



“To be able to carry a child is a gift, giving birth in Sweden is a privilege, to be cared for according to NIDCAP is beyond everything.”

—Magdalena Persson Pettersen
and André Persson

“**Connection is essential.**”
— Jacques Sizun MD

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FAMILY VOICES

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Magdalena Persson Pettersen, André Persson and Stina Klemming

NIDCAP from a Parent’s Perspective

It was August 15th. Magdalena’s water breaks and we travel at a high speed to the hospital. Early in the pregnancy we had been told Magdalena could not sit, only lie down. We are keeping positive thoughts. The baby is healthy and is strong. Should we call before leaving for the hospital? Remember the Vitamin K injection. We can do this! In a chaos of thoughts, words, and exhortations between the contractions, we try to be brave and remind ourselves that “nothing has happened before it happens”.

After a troublesome pregnancy, we are finally here. The day when our boy decided to see the light of day. We arrive to the hospital. Like flies around a piece of sugar, the hospital staff flocks around us and do their utmost to stop the contractions and skillfully manage to give us a break of a few hours. An obstetrician rushes into

the room to announce that a research study on immediate skin to skin contact directly after birth is being conducted at the hospital and that we match the study group, as we are now expecting the preterm birth of our son. She gathers herself as if she understood very well that this was not really a good time for us to receive a lot of new information. But because she says so, we are attracted to next steps. We consider the pros and cons and decide to take our chance on the practice explained to us. The doctor responsible for the study is called to the hospital and a meticulous presentation about the study and its risks versus benefits is pointed out for us. There are no risks in our heads. Just a win. Now the problem remaining is that the chance to hold our boy right from the start is decided in the toss of a coin.

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There is nothing natural about being separated from your child.

The doctor's obvious joy cannot be missed when she informs us about the outcome of the draw. We will get to hold our son from the very first second. We will not leave him.

A large weight falls from our shoulders and from this moment on, we are convinced that everything will go well.

The midwife looks in on us in the middle of the night just to see how we are. There were no contractions, and everything was calm, and we agree on a quick check just to be sure. The eyes of the midwife are wide-open as she throws herself at lamp buttons and the alarm buttons and loudly and joyfully shouts "we are giving birth here!" In an instant, the room is filled with medical staff and machines. The birth comes in what we think can be called rocket speed. Benjamin arrives into the world after nine minutes and lays on his mother's chest. He is a small wonder and is checked and connected to devices. He gets help to breathe. The focus and seriousness in the eyes of healthcare professionals is unwavering. We observe them all in detail. Their facial expressions and behavior reassure us. Dazed and dizzy, we rest in their safe hands. We look at our beautiful baby boy and feel proud and calm.

After two hours we are transported to the neonatal ward. We are all good. Our son is with us and still on his mother's chest and is healthy and strong. He just needs a little help to get on track, grow and develop. Just as the doctor informed us about many weeks earlier when we were getting ourselves ready for childbirth in week 25.

Anyone can have children. But it takes something special to become a parent.

The IPISTOS (Immediate parent-infant skin-to-skin) study that we were included in emphasized that skin-to-skin care should be carried out for at least six hours to provide positive effects. We were both convinced that our little boy needed us 24/7 and divided the day into eight-hour shifts to be able to give the best care for him. We took turns having our little one on our chest, skin to skin. The days went by, and seven days passed before Benjamin was put in his bed.

With a firm and secure hand from the healthcare team we were surrounded by, we were guided through newborn care and parenthood. We learned how important it is to speak in a lowered voice; how to provide positive touch and not to "stroke" Benjamin on his skin; how to protect him against bright light; how to support him with soft hands, arms and our bodies; how to provide safety and calm; how to feed and comfort him; how to wash him, care for him, and when that time came, how to arrange his bed for best support. When placing Benjamin in his own bed for the first time at seven days of age, we got to learn about the importance of providing a blanket with our scent for Benjamin to feel our presence. All this was given to us allowing time for us to adjust and become



Immediate skin-to-skin with Magdalena after Benjamin's birth

comfortable caring for Benjamin. We got the best for our son and with that we were shaped into secure and calm parents who could focus on providing love and care to our son.

It was unclear whether Benjamin could be breastfed due to a previous operation. But after a few days with Benjamin on our chest, we were asked to try breastfeeding. It was a fantastic feeling when Benjamin was put to Magdalena's breast and with the help of a small "taste portion" (breast milk in a syringe) and with enormous willpower, Benjamin took the breast for the first time. He who was so small. How could he know? How could he cope? By alternating tube feeding and breastfeeding, he got his meals.

Can you stay in the hospital forever?

The days and nights passed, and we were moved into a family room. The breathing alarm went awry the first night and we were scared for the first time. When we lived in the intensive care unit, the staff kept an eye on the screens, and we kept an eye on Benjamin. Now it was just us. Were we supposed to keep an eye on him while sleeping? We do not know if it was

"If there is a time in life when you have to try your luck, it must be when having a chance for "special treatment " to get the best opportunity to protect your child."

*—Magdalena,
Benjamin's mother*

exhaustion or a feeling of safety that made it possible for us to sleep, but the night passed, and we heard neither beeping nor howling except those from our own alarm clock that rang at Benjamin's feeding time.

At rounds the next day it was announced that we would have the opportunity to go home any day. Benjamin was strong and healthy. But how could we leave the NICU? It was evident that the doctor was used to parents' concerns, and she reassured us and conveyed security. She reminded us of everything we had learned and that we were well prepared for taking Benjamin home. We also got relevant CPR and first aid training and before discharge and had a mandatory conversation with a counselor.

On August 31, after thorough checks, Benjamin was transferred to neonatal home care. We carefully positioned him in the car seat, carried him out of the NICU and lifted him into the car. The same car that almost one year earlier, we had to leave empty-handed after a previous pregnancy. Memories hit us and fear was a fact. We took a few deep breaths, looked at our son and brought out all the strength we had built up over the last few weeks and off we went! The feelings we experienced at that moment cannot be described in words. We were full of fear and were crying and laughing at the same time. Benjamin was here with us, and he was fine. He curled up in his car seat with his pacifier blanket next to him. He was newly fed, calm, and relaxed, was breathing well and had a nice complexion - everything that is important. Let's go home! Home to us - the three of us!

In the home care unit, we had a primary care nurse and she visited us twice a week to check Benjamin's weight and food intake. She patiently answered millions of questions from us. Benjamin grew as expected and made giant steps in his development. After only a few days in home care, Benjamin chose to eat full meals with a bottle and even cuddled at the breast afterwards. On September 11, Benjamin's feeding tube came out with a sneeze. He was probably as fed up with the tube as we were. We agreed that food should be enjoyed through the mouth and the tube was history.

When we were discharged from the hospital and the NICU - what an indescribable feeling! At last, we were just like an ordinary family dealing with vomit, diapers, and visits to the health center. One thing that we continued to do, however was to enjoy our little boy skin to skin as soon as opportunities arose.

Gratitude and sadness.

We are so grateful for getting the opportunity to be with our son from the very start... to be able to be close to him all the time, never to be separated, and to hold him skin-to-skin. We also look back at all the help we got to become the best parents for our boy. Only the stars know what life would be like if we did not end up right there and then in this country, at this hospital, and in the skin-to-skin study!

Now, two years after Benjamin's birth, we understand that we had a journey in newborn care that is not offered to

everyone. This makes us so sad. Never had we thought about what newborn care could look like and does look like for many premature babies. We have been asked if we were afraid or worried about having a prematurely born child. Our only fear now, when we know that other possibilities exist, is that someone, somewhere will have to be cared for according to "routine" care in an extremely old-fashioned way and will have to be separated from their little one.

Being able to care for your child skin to skin, when there is a medical possibility, feels like such an obvious thing. To be able to care for your child skin to skin after a turbulent time where the odds have swayed is indescribable. A small child needs his parents, a tiny child needs them even more.

And if a parent's love and closeness is not paramount in a child's wellbeing, then what is?

Thank you everyone at The Astrid Lindgren's Children's Hospital and everyone fighting for newborn and small babies and their parents to be able to be together always!

Erratum: authors amended

"Give the children love and even more love and the common sense will come by itself."

—Astrid Lindgren



Benjamin was 2 years, 2 months corrected age in December! He lives with his proud parents, Magdalena and André in Stockholm, Sweden