

# IT'S NOT JUST PHYSICAL

A report putting a spotlight on the mental health of people with spinal cord injuries





# Introduction

This report was undertaken by the Spinal Injuries Association (SIA), the University of Reading and the University of Buckingham to examine the mental health of spinal cord injured (SCI) people, and to identify gaps in mental health support for them and their unpaid carers in the UK.

More than 300 members shared their views on the mental health support they receive, with a focus on depression and post-traumatic stress disorder. A further 16 unpaid carers - partners and parents - took part in interviews to gain a full picture of the services received.



IT'S NOT JUST  
**PHYSICAL**

## Executive Summary

It's really not just physical. The findings of this seminal research is a wake-up call for the NHS, healthcare planners and policymakers to provide better mental health support services for SCI people - and their unpaid carers - as a matter of urgency.



We heard that SCI people are leading unnecessarily miserable lives because they have no access to the mental health support they so desperately need.

Perhaps most alarming of all, the findings reveal that a person with a spinal cord injury is three times more likely to consider suicide than a person without injury. We found 28% of SCI people reported having had suicidal thoughts, compared to just 8% among the rest of the population. And that half of the participants have had mental health struggles.

Spinal cord injury is so much more than a raft of physical conditions; in very many cases, sustaining a spinal cord injury causes mental health problems too. The psychological damage caused by a spinal cord injury is, at best, considered as an afterthought, and at worst, completely ignored by the medical profession.

Continuous pain, anxiety around leaving the home because of bladder and bowel management problems and struggling to grasp the enormity of a life-changing injury were all common themes expressed by our members and their families.

So, what can be done?

This in depth research examined the mental health concerns of a significant sample of SCI people and their unpaid carers and recommends actions for the NHS to progress.

Here at SIA, we have committed to immediately expanding our existing spinal cord injury-led counselling service, and we will be commissioning further research into therapies and interventions to build up the clear lack of specialist mental health interventions found by the research. And as importantly, our advocacy team will focus on increasing its capacity to fight for better mental health support for the increasing numbers of SCI people and their families asking for our help.

Above all, this report shows that for too long, spinal cord injury has been dealt with almost entirely through the lens of the physical condition by healthcare planners and policy-makers, while the reality emerging from this research reveals the massive and underserved mental health needs experienced by so many of our members and their families..

Allowing SCI people to suffer from often treatable psychological conditions is totally unacceptable. Change must happen and must happen now.

**Nik Hartley OBE**  
Chief Executive



# Key Findings

The report reveals that a person with a spinal cord injury is three times more likely to consider suicide than a person without injury. When we asked SCI people about their mental health, we heard:

**28%**

reported having suicidal thoughts; three times higher than the rest of the UK population

**47%**

reported experiencing mental health problems in one or more of the assessed mental health conditions

**68%**

of those that had successfully accessed standard mental health services, withdrew themselves from treatment early without experiencing any gains or resolving their mental health difficulties, with some finding services worsened their issues.

## Mental health problem prevalence among SCI people v non-injured people



### Suicidal thoughts

8%

28%

### Moderate depression

17%

40%

### Moderate anxiety

21%

26%

### Post-traumatic stress disorder

4%

34%

SCI people

Rest of population

# We heard

When you realise there's no one there to help you if you fall, or if you cut yourself, or if you get an infection, you've got to sort yourself out. That's when the mental struggle begins, I think. And that really hit me.

Toby, 37, complete paraplegia

You get put in positions that make you feel completely helpless. And for me, that's the biggest trigger. I can sort of accept that my life is how it is, I'm in a chair, and I'm not gonna climb a spiral staircase. But what I find very difficult to accept is that feeling of helplessness.

John, 47, complete tetraplegia

They sent a mental health team round to my house. And there's a pair of them sat on the sofa and they discussed it, and they basically left it at: 'Oh, there's nothing we can do for you, we don't know about spinal injuries, sorry'. It's not what you want to hear when I needed help at that point.

Scully, 47, complete tetraplegia



reported having suicidal thoughts; three times higher than the rest of the UK population

# Factors affecting mental health

The key factors that led to the most common mental health problems experienced by SCI people - depression, anxiety and post-traumatic stress (PTSD) - were ongoing pain, being of low socio-economic status and having an existing mental health diagnosis, pre-injury. The length of time between requesting and getting mental health support was another key factor.

## Pain

72% said they were currently in pain. On a scale of 1 to 100, where 0 represents no pain at all and 100 represents the worst pain imaginable, 67% of participants told us they experienced pain intensity of more than 50.



## Injury type

There was a difference in the level of depression and anxiety experienced by those with a complete or incomplete injury. The research showed that people with an incomplete spinal cord injury were more at risk of developing depression and anxiety.



## Socio-economic factors

SCI people with a lower level of education, income and overall standard of living were highlighted as having worse mental health than those with higher levels.



## Pre-existing mental health conditions

21% of our participants had a mental health diagnosis before injury. They were more likely to suffer from depression, anxiety or PTSD, and significantly more likely to have suicidal thoughts post injury than those who had no history of mental health.



I was told it would be six months or more, when I put my name down. The problem is, you don't want it tomorrow, next week, or a month away. I know it's not possible, but you need it now at that point, where you can't get out of that dip. You're constantly crying, and you try and try again. And then, you just go deeper in. And literally, there's no way out. I can honestly say, if I could kill myself I would. I don't have an issue with that.

Rachel, 68, complete tetraplegia



12 weeks isn't good enough, someone could take their own life in 12 weeks. Somebody could be a lot worse in 12 weeks and it needs to be done now, people need me to access things now.

David, 52, complete paraplegia



of our participants  
had a mental health  
diagnosis before injury.



# Carers and their mental health

The report identified that the unpaid carers - usually the partner or parent of the injured person - desperately need their mental wellbeing supported too. From the partners and family members in the interviews, we heard:

<p><b>100%</b> felt they lacked knowledge and understanding of spinal cord injury</p>		<p><b>81%</b> felt a shared sense of trauma with their injured family member</p>
	<p><b>80%</b> felt unsupported by the NHS during period of hospital discharge</p>	
<p><b>75%</b> felt their own mental health needs had been side-lined</p>		<p><b>75%</b> masked their own mental health issues in front of their injured family member</p>

# We heard

At the beginning of his spinal injury, it (suicidal thoughts) happened two days into his injury, I felt the same. How will I cope with this? I can't cope with it. And actually, selfishly, probably my first thoughts were 'now I can't kill myself' because I'm his only support, and that was a very scary place to be.

Kate, 66, spouse

The first one (comment on a support group) resonated with me. It was like "the best place to cry all day is in the shower, you can hide in the shower." And then there was like 50 comments going 'Yeah, we all cry in the shower' and I cried, that's why I read it.

Lucy, 54, Spouse

I know that I need to look after myself in order to be able to look after (person with spinal cord injury). But it's just so hard to do that. I don't feel able to do that when the whole time it's about focusing on the person you're looking after, and everyone else is focusing on them. So, we usually tend to put yourself at the end of the list, I suppose. I think I would ask for more help if I felt that there was sort of a better understanding of what I'm struggling with.

Alice, 60, spouse

**47%** reported experiencing mental health problems in one or more of the assessed mental health conditions



# Interventions and a way forward

There is so much that could be done to help the spinal cord injury community and their carers.

## Policy Demands

Based on the findings of the research, we are calling for the NHS, healthcare planners and policymakers to provide:

1. Access to much more and more appropriate psychological support for SCI people at all stages of their post injury journey: immediately following injury; when they are discharged from hospital to another care setting or to their home; and for the rest of their lives
2. Newly-injured people must be screened for pre-existing mental health issues
3. A full risk assessment must be carried out before a SCI person moves from a care setting (hospital, nursing home, care home) into their own home

4. Medical staff supporting SCI people with their mental health must also understand how their physical problems can impact their mental health, and be trained accordingly in bladder, bowel, skin and pain management.



**SCI people received 375 counselling sessions from our BACP-qualified counsellor**

## SIA Commitments

Based on the findings of this report, SIA will:

1. Increase its specialist counselling service to provide triage and one-to-one support (online or by phone.)

SIA currently employs one BACP-qualified counsellor. Our counsellor, Ian Younghusband, is spinal cord injured, and has been tetraplegic since 1998. In his first year, he provided counselling for 57 SCI people, via 375 sessions.

The service is currently available four days a week. Our initial ambition is for more qualified counsellors to be available to support SCI people five days a week.

2. Create a bursary scheme to encourage SCI people to qualify as counsellors and join our team. The success of our first peer-led counselling service shows that service users truly appreciate being helped by someone who understands what they are experiencing.

The scheme will run a pilot programme to develop a cohort of trainee counsellors to support calls to our national helpline, as part of their 100 hours of practice requirement.

3. Offer more mental health support for the family and friends of SCI people, expanding it to include peer support and regional support networks as part of the follow up from counselling.

4. Help more SCI people and their families get access to mental health support from the NHS, healthcare planners and policymakers. A mental health advocacy worker will act as a voice for SCI people and their families when needed, and be able to recommend useful organisations, advice lines and other resources.

5. Commission further research into testing interventions which will help SCI people manage their mental health symptoms. These include cognitive behavioural therapy, eye-movement desensitisation processing, acceptance and commitment therapy and mindfulness.

## Client feedback on our counselling service

Being able to talk to someone with a spinal injury means there is real understanding of our struggles.

Having a person who has a spinal cord injury to help me navigate my feelings and priorities not only challenges my thoughts and behaviours, but also provides me with personal insights into handling similar situations.

The compassion and understanding from my counsellor, who had first-hand knowledge of what I was going through, was so beneficial. It was helpful to speak to somebody who understood exactly what I was going through and how I felt – because they had gone through it themselves. It was reassuring to know that I was understood. I felt as though Ian knew completely what I was feeling.



### Methodology

318 people with a spinal cord injury completed the online survey, Spring 2021

166 female, 148 male, 1 non-binary

Age range: 18 - 85. Mean average age: 53

16 carers of people with a spinal cord injury participated in interviews

39 charities participated in the literature audit

### Research authors:

Dr Katherine Finlay: Project Lead, Lecturer in Psychology, University of Reading;

Katherine.finlay@reading.ac.uk

Dr Margaret Tilley: Co-Investigator, Lecturer in Psychology, University of Buckingham;

Margaret.tilley@buckingham.ac.uk

### Research assistants:

Phoebe Brook-Rowland: Tenured Research Assistant, University of Reading;

p.i.brook-rowland@reading.ac.uk

Louisa Dosanjh: Voluntary Research Assistant, University of Reading

Adam Madhani: Voluntary Research Assistant, University College London

Suzanna Miles: Voluntary Research Assistant, University of Bath

### 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