

Widening Digital Participation

Susannah & Alice's journey to St Thomas's

Tell us a little bit about yourself.

My name is Susannah and I have a daughter, Alice aged 14, who has Usher syndrome. The syndrome causes hearing and sight loss due to a condition called retinitis pigmentosa (RP) and, in some cases, it causes balance difficulties too.

Where did you go today?

Alice has an appointment at St Thomas's to set up her new radio aid system, they also checked in with me to ensure she had adequate accessories.

Alice doesn't mind the appointments here as I always drive it much easier and quicker than getting the train, and certainly less stressful. The appointment was only a short one so within 20 mins we were on our way back home.

What are the challenges you experience?

When we arrive parking is always a nightmare and for the most part the spaces are undercover. It's very dark and not well lit so Alice grabs hold of my arm until we get into the open air.

When getting into the hospital at lower ground one of the two lifts were out of order. We waited what seemed to be ages for the lift to come. We used to use the stairs but now because Alice has no depth perception its take a lot longer to use these, and normally results in tripping or falling, and bruises. On returning to the lobby the lift was still out and we waited nearly 15 mins to get the lift back down. It turned out that the porter lift was broken too so the whole wing was relying on just one lift.

What helps?

The team are great at St Thomas's. They always come over to Alice instead of calling her name from the room, quite often they place a hand on her shoulder if she hasn't noticed them coming over to her. In all probably the better of the hospitals that we visit.