

The **Stoke Mandeville Spinal Foundation** is a foundation established to promote research to improve the quality of living with a spinal cord injury. It hopes to establish a research institute at Stoke Mandeville Hospital to promote clinically relevant research that will address the full range of people's needs following spinal cord injuries. If you are interested in finding out more information or making a donation please write to:

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Spinal Cord Injury Research

By the Department of
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The Department of Clinical Psychology at the National Spinal Injuries Centre (NSIC) has been carrying out research with people with spinal cord injury (SCI) for over 20 years. The main aim of our research is to improve rehabilitation and help support people with SCI through the adjustment process. Over the last two years our research has focused on three distinct areas: (1) coping and adjustment; (2) social and community life; and (3) the development of measures to assess rehabilitation. The following is a brief overview of this research.

Coping and Adjustment

Research has been carried out to investigate **how the way people with SCI think about themselves and their situation influences Post Traumatic Stress Disorder (PTSD)**. The study found PTSD was more likely to be experienced by those people who evaluated themselves or their situation negatively (e.g. believing "I can't manage this situation" or "this situation will never get better"). Symptoms of PTSD include flashbacks, nightmares, and intrusive thoughts and images which can be triggered easily. PTSD can interfere with everyday life and effective rehabilitation, and it is therefore important to treat it appropriately. The Clinical Psychology Department at the NSIC can offer assessment and treatment for PTSD. Alternatively you can talk to any health professional should you be concerned or want more information about this.

Our research has also investigated the **emotional impact of SCI and the strategies people use to cope with their injury over time**. The research indicated that many people successfully use helpful coping strategies to manage the consequences of their injury, for example: using a problem-solving approach to identify

Finally, we would like to thank all the patients and staff who contributed to this research. The NSIC place an emphasis on research in order to further knowledge about SCI and improve health services. Much research is carried out at the NSIC by professionals from a range of disciplines. If you would like any further information regarding this research please contact the Department of Clinical Psychology at the NSIC.

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Development of Measures to Assess Rehabilitation

A measure of rehabilitation performance called the Needs Assessment Checklist (NAC) has been developed by Department of Clinical Psychology at the NSIC. It is used to highlight individual needs and provide personal rehabilitation programmes. A new version of the NAC has been developed for children called the **Child's Needs Assessment Checklist (Child NAC)**. It is both developmentally based and responds to changing needs as a child grows. Results from children and adolescents who completed the Child NAC demonstrated its effectiveness in achieving good rehabilitation results, and the Child NAC can now be used confidently in the clinical setting.

Some of our research has also focused on assessing the quality of the **Hospital Anxiety and Depression Scale (HADS)** which is currently being used to assess anxiety and depression in the SCI population. The HADS was completed by SCI patients living in the community, and the results confirmed that it can be used confidently as a clinical assessment tool for anxiety and depression in this setting.

An assessment tool called the "**Spinal Cord Lesion-related Coping Strategies Questionnaire**" has been developed in Sweden to identify which coping strategies patients use. We conducted some research to determine whether the translated versions of the questionnaire are accurate outside of Sweden. After a group of patients from four European countries completed the questionnaire, some questions were highlighted as needing revising and retesting. The questionnaire therefore needs attention before it can be used confidently outside of Sweden.

and tackle current difficulties; seeking good quality advice and support from others; accepting that changes have occurred, and identifying personal strengths to help pursue important life goals. The results of this study have been used to help form the approaches used in rehabilitation at the NSIC and emphasise the importance of targeting helpful coping strategies early on. A leaflet on "Coping with Spinal Cord Injury" has been produced by the Department of Clinical Psychology and can be found on every ward in the spinal centre.

An international research study **compared the quality of life, life satisfaction and mood between Chinese and British people with tetraplegia**. The British patients were found to be overall more satisfied than the Chinese group and reported lower levels of anxiety and depression. This difference was considered in part due to the emphasis on support and adjustment in British centres.

We are currently carrying out an international research project which investigates the **psychological responses, perceptions, and coping strategies of patients following SCI**. People from a number of European countries are completing questionnaires four times over a three year period. We hope to gain more knowledge about which coping strategies are helpful, and which are unhelpful, with the management of problems associated with depression, anxiety, and adjustment to SCI.

Another ongoing research project is looking at the **pattern of adjustment and coping in children with SCI, their parents and their siblings**. Children and their family members are being interviewed three times over the first two years after the injury. It is expected that the results of this study will help

healthcare professionals to better understand the impact of SCI on children and their families. This study aims to help develop services which can support children and families in coping and adjusting to life after injury.

Social and Community Life

We undertook some research to **identify areas of social and community need for people with SCI in four European countries**. The findings highlighted employment, sexual activity and relief from pain as the main areas of unmet need which require addressing. Needs which were particularly well addressed were skin management, wheelchair needs and accommodation.

The importance of supporting the **participation in sport and leisure pursuits** was shown in another study which investigated the benefits of an activity course organised by the Back-Up Trust. Those who took part described improved satisfaction with life and leisure, greater enthusiasm to participate in activities, and improved mood levels. Participants also rated the positive impact of going on the course on rehabilitation, meeting others with SCI, improvements in confidence, the development of new skills, and the broadening of their perceptions about their capabilities. The Back-Up Trust is a national charity that supports people, young or old, with SCI. They run a variety of services that encourage self-confidence, independence and motivation following a SCI - for further information about this ask a member of staff at the NSIC or visit their website at www.backuptrust.org.uk.

A further study recommended that **attention should focus on educating people about leisure and equipment facilities** relating to interests prior to their injury. Involvement in more active recreation may also reduce the likelihood of developing secondary complications. The study identified older people and people with high lesions as groups which could particularly benefit from extra support and education about this.

We have also been involved in research into the issues related to **skin management** and the **development of pressure sores**. As might be expected, people who held positive attitudes towards skin management were more likely to actually perform pressure relief and skin checking. Less skin care knowledge was found for people who had developed pressure sores. This emphasised the importance of patient education to promote skin management and appropriate follow-up. The importance of educating family members on skin management was also suggested in order to increase the likelihood of pressure relief and skin checking being performed.

A currently ongoing piece of research seeks to look at the **community needs of people who have recently been discharged** from hospital. The main aim of the study is to identify which needs in the community are not currently being met from a physical, psychological and social point of view. This will help identify gaps in rehabilitation services and indicate areas which will need to be addressed in order to help people get back into their community life. It will also highlight areas which will need prioritising in the rehabilitation setting to prepare people for discharge, and identify specific groups of patients whose needs are not currently being met.