

Lucy

By Karen Harris



Lucy was born in August 2007. Shortly after her birth we received the news that Lucy had Down's syndrome. Lucy had no heart conditions but we did find out that she had a thyroid condition. She has chronic constipation, which can be a struggle to manage at times.

Around the age of 2½ Lucy started to show some behavioural issues that concerned us, which at first we put these down to the "terrible twos".

As time continued, certain behaviours were becoming more and more worrying. For example, I was unable to enter our local supermarket without it causing distress to Lucy. In fact it was so distressing she would just scream all the way around the shop, and not just a moan but an ear piercing scream, which would leave her upset for the rest of the day.

Lucy had also become fixated on putting all her books in piles regularly, lining objects up and bashing her bricks together. On the face of it Lucy really seemed to enjoy this activity and spent more and more time doing it for hours on end, and then getting very cross when we tried to distract or intervene. This would result in her screaming and becoming what appeared to be angry with us.

Our paediatrician took our concerns on board and decided that Lucy should come in to have a full multi disciplinary assessment.

Lucy and I had a week long assessment with a speech therapist, occupational therapist, psychologist portage, paediatrician and physiotherapist. They observed her and at the end of the week we were given the additional diagnosis of Autism (ASD).

While it was sad to hear news of the additional diagnosis, it helped us to understand why Lucy was doing what she was doing.

The main issues with Lucy and how her ASD affects her are, extreme anxiety around separation issues. Settling at pre-school was very difficult and I ended up staying for a year, out of sight, but on hand when she did become distressed. She also has an extreme fear of anything medical, which makes life very interesting given all her hospital appointments. Lucy gets very upset if she sees a doctor, dentist or vet on the television and will scream and hide until it has been switched off, but can remain agitated for some time. Her need for consistency in her routine is so important, even the smallest change, like a chair or her toys not in their usual place can cause anxiety and distress.

Lucy's distress can become apparent in a number of ways. Sometimes subtle clues will tell us she isn't happy, like teeth grinding or screaming. If we haven't picked up on her anguish quickly she will then start to pop her joints out, usually her hips, knees or thumbs. Luckily they have always popped back into place. She can also lash out at times when she cannot explain what is troubling her. We don't think for one minute she means to harm anyone. It's just her way of dealing with the situation.

Lucy can become very obsessive over certain programmes, wanting to watch the same programme over and over for weeks on end. She has to watch the end credits too or music, Abba being the most recent one.

Lucy likes certain jobs to be done by specific people. When Lucy's arm was bandaged recently and a nurse was present, only the nurse could change it but when no nurse was present my husband or I could change it. This can sometimes cause problems with simple things such as changing a nappy. If my husband is here he has to do it, if not I can do it.

When we are out, nappy changing can be very difficult. From an early age Lucy took an extreme dislike to the changing facilities in shops. It felt like you needed another pair of hands to change her. So it became an impossible task and I had to avoid it whenever possible, which resulted in changing her on the back seat of the car. This is when we realised it was her dislike of plastic or cold hard surfaces, which would later affect our ability to potty train.

Anxiety over bathing. This started around the age of 12-18 months. She dislikes the feel of the water on her hair and

skin and it's just too dangerous to bathe her on my own. My husband and I have to bath Lucy together to make sure she is safe, as she could be unpredictable and a danger to herself.

Lucy is obsessive about piling her toys somewhere, usually onto someone. Lucy will do this several times throughout the day, sometimes she will even have several piles of toys. When Lucy piles them onto a member of the family or a visitor she is very single minded about emptying the toy box onto the person and is happy to leave it at that. But if you then give her one of the toys back to replace it in the toy box it will become a game and she will laugh and smile while doing it.

Lucy has some sensory issues that can cause her to seek comfort with an adult. For example, certain noises really upset her, especially things like drilling or banging. Through friends we discovered ear defenders and they have helped immensely.

Food is usually the same every day. She is happy to try different food from someone else's plate, but her plate must be the same every day. Lucy drinks for England and it must be apple and blackcurrant squash. But she will drink another flavour if it's in a different cup and she thinks it belongs to someone else.

Lucy likes her own space more than some children her own age. Lucy doesn't like anyone unfamiliar being too close to her, however when she becomes familiar she will accept it as long as she has instigated it.

Lucy has always had a very disturbed sleep pattern. We have had help from a sleep clinic and give Lucy melatonin to help settle her.

To try and help Lucy as much as possible, we use a variety of ways to communicate, such as Makaton and PECS. She does have some words but generally only uses them with familiar people. We use visual time tables to show Lucy how her day will progress, and give as much warning to her when things are going to change.

Lucy has just started mainstream school and is settling in very nicely. She appears to be enjoying it and so far we have not had any separation anxiety. We do however have issues when she comes home from school, where she will sit and flap her hands for hours on end, and cannot be distracted. We are currently waiting for the OT to help with this issue. On the days she goes to school, this has become more of a problem. It has even affected her sleep as she wants to "stim" and flap her hands but gets cross because she cannot see them. In the early hours of the morning

Lucy will often wake up and start to stim immediately using visual flapping of the hands and audibly shouting loudly "EEEEEE" constantly.

We have learnt that to keep Lucy as calm as possible, our day starts and ends exactly the same way, even if this means we are sometimes late for school. It is far more important to do everything in the usual way than to rush and upset Lucy for the whole day.

Lucy is a beautiful girl, and it can feel sad to see her feeling uncomfortable and at times unable to express how she is feeling. But I am certain that we as a family will help Lucy reach her full potential. We have learnt a great deal from Lucy but regardless of the obstacles ahead or the ones we have overcome we will always Love Lucy.

Some children have extra conditions that result in them having more complex needs. A small proportion of children with Down syndrome have additional medical complications, which affect their development. A relatively small proportion of children also experience autism spectrum disorders (ASDs), or attention deficit hyperactivity disorders (ADHDs). These extra difficulties affect about 10% of children with Down's syndrome. If you think that your child or young person may have any of these extra difficulties, ask the practitioners who are working with your family for an assessment and advice.

