



3. Practising inclusive education

3.3c Emotional support

Introduction

Students returning to school after a spinal cord injury will need support in all elements of education – learning, social, extracurricular, career planning and more. For a child or young person to be appropriately and fully included, as is their right, schools should recognise and offer this multi-faceted need for support. This section covers emotional, psychological, relationship and sexuality support.

“ **The school could have been more understanding of the emotional impact that it had on our son. He went off the rails a bit as he lost confidence in the system and was frustrated. It was a bit of knock for him and his anxiety could have been recognised by the school better, even though it was a few months after the operation they could have been more supportive.**

Janet, mum of son aged 17

When developing relevant and appropriate support for a child or young person with spinal cord injury, consider the same aims and outcomes you would use for any child or young person. Think about the bigger aims related to learning – both academically and socially – but recognise that you may need to make extra adjustments to achieve the outcomes. It is important that any plan be age appropriate and developed with the particular child or young person at its centre.

Emotional and psychological support

Children or young people with a spinal cord injury will inevitably experience psychological and emotional adjustment alongside changes in their body. These adjustments may be short-lived or recurring and will change as they interact with the significant development processes that occur naturally at these ages.

“ **As [children and young people with an SCI] are growing and developing, they are going through normal developmental patterns and on top of that they've got to negotiate their injury. From a psychological point of view, new issues might arise at different stages. There is a need to review both physical and emotional issues along the way as individuals go through different developmental stages.**

Zoe Chevalier, Clinical Psychologist, National Spinal Injuries Centre, Stoke Mandeville Hospital

However, despite facing significant trauma, research shows that people with a spinal cord injury are resilient and go on to have positive outcomes.

“ **At Stoke Mandeville, we have a strong research and clinical background, and from that are able to say that most people adjust and cope really well in the long term and do go on to do really well and get back to school and education and create relationships. This is a really important message to get across. It's not the norm that people with spinal cord injuries have long-term psychological trauma and difficulty. It's more normal to cope and make adjustments.**

Zoe Chevalier, Clinical Psychologist, National Spinal Injuries Centre, Stoke Mandeville Hospital

None of this has been easy for our son. That said positive messages, examples and support all contribute to making the life of a young man far more manageable. He does not think of the problem that he faces, but is driven with an ambition to do things, get about, run his own affairs and to carry on as normal. These aspirations are supported by Back Up and assist us in reinforcing the positive in his mind, and also the minds of those with whom he comes into contact. I believe that Back Up' schools and families inclusion service is extremely important for those youths who suffer injury early in their lives, as it reminds us all that life goes on, and that spinally injured individuals continue to have ambition and desires in life, and that they should not be treated differently from others.

Parent of son aged 17

While in hospital, children or young people with a spinal cord injury will have access to a Clinical Psychologist who will meet with them and their families to see how they are coping. They may be referred to a mental health specialist in the community if there is seen to be a clinical need, but this is relatively rare.

- Children and young people who have a spinal cord injury may feel reluctant to return to school or engage with anything that reminds them of their impairment. Offering emotional or psychological support, as well as being sensitive to their situation, are some strategies to address this.
- Research has shown that re-connection to their communities and social networks are linked to more positive outcomes and adjustments for children and young people with a spinal cord injury.

One of the main messages we want to give is that we know from research that people with spinal cord injuries who do better in the longer term are people who are able to participate in social and community activities, like being included in school, hobbies, or sports. If children or young people are able to be connected and participate in their communities, go back to studies, have support regarding their career options, and go out with friends, they will do better in the longer term.

Zoe Chevalier, Clinical Psychologist, National Spinal Injuries Centre, Stoke Mandeville Hospital

- Recognise the critical importance of peer support and of maintaining friendships. Assistance that schools can provide in this area will be beneficial, especially during the teenage years.

In terms of friendships, that has been the most difficult area, trying hard to encourage situations where her friends can take on role of helping A. eat. We want to leave her to her friends when she can socialise. I want the 6th form to really be the time when she spends more time with friends away from adults, and becomes a more independent learner.

SENCO, Gloucestershire

Relationships and sexuality support

“ Sexuality is not often an area people are open about. For me, it is about finding out where that person is in the beginning and never assuming what the experience of this young person is. It’s also about not having any judgments.

Michelle Donald, Psychosexual Therapist, National Spinal Injuries Centre, Stoke Mandeville Hospital

“ Many [teenagers with a spinal cord injury] are terrified about what lies ahead for them in relationships and with sex ... But the issues for teenagers are very much the same for everyone else. Having a spinal injury takes you back to ‘I’ve got to start again’ and ‘How do I map my body?’ and ‘How do I know what I like?’ It’s important to go back to the element of play. That’s often what I’ll talk about – let’s start playing again. I put it back onto a level playing field and normalise it.’

Michelle Donald, Psychosexual Therapist, National Spinal Injuries Centre, Stoke Mandeville Hospital

Relationships and sex are huge issues for all young people and those with a spinal cord injury have the same desires, aspirations and anxieties around relationships that everyone else does. However their relationship to their body has changed and it is common for their self image and confidence to drop. Some young people have said they don’t feel like sex and relationships are possible in their lives anymore or that they can’t believe anyone will ever fancy them. They need to hear the message that they are capable of being attractive and part of happy, healthy, loving relationships just like everyone else is. Schools should help tackle this message early on in a young person’s return.

“ Changes in sexual function are common after spinal cord injury, but we know from experience that people do go on to form romantic and sexual relationships, and it is possible to build a family and have children. It’s important to let people and their families know that this is possible. Some parents wonder, ‘Are my children going to have relationships? Will I have grandchildren?’ There may be some hurdles or prejudice but people need to receive good information when the time is right from a trusted source about the potential changes in sexual function after injury, how these may affect them, and what help or options are out there.

Zoe Chevalier, Clinical Psychologist, National Spinal Injuries Centre, Stoke Mandeville Hospital

Discussing relationships and sexuality – including sex education – with children and young people with a spinal cord injury can seem an intimidating, awkward prospect. Indeed, many disabled young people have reported finding sex education classes presented in such a way to be irrelevant and discouraging, which can add to the feeling that sex and relationships are not possible for them. It is vital that children and young people receive relevant, accurate, and positive information about these issues in a sensitive, inclusive way.

“ **As an adult with a spinal cord injury, people are more likely to talk about sex. Whereas with a child or teenager, it’s one of those things that unfortunately does still get left out. People ask what is the appropriate age to start talking about these things but there isn’t one – it’s very much dependent on the individual and what they want to know. I think any age you could start with sexual education and the earlier the better – it just needs to be age appropriate.**

Michelle Donald, Psychosexual Therapist, National Spinal Injuries Centre, Stoke Mandeville Hospital

“ **One thing that’s important is to talk to a young person about things like masturbation even if they’re not going to feel it. When they go to school and all their friends are talking about it, they can still be included and still know what they’re talking about. They may not feel it but what they are going to get is what people are talking about at school.**

Michelle Donald, Psychosexual Therapist, National Spinal Injuries Centre, Stoke Mandeville Hospital

Here are some ideas on how schools can support this area of work:

1 Provide a key worker or staff member for the young person if they want to talk about relationships and sexuality. This should ideally be someone they are close to and who they can bring questions or concerns to. Ensure this staff member has access to information or other support networks to find out answers to questions the young person may have (resources are listed below).

2 Challenge discriminatory attitudes in school, particularly the idea that it is taboo for disabled people to have sex, relationships and families. Present positive images and role models that dispute this idea. This is a message that should be presented early, sensitively and regularly.

3 Ensure sex education classes are done inclusively and sensitively:

a. The teacher may want to speak individually to the young person before the session to discuss any concerns or to find out any pertinent questions in advance. Young people may not want to participate in sex education classes and may prefer to receive information or talk to a counsellor at school or a key staff member they are close with.

b. Support teachers to find out what is relevant and important for a particular young person’s situation. Pertinent information may relate to physical (eg erogenous zones, increased or decreased sensitivity, sensuality, physical dysfunction and possible adaptations, contraception options), practical adjustments (‘How do I get out of my chair?’ ‘How can I be intimate when I have a catheter bag?’) and emotional (feeling unattractive, unsexy, anxious) questions.

c. Sex education classes should be run so that they are relevant and pertinent to all students who are accessing them. Disabled students should not be excluded from sex education classes.

d. Remind students that all people are individuals and what one person may enjoy, another may not – regardless of impairment.

e. Students with impairments have a right to receive specialist sexual health and education information. However they should also be given the information that everyone is given, as well as any additional handouts or resources that are particularly

relevant to them.

f. Ideally, the information that may be particularly relevant to a student with an impairment should be presented and offered to all students. This means one student is not singled out or separately acknowledged. If the information is integrated sensitively into a session, it can help everyone have a more equal, inclusive perspective on sexuality.

4 It can be daunting to try to start a relationship with a person who is always accompanied by another adult. Ensure support staff are not constantly present, giving the young person room to form relationships and develop their own identity with their peers.

5 Support families to allow their child to grow up, develop and participate in ordinary teenage experiences. Some parents or families may become overprotective of their child after an injury and need support in allowing their child to make choices and take risks that all teenagers make. Some families may find discussing relationships and sexuality particularly difficult. More information on organisations and networks that support families can be found in section five.

Resources

- [Growing Up: Sex and Relationships](#) – information and resources for young disabled people on sex and relationships
- [Growing Up: Guide for teachers](#) – information for teachers on supporting sex and relationships education for young people with physical impairments
- [Sex Ed for Youth with Physical Disabilities](#) resources/guides from Canada
- [Thesite.org](#) – web resource on young people, sex and disability
- [Relate](#) – Relate offers advice, relationship counselling, and sex therapy
- [Outsiders](#) – ‘club’ for disabled people – includes information about the Sex and Disability Helpline
- [Outsiders](#) – Particular information about sexual health for people with impairments
- [Outsiders](#) – Disability and body image
- [British Association of Sexual Educators](#)
- [Leonard Cheshire’s ‘In Touch’](#) - a site about sex, sexual health and relationships, especially for young disabled people
- [Sex Unzipped](#) – web site for over 16s about sex, relationships and sexual health
- [Spokz](#) – equipment site for wheelchair users – includes section on sex aids and advice for over 18s
- [Sexuality and Access project](#) – Canadian community access and research project on sexuality and access for disabled people
- [I-Said](#) – training organisation that offers workshops or training for health and education staff on managing sexuality and relationships with disabled people