

## **ESCIF Policy Statement on the treatment, rehabilitation and life-long care of persons with spinal cord injuries (SCI)**

**The following Policy Statement was unanimously approved and accepted by the ESCIF Assembly of Delegates on 26 April 2008 in Umag, Croatia.**

### **1. Establishment of regional and/or national spinal cord registers in all European countries**

At present very few countries in Europe have regional and/or national registers of spinal cord injuries; even in those that do, access to the information recorded is often restricted. Furthermore, direct comparisons of national statistics are made impossible by a lack of uniformity in the definitions used and the recording practices employed.

The member organisations of ESCIF agree that regional and/or national registers should be established in all European countries. The primary purposes of registration are as follows:

- Registration will inform and facilitate national health sector budgeting and investment initiatives;
- Registration will provide researchers with useful information regarding the prevalence, incidence and causes of spinal cord injuries in individual countries and allow direct comparison between countries, the identification of both cross-national and longitudinal trends and, thus, will provide indicators for directions of future relevant research; further, the information gathered may provide useful indicators to assist in the improvement in the outcome of rehabilitation;
- Registration will enable organisations for persons with spinal cord injuries to channel and target their efforts and activities both in the individual countries but also on a pan-European level;
- Registration will inform and facilitate national information campaigns (both governmental and organisational) aimed at preventing SCI and/or at raising awareness of SCI among the general public, healthcare professionals, educators, potential employers etc.

In order to facilitate the collation and comparison of the regional and national data, it is essential that the recording practices used are uniform and transparent. While, for ethical reasons, the individual should retain the right to demand that his/her medical journal should be confidential, the statistical information recorded in the regional and national registers should be accessible.

## **2. Centralisation of the treatment, rehabilitation and life-long care of persons with spinal cord injuries**

While the incidence of spinal cord injury (both traumatic and non-traumatic) is relatively low, the physical, medical, psychological, social and financial consequences of such injuries are highly complex and, potentially, devastating for the injured person and his/her family. Thus, we find ourselves faced with a classic health sector dilemma; a small group of people with a diagnosis that demands the highly-specialised knowledge and experience of a wide range of medical, clinical and counselling personnel over a long period of time.

ESCIF and its members will work to promote the centralisation of the treatment, rehabilitation and life-long care of persons with SCI and the creation of dedicated centres of excellence in both the treatment, rehabilitation and care of spinal cord injury and of research in this field. The centres must have the ability to manage all requirements of persons with SCI through direct access to the other medical and clinical specialisations upon which this patient group relies – for example, neurosurgery, neurology, orthopaedic surgery, urology, gastroenterology, plastic surgery, gynaecology and obstetrics, fertility, sexology, respiration, gerontology, physiotherapy and occupational therapy. The services offered by the centres will be available to all paraplegics and quadriplegics/tetraplegics and the relevant national authorities should ensure that all persons who have sustained a spinal cord injury are referred to a specialised spinal cord injury centre.

Centralisation provides many benefits including the opportunity to:

- Create and maintain multidisciplinary medical, clinical, nursing and therapy teams with the knowledge and expertise to offer an informed choice of treatment and provide the best possible treatment, rehabilitation and care of persons with SCI.
- To offer expert counselling services with a specific focus on the needs of persons with SCI and their families; services provided by, for example, psychologists, social workers, vocational counsellors, dieticians.
- To provide expert information and advisory services relating to mobility aids, housing adaptation and modification, transport etc.
- To create a centre of information, education and advice concerning the treatment and care of persons with SCI that will be of benefit to the persons with SCI themselves, the families of persons who have sustained SCI, personnel at general hospitals, doctors and physiotherapists in general practice, as well as local care-givers and those working as social workers or case officers in the local community.
- To establish purpose-built centres fully-adapted to the needs of persons with SCI and offering a wide range of relevant treatment, therapy and training facilities.
- To provide peer-support for and between persons with SCI, for and between the partners and/or relatives of persons with SCI as well as carers, both during and following rehabilitation, through the contacts formed at the centre with local and national SCI groups and organisations, sports and wheelchair clubs etc.
- To create a natural forum for research into many different aspects of SCI and to participate in international research collaborations.
- To provide a practical training facility for future medical, clinical, nursing and therapy personnel who wish to specialise in the field of SCI.

- To exploit any economies of scale afforded by the gathering of consumers and personnel into larger units.

### **3. Peer-counselling and peer support services**

In a recent study carried out by ESCIF<sup>1</sup> there was general consensus that newly-injured persons with SCI undergoing rehabilitation can learn a great deal from meeting people already living with a spinal cord injury; this includes everything from “tips” that can be used in everyday activities, through the more sensitive issues of sexuality and identity, to the overall problem of “coming to terms” with what has happened and how to move on.

It is, however, not enough to rely on chance meetings or ad hoc voluntary activities; in order to gain the maximum benefit from this invaluable source of information and experience, a comprehensive peer-counselling/peer support service must be established at the spinal cord centres or rehabilitation centres.

ESCIF and its member organisations have experienced that peer-counselling makes a significant and positive contribution to the rehabilitation of people with spinal cord injuries and will, therefore, work to establish peer-counselling and peer support services and activities in all ESCIF member countries. In order to achieve the best results it is essential that these services receive regular and sufficient funding from the relevant authorities.

The role of the peer-counsellor is multi-faceted:

- To provide a role model who demonstrates the possibilities for life with SCI and not just the limitations.
- To offer advice based on experience; particularly useful in sensitive areas like sexuality and relationships.
- To suggest solutions and coping strategies that are not anchored in the routines and regimens of a hospital-like environment.
- To use the organisation’s network to help make further contacts with other persons with SCI who can provide support and inspiration.
- To collaborate with personnel to arrange activities and events for the patients and their families.
- To introduce the activities and facilities that are available after the rehabilitation process – sports activities, wheelchair clubs, seminars and courses etc.

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<sup>1</sup> Acute care and primary rehabilitation in ESCIF member countries 2007. See [www.escif.org](http://www.escif.org)

#### **4. Proactive support for the families of persons with spinal cord injuries**

The consequences of a spinal cord injury affect not only the injured person but also the families, friends and even colleagues of that person. In the study mentioned above, it was shown that most of the member organisations are acutely aware of the problems faced by partners and families – problems that have been largely ignored by the national healthcare and social systems. Many of the member organisations are already working to rectify this situation.

ESCIF and its member organisations agree that proactive support – counselling, information, advice and education – is vital for the partners and families of persons who have sustained a spinal cord injury. In order to be able to offer the best and most qualified support, it is essential that medical, clinical, therapy and counselling personnel collaborate closely with the national SCI organisations. The organisations should receive financial support from the relevant authorities (government, health or social sector etc.) to fund their contribution to these services and activities.

When devising a proactive family support system, the following points should be remembered:

- Following a spinal cord injury the need for proactive support is acute; the system must be in place and support must be available immediately
- Family members and others close to the newly-injured person are also traumatised; some will require psychological counselling
- In addition to the psychological and emotional shock, family members confront a wide-range of practical and financial issues
- Family members need information – not only about the physical effects and consequences of a spinal cord injury, but also about the future possibilities
- Many family members want to talk to others who have been in the same situation
- The need for support, information, counselling and advice continues over time and does not disappear when the injured person is discharged; in fact, studies show that this is a critical time for the family
- In the same way that persons with SCI need lifelong follow-up care, their families need ongoing access to support services to help them cope with later problems

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