



# Fulfilled Lives

SIA Strategic Plan 2017-2022



**sia** spinal  
injuries  
association  
FOR LIFE AFTER SPINAL CORD INJURY

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**Evidence Driven  
User-led Passion  
Expert Commitment  
Targeted Impact**



## Fulfilled Lives is SIA's strategy for the next five years.

**It sets out the work we will do to achieve the vision of fulfilled lives after spinal cord injury (SCI) and the objectives that will shape our services, governance and income generation.**

It is driven by the evidence of spinal cord injured people and healthcare professionals, our forty-three years of experience, and a commitment to developing expertise in spinal cord injury.

We have spent the last nine months listening to spinal cord injured people and analysing the challenges they face.

- **Our staff listened to over 1,000 SCI people as they delivered direct support.**
- **Our SCI Nurse Specialists, with years of experience as senior spinal centre nurses, have analysed patient care needs.**
- **We surveyed our 7,500 SCI members.**
- **SIA Chair, Michelle Howard, served as Co-chair of NHS England's first full review of specialist spinal services.**

We are inspired by a user-led passion for fulfilled lives and a determination to focus SIA's impact on what matters most to SCI people.



**Michelle Howard**  
Chair



**Sue Browning**  
Chief Executive

### **Our VISION**

is a fulfilled life for everyone affected by spinal cord injury.

### **Our PURPOSE**

To be in partnership with the spinal cord injured community to create quality and equality of life by campaigning, educating and supporting

### **Our VALUES**

- Work together in an environment built on **respect** and mutual support.
- Always be **user-led** in our decision-making and development.
- **Empower** SCI people as the experts in managing their lives.
- Be **committed** to the ever-changing needs of SCI people by campaigning for the best treatment and care.
- **Challenge** perceptions and behaviours towards SCI, ensuring a more **inclusive** society
- Have **integrity** in our work, collaborating with others where a greater impact can be achieved.



## Spinal Cord Injury

**Every year in the UK, 1,000 people sustain a SCI. The damage can be partial or complete. It leads to loss of muscle movement, sensation and control of body function below the injury.**

Research into repairing this damage continues, but currently there is no treatment that reverses paralysis.

SCI can happen at any time, through an accident at work, leisure or whilst travelling. It can also be caused by specific diseases or as a consequence of treating other medical conditions.

SCI is life changing, but not life ending. With rehabilitation and support, people can adapt to their condition and go on to live fulfilling lives.

- **3 people sustain a spinal cord injury every day in the UK**
- **Just over half of these new injuries result from an accident, the rest have non-trauma causes, such as infections or tumours of the spine**
- **There is currently no treatment that reverses paralysis**
- **At least 30% of newly injured people are not admitted to a specialist spinal care centre**
- **There has been a decrease in NHS spinal cord injury beds from 428 in 2008, to 390 in 2013/14**
- **People undergoing rehabilitation in a specialist spinal care centre have significantly better outcomes in all aspects of their reintegration into society**
- **1 in 4 SCI people fear for their financial security**
- **Less than 1% of SIA funding comes from statutory sources**

## Meeting the greatest challenges today

**Since 1974, SIA has led campaigns that have changed public attitudes and improved specialist healthcare for spinal cord injured people. We have provided a strong and credible voice for the whole community.**

We introduced innovative services like peer support and specialist education. In 2016, we added expertise through our SCI Nurse Specialists; experienced spinal care nurses who can support SCI people and the professionals who care for them.

For over forty years, SIA has adapted to new needs. This strategy maps out how we are adapting again, to meet the new challenges facing spinal cord injured people today.

Our research over the last year, has defined the five immediate challenges that need to shape our strategy.

### Quality of care for the newly injured

The development of specialist spinal care centres was a big advance in the treatment of spinal cord injured people. But research last year showed that at least 30% of newly injured people are not admitted to the spinal centres.

They are being treated in non-specialist settings where clinical staff do not have the highly specialist experience of treating the complex needs of a spinal cord injured patient.

This frequently leads to additional complications whilst in hospital and patients being discharged without knowledge of issues like bowel, bladder and skin management, vital for their health and quality of life. Some patients are also being discharged into inappropriate locations.

Many patients, in all settings, can also miss out on essential psychological support for the emotional impact of their injury.

This combination of less expert care and inadequate rehabilitation before discharge leads to much reduced health and social outcomes and lower quality of life.

### Quality of Care for life after hospital

Continuing Healthcare and Social Care are under massive pressure and many spinal cord injured people are losing the support they need to live their lives.

Budget decisions are taking away SCI people's independence and leaving them vulnerable to medical complications.

These can lead to hospital readmissions, which are a poor outcome for both the individual and the NHS.

Most spinal cord injured people are dependent on NHS and Social Care services for this support for their daily lives.

### Financial Security

The squeeze on funding and barriers to returning to paid employment are making SCI people fearful for their financial future.

People feel that the system is loaded against them. Too many vulnerable people are struggling against unreasonable pressure to change their well-run care plans.

We estimate that only one out of five injured people receive compensation from a claim, so four out of five depend on publicly provided support for many everyday tasks.

### Inclusion

Despite legislation on disability rights, spinal cord injured people still face many challenges to a life of equality.

It is important that they understand their rights and opportunities and are supported in accessing those rights when they feel disadvantaged.

### Wellbeing

The average age at injury is increasing and SCI people are living longer.

Their needs are much more complex and people need solutions to the challenges of aging well in order to maintain health and independence throughout their life.



## Ambition built on experience

The concept of 'Fulfilled Lives' has been central to SIA's forty-three year history and it makes a fitting title for our new five-year strategy.

The new strategy is ambitious. It draws on the user-led passion of our membership, the expertise of the professionals we work with and all the evidence we gather from spinal cord injured people and their families about their everyday lives.

It builds on the success of our existing services and focusses directly on the issues that matter most to SCI people, so that we can deliver the greatest impact where it is needed most.

We recognise that successful delivery of our strategy does not depend solely on the design of our services.

We also need to build our engagement with the SCI community and develop our own organisational strength to deliver the new strategy in a sustainable way.

Maximum	<b>Impact &amp; Delivery</b>	for SCI people
Effective use of	<b>People &amp; Resources</b>	by SIA

### Our objectives are spread across four key themes:

**Impact** – Making the biggest difference on the issues that matter most

**Delivery** – Focused and effective services

**People** – Harnessing the enthusiasm and expertise of the wider SIA team

**Resources** – Modern and robust business practices and a long-term approach to sustainable income generation.

The first two are externally focused on making the right impact on the lives on SCI people, the second two are the internal foundations that SIA needs to ensure we can carry this ambition through.

## Focused on the goal of fulfilled lives for SCI people

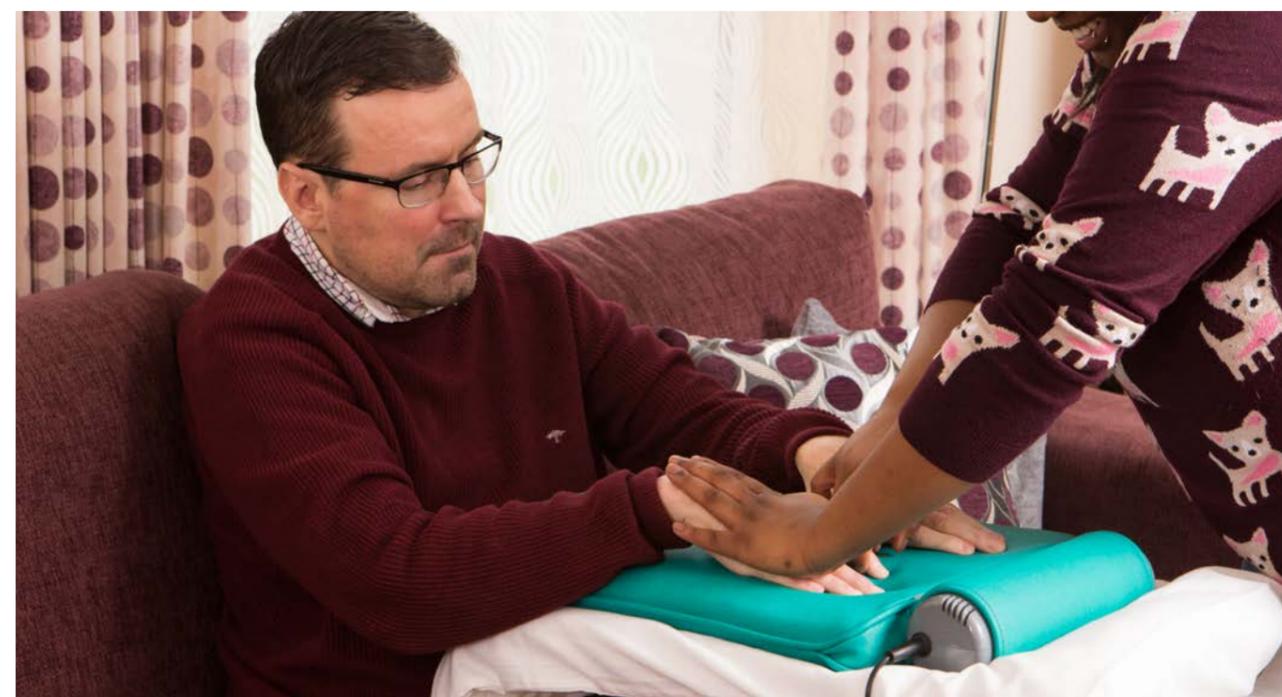
We passionately believe that everyone has a right to live a fulfilled life and that means the life that they choose, a life that has the same opportunities as everyone else. Equality can only be achieved if people have independence and informed choice.

### Our Priorities Maximum Impact & Delivery

- Influence the quality of health and care services received by SCI people
- Support the wellbeing of spinal cord injured people and their families
- Enhance inclusivity of spinal cord injured people in society
- Build engagement with SCI people and their families to make SIA a stronger voice for the community and deepen the user-led influence on our development
- Deliver our existing and new high impact services to support SCI people

### Our Priorities Effective People & Resources

- Work in partnership with key stakeholders in the SCI community
- Harness the expertise and enthusiasm of the wider SIA Team to deliver change
- Grow SIA's revenue streams to provide a robust and sustainable platform for success



## Our Goals for 2017-2022

### Maximum Impact & Delivery

#### Influence the quality of health and care services received by SCI people

SIA will focus on improving the quality of care that SCI people receive in non-specialist settings. Our SCI Nurse Specialists will support individuals and the professional staff treating them to improve the quality of care they receive.

- We will support individuals to secure and retain the care packages they need after discharge from hospital.
- We will campaign to increase the capacity of specialist spinal injury care, reducing the number of patients at risk from unsuitable care or discharge without adequate rehabilitation.
- We will extend the work of the SIA Academy to increase the specialist skills of health and care professionals.

#### Support the wellbeing of spinal cord injured people and their families

SIA will support the wellbeing of spinal cord injured people and their families.

- We will improve the availability and ease of access to high quality information and education for those living with spinal cord injury and those who treat and support them.
- We will provide support and advocacy (expert advice and representation) for those most in need and campaign for appropriate levels of psychological services through the NHS where they currently fall short.
- We will add an online learning platform to the SIA Academy, providing easy access to SCI-related learning.

#### Enhance inclusivity of spinal cord injured people in society

Through our services and campaigning, SIA will help SCI people to be more included in society, enabling them to live a fulfilled life.

- We will develop a cohesive approach across the charity to deliver information, support and advocacy so that SCI people understand their rights and the opportunities available to them.
- We will support the most vulnerable to access their rights to Continuing Healthcare, Social Care and other vital support services, and campaign for fairer provision of support and the legal rights of SCI people to be included equally in society.



#### Build engagement with SIA to make our voice stronger

Being a user-led membership organisation is an essential element of SIA's values and ensures that our strategy and policy is always driven by the needs and priorities of SCI people.

- We will build our membership to ensure we represent the whole SCI community, and recruit families, friends and health professionals to inform and support the people central to their lives.
- We will work with the specialist spinal centres and communicate more effectively across all channels to make sure that all SCI people get the opportunity to engage with SIA.
- SIA will provide a well-informed and expert voice for SCI people in the UK.

#### Deliver our existing and new high impact services to support SCI people

SIA will deliver effective services to spinal cord injured people, their families and friends, health and care professionals, and volunteers.

- We will measure the impact our services make for each group and adapt to the new challenges of a changing environment.
- We have structured our services to deliver clear objectives through our specialist Peer Support, Advocacy, Education and Quality of Care, and Policy and Public Affairs teams.



## Our goals for 2017-2022

### Effective People & Resources

#### Work in partnership with key stakeholders in the SCI community

SIA will work with all the key organisations that serve the SCI community – health and care professionals, legal and other service providers, and other charities to deliver the maximum benefit to SCI people.

- We will continue to lead SCI UK, the tri-partite forum of the SCI charities, SCI medical professionals and SCI clinicians.
- We will lead developments that bring service providers together to improve the quality of care.

#### Harness the expertise and enthusiasm of the wider SIA Team to deliver change

SIA will build a network of people working on behalf of SCI people and SIA to build our capacity.

- We will recruit and support more volunteers to extend the reach of our services.
- We will recruit individuals to act as advocates for SCI people and ambassadors for SIA, raising awareness and inspiring people to donate their time, expertise and financial support.

#### Grow SIA's revenue streams to provide a robust and sustainable platform for success

- SIA delivers free support to all who need it, but we also have the credibility and expertise to deliver paid services where funding is available through partnerships and social enterprise. We will develop this area to deliver more sustainable income.
- We will grow the support of individuals and businesses, communicating effectively on how they help through donations and sponsorship, and reporting back effectively on how their contribution changes the lives of spinal cord injured people.

## Spinal Injuries Association

For more than forty-years, SIA has delivered support to spinal cord injured people England, Wales and Northern Ireland, and demand for our services is growing rapidly as many SCI people face tough challenges.

- Our **Peer Support** Officers, all SCI themselves, provide vital help and advice.
- Our **Public Affairs** team campaign to improve the health and social care services available to SCI people, whilst our **Advocacy** staff support individuals battling to receive the support they need.
- Our **SCI Nurse Specialists** support SCI patients being treated in non-specialist setting.

Priorities have changed over that time as spinal cord injured people face new and different challenges. SIA has evolved too, adapting to new challenges. But the mission has always been the same – fulfilled lives after spinal cord injury.

## In 2016/17, SIA...

**4,733 Peer Support** sessions were provided to **SCI** people in hospitals, NHS spinal cord injury centres, out in the community, and in people's homes.

The **Advice Line** dealt with **1,655** enquiries and **96%** of people would consider using the **Advice Line** again in the future.

**216** healthcare professionals attended **SIA's Study Days**.

**92** solicitors attended **training days** to improve their knowledge of offering legal representation to someone with an SCI.

**83** people received support and advice related to **Social Care** funding for SCI people (e.g. spinal cord injured people, relatives, friends, and carers).

**92** people received support and advice related to **Continuing Healthcare** funding for SCI people (e.g. spinal cord injured people, relatives, friends, and carers).

**69** SCI patients received **clinical advocacy** during the acute stage of their care in a non-specialist hospital.

