

THE FINNISH ASSOCIATION OF SPINAL CORD INJURED AKSON  
 SELKÄYDINVAMMAISET AKSON RY  
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INTERNATIONAL  
 SURVEY

16.12.2016

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### **International survey of spinal cord injury (SCI) treatment and rehabilitation, "patient" perspective, Finland**

The Finnish Association of Spinal Cord Injured Akson want's to thank The Swedish National Board of Health and Welfare for this opportunity to give "patient" perspective of SCI centralising in Finland.

Akson is a Finnish national patient organization founded on 2009. Organization represent over 850 person with SCI. Akson maintain, develop and improve the benefits and rights of SCI people and their families.

One of the main goals for the first years of Akson was making acute phase of hospitalization, the immediate rehabilitation and life-long monitoring centralization for three (3) centers (university hospitals). This Act was circulated for comment in the autumn of 2010. Akson and The Finnish Association of People with Physical Disabilities gave a statement together. Regulation of spinal cord injury treatment centralization came into force on 1.5.2011. Our goal was achive, but the work to make the centers operate way the regulation says, it's still going. Also European Spinal Cord Injury Federations policy, recarding of Centralisation, had a big infulece to the Act ([http://www.escif.org/ESCIF,,members\\_downloads,escif\\_policy.htm](http://www.escif.org/ESCIF,,members_downloads,escif_policy.htm))

#### **a) What do you think of the way SCI treatment and rehabilitation is organized in your country?**

Tampere University Hospital (TAYS) was first SCI central that started operate, after that came Oulu University Hospital (OYS) and latest Helsinki University Hospital (HUS). TAYS and OYS have acute care, the immediate rehabilitation and life time care, but HUS has out-patient clinic so far. We also have few SCI clinics that are still working in bigger hospitals. Patients are confused about those clinics and mixing them to SCI-centrals.

In Finland there is five teaching university hospitals (include TAYS, OYS and HUS). In Turku (TYKS) and Kuopio (KYS) there is no official SCI-centres and actually we don't know the situations in these regions. There are apparently big regional differences regarding to SCI care and centralization doesn't apply evenly thru nationwide.

There is still lot of work ahead. Centralization came into force five and half years ago, but a clear division of work between basic healthcare and SCI-centres isn't yet working seamlessly. There are also problems between SCI-centres, cause they all have their own guidelines and ways to operate. Centrals are improving cooperation to make mutual guidelines, but it's taking time to get there.

Knowledge and awareness of SCI-centres are increasing among patients and professionals, so pressure to treat every person with SCI the way Act obligates is increasing everyday. There is still smaller SCI clinics working among SCI centres and Akson is concerned about expertise of those clinics.

Although SCI treatment has been getting better after the Act and patients are getting better care. Especially those patients benefit centralization that normally would be treated in neurology units etc. (non-traumatic). Also SCI awareness has increased among health care professionals, so more patients are getting right care in right time (patients are send directly to SCI-centres).

**b) What are the greatest challenges vs. benefits of how SCI treatment and rehabilitation is delivered in your country today? Any challenges with respect to availability, access etc.?**

Main challenge is SCI-centres have too little sources to take care of all patients (acute, rehabilitation and life time care). All centres need more professionals (doctors, nurses etc.) and more "bed units". Now days more and more people with SCI know about SCI-centres and know their rights to get treated in those places, but limited sources of staff is making waiting time too long (avg. waiting time is, depending the unit, is 3 months up to 3 years).

Another challenge is to spread awareness about patients right to get treated in SCI-centres. Finnish SCI registry has been created in 2015 and today all centres are using it. But it is still in progress and only small amount people with SCI are in that register. In Finland there is around 5000-10000 people with SCI, but we don't know for sure, cause lack of register before. One challenge is to evaluate right amount of patients, both traumatic and non-traumatic.

Benefit of these units is definitely special knowledge of SCI and understanding of all the problems that comes with it. There are so much specialized details about SCI that the doctor or other professional in basic healthcare don't know or understand. It is very important to have these centres to provide SCI expertise to patients and other professionals. Centralization can also prevent many health problems like pressure ulcers after injury. Also after acute trauma, the rehabilitation can be started sooner and more effective in SCI-centre than in basic health care.

**c) Are there any negative aspects and or risks with SCI centralization that we should be aware of?**

- The amount of patients is estimate too low/wrong, that effects centres staff capacity, which is going effect waiting periods to get too long example doctor's appointments and medical examinations
- Finding enough specialize medical professionals
- Other health care units want still treat SCI patients and don't send them to centres, even they don't have enough knowledge to treat them right

**d) What do you think is most important when it comes to SCI care and rehabilitation (organization, structure, staff etc.) and how would you prioritize when it comes to quality/competence and/or closeness to the home?**

Most important is, that every person with SCI can be and have possibility to get treated in SCI-centre with specialize expertise they deserve. Those centres should have enough experts and knowledge to handle all different medical or medical relative problems regarding to SCI. Centres capacity should be realistic and not under evaluate. Also extremely important is, that all centres should have mutual and predefined guidelines how to operate and take care of patients.

Helsinki 16.12.2016

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