



## 5. Support for families

### 5.3 Accessing advocates and support

## Introduction

As a parent of a child with a spinal cord injury you might have concerns ranging from education, access to services, respite and your other children's needs. This section is about letting you know about some of the support that is out there. This support can bring you together with other parents who have child with a spinal cord injury, or organisations that can provide advice and support.

“ **Spinal cord injury is a life-altering experience not only for the person with injury but for spouses, parents, siblings, and children of the person. Family members suffer from stress, grief, and depression when a spinal cord injury occurs in the family.**

Wise Young, Ph.D., M.D. Family and Spinal Cord Injury, 2003

Support from parents of children with disabilities

## Mentoring service at Back Up

We understand that spinal cord injury affects the whole family. Families who have children and young people with a disability very often deal with similar issues and challenges. Family mentoring is a service to support parents and partners of people with spinal cord injury. Being introduced to an experienced mentor parent could help you feel more positive about what the future may hold for you and your family.

“ **It's like having a lifeline to someone who has been there. It's different from speaking to a friend and different from talking to other parents whose children are at the same stage. My mentor Pete was great, I didn't have to pretend!**

Mum of tetraplegic son aged 17 when injured

“

**I realised how much help it would have been for me, being able to share experiences and thoughts with someone who had been through this totally new, consuming and life changing scenario.**

Back Up family mentor whose son was injured age 15

If you want to find out more about this service email [Kyra](mailto:Kyra) today or call 020 8875 1805.

## Online forum for parents

[Parents of disabled children](#) is an online forum that aims to bring families together for friendship, to share information and to support one another. The forum was created by parents who have children with special needs and is run by parents.

## Supporting siblings

[Stoke Mandeville spinal injury centre](#) runs events for brothers, sisters, relatives or friends who are children and are connected to a person with a spinal cord injury. In March and November, they host a 'Relatives Day' for children aged 6-16 where they can meet other people affected by spinal cord injury. The purpose is to raise awareness, play fun games, talk about their experiences, express feelings about their brother or sister or friend.

For more information, contact Stoke Mandeville Psychology department on 01296 315823.

**Sibs** is the only UK charity representing the needs of siblings of disabled people. Siblings have a lifelong need for information; they often experience social and emotional isolation, and have to cope with difficult situations. They support siblings of all ages who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition.

Contact them:

By phone: 01535 645453

By email: [info@sibs.org.uk](mailto:info@sibs.org.uk)

## Sibling support from Back Up

There are opportunities for siblings to come with their injured brother or sister and a parent on a Back Up under 13 course.

Back Up is also exploring mentoring for siblings from 2013. You can call Kyra to find out more about this on 020 8875 1805.



**My younger daughter got to try out wheelchair skills on the course and it was good for her to realise the challenges her sister faces.**

Mum, daughters, 11 and 7

## Resources

General Advice

- **[IPSEA](#)** – IPSEA is a national charity providing free legally based advice to families who have children with special educational needs.
- **[Special Educational Needs and Disability Tribunal](#)** (although no longer functioning page has advice on new system)
- **[Advisory Centre for Education](#)** – provides free, independent advice for parents in education issues
- **[Coram Children's Legal Centre](#)** – CCLC provides free legal information, advice and representation to children, young people, their families, carers and professionals, as well as international consultancy on child law and children's rights.
- **[Contact A Family](#)** – charity supporting families with disabled children
- **[Contact A Family](#)** - a booklet to support parents of young disabled people
- **[Disability Law Service](#)** – provide information and advice for disabled and Deaf people
- **[National Parent Partnership Network](#)** – statutory services offering information advice and support to parents and carers of children and young people with special educational needs
- **[Network 81](#)** – support and information for parents regarding SEN and inclusive education
- **[Parents for Inclusion](#)** – support network and information for parents and advocates for inclusive education
- **[First 4 Disabilities](#)** – non profit social enterprise company limited by guarantee, that

offers a range of services to children, young people and their families with disabilities

- Read about research from the Family and the spinal cord injury organisation [here](#)
- [Alliance for Inclusive Education](#)
- Department of Education, information about [Aiming High for Disabled Children](#)
- [Coram children's legal centre](#): School Admissions and appeals factsheet
- [Coram children's legal centre](#): Duties of Local Authorities
- [Coram children's legal centre](#): Advice on Special Education Needs