DESPAIR, DETERMINATION AND EXPECTATIONS SURPASSED

Viv Nightingale

Patient's experiences provide a unique perspective to our ongoing learning. Articles from patients who have a story (with or without commentary) would be welcomed for consideration.

WE WERE catapulted into the field of mental disability not by design, but by accident. Matthew, our first child, was born on 15 November 1977 with Down Syndrome after a healthy pregnancy. Neither my husband nor I anticipated that anything would be wrong, and we were quite unprepared for what lay ahead of us.

I wished that the world would end. I couldn't imagine ever laughing or feeling happy again. I felt ill every time I thought of Matthew's diagnosis or the future.

My husband adopted a more pragmatic approach to the situation, while I struggled with immensely ambivalent feelings of maternal love and needing to care for my child, yet wanting nothing to do with Down Syndrome. Denial of the diagnosis was very high until three months later when we received confirmation following analysis of Matthew's chromosomes. A comprehensive and empathic genetic counselling session enabled us to better understand what had caused the Down Syndrome and our risks in future pregnancies.

Even then, if we had to accept that Matthew had Down Syndrome, we would make sure that he would be the brightest and best child with Down Syndrome.

Desperately needing information and guidance, I wrote to the then Down's Babies Association in England. I received a great deal of literature, but still felt very isolated and alone. When Matthew was six months old I was invited to join a support group organised by the Southern African Inherited Disorders Association (SAIDA) where I met other mothers of babies with Down Syndrome. This proved to be immensely helpful. Here were people with whom I could share – joys, anxieties, and all those other feelings which were experienced by most other members in the group.

Bouts of depression were common in the early months, as were feelings of extreme anger and helplessness. As time went by I became more accepting of the fact that I had a disabled child. We visited Sunshine Centre and decided that this was the place for Matthew to spend his preschool years. Their progressive attitude and philosophy of parental involvement appealed to us, and we felt confident our son's special needs would be met.

During the four and a half years Matthew spent there, he received a very solid grounding in all areas of development. At the age of six he moved on to Casa do Sol and within a couple of weeks he was reading simple sentences and doing basic number work. We were ecstatic!

In the meantime, I became very involved in the field of mental disability and Down Syndrome in particular.

We are currently campaigning for the broader concept of 'inclusion' of people with a mental disability (the acknowledgement that they are part of society and have a right to be accepted as such) to be more widely embraced. It is our fervent hope that through public education and awareness programmes, positive attitudes and the willingness to 'give them a chance', the disabled will ultimately regain their dignity and take their rightful place in society.

Finally, I would like to highlight what having a child with a mental disability has meant to our family. Matthew has surpassed everything that, all those years ago, we were led to believe he would or, more to the point, would not, achieve. He leads a busy and fulfilling life. He enjoys playing the piano, although his great ambition is to become the drummer in a band! He has a girlfriend of long standing whom he loves dearly. He has brought us both immense pain, and immense joy – I am sure any parent will agree that we are never more vulnerable than through our children! We have found ourselves bursting with pride at Matthew's determination and his achievements, often against great odds, and disappointed when we feel that he has let himself down. He has a gregarious personality and is a very confident young man. He is also sensitive, helpful, witty, charming and delightful, but on the other hand he can be stubborn, wilful and cheeky, and at times downright impossible! His younger brother and sister and their friends have accepted him quite automatically. Matthew is responsible for his share of the chores of the household. He is held accountable for his misdemeanours and praised or rewarded when he does well.

Above all, he has taught us that everyone is an individual with strengths to be cherished and valued, and weaknesses to be recognised and accepted, and his disarming acceptance of everyone without reservation is a lesson from which we can all learn. We cannot imagine what our lives would have been like without him!

I leave with you an anonymous quote I read many years ago, which made a great impression:

Don't walk behind me, I might not lead.
Don't walk in front of me, I might not follow.
Just walk beside me, and be my friend.

(See SA Family Practice November 1996 for more information about SAIDA – Editor.)

COMMENT

DOWN SYNDROME OCCURS IN ABOUT ONE IN 700 INFANTS IN ALL population groups. About half the parents of these infants are in the older age group, ie 35 years or older. The condition is caused by an extra chromosome 21 which comes from the mother in about 80% of cases and from the father in 20% of cases. About 20% of affected children die in the first year from their heart defect or multiple infections. The IQ, usually between 30 and 70, is positively correlated with the parents' IQ.

The Nightingales are a young couple whose first child has Down Syndrome of the regular sporadic type and therefore their recurrence risk is 1%. This risk is much higher (up to 10%) if the Down Syndrome is of the translocation type and if one of the parents is a balanced carrier. Because of their risk the Nightingales requested amniocentesis and prenatal diagnosis, mostly for reassurance, in their two subsequent pregnancies, and fortunately the results were normal in both cases.

Most parents go through various emotional stages after the birth of a disabled child. These stages include shock, sadness, hopelessness, guilt, anger, denial and finally acceptance and appropriate behaviour directed at providing for the child's special needs. Many parents vacillate between stages and are ambivalent for months or even years, and most experience chronic sorrow. Their medical practitioners should be aware of these emotional issues surrounding the birth of a disabled child. Also, all parents should have the benefit of a visit to a genetic counselling clinic and should be put in contact with SAIDA and its groups. These activities can be very beneficial as indicated in the Nightingales' story and all parents should be informed about these services.

JGR Kromberg
Associate Professor
Department of Human Genetics
Wits and SAIMR

SAIDA (Gauteng)
PO Box 1038
Johannesburg
2000 Tel: (011) 484-3281 Fax: (011) 489-9209