

Supporting children when their parent has a Spinal Cord Injury

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

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Patient information leaflet

If you require a translation or an alternative format of this leaflet please call PALS on 01296 316042

Safe & compassionate care,

every time

Introduction

When someone in the family suffers a spinal cord injury it can be an enormous shock for everyone that is hard to adjust to. It can be even harder to sort out your own feelings when there are children in the family to think about. Children, just like other family members, are affected by your injury and the changes this brings. Most children cope well with the situation and it is unlikely to cause them problems in the long term. In fact, coping with difficult situations often brings out the best in children and can have a positive effect on their overall development. However, often children need your help and support in order to adjust effectively.

Your child probably already knows something about your injury and the fact that you are in hospital. You may still feel unsure about what to tell them and how to explain things to them. It is probably very difficult for you and your child to be apart unexpectedly and for such a long time. You may have concerns about your child's visits to see you in hospital or about having physical contact with your child. You may have thoughts about whether your injury will affect the activities that you are able to do with your child.

We hope this booklet will help you to think about some of these issues. Information in the booklet is based on what we know from research findings about the impact on children and also includes ideas suggested by other parents who have experienced a spinal cord injury.

Concerns

If you have any concerns about the treatment and rehabilitation you receive, or about your experience at the NSIC, please raise them with a member of staff.

If you are particularly satisfied about the service you have received at the NSIC, you are welcome to let us know, preferably in writing.

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.

Gingerbread

A support organisation for lone parent families.

Helpline: 0800 018 5026 - 9am-5pm Monday to Friday

www.gingerbread.org.uk

Parentline Plus

A national charity that works for, and with, parents.

Helpline: 0808 800 2222

Text phone: 0800 783 6783

www.parentlineplus.org.uk

Parents with Disabilities Online

American site with information on various resources.

www.disabledparents.net

REMAP

Volunteer engineers who invent, design and make devices to solve individual problems.

Tel: 0845 1300456

www.remap.org.uk

Spinal Injuries Association

Provides a range of support services for people with SCI and their families.

Motherhood fact sheet – women with SCI describe their experiences of pregnancy & parenting.

Helpline: 0800 980 0501 - 9.30am-4.30pm Monday to Friday

www.spinal.co.uk / sia@spinal.co.uk

Young Minds

A charity committed to improving the mental health of all children and young people. They also have a Parents' Information Service.

Tel: 020 7336 8445

www.youngminds.org.uk

Coping with being in hospital

Just the fact of being in hospital can be difficult when you are a parent. For most people their injury will have occurred suddenly and unexpectedly, and so it is unlikely that you had any opportunity to prepare your child for the fact that you will be in hospital for some time. Being separated from your child and unable to fulfil your usual role with them can be very difficult for both you and your child.

It is important for you that you know that your child will be well looked after and safe in your absence. If your partner is at home and able to focus on your child's needs, this can be very reassuring to you. It is likely that your partner may be spending a great deal of time with you in hospital or they need to work or have other responsibilities. It can help if other relatives or friends are able to help out with childcare. As much as possible, try to stick to people that your child knows well, as children feel more secure when they are with familiar people and when there is not too much change. Trying to maintain their usual routine and activities can also help.

It is also important for your child to know where you are and why you are unable to be at home at the moment. Your child needs to know that they will be able to see you and keep in close contact with you even though you are staying in hospital.

Visits

It is important to maintain as much regular contact with your child as possible whilst you are away from home. Hospital visits can bring you a tremendous amount of pleasure but they can also be a source of stress, and may be upsetting for both you and your child.

It can help if you are able to plan for your child's visit to try to minimise problems. With small children it may help if an extra

person is able to come along, in addition to your partner. An extra pair of hands can be helpful, especially if your partner wants to spend some time with you without having to worry about supervising a child for all of the visit as well.

Children will probably be used to seeing you in bed, so this will not be so strange for them. If there are tubes or other medical devices on display, this may be more off putting for them. Allowing them to look and explore as much as is safely possible should help to satisfy their curiosity and help them feel more comfortable with the equipment. Also if you are on the ward, seeing other patients who may be unwell could be frightening for a child. It can help to talk to children about this.

If you are mobile, visits can be made more enjoyable and private by using the Family Room (near St David's ward). It may be possible to use the outdoor play area but please bear in mind that this is part of St Francis ward, with access only through that ward, so this is at the discretion of St Francis ward staff.

Thinking about the timing of visits may also be important. Young children are usually most cranky at the end of the day and you may also be more tired in the evenings. Arranging earlier visits wherever possible may help make it a more enjoyable experience all round.

Physical contact with children

It is important for children, especially younger children, to be able to have physical contact with you. This will be easier if you are paraplegic and able to use your arms to cuddle your child. If you have limited use of your arms, the prospect of physical contact may be more worrying for you. You should still try to allow children the opportunity to cuddle you and let them realise that you are still the same person.

Resources

Books to read with your children

Let's talk about disabled people. A Watts/Gloucester Book

Are we there yet? and Boots for a Bridesmaid by Verna Allette Wilkins. Tamarind Books produced by the Spinal Injuries Association.

These are story books in which a parent has a spinal injury. The injury is not the focus of the story but there are lovely pictures of a parent in a wheelchair participating in every day activities with their child.

Toys

For a list of children's toys that feature wheelchairs or other aspects of disability see www.disabledparents.net/toys.html or try a Google Product search at www.google.co.uk (click on 'Products' on the Google homepage) using the term 'wheelchair toy'.

Organisations

Disability, Pregnancy & Parenthood International

Provides fact sheets on changing nappies, bathing babies, choosing cots and carrying a baby on a wheelchair
www.dppi.org.uk

Disabled Parents Network

Helpline and nationwide network of parents with disabilities.
Helpline: 08702 410 450
www.disabledparentsnetwork.org.uk

It can take some time to re-establish relationships after long separations. Each stage of your recovery and rehabilitation will bring different feelings, different worries and different highs and lows. But if you are able to talk honestly and openly together at each step, you will hopefully find that your family can be a great source of love and support.

Summary

- Children need to be able to learn about spinal cord injury.
- Keep information simple and honest.
- Give your child a chance to talk about or show you how they are feeling – this is more important than what you actually say.
- Encourage your child to ask questions.
- Try to maintain regular contact with your child.
- It will help your child if their routines remain as normal as possible.
- Keep updating children as things change.
- Try not to make false promises.
- Ask for support and help for your child if necessary.
- Ensure that you and your partner get the support that you both need.
- Your injury can take the attention away from your child. They need plenty of reassurance that they are loved and will still be looked after.

Particularly with younger children who are less able to respond to verbal prompts and need more “hands-on” guidance, doing this with supervision from another person will reassure you that your child is safe and also reduce the risk of them hurting you or pulling at things they should not!

You and your child may need to re-learn ways of sharing physical closeness, which may mean your child accepting verbal instruction rather than physical gestures, and you being comfortable in allowing them to get close to you without physically being able to restrain them yourself. It may help to invent your own ‘special hugs’ that you and your child can do which work for you according to where you have movement/sensation.

Activities with children

It may help to think in advance about what activities you can do with your child during a visit. If you are on bed-rest or have limited use of your arms, you may need to think more carefully about what activities you plan.

Talking about what your child has been doing, telling stories and playing verbal games are all possibilities. Your child may be able to show you pictures, you could watch a film together or your child could bring paper and pencils and do some drawings for you.

If you are mobile and able to use your hands, there are lots of games you could play with your child sitting at a table: board games, playing with figures, jigsaws, drawing, etc. You might also want to spend some time away from hospital in the local area. Arranging for your partner (or whoever is looking after the children) to bring in suitable activities can make the visit more fun and normal for the child.

With babies and toddlers, putting them on a table to play rather than on the floor will mean they are at the right height for you to interact with them. Again, supervision from another person is important to ensure they do not fall.

Wheelchairs

You may have concerns about your child seeing you in a wheelchair for the first time. Wheelchairs can provide a source of great interest to your child. Talking about wheelchairs will help children to understand what they are. Using a wheelchair means you will be able to move to other places with your child. They may enjoy riding on your knee, or pushing or pulling you along. Babies can be carried in a baby carrier or sling. Children tend to be very accepting and quickly get used to that fact that you are using a wheelchair.

Children helping with care

Sometimes questions arise over whether children should be involved in helping with any care you might need. In general, our recommendation would always be to avoid giving children responsibility for providing care to parents on a long-term basis and your care needs should always be met by professional carers, or adult family members if this is your choice. But children often like to be involved in helping you with small tasks, as part of their natural wish to help and show you their affection. For instance, they may like to push your wheelchair, help you by fetching objects you can not reach and so on, or older children may wish to be involved in more formal aspects of care, for instance learning how to range your hands.

There are no hard and fast rules about this and often it will depend on what you as a family feel comfortable with. The main things to consider are to make sure your child is comfortable with the task and able to handle it – physically, intellectually and emotionally - and to avoid the parent-child relationship becoming reversed.

It is important to remember that most children are very resilient and can cope well with a parent being injured if they have sufficient information and support.

If extra support is needed

Most families find their own way of coping during this difficult time. However, if you have concerns about your child or worries of your own about how to interact with them it may help to speak to someone about this. There are many people at the NSIC who can offer you and your child support.

Any members of staff you get on well with can be good people to speak to for general support and advice. If you have specific concerns that you would like to discuss in a confidential setting, please contact one of the Clinical Psychologists. They should be able to assist you with obtaining professional support for your child close to home if you feel this is needed. The Department of Clinical Psychology has some books and leaflets especially for children which may help them understand what has happened.

Planning ahead

Many changes can take place during rehabilitation – to you and to your family situation. It is important to keep children informed of changes or new plans that are made. This helps them to feel involved in what is happening. This is especially important when you are ready to have visits home and when you are eventually ready to leave the NSIC. There may be little that children can control or have a say in about such changes but it is helpful to give them as much choice as you can in areas where this is possible. For instance, if you need to make space at home for a temporary arrangement with a bed downstairs while you are awaiting adaptations, children could help by choosing which of their toys to keep and which to pack away.

School

It is important your child's school is aware that you are in hospital. This will help them to understand if your child becomes upset in school or if there are any changes in their behaviour. The school routine can help things feel 'normal' for children and their teacher may be a good extra source of support. School may have a counsellor who is available for your child to talk to.

Your children's friends are an important source of support for them. However, they may ask your child questions or even make thoughtless remarks about what has happened. Young people are under considerable pressure to be the same as their friends. Differences make them feel uncomfortable. They may fear that their changed circumstances will make them different from others.

It might be a good idea to talk to your child about this and plan what they will say and do to help cope with such situations.

Children may feel guilty about having fun when they can see the strain you and others in the family are under. It is important to reassure them that it is OK to enjoy things, that you are glad they are having some fun and are interested in what they have been doing.

What else helps?

Ensure that you and your partner have the support you need. This will help you both to be able to support your children better. NSIC staff should be available to listen and talk things through with you.

It is also worth remembering that there will be days when you both feel less able to cope with the needs of your child. This is normal given the stress you are under.

Sometimes children take on a parental role if a parent is away or injured, and this might show up as a desire to carry out some of your care. This can be a burden to children in the long run and it is important for them to be reassured that you are still the parent and are there to take care of them, even when you are in hospital.

Other ways of keeping in contact

In addition to visits, you can also maintain contact with your child through letters, phone or video calls and email. Asking your partner or other family members to take regular photos and home-videos of what your child has been doing can help you to share in your child's life and development throughout the period you are in hospital. Having seen them participating in day-to-day activities will also give you things to talk to them about when you do see or speak to them.

It will help to make sure your child has photographs, or other physical reminders of you at home, so they can feel close to you.

Children will probably also enjoy seeing pictures of themselves pinned up on your hospital board, reassuring them that you are thinking of them while you are away.

Talking to your child about your injury

All parents worry about what to say to their children during this difficult time. You and your partner may be afraid of saying the 'wrong' thing or of upsetting your children. Some people may try to protect their children by not talking about what has happened in front of them.

Every family is different – and you will know what suits yours best. However, we think it is usually helpful to everyone if children know something about the events that are affecting their family. Children of all ages are very good at sensing there is something wrong. They may want to ask questions but could be afraid to do so in case it upsets you.

Conversations with children about the injury can be difficult but talking to them is a sign that it is okay to discuss upsetting matters and it is important for clearing up any misunderstandings or worries that they might have. The truth is not likely to be as awful as their fears. Without accurate information children’s imaginations can run riot.

What should children be told?

There are no right or wrong answers – every family’s situation is different. **Being willing to talk and listen is often much more important than what is actually said.**

What to tell your children will probably depend on a couple of things – **How comfortable you are talking about what has happened and how old they are.** Whatever their age though, children need clear and honest explanations.

Children of all ages like and need to make sense of the things that happen to them and their family. As far as possible try to explain what has happened, how it was caused and what the effects are. Children may ask you questions that you do not know the answers to. It is okay to tell them that you do not know yet either.

Older children may be reluctant to share their feelings with you – but this does not mean that they do not have any. As part of normal development, adolescents need to be able to think about themselves, and they may be struggling to cope with everything that is happening. When they do let you know their feelings, either in words or by their behaviour.

Adolescents are going through a period of pulling away from the family and getting closer to their friends and peer group; this is completely normal but can make a family crisis difficult for them when the family is often drawn closer together.

Their reactions may be mixed and they may seem as if they do not care (e.g. refusing to visit, or help out with chores at home). This can be difficult and upsetting. It helps to remember that adolescence can be a time of conflict between children and parents anyway – having an injury just makes it harder to cope with.

Try not to give older children too many new responsibilities all at once and it helps not to burden them too much with your own feelings. It is important that previous family rules remain in place, e.g. the time they are expected to be home in the evening. This will help to maintain a sense of routine.

The kinds of concerns that teenagers have are often to do with justice and fairness (particularly if you were involved in an accident). They may, just like you, be asking themselves “Why us?” They may feel cheated or resent any changes which are occurring in their lives.

Older children and teenagers often like to gain support from other young people the same age who are coping with a similar situation. They may enjoy meeting other patients’ teenage children when they visit you in hospital, or there may be groups for older children run by disabled parents’ organisations in your home area.

During this time children will need lots of physical contact and reassurance. They will also need reminding that what has happened was not their fault. Children around this age learn a lot from what they see around them and by what others do. How you speak and act will influence your child's reactions and feelings.

The kinds of concerns that children at this age have are usually very concrete and related to themselves. They are likely to ask questions such as "Will I have a spinal injury? Who will take me to football?" Again, reassurance is very important.

7-10 years

Children may want to talk more about what has happened and ask many questions. Try to answer these questions as honestly as possible and support children to cope with any fears that they have. Encourage children to talk about their feelings and give them lots of reassurance.

11 and up

Older children and teenagers, like adults, may experience a mixture of feelings such as sadness, anger and fear, and they may feel quite confused by this. Their behaviour is likely to be quite different from that of younger children (although they may too regress to younger ways of acting). They might not want to visit hospital and may feel embarrassed by physical changes such as loss of bladder or bowel control. They may also have problems at school, either with their work or their behaviour; if they had such problems before these can get worse.

Under 7's

Younger children do better with simple, uncomplicated explanations about what has happened, e.g. "Daddy has had a crash in the car and hurt his back". They may compare this to injuries that they themselves have had or to things they have seen on the television and it will help to talk about this with them. Drawing pictures or using toys may help you to explain things. Playing and acting out situations is familiar and enjoyable to young children. It can help them understand and may encourage them to ask you questions.

Young children see the world as revolving around them and can easily imagine that they must have had something do with what has happened. They may not actually tell you this though, so it is important to say that it was not their fault. They may also be concerned that the same thing will happen to them and will need to be reassured about this.

People often think that babies and toddlers will not benefit from explanations about what has happened but bear in mind that toddlers are able to understand a lot more than they can talk about. Involving them in explanations to other family members, e.g. older siblings, may mean that they understand some of the information and they will certainly pick up on the atmosphere of 'It's OK to talk about it, we can handle it as a family'.

7-10 year olds

As children get older they can understand explanations that are a little more complicated. This is because they are a bit more advanced in their development and have more experience of the world. They know about 'accidents' and don't always see things as happening because of something they did. They often have more questions than younger children do.

11 and up

Older children and teenagers' levels of understanding can be very similar to adults. They have more knowledge of the world and life in general. As a result they are aware not only of the obvious physical changes that occur after a spinal cord injury (e.g. being unable to walk) but also of the feelings and emotions that the parent might have about what has happened to them. Older children may want to borrow books or look on the Internet to find out more.

Talking about the future

Acknowledge that this may be a time of change for all the family. It may help children to know that you are not sure what will happen, and you are trying to get used to doing things in different ways and being in hospital. It is very important not to make any promises that might not come true.

How do children feel and react when a parent is injured? What helps them cope?

Children are all different and how they react depends on many factors, such as their personality, how old they are and what they understand about what has happened.

Not all children react badly when a parent is injured. However, unlike adults, when children are upset or worried they don't always talk about it, so it is important to look for clues in their behaviour. Children's reactions and behaviours are not always easy to handle, especially when you are yourself under stress. It helps to remember that the things children do (good and bad!) are usually their attempt to cope with a problem – even if this does sometimes cause problems for other people. However difficult the behaviours and feelings, children need to know that they will be listened to and helped.

Under 2's

Babies and toddlers may not seem as if they have been affected. However, they are very sensitive to separation from their parents (or other caregivers) and changes in their routines, and can tell when those that are looking after them are tense or upset. It helps all children, but especially very young ones, to have their normal routines maintained as much as possible. Keeping a calm atmosphere in the child's presence and providing additional soothing activities can also be helpful.

It is important that young children are cared for by the smallest possible number of familiar people to minimise the number of changes they must adapt to.

3-7 years

As children get older there may be more obvious signs that they are upset. Children may seem clingier towards you or get upset when they have to leave you. Alternatively, they may be more clingy with your partner and reluctant to come to you. This can be difficult and upsetting for you if it happens. Bear in mind that it is because of the new situation and you may seem different to them. Children usually overcome this as they get more used to the situation and realise that you are still the same person, despite the injury and being in hospital.

Young children may have more tantrums, may seem louder (or even quieter) than they used to be, start bed-wetting again, have nightmares, lose their appetite or have fears about things that did not frighten them before, e.g. the dark, travelling in cars. They may seem as if they are acting much younger than they are. These behaviours are usually a sign that they are looking for attention and reassurance.