



Spinal Injuries Association

"...because life needn't stop when you're paralysed"

Introduction

The Spinal Injuries Association (SIA) is the national charity for spinal cord injured (SCI) people. It was founded by Baroness Masham of Ilton and fellow SCI people in 1974 and today has over 5000 SCI members.

Significant numbers of spinal injuries result in paralysis having a profound effect on the life of the individual concerned and their families. The SIA exists to provide support to spinal cord injured people and their families from the time of their injury for the rest of their lives.

Our aim is to promote the integration and full participation in society of our members. Indeed, 57% of our staff at the SIA have SCI. We provide a range of services to encourage and enable our members to lead full and independent lives. We also campaign for greater awareness and understanding of the causes and consequences of spinal cord injury, and for improved medical care and research in the field.

Every year in the UK we estimate that up to 1000 people experience a spinal cord injury; there are an estimated 40,000 spinal cord injured people in the UK alone. Our support system is designed to adapt to the needs of each of these individuals depending on the level of their injury and their circumstances. Amongst other services, we offer a Freephone Helpline, Community Link Scheme, Peer Support Service and Healthy Living Roadshows for SCI people.

Spinal Cord Injury Centres: A Specialised Service

Today, there are 8 NHS Spinal Cord Injury Centres (SCICs) in England and one each in Northern Ireland, Scotland and Wales. An SCIC should be a centre of expertise with appropriate facilities and trained staff to manage SCI people from the acute stage, to rehabilitation back into the community, and provide lifetime specialist health support for the life of those with paraplegia (paralysis of the lower limbs) and tetraplegia (paralysis of all four limbs).

SCICs are classed as specialised services under the Department of Health (DH) National Definition Set. Specialised Services are those with low patient numbers requiring a critical mass of patients to make care cost effective. Specialised services are vital but expensive in isolation and Primary Care Trusts (PCTs) currently come together to form consortia to commission these services collaboratively.

The SIA welcomes the recent publication of the Government's Commissioning Framework¹. This framework includes many of the recommendations made by the independent review of commissioning arrangements for specialised services, led by Sir David Carter, and has the potential to greatly strengthen the planning, funding and delivery of specialised services.

In particular, we welcome the decision to establish Specialised Commissioning Groups (SCGs) within each SHA, to be responsible for all specialised commissioning arrangements by member PCTs and other joint working such as the setting up of national and regional clinical databases. The proposed National Specialised Services Commissioning Group will also play a vital national coordinating role.

It is important that these reforms are now carried out in full. SCGs must be provided with sufficient funds to fulfil their role and patient groups should be represented and actively involved in their development.

Key SCIC Issues and Suggested Ways Forward

The UK needs a renewed and modernised SCI service. A modern national SCIC service offering improved levels of care would increase the number of people surviving SCI and the life expectancy and life quality of these patients. The associated costs to the NHS would also be reduced significantly. The SIA has identified several areas of major concern within the current system:

➤ Funding

There is a lack of financial transparency and consistency in the funds provided for the 9 specialist SCI Centres in England and Wales. Too often, funds are diverted away from these specialist services to plug leaks elsewhere within the NHS Trust where the SCIC is sited.

¹ Health Reform in England: Update and Commissioning Framework, 13th July 2006, Department of Health

There must be total transparency within Trust accounts to ensure that commissioners can verify that those funds they have allocated benefit the patients of the intended specialist service, as recommended in the recent Carter Report.

Department of Health should establish a single body to monitor, evaluate and fund the SCI service.

➤ **Capacity**

Since 1980 the number of beds has fallen whilst the proportion of people surviving spinal cord injuries has increased. Up to 20% of SCI people have never attended a SCIC.² Pressure on specialist SCI beds has led to long-term SCI people being admitted into non-SCI specialist hospitals where they are not offered basic SCI care requirements and often develop complications unrelated to the cause of their admission. These complications increase rehabilitation time and reduce final outcomes. They also increase long term costs to the NHS.

This pressure is increased by the routine admission to SCICs of patients who have undergone surgery but without SCI or neurological deficit. In the drive to reduce waiting lists, it has become common for parent hospitals to force their SCIC to accept post-surgery orthopaedic patients. This is an unacceptable use of specialist resources.

Long-term SCI people should not be admitted to non-SCI specialist hospitals except in an emergency and specialist resources should be reserved for those with equivalent needs.

➤ **Location**

For historical reasons SCICs are inconveniently situated away from contemporary centres of population. Several areas of the country lack convenient access to an SCIC and some facilities are well below capacity for the populations they serve.

New SCI Centres must be enabled and encouraged to develop in the geographical areas where they are most needed. They should only be established at a University Hospital with a Medical School to ensure the full range of NHS specialties is available.

➤ **Statistics**

No national statistics are available on the incidence of SCI or its treatment and sharing of patient records between SCICs is limited.

Patient records should be electronically compatible between SCICs and a database for the collection and dissemination of incidence and prevalence figures should be established.

The Need for a National Model

There is no clear framework for how a SCIC should perform; a national model should therefore be developed to provide for minimum standards in SCI care. The SIA has produced a model for the service which lays out our vision for SCI care and seeks to incorporate the issues above and more. We have also been working closely with PCTs and SHAs in the South of England to develop and implement standards for the care of SCI patients in the region.

If a national model for SCICs was developed in line with this approach and reflecting the content of the SIA's national model, the quality of patient care would be significantly increased and costs to the NHS would be reduced.

The SIA's campaign is fully supported by the two major professional organisations in the field:

BASCIS

The British Association of Spinal Cord Injury Specialists is the national organisation of senior medical professions working within SCICs. BASCIS works to improve the quality of care for Spinal Cord Injury patients and the training of doctors in the speciality. www.bascis.pwp.blueyonder.co.uk

MASCIP

The Multidisciplinary Association of Spinal Cord Injury Professionals is the national organisation of professionals working within SCI. The Association's prime objective is to provide a national professional forum to promote standards in clinical practice, foster research and encourage the development of health and social care services for people with SCI. www.mascip.co.uk

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² Making the Difference, SIA (1999) and additional figures provided by the British Association for Spinal Cord Injury Specialists