

RSI AND OVERUSE INJURY ASSOCIATION OF THE ACT Inc.

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# Pregnancy & Parenting with RSI

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and other arm problems

2016 edition

With new  
illustrations



## **PREGNANCY AND PARENTING WITH RSI AND OTHER ARM PROBLEMS**

## TABLE OF CONTENTS

1. GETTING THE HELP YOU NEED	3
2. PREGNANCY	3
3. LABOUR	4
4. THE FIRST DAYS AFTER BIRTH	4
5. SELF-AWARENESS AND CARE	4
6. NAPPIES	5
7. NAPPY CHANGING	6
8. CLOTHING	6
9. BATHING	6
10. CARRYING AND HOLDING	8
11. SOOTHING BABY	9
12. FEEDING	9
13. LIFTING	11
14. SLEEPING	12
15. CAR TRAVEL	13
16. PRAMS AND STROLLERS	13
17. HELPING YOUR CHILD TO HELP YOU	14
18. GETTING EXERCISE	14
19. SOCIAL CONTACTS	14
20. STORIES FROM OUR MEMBERS	
KAREN JACKSON, DUTCH RSI ASSOCIATION	15
LISA	17
MELISSA	20
21. HEALTH, PARENTING & CARE CONTACTS	27
22. RSI ASSOCIATION MEMBERSHIP BENEFITS	27
23. APPLICATION FOR MEMBERSHIP	28

## 1. GETTING THE HELP YOU NEED

When we decided to put this book together, we first talked to a number of mothers with RSI. And there were two important themes that came up every time in our conversations. All our mothers emphasised the importance of, firstly, planning ahead and, secondly, getting help. They said things like:

*Throughout the pregnancy there was a lot to think about and organisation was very important. My partner and I had to anticipate the problems that might arise and how we would cope so we gathered as much information as we could. We read everything we could find and spoke to other people with RSI who'd had children to learn how they coped. We also found community resources and services we could use, such as community nurses.*

-Lisa

*During my pregnancy, I tried to really think and plan ahead for the baby. It was surprising how many agencies dealing with people with disabilities were unable to offer much help. But I've managed to get scraps of advice from different places that have made a real difference.*

-Melissa

*I had the Occupational Therapist at the health centre undertake a home assessment and this was really useful.*

-Anna

## 2. PREGNANCY

Most mothers we talked to had a pre-existing injury, but it's also possible for RSI to start during pregnancy. Whether you are in the first or the second category, it's important to think about carrying out everyday activities in a new way to reduce the strain on your muscles. For example, you can make sitting easier on your arms as you get heavier by sitting on chairs that are a little higher.

If you need to help yourself get out of a chair, don't bend your wrists but support yourself by clenching your fists and keep your knuckles in a straight line with your arm. As your tummy gets bigger, it's a temptation to hold anything that you're doing up at chest height. If you do this for any length of time, you may reduce circulation in your arms.

Pregnancy is a good time to:

- talk to your insurer (if you are on worker's compensation) about increasing or starting household help after the baby is born. You may be able to get help managing the baby as well.
- talk to your partner about planning for the birth and who will be responsible for what chores after the baby arrives
- learn relaxation techniques which will help you learn to move in new ways and do things with less effort.

- find a yoga school that runs classes in relaxation and ‘beginners’ or ‘pregnancy’ yoga.
- visit an Independent Living Centre to get advice on managing your baby successfully and on the latest products to reduce the strain.
- build up a store of frozen meals for the first few months after the birth, for example pasta sauces.
- plan ahead for the support you need after the birth. It will really help if you can get regular time away from childcare to relax, maintain therapies and get some exercise.

### 3. LABOUR

Nursing staff in the labour ward may be unaware of birthing problems caused by overuse injuries. Many labour positions put a lot of strain on the arms, hands, neck and back. Develop a birth plan with your midwife or obstetrician that includes strategies for avoiding positions that may aggravate your condition.

*I had a bad flare-up of symptoms after labour, therefore I wasn't able to cope with learning new things.*

During birth, you may forget to protect yourself, so your partner should be aware of what you need in order to help you.

### 4. THE FIRST DAYS AFTER BIRTH

Try to make sure your partner is involved right from the beginning. You will probably be very tired after the birth and physical and emotional support from your partner will be important.

Partners can develop more confidence and a closer relationship by helping with nurturing tasks such as rocking, soothing, bathing and taking the baby for a walk.

### 5. SELF-AWARENESS AND CARE

One of the keys to successfully managing a baby when you have an overuse injury is to limit household tasks and focus on yourself, your baby, and surviving those first few months! This may mean that you need to cut back on cooking, washing and cleaning. You may have to lower your standards in housework (most mothers have to do this anyway, as children and mess go hand-in-hand).

*Taking a rest during the baby's sleep times is most important for self-preservation!*

We all know that when you are in pain, it's easy to be impatient and irritable – which is just what you don't want! So make staying pain-free one of your top priorities – and think ahead about how to manage a flare-up. Although you might want to be as independent as possible, it's really important to ask for help when you need it.

*Remember that the most valuable thing you can give your child is your love and attention.*

You may need to explain to your partner, family and friends exactly what is difficult for you and what help you would appreciate receiving.

Try to stay clear in your own mind about what your priorities are. Don't forget to seek help from a supportive doctor, maternal and child health nurse, lactation consultant, counsellor or occupational therapist. If you can afford it, a cleaner once a week could make a big difference.

*I realised that I needed to look after myself so that I could manage and care for the baby.*

Try and foresee difficult situations and work out how you are going to deal with them so that your arms don't end up hurting too much. As the parent of a small child, you usually don't have the option of taking a holiday or a rest.

This means that you have to be even more careful about not exacerbating your injury than you would normally be. You might have to learn to be very up-front about your injury and ask for what you need.

## **6. NAPPIES**

The whole process of changing a wriggling baby, scraping, soaking, washing, hanging out, bringing in and folding nappies can place a lot of strain on your arms. Weigh up the pros and cons for you with the following possibilities.

### **Disposables**

- Some are easy to fasten, some are really difficult (experiment)
- need changing less often, as they absorb a lot
- don't need washing

### **Regular nappies (cloth)**

- lots of washing and folding
- easier to fasten with a 'Snappy Nappy' than with a pin
- can be hard to get on a wriggling baby
- easier if you own a drier
- nappy liners can be washed and re-used when wet and disposed of when soiled, reducing the need to scrub nappies

### **All-in-one nappy and pilcher**

- easy to put on and to fasten
- can take much longer to dry than regular nappies

### **Velcro-fastened pilchers**

- can use a regular nappy with more layers than usual, so you need to change them less often
- easier to fasten

## 7. NAPPY CHANGING

Set up a nappy changing area with everything you need on hand. This may be a changing table at a good height for you, preferably one with a tray underneath for nappies and so on, or it could be a changing mat on the floor next to some shelves.

It's a good idea to hang a mobile overhead to hold baby's attention and also to keep a supply of toys and distractions nearby. Women with RSI have emphasised it is vital to think about the set-up of the bathroom, baby's room and kitchen.

*It is really important to have frequently used items at waist height.*

## 8. CLOTHING

If you find it difficult doing up jumpsuit poppers, put your baby in a short nightgown. You can then change the nappy without having to do anything with the rest of the clothing. Change your baby only when necessary, rather than as a routine.

If buttons are difficult to manage, buy envelope-neck nighties available by mail order from the Australian Breastfeeding Association (see Social Contacts at the end of this booklet) or you could replace buttons with velcro circles. These can be stuck on and then stitched over.

Another alternative may be zips or velcro at the crutch of jump suits which makes nappy changing easier. Zips can be made easier to operate by inserting a split ring into the zip pull. Use socks instead of booties, or in warm weather, let your baby enjoy her feet.

Encourage your child to participate in dressing activities at an early age and to dress herself or himself. Choose clothes with large openings and easy fastenings at the front and remember to check clothes you're buying for unnecessary fastenings. Buy shoes with buckles or velcro fasteners.

## 9. BATHING

You can buy baths for small babies that give them a lot of support and leave your arms free for washing them. You can also buy a sling that supports your baby to lie safely in a baby bath or in an adult bath with or without you. However, never under any circumstances leave a baby or toddler unattended in the bath. You can find most of this equipment at baby shops and large variety stores with a baby equipment section. Babies can also be "spot washed" with a flannel, rather than needing a full bath every day.

Preparation for bath time is essential:

- arrange everything you need around you before beginning bathing
- try washing your baby in or near the kitchen sink. Some people like to wash a baby on the draining board and rinse off with a spray attached to the tap.
- you could leave the bathing to your partner while you take a walk or have a rest.

Bath time is a good opportunity for parents to get to know their babies and share a pleasurable activity with them.



**Baby bath in sink**



**Baby bath sling**

When the baby grows beyond the baby bath, again you can use the kitchen or laundry sink. This helps you to maintain good posture and makes lifting easier and safer. A bath seat supports babies who are almost able to sit by themselves in the bath.

When the toddler progresses to the family bath, use a step or stool and encourage the toddler to climb in with your help, rather than being lifted in.



**Supportive Baby bath**



## 10. CARRYING AND HOLDING

One of the biggest problems if you have an overuse injury is carrying the baby. For small babies, some of our members have found that the following baby carriers distribute the weight well and are comfortable to use:



**Hugabub**



**Babybjorn**

When your baby gets to about four months, you can use a ‘hippy-chick carrier’ which is rather like a large stiff bum bag with a very wide strap that goes around your hips. This will enable your baby to sit on your hip with just a little support from your arms. It will take your baby through from about four months to two years. Parents we know with overuse injuries have found it very helpful.

However, you still may not be able to hold your baby for a long time because just supporting your baby places a static load on your arms. If your arms are really sore and your baby is crying to be picked up, try sitting down in a chair or on the floor with him or her, perhaps looking at a book or playing with a toy together.

Even if you’d like to get on with your chores and hold your baby with the other arm, giving up on the chores for a while may be easier for both of you. Another idea with a crying baby is to lie down on a big bed together and cuddle or play.

*I used the pram to wheel my baby around the house, or pushed the bouncinette with my foot.*

Baby slings, particularly those worn across the back and with a waist strap can be useful, but they may also worsen shoulder and neck problems. There are many types of slings available; try them out in the store for comfort and ease in putting on and taking off or discuss this with an occupational therapist.

Don't forget outdoor stores as a good source of baby-carriers, especially ones designed to sit on the hips. Unfortunately, the most expensive ones are also the most comfortable! It's also possible to reduce carrying by arranging equipment so that it's near at hand and easily accessible. Keep sterilising equipment, cutlery, bowls, etc. close to kitchen benches and preferably feed your child near this area to save carrying.

## **11. SOOTHING BABY**

Many techniques that parents use to soothe babies can be very difficult when you have an overuse injury. Things like patting, rocking, pushing backwards and forwards in a stroller and holding for long periods can be just too hard! Leave them to other people—your partner, friends and relatives.

You'll develop your own soothing techniques which could include

- singing
- soft reassuring talk
- sitting with your baby in a rocking chair
- foot-rocking baby in a bouncer or baby chair
- swinging with your baby in a hammock or swing-seat
- a dummy
- breastfeeding your baby
- a rocking carry-cot that sits on the floor and moves with a gentle foot motion—look for one with handles that you (or someone else) can carry from room to room.

Most of these techniques won't need to be used after your baby is about six months old and is more settled.

Be very careful about holding your baby for long periods of time, even if you are sitting and your baby is partly supported. Your lack of movement means less blood flow to your arms and any prolonged load on your muscles, even if slight, can hurt afterwards! Talk to the maternal and child health nurse about ideas for soothing and settling.

## **12. FEEDING**

If you are taking any drugs for your RSI, remember to check with your doctor before breastfeeding that none of them could be harmful if transmitted to your baby in your milk. Alternative safer medications will likely be available.

As well as all the health pluses of breastfeeding, there are practical advantages too — breast milk is warm, sterile and ready to go! However, the static holding involved may be very fatiguing and painful.

On the other hand, unless someone else is generally available to bottle feed your baby, this involves even more holding—the baby and the bottle as well. If you are bottle feeding and your grip is weak, a bottle holder may be useful. Bottles with handles or a contoured grip may be easier to grasp.



**Poddee baby bottle**



**Beebo bottle holder**

If you have an overuse injury and you wish to breastfeed, find a really supportive chair. An old fashioned arm-chair with armrests is probably the best thing. Use a pillow or two to prop your baby up while you're feeding (the same with bottle feeding). Just because you are not supporting your baby's weight doesn't mean you can't give your baby the warmth of your affection by putting your arm lightly around her.

When your baby gets bigger, you may find that you can rest her on your knee by crooking your leg up onto your seat if you're away from your armchair. Specially shaped cushions to support babies during breast-feeding are available from baby shops and catalogues.

If you're feeding your baby lying down, be very careful not to rest baby's head on your shoulder or upper arm, as this can cause a lot of soreness in those areas and in your forearms.

Your baby can lie flat beside you, below your outstretched arm as you lie on your side and feed. You need to have your head on a cushion or the edge of a pillow. Make sure the pillow doesn't get in the way of your arm.

This 'lying flat' position won't suit all babies or mothers, so do talk to a lactation consultant or other health professional if you need help to find a way of feeding your baby comfortably.



*After a week of breastfeeding my new baby, my neck was a wreck! I had been watching her face for the hour or so each feed took. Then I decided we'd get our eye contact at other times, when I could put her in a better position – generally on my lap and some cushions, right in front of me.*



**Breastfeeding support cushion**

When you introduce solid food, it might be easier to hold a light mug than a bowl. When you're cooking, think about whether the food you are making could suit your baby as well as yourself – no need to cook two meals! When your baby is learning to feed herself, put down newspapers that can easily be thrown away, have a picnic outside in fine weather or use a plastic cloth on the floor.

Blenders and food processors are great for chopping and mashing. You can also find jar and bottle openers specially designed for people with weak hands that will be a great help with pre-prepared baby foods. Finger food—a carefully trimmed cutlet bone, some cooked vegies, a rusk or crust—is fun for your baby and helps you, BUT always stay with a baby who is feeding herself, as choking may be a problem.

Baby seats which hook onto an adult dining table can be used from about four or five months to three years. The soft cloth versions are more suitable for younger children and your baby can be given extra support with a pillow. These seats enable your baby to sit at a table with the family, play with their toys and be involved in family dining and other activities. Another option is a wheeled highchair.

### **13. LIFTING**

When you have to lift, hold the baby very close to your body, with both arms taking as little weight as possible through the wrists: develop a scooping method to take the baby's weight on your forearms instead of on the hands and wrists.

Use the muscles in your legs to lift by squatting to pick up baby and then standing up. With a toddler, encourage her to stand with her back to you, arms bent and held slightly away from the body. You can then lift her taking the weight on your forearms, instead of your hands and wrists.

Often babies and toddlers demand to be lifted because they want your attention or they want to be held, so a cuddle on the floor or a game will meet their needs just as well. For a toddler, you can sit down and encourage them to climb onto your lap. And sometimes you just have to say: 'I can't come to you now, I'm going to finish this and then I'll be with you.'

## **14. SLEEPING**

You have several choices here.

### **Bassinettes**

These put your baby at a better height for lifting in and out, but can only be used for three to six months. Those on castors can be useful as your baby is easily moved. (Castors on cots can, however, cause problems where a vigorous toddler can move the cot.)

### **Cots**

When buying a cot

- refer to Choice magazine for those cots that meet the Australian Standard. Many still have hazards
- consider the height of the sides (for lifting your baby in and out)
- look at whether the catches on the drop side require one or two hands to operate
- consider the possibility of an outward opening side
- think about an adjustable height base to reduce lifting
- fitted sheets can reduce lifting when making up a cot
- you can also get cots for small babies that fasten on to your bed.



**Adjustable height cot**



**Side opening cot**



**Bednest**

## **15. CAR TRAVEL**

Car safety capsules and seats can be a major problem for people who suffer from overuse injuries. Mount the capsule on the passenger side of the car rather than the middle, where it is extremely awkward to get your baby in and out. In general, it is better to put the capsule into the car first and then place your baby in the capsule. Even though you might be tempted to lift out the capsule with the baby in it while you do some shopping or pop into the bank, this can put a big strain on your arms. There are baby-seats available for babies from birth onwards—if your baby isn't under the weight recommendation, this could be a better option than a capsule.

## **16. PRAMS AND STROLLERS**

Pushing a stroller can be very difficult when you are suffering from an overuse injury. Some strollers are much easier to push than others. The large 'jogger' type strollers with really big wheels are easiest to push but not always great for busy and crowded shopping malls. Shop around, try out friends' strollers with children in them before you buy one. You can also try out strollers in large shopping malls that lend them out to shoppers at little or no charge.

One thing you can do is to enlarge the handles of your stroller with bradflex, available from plumbing suppliers, or bubble wrap. Limit yourself to short walks so that you don't have a long exhausting trip home with sore arms. When buying a stroller, think about the following

- can you vary the way you push it and use different arm positions?
- can you fold it up easily (a foot operated folding mechanism is easier)?
- are the handles at a comfortable height?
- if you'll be using it mostly in shopping centres, is it easy to manoeuvre (some strollers are much easier to turn than others)?
- are the straps holding the baby easy for you to fasten and unfasten?
- is it light enough for you to lift in and out of the car or bus?

The selection of a good pram or stroller is important—an occupational therapist can be a great help here. Other points

- Prams are heavier than strollers but are better balanced.
- Light Strollers are generally poorly balanced and inclined to tip back.
- Foot operated brakes and collapse mechanisms are preferable.
- One continuous handle is easier than two separate handles.

## **17. HELPING YOUR CHILD TO HELP YOU**

From about six months on, many babies are learning to understand short simple phrases. By repeating the same phrases as you do things with them, they will learn to help you in achieving everyday tasks like dressing. For example, say 'arms up' as you lift their arms to get a jumper on. Say 'move back' as you get them into the right position in their car seat. Build on their natural desire to do things for themselves as they get older. In the short term a toddler feeding herself may create quite a mess (a sheet of plastic or some newspaper on the floor will make this easy to clean up or have a picnic outside in good weather). In the long term, a child who can feed herself will make life much easier for you. Give your child plenty of time to accomplish tasks for themselves. A two-year-old can get in and out of a car, put on trousers and jumper, climb into a high chair, flush the toilet, and accomplish many other tasks with pride and pleasure.

## **18. GETTING EXERCISE**

When you can't go for walks because you can't carry or push your baby, it can be really difficult to keep up the exercise that promotes circulation and healing for people with overuse injuries. Try to get into the habit of making a time for your partner or a friend to mind your baby or to go for a walk with you so that you can keep up your exercise. Maybe somebody can mind the baby while you go for a swim or do some water exercises. Perhaps a friend with a baby is happy for her pusher to hold both her child and yours while you go for a walk together.

## **19. SOCIAL CONTACTS**

Many women with young children find that they are very isolated and a mother with an overuse injury can be even more isolated because of the difficulties involved in transporting the baby. It really is worthwhile making every effort to meet other mothers in your neighbourhood. The following are worth exploring:

- The ABA holds weekly coffee mornings and welcomes bottle-feeding mothers as well as breast-feeders. The ACT and Queanbeyan region can be contacted on (02) 6258 8928
- The Play Groups Association can let you know about a play group in your area and you can join when your baby is very young. Phone (02) 6251 9889
- Child health clinics hold parenting courses for new parents in local areas and these can be a great way to make contacts.
- Parent groups at the Canberra Hospital.

As well as meeting people through these groups, you can often learn about local resources such as toy libraries, pick up useful parenting tips and see children at different stages of development.

## 20. STORIES FROM OUR MEMBERS

### 1. Karen Jackson, Dutch RSI association

I was impressed with your 'baby and rsi' pack - especially the bit where it reminds you that unless you don't do stuff like cleaning, you will be in more pain and therefore be less patient with your baby. I applied for a home help when I realised that! It's funny but I've struggled with household tasks for years, not wanting to go to the trouble of getting a cleaner just for myself, but now someone else's wellbeing is involved it's been much easier to justify. Perhaps some of the points below might be helpful to your readers?

#### **Washing**

I think the pre-birth 30% extra blood flowing around in my body and the hormone Relaxin (great for relaxin') lulled me into a false sense of security with regard to what I'd be able to achieve once Kay was born. Also I had underestimated things like washing. I only took Kay's clothes into account but not the (many!) extra changes of clothes for me and Derek. One thing I never knew about baby poo stains on white cotton, is that you don't actually have to go to too much trouble to get rid of them. The sun does it for you! And there was I scrubbing away, soaking the things in various chemicals, and so on. Durrrrr!

#### **Nappies**

Pre-formed cotton nappies that you 'just' soak and wash at 60 degrees (and insert a fiddly liner into, and peg out on the line to dry, and change more often than disposables, etc., etc.) seemed a great idea at the time but I wish I'd left this environment-friendly bit to the non-rsi sufferers of the world. We now operate a dual system. Kay's dad's in charge of cotton nappies, I use disposables!

#### **Bibs**

I've found the bibs that just pull over the head the best. No trouble to fasten at all. Velcro fastening ones come in a close second. The ones that you tie are hopeless for me.

#### **Job sharing**

We are doing pretty well. My husband is in charge of bathing and bedding Kay, which gives him some good contact time with her. It's a lot in addition to his already busy schedule of working full time, shopping, cooking, massaging, etc. but we are hoping to move nearer to his work to at least cut down commuting time. And at least he's been relieved of cleaning.

#### **Transport**

I live in a 3rd floor flat with no lift and mice in the cellar. This means a lot of pram carrying if I want to take Kay out in it. I have convinced myself that mice only come out at night (!?) and that therefore it's ok if my husband carries everything down to the cellar in the morning pre work and takes it back when he gets home. If you know otherwise please don't tell me.

Spontaneous short trips out I do with a baby carrier in the form of a huge length of cotton jersey (about 3.5 metres), tapered at the ends. It takes some practice but you can spread the cloth in such a way that the weight is really well distributed, even around your hips. The only disadvantage is it's not easy to get a distressed baby out of there quickly (or indeed to get her back in afterwards!). And it's sometimes too hot in summer. We don't have a car. Trains would be a nightmare were it not for the fact that there's always someone willing to help you with a pram. If you're going to do much train travel, remember to get a small pram too. They don't all fit. Kneeling buses are my favourite - a cinch even on your own.



Trams get the thumbs down - narrow and steppy - though not impossible if you're determined and it's not rush hour. Once Kay can sit up alone, she'll be able to travel by bicycle of course, like all good Dutch babies. We're looking forward to that!

### **Feeding**

I plan to continue breast feeding Kay for as long as possible. It saves faffing with bottles, is always on tap and is great stuff by all accounts.

One advantage of not working is that I can afford to do that. I use a banana-shaped feeding cushion so that I don't need to hold her at all, or alternatively I feed her lying down - either on the bed or on the floor. That way when she nods off I can sneak away unnoticed and peg the washing out, make a phone call, type a quick email or whatever. If we're out and about I find it easiest to sit on the floor with my back against a wall and support her with my legs. Or in a restaurant I do the same but on chairs. It was tough at first to keep my shoulders relaxed while feeding. I tended to 'freeze' in one position and not dare to move in case I disturbed her. Sometimes, if she's crying very persistently, I still make the mistake of grabbing her any old how instead of arranging everything for maximum comfort first. I always regret it. Ouch!

Anyway, the babe awakes so I must away. I hope (some of) the above is useful.

## *2. Lisa*

Lisa got RSI early in her career. She struggled with it before realising the extent of the problem, but decided not to let it stop her having a child. She now has a two-year-old daughter and works part-time. While raising a child hasn't been easy, she has found solutions to many of the problems that arise.

I'd had RSI for about six years when my partner and I decided we wanted to have a child. At that time, in 2000, I was working full time and attending regular treatments to manage the pain. It was a difficult decision because we were both nervous about the kind of impact pregnancy and looking after a baby would have on my body.

I was 31 at the time and my biological urges had set in so I wasn't going to let RSI leave me with the regret of not having a child. I knew that looking after a child wouldn't be easy. I also knew I could work out ways to deal with problems that arose. It has proven to be an ongoing process and challenges arise all the time. But having a baby is great fun and she reminds me of what is important in life.

During the first trimester of my pregnancy I was worried about my body's ability to carry a child. I felt because I had one illness something else would go wrong. It took a couple of months to realise that my body could cope just as well as any one else's and after that I didn't worry so much. Being pregnant turned out to be a lovely feeling and I had such a positive attitude towards my body. I was producing another person!

The pregnancy was like a holiday from RSI. My pain levels were the lowest they had ever been, I guess it was because of all the hormones. The little pain I did have I could manage through heat, stretching and walking in the pool to keep mobile. I couldn't have the full range of treatments because of the pregnancy, but these three were enough to get me through.

Throughout the pregnancy there was a lot to think about and organisation was very important. My partner and I had to anticipate the problems that might arise and how we would cope so we gathered as much information as we could. We read everything we could find and spoke to other people with RSI who'd had children to learn how they coped. We also found community resources and services we could use, such as community nurses.

There were a lot of practical things we had to consider. Finding the easiest options, such as using disposable nappies and finding the highest cot, high chair and change table so I wouldn't have to lift so far were big considerations. The options weren't always cheap, though we found that we could invent solutions too. For example, we raised the height of the cot by tapping together Yellow Pages to put under each leg.

The labour and birth experience was challenging because there were only a few positions I could use without aggravating my neck or arms. The constant stress and tension didn't help either, but I got through it. The biggest shock though, as it is for all new parents, was the complete dependence and demands of a newborn baby. I had no idea how hard it was to look after a baby let alone with an injury. Broken sleep, coping with breast-feeding, settling the baby without rocking or patting her and being able to get to treatments were the biggest challenges.

Broken sleep was hard because it's like a form of torture. It affects your ability to think clearly, and with chronic pain your ability to rest and heal at the end of each day. My stress levels and the soreness of my arms increased dramatically and some days I would just be sobbing

because there was nothing I could do to ease it. Nor was there any way around it. I had to get up and feed her; no one else could do it. I found relaxation techniques helped when I was trying to get back to sleep and I took every opportunity to sleep while my daughter was sleeping. My partner and I attended the sleep clinic for advice on techniques to get her to sleep longer and wake less during the night. This helped with her sleep time, but getting her to sleep was particularly difficult for both of us. I couldn't rock her or pat her to sleep so I had to put her down and let her cry which made me very sad. Taking her for a walk in the stroller helped get her to sleep while she was small.

Breastfeeding wasn't easy either. I had difficulty holding her for long periods but I found a number of things to help me. A lactation consultant came to the house to show me the best way to position my daughter when I fed her so I was putting as little strain as possible on my body. This was really helpful because I was feeding eight times a day and had to be able to sustain this. I also learnt how much time was necessary to feed her and how I could reduce the amount of time I was spending. One of the best purchases I made was a special breastfeeding pillow that wrapped around my waist so I didn't have to use my arms at all. I took this everywhere, even to shopping centres.

Getting to appointments for myself and my daughter was a struggle in the beginning. I had a community nurse come to visit me at home for the first couple of months which helped. However, I had to take her to appointments for my RSI and this was hard. Just moving her around was difficult when I couldn't carry her for long periods. I did find a massage therapist who came to the house which was a huge relief. I also learnt to give self-treatments like baths and stretching when I got sore.

Some of the difficulties do take the edge off having a baby because you are always thinking about the strain. Seeing other mums settling their babies and carrying them around was hard at times too. But at the same time having a child is an amazing experience. She is two now and there is so much laughter around the house that I often don't have time to worry about being in pain. The reality is that there is a lot of happiness and also a layer of complexity.

Each stage has difficulties, though I think it gets better every 6 months. Now that she is two she doesn't need to be picked up as much as she did when she was 18 months old. I can encourage her to do a lot more for herself now which is good. I also think that she crawled and walked early because I encouraged her to do these things as quickly as possible!

Inventing and changing is constant. Even now I have to stand back and think about changes that can be made. For example, I recently asked myself – does she still need to use the high chair? I decided that she was ready to use the kid's table and chairs I had bought, which means that I don't have to lift her into the high chair any more. I look at each activity and ask myself 'is this the best way?' If I decide it's not, I find or invent another way.

My partner is very important to me, he has been so accommodating and supportive. There has always been the extra pressure and the physical load on him has been much greater. From the beginning there have been certain things I couldn't do, such as bathing our daughter or chopping vegetables. We have different roles and our daughter has learnt this too. She knows that mummy can't play certain games that daddy can, and she knows that mummy gives hugs on the floor and daddy doesn't. She copes well with this, I think children just adapt to what you teach them. Going back to part-time work was, at first, a challenge. Now I think it helps me. It's easier with my daughter in childcare so I can go to treatments without having to take her with me. It also helps to create a nice balance for me. I alternate days at work and home so that I can alternate the types of activities I am doing.

Since she was born I have also had to set rules for the overall management of my RSI. This means only going out once a day, carrying her as little as is absolutely necessary, and ensuring that things are within easy reach. Learning to say no to her has been important also, but very hard, especially now that she is learning to talk back!

I have had two flare-ups over the past year which have forced me to take four or five weeks off work. Both times it was because my daughter was sick and I had to break my own rules. At those times I had to hold her more than I knew I should because I had no choice – she was ill and needed comfort. There are also times that I have to put strain on my arms by just catching my daughter to stop her falling and that sort of thing. These are things you just have to do with a child.

I don't work full days because my threshold is almost reached through other activities. My managers and most of my colleagues are understanding. I try to be very clear and upfront with my managers about what I can and can't do. I also try to give them as much room to move as possible and do as much as I can. It's a two-way thing, I can't just demand they accommodate me because there is work to be done and other people to think about. There has to be communication both ways and as a result people tend to be supportive and respectful of my situation.

I believe something happens to everyone in their life. I was young when RSI happened to me and there have been some benefits. I am kinder to myself these days and take much better care of myself. I am far more assertive than I used to be and it's because I believe I'm worth it now. I consider these to be good things that have come from my RSI.

Life is much less predictable than I thought it was before RSI and I now focus on the journey rather than the destination. These days I think about how, or even if, I am going to get there and ask what the rush is anyway. For the moment I am just focussed on raising my daughter. I'm not negative about my work but it's not my priority. The only doubt I have is whether or not I will have any more children. My partner and I will have to decide that in the future when our daughter gets a little older.

My advice to anyone with RSI wanting to have a baby is that it's achievable, though it's not easy. However, while it's important to focus on getting the 'mechanics' of taking care of a child, the joy of being a mother - the joy of creating your child, nurturing your child, taking care of their emotional needs, laughing with your child and loving your child – is wonderful. During the times it does get hard, I found this quote has helped me:

‘When the heart weeps for what is lost, the spirit laughs for what is found.’  
- Sufi Aphorism

### 3. *Melissa*

It was a difficult decision to have a child because of my condition, but now I have my son I feel very blessed and thankful. Don't get me wrong, it's not easy, but his love, cuddles and smiles make it well worth it. If you are deciding whether to have a child because you suffer from occupational overuse, RSI, chronic pain or any other condition (or even a combination), I'd like to say it is possible, there are ways to manage and it is worth it. There are many things I do and have in place to help me care for my son. Sometimes it requires a lot of effort but it's necessary in order for me to manage.

During my pregnancy I tried to plan ahead as much as possible. It was difficult because this was my first pregnancy/child and I really didn't have much idea about what to expect or what would help me. It was important to me, and still is, to find solutions to any challenges that I could foresee or that come up. I anticipated that having a child would add to my pain levels. So, very early in my pregnancy I came up with ideas for equipment that would hopefully lessen the physical demand.

It was surprising that I only found limited information from agencies dealing with parents with disabilities and chronic conditions. The RSI association handout "Parenting with RSI" was detailed and about the best (not all of it worked or was right for me but it's about getting information and using what works for you). I managed to get little pieces of advice and information from other organisations as well e.g. Independent Living Centre, Technical Aid to the Disabled and the Arthritis Association. There was very little information anywhere on modified equipment. I did lots of internet research, which added to the information I obtained. I felt more comfortable knowing I had some information, even if it was only minimal.

I contacted Technical Aid to the Disabled, ACT (TADACT) when I was about three months pregnant to discuss a number of ideas for modified equipment e.g. attaching a motor to a pram, gates to a cot and a low bassinette stand. My husband and I did lots of research at baby stores. I tried to find shop assistants who really knew the products they were selling (very hard to come by!). I took a doll with me to try out products and make sure they worked for me.

I tried to think of as many factors as I could that would be involved in the use of the equipment that I bought, e.g. the type of clips on the safety harness of a pram/highchair/baby car seat. It was also really important to buy everything at the right height for me, e.g. the change table, highchair & adjustable handle on the pram – something that The Independent Living Centre really emphasised. Some of the products and practices that are very useful for me include:

#### **Pram**

I purchased a three wheel pram on the commercial market and TADACT attached a motor (this was a prototype so it took some time to make). Firstly, I purchased a sturdy pram made of aluminium (so that it wasn't too heavy) and TADACT added a motor, battery and drive mechanism (which includes safety features). I was very clear with TADACT about safety standards because any modifications to baby equipment need to be safe. The motor has a number of speed levels which means it can go uphill.

As well as having my son in the pram, I can fill the basket underneath and it still motors along well. The battery lasts about 2.5-3 hours and I can get out into the open air and get some much-needed exercise. I feel much less isolated and have much more freedom than I would if I didn't have it attached to my pram.

TADACT have been very helpful in attending to any 'teething' problems with it. My pram also has a few other features including the safety harness clip and recline mechanism that are fairly easy-to-use (because of safety issues, no safety harness clip that I found was REALLY easy to use). You have to find your own balance between safety & user friendliness.



**Three wheel pram with motor attached**

### **Low height Bassinette Carrier**

TADACT made a wooden bassinette stand to fit my bassinette and position it at the right height for our bed. This allowed me to move my son from our room to his without getting him out and carrying him. It minimised the number of times I needed to get him out during the night to settle him. It put less strain on me when getting him out to feed him.



**Foot-operated cot opener**

When he was smaller the bassinette and stands (I also had a taller stand upstairs) allowed me to move him around the house when I needed to. I loved using the bassinette and stands when he was young, as I could have him around me much more.

### **DECPAC Wheelchair Ramp**

I purchased a sturdy, non-slip DECPAC ramp. I put it over the steps at the rear of our house so I could easily get the pram in and out of the house. I tested a number of ramps (and considered a permanent ramp), but the DECPAC ramp was the best design for the three wheel pram with motor attached.



### **Sturdy Wooden Cot**

I purchased a cot with an adjustable height mattress base and drop-side. TADACT modified it by replacing one side with gates that open outwards and have foot-operated opening mechanisms attached at the base of the gates.



**Side opening cot**

They also raised the height of the whole cot so that I would not have to bend down so far to pick up my son. Also, I can kneel, settle and comfort him without having to bend into the cot or pick him up. I purchased a light but firm mattress to go in the cot and fitted sheets with a depth of at least 19-20 centimetres so that I don't have to use too much effort to stretch them over the mattress.

### **Clothing**

There are a lot of different types of clothing that I found/find helpful e.g. nightgowns for very young bubs (lots of nappy changes!), clothing with zippers (you can attach large ring pulls if necessary) and clothing with envelope style/very stretchy necklines. My Mum adapted lots of my sons clothing by replacing press studs and/or buttons with Velcro tabs/extensions. With some suits that haven't been modified (the ones with press studs at crotch & no pants attached), I close one press stud instead of all of them. I find that these suits are easier than having full suits with heaps of press studs. Bonds have recently brought out their range of 'Easy-suits', which have no buttons or studs. They are quite stretchy and fairly user-friendly. I use mostly Velcro and pullover bibs. I do have a few bibs with a press stud but I only purchased these 'Dry Bibs' because they keep moisture away and require much less changing, hence less hand work.

### **Highchair**

I purchased a very sturdy highchair, with adjustable height/seat recline and sturdy wheels with brakes. As well as using it for a highchair I regularly use it to wheel my son around the house (safely strapped in of course!). The lower I have the adjustable height the safer it is to wheel him around. It has a one-handed operation seat recline (advertised for ease of use for able-bodied beings!), but I find it much easier to use both hands to pull up on each side of the operating mechanism. It also has one-handed tray removal at the front, but in my efforts to find the easiest possible way to use my equipment, I found that I can use the mechanism on each side of the tray to just lift it off. The harness clip is also fairly easy to use.

### **Playpen**

I purchased a very sturdy playpen with a safety gate. There are only a few playpens on the market that have a safety gate. The others don't have gates at all and you have to lower the child in from the standing position or step over the side with child in arms! Not very friendly ... I added extensions to our playpen so that my son was able to roll and crawl around without

being too restricted. Even though I find the playpen a physical saviour, emotionally I find it difficult having to put him in there - hence the extensions for less restriction! The gate has a one-handed operation but I need to use both. On the odd occasion when I have been operating on much less sleep than normal (!) and not thinking properly, I have used one-hand but have suffered awful acute pain :( Having the playpen reduces the amount of lifting and handling that I would otherwise need to do with my son. I started using the playpen early so that my son got used to it and would be happy to stay in it. Now that he is crawling and pulling himself up on our furniture I ensure that he also has some supervised cruising time in the whole house.

### **Baby sling/carrier**

I purchased a Baby Bjorn 'Active Back' baby carrier which was very useful. Unfortunately, I only use it when absolutely necessary now because my son is too heavy for me to carry him in it. The 'Active Back' was very supportive and lessened the amount of strain on my upper body. I tried the 'Hug-a-Bub' baby sling and it was ok (especially when he was very small). However, I found the amount of material and the way I needed to lift and hold him whilst getting him in and out of the sling, painful and awkward.

### **Baby Car Seat**

My husband took some long service leave when our son was born, so we were lucky to be able to use a baby capsule for the first few months. They are supposed to be the safest car seat on the market for a newborn. It was too painful for me to use, so when my husband went back to work we purchased a 'Turn-a-Tot' baby car seat. In the rear-facing position the car seat turns out toward the door so I can just lift my son in and out without having to twist into the car in a very painful and awkward position. Unfortunately, it only turns toward the door in the rear-facing position. Once it becomes forward-facing I can no longer turn him toward the door to get him in and out.



**Turn-a-tot revolving car seat**

Hopefully soon he will be pulling himself up more so he can help me get him into and out of the car seat. The 'Turn-a-Tot' is invaluable and I don't know what I would do without it! I'm not looking forward to forward-facing...



## **Nappies**

This was a hard decision for me as I was determined not to use disposable nappies. I did lots of research and comparisons for ease of use and environmental impact, of all the types of nappies on the market. There are an overwhelming number of web sites about this topic and I really didn't know what the right decision was! After my son was born we started on disposable nappies, as they recommend them in the maternity ward. I tried a few all-in-one cloth nappies, but found that they were too much work to put together, rinse, wash, hang out, bring off and put away. I continue to use disposables because they're really easy to put on and take off. They fit well too - so rarely a messy cleanup - which also reduces a lot of work. We try and use biodegradable and/or environmentally friendly nappies as much as possible.

## **Nappy Change Pad**

I purchased a 'Willi Lilli' Amazing Buddy nappy change pad/portable highchair/elevated floor pad/trolley seat. Sounds all a bit too strange doesn't it?! It folds up to about the size of a slim-line laptop case and is very portable. At home we use it as a nappy change pad and have it secured to his change table. When he is secured to it he is unable to move and roll as much and changing his nappy is a MUCH less painful exercise than it used to be. I know there are some people out there who don't like restricting their babies but for me it is essential to minimise my pain levels.

## **Breast-feeding Pillow**

I purchased a 'Milk Bar' twin feeding pillow. It was made for women who have twins but I found it really helpful because I could secure it to myself. It is shaped like a half circle and has a strap & safety clip to secure it around the waist. It was much easier to handle and more stable than a pile of pillows and very comfortable for a baby to lie down on (I used to take it when I went out and just carried it around on the top of my pram). I was also able to carry him on it for a short time after I breast-fed e.g. down to bed/change table etc. As my son got bigger, I opened it up and took out some of the stuffing to make it more comfortable for us both. As he got bigger I found a boomerang pillow with another pillow underneath also useful for breastfeeding.



**Milk Bar feeding cushion**

## **Stroller**

When my son got bigger and was not sleeping so much, I purchased a very light, four wheel stroller. It only weighs about 5-6 kilos and is very easy to put up and down. Although light, it still has a carry basket, a sun-hood and reclines for sleeping. Unfortunately the safety clip is not very user-friendly. I still use the three wheel pram for walking but we leave the four-wheeler in the car for quick trips or using outside. Knowing now how easy the four-wheeler is to use, I should have bought it earlier for quick trips!

## **Electric Breast Pump**

I purchased a small electric breast pump because it was too painful for me to hand express or use a manual breast pump. I found it necessary to have milk stores, so that my husband could feed our son when I was too sore or too tired. It only does one breast at a time but there are ones on the market that pump both breasts at once. I haven't tried them but they may be quicker and easier then doing one breast at a time! You can also hire electric breast pumps.

Unfortunately, I found that the products that worked well for me were also expensive. Having to purchase products, that I would not have had to purchase if it weren't for my overuse condition, has been a costly exercise. After a long, drawn-out process (even with the assistance of my Advocate), my insurance company agreed to reimburse me for some of the monetary expenses associated with modifications and special equipment. This was helpful in covering some of the out-of-normal baby expenses.

## **Breast-feeding**

Breast feeding was very challenging but I got a lot of good advice and education from my Feldenkrais practitioner and the community physiotherapist about breast-feeding posture, positions and movement. I found lying down with him useful at times but not when my arms or shoulders were sore. I'd really encourage any mother with occupational overuse/RSI/chronic pain to consider breast-feeding if they can. There are health benefits and it's also great for bonding & comfort.

## **Bathing**

I purchased a baby bath that rested on and stood about 75cms above our bath. We only used it a few times because it was very uncomfortable. I find that sitting in the bath with my son is the easiest for me. I sit on a folded towel for support and use my legs to rest him on rather than holding him. I can't have a long bath with him but it is a wonderful experience! When he was small I had short showers with him occasionally. Now he's too heavy and moving around too much for that. (A little tip – showering gets babies used to having water on their face, which prepares them for learning to swim).

## **Carer**

In the past six months I have employed casual private carers to assist me with the physical aspects of caring for my son. I usually have someone come to our home between 10-20 hours per week. This has been very beneficial for me and when I can get someone regularly my pain levels are much lower. My carer helps with carrying, lifting, nappy and clothing changes, bathing, washing, cooking meals, getting him into the car, putting the prams up, down, and in and out of the car and lots of other tasks that I find painful and difficult. Although I have a carer, I still regularly participate in looking after/raising him (which is very important to me), just without a lot of the physical strain. As my husband is a registered carer for me through ACT Carers, they assisted us in the short-term by paying for a carer.

Again, after a long drawn out process (even with the assistance of my Advocate and Solicitor), my insurance company agreed to reimburse me for some carer expenses.

I would have got a more regular carer earlier but we could not afford the cost. Unfortunately, part of the difficulty in getting reimbursement approval was that my insurance company only recognises 'attendant care services' for the 'injured party' and not other persons requiring care by the 'injured party' e.g. their children!

I find it necessary and very useful to plan ahead when going out. I have contingencies in place for when things might go wrong e.g. when I go shopping or on an outing, I know where the parents with prams car parks are, where the lifts/escalators are, where the wheelchair access is (great for three wheelers), what I need to buy and where it is located and where the best parents rooms are. If I don't know I ring the centre management/restaurant etc to find out. Some shopping centres have lockers to store your shopping, which can be really useful. I don't use these much anymore because I now have a motorised pram.

I find that having a routine is very important for all of us. I make sure I stick to it as much as possible even when I'm going out. For example, I always take his food/bottles with me in a soft, small carry esky so that he gets fed on time and if we are running late his next meal is with me. It means less rushing which means less pain!

My Feldenkrais practitioner has been invaluable in teaching me improved options for movement and posture. This includes different ways of holding my son for breast-feeding, carrying, feeding, bending and lifting him, turning and twisting and pushing the pram.

I try to be more open about my condition to others now and the ways that I need help. Even though it is not part of my nature, I find it necessary to ask for help (especially now that I have someone else to care for). If I explain my situation and that I have a young child, most people are willing to assist me e.g. some of the mothers in my mothers group offer to help me with my son or we have meetings at my place more regularly, my local grocer assists me with carrying groceries to the car and/or I have my groceries delivered, my husband comes home from work when I am very sore and there is no one else to look after us.

Overall it's been a challenging 13 months, but I have found solutions to difficulties and problems, practice many pain management strategies/techniques, make sure I plan ahead as much as possible, find support wherever I can, focus on how truly blessed I feel to have my beautiful son, and rest as much as I can!

And finally ... I have a wonderful, loving, caring husband who is extremely supportive and understanding. It would be very difficult to function without his help. (During this story I have referred to most things as "I" because it is 'my story' but my husband is an integral part of my life and everything I do.)



## **21. HEALTH, PARENTING & CARE CONTACTS**

ACT Community Care has a range of pre and post-natal services available at Child Health Centres and regional health centres. More information is available as follows:

Postnatal, Parenting Information Referral Service (PPIRS): (02) 6205 2000 (9am-4.30pm)

Tresillian

After hours helpline: 1800 637 357

Maternal and Child Health Clinics

Appointment Line: (02) 6207 1043

Independent Living Centre, ACT

(02) 6205 1900

Technical Aid to the Disabled, ACT

(02) 6287 4290 <http://www.tadaustralia.org.au/>

This service will create and modify equipment especially tailored to your need

Australian Breastfeeding Association, ACT (02) 6162 2716

Helpline: 1800 686 268

## **22. RSI ASSOCIATION MEMBERSHIP BENEFITS**

Join the RSI Association for access to:

- Our quarterly Newsletters contain treatment information, product reviews, hints to make life easier and the latest news on medical research.
- Our telephone referral and information service is available to anyone seeking information on any issue related to RSI.
- Events include guest speakers, voice-operated computing courses, chronic condition management courses and social events.
- Information on topics such as:
  - Assistance to stay at work, including safer mousing, clickless software, and voice-operated computing
  - Understanding overuse injuries
  - Treatments
  - RSI and the law
  - Managing daily life with RSI, from cooking to gardening to sex – how to make life easier.
- Contact with other people who understand their condition and have also suffered RSI.
- A loan service of ergonomic devices, tools and gadgets to make life easier.

### 23. APPLICATION FOR MEMBERSHIP

Help us to provide continuing support, advice and information to those suffering from overuse disorders. Become a member of the RSI and Overuse Injury Association of the ACT.

Name: (Ms/Miss/Mrs/Mr)

Address:

Phone:

Would you like to receive your newsletter via email?    Yes                      No

Email:

I enclose: (please encircle)

Membership:

\$10 (low income)

\$20 (standard)

\$30 (high income)

#### SPECIAL OFFER

Buy an additional year's membership for only \$10!

Booklets available:

RSI Information Kit (over 100 pages, recently expanded and improved)	\$15
Moving on with RSI (stories of people successfully managing chronic RSI)	\$5
Pregnancy and Parenting with RSI	\$5

DONATION    \$\_\_\_\_\_

TOTAL        \$\_\_\_\_\_

Please make cheques payable to the RSI and Overuse Injury Association of the ACT.

PLEASE NOTE: Subscription is for an annual membership.

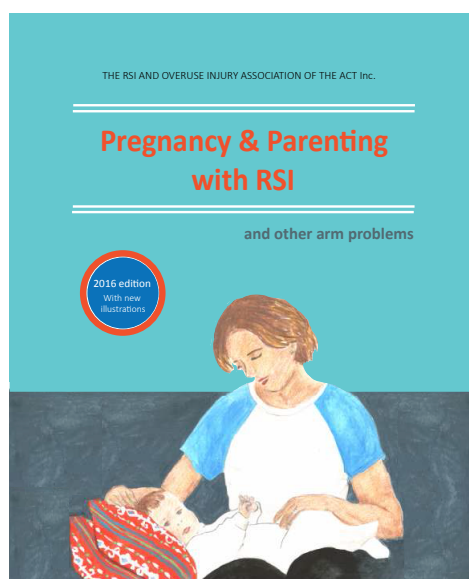


*"I knew that looking after a child wouldn't be easy. I also knew I could work out ways to deal with problems that arose. It has proven to be an ongoing process and challenges arise all the time. But having a baby is great fun and she reminds me of what is important in life."*

- Lisa, a mother with RSI

## Do you have RSI or some other kind of arm problems – and you want to have a baby?

"Pregnancy and Parenting with RSI" is full of useful tips and practical suggestions on how to manage looking after a baby when your arms don't work very well. We have used the experiences of women with overuse injury who have successfully managed to look after a baby to give you the help you need. There are tips on breast and bottle feeding, soothing and sleeping, bathing and carrying – and lots of ideas on useful products to help make every day tasks easier.



## RSI AND OVERUSE INJURY ASSOCIATION OF THE ACT Inc.

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