69% of respondents answered 'yes' to experiencing challenges around mental health



Daily Life



HAVING YOUR VOICE HEARD

"I have been served with three eviction notices in the last 12 months in the house I have lived for 15 years. I am clinging on by a strand. I have been on the housing register for three years and nothing has become available to suit my needs".

"Public transport – have been verbally abused by bus drivers, been laughed at/patronised by Transport for London staff. I often need to book passenger assistance for rail and coach and just meet some really bizarre responses. I'm frequently spoken to like a toddler and people have a limited understanding of the extra space you need for mobility kit".

"Travel insurance I find is extremely expensive now, also car insurance for disabled vehicles as they are seen as modified vehicles".

"DWP ruthless. One assessment by phone told advisor I'm a tetraplegic. She said tetra meant three, so which three limbs were affected? Huge anxiety over a recent PIP renewal, stuck in the process as not complete spinal cord injury".

"Stopped my travel (I have no interest in planned travel/nice hotels/cruises etc). I lost the spontaneity of being able to get up with a rucksack and go".



93%

Said they'd experienced challenges when accessing hobbies



The Report

The survey was sent out via Survey Monkey and was open for four weeks during February and March 2024. It was well publicised to both our membership and the wider spinal cord injury community, as well as to partner organisations and across social media.

Appendix

Core Survey Questions

- Q1.** To help us understand what really matters to those in the spinal cord injury 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.** In the last two years have you been an in-patient within a general medical setting?
- Q3.** Have you had a pressure ulcer in the last 12 months?
- Q4.** Was this correctly diagnosed and treated?
- Q5.** Thinking back to your last hospital admission, how well-managed was your bowel function by the hospital-based healthcare professionals?
- Q6.** 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.
- Q7.** Have you experienced challenges with your mental health? If yes, please select what challenges you experience(d) from the list below. Select all that apply.
- Q8.** Have you discussed your mental health support needs with anyone?
- Q9.** From the list, please choose FIVE key areas that are important to your sense of wellbeing. Please list these in order of priority to you – from one to five – starting with the most important, (eg priority one).
- Q10.** Have you experienced any of the following challenges or issues when accessing mental health or wellbeing support? Please select all that apply.
- Q11.** To help us understand what really matters to those in the spinal cord injury community, please choose FIVE areas of support you feel should be prioritised. Please list these in order of priority to you – from one to five – starting with the most important.
- Q12.** Please say below how much having an spinal cord injury has affected access to the following: employment, education and vocational activities.
- Q13.** Please say below how much having an spinal cord injury has affected access to the following: finance, benefits and legal services.
- Q14.** Housing matters. Please say below how much having an spinal cord injury has affected access to the following.
- Q15.** Getting around. Please say below how much having an spinal cord injury has affected access to the following.
- Q16.** Care and support. Please say below how much having an spinal cord injury has affected access to the following.
- Q17.** Media representation towards disabled people.
- Q18.** How well do you feel spinal cord injury is represented in the media?
- Q19.** Public opinion towards people with a spinal cord injury.
- Q20.** What has been your experience with public opinion/ attitudes?
- Q21.** Buildings, services and leisure. Please say below how much having an spinal cord injury has affected access to the following.
- Q22.** Do you think the health and care system works for people with spinal cord injuries?
- Q23.** Have you had difficulty accessing routine and/or diagnostic tests in a healthcare setting? If yes, please provide more details of what you were trying to access, eg MRI, mammograms, cervical smears, or any other such tests.
- Q24.** With a spinal cord injury, have you struggled to access specialist gynaecological help, for issues such as pregnancy, menstrual health, menopause or anything else?
- Q25.** 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.
- Q26.** How has having an spinal cord injury affected your life in terms of work, relationships with family and friends, hobbies and interests, general health, and mental health and wellbeing?
- Q27.** To better serve you, we want to know what spinal cord injury people would like from us. So, how can we help you and other spinal cord injury people lead a fulfilled life?
- Q28.** 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 913 qualitative and quantitative responses we received to our What Matters? survey. Of the respondents, 720 were people with spinal cord injury. 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 spinal cord injury community. We remain dedicated to listening to everyone affected by spinal cord injury to understand the issues they face and enable us to continue to give our support in the best way possible.



1974 - 2024
sia 50
for life after spinal cord injury

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