

Information Booklet for Relatives and Friends

National Spinal Injuries Centre (NSIC)
Stoke Mandeville Hospital

How can I help reduce healthcare associated infections?

Infection control is important to the well-being of our patients and for that reason we have infection control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to or after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser. Staff will let you know if this is the case.

www.buckshealthcare.nhs.uk

Follow us on Twitter @buckshealthcare

If you require a translation of this leaflet please call 01296 315858

Author: S.Standish,L.Robinson
Issue date: October 2015
Review date: October 2018

Leaflet code: WZZ-1305
Version: 3

Safe & compassionate care,

every time

INDEX:

Contact numbers	Page 4
Frequently asked questions	Page 5
Wards within the NSIC	Page 6
Visiting times	Page 8
About yourself	Page 8
About your relative	Page 9
Processes through Rehabilitation	Page 10
Rehabilitation information meeting	Page 10
Needs assessment checklist	Page 10
Goal Planning Meetings	Page 11
Discharge Planning Meeting	Page 11
Discharge from the NSIC	Page 11
Staff within the NSIC	Page 11
Case Management Team	Page 11
Clinical Psychologists	Page 12
Consultant	Page 12
Family Counsellor	Page 12
Psychosexual Therapist	Page 13
Key worker	Page 13
Named Nurse	Page 13
Patient Education Co-ordinator	Page 14
Occupational therapist (OT)	Page 14
Physiotherapist	Page 14
Patient Support Officer	Page 15
Peer Support Adviser	Page 15

Notes:

Trust Policies

The following is strictly forbidden by the Trust:

Alcohol: The consumption of alcohol is not allowed anywhere on Trust premises. This includes all areas within the hospital, courtyards, footpaths or car parks.

Smoking: The Trust is a smoke-free site and smoking is forbidden everywhere on site. Please note that this also applies to cars parked in the hospital grounds.

Violence: Violence against staff working in the NHS is a crime and will be reported to the police. Staff working in the NHS are carers of others and therefore do not come to work to be the victims of violence or abusive behaviour. Any form of aggression, violence, threatening behaviour, verbal or racial abuse are not tolerated.

Illegal Substances: Possession or consumption of unauthorised/illegal substances is **strictly forbidden**. Such possession is against the Law and the Police will be notified of any person found to be in possession. Any unauthorised/illegal substance found in the Centre will be confiscated and handed to the Police for disposal and the individual will be asked to leave the Centre.

We thank you for abiding by these rules. Further community guidelines and regulations can be found within the Patient Information folder given to each patient.

What's available within the NSIC	Page 15
Accommodation	Page 15
Baby Changing Facilities	Page 15
Barbara Bus	Page 16
Bungalow	Page 16
Cash Machine	Page 16
Chaplaincy & Prayer Room	Page 16
Eating	Page 17
'Moment to Eat' restaurant	Page 17
RVS coffee shop	Page 17
Coffee Bar and Paper Shop	Page 18
Family Room	Page 18
Information Screen	Page 18
Laundry	Page 18
Lifts	Page 18
Parking	Page 19
Patient Advice and Liaison Service (PALS)	Page 19
Patient Education Room	Page 19
'Friends and Relative's Day'	Page 20
Child and Siblings Relative's Day	Page 20
Patient Information Folder	Page 20
Post Box	Page 20
Quiet Rooms	Page 20
NSIC Website	Page 20
Telephones	Page 21
Toilets for Visitors	Page 21
WiFi/Internet Access	Page 21
Transport	Page 21
Trust Policies	Page 22
Illegal Substances	Page 22

Contact Numbers

Wards

St Andrew Ward	01296 315800 / 5801
St George Ward	01296 315807/ 5808
St David Ward	01296 315803 / 5804
St Joseph Ward	01296 315810 / 5811
St Patrick Ward	01296 315828/ 5829
St Francis Ward	01296 315805 / 5806

Other Departments

Case Management Team	01296 315839
Chaplaincy Team	01296 316675
Clinical Psychologists	01296 315823
Family Counsellor	01296 315858
Occupational Therapy Dept.	01296 315862
PALS	01296 316042
Patient Education Co-ordinator	01296 316028
Patient Support Officer	01296 316601
Peer Support Adviser-SIA	01908 604191
Physiotherapy Dept.	01296 315863
Psychosexual Therapist	07775 927 533
Rehabilitation Lead	01296 316307
Spinal Out-Patients Dept.	01296 315828/ 829 (<i>same as St Patrick's Ward</i>)
Spinal Injuries Association	0845 678 6633

Telephones: Mobile phones can be used with discretion in most areas. There are public telephones located in the New Wing adjacent to the main reception desk, Mandeville Wing main waiting area, Claydon Wing entrance and the Moment to Eat restaurant.

Toilets for Visitors: Male and female toilets are located in the main reception area at the NSIC. There are also adapted toilets which are accessible for public use within this area. There is a visitors toilet in the Family Room on St. Andrew's ward.

Wi-Fi/Internet Access: Personal laptops can be used throughout the Centre or patients may use the computers provided in the cybercafé in RVS café . Passwords can be obtained through the Admin office near Reception for both.

Transport Buses

For details of local bus services visit the NSIC website on www.buckshealthcare.nhs.uk, follow the link to [Arriva Bus site](#) or the [Tiger Bus site](#) which has details of buses to [Stoke Mandeville Hospital](#)

Taxis: The Hospital Switchboard (Tel: 01296 315000) holds a list of local taxi firms or please ask your ward staff for help.

Trains: Aylesbury Station. Train times can be obtained on Tel: 08456 005165 or via www.chilternrailways.co.uk. or [Travel Line](#) or Transport Direct websites.

‘Friends and Relative’s Day’: Held 3 times a year and provides fundamental and practical knowledge about SCI for family members. (Booking forms are available from the Patient Education Co-ordinator. Relatives can also attend after a patient has been discharged from the NSIC).

Child and Siblings Relative’s Day: Children who have a relative with a spinal cord injury are invited to attend a workshop to gain peer support and education within a fun creative setting. It is open to all children even after their relative has been discharged from the NSIC. This is held annually. For more information, contact the Clinical Psychology Department on 01296 315823.

Patient Information Folder: This is available to each patient and will cover all the aspects of your relative’s stay in hospital. If you are unable to find the answer to a question in this leaflet, please refer to the folder or speak to a member of staff.

Post Box: This is located outside the Wendover Wing.

Quiet Rooms: There are 2 quiet rooms available within the NSIC (*one on the ground floor, near St. Francis Ward and one next to the Department of Psychology offices*). These rooms are available for both patients and their family if privacy is required and can be booked via the Admin Office near Reception.

NSIC website: Please visit our website for additional information and resources:

www.nsic-online.org.uk

We hope that this booklet answers any questions that you may have about the NSIC and its services. The NSIC is a purpose built spinal injury centre. Patients are normally admitted to St Andrew Ward for acute care after an injury, but may be admitted to one of the other wards appropriate to their clinical needs.

This booklet is not comprehensive but is meant as a guide to help orientate you to the Centre. If you have any questions that are not answered within this leaflet, please do not hesitate to ask a member of staff.

Frequently Asked Questions

What is Spinal Cord Injury (SCI)?

SCI can happen due to trauma caused by an accident or through an illness and means that the spinal cord has been damaged in some way. This may result in paralysis and loss of some sensation from the point of injury down.

What are the effects of a SCI?

Generally, the higher up the back or neck that the injury occurs the more loss of function and sensation the person will experience. It will also depend on whether the spinal cord is completely severed or partially damaged.

Why won’t my doctor tell us the exact prognosis?

The time it takes the body to recover from a SCI varies so a clear and 100% correct prognosis is difficult to give, especially in the cases of incomplete SCI.

Is there a cure for SCI?

At the moment there is no cure for SCI. There is good quality research being performed but most significant advances have been in laboratory-based work on animals.

All research must be assessed for its risk to harm and more studies are required before the research can be tested on humans. It is important to keep an open mind about such research and to understand that it is at an early stage but we are happy to discuss what is currently occurring.

Please refer to the grey '**Patient Information**' folder for further 'Frequently asked questions' including the following:

- I keep hearing 'Paraplegia', 'Tetraplegia', 'Complete' and 'Incomplete' – what do these mean?
- Is it just my relative's arms and legs that may be affected?
- Can a person recover from SCI?
- How long will my relative be in hospital?
- What about fertility? Will we ever have children?
- Will my relative ever be able to work again?

If your relative does not yet have a Patient Information folder please ask a member of staff for one.

Wards within the NSIC

St Andrew Ward (First Floor): Admits adult acute SCI admissions who are newly injured and need acute spinal management. Care is also given to patients who are on respiratory support and those who have undergone major spinal surgery.

Parking: There are designated free disabled parking spaces available in all of the hospital car parks, however demand for parking is high. A map of where to park at the hospital is available by visiting www.buckshealthcare.nhs.uk together with a list of parking charges and information about alternative means of travel to the hospital. If you are going to be visiting your relative every day, please speak to the Car Park Officer, based outside A&E, about any possible concessions.

Patient Advice and Liaison Service (PALS): This service is available to all patients, relatives and carers who may need to turn to someone for on-the-spot help and support whilst using the hospital. PALS is located on the first floor above the Moment to Eat Restaurant in the Wendover Wing. The service has been set up to support patients, their families and carers, listen to concerns, help solve problems and provide information on NHS services. They do not belong to any one department. They aim to be as independent as possible and have direct access to the Chief Executive. PALS can be contacted on 01296 316042 or via email on PALS@buckshealthcare.nhs.uk

Patient Education Room (Situated next to RVS café): There is a variety of information on SCI that can be accessed via this room. Please contact the Patient Education Co-ordinator on the number listed at the front of this leaflet for access to any relevant reading material. Your relative is also likely to attend an intensive three week education programme on SCI and other related issues within this room during their rehabilitation. Teaching sessions on SCI are also available to you, and any other close family members who may wish to attend.

Coffee Bar and Paper Shop:

Follow signs to A & E, Entrance 4

Opening hours:

Monday – Friday 9 a.m. – 4.30 p.m.

WH Smith: (opposite 'Moment to Eat' Restaurant)**Opening hours:**

Monday-Friday 7a.m. – 7 p.m.

Saturday & Sunday 8 a.m. – 4 p.m.

Family Room (*Ground floor*): This provides a comfortable area for you to take children. It has some toys and a television with a DVD player. The children are welcome to bring their own toys and DVDs to use in the room. Please note that all children must be supervised by an adult and we would be grateful if you could leave the room tidy after use.

Information Screen: This is situated on the wall of the foyer, opposite the *RVS café*. It displays up-to-date information about talks being given, visiting stall holders and events being run both within the NSIC and locally, which may be of interest to both patients and visitors.

Laundry (*In-house*): Washing machines are provided on each ward for your relative's personal laundry but they will need to use their own washing liquid.

Lifts: There are two lifts for public use located in the main corridor between St George and St David Wards.

St Patrick Ward (*First Floor*): Generally for re-admission, patients having further investigations or surgery and occasionally for newly injured patients with pressure ulcers.

St George and St David Ward (*Ground Floor*): Two rehabilitation wards encompassing all aspects of care needs, including nursing, physiotherapy, occupational therapy and emotional support. These wards encourage patients to become independent (either physically or verbally) and start their reintegration back into the community.

St Joseph Ward (*Ground Floor*): Here the emphasis is on teaching and supporting patients in the latter stages of their rehabilitation programme in preparation for discharge from the Centre. The ward also has patients who have been readmitted for further therapy goals who may only stay for a short period of time and pregnant SCI mums who are admitted prior to their baby's due date in preparation for the delivery.

St Francis Ward (*Ground floor*) is the first specialist ward in the United Kingdom for the assessment, treatment and rehabilitation of children and young people with SCI. The ward promotes age appropriate independence to enable the child or young person to reintegrate back to their family and community. The ward includes facilities and equipment to maximise independence.

Spinal Out-Patient Services (*Ground floor by the entrance to the NSIC*): Gives life-long support with any matters relating to SCI following discharge from the Centre. Appointments can be made to see any member of the Multidisciplinary

Team, and nurses and therapists can occasionally make visits into the community for any relevant issues. There are also many SCI specific information leaflets available for patients and community professionals held in this department. Due to the large geographical area that we cover, telephone or e-mail are frequently used to problem solve some issues.

Visiting times

It is essential that patients are allowed adequate time to rest and recuperate following trauma and/or surgery and to allow clinical staff time to review patients. We would be grateful if you could adhere to set visiting times, which vary from ward to ward, unless alternative arrangements have been agreed with the ward or department manager.

Please also note that there is no visiting on the wards between 12.00 p.m. and 1.00 p.m. unless you are assisting your relative with their lunch.

Children are welcome on most of the wards at the discretion of the ward manager and as long as they are supervised.

Parents and children are also welcome to use the Family Room - please see page 15 for further information.

About Yourself

Taking Care of Yourself: When you arrive at the hospital, please ask if you would like to be shown around the NSIC in order to help familiarise yourself with the Centre. It is likely that you will be receiving a lot of information about SCI over the coming weeks and may naturally have many concerns about your relative during the early stages of their stay in hospital.

The prayer room is non-denominational and is open 24 hours a day for prayer and quiet reflection. It is situated in the Wendover Wing on the first floor above the Moment to Eat Restaurant.

Morning Prayer	8.30 a.m. Monday – Friday
Holy Communion	2.00 p.m. Sunday
	9.30 a.m. Wednesday
Muslim Prayers	From 1.15 p.m. daily

Eating: Refreshments for visitors are not offered on the wards. The following sites provide food and hot or cold beverages:-

‘Moment to Eat’ restaurant is situated in the main foyer of the Wendover Wing; this serves a selection of hot and cold drinks, meals and snacks.

Opening hours:

Monday - Friday	7.30am - 8pm
Saturday - Sunday	8.30am – 6.30pm

RVS coffee shop: RVS café is located within the National Spinal Injury Centre on the ground floor and sells hot and cold drinks and snacks.

Opening hours:

Monday - Friday	9am - 8pm
Saturday - Sunday	11am - 6pm

There is also a **vending machine** with 24 hour hot/cold drinks and sandwiches.

Barbara Bus: This is a wheelchair accessible vehicle that can be driven by relatives and friends. Anyone wishing to register as a driver with the Barbara Bus charity should telephone 020 8416 0733 between 10 am and 3.30 pm, Monday to Friday, or email: office@barbarabus.com. Further information is available at the NSIC Reception desk.

Bungalow: The bungalow is within the grounds of Stoke Mandeville Hospital, adjacent to the NSIC. Patients, together with close family members and/or a carer can stay for a brief period. The bungalow is a safe environment intended to recreate home surroundings, where any likely challenges and difficulties can be encountered and resolved before your relative is discharged home.

It is possible that NSIC staff may be made available to assist your relative by arrangement with the Ward Sister and for you to be taught any necessary techniques to help your relative when they return home. The bungalow booking is made between your relative and their treating OT, once the need has been identified at their Goal Planning meeting or through the consultants, ward round.

Cash Machine: This is situated on the wall between St Joseph Ward and RVS café on the ground floor.

Chaplaincy & Prayer Room: The chaplaincy team offer spiritual support and religious care to patients and relatives of all faiths and religions. Their contact details are listed in the front of this booklet.

Meeting new people, getting used to the hospital environment, worrying about travelling and parking, as well as getting over the shock of your relative's injury can sometimes feel overwhelming and draining. It is therefore important that you allow your friends and relatives to offer help whenever necessary and to also take care of yourself. This may mean trying to give yourself some rest whenever you can, finding ways of relaxing, eating regular and healthy meals and trying to take some exercise each day.

At the NSIC you will receive support from an experienced team of health professionals who will be looking after your relative. Whilst you are in the hospital, it may help to talk about your own feelings, either with close family and friends, or with staff members such as the Family Counsellor, a Psychologist, a member of the Chaplaincy team or another healthcare professional.

About your Relative

Looking after your relative: On a practical level you will need to bring loose and comfortable clothing with smooth seams for your relative, as well as toiletries and washing liquid for their laundry. Clothing such as tracksuit bottoms, T-shirts, socks, cotton underwear (boxer shorts are good) and soft shoes with a rubber sole, slightly larger and wider than normal, are all necessary to bring in. If possible, please mark the clothes with your relative's name in order to avoid any confusion or loss of property.

Practical Tips: You may find it useful to have a notebook to write down details of your relative's treatments and rehabilitation programme, contact numbers for key members of staff and a place to write any questions you may need to ask. You and your relative will have a lot of information to digest over the weeks and months of their rehabilitation programme.

Processes through Rehabilitation

Rehabilitation Information Meeting (RIM): This meeting will take place prior to your relative being transferred from the acute ward to a rehabilitation ward. Up to two family members may attend the meeting. This meeting provides an opportunity for the team to outline the rehabilitation process and will give you an opportunity to ask questions.

Needs Assessment Checklist (NAC): Once your relative is able to get out of bed and attend the Physiotherapy and Occupational Therapy departments, a member of staff (usually your relative's Key Worker) will discuss their current and future needs by going through a detailed checklist. A summary and graph will then be created and distributed to your relative and the team of healthcare professionals looking after them.

A second Needs Assessment Checklist will be administered once your relative has moved to St Joseph' Ward pre-discharge. This will highlight their achievements and identify any outstanding areas of need that still require attention in the run-up to their discharge.

Patient Support Officer: This support service is available for any patient, family member, relative or friend . The Patient Support Officer can mediate between you and the staff about any concerns that you may have or feedback your experiences to improve the delivery of the services within the Centre. They can also act as a support to patients by attending goal-planning, discharge planning meetings or outpatient appointments with them. The Patient Support Officer's telephone number is listed at the front of this pamphlet.

Peer Support Adviser: The Spinal Injuries Association (SIA) have Peer Support Officers (all of whom have a spinal cord injury themselves) working at all the Spinal Injuries Centres. At the NSIC, the Peer Support Officer visits each week to support injured people and their families. They can talk to you and your relatives about any concerns you may have, answer any questions about living with a SCI and source information for you on a wide range of topics. The contact number for the SIA's Head Office is at the front of this leaflet and their website address is: www.spinal.co.uk

What's available within the NSIC

Accommodation (Short-term): We regret that there are no guest rooms for visitors, however a list of short-term accommodation can be found by visiting the NSIC website on www.buckshealthcare.nhs.uk or by asking at the NSIC Reception Desk.

Baby Changing Facilities (on ground floor): Situated in one of the disabled toilets in the reception area next to the main entrance doors to the NSIC.

Patient Education Co-ordinator: Responsible for organising the Patient Education Programme covering SCI and other related topics. Understanding SCI enables patients to regain control and responsibility for themselves in order to avoid medical complications and to stay healthy. Knowledge inspires confidence and thereby patients can make informed choices about their lifestyle following discharge from the NSIC. They are also responsible for organising a regular information day for relatives and friends of the patient. Details on the 'Friends and Relative's Day' is circulated within the NSIC (see page 17).

Occupational therapist (OT): An OT will help your relative to become as independent as possible with daily living tasks. They will give advice on equipment and liaise closely with community services, including arranging an assessment of the home environment. The OT will also help with issues regarding employment, education, leisure and driving.

Physiotherapist: A physiotherapist will assess your relative within the first 24 hours after admission. They will help your relative with breathing and pain and will support them during the transition from acute care to mobilisation and rehabilitation. In order for your relative to become independent, they will also be helped to apply the physical skills of strength, balance, joint mobility, co-ordination and transfer skills. They will also liaise with community services in respect of supplying appropriate equipment such as a wheelchair and cushion.

Goal Planning Meetings: These meetings will take place usually every 2-3 weeks with your relative and their treating team. Goals will be set, based on the results of the NAC. One relative may attend these meetings at the patient's request.

Discharge Planning Meeting: If your relative needs the support of a carer after discharge, they will require a care package and will have a Discharge Planning Meeting during the later stage of their rehabilitation. The meeting may involve representatives from the Continuing Care Association, a social worker, district nurse, community occupational therapist and occasionally other outside agencies as well as members of your relatives treating team.

Discharge from the NSIC

Once your relative has reached their required level of realistic functional skills and goals, they will be discharged from the hospital either back home or to the next appropriate level of care. Where possible this will be to a suitable venue of their choice, but sometimes interim options have to be considered in order to deliver appropriate treatment.

Staff within the NSIC

Case Management Team: *(based opposite RVS café on the ground floor).* A case manager will be assigned to your relative at an early stage. They will ensure that your relative's rehabilitation programme is consistent towards ensuring a safe, timely discharge and will ensure that your relative's rehabilitation programme is followed.

There is also a DWP Visiting Officer who visits patients and can advise on benefits, sick pay and applying for Personal Independence Payments (PIP). She can be contacted via email at hil.mullis@dwp.gsi.gov.uk or through the Case Managers' office. Relatives are welcome to make an appointment to speak to either a case manager or the DWP Visiting Officer if needed.

Clinical Psychologists (*First Floor, adjacent to St Andrew Ward*). Clinical Psychologists provide patients at the NSIC with confidential support to help manage the emotional aspects of coping with an injury. This includes supporting people to maintain a sense of control and find ways of adjusting for the future. They can also provide support for other difficulties such as managing pain or memory issues, concerns about relationships and sexual function. Most patients see a Clinical Psychologist at some point during their rehabilitation, either for 1-1 support or on a group basis. A liaison Psychiatry Service is also available, which supports people with complex mental health needs and can be accessed through the Clinical Psychologists. Referrals can be requested by a patient, their relative or any member of the team.

Consultant: This is a senior doctor who is responsible for your relative's medical care. Once your relative's condition has been stabilised, the consultant will discuss with them (*and with yourself, if you are the closest family member*), the nature of their injuries and the possibility of any recovery. Relatives are welcome to make an appointment to speak to the consultant if required.

Family Counsellor: Counselling offers support to any family member or close friend. Relatives and/or friends are welcome to talk in confidence to a fully trained and experienced counsellor about feelings of sadness, anxiety, relationship difficulties, communication, guilt and other emotional concerns.

Counselling can help give you some time and space to talk but also to put needs and problems into perspective. The counsellor can be contacted directly on the telephone number listed at the beginning of this pamphlet. Leaflets about the service are displayed on all the wards and in the NSIC foyer.

Psychosexual Therapist: This confidential service provides an opportunity for patients and their partners to receive help and information about how the SCI may have affected their sexual lives. With an experienced and accredited therapist, a discussion can be held around how relationships have been affected and the changes that can be made to continue to enjoy an intimate relationship.

The service involves education about how sexual function may have been affected and discussions around feelings and thoughts about the impact. A range of techniques to help with intimate life are discussed and later in rehabilitation a tailor made plan can be devised. The importance of intimacy and the ability to enjoy it is different for every person and this service will focus on an individual's needs in their current or future relationships.

Key worker: The Keyworker is a member of the patient's treating team that co-ordinates their rehabilitation and Goal Planning Meetings. A Needs Assessment Checklist is completed with each patient; this forms the basis for involving the patient and relatives in decisions about rehabilitation.

Named Nurse: Whilst on a ward, your relative will be assigned a nurse to support them. Their role is to liaise with outside agencies and to act as a patient advocate. They will assist with teaching and help your relative to gain independence, either physically or verbally.