

## Summary

- > People are not alone in their issues and perceptions of ageing with an SCI.
- > More should be done to encourage healthy lifestyles to lower the risk of many health problems.
- > SCI people's perception of health is a fair reflection of their actual health status.
- > Perception of health is not determined by level of injury.
- > It is more important to consider how long you have been injured rather than your age.
- > Men and Women have similar experiences with SCI but differ in the care they require and their health priorities.
- > SCI people are worried about the impact of ageing on themselves and their carer.
- > Where you were initially treated for your SCI has a significant impact on your health and perception of health.
- > Treatment at an SCI Centre helps you to age well.

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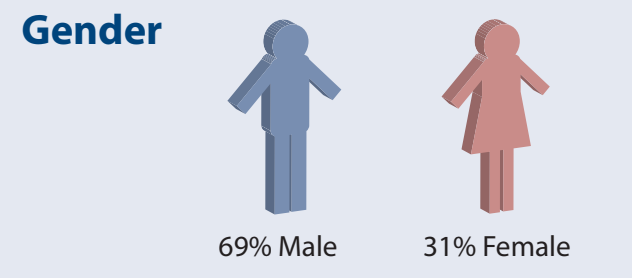
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# Spinal Injuries Association Survey on Ageing with a Spinal Cord Injury

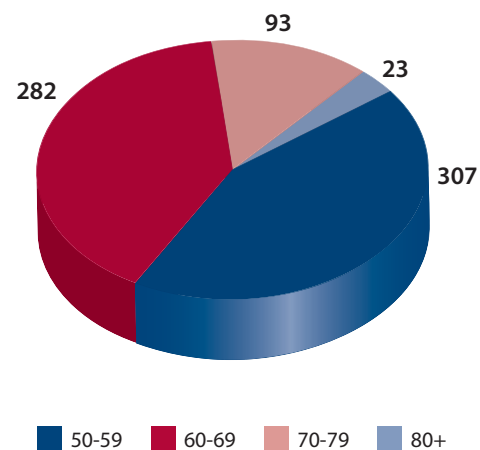
The Spinal Injuries Association (SIA) is a UK member based, user led charity. SIA members were invited to respond to the Ageing with a Spinal Cord Injury (SCI) Survey as part of the Big Lottery funded Ageing Well Project.

This survey was designed to collect important health and social information from SIA members and others on ageing with SCI. Many have generously shared their experiences – over 700 in all.

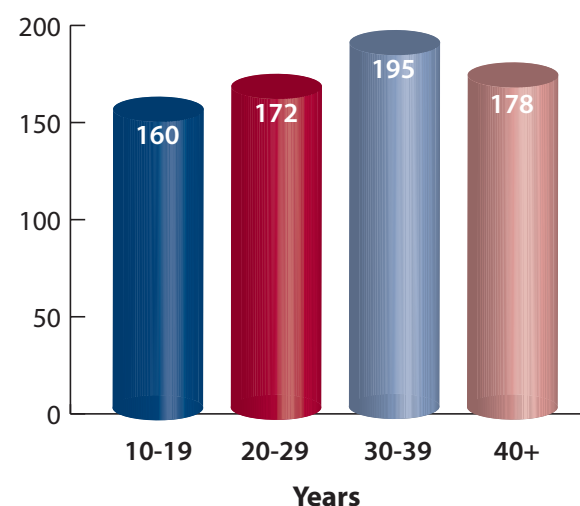
## A snapshot of those who completed the survey



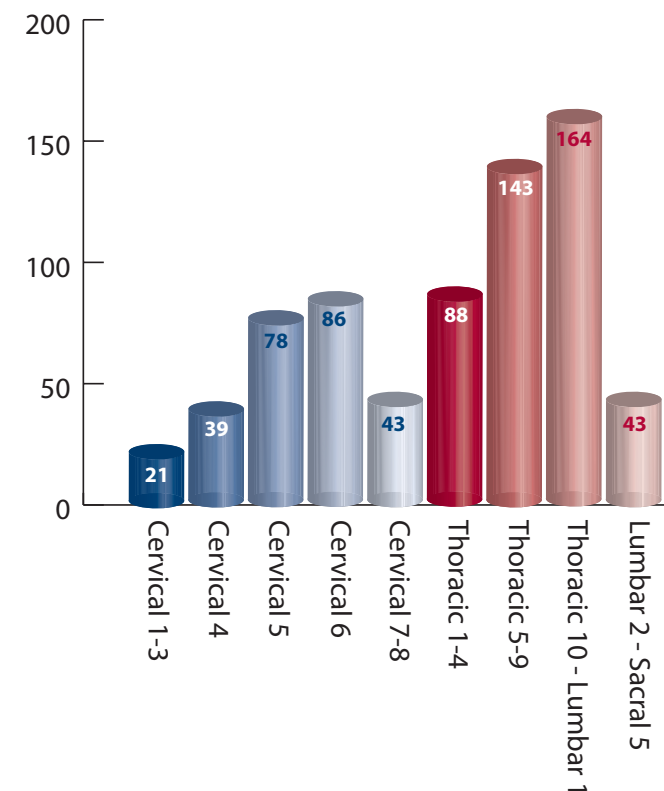
### Age Range in Years



### How Long Since Injury



### Level of Injury

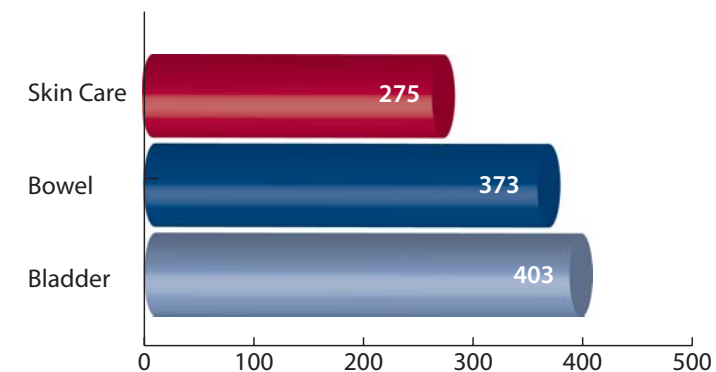


*“My wife says that my paraplegia has catapulted us both straight into old age and all the problems thereof.”*

### Type of Injury

Complete	60%
Incomplete	40%

### The Top Three Health Priorities



### The Health Issue most people experience increasing difficulty with

- > Over the past 10 years 54% reported increasing difficulty with shoulder and wrist movement.

*“I noticed in the last 10 yrs – increased shoulder and elbow pain, making lifting and transfers more difficult.”*



### KEY FINDINGS:

You are not alone in your experiences – many are similar in age; time since injury; level and type of injury and in health experiences of SCI.

More should be done to encourage healthy lifestyles to lower the risk of many health problems.

### Lifestyle

- > Over half of respondents are retired (54%).
- > Most live with a husband, wife or partner (64%).
- > Whilst many live alone (24%).
- > 22% are never involved in active exercise with a further 10% engaging in active exercise less than once a week.
- > 65% never have passive exercise with a further 7% engaged in passive exercise less than once a week.
- > Many respondents are not eating 3 meals a day regularly (29%).
- > Most respondents never or only sometimes achieve the recommended 3 servings of dairy food a day (77%).
- > Only 18.9% of SCI people always eat 5 portions of fruit and vegetables per day with 10.5% never achieving this.
- > In the general population 32% of men and 34% of women aged 55-64 years, include at least 5 portions of fruit and vegetables per day. (National UK Statistics 2006).

## As Time Goes By

As the length of time since injury increases, more people experience health problems such as weight increase, spasms, pain, urinary tract infections and skin problems.

The length of time a person has lived with an SCI has a significant impact on increasing care needs for daily tasks (tasks include transferring in and out of bed/car; wheelchair propulsion; personal tasks such as hygiene, eating and dressing).

Interestingly, a person's chronological age did not have the same significant impact on health problems.

## Health Perception



*“Getting older with SCI is worrying – it’s not going to be as easy to transfer and get around as we have been doing. I already have arthritis in my hands that are used a great deal and take a lot of weight! My husband gets aches and pains and gets tired. We don’t want to be a burden to our family.”*

**KEY FINDINGS:**  
It is more important to consider how long you have been injured rather than your age.

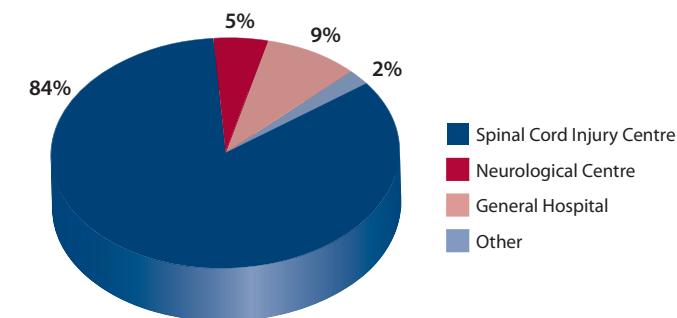
Health perception is a fair reflection of health status.

The majority of people consider themselves to be in ‘good’ or ‘very good’ health (63.8%).

Level of injury did not significantly affect people’s perception of their health status. SCI people’s perception of health is actually a fair reflection of their health status.

## Location Location!

Location of Treatment



The initial location of treatment after injury has a significant effect on SCI people’s perception of health status. If you were initially treated in an SCI Centre, you are more likely to have a positive health outlook.

People report more problems with spasm, pain, urinary tract infections and skin care if they are not treated in an SCI Centre. Conversely, there are less reported difficulties with mood changes, sleep patterns, appetite, posture, circulation, breathing, intolerance to medications, bladder, bowel, shoulder or wrist movement and libido (sexual desire) if treated initially in an SCI Centre. For example:

Over the last ten years...	SCI Centre Treated	District General Hospital Treated
Increase in pain	49.7%	73.5%
Increase in Urinary Tract Infections.	32.3%	50%

*“Re-admission to a spinal hospital (centre) is almost impossible and most general hospitals haven’t got a clue.”*

45.6% of people attend an SCI specific medical check-up at least annually. Only 22.6% of the District General Hospital treated group go for SCI specific medical checkups at least annually.

*“I feel everybody should be able to attend a Spinal Unit for regular checkups. I have found General Hospitals seem unable to cope with the needs of older SCI people.”*

*“Whilst it is desirable for each SCI person to receive an annual review of their SCI, the provision of, or access to, sufficient staff, equipment and screening resources may mean that this is not always possible.”*

Managing SCI in the Community, 2007, page 69.

74.3% of respondents attend an SCI Centre for SCI specific medical check-ups but only 23% of the DGH group do so. Also, more from this group never attend a check-up (29.3% vs. 10.6%). Some of the reasons given include:

*“because it has never been proposed... by my GP or anyone else.”*

*“the effort, the distances, the pain afterwards.”*

*“Nowhere to go...my GP is no good for SCI.”*



*“The local health authority would not refer unless there was a specific SCI medical problem. The concept of having regular SCI MOT’s and ongoing aftercare for years is lost on them.”*

**KEY FINDINGS:**  
Where you were treated following your SCI has a significant impact on your health and your perception of health.

Treatment at an SCI Centre helps you to age well.

## Mars vs Venus

Men and women have similar perceptions of their health status.

*“I wonder who will last the longest – him or me.”*

The main difference between the sexes was found to be in care requirements. Women need less assistance than men with activities such as transferring out of car/bed and wheelchair propulsion. This begs the questions, do men deteriorate quicker or are they just needier?

The health priorities of women differ slightly from men. Their top three include weight management (37%), although Bladder (57.6%) and Bowel (55.2%) still rate highly as health priorities.

**KEY FINDINGS:**  
Men and Women have similar experiences with SCI but differ in the care they require and their health priorities.

## The Social Impact of Ageing on SCI People and their Carers

A few of the respondents identify that they are *“in good health and both happy.”*

or suffer *“no long-term problems.”*

This signifies that they appear to be dealing with the prevailing condition well as a couple. Others go further to explain how the experience of dealing with adversity has made their relationship stronger and a greater appreciation of what life has to offer.

One respondent identified that *“...she (my wife) is my rock...”*

another stated that *“...my husband is fit and well, pushing my wheelchair keeps him fit.”*

and another mentioned that *“we have become closer despite everything.”*

A lot of other positive responses discuss a capable current state but hold reservations for the future. Comments include:

*“My husband is very fit and willing to look after me...I am completely dependent on him being well. This could mean we should plan for an alternative way of coping.”*

and *“...I am in reasonably good health and am able to look after my husband... long may it continue.”*

## Concerns

*“tiredness, arthritis...concerns about future care as we grow older.”*

*“as he (husband) gets older, certain activities get harder.”*

and *“my wife is my main carer and as she gets older she suffers pain in her joints and gets more tired.”*

Also comments like *“...we will need outside help, perhaps within the next 5 years.”*

Many make bland reference to age such as *“I live with my father who is an OAP at 74.”*

*“...my husband is 83...”*

*“(my) wife (is) not as active as 10 years ago.”*

and *“my wife...feeling plain tired...is 69 years old.”*

To causal impact

*“Has affected wife’s health quite a lot. Now has mobility problems of her own.”*

To the extent that some respondents indicate *“...my husband and I separated 15 years ago. He had a mental health crisis.”*

*“My partner left me in 1995.”*

*“Divorced.”*

*“Now separated.”*

and *“It has become very detrimental over time, aggravated by financial restraints.”*

The strain includes *“it causes us to get tired, frustrated and sometimes irritable...”*

*“visiting friends and relatives is difficult or impossible.”*

and *“the main area affected is spontaneity... restrictions you face and the need to plan...”*

Also *“know he’s trying to look after me, but sometimes I get frustrated and want him to go out so I can get on with things I want to do.”*

and *“we are now unable to go on holidays together, so my wife has to go on her own for a break.”*

*“My partner took early retirement to care for me; some days I think I am just a burden to everyone.”*