

## **ESCIF Congress at MSF in Lobbach**

### **Nutrition, creativity and awareness of the body**

**18 April 2007, 14.00 – 15.30**

#### **Summary of discussion**

The open discussion session followed an earlier presentation on "Nutrition and well-being" by Kevin Schultes from the Manfred Sauer Foundation and a guided tour of the centre's facilities.

The presentation in the morning explained the philosophy and aims of the Manfred Sauer Foundation with special emphasis on the field of nutrition:

- To investigate the role of food in the facilitation of bowel management
- To use dietary measures to replace the need for medication
- To use an understanding and knowledge of nutrition to prevent weight gain (and the risk of diabetes 2) that so commonly follows SCI
- To encourage a creative approach to cooking and food preparation and to enjoying a healthy diet

Furthermore the basic philosophy of the Manfred Sauer Foundation is supported by two further "pillars": "awareness of the body" and "creativity and activity". The aims of the Foundation, with particular regard to people living with spinal cord injury, can be briefly summarised as follows:

- To create a platform to enable people to cope with SCI – both the person who is injured and their families
- To encourage strategies for a better well-being
- To develop creative talents in the handicraft workshops

The afternoon discussion session was opened by Kevin Schultes who encouraged the participants to ask questions and air their views – not only on the subject of nutrition, which had been the primary focus of the morning presentation, but also on the topics of well-being, creativity and awareness of the body. The aim of the session was closely tied to that of the foundation as a whole; to encourage the exchange of views of "experts" in living with SCI.

Kevin elaborated on the ideas and aims of the working group set up by MSF over two years ago. The group comprises two doctors (one the head of a spinal unit and specialist in alternative therapies, the other a reputed proctologist), two members of staff from MSF (Kevin himself and Veronika Geng), Manfred Sauer and Karola Schwarz from the board of the MSF and a delegate from the German Spinal Injuries Association, a paraplegic herself. The long-term aim of the work is to be able to recommend specialised diets to alleviate or overcome the difficulties faced by individuals with SCI and if possible minimize the need for medication. Until now the group has studied different dietary traditions and tried to review the existing research material. It plans, however, to initiate a multi-centre study to

collect existing information, to establish an international database, to compile trends and strategies based on countries with different dietary customs – perhaps in collaboration with ESCIF.

Jan Reinhardt, a researcher from Swiss Paraplegic Research, drew attention to a systematic review on environmental factors in SCI that is currently being conducted in Nottwil and Munich. Since food is an environmental factor, according to WHO's International Classification of Functioning, Disability and Health (ICF), the role of nutrition/food in living with SCI will also be systematically reviewed. Dr Reinhardt offered to look specifically at the relationship between nutrition and bowel management in this context and report the results to ESCIF and the MSF.

The discussion turned to the importance of this area of research. It was generally agreed that bowel management is, for people living with SCI, one of the greatest challenges. The inability to cope successfully with this problem is highly detrimental to "quality of life", making work and social activities extremely difficult. After many years of research into the problems of bladder management, it seems that focus is now turning to that of bowel management in particular and nutrition in general. Some specific examples of this were mentioned

- The spinal centre at Bad Wildingen in Germany is discussing a centre specialising in bowel management
- The World Health Organisation has been carrying out a project on food and nutrition. The results of the study will be available at the end of 2007.
- A researcher from Finland (who is a paraplegic herself) has been carrying out a study of bowel management problems at the University of Illinois
- In Denmark, Klaus Krogh has recently completed a study of practices and problems in bowel management that follows up an investigation carried out ten years ago. As the same sample has been used in the second study, this should make it possible to make comparisons over time. The results will be presented at the ISCoS/NoSCoS 2007 conference on Iceland.

Some delegates expressed certain reservations about gathering information on this topic: both in terms of the methods that could be used and what information might be useful. Some felt that the response rate for questionnaire surveys was so low that the method was unwieldy: a researcher working in the field of SCI assured the group that the response rate among people with SCI was usually quite good – around 60%. The group agreed that a survey in an area so central to the lives of people with SCI would probably yield a high response. It was, however, pointed out that it had proved extremely difficult to draw useful conclusions from a questionnaire survey on bowel management that had been carried out in Croatia, despite the fact that 100 people completed the questionnaire; the variety of the responses and the fact that answers often contradicted each other meant that no general trends or strategies could be discerned.

It was suggested that one potential source of information could be nursing databases – on the basis that nurses working in this area have, perhaps, more practical knowledge than doctors trained in gastro-enterology. This suggestion gave rise to a number of direct and indirect responses: the delegate from Ireland pointed out that the bowel management

skills taught and learned during rehabilitation are better suited to the hospital environment than to everyday life outside the hospital. This could be the cause of problems in the long-term. The UK delegate recounted problems that SCI patients can face when hospitalised on general wards: where the nursing staff has no knowledge or experience of caring for patients with SCI. He showed the group a "plastic card" with his name and details, which actually described the "bowel evacuation" method required.

Daniel Joggi felt that most people with SCI know what they should eat and what they should do to avoid problems with bowel management – the important question is why they do not follow the regime. It was suggested that this was related to Colm Whooley's earlier point that hospital regimes are not always applicable in real life and, further, that people with SCI attempt to follow what they learned during rehab but that physical conditions can change over time. In addition, they may not always be aware of newer, improved methods that do not have the same long-term side-effects of using, for example, medication to facilitate bowel management.

Spain introduced a new topic - that of osteoporosis – and asked how this problem was tackled in different countries. There was a general discussion concerning the efficacy of calcium supplements, walking and standing practice, and the use of FES but no general consensus was reached. The delegate from Switzerland pointed out that recent research has indicated that applying load is not enough to maintain or improve bone mass; a new study has shown that standing for 20 minutes, twice a day, on a vibrating plate yielded a positive result after three months. This method was based on that developed for astronauts working in zero-gravity conditions who also experience loss of bone mass.

Finally, the discussion turned to the general question of activity. In a short presentation on the first day of the congress, Manfred Sauer had explained that the centre offers creative activities because the situation in Germany at present makes it unlikely that people with SCI are able to return to the labour market. Therefore, it is important to find and develop new skills to work with. It was suggested that this may not be the case in all member countries. In some ESCIF countries unemployment is currently so low, and the demographic trends are such, that it may become easier for people with SCI to return to work or, at least, to retain some connection to the labour market. It was, however, generally agreed upon in the group that the important goal should be to encourage some kind of activity that will enable the newly-injured person to find meaning and quality in life, irrespective of whether this is work, sports, creative activities or family and social activities.

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