ESCIF European Spinal Cord Injury Federation

Centralisation of the treatment, rehabilitation and life-long care of persons with spinal cord injury

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Foreword and introduction

ESCIF policy working group 2 has been looking into the most appropriate way to promote and convey the crucial merits of the centralisation of the treatment, rehabilitation and life-long care of persons with spinal cord injury (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.

We discovered rather early in the process that while centralisation seems to be widely accepted as "the best way forward" among SCI specialists and clinicians, very little evidence actually exists to support this – few systematic studies have been carried out to investigate this commonly-accepted notion.

The group therefore decided to rely primarily on its experience as consumers of the treatment, rehabilitation and care system, and on the expertise we have gained from living with a spinal cord injury. We approached the issue from the angle of the challenges, successes and disappointments that we have experienced in our contacts with the systems in our respective countries. We used this insider knowledge (supplemented by a great deal of reading as well as discussions with SCI professionals and others living with SCI) to arrive at the recommendations outlined in this report.

It can certainly be argued that the report is not entirely comprehensive or exhaustive! There are many areas, for example, relating to capital investment in equipment or operating expenses, that we have either only touched on or not considered. We present the consumer's view – a view that has not always been fully recognised or accepted as valid by healthcare professionals or the healthcare authorities. We feel that it is time that our views and opinions become an integral part of the SCI agenda.

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Why centralisation?

Rehabilitation has been defined by the World Health Organization as a progressive, dynamic, goal-oriented and often time-limited process, which enables an individual with an impairment to identify and reach his/her optimal mental, physical, cognitive and social functional level. If we look at the international definition of rehabilitation, its success is measured on the overall outcome of the process and is not limited to simply being able to manage personal care and hygiene. The cornerstone of a good rehabilitation programme is patient-centred and goal-oriented. Patients play an active part in making informed decisions concerning all aspects of their rehabilitation. The rehabilitation process encourages and empowers patients to return to and participate in life in the community, including voluntary work, paid employment or education.

It is important that we identify what we mean by rehabilitation for a person with a spinal cord injury and what the ultimate goals of a rehabilitation programme should be. With appropriate rehabilitation, most individuals who sustain a spinal cord injury can live full and active lives. Forty years ago the goal for any rehabilitation program was simple; to prevent people who had sustained a spinal cord injury from dying from serious pressure sores or from serious kidney infections. While it is still essential that these issues are addressed, we have now reached a stage where we should be creating achievable expectations where people can embark on a vocational and social programme while still a patient in the rehabilitation centre; a programme that continues and is consolidated when they return to the community. Studies on spinal cord injury throughout the world have proven that being actively involved in work, sports and social aspects of life create knock on effects that are very positive for a healthy lifestyle which, in turn, reduces associated health risks. The reality is that people tend to manage their health better because they have a more positive outlook on life. It is widely recognised that quality of life after a spinal cord injury depends on the way a patient learns to adapt to the traumatic change in his or her life that the injury incurs. It is not enough to just train people to dress and manage their bowel, bladder, skin care and transfer from the chair. We have to give people a reason for applying these skills.

While the incidence of spinal cord injury (SCI) 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. International evidence of treatment, outcomes and quality of life shows that these complex medical challenges can best be met in a co-ordinated system that includes properly-trained and equipped medical service providers. The rarity of the condition necessitates the centralisation and concentration of expertise, and expert opinion supports the provision of medical and therapeutic rehabilitation services in dedicated centres of excellence receiving a critical mass of patients and allowing for the development and maintenance of the required specialist skills by staff.

If reintegration of individuals who sustain a spinal cord injury into the community is to be achieved, it must part of a coordinated approach that is managed early on in the individual's rehabilitation. A seamless approach is required that addresses the medical, vocational, social

and the community effects of SCI. For this service to be optimal, it needs to be based in a centre of expertise with appropriate facilities and staff trained to manage people with SCI from the acute stage, through the process rehabilitation and back into the community, and geared to provide lifetime specialist health support for persons with SCI. Due to the low incidence of SCI and the demands for highly-specialised knowledge and experience of a wide range of medical and clinical professions, the need for centralisation is obvious.

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.
- Offer expert counselling services with a specific focus on the needs of persons with SCI and their families.
- Provide expert information and advisory services relating to mobility aids, housing adaptation and modification, transport etc.
- 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 caregivers and those working as social workers or case officers in the local community.
- 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.
- 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. The need for practical and psychological/emotional support for the person with SCI and their family/close group of friends is critical following discharge from primary rehabilitation – this should be facilitated by the SCIC.
- Create a natural forum for research into many different aspects of SCI and to participate in international research collaborations.
- Provide a practical training facility for future medical, clinical, nursing and therapy personnel who wish to specialise in the field of SCI.
- Exploit any economies of scale afforded by the gathering of consumers and personnel into larger units.

What is centralisation?

Unfortunately, while there appears to be worldwide recognition in the rehabilitation community that centralisation is by far the most appropriate approach to delivering a comprehensive service, there does not appear to be any evidence – in the sense of systematic studies – to support this.

However, if we consider that the first spinal rehabilitation centres were only set up and developed after the Second World War, and that regimes for avoiding pressure sores and the threat of kidney failure first emerged after this, we also realise that we are among the first generation of consumers of this service who have lived for decades with SCI. We have a huge personal and shared expertise on which to base our recommendations as to the best option for our peers. As consumers we feel it is time that our opinion was taken on board.

Centralisation of treatment and rehabilitation services for those who sustain a SCI is more than the issue of the degree of the centralisation and its location. While it is often seen as desirable that individuals who sustain a spinal cord injury are rehabilitated close to their family and community, the consensus within ESCIF is that a centralised, dedicated service, rather than local intervention, provides a better opportunity for individuals to gain the most from a rehabilitation programme. In a centralised system persons with SCI can access the highly specialised services, specialised staff and, equally important, learn from their peers. The services and resources available also dictate the quality of the service. It is the quality of the service rather than distance to a person's home that should be of paramount importance.

Rehabilitation of people with SCI is centralised when the care is concentrated in Spinal Cord Injury Centres (SCIC) that treat

- both traumatic and non traumatic spinal cord lesions.
- a minimum of 40 – 50 newly-injured persons per year.

The services offered by the centres will be available to all persons with SCI and their families. A SCIC will treat people of all ages and include people needing ventilator support. Children and adolescents with SCI require special concern and attention since this group often "falls between the gaps" in current healthcare systems. If the population is large enough, the SCIC should have staff and facilities specialised in the needs of children and youngsters, and should be capable of receiving them. If the population is too small, it might be a better option to rely on the care of paediatricians (as is the case in most European countries today) but in close cooperation with the SCIC. This will facilitate the continuing rehabilitation process as children become older and take over more and more responsibility for their personal care. If there is more than one SCIC in the country one of them could be specialised in catering for the treatment and rehabilitation needs of children and young people (including the often overlooked need for suitable onsite accommodation for parents).

Relevant national authorities should ensure that all persons who have sustained a spinal cord injury are referred to a SCIC.

What is a Spinal Cord Injury Centre (SCIC)?

An SCIC is a dedicated centre of excellence in the treatment, rehabilitation and life-long care of persons with SCI and of research in this field. An SCIC is located at a university hospital and

- employs permanent multidisciplinary teams, headed by SCI consultants and consisting of nursing staff, physiotherapists, occupational therapists, recreational therapists, psychologists, social workers and counsellors. All members of staff must have expertise in SCI
- has direct access to the other medical and clinical specialisations upon which this patient group relies. These include neurosurgery, neurology, orthopaedic surgery, radiology, rehabilitation medicine, anaesthesiology, urology, gastroenterology, plastic surgery, gynaecology and obstetrics, fertility, sexology, respiration, gerontology, paediatrics, hand surgery, dentistry and dietetics
- gathers and submits information to a regional/national/international SCI registry
- provides peer support that is organised by the peer counsellor(s) who are employed by the centre or by the SCI organisation
- provides proactive support for families
- cooperates closely with the SCI organisation. Information from voluntary SCI organisations should be available in each SCIC. A programme of awareness amongst patients and their families should be incorporated into the rehabilitation programme. This will enable patients to gain access to information about living options and learn coping strategies from others with the same impairment
- provides expert counselling to other health care professionals, persons with SCI and their families and carers
- performs research in many different aspects of SCI and participates in international research collaborations
- educates and trains community-based health care personnel and future health care professionals. ESCIF recommends that there should be a better support framework and backup for doctors in the community and general hospitals should they need advice in any area of spinal cord injury care. Doctors and hospitals should be able to link into expert advice on SCI from the SCIC at any time of the day or night.

Stages of care provided by the SCIC

An SCIC provides individualised rehabilitation in accordance with personal rehabilitation plans that focus on the motivation, integrity and dignity of the person with SCI and which are devised in consultation with him/her. The length of stay at the centre is based on the expected outcome that is defined in the individual rehabilitation plan. It is recommended that rehabilitation commences as soon as possible.

ESCIF proposes that there are three main stages of rehabilitation from the acute stage to reintegration into the community. The stages of care provided by a SCIC comprise

- **Acute and emergency care**

  ESCIF believes that spinal cord injury acute and emergency care should be based in the university hospital where the SCIC is located. Rather than the individual being admitted to a general hospital the entire system of care for spinal cord injury should be within the one specialised hospital setting.

  Acute and emergency care is designed to save lives and minimise impairment and disability as well as preventing secondary complications. This stage will require liaison with the Ambulance Service and with all Accident and Emergency Units and Acute Trauma/Orthopaedic Units in the region. It will include the provision of guidelines for acute care and transportation.

  The care will have the support of a fully equipped A&E Unit and Trauma Service to deal with the admission of patients both directly from the local accident scene and for those who have been transferred. This is necessary since the original diagnosis may not be complete.

  Helicopter landing facilities must be available on the hospital site.

  Provision for 24-hour interventions is required to include MRI/CT scanning, radiology, ultrasound, cardiac arrest service and full pathology service, also lithotripsy, neuro-physiology and urodynamics, 24-hour access to theatre time and appropriate equipment.

  The hospital must have the capability of managing multiple injuries and patients requiring ventilator support.

- **Primary rehabilitation**

  ESCIF believes that the primary rehabilitation should continue within the same university hospital as the acute and emergency care – but in a purpose-built facility

  The purpose of care and rehabilitation should be to

  - manage the impairment
    This should involve receiving nursing care, physiotherapy, occupational therapy and trauma counselling.
  - alleviate the concerns of the person with SCI and the family
    Support should also be available for helping the person and family members come to terms with the situation and manage social and family problems arising from it.

These problems will range from the practical – financial, housing etc – to the emotional – coping in a relationship, family roles etc.

- train the person with SCI in managing the impairment
  A programme of training should demonstrate the different options available in managing the impairment e.g. bladder and bowel management techniques, pressure relief. Such a programme should enable the person to make informed choices about how to manage such issues, with the staff helping the consumer to identify the advantages and disadvantages of each. Adequate consideration must be paid to the conditions of living outside a hospital environment – taking into account the demands of work, social and family demands. Peer support and counselling is crucial.
- train the person with SCI in techniques for daily living
  A programme of training should be developed that promotes the full use of the person's physical abilities and which helps the person to become proficient in carrying out activities of daily living. This stage should also include supporting the person in exploring new opportunities such as employment, wheelchair sports etc.

  Supported and monitored self-care facilities should be available so that the person can practise self care and daily living skills in a safe and supportive environment. The opportunity to spend time in, for example, an on-site training apartment is highly beneficial.

The primary rehabilitation must, at the end of the period, tie into the next stage of rehabilitation which is preparing the person to return to the community. Short trial periods, gradually extending the time away from the SCIC, should be implemented. Regular structured reviews should take place so that problems can be addressed. A social worker and the person with SCI would organise pre-discharge home visit(s) to facilitate community assessment and a gradual transition home.

- **Continuing care services**
  ESCIF believes strongly that a person who has sustained a spinal cord injury needs a great deal of support in the initial stages of returning home to their community.
  - reintegration in the community resource
    It is essential that the person with SCI – following rehabilitation at the SCIC – can draw upon counselling and advisory services from the SCIC that can help with all aspects of returning to the community including practical and emotional problems.

    It is while the person is still undergoing primary rehabilitation programme in the SCIC that the person should be introduced to a range of possible career opportunities for education, re-training or returning to work. Links should be established with previous employers and with community and vocational services. When the persons return home the vocational training programme started in the primary stage should continue.

    It is also essential that the person with SCI – following rehabilitation at the SCIC – can draw upon counselling and advisory services centres at the SCIC that can help with all aspects of returning to the community -

In order to make a successful transition between primary rehabilitation and community, services, such as housing, employment, and education or retraining must be planned in a coordinated way.

- life-long follow-up

  The SCIC should provide a system to follow up the person with SCI on a regular basis for the rest of that person's life. Follow-up care should address all areas of concern for the person with SCI such as physical, psychological and social complications due to the SCI. Issues related to ageing should also be addressed and worked with proactively.

  The need for life-long follow-up care is frequently cited as an argument *against* centralisation: how can the system demand regular return visits to a centre that may be far away or difficult to access due to geographical or infrastructural problems? The need here is to think and plan laterally – and to adopt new technology to facilitate communication. It may, for example, be possible for some routine tests to be carried out at the nearest hospital – it is, however, essential that the interpretation of test results and decisions for future action are made by SCI specialists. Another possibility could be the establishment of SCI "task forces": specialised personnel who make scheduled visits to regional hospitals in order to carry out follow-up examinations of persons with SCI in that area. Finally, of course, one must not forget the opportunities offered by new technology and telecommunications. Many consultations could be carried out over the internet (using webcam devices if available). Even treatments such as the long-term treatment of pressure sores could be monitored in this way by SCI experts.

  Certain results from the follow-ups could be registered in the SCI registry to enable comparisons on an individual, group and societal level over time.

- rehabilitation periods

  Regularly occurring rehabilitation periods should be offered to the person with SCI by the SCIC to enable the person to maintain autonomy and a high standard of functioning.

- re-admissions for treatment according to needs

  In more serious cases of care specific to living with a spinal cord injury, for example serious pressure sore care, individuals should be re-admitted to an SCIC.

  SCICs should provide ongoing support to all people who have been rehabilitated by them, on all aspects on managing spinal cord injury. This should prevent problems arising or catch them at an early stage, thus reducing the chances of readmission.

Facilities at the SCIC

Wards for acute and rehabilitation patients with adequate space and storage.

Room and ward profile

- Single rooms en-suite*
- Twin bedded rooms en-suite (for patients and carer/personal assistant)*
- Isolation rooms en-suite*
- Meeting room/consultation room
- Day room
- Kitchen facilities
- Dining area

* All rooms must be equipped with electric, height-adjustable beds and fully-adapted toilet and bathroom facilities. In order to ensure that nursing and other staff do not risk injury by heavy lifting and turning of patients, the rooms must be equipped with ceiling hoists/lifts and other appropriate aids.

On Site

- Training apartments
- Family accommodation
- Fitness room and sports hall
- Swimming pool
- Outdoor recreational and training facilities
- Seating and posture clinic
- Vocational training facilities
- Dental facilities
- Restaurant (staff, patient, visitor)
- Internet café
- Library
- Shop
- Helicopter pad
  Facilities are needed for helicopter transfer and to accept patients with multiple injuries
- Offices and facilities for personnel and therapists employed

Access

- Patients' mini bus
- Specialised driving tuition

Appendix
Effective Rehabilitation and Best Practice
A brief review of previous literature

An editorial in 'Clinical Rehabilitation' (2005) purports that 'rehabilitation is an astoundingly effective health care process'. Specific to spinal cord injury they comment that 'most dramatically, people would die after spinal cord injury without rehabilitation but they live lives of near normal duration'. They then focus on an important point that becomes increasingly evident as literature is searched; they comment on the difficulty we face in accurately describing the 'specific effective rehabilitation interventions'(2005; 811). Although the need for rehabilitation and the positives outcomes are well documented, the specific elements of rehabilitation programmes for patients post spinal cord injury are poorly documented which hinders research and 'reduces its credibility in the competitive health care market' (2005; 811)

Kirshblum et al (2007) emphasise the need for rehabilitation to begin in the intensive care setting highlighting the issue of medical complications and commenting that if they can be prevented the inpatient rehabilitation course is facilitated and the total cost of care is lessened. The rarity of the condition necessitates the centralisation and concentration of expertise and expert opinion would suggest the provision of medical and therapeutic rehabilitation services in one centre which would receive a critical mass of patients and allow for development of very specialist skills by staff.

Hammell (2007) suggests that 'the most important dimension of rehabilitation for people with SCI is the calibre and vision of the rehabilitation staff'

www.brainandspinalcord.org is an online resource for brain and spinal cord injury survivors. They advocate the following programme elements as being basic in ensuring that a rehabilitation centre fits the needs of the patients:

- A physician in charge who specializes in physical medicine and rehabilitation
- Physician coverage seven days a week, 24 hours a day
- A support staff that is specifically trained in spinal cord injuries
- The availability or rehabilitation nursing and respiratory care on a 24 hour basis
- Treatments for at least three hours per day
- Specialties offered such as driver education, rehabilitation engineering, and therapeutic recreation
- A full roster of weekend and evening activities for residents
- Programs that include family and loved ones in the care and rehabilitation of the survivor.

a. Medical/physiological sequelae

(1) Autonomic dysreflexia.
(2) Bladder function.
(3) Bowel function.
(4) Circulation.
(5) Dysphagia.
(6) Fertility
(7) Infectious disorders.
(8) Medication.

(9) Musculoskeletal complications.
(10) Neurological changes.
(11) Nutrition.
(12) Pain.
(13) Respiration.
(14) Sexual function.
(15) Skin integrity.
(16) Spasticity.

b. Functional:

(1) Activities of daily living.
(2) Assistive technology.
(3) Behaviour.
(4) Cognition.
(5) Communication.
(6) Community integration.
(7) Driving.
(8) Durable medical equipment.
(9) Emergency preparedness.
(10) Environmental modifications.
(11) Leisure and recreation.
(12) Mobility.
(13) Orthoses.
(14) Personal care assistants.
(15) Prostheses.
(16) Seating.
(17) Vocational.

c. Psychosocial:

(1) Behavioural health.
(2) Chemical use/abuse/dependency.
(3) Family/support system counselling.
(4) Peer support.
(5) Sexual adjustment.

d. Education and training for:

1 The person served.
2 Their families/support systems.
3 The community.
4 The professional community.

e. Research capability.
f. Aging, including:
(1) Aging with a disability.
(2) Spinal cord injury and dysfunction in an aging population.
g. Case management.
h. Resource management.
i. Transition planning.
j. Life-long follow-up.

k. Life-long health promotion.
l. Resources for independent living and community integration.
m. Prevention related to potential risks and complications due to impairments, activity limitations, participation restrictions, and the environment.
n. Safety for the persons served and the environments in which they participate.

O'Connor & Murray (2005) describe SCI as a *'life threatening condition that requires a coordinated multidisciplinary approach to manage the injury itself and the potential secondary complications satisfactorily'.* The ever increasing life expectancy of those who have suffered spinal cord injury demands for the service to provided ongoing follow up and interim care and rehabilitation. BSRM state that those with SCI are at greater risk of hospital admission every year following their injury compared with the general population. As there is often not an immediate route back into rehabilitation services they are likely to be cared for by general physicians in acute hospital settings. As a result complications related to the SCI itself as opposed to the reason for admission are very common in hospitals where SCI patients are rarely seen and their specialist needs not addressed. *(2008;2)*

All of the above factors point to the need for a concentrated centre of excellence to care for these patients to ensure that SCI specific needs are addressed. This would facilitate each person to '*meet his potential in terms of medical, physical, social, emotional, recreational, vocational and functional recovery'* **Kirshblum (2007)**

Burns & Ditunno (2001) report that the ability to predict the neuro-recovery and expected functional outcomes after SCI is very important as this information is used to justify medical and rehabilitation interventions in terms of value for money and also to begin the process of planning for care post discharge.

Schonherr et al (2000) found that predictions of functional outcome post injury were most accurate if expectations of the team and the patient were combined and often needed gradual adjustment of objectives during the rehabilitation process which would highlight again the need for professionals who have experience with this client group.
Positive expectations regarding the ability to return to work post SCI has been found to be a successful indicator of successful reintegration in work **(Schonherr et al 2004).** However they emphasise the need for an active role to be played by the rehabilitation team in developing a reintegration plan which would prepare the client, the employer and all professionals involved in the reintegration process.

A study carried out in the Netherlands and Flanders indicates that the characteristics of patients with traumatic and non-traumatic SCI differs but that rehabilitation is equally as efficient for both groups (**Osterthun et al 2008). Gupta et al (2008)** found that inpatient rehabilitation intervention for patients with a non-traumatic spinal cord injury resulted in significant recovery both neurologically and functionally.

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