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The Newsletter of SWAN UK

Life Without a Diagnosis



Contents

- 2 SWAN UK Update
- 3 Living Without A Diagnosis : Information for Parents
- 4/5 Family Stories
- 6/7 'I don't know how she does it' - Coping with Stress
- 8/9 Tomcat Trikes 'Turn2us' - Supporting Families in Financial Need
- 10 Special Siblings
- 11 Q and A : Your Questions Answered
- 12 Glossary : Education

SWAN UK is a project run by Genetic Alliance UK offering support and information to families of children with undiagnosed genetic conditions.

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If you are interested in becoming a member of SWAN UK contact Lauren on 0207 704 3141
SWAN@geneticalliance.org.uk
Facebook www.facebook.com/SWANchildrenUK
Twitter @SWAN_UK
www.youtube.com/SWANchildrenUK



Genetic Alliance UK
Supporting. Campaigning. Uniting.



SWAN UK Update

It's been a busy few months for SWAN UK since our first newsletter came out. Word is spreading about the support we offer and our community of families continues to grow.



Map showing members location

The SWAN UK Facebook group is **thriving and it's brilliant to see so many friendships developing**. Parents are logging in regularly to share the good times and get support for the not so good times. The Facebook page is steadily getting more attention so if you are a Facebook user be sure to come and find us at [facebook.com/SWANchildrenUK](https://www.facebook.com/SWANchildrenUK) and give us a 'like.' Or if Twitter is more your thing come and follow us @SWAN_UK.

The project blog swanuk.wordpress.com has developed to include a members only area and lots of families are now contributing posts to share their experiences. There are now a number of videos on our YouTube channel where you can watch videos made by other families about their children and how wonderful siblings can be [youtube.com/SWANchildrenUK](https://www.youtube.com/SWANchildrenUK)

Families often talk about how they feel incredibly isolated, even within **the disabled children's community**. We were delighted therefore when the award winning site Netbuddy.org

set up a page of tips specifically for parents of children with undiagnosed conditions - you can check them out and add any tips of your own at netbuddy.org.uk/

In September the SWAN UK bike riding team were blessed with favourable weather and managed to complete the London to Brighton bike ride raising about £1250 towards future editions of the newsletter. A number of families have also started volunteering to fundraise so the project team are working on putting together a fundraising pack with tips and suggestions that should be available soon.

Also in September the project Advisory Committee met for the first time. Made up of parents and professionals, the meeting was a great success with lots of discussion about work we can do in the coming



The SWAN UK bike team at the London to Brighton finish line

UK families which were broadcast across the country on the 13th of **December**. We'd like to say a very big thank you to all the families who took part. This is a fantastic way to raise awareness of the issues you all face and hopefully attract us lots of new members.

If you are the parent of a child with an undiagnosed genetic condition and would like to join us please contact Lauren, the project coordinator on 0207 704 3141 or SWAN@geneticalliance.org.uk



months to make things easier for families - including a leaflet for families about how to get a referral to their Regional Genetics Service.

As the picture above shows, SWAN UK has also celebrated its first playdate with two of our families meeting up to feed the ducks in the park. As our community continues to grow we hope to have many more pictures like this to share!

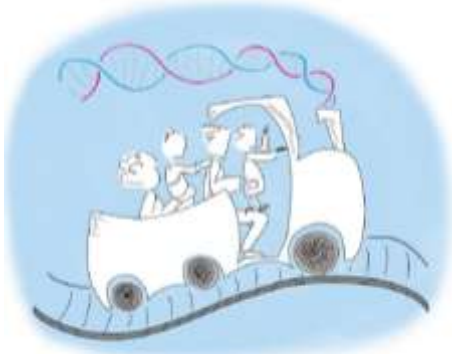
Perhaps the most exciting thing to happen however were the ITV interviews with a number of SWAN

SWAN UK is funded by the National Lottery through the Big Lottery Fund



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Living Without A Diagnosis : Information For Parents



Doctors and specialists

"If you are able to go in and say, 'He's got so and so disease' then they go 'Okay that is fine,' but you can't. You have to go back from birth when you were first told, and explain the whole thing." (Parent)

When your child is undiagnosed it is likely you will see lots of doctors. Going to lots of hospital appointments and seeing different specialists can be a frustrating and time-consuming experience for some parents. Some parents have talked about how they find this very difficult. They say it feels like their child is 'fragmented' into different pieces depending on which doctor they are seeing. It can also be a very negative process as the focus is always on 'what's wrong' or what the child cannot do.

Often, a number of different specialists are involved and children are referred from one specialist to another during the search for a diagnosis. Parents sometimes feel that communication between different specialists is not as up to date as it should be. Many take an active role in keeping their GP and other specialists such as their paediatrician and geneticist up to date with any tests done, results given or specialists seen.

"I carry all the letters I've received from the paediatric consultant and geneticist to every appointment, and

sometimes those letters haven't yet been put on file. Sometimes I have to pull out the letter and show it to them." (Parent)

Remember that you are ultimately **the expert in your child's condition**. If there are developments in your **child's condition**, or if **new milestones** are reached, you should keep a record of these to discuss with the specialist at your next appointment.

Advice from parents

- Take a notebook to all your appointments so you can make a note of anything you think is important. If there is a word you don't understand, ask the doctor to write it down for you so you can come back to it later or discuss it with other professionals.

- Make sure you receive copies of all the letters sent by different specialists, to ensure you are kept up to date and informed

- Take responsibility for ensuring that all the different specialists, including your GP and healthcare worker, are kept up to date of any appointments and developments.

- Keep a paper trail. Keep copies of all letters, appointments, test results, etc. in a folder.

- **Keep a record of your child's progress.** Keep a diary, take photos and videos if possible. As well as being a useful record to show to doctors, it can also be comforting to look back and see the progress your child has made.

- **Create a 'passport' for your child.** This can be a series of flashcards that explain things such as your **child's health history**, what your child can and cannot do, medications that they have tried or are currently taking, any health problems they have etc. These can be taken to appointments and are a quick and easy way of passing on information to the specialist about your child.

- If you feel that you need to see a specialist, or if you think you may **have somehow got 'lost in the**

system', don't be afraid to phone and find out. Ask to speak to the **doctor's secretary to find out what is happening with your child's appointment.**

- Whenever you think of a question that you want to ask the specialist, write it down immediately so you **don't forget it**. A number of parents, for example, kept a note-pad handy on their fridge, to jot down their questions.

- **Don't be afraid to ask your specialist questions** that are concerning you, however silly or insignificant you think they may seem.

- Take someone else with you to your **appointments as a 'second pair of ears'**. This person can take notes of the discussion you have with the specialist. These can be a great help later on when you try to remember what was said.

- If possible, try to stick with the same **professionals so you don't have to keep repeating your child's life story.**

This information was taken from the **Genetic Alliance UK Leaflet 'Living Without A Diagnosis'** which is available to download from geneticalliance.org.uk/docs/living-without-a-diagnosis.pdf



Illustrations by Rebecca Kent

Josh and Michael's Story

Hi, my name is Sharon, we live in Cumbria and I am single Mum to Liam (18 nearly), Josh (13) and Michael (11 nearly). Josh and Michael have what we think is an undiagnosed genetic condition.

Josh was born 12 days early after a problem free pregnancy. He was born very quickly and was 7LB 1oz (same weight as his brother Liam), Josh was a VERY placid baby, and he was referred to a paediatrician at around 12 months old because the back of his head was so flat. He had a CAT scan and everything was as it should be. I had mentioned to the paed that I was concerned about his development, he left everything to the last minute to achieve, and he showed little interest in his surroundings and was just lacking **that, I don't know, zest and interest in life!!** But of course he had done everything within the guidelines so they told me not to worry and that he was fine.

By this time I was pregnant with Michael, another problem free pregnancy, on my 17 week scan they picked up that he had talipes (clubfeet) but could find nothing else wrong. So Michael arrived 10 days early and weighed in at 6lb 15 1/2 oz, all was fine, except for his feet which were quite severe and would need surgery at 6 months for correction. Michael had a choking episode at 5 days. Luckily the midwife was there, we were blue lighted to hospital and SCBU. (Special Care Baby Unit) No cause was found and the next day they told me to take him home, I refused. He went blue again, they sucked his nose and mouth out and the amount of **"gunk" that came out was gross, that was the reason for it, they hadn't** sucked him out properly at birth!!

We had to go to the hospital 3 x a **week to have Michael's feet** stretched and new splints made, Josh was seeing SALT, OT and I had started the statementing process. So, busy times and no time to think really. Michael got to 6 months and so the surgery on his feet began. He



had 3 ops a fortnight apart. By this time I knew there was something else wrong, the nurses kept asking me if Michael wanted to sit up and play.

He didn't play and he couldn't sit up, he was like a bag of jelly. So the referrals began.

The professionals were now interested (no surprises there then!!)

There were 2 other undiagnosed children on my side of the family so the thought has always been that it is x chromosome linked. All of the children are different but they all have ataxia and learning difficulties. My niece also has 3 children, her youngest son is very much like Michael, he is also undiagnosed.

All of the tests that the boys have had have come back normal, except **Michael's last MRI which showed** moderate cerebellar atrophy. His CGH array showed a duplication on chromosome 8 but I was then tested and I have the same duplication so it is not thought to be the cause.

Michael has always had a rather odd head and eye movement, nobody could tell me what it was so I **asked to see an expert in children's** movement disorders. So I went to my GP and managed to get a referral to the person in Oxford that Ataxia UK had recommended. She thinks it may be a dystonic movement but there is no test to confirm it.

We had had just about every test in the book. Our clinical geneticist from Manchester had put the boys on the GOLD study in Cambridge, the woman in Oxford put us on another 2 research projects, one for ataxia and one for brain malformations. At least with research studies someone is still looking instead of throwing their hands in the air and saying you probably will never find out and maybe I ought to accept it!!!

So today, Josh is in mainstream school and doing well with 11 hours support, he still has a flat head, some learning and organisational problems, auditory processing difficulties, gross and fine motor problems, low tone and social immaturities.

Michael, is in mainstream school with full support. He has severe learning difficulties, low tone, hyper flexible hips, knees and hands, very unclear speech, fulltime wheelchair user, double incontinence, wears glasses (well should do but is refusing to at the moment), dysmorphic features **(don't you just love that word?)**

I am presently trying to figure out where he is going for secondary school, I am thinking dual placement at the moment!!

So life has been a rollercoaster, life is pretty full on. I left my husband behind on the way, very sad really but there is only so long you can carry an ostrich that refuses to pull his head out of the sand. Sounds a bit hard hearted but we lived separate lives in the end and was actually a relief when we separated.

My 17 year old has tagged along through all of this. He is now at college and doing well. I really think that siblings of special needs children grow up with an extra quality, he has the patience of a saint. He has an empathy with other children that I **don't think his friends have and he is** such a caring person (well for a 17 year old anyway). He has attended young carers and the online support group that I have belonged to for years has a sibling section. He has made some fantastic friends on there **that "just get it".**

My main reason for searching for a diagnosis is for Liam, he has already **asked me, "When I have children, will they be disabled"?** At the moment I can't answer him but one day hopefully I will be able to.



Lexi's Story



Before I had children I'd always thought, in as much as I'd ever thought about it, that if you had a disabled child you would know from the start. Possibly you'd find out at the scan, maybe not until birth, but you'd know. A doctor would sit you down and tell you, and it would be a shock, but at least you'd know. And you'd know what would happen next, probably not in detail, but you'd have a clear idea of what to expect. This is one of many things I thought that have turned out to be wrong!

My second child, my son Lexi, was born in 2002. It was a very fast labour, he arrived within seven minutes of my getting into the delivery suite of the hospital (and five of those minutes were me arguing with the midwife because I wanted pain relief, she said there was no time!).

After the birth both my body and Lexi's were a bit in shock and exhausted. I couldn't stop vomiting, his temperature dropped and then he slept for 24 hours. He seemed a "normal" baby. At the hospital they assumed he was late because he was hairy, in fact he arrived two days before my due date, they decided my waters must have broken unnoticed earlier in the week.

Nothing major happened to make us question that he was a "normal" infant. He never managed to move from breast to bottle, which was a strain when I had to return to work. But other than that nothing. At 18 months my health visitor was concerned that he wasn't walking, but his sister hadn't walked until late and by the time we'd been referred to a paediatrician he was toddling a bit. Shortly after he turned two we

realised he had intermittent deafness, which was diagnosed as glue ear, and he had grommets fitted. It all seemed typical childhood stuff.

By the time he started nursery his speech was delayed and he was seeing a speech therapist through Sure Start. This was put down to the hearing problems. But I was starting to worry about how much difficulty he was having compared to his peers. His movements were clumsy, he struggled with things other children found easy, but it was hard to put my finger on exactly what the problem was. I wasn't helped by his teacher, who saw every problem as deliberate ("Lexi refused to put his socks on again today" she would report when he was not yet 3, even now at 9 Lexi struggles with socks).

I struggle to remember the order everything happened in. Somewhere around aged three we were referred to a paediatrician. Somewhere around aged 4/5 she sent him for a DNA test, to rule out a known condition that has some, but not all, similarities with Lexi's condition. It took a long time. Meanwhile he was falling further behind his peers. The DNA result finally came, and showed an extra chromosome, but not the one they were testing for. They knew it was there, but they couldn't say what it meant.

At aged 5 it was agreed that Lexi presented as dyspraxic. At least I had something to look up then, some way to understand it.

No one mentioned learning disabilities until he was 7. When they said it I felt like an idiot for not having realised sooner. But so many people had told me for so long that he would catch up, it never crossed my mind to doubt them.

We returned to the geneticists when he was 8. Since we last saw them they'd been able to identify that his extra chromosome is made up of genes from chromosome 4, but isn't linked to any known condition. They asked permission to put him on an international database. No one else on it has this combination of extra genes, yet.

Now 9 Lexi is a happy and friendly boy. His speech and behaviour are typical of a younger child (and take it from me, you get a lot more public sympathy when your cute toddler throws a huge tantrum than you do when your hulking nine year old does!) He is dyspraxic and dyslexic and has real issues with gross and fine motor skills. He has problems with sequencing, he struggles to differentiate fact from fiction, and he has no concept that a belief is different to a fact. We recently had to adjust his IEP (individual education plan) when a speech therapist pointed out that Lexi will not be able to say that he doesn't understand, because he doesn't understand the concept of understanding. Concepts that we all take for granted are really difficult for him. All the professionals involved agree that the chromosome is the most likely explanation for all this.

So what are the hardest things about having a child with a syndrome without a name?

- I can't plan for the future. I don't know if he'll keep being a few years behind his peers or if he'll "level out" where he is now. I have no idea what happens next.
- His sister has had to take on too much too young. She's the one other children go to for answers about her brothers behaviour, and there are no answers to give. And he needs more time, so there's the guilt of not spending as much with her.
- People assume if there isn't a name for it then it isn't serious. Or isn't as serious as things there is a name for. There are other hard things. It IS hard. But it's worth it. I don't know what's going to happen, but I know we can get through it, and we'll have fun.



"I Don't Know How You Do It" Coping With Stress

Stress affects everyone differently and we all have our own individual coping skills. The way stress impacts us has a lot to do with how we perceive it. Some people are naturally positive and solution-oriented while others tend to lean towards the negative and fall victim to circumstance. We all find our own way of dealing with the abundance of stress in our lives whether it be through our spiritual beliefs, nutrition, exercise, meditation, art, medication, social support and the list goes on. There is no right way to manage stress but some ways may be healthier than others.

Our bodies and minds are connected in such a way that what happens with one affects the other. If you are rundown in your body, you will find that your ability to mentally and emotionally cope with situations goes way down as well. And the reverse is true, too. If you do not tend to your emotions and your mental health, you may find that you experience chronic pain, headaches or back aches, chest tightness, heart palpitations and the list goes on. Sometimes it can be a **'what-came-first?' scenario.**

For example, while in the midst of this hell hole of sleep deprivation, I have a mantra that I say to myself which goes along the lines of, **"This will pass. We will get through this. We will survive."** I could just as easily tell myself, **"This is horrible. What if we never get sleep? What if I get sick? What if I am unable to care for Meredith?"** I would be lying if I told you that those "what if?" thoughts never crossed my mind. Oh, they do, especially when my

resilience is down as it has been this week with no sleep while fighting a head cold. I have learned, though, that any sentence beginning with **"What if?"** is usually an anxiety producing thought. It is a thought about an imagined possible future and it serves no purpose but to get my nervous system rattled. The truth is: I KNOW this stressful time will pass as all others before it. I know I will sleep again and I know that the things we imagine happening are often far worse than the reality of dealing with whatever happens. We are much stronger than we think.

So how do I, personally, do this intense care giving day in and day out? First of all I would say I am very motivated and solution-oriented. Perhaps, this is genetic or has something to do with the Irish blood that runs through my veins. It could also be that I am simply stubborn and I refuse to let stress or life circumstances bring me down. There have been times, though, where it seemed that no matter what I did, my body and mind could not handle one more minute of stress. In those times, I may have to resort to a stiff drink and a cry. Never underestimate the power of a good, snotty bawl.

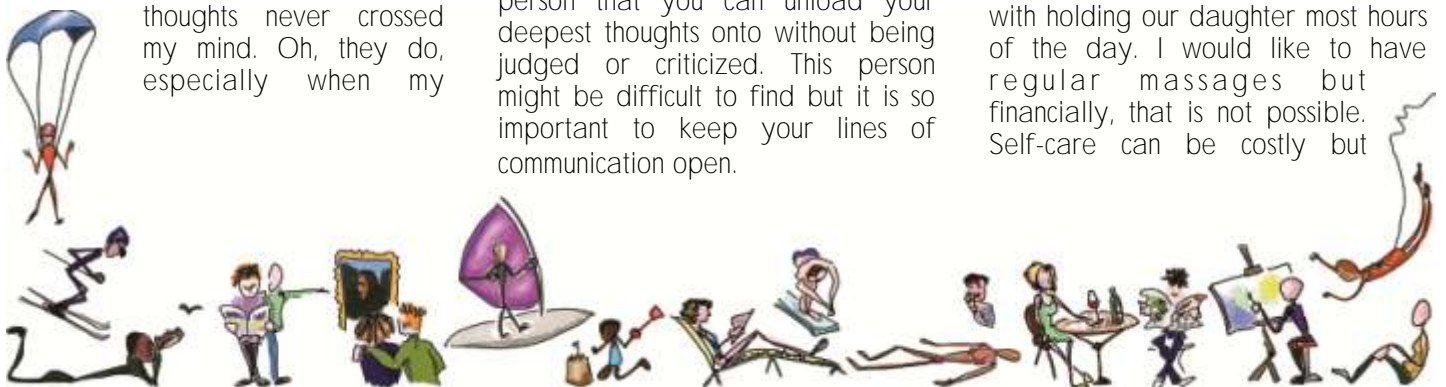
I think that it is critical that we have social support whether this be through our family and friends, other parents who experience similar things or even support through parent groups through local agencies or private counselling as needed.

It is so important to have at least one person that you can unload your deepest thoughts onto without being judged or criticized. This person might be difficult to find but it is so important to keep your lines of communication open.

I try to take care of my physical health as I know the strain that stress can put on the human body. Exercise has been a big part of managing my stress although I have recently developed exercise-induced asthma (likely stress related ironically!) and so I have had to make major adjustments to my exercise regime. I am knowledgeable about the impact of food/nutrition on our bodies and minds and so I try to follow a whole foods diet as much as possible avoiding fast and processed foods, sugar, caffeine, alcohol and simple carbs. I am gluten sensitive which makes it easier to pass up the treats that most of us like to consume in times of stress. I do have to admit that when the stress is high, my ability **to refuse a Reese's Peanut Butter Cup** is low.

I think that we can derive the majority of our nutrients from good quality food but when the body is taxed from too little sleep and too much stress, you might want to consider supporting your body with supplements that are traditionally helpful in strengthening your ability to cope with stress. I take fish oil everyday (also a depression fighter!), a high potency, B-complex vitamin, extra B12, Vitamin C and Vitamin D. At night I take a calcium/magnesium supplement. In the past when I am feeling like I need some extra help, I have visited a Naturopath who has recommended traditional herbs which help support the adrenal system making it more resilient to stress.

Regular visits to our chiropractor have been a necessity as we have so much additional strain on our backs with holding our daughter most hours of the day. I would like to have regular massages but financially, that is not possible. Self-care can be costly but



there are ways to make it affordable. Going for walks and stretching afterward is free and can do amazing things for your mood and your sense of well-being. We do not spend money on vacations, expensive toys or gifts so we will spend a bit more on ways to keep ourselves healthy as in the long run

and I did not have the courage to **say "no" even to things that I might** really want to do. If these things will deplete me of energy that is needed for more important things, I have to pass them up. I used to be very independent but our daughter taught me that asking for help was a sign of wisdom and not weakness. I also

learned that people are always ready and willing to help if you just ask for it.

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this will cost less in more ways than one.

Recently, I have decided to incorporate meditation and relaxation exercises into my daily routine although I am sure this will initially be challenging. I am willing to try almost anything to keep myself well.

And finally, there are two important things that all parents (whether your children have special needs or not) need to master. These are: 1) Asking **for help** and 2) **Saying "No."**

There is no way, I would be in the shape I am in 8 years into this if I did not ask for help when I needed it

Tips from other parents

"My coping mechanism is running or exercise of any sort. No matter how tired I am, fed up, stressed out or down - if I can manage to drag myself out for even a 20 minute run I feel a million times better afterwards. I have more energy and just generally feel more positive."

"Just taking a deep breath and looking at the most beautiful thing I have ever done in my life - my daughter - and realising that all the stress, heartache and sometimes panic is all done for her, to ensure she has a better life, keeps me positive, it's all for her!"

To cope with stress, I write down exactly what is stressing me and why it's stressing me...for example if S is having a tantrum (which are getting more and more frequent and more severe) I'd write down that her screaming and shouting at me with no apparent reason and her refusal to do anything is stressing me, for why it's stressing me it would be that I have no idea why she is so angry and upset to be behaving in the manner she is...I'd then close my book and leave it be for an hour or so - go have a bath, watch a TV programme, read to the children...then go back to the book and see if I can come up with resolutions or reasons why she is doing **what she is...."**

Tomcat Trikes

A lot has happened since our last appearance in the SWAN Newsletter in 2003 - now it is not just trikes we have been busy building to help children and young adults with special needs. We also build school and workplace chairs and safeguard and travel beds. At Tomcat, we like to approach from the individual's point of view... no two people are the same, so we don't build two trikes the same!

Bob Griffin, now the MD of Tomcat, first became interested in special needs when he met his partner's son, Tom. She would have loved Tom to ride a trike, to give him a safe activity outdoors and to tire him out so he would sleep at night, but though physically able, he had severe learning difficulties and therefore no idea about steering, braking or the Highway Code! Being a professional engineer, Bob reasoned that if Tom couldn't make these decisions himself, then he must design a trike where Anne, his partner, could steer brake and control speed for him. Anne thought it was wonderful idea and suggested that she could control things from behind to avoid distractions and give Tom a sense of self-achievement and independence.

Tomcat don't think about launching new products until we met someone that inspires us to do so. Our new Tamara Trike is named after the first person we built it for; a girl who needed a swivel saddle and a back rest that tilted out of the way while she got on and off. Because of her, we can now offer trikes to hoisted cyclists: imagine being in a bed or a wheelchair all your life then suddenly being able to go out on a trike!

Sometimes we hear parents or carers say, "My child can't ride a trike," but in our experience, it is rarely true. With the right trike - one that has been custom built especially for them - they can! Self-esteem is so important, as children with special needs want to succeed, as we all do, don't we? Children with physical difficulties may reject a trike for



many reasons, ranging from anxiety to pain in over stretched muscles; well, you wouldn't want to ride a big heavy mass produced trike when you have poor muscle tone, would you?! Nevertheless, it is always the child who gets the blame and never the trike. In reality, it is the other way around: you can't change the child but you can always change the trike.

We also met a man called Ray with cerebral palsy, who became our inspiration for the multi-gear trike, The Roadhog (it ain't for making friends, it's for over-taking!), which can still be taken apart into two for easy transport and storage, so it can be taken far and wide for adventures. The Tomcat Trailer Trike has been a firm favourite for years. The trike part is for independent cycling which provides therapy and



exercise and the trailer bar means it can turn into a tag-along to fit behind mum or dad's bike. It can attach to almost any standard adult bike so that all the family can go cycling together and you know your child is safe and having fun watching the world go by behind you.

The latest excitement at Tomcat has been around Tomcat's new travel bed, which is perfect for holidays or respite care. We know how hard caring for someone with special needs can be; sleep can be a huge issue all on its own. A child gets out of bed in the night, starts pulling off the wall paper, falls over, hurts themselves, or something similar: and it is a worry. A bed like a Tomcat Safeguard bed, designed to look like a decorative cot is great for home use, but what about when you want to take the family on that much needed holiday, or when your child needs to go into respite care while mum is in hospital having a baby? Where do they sleep then? Bob Griffin has been designing and developing the Tomcat Transportable Bed for six years to give carers and parents that much needed helping hand. This bed will give parents and carers the freedom to be able to go on holiday, to see granny or when respite care is needed - it is strong, lightweight and comes apart and fits

together in just minutes with no spanners! Once taken apart, it fits into two suitcases and straight into the car! And it's as easy as that.

Tomcat have also won awards for our work chairs, which are designed to enable independent sitting at a workstation - in the office, at school or at home. The chair was developed alongside OTs and makes on and off transfers simple and all manual handling by support staff is removed. It is easy to set up and take from



class to class and is designed to look just like a stylish office chair, so it fits in with any busy work place!

For more information, including how to look for funding to buy a trike, get in touch! We would love to hear from you.

tomcatspecialneeds.co.uk
[facebook.com/Tomcat.Trikes](https://www.facebook.com/Tomcat.Trikes)
@TomcatSNILtd
info@tomcatuk.org
01452 616900

"We found out about tomcat trikes when we attended Kidz south for the first time in July 2010!! We were really impressed with the trikes and felt that Jonah, our profoundly disabled son, could really benefit from one! So we arranged a visit from the tomcat rep to visit Jonah's school! It went really well and we decided along with Jonah's physiotherapist that it would be a great piece of equipment to strengthen Jonah's legs! We looked into funding and contacted cerebra who funded the majority of the bill, with us making a small contribution! The company have been so helpful and even got the bike made in time for Jonah's 5th birthday! Jonah loves his bike and it now means we can all go out as a family for bike rides!!!" (Jonah's mum)

Supporting Families In Financial Need

If you're looking for a way to check that you and your family are receiving all the money available to you through welfare benefits, charitable grants and other financial help, then Turn2us could be the answer you're looking for.

Turn2us, part of the charity Elizabeth Finn Care, offers a free, accessible website – www.turn2us.org.uk – designed to help families on low incomes find appropriate sources of financial support, quickly and easily, based on your particular needs and circumstances. It does this by providing several different tools.

The website offers a simple Benefits Checker to help people with

dependent children check that they are receiving all the welfare benefits they are entitled to. Clear and concise information is provided on welfare benefits, who can claim, how much can be received and how to apply.

A Grants Search contains the details of over 3,000 charitable funds (national, regional and local) that may be able to provide financial support, in the form of one-off or regular grants and other services, such as new goods (cooker, washing machines or beds) or even helping with the cost of going away on holiday.

There's also a 'Find an Adviser' tool,

which can help you to locate practical, face-to-face support in your area, for example, to assist with benefit claims.

The Turn2us website also offers a wealth of information and resources on subjects related to welfare benefits, grants and managing money.

You will find Turn2us an invaluable service to ensure that you and your family are not missing out on any vital financial support.



Special Siblings



Evie helping Freddie

I was inspired to write this post at the end of a day when I had been really struck by how much my daughter misses out on because the focus is always on her brother. I have two children. My daughter is eleven, and will be moving up to secondary school this year. She is funny, clever and confident. This week she was a star in her school leavers assembly. Not only was she up on stage talking and singing, she also wrote one of the sketches. She has a real gift for words, and for comedy. At the end

of the show, while all the other children were being congratulated and given hugs by their proud parents my daughter, uncomplainingly, chatted to her teachers while I consoled her younger brother, who was having hysterics having been overcome by the noise, the emotion and the fear of his sister not being at school with him any more. I was gutted that even on this huge and important day for her I **couldn't put her first, but she was fine with it, because she's used to it. Because my disabled son doesn't handle change well his sister has to take change in her stride.**

Like any sibling of a disabled child my daughter has a whole raft of issues and challenges to deal with that the majority of her peers just **can't comprehend. And because her brother is a SWAN child (he has a [Syndrome Without a Name](#)) she has to cope as much as I do with the uncertainty and the lack of answers.** She has to respond to a barrage of questions about her brother wherever **we go, and children aren't as tactful as adults in phrasing their questions**

carefully. I find it hard to explain that he has complex special needs caused by a rare chromosome abnormality so unusual that, not only **is there no name for it, there also isn't** anyone else (diagnosed yet) with the same abnormality. Imagine being a child having to explain all that to **other children who don't know** anything about chromosomes or learning disabilities.

My daughter is quiet and thoughtful, and usually only lets her funny side be seen by people she's used to. **People think she's very serious, but then she'll lick her own elbow and stick her tongue up her nose (though not at the same time!) just to see their reactions.** She has a sense of humour **that's pure Monty Python, and a sense of justice that the real world rarely matches up to. She's just as special as her brother, and I'm so proud of both of them."**

This blog was originally published at lexilil.wordpress.com/

Sometimes by Rebecca Elliot

"There are a large number of books on the market that are fantastic at explaining about a variety of special needs to children of all ages and abilities. Autism, Down's syndrome, ADHD and dyslexia are all covered, but it starts to become more difficult to find something if your child is undiagnosed and doesn't have a 'label'.

I trawled the internet looking for books that would cover the difficulties we faced **as a family to explain to 'Special Sibling'** about his younger swan brother. Special Sibling is just two and a half so it needed to be fairly basic.

I contacted various organisations and charities for their advice. I looked at the individual difficulties we faced such as epilepsy, but even books about that **didn't really cover the things I wanted explained.**

I prioritised, what EXACTLY do I want this book to focus on? I decided that the thing having the biggest impact on Special Sibling **wasn't the unnamed syndrome as such, nor the epilepsy per se, nor the oxygen in the house or the fact his brother couldn't walk or talk but the repeated hospital trips and admissions.**

I contacted Sibs sibs.org.uk/ a charity that supports siblings of disabled children and adults. I explained my predicament and they recommended the book **'Sometimes' by Rebecca Elliott.**

I read it alone at first and I cried. It is a fantastic book, beautifully illustrated by the author and was perfect for my needs. It focuses on the relationship between Toby and his big sister Clemmie who spends time in hospital. Although not stated outright, the pictures and text imply Clemmie is non-verbal, that she is physically disabled and tube fed. But it is the wonderful loving relationship between brother and sister that is so heart-warming that made me cry; how he worries when she gets very poorly, how they play delightfully imaginative games in her hospital bed – sailing to far off lands, how he throws a party when she comes home and how Clemmie cuddles him tightly. The language is simple and the pictures are a great tool **for discussion appropriate to the child's level of understanding.** There is a page where they meet friends on the ward and a variety of injuries, illnesses and disabilities are illustrated.

For now, Special Sibling enjoys looking at the pictures and laughing at the idea of taking a dragon to hospital. I have pointed out similarities between Clemmie and his swan brother – the special chair and the tube feeding, and he has questioned whether his brother is brave, like Clemmie, when he is in hospital. But as he gets older, there are other discussions that can be had – why



Clemmie isn't dancing at her party, what reasons she could be in hospital, how we can tell that Clemmie loves Toby even if she can't say it.

'Sometimes' is a wonderful book and is perfect for Special Siblings. It highlights the positive aspects of the relationship between brother and sister but the differences between theirs and a typical sibling relationship is apparent through the pictures and some of the text. It opens up the opportunity for discussion then, if this is appropriate, but if not, the story and the delightful pictures are **enchanting anyway."**

Glossary - remember to keep this page as it will be different each edition

Academy: Publicly funded independent school.

Advice: Reports that are written about a child's special educational needs. They can be written by a parent, teacher or other professional - like a physio.

Advisory support teachers (AST): Specialist teachers who offer advice to parents and teachers about a child's special educational needs and what support they need. It is especially common to have these for children with hearing or visual impairments.

Appeal: Parents have the right to appeal against some Local Authority decisions they are not happy about, such as a refusal to assess a child's special educational needs.

Amendments: When a draft Statement of SEN is issued by the local authority parents have the right to ask for the statement to be amended if there is anything they don't agree with or that they think is missing. The Local Authority might not always agree but you should read the draft carefully and write to them about anything you are not happy with.

Assessment of SEN: This is also known as 'statementing.' The first part of the statementing process is the Local Authority deciding whether or not to proceed with assessing a child's special educational needs.

CAF: Common Assessment Framework - This is a form that you can be asked to be filled out by any professional working with your family if you feel your child needs extra help in any area of their life. It is a way you can sometimes access support if your child's needs are not high enough to get support from social care services.

DfE: Department for Education.

DDA: Disability Discrimination Act 1995 - this has now turned into the Equality Act 2010.

Disagreement resolution: This is a service that tries to help parents and Local Authorities agree so that appeals do not end up going to tribunal. Parents can ask the Local Authority to provide mediation - this does not affect your right to appeal decisions you do not agree with.

Early Years Action/Early Years Action Plus: This is extra support for under-fives (equivalent to School Action and School Action Plus).

EP: Educational Psychologist.

EOA: Equalities Act 2010.

IEP: Individual Education Plan. Parents should be involved in the IEP process and you should always be told how your child has met the targets in their previous IEP before new ones are issued.

IPS: Independent Parental Supporter. This is a volunteer that you should be able to ask your local Parent Partnership Service to provide to support you around educational matters.

LEA: Local Education Authority.

LA: Local Authority.

LSA: Learning Support Assistant. This is someone who helps children with additional needs in the classroom.

Mainstream school: This is a state school which can meet the needs of most children.

Note in lieu: If the LA decides after assessing a child's needs not to issue a statement of SEN they can issue a note in lieu. A note in lieu is not a legal document.

Ofsted: Office for Standards in Education. Ofsted inspects and reports on how well schools are doing.

OT: Occupational Therapy.

Paediatrician: Doctor specialising in babies and children health.

Peripatetic specialist teacher: Teacher with knowledge of particular disabilities or special educational needs, who travels from school to school.

PPS: Parent Partnership Service - Every local authority should have one to provide information and support to parents of children with special educational needs.

Portage: Home-based educational support for pre-school children with SEN.

School Action/School Action Plus: Support provided by the school for children with special educational needs.

SEN: Special Educational Needs.

SENCo: Special Educational Needs Co-ordinator. A teacher in a school who is responsible for arranging the help for children with special educational needs.

SENDA: Special Educational Needs and Disability Act 2001.

SLT or SALT: Speech and Language Therapy.

Statement of SEN: Some children have special educational needs that cannot be met by school action or school action plus so the Local Authority assesses their needs. If their needs are high enough they can be issued with a statement of SEN that tells schools what support the child needs. Statements should be unique to each individual child and should be specific and quantifiable.

TA: Teaching Assistant.

For more information about educational issues visit www.ipsea.org.uk

Or call Contact A Family on 0808 808 3555

www.cafamily.org.uk