**Accord** is the official journal of Spinal Cord Injuries Australia, the major Australian provider of information to people with or interested in spinal cord and other severe physical disability.

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Amer Hessenthaler gave birth to her son, Aden, in the late evening of 24 June 2004 at Sydney South West Private Hospital in Liverpool. Amber who is 25 years old has had C2/3 incomplete quadriplegia (with the ability of a person with C4/5 quadriplegia) all of her life resulting from a lack of oxygen during her birth.

Although Amber’s pregnancy wasn’t planned, she knew from an early age that she wanted to have a child and had been for check-ups to establish that she should be able to fall pregnant at some stage.

Amber recalls dismissing some of the possible early signs of her pregnancy, “I’ve always had an irregular menstrual cycle and lots of urinary tract infections (UTIs) and so I didn’t think too much about missing a couple of my periods and other symptoms, which I put down to early signs of a UTI. My first real symptom was of feeling sick from the smell of coffee in the food court at the local shopping centre.” This symptom persisted throughout her pregnancy and included reactions to other food smells. “The worst was the smell of barbecued chicken, that’s something I inherited from my mum. She had the same reaction when she was pregnant with me.”

After a home pregnancy test gave a positive result, Amber followed up with a visit to her specialist who confirmed that she was definitely pregnant. Amber said, “I was totally ecstatic and excited about the news. This was something I hoped would eventually happen.”

She had no feelings of doubt about the challenges that lay ahead. She maintained her usual positive attitude and was encouraged wholeheartedly by her specialist and parents. “Everyone was so happy. I basically have a non-disabled life because of all the support I’ve had,” said Amber.

While Amber did attend antenatal classes at Sydney South West Private Hospital and the staff tried to help her, little of the information about exercises and positions for labour was relevant to her. Because Amber experiences normal sensation she was able to feel the many bladder spasms and discomfort resulting from the position of the baby. She had many UTIs, bladder infections and bouts of autonomic dysreflexia during the pregnancy. Amber said, “Aden was continuously upside down in my stomach and he liked to put his head against my bladder. That caused my catheter to be blocked and gave me lots of bladder spasms. In the last part of the pregnancy I had problems with him under my ribs. He was everywhere he wasn’t meant to be, just like he is now, but I found the most comfortable position for me was sitting in my wheelchair.”

Amber was admitted to Sydney South West Private Hospital in Liverpool numerous times, about every three weeks in the latter stages of the pregnancy. She expressed her great appreciation for the staff at the hospital, “They’re absolutely fantastic, they deserve so much credit. They were so supportive and couldn’t do enough to help me.”

As a healthy, bubbly little boy walked into the room during our interview, Amber reflected on her concern over the drug Ditropan, which she took reluctantly for her bladder spasms, and how it might affect him. Her concern was unfounded.

Amber thought the baby would be born very early because of how low she was carrying him. Five weeks before her due date she went into labour. “Even so, because I had regular bladder spasms, which also caused contractions in the uterus, I wasn’t aware that I was actually in labour until I went to my regular weekly check-up. My specialist did some tests and told me that my cervix was two centimetres dilated. He didn’t want me to be in labour too long because of the risk of autonomic dysreflexia and so we decided that I should go into hospital. I was admitted to Sydney South West Private Hospital that afternoon and had a caesarean that night. Aden was born at 11.56 pm.”

It wasn’t possible for Amber to have an epidural because of the daily injections she was having to prevent clots in her legs. Instead she had a spinal block to numb the lower part of her body. “Even though the
labour pains and the spinal block injections, which they had to try seven times, were very painful, it was all worth it. Having Aden has been a great achievement,” said Amber.

Immediately after his birth Aden was shown only fleetingly to his mum as he had severe respiratory distress syndrome, which meant his lungs were not absorbing oxygen, and he needed to be placed on a ventilator. Amber was told that even full-term babies sometimes have this condition. Aden was transferred to Liverpool Hospital next door where he spent his first week of life in intensive care, unable to be held or fed by Amber.

Meanwhile Amber had no complications following the birth and recovered well. She said, “After Aden was born I felt the best I’ve ever felt but it was hard seeing him so sick. While he was in intensive care I could only hold his hand.” In that first week Amber would regularly wheel over to see Aden and she was allowed to spend as much time as possible with him.

Aden was then brought back to Amber and, even though he was still on oxygen, she was finally able to hold and feed him. “I absolutely loved breastfeeding him, it was a great experience. I used a breastfeeding pillow, which you can buy at any baby shop, and that provided some extra support.”

Amber and Aden came home in mid-July 2004. Early on Amber received emotional support from a baby health nurse’s weekly visit. Because she is totally dependent on other people for picking up Aden, dressing and changing him, Amber tried without success to find carers that she was able to afford or a service which would assist him.

When Aden was two months old Amber had to stop breastfeeding because she was prescribed Celebrex for her pelvic pain. “The pain is because my pelvis hasn’t closed properly, it’s supposed to move back into place after the delivery. The pain is still a problem but I take Panadeine now instead.”

When asked to comment on her experience of motherhood so far, Amber said, “Even though it was very hard it’s worth every minute. I wouldn’t change what I’ve done because I have this beautiful boy here. He’s my everything. I still have some of the weight I gained during my pregnancy but I’m proud of how I look because I know I’ve achieved a miracle.”

In the early days of her pregnancy Amber searched the internet for relevant information but only found a few articles which weren’t very helpful. She contacted Through the Looking Glass (see below) to buy one of the publications on their website but didn’t find them helpful at all, and she never received the book. At the time Amber was unaware of the informal network known as Paraparents* and she feels that pregnancy and motherhood should be publicised a lot more for people with disabilities.

To this end a list of websites on reproductive health and pregnancy which you may find useful is included below. For resources available on loan from our library, including a video featuring some women’s experiences of pregnancy and delivery, contact Jane Robson tel: 02 9661 8855, 1800 819 775 (for consumers outside Sydney) or email: j.robson@spinalcordinjuries.com.au.

Amber is interested to hear from mothers with disabilities and women contemplating pregnancy. If you would like to communicate with her (email is best for Amber) please contact SCI Australia and we will pass your details on to her.

*Paraparents is dedicated to providing information during or after pregnancies for mothers and families living with a physical disability. It is coordinated by Luisa Silva, who is also employed by SCI Australia as a peer support officer. To contact Luisa tel: 0403 588 888, email: lsilva@yahoo.com or luisa@spinalcordinjuries.com.au.

RESOURCES

Videos

Reproductive Health for Women with SCI—Part I

Online

Parents with Disabilities Online
www.disabledparents.net

Through the Looking Glass
www.lookingglass.org

Pregnancy for Women with SCI
– Infosheet # 14
www.spinalcord.uab.edu/show.asp?durki=22442

Center for Research on Women with Disabilities (CROWD)
www.bcm.edu/crowd

Health Promotion for Women with Disabilities Project
www.nursing.villanova.edu/WomenWithDisabilities