

# TALKING TO YOUR CHILDREN ABOUT SPINAL CORD INJURY:

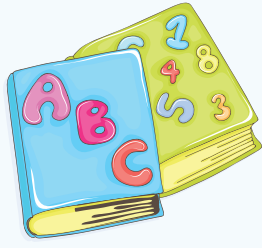
## A Practical Guide For Families



NSW  
SSCIS

NSW State Spinal Cord Injury Service





### Authors:

Candice Unger – Senior Social Worker, NSW Spinal Outreach Service, Royal Rehab

Leanne O'Reilly – Senior Social Worker, ParaQuad NSW

Laurissa Serratore – Senior Social Worker, NSW Paediatric Spinal Outreach Service, Northcott

Catherine Tulinsky – Social Worker, Spinal Injuries Unit, Royal North Shore Hospital

### Contributions also from:

Angela Pong – Senior Social Worker, NSW Spinal Outreach Service, Royal Rehab

Helen Tonkin – Senior Social Worker, Spinal Injuries Unit, Royal North Shore Hospital

Nadia Gibson – Senior Social Worker, NSW Spinal Outreach Service, Royal Rehab

Kate Jones – Social Worker, Spinal Injuries Unit, Royal Rehab

Stephanie Bortolussi- Social Worker, NSW Paediatric Spinal Outreach Service, Northcott

**Steering Committee:** NSW Spinal Social Workers' Forum

**Editor:** McNair Editing Services

**Illustrations:** Luce Suric and Florence Wee, Northcott

Published Aug 2013. Next Review 2027.

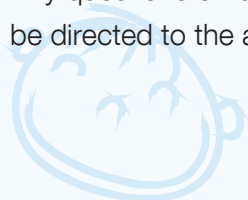
© State of NSW (Agency for Clinical Innovation)



We extend a special thank you and acknowledge the families who have shared their story and experiences. Their contributions to this project have helped to shape this resource to reflect the needs of family members of all ages, after spinal cord injury.

This has been a partnership project within NSW State Spinal Cord Injury Services.

Any questions or further information regarding this project can be directed to the authors: [rscis@royalrehab.com.au](mailto:rscis@royalrehab.com.au)



## FOREWORD

Spinal cord injury is one of the most challenging conditions that a person will ever have to face in life, impacting not only on them, but also on the loved ones around them. The days, weeks and months in acute care and later intensive rehabilitation following a serious spinal cord injury can cause family members to become isolated, particularly children who may be less involved day to day. Seeing a loved one severely injured can be very confronting, with hospital environments often disorientating and medical jargon confusing, all of which adds to the stress, turmoil and uncertainty that already exists.

This unique resource grew from the identified need to provide parents and families who are experiencing a spinal cord injury in a relative with developmentally appropriate guidance and very practical advice about effective ways to support and communicate with child relatives and remain connected to their lives throughout the patient journey after spinal cord injury. I believe it will make a really valuable contribution to the psychosocial care and well being of families during the period of acute care, rehabilitation and community reintegration after a spinal cord injury.

*Dr James W. Middleton MBBS, PhD, FAFRM(RACP) Director, NSW State Spinal Cord Injury Unit, Agency for Clinical Innovation, and Associate Professor, Rehabilitation Studies Unit, The University of Sydney.*

## BACKGROUND

As social workers in the spinal cord injury (SCI) field we acknowledge that there has been a gap in services, resources and support for parents and families to explain their injury to children.

Parents engaged in NSW Spinal Services provided informal feedback regarding the lack of specific resources available to them to assist their child relatives through the impact of spinal cord injury on their family.

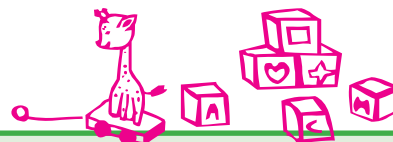
The NSW Spinal Social Workers' forum, on hearing this feedback, established this practical guide for families.

A subcommittee was created to drive this initiative and representatives from NSW Spinal Outreach Service, ParaQuad NSW, Royal North Shore Hospital and Northcott NSW Paediatric Spinal Outreach service have worked with families to create this resource.

This resource has been developed with consideration given to the concerns that have been raised by families in the past, in conjunction with an understanding of child development, and practical experience from a variety of practice settings in spinal cord injury, and recent literature and research.



# CONTENTS



## 7 FIRST THINGS FIRST

- 7 WHEN AND HOW TO TALK TO YOUR CHILDREN
- 8 YOUR OWN ADJUSTMENT
- 9 VISITING THE HOSPITAL - KIDS BEING KIDS
- 11 STAYING IN TOUCH
- 12 FAMILY LIFE — WHEN IT IS TIME FOR DISCHARGE

## 13 CONSIDERATIONS AT ANY AGE

- 15 YOUR CHILD'S AGE
- 16 TIPS FOR LISTENING TO CHILDREN
- 16 SIGNS YOUR CHILD MAY NEED FURTHER SUPPORT
- 17 SOME TOUGH QUESTIONS
- 17 WHAT IF I GET IT WRONG?

## 18 THE FAMILY MEMBERS WHO ARE AT HOME

- 18 PARENTS NEED BREAKS — LOOKING AFTER YOU!
- 18 PARENTAL RESPONSIBILITIES
- 19 WHERE CAN I GET SUPPORT OR FURTHER INFORMATION?

## 20 RESOURCES

- 20 RESOURCES FOR ME:
- 20 RESOURCES FOR MY CHILD:
- 21 RESOURCES FOR ME, MY CHILD AND OUR FAMILY:
- 22 REFERENCES AND FURTHER READING:
- 23 WORKSHEET

# TALKING TO CHILDREN ABOUT SPINAL CORD INJURY – A PRACTICAL GUIDE FOR FAMILIES

A spinal cord injury is a major life event, for both you and your family. This resource has been developed to assist you and your family to talk to your children about spinal cord injury, or SCI, and how it might affect your lives.

A spinal cord injury often happens suddenly and can bring significant change within a family. It is important for children to have an understanding of what has happened, to be kept informed about the changes they might expect to family life, be given a voice and to continue to be nurtured during this stressful time.

This booklet outlines some of the challenges that may arise, and lists supports and resources available to help you tackle these.

It also aims to offer assistance in choosing the best approach with consideration of your child's age and personality while taking into account your own adjustment.

This resource has been developed for parents with a spinal cord injury and also their partners. The resource may also be useful for:

- grandparents
- guardians
- foster carers
- health professionals working in spinal cord injury.

## FIRST THINGS FIRST

### WHEN AND HOW TO TALK TO YOUR CHILDREN



Depending on the circumstances surrounding your spinal cord injury, you may not be the first person to talk to your child about what has happened. However, like you, your child may still have many unanswered questions about your injury, hospitalisation and life after hospital.

As a parent, you are the expert in knowing the best way to communicate to your child, how to comfort them when they are upset or scared, and what are the best circumstances to approach your child.

To assist in explaining some of the concepts of spinal cord injury, you may wish to involve some of the hospital staff in explaining spinal cord injury to your child. Ask staff questions you might have, before you talk with your children, so you can best explain what is happening. You could also find out what other resources are available at your hospital for children – written resources, story books, visual aids, toys or any other tips from the hospital team.

#### Give some thought to your approach

- ★ It is important that your child receives consistent information. If there are other adults that are involved in your child's life, ensure that they are able to provide a consistent message if your child asks them questions too.
- ★ Try and choose a quiet time to talk to your child. Somewhere that is comfortable or private. This will help avoid or reduce the distractions for you and your child.
- ★ If you would like, you could contact the social worker to perhaps plan or practice your approach before speaking to your child.

## YOUR OWN ADJUSTMENT

It can be hard enough dealing with the impact of a spinal cord injury on your own life, without thinking about how to explain circumstances you hoped you would never face, to your child. Your child will be sensitive to your feelings, maybe more than you may realise. It is important to acknowledge your own emotions before you speak with your child.

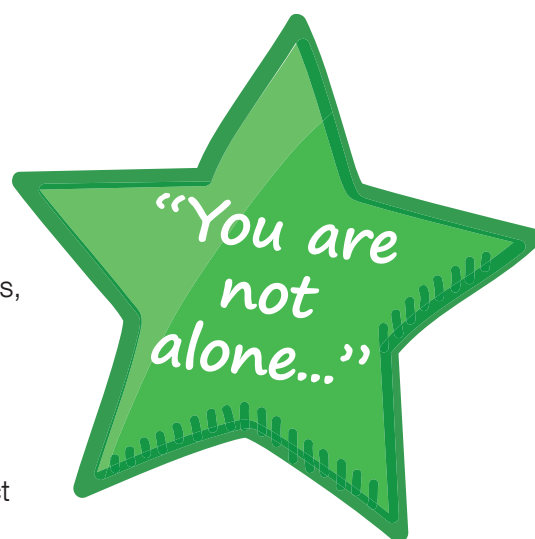
It is natural to feel an array of emotions after a spinal cord injury. However, be mindful that a child can misconstrue overwhelming emotions, such as anger and sadness, as being their fault. Similarly, a child can translate anxiety and worry as the problem being worse than it is. It is important to be calm, honest and factual when speaking with your child to reduce their anxiety and encourage openness. It is okay to be upset in front of your children just make sure that your child is reassured that they are not the cause for your upset.

If you are finding it difficult to talk to your child it may be because of your own understanding of what has happened, or your fears and concerns. It could be helpful to have a family member, friend or health member to support you to talk to your children about your injury. Just ask!

While you may feel alone during the initial stages of injury, there are many families that have been at this same place. Hearing about the experiences, challenges and successes of other families affected by spinal cord injury could be helpful when considering how to talk to your child about your spinal cord injury.

If you think that this would be helpful for you and your family, then contact the hospital or community social worker. You could join a family support group or get in touch with a peer support service, listed at the end of this resource on page 16. Don't forget that every family is different, and what works for one family may not be the right fit for your family.

*It is okay to  
be upset in  
front of your  
children*



## VISITING THE HOSPITAL - KIDS BEING KIDS

Including children and young people in rehabilitation and hospital life can be challenging and it is often over looked.

Your family's needs and the practicality of involving your children in hospital life should be considered.

Some of the benefits include:

- ★ Help you and your children stay connected.
- ★ Give you or your family a greater sense of control.
- ★ Help your children feel like they belong and are included.
- ★ Your child can see for themselves how you are going.
- ★ Your child will have a mental picture of where you are.
- ★ Fostering your child's understanding of your injury.

Some of the challenges include:

- ★ Regional location
- ★ Geographical distance
- ★ Concerns about how your child will react when seeing you in hospital.

Whoever is bringing them to visit you might need to know some general tips to assist with smooth hospital visiting.

Some tips for hospital visits are listed below.

- ★ Give a child warning about how their parent will look, the medical equipment and what else they might see before they arrive, especially if they have not been to a hospital before.
- ★ Take a close family member or friend with them. That way, your child can decide how long they would like to stay, and can leave when they are ready to go.
- ★ After the visit, a close family friend or relative or even you if possible, should sit down and talk to the child about how they feel, what they remember from their visit and ask if they have any questions.

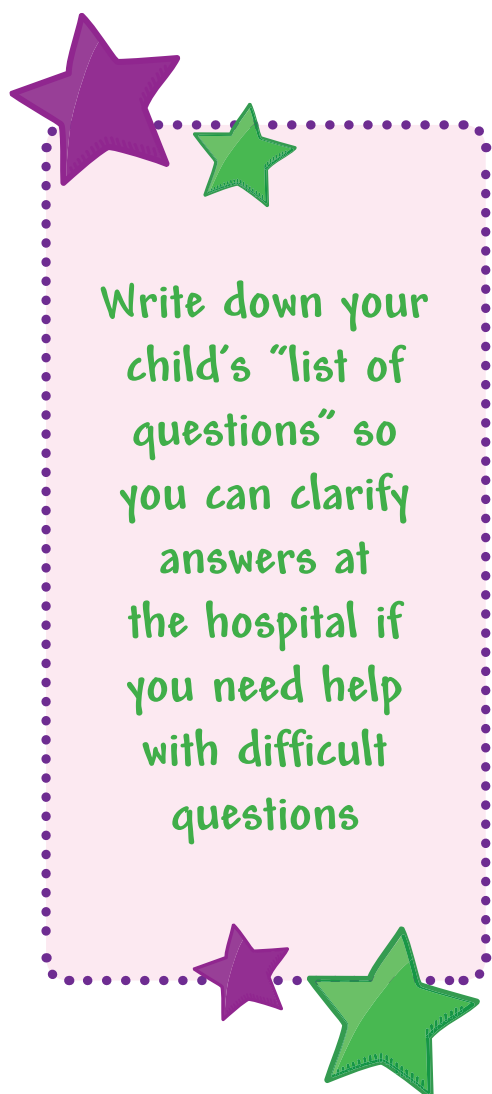


If you do involve your children during your rehabilitation, then you should expect to receive help from the hospital staff when it is required.

Remember, you do need to speak to the staff if you would like some additional support.







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 rehab ward, this could be an invitation to talk about some of their concerns or fears.

Some things that should remain the same after a SCI:

- ★ Continue to let your child know that you love them.
- ★ Your child should continue to go to school regularly.
- ★ Your child should be encouraged to continue normal activities as usual – see friends after school, keep up their hobbies, attend school excursions and have 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 excursions and class projects if you are finding this difficult.
- ★ Keep celebrating special occasions such as birthdays, name days and significant religious events.
- ★ Other normal family routines should remain intact as much as possible, like family meals together, or sport on weekends.

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 about tips or equipment to help, so you can get involved with play activities and outings with your children.

Throughout the inpatient stay it is important to keep your child informed about what is happening in the household and what is occurring in the hospital. Some people invite their child to attend a therapy session when possible so they can be involved in the rehab process and know how you are progressing. Encourage your child to meet your treating team. They can learn who the physiotherapist, doctor, social worker and occupational therapist are.

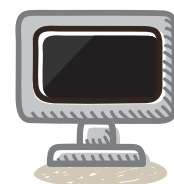
It is recommended you inform your children's school of the injury and the family's current circumstances. Schools can be very supportive and flexible if communication channels are kept open.

## STAYING IN TOUCH

Whilst in hospital or during the initial stages of spinal cord injury, it may be difficult to spend time with your children or to stay in touch. This is especially true if you and your family live out of the city. You may be admitted to a spinal unit at a major hospital in the city for quite some time. It is possible that your family will remain living at home, and you may not have the opportunity to see them as often as you would like.

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

- ★ Ask your children to make you some artwork to put up in your room at the hospital.
- ★ Use the internet; you can call long distance (computer to computer) for free using Skype.
- ★ You could read them their favourite story over the phone or on Skype.
- ★ Write them a letter and send it in the mail.
- ★ Exchange photos with your children so they can see how you are going and what you are doing and vice versa.
- ★ Set up a Facebook, Twitter or other social networking account, (if you haven't already got one), to stay in touch. Your children may already have a preferred social networking site they use.
- ★ Have a set time to call them each day.
- ★ Send them a recorded video message.



## FAMILY LIFE – WHEN IT IS TIME FOR DISCHARGE

Your family may have experienced a lot of change since your spinal cord injury. Returning home from hospital may bring more change to the way your family operates day to day.

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

- ❁ Changes to their physical environment (i.e. ramps, stair lifts, modified bathrooms) and what this could mean for them when having friends over.
- ❁ New morning routines including the extra time you may need in the bathroom.
- ❁ Having personal care attendants or support workers in the home to help with your routines.
- ❁ There may be extra people in the house from time to time (i.e. nurses, social workers, physiotherapists and occupational therapists).
- ❁ 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.

Some children may be keen to get involved and wish 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 the brakes, folding a manual wheelchair and placing in the car safely, setting up drinking systems, recognising signs of autonomic dysreflexia and what to do in an emergency. Consider your child's age, ability to cope and appropriateness when considering what they should learn and, subsequently, how they can help.

While your child may want to be involved with aspects of your care, it is important to set some boundaries and consider how to protect your child from becoming a carer. Your child should not be an alternative to accessing professional care services, or replace an adult relative providing care.

Once you are home, try to remember these suggestions.

- ❁ Continue to be involved in your child's life and in their schooling.
- ❁ Your child's education is so important. Never keep them at home if they are not sick.
- ❁ Make special time to talk with them about their interests.
- ❁ Set clear boundaries with your professional carers, they should not take on a parenting role.
- ❁ Ensure your child has adequate privacy, especially when carers or health workers will be in your home
- ❁ Attend events that are important to your child.
- ❁ Know your child's friends and their parents. Encourage your child to invite their friends over.
- ❁ Help your child to understand your access needs and what they can do to help. i.e keeping their toys off the ground in areas you need to use your wheelchair.



## CONSIDERATIONS AT ANY AGE

Focussing on your strengths and abilities post 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 new changes however there are many things that will be the same and you can continue to do together as a family. There are some children's stories listed in the resource section of this booklet that you might find useful and fun to read with your children. In preparing to talk to your children think about the following ideas.

- ★ Consider your child's personality and ways they cope. This will help you think of a good approach.
- ★ You may 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 that your child can understand.
- ★ Reassure your child that they can ask you questions any time and that you appreciate them asking you questions. Try saying encouraging statements like, "You have such great questions," or "That is a very clever question."
- ★ If you don't know the answer to a question, tell your child that you don't know. You can find out yourself and get back to them, or use this time to find out the answer to their question together.





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

It is likely that even though you have not yet spoken directly to your child they are already making their own understanding of what is going on. It is important to listen to your child's responses to questions and clarify any misconceptions that may be causing them distress.

Sometimes children can find the hospital environment overwhelming. Some people who have younger 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 and provide your child choices to help them feel a little more in control at a time where things may seem beyond them.

Some families have talked about the benefits of "question and answer" (Q & A) sessions with the treating team. Please ask for a family Q & A session if you think this would be helpful for you and your family.

**"No matter  
what,  
BE  
HONEST!"**

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


**The doctors have been using lots of new words since I have been in hospital.**

- 😊 **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 still think will be the same?**
- 😊 **What are some of the things that you are worried about?**
- 😊 **How do you feel about what has happened?**

# YOUR CHILD'S AGE


Children process information differently at different ages and this is an important consideration when deciding which approach you will use when speaking to your child.

## Birth - 5 years:

- ★ Young children are concrete thinkers and will pick up on your cues, provide reassurance and through physical contact, like hugs and kisses, and a comforting tone of voice e.g. "Even though my body is not working the same, I am still the same person and I love you."
- ★ Smile at them. 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, use simple terms to explain your injury and medical concepts. For e.g. "I hurt my spine and that is why I can't walk." "I am going to use a wheelchair to help me move around because my legs aren't working." "The hospital is going to help me get used to all the changes."
- ★ Use pictures and play to help explain basic concepts and as a way to encourage questions and concerns.
-  Tune in to how your children are playing, this might give you clues to what they are thinking and feeling.

## Primary 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 terminology, and treatment.
- ★ Take the time to listen to questions and clarify any 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 will hear, but to use age appropriate language to help your child's understanding.
- ★ Remember to pace the amount of information you provide your child, to avoid overwhelming them. The use of interactive learning, such as visual prompts will assist your child's understanding of more complex medical terms.

 Try the worksheet activity (see page 21) with your children.

## Adolescence (13 to 18)

- ★ Most adolescents have the capacity to understand medical terms and concepts at an adult level.
- ★ Adolescence can be an already tumultuous time when your teenager is striving for independence and control. It is so 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. This 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 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.

## TIPS FOR LISTENING TO CHILDREN .....



One of the greatest things you can do for your child is 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. Show this by making good eye contact, and giving them time to express their concerns or questions.
- 😊 Be encouraging of their questions and pick a time when there are minimal distractions.
- 😊 Children usually talk about difficult or painful things in a roundabout way.
- 😊 Children need assurance from adults that it's okay to talk about upsetting things.
- 😊 Children often drop hints when something is wrong. They might indirectly talk about a problem. For example a child might say "Will I need a wheel chair?" which may indicate they might not understand how the Spinal Cord Injury was caused.
- 😊 It is not uncommon for physical symptoms to be an indication for worry or stress. For example your child might say, "I don't feel well or I have a sore tummy."
- 😊 Children get confused when adults don't understand their signals or don't respond to their message. By being observant, adults are also able to pick up the non-verbal clues that something is wrong in a child's life even when a child is not aware of it.
- 😊 Encourage your child to be open about their feelings and reassure them that it is normal and okay to feel lots of different emotions and that you are also feeling them. This will help invite further discussion and build your child's resilience and emotional coping skills.
- 😊 Help your child work out what ideas they have about coping with a problem, talk with them about which ideas might help or not help, and why!

## SIGNS YOUR CHILD MAY NEED FURTHER SUPPORT

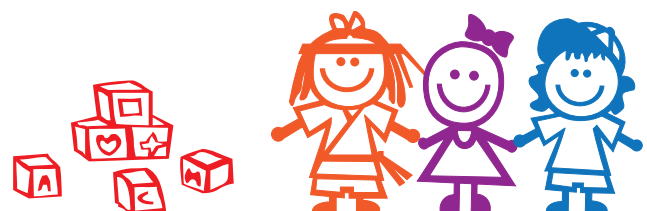


Even though it is natural to feel different emotions during the adjustment period, it is important to recognise the signs that show your child may need additional emotional support. Some of these signs may include the following:

- 👉 Low mood
- 👉 Low motivation
- 👉 Sleeplessness or nightmares
- 👉 Social withdrawal or isolation
- 👉 Refusal to go to school and or to engage in routine activities over an extended time
- 👉 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

Any of the above listed changes in behaviour, would be a signal to let you know your child needs further support.

If you have concerns about your child's coping mechanisms, speak with a social worker, psychologist, school counsellor or mental health professional about getting the right support for you and your child.



## 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. What do you think would make things easier?"

### 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."

### Should I tell my friends what has happened?

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

### Should I tell my teachers?

"Yes! It is crucial that all the 'important people' in your life know what has happened so they can help you if you need it."

### 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 can't tell me when I need to go to the toilet- I can't control when I need to wee, so I need this bag to catch my urine (wee)."

*This may lead to other questions about bladder management. Talk to your health team about other ways to answer some of the difficult questions that may come up about your bladder management.*

### 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. It's important to talk with someone about how you feel, but it's up to you who you would like to share your feelings with. You can also talk to the health staff at any time."

???

"If your child has the courage to ask a tough question then they deserve the tough answer."

## WHAT IF I GET IT WRONG?

It is likely that you may make some mistakes when telling your children about your injury. Don't panic, it is okay to make mistakes. Don't expect to get it right all the time. There is no such thing as a perfect parent!

Talking to your children can be difficult and often upsetting. It may not always go according to plan. If things don't work out as you planned them, then 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!



# THE FAMILY MEMBERS WHO ARE AT HOME

It may be difficult to find a balance between keeping routines, visiting and supporting your injured family member in the hospital and keeping on top of everything you need to. There may be days when you are unable to do much at all, and are feeling overwhelmed. This is okay. You can only do your best, so sometimes taking a break is the best option. We all need time to rest!

## 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 on their own all of the time. Everybody needs a break, and this is normal. Having a break is not a sign that you cannot cope, but rather an indication of your strength to pool the resources available to you to give you and your family the best support available.

If a friend or family member you trust can look after your child for a few hours or even a day, take this time for yourself. If you don't have

someone you can call on, ring your local council and ask about child minding services in your local area. It is very important to take some time out regularly, and this way you will be better able to give your children the love and attention they need.

Whilst caring for children is a special job, we all need time for ourselves. Sometimes this "break time" is called "respite." There are several options for formal respite services – you may find it useful to explore this further, additional information is in the resource list on page 18.

Often during a family crisis relationships with people will change. Some people may feel overwhelmed by the support or lack of support offered by friends and family. It is 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 feel obliged to spend as much time as possible at the hospital, if you need some time out that is more than okay.

## EVERY PARENTS' RESPONSIBILITY

It can be difficult to balance the needs of your child or children in the midst of adjusting emotionally and physically to your own spinal cord injury. Even at this challenging time it is imperative to be mindful of your parental responsibilities to ensure 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, a legal requirement.
- ★ 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, well being, and development of emotional bonds. This love and reassurance can really assist in their adjustment to your injury.

*Note: The deprivation of love, attention, affection and speaking to your child in a negative way, can have short and long term effects on their sense of security, self esteem and on their overall emotional well being.*

Remember! Meeting the above needs for your child is not only a parental responsibility, but a legal requirement of being a parent or legal guardian.

**If you find you are having difficulty meeting your child's needs during this challenging time, it is important to ask for support from family and friends, or your treating medical team. It is more than okay to ask for help!**

## WHERE CAN I GET SUPPORT OR FURTHER INFORMATION?

If you are not sure where you can get help, a good place to start is a member of your rehabilitation team. If you are able to articulate what help you need, they can point you in the right direction to get you started. So what can each of the staff help me with?

**Medical staff:** can provide medical information about spinal cord injury to family members and children.

**Nursing staff:** can factor in regular family time and they realise the importance of maintaining family relationships whilst on the ward.

**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 ball game together.

**Occupational Therapist:** can include children in therapy sessions and activities such as community outings, support during therapy sessions to maximise independence in playing with your child.

**Social Workers:** can help involve your child relatives in discharge planning, resourcing, emotional impact of situation on children, assist to liaise with relevant agencies that the child is connected to, connect to networks to build and assist with coping. Social workers can also provide support to optimise the welfare and safety of your child during stressful times, such as a spinal cord injury.

**Clinical psychologists:** can help to focus on developing your child's coping skills.

You may find it helpful to talk to your child's teacher, as they are able to readily access the services of school counsellors. If you are concerned about contacting your child's school, it might be useful to ask a social worker to assist you with this. In fact, a social worker will be able to help you liaise with a wide range of other services that can support you and your child.



# RESOURCES

## RESOURCES FOR ME:

### Parentline

Provides advice and information for parents with children up to 18 years.

02 9787 0855 or 1800 637 357

<http://www.parentline.com.au>

### Karitane

Provides 24 hour parenting information and counselling.

02 9794 2350 or 1800 227 464

<http://www.karitane.com.au>

### Tresillian

Provides 24 hour information and counselling for parents or carers of children under 5 years.

02 9787 0855 or 1800 637 357

<http://www.tresillian.net>

### Peer Support SCIA

Peer Support is available through Spinal Cord Injuries Australia both individually or in social groups. Peer Support workers are also available to people with a spinal cord injury living in regional areas of NSW.

02 9661 8855

[www.scia.org.au](http://www.scia.org.au)

### Carers NSW

An organisation for relatives and friends who care for a person living with a disability or chronic condition. For carer support, information or counselling contact:

1800 242 636

[www.carersnsw.asn.au](http://www.carersnsw.asn.au)

## RESOURCES FOR MY CHILD:

### Kids Helpline

Free telephone and online counselling service specifically for young people

1800 551 800

<http://www.kidshelp.com.au>

<http://www.kidshelp.com.au/teens>

### Reachout!

A web based resource to help young people get through tough times

<http://au.reachout.com/>

### Young Carers

Provides support to young people who support a family member with a disability

9280 4744

<http://www.youngcarersnsw.asn.au>



## RESOURCES FOR ME, MY CHILD AND OUR FAMILY:

### Playgroup NSW

Caters for babies up to school age children and their caregivers, to get together and meet with other children and caregivers in a relaxed environment.

1800 171 882

<http://www.playgroupaustralia.com.au>

### Child, Adolescent and Family Health Service

To find your local service, head to [http://www.chw.edu.au/healthykids/nsw\\_child\\_and\\_adolescent\\_mental\\_health\\_services.pdf](http://www.chw.edu.au/healthykids/nsw_child_and_adolescent_mental_health_services.pdf)

### SpinalTalk

Opportunity to share your experiences, ask questions, share your thoughts and concerns with other people whose lives have been impacted by a spinal cord injury.

(02) 9808 9628

<http://www.spinaltalk.com.au/>

### Before and After School Care (OOSH)

Your child's public school will have this service. Explore this option further with your school.




### In-home child support program

This is for young children (non-school age) and can assist with parenting support. Talk with your social worker about a referral.

### Commonwealth Carer Respite Centre

1800 059 059

## ACTIVITIES WITH YOUR CHILDREN

-  Suggest they make a "photo journal" to share their story. It may assist them with processing and make meaning of what they have seen and learnt in the hospital environment. It can also be used as a tool to help teach children about Spinal Cord Injury.
-  Try the worksheet activity developed as part of this resource it is found in the appendix.
-  Read story books where a character has a spinal cord injury, some suggestions are below.

## STORY BOOKS

Cowen-Fletcher, J. (1996) *Mama Zooms*, Turtleback Books, St Louis.

Turner, D. (2006) *Dad had a Spinal Cord Injury, and what happened next*, NSW Ministry of Health, North Sydney. Download for free from [http://www.aci.health.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0010/155287/dad\\_had\\_a\\_sci\\_Oct2406.pdf#zoom=100](http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0010/155287/dad_had_a_sci_Oct2406.pdf#zoom=100)



## Where to look for more information

### NSW Commission for Children and Young People

(02) 9286 7276

[www.kids.nsw.gov.au](http://www.kids.nsw.gov.au)

### Parent Line

13 20 55

### Tresillian (for babies)

02 9787 5255

### Kids Help Line

1800 55 1800

### Docs Help Line

13 21 11

### Young Carers Program

(02) 9280 4744

### Websites

[www.parenting.nsw.gov.au](http://www.parenting.nsw.gov.au)

[www.youngcarersnsw.asn.au](http://www.youngcarersnsw.asn.au)

## REFERENCES AND FURTHER READING

**Raising Children** Information sheets: NSW Commission for children and young people  
[www.kids.nsw.gov.au](http://www.kids.nsw.gov.au)

White, P (1996) **Acquired Brain Injury, What Children Should Know**, The Hunter Brain Injury Rehabilitation Programme, The Junction, NSW, Australia.

**When a parent has cancer: how to talk to your kids A guide for parents with cancer, their families and friends** (2005) The Cancer Council of New South Wales. Download for free from <http://www.cancerwa.asn.au/resources/2010-07-13-When-a-parent-has-cancer.pdf>

Johnson J & Sykes, J. (2010) **Talking with Kids about MS**, Multiple Sclerosis Trust. Hertfordshire, London. Download for free from <http://mstrust.org.uk/shop/product.jsp?prodid=316>

### ARTICLES

Alexander, CJ, Hwang, K & Sipski, ML 2002 **“Mothers with spinal cord injuries: Impact on marital, family, and children’s adjustment”** Arch Phys Med Rehabilitation Jan;83 (1): 24 – 30  
<http://www.ncbi.nlm.nih.gov/pubmed/11782828>

Jaworski, T & Richards, J. Scott, Revised 1998, **“Family Adjustment to Spinal Cord Injury”**.  
Spain Rehabilitation Center, Department of Rehabilitation Medicine  
<http://www.paraquadtas.org.au/files/Family-Adjustment.pdf>

Webster, G, Daisley, A & Cardoso, K (2003) **Family Focused Rehabilitation in Brain Injury: Working with Child Relatives** – A resource pack for teams, Department of Neuropsychology, Oxford Centre for Enablement. Nuffield Orthopaedic Centre NHS Trust; Headington, Oxford.


### BLOGS

Several people with SCI share their experience explaining their injury to the children in their life.  
<http://blog.easystand.com/2011/12/xplaining-sci-to-kids/>

A forum for parents with SCI to share their experiences parenting after SCI.  
<http://www.apparelyzed.com/forums/forum/29-parents-in-wheelchairs/>


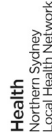




# What happens to the body after a Spinal Cord Injury?

A visual tool to help children understand  
the impact of spinal cord injury



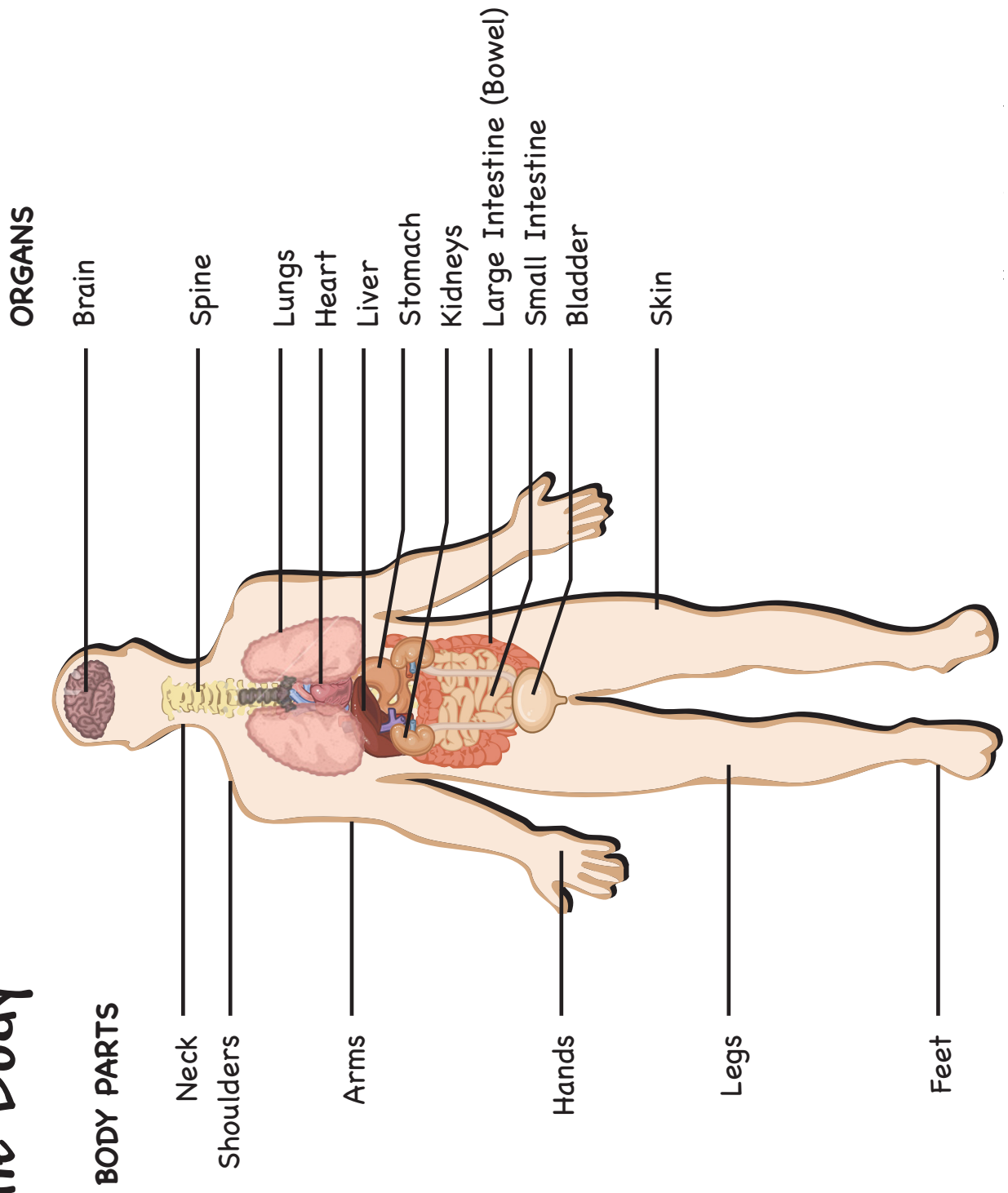
Developed for Northcott by Laurissa Serratore, Social Worker for the NSW Paediatric Spinal Outreach Service in consultation with clinicians of the NSW Paediatric Spinal Outreach Service. Graphic Design by Luce Sikic, Marketing Communications Media. © Northcott Disability Services 2012

In partnership with



Edited by  
Dr Soyoung Kim,  
Spinal Outreach Service Spinal Registrar

# Parts of the Body



# Parts of the Spine

Your spine is located in the middle of your back, it runs all the way from the bottom of your head, down your neck, back and down to your tail bone.

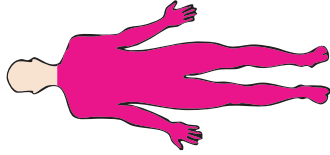
The spine is divided into different areas. Each of the vertebrae in these areas are given a number.

The spine is divided into 4 different parts; you will see in the picture that each part is given a name, and each vertebrae (bone) is given a number. When doctors talk about an area of the spine they will often say a letter and a number. For example if you hear "C7", they are talking about the Cervical (neck) part of the spine at the area of vertebrae number 7. Can you find this on the picture?

Giving an area of the spine a letter and number helps us to find an exact part of the spine that is injured. Each injury results in different parts of the body's function.

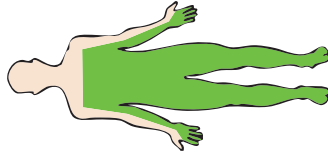
## **Cervical (Neck) (C1 - 7)**

Neck  
Shoulders and Chest  
Chest and Lungs  
Arms and Hands  
Bowel and Bladder  
Legs and Feet



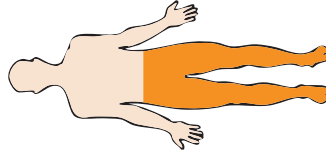
## **Thoracic (Middle Back) (T1 - 12)**

Chest and Lungs  
Arms and Hands  
Bowel and Bladder  
Legs and Feet



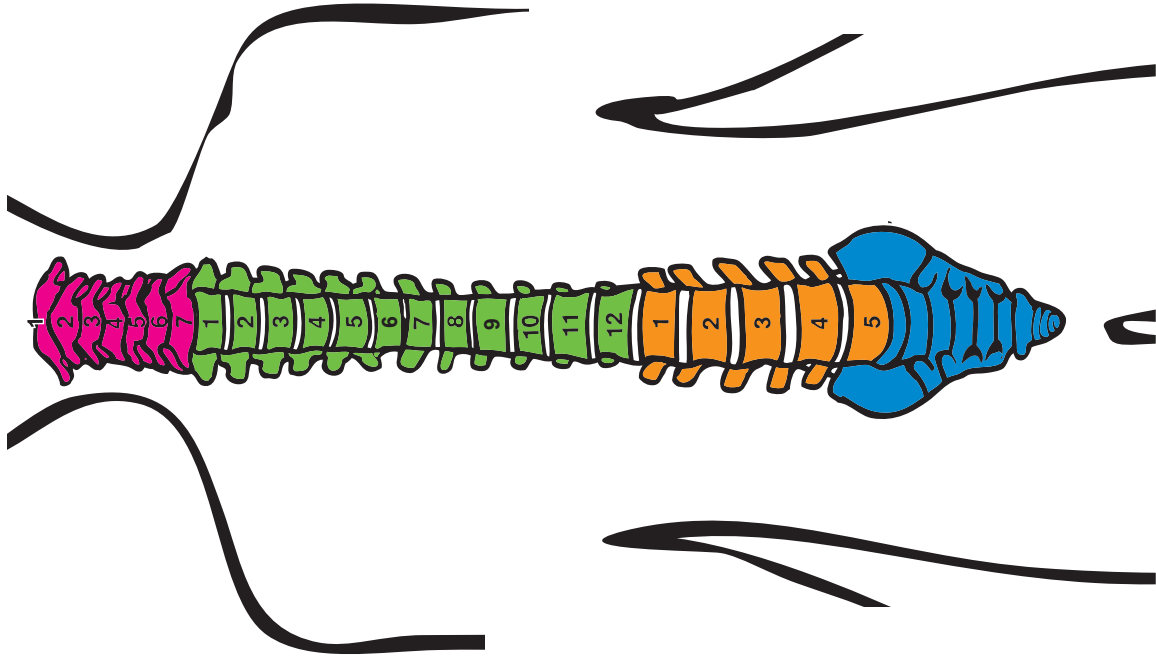
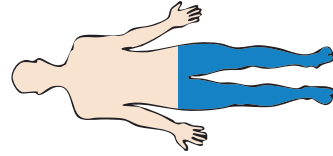
## **Lumber (Lower Back) (L1 - L5)**

Bowel and Bladder  
Legs and Feet



## **Sacrum & Coccyx (Tail bone)**

Bowel and Bladder  
Legs and Feet





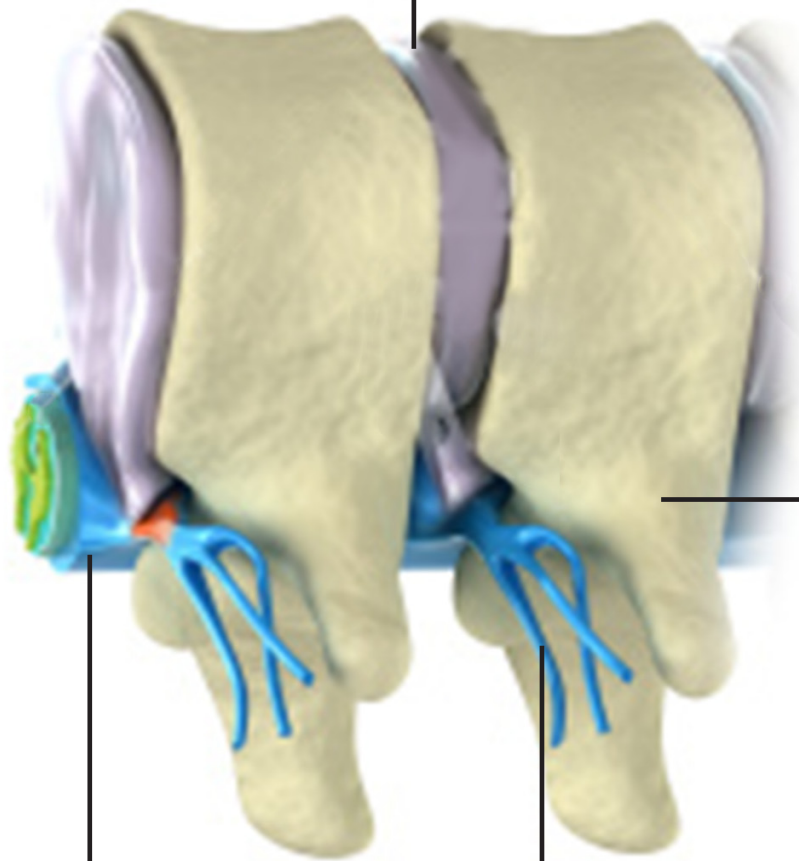
# Close up of Spine

## Spinal Cord

The spinal cord is long and tube shaped and runs down the whole length of the spine. The spinal cord is full of lots of delicate nerves. It carries messages from the brain down the spinal cord to the rest of the body, telling it what to do, feel and act.

## Nerves

There are 31 pairs of nerves that come from the spinal cord and connect to lots of nerves within the body. Spinal nerves are like delicate telephone wires that send messages from the spinal cord to the rest of the body and back again.



## Discs

Discs sit in between the vertebrae and are like small cushions that help us with flexibility (to bend).

## Vertebrae

Vertebrae are bony parts that surround the spinal cord to protect it from being damaged. The vertebrae in your spine have another important job and that is to help to support and carry the weight of our body.

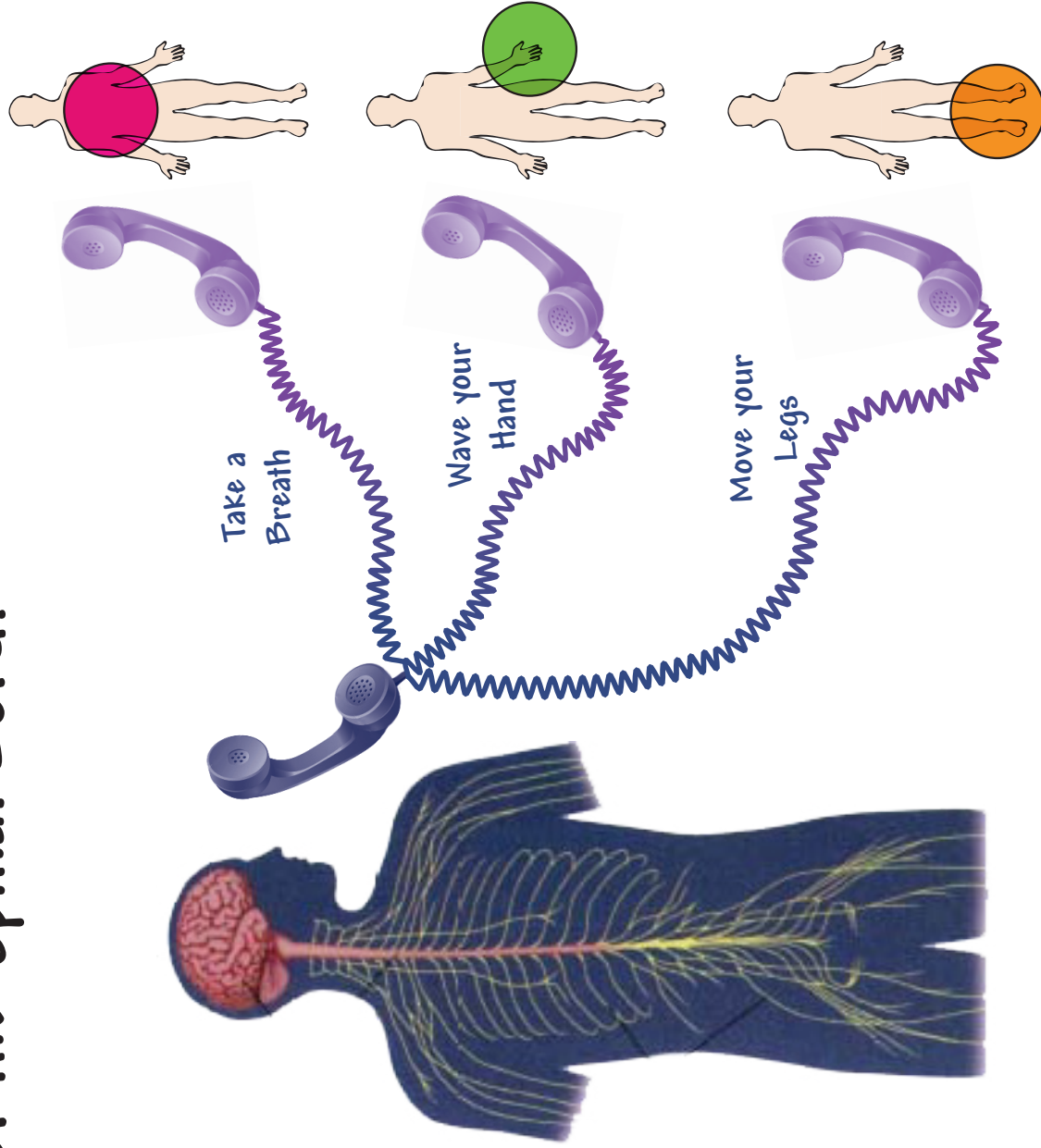
# What is the job of the Spinal Cord?

The spinal cord has the very important job of sending messages from the brain, down the spinal cord and to different parts of the body telling it what to.

Spinal nerves are like delicate telephone wires that send messages from the spinal cord to the rest of the body and back again.

The brain and the body talk to each other through the messages carried along the spinal cord and nerves. These messages that go through the spinal cord are what controls the way we walk, run, play, breathe, feel if things are hot or cold, move our muscles and even go to the toilet.

Each part of the spinal cord is responsible for controlling different parts of the body. (See page 23)



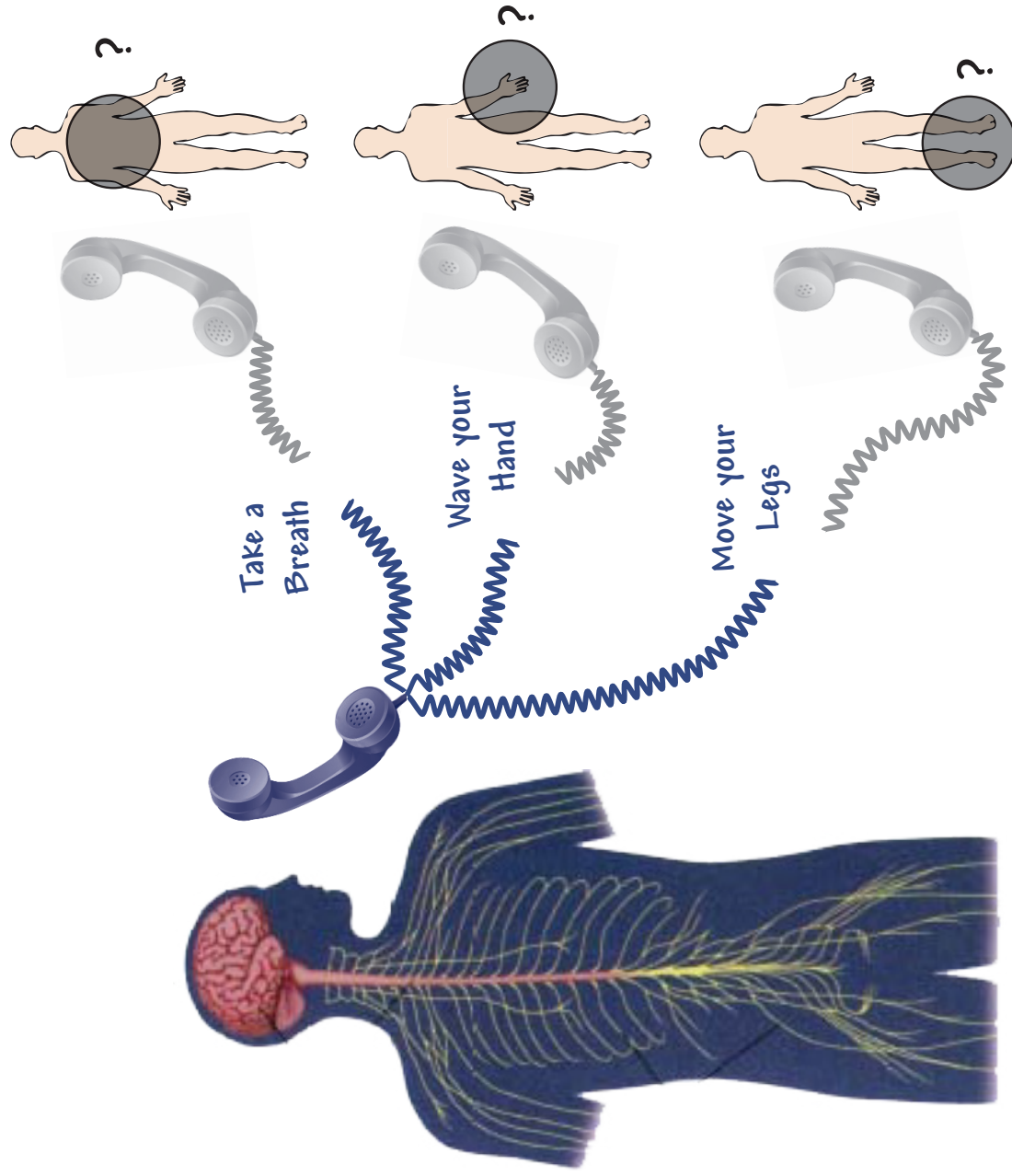
# What happens to the body after a spinal cord injury?

A spinal cord injury happens when the spinal cord is bruised, crushed or cut and can happen after a serious accident, or illness.

The nerves within the spinal cord are very delicate and when they are damaged, the spinal cord is no longer able to send messages between the brain and the body.

This means that when someone has a spinal cord injury the brain and body are no longer able to talk to each other. Messages can't get through, like if a telephone wire is cut. This also means that the spinal cord is no longer able to control the parts of the body below the injured part of the spinal cord. (Refer to page 23)

A spinal cord injury can cause a loss of movement (paralysis), feeling (sensation) and can weaken muscles below the injured area of the spinal cord.



# What are the different types of Spinal Cord Injury?

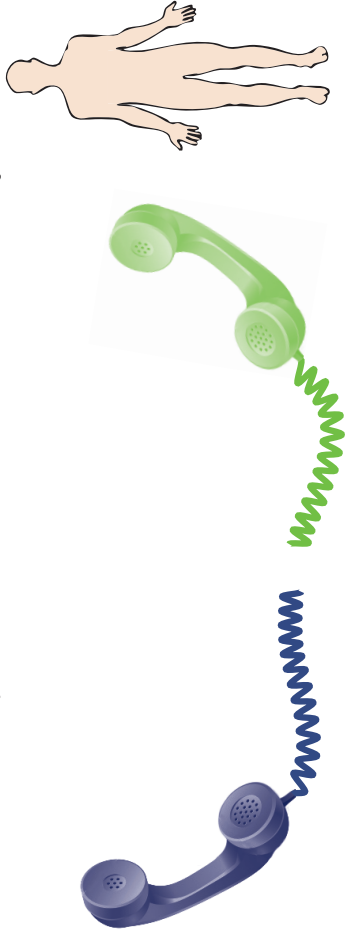
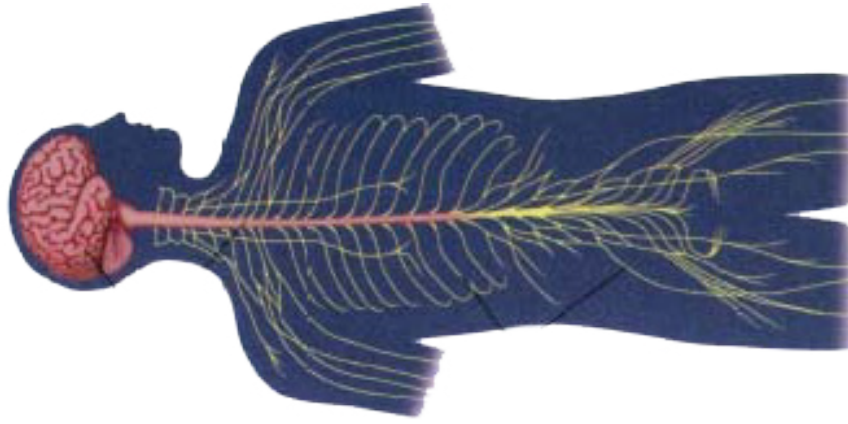
The type of spinal cord injury will depend on what part of the spine was damaged.

Knowing what area of the spine has been damaged helps us to understand what parts of the body have been affected and work differently.

There are different names and different types of spinal cord injury, these are:

Tetraplegia – Tetra means 4, so all 4 limbs (arms and legs) have been affected and the injury was higher on the spinal cord.

Paraplegia – Para means 2, so only 2 limbs (legs) have been affected and the injury was lower on the spinal cord.



## Complete spinal cord injury:

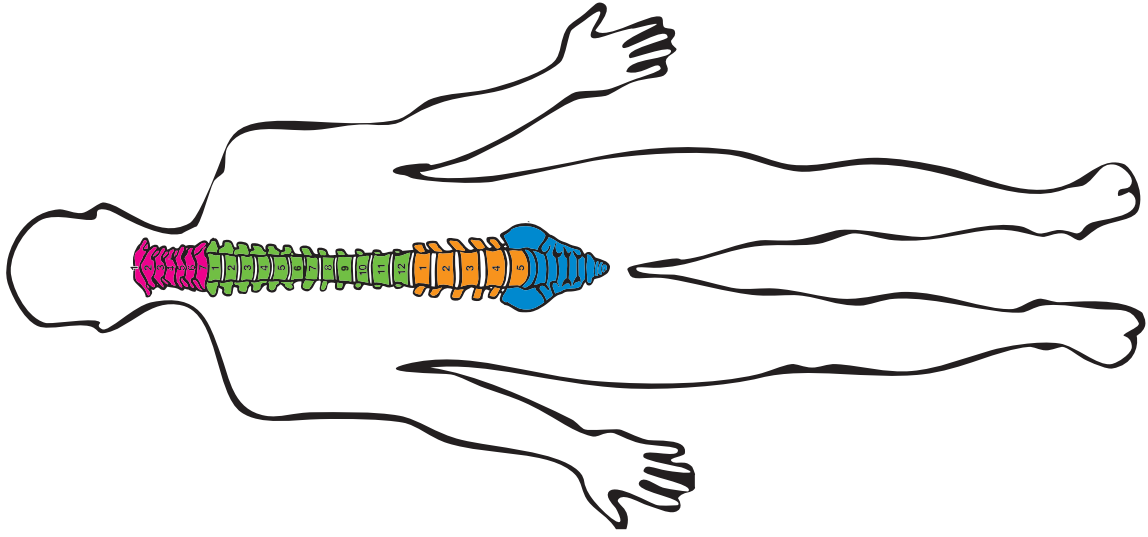
A complete spinal cord injury is when all of the spinal nerves at the level of injury have been damaged and no messages are able to get past the injured part of the spinal cord. This means that the person with the injury will have no movement or feeling below the injured part of the spinal cord.



## Incomplete spinal cord injury:

An incomplete spinal cord injury is when only some of the spinal nerves at the level of injury have been damaged. This means that some of the messages are still able to get past the injured part of the spinal cord, but they might be a little bit fuzzy or unclear. This means that the person with the injury will still have some movement or feeling below the injured part of the spinal cord.

# How does spinal cord injury affect my relative or friend?



1. What level on the spinal cord is your relative's injury? (see if you can find the exact level of injury on the picture, when you find it write down the part of the spine and the vertebrae number)  
\_\_\_\_\_  
\_\_\_\_\_
2. Is their injury complete or incomplete?  
\_\_\_\_\_  
\_\_\_\_\_
3. What parts of their body work differently since having their spinal cord injury?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
4. What parts of their body are strong and still work the same as they did before their spinal cord injury?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
5. What types of things do you like doing with your relative?  
\_\_\_\_\_  
\_\_\_\_\_
6. What are some of the things they are good at?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
7. If you have questions about your relative's spinal cord injury or the way you feel, who will you talk to?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Also supported by



**Health**  
Northern Sydney  
Local Health District

Download a copy of this NSW State Spinal Cord Injury  
initiative resource from [www.aci.health.nsw.gov.au](http://www.aci.health.nsw.gov.au)  
under spinal cord injury consumer resources

