

The challenges caused by language and cultural barrier



Awais and his wife were told that their unborn son had hydrocephalus, during a routine ante natal scan. Hashmet was born at a specialist neurocentre and had his shunt fitted at two days old. As a Pakistani/Kashmiri family, they have experienced cultural challenges and language barriers through pregnancy, diagnosis, and treatment. Awais shares some of their experiences here.

As I am fluent in English, I offered to translate to my wife when we received the hydrocephalus diagnosis in early pregnancy. The medical team declined this offer and my wife was given a male translator over the phone, with no cultural sensitivities. She would be in tears, because they kept asking if she was being forced to continue with the pregnancy and telling her that she could have an abortion. As Muslims, abortion is against our faith, but we were told some Muslims do have abortions. I felt it wasn't handled sensitively.

We felt as if we were hiding how we felt during pregnancy.

When my wife developed post-natal depression, they asked her about domestic abuse and she missed out on vital support. My wife was scared to talk with health professionals.

Anything I say may be misconstrued, my husband may be arrested, they may take my son away.

After Hashmet was born, we noticed that his skull was becoming a different shape, so I worked extra shifts to pay privately for an expensive helmet to help to maintain his head shape. Then, just before he turned one, we took his helmet off as it was a hot summer's day. Unfortunately, Hashmet fell backwards on his shunt and began vomiting.

We had an open-door policy at our local hospital where we took Hashmet. He received a CT scan which looked clear, and he was discharged home. During the triage process we were asked why we had removed his helmet. This made me feel guilty, even though protecting his shunt wasn't the purpose of the helmet.

Didn't want to be those parents who end up bubble wrapping our son.

On returning home Hashmet was vomiting continuously, so we took him to our GP who told us it was probably just a bug. But this had all started after his fall and, by day four, he was very poorly.

As a parent, you can tell

We went back to our local hospital and were made to wait in the waiting room, despite the open-door policy. After triage, they put Hashmet on a fluid challenge which he tolerated initially. My wife is not fluent in English, so I dealt with the doctors and my wife rested as she had been up all night. The doctor left, telling me that Hashmet was tired and needed to sleep.

Poor communication meant that the open-door policy didn't work.

I went to take a photo of my beautiful son and that was when I realised something was wrong. I thought he might be having seizure. One side looked strange, no response, water leaking from his mouth. I called a 'nurse' for help, who got annoyed because she was a doctor. She looked at him and called the crash team. He was grey and lifeless. I passed out in shock.

He had started having a stroke.

They put Hashmet into an induced coma, gave him a CT scan and took him in an ambulance to the specialist neurocentre who told us that he had suffered a stroke. He underwent shunt surgery and remained under sedation for two days, but his shunt failed again so he underwent another surgery to replace the shunt. He finally woke up after five days and celebrated his first birthday in hospital.

As a parent, you put your trust in doctors. I don't believe that my son would be alive today if I hadn't been there.

Our neurocentre were brilliant and, as it is the same distance as our local hospital, we drive directly to the neurocentre if we think the emergency is shunt related. I feel as if we must do the checks at our local hospital and tell them what to do. This is even more frightening when you don't have English as a first language.

We don't use our local hospital's open-door policy because we have lost faith.

My advice to other parents would be to learn as much as you can, write down questions and be persistent in getting answers. Please don't blame yourself, as guilt creates negative energy which you don't want to pass on to your child.

Enjoy making memories.

Finally, some thoughts on cultural awareness and the importance of respect.

In our culture, we are taught to respect elders, clever people and, especially, doctors.

My parents even told me to listen to the doctors because they know best. I felt like that initially but that has changed now. I have learnt that you do need to question.

I am even conscious of the way I dress, as doctors talk to you differently depending on your appearance.

They give you get more respect if you look smart. They treat me differently when I turn up in joggers and hoodie during an emergency. They speak to me more on need-to-know basis. I am not your average parent, whose child has come in with a grazed knee.

I want to know everything.