

Rehabilitation and Goal Planning at the National Spinal Injuries Centre (NSIC)

Introduction

“Goal Planning does help you understand your injury, and it gives you a more informed way of talking about your injury... in your head, things can seem like a mountain and it can help you bring it back into proportion”- M, NSIC Patient



A spinal cord injury (SCI) is a new situation for most people, so it can be easy to feel frightened and overwhelmed because of all the things you need to adjust to, and learning how your body has changed. The impact on your life can seem very big, especially when first in hospital, and it might seem that everything is different - friends and family, work, hobbies and interests.

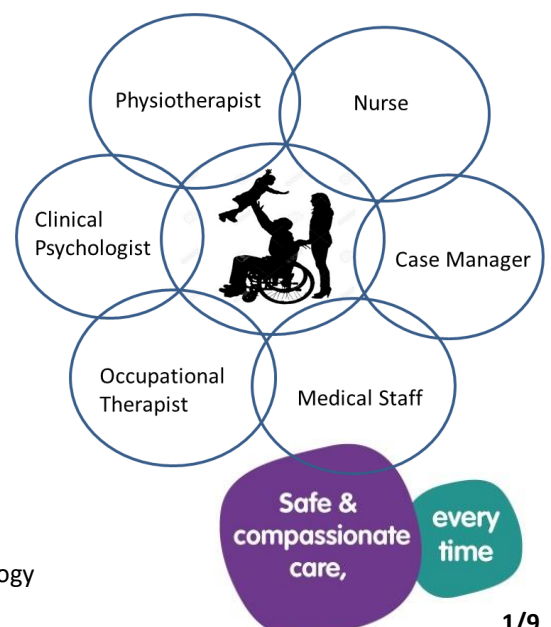
The rehabilitation process involves you and your team setting goals to help you learn, adjust and manage any long-term changes successfully, with support being provided along the way.

Goal planning is a way of assessing and meeting your individual needs and setting goals with you. It helps you to leave us with the resources and confidence to cope with a new or adapted home, if needed, and live well in the long term. This leaflet aims to help you understand more about your rehabilitation and gain a sense of control.

Who and what is involved in Goal Planning?

First, we assess your needs together using the **Needs Assessment Checklist**. This helps you and the team to understand your priorities, set rehabilitation goals at the right level for you and involve you in making decisions. The assessment looks at what you know about your body and how to look after it after a SCI, what you can do and what you need to learn to do again. It helps to ensure that your rehabilitation programme is geared towards your individual needs, building on the strengths you have and the things that are important to you. We have found that involving patients in setting small, manageable targets and goals helps their adjustment to SCI and makes rehabilitation easier for you to understand and participate in. There is good research evidence that shows when **people work together with their team and participate** in their rehabilitation and set their own goals, they are **less likely to feel overwhelmed and more likely to cope** and adjust in the longer term.

You will have a range of people working with you in rehabilitation: nursing and medical staff, physiotherapists and occupational therapists (OTs), clinical psychologists and case managers as well as other members of the team such as speech and language therapists as needed. One of these people will also be your **Keyworker** – someone who helps co-ordinate your rehabilitation by supporting you and the team to set goals and co-ordinating the goal planning meeting and rehabilitation process.



“The whole process allowed me to understand and focus on the things that mattered, and to monitor them between meetings” - A, NSIC Patient



What happens?

First, you will complete the **Stoke Mandeville Spinal Needs Assessment Checklist (SMS-NAC)** with your Keyworker or named nurse. The SMS-NAC is a measure of your knowledge and understanding of spinal cord injury and the progress you have made. At the beginning of your rehabilitation, your knowledge will understandably be limited but the SMS-NAC helps us guide rehabilitation around your needs. It was developed here at the NSIC and different, updated, versions of it have been used for over 30 years to guide our rehabilitation programme. It is also used by Centres across the world as it sets out standards about spinal cord injury care and rehabilitation based on current evidence and best practice. We also use it to measure the outcome of your admission and the service provided here at the NSIC. You will complete a second SMS-NAC about 4-6 weeks before your discharge, which also helps us to help you identify any further goals.

After you have completed the SMS-NAC, you will receive a summary a few days later. A graph will show the areas of rehabilitation you have already learnt about and are able to manage, and the summary will list the needs that you now have because of your injury. These needs will be used to set targets and goals for your rehabilitation programme.

“I feel goal planning is a very empowering part of my rehabilitation. Through careful planning, it showed me I could do things that I did not think were possible”
- S, NSIC Patient



Goal Planning involves you and your team meeting to set short-term targets (things you will focus on over the next few weeks) and longer term goals. Goals will be very practical, clear and constructive: things like learning to get dressed or transfer into a wheelchair, and looking after your body now, or they may involve setting goals about going home for the weekend. They will also include your target discharge date and steps you may wish to take to prepare your home and your family and friends. Goal planning meetings will take place all the way through your rehabilitation at the NSIC. Each meeting will review the goals from the last meeting and help set new goals as you progress. Your family and friends may also attend these meetings.

The primary aim of goal planning and rehabilitation is to support you in gaining the skills to deal with the new challenges and adjustments relating to your injury, leading to a safe discharge.

You can use the link below to watch a short you tube video to show you how the SMS-NAC and Goal Planning work at the NSIC - <https://youtu.be/yPt7cvqzSKk>

We have a number of leaflets that previous patients at the Centre have helped us to create to show how people with different levels of injury, age and personal experience have got on in rehabilitation and their recommendations for what can help. Please visit www.nsic-online.org.uk or ask your Keyworker if you would like a paper copy of these.

What does your keyworker do?

Your Keyworker is a member of the team, they might also be your Physiotherapist, OT, Case Manager, Nurse or Clinical Psychologist. In the Keyworker role they will:

- Support you to understand the needs you now have after your spinal cord injury
- Give you information and advocate on your behalf
- Coordinate and oversee your rehabilitation

If you have any concerns or worries about your rehabilitation, please speak with your Keyworker - part of their role is to help support you.

Some Frequently Asked Questions:

In the next section of this leaflet, we go through some of the questions people often have about their needs and the different elements assessed by the SMS-NAC and areas for rehabilitation goals.

What are my needs now?

Spinal cord injury is a very complex injury involving many interlinked systems in your body. The SMS-NAC looks at each of these areas and the knowledge and skills that you need to gain.

Physical Healthcare - asks about your previous health and includes new aspects that may have been affected, such as breathing. It asks about any pain or other problems you might now have and also your knowledge of medication. The nature of your injury and the extent of any paralysis can be discussed with your doctors at any time, and if you have questions please raise these during the medical ward round. A separate, private appointment can also be made which can include your family.

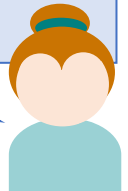
Daily Living Activities – includes day-to-day aspects like eating and drinking, washing and personal hygiene. Occupational therapists will work with you on all these skills.

Skin and Posture Management; Bladder Management; Bowel Management – these sections go through all the essentials of how an injury can lead to changes to your body, and your knowledge and skills in caring for them. Depending on the severity of your injury, these aspects will all be affected and may need long-term management and changes. Nursing staff will provide you with practical advice on how to manage these and your general healthcare.

“I think my biggest personal achievement has been in my bladder and bowel care, where I have been able to make a great deal of progress, leaving the centre without a catheter and with full control. When that last piece of the puzzle fell into place, I was really proud of myself.” - E, NSIC Patient



“Initially it’s quite daunting, and you’re quite scared. You don’t really know what you need to do, and the staff help you to understand... Even things like understanding bladder problems and bowel problems, which you never even thought of being long term problems, the staff help you to understand that and manoeuvre your way through the system.” - M, NSIC Patient



Mobility; Wheelchair and Equipment - Getting out and about is as important now as it has always been. The physiotherapists can help you prepare for this by involving you in exercises to improve your strength, balance, coordination and range of movements. They will assess your wheelchair and cushion needs to enable you to get around as independently as possible.

If you require a powered wheelchair, the OTs will provide you with advice. Any other equipment requirements will be identified with you and arrangements made for these on discharge.

Community Preparation - It is important to be able to participate again in the things that are important and of value to you and return as much as possible to your interests before SCI and admission to hospital. This will involve resuming your role within the family, at work, going out and meeting up with friends. It is a gradual process that will begin while you are in hospital, often starting with small trips, maybe a weekend in the NSIC bungalow and weekends at home. OTs and other staff will talk with you about all these aspects, and your hobbies and interests, so that rehabilitation is personal to you. As part of your weekly rehabilitation programme, time is available for ongoing sport and recreation.

Learning about your health needs and SCI is important in helping you develop independence and control.

““I like to take care of my skin, [and] I’ve learned that here, [that] it’s very important: skin, bladder, bowels. All the things that I’ve learned, I’ve learned here, in patient education – I’ve learned a lot of things.” - M, NSIC Patient



The **Patient Education Coordinator** organises a group teaching programme for patients, and a Relatives' Day for your family and friends. We also offer a day specifically for child relatives each year - please ask for information.

We encourage you to nominate a family member as our link and for this person to attend your goal planning meetings and help support your discharge.

Psychological Health - There is no set way of feeling or coping and people often say they experience a range of emotions and thoughts, and worry most about the everyday things. There are few events in life that can prepare us for such a sudden change. Previous patients have described sometimes feeling low in themselves about losses and changes, feeling anxious because of fears and doubts about the future, or get angry at a sense of injustice and ask 'why me' or think 'if only I.....'. All these feelings are normal emotions.

The process of adjustment and adaptation may produce emotions which are difficult to cope with alone. There are a variety of people who can help. Talking with family and friends is a great support, in addition to this the NSIC has a range of other people who provide support and information about SCI which can help you cope:

- volunteers who have a spinal cord injury and SCI charities
- all members of the team are trained to help you talk through times you might feel low or worried
- our Clinical Psychology team use a practical, evidence-based approach from years of experience to confidentially talk through your concerns

"During my rehabilitation, Clinical Psychology was particularly helpful for me... Getting through the experiences I have had is not easy, but there is always a way."
- M, NSIC Patient



You might also find it helpful to look at our leaflet on emotional health after SCI for practical information. Our experience indicates that most people learn to manage the consequences of their disability well and go on to live a quality of life consistent with their pre-injury expectations.

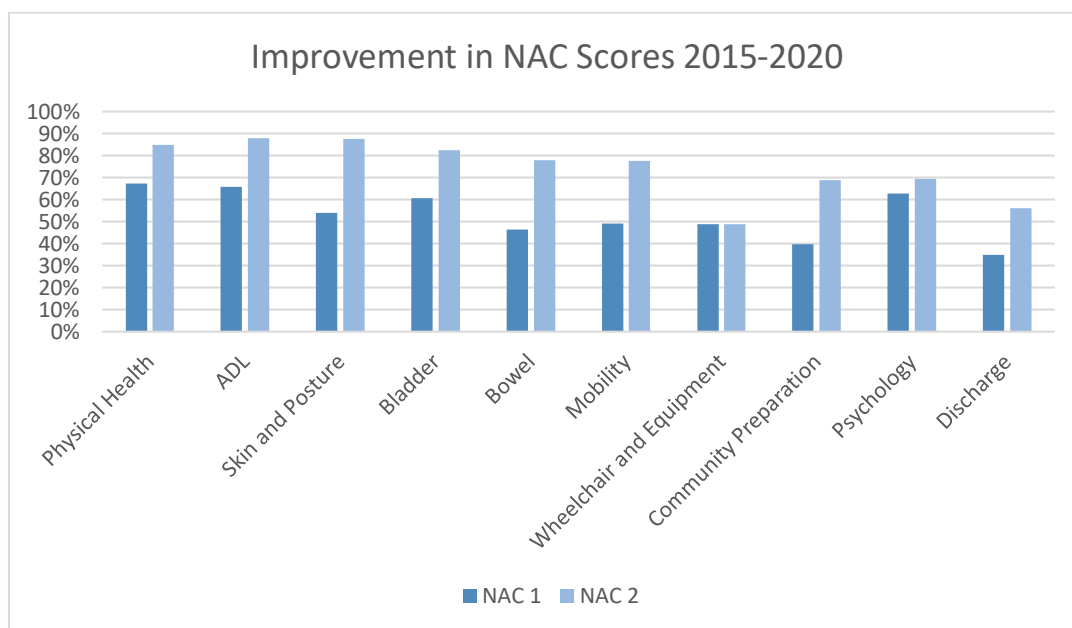
Research shows that people's sexual needs often remain the same after SCI, even if there are changes to sexual functioning associated with the injury. Medical staff and members of the Spinal Outpatient team are available to discuss issues related to fertility and the physical aspects of sexual functioning. Clinical Psychologists can discuss other emotional and partnership concerns with you. The most important thing is to find someone that you feel comfortable talking with.

Discharge Coordination - The process of planning your discharge from hospital starts from the day of admission to the NSIC. Contact will be made with services in your local area to plan for the things you may need. This could include adaptations to your home or maybe a package of care to help support you to live in your own home.

Case managers at the NSIC coordinate your discharge and will meet with you early on in your rehabilitation to discuss what best suits your needs and identify people, such as a Social Worker, who can support your home and care needs.

We set a discharge date with you at the second goal planning meeting so that we can give your home area as much notice as possible to meet your needs. After your discharge from the NSIC, you will be given an appointment and followed up from the Spinal Outpatient Service, based at the NSIC.

The chart below gives an example of NAC checklist scores at admission (NAC1) and discharge (NAC2), and how knowledge and confidence increases for patients over time



“It took me a very long time to realise the importance of being verbally independent and being able to state how things should be done and how I would like them to be done. It was the best thing I could have achieved.” - S, NSIC Patient

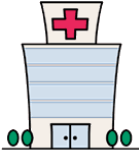



Your level of SCI may mean that you need care support for some things, like dressing. The essential goal in this is to enable you to remain in control of your life, with physical help if needed. “Verbal independence” (having knowledge of your care needs and being able to say to people how to provide your care) is critical to your successful return home and is a skill that is learnt as part of your rehabilitation. Advice about personal assistants and the recruitment and training of carers is available. Your Case manager will also talk with you about your financial well-being and can assist you in claiming benefits, if needed. Applications for assistance from charitable sources can also be arranged where a specific need is identified.



Marius, in his 30s, has a C4 A SCI



Marius' Highest Achievements

	Bowel Management	Community Preparation
 On Admission	25%	30%
On Discharge 	92%	89%



Elaine, in her 50s, has a C5 C SCI



Elaine's Highest Achievements

	Activities of Daily Living	Community Preparation
 On Admission	24%	27%
On Discharge 	89%	76%



Sandra, in her 70s, has a C6 A SCI

Sandra's Highest Achievements

	Activities of Daily Living	Bowel Management
 On Admission	10%	8%
On Discharge 	92%	92%

Who is available to help me?

SCI is a complex injury needing specialised care and rehabilitation. All members of the team contribute to your rehabilitation and examples about some of their roles have been talked about already.

Other people who can help support you specifically are:

The **Patient Education Team**, which includes people with lived SCI experience who have often been a patient at this Centre themselves and therefore understand some of the issues or concerns. A member of this team also sits on the governing board of the NSIC which helps to change/develop our service to meet our changing patients' needs.

The **Family Counsellor** is a point of contact for any member of your family and can provide support for them. We are very aware that your injury will have affected not only you, but the people around and important to you as well. It is important that your family and friends know about your condition and progress. Your family will be invited to attend Relatives' Day. Members of the team are always available to discuss with your family any specific concerns.

As part of your rehabilitation you may see other staff to help you with specific needs, such as nutrition and diet, or staff to advise on specific aspects of care.

We have a range of charities, the **Spinal Injuries Association**, the **Back Up Trust** and **Aspire** who all visit the Centre regularly and can provide a wealth of personal experience and signpost you to resources in your home area.

Concerns

If you have any concerns about the treatment and rehabilitation you receive, or about your experience at the NSIC, please talk with your Keyworker or another member of staff, if you are more comfortable with them. You can also raise concerns confidentially through Buckinghamshire Healthcare NHS Trust. Please see Patient Advice Liaison Service (PALS) information below.

If you are particularly happy or unhappy about the service you receive at the NSIC, you are welcome to let us know, preferably in writing (please email bht.compliments@nhs.net)

All NHS Trusts have a commitment to monitor and improve the quality of their services and therefore comments from users of those services are especially helpful.

Please remember that this leaflet is intended as general information only. We aim to make the information as up to date and accurate as possible, but please note that it is subject to change. Please therefore always check specific advice on any concerns you may have with your doctor.

How can you help reduce healthcare associated infections?

Infection prevention & control is important to the well-being of our patients and for that reason we have infection prevention & control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. Please follow our infection prevention and control guidelines when visiting our healthcare sites. Further information is available on our website.

Patient Advice Sheet

If you would like a copy of this information on audiotape, **in large print** or translated, please call the Patient Advice Liaison Service on 01296 316042 or email bht.pals@nhs.net