

CILT's Parenting with a Disability Bulletin

Volume 6 Issue 1
February 2003

PDN Valentine's Party

By Kimberly McKennitt, PDN Coordinator

Despite the sub-zero temperature, a cozy group of celebrants made it out for our Valentine's Day party on February 8th.

Prime Timers, PDN members, and their children gathered in CILT's boardroom for an afternoon of getting to know each other over tasty snacks and cake. Between the heated battle of kids vs. adults over Pop-O-Matic Trouble and the less frantic proceedings at the Trivial Pursuit table, a fun day was had by everyone.

Congratulations to Gregory and his family for winning our Valentine's chocolate raffle. And thanks to everyone who came out and made this a successful event!

IT'S A BOY!

Congratulations to PDN member Michele Gardner and her partner Dale Thorne, proud parents of Seth Winston Gardner-Thorne who was born on January 23, 2003 at St. Michael's Hospital, weighing a healthy 7 lbs.

In preparation for Seth's birth, one of the items Michele knew she would need was a wheelchair accessible crib. The PDN referred her to The Tetra Society where she was matched with a volunteer who adapted a ready-made crib to her specific requirements. Hear more about Michele's experience and Tetra in the next issue of the PDN Bulletin.

UPCOMING EVENTS

The Price of Motherhood

The Association for Research on Mothering presents:
Ann Crittenden, speaking on "**The Price of Motherhood**"

Ann Crittenden is an independent author, a senior research associate of the Council on Contemporary Families, and a member of the board of the

International Center for Research on Women. Her research for *The Price of Motherhood: Why the Most Important Job in the World is Still the Least Valued* combines current research in feminist economics, sociology, family law, child development, and anthropology, with hundreds of interviews to describe how employment practices, law, and social policy ignore the work of caring for dependent family members -- to the enormous economic detriment of women.

When: Friday May 2, 2003

Time: 7:00-9:00 p.m.

Location: Harry Crowe Room, 109 Atkinson, York University, Toronto

This event is wheelchair accessible, free and open to the public.

For more information call (416) 736-2100 ext. 60366

Email: arm@yorku.ca

Internet: www.yorku.ca/crm

THE WEDDING CHAIR

COPYRIGHT 2003, Paralyzed Veterans of America, by Permission of PN/Paraplegia News.

Ah, February... the month of romance, with Valentine's Day marriage engagements galore. When the euphoria wears off a bit, prospective brides and their families will be planning weddings.

Arlene Diehl, of East Helena, Mont., submitted this wheelchair-using father's solution to escorting his daughter down the aisle.

Winter had concluded, and spring was upon us. The April 5 wedding date was not far away. Paige's wedding had been on the front burner for several months, and the female attention to planning every aspect of the big day had begun to wear thin on the wedding's male components. Nonetheless, the day was fast approaching, and the dreams were beginning to encroach upon reality. So, following the advice of several wedding-planner books, we made preparations for everything from etiquette to reception details. The women from our church transformed the old community center into a western-style banquet hall and strung white Christmas lights and positioned straw bales to create the ambiance of a Montana night under the stars. With the decorating completed, it was time to rehearse.

The wedding consultants had covered every practical to-do list and advised for every awkward family arrangement. Their ready-made counsel seemed all-inclusive, except for our dilemma: how to get Paige down the aisle. Our situation did not include a blended family or deceased parent. No dysfunctional relationships had clouded this aspect. Paige had a healthy love and virtuous respect for her father, David. There was no question of who was to escort her. The problem was a matter of "transportation."

How would David escort Paige, his first daughter, to meet the man with whom she had chosen to spend the rest of her days? Our transportation dilemma concerned David's wheelchair.

Six springs had come and gone since David's bout of transverse myelitis. We had learned to adapt to his paraplegia. Using creativity and ingenuity, we had resolved nearly any accessibility issue.

We discussed the options. With years of physical therapy, David had acquired the strength to ambulate with long leg braces. But since he had never recovered the nerves for sensory or motor function, his gait was difficult and dangerous without a strong escort assisting every step. Technically, he *could* walk her down the aisle.

Or perhaps David could hold Paige's arm, while I followed, pushing the chair from behind. Or how about both of us gripping the wheelchair and sandwiching David in Between while steering our way to the front of the church? None of these was the picture we were hoping to create.

Then Jill, our wedding organizer, made a suggestion. Why not take the escort while sitting on David's lap? No, this was not "normal," but neither was it abnormal, since Paige was quite comfortable climbing onto her father's lap for far less important occasions.

So, having eliminated all other possibilities, it was decided. At an ordained moment, Paige was to appear at the top of the stairs. When all was ready, she would seat herself on David's lap, receive her bouquet, and make ready for the escort. David, strong and muscled, would wheel the chair forward and carry his passenger to the front of the church, where the groom would then take Paige's hand and help her to her feet.

Rehearsing brought confirmation and emotion to all. And since this was what Paige and her dad wanted, it was natural for them. We knew the real moment would be a tearful one, even if David could walk.

All the effort put into the planning was not in vain. But all the painstaking anticipation did not predict that the plans of a girl and her father would upstage every detail with stunning display. Every eye would record the picture of the bride's radiance and her father's victory over adversity as the two redefined the traditional trip down the aisle.

Did we remain composed? Of course not! And even though I knew how the story would unfold, I still had to fight hard to protect my makeup from the tears bursting from within.

With a curious mix of joy and sorrow, my wish for "normalcy" was drowned by the immeasurable gladness for the two passengers on that wheelchair. A collective hush came from the guests as father and daughter forged ahead, unfazed by the outpouring of surprise and emotion erupting all around them.

The rolling escort concluded with a graceful assist to stand. Paige was ready to say her vows and to be joined to a new escort on her journey into life.

David Diehl is a T10 para as the result of transverse myelitis in 1991. Doctors diagnosed his multiple sclerosis in 1998. He and his wife Arlene reside on the family ranch near Helena, Montana.

A roller coaster ride: questions but no answers

By Meenu Sikand, PDN member – Ontario

This article originally appeared in Disability, Pregnancy & Parenthood International, Issue No. 40, October 2002. Reprinted with permission from the author.

I am a woman who is known for being spontaneous in life. To become a mother was a decision that I didn't make spontaneously. Ever since I was a young woman I wanted to be a mother. I have an extraordinary mother and I was determined to follow in her footsteps. Being aware of my physical limitations, due to a spinal cord injury (SCI) that resulted in paraplegia at T5-T7 level, I wanted to prepare myself financially, emotionally and physically before I had a child of my own. I wanted to be a responsible parent, not an accidental one.

Finally, I was 35 years old when I considered myself to be ready. My strong network of family, friends and other resources was ready to support me during and after pregnancy. So here I was ... **Pregnant**. My body experienced changes and I started to have many questions on my mind that my doctors were unable or unwilling to answer. While answering they used phrases such as 'For a normal woman the experience will be...' or, 'Under normal circumstances the delivery plan will be...' I started to feel very agitated and hated the word 'Normal.' I simply wanted to know about the care I would need or delivery plan my doctor would follow. I wanted answers specific to my situation not to some hypothetical scenario. I planned for 35 years to become a mother and here I was at the mercy of medical professionals who couldn't help me in planning for the next nine months. They had no answers for an expectant mother who happened to have a disability.

Many times I was asked to contact my rehab doctor to investigate my care even though I was not considering any rehabilitation at this time. My stress level continued to rise as I started to ask more specific questions and got inadequate answers. I didn't have access to proper equipment or services like other

expectant mothers during my regular check ups at the hospital. As I started to gain weight it became impossible for me to fit in my chair, to push my wheelchair, or to transfer to the examination table or even to drive to the hospital. No one had any recommendations for any alternatives. I was experiencing all day long morning sickness, frequent migraines, bladder infections and severe back pain and was very worried about taking antibiotics and other medication, as there wasn't any data available from the local health department about its risks. No one has done any research on the risks of medication for women with SCI. Once again, No Answers. My anxiety level started to build up.

Seeking support

I started to look into the local parenting with disability network to seek advice or peer support. I contacted the local Independent Living Centre to network with other mothers with spinal cord injury. To my surprise no one with SCI was a member of the group. By this time I was feeling extremely lonely and vulnerable. The information developed by the parenting network concentrated more on addressing the physical needs of parenting with a disability. These needs are very real and extremely important, however no one can deny the emotional needs. Even though I knew many women with whom I could talk about their experiences, they didn't have any special needs, so didn't experience the barriers that I was facing. I was waiting to connect with other women with SCI and for them to share their experiences with me. I was able to receive information about adaptive equipment and a program through which I could secure funding to hire a Nurturing Assistant, to assist me with the tasks that I wouldn't be able to perform for my baby due to my disability. It was great. However I still didn't know whether I would be able to feel the labour pain and reach hospital in time for the delivery. Would I be able to tell if something was wrong and my baby had stopped moving suddenly? Would I be able to carry my baby to full term? No one could answer, as I wasn't a 'normal case'. I continued to lose sleep because of the unknown.

I was so thrilled to be pregnant, but at the same time I was reaching the lowest point of my life. I was worried about losing the baby due to transfers or giving birth to a premature baby because I was sitting all day and the baby had no room to grow properly. During the last two months of my pregnancy, I was confined to my bed. There had been so many questions in my mind with no answers either from the medical professionals or my peers from the Parenting with Disability Network.

I started to doubt that I would be able to cope emotionally with the arrival of my baby. I was too ashamed to admit this to anyone because I thought I had planned well and was ready, able and willing to have this child.

I survived this emotional roller coaster and was blessed with a beautiful son, Manav, at the end of 36 weeks on May 22nd. My 12 days stay in the hospital was

not a joyful experience as I continued to feel discriminated against, due to my disability. Staff were unprepared to handle a new mother with mobility limitations after a Caesarean section. Their special treatment left me extremely angry and I wanted to go home as soon as possible. My family was asked to stay with me for ten days in the hospital, as there were no extra staff to meet my special needs. They asked my husband to assist me with transfers because staff didn't have enough experience. My mother had to help me with the baby, as I could not walk to the nursery. The worst thing of all was that they used a surgical tape that I was allergic to. This caused blisters on my lower body.

I arrived home, with a newborn baby, totally confined to bed due to the blisters caused by the tape and a messy home as we had been in the hospital for the past 12 days. I had planned in advance for the assistant who would help me with my son and my daily tasks, but that was insufficient due to the extra help I now required because of the allergic reaction. By this time, I had already been confined to my room for the past three months and was becoming an emotional wreck. I was not prepared for the fact that I wouldn't even be able to hold or comfort my newborn baby. I could barely breast-feed him. I needed a nursing assistant every day to look after the blisters for the next ten weeks.

The strain takes its toll

When I started to sit in the bed and move around in my wheelchair, I realized that I was a completely changed woman. I had difficulty in coordinating my time to do anything for Manav. Most days I stayed in my nightgown and hardly did anything for myself, except brushing my teeth. I was forgetful, emotionally wrecked and cried about everything. My family was afraid to upset me about anything. Most of the time, I was withdrawn from people around me. During those days, the only time I was happy was when I was singing to Manav. He loved my singing and it created a special bond between us because no one except me was able to calm him with a song.

I had all the symptoms of depression and no help to deal with it. The home care nurse did not recognize these symptoms and in Canada there aren't any home care psychiatrists who make home visits. Once recognized by my physician, taking an anti-depressant wasn't a safe option, because I was breast-feeding. Another four months passed by while I struggled to manage my depression without making it public. I started to feel better, slowly, once I started to drive again. I also started to visit a psychiatrist on a weekly basis. When the winter arrived, I once again noticed a drastic change in my mood and couldn't cope with my parenting tasks any longer. I was feeling extremely powerless because I couldn't manage my emotions and was feeling extremely useless, embarrassed and a total failure. It started to affect my relationship with my family, friends *and my son*.

Back in control

On January 13th it was Manav's first Lohri, which is an extremely important day in East Indian culture for a newborn boy. It was the day I suddenly realized that I couldn't even enjoy this most important day because of an illness, which could be managed if I chose. It was the day that I made the brave decision to stop breast-feeding and start my anti-depressant. The welfare of my son was tied to my emotional well-being. As a responsible parent, my duty was to take care of myself so that I could look after him adequately. Even if that meant that I needed to stay on the anti-depressant for the rest of my life. I was ready to do it for my son and for my family who had been so supportive of me during all this time. I started to see an improvement in the next three to four weeks.

By April 2002 I was the same woman again, who enjoyed life to the full. I also decided to be vocal about my experience and agreed to speak at the second international conference in Berkeley, California. My intentions were to share my experience with other would-be mothers and professionals as well as organizations which provide services to disabled people, hoping they would talk about the symptoms of post-partum depression and develop resources/strategies to help new mothers deal with it. Most people with disabilities are extremely vulnerable to isolation, which often leads to depression. Traditional medical services do not accommodate the special needs of women with disabilities. This raises the anxiety level of expectant mothers to a dangerous level and later increased responsibility could trigger post-partum depression easily. It is extremely important to recognize and treat this as a barrier that a woman with a disability could experience.

Since the conference, I have seen some reports published about the findings. Unfortunately, all the reports or articles that I have seen have chosen to ignore this very disabling and real illness that could compromise anyone's parenting ability.

On a personal note, I am off the medication now and am enjoying being a mother of a very happy and active boy. And as a responsible parent, for the rest of my life I will always be monitoring the symptoms of depression.

Tips for Expectant Moms with Disabilities

1. Connect with peers.

Every woman's pregnancy is unique but when doctors can't answer your questions it is important to talk with others who have "been there" and who can share their experiences with you. Whenever possible, try connecting with women with the same disability. Doing so can alleviate a lot of fear and anxiety and give you an idea of what to expect.

2. Try to find a doctor or midwife who has experience working with other women with your disability.

It is not always possible but ask around. It's worth the effort and can make the difference between enjoying your pregnancy and dreading it.

3. Attend prenatal classes.

Attending prenatal classes is a really important part of preparing for your labour and delivery. Consult with your doctor or midwife and find a prenatal class that is offered in an accessible environment.

4. Develop a birthing plan.

During your delivery, you may not be in a condition to make decisions so it is important to consider all scenarios and to decide how you want things to go, ahead of time. Brainstorm with family members, peers or even your local ILRC. Be sure to share your plan with your doctor or midwife and all the people who will be attending your labour. Make sure you consider your individual needs, your cultural needs and the needs of your family.

5. Visit the hospital before delivery.

It's important to visit the hospital ahead of time, so that you know what to expect and so that you can introduce yourself to the nursing staff, let them know about your disability and discuss your birthing plan (take an extra copy to leave with them) and any concerns or special accommodations you may need.

6. Arrange for help from friends and family whenever possible.

When people offer to help, take them up on it. And if no one comes forward, ask. Help with housecleaning, picking up groceries or having a meal prepared for you in those first weeks can make a huge difference and alleviate unnecessary stress.

7. You need to eat, drink and sleep too!

It is all too easy to forget about your own needs when your beautiful new bundle of joy arrives. But it is important to keep your strength up, replenish your fluids and get some rest. If possible, prepare and freeze some of your favourite meals, buy frozen foods and stock up your freezer ahead of time. Try to sleep or get rest when baby sleeps. And make sure you are getting enough food and liquids throughout the day.

8. Consider setting up some visits for the first 2-3 months after baby's arrival, especially if you know you won't be able to get out.

Peer support is just as important after baby's arrival and will help combat feelings of isolation and help you stay connected with your community. It is often assumed that calling will interrupt you or be intrusive at this special time so let people know that it's okay to call and follow up.

9. Don't feel you need to prove yourself to others or that you need to control and do everything.

Asking for help when you need it and sharing the responsibilities of a new baby with your partner and/or family members is important (for all involved) and in no way diminishes your value or capability as a mother.

10. Be aware of your feelings and seek help if you need it.

Most new parents expect the arrival of baby will be a wonderful and happy time in their lives. For many it is a very emotional time and no matter how prepared you are, it can often leave you feeling completely overwhelmed. If you find yourself overwhelmed and are experiencing feelings of sadness, fear, anxiety, dread and/or depression it is important to acknowledge and monitor these feelings. Don't hide or ignore them. Share them with your family. If they persist for more than two weeks consult your doctor immediately. Left untreated these feelings can escalate and leave you unable to function. Proper treatment and support should get you back on track and enable you to enjoy your baby and life again.

Postpartum Concerns

The following is an excerpt from The Parenting Book for Persons with a Disability: From planning your family to raising adolescents (1999), pg. 37.

Normal situations like postpartum anxiety can be blown out of proportion by an observer with a negative or uninformed attitude about living with a disability. One mother reported that while she did in fact need more physical support with her new baby, she felt that in order to get it she had to put up with clumsy and unwanted efforts at emotional support from her home care worker. (Ora Prilleltensky, 1998) Another was concerned that the visiting therapist she relied on as a "gatekeeper to needed services" would make unfair judgements about her potential as a parent. As a result, she put up with too-frequent visits, which she experienced as intrusions. (Ora Prilleltensky, 1998)

Postpartum Depression

"Postpartum depression is the name given to a wide range of emotional and physiological reactions to childbirth." It is important to realize that depression is a physical disorder, and is not self-induced. A woman cannot 'pull herself together' any more than she could if she had the flu, diabetes or heart disease." (Robert G. Logan, 1989)

If you have some of the following symptoms, and they have lasted for more than two weeks, you may have postpartum depression:

- Chronic exhaustion, which does not go away even if you do get a few nights of uninterrupted sleep
- Extreme irritability, frustration or anger
- Feelings of hopelessness
- Trouble sleeping, even when baby is sleeping
- Loss of appetite or extreme weight gain
- Difficulty concentrating or remembering things
- Excessive worries about your baby's health or your own, even after your doctor has checked both of you physically
- Crying for no reason
- No interest or pleasure in your baby
- Overwhelming feelings of guilt or worthlessness or that you are a "terrible mother"
- Hot sweats or heart palpitations
- Anxious or panicky feelings
- Not wanting to be with friends or family members you once previously enjoyed
- Scary thoughts about harming your baby. (Eileen Beltzner, 1995)

COMMUNITY

Postpartum Depression Resources Women's Health Centre, Maternal Support Program

St. Joseph's Health Centre
30 The Queensway
Marrow Wing, Ground Floor,
Toronto, Ontario M6R 1B5
Hours: 8:30 - 4:30, Mon - Fri
Contact: Grazyna Mancewicz
Tel: (416) 530-6850
Fax: (416) 530-6629
Website: www.stjoe.on.ca

Self-referral, confidential, wheelchair accessible, no fees. They offer individual counselling, regular telephone contact, group support every Tuesday, current information (packages available for women and their families), brochures in 6 languages, referrals to other professionals. Limited child care is available, free of charge - some restrictions do apply.

Partners for Health, Post Partum Depression Program

825 Coxwell Ave.
Toronto, Ontario M4C 3E7
Contact: Rita Zalitach
Tel: (416) 469-7608
Fax: (416) 469-6805

Self-referral, no fees. This is a small program, offering telephone counselling and support. Weekly meetings are held off-site, at a wheelchair accessible location. Child care is not available but mothers can bring their babies.

Women's Health Concerns Clinic St. Joseph's Healthcare

50 Charlton Ave. East
Fontebonne Building
Hamilton, Ontario L8N 4A6
Hours: 8:00 - 5:00, Mon -Fri
Contact: Debbie Casperson, In-take Worker
Tel: (905) 522-1155 ext. 3979
Fax: (905) 521-6098

Serves Hamilton. Self-referral, wheelchair accessible. Consultation, assessment and referral to appropriate services provided. Follow up is not typically part of the service.

Mothers Offering Mothers Support – MOMS

Parent Resource Centre
Postpartum Depression Support Groups (English & French)
300 Goulburn Private
Ottawa, Ontario K1N 1C9
Contact: Carolyne Dobson
Tel: (613) 565-2467 ext.410
Fax: (613) 565-1144
Hours: 9:00 - 3:30, Mon –Thurs

Serves Ottawa. Self-referral, wheelchair accessible.
No counseling services offered. 3 weekly support groups - west end, central & east end. Groups are facilitated by Carolyn Dobson and a staff member from the Parent Resource Centre. Information packages are available for \$5.00.
Lending library.

Guelph Community Post Partum Support Network

176 Wyndham St. N., Suite 1, Guelph, Ontario N1H 8N9
Contact: Shelly Johnson
Tel: (519) 821-5363 ext.320
Fax: (519) 821-6148
E-mail: sjohnson@gchc.on.ca
Serves Guelph and surrounding area. Self-referral. 2 weekly group meetings and a fathers' support group. One-to-one counselling and one-to-one volunteer support available by phone or home visits.

Postpartum Partnership

16 Normandy Crescent
Richmond Hill, Ontario L4C 8L9
Contact: Marcia Starkman, MSN, RN, CS
Tel: (905) 770-1447
Fax: (905) 770-5645
E-mail: marciastarkman_rn@rogers.com;
Website: www.marciastarkman.com

A registered nurse specializing in women's mental health issues provides home visits and telephone support on a fee-for-service basis. This service is not covered by OHIP, but could be eligible under the client's extended health benefits.

BOOKS

"Postpartum Depression and Anxiety: A Self-Help Guide for Mothers"

A practical guide for mothers, families, and those involved in postpartum mother care, this book is based on the experiences of thousands of women and describes what helped them get through this difficult time.

Price: \$12.00 plus shipping and handling. To order a copy contact **Pacific Post Partum Support Society**, #104-1416 Commercial Drive, Vancouver, BC V5L 3X9; Tel: (604) 255-7999; Fax: (604) 255-7588

WEBSITES

Pacific Post Partum Support Society (PPPSS)

www.postpartum.org

PPPSS is a non-profit society which provides support to women and families experiencing depression or anxiety related to the birth or adoption of a baby. Their website includes personal stories, information for new moms and dads and resources.

Postpartum Support International (PSI)

www.postpartum.net

A comprehensive site which includes postpartum information and resources, international support groups, chats, bulletin boards, e-mail groups and more.

Postpartum Depression Support for Fathers

www.infotrail.com/dad/html/fathers.html

A component of the Cleveland, Ohio Postpartum Support Group website, this section offers resources for fathers and stay-at-home dads.

The PARENTING WITH A DISABILITY BULLETIN is a publication of the *Centre for*

Independent Living in Toronto (CILT) Inc.

To become a member of *the Parenting with a Disability Network (PDN)* or to submit an article to the PARENTING BULLETIN, contact *CILT* at:

205 Richmond St. West, Suite 605, Toronto, Ontario, Canada, M5V 1V3

Tel: 416-599-2458

Fax: 416-599-3555

TTY: 416-599-5077

Toll-free in Canada: 1-800-354-9950

E-mail: pdn@cilt.ca

Website: www.cilt.ca

The PARENTING BULLETIN is also available on audiotape or in Braille.

Articles on products, agencies or services are for information only and are not meant as endorsements.

The opinions expressed in this newsletter are those of the contributors and may not reflect the views of *CILT*.

Funded by: United Way of Greater Toronto

ISSN 1481-918X