National Rehabilitation
University Hospital

An tOspidéal Náisiúnta Athshlánúcháin

Parenting Resource

A resource for parents with Spinal Cord Injury and their families

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A Resource for Parents with Spinal Cord Injury and their Families

Based on the New South Wales Resource "Talking to your Children About Spinal Cord Injury: A Practical Guide for Families" with kind permission from the authors.

Foreword

Spinal Cord Injury (SCI) is a life changing and generally sudden event which impacts not only the person with the injury but also their family and friends. It is one of the most difficult challenges to face in life.

The impact on children and young people can be reduced by understanding how to help them with their questions and concerns. Recently more research has been undertaken to help families and professionals understand children's experience of living with a parent with SCI. Open communication, and including children in the rehabilitation journey, in an age-appropriate way, has been shown to be helpful for the whole family.

The days, weeks and months in acute care and rehabilitation following a serious SCI can be a frightening and overwhelming time. The person with a SCI and their family will themselves be learning about the injury, medical jargon, treatment plans and life after rehabilitation. There may be a lot of uncertainty about how well the person will be, as well as practical issues such as housing, care at home, return to work and relationships.

Children and young people may not be as involved as other relatives due to the distance from home or parents hoping to protect the child. Parents may also be trying to maintain day to day routines or feel unsure of what to say to the child or young person. When trying to come to terms with the impact of the illness or injury yourself this can be an additional worry.

This resource looks at ways to support and communicate with young people whose parents have experienced SCI. It is based on the New South Wales Resource "Talking to your Children About Spinal Cord Injury: A Practical Guide for Families" with kind permission from the authors.

This resource has been completed by health care professionals working in the National Rehabilitation Hospital in collaboration with parents with SCI and based on feedback and research. We hope that this resource can provide guidance and practical advice to parents and families impacted by SCI as they reach towards a "new normal" for their lives.

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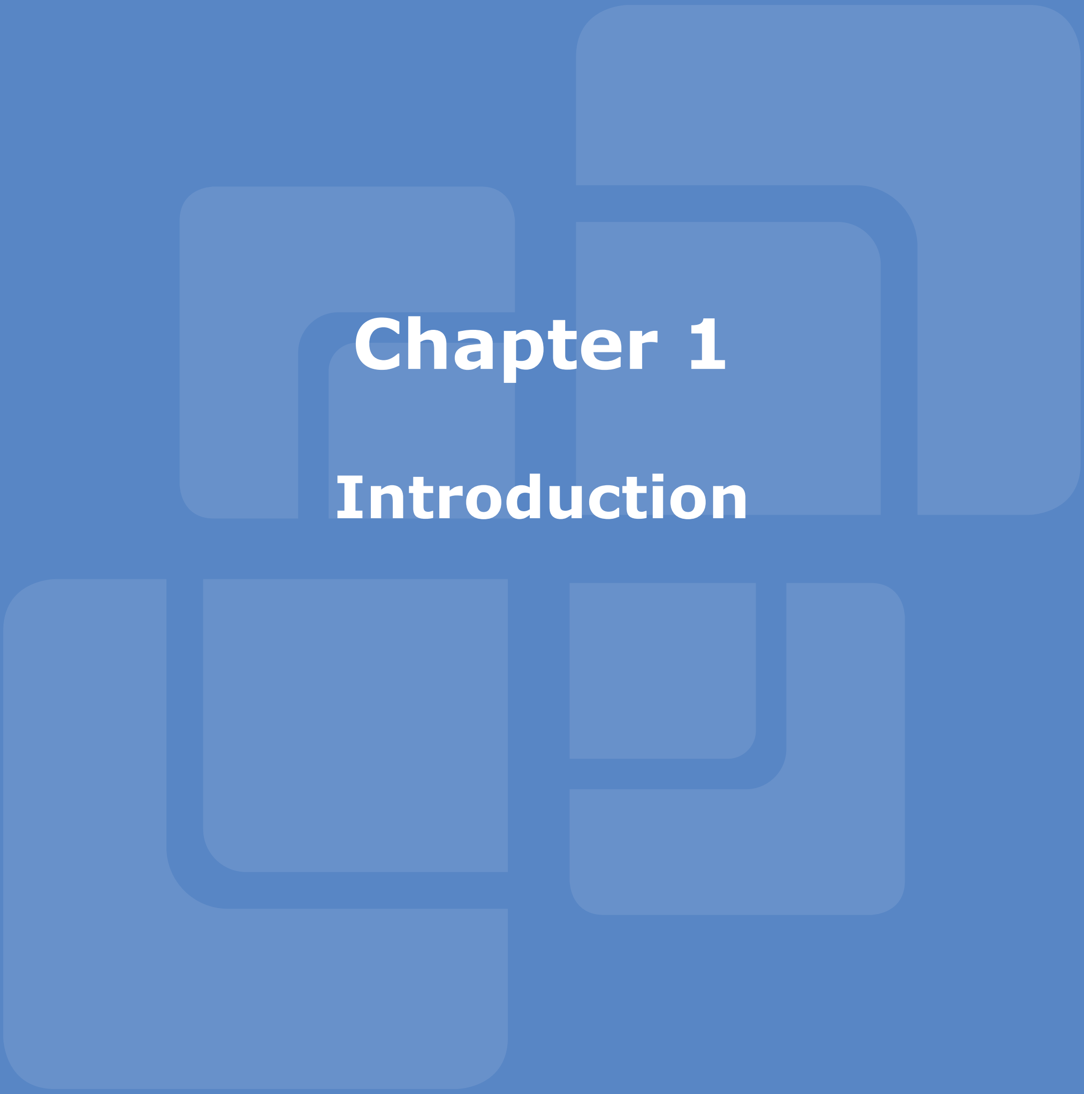

Chapter 1

Introduction

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Introduction

A SCI often happens suddenly without any warning, leaving no time to plan or prepare, and it can bring significant change within a family. There may be a sudden upheaval where one parent is in hospital and the children may have to stay with family, friends or neighbours.

Children may have questions about what is happening, and it is important to provide them with information and to help their understanding in a child friendly and age appropriate way. As you learn more and develop greater understanding of your SCI, it can be helpful to have open conversations with your children about SCI and what this may mean for the family. This booklet aims to assist you, your family and your children on this journey.

Most children cope well with having a relative who has a SCI and don’t experience long term difficulties – in fact they can learn coping and resilience skills which will stand to them if they are supported and included. To do this, they need your support and they need to see adults around them managing the situation well.

This booklet outlines some of the challenges that can arise, and lists supports and resources available to help. It also looks at the best approach, depending on your child’s age and personality, while considering your own adjustment.

The resource was developed for parents with a SCI and their partners. It may also be useful for:

- Grandparents
- Guardians or anyone caring for the child
- Teachers
- Health professionals
- Friends of the family

The information in the booklet is based on research findings about the impact of SCI on families and children. It is also based on the knowledge and shared experiences of families who have experienced a SCI in their own lives. We would like to particularly thank all those families who gave their time and examples of their personal experience to contribute in the development of this resource.

Every family is different and must find their own way through this journey, but it can be very helpful to hear and learn about other families’ experiences.

Chapter 2

First things first

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First things first

2.1 Your own adjustment

It is very natural to feel a lot of emotions after SCI. It can be hard enough dealing with the impact of your injury on your own life, without also having to think about how to explain circumstances you never thought you would have to face, to your child.

Your child will be sensitive to your feelings, maybe more than you realised. It is therefore important to acknowledge your own emotions first; before talking with your child. You may have heard the phrase about the importance of putting on your own oxygen mask first before placing them on your children.

At times people may suppress what they are feeling as they believe it will protect others. However, it is absolutely ok to be upset in front of your children; just try to ensure your child is reassured that they are not the cause of your upset.

A child can misinterpret overwhelming emotions, such as anger and sadness, as being their fault. Similarly, a child can translate anxiety and worry as the problem being worse than it is. It is important to be calm, honest, and factual when speaking with your child, to both reduce their anxiety and to encourage openness.

If you are finding it difficult to talk to your child you may find it helpful to have a family member, friend or a member of your rehabilitation team support you to talk to your children about your injury. Please just ask your team!

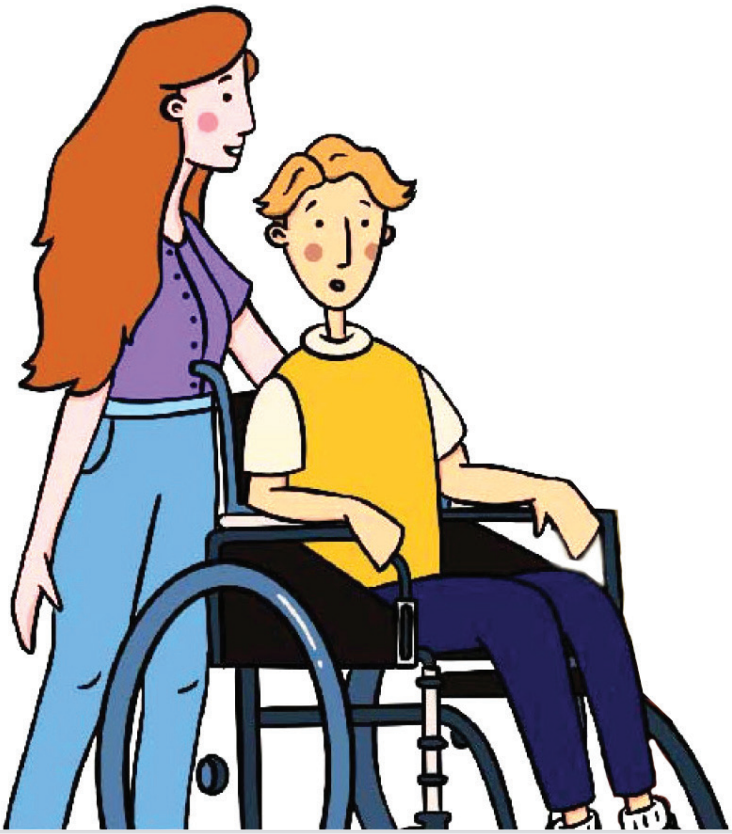
While you may feel alone during the initial stages of your injury, many families have been in this very same place. Hearing about the experiences, challenges and successes of other families affected by SCI could be helpful when considering how to talk to your child about your SCI. If you think this might be helpful for you and your family, link in with your team and a peer support worker can meet with you.

It is likely that your child has been told you are in hospital with an illness or having sustained an injury. It is also possible that you might be finding it quite difficult to think about your own feelings, let alone those of your child at this time.

Being in hospital and away from your children is already difficult and you may feel some uncertainty regarding what exactly to say to your children, how best to say it and how you're going to manage as a family. It is important to remember that every family is a unique unit with its own ways of doing things.

You are getting through this as a family and trying to get used to doing things in a different way. It's OK not to have all the answers and to try to figure them out together.

Every child is different and has their own unique and special personality. Equally, they may be different ages and at different stages in their lives (refer to 'The Developmental Phases of Childhood' - **page 12**). Some children may already have experienced significant changes and adjustments due to previous events that have happened in their lives; while for others these changes are new.



It is important to say that not all children will react the same nor will all children react in a negative way when a parent has an illness or injury. However, unlike adults, they don't always express their feelings, but they may send some clues through their behaviour. Their behaviour and reactions may not always be easy to respond to when you yourself are under stress, but it is important they feel listened to, supported and provided with the space to communicate when ready.

One helpful thing to do is to try to keep as many of the normal routines and activities consistent and keep familiar people around your child. Your partner, parents, siblings and friends may be involved, and you will need that back-up.

It's also important that children are given information, in an age-appropriate way, as to what is happening, where you are and when they can see you. Not being given any information and imagining 'what might be happening' and 'why' can be more damaging for a child.

Unfortunately, sometimes people may say thoughtless things without meaning to, that you or your family might find hurtful. If you think it might be helpful for you and your family, link in with your team and together you can have a conversation about how to manage these interactions if they happen.

2.3 The developmental phases of childhood

Children process information at different ages and this is an important consideration when deciding which approach to use with your child. Keep your child's developmental phase in mind when making your way through this booklet.

Every child is unique and different!

Birth to 5 years

- Young children are concrete thinkers and will pick up on your cues.
- Provide reassurance through physical contact like hugs and kisses and a comforting tone of voice, for example "even though my body is not working the same, I am still the same person and I love you".
- Separation is hard for this age group – changes in routine can also affect a toddler. Keeping routines and known carers as much as possible really helps. Bonding and attachment theories explain the importance of facial connection for children and their families regardless of their age. Babies in particular bond and attach to smiles.
- A young child will be satisfied with simple explanations so use simple terms to explain your injury, such as "I hurt my spine and that is why I can't walk", "I am going to use the wheelchair to help me move around because my legs aren't working" or "The hospital is going to help me to get used to all the changes".
- Often children at this age believe that the world centres around themselves and may think that something they did caused the injury or situation. It's important to find out if they have these concerns and to address and reassure them.
- Use pictures and play to help explain basic concepts and as a way to encourage questions and concerns.
- Tune into how your children are playing - this might give you clues as to what they are thinking and feeling.
- They may need more soothing and reassurance as they can seem to "regress" to an earlier emotional stage when upset, for example they may be more "clingy" to you or reluctant to come to you until they know you are still the same person – which can be upsetting.
- You might see more temper tantrums, bedwetting or new fears – they generally mean that they need more reassurance and attention.

Primary School years 6-12	• As your child gets older, they move from being concrete thinkers to being more reflective. • It is likely they will have more complex questions about your injury, its impact on your body, medical terms and treatment. • Take the time to listen to questions and clarify misconceptions. • Despite improved verbal and reasoning skills, your child will still process terms differently to an adult. It is important to use the correct terminology, as these terms are what they are likely to hear from others. Use age-appropriate language to help your child's understanding. • Remember to pace the amount of information you provide to your child to avoid overwhelming them. The use of interactive learning, such as visual prompts will help your child's understanding of more complex medical terms.
Adolescence 13-18 years	• Most adolescents have the capacity to understand medical terms and concepts at an adult level. • They will have more adult-like and mixed emotions such as anger, sadness, resentment, fear and may feel confused and angry about these feelings. • Adolescence can already be a challenging time when your teenager is striving for independence and control. It is very important to maintain open communication with your child around questions and concerns. • Try to offer choices as to what level of information they would like to know and how you can best support them. The helps to build a sense of control for your teenager by letting them make their own decisions. • Have more in-depth discussions regarding medical concepts and the impact of the injury both physically and emotionally as well as the impact on your family. • Visual anatomy and explanations can also be helpful for the adolescent's understanding of complex terms – but remember that adolescents might find it embarrassing to hear about bodily functions. • This age group may like to read information or look at relevant websites in their own time.

Chapter 3

Staying in touch

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Staying in touch

At the NRH we know visits from your children are especially important for all the family, and that staying connected is vitally important.

While you were in the acute hospital, or during the initial stages of your rehabilitation journey, it might have been difficult to spend time with your children or to even just stay in touch. This is particularly true if your family live a long distance from the hospital. Your partner may be staying in Dublin, near the Hospital, or commuting regularly, and may be away from your children.

Here are some ways that you can try to stay connected with your children:

- Ask your children to make some artwork to put up in your room in the hospital.
- Your phone is a great way to stay in touch (via phone call, video call, WhatsApp, FaceTime, using 'Siri' or 'OK Google' can assist with staying in touch).
- You might read them their favourite story over the phone or on video call.
- Perhaps write them a letter or have someone assist you to do so.
- Exchange photos with your children so that you can have mementos of each other close by.
- Have a set time to call each day.
- Send a recorded video message – the staff or volunteers will be happy to help you.
- Ask your child – "how can we make coming to the hospital easier for you?"
- If you can go on therapeutic leave from the hospital this will give you a chance to be at home with your family and provide you with an opportunity to talk to your children in their own environment.

3.1 Visiting the Hospital – kids being kids

Including your children and young people in your rehabilitation journey and hospital life can have many benefits such as:

- Helping you and your children to stay connected.
- Giving you and your family a greater sense of control.
- Helping your children to feel like they belong and are included on this journey.
- Your child can see for themselves how you are doing.
- Your child will have a mental picture of where you are.
- It will help your child to gain a deeper understanding of your injury.

Some of the challenges include the distance that your family might have to travel to the NRH and concerns about how your child will react when seeing you in hospital.

Whoever is bringing them to visit you might need some general tips to assist with making this experience as easy as possible:

- Pre-visit preparation:
    - prepare your child for how their parent will look
    - let them know what medical equipment is being used in the room and show them what this will look like.
    - prepare your child for what they can expect to see before they arrive to your room (particularly if this is a first visit to a hospital).
    - showing your child some pictures of you in hospital can be very helpful.

- Organise for a close family member or friend to be with your child. This will help them to decide how long they would like to stay, and they can leave when they are ready to go.

- Think about the best time of day for small children in particular to visit, as they could feel tired and irritable if they are due a nap or if it is past their bedtime. The visit might not go as well as you would like in this instance.

- If a small child hasn't seen you for a few weeks, expect that they might be a little withdrawn or perhaps overexcited.

- Try to have some physical contact or cuddles with your child so that they know you are still the same person. If you need some assistance please ask. It's important that you maintain physical contact with your children, even if it is in a different way.

- It might be good to have things to do with your children when they come in, such as bringing them to the Café or have them do a drawing for your room. Ask your team for any support or items that will help make your child's visit go well.

- After the visit, a close family member, friend or even yourself, if possible, should talk to the child about how they feel, what they remember from the visit and whether they have any questions or particular concerns that you or your family, friend or rehabilitation team may support with.

Each child will respond differently to visiting, based on their age and personality. It is important to consider their reactions and how they feel. If a child does not wish to return to hospital or the Unit, this could be an invitation to talk about their concerns or fears.

If you wish to involve your children in the rehabilitation journey then you can ask for assistance from your Social Worker or other members of staff... just ask!

Keep note of your child's list of questions so that you can clarify answers at the hospital. If you need help with difficult questions your rehabilitation team will be happy to help.

Chapter 4

I don’t want to talk,
I’m not ready to talk

Chapter 4

4.1 I don’t want to talk, I’m not ready to talk

As you are learning more about your SCI or new diagnosis, you may be unsure of how to talk to family, friends and in particular your children, especially if you are afraid this will cause worry or upset.

• Process your own feelings about what has happened

Start by allowing yourself to process how you feel about your SCI, and know that emotions like shock, fear, anger or sadness are normal and understandable. This brings us back to putting on your own oxygen mask first before placing them on your children. Know that there is support available from your team to help you explore the emotions you are feeling and to help bring you to a space where you may feel more comfortable speaking openly to your children, in an age-appropriate way.

• Know what’s most important to others

The early stages can be very frightening and without information children can jump to incorrect conclusions. The most important thing for them to know is that you and their family are safe and well. This is where staying in touch can offer reassurance.

• Answering Questions

As you yourself may be coming to terms with SCI, it may not be possible to answer questions children or relatives may have as you may simply not yet have the information. It is ok to say to your child, in this instance, that they have asked a really good question but you don’t know the answer just yet, but when you learn a little bit more about your SCI you will be able to let them know the answer.

You may wish to have a person from the NRH to support you in talking with your child. This can be helpful when thinking about what you might like to share and how you may like to share it.

Chapter 5

How and when to talk to your children

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How and when to talk to your children

Depending on the circumstances surrounding your SCI, you may not be the first person to talk to your child about what has happened. Your child may, however, still have many unanswered questions about your injury, hospitalisation, and life after rehabilitation.

As a parent, you are the expert in knowing the best way to communicate with your child, and how to comfort them when they are upset or scared. You will know when the best time is to approach your child and to have a conversation about how they are feeling.

It is important to be open, honest and to keep information simple and age-appropriate when speaking with your child; this can help minimise the risk of making false promises. Feedback from children and young people whose parent have experienced a SCI is that they value honesty and can sometimes find it unhelpful where they are being told to have 'hope', rather than being informed of the extent of their parent's injury.

To assist in explaining some of the aspects of SCI to your child, you may wish to involve some of the hospital staff to help you. Providing information that is age and developmentally appropriate, while also catering for the uniqueness and individuality of each child, is important. The rehabilitation team can help in supporting you with this. Please ask a member of the team any questions you may have, before you talk with your children, so that you can best explain what is happening and why.

It is important to have open conversations about SCI within the family to ensure your child has a space to express their emotions and to reduce the risk of them feeling "selfish" for speaking about how they are feeling. When managed correctly, many children report that relationships within the family were strengthened because of open communication as they "had to get through it together" and it was "something that we could all relate to".

Through conversations with your team you may also discover what other resources and supports are available to help in assisting your child. Some of these resources are listed on **page 45-47.** However, there may be more support or information available that is not listed.

5.1 Give some thought to your approach

- Children can and do learn about SCI.

- It is important that your child receives consistent information. If there are other adults involved in your child's life, ensure that they give a consistent message if your child asks them questions too. This can help to ensure that your child is not receiving different or conflicting answers to the same question.

- Try to choose a quiet time to talk to your child in a place that is comfortable and private. This will help avoid or reduce distractions for you and your child.

- If you would like, you can contact the social worker and ask to plan or practice your approach before speaking to your child.

- If you are using a wheelchair, this can be a source of great interest to a child and they might want to sit on your knee or push it or have a go themselves. Once they know that you are using this wheelchair to get around and that it allows you to be part of their lives, younger children generally accept this very quickly.

- Keep the information simple and be honest with them.

- Allow and encourage questions – let them lead on how much information they want and when.

- Be careful of phrases like "when I will be better" if you mean "improve"…..Younger children can be very literal in terms of meanings.

- Update the information as things change or as your children ask more questions.

- Let your child feel involved in an age-appropriate way.

- You can also ask for your child to be seen by a member of the Social Work or Rehabilitation Team with or without you being present – many families ask for their child to have a session with someone on the team even just for reassurance. The social worker or rehabilitation team member can talk you through how a session may look, and also provide feedback to you after this session. Sometimes children will protect you by not talking about their own worries and upset and they might talk to someone who is not a parent for this reason. They might also like to meet other kids in a similar position. A referral to a local service can also be discussed and arranged.

It is known that for many children, the process of adjustment to their parent's SCI can take several months or years; therefore, there is a need to revisit the topic over time as children come to accept their parent's SCI. We cannot force children to speak with us, but it is important that we make them aware that we are available, and that you as their parent are open to having such conversations when they are ready. It is not just one conversation, rather it is an ongoing conversation that your child can bring to you at any time.

When there is any major event that changes us, it changes things in our relationships. These are not necessarily negative changes but there will be changes in your parent-child role and relationships. However, you are still their mum or dad.

5.2 Considerations at any age

Focusing on your strengths and abilities following your injury can assist your child in seeing these strengths also. Talk about some of the things that will be different and acknowledge that it may take some time getting used to the changes. Explain that many things will be the same and that you can continue to do these together as a family.

- Consider your child's personality and ways they generally cope. This will help you to think of a good approach.
- You might find it helpful, if you have more than one child, to talk to your children together. This shows honest communication as a family and they may be more likely to ask you questions.
- Be guided by your child's questions – what do they want to know more about?
- Use simple language and avoid big medical terms. Use language that you know your child can understand. Be careful of words like "better" as opposed to improving.
- Reassure your child that they can ask you questions at any time and that you appreciate them asking questions. Try using encouraging statements like "you have such great questions" or "that's a really clever question".
- If you don't know the answer to a question, tell your child that you don't know but that you will try to find out and get back to them. For an older child you might decide to look for the answer together, or perhaps no-one knows the answer to some questions and the child needs to know that too.
- Children can learn about SCI and indeed it is very important that they understand what is happening and why, to clarify any misconceptions that may be causing them distress.
- Children can try to hide their feelings to protect themselves and their parents. It is likely that even though you may not have spoken directly to your child yet, they are already making their own sense of what is going on. This may or may not be accurate.

It is so important to listen to your children. They often won't say that they are worried. Remember to give children many opportunities to talk about their concerns.

Sometimes, children can find the hospital environment overwhelming. Some people with young children have found it useful to get down to their child's height, to see what your child is seeing. It's a powerful way to see the experience from your child's perspective.

Where possible, try to provide your child with choices to help them feel a little more in control at a time when things may seem beyond them. The doctors and the team have been using lots of new words since I have been in hospital.

Try using open-ended questions to generate discussion. Some examples are listed below:

- What words have you heard?
- What do you think they mean?
- What do you think happens when you have a SCI?
- How do you think things will be different now that I have a SCI?
- What things do you think will be the same?
- What are some of the things that you are worried about?
- How do you feel about what has happened?

5.3 Some Tough Questions

Will you ever walk again?

"At this time, there isn't a cure but there are lots of people trying to find a way to help me and other people who have had a SCI".

Why can't you come home?

"I need to be at the hospital so I can get as strong and as well as I can be before I come home" (for good).

Should I tell my friends what has happened?

"Yes, you should because it's important for your friends to know what's going on in your life. They can support you if you need help, or just a friend to listen".

If your back is broken, why don't your legs work?

"Because the message from your brain to use your legs goes down your back through the spinal cord, and that's where the message gets broken".

Why do you have a leg bag?

"Because the messages from my brain don't tell me when I need to go to the toilet – I can't control when I need to pee, so I need this bag to catch my urine (pee)".
You can choose age-appropriate answers to give your child.
(This may lead to other questions about bladder or bowel management, and you might like advice from the team on how to answer some of the more difficult questions).

If the leg bag catches your pee, what catches your poo?

"Because the messages from my brain don't tell me when I need to go to the toilet – I can't control when I need to poo, the nurses here are helping me to manage going to poo. Sometimes I might have an accident, but that is ok and normal".
(You can choose the amount of information you decide to share with your child when it comes to bowel care. Some people have anxiety and a fear of bowel accidents which may be eased if you feel comfortable discussing it with family members).

I just saw you move your legs?

"This is called a 'spasm' and this can happen sometimes when my muscles become tight. These spasms happen without me knowing or controlling them. But they are very normal."

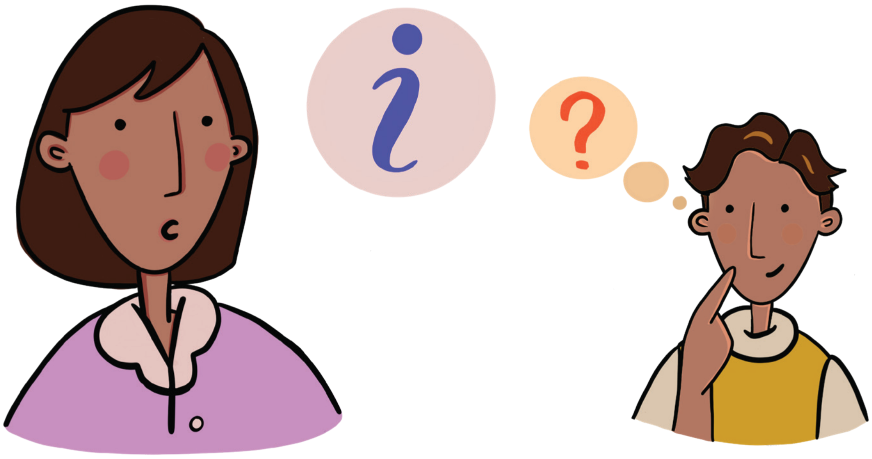
Who can I talk to about how I feel?

"You can talk to your mum or dad or any other trusted adult. You can talk to friends or teachers or someone at the NRH who talks to kids and young people. It's important to talk to someone about how you feel, but it's up to you to decide who you would like to share your feelings with".

Why do you get bad headaches or get very hot and people start to panic or worry?

"These headaches and feeling hot can happen to me very fast, without me knowing that they are going to start. When I feel these headaches or hotness I follow a plan to make sure they don't get any worse. Mammy (or Daddy) are part of this plan and sometimes they might give me the medicine to make me feel better, check my leg bag or sometimes they might need to take me to the doctor."

It may be an idea, where appropriate, to include your child in your Autonomic Dysreflexia plan by letting them know where the medication (Nifedipine) is kept so they can retrieve it for you should it be required.



5.4 What if I get it wrong?

It's likely that you may make some mistakes when telling your children about your injury. It's all very new to you, never mind your child.

Don't panic if you feel you got it a bit wrong – it's OK to make mistakes. Don't expect to get it right all the time, there is no such thing as the perfect parent!

Talking to your children can be difficult and often upsetting. You are upset for the losses and changes they are going through as much as for yourself. It may not always go to plan. If things don't work out as you planned, consider what you might do differently when you talk to your children again.

Children will be able to manage if a conversation doesn't go according to plan. Just remember to be honest!

5.5 Tips on listening to children

One of the greatest things you can do for your child is to listen to them. Sometimes what children are saying isn't said through their words.

Here are some tips for listening to children:

- Give children time to make their message clear and show them you respect how they feel. Do this by making good eye contact and giving them time to express their concerns or questions.
- Be encouraging of questions and pick a time when there are minimal disturbances.
- Children usually talk about difficult or painful things in a roundabout way.
- Children need assurance from adults that it's OK to talk about upsetting things.
- Children often drop hints when something is wrong or they might indirectly talk about a problem, for example, a child might say "will I need a wheelchair?" which may indicate that they don't understand how the SCI was caused.
- It's not uncommon for physical symptoms to be an indication for worry or stress – for example, your child might say that they have a sore tummy.
- Children get confused when adults don't understand their signals or don't respond to their message. The non-injured parent can also be stressed and distracted. By being observant, adults are also able to pick up the non-verbal cues that something is wrong in a child's life even when a child isn't aware of it.
- Other adult relatives may help you with this – for example, having one to one time with a grandparent.
- Encourage your child to be open about their feelings and reassure them that it's normal and OK to feel lots of different emotions and that you are also feeling them. This will help invite further discussion and help to build your child's resilience and emotional coping skills. You could say – What I do is...
- Help your child work out what ideas they have about coping with a problem, talk with them about which ideas might work or might not help and why.
- Remember that children will have different questions as they grow and develop, and you need to be able to answer these as they arise. Keep updating children as they and the situation changes.
- Older children may not find it easy to talk about their feelings – teenagers are already moving away from parents and towards their peers and the injury will come on top of that normal adolescent process. Often at this age, there can be tensions with parents, wanting to keep things to themselves or wanting to be independent. Like adults, they will have thoughts of "why our family" and they may rail against the unfairness of the situation.

Remember, teenagers are often concerned about justice and fairness.

5.6 Some things that should remain the same after SCI

- Continue to let your child know that you love them.
- Normal family routines should remain intact as much as possible, like family meals together, watching movies together and going to social groups.
- Your child should continue to go to school regularly.
- Your child should be encouraged to continue normal activities as usual, such as seeing friends after school, keeping up hobbies, sports and having fun.
- It could be helpful to ask the parent of your child's close friend to help you to keep track of special events, school trips and class projects if you are finding this difficult.
- Keep celebrating special occasions such as birthdays and significant family events, such as Communions.

With everything that is going on, make the most of your good days and do something fun with the family and spend some quality time together. You could also speak to your Occupational Therapist (OT) or Recreational Therapist about tips or equipment to help so that you can get involved in play activities and outings with your children.

Throughout the inpatient stay it is important to keep your child informed about what is happening at home and what is happening in the hospital.

Some people invite their child to attend a therapy session, when possible, so that they can be involved in the rehabilitation process and see your progress. Encourage your child to meet your treating team and get to know their names and how they are working with you.

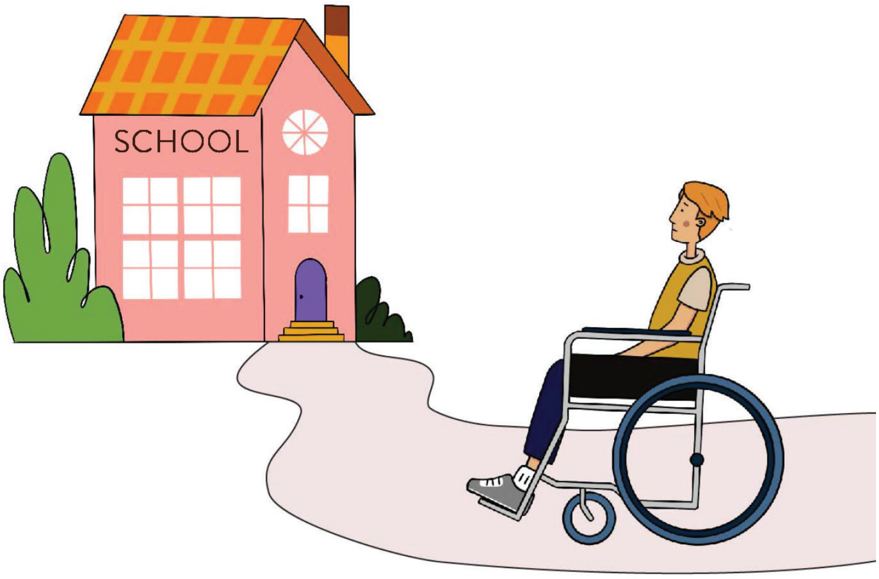
5.7 Talking with the school

It is recommended that you inform your children's school of the injury and the current family circumstances. Schools can be very supportive and flexible if communication channels are kept open.

You may find it helpful for you or your partner to talk to your child's teacher as the school may have support services such as a school counsellor. The teacher can also 'look out' for your child in a particular way and observe if there are any concerns or anxieties raised at school. Your Social Worker can assist you to make contact from the NRH if you would like support in doing this.

Some children have reported that school is also a source of support and provides a positive 'distraction' from home life by giving the opportunity to have time for fun with their peers. Your child's friends and peers can be an important source of strength and normality. Your child might like to tell their close friends that their parent is in hospital or had an injury, and they need the words and support to do this.

Older children and teens might decide to keep it more private and to get away from their worries when they are with their peers. Often children and young people don't want to be different than their peers and will want to keep things as normal as possible in school. They may also feel bad for having fun while others in the family are upset and it's important that they know it's OK to keep doing their usual things as much as possible. Peers are particularly important for adolescents as they are growing in independence as part of this life stage.



Chapter 6

Family life -
life beyond the NRH

Chapter 6

Family life - life beyond the NRH

Your family will have experienced a lot of change since your SCI. Returning home from hospital may bring more change to the way your family operates each day. It may also highlight some of the changes you will be adjusting to.

Preparing your children for the changes they can expect when you come home is important, even if your children are not living with you all the time. Some things to consider when preparing them for home could include:

- Changes to the physical environment such as ramps or adapted bathrooms, and what this might mean if they are having friends over.
- New morning routines, including the extra time you may need in the bathroom or to get up in the mornings.
- Having PAs (Personal Assistant) or support workers in the home to help you with your routines.
- There may be extra people calling in from time to time such as physiotherapists, public health nurses or other health professionals.
- You may have to change the family car.
- Equipment may take up more space in the house.
- If you are sick, it may mean staying in bed to get better and missing out on some family activities.
- Children may have different or increased role responsibilities around the house, depending on their age. It's important that you remain in the role of a parent and that they don't think it's their job to mind you or your partner. Sometimes, other people may say things like "you're the man about the house for now" which although well meant, is not what your child needs to hear. They need to know that their parents are still their parents and that they can take care of things.

It is likely that any adaptations along with the delivery of equipment will take place while you are in hospital.

It can be helpful to include your child, where appropriate, about plans to make changes to the home, while also giving an understanding of some of the equipment that may be needed.

6.1 Weekend leave - first day of leave at home - Woodpark

Before your discharge home from the NRH, you may have the opportunity to visit your home for day leave or an overnight stay. Alternatively, you may have the opportunity to access 'Woodpark' within the NRH, which offers a self-contained apartment set-up, where you, your family and children may be able to book an overnight stay prior to your discharge.

When you are planning for your first visit home or your stay in 'Woodpark', preparation is key. It is very normal for the initial visits home to be emotional for both you and your family as this is a momentous occasion on your rehabilitation journey and often the first opportunity to return home since you entered the hospital.

Speaking with your child about the planned visit home, how long this visit or stay will be for and what room you may be sleeping in can be helpful in best preparing your child. There may be new equipment in the home to assist your visit or overnight stay, equipment can sometimes take up a lot of space in the home and it can be helpful to speak with your child, in an age appropriate way, about what these different pieces of equipment are used for.

To support this visit home, it may be that carers are being introduced to the home for the first time. It can be helpful to inform your child on the role of the carer and the role they do not play; they are not there to provide a parenting role and similarly, your child is not there to provide a caring role.

It is recommended for the initial visit to your home, to try and keep this visit quiet and to have boundaries in the number of guests who come to your home. This can allow the opportunity to spend time with your partner and children and to be present in your home.

Many people with a spinal cord injury experience fatigue and it is important to be mindful of this while visiting home. Communicating with your child about your fatigue can be helpful as children can often be eager for you to play games with them or read them a story when you are home.

Having a plan in place with your child where you take a rest break can be helpful. This plan may look like – "I would love to play that game, but first I am going to close my eyes for 30 minutes so that I can make sure I am fully ready to play this game". This can help keep children informed and can better help in understanding, compared to being told 'not now', 'maybe later' or 'I am too tired'.

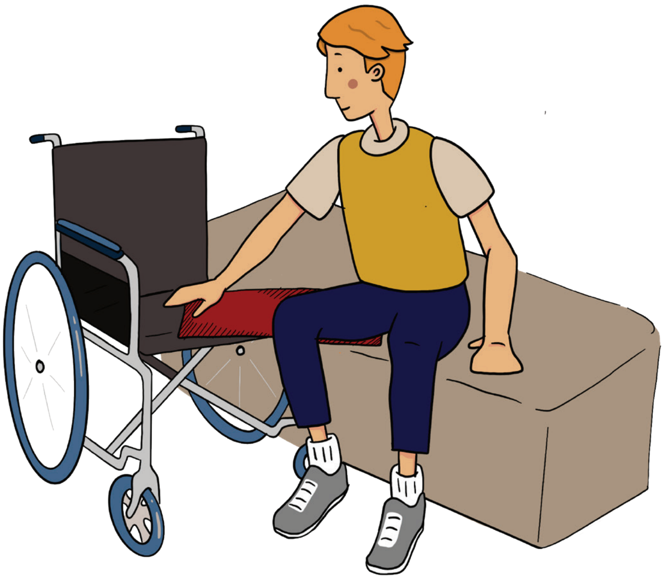
Some children may be keen to get involved and want to learn about aspects of your care. If this is the case, some education may be required for basic tasks such as manoeuvring the wheelchair, applying brakes and what to do in an emergency. Again, appropriate education can be covered with your treating team in the rehabilitation unit. It is important to consider your child's age, ability to cope and what is suitable when thinking about what they should learn and how they can help.

Your child should not be an alternative to professional care services or an adult relative carer, but they often like to be involved in tasks that make them feel connected to you. You will need to work this out as a family - you and your partner will know what your children are able for physically and emotionally at various stages.

Take some time to speak with your child about this, allow them to share their concerns or ask questions. For some children and young people, feeling comfortable with this 'role reversal' is a process. While some children adjust relatively quickly, the concept of looking after your parent is difficult to accept, with one child previously saying "It's just like when you hear the words look after your dad, I'll always think like, he's my dad, and I feel like he's still meant to be looking after me, so when I'm here to look after my dad it's just a bit.... I don't think I'll ever really get used to it".

The language used can also be very important in how this role is seen by children and young people, asking them what words or phrases are most comfortable for them to hear can minimise the risk of them feeling as though they are a carer for their parent.

Sometimes the family home may not be the plan for discharge or immediate discharge from the NRH, with other options being explored instead. It is important to use the information above in helping to make your room and environment a child friendly, homely and welcoming space.



6.2 Pacing and parenting - fatigue

Many people with a spinal cord injury can experience fatigue. Fatigue is not about laziness, lack of motivation or not being 'bothered', rather it is a real and frustrating part of living with a spinal cord injury. Communicating with your child about your fatigue and how this can impact you is helpful, as often children can be eager for you to play games with them, go outside, read them a story, among lots of other things. Keeping your child informed of your fatigue can help them in understanding when you may feel like you don't have enough energy.

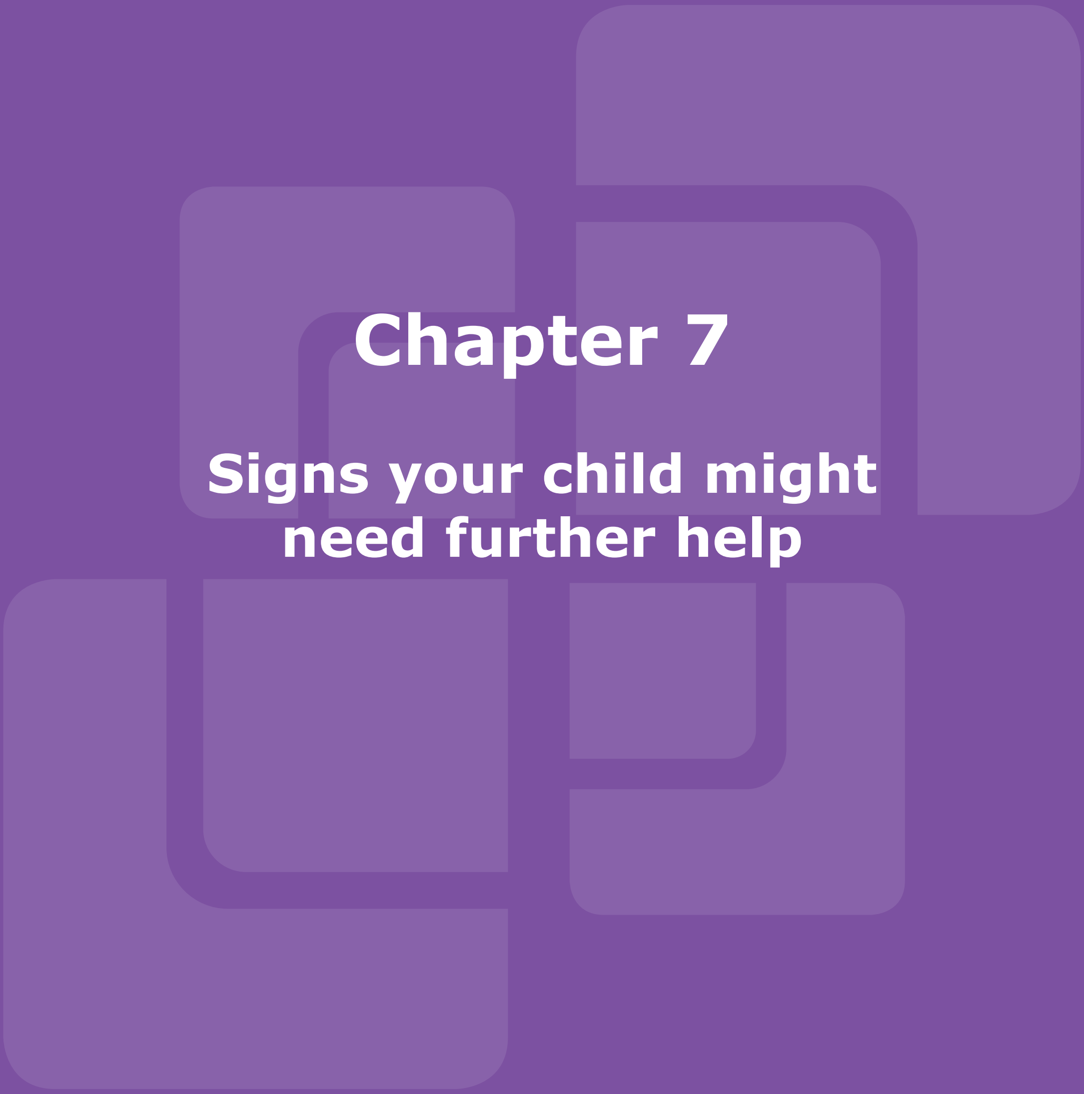
Having a plan in place with your child can be helpful for when you feel that your energy levels are low and that you are in need of a rest break. This plan may look like – 'I would love to play that game, but first I am going to close my eyes for 30 minutes so that I can make sure I am fully ready to play this game'. This can help keep children informed and can better help their understanding, compared to being told 'not now', 'maybe later' or 'I am too tired' which can sometimes make children feel that you don't want to play with them.

Other helpful tips in managing fatigue include:

- Stress management: Rest and Relaxation (progressive muscle relaxation, visualisation, mindfulness…)
- Pacing your routine (particularly in the morning time)
- Music – relaxing and energising
- Yoga, Pilates and physical exercise
- Receiving support from friends, family and professionals in adjusting to 'new normal'
- Setting daily priorities and goals
- Doing something you enjoy everyday
- Balancing lifestyle: self-care, productivity and leisure activities
- Energy conservation – 4P's – planning, preparing, pacing, prioritising
- Efficient transfer techniques and minimising transfers throughout the day
- Accepting assistance to help focus on your priorities
- Review your diet and nutrition

6.3 Suggestions for when you return home

- Continue to be involved in your child's life and their schooling.
- Your child's education is important and they should be encouraged to continue going to school or college as planned.
- Make special time to talk to them about their interests.
- Set clear boundaries with your professional carers that they should not take on a parenting role.
- Also, set clear boundaries with your child that they do not assume a carers role.
- If possible, have a designated room for your child that is not their bedroom and that the carers will not be entering. This can be their "safe space" if they are finding it difficult to adjust to new people being in their home.
- Attend events that are important to your child as often as you can: if there are issues around accessibility, or you are unable to attend, ask your child about the activity afterwards.
- Know your child's friends and their parents; encourage the child to invite their friends over.
- Help your child to understand your access needs and what they can do to help, such as keeping toys off the ground in areas you need to use your wheelchair.



Chapter 7

Signs your child might need further help

Chapter 7

Signs your child might need further help

Even though it is natural to feel different emotions when you are adjusting to life with a SCI, it is important to recognise the signs that show your child may need additional emotional support.

Some of these signs may include the following:

- Low mood (over an extended period)
- Low motivation
- Sleeplessness or nightmares
- Social withdrawal or isolation
- Refusal to go to school or to engage in routine activities over an extended period
- Increased anger and verbal or physical aggression
- Conflicts in relationships with family or friends
- Risk-taking behaviours such as drug or alcohol abuse, fighting or sexual experimentation
- Denying emotional pain while at the same time acting overly strong or mature for their age.

Any of the above changes in behaviour, could be a signal to let you know that your child might require further support.

If you have concerns about your child's coping mechanisms and how they are managing, speak with a Social Worker or Psychologist at the NRH, a school counsellor (**see page 29**) or your GP about getting the right support for you and your child.

7.1 Signs your child might need further help

If you are not sure where to get help, a good place to start is to ask any member of your team. If you can say what your concerns are, they can point you in the right direction to get you started.

What can each of the staff help you with?

Medical Staff can provide medical information about SCI to family members and children

Nursing Staff can factor in regular family time and welcome children onto the Unit at agreed times. They can facilitate you to go down to the NRH coffee shop or other areas in the hospital with your child(ren).

Physiotherapists can involve children during treatment sessions to explain some of the treatments used and demonstrate the progress their family member has made through activities such as playing a game together or managing safe floor play.

Occupational Therapists can include children in therapy sessions and activities such as community outings and can offer tips and support in therapy sessions to maximise independence in playing with your child.

Liaison Nursing is available to you after your discharge from the NRH. The liaison nurse can be your point of contact with the hospital and may be able to guide you or put you in contact with other members of the Outpatients team if you have any questions on supports that you or your child may need to access.

Advanced Nurse Practitioner: The overall purpose of the Registered Advanced Nurse Practitioners (RANP) in spinal cord injury is to provide safe and timely evidence-based nurse led care to patients and their families at an advanced nursing level. The RANP can be a good support to you and your family following your discharge should you need nursing advice or support. After your discharge, you may be invited to attend a RANP clinic if required.

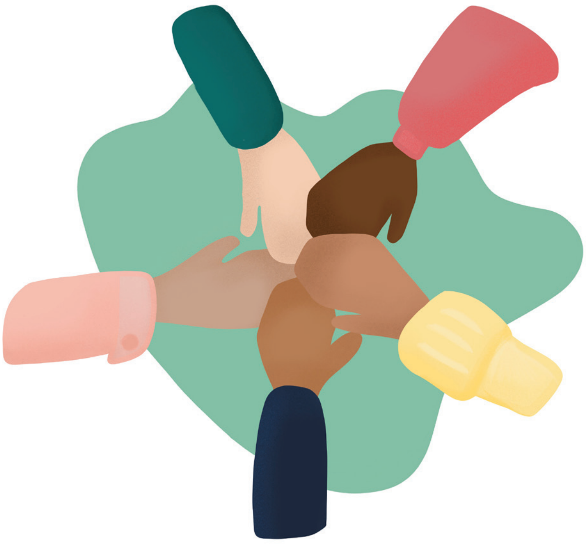
Social Workers can help involve your child relatives in discharge planning and resourcing, to address the emotional impact of the situation on children; assist you to liaise with relevant agencies that the child is connected to; connect you to peers and voluntary agencies to support coping. The Social Workers in the NRH can arrange for your child to be seen on their own, or with you or your co-parent. They can also arrange for referral to specialist services. They have a particular focus on assisting the family as a whole.

Clinical Psychologists can help with your own adjustment, can give advice on developing your child's coping skills and arrange for referral to specialist services

Peer Support Workers can offer advice, and share personal experience of parenting with a spinal cord injury.

Recreational Therapist can assist in exploring activities, hobbies and games that you may wish to play or engage in with your child.

Irish Wheelchair Association (IWA): The IWA has a liaison worker in the NRH who can assist you to participate in recreational sports activities, while also providing the opportunity to discuss supports available through the IWA. Where appropriate, children can be invited to take part in recreational sports activities during your time in the NRH.



Chapter 8

The family members who are at home

Chapter 8

The family members who are at home

It can be difficult to balance the needs of your child or children in the middle of adjusting emotionally and physically to your own SCI. Even at this challenging time, it's imperative to be mindful of your role as a parent to ensure that your child:

- Is safe and well
- Has their basic needs met, like food, shelter, and medical treatment
- Continues to attend school regularly and has access to education
- Has emotional support which will help to provide some comfort and security during a time of uncertainty
- Has love, attention and affection as well as reassuring words, to support your child's health, wellbeing and development of emotional bonds. This love and reassurance can really help in their adjustment to your injury.

If you feel that you are having difficulty meeting your child's needs during this challenging time, it's important to ask for support from family, friends or your treating team. Remember, it's OK to ask for help!

8.1 Parents need breaks - Looking after you!

Being able to look out for the needs of a young person effectively involves being able to look after your own needs too. Don't be afraid to ask for help. No one can look after a child or children on their own all of the time. Everybody needs a break and that's normal.

As a parent, you may have temporarily lost the practical support of your co-parent or be unwilling to burden them with day-to-day worries. You will be going through your own reaction and emotions and might be feeling overwhelmed and distracted.

Having a break is not a sign that you can't cope but rather an indication of your strength.
If a friend or family members you trust can look after your child for a few hours or even a day, take this time for yourself.

Your extended family, friends and good neighbours will all want to help and giving them something practical to offer can be a support to everyone. It's important to take time out to come to meetings in the hospital, to make future plans and decisions, and to see your partner as well as to take time out for yourself. You will be better able to give your children the love and attention they need if you look after your own needs.

Often during a family crisis, relationships with people will change; some people may feel overwhelmed by the support or lack of support offered by relatives and friends. It's important to communicate your own support needs. If you find this difficult, a close family member or friend may be able to organise this on your behalf. Families might think they are helping by spending a lot of time in your house or the hospital whereas you might need some time and space to yourself or alone with your partner.

This is new territory for all of your friends and family and they may need guidance on what help you need and when you need it.

There will be times when you and your partner are overwhelmed and don't feel able to parent in the way you would like which is completely understandable given what you are coping with – having supportive family and friends who can take over for a while is vital.

Chapter 9

Resources

Chapter 9

Resources

NRH supports and resources

During your NRH admission you will have the opportunity to work closely with the team in exploring, discussing and working towards your goals. If you have any questions about supporting your child, communicating with your child, or participating in activities with your child, the team in the NRH would be happy to explore and support with this with you.

After your discharge from the NRH there will also be the opportunity to avail of the Outpatient Department (OPD) services, Liaison Nursing and or the Advanced Nurse Practioner Service. These services can also support you with any questions which arise post discharge or help in recommending community supports and services.

Throughout your time in the NRH, there may be peer events which take place including, though not limited to: Women's Day; Men's Day; Farmer's Day; Family Information Day and other online information sessions. These events offer the opportunity to meet with peers and provide a shared learning experience. If these events are not scheduled during your admission, certain events can be accessed as an outpatient, so please do speak with your medical social worker regarding these.

A twelve-week block of weekly education sessions take place on the Spinal Cord System of Care (SCSC) programme. These sessions cover a range of topics relating to spinal cord injury. Ask any member of your rehabilitation team for a list of topics that are covered in these sessions.

Irish Wheelchair Association supports and resources

The Irish Wheelchair Association (IWA) have a liaison worker in the NRH, who can assist with participation in recreational sports activities, while also providing the opportunity to discuss supports available through the IWA. Where appropriate, children can be invited to take part in recreational sports activities during your time in the NRH. The links below offer further information on the supports and services which are available through the IWA.

IWA-Sport –IWA-Sport Website – www.iwasport.com
Further information on the sports available through IWA can be seen on Twitter @IWASport or Facebook @IWA-Sport, with a list of local community sports teams available through IWA-Sport Clubs – Junior, Senior - https://iwasport.com/clubs-sport-sections/

To become a registered IWA general member please follow the link: https://www.iwa.ie/get-involved/join-irish-wheelchair-association/membership-form/
or visit IWA.ie.

To become a registered IWA sports member, follow the link https://www.iwa.ie/sport/join/
or visit IWAsport.com.

Further information regarding the supports, services and resources available through the IWA can be found on their website, IWA.ie, or through contacting customer care at:
01 818 64 85 or e-mail - customercare@iwa.ie

Spinal Injuries Ireland (SII)

SII offer information and support in relation to, managing relationships with family and friends, financial assistance and advice, peer support, family support and professional counselling support. SII facilitate monthly peer support evenings in the NRH, while also facilitating lunch time events on occasion. Please ask a member of your team when the next upcoming event may be.

SII can be contacted on 01 653 2180 Email: info@spinalinjuries.ie and are located at:
G3, The Pottery Business Centre, Pottery Road, Dun Laoghaire, Co. Dublin. Further information is available at spinalinjuries.ie.

Sports and Leisure

Sports can offer an opportunity and outlet to spend time with your child and family, while also providing a positive impact on our health, mental health and wellbeing.

As detailed above, the Irish Wheelchair Association offer sports memberships and outline community clubs which facilitate different sport groups. However, you may wish to explore your own community and the local gyms, swimming pools, sports, and recreational activities available, to see what is on offer. It can be important to contact local services first to ensure accessibility is available.

Paralympics Ireland offer the opportunity for sporting potential to be uncovered, whether at local, national or international level. Information on the sports available within the Paralympic Games is available at www.paralympics.ie.

The Irish Paralympics have hosted the 'next generation' campaign across Ireland, seeking to recruit members and uncover sporting talents, further information available through: Permanent TSB NextGen - Paralympics.

Active Disability Ireland seek for all people having equal opportunities to be active. This service aims to increase access and opportunities for people with disabilities to engage in sport. www.activedisability.ie.

Parenting Resources and Equipment

Spinal cord injury and parenting - www.sciparenting.com

Breastfeeding pillow review:
https://mumernity.co.uk/a-mums-review-of-the-hippy-chick-breastfeeding-pillow/

Hands-free baby seat aid:
https://www.lap-baby.com/products/lap-baby

Free hand baby bottle holder
https://www.amazon.com/Beebo-Bottle-Holder-Charcoal-Improved/dp/B07B7R6VQR

Snugglebundl lifting blanket: -
https://snugglebundl.co.uk/blogs/all/video-thesnugglebundle-1

Eating aids and adaptive utensil holders:
https://eazyhold.com/

Easy hold straps
https://www.activehands.com/product/eazyhold/

Adaptive parenting project:
https://www.youtube.com/c/AdaptiveParentProject
And website https://www.adaptiveparentproject.org/

Wheel protector to help keeping little fingers from getting caught -
https://www.izzywheels.com/

Cars, travel and public transport

During your NRH admission, you may wish to explore a return to driving, accessible vehicles that may be available and or travel on public transport. Conversation with your occupational therapist may assist in exploring which options may provide the best support.
Further information on vehicles, vehicle adaption, tax relief and accessible public transport are detailed below.

- IWA Motoring Queries: https://www.iwa.ie/services/motoring/
- NSAI Approved Conversion Companies: https://www.ddai.ie/nsai-approved-conversion-companies
- Revenue (Fuel Rebate): https://www.revenue.ie/en/importing-vehicles-duty-free-allowances/guide-tovrt/reliefs-and-exemptions/scheme-for-persons-with-disabilities.aspx
- Travel Info for People with Disabilities | Transport for Ireland

Child Support Services

Support service	**website**	**contact**
Parentline	www.parentline.ie	01 8733500 info@parentline.ie
Family carers Ireland	www.familycarers.ie	1800240724
Disabled Parents Network	www.disabledparentsnetwork.org.uk	Via website
Tusla	www.tusla.ie	info@tusla.ie
CAMHS	www.hse.ie/camhs	Hselive@hse.ie
Pieta House	www.pieta.ie	info@pieta.ie
Rainbows Ireland	www.rainbowsireland.ie	ask@rainbowsireland.ie
Sibshop – siblings support project	www.siblingsupport.org/sibshops	
Barnardos family support service	www.barnardos.ie	info@barnardos.ie
Children’s Grief Project	www.childrensgriefproject.ie	info@childrensgriefcentre.ie
Parenting plus	www.parentsplus.ie	admin@parentsplus.ie
HSE Counselling in Primary Care (CIPC)	www.hse.ie	hselive@hse.ie
YAP – Youth Advocate Programmes	www.yapireland.ie	info@yapireland.ie
ISPCC – Irish Society for the Prevention of Cruelty to Children	www.ispcc.ie	01 234 2000
Jigsaw	www.jigsaw.ie	www.jigsaw.ie/services-in-your-area

Chapter 10

Bibliography

Chapter 10

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NRH

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