



## **Got My Back:**

**Young people and families putting themselves  
in control of postural care**



**No one is too disabled,  
or too affected by  
mental health difficulties,  
to lead an ordinary life**

Cover image credit: Nicola Parry Photography

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## Introduction

As a rights-based organisation, Changing Our Lives has a long history of working with disabled people to raise awareness of health inequalities, challenge the systems that perpetuate them and remove barriers to healthcare. Our vision is that no-one is too disabled to live an ordinary life, and this includes having equal access to good health outcomes.

A healthy posture is important for us all. The way we move, the way we sit, the way we lay in bed at night, all have an impact on our spine and body shape. Most of us are born with a symmetrical body shape. For people with reduced mobility, it is more difficult to maintain a healthy posture. This means that over time, some people with reduced mobility develop body shape distortions. These changes are not inevitable. Postural care is any intervention which protects a person's body shape and reduces their risk of health complications associated with distortion.

For some people, poor posture can be a silent killer. A change in body shape affects the internal organs, and can lead to hip dislocation, scoliosis and increased respiratory infections. The most recent Learning Disabilities Mortality Review (LeDeR) report showed that respiratory illness was the most frequent cause of death in adults with learning disabilities, and called for particular attention to postural support (Heslop et al., 2020). For people with the label of profound and multiple learning disabilities (PMLD) in particular, good postural care is linked to a person's quality of life. Being supported to sit up straighter enables a person to eat safely and in comfort, allows more opportunities to initiate communication through eye contact and can increase a person's independence.

In 2019, NHS England and Improvement commissioned Changing Our Lives to write the stories of 6 people who demonstrate the benefits of good postural care. Not all the people we spoke to have learning disabilities, but all show how postural care can be the cornerstone of an ordinary life.

In 2021, Changing Our Lives will continue our work on postural care, particularly with people who have learning disabilities. We are developing a Digital Postural Care Passport, which will enable people with learning disabilities and their families to take ownership of their postural care. We are also planning a postural care conference aimed at raising awareness and skills in Learning Disability Nurses.

Reference: <https://www.bristol.ac.uk/sps/leder/resources/annual-reports/>



# Sam and Rachel's story

Rachel Wright is a qualified nurse and an unqualified mum of 3, parenting a son with complex disabilities and life-limiting epilepsy. Author of two books including *The Skies I'm Under*, award winning blogger, speaker, CPD accredited trainer and founder of *Born at the Right Time*, she's passionate about effective communication, co-production, community and embracing life's challenges. An expert through lived experience, Rachel works towards bridging the gap between families of children with complex conditions and the practitioners who support them.



## No one is prepared for the chaos of parenthood.

The change from 'Keys, wallet, phone,' to, 'Bag, wipes, nappies, cream, change of clothes, muslin, nappy sacs and on and on and on.' Just leaving the house is difficult. But when our first son was born, it was even more complicated than we anticipated. Sam was born by emergency C-section, having not felt him kick for a few hours. When he did arrive, he failed to breathe and was immediately ventilated. Instead of cooing over a new-born and try to breastfeed, my husband and I peered into a clear, plastic incubator with tubes, wires and our son. From the beginning, our life as parents was not what we had expected it to be.

At 10 weeks old, an MRI scan of Sam's brain confirmed our greatest fears. He had severe and complex brain damage. This would result in life-changing disabilities although we didn't know what the future would hold.

## Our hopes were replaced with fears and anxieties.

Initially, our little boy smiled and babbled like his peers but after only a few months he was noticeably different. Where my friends' babies grasped toys and rolled, my son's minimal movements continued on repeat, rarely changing. He was like my teenage Game Boy with black and white Tetris, while my friend's children were flying high with the latest version of Forza Motor sport on the Xbox. The comparison felt mind-boggling at times.

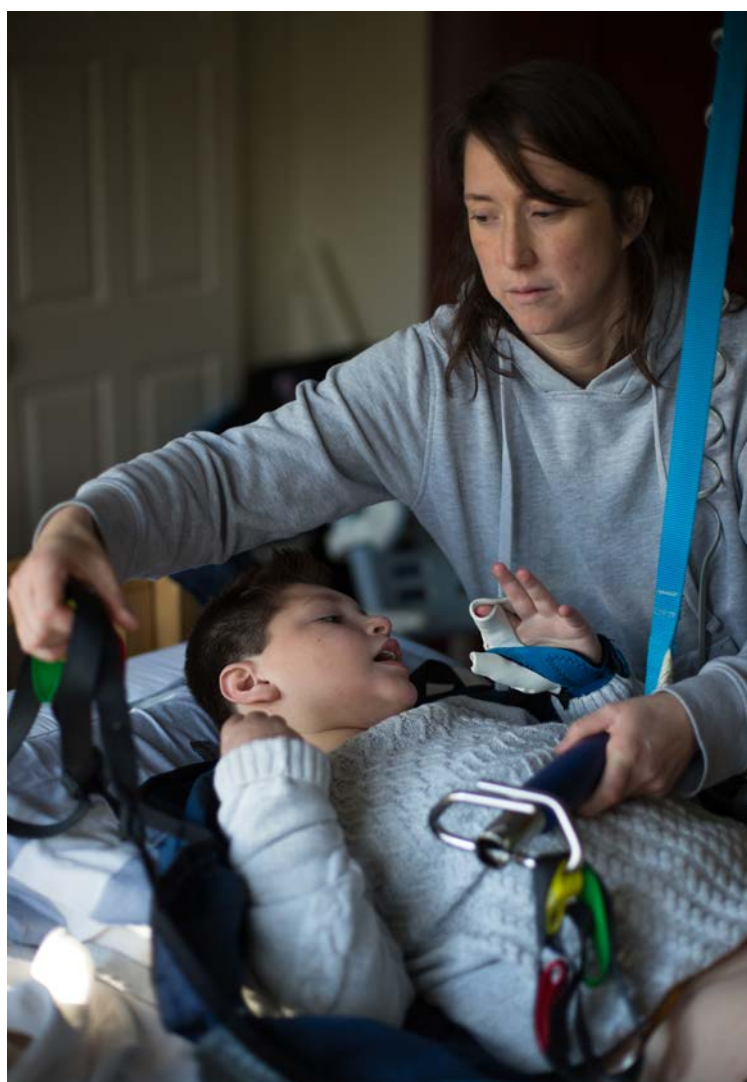
As I held my nephews, I noticed they sat differently on my hip. I looked on enviously as they whimpered when their mothers left the room. Then their soft, hopeful arms reach into the air on their mums' return. Each difference stung with a painful reminder of what we were missing. In our terraced house, left alone I doted on my son and cherished every smile and giggle. I loved him in a way I hadn't before experienced. Yet, when in the public eye, I hid my grief as best I could for all the 'what ifs' and losses I felt.



I had stepped beyond my world of understanding into an unpredictable alternate universe. As a nurse I felt capable and empowered. As a parent I was unqualified and daunted. Initially we lived in the eye of the storm, where everything happened automatically. Then our lives were invaded. From every angle people were telling me what to do. Whether it be the specially trained professionals or my friend's hairdresser who read an article in the Daily Mail. Everyone had advice about how this would all get better or simply go away. The resulting emotion was one of vulnerability. I could no longer live under the myth that I was in control of my life. It seemed every action, every decision, piece of equipment or therapy, was determined and controlled by someone else. I was exposed and ill-equipped for the life I was living.

By nine months of age, sitting remained a dream for Sam and all the beautifully decorated baby equipment didn't meet his needs. High chair, push chair, play mats and bath seats, all needed to be tweaked or adapted to provide enough support. Soon I had made friends with the workers in a local furniture repair shop who would cut and cover bits of foam for me. The wheelchair service at the time included an angel in the form of a woman who sewed and crafted wedges and supports in just the right shape.

### The changes were breath-taking.



The professionals who took their time to explain not just what needed to be done but why, empowered me to use that knowledge in all of Sam's life. Before long we were looking at Sam's first piece of disability equipment and it made me wince. Straps and supports, footplates and headrests, it looked more like torture equipment than the bright and cheerful items I saw in magazines. I found myself in the strange position of having to argue and fight for pieces of equipment I knew Sam needed and would benefit from. Then when they finally arrived, I realised I didn't want them at all. They were ugly and cumbersome and reminded me of how different life was – at a time when I simply didn't feel ready. But maybe we are never ready until we are forced to be.

Then the day came when the idea of support during the night was shared with me. Despite being a nurse, I had never seen a sleep system in place. After another routine physiotherapy session, I slumped into a chair and wept with a friend about how nothing in our lives was sacred.



Sam's sleep system

**Everything had been affected by the impact of disability.**

I couldn't feed my son the same way.

I was instructed to play with him differently.

I was encouraged to alter the way I spoke to him.

We struggled to find a mobile high-chair which gave enough support (the Goto and Scollop hadn't been invented).

His high chair at home was wooden with straps and headrest instead of cartoon jungle creatures and bright colours.

A normal buggy left Sam slumped to one side.

The baby bath seat was too small and the toddler one didn't have enough support.

All the age appropriate toys weren't appropriate at all.

## I felt overwhelmed at life feeling so different.

Now I couldn't even put my son to bed without someone else telling me how to do it. At the same time as trying sleeping positioning, Sam started having seizures. His nights were disturbed and whatever equipment we tried were required to be taken away two hours later. I needed to resettle him without equipment before he would finally drift off. Then once asleep, I would put the equipment back in place trying not to wake him. The disruption to my own sleep made life even more challenging. After worsening epilepsy and various attempts, we settled on Sam sleeping on his side with support to minimise the impact on his spine and hips. It felt like a compromise but one which worked for us.

From the outside, the hard work we had put into place to support Sam 24-hours a day had worked. From the inside what had once felt strange became our new normal. We lived life well and made all sorts of wonderful memories. We ensured we had equipment that meant we could explore and camp in the outdoors. Being in nature was a big part of our life and with hard work and creativity this continued. We dragged Sam in his Hippocampe up mountains, across rivers, in the sea and along country lanes. As a family we went on adventures to our local beach and the heights of Norway. We were like every other family making memories and having fun. Yet we weren't like every other family. Activities taken for granted by many only happened with thousands of pounds of equipment, a lot of energy and the military precision of launching a rocket into space.





## Sam is so much more than what he cannot do.

As Sam has grown, he has exerted his personality. His love for music is firmly established along with swimming being his favourite pastime. He knows his favourite films and is obsessed with the game show *Pointless* (I think I hear Alexander Armstrong's voice more than my husband's). He makes sure his brothers know when he isn't happy with their choice of programming - screaming, shouting and crying, all of which will instantly stop as soon as he has his own way. With a growing team of carers, came Sam's preference for the attention of young women. When young carers come to play or take Sam out, he makes it very clear his mum is not welcome. Sam prefers safe and known, gravitating towards what he has already done. Every day we continue to try and expand his world and give him a variety of experiences.



## Some days it even feels like we are winning.

Sam can sit relatively straight (when supported) in his chair or bed. He can lift his head and open his hands. He can lie on his front and enjoys time in his walker. Painful spasms are rare and Sam enjoys a good quality of life with a variety of experiences in his day.

At least, that was true until aged 12, when parts of Sam's life started being limited because of pain. Once previously enjoyed activities were no longer possible. When we decided these changes affected his quality of life, Sam was booked in for surgery to reconstruct both of his hips.



## The flood of guilt took my breath away.

Now the 'What if's' sat firmly at my own feet.

What if I had tried harder?

What if I had been more creative in using the equipment?

What if I had persisted?

Could I have managed to avoid the deterioration in his body and resulting major operation?

So many unanswerable questions.

Working with the incredible team at Simple Stuff Works changed everything. I began to more fully understand the mechanisms of body shape changes which occur in children (and later adults) with movement limitations. A person with no physical restrictions moves throughout the whole day. Whether it is rolling around in bed when asleep, walking, running, raising an arm to open a cupboard door or catch a ball. Movement happens 24-hours a day and our body is protected through it. But the smallest of limitations can change our movements in a way that can put extra stress on our body.

Everyone knows how a sprained ankle can give backache because of the way we start walking differently to avoid pain. Multiply these small, persistent movement changes to all day and all night, every day and every night for decades. What seems insignificant can, over time, have a major influence on long-term health.

When Sam was small, his body naturally wanted to curl up into a foetal position to sleep. Without the usual rolling and changing position the result of staying in one position for a long period of time was badly affecting his body. It wasn't dramatic or alarming. Rather like the silent killer of carbon monoxide poisoning, the slow, persistent effect of a poor position was quietly having a life-changing impact.

## Simple Stuff Works worked with me.

In sharing my real life, my fears, goals, restrictions and routine, Simple Stuff Works helped me to replace my guilt with change. Small positive steps which meant we were heading in the right direction. It became clear the work with postural care is relentless. Sam and his body are constantly fighting gravity, the tightening of muscles and altered growth of bones, just to stay straight and pain free.

Our postural care for Sam didn't change overnight. With knowledge and the support of a team ready to listen and work with us, hurdles were faced together. Small sustainable changes have been made. Over a year after surgery, Sam is no longer on daily painkillers. He continues

to move his legs more and now sleeps on his back. But as he heads into puberty, we know that keeping his spine straight will be a long fought battle that will carry on whilst I'm doing laundry, cooking dinner, working, trying to live my own best life and even when we are all sleeping.

**I wish I'd realised Sam had one precious body which needed protecting.**

I only carry eggs in an egg box and always put my young children in a car seat. In the same way, one of my vital roles as a parent is protecting Sam's one body. He uses that body to turn his head and watch the TV, to feel his environment, to splash the water and relax at night. I think I saw the equipment and changes in position as restrictions and work. Now I can see they give him his freedom and best kind of future. What once felt like the constraints of disability, I now see at the gateway to opportunity.

**Caring for Sam's body through 24-hour postural care is simple, but not easy.**

### The principles we look to are simple;

1. Support Sam throughout the day in a way which keeps his body naturally straight from head to toe. Allowing movement of arms and legs where possible. With arms forward, avoiding slumping to one side and avoiding head dropping forward.
2. Ensure Sam changes position every couple of hours – sitting, lying (front and back), free movement swimming, cycling, standing sling, walker. Using whatever equipment he enjoys and can relax in.
3. Encourage daily active movements. It is easy to always to 'do to' Sam but it is vital to let his body learn what happens when it tries to move itself.
4. Sam to lie on his back at night. This keeps his body in the best natural position. He has support under his knees, along his chest and under his heels. This means when Sam is relaxed and asleep his body is able to grow without distortion helping him to have maximum fun during the day.

## It's a team effort.

From the carers who help us at home, to the staff at school, everyone knows what Sam's needs are and the principles of care we are working to. We know this is a marathon, not a sprint. Everyone is trained and supported as needed. Some days we work hard and get it right. Some days are filled with other priorities like a family day out, camping under the stars or simply relaxing.

## Parents like me.

I frequently feel as though I have a shopping trolley full of advice which I simply don't have the emotional or physical energy to 'pay' for. So I try to remind myself every day that I only have two hands, 24-hours a day and one precious life. As much as I love my children, I want them to see me living well too. I want them to grow up knowing they deserve a life of love, laughter and hope – just like their parents. So I will continue to try and do what I can, and leave my guilt with the great undone at the end of the day. I will prioritise fun and rest as much as work and therapy. I will work with professionals, using their skills and expertise, being clear with boundaries and expectations. I will choose my mental health in conjunction with my child's physical health because I know I need to be on the top of my game for my family to not just survive but thrive.



## #Bridgingthegap

In 2015 I shared our story of becoming the parents of a child with complex needs in [\*The Skies I'm Under\*](#). Since then I have slowly built a business focused on bridging the gap between families of children with complex needs and the professionals who support them. Through public speaking and CPD accredited training, I empower professionals with the reality of lived experience, research and best practice. We aim to promote effective communication and co-productive working with relatives and carers. I know first-hand that the greatest support, advice and consultations happen when my vulnerability as a parent sparks listening, creativity and collaborative working on the part of the professional.

Postural care, like so much, can feel like a mountain to climb. This particular peak however, is best faced alongside experts who listen, encourage and equip us for the journey and inevitable hurdles ahead. It helps to know that this complex and sometimes painful life is also blessed with the most profoundly beautiful and breath-taking views only found at the top of a mountain.





# Mia and Frances's story



Mia is an outgoing, fun-loving 19-year-old with an independent spirit. She likes music, dancing, books, jigsaws and her favourite computer game, which she operates with her eye gaze. Despite having a severe learning disability, she has a knack for learning new things that can be surprising to people who don't know her, and a keen memory for people and places. Mia has a lot of fun with her younger brother and sister, who she is really close to and is starting to establish a circle of friends at college, where she started this year. An ideal day for Mia would be a walk somewhere interesting with one of her favourite personal assistants followed by a good dinner. She's a happy person who has been through some really difficult times.

## Mia's early years

From when Mia was a baby she didn't grow as expected and she had episodes of twitchiness, which looking back we now know were down to her epilepsy. She was put on epilepsy medication early on, and when her symptoms are being managed well she is very sociable and loves being around people, making makes lots of eye contact, vocalisations and gestures. Mia's epilepsy has been very difficult to control and we have had to try numerous different things over the years including the ketogenic diet and vagal nerve stimulator. She progressed well until the age of 3, albeit delayed. She walked at 20 months and had about 20-30 words which she used appropriately.

However, between the ages of 3 and 5 Mia had a spell of really poor health with her epilepsy and she went through the most devastating loss of skills. She could no longer communicate with words and she lost the use of her legs, going from being an active toddler to going everywhere in a push chair. It was a massive challenge to get her back onto her feet again. Unfortunately, her first school were quite risk averse; they hadn't known Mia as a toddler and didn't see her as a child who had walked and had the potential to regain these skills. She wasn't given the opportunities to practice her walking at school and was just getting to practice during her weekly physio. I wanted her to be challenged to practice throughout the day every day at school as well as at home as she had when she'd learnt to walk the first time round as a toddler. Eventually, she moved to a school with an integrated therapy approach and over time regained the ability to walk with adult support.

## A change in perspective

I have worked as a children's physio for 25 years and had always been very proactive when it came to encouraging Mia's development. I was less focused on her postural needs though and it wasn't until a colleague arranged for Sarah Clayton from Simple Stuff Works to come in and meet our team back in 2015 that this changed. Even though I had always understood about the importance of using 'postural' equipment to promote function and independence I now had real insight into the direct connection between the position that someone is in for long periods of time, particularly overnight, and the tightness and contractures they develop slowly overtime. My reflection was that if this wasn't intuitive to me as a physio then why would this be obvious to the families that I worked with?

I started to think differently about how I could be more proactive both at work and at home about protecting a child's growing body shape and I became a keen advocate for postural care.

## Mia's postural care journey

At this time, Mia was 15 and I started reflecting on the many months and years that she'd had with poor health and the associated impact this had had on her motor skills as well as on her posture and body shape. By this stage she'd been referred to the spinal team at Great North Children's Hospital in Newcastle and was seen annually for x-ray monitoring. She had developed a slight scoliosis, in hindsight from many hours of lying in asymmetrical postures in her preferred position, and her feet had collapsed to the point that she was walking on the insides of her feet and needed re-enforced splints to correct their position.

Mia has always had really broken sleep, so sleep is really important to her, and for us as parents it is the absolute priority especially when trying to juggle Mia's care, our work and her brother and sister's needs. Previously I must confess that even as a children's physio I had never really considered her sleeping position but just focussed on whether or not she was sleeping. On reflection I think this is common; postural care is not intuitive and therefore not something that you think about when you are just dealing with the 'here and now'. With my new awareness however I observed that she used to sleep in one position on her left side for about 90% of the time. Whilst not wanting to compromise on her sleep at all we did start to make small changes; we started placing her on both sides to sleep and on those rare occasions that she was in a good sleep we placed her onto her back. When she was settling off to sleep she rolled onto her preferred side and it has taken ages for her to be happy to settle on her back; but she will sometimes do this now for a few hours if she's having a good night's sleep. We also started to place her on her back to rest on days when her seizure activity wasn't good and have introduced parts of a sleep system; a hip support and some side supports for these times. Sleep continues to be her main difficulty and she now has overnight care to support us with this. I have explained to her carers the importance of why we are helping Mia to move into different positions overnight.

Mia's efforts with her physio, and our support with her posture have had a positive effect on her mobility. Now at the age of 19 she continues to be able to walk unaided at home on occasions when she is very well. She has used a Pacer, which is a walking aid, for the last 5 years which has enabled her to stay on her legs once she got to an age and size where it was becoming more difficult to walk her with one person. Since using the Pacer her fitness levels have increased massively. From just walking around home or school she can now walk for 2 miles and has changed from feeling like we were dragging her out to enjoying the freedom of a good walk. Mia's mobility is a big part of her communication. One of the ways she communicates her needs is to take you by the hand and take you there.

Additionally, at 18, her spine was much straighter, which I'm sure is due to her increased fitness and the efforts to protect her body shape. She has now been discharged from the spinal surgeon.



## Setting up a postural care service

Professionally I had a new enthusiasm for passing on the insights that I'd had with the families that my team worked with. I got involved in the National Postural Strategy meetings with Jayne from Changing Our Lives, where we discussed and agreed on what we felt the key principles of postural care were.

I tried to pass on this enthusiasm to my colleagues but we just didn't have the capacity to set up a postural assessment clinic. I applied for an Innovation Fund and was able to pay for two members of staff to dedicate one day a week to setting up a postural care service. We set up a local steering group along the same lines as the national group which brought together occupational therapists, physiotherapists and families. We consulted colleagues across the UK who were already delivering a more comprehensive postural care service. We had 3 meetings in which we discussed how the new service should look and came up with our criteria for a successful postural care service. Parents told us that they wished they'd been told earlier that their child was at risk of body shape changes and therapists told us that they didn't feel comfortable with how and when to have those conversations.

The postural care clinic has been running for a few years now. We've just done a service evaluation and parents have told us that the clinic reassures them and empowers them to take an active role in protecting their children's body shape.

It feels like we've learned as we've gone along. Doing measures of body symmetry can be tricky with little wriggly ones and you do wonder how reliable the measurements you're getting are. However, the big priority with our youngest patients is for us to just lay eyes on them with their parents and start to have those discussions about why we're doing the measurements and what they can do to protect their child's body shape.

Another priority for us is building a bank of resources that will fit all different children and families. We can share videos, leaflets, things that just scratch the surface and more in depth information, depending where people are on that journey.



## Being a mum and a professional

Mia's experiences give me the drive to make sure that all the parents I meet at work have the knowledge they need to avoid additional impairments that their child needn't develop. When I look at our experience it strikes me that I wouldn't have thought Mia was at risk with her postural care, but I would have appreciated one of the health professionals involved informing us that there were simple things we could do to help protect her body shape during those years when she was very unwell. I felt that a lot of health professionals were more accepting of where Mia was with her development than I was. I loved it when we came across someone who saw her the way we did and saw a glimpse of her potential and cheeky personality.

In my experience parents want professionals to be clear about all the options available. I think sometimes we as professionals can hold back with knowledge for a number of reasons, and as a parent you just want to know it all. Parents often hear things that they feel will help their child from the each other and from social media or google searches but I think they value professional's opinions and having more open conversations. In our experience professionals all have good intentions, and often their motive is that they don't want to upset families or give people false hope but most parents are stronger than they're given credit for and it's really important that health professionals have clear, honest, informed conversations but still allow parents to have some hope that keeps them going.

I think for professionals the world of postural care has moved on massively since our team first got involved in it. The NICE guidelines for paediatric postural care have moved on, and the information is so much easier to find. Postural care (including assessments) is a routine aspect of paediatric services now.

Unfortunately, I think postural care is still not at the forefront of people's minds, especially across different disciplines and teams. It can be really hard, for example, if a person with postural care needs is admitted to an acute hospital. Acute hospitals can be stressful and unfamiliar settings, and parents may feel disempowered because you feel you have to fit in with the rules and the way things are done on the ward. Families don't always feel confident about advocating for a 24-hour postural care approach in that situation, and so I've seen some people coming home from hospital with a worse body shape than when they went in. I think the concern is that this may also be one of the consequences of long periods of lockdown on children with disabilities. There's still more to be done to ensure everyone with postural care needs and their families and carers have access to good postural care, but the benefits if we get it right for that person can have such a positive impact on their quality of life.

# Charlie's story

I've been described as an old-soul, a ray of sunshine, a cheeky chap, and a disability rights champion. I'm not sure about all that though, I'm just me, and I've never known any different. I'm 16, and like many boys my age I've been a big gamer from an early age. I love animals, and I'm going on to study Animal Care at college next year, with a plan to get a degree that will set me on my way to training assistance animals. I'm really close to my mum, Mandy - you could say we've been through a lot together, but whatever we've got ourselves into, we always find a way out!



## Early years and diagnosis

It's hard for me to pin down my earliest memory of the 'medical' side of things. Mum has always been open with me about things and given me a choice in everything to do with my health and care. It's just normal to me - it's been with me all my life.

I have spastic diplegia, which is a form of cerebral palsy. I don't really live under that label though. It's just one part of what makes me me.

I was diagnosed at age 2 and a half because I wasn't walking. When my mum and dad first took me to be seen, they met a consultant who told them to look at the Scope website and come back in 6 weeks. My mum had already started to suspect it may be cerebral palsy by that point. She wasn't sure at that point how it would affect me. One health professional told her I wouldn't walk or talk. I can walk now, although I've not long had an operation on one leg and I'm due for an operation on the other leg. It's likely that as time goes on I'll eventually have to use my wheelchair full-time. At home I have my own ways of getting about, as long as it works, I'm happy. As for talking – just ask anyone who's ever met me and they'll tell you I can chat till the cows come home just fine!



## Working with professionals

If I'm really honest, postural care hasn't played a big role in my relationship with health professionals. Many professionals I've worked with haven't known about it. One physiotherapist I had told me to sit up straight because it would be good for me in the long run. There was no real explanation why, so it all seemed a bit alien to me. Creative communication wasn't really her strong point, she did tell me *"Grit your teeth and get on with it."* The less said there, the better!

I've had 16 physios in 14 years and they've all been somewhere on the scale from absolutely brilliant to downright rubbish! There have been some really good physios who really get me, and one or two I keep in touch with, but for me the problem is that even the good ones don't last for long. They all have a different perspective, and by the time you've got used to how they work they've moved on.

For me, a good physio will listen to me and not just read my papers. It's important to me how they speak to me and their overall communication skills, with other professionals and with my mum. The poor ones think they know everything and I know nothing. My mum and I live with my condition day in day out. Some people think they know better because it's written in a text book.

The really frustrating ones are those who come along and want to repeat everything we've already tried over the last 14 years. Believe me, we've tried everything under the sun and it's really frustrating to tell someone *"I've already tried that!"* One person even said, *"I know, but I want to try it first."* It's as though it's all about them getting through their tick list, not about me and what I know works for my body and my life. Some people just see what they want to see. They have this perfect body and perfect shape in their heads, and they want us all to work towards it.

Luckily, I won't just sit back and let this happen. I'm quite happy to speak up if something's not working for me, otherwise I've found that nothing actually gets done. I always make sure a member of staff writes down everything that's been said so I have my own reference that I can go back to. That way plans can't be forgotten or changed. You might think that's unusual for a 16-year-old boy, but I got it from my dad, who was a manager. He taught me to make a note of everything and never to be afraid of complaining if people don't keep their promises.

It can be frustrating when you get mixed messages though. When I had my operation, the team at the hospital told me to make my recovery work for me. I came home and me and mum just got on with things our own way. We'd found a few weird and wacky ways for me to move about and do all my transfers in a way that suited me. 5 days later a different health professional came to visit us and told us we'd been doing it all wrong! It would have been helpful if someone had spoken to us before the operation and said *"This is how it could be done,"* so that we could prepare. Could not *should*, mind you. There's a difference!





## Finding my own solutions

I keep my body healthy in the same way as an able-bodied person would. I've not been that active for the past 18 months because I was off my legs for 2 months before my operation, then COVID-19 hit, but over the years I've done karate, horse-riding, rock climbing, canoeing...

Some people may look at my life and think I've overcome some major challenges. I don't see it that way though. When I encounter a new situation, I just step back and think how I can tweak things to make it work for me. I love it when people are willing to get creative with me and make it work. Some of the best people for this job aren't disability experts at all.

If you saw my old karate coaches, Leigh and Shane, in a dark alley, you'd run a mile in the other direction, but if you got talking to them you'd see they're the nicest people you could ever want to meet. I used to train with one person in front of me and one person behind me (there is a method to my madness). Leigh and Shane would show me in pictures, *"This is what you're going to need to do,"* and ask me, *"Can you think of a way of doing this?"*

I used to do a lot of swimming before lockdown. Mum says her approach to helping me with swimming is getting me to the side of the pool in my wheelchair, chucking me in and hoping for the best! I'm quite well known down the baths. I know all the receptionists and all the pool staff. You might think that's because of my winning personality (*and, to be fair, it probably is!*) but for me, it's more than that. If I ever struggled in the pool, I'd want everyone in that team to know who I am and know how best to help me.



I've also got a specialist bike, like the Paralympians use. I had a particular saddle when I used to do horse riding, although I'm not quite sure how you'd get me on a horse these days!

These little tweaks allow me to get on with life, just like any other kid my age. After all, no-one in this world is *"normal"*.

## Getting involved in campaigning

Apart from that one physio who wanted me to sit up straight, I hadn't really given any thought to my posture until I started doing some work with Changing Our Lives. At that time, I was up for getting involved in anything, and the CEO, Jayne, approached me and asked if I'd like to help with their Postural Care campaign. From what I've learned over the years, postural care is crucial. However, the one thing I would say is don't use so many technical terms! Don't overload it so it's too complicated for people like me to understand.

My mum has been helping Changing Our Lives to design a Digital Passport that will allow people to record and share their postural care needs. She says it's been really informative. I think the Passport is going to be helpful for people to not have to keep explaining their needs to professionals over and over again. Mum thinks that I would be fine without a Postural Care Passport, because I've learned to communicate my needs really clearly, but she thinks it will be valuable for anyone who doesn't communicate with words or those who don't like opening up about their story to professionals all the time.



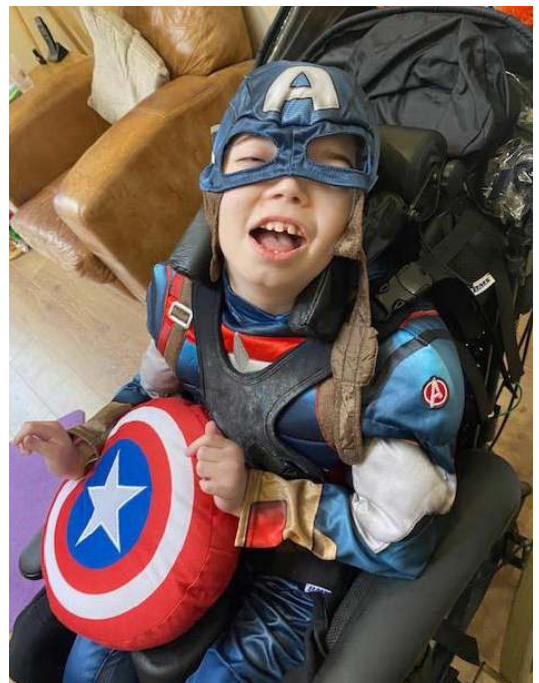
## Advice to others

We asked my mum what her advice would be to other parents of disabled children. She says "When your child is diagnosed you feel like your whole world has come to an end. You think 'Why me?' But you will adapt. Pick yourself up, dust yourself down and have a positive attitude. Your child just works a bit differently to others, so don't compare them."

As for me, I don't think I'm different to anyone else. Like I said before, I'm just me! My advice for people younger than me would be "No matter what seems impossible, where there's a will there's a way." This has always been my life and I have no regrets whatsoever.

# Nate and Rachel's story

Nate is 10. He's a happy, lovely little lad who loves music, Disney and The Avengers. He's always on the go, walking the dog with the family, supporting his sister at football or splashing about at hydrotherapy or swimming. He has an extremely rare genetic condition and since birth we haven't really known what to expect. Nate wasn't diagnosed until he was nearly three and in those early years there was a lot of uncertainty. No-one who was involved with Nate knew what the future held and this had a big impact on what equipment he accessed and his care. In the beginning the focus was purely on survival. We had no idea then of the impact of postural care, nor how important it would be for him.



## "Living in a dynamic risk assessment"

Our goal every day is for Nate to have the best quality of life he can possibly have. We definitely take some risks to enable Nate to have those experiences that other children do – sledging being the most recent example. It's like living in a constant dynamic risk assessment. If we go on holiday as a family, we have to think '*where's the nearest hospital?*', '*what can we access when we get there?*', '*where can we change him?*', questions that other families don't need to think about. Personal care on a long journey is still a huge challenge: although there is a gradual increase in service stations that have Changing Places facilities, they do seem to be predominantly in the south. It was always really important to us that we would still be able to do things as a family; but we have to be creative about how we involve Nate in all of that. Everything is planned to the letter.





We're quite a busy family, and over the years we've always been out and about. We love the beach, going to castles, exploring – all those things that a family with young kids enjoys doing together, so it's really important that any equipment Nate has supports him to do this, which has been tricky. Even in the early days just getting him in the car safely and comfortably was a battle. Before we had a mobility car we had a normal car and we needed to find a car seat that wouldn't obstruct his breathing. Because he was so floppy, lifting and twisting to get Nate into the car seat put increasing strain on our backs. We got to the point where he needed to travel in his wheelchair, but there were issues around the chairs not being crash tested to his weight and keeping his head up and supported. One solution was using a Hensinger collar; however, our wheelchair services weren't keen. It often feels like professionals tell us what we can't or shouldn't be doing, but without suggesting actual solutions.



Sometimes you'll find an adaptation that solves one problem but poses other difficulties. Take the beach, for example. Many coastlines are inaccessible with very steep ramps or steps. Two of our local beaches have started offering beach wheelchairs, which is amazing because we can get him right into the sea, but they are basic wheelchairs and with his tone we need to find a way to strap him in with appropriate support to sit upright safely while we bump him across the sand. We looked at getting a 3-wheeled chair for going off road, and tried one out but it wasn't supportive enough. We would love to be able to find an appropriate chair to be able to increase Nate's access to his environment and expand his horizons.

## Early days

We've been on a bit of a rollercoaster when it comes to Nate's health and care. He was really poorly in his first few years and spent a lot of time in hospital with chest infections. In those days, he would get better from one thing and then he'd face another problem with something else. We would have a gap in information for quite a long time, then be bombarded, and the next thing you know, it's all wrong and you have to change things again.

I wish I'd known back in those early days what I know now. As a parent you become an expert in your child over time, but at first it's such a steep learning curve. Before Nate started school, and even in those first few years of being in school, I didn't understand the importance of posture. In hindsight it's really difficult to remember how much we were told about positioning. Did professionals avoid the topic because they didn't want to add to our stress? Was it because Nate wasn't expected to live very long? Or was something lacking in their provision? Nobody was blunt enough to sit us down and say, *'With how floppy he is, he's probably going to end up with scoliosis and need surgery.'* Services in the community were so patchy that if you managed to pin one person down, they didn't know Nate very well and we struggled for advice and resources.

Eventually we began to accumulate lots of equipment for different things, like a supportive chair with tray for eating (with a head rest that no one could get right for Nate's breathing and feeding) and a profiling bed that helped with secretions at night to reduce chest issues. Throughout all of this, keeping straight wasn't mentioned. These were pieces of equipment for other things entirely. It was time consuming and difficult to go through the process of getting an assessment and equipment. I remember having hoisting put in, and slings arriving but no one showing us how to use the slings, nor how to work out which loops to use! You felt like you were chasing services. Often there was a lack of experience within community services, or people managing huge caseloads and under increasing amounts of pressure. We were lucky to eventually have great people working with us and Nate.

But it shouldn't be luck though, *should it?*

## Clicking into place

When it came time to choose a nursery we found a special school that was starting to take nursery age pupils. It was such a friendly, nurturing environment with staff who were incredibly experienced in medically complex children. They had an open door policy, so we were always welcome as parents and you felt you could ask those questions and build up relationships with professionals over time. Consistency is so important for families like ours, those positive relationships mean you can discuss anything, no matter how difficult.



School was where we first heard about postural care finally in an explicit way. We met Frances Slowie, who was working as a physiotherapist with the school. Prior to this I didn't even know postural care was a thing. They started to do postural assessments in school which made things clearer. Referral to the spinal team at our local hospital provided 6 monthly and then yearly spinal x-rays to monitor scoliosis and kyphosis. On-site physiotherapists and occupational therapists were invaluable. Those OTs don't mince their words! As tired parents with a hundred other things on their plate, subtlety often gets lost on you. We're so fortunate that Nate got into this school; they have been so helpful with liaising with the community teams about his equipment needs too.

Since then I've also started working at the school teaching teenagers with a label of profound and multiple learning disabilities alongside complex health needs. This has deepened my knowledge and understanding. It's only been through observing body shape change over time in a professional context that I really understand what to expect as Nate gets older, and the importance of trying to prevent deterioration. I also understand even more that you can put all the support in place at school, but unless it's followed up at home you lose that impact. It has to be a real collaborative effort between home, school and health services. Equally, for many of us, 24-hr postural care can feel impossible.

## Struggles

Like all parents we've had a few challenges when it comes to doing the best for Nate. It's a constant battle and a lot of waiting for funding approval. This has become part and parcel of every aspect of Nate's life for the last 10 years. It can take a long time to get money approved for something we know Nate needs. Nate has a paediatric bed, which he has outgrown. You would think that it would be straightforward to get the same bed in adult size but everything requires referral, evidence, assessment, and application to panel for funding. The OT who came out was fantastic and gave me an update a few weeks later to say the application was going to panel. I was stunned to get an update truthfully as usually we have to chase these things. Hopefully he has a new bed soon!

In the early days I didn't know you had to really push and make yourself heard. I didn't realise that if a professional says your child doesn't need something, it might not be because they don't really need it. It might be because the funding doesn't stretch to that, or the professional isn't an expert in that area. We have found that professionals in community based services are more experienced in general issues. When your child has needs that are a bit different and unfamiliar, professionals themselves can be at a loss as to what to suggest.

We have had to apply to charities for some pieces of equipment where local authorities have refused to fund them such as a specialist car seat. It can also be a struggle to try something new, like Nate's lycra suit. Back when Nate was first assessed for one they weren't very well known. Some clinicians don't agree that they make any difference long term to spinal position as there isn't much evidence, but I could see the difference when he wore it, and it was much easier to position him while wearing it. Subsequent funding applications were easier as we had evidence that it was working for Nate. If you're breaking new ground with something the funding body haven't seen before, it can be hard to make the case. Some things are easier, such as Nate's sleep system as it was quite clear he needed one, the issue then came down to finding the right one that meets his needs.



## This “complex” life

As a parent I’ve always been keen to try new things in the hope they will improve Nate’s quality of life. For many years he sat in a P-Pod, because it’s relatively affordable, it looks nice and it’s comfy. It’s what a lot of his friends would have had too. It wasn’t until much later we learnt it’s really not that supportive, but you just don’t know!

This “complex” life is quite complicated. Unless you know what you want equipment wise people aren’t forthcoming with what’s available. It’s frustrating. There could be a bit of equipment out there that’s far more appropriate for your child but they may not mention it to you, or perhaps they don’t know it’s there either. We’ve had to tell some professionals what we’ve found out from our own research. You hope that money doesn’t influence these decisions, but ultimately you know it does.

I want to try everything. When the Upsee came out, I was on that website hitting refresh over and over again to buy one. The website was crashing, but it was such a brilliant idea. It’s a harness so Nate could stand upright strapped to me and walk with me. When it arrived we were so disappointed as it just didn’t work for us. Nate’s inability to hold his head and trunk well put huge stress on my back. For the short time we were able to use one it was an amazing experience for Nate - dancing, walking and playing football in the garden with his sister.



Above: Nate in his P-Pod



Right: Nate’s current sleep system



So at the minute Nate uses a sleep system, a wheelchair and a comfy chair with supports. He has moved from the P-Pod which was a bit too comfy, to something more structured. When he's not in something supportive he's on the floor having some freedom to roll and wiggle around. This is really important for his spinal health too. He can lie straight as an arrow when he's on the floor and you look at him and think, *'I never knew you could do that!'*

The biggest challenge posturally over the last few years has been getting the right sleep system. Nate's like Houdini - he can get out of anything! Our current sleep system is comfortable and he can't get out of it (*although Nate has recently started to shout and refuse to go to sleep until we take him out of it...*). At first the sleep system was just to keep him in place as he got tangled in his wires and he would end up moving to the bottom of his bed, but now we know how useful it is for his spine too. He has a stander, which isn't normally at home as it's so big and heavy, but when lockdown hit his school sent it home so he could use it here. It hardly fits in the house!

## Moving forward with Nate

With postural care you need to be prepared to try things, and persevere. It doesn't mean you're going to fix everything, it's not a guarantee on preventing surgery but at least it can slow the rate of deterioration. Nate sees a specialist for his spine, and at his last two annual appointments the curve in his spine hasn't changed. It's still there, but it hasn't got worse. This is all since we've been working on his posture a lot more.

It's sad to say but as he's getting bigger his life is becoming more limited. Things we want to do with him are more difficult, we can't shy away from that. Even when going out with the family dog we have to think in advance where to go. Sometimes you research a place and then turn up and *"Oh no! steps!"* Getting him to football pitches so he can see his sister play can be challenging. They don't half put football pitches in some weird and wonderful places! He loves swimming and there's a pool on our street with a Changing Places toilet for him to get changed in, but they haven't put anything poolside to help you get him in the water. Or you turn up and they've let a family go in the Changing Place to have more space. We definitely need greater understanding in our local communities about access.

It's difficult to know what impact better postural care has had on Nate as changes over time can be subtle. This is why it can so often be neglected. I can't predict what the spinal x-ray will show and whether the news will be good or bad. I dread those appointments for that reason (and for the work out getting Nate on the chair thing to have the x-ray itself). I know that spinal fusion is inevitable – he will need surgery at some point, but we're putting it off for as long as possible by protecting his body shape. We just want to reduce any deterioration and this collaborative effort is well worth it, even if it doesn't replace the eventual need for surgery.

## The future for postural care

The importance of postural care needs to be made clear when our children are young. If families aren't in the right place mentally to take information in, professionals must revisit the topic over time. Posture is the furthest thing from your mind when you're just trying to keep your child alive. Be clear about what could happen with a child's spine over time. Don't suddenly bombard parents and carers with information- start that drip feed of information right from the beginning.

The fact that postural care needs to be a 24-hour consideration requires careful explanation. Also, you can't do it all perfectly all the time. If it comes down to sleep vs sleep system, let's be real, sometimes you have to choose sleep. Needs must, but you need the information to be able to make those decisions.

We are lucky Nate gets on so well with his postural care, but I know that many people can't tolerate it, which must be incredibly difficult. There needs to be more awareness of what equipment works in different situations. New things are coming out all the time, it's really important that therapists and parents know what's out there. Some of the best experiences we've had are with the medical team around Nate who are fantastic about saying, *'Have you got this?'* and *'Have you heard of that?'*

## Advice for families

Accept that some of the stuff your child will need is going to be clinical and medical, but it will be useful over time. Accept that some of this stuff just looks shit. I know some families who have really jazzed up their child's equipment because it just looks so ugly!

It is really difficult when you've got a really poorly child and you don't know how long they're going to live for, but try and be open minded and build your own knowledge base. Sometimes this is really hard to do. Those people you've left messages for, ring them back. Be prepared to chase things up because they won't do it for you. Sometimes you feel like your child's personal assistant. Get a diary! Take notes of who you've spoken to and what they've said they're going to do. It's no one's fault, but therapists have big caseloads and don't realise what a priority certain things are for parents and carers, and how much anxiety waiting causes. You can blink and 3 months have passed. Keep a note of their name, number, timescale, what's going to happen next.

Explore, research and talk to other families. Persevere over time. If something's not working don't just abandon it, try other types of that thing, ask for help or new ideas. A lot of the time families feel powerless, but with more information we can push for things. Knowledge is power after all!



# Katy's story

My relationship to postural care and my body generally hasn't always been great, but it is something that now, as an adult with Cerebral Palsy (CP), I am taking control and ownership of. Growing up, my experiences of the various health interventions were quite negative – often things were done *to me* rather than *with me*.



My early experiences of medical interventions were rooted in the medical model and gave me the message that I was wrong and needed to change by standing straighter or walking steadier. This wasn't helped by being surrounded by non-disabled children who I longed to be like. The interventions designed to improve my posture made the divide more obvious because I had to sit in my supportive green chair whilst everyone else sat in red chairs and I was strapped into a standing frame whilst everyone sat on the carpet.

I understand children don't always have the level of capacity to be fully aware of the reasons for things but I was shut out of the discussion so much that it made me resentful and rebellious. Interventions often felt as if the goal was to 'normalise' me rather than being embedded in my everyday life with a focus on enabling me to do the things that mattered to me. Maybe if I had been given an age-appropriate understanding of why things were needed and been included more, my splints wouldn't have been "lost" on so many occasions...



## Being involved

The saving grace was when I was selected to be in a clinical trial examining whether lycra body suits improved the posture and abilities of people with neurological conditions. This was different to all my other experiences as I was at the centre of everything and my thoughts and opinions mattered. I was the one to set the goals which were based on what was important to me at the time. I was fed up of being left out of playtime games so one of my main goals was to play hopscotch. Whilst this wasn't a key activity which would be vital to my future, the coordination and strength I gained from working towards this goal transferred to other areas of my life. This was a more dynamic approach than my physiotherapy sessions which, whilst sometimes fun, didn't seem to correlate to my everyday life in a meaningful way from a child's perspective.

I worked with a multidisciplinary team who all worked towards my goals from their own specialisms. They saw me in clinic, school and home which allowed them to gain a holistic picture of my life and get to know me as a rounded individual. This enabled them to tailor the program further to my interests such as researching a doll's buggy which would be steady enough for me to use as a walking aid and using my competitiveness to beat my walking targets on the markings in the corridor. I was treated as an individual and never made to feel like a set of symptoms needing to be 'fixed'.

Everything was explained to me and my cooperation was never taken for granted. I was in charge of the process from choosing the colour of the suit to what should be included in the training they gave my school. The suit gave me many benefits, enabling me to stand and walk and improved my abilities in all areas of my life but it wasn't an easy process. The suit was extremely tight, hot and uncomfortable especially as it wasn't designed to be sat in so I had to stand for five hours a day. Therefore, my cooperation was key to its success. In other encounters with healthcare my experience of pain and discomfort was often glossed over, giving me the message that I shouldn't complain, but this time the team made space for me to share this and it was always acknowledged and respected.

When I decided to stop wearing the suit, this decision was respected despite me being a child – it was the first and sadly one of the few experiences of having agency over my body when I was growing up.





## My wheelchair unlocked independence

From the age of twelve my powered wheelchair has liberated me, allowing me to access the world independently. As a large portion of my day is spent in my wheelchair postural care has been crucial for both maintaining my body position and enabling me to access my environment. Sometimes it's a delicate balancing act between the two.

I was once given a seat with large lateral supports to hold my body upright. I found this too restrictive and resented how this made my everyday activities hard as my movement had suddenly been restricted. The team at wheelchair services compromised with a rounded backrest which gave me some support whilst also allowing the movement I valued. I was anxious when they later decided I needed a pommel to separate my knees because I knew standard pommels would be too difficult for me to remove myself which would prevent me transferring and using the toilet independently. They instead worked around my capabilities to design a pommel I could use. This meant the pommel did get used because, for me, sacrificing my independence for my body to be in a good position wasn't an option I was going to take as a teenager.



My wheelchair is a prime example of my social and health needs having to be considered in equal measure. When ordering a new wheelchair there is a conversation about my seating needs as well as the daily activities that are important to me. Dog walking is a central part of my life now - my chair is often covered in a thick layer of mud as I'm not one for sticking to paths, so I push NHS wheelchairs to the max! This has been further enabled through a stable wheelchair with a high level of suspension, and a supportive headrest and seating to hold me in place over the bumps. When deciding which footplates to order the team even worked with my assistance dog to see which were the easiest for her to move so she could continue helping me transfer.

Unfortunately, health and social needs can also be a source of contention when it comes to funding. In recent years I have been experiencing debilitating neck spasms. As the main trigger is reaching and looking up, a physiotherapist recommended a riser should be added to my new wheelchair. This was refused by wheelchair services who classed it as a social need which led me to fight for a year to prove it was a health need in order to have it funded. Since having the riser on my current chair I experience less spasms as I can reach higher shelves with ease as well as feeling more socially included because I can now be at eye level with my non-disabled friends – when you have spent over half your life constantly being faced with people's bums, that's huge!



## CP is for life not just childhood

The input and equipment I received as a child mostly vanished when I turned 18. In addition, there's a distinct lack of research focused on adults with CP. I was told I can only access time limited support when an issue arises which seems a short-sighted approach - the importance of maintaining things is overlooked. Whilst having my allocated six weeks of pain management sessions I asked the physiotherapist if any services could support me long-term and I was told no because my CP wasn't going to get better and I just had to live with it.

The only specialist input I have now is a yearly review at a spasticity clinic. The clinic uses a questionnaire to assess how a person's spasticity impacts on various areas of life. I was particularly impressed to see intimate relationships included in this as no other health professional had broached the subject before despite this being an important activity for most adults. My CP impacts on this but can be alleviated using positioning cushions – something many disabled adults remain unaware of. The team have also respected my preference to use physical activity over medication to control my spasticity and we have worked together to strike a balance. My plan was to try stopping the medication this year as I felt I'd built my physical activity up to a point it was controlling my pain and spasticity well. However, the lockdown and closure of all the leisure services I relied on prevented that and I am still struggling to build my physical abilities back up five months after places reopened.

It is now my responsibility to maintain my postural care, pain management and abilities as much as I can even though I don't have the professional knowledge or financial resources to fully meet this need. However, it has freed me up to find activities which I can do in the 'real world' alongside other people. I am a member at a fully inclusive gym and my programmes focus on my goals and challenging me within my capabilities. I also have a membership at a local hotel's leisure facilities as their heated pool relaxes my muscles and allows me to benefit from the exercise as opposed to the full body spasms I experience in most other pools due to the cool temperature. I have become a huge fan of rock climbing which allows me to be out of my wheelchair and focus on what my body can do. It has given me greater understanding of dealing with my spasticity by allowing spasms to come and pass because going against it makes climbing harder. I see a sports massage therapist and have educated her in how CP affects my body and we work together to manage my spasticity so my life is easier.

By taking on the ownership for my postural care needs I have become more aware of my body and this increased understanding has allowed me to know what works best for me. Hormonal changes significantly impact on my body tone so I know I need to be on top of my postural care during this time to minimise pain and be more forgiving when increased spasticity makes daily life harder, especially as stress increases the spasms further.





I have learned to adapt things so I'm able to do daily activities whilst also maintaining my postural care. To minimise the spasms when I eat, I developed an unhelpful habit of contorting my body into uncomfortable positions to steady my arm. This was taking a huge toll on my body so I invested in a height adjustable table to make eating easier. I know from older friends that CP can put a huge strain on our bodies due to the increased wear and tear which increases with age. I would like to have a family one day so I feel a pressure to maintain my current abilities and posture so this is as easy as possible. However, it can be difficult constantly juggling these needs with my everyday life. I know a long day out in my wheelchair should be followed by an evening not being in my wheelchair but this doesn't always fit into my plans and I pay the price in terms of increased spasticity and pain if I choose to ignore this need. When I don't get the balance right it has a knock-on effect on how I can function in my everyday life.

Throughout my life I've come to understand that postural care cannot be looked at in isolation, but instead needs to be fully incorporated into a person's life and tailored to their goals and lifestyle. The person should be involved in decisions as much as possible and the focus should always be on enabling them to live their best life and access the things that are important to them.





# Tegan and Julie's story



My daughter Tegan is the centre of our family and our world. She has a profound and multiple learning disability, but she's just Tegan to us and we wouldn't have her any other way. She can't sit up, she is peg fed, and doesn't use words to communicate.

For her 13th birthday in January 2020 we had a massive celebration with over 200 people. When she was born the doctor said she wouldn't survive the weekend so when she got to five, we were overjoyed and then when she got a little older we were gradually more and more relieved, but to get her to a teenager is like a weight has been lifted off our shoulders. What a joyful day that was!

## Being an advocate for your child!

As a mum you are in a position where you really have to trust people, especially when they are advising you about the health of your child. I used to be nervous about telling staff or professionals what to do but as a mum you have no other choice but to fight for your child. Now I'll tell them quite easily what she needs. Having Mark, Tegan's dad, beside me is also a source of strength. We make a great team as we are both fighters! As a result, Tegan has a really good life and health and we are very proud of this.

All I want is for Tegan to be happy and well. Your health is so important and children like Tegan teach you that if you haven't got good health, you will struggle in other areas of your life.





## Postural care is 24/7!

Postural care has been a lifesaver for us because it has kept Tegan well all these years. It's very much an everyday thing: it's a 24/7 regime and it comes with a lot of kit! When she's sitting we make sure she is sitting in a good position. She's has a wheelchair with a specially moulded seat. When she's lying she has a night time positioning system in a profiling bed. She also uses a standing frame and splints every day at school. She has support from a specialist team led by Suzanne Carter from Mid Yorkshire NHS Trust. They support her with all of her postural care including annual hip X-rays, any support she needs with her wheelchair, standing frame or the splints she has for her feet and one hand when they are not fitting well, and a sleep system which she's had from when she was very little.

Making sure Tegan has good postural support makes me feel as a mum like I've done a great job. She is keeping her body shape and that means the world to me and her dad. We keep up with this regime otherwise she could risk going in for surgery and we don't want that. We know that some parents find it really difficult to keep up with a 24 seven postural care regime but for us it's like breathing; it's become so normal and every day. We also know that for some young people surgery is necessary but we honestly believe having a planned approach to postural care has stopped her having surgery. We are committed to postural care because we don't want Tegan in pain and know that when her posture is in a good position, she's pain free.

Tegan's routine is a lot to keep up but it keeps her well so we are so grateful. Although she has a set routine at school and at home, there have been real difficulties over the years like chest infections and other illnesses so it's been up-and-down. We have learnt to take every day as it comes.

## Postural care from an early age

For the first few years of Tegan's life she was in and out of hospital so the family had to learn pretty quickly how to carry on in everyday life. We had to really think on our feet and we've been thinking on our feet ever since. We were fortunate because ever since she was two years old she's had postural care support.

We had great support from Suzanne Carter and her team at Mid Yorkshire NHS Trust over the years in relation to Tegan's postural care. We know she's at the other end of the phone if we need her; she's always there for me. We also know that the support we get in this area of Wakefield is fairly amazing and the equipment we get access to as well.

## Being active

Tegan has always loved having fun and being active. As Tegan has high muscle tone, regular postural care has helped relax her muscles and this has meant she is able to do things like swim in school, which she does every week under normal circumstances. These active routines keep her in good shape and swimming in particular relaxes Tegan a lot and helps with the high muscle tone.

We've also got two dogs Bruce and Beau her and they really keep her calm. She loves watching the puppy and this keeps her really amused. Staying calm is important as she can go into spasm.



## Being sociable

Tegan is really sociable and she's always out and about. It can be hard for her to enjoy the same things as other young people but nevertheless she still goes bowling, she uses the hydro pool at school, she goes out for lots of walks and goes on holiday to adaptive places in England. I've got a portable hoist for when we go to some places. When we go out you want to see the amount of equipment we have to take with us. It's a mammoth task. We take oxygen, a nebuliser and a sats monitor just in case we need it as well as a feeding pump and a suction machine.

She's at the heart of our family and everyone loves her. Her sister Jessica won a champion child award for supporting her sister so well. Jessica was 14 when Tegan was born and she was going through her exams at the time. When my grandson was small he used to lie on the floor with her and read her stories, he still does this now, he's 9 now and still plays noughts and crosses with her. He plays football and he likes mom and dad to take Tegan to watch him.

As Tegan is incredibly sociable she gets on really well at school. She loves being with others but she particularly likes being with boys more than girls. So in her class which is a mixed gender class at high school she has a great time when she gets to sit by lads.



## A live wire!

Tegan is a live wire and needs to be occupied, as she gets bored very easily. Sometimes she doesn't sleep a great deal, so me and her dad take it in turns to get up at night. We are also very fortunate to have carers coming to support us four nights a week as not sleeping puts an incredible strain on the family, as much as we love her.

The carers that come in at night are great. We employ one local lady from down the road who is like Mary Poppins; she is just wonderful. We also have some great staff who come in from the NHS.



## A great communicator!

Tegan has a fantastic character and although she doesn't use words to communicate, she communicates really well in her own way and vocalises whatever she wants.

For example, if she is in the living room and she wants the television switched to another channel like the music channel, she'll make it really clear with the noises that she wants the TV turned over. She'll start with some fairly vocal noises and they turn into a moan and then if she doesn't get the correct channel in exceptional circumstances she might cry. Although she doesn't cry a great deal because she is a very happy young woman. When my grandson comes over he turns the TV over to listen to the football results. This is a mistake! Tegan is never very happy about this and makes this known through the ways she vocalises.

When her sister comes on the phone and I put the phone to Tegan, she vocalises as she is happy to hear her sister. When she sees her sister her eyes light up. I know that Tegan understands things really well from the way she responds to me.

Tegan uses eye-pointing in school. At the moment she can choose from three different things by eye-pointing. She is very clear with the school and tells them through her communication what she is happy with and what she's not happy with.

## Being a teenager

Tegan is very much the young teenager who wants to be in control of her life. Just because she is disabled and doesn't use words to communicate, doesn't mean she is any less of a teenager. She's started high school 3 years ago. I couldn't wait for her to go to high school because she'd really outgrown her primary school and wanted more of a challenge.

Tegan had a great time at her birthday celebrations and I knew she was really happy because she really likes to socialise but I also knew that she wanted her own space so at the end of her celebrations when she came home she was so relieved. As soon as she got home she was laughing and just smiling to herself. She just wanted a lie down with the music on and she kept continually laughing. What a day!







## Creating a home around Tegan's needs

We work as hard as we can to make Tegan's living environment really suitable for her. We live in an adapted bungalow and we have created a sensory garden and a sensory room for Tegan. We can honestly say hand on heart that we've done the very best for Tegan and we know as a result she's really happy. This year we are developing a fairy garden outside of her bedroom window.

We've made loads of sensory things for Tegan over the years. She has a projector where lights are projected onto her wall which she loves. She also loves fibre-optic lights. When we built the sensory garden we made the fences more interesting by cutting shapes and making things with bottle stops like a snail, fish and a giraffe. In the garden she has a swing, sandpit a roundabout and the adapted trampoline that holds a chair. Tegan has books read to her and she'll touch the symbols. She also loves her tablet!



Although Tegan has a great life, we have learnt to take every day as it comes. We work really hard to keep Tegan in a good position 24/7 as we know this keeps her healthy and if she is healthy, she is happy.







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