

2022

WHAT MATTERS REPORT

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



Introduction

Spinal Injuries Association (SIA) began conducting an annual survey last year to better understand the main obstacles for spinal cord injured (SCI) people living in the UK today. The findings outlined in this year's report provide a snapshot of what it means to live with SCI, direct from the community itself, while also offering a comparison to last year's findings.



REPORT FINDINGS

The report's findings will be used to further build and refine our programmes and campaigns and to support and raise the voice of all SCI people across the UK. We remain committed to increasing dialogue and collaboration with the SCI community and to improving our ability to be the representative body our members demand and deserve.

We asked our members to share their opinions and experiences on the impact spinal cord injury has had and the challenges that prevent them from living a fulfilled life. A total of 586 SCI people completed an extensive survey and of those, 134 people are now in the process of being provided information, support and advice.



586 SCI people completed an extensive survey

Executive Summary

We've had an overwhelming response to this year's 'What Matters?' survey, with even more of you taking time to answer vital questions; from every one of us here, thank you. We are nothing without your voices and unique experiences and by sharing them, you give us a living, breathing picture of what it really means to live with a spinal cord injury.



It is clear from your responses that many of you face tough and unnecessary barriers – undermined by a beleaguered health and social care system which is too often letting down the people it aims to serve.

In the qualitative feedback I've been struck by the feelings of frustration,

hopelessness, and abandonment you've described. One of you said that 15 years on from your injury, you are having to fight for the right support "more than ever before", wondering why you can't receive the help you need "without having to create a storm to be heard."

This annual survey exists so we can find out what barriers stop you from living a fulfilled life. Something we notice emerging across these barriers is 'specialism' – or the complete lack of it outside the specialist centres: e.g., 72% of respondents said they were concerned by health care professionals' lack of any SCI knowledge when it came to basic bowel management and care. Many of you told us you worried about visiting a general hospital or care home as you feel staff are untrained in dealing with SCI patients.

This theme is true with mental as well as physical health needs – 41% of you shared that you're affected by anxiety or depression, with just under half revealing that access to counsellors who understood SCI was what you really needed.

When it comes to living daily lives, we were troubled to learn that 92% of our respondents believed the public itself impacted on their ability to achieve a fulfilled life as a disabled person, alongside financial fears, employment anxiety and assessment for care eligibility.

So, what will we do? Building on last year, our specialist support services continue to grow. We are expanding specialist services for you – counselling, occupational therapy, as well as our specialist nurses – while at the same time creating a set of resources and trainings for non-specialist settings – care homes, hospitals, and GPs. We will make the case to all levels of the NHS that constructive, informed investment to build knowledge and expertise in SCI across these sectors will save money in the long term, and crucially, it will save lives.

Returning to the respondent I mentioned at the start – we want to build evidence by expanding our models of specialist services, so we can raise our voice together to make change happen. We're here to do that on your behalf but it is your collective voices – your stories – that will influence this change. Help us elevate your voices by supporting our work, joining our emerging community groups, and campaigning with us.

Nik Hartley, OBE
Chief Executive

This annual survey exists so we can find out what barriers stop you from living a fulfilled life.

Key Findings

Our survey covered three areas: physical health, mental health and daily life. We asked participants to tell us what their greatest concerns were across these principal areas.

The Body



Top physical health concerns

- 72% said bowel management
- 66% said bladder management
- 51% said pain management
- 33% said skin care and management including accessing information on pressure ulcers
- 28% said fitness and exercise
- 25% said ageing with a SCI

Many told us you worried about visiting a general hospital or care home as you feel staff are untrained in dealing with SCI patients.

The Mind



Top mental health concerns

- 46% said lack of access to counsellors and therapists who understand SCI
- 45% said lack of specialist rehabilitation support
- 41% said specifically anxiety or depression has impacted them
- 35% said lack of availability of services that support wheelchair provision or housing adaptations
- 34% said isolation or loneliness is a factor
- 30% said their self-confidence has been affected
- 28% said relationships have been impacted by their SCI

Daily Life



Top barriers to leading a fulfilled everyday life

- 92% said society's attitudes towards people with disabilities
- 89% said they were worried about adapting their homes to suit their needs
- 80% said they were concerned about locating and acquiring accessible housing
- 75% said access to employment is a barrier to leading an equal life
- 69% said funding their care needs with a further 62% saying accessing social care was a concern
- 65% said their eligibility for care was concerning
- 52% said standards of care was a worry for them
- 38% said access to wheelchair and mobility equipment is a concern

The Body



Access to specialist services. I am so fed up with physios or therapists telling me this is not their speciality. Although I have bowel problems, self-catheterise, and cannot walk far, I am not 'bad' enough to qualify for specialist services at a rehabilitation centre. I look 'normal' but I am at my wit's end trying to cope with managing to live without any support.

...several referrals were made to my local SCI specialist hospital. Unfortunately, I went under the radar for whatever reason and only had support from non-specialist community services, who at times were reluctant to even advise on my care needs in case they made my situation worse.

I'm concerned about the care and availability of care provided by spinal units and general hospitals. Over the past three years consultants and other staff are leaving and not being replaced - this concerns me more as I age.

General hospitals MUST train staff in the basic care of SCI. Bowel management is non-existent in a general hospital and this causes the most distress and danger to a spinal patient.



72%

Highlighted health professionals' lack of knowledge around bowel management as a concern

The Body



A lack of medical expertise

Lack of medical expertise outside of spinal cord injury centres continues to be a key issue for SCI patients. Respondents said they felt health care professionals in general hospital or care home settings have little or no experience of caring for someone with SCI or lack awareness of the specialist medical and social care needs of a SCI person .

Additionally, 20% of our respondents have suffered a pressure ulcer in the past year. Most of our respondents who experienced one (37%) said they had healed within six months but 20% of those affected by a pressure ulcer are still suffering more than 12 months later.

One SCI person told us they were currently, "On 24hr bed rest for a pressure sore so everything is impacted."

WHAT CHANGE IS NEEDED

- Access to appropriate health care from suitably qualified and trained health care professionals
- GP's and other health and social care professionals to have 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 and social care professionals recognising that SCI patients can be experts in their own condition



20%

Said they have suffered a pressure ulcer in the past year



The Mind



I would like to see the standard which people can be rehabilitated return to the expectations from when I was first injured. Rehab has become bowels, bladder, skin...out the door. What happened to sports, recreation, social interaction? No matter what level injury or impairment, the SCI community should be encouraged to socialise and live a fulfilled life.

Dealing with the sudden change from a healthy young parent to a disabled adult. Losing independence. Losing confidence in independent outings. Not having enough day-to-day care and support in parenting and self-care.

When coming out of hospital into the community my mental health deteriorated very quickly - so bad I had suicidal thoughts. Didn't know where to turn.

I'm still adjusting and learning to accept the new version of me. My relationship has been significantly impacted and therefore so much in my life has changed. It's been the hardest thing my family have ever had to deal with.



46%

Said having access to counsellors who understood spinal cord injuries, from the point of injury (and after discharge) is crucial

The Mind



A sense of isolation

Following last year's survey results and our subsequent 'It's Not Just Physical' report, this year we wanted to take a closer look into the wellbeing and mental health of survey participants by asking more in-depth questions around this area.

Feelings of isolation and loneliness experienced at the height of the Covid pandemic and during lockdowns have not drastically reduced. Last year, 38% said they'd experienced these feelings while this year, 34% told us they'd felt isolated or lonely. It's a minor reduction but is still a significant factor for more than a third of our respondents.

Last year almost half of respondents told us that poor mental health was a barrier preventing them from leading a fulfilled life, with many saying they could not access mental health support. Others told us that there was little support available for families of SCI people. This continues to be the case this year, with respondents reporting that issues around self-confidence, self-image, Post Traumatic Stress Disorder (PTSD), access to specific and general mental health services and relationships continue to have an impact on their lives.

WHAT CHANGE IS NEEDED

- Access to psychological support at the point of injury and rehabilitation
- Ongoing counselling and mental health support offered to all after hospital/spinal centre discharge
- Mental health support to be made available to the families of SCI people
- Training for mental health and general health service professionals to ensure a better understanding of the psychological issues faced by SCI people



**Told us that they'd
felt isolated or lonely**

Daily Life



Very hard to do many activities as a family. Any trip requires a lot of planning and in most cases more money.

Getting into friends' and family's homes - I cannot get into any of my relatives' homes and only three friends' houses.

More access to affordable adapted housing and to specialist services for SCI people.

My work life vanished overnight; it has taken me 15 years to get to the point of being self-employed. I couldn't find a job that fitted my disability, so I created my own!

Knowledge and attitude to spinal injury in the general public and general hospitals is still (after 15 years injured) absolutely shocking. There seems to be no support from healthcare professionals, social workers, care companies or any personal assistants to name a few without having to fight more than ever before...I would love to see especially the newly injured get information and be better informed on the world they face now, and myself and others treated and helped without having to create a storm to be heard.



92%

Said the public's attitude towards people with disabilities is one of the greatest barriers they face

Daily Life



Financial fears, employment anxiety and wheelchair woes

Financial fears, employment anxiety and wheelchair concerns continue to affect our community. When we asked our participants what barriers prevented them from leading a fulfilled life, we were told about everything from concerns around accessing benefits and being assessed for care eligibility, the cost of living with a disability, wheelchair, and equipment provision to getting out and about and other peoples' unhelpful attitudes to people with a disability.

The challenges of simply getting around remain a problem area, with 68% to 95% of respondents reporting issues with access to the outdoors/countryside, parking, shopping, hotels, leisure, public transport, air travel and blue badge schemes. Care standards, eligibility for funding and access to paid carers again remain issues for our community too in addition to financial concerns about paying for home adaptations, carers and a lack of accessible housing being available.

➔ WHAT CHANGE IS NEEDED

- Social care that provides for SCI people's ongoing needs
- Care support that is built around and reflects the SCI person's needs
- A house that has been adapted to make it safe to live in
- Wheelchair or mobility aids that are fit for purpose
- A job that reflects their skills, experience, and aspirations
- Health and leisure opportunities and access to outdoor spaces
- A decent standard of living and a valued place in society



95%

Of respondents reporting issues with access to the outdoors/countryside, parking, shopping, hotels, leisure, public transport, air travel and blue badge schemes.



The Report

Methodology

The survey was sent out via Survey Monkey and was open for four weeks in March 2022. It was publicised widely to both our membership and the wider SCI community as well as to partner organisations and across social media.

Appendix

Core Survey Questions

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| <p>Q1. To help us understand what really matters to SCI people, please choose the five issues which have the biggest impact on SCI peoples' lives?</p> <p>Q2. Have you had a pressure ulcer in the last 12 months?
- Please share the severity or grade of this if known.
- How long did this take to heal?</p> <p>Q3. To help us understand what really matters to SCI people, please choose the five issues which have the biggest impact on SCI people's mental wellbeing and happiness.</p> <p>Q4. Employment, education, and vocational activities. Please indicate below how much impact you feel your SCI has had on access to the following.</p> <p>Q5. Finance, benefits and legal services. Please indicate below how much impact you feel your SCI has had on access to the following.</p> <p>Q6. Housing matters. Do you think that having a SCI impacts on the following?</p> <p>Q7. Getting around. Please indicate below how much impact you feel your SCI has had on access to the following.</p> | <p>Q8. Care and support. Please indicate below how much impact you feel your SCI has had on access to the following.</p> <p>Q9. Attitudes towards disabled people. Do you think that having a SCI impacts on the following?</p> <p>Q10. Access to buildings, services, and leisure. Please indicate below how much impact you feel your SCI has had on access to the following?</p> <p>Q11. 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 see take place in the future.</p> <p>Q12. What was (or still is) the impact on your life considering your ability to work, your family life and/or your mental health?</p> <p>Q13. We really would like to know what SCI people would like from SIA; what can we do to help you and other SCI people live a fulfilled life?</p> |
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Acknowledgements

The data and comments included in this report were collated from the 586 qualitative and quantitative responses we received to our 'What Matters?' survey made by people with a SCI. 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; SIA will continue to listen to everyone affected by a spinal cord injury, to better understand the issues they face and to continue directing our invaluable support in the best possible ways.

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