

Kareem Yeo 27 August 2004 – 5 February 2005 Shakeel Yeo 27 August 2004 – 6 February 2005

Kareem and Shakeel were born prematurely at 31 weeks and 15 minutes apart. We thought that it was only a matter of time before we could bring them home. Home they did come, only to leave us forever. After five months of struggling, we took them off life support, and said goodbye to our beloved twin boys one after the other.

Written by Aida Shariff, Kareem and Shakeel's mother

Raouf, my husband, and I were very excited when, at our first scan, we were told that we had twins. Raouf couldn't stop smiling and proudly told everyone he knew. The pregnancy went by smoothly without any complications, until my gynaecologist suspected that delivery might be early as there was too much water in both bags, and referred us to another hospital.

It all began on Saturday 22nd August 2004. I was bleeding slightly and then felt contractions during the night. On Monday morning, I was admitted to hospital as my cervix was dilated to 2 cm. They tried to stop the contractions but it didn't seem to work and my contractions got worse. They put me on a drip and gave me all kinds of stuff just to delay the delivery. I felt like a guinea pig being put on a test. I felt weak. I couldn't eat, couldn't sleep and I felt terrible. I couldn't bear these painful contractions and I just wanted the babies out. I told the doctors that I was ready to have them delivered but they kept fighting to delay delivery, warning me of the risks of premature labour. It was on Thursday when my cervix opened to 4 cm that they decided to have the boys delivered.

farewell, my child

Kareem was born at 1917 hrs weighing 1.975 kg. I remember hearing a weak cry and I managed to have a quick look at him before they took him away. Shakeel was born 15 minutes later. There was no cry. He was tiny but at 1.68 kg, he was far bigger than many other premature babies. Raouf was not allowed in the operating room in case they had to do a C-section on me—I needed him with me so much and wished they had let him in as in the end, I had a normal delivery. Raouf was always there with me throughout my hospital stay. He cancelled all his flights just to be with me and went home only for showers. His presence comforted me and somewhat eased the pain.

I got to see my boys the next day at the Neonatal Intensive Care Unit (NICU). I remember feeling nothing. I was just glad that they had been delivered, had good weights and most importantly, they were stable. I tried expressing milk immediately as I knew the importance of breast milk especially for premature babies but nothing came. Four days later, I met the lactation consultant. It was an experience more painful than my labour but it got the milk flowing. I expressed milk three hourly religiously so that both my boys would have enough. After four months, I had to gave Kareem formula on top of breast milk as I just couldn't express more than what I normally could. Kareem and Shakeel needed more each day. I tried my best to give them as much as I could. Shakeel got full breast milk while Kareem was on alternate formula. Raouf thinks I'm super as expressing milk every three hours was tough especially in the morning when everyone was fast asleep. To me it's what every mother would do for their babies. I couldn't feed while holding them in my arms at home. Most of their lives were spent in the hospital being fed by different nurses through tubes that went straight to their stomachs. The least I could do was to give them my milk.

Everything seemed to be under control in those early days. Although it was difficult to see their babies intubated and on ventilation support, it all seemed like normal premature procedures. There were various complications, but nothing major. After a month, Shakeel the younger twin was able to breathe on his own and so was released from the CPAP. Kareem was also doing well, but was still under an oxygen hood. Kareem had an infection and so the boys had to be separated in different ICUs. The following day, we were delighted when Shakeel was transferred to the special care nursery, and felt that he would soon be coming home. But two days later, he had a seizure, and had to return to the NICU. It was then that our hearts sank—we were told that our boys suffered from serious complications. They had jerking movements and when they opened their eyes, they didn't focus. Doctors suspected that they had a rare condition hardly known in Singapore. As some cases were known in Germany, there was a research lab in Germany willing to test the boys' blood to confirm the diagnosis, but as a research body, they had no obligation to run the tests immediately. There was nothing the doctors could do. They ran hundreds of tests, all of which came back negative except the thyroid test. Kareem had hypothyroidism while Shakeel had hyperthyroidism—but this was not a big problem, as it could easily be treated with medication.

We waited. Days turned to weeks and weeks became months. We still had nothing. All we knew was that Kareem and Shakeel were not normal, to what extent we didn't

know. Whether they would grow up to be normal or not, the doctors couldn't say. It was frustrating to get nothing when I visited them every day, hoping to get some answers. I began to feel afraid. How was I going to cope if my two sons were both abnormal? Through it all, I turned to God for strength and guidance. If it was meant to be for Kareem and Shakeel to be abnormal, I'd accept it as a challenge in my life. I'd love them all the same.

On 15th December, Kareem finally came home with a nasal canula for breathing. We took him to my mother's house as we needed as much help as we could get, particularly as Raouf was away so much flying. I also visited Shakeel in the hospital every day to take him my expressed breast milk. It was exhausting as I couldn't have more than three hours of sleep each day. Most of my time was spent cleaning the bottles, expressing milk, feeding Kareem every three hours and driving to hospital to see Shakeel. Even though Kareem was home, I felt I didn't have any quality time with him. The only time I had with him was when I bathed him, fed him or slept beside him. I was always doing something. There was no time for me to just take a moment and talk to him or just hold him in my arms. Something I wish I had been able to do.

Shakeel was due to come home on 20th December, but just two days before, his breathing deteriorated and he had to go back to NICU. Two weeks later, Kareem's condition also worsened and he had to be re-admitted to hospital. He had seemed more sleepy and was experiencing breathing difficulties. Imagine my disappointment as both my boys were in ICUs. We were back where we started.

Kareem went into the Children's High Dependency ward and the CICU the next day. His carbon dioxide retention was too high which was why he was always sleeping, so again he had to be intubated. During this stay Kareem was evaluated by another doctor, who concluded that his brain wasn't functioning, and that Shakeel would most likely be in the same condition. I was devastated. Questions ran through my mind, questions to which I had no answers. Why me? What have I done?

Less than a week later came the terrible news. Kareem and Shakeel wouldn't be able to survive much longer. Their lungs would fail more and more often. Every time that happened, they would be intubated and each time it would get harder for them to wean off. They would weaken and it would only be a matter of time before they perished. We were given two options. One was to continue to keep them on the life support system that they would need for the rest of their lives. They would be bedridden. They would grow physically, but would never develop mentally. The second option was to put them on minimal support, make them as comfortable as possible, spend time together as a family and let nature take its course.

I felt sad, disappointed, angry and lost. What should we do? Those were not options! That night, we prayed to God for guidance, to give us signs as to what we were supposed to do. We couldn't stop crying. The next day when we visited Kareem, he opened his eyes and suddenly his breathing laboured. This happened a few times. Each time, I could see that he was in pain. His eyes were telling me something. In that instant, I knew what we had to do. A few days later, we decided to have the two boys together in the same

room so that we could spend a day or two with them as a family before we started palliative care. We would try to make them as comfortable as we could and leave everything else to God.

When we told our family about our decision, they were very supportive. We even told Kareem and Shakeel about it. I remember telling them that if God wanted them back and it was meant for them to return to Him, then we were letting them go. We told them that we loved them and that we did not want them to suffer any more. We hoped they would forgive us if we had not done our duty as good parents. After we told our babies about our decision, Kareem no longer seemed agitated. He was calm and very peaceful. Shakeel was sleeping. We were at peace.

The day came when Kareem and Shakeel were wheeled to the special "Quiet Room". I was happy yet sad. Both my boys were finally together but not on a happy occasion. We knew that the day was drawing nearer. We spent two days with our boys. During that time, we had family, relatives and close friends come to visit. I tried not to sleep at night as I wanted to spend as much time as I could with them. Something I shouldn't have done as I needed to rest. On the third day, my body could not take it and I came down with fever. How could I fall sick at a time like this? My babies needed me. Kareem and Shakeel were put on nasal canula in the morning. At this point, there was no turning back. Should either one's breathing deteriorate, we would have to let them go. That night, I vomited four times. I was so sick that I slept through the night leaving Raouf to do all the feedings. Luckily for him, the kind nurse on duty that night helped so he managed to get a little sleep. The next day, I felt better and we brought the boys home to my mom's place.

Once home, we found ourselves so busy with feedings. It was chaotic. The boys had a lot of secretions and had to be suctioned before every meal. We tried to alternate shifts so that we could get some rest. Shakeel slept most of the time, but Kareem was in bad shape, turning pale quite frequently—each time we told him how much we loved him and said that if it was meant for him to go home to God we were willing to let him go. Every time we said that, his breathing stabilised. After two long nights, we woke for the morning feed but saw that Kareem was not moving. We thought it was one of those episodes and that he would be leaving us soon but what we didn't know was that he was already gone. We called Raouf's parents and told them to hurry down. My sister who is a nurse came shortly after. Once she saw Kareem she told us to call the doctor. It was only then that we knew he had left us. I was sad but somewhat relieved. I knew this day would come. I knew he would leave me and that I would miss him so much but I also knew it meant he wasn't suffering anymore. He's resting now and when the time comes, he will definitely go to heaven.

The doctor came and confirmed that Kareem had passed on. We proceeded with the burial immediately. Once everything was over, we focused on Shakeel. I felt sorry for him. We had been busy with Kareem and had somewhat ignored him. Shakeel was my beautiful baby who kept quiet while his brother left us so that we could settle everything without having to worry about him. After the burial, when everyone except our family had left, Shakeel started to turn pale just like Kareem did before he passed on. We knew then that Shakeel would be leaving us too. The next day after I fed him at 3 pm, I put

him on his side and I lay down beside him. Raouf was talking to me and suddenly noticed that Shakeel had his face down on the bed. I picked him up and realised he was lifeless. I knew he was gone. The night after his brother left Shakeel had tears in his eyes. The tears remained till he passed on. I supposed he knew he was leaving us and he felt sad. My only regret was that I hadn't spent enough time with him. Shakeel knew home for only three days of his life and even then we were always busy with Kareem. I hope he knows that I love him as much as I love Kareem. That he's my baby too. Every time I visited him at the hospital he was always sleeping so I didn't want to disturb him. Instead, I went to see Kareem who was always awake and agitated. So I spent most of the time calming Kareem down. I may have spent more time with Kareem but that wasn't intentional. I did whisper in Shakeel's ears a couple of times to tell him that I love him too. I also made it a point to give Shakeel full breast milk. I hope by doing so, he knew how much I love him. It was impossible to spend my time equally among my two boys but that did not mean I loved one more than the other.

I still cry every now and then, especially at night. I feel lonely; after the long struggle I suddenly have nothing to do. Despite the hurt, life has to go on. Kareem and Shakeel have taught Raouf and I a lot. That life is precious and unpredictable. We have learned to cherish our loved ones and see things differently. The sounds of children crying no longer irritate us. We longed to hear our boys cry—the breathing tubes they were on most of their lives affected their vocal cords so we seldom heard them cry. Even when they did cry, it was weak and soft. When I see little boys on the streets I see Kareem and Shakeel and wonder what it would be like if they were still around. It isn't easy to move on especially when your own mother keeps blaming you for what happened. My mom thinks I didn't eat right when I was pregnant and that the pills I took when I was carrying them caused their brain damage. But I did eat right, and those pills were multi-vitamins prescribed by my doctor. By blaming me, she makes me feel like I was a terrible mother.

Raouf is my solace—whenever I felt down he was always there for me. He took time off his work, has always been very supportive, and never once blamed me for anything. He helps me be positive. But I know he's hurting too.

Kareem and Shakeel have brought us closer to God—we believe they were sent to us to remind us of God's power; to bring us back on the right path. Neither of us were very committed Muslims before, but now we are doing our best to pray five times a day and learn more about Islam. We promised our boys that we would be good people and fulfil our obligations as Muslims so that we can meet them again in Heaven. Kareem and Shakeel are resting in peace now, and when the time comes they will be brought to Heaven. We know they'll be waiting for us there; we don't want to disappoint them.

The journey ahead will not be an easy one. We will constantly be reminded of Kareem and Shakeel. They will always be our babies and nothing can change that. Our plan for the future is to hope that we will be blessed with many more healthy children, to have a chance to be good parents, to take care of our kids and mould them to be good people who will be useful to society. We will definitely tell them about our babies Kareem and Shakeel; and how they were so beautiful and perfect that God wanted them home with Him.

SAYING GOODBYE ...

It is heartbreaking to have your baby die on you. It is gut-twisting when you have twin babies die on you. But our Muslim faith stood us in good stead when first Kareem and then Shakeel left us—all within 48 hours.

I wasn't a pious Muslim who would don the *tudung* and pray religiously. But I was aware when I became pregnant that I would have to set a good Muslim example for my twin boys. My husband is Chinese and was a Catholic. For our marriage, he had to convert to Islam and take on its full obligation of rituals and ceremonies.

When we brought the boys home after instructing the doctors to withdraw medical care, we knew that we had precious little time left as a family. Kareem breathed his last at around seven plus in the morning. According to Muslim law, the dead must be buried as soon as possible after all the rituals have been performed. The doctor was called in to pronounce and confirm his death, after which my brother-in-law dashed off to the police station to obtain a death certificate. With that in hand, it was then necessary to proceed to the cemetery to reserve a plot of land for our baby's burial. Raouf was new to the religion and was bewildered when his request for a neighbouring plot of land to be reserved for our other son had to be turned down.

Deaths are not predictable and, as Muslims, we have no right whatsoever to dictate the exact location of a burial plot, even if our sons are twins. That they could be buried together or next to each other would be possible only if they died within minutes or hours of each other. Our other son, Shakeel was still hanging on by a thread.

As a death is a communal event, relatives, friends, neighbours and even strangers would volunteer and delegate the various responsibilities of settling the burial rites among themselves. A small event such as offering a prayer even by a stranger would be welcomed in the Muslim tradition of death. Such was the communal nature of death in Islam and such was our situation when friends, relatives and even distant acquaintances turned up during our bereavement.

In the Muslim tradition bodies must be cleaned; even our little boy who, as a baby, was considered pure and innocent. Raouf, who all this time since the birth of his sons never had the opportunity to bath them because of his travel work commitments; bathed him, dabbed him with fragrant salts and gently patted him dry, taking care not to wipe the salt off. All dead bodies must be respected, even more so a little baby, so Raouf had to be extra careful and gentle with his son. Tender loving care was the key.

Raouf covered Kareem's body totally with cotton wool, then covered him with a robe and brought him out to the living room for everyone to kiss him and say our goodbyes. Although our tears were flowing, we had to make sure that no tears must touch him as it is impure to do so. We then wrapped him in a big white cloth and carried him in batik to transport him to the cemetery. All this while, the Orang Khairat Kematian, the person who was in charge of death rites, was present throughout the proceedings. After final prayers were completed, Raouf then carried Kareem and took three steps with his right foot first out of the front door. Each step was alternated with a short prayer. Then, we made that last journey with our son to the cemetery.

At the cemetery, a smaller hole within a hole had already been prepared. Raouf placed our little boy down in that smaller hole, his body turned sideways facing in the direction of *Qiblat*—the direction in which all Muslims face when saying prayers. Then, a four-sided cover with no base was placed on top of Kareem. It is imperative that the body touches the ground for Muslims believe that we all originate from *tanah*—the soil.

As soil was being shovelled to cover the grave, we wept silently for to wail would have saddened his little soul, and covered his grave with flowers and then poured water around it.

Going home to Shakeel was hard after leaving his elder twin brother behind. As if by Allah or God's will, Shakeel might have known of his elder brother's passing and began to deteriorate gradually. But these hours were poignant as we turned our undivided attention to our younger son. All our relatives showered him with love, blessings and attention and then, on late Sunday afternoon, he too slipped away.

We could only proceed with Shakeel's funeral arrangements the next day as the burial office was closed. To wait out this period, we laid him gently on the bed and all of us took turns to chant the customary "Surah Yassin" prayers for our baby. However, grief and exhaustion overtook us and only one of my sisters managed to last the night. It is important for these prayers as upon recitation, all sins would have been forgiven. It was also a means of Allah lessening the agony of the departing soul. But Shakeel was a baby and did not have sins, so even though the prayers had to be said, we were very comforted that he had gone to a better world.

When day broke, we made the same arrangements for Shakeel as we did for Kareem, right down to making sure that his body was laid in the same manner as his older brother. As our little boys were babies, they were pure and had no sins. So we were heartened and gratified to know that they were guaranteed a place in heaven.

Our boys may not have been buried together or even next to each other but we could never forget how even in their pain and suffering, both were almost intuitively aware of each other's presence. We have lovely pictures of them reaching out for each other's hands and we most certainly know that even though they have left our side, they are together in spirit as twin brothers should really be.