

# LIVING WITH SCI

## FACTSHEETS

**sia** spinal  
injuries  
association  
FOR LIFE AFTER SPINAL CORD INJURY



# MOTHERHOOD

## Motherhood

Mothering is an integral part of life for many women. Spinal cord injury may change the style but not the substance and we hope that this factsheet will provide an insight into the many facets of motherhood. The advice given has been taken from the experiences of SIA members who hope that you will be encouraged and enlightened into the pleasures, trials and tribulations of pregnancy, childhood and motherhood.

For all women contemplating motherhood it is a unique and very special time. No two pregnancies will be the same and there is no text-book scenario. To have feelings of anxiety, trepidation, mixed with excitement and elation as you embark on a growing future, are perfectly healthy and expected.

### Fertility

Spinal injury does not affect a woman's fertility. If you are trying to conceive do not be surprised if it happens sooner than you anticipate, as one contributor wrote ***“I was encouraged by doctors to try to become pregnant, and I did, the first time without contraception.”*** Many expressed surprise and shock at how quickly they conceived. Therefore, be careful if you do not want to become pregnant and take precautions.

If you have concerns regarding fertility, the official NHS advice is to see your doctor if you have not conceived within a year of trying.

## Pregnancy

You are pregnant and at the end of 40 weeks – if not sooner – the wait will be over and you will go through childbirth. However, to get there a momentous amount of changes will be happening to your body and the addition of a spinal cord injury may present some of the following:

Stephanie, T4

***“The main problems I encountered during my pregnancy were as follows: firstly, my legs and ankles became very swollen especially towards the end and I was ordered to get plenty of 'feet up' rest. Also, indigestion became a real nuisance, made worse because of sitting down. Transferring was made more difficult because of my increased bulk and weight. It was especially difficult to climb in and out of the car (although I managed to keep doing it right up til the end). I borrowed an outdoor electric wheelchair for the last couple of months for short trips to the shops. I found that I had much less spasm and was in fact very relaxed. This was a big advantage as my spasms are very strong.”***

Alison, T10

“My pregnancy was fairly uneventful – chronic sickness for the first three months, swollen legs and terrible indigestion, although thankfully normal blood pressure and nothing abnormal in my urine. I found the last three months of pregnancy very uncomfortable due to carting around the extra weight.

“Weight gain and its implications are common to most women; be very aware of pressure relief and in pregnancy it’s vital that you are vigilant at monitoring vulnerable areas and take appropriate action if necessary. Whilst the extra weight can make transfers harder many women continue to transfer right up to delivery, though taking extra care 'I placed a piece of satin between me and the sliding board and this really helped to make transfers easier'.

“Obviously, the weight of the baby lying over your bladder and bowel will create extra stress 'I was getting larger in front and felt I was being squashed; the bladder takes a lot, but I was always on the loo', and can cause further incontinence issues and a frequent need to empty the bladder. Constipation may occur; if so munch on a natural aid such as 'Bran Flakes'.

“If you normally use medication then discuss this with your doctor as you may be required to change your medication during pregnancy. If you intend to breastfeed then talk to your doctor or midwife, as some drugs can pass into breast milk.”

Vivienne, C5/6

“With no morning sickness I thought my pregnancy was relatively straight-forward. However, this changed in the 2<sup>nd</sup> trimester when I started to sweat profusely around the neck area. It was a constant source of irritation which thankfully stopped after three months. The main pest of my pregnancy was catheter by-passing; the more the baby grew the more frequent this became and a supra-pubic catheter would not last longer than two weeks before needing to be changed. Feeling light headed/faint in the mornings was a common occurrence. During my pregnancy I spoke to two other SCI mothers and found this very beneficial. They shared their experiences, advice and gave hints and tips. I cannot stress how useful and encouraging this was to me.”

Stephanie, T4

“I really enjoyed being pregnant. I can't deny that a small part of the pleasure came from demonstrating that, despite being disabled, I was just a normal woman having a baby. My husband John and I were often amused at the looks of shocked amazement we received on our 'shopping for baby' trips.

This statement enhances many of the views of our contributors and is the essence of pregnancy. Pregnancy is a great leveller; you are a woman having a baby.

## Childbirth

Childbirth is unpredictable and you may not know when labour has started or you may have signs too obvious to ignore. If you are at risk of autonomic dysreflexia this may occur during birth, or it may not - the following contributions give an insight into the possibilities.

Stephanie, T4

“During my first pregnancy the hospital were worried that spasms would interfere with my labour, so they insisted on early hospitalisation and induced me at term with an epidural almost straight away.

“For the second pregnancy the hospital was less concerned as all had gone well the first time. My labour started two weeks early. I didn't realise at first as I had no pains, I just happened to notice my tummy going hard at regular intervals. I was kept on an observation machine throughout labour - I slept on and off through much of it - and had a forceps delivery.”

Ruth, C6/7

“I stayed at Stoke Mandeville a month before I was due. I showed blood (a week early) and that night the doctor broke my water at 12am to help things along.

hospital have been specially trained and they recognised that I was in labour (plus I was put on a monitor). When the headache became continuous, they knew that my cervix was fully dilated and the baby ready to be born. He was delivered with the aid of Ventouse (a device with

suction **placed on the baby's** head which is pumped to create a vacuum to bring the baby down the birth canal). I had my son at 5pm. I had a similar brief headache when the after-birth came away. I came home after a couple of weeks.”

Alison, T10 (A mother of three)

“Thankfully the day before the baby was due, I went into spontaneous labour when my membranes ruptured. Being a T10 para I felt the last four hours of labour pains quite strongly and practised my breathing which I had learnt at classes. The actual birth was very quick and relatively painless, taking only a dozen or so pushes to have the baby. I needed no forceps, gas or air. I was the proud mother of a beautiful daughter in just over 12 hours from start to finish.

“I also must add that, although I had relatively trouble-free pregnancies, after each one I had a haemorrhage exactly three months after each birth. With pregnancies one and two, the placenta got stuck and had to be removed manually. This resulted in loss of a lot of blood and iron after the birth. So although the pregnancies were OK, I was pretty weak for a few months after and this **is something to watch out for.**”

Vivienne, C5/6

“It was only when I was being hoisted into bed for the night that a vigilant nurse suspected labour had started – the damp patch on my cushion! I had not realised that the light 'stomach cramps' and slight flushing I was experiencing were the signs labour had started – they felt so insignificant and plus my due date was not for another 3 weeks! Early labour was confirmed and after a blissful **night's sleep, a scan revealed that my 'head engaged'** baby was actually breech so the natural delivery I had planned became an emergency Caesarean. An epidural was given to prevent leg spasms and my blood pressure was monitored for signs of autonomic dysreflexia. However, I did not experience autonomic dysreflexia and my Caesarean delivery was straight-forward.

“If there are no pelvic complications for the mother then a spinal injury does not prohibit a natural delivery and in most cases this is planned. However, for some it may be necessary to have an emergency or planned Caesarean.

“The pain of contractions in labour can trigger autonomic dysreflexia and, if you are at risk, then the monitoring of blood pressure throughout labour and the preventative use of blood-pressure lowering drugs may be used if necessary.”

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## Post-Childbirth

The length of time you remain in hospital post-birth will depend on numerous factors. Some women stay only for a few days while others, particularly those who have had a Caesarean delivery, stay for up to two weeks. During this time, help and assistance will be given to establish breast-feeding, and your own physical well-being will be addressed.

Most women we spoke to had no problems with breast-feeding, although a C5/6 tetraplegic found that, due to limited sensation, she could not produce enough milk and had to give formula milk alongside breast milk. When the breast milk kicks in, usually after about three days, this may raise your body temperature, a factor doctors and hospitals should be aware of in case they suspect the raised temperature is due to something else.

If you have had a Caesarean delivery, or have needed stitches, then these must be cleaned regularly to ensure healthy healing. A lack of sensation means that the normal warning signs of 'soreness' or 'burning' are not so apparent and therefore wound sites and stitches must be monitored closely for signs of change and preventative measures must be taken to avoid the risk of infection.

Be aware of the effect a Caesarean delivery can have on your ability to transfer post-birth. Even if there is no sensation at the scar area, care needs to be taken not to pull or stretch the scar and surrounding area.

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## The Early Years

Looking after a baby is an enormous responsibility and a full-time role, there are many issues to consider and for a spinal cord injured woman, a major concern is that of help; both supportive and practical. How will you physically take care of your child and what items of equipment will suit your needs best?

Being a new mother is both tiring and daunting as you adjust to answering your baby's needs. You will need help and, like any new mother, you will need lots of it 'even if a woman has not needed help before, she should not feel there is anything wrong with needing it now'. It is apparent from comments given that support from husbands, partners, family and friends can never be underestimated 'you will need the help of others ready at hand in the years to come'.

If personal assistance is needed in daily living, then it is essential to have this organised and in place for help with parenting. Social Services and Direct Payment assessments have to take into account the support a mother needs to carry out her parenting responsibilities. The 'Disabled Parents Network' can advise on this matter and they have a series of information briefings that explain your rights to assessments, what the law says and Direct Payments (see Useful Organisations for contact details).

Ruth, C6/7

“First, I wondered if I would ever manage. At home, I had a carry cot on blocks so I could lean over and lift baby in and out myself - he was my son and I wanted to manage him myself as much as possible. He had easy pull-on **tops of stretch towelling and ‘envelope’ necks on most** things and stretch pants over his nappies and plastic pants. I managed most of his dressing and undressing, washing etc. John bathed him each evening - it was our real together event - and I helped where possible. In the night for feeding, John got up and gave him to me in bed. Same in the mornings before John went to work so I could get the extra hour in bed before the routine of the baby, house, meals and a little cleaning. I had a home help twice a week and the help of a family living next door.”

Vivienne, C5/6

“As I myself require 24/7 help, the relationship between PA is vitally important when you become a mother. I acted on instinct with childcare and had to direct my PA to look after my baby as I wished, under my direction, whilst also looking after me. At times it was very frustrating watching another person taking care of my baby. One given rule is that if your child is crying then they must be turned towards you and placed on you when being picked up so that they always associate your face with comfort and reassurance. You are the decision **maker and any requests for “I want”, “can I have” etc.**, must be decided by the mother and not a Personal Assistant. Baby will learn to recognise this and turn to **'mummy' first.**”

Barbara, T5/6

“Once the baby is born (or before the birth if mother is wise) the questions of alterations and aids to help with the day to day care arises. Usually the health visitor can put the mother-to-be in contact with the relevant person in Social Services, as well as herself having much detailed knowledge of what equipment is vital for the baby. Most of the problems experienced by the disabled mother are common, in some degree, to all mothers, as a visit to the local baby clinic and a chat to other mothers demonstrates. I would advise any prospective mother to build up a large circle of friends with babies, especially from ante-natal classes because these children will be of the same age as her own.”

Mary, T10

“I had no difficulty with breast-feeding and the pressure places had healed before I left hospital - the quickest healing I have ever experienced. I had a carry cot on wheels which I could push around the house and used a high table for bathing him when he was tiny. My arms are quite strong, so that I had no difficulty in picking him up as he was only a few feet off the ground or I could brace my forearms against something such as the playpen to keep my balance. When he got to the crawling stage, I always kept a harness on him, the sort you fasten reins to. With this *harness, I could pick him up.*”

Stephanie, T4

“I think it's important at the beginning that however nervous you feel when confronted with a tiny baby to care for, not to allow people to do too much for you. The baby must get used to the way you do things and the way you handle him/her, however unconventional that might be. My policy from the start was to encourage early independence. Make everything you can safe and put breakables out of reach rather than relying on trying to get there first. My husband took them in the bath with him from when they were quite tiny and I sat ready with the towels and nappies.”

## Childhood

Stephanie, T4

“The girls have gained a sense of security in knowing that I can't be far away and they always have a lap to sit on! There are always lots of cuddles and what they may be missing in country walks and trips to the shops, we make up for in exploring books and puzzles and I have plenty of time to sit and talk. Because it's not always possible to physically restrain a child, I've always tried to keep my 'No' for really important moments so that they know that I mean it. I made a special effort to get to know other mothers with small children. Other children were always very interested in my wheelchair but soon accepted me as just another mum.

I have a fantastic husband who, right from the start, has fully involved himself in every aspect of caring for our two daughters. Being non-disabled, he has also been able to fill in the gaps there may have been like teaching them to skip, play hopscotch and ride a bicycle. He makes it possible for us to enjoy camping holidays, trips to the seaside, country rambles etc. - in fact live like the normal active family that we are.”

Ruth C6/7

“I must say that it is hard work and there's more to it than just having a child - soon it will be school and all that goes with growing up. My son has given me a lot in life and made me feel a real person, enjoying life as a mother and being a family of three **who all care for each other.**”

Mary, T10

“As for childhood years, I think it was important that I always encouraged my son's friends to come and play with us. In this way, his friends soon accepted me as another mother and that helped when my son noticed I was a different sort of mother. We specialised in messy activities, painting on rainy days, and clutter in the **garden. The neighbours' children liked to come here** - their mothers were only too pleased to let them, and the children accepted me. Most of the mothers in return made a special effort to include my son on long walks and picnics which was an important bonus for both of us.

“During adolescence, things went quite normally, that is no more roughly or smoothly than for anyone else. I haven't said anything about the great pleasure and happiness which this child brought to our family because that would be impossible to measure. I would never have missed the experience, even if I had known beforehand about all the sleepless nights, mess and hard work involved. But then that is what any parent would say, isn't it?”

Alison, T10

“I realised early on that I would not and did not want to clear up after them all their lives so I let them take most of the responsibility for their rooms. They help with the washing up and hoovering and hanging out the clothes. They are all very intelligent and doing well at school.

I thought it would be a good idea to be involved as much as possible with school. I feel that this has helped to present our family as normal and this I felt was important. I also did not want my children to miss out on a 'normal' childhood, so I tried to involve them as much as possible with various activities. Apart from being involved in various play schemes, we traipsed to parks, seaside, farms, museums - you name it - we've been there. They've been to swimming lessons, ice-skating, art clubs, on field trips, Brownies, Beavers, Cubs and Guides. They would love to see me without a wheelchair but are not living in hope for the day when I will walk again. (I don't think they notice the wheelchair much anyway). I am always honest with them and answer any of their questions truthfully, no matter how embarrassing. I think this has been rewarding in that they tend to be mature in outlook and ***very good at problem solving.***”

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## Aids and Equipment

There is very little baby care equipment designed specifically for a parent with disabilities. Many commercial products may be suitable and a trawl round the stores to try out/test will be necessary. The key to aids and equipment is adaptability; can the item be altered/adapted to make it suitable 'a man who mended my wheelchair also made a step half way up one of my footplates to help the baby climb onto my lap when she got bigger so that I didn't have to keep bending to pick her up'.

Your OT may be able to advise on suitable equipment and the charity REMAP can design or adapt equipment free of charge. The experiences and ideas of other parents is a must and if you look at the Resources section at the end of this factsheet, there are websites and organisations listed that give suggestions and advice on adapting equipment.

Ruth, C6/7

“A pillow or breast feeding pillow on my lap was a must for carrying him around. When he was older, I got straps made to slip over the back handles of my wheelchair and across me and baby, and Velcro round the front of the wheelchair to help stop active baby falling off my lap. From carrycot he progressed to cot with drop sides, ideal to lean on for balance and I would lean in and put him over my shoulder and lift him out.”

Stephanie, T4

“I used a baby sling when they were very small and couldn't support their heads, then I graduated to an ordinary high chair harness which the baby wore all the time and the reins were adjusted to fit around the back of the wheelchair. At first I used a carrycot and transporter which I pushed around the house with me, and kept beside the bed for night feeds and then, as she grew, used an ordinary drop-side cot.”

Vivienne, C5/6

“The one essential piece of equipment for me was a long nursing pillow, we sewed straps to it and tied it around me which meant I could safely hold and feed my baby in this unaided. For my limited hand function I used very small/light baby bottles that I could hold for feeding. These were given to me at the maternity unit, so it's worth asking your midwife for availability.”

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## Experiences of Motherhood

We wanted to include personal accounts of motherhood that were printed in their entirety and in the mother's own, unedited words, and are grateful to the mothers for allowing us to include the following:

Emily, C5/6 Incomplete

“Deciding to have a baby is not an easy thing for anyone, let alone if you live your life on four wheels instead of two **feet. There’s so much to consider: Can I provide for my child? Will I be a good enough parent? How will it affect my relationship with my partner? Let alone all the practical challenges that will come with being a disabled parent. I was just twenty-two years old when I was involved in a car accident that left me as a C5/6 incomplete tetraplegic. At the time I had everything going for me; I’d just left university with a BA Hons and started a new dream job and had, just a month before, moved into a new house sharing with two lads I went to Uni with.**

“As I lay on bed rest with my head in traction, not knowing what the future held, I remember quite vividly one of the doctors coming to my bedside and saying **“don’t worry, you’ll still be able to have children.” I was so shocked, that was the last thing on my mind. Now here I am eleven years later and I’m the proud Mum of a seventeen month old little girl; Freya. I can’t remember my life before her, it pales into insignificance. I do remember however, that I didn’t know what busy meant until I became a Mum!**

“My pregnancy brought about many challenges and prior to conceiving I tried to do a lot of research into adapted furniture (e.g. cots, baths, etc.), and looked into what kind of help was available. I felt a bit in limbo being an **incomplete. I’m self caring and don’t need any assistance** when it comes to managing me or my home, but I only have limited use of one hand and this makes it difficult to **care for a baby. I felt I didn’t need a full-time carer** (I thought they would expect to be more involved in my **personal care), or a nanny (I didn’t want someone to come in and completely take over the care of my child).** I needed someone who could come in to my home the same hours my husband was out to work, someone who would assist me in caring for Freya and help me overcome the challenges I faced as a disabled Mum without taking over or pushing me out.

“Just as I was starting to feel overwhelmed by the decision, somebody mentioned Doulas to me. Doula is a **Greek word and it basically means mother’s help. I**

looked it up online and found Doula UK [www.doula.org.uk](http://www.doula.org.uk) a non-profit association for Doulas and found two lovely ladies that lived locally and could work the five day week between them. Although Freya is now at nursery, I still have a similar set-up and one of the Doulas has stayed with me since Freya was born and continues to work three mornings a week.

*“The hardest part of having help to look after my daughter (to me), is the feeling that you’re constantly being judged. It’s ridiculous really, but sadly inevitable when you’re a mother. You will never be a good enough parent in your own eyes and you will always feel that if anything is wrong, it’s your fault. The good thing is, every parent (disabled or not), who cares about their child feels exactly the same and the only person judging you is you. If you can accept this, you’ll be able to get on with just doing the best you can.*”

*“The past year has been an emotional rollercoaster and frustration about not being an independent Mum has been the hardest thing to get to grips with. When you mix that up with the hormones, emotional side effects and the eternal guilt complex that comes with motherhood, it makes for a heady mix. Luckily I have the most wonderful husband and network of family and friends, without whom I would not be the person I am. I’ve had enough of crying for the things I’ve lost; after all I have so much to be thankful for.*”

*“Prior to Freya’s arrival, I borrowed a life-sized baby doll (Stevie), from a contact through SIA. I was able to practise things like dressing, nappy changing, picking up and carrying the baby, etc. I wanted to be as independent as possible in caring for my child. As time has gone on I’ve realised that the practical tasks aren’t necessarily the important elements in raising my daughter. Being her emotional support and controlling the things she eats and the co-ordination of her care are far more important to me now. Plus, I could struggle on being fiercely independent, but we’d never get out of the house in the morning if I had to do it all myself!*”

*“Breastfeeding was extremely important to me as I felt it was the only thing I could do for my baby exclusively. It didn’t come easy and all the odds were stacked against us. Freya was premature, I’d had an emergency C-Section, my iron levels were low and she had a tongue-tie. But with perseverance, determination and a lot o*

good support, I became pretty good at it and managed to feed her for just over a year. My husband Tim was incredibly supportive and helped me with the night feeds. We had a cot where the side drops underneath and completely out of the way (Cosatto, Close To Me). I could have the cot right up next to my side of the bed and could reach out to Freya in the night without having to get up. Instead of a normal changing table I use an old desk with a change mat on top, so that I can wheel right underneath. And for bathing, we used a shallow storage box for the first six months or so. We used to put it on top of my wall mounted shower seat with a towelling seat in it for Freya. I could then play with her whilst Tim **bathed her. Now she's in the big bath** and it has become daddy/daughter time when Tim comes home from work.

**“Every day my daughter grows and so I adapt. She's mobile now and able to help me pick her up by standing at my chair and climbing up onto my lap. I used to often wonder if I'd miss out on certain things because of my disability. But when I talk with my non-disabled Mummy friends I discover my frustrations and worries are much the same as theirs. I'm sure each stage of my daughter's development will bring with it new challenges for us both. I could never have any regrets. Look at what I've got; a lovely, beautiful, young girl. This is only a short phase of her life, she won't remember it or be emotionally scarred by it. Once she's walking and talking properly, things won't be so challenging... I hope!”**

Clare, T4

“I was plagued by all the usual problems of pregnancy, although somewhat worse than most – sick every day for 20 weeks, then dreadful heartburn right up till the birth! I had to make a decision about what type of birth to go for. I did lots of research and concluded that a Caesarean section would be my first choice. However, I had to persuade my consultant that this was the right thing – his only previous experience with a paraplegic patient had been an induced labour and he wanted me to follow that route too. Fortunately, he was happy to go along with my wishes. I was monitored closely right through, with extra scans, because of my limited sensation. The staff of the Southern General maternity department were wonderful throughout – very reassuring, and keen to listen to my opinions throughout. They liaised with the Spinal Centre with regard to my care.

“We carried out the usual preparations for baby's arrival.

We had a cot specially made in order for my knees to fit ***underneath but everything else was “off-the-shelf”***. The OT department at the Spinal Centre were very helpful too.

“After a nerve- wracking morning, Patrick James was delivered with no complications at 2.10 pm weighing in at 7lbs 1 oz. We had great fun phoning round and breaking the news to everyone. I was in hospital for five days in total. I had my own room and the midwives and nursing staff could not have been more helpful. It was great to go home with Stephen and our lovely new son. He settled in and we wondered what we ever did with our time before Patrick arrived! Because Stephen was studying with the Open University he was able to be flexible with his hours of work and we worked as a team. We shared all the duties wherever possible and settled in to a routine where Stephen would be chief nappy-changer before bringing Patrick to me to be fed (I breast-fed for nine months).

“While Stephen was completing his MBA it was time to ***involve a few more people in Patrick’s care to enable*** Stephen to put in the time required. We employed a child minder to come to the house a few hours a week, and ***Patrick’s newly-retired gran*** was a great help – particularly when it came to nursery time. Some frustrations continued for me – ***I couldn’t manage to get Patrick in and out of the car by myself, so I didn’t have*** the freedom of being able to up sticks and take him out visiting, shopping, or even to the doctor without help. And I had to be sure there was somebody available to get him to and from nursery in the mornings. It was worth the effort though as he flourished at nursery – we had encouraging reports from the staff.

“As school time approached, I did feel some trepidation. I was worried about finger pointing, and the pupils maybe bullying Patrick because of me. I have to say, my fears were totally unfounded (this far anyway!). The school is ***wonderful and he is doing exceptionally well (not that I’m biased of course)***. ***Both his teachers have sung Patrick’s praises and we’re so proud of him. I’ve been going*** up to the school and helping from time to time, reading stories and doing little activities with the children – not only ***Patrick’s class. The children are a joy*** – keen to hear about the wheelchair, and to share their experiences of people they know with disabilities. And Patrick gets so ***excited when he knows I’m visiting the school. The cake*** decorating classes I did after I was discharged from hospital have also come in handy here – the kids tend to

*think of me as “the cake lady” rather than “the wheelchair lady”! We’re lucky in that there’s a bus provided for children in our village to take them to school in the next town, and bring them home. So the dreaded “school run” isn’t an issue.*

*“My independence with Patrick improved greatly when he became able to get into his car seat and fasten his own **seatbelt correctly. He is well behaved and I’m able to take him out to the cinema/shopping etc. without a problem. I’m lucky to have helpful family, as well as fabulous neighbours, so I know that if I’m ever stuck there will always be someone to help out.**”*

## Research

The following has been taken, with permission, from a Doctoral Dissertation, Oxford Doctoral Course in Clinical Psychology, University of Oxford. This dissertation is the result of research and interviews with eight spinally injured mothers on their experiences of childbirth.

The description of childbirth as a positive experience was evident throughout the interviews. Even when women had encountered difficulties and complications with their birth they were still keen to present their overall experience of pregnancy and childbirth as a positive one. As well as being a positive experience many women described childbirth as a very straightforward experience. A number of women reflected on how they would like to have more children and how their previous experience(s) would not put them off at all. Overall participants were keen to emphasise the positives of going through childbirth and having children. They were keen for other women not to be put off having children because of a spinal cord injury.

Many women reflected on the practical difficulties relating to a lack of adapted equipment available. Some participants also reflected on their initial anxieties and frustrations related to caring for a baby/child, as a parent with an SCI. Participants indicated that though such anxieties and frustrations do exist they were still able to recognise themselves as good parents and acknowledge what they were able to do. Participants highlighted that focusing on what you can do rather than worrying about what you can't was an important skill for a mother with an SCI.

A number of women had also approached other spinal cord injured women who had given birth to get first-hand information about the process. Women with first-hand experience of the event were seen as providing a valuable insight and women who had not spoken to mothers with a spinal cord injury reflected that they would have found this useful. Though the women had

obviously spent a great deal of effort in an attempt to prepare for their birth, they also recognised childbirth as an unpredictable event, and an event for which you could never feel truly prepared.

Though there have been a few small scale qualitative papers outlining the experience of child birth for women with disabilities (which have included women with SCI), to date, there does not appear to be any research looking at this experience for women with a SCI specifically. This study aims to begin to address this gap in the literature by focusing on exploring the experience of childbirth for this client group. It is hoped that the results of the study may help inform professionals working with women with SCI who are preparing for birth, the professionals supporting women through childbirth itself, and also women with a SCI who may be considering parenthood. The literature highlights that women whose expectations of childbirth are met generally have a higher satisfaction with childbirth and therefore, it is important that we are able to provide these mothers-to-be with as much accurate information as possible.

The dissertation paper is currently under editorial review and its findings are not yet available. When published and available this factsheet will be amended to include the relevant details on how to obtain a copy.

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## Resources

### [Bigger than the Sky – Disabled Women on Parenting](#)

Published by Women's Press, 1999 ISBN 0704345455

Available from any good book shop or online from [www.amazon.co.uk](http://www.amazon.co.uk)

### [National Childbirth Trust Publications](#)

T: 0845 8100 100 or buy on line at [www.nctshop.co.uk](http://www.nctshop.co.uk).

### [Ricability](#)

T: 020 7427 2460

W: [www.ricability.org.uk](http://www.ricability.org.uk)

Produce various booklets and reports for parents with disabilities; bottles, warmers & sterilisers, safety gates, baby carriers, pushchairs and highchairs.

### [The Disabled Woman's Guide To Pregnancy And Birth](#)

J Rogers, 2005 Demos Medical Publishing ISBN 1932603085

A thoroughly researched guide based on the experiences of ninety women with disabilities, covers all aspects of pregnancy and birth.

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## Useful Organisations

## Adoption UK

Linden House  
55 The Green  
South Bar Street  
Banbury OX16 9AB  
T: 01295 752240  
Helpline: 07904 793974 or 07539733079  
NI Tel: 028 9077 5211  
Wales Tel: 02920 230319  
W: [www.adoptionuk.org](http://www.adoptionuk.org)

Support, information, advice and encouragement to adopters.

## Disability, Pregnancy & Parenthood international

National Centre for Disabled Parents  
106 Muswell Hill Road  
London  
N10 3JR  
Website: [www.disabledparent.org.uk](http://www.disabledparent.org.uk)

Information service for disabled parents and professionals. Quarterly journal available by subscription. Extensive variety of publications and factsheets.

## Family Planning Association

23-28 Penn Street  
LONDON N1 5DL  
W: [www.fpa.org.uk](http://www.fpa.org.uk)

Advice and information on aspects of contraception, pregnancy and sexual health. See website for regional offices.

## Gingerbread

520 Highgate Studios  
53-79 Highgate Road  
London  
NW5 1TL  
Helpline: 0808 802 0925  
W: [www.gingerbread.org.uk](http://www.gingerbread.org.uk)

Charity for single parents - Useful contact point for information, including holidays and local groups.

## Fertility Network UK Ltd

Forum at Greenwich  
Trafalgar Road  
Greenwich

SE10 9EQ

T: 00424 732361

W: [www.fertilitynetworkuk.org](http://www.fertilitynetworkuk.org)

@: [info@fertilitynetworkuk.org](mailto:info@fertilitynetworkuk.org)

Advice, support, newsletter, fact sheet and Helpline.

**Parents with Disabilities On-line**

W: [www.disabledparents.net](http://www.disabledparents.net)

Provides information, support and resources to parents with disabilities. Informative adaptive aids and equipment section.

**The Fostering Network**

87 Blackfriars Road

London SE1 8HA

T: 020 7620 6400

@: [info@fostering.net](mailto:info@fostering.net)

W: [www.fostering.net](http://www.fostering.net)

Provides support for foster carers

**The National Childbirth Trust**

30 Euston Square

London

NW1 2FB

Enquiry Line: 0300 330 0770

W: [www.nct.org.uk](http://www.nct.org.uk)

Information, ante-natal classes, breastfeeding and post-natal support through 400+ branches nationwide. They sell the Bed Nest – Alongside cot.

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## Practical Aids and Equipment

**Cotswold Cots**

Grawins Rock Close

Carterton

Oxon OX18 3BP

T: 01993 842885

W: [www.cotswoldcots.co.uk](http://www.cotswoldcots.co.uk)

Cots and beds designed for individual requirements (including concertina opening cot – particularly for wheelchair users). Demonstration video available on request.

### DEMAND - Design & Manufacture for Disability

The Old Chapel  
Mallard Road  
Abbots Langley  
Herts WD5 0GQ  
T: 01923 681800  
@: [info@demand.org.uk](mailto:info@demand.org.uk)  
W: [www.demand.org.uk](http://www.demand.org.uk)

Charity designing and manufacturing special equipment and furniture for disabled parents and children, specialising in tailor-made solutions to individual problems.

### Disability Equipment Service

T: 07845 041678  
W: [www.disabilityequipmentservice.co.uk](http://www.disabilityequipmentservice.co.uk)

An Internet based service providing information on used second-hand disability equipment, updated daily.

### Disabled Living Foundation

Unit1, 34, Chatfield Road  
Wandsworth  
LONDON  
SW11 3SE  
T: 0300 999 0004 (10am-4pm Monday to Friday)  
@: [info@dlf.org.uk](mailto:info@dlf.org.uk)  
W: [www.dlf.org.uk](http://www.dlf.org.uk)

Provides up-to-date information on aids and equipment available for disabled mothers and children.

### Funpod

W: [www.littlehelper.co.uk](http://www.littlehelper.co.uk)

A height adjustable standing frame for the child, that allows them to safely play alongside you. Plus range of sleeping suits.

### Parents with Disabilities On-line

W: [www.disabledparents.net](http://www.disabledparents.net)

Comprehensive section on adaptive aids and equipment.

### REMAP

D9 Chaucer Business Park  
Kemsing  
Sevenoaks  
Kent TN15 6YU  
T: 01732 760209  
W: [www.remap.org.uk](http://www.remap.org.uk)

@: [data@remap.org.uk](mailto:data@remap.org.uk)

More than 100 branches around the country, REMAP makes or adapts aids for disabled people at no cost to the disabled person when not commercially available.

### **Women's Design Service**

Third Floor  
Tindlemanor  
52-54 Featherstone Street  
London EC1Y 8RT  
T: 020 7490 5210  
@: [info@wds.org.uk](mailto:info@wds.org.uk)  
W: [www.wds.org.uk](http://www.wds.org.uk)

Community safety and regeneration - specialised library, information centre, and consultancy service on issues related to women & the built environment - children, play facilities, shopping centres, housing design etc.

### **Disclaimer**

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Revised February 2019

## About SIA



The Spinal Injuries Association (SIA) is the leading national user-led charity for spinal cord injured (SCI) people. Being user led, we are well placed to understand the everyday needs of living with spinal cord injury and are here to meet those needs by providing key services to share information and experiences, and to campaign for change ensuring each person can lead a full and active life. We are here to support you from the moment your spinal cord injury happens, and for the rest of your life.

For more information contact us via the following:

Spinal Injuries Association  
SIA House  
2 Trueman Place  
Oldbrook  
Milton Keynes  
MK6 2HH

T: 01908 604 191 (Mon – Fri 9am – 5pm)

T: 0800 980 0501 (Freephone Advice Line, Mon – Fri, 11am – 1pm/2pm – 4.30pm)

W: [www.spinal.co.uk](http://www.spinal.co.uk)

E: [sia@spinal.co.uk](mailto:sia@spinal.co.uk)

Charity No: 1054097

Brought to you by:



# Please support SIA

SIA relies on fundraising, donations and gifts in wills to provide services that help spinal cord injured people rebuild their lives.

With your help, we can provide the right support to spinal cord injured people and their families and friends so they can enjoy a full and independent life after injury. Your donation today will go towards changing someone's life.

I would like to give: £15  £20  £50  other amount £.....

### Method of payment

I enclose a cheque/postal order/CAF voucher made payable to Spinal Injuries Association.

I would like to pay by Mastercard/Visa/Maestro/Switch (delete as appropriate)

Card number

Start date

Expiry Date

Security Code

Signature

Date ...../...../.....

Name.....

Address .....

.....

Postcode ..... Tel no.....

Email address.....

Please gift aid my donation

If you tick the box it means for every £1 you donate we can claim an extra 25p from the taxman, at no extra cost to you. You need to pay an amount of income tax or capital gains tax at least equal to the tax we reclaim from HM Revenue and Customs – currently 25p in every £1 you give.

Please send your donation to: FREEPOST SPINAL INJURIES ASSOCIATION or you can donate online at [www.spinal.co.uk](http://www.spinal.co.uk)

## Thank you for your support!