Preterm birth, long-term outcome: how an early start affects school-aged children

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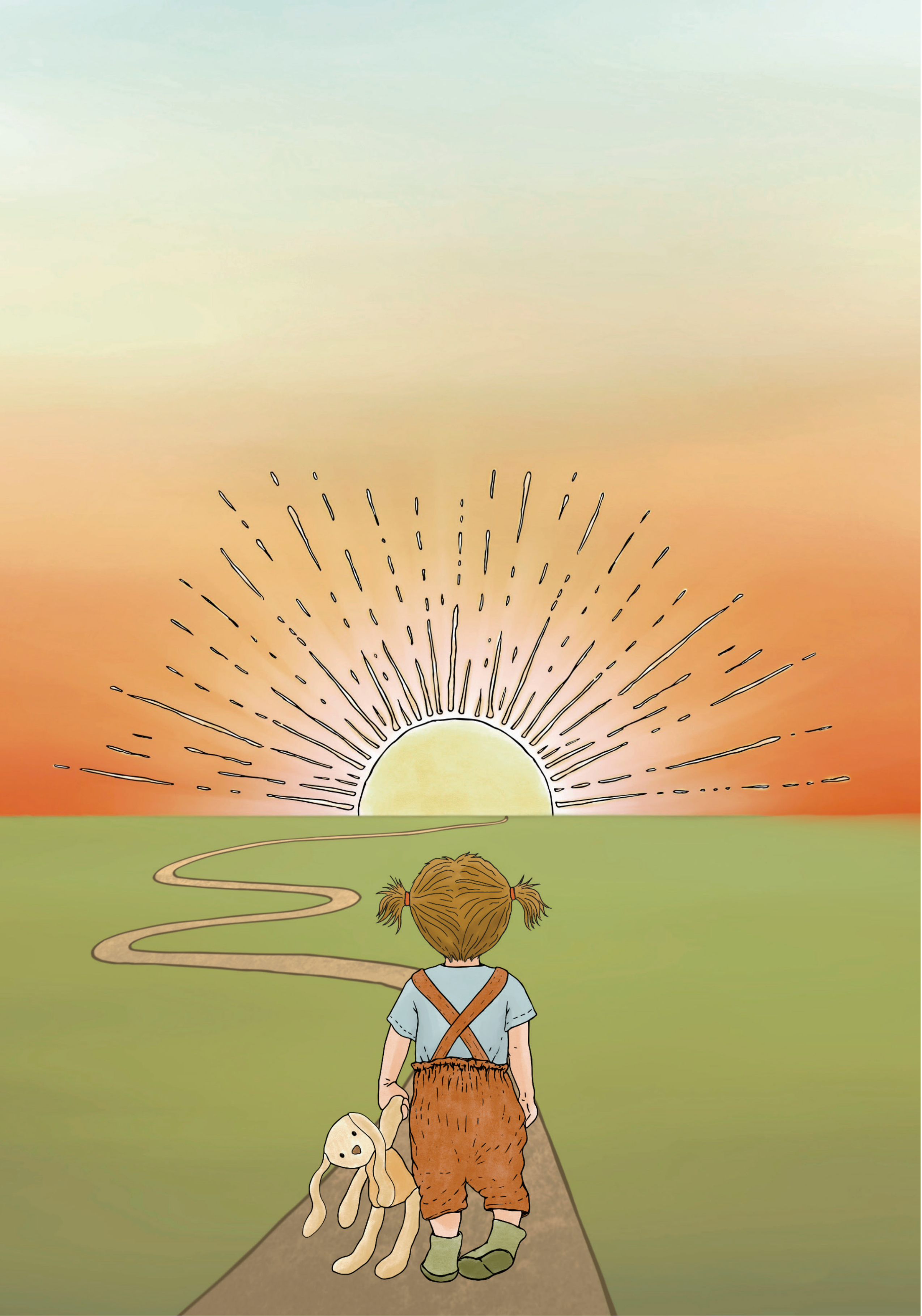

PART ONE

PATIENT JOURNEY

At first glance, Kevin (age 14) and Nizar (age 15) are two adolescent boys like any of their peers. They both attend secondary education and playing sports is an important part of their life. However, they were also both born extremely preterm, at 25 weeks' gestation, and therefore had a difficult start of their lives.

In 2007, Kevin's parents (Arjan and Annemieke), were expecting their first child. Even though the prenatal ultrasound scans and appointments were all normal, the delivery started suddenly, at 25 weeks and three days. Kevin's mother was rushed to the Leiden University Medical Center (LUMC) by ambulance. She received tocolytic medication in an attempt to stop premature contractures and corticosteroids to enhance fetal lung maturation. Parents were told that, if their baby was born before 26 weeks' gestation, he would have to show signs of viability after birth, or life-prolonging treatment would be discontinued. Unfortunately, the medication had no effect and Kevin was born after a pregnancy of 25 weeks and 4 days, weighing 950 grams. Even though Annemieke has little active memories of the delivery, she strongly believed that Kevin would survive. She remembers a staff member mentioning that their baby would have had better chances of survival if the gender would be female, a very painful comment given the circumstances. After birth, Kevin was taken to the Neonatal Intensive Care Unit (NICU) where his parents met their son several hours later. They had to wait three more days before they could hold him in their arms for the first time (figure 1).

Nizar's mother (Ilham) already had a frightening experience during her first pregnancy of Nizar's brother. She developed preeclampsia and was admitted to the intensive care after his birth at 34 weeks' gestation. It took Nizar's parents eight years to feel confident enough to get pregnant again. Due to her medical history, Nizar's mother was closely monitored at a local hospital. After five months of pregnancy, her blood pressure started to rise. She was admitted and treated with antihypertensive drugs, but despite the medication, her blood pressure reached alarming levels. After transfer to the LUMC, a cardiotocography showed that their baby was in serious distress. An emergency caesarean section was performed and Nizar was born at a gestational age of 25 weeks and 4 days, weighing 670 grams. He was intubated immediately after birth and admitted to the NICU. It took Nizar's parents a few days to realize what had happened. Due to the acute situation, parents were not counselled before birth. After birth, they felt overwhelmed when they heard about the possible risks and consequences of Nizar's extremely preterm birth.

Time in the hospital

Due to immaturity of their lungs, both Kevin and Nizar remained in need of mechanical ventilation during the first weeks after birth. Their parents were faced with the choice of treatment with Dexamethasone, a medicine that would likely benefit the development of the pulmonary system and help them to get of the ventilator. However, treatment could also have severe side effects including motor and mental retardation. Nizar's parents decided quickly that this was the only option, but, feeling overwhelmed with emotions, remember that they did not speak to each other for the rest of the day. Kevin's parents considered it a very difficult and emotional decision, but at the end also felt that there was no other option (figure 2). Besides concerns about pulmonary problems, preterm babies are also at risk for neurologic complications and both boys received weekly cranial ultrasound scans. Kevin's parents remember that the doctors talked about white flaring in his brain. This could have serious consequences for Kevin's development, especially if it became worse. Therefore, every ultrasound was nerve wracking, but luckily the results were optimistic.

As the boys remained at the NICU for over two months, their parents drove to the hospital every day, only returning home to sleep. Despite the anxious and fearful moments, their parents describe the experience with the NICU as positive as they felt supported by the medical staff and nurses. After 9-10 weeks of NICU admission and several weeks in a local hospital, Kevin and Nizar were discharged home.

Kevin's parents were told that they would have a baby with a chronic lung condition and an uncertain future due to treatment with Dexamethasone. They were concerned about their home environment, as they lived at an old farm and worried whether this would negatively affect the pulmonary problems. Nizar's parents were thrilled to take him home, but found themselves during the first weeks constantly checking whether he was still breathing. Since the doctors were not able to make any predictions on Nizar's future functioning, parents also worried about what they could expect.

The first years

During the first years, parents were supported through home visits from a physiotherapist and were regularly invited for follow-up appointments at their local hospital, the LUMC and, as is the case for all Dutch infants, a children's health care centre. During these years, Kevin's parents still worried whether the Dexamethasone treatment would affect his ability to reach age-appropriate milestones. Nizar's parents noticed early on that Nizar developed well behind his peers. This was not a concern to them, for they felt adequately informed and expected this to happen. They were happy that Nizar was home, able to see and hear, and felt confident that he would learn to walk and talk in his own pace.

At the age of two, Kevin and Nizar underwent an extensive follow-up assessment in the LUMC, where they were seen by a paediatrician, physical therapist and child psychologist. Besides a minor neurological dysfunction, Kevin's outcomes in the motor, cognitive and behavioral domain were all in the (above) average range. During this visit, parents were told that he developed well, and that no major problems were to be expected in the future. However, Kevin did experience a delay in speech development in the following years, and received support from a speech therapist on a regular basis till the age of eight. Nizar showed a normal cognitive development, but a delay in his fine motor skills and speech for which physio- and speech therapy was started. He also transferred from a regular to a medical day care for extra developmental stimulation.

Elementary school

At four years of age, Kevin started to attend mainstream education. The first two years were difficult for him, as he had struggled with unexpected change and showed difficulties in play, playing mostly with a deck of cards which he piled into little stocks. Due to Kevin's social and emotional functioning, his parents wondered whether it would be better for him to prolong preschool. However, the teachers of his school, who were aware of his difficult first period of life, thought he would be better off in first grade. To assess Kevin's functioning, he was observed at school and received a cognitive assessment, showing adequate social skills and an above average IQ score with specifically a very high processing speed. Kevin continued to first grade, where he immediately thrived within the structure. The rest of his years in elementary school were characterized by easy learning, but social difficulties. Kevin was anxious to have play dates, and his mother was concerned whether he would be able to form friendships.

When Nizar reached the age of four, his parents were advised against mainstream education due to his need of additional support. Parents decided on an elementary school specialised in language and speech problems. Three years later, Nizar no longer needed to remain at his school, and parents were faced with the choice between mainstream or special education. His parents visited several schools, but found the large group sizes of mainstream education overwhelming. Since Nizar was easily distracted and very sensitive for sensory stimuli, they decided he would be better off in a smaller class in special education. Nizar felt right at home at his new school and performed well within his level of education. He finished his assignments quickly and received additional work. His mother recognizes that this might have been different in mainstream education, since his school had enough resources to support him, mostly in terms of concentration. The transfer had however negatively affected his social contacts, as he was unable to maintain his friendships from his former school.

At ten years of age, Kevin (Figure 3) and Nizar and their parents were again invited for follow-up in the LUMC. For Kevin, the results of the neurological, cognitive, motor and behavioral assessment were almost all in line with the two-year assessment, showing (above) average outcomes in all domains. In contrast, the outcomes of Nizar's assessment at ten years of age were different compared to those at two years of age. The biggest change was within his cognitive capacities. Despite an average score at two years of age Nizar showed significant problems at ten years of age, especially with tasks relying on his visuo-spatial abilities.

Now

Nowadays both Kevin and Nizar are healthy and happy boys who are doing well according to their parents. Kevin attends the third class of general secondary education and has an interest in numbers and mathematics, plays volleyball and has a steady group of friends. He tends to be a bit shy, and still likes to know what he can expect in certain situations, but parents see him bloom and gain confidence. Nizar is also doing well at school, attending the third year of practical education and hoping to be able to transfer to secondary vocational education afterwards. He likes kickboxing, soccer and playing videogames. Although he easily connects with others, it has been difficult for him to maintain friendships over the years.

Both the parents of Nizar and Kevin mention that the history of preterm birth is a closed chapter in their life. They consider themselves lucky with how well their sons have developed over the years. As an advice to parents of preterm babies today, Kevin's mother states it was a true rollercoaster, and parents should be prepared for rapid shifts between good and bad days. She advices to write things down, and talk to others in order to process everything that happens. But her main advice would be: don't use Google as the internet is full of negative stories. Believing in your child is the most important thing to do. Nizar's mother states it is important to have faith in science and the medical staff, but also to stay connected with your feelings. If something doesn't feel right, make sure you receive all the information. And, despite the hardship, try to keep a positive spirit as negativity is not what your baby needs while fighting for its life.

Figure 1. Kevin is being held by his father for the first time, four days after birth.

Figure 2. Kevin is taken of the ventilator and able to breathe on his own for the first time.

Figure 3. Kevin at 10 years of age.