UP ABOUT DOWN A LETTER TO NEW PARENTS

Hello-

My name is Lin, and a while ago I was sitting in my hospital room, much like you. Moments after our second son's birth we were gently informed that all was not as we expected. Our son was diagnosed as having Down Syndrome. Our world fell apart.

We went through all the expected normal reactions to the news. The fear, anger and the sense of loss. Where was the perfect baby we were expecting? I was so scared – scared of how I would cope, how this baby had changed my life, wondering what the future held for us. I was hurt and confused, and scared of the person Ryan might become. I wondered why this happened to our baby.

Ryan is older now, and sometimes I catch myself watching him play and wondering what all the fuss and commotion was about when he was born. He is so ordinary in such important ways! The day he smiled, many of our fears vanished.

It took a while to work through our feelings and apprehensions. We all have to sail this sea of emotional turmoil ourselves, in our own way, to arrive finally at accepting and coping. I can't say there was anything easy about it, except how easily Ryan accepted us!

When Ryan was about one month old, we became involved with an infant stimulation program. At that point, I feel the program did more for me than Ryan! Our therapist came to the house bringing reading material and information on child development, empathy, and buckets of moral support. She showed us ways of stimulating Ryan to encourage his activity. It was good to feel that we were actually doing something to help him. She was able to deal with our questions, and steer us in the right direction for other services.

Early on it was sometimes hard to remember Ryan was just a baby that needed lots of love and cuddles as much as exercise and other stimulation. My husband and I learned not to overload ourselves with information, or to think too far ahead. It is easier to simply take each day as it comes.

Brad and I worked hard to find time for ourselves. A good babysitter is worth their weight in gold! When tired and run-down, everything looks darker, and I can't stress enough how important it is to look after yourselves, too.

So I'm saying – take heart. It's probably the hardest right now. Besides this news, your bottom is probably sore, your hormone level may be doing strange things, you haven't had much sleep, likely, and your mind is spinning. Whether this is your first baby, or your fourth, you never really know how much of what you're feeling is the result of the news, or general uncertainties about being parents, again or for the first time!

Get all the information YOU need. Then take the time to put things into perspective. None of us will progress through this exactly the same. You may be miles ahead of me already.

I hope you are lucky enough to make new friend through contact with other parents and support people. That's an extra bonus. The parent association in Windsor, Up About Down, just like the group in my area, has brought many parents together. In addition, my husband and I have met some delightful folks who just happen to have a child with Down Syndrome too!

The Association has put this folder together to help see you through this time between finding your child is not exactly the baby you were expecting – and the business of getting on with life and coping. I wish there were some way I could speed up the process you have begun working through – but we all do it in our own time. I wish you luck, and think that you will find strengths and resources you may have had no idea you posses!

Take care of yourselves, and don't be afraid to ask for help. Good Luck!

With warm thoughts and best wishes for your future -