

WHAT MATTERS

A report on what really matters to
spinal cord injured people in the UK today



Introduction

This report was undertaken by the Spinal Injuries Association (SIA) to ascertain the main concerns of spinal cord injured (SCI) people living in the UK today. Our findings provide a snapshot of the experiences of the country's SCI community.

We asked our members to share their opinions and experiences about what obstacles get in the way of them leading a fulfilled life. A total of 476 SCI people completed an extensive survey, and 40 SCI people followed up, sharing their thoughts with us during focus group sessions held online during summer 2021.

The findings of this report will be used to build and refine programmes and campaigns to support and raise the voice of all SCI people across the UK. It is only the beginning of increasing our dialogue and collaboration with the SCI community to improve our ability to be the representative body our members demand and deserve.



476 SCI people completed an extensive survey



Executive Summary

We were tempted to pause on this survey as the pandemic took hold, but in fact when we spoke to our members it became clear it was exactly what we needed to do – as the pandemic has not just affected but exposed so many much longer-term barriers to SCI people day in day out.



The most striking point the survey and focus groups has revealed is, whatever the subject it comes down to a **lack of access**; to services, to medical expertise, to mental health support, to information, to physiotherapy.

Even the most fundamental health priorities - bowel and

bladder management - important to almost all respondents, shockingly found 40% of people telling us their GP didn't understand bowel management.

We heard that access to **mental health support** was hugely important, especially during lockdown, yet nearly half the people surveyed told us they found it difficult to access any support at all. Some told us they felt abandoned. The strength of response to mental health has in fact been so strong, we have made a commitment not to wait for our longer-term plan and outcomes but to rapidly work out how to both expand our own professional peer-led counselling service but also to build a mental advocacy offering and crucially launch research to lobby for change. Watch this space.

Perhaps most startling was how many voiced their fears about ever **going to hospital** and being cared for by medical professionals with little or no SCI specific knowledge. Almost half the respondents told of general health services not understanding the clear and present danger of pressure ulcers as an SCI person.

Less surprisingly, more than half of the respondents told us they felt lack of access to **employment** was a major obstacle to living a fulfilled life, and yet the stand-out was **care** - over 70% told us a lack of access to **social care** was their biggest worry.

This lack of access to the fundamental social, support and health services that you will read throughout this document – is a tough read for anyone who cares. It exposes the gaping valley between what people without an SCI or disability would take for granted – and what someone with an SCI should simply not have to face.

Covid has clearly had a detrimental impact on our community with, amongst other things, a lack of guidance on shielding, the repurposing of specialist spinal cord injury centre beds, an inability to access GPs and care workers, and confusion about vaccination status and priority.

But the messages you will read confirms things have got to change well beyond the pandemic. Using this research as our foundation and catalyst for change, SIA commits to a) re-double its services in the key 'body, mind and life' issues that you have told us about, and b) as crucially to build more research, advocacy and campaigning around each to fight for the changes that the SCI community so desperately needs.

Nik Hartley OBE
Chief Executive

Key Findings

The survey covered three areas: physical health, mental health, daily life. When we asked SCI people what their main concerns in life were, we heard:

The Body



Top physical concerns

- 77% said bowel management
- 75% said bladder management
- 46% said pain management
- 40% said ageing with an SCI and skin management, including accessing information on pressure ulcers

The Mind



Top mental health concerns

- 42% said having access to therapists who understand SCI
- 38% said lockdown had given them a sense of isolation and/or poor self-confidence
- 25% said lockdown had made developing and/or maintaining a personal relationship difficult

Daily Life



Top barriers to leading a fulfilled everyday life

- 70% said funding their care needs and accessing social care were their biggest concerns
- 55% said access to employment is their biggest barrier to leading an equal life
- 44% said they believe the public is the biggest barrier regarding society's attitudes about people with disabilities
- 40% said they were worried about adapting their home for their needs
- 25% said their eligibility for care was a major concern
- 22% said access to wheelchair and mobility equipment is their biggest concern

The Body

My GP didn't know anything about bowel irrigation system and the surgery nurse's attitude was she can take laxatives and do manual removals, which I have been doing for the last three years, and apart from the fact it's degrading. Professional ignorance astounds me no end.

I have spent 60 years managing my SCI with very little help or advice from a GP or hospital. My condition is much worse with age, and the splints that were made for me are disgusting.

I have anxiety about becoming unwell and needing to rely on community or local health care professionals who have no knowledge of SCI and are often unwilling to listen to concerns. For example, being told in A&E that an increase in blood pressure is due to stress and dismissing concerns about autonomic dysreflexia* without even knowing what it is.

Physiotherapy costs a fortune and now reduced to living on benefits it is not accessible for me.



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

*a potentially fatal condition

The Body

Fear and lack of specific medical expertise

GPs play a key role in connecting SCI patients to specialist medical and social care, yet with relatively few instances SCI it can mean that some doctors have never had the experience of caring for an SCI patient.

Many of our respondents voiced their fears over what might happen should they need to be cared for in a general hospital or care home where staff were not sufficiently trained or experienced in caring for the specific medical needs of people with an SCI.

Top physical health concerns

77% lack of health professionals' knowledge of bowel management

75% lack of health professionals' knowledge of bladder management

46% pain management

40% ageing with an SCI and skin management

Urgent change needed

To help improve the long-term physical health of SCI people, we need to urgently upscale, research and campaign for:

- Access to appropriate health care from suitably qualified and trained health care professionals
- GPs and hospital medical staff to be made aware of the clinical implications of spinal cord injury
- Access to regular physiotherapy and rehabilitation following injury
- Access to good patient educational resources to help with self-management
- Healthcare professionals to listen and recognise that SCI patients can be expert in their own condition



Listed pain management as a concern



The Mind

“ I’ve been quadriplegic for 32 years following a horse-riding accident. Ever since then I’ve just been abandoned and left to get on with my life. I believe there should be more help for SCI people after injury.

“ I could have used some one-to-one counselling in the first few years of SCI to help build my knowledge and self-confidence.

“ I would think having the right psychological help would be the key to creating “a life” after leaving the hospital.

“ I would like easier access to physio needs and speedier access to specialist spinal injury mental health help.



42%

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

The Mind

A sense of isolation

It's widely accepted that the Covid pandemic and periods of lockdown have made a significant, negative impact on the nation's mental health – but within the SCI community it has clearly been exponential.

Almost half our respondents told us that poor mental health was one of the biggest barriers preventing them leading a fulfilled life, with so many telling us they couldn't access mental health support. Others told us there was also very little mental health support available for the families of SCI people. Many told us that lockdown had simply isolated them further, with even less or no access to health care or support workers.

Urgent change needed

To help improve the mental health of SCI people we need to urgently upscale, research and campaign for:

- 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 a better understanding by general mental health professionals of the psychological issues faced by SCI people

Top mental health concerns

42% said having access to counsellors who understood spinal cord injuries, from the point of injury (and after discharge) are crucial

38% said lockdown had given them a sense of isolation and/or poor self-confidence

38% said lack of access to mental health support made them feel isolated

25% said lockdown had made developing or maintaining a personal relationship more difficult



Said lockdown had given them a sense of isolation and/or poor self-confidence



Daily Life

“ The benefits process was degrading and confusing... all the stress contributed to a major deterioration in my physical and mental health.

“ Means-testing assumes you will only need care for me a short while, not the 70 years it might realistically be for me. I'm using family as carers so I won't decimate the family finances.

“ Pavements with cambers and holes and kerbs are a nightmare, and in many instances pavements and walkways are not suitable for wheelchair users.

“ The impact of fewer carers being available to work during the pandemic, together with the worry that anyone who comes in close contact with you could potentially give you the infection.

“ There's been an unacceptable turnover of carers supplied by the care agency allocated by my continuing health care package. We have two full-time live-in carers and have had a total of 30 different people during the one year since my discharge from the spinal unit.



Said access to employment is the biggest barrier to leading an equal life

Daily Life

Financial fears, employment anxiety and wheelchair woes

We asked our community what barriers prevent them from leading a fulfilled life. Their answers covered everything from fears about accessing benefits, to wasting money, to wheelchair provision and other people’s unhelpful attitudes to people with disabilities.

Eligibility for NHS care packages was highlighted as a primary concern for many, while others voiced their fears about financial hardship caused by paying for a lifetime need for carers, wheelchairs and home adaptations.

Over half our respondents cited limited access to employment as their biggest barrier to leading an equal life. One SCI person told us, “I feel worthless and on the scrapheap since my injury five years ago. I don’t fit in anymore. I’d like some kind of employment scheme, but now due to Covid redundancies there will be even less chance of gaining employment.”

Others spoke of their worries about the attitude of the general public, with one person telling us, “Some shop assistants need training regards speaking to the person in the wheelchair, not the person stood next to them”.

Access to transport also came through clearly as an area of worry, ranging from the funding of mobility needs, public transport, accessible parking, the Motability scheme and air travel.



Said funding their care needs, accessing benefits and accessing social care support are their biggest concern

Biggest barriers to leading a fulfilled life:

70% said funding their care needs, accessing benefits and accessing social care support are their biggest concern

55% said access to employment is the biggest barrier to leading an equal life

44% said that the public remain the biggest barrier regarding societal attitudes about disabled people

40% said they were worried about adapting their home for their needs, post-injury

25% said their eligibility for NHS continuing health care and care packages was a major concern

22% said access to wheelchair and mobility equipment is their biggest worry

Urgent change needed

To help SCI people have access to all the things that ‘level the playing field’ with able-bodied people, and which enable them to lead a fulfilled and happy life, we need to urgently upscale, research and campaign for:

- Healthcare that provides for SCI people’s ongoing needs.
- Care support that is built around and reflects the SCI person’s needs.
- A house that’s 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.



The report

Methodology

The survey was sent via SurveyMonkey to 6,871 members of SIA, from 11 March - 30 April 2021. 476 members completed the survey. 40 members of SIA took part in online focus groups in May and July 2021.

Appendix

Core Survey Questions

- 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.
- Q2. To help us understand what really matters to SCI people, please choose the four issues which have the biggest impact on SCI peoples' mental wellbeing and happiness.
- Q3. Please consider each of the key areas below and select your top three.
- Q4. Employment, education & vocational activities. Select one issue from the list below where access to this service or life opportunity has either been a significant issue for you, or where you believe there must be change if SCI people are to live truly independent, more equitable lives.
- Q5. Finance, benefits & legal services. Select one issue from the list below where access to this service or life opportunity has either been a significant issue for you, or where you believe there must be change if SCI people are to live truly independent, more equitable lives.
- Q6. Housing matters. Select one issue from the list below where access to this service or life opportunity has either been a significant issue for you, or where you believe there must be change if SCI people are to live truly independent, more equitable lives.
- Q7. Getting around. Select one issue from the list below where access to this service or life opportunity has either been a significant issue for you, or where you believe there must be change if SCI people are to live truly independent, more equitable lives.
- Q8. Care & support. Select one issue from the list below where access to this service or life opportunity has either been a significant issue for you, or where you believe there must be change if SCI people are to live truly independent, more equitable lives.
- Q9. Attitudes towards disabled people. Select one issue from the list below where access to this service or life opportunity has either been a significant issue for you, or where you believe there must be change if SCI people are to live truly independent, more equitable lives.
- Q10. Access to buildings, services and leisure. Select one issue from the list below where access to this service or life opportunity has either been a significant issue for you, or where you believe there must be change if SCI people are to live truly independent, more equitable lives.
- Q11. Brexit-related issues. Select one issue from the list below where access to this service or life opportunity has either been a significant issue for you, or where you believe there must be change if SCI people are to live truly independent, more equitable lives.
- Q12. Impact of the Coronavirus Pandemic. Please state what the Coronavirus pandemic, and the response to the pandemic, has revealed about treatment, support and barriers faced by SCI people in the UK.
- Q13. Body, Mind and Life. This is where we want to be clear about the one issue that matters to you the most or you feel is the top priority to be fixed. Please expand or clarify any of your answers above to explain in more detail about any one issue, and what changes or improvements you would like to see take place in the future.

Acknowledgements

The data and comments included in this report were collated from the 476 qualitative and quantitative responses we received to our 'What Matters?' survey. We would like to thank everyone who completed the survey, and also those people who were randomly selected to take part in the subsequent round of Focus Groups and contributed their time and observations 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 understand the issues they face and so we can continue to direct our invaluable support in the best possible ways.

Spinal Injuries Association

SIA House, 2 Trueman Place,

Milton Keynes, MK6 2HH

Tel: 01908 604 191

Freephone support line: 0800 980 0501

sia@spinal.co.uk

spinal.co.uk

 @spinalinjuries  Spinal Injuries Association  Spinal Injuries Association