

Parenting babies and toddlers: A practical guide to equipment that can help parents with spinal cord injuries

The Queensland Spinal Cord Injuries Service
Spinal Outreach Team (SPOT)



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For further copies contact:

Ph: +61 7 3176 9507
Ph: 1 800 624 832 (Freecall for clients)
Fax: +61 7 3176 9514
Email: spot@health.qld.gov.au

PO Box 6053
Buranda QLD 4102
AUSTRALIA

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Introduction

The Spinal Outreach Team (SPOT) developed this booklet in conjunction with final year occupational therapy students from the University of Queensland, in consultation with parents with spinal cord injury (SCI), health professionals and support organisations. A literature search of articles from the last 10 years found limited practical information available, so this booklet emphasises practical advice from parents with SCI for other parents with SCI, based on their lived experiences.

The aim of this booklet is to give parents with SCI ideas to help them find solutions to parenting difficulties, through the use of equipment.

Information in this booklet is categorised into seven common parenting activities, plus information for parents with limited arm and hand function and another on general safety issues. Under each heading are ideas that may make an activity easier and equipment that may be useful. A search of key words in the figure captions should help find suppliers of equipment shown.

This booklet is not intended to provide a complete list of all the equipment that is available and suitable for parents with SCI. LifeTec (<http://www.lifetec.org.au/>) and the Independent Living Centres of Australia websites (<http://ilcaustralia.org.au/>) offer comprehensive equipment databases.

For any other enquiries about SCI please visit the SPOT website (<http://www.health.qld.gov.au/qscis/html/health.asp>) or contact us using the details inside the front cover.

New ideas?

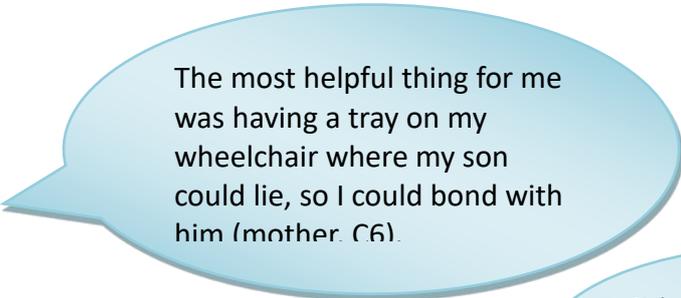
If you have ideas that you would like to contribute to this booklet, please email them to spot@health.qld.gov.au, as the booklet will be updated regularly.

Parents with limited arm and hand function

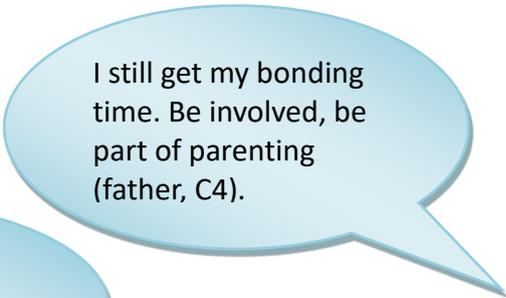
In this booklet, the term “parents with limited hand function” refers to parents who are able to move their arms but have reduced hand function, while “parents with high level tetraplegia” indicates parents with minimal or no upper limb movement. The strategies for parents with high level tetraplegia are similar in each of the parenting activities covered in this booklet.

Parents who are unable to help physically are still able to be actively involved in parenting. Some ways of achieving this are shown below.

- Overall, being present and engaging in activities as much as you can is the key to developing a bond between yourself and your baby/toddler.
- To promote interaction with your baby/toddler during parenting tasks, ensure both you and your baby/toddler are able to see each other. This may necessitate thinking about the height of the surface that your carer/partner is using.
- You can entertain your baby/toddler by talking to him/her about what is happening, and joining in with word games and rhymes appropriate to the activity.
- Your lap or wheelchair tray can be used as a makeshift table, holding items needed for the task such as clothing, nappies, towels, lotions and so on. Your baby/toddler will learn to associate you with these activities, just as much as the person performing the activity.
- You can participate by giving instructions to your baby/toddler and making suggestions to your partner/carer about how to undertake or modify a particular task.
- Your partner is likely to appreciate verbal support in parenting tasks.



The most helpful thing for me was having a tray on my wheelchair where my son could lie, so I could bond with him (mother, C6).



I still get my bonding time. Be involved, be part of parenting (father, C4).



It is ok to ask for information, advice and help (mother, C6).

Safety

Your safety and that of your baby or toddler is paramount when thinking of strategies or adaptations that could assist with parenting tasks, so it is wise to:

- Ensure that any adaptations made to commercially available products do not interfere with safety regulations, especially car seats and cots
- Ensure that any adaptations to your wheelchair do not interfere with the weight balance of the chair. If you are unsure, contact SPOT before making any changes
- Think in advance about what you might find particularly difficult or actions that you think could go wrong, so you can avoid these situations occurring.

Baby slings and pouches

The Australian Competition and Consumer Commission (ACCC) released a safety warning in 2011 about using slings and pouches to carry babies. This warning states the following:

Babies have suffocated while using slings. They are at risk if placed incorrectly in a sling because they do not have the physical capacity to move out of dangerous positions that block their airways. Two positions present significant danger:

1. Lying with a curved back, with the chin resting on the chest.
2. Lying with the face pressed against the fabric of the sling or the wearer's body.

Babies who are under four months old, premature, low birth weight or having breathing difficulties appear to be at greater risk. Consult a paediatrician before using a sling with a premature baby.

When choosing and wearing a sling:

- Ensure any sling you buy comes with detailed instructions for use. Always follow these instructions
- Take your baby with you when you buy a sling to ensure that the product you buy is a safe fit for you and the baby—if a sling is too large or worn incorrectly, the baby may be in danger
- Ask for a demonstration of how to use the slings you are considering, according to the instructions that come with each sling
- Never use products, such as bag or pouch slings, that are described as 'womb-like', or a 'cocoon', or placing the baby in a 'foetal position'. These slings place baby in a dangerous position with a curved back. A foetus doesn't need a straight back to breathe, but a baby does
- When using the sling for the first time, have someone to assist you
- Lie baby in a flat position with a straight back to ensure baby's chin does not rest on his/her chest
- Ensure baby's chin is up and away from his/her body, as any pressure on the chin can close the airway

- Ensure you can see baby's face at all times and that his/her face remains uncovered by the sling or your body
- Put baby in a slanted or upright position. This will give baby a straight, flat back with head support, the chin up and the face clearly visible.

Co-sleeping

The Victorian coroner recently made recommendations based on his findings following investigation of the cases of four Victorian babies who died in 2009 and 2010 who shared a sleep surface with another person, usually an adult care giver. The coroner recommended that on current evidence, the safest place for an infant to sleep is on his/her back on a separate sleep surface in a safe cot in the same room as a caregiver for the first six to 12 months of life.

Sharing a sleep surface with a baby increases the risk of Sudden Unexpected Death in Infancy (SUDI), including Sudden Infant Death Syndrome (SIDS) and fatal sleeping accidents in some circumstances. Sharing a sleep surface with a baby must be avoided in the following circumstances:

- baby shares the sleep surface with a smoker
- care-giver is under the influence of alcohol or drugs that cause sedation
- baby is premature, small when born, or less than 3 months of age
- care-giver is overly tired
- there is adult bedding, doonas or pillows that may cover the infant
- baby could be trapped between the wall and bed, fall out of bed or could be rolled on
- baby is sharing bed with other children or pets
- baby is placed to sleep on a sofa, beanbag, waterbed or sagging mattress

SIDS and Kids recommends six ways to sleep baby safely and to reduce the risk of SUDI:

1. Sleep baby on the back from birth, not on the tummy or side
2. Sleep baby with head and face uncovered
3. Keep baby smoke free before birth and after
4. Provide a safe sleeping environment night and day
5. Sleep baby in his/her own safe sleeping place in the same room as an adult care-giver for the first six to twelve months
6. Breastfeed baby if you can

SIDS and Kids recommends that after feeding and cuddles, place your baby into his/her own separate and safe sleeping place, next to your bed.

For more information about Safe Sleeping visit the SIDS and Kids website.

Bathing

Using a standard bath for bathing a baby is difficult for anyone, because of the bath height, the distance you have to reach, and the slipperiness of the baby. Choosing the right bath ensures that your baby/toddler is as safe and secure as possible. Key points to consider include the height of the bath, and how easy it is to fill and empty.

Bathing your baby

Helpful ideas for bathing babies include:

- A portable baby bath can be placed on a table that is a good height for you (Figure 1.1).
- A bath with a sling provides head support and can help to hold your baby in the bath (Figure 1.2).
- A portable inflatable bath may help to support your baby's head (Figure 1.3). This type of bath is light and easily transportable, so it can be easily placed on a surface that is the best height for you.
- A height adjustable change table with a pull out bath lets you wash, dry and dress your baby without having to move around much (Figure 1.4).
- A baby bath seat supports your baby/toddler without you having to hold on so firmly (Figures 1.5–1.7). These seats provide additional support to the baby but are not safety devices, and should always be used with supervision.
- A table with a hole cut out to fit the bath may suit you, as you can wheel under the table to wash your baby. If the table is big enough, it can also be used for drying and dressing your baby
- If you use a wall-mounted shower bench, you may be able to safely put your baby bath on it, for example by placing a non-slip mat on the seat and using a strap to tie it on. Similarly, this might also be possible with a static transfer bench. You can then use your hand held shower hose for bathing your baby.
- A quick “top and tail” wash can be achieved by placing your baby on a pillow on your lap and washing him/her with a washcloth.
- Maybe you could use your kitchen sink or laundry tub as a baby bath, if it is the right height for you.



Figure 1.1 Portable baby bath e.g. Bubs



Figure 1.2. Baby bath with sling insert e.g. first years newborn to toddler tub with sling insert



Figure 1.3. Inflatable baby bath



Figure 1.4. Pull out bath e.g. Bubs



Figure 1.5 Bath seat birth – 10 months e.g. Infant nellie bath support



Figure 1.6 Bath seat from 4 months up e.g. Infa secure baby ace chair



Figure 1.7 Penguin bath seat

Bathing your toddler

Strategies for toddlers differ slightly, as generally a toddler can be bathed in a standard bath or shower as opposed to a baby bath.

Helpful ideas for bathing toddlers include the following:

- A suction seat that fits into the bath may help to stabilise your toddler (Figure 1.8).
- You may want to avoid items such as bubble bath when bathing your toddler as these can make both the bath and your toddler slippery.
- A bath visor for hair washing helps stop water/soap getting in your toddler's eyes (Figure 1.9).
- Long handled hygiene aids can help you reach to wash your toddler without losing your balance (Figure 1.10).
- Another way to help you maintain your balance is to use a chest strap with some degree of stretch such as neoprene. This allows you to partially lean forwards in your chair without falling. However, if you bend too far, it won't stop the chair from tipping forwards.
- A soap mitt or soap on a rope overcomes dropping the soap during bath time (Figure 1.11). You can easily make your own version by placing the soap in one leg of a pair of pantyhose (Figure 1.12).



Figure 1.8 Bath suction seat



Figure 1.9 Bath visor

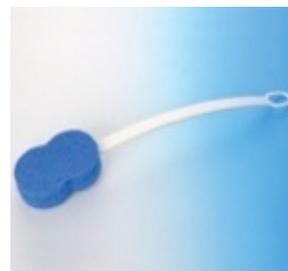


Figure 1.10 Long handled sponge



Figure 1.11 Soap on a rope

- If you have problems setting the bath water at the right temperature, a floating thermometer (Figure 1.13) or non-slip stickers that change colour with heat (Figure 1.14) may be helpful.
- Sometimes it's easiest to bath or shower with your toddler. Your toddler could sit on the shower recess floor, stand leaning against you, or sit on your lap



Figure 1.12 Soap in a stocking



Figure 1.13 Floating bath thermometer



Figure 1.14 Heat sensitive stickers e.g. Heat alert anti slip stickers

Transferring in and out of the bath

Many parents with a SCI find that one of the most difficult aspects of bathing is helping their toddler into and out of the bath.

Helpful ideas for safely getting your toddler in and out of the bath include:

- Being prepared. Some parents prepare a change mat next to the bath and lay out a towel and clean clothes in advance.
- Using a bath board which can also be used in combination with a small set of steps so your toddler can lower him/herself into the bath, while holding your hand (Figure 1.15).
- A cloth sling may help (Figure 1.16). Refer to page 7 for safety advice.
- If renovating your bathroom, you could consider a bath with a door (Figure 1.17). This would allow your toddler to walk into the bath before you fill it, and it could be a great way for you to have a soak too. However, these baths are more expensive than standard ones.
- Non-slip, interlocking steps may help your toddler to be more independent getting into the bath (Figure 1.18).
- Some parents have suggested that you ask your toddler to stand up and wrap his/her arms around your neck while you are leaning forwards, so you can lift him/her out as you straighten up. A non-slip mat in the bath will reduce its slipperiness.



Figure 1.15 Bath board with step



Figure 1.16 Cloth sling



Figure 1.17 Bath with door



Figure 1.18 Bath step e.g. Savannah modular bath step

Suggestions for parents with limited hand function

- You probably already use pump bottles rather than flip-top bottles. These are great for baby products too such as shampoo, conditioner and baby lotion.
- A soap mitt or a sponge with shower gel overcomes the need to hold a cake of soap (Figures 1.11 and 1.12).

Suggestions for parents with high level tetraplegia

- Refer to the section on page 6 of this booklet.

I was able to be hoisted into the bath, and my baby would then be passed to me so we could bath together (mother, C6).

I sit next to the bath and play with my child while my wife does the bathing (father, C4).

When my daughter was able to stand up, I'd get her to stand up and wrap her arms around my neck so I could help her in and out of the bath

Dressing and Grooming

The level of involvement in dressing your baby/toddler and the strategies and adapted techniques used will naturally vary depending on your level of SCI.

General suggestions for dressing your baby/toddler

- You might want to consider the amount of space you have to dress your baby/toddler. A larger surface area, such as your bed, provides a large area all at the same height.
- Another benefit of using your own bed for dressing your baby is that it should already be a good height for you.
- Using pillows or rolled towels around your baby can minimize the risk of him/her falling off the bed. Pillows specially designed for this purpose can be purchased or you can use pillows you already have at home.
- Gathering together all the items needed for dressing and placing them where they are easy to reach can be helpful.

Dressing your baby

These strategies are predominantly for parents with reduced hand function:

- Clothing and bibs made from stretchy material are often easier to use, as they tend not to need buttons, zips or other fasteners.
- Clothing that is a size or two too large for your baby can make dressing easier
- Tops with a round neck can be more difficult to manage than those with envelope, scoop, or v-shaped necklines. Similarly, raglan sleeves are easier to manage than set in sleeves, as the top of the sleeve has more space (Figure 2.2).
- Adapting clothing and adding thumb loops can be helpful (Figure 2.3). Loops can also be attached to the zipper pull tag. They can be made from cloth tape, split rings (for keys) or string, or can be purchased online (Figure 2.4).



Figure 2.1 Chair for stable positioning e.g. Bumbo



Figure 2.2 Clothing with envelope neck



Figure 2.3 Clothing with loops



Figure 2.4 Zipper loops e.g. Caregiver loops

Dressing your toddler

The strategies and principles for dressing toddlers are similar to those for dressing babies. For parents with limited hand function there may be a heavier emphasis on communication when dressing your toddler. It may also be important for your toddler

to understand that you have difficulty with particular types of clothing, for example buttoned shirts. In this case your toddler may need to ask someone else for assistance until he/she learn how to do it independently. Basic strategies for promoting independent dressing:

- Some parents use a chair such as a high chair or a baby seat on a table that stops him/her escaping so readily (Figure 2.1).
- Letting your toddler “help” by finishing putting on individual items of clothing helps him/her become more independent. You dress your toddler up to the last step and allow him/her to finish the process. For example, when putting on socks, put the socks on his/her feet just over the heels and ask him/her to pull the sock up the rest of the way.
- Talking about each step you are doing can assist toddlers when they attempt to dress themselves. You may want to prompt your toddler to vocalise the steps as he/she “helps”, e.g. putting on a shirt – “one hand, two hands, over the head and pull down.”
- Each toddler will respond differently to different cues such as songs, rhymes, step by step pictures and picture books.

Grooming

These strategies are predominantly for parents with limited hand function:

- Hairbrushes can be adapted to make them easier to hold, using a Velcro or plastic hand strap on the handle (Figure 2.5). This adaption can be made by using your own brush and Velcro or moulded thermoplastic (Figure 2.6).
- A massage brush with a slide on handle (Figure 2.7) can make brushing your toddler’s hair easier and reduces your toddler’s discomfort.
- Hair accessories such as headbands or larger clips may be easier to use than hair bands or bobby pins (Figure 2.8).
- It may be easier to keep toddlers hair short until they can brush it themselves.
- For teeth cleaning, your toddler could use an electric toothbrush with a two minute timer to remind him/her how long to brush. These brushes have a larger handle, so are easier for toddlers to hold, and the inbuilt brushing/ vibration motion promotes good oral health.



Figure 2.5 Universal hand clip e.g. caregiver hand clip



Figure 2.6 Adapted hair brush e.g. Easy-pull hair brush



Figure 2.7 Hand massage brush e.g. hand palm design washing head hair massage brush



Figure 2.8 Headband

Nappies

For information on changing a nappy see the toileting section on page 30.

Suggestions for parents with high level tetraplegia

Refer to the section on page 6 of this booklet.

Feeding

Feeding and mealtimes are a great time for interacting with your baby/toddler. The ideas, equipment and modifications listed below may assist your involvement.

Breast feeding

General suggestions for breast feeding:

- Try lying your baby on your wheelchair tray (Figure 3.1), with or without a cushion on the tray, to support your baby at an appropriate height for breastfeeding.
- A nursing/breast feeding cushion may be helpful, as it helps to support your baby/toddler closer to your chest (Figures 3.2 & 3.4). The cushion can be placed on your lap or on a wheelchair tray for extra height. Each mother will have a different opinion on whether a strap attached to a nursing cushion is helpful or difficult to use.
- A baby sling (Figure 3.3) may allow you to position your baby in the best spot during breastfeeding without needing to use your arms. Some mothers may require help to position their baby. Refer to Safety section on page 7 for further important information about slings.
- Similarly, a chest strap may help to stabilise both you and your baby/toddler.



Figure 3.1
Wheelchair tray



Figure 3.2 Nursing
cushion



Figure 3.3 Baby sling



Figure 3.4 Nursing
cushion

Bottle feeding

General suggestions for bottle feeding:

- You may be able to give your baby a bottle by laying your baby on a pillow on a table, so you can roll your wheelchair underneath it or pull up beside it. The height of the table should be comfortable when using your arms.
- You may be able to give your baby a bottle by laying your baby on a solid wheelchair tray, with or without a pillow or cushion (Figure 3.8).
- As your baby gets older, try tucking one of your baby's arms around your back while he/she is lying on your lap and support him/her with your other arm.

These strategies are predominantly for parents with limited hand function:

- Small, light-weight baby bottles may be easier to use.
- A bottle sling attached to your baby's highchair or pram could be helpful (Figure 3.5).
- A Velcro baby bottle wrap/cuff, may help you to hold the bottle (Figure 3.6).
- A baby bottle with rubber webbing may be easier to grasp (Figure 3.7).
- Check out the different bottle shapes in your local discount department store. Some have a cut out section in the middle, which may make it easier to grip.



Figure 3.5 Bottle sling e.g. Bebe bottle sling



Figure 3.6 Bottle cuff e.g. elearn SCI



Figure 3.7 Rubber webbing



Figure 3.8 Wheelchair tray

Choosing a high chair

There are many different high chairs that can be suitable for parents with SCI. Characteristics of high chairs that may assist in feeding include:

- Hanging chairs that attach to a table (Figure 3.9) to allow you to roll up to and under your baby/toddler.
- Height adjustable chairs that match your wheelchair height (Figure 3.10).
- Chairs on wheels that can be moved around as needed (Figure 3.10).
- Chairs with easy openings such as a side opening (Figure 3.11) or swing away tray (Figure 3.12).
- Chairs with a wide based frame that allow you to come in close to your baby/toddler (Figure 3.12).



Figure 3.9 Hanging high chair



Figure 3.10 Height adjustable, wheels



Figure 3.11 Highchair with side opening



Figure 3.12 Swing away tray, wide base

See page 21 for information on transferring your baby/toddler in and out of a high chair.

Spoon feeding

These strategies are predominantly for parents who have limited hand function.

- A high chair keeps your toddler in one place at the best height for you.
- An angled spoon (Figure 3.13 and 3.14) may be useful if you have reduced wrist movement.
- A plastic guard (Figure 3.13) around the neck of cutlery prevents the spoon or fork going too far into your baby's mouth.
- Ringed cutlery or a palmar cuff or pocket may help you hold the spoon or fork (Figure 3.14 & 3.16).
- A high-lip suction bowl (Figure 3.15) allows you to scoop food onto a spoon or fork by pushing against the side of the bowl without it tipping or slipping.

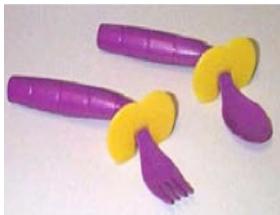


Figure 3.13 Angled cutlery with guard, e.g. LifeTec



Figure 3.14 Cutlery with rings

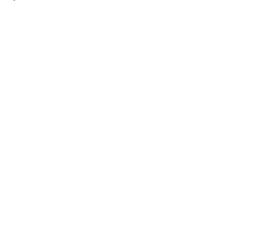


Figure 3.15 Suction scoop bowl



Figure 3.16 Cutlery cuff or strap

Bibs and feeders

These strategies are predominantly for parents with limited hand function:

- You might find that bibs that can be pulled easily over your babies/toddler's head are easier to get on and off, as they don't need fastenings. Instead they use t-shirt ribbing around the neck hole (Figure 3.17).
- Plastic bibs with a 'gutter' at the bottom catch most of the mess when your baby/toddler is learning to finger feed and self-feed (Figure 3.18), making cleaning up a little easier.



Figure 3.17 Pull on bib



Figure 3.18 Bib with catcher

Suggestion for parents with high level tetraplegia

You can be involved in deciding what your baby/toddler eats and when meals and snacks are provided.

Refer to the section on page 6 of this booklet.

My husband bent my ringed cutlery so it was easier for me to get the spoon into my son's mouth. The highchair was height adjustable and on wheels, so I could get up really close to feed him (mother, C6).

I think I'll be able to feed him the same way I feed myself (father, C4).

I use a cold touch kettle to heat water to heat the baby's bottles. This ensures that I don't burn myself (father, C6)

It is easier for me to use smaller bottles for feeding him (father, C6).

Lifting, moving and carrying your baby/toddler

This section provides handy tips on how to help you move baby/toddler from one place to another.

Transferring your baby/toddler in and out of a high chair

Taking time to research various features of high chairs is time well spent. Some considerations are listed here:

- A highchair with a swing away tray allows you to place your baby/toddler in the chair without lifting him/her over the tray (Figure 4.1).
- A highchair with a stomach rail and fabric straps allows the high chair to be opened at the side (Figure 4.2).
- A height adjustable highchair (Figure 4.4) enables you and your baby/toddler to sit at the same height, making it easier when lifting him/her to and from the chair.



Figure 4.1 Swing away tray e.g. Phil and Teds and Poppy high chair



Figure 4.2 Highchair with side opening e.g. Spinalistips



Figure 4.3 Swivel baby car seat



Figure 4.4 Height adjustable highchair e.g. Kaylula highchair

Transferring your baby/toddler in and out of a car

General suggestions for transferring your baby/toddler in and out of a car:

- Shop around and try to find a car seat that has low sides and minimal obstacles between you and your baby.
- A swivel baby car seat may make it easier to place your baby into the baby seat, and to buckle him/her in more easily (Figure 4.3). Once strapped in, simply swivel the seat so it locks in place.
- A baby carrier that straps to your chest may assist transferring your toddler from your chest to the child seat as he/she is already at the right height for the car seat, so does not have to be lifted out of a stroller/pram.

- If you find transferring your baby/toddler to and/or from the car too difficult, plan ahead and arrange for someone else to help you.
- There are times when all parents find it easier to leave their baby/toddler at home with a responsible adult when going to the shops or other appointments. This eliminates the need to transfer your baby/toddler in and out of the car, and gives you some time without the physical, mental and emotional demands of being a hands-on parent.
- Wheelchair accessible public transport may be suitable for you and your baby/toddler, should using a car prove to be too difficult.

Transferring your baby/toddler on and off the floor

General suggestions for transferring your baby/toddler on and off the floor:

- A lifting harness (Figure 4.5) helps you to lift your baby/toddler off the floor and put him/her down on the floor, using the strap sewn on the front and back of a vest that your baby/toddler wears.
- Lifting your baby/toddler by reinforced straps on overalls (Figure 4.6) uses the same idea as a lifting harness.
- When your baby/toddler is small, you may be able to slide your hand between his/her back and shirt to pick up from the floor.
- To lower your baby/toddler onto the floor try turning him/her onto his/her stomach whilst he/she is on your lap and sliding his/her feet down to the floor.
- When your toddler is a bit older, you may want to try to develop a signal, such as quietly saying “up” then his/her name to prepare for a transfer. A toddler or older child will often respond to this by keeping still and will wait for you to move him/her from one spot to another.
- Your wheelchair manufacturer/supplier may be able to attach a metal climb-up step onto the front of your wheelchair between your wheelchair footplates, to help your toddler climb onto your lap.



Figure 4.5 Lifting harness e.g. Spinalistips



Figure 4.6 Baby overalls

Transferring your baby/toddler in and out of a cot

General suggestions for transferring your baby/toddler in/out of a cot:

- A drop-side cot may enable you slide your baby/toddler in and out of the cot, eliminating the need to lift him/her over the cot rails (Figure 4.7).
- Another cot that eliminates the need to lift your baby/toddler over the rails is one that has a track mounted sliding side rail/gate (Figure 4.8).
- A cot with an outward swinging gate may be useful, as long as the gate doesn't get in the way of your wheelchair.
- A wheeled porta-cot that suits the height of your wheelchair may be useful, as it can be wheeled to beside your bed, so you can move your baby/toddler easily between these surfaces (Figure 4.9).
- If the cot is too low, you could raise it on chair/bed blocks so it is easier for you to reach in to your baby/toddler.
- A lifting harness (Figure 4.5) may help you to lift your baby/toddler in and out of the cot, using the strap sewn on the front and back of a vest that your baby/toddler wears.



Figure 4.7 Cot with drop-down side e.g. Arms reach mini classic co-sleeper



Figure 4.8 Cot with half slide away rail e.g. Instructables modified crib



Figure 4.9 Cot on wheels e.g. Grottime patsy bassinet

Using a pram

As for other items of equipment for babies and toddlers, some pram features are easier to use than others, as suggested below:

- It may take some time to find yourself the perfect pram. Lightweight prams are optimal; however, the height of the pram is an equally important consideration. A lower style pram with an adjustable height handle and adjustable seat direction may make it easier for you to get your baby/toddler in and out (Figure 4.10).
- You may like to consider using an attachment from your pram to your wheelchair to make it easier for you to push the pram (Figure 4.11). Technical Aid to the Disabled Queensland (TADQ) or other modification specialists may be able to help by making a custom attachment for your wheelchair.



Figure 4.10 Pram with adjustable seat direction e.g. Strider plus 4 stroller



Figure 4.11 Pram attached to wheelchair e.g. Cursum stroller



Figure 4.12 Pram/bassinet wheels

Transporting your baby on your lap

General suggestions for transporting your baby/toddler on your lap:

- A soft structured baby carrier can hold your baby close to your chest so that your hands are free to push your wheelchair (Figure 4.13). Consider the amount of padding built into the shoulder straps; you may find it more comfortable to add extra padding to relieve pressure on your shoulders. Refer to Safety section on page 7 for further important information about slings and baby carriers.
- Similarly, a baby sling or baby wrap can also leave your hands free to propel your wheelchair (Figure 4.14). Refer to Safety section on page 7 for further important information about slings and baby carriers.
- When your baby is young and still needs head support, position him/her in the sling or baby carrier facing towards you while you use your chair. As babies grow older and develop head and trunk control they can then face outwards. Refer to Safety section on page 7 for further important information.
- A LifeTec webinar, provides clear advice regarding safety issues relating to positioning babies in wraps, ring slings and soft structured carriers. See <https://www.youtube.com/user/LifeTecAT/>.
- A neoprene strap with Velcro closures may help you nurse and carry your toddler.
- A breastfeeding/doughnut cushion can provide additional support for your baby/toddler.
- A pillow on your lap may offer a larger, flatter support surface than your thighs, resulting in greater support and comfort for your baby/toddler.
- Your baby/toddler could lie/sit on a wheelchair tray (Figure 4.15). A non-slip mat on the tray can reduce slipping.



Figure 4.13 Baby carrier

Figure 4.14 Baby sling

Figure 4.15 Wheelchair tray

Accessing the community with your baby/toddler

General suggestions for accessing the community with your baby/toddler:

- Adapted walking security straps (leads) may help you keep your toddler close to you. Some are attached to child size backpacks, making them more fun and acceptable to many parents and children alike (Figure 4.19).
- Sit your baby/toddler securely on your lap whilst accessing the community – refer to previous page for ideas on this.
- Try to choose a nappy bag that can attach to your wheelchair with easy access to pouches and zip compartments, or that easily fits in or under the pram.
- Your toddler may enjoy riding a tricycle alongside your wheelchair.

Transporting your baby/toddler

General suggestions for helping to transport your baby/toddler:

- A bassinet on wheels or a pram enables you to push or pull your baby around the house (Figure 4.12).
- An attachable seat/stand with wheels can be secured to the back of your wheelchair (Figure 4.16). This allows you to wheel your wheelchair and transport your toddler at the same time. A stand attachment designed for a pram, stroller or buggy with a cross bar or axle could possibly be adapted to fit into the back of a wheelchair (Figure 4.18).
- A baby seat can be attached to a power wheelchair (Figure 4.17).
- If you are keen on hand cycling, you may be able to modify this to make a tandem bike for outings with your toddler.



Figure 4.16 Sit/stand attachment for stroller/wheelchair e.g. Veebee EZrider



Figure 4.17 Baby seat for powered wheelchair



Figure 4.18 Toddler platform e.g. Valco toddler tourer



Figure 4.19 Walking harness e.g. Harness buddy

Suggestions for parents with high level tetraplegia

- Your partner or carer may be able to secure a baby sling or soft structured baby carrier to your body and position your baby/toddler in the recommended, safe position. Refer to Safety section on page 7 for further important information.
- Secure a stand to the back of your powerdrive wheelchair for your toddler to use when accessing the community (Figures 4.16 & 4.18) or a baby seat to the front of your chair (Figure 4.17).
- Refer to the section on page 6 of this booklet.

The legalities of travelling with your child on your lap

According to the Queensland Police Service, powerdrive wheelchairs are covered by the Transport Operations (Road Use Management – Road Rules) Regulation 2009. (TORUMS (RR)). These regulations state that you may travel with your child on your lap in your powerdrive wheelchair, providing the chair travels at less than 10km/hr. In Queensland, powerdrive wheelchairs are usually speed limited by the supplier to prevent the chair travelling at or over 10km/hr. If your powerdrive chair travels at or above 10km/hr, the chair is then classed as a vehicle, so a child cannot sit on the lap on a road or road related area.

A road related area is defined as:

- An area that divides a road
- A footpath or nature strip adjacent to a road
- An area that is not a road and that is open to the public and designated for use by cyclists or animals
- An area that is not a road and that is open to, or used by, the public for parking vehicles
- Any shoulder of a road, defined as, any part of the road that is not designed to be used by motor vehicles in travelling along the road, and includes:
 - For kerbed roads – any part of the kerb, and
 - For sealed roads, any unsealed part of the road and any sealed part of the road outside an edge line on the road, but
 - Does not include a bicycle path, footpath or shared path.

These regulations **do not** apply to manual wheelchairs, as they are not regarded as vehicles pursuant to the TORUMS (RR) act.

Play

No matter your level of spinal cord injury, there are many ways in which you and your baby/toddler can play together. All families need to be 'baby-proof' their home before the baby develops a way to move around independently.

Floor play

General suggestions for involvement in floor play:

- Switch adapted toys with a long cord enable you to activate toys on the ground/table/your wheelchair tray from your wheelchair (Figure 5.1). Switches can be purchased and attached to most battery operated toys. LifeTec (refer to contacts list) can provide information on how to modify toys.
- Toys with loop strings and rings allow easier handling and operating for both you and your baby/toddler.
- Long handled reachers can be used to pick up and move toys and play equipment. Some reachers are activated by gripping, while others are operated by wrist flexion and extension; these can be individually modified for various purposes (Figures 5.2 and 5.4).
- You may find it easier to play with your baby/toddler if you set up a raised play area (Figure 5.3). For those able to transfer, this may be an effective place to sit at the same level as your baby or toddler while they play. The play pen could also be placed adjacent to your bed so you can be lying in bed while interacting with your baby/toddler, or positioned somewhere where you can easily observe and interact with your baby/toddler.



Figure 5.1 Switch-adapted toy



Figure 5.2 Wrist activated reacher

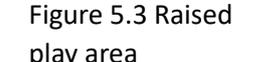


Figure 5.3 Raised play area

Figure 5.4 Long handled reachers

Table top play

General suggestions for involvement in playing at a table:

- If safe to do so, place your baby/toddler on your lap or wheelchair tray, so that together you may be able to play with toys, books, electronic games or simply communicate with or cuddle each other.

- A stand for electronic games such as iPads (Figure 5.5) can be attached to your wheelchair frame so you and your toddler can access this device together while sitting together in the wheelchair.
- A wheeled over bed, adjustable height table could enable both you and your baby/toddler to play together, while he/she is on your knee.
- An angled surface (a feature of some over bed tables) or a slope board (Figure 5.8) may be handy for drawing, painting, felt board pictures, puzzles, supporting books while reading to your baby/toddler, etc. The sloping surface allows you and your baby/toddler to easily see and reach the table surface while he/she is sitting on your lap.

These strategies may be useful for parents with limited upper limb function:

- For painting, you can modify how you use the brush by wearing a paint brush splint, building up the handle or using an adapted reacher (Figure 5.6).
- Use a plastic thumb grip or thimbles to assist turning the pages of books when you are reading together (Figure 5.7).



Figure 5.5 iPad stand



Figure 5.6 Adapted object holder



Figure 5.7 Rubber thimbles



Figure 5.8 Slope board e.g. Pencil grips plus writing slope board

Outdoor play

General suggestions for involvement in outdoor play:

- Baby proof your outdoor area. For example, having a fenced off area free of hazards where your toddler can move around independently (Figure 5.9).
- A ride on/in toy with a long handle may allow you to push it from your wheelchair (Figure 5.10).
- You may feel your toddler is safer using public play areas that are fenced or away from busy roads.
- Wheelchair accessible parks and playgrounds may broaden the range of activities you and your toddler can do together. Your local council will be able to let you know the location of these playgrounds.
- A ball thrower is often used by dog owners, but these toys may help you to pick up a tennis ball off the floor and throw it to your toddler without needing to lean over in your wheelchair (Figure 5.11).
- Trial a bicycle or tricycle with a long handle to go on rides with your toddler (Figure 5.12).

Other suggestions for play

- Toy storage may be easier if boxes/crates/tubs can be easily accessed from your wheelchair. Those on castors may be preferred, particularly if they have sturdy grab handles, for you and your toddler to use. Tongs and long handled reachers can be used to pick up and put away, and may be fun for your toddler to use too.
- If it is safe to do so, your toddler could climb up onto your wheelchair tray to enable you to play close together.
- Play games such as hide and seek in wheelchair accessible areas.
- Your toddler will probably require little encouragement to invent games you can play together



Figure 5.9 Fenced-off play area



Figure 5.10 Push toy with long handle



Figure 5.11 Ball thrower with long handle



Figure 5.12 Tricycle with long handle

Suggestions for parents with high level tetraplegia

- 'Kick' a ball using wheelchair footplates.
- Refer to the section on page 6 of this booklet.

My son lies on top of me in bed so I can read him stories

I had an attachment for my iPad on my wheelchair so we could play activities and read together (mother, C6).

I really liked the play area that was built on a table, with a cot-like gate (mother C6/7).

I used my wheelchair tray to bring him closer to me so I could play with him. I also had a big play pen so that I knew where he was (mother, C6).

Sleeping

There are many ways in which you can help your baby/toddler with sleep.

General suggestions for involvement in your baby/toddler's sleep routine

- If your baby/toddler wakes frequently during the night, position his/her cot or bassinette next to your bed, so you don't need to transfer to and from your wheelchair during the night. (Figure 6.1).
- An "Arms Reach" bassinet can attach to the side of your bed (Figure 6.2). These bassinets have one side that is open which allows easier access to your baby during the night.
- Due to the risk of baby deaths associated with co-sleeping, you must use a baby barrier to prevent you or your partner from rolling onto your baby/toddler if you wish to have him/her sleep in your bed. Purpose-made baby barriers are available (Figure 6.3), while some parents use a number of pillows to achieve the same effect. If you plan to use co-sleeping, research the risks associated with this. Refer to Safety section on page 8 for further important information on co-sleeping.
- You might find it easier to raise the cot. TAD Queensland can custom made such modifications (refer to contact information later in this booklet). The picture on page 33 shows one example of a height adjustable cot.
- Many parents use a baby monitor or TV monitor when your baby/toddler starts to sleep in a different bedroom (Figure 6.4 in Equipment List). This can be helpful to reassure you of your baby/toddler's well-being.
- A play swing may help rock your baby/toddler to sleep. These can be hand or battery operated.



Figure 6.1 Side opening cot next to bed e.g. eLearnSCI



Figure 6.2 Co-sleeper cot e.g. Arms reach mini classic



Figure 6.3 Baby barrier for co-sleeping



Figure 6.4 Baby monitor

Suggestions for parents with high level tetraplegia

- Remember to give positive verbal support to your partner. Reassurance from a loved one can make a big difference when first starting out as a new mother or father.
- Refer to the section on page 6 of this booklet.

Toileting

As your baby grows through the stages of using nappies, potty training, toilet training, and finally independence in toileting, there are different strategies that you can use.

Change table set up

Consider the height of the change table and whether there is space underneath the table that allows you to get close to your baby/toddler.

General considerations for choosing a change table:

- A height-adjustable change table will be useful for all those involved in caring for your baby/toddler (Figure 7.1).
- A wall-mounted, hinged change table doesn't have any legs, so may be easier for you to wheel under, and may also be useful if space is at a premium (Figure 7.2).
- A change table that swings around off a table top gives you space for your wheelchair underneath and a flat surface next to it for the items you need (Figure 7.3).
- A desk or table with change pad on top may give you space for your wheelchair underneath and a flat surface next to it for the items you need.
- If the change table is too low, you could raise it on bed or chair blocks to get it to the height that best suits you.
- A mobile cart beside the change table may be helpful for storing the necessary items for nappy changing, instead of using a change table with storage space being below.
- This will enable you to wheel underneath the change table while still accessing the things you need.
- A commercially available change pad with an extra security strap (Figure 7.4) can assist to keep your baby safe.



Figure 7.1 Height adjustable change table e.g. Spinalistips



Figure 7.2 Wall mounted change table e.g. Spinalistips



Figure 7.3 Swing out change table



Figure 7.4 Change pad with strap

Changing a nappy

General strategies for changing a nappy:

- Having nappies, wipes and other requirements within reach is generally easier and is safer once your baby starts wriggling during nappy changes.

- You may benefit from trying various styles of nappy such as disposables, pull-ups, pre-shaped cloth nappies (figure 7.8) with Velcro or stud fasteners, or cloth nappies with a rubber stretch Y strap (Figure 7.5) to find which are the easiest for you to manage.
- Changing your baby's nappy may be possible on your wheelchair tray (Figure 7.6). A pillow on the tray will make it softer but will also increase the height of the tray surface.
- You may prefer to change the nappy with your baby/toddler on your lap (Figure 7.7) As this photo shows, place him/her on his/her stomach across your lap, using one hand to secure him/her while changing the nappy with your other hand.
- Finger loops on the pull tabs of non-disposable nappies may be helpful (Figure 7.8).
- Roll your baby/toddler on his/her side to place the nappy under his/her bottoms instead of lifting up his/her legs.



Figure 7.5 Y-shaped nappy fastener e.g. Nature's child nappy fastener



Figure 7.6 Changing on wheelchair tray



Figure 7.7 Changing nappy on lap



Figure 7.8 Nappy with material loops e.g. eLearnSCI

Toileting a toddler or young child

General strategies for toileting a toddler or young child:

- A higher potty may make it easier for you to help your toddler on and off the potty (Figure 7.9).
- A toilet seat trainer that moulds gently around your child as he/she sits down can provide support and security (Figure 7.10).
- A single step or small set of steps at the front of the toilet and/or sink may help your toddler to be more independent (Figures 7.11; 1.18).
- A child seat on the toilet (Figure 7.12) can help to you toddler sit safely. Seats with side handles give your toddler something to hold on to, and may reduce the need for additional support while he/she is on the toilet.



Figure 7.9 High potty



Figure 7.10 Bumbo toilet trainer



Figure 7.11 Toilet seat with steps



Figure 7.12 Toilet seat with handles

Suggestions for parents with high level tetraplegia

- Hold your baby/toddler secure when the nappy is being changed, for example, by putting your arm across your baby/toddlers body.
- Refer to the section on page 6 of this booklet.

I couldn't physically change his nappy, but I'd be involved by talking to him and holding his hand while my husband changed the nappy (mother,

I come in and watch him getting his nappy changed (father, C4).

I used a plastic garden table for a change table, as this was easiest to wheel under (mother C6/7).

Advice from current parents with SCI

Don't panic; look for another solution.

Spend as much time as possible with your child. Do everything as normally as you can, just as any other parent would do. You might just have to approach it another way.

It is important to still get your bonding time with your child. Be involved, and be part of their lives



Don't stress; it's not supposed to be hard. There is always a solution.

Being a wheelchair bound parent puts you in the unique position of being a permanent captive audience for your child's attention. Use this to your advantage to teach, encourage and mentor.



Just enjoy the experience and don't become too frustrated, as there will be a solution to most problems.

Photos from Spinalistips website

Contact information

Spinal Outreach Team (SPOT) - Author/owner of this document

SPOT is the community based team of the Queensland Spinal Cord Injuries Service (QSCIS), comprising experienced health professionals from nursing, occupational therapy, social work, physiotherapy, and a community rehabilitation registrar.

SPOT provides information and advice about equipment, support services, health issues, work, recreation and many other aspects of life with spinal cord injury, and supports people with spinal cord injuries in Queensland, their families and friends. SPOT also educates and informs service providers about issues to consider when assisting people with a spinal cord injury. Further information on SPOT and spinal cord injury can be found at www.health.qld.gov.au/qscis.

3rd Floor, Buranda Village
Cnr Ipswich Road and Cornwall Street
(PO Box 6053)
Buranda, QLD, 4102
Ph: (07) 3176 9507; 1800 624 832 (freecall for clients) Fax: (07) 3176 9514

Email: spot@health.qld.gov.au

LifeTec

LifeTec provides specialist information and advice to maximise an individual's independence and safety. Their qualified health professionals provide impartial advice to enable their clients to make informed decisions about what is best for each individual.

LifeTec works directly with members of the community to solve individual problems of access and independence, raise community awareness and understanding of how assistive technology can be used to overcome obstacles in everyday life, and educates health professionals on the application of assistive technology.

In April 2014, LifeTec released "Assistive technology for the new parent", a webinar presented by Amy McKenzie, subtitled "Making life easier for new parents: equipment suitable for parents and carers of newborns and toddlers". It covers:

- Feeding baby
- Bathing your baby
- Out and about with baby
- Sleeping baby

Access this and other Lifetec videos at <https://www.youtube.com/user/LifeTecAT/>.

LifeTec Brisbane Display centre

Level 1, Reading Newmarket
Cnr Newmarket/Enoggera Rd
Newmarket QLD 4051
Ph: (07) 3552 9000,
Ph: 1300 885 886
Fax: (07) 3552 9088

LifeTec Townsville Display centre

Shop 3a Domain Central
103 Duckworth St
Townsville QLD 4814
Ph: (07) 4759 5600
Ph: 1300 885 886
Fax: (07) 4759 5688

Email: mail@lifetec.org.au

Website: <http://www.lifetec.org.au/services/product-search>

Spinal Injuries Australia (SIA)

SIA provides support to people with spinal cord injuries with services including personal assistance in the home, employment assistance, peer support, advocacy on a wide range of issues, and healthcare and lifestyle advice. SIA is committed to rebuilding lives, promoting and celebrating independence, and preventing injuries.

Brisbane office

109 Logan Road
Woolloongabba QLD 4102
PO Box 5651
West End QLD 4101
Ph: (07) 3391 2044
Fax: 07 3391 2088
Freecall: 1800 810 513
enquiries@spinal.com.au

Townsville office

488 Ross River Road
Townsville QLD 4814
PO Box 618
Aitkenvale BC QLD 4814
Ph: 07 4755 1755
Fax: 07 4723 8677
Freecall: 1800 024 422
nqenquiries@spinal.com.au

Cairns office

Unit 1, 325-327 Sheridan St
North Cairns QLD 4870
PO Box 452
North Cairns QLD 4870
Tel: (07) 4755 1755
Fax: (07) 4723 8677
Freecall: 1800 024 422
nqenquiries@spinal.com.au

Website: <http://www.spinal.com.au/>

Technical Aid to the Disabled, QLD Inc (TADQ)

TADQ is a not-for-profit organisation and registered charity that provides technical support for people with disabilities and the frail aged to assist with their everyday living. A project team works with TADQ volunteers to design, modify and manufacture pieces of equipment not commercially attainable, at a minimal cost to their clients.

Unit 1 “Nexus” 23 Ashtan Place, Banyo QLD

PO Box 158, Virginia BC QLD 4014

Ph: 1300 663 243 or 3216 1733

Email: tadq@tadq.org.au

Website: <http://tadq.org.au/>

SPINALpedia

SPINALpedia is a social mentoring network and video archive that allows the spinal cord injury community to motivate each other with the knowledge and triumphs gained from their individual experiences.

Website: <http://www.spinalpedia.com/>

Parenting specific videos can be found by selecting the ‘videos’ tab, then selecting ‘life’ then ‘parenting’ from the categories menu.

Spinalistips - Tips and tricks from people with spinal cord injuries

The website www.spinalistips.se is designed for people with spinal cord injuries, their families and rehabilitation staff. This website recognises that many people with spinal cord injury have themselves become experts on their disability, and have been imaginative and inventive when it comes to tools and tricks for facilitating everyday life. Click on the tab titled assisting others/childcare.

Parenting resources for child behaviour management

While all children need to listen to and follow their parent's instructions, this is possibly more critical for children of a person with a SCI than for children of able bodied parents, simply because parents with spinal cord injuries may not be able to physically stop their child from potentially dangerous behaviours, such as running onto a roadway, putting hands under very hot water etc. Parenting advice is provided by various organisations.

Triple P Parenting program

The "Triple P: Positive Parenting Program" offers a 12 week group program or eight on-line modules for parents with children between the ages of 2-12 years. It offers parents simple and practical strategies to help them confidently manage their children's behaviour, prevent problems developing and build strong, healthy relationships. All strategies suggested through this program are relevant for parents with SCI. Find your nearest provider of this program at:

<http://www.triplep-parenting.net/glo-en/get-help/find-a-triple-p-provider/>

PO Box: 1300 Milton, Qld, 4064, Australia

Ph: (07) 3236 1212

Fax: (07) 3236 1211

Email: contact@triplep.net

Website: <http://www.triplep-parenting.net/glo-en/home/>

Parentline

Parentline provides individually-paced over-the-phone parenting skills training through counselling, information and referral. Counsellors can assist to identify immediate parenting concerns, and develop strategies for making meaningful change, while recognising unique family relationships.

GPO Box 2469, Brisbane QLD 4001

Phone: 1300 301 300

Fax: (07) 3367 1266

Email: admin@parentline.com.au

Website: www.parentline.com.au

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The things I found most difficult were holding and cuddling him. I couldn't lift him up, hold him or change his nappy (father, C4)

When my son was a baby, I used a feeding pillow to give him his bottle. The pillow helped me nurse him as well, but the nursing pillows with a strap around the back were difficult to use. When he was a bit older he'd move around a lot, so I would tuck one of his arms around my back and hold him tight with my other arm (father, ...)

When she was old enough, she would crawl to my chair and onto the foot plates. I could then slowly lift her up (mother C6/7).

At the moment my baby is being breast and bottle fed. Once he's old enough to have solids, I think I will be able to be involved with spoon feeding if he is fastened in his chair and he has spoon – Perhaps I could use a bent spoon (father, C4)

When my daughter was learning to walk, she would hold onto the side of my wheelchair (mother C6/7)

Appendix: Parenting Checklist



The aim of this checklist is to assist parents and health professionals determine key issues that may need to be explored further to enhance parenting.

Name : _____

Age of Child/ren : _____

Please turn to appropriate section (i.e. baby/toddler, preschool, school aged)

Baby/toddler

Feeding

Bottle feeding (includes preparing formula, screwing on bottle top, positioning baby)

Breast feeding (includes positioning baby, managing bra, breast pads)

Solids (includes food preparation, high chair - putting infant in and getting out, use of feeding utensils, cleaning up)

Lifting and Carrying

Carrying baby/toddler from A to B (includes balance in wheelchair, positioning options, equipment required)

Use of pram (includes balance/pushing abilities, lifting baby/toddler in and out of pram, where it's to be used)

Transporting baby/toddler in car (includes positioning of car seat, transfer of baby/toddler, positioning of wheelchair)

Lifting baby/toddler from table height to chair and floor height to chair (includes position used, balance, equipment required)

Dressing

Managing nappies (includes change table setup, type of nappies, change mat style)

Management of other clothing (includes style of fasteners, ease of changing)

Sleeping

Cot access (includes type of opening, lifting baby/infant out, making up the cot)

Hygiene

Bathing (includes equipment needed, filling and emptying bath, lifting baby in and out, supporting baby in bath)

Preschool

Meals

(includes food preparation, cutting up food)

Transporting

(includes car seat, pushing and manipulation of pram, additional weight on wheelchair)

Hygiene

(includes bathing – running bath, getting child in and out, washing hair. Also toilet training issues – getting on and off toilet, adjusting clothing, cleaning up accidents)

Safety

(includes safety locks for cupboards, stair gates, child restraints, gates to property)

Community Access

(includes playgroup, shopping centre access, parent networking, kindergarten access, other activities e.g. swimming, day care, music etc.)

Play Opportunities

(includes equipment required, ability to manage child outside, getting down to floor and back, manipulation of toys/craft etc)

Discipline

(includes options for control, safety aspects, style/type of disciplinary options, literature available)

School Age

Transporting (includes ability to drive, ability to support and assist with out of school activities)

Discipline (includes options for control, safety aspects, style/type of options, literature available)

Outdoor Activities (includes safety aspects, assistance required, ongoing commitment needed)

Indoor Activities (includes homework assistance required, supervision of household tasks, safety considerations ie. when cooking etc)

School Involvement (includes potential for involvement in class, in P&C, contributions for special events)
