



## 2. Preparing for Inclusive Education

### 2.1 Knowing what to expect

## Introduction

It can be daunting for a school to first consider how to include a child or young person with a spinal cord injury, particularly if it is the first time this has been an issue for the school. It is important to remember that other schools have done it and there are support networks, information and resources available that can help. This section covers:

- Learning about the child or young person's specific requirements
- Health issues after spinal cord injury

Remember that every child and young person with a spinal cord injury is unique and will have individual specific requirements and needs. Involving the child or young person, their family and the health teams working with them from the outset will help make sure you understand and learn how to meet these individual requirements. While many of the requirements will be related to the physical and medical impact of having a spinal cord injury, schools also need to consider the impact on the student's academic, social, and emotional/psychological lives.

If the process feels difficult or daunting, contact the local authority to find out what support is offered. Most local authorities will have Advisory Support Teachers, who help schools prepare for and include students with various specific needs – including making adaptations, using assistive technology, training staff, using Teaching Assistants, and ensuring inclusive policies and practices. Additionally, your school will have put other inclusion policies or practices in place and these can often be transferred or adapted

## Learning about the child or young person's specific requirements

One of the most important things to do is to collect accurate and useful information about what the child needs in order to be included in school. This could involve:

- the child or young person's specific medical requirements and subsequent implications on their life at school (e.g., mobility, bowel and bladder management)
- any medical issues that may arise at school or what ongoing medical treatment schools may need to accommodate (e.g., physiotherapy)
- any changes to the way the child communicates or learns (e.g., if they become primarily an auditory learner)
- considerations on how the child can be re-integrated socially into the school community
- transport requirements
- what equipment or technology the child or young person may need
- guidance on providing any necessary emotional and psychological support. Remember that the child may have or may be experiencing Post-Traumatic Stress and that families and siblings will often also be going through a difficult time.



**In a school setting, it is very important for teachers to understand the needs and abilities of individual students with spinal cord injuries, and not to assume that all spinal cord injuries will be the same, or that students will have the same sensation and movement control. It is helpful to learn about individual students and ask what support and assistance they need. It is also important to be sensitive to issues such as bladder and bowel management and the need for assistance with activities**

Dr. Angela Gall, Consultant London Spinal Cord Injury Centre, Stanmore

**“ My school was really good. They were eager to get me back. The teachers were understanding about everything, for example if I wasn’t well or couldn’t go in or if I had a hospital or doctor’s appointment. They understood that it was not going to be the same as before. They gave me extra time to do things.**

**My advice to schools would be don’t act differently because the young person is in a chair because they are exactly the same person, apart from going from walking to sitting. That was what I didn’t like – the teachers were constantly asking if I was OK.**

Danielle, 17

This information can begin to be gathered from the child’s health team at the spinal cord injury centre or general hospital. Schools should have contact with a spinal cord injury centre or a general hospital while the student is in hospital. Before discharge, most spinal cord injury centres and hospitals will contact the school and arrange meetings to discuss the child or young person’s requirements – including access, medical, emotional and learning needs. Often, an occupational therapist will visit the school – sometimes with the student – to discuss necessary physical adaptations or required equipment.

Schools should also be invited to the child or young person’s ‘Discharge Planning Case Conference’ when they are discharged from hospital, during which a report will be given on the medical issues. Additionally, health professionals such as a case manager or liaison nurse will go to schools and provide health education to whoever will be the responsible person at school – possibly a school nurse, SENCO or the head teacher. Depending on the child’s requirements, other health care professionals such as a community physiotherapist may also become involved in the school.

How a school uses the information about a child’s specific requirements depends on the situation. If a SEN statement is in place, there will be a structure and procedure for providing and reviewing support. Similarly, if the child or young person has complex medical needs, a Health Care Plan should be developed alongside health professionals. However it is structured, schools should devise a plan on how to meet the child or young person’s academic, social, personal, medical and emotional needs – and do this alongside that child and their family. See section 2.2 for more information on who to involve.

**“ Schools can promote inclusion by getting good advice from spinal centres and hospitals about access and the management of the spinal cord injury. Questions such as “Is this the right place for them?” “What if there is a medical concern during the school day?” “How can we fit in standing regimes?” need to be considered in context, with accurate and up-to-date information.**

Zoe Chevalier, Clinical Psychologist, Stoke Mandeville Spinal Injury Unit

**“ Schools are often scared. The fear is about not understanding, not knowing. Many schools don’t know what having a spinal cord injury is so we start by sending them information, getting them used to things like catheters, pressure relief, bladder and bowel issues. Then we invite them to come into Stoke Mandeville to meet together with the young person and family and talk**



about any concerns they might have. They have an opportunity to talk about autonomic dysreflexia with the medical staff which is something most schools find challenging but it just needs a plan in place to deal with it like schools have plans for dealing with anaphylaxis, diabetes or asthma attacks. We really hope this will start the process of breaking down that fear for them

Jo Jones, Teacher in Charge, Blueprint Hospital Teaching Service, Stoke Mandeville Spinal Injury Unit

## Useful medical information for schools and staff

This section has been supported by materials provided by the Spinal Cord Injury Centre at the Royal National Orthopaedic Hospital, Stanmore.

### Health issues after spinal cord injury

Spinal cord injury in childhood can affect health over many decades. Most complications are now preventable. It will be helpful to the child if you ask what help, assistance or special attention they will need, obviously with sensitivity in aspects of personal care.

#### Bladder

After spinal cord injury the nerve connection between the bladder and brain is lost and the young person may not feel when the bladder is full or be able to control passing urine. The bladder usually cannot empty as it did prior to the injury and artificial means are required for emptying.

Emptying the bladder is often done by intermittent self-catheterisation. The technique can be performed by the young person themselves or the parents or a trained carer or health professional.

Some young people, especially with higher level injuries will have a permanent catheter in (usually a suprapubic catheter – which goes in above the pubic bone). Catheters are connected to a drainage bag which can be emptied every few hours.

#### Bowel

After spinal cord injury the nerve connection between the bowel and brain is lost and the young person may not feel the urge to open their bowel or be able to control the anus. This means there is a risk of accidents, however most young people have a bowel routine that they do at a fixed time of day at home to empty the bowel and this usually prevents any further emptying during the day.

#### Skin

Because of reduced sensation and movement, after a spinal cord injury the body's usual warnings of impending damage (pressure causing discomfort) will no longer be present and the skin and tissues are at risk of damage. Because movement is reduced, pressure continues. This can affect the blood supply to the skin and lead to pressure sores. Pressure sores can develop in a short period of time but may take many months to heal, which may mean long periods of bed rest and even surgery. To help prevent this young people will usually have to sit on specialist cushions and have regular pressure-relieving routines put in place such as sitting forward in their wheelchair for 2 minutes every hour, or using standing equipment to change position during the day.

## **Temperature Regulation**

Children with spinal cord injury above the T8 level (the neurological level of cord injury) may have difficulty regulating body temperature and are susceptible to overheating or hypothermia. Attention to environmental temperature is therefore important.

## **Autonomic Dysreflexia**

This is a condition unique to people with spinal cord injury when the injury is at or above the T6 level. Autonomic dysreflexia is a very raised blood pressure, usually with a headache and sometimes a skin rash. It can be considered as the body's response to painful or potentially damaging conditions below the level of the spinal cord injury. Instead of the young person feeling pain or having specific complaints such as a tummy ache or a painful leg, they may get autonomic dysreflexia. Such things as a very full bladder, bowel problems and skin sores can cause the condition.

Although it is usually easily treated, it is an emergency situation and it is important that everybody involved with the young person knows what to do, which can include: establishing and resolving the cause (usually by checking the bladder and bowels are empty), adjusting the person's posture so that they are sitting as upright as possible, loosen any tight clothing or garments and, if necessary, ensuring administration of medication by a responsible person. Medication can be Nifedipine or GTN Spray. The school should always seek advice from the child's medical professional on autonomic dysreflexia before the child returns to school.

## **Chest**

Breathing function may be affected due to weakness of the chest and abdominal muscles. They may be more at risk if they have a cold or other infection. Some young people's injuries are very high and all breathing muscles are paralysed; they will need a ventilator to breathe. They will have carers who are trained in the management of the ventilator and the associated equipment and any treatment required and have input from a physiotherapist.

## **Spasm**

Spasms are involuntary movements of muscles. A spasm may involve only one muscle or be more generalised and may be very short lived or last a long time. If spasms are troublesome then there are physical and medical treatments for them. Spasms can be useful, for example, for transferring in and out of the wheelchair and moving around in bed. Spasms can occasionally help people with incomplete injuries to stand up and take steps.

## **Lower limbs**

A standing programme is usually recommended for young people with spinal cord injuries. Usually they will have equipment such as a static or mobile frame, an upright stander or walker, or callipers. Weight bearing is considered to be important to provide a sustained stretch to the joints and soft tissues. Standing may also be beneficial to enable the young person to interact with others at eye level.

## **Upper limbs**

Depending on the level of the spinal cord injury the arms and hand function may be affected. The young person may require a programme to stretch the arms or hands, or may have splints to do this, or to help them use their hands.

## **Posture and growth**

Following spinal cord injury the trunk muscles may be affected and this can lead to changes in the shape of the spine over time. It is important the young person maintains a good posture to try and prevent this (as well as to optimise function, skin care and appearance). This may require the use of a supportive system e.g. cushion, backrest, headrest, armrests and/or a brace.

## **Fitness and Diet**

It is important that young people maintain an optimal level of fitness (see section on play below).

What young people eat and drink will also have a big impact on their general health, in the short and long term. In general, it will involve drinking adequate amounts of water and eating the standard recommended healthy diet, high in fruit and vegetables and low in fat.

## **Sexuality and sexual function**

Sex and spinal cord injury is a complex issue but many people with a spinal cord injury do have full, loving relationships and schools should promote this message.

With any level of spinal cord injury, the person will most likely have some sexual impairment. Women might expect to have changes in sensations in the vaginal area, which might cause them to become either less sensitive or lose all sensitivity. Vaginal dryness caused by reduced lubrication may also be a problem. Men may have difficulty or an inability to get an erection, and may notice less sensation in the penis. They may also note difficulty with ejaculation. Because each spinal cord injury is different, the impact of injury on sexual function can also differ.

Other issues that might inhibit sexual function are spasticity which might cause cramping of the adductor muscles of the thighs, making them difficult to separate. Pain syndromes can make response unpredictable, making what once felt stimulating now feel painful. Bladder or bowel continence can cause embarrassment and anxiety, and an indwelling catheter may lessen sexual interest. In addition, weakness, fatigue, and breathing difficulties can also be barriers to sex as it used to be.

Spinal cord injury centres can assist teachers in getting relevant information required for young people with spinal cord injury. Section 3.3c also has lots of information and resources for teachers on supporting sex and relationships education for young people with physical impairments. Remember, sex with a spinal cord injury might be different than before one's injury, but the important message is that many people with a spinal cord injury go on to have good long term relationships, get married and have children.

## **Resources to link to or include**

- [Blueprint guide 'Going Back to School: Supporting Young People Returning to School with Spinal Cord Injury: A Guide for Schools'](#)
- [Department for Education Guidance: Access to education for children and young people with medical needs, 2001](#)