

Life with a premature baby

Yesterday my son managed to get to his toy box all by himself.

It took him more than ten minutes to travel the less than two metres. He bunny-hopped, shuffled, fell on his nose a couple of times, spun around once or twice - and yes, he also succeeded in crawling a little.

When at last he grabbed the edge of the box with both hands, he was completely out of breath. But he glowed so with pleasure and pride that from sheer joy I burst into tears.

Because at almost 17 months old Wynand had at last had managed to move forward by himself.

It is a skill his American cousin had already mastered at 6 months old. And while Wynand is now starting to crawl, his friends of the same age are all marching about confidently.

You'll have to be very patient, the sisters warned us when he was discharged from hospital a year ago. Premature babies develop at a slower rate, but most catch up eventually.

And my mother-in-law: "Remember, you've already had *one* miracle..."

When Wynand was born more than fifteen weeks prematurely two Decembers ago, the hospital staff had little hope for him. He weighed only 540 grams, at the time the smallest baby ever to have been born in the hospital.

Months later one of the sisters confided that they had not even prepared a bed for him in the neonatal unit because they were told his delivery would be a "termination".

But tiny as he was, Wynand was born so full of life, so vigorously, that the doctors *had* to give him a chance. And he astonished all of us. Day after day, week after week, he battled ahead, fought relentlessly for his little branch on the tree of life.

"The angels are calling, but he's not listening," one of the sisters said. And his paediatrician: "It is nothing less than a miracle."

He was in hospital for almost five months, three of them attached to a ventilator to help him breathe. In this time we became used to the rollercoaster ride that is the health of all premature babies and we learned to cope with almost everything.

Except for the frightening convulsions Wynand suddenly developed at 7 weeks old, and the subsequent diagnosis of periventricular leukomalacia (PVL) – damage to a small part of his brain due to problems with the flow of blood and resulting oxygen shortages.

It is strange how one can handle almost any setback in your child's health, but when it comes to his brain, you are shattered. I would fret endlessly about where end when the oxygen shortage could have occurred. I knew the PVL could cause developmental problems, but was too scared to ask for more details. It was all too upsetting.

Two months later the rollercoaster went up again and the PVL suddenly became invisible on the brain sonar. "It is probably because so much new brain tissue has formed that it has completely dwarfed the already small PVL spot," the radiologist speculated.

Different parents react differently to their premature babies. Rolf, my husband, read everything he could lay his hands on. He knew exactly which threats Wynand faced, and today he still is overprotective and neurotic about his son's wellbeing.

I, on the other hand, didn't want to know a thing because all the possible dangers disturbed me too much. On the one hand it was good, because my lack of knowledge kept me optimistic and full of hope. On the other hand my ostrich tactics caught up with me after Wynand came home. Like all new moms I armed myself with a book on month-by-month development before I was brave enough to tackle the challenge of raising a child.

But from Day One Wynand's development did not at all correspond to the book.

I knew he could not be compared to full-term babies. A premature baby is measured by his "corrected" age, i.e. the age he would have been had he been born on his due date. If a baby has in addition been as seriously ill as Wynand, you have to allow even more time.

The situation was further complicated by the fact that Wynand's lungs had been damaged by the ventilator. He contracted serious bronchopulmonary dysplasia or BPD (damage to the lung tissue) and was till the age of 11 months continuously on oxygen support.

BPD is a condition which gradually improves as a baby's lungs grow and new, healthy tissue develops. But until that happens, he uses up so much energy just to breathe, that he has little strength left for growth and development.

After comparing Wynand's development to my book for three months, I began to lose confidence. Other babies smile at 6 weeks old, Wynand gave his first smile at 9 weeks corrected. When his friends from hospital were already looking about alertly, Wynand was still completely disinterested in his environment. Sometimes his paediatrician was satisfied with his condition, at other times he looked worried.

I eventually packed the book away and concentrated my energy on the stimulation of my baby. His paediatrician had early on insisted that he should go for physiotherapy. To that I added massage and brain gym (and later occupational and speech therapy), as well as all the other kinds of stimulation recommended for “normal” babies.

I learned that one should never judge a premature baby before he is at least two years old. And I tried not to compare him to his peers.

That was easier said than done. One of the highlights of a hospital’s neonatal unit is the warm friendships that develop with other parents of premature babies.

After hospital these friendships continue, but I grew cold with fear every time I saw how rapidly Wynand’s fellow patients were developing, how they did new things from week to week, almost from day to day.

Like most premature babies they had no damage at all. “But of course none of them were ever as small, as sick or in as much danger as Wynand,” I tried to cheer myself up.

And then there was the incredible joy and pride when he did in fact have a little development spurt: his first smile, the first time he tried to hit an object, his first clumsy attempts at picking up toys.

As the months went by, a very special personality emerged – a fiery and determined little fellow (how else in a baby who had to fight so many wars?), but also a warm-hearted, happy boy who stole hearts immediately with a flutter of long eyelashes, a mischievous smile and dancing eyes. With Wynand’s social development there was obviously nothing wrong.

When at 13 months he still could not sit, I began to suspect that there was more to his delayed development than simply prematurity, that my baby might suffer from neurological complications. But I was too scared to confront the paediatrician or the physiotherapist, terrified by what they might confirm.

Until about six weeks ago, when in the course of my job I encountered yet another mother who at first blamed her child’s delayed milestones on prematurity, just to learn afterwards that the child suffered from cerebral palsy.

The next day I asked the physiotherapist straight out whether my son had the same diagnosis. “There is a strong possibility,” she said, and although it was not a complete surprise, I was simultaneously devastated and furious that no one had told me before.

“But if you had been told earlier, you would not have been able to handle it,” a friend comforted me later that day.

She was right. I realised that for the first time I was ready to be honest and realistic about Wynand. I did not want to play the ostrich any longer. For the first time I wanted to know exactly which challenges my son might expect, and what I could do about it. I unpacked my book.

The next week I confronted the paediatrician, who cautiously diagnosed “mild spastic diplegia” – a form of cerebral palsy which is one of the most common complications of premature birth. It is also associated with PVL and means that the muscles of Wynand’s legs are spastic or stiff.

That, in addition to his weak lungs, were probably the cause of his developmental delays.

The prognosis is not quite clear, but it is unlikely that Wynand will one day be in a wheelchair. He may not be able to walk the Fish River Canyon, and at his matric dance his girlfriend will probably have black and blue toes. But he should be able to walk one day, even if it is with difficulty and the support of splints.

There is a possibility that his intellect may have been affected by the cerebral palsy, but at the moment his doctor is cautiously optimistic about this. And since Wynand’s diagnosis, his development has ironically exploded like a Chinese firecracker. For the first time I feel like the parent of a six month old baby who achieves something new almost every day.

He sits without support, tries to stand up against furniture, practises his milestones, gets a real kick out of his environment and responds to simple commands. Within eight weeks he has caught up almost four months of development, thanks to healthier lungs and more energy.

I now look forward to the future with my son. Disabled or not, he has become my perfect child. I am not saddened anymore to see the toddlers who were in hospital with him – I rejoice with their parents that they, all born ten to twelve weeks prematurely, survived with few or no problems.

And when Wynand goes for his paediatric check-up later this week, I know he will boldly *crawl* into the doctor’s room. This time without falling over.

BOX BOX BOX

Ready references

Many doctors tend to adapt a wait-and-see attitude before sending a premature baby for therapy. If you suspect that your child is developmentally at risk, take him immediately

for an evaluation by a neuro-developmental therapist (NDT). One can never start therapy too soon.

One therapist usually suffices for the first year, as long as it is an NDT specialist. Later you can extend your team to a physiotherapist, occupational therapist and speech therapist. Brain gym, massage and hyperbaric oxygen treatments are also effective complementary therapies.

You can also have your child evaluated by a paediatrician who specialises in neuro-development.

- SA Neuro-Developmental Therapists' Association (Sandta). Rene Walker on (011) 868-2614
- Institute for Occupational Therapists in Private Practice (Instopp). Head office on (012) 365 1317 or Wilma Smit (chairperson) on (011) 888 4402
- SA Association of Physiotherapists. (011) 485 1467
- There are also a few early intervention therapy centres in South Africa where several NDT specialists work together under one roof and treat special needs children under 3 years old. One of these is the Baby Therapy Centre in Lynnwood, Pretoria on (012) 348 2060.
- Best preemie support group on the internet: www.egroups.com/group/preemie-list
- Gauteng preemie parent support group: Joan van Zyl on 083 30 333 50

BOX BOX BOX

How to help your premature baby

The good news is that most premature babies turn into completely normal children.

- A multidisciplinary team is needed to look after a premature baby with complications or who is developmentally at risk: paediatrician, nurses, therapists and possibly a dietician and/or and eye or hearing specialist. In addition parents may also need psychological support to help them accept and cope with possible complications.
- You can also investigate complementary therapies such as brain gym, hyperbaric oxygen treatments and massage.
- Your premature baby has to be evaluated by a specialist regularly in its first three years of life.

- Take him for neuro-developmental therapy from as early an age as possible – especially if your child has been born at 30 weeks gestation or earlier. 3 to 6 months corrected is a good age to start therapy, and the first year of life is optimal.
- Do not label you baby before he is at least 2 years old – even older in the case of a baby who was very sick.
- Each baby is unique and develops at its own pace. It is difficult, but try to compare him only to himself, not to his peers.
- Remember to measure his development against his corrected age, and even younger.
- Stimulate him in all the usual ways, and keep him as healthy as possible.
- The quicker a baby with lung problems gains weight, the quicker his lungs will grow, which will help his development.
- Have the patience of Job!

(This article first appeared in Sarie magazine, 4 October 2000.)*