

## People with Spinal Cord Injury in Norway

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### EPIDEMIOLOGY OF SPINAL CORD INJURY IN NORWAY

In 2014, 122 new cases of spinal cord injury (SCI) were registered in the Norwegian Spinal Cord Injury Registry (NorSCIR), of which 80 were traumatic and 42 were non-traumatic.<sup>1</sup> Written consent is obtained from the participants before entering data into the registry, and permission is only requested from SCI patients submitted to a specialized SCI unit in Norway. Such permissions are obtained from 91% to 93% of the relevant patients. Data from 419 individuals are included for the period 2011–2014: 250 with a traumatic SCI and 169 with a nontraumatic SCI. Historical data on incidence and prevalence of SCI in Norway are relatively sparse. In 1974–1975, the incidence of traumatic SCI was reported to be 16.5.<sup>2</sup> For the period 1952–2001, it was found to be 13.9 in western Norway.<sup>3</sup> Thus, a relatively stable trend is found during the past 50 to 60 years. The etiology of SCI, based on the 2014 data from NorSCIR,<sup>1</sup> are nontraumatic causes, 34.4%; traumatic causes due to falls, 29.5%; sports, 13.9%; transport, 13.1%; other traumatic, 8.2%; and assault, 0.8%. The main causes of traumatic SCIs have been unchanged for the past 50 years,<sup>4</sup> except for an increasing trend toward higher incidence of fall-induced SCI among persons older than 50 years.<sup>3</sup> People with traumatic SCI have an increased mortality rate (1.85) compared with the Norwegian population.<sup>4</sup> Women with SCI have a significant higher mortality rate than men.<sup>4,5</sup>

### THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

The Norwegian emergency medical service system consists of specialized rescue teams for acute medicine and traumatology including SCI and provides assistance regardless of time, place, and insurance by a uniform alert and response system. A dedicated toll-free phone number, 113, routes calls to emergency medical dispatch centers (EMDCs). Ground ambulances, boats, and/or helicopters are dispatched with

specialized teams including medical doctors based on criteria in the Norwegian Index for Medical Emergencies,<sup>6</sup> a decision tool to secure appropriate responses to medical emergencies. Each call is classified as either “acute” (highest priority), “urgent” (high, but lower priority), or “not urgent” (lowest priority). When “acute,” both ambulances and the medical staff on call are alerted. Together with the emergency medical dispatch centers and increasing competence of ambulance personnel, the emergency medical service of serious accidents and/or illnesses has improved.<sup>6</sup>

In cases of accidents where a traumatic SCI cannot be excluded, the patient is assessed and stabilized as soon as possible by specialized emergency medical staff and, with some exceptions, transported to 1 of 4 specialized trauma hospitals. These hospitals are located in the cities of Oslo, Bergen, Trondheim, and Tromsø and cover 20 emergency regions.<sup>7</sup> In 6 of the emergency regions, the transport time is less than 2 hours. In northern Norway, it is more than 4 hours in 2 of 5 regions.<sup>8</sup> If transport time is more than 45 minutes to a trauma hospital, the patient will be transported to the nearest acute care hospital.

In Norway, there are 3 specialized SCI rehabilitation units; these are located at Sunnaas Rehabilitation Hospital, Haukeland University Hospital, and St. Olav's University Hospital. Each SCI unit covers a designated part of Norway; Sunnaas Rehabilitation Hospital the southeastern part, Haukeland University Hospital the western part, and St. Olav's University Hospital the mid- and northern part of Norway.

### LIVING WITH SCI

Norway has a number of laws and regulations aiming to reintegrate people with disability back to employment. Important regulations are the Disability Discrimination Act,<sup>9</sup> The Working Environment Act,<sup>10</sup> and the Agreement on Inclusive Working Conditions between the government, the labor unions, and the Norwegian Federation of Employers.<sup>11</sup> The UN Convention on Disability from 2006 was implemented into the Norwegian legal system in 2008.<sup>12</sup> Norway is among the top spenders on publicly sponsored reeducation and back-to-work programs in Europe.<sup>13</sup>

Studies of the Norwegian SCI population show that approximately 65% to 70% is employed at some time after injury (Leiulfstrud A, Solheim E, submitted for publication, 2015).<sup>15</sup> Important factors predicting employment after injury are levels of education and the opportunity to continue working in the same organization as before the SCI (Leiulfstrud A, Solheim E, submitted for publication, 2015), and also age and severity of the injury.<sup>15</sup> Women have been reported to have significant lower employment odds in the past,<sup>15</sup> but more recent data

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show small sex differences in employment patterns (Leilulfsrud A, Solheim E, submitted for publication, 2015). People with SCI are expected to marry and have children and to take part in social activities at the same level as other citizens.

## THE HEALTH AND REHABILITATION SYSTEM

Norway has a universal public health system including all citizens with a permanent address in the country. Some have additional private health insurance coverage or health insurances sponsored by their employers.<sup>16</sup> However, this only applies to less than 5% of the population. Moreover, neither is there a private hospital with acute services for SCI or other severe injuries, nor a private specialized rehabilitation facility for SCI. The public health system offers people with disabilities access to disability pension if they are unable to work.<sup>17</sup> A national health strategy covers all citizens.<sup>18</sup>

Community services are available, and individual rights are protected by legislation. The act relating to municipal health services obliges municipalities to provide a number of health services including general practitioner arrangement, physiotherapy, home nursing, and nursing homes. The law provides the right to receive necessary health services for all who live in a municipality. The Social Service Act and the Patient's Rights Act also cover the rights as a recipient of health services and describe what the members of the community are entitled to.<sup>19</sup> In addition, the Norwegian Labour and Welfare Administration will assist the users in returning to work and reintegrating to the community.<sup>11</sup>

## WHAT IS THE STATE OF SPECIALIZED CARE?

Specialized spinal cord rehabilitation units are integrated at Haukeland University Hospital and St. Olav's University Hospital, with 10 and 12 beds, respectively, dedicated to SCI. Oslo University Hospital transfers sub-acutely their patients with SCI to Sunnaas Rehabilitation Hospital, which has 34 beds available for primary rehabilitation and 17 beds for follow-up. The average length of stay in hospital from acute care until end of primary rehabilitation in 2014 for all SCI units was 121 days for traumatic SCI and 91 days for non-traumatic SCI.<sup>1</sup> The SCI units have well-trained multidisciplinary rehabilitation teams that may include physiotherapists, occupational therapists, social workers, psychologists, teachers, sports therapists, peer support specialists, nurses, and medical doctors. Examples of rehabilitation services provided are mobilization, pain and spasticity relief, urinary tract and bowel management, vocational training, patient education, strength and endurance training, wheelchair skills development, adaptation of assistive devices, adaptation of home environment, assistance with economic issues, nutritional advice, and psychological assessment and support.

All SCI units have a commitment to life-long follow-up for persons with SCI. After the primary rehabilitation, they will be admitted for regular checkups depending on their needs. In addition, the users can contact the hospitals if they have specific issues that need solving, or they can contact the ambulatory rehabilitation team, which will be able to support them, and the health care providers in the community.<sup>20</sup>

## THE SOCIAL RESPONSE TO SCI

According to Norwegian law, all people have equal rights to necessary health care, both in the primary and specialist health care services.<sup>21</sup> All disabled people have access to assistive technology such as wheelchairs, equipment for home, and communication systems. To reduce social stigma against disability, campaigns are designed and all new public buildings and transportation, except flights and ships, are required to have a universal design according to the Anti-Discrimination Act.<sup>9</sup>

Most disability organizations in Norway operate under the umbrella of the Norwegian Association of Disabled<sup>22</sup> or the Norwegian Federation of Organizations of Disabled People.<sup>23</sup> Persons with SCI may hold a membership of the Norwegian Spinal Cord Injured Association (Landsforeningen for Ryggmargsskadde [LARS]). LARS is based on the philosophy of empowerment, and runs on a voluntary basis by their members, and is organized with a national executive board and 10 local autonomous branches. LARS arranges meetings, different activities, and is carrying out peer support at the SCI units. LARS has a good collaboration with the SCI units on different projects, and work for better rehabilitation, technical aid equipment, and research on SCI, among others.

There is no specific organization providing funding to persons with SCI in Norway, but LARS may apply for project-specific funding from a National Lottery (<http://www.extrastiftelsen.no/>), the Norwegian Directorate of Health, or get financial support to arrange meetings, etc., from private sponsors.

## THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

### What Do We Hope to Gain from Participating in the InSCI Study?

The Norwegian international SCI Survey (InSCI-Nor) will supplement the already superior epidemiological data from NorSCIR, by adding information about the full-lived experience of SCI, and the perception on the part of patients with SCI of the nature and adequacy of the social response to their needs.

### THE NATIONAL STUDY PROTOCOL

The survey questionnaire will be translated into Norwegian "bokmål", as this is the language used and understood by most of the population. Eligible persons for the study will be those with traumatic and nontraumatic SCI, age older than 18 years, who have completed primary rehabilitation since year 2000. In addition, they are required to have permanent residency in Norway and being able to respond to the questionnaire in Norwegian. Those with progressive etiologies, including other nontraumatic etiologies, such as congenital, inflammatory and autoimmune diseases, malignant tumors, and injury due to toxic agents and radiation, will be excluded. The electronic medical records at the 3 SCI units will be reviewed to identify eligible participants.

To recruit respondents, written invitation letters will be sent via the postal service. Reminders will be sent, either by post, telephone, or SMS. The invitation letter will contain information about the study, an informed consent form, the paper questionnaire, and a personal log-in code for the Web-based

questionnaire. Participants can choose between different response modes, either a self-administered paper- or a Web-based questionnaire or a telephone interview (upon request).

Each eligible participant will be assigned a unique anonymous international study ID. The paper questionnaire will contain this ID on each page. The key for linking the international ID to the national personal ID, as well as electronically scanned paper questionnaires, will be securely stored by the study coordinators at Sunnaas Rehabilitation Hospital. Data security and confidentiality will adhere to Norwegian legislations. A central international database is envisioned. The national leader and survey coordinators will have access to this password-protected central database.

Applications for approval will be sent to the regional committees for medical and health research ethics.

### OPTIONAL NATIONAL MODULE

Additional modules for InSCI-Nor will be developed addressing issues such as employment, nutrition, physical activity, and shoulder pain. The modules will be part of PhD/postdoctoral or other research projects. Each module requires approximately 5 additional questions: questions on *employment* will be part of a postdoctoral project at St. Olav's University Hospital to get more in-depth information about the employment and work situation before and after injury; to assess the importance of work autonomy and empowerment at work; and to study the relative differences between occupational class groups in level of living and their overall life situation. Questions on *nutrition* will be part of a PhD project at Sunnaas Rehabilitation Hospital aiming to survey nutritional status in the SCI group. Questions on *physical activity and training* will be a continuation of previous research at St. Olav's University Hospital to study the overall importance in health and quality of life between those actively engaged in physical activity and training and those less active. Questions on *shoulder pain* will be part of a PhD project at Sunnaas Rehabilitation Hospital aimed at investigating prevalence of shoulder pain and exercise interventions in the management of upper extremity pain.

### CONCLUSION

The present survey gives an overview of a relatively good health and social system for persons with SCI in Norway. The planned study is an excellent opportunity to compare the Norwegian system with many others around the world, thus establishing a basis for discussing current challenges concerning SCI, especially the most encouraging and discouraging signs for the future. In addition to the comparative dimension of the survey, the systematic sampling of

Norwegian data facilitates further studies of the Norwegian SCI population, and similar national studies can be made in participating countries.

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