

Today's Parent Baby & Toddler, Spring/Summer 2009

### **A Child with Special Needs**

It can be overwhelming and heartbreaking to learn your newborn or toddler has a disability. But with time, and by taking these key steps, parents can move on to build a good life for their family.

By Lisa Bendall

Melanie Lepage expected a perfect baby, just like the ones all her friends were having. So after she gave birth, she and her husband were utterly side-swiped by the news that their son had Down syndrome. "I was very upset," remembers his mom, in Saskatoon. "I was angry. I was sad. I thought our lives would never be the same."

But three years later, she calls herself lucky as she gushes about her healthy, independent little boy. "Daniel is disgustingly adorable," she laughs. "He's a huge flirt. I see a lot of brightness in his future."

How do you get from grieving to gushing? For sure, it can be overwhelming and devastating to learn your newborn or toddler has a disability. But with time, and by taking a few key steps, you can surely move on to build a good life for your family.

### **Deal with the feelings**

"The initial diagnosis period is very stressful for parents, and they're very emotional," says Tammy van der Kamp, family and individual support worker at the Cerebral Palsy Association of British Columbia. She meets parents who are guilt-ridden, raging or in denial, before they get to acceptance. "Those are perfectly normal responses."

Doreen Wingrove-Burke agrees. As a family liaison nurse with Discharge Planning at Saskatoon's Royal University Hospital, she's seen it all. "It's important for parents to feel they've got permission to react in whatever way they need to."

And spouses shouldn't expect always to feel the same way at the same time. Dad may be driven to reconnect with the rest of the family, while Mom's burning to google their scary-sounding new vocabulary. That's all right because they can take up different roles: caregiver and fact-finder.

It's also helpful for parents to acknowledge that they aren't the only ones reeling. Siblings and relatives are coping in their own ways. For instance, grandparents may react by blaming the doctors — when what they're really trying to do is protect their adult kids. And siblings may clam up, afraid to burden their parents with their own needs.

Acceptance will be a lifelong process, adds Wingrove-Burke, especially as the child grows through different ages and stages. "It isn't an aha! moment. Don't rush yourself."

### **Get the lowdown**

"Knowledge is so powerful," says Cindy Smith of Edmonton. She learned while still pregnant that her son Nathan (now seven) had spina bifida. Terrified by the bleak picture being painted by medical specialists, she determined to read as much as she could about her unborn baby's condition. She also found comfort talking to a neurosurgeon who had experience treating kids with spina bifida.

“The more you know, the more you’re capable of dealing with things,” van der Kamp notes. Being informed means you’ll have a better idea of what to expect, what decisions to make, and how best to provide for your child.

To get the facts, parents can comb the Internet (look for reputable sites produced or recommended by hospitals, government, universities or established support organizations) and read books. Contact disability organizations, and attend the workshops and conferences they often host. Talk to specialists. “Ask questions,” says van der Kamp. “If you don’t understand something, keep asking until you get the answer.”

### **Meet the parents**

A huge source of support can come from meeting families who know just what you’re going through. When Smith’s son was six months old, she took him to a playgroup run by her local spina bifida association — and is immensely glad she did. “By far, the most helpful thing was connecting with other parents dealing with similar issues,” she says. Those moms and dads have given her leads on equipment and tips on daily care that she’s convinced she wouldn’t have known about otherwise.

When Kim Milton’s four-year-old son, Michael, was diagnosed with an autism spectrum disorder, she set up a support group of parents in her Riverview, NB, community. “We try to get together once a month to talk and to share frustrations. It’s helpful to know that we’re all dealing with similar situations,” she says.

If you can’t find parents in your community or through local disability groups, try hooking into an online forum or Listserv mailing list. Many folks find emotional support here, even if from the other side of the world. “The gift of the Internet is that when Mom’s up all night and going crazy, the Internet is there,” says Wingrove-Burke.

### **Learn how to advocate**

All kids need their parents to step up for them from time to time. Moms and dads of children with disabilities quickly learn that strong advocacy skills are essential to getting the right services and education for their kids. After all, no one knows more about your child’s needs than you.

“Parents need to know how to navigate the system,” says van der Kamp. Her organization equips parents with advocacy tips like seeking alternative solutions, keeping records, writing letters and being assertive.

Advocacy doesn’t mean coming out swinging. Parents can promote understanding of their kids’ disabilities simply by communicating openly about them. On Nathan Smith’s first day of kindergarten, his mom came along to introduce him to the class. “The kids had all these questions. I explained the differences, emphasized the similarities.

“Now,” she says, “those kids are such good friends to our son.”

### **Allow your kid to be a kid**

“Life can’t be about disability,” points out paediatrician Sarah Shea in Halifax. “Don’t lose track of the fact that kids need to have a childhood.”

That's not easy at first, when it seems like everyone in your child's young life is obsessed with his diagnosis. Lepage says that after Daniel was born, it took her several months to think of him as a baby, not a medical condition. "All I saw when I looked at him was Down syndrome."

Having trouble seeing your child as a baby first? Think about your pregnancy. Before she was born, was your infant feisty, kicking all the time? Did she settle to Dad's lullabies? You didn't know then that she had a disability, and nothing's changed. She's still the same sweet baby. And she has the same needs as every other baby: her parents' love and care.

As your little darling gets older, give him every opportunity to enjoy a regular childhood. "Parents get so focused on fixing the child, they're focused on all the therapies all the time, and don't leave enough time for the kid to play," says van der Kamp. "A kid needs time to be a kid."

And chances are high that you'll cherish that kid. "Nathan delights everybody," Smith says. "People refer to him as a little light bulb because he lights up the room. He is such a blessing in our lives, and such a joy."

Sidebars:

### **What if it's just a hunch?**

Kim Milton had a feeling that something was different about her third son, Michael. At 18 months, he wasn't talking, and he never brought toys over to show his mom. But his doctor said he was simply independent. Friends and family suggested Milton was overly concerned: "They made me feel as though I was looking for something that wasn't there."

Finally, after much research on her own, Milton found a private psychologist who assessed Michael and diagnosed him with an autism spectrum disorder called pervasive developmental disorder (PDD). Milton's been able to hook Michael up with speech therapy and daycare, and now, at age four, "he's doing great," she says.

"The parent radar is unbelievably good," notes paediatrician Sarah Shea. "If parents are thinking there's a concern about their child's development, they're usually correct."

### **What should parents keep in mind?**

- It helps to be knowledgeable about normal development. Spend time observing other kids about the same age as your child, or talk to other parents.
- To find out if your baby's missing milestones, refer to the Development section of the Rourke Baby Record. Visit [cfpc.ca](http://cfpc.ca) and search for "Rourke Baby Record."
- If a doctor won't address your concerns, don't let it drop. Ask for follow-up in a couple of months — or ask for a second opinion.

### **Resources**

- Speak Up! Tips for Becoming an Effective Advocate, [bccerebralpalsy.com](http://bccerebralpalsy.com)

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