

Sandhya's story

Taking part in a clinical research trial has allowed Sandhya to become more involved in her young daughter's life.

For as long as I can remember, I've had a problem with pain. It didn't seem so bad at first, just a bit of a nuisance. If I was wearing a bag, my shoulder would be sore the next day, but I'd just take some over-the-counter painkillers and it would go away. I thought nothing of it.

But after I gave birth to Rosa in 2012, that changed. The pain was excruciating. I couldn't get out of bed, I couldn't walk, I couldn't even prepare my baby's food, look after her properly or enjoy caring for her. I had to call on friends to help me. It was devastating. I'd always been such a busy person. I loved my job in the women's rights sector and often worked long hours, but now I just couldn't cope. I was living in London back then, far away from my family in Manchester, and I felt isolated and miserable.

The doctors did some tests and I was diagnosed with chronic rheumatoid arthritis in 2013. They started me on two medicines called Methotrexate and Naproxen and at first they helped a bit - at least I could get out of bed - but the pain was still locking me out of my life. I was sat at home all day, it hurt too much to get dressed, to shower, even to make a cup of tea, and I had lost a lot of weight. Looking after my daughter was too much for me, and the resulting depression was putting strain on my relationship with my partner. I just wasn't myself and my partner had to deal with a lot of my care needs as well as my daughter.

Eventually, we returned to Manchester to be closer to my family and networks, and that's when I started going to The Kellgren Centre at Manchester Royal Infirmary. I assumed there would be little they could do other than help me manage my pain, but they provided so much more than that. My consultant recognised that my response to the medicines I was on wasn't great and invited me to take part in a clinical research trial that was testing how a biologic therapy called Tocilizumab worked in combination with the Methotrexate I was already on. I had never tried a biologic therapy before, but when I did, it changed my life.

The change was incredible. Since taking part in research, my pain has disappeared and I can be a bigger part of my daughter's life.

The pain disappeared. I could play with Rosa, and really enjoy and engage with this precious time of her life, and my relationship with my partner is much more on an equal basis as he doesn't have to care for my health needs. I've even started volunteering in the field I'm passionate about - women's rights.

Taking part in the research also meant I got a lot of human contact from the Kellgren Centre. The team there really grasped the psychological impact of the disease and gave me a huge amount of sensitivity, support and understanding. That's so important, particularly in the early stages of the disease. I was going in twice a month - once to have my bloods done, and then again for my infusion, which takes around three hours. I was happy to give up the time for that. I got to know the staff and I'll miss them when my follow-up appointments are finished!

I've been told that the response I've had to biologics is particularly profound, and I understand that everybody is different. Many people have a better time on Methotrexate alone, and for others biologics don't have the life-changing impact they have had with me. I feel really lucky to have found a medicine that suits me so well, and that I will be able to continue with it after my follow-ups by self-injecting at home. I couldn't have done so without this research trial.

Finding out what works for one individual and not for another is one of the really great benefits of research. We still don't know a huge amount about biologics or their long-term impact, and doctors are really keen to find out who they work best for so they can prescribe the best treatment for each rheumatoid arthritis patient first time.

I'm really happy to have been part of a trial, I have benefited from having increased care and support which has been extremely positive. Someone has to step forward to test new ideas. I never thought it would be me, but it's really important to be that person and hopefully make a difference to other patients.

Did you know?

By bringing together nurses, consultants and pharmacists to assess a patient's needs and eligibility for clinical research studies our virtual clinic has:

- Halved the time taken to get biologics to those who need them
- Recruited twice as many patients into research studies
- Saved the NHS over £100,000 per year

Learn more about research at [Manchester Royal Infirmary](#) and [get involved](#) in research.

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