

I am number 17
Zainab and Adnan's experience

However, we had never imagined quite how much our lives would change. Adnan was rushed to intensive care as soon as he was born. He had breathing difficulties, a low birth weight, bone deformities, and facial features which the doctors were concerned about. After a few weeks of multiple tests, the doctors told us he may have a rare genetic disorder called mucopolysaccharidosis type II, also known as MLII or i-Cell disease. I did my research and found out that this condition affects less than 2 people in a million. I also learnt that the average life expectancy was 3-5 years old and that there was no treatment, and no cure for this rare disease. I didn't want to believe it - these kind of things happen to other people but not us. Not our son. I told myself the doctors were wrong.

A few weeks later we went to Great Ormond Street Hospital to meet with the metabolic consultant. As soon as I walked into the room and saw the look on the faces of the doctor and the nurse, I knew it wasn't going to be good news.

We suddenly had appointment after appointment with multiple specialists and therapists. I spent hours researching clinical trials and bone marrow transplants and speaking to various experts. We became the experts ourselves, explaining the ins and outs of the condition to doctors who had never heard of MLII.

I felt lonely, sad and hopeless, knowing my son would not survive early childhood, whilst also not having anyone to get advice and support from because of the fact the disease was so rare. We felt like there was no one we could talk to who completely understood how we were feeling.

As the days went on, we found other families who also had children with the same condition and felt less lonely. We stopped being sad and embraced our new lives, not focusing on the future and what we were told would happen and instead living for the moment and celebrating every little milestone. Our lives may not be how we imagined they would be before we got Adnan's diagnosis, and although we have daily struggles and we still worry about the future, we have discovered a whole new world full to the brim with love, hope and joy.

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