**This is Caring: Suneta**

**Suneta from Coventry cares for her 10-year-old son, who was born with an undiagnosed genetic syndrome and requires round-the-clock support. In April this year, Suneta took on the incredible challenge of running the London Marathon to raise awareness and funds for Carers UK.**

My husband and I both work full time whilst sharing caring responsibilities for our son, and we also have two other children. I dedicate myself to ensuring our son can ‘access the world’ as much as possible and enjoy a good quality of life, despite his complex disability. Born with significant feeding difficulties and problems with swallowing, he was tube fed until the age of seven. He has multiple and severe food allergies, communicates non-verbally, has sensory processing challenges and needs all of his personal care needs to be attended to. All of these factors make social activities very difficult to access. This means a trip to a park, cinema or restaurant (straightforward for most families) involves meticulous planning, but we are determined to be a ‘normal’ family as much as possible, and ensure that we don’t miss out on anything. I believe this is essential to the wellbeing of our other children.



As our son’s genetic condition is undiagnosed, his prognosis is also unknown. There are numerous medical and health issues which are unpredictable, which involves a number of medical professionals. A strong network of support from family and work are key. My two other children, aged 12 and 9, are amazing carers who show him so much love, care and attention on a daily basis. This warms my heart and fills me with pride. The caring role has become a natural part of who they are and their little personalities.

I spent most of the first two years of my son’s life in and out of hospital with him. Dealing with the uncertainty of his prognosis put a strain on my own mental and physical health. Being told he wouldn’t sit, crawl or achieve milestones was difficult. We were told that he wouldn’t live past the first few years. How does any parent cope with that being a prognosis for their own child? I was immensely challenged in terms of my own wellbeing. After the first two and a half years, however, his health picked up and we began to see progress. He began achieving milestones that were not expected. This encouraged me and impacted positively upon my own mental health.

I returned to work, part-time at first, and my employers were supportive, allowing flexibility around caring commitments such as appointments and therapies. As a carer, having supportive employers was essential for my personal and professional development, and it meant I was even more committed to my role as a result of their understanding.

Caring has completely transformed my life and personality – I don’t take anything for granted, I am grateful for every little thing. Since becoming a carer I have experienced a deep sense of humility. I value life’s experiences and encourage my able bodied children to do the same. Although the role of a carer is wearing and difficult, I do feel that it’s an honour and a privilege to look after my son. Serving others is a big part of my values and belief system. His vulnerability means I feel very deeply protective and compassionate towards his needs. I’ve learned to look after myself as a carer and understand the importance of making time for myself. Someone once told me that looking after oneself is like depositing in a bank account, it pays out dividends later. I do believe that to be very true!

Although caring has turned myself and each member of my family into very selfless individuals, it is equally very important for us to be selfish at times and take care of ourselves. This is where Carers UK can help and why I chose to fundraise for them. Caring requires providing round-the-clock care and is a very different role to parenting. Caring for those who are entirely dependent upon you is both physically and mentally exhausting. I wanted to help other carers who require support in fulfilling their challenging role and eradicate any isolation they may be feeling.

As a family we have developed much resilience. I used this strength and channelled this energy to overcome the challenge of training for and running the London Marathon. The greater challenge was fitting in the training! Your schedule is so unpredictable when you’re working, caring, and a parent. A lot of the time I was only able to run at the weekend, so I’d get up at ridiculous hours to run on Saturday mornings, before the children were awake, and go for longer runs to build up mileage on Sunday afternoons.

It’s not advisable to do two long consecutive runs like that, but it’s the only way I could make it work! Where there’s a will – there’s a way! I was determined to get the training done without letting it interfere with time spent with my kids, so I’d get back from my long Sunday run and look at my diary for the week ahead to see which days I could squeeze in a few miles. My other trick was to take my kit bag to the office and leave it by the door in the afternoon so that I’d have to move it out of the way to go home. I’d get changed, drive home, and go out for a run before even going through the front door.

On marathon day itself, I couldn’t believe how much I enjoyed it – particularly the infamous feeling of exhilaration afterwards! I’d heard that it was likely to be the hottest London Marathon ever, and it was. Training in the cold certainly didn’t prepare me for that! But I was so determined throughout, that quitting didn’t even cross my mind. It was really challenging - but the crowds really do keep you going and it felt like the whole of London was cheering for me!

I have kept up with some training since then, but nowhere near the level of discipline, pace or momentum like when I was building up before the marathon. I’m doing the Birmingham Half Marathon in October so I still have some determination left in me yet!