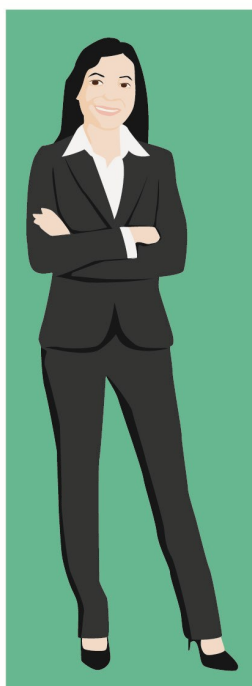
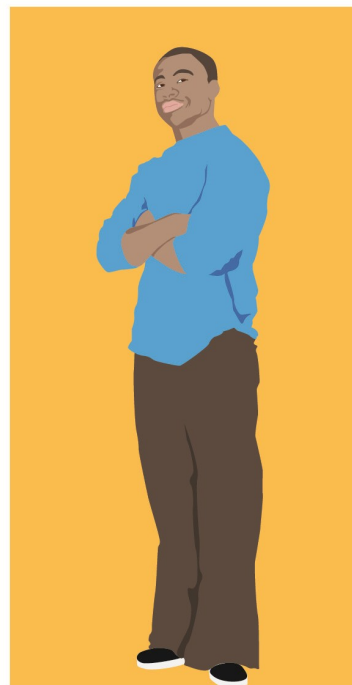
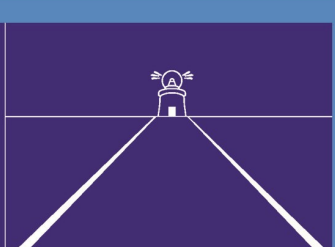


Adult Autism

The Family Perspective



PASDA
Parents of Autistic Spectrum Disorder Adults



LTCAS
LONG-TERM CONDITIONS ALLIANCE SCOTLAND
people not patients

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Stories written by members of PASDA and their families.



Welcome to PASDA's collection of stories written from the perspective of parents and siblings of adults on the autistic spectrum.

Autism is a complex neurodevelopmental condition that affects each individual differently and brings its own unique set of challenges. Autism is an oft-misunderstood condition and many families struggle to access the right support, especially once their family member enters adulthood. The voices of these families regularly go unheard.

We hope that the publication of these stories will open people's eyes to the many challenges faced by families in gaining a diagnosis, coming to terms with the condition, accessing help and in supporting their family member to navigate daily living issues whilst striving for an independent life.

We also hope that these stories will help people understand the condition better and how every individual has the potential for a good life given the right support and acceptance.

- PASDA

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The Long and Winding Road

It's a strange life, the life of a parent of a child with autism. It means that you are never sure of the future. There is no confidence to look forward and think that your child will own their own home or have a partner and the bigger question of what happens when you and your partner are no longer there, is so anxiety-inducing that it's best not to even think about it.

When your baby is born with autism, of course it is not apparent. The baby looks healthy with no visible handicap so on you go with your life. Then little things start happening that are not 'normal' and you start the health visitor/GP/speech therapist route that seems never to stop but stop it does even though there still being many needs and problems unmet.

It's very difficult too, making friends with other parents with children who are not on the spectrum. Often people look disapprovingly at your difficult child and you just know that they are either looking down their nose at you or congratulating themselves in bringing up their own children to be well behaved. It is never simple explaining the problem while telling yourself that their opinion doesn't really matter.

You are assured that it is very important to get an early diagnosis but equally assured that there is no cure and well....that's about it. Once out of education all contact with professionals stops. Why are there no follow up clinics to look at how a person is coping? Why does speech therapy stop? There are numerous problems that remain and become more pronounced as the adult with autism becomes more removed from mainstream adult life.

Unlike a lot of other parents, we can never plan for the day when we won't be needed. Our lives are perpetually on hold. We love our son so much and he brings a lot of joy into our life but the knowledge that he is often unhappy and lonely is heart-breaking. We can never substitute for a partner.

My hope is that some day there will be a cure for this condition although I am aware that this is a controversial view. For many people the important thing is to embrace difference. I agree with this point of view but the life of a person with autism can be so difficult, not having to struggle with understanding and communicating with the world, must surely be a better prospect.

We are lucky in that we have a large extended family who help and support us.



- Linda

Mark, Age 20

It's 2009 and my only son, Mark, has been diagnosed with Asperger's Syndrome and a social phobia- it's the cherry on the cake of life that has seen him in the last several years lose beloved grandparents, seen his parents divorce and have major traumas at high school.

Enough to make anyone run for cover.

As we made our way home from the hospital, it dawned on me sitting on the bus, that to support him properly I had much to learn about Asperger's. So for a couple of years it became my primary focus to put all my energy into caring for Mark and equipping myself with all the tools necessary for the job in hand.

First stop was the library to get books on the subject, I also found interesting articles on the web but by far the best thing I did was to join a support group. I joined PASDA where I met other parents who have an Aspie (or two) in their life and as they all shared their stories I felt at home and I didn't need to cope alone. I had a whole new extended family.

In the following couple of years I learned so much from others who had been in my shoes and had gone forward on to better things.

For Mark to function properly he needs routine. He likes to plan ahead and to have rules to follow. Meltdowns can happen when even the slightest thing goes wrong and so I now know to try and react with calm reassurance. Shouting makes him worse. He needs practical solutions.

It helps having a good sense of humour too.

Mark also has a very low self esteem and does not think himself worthy of getting help. I was his mother and was supposed to be at his beck and call and do stuff for him. That was the norm. The thing that made Mark a bit more receptive to feeling better about himself were the visits from a worker at Number 6. He started to gain confidence.

Empathy is an alien concept for Mark, but on his good days he can give me a mini hug or even a morning cuppa. He just had to do things his way and that is the key to having a good relationship...adapting to each moment and going with the flow.

Mark is starting to flourish now after a couple of rocky years getting used to his diagnosis. He understands that he can do things for himself, at his own speed so feels comfortable with what the future may bring.

Guiding Mark through these last few years has been an exhausting and fulfilling journey, I just wish I had had the map sooner....



- Sheila

Andrew, Age 27



Andrew was a healthy, intelligent but eccentric child with all the hallmarks of an autistic spectrum disorder (ASD) from the outset. We muddled along with some difficulty until he moved to secondary school without the group we had so painfully built up for him in primary, and things began to become much more difficult. The school referred him to the guidance teacher and the school psychologist because of his lack of participation in group and class work, difficulty in completing work on time, and increasing absences. They told me that my concerns about ASD couldn't be right 'because he speaks'. They suggested that if his attendance continued to be erratic, he should leave before the exams, as he would be unlikely to pass (and this would impact on their pass rate.)

On leaving school (as a consequence of being asked to leave) he refused to see any of his classmates, and retired further into a world of his own and became completely withdrawn. We moved house to another area, where he

hoped to have a fresh start, but he became increasingly withdrawn and eccentric. By the time he was in his twenties, he was spending most of the day walking round the village carrying out even more bizarre and obsessive routines, in snow, wind or rain, in the same clothes he always wore, full of holes and obviously completely out of it.

Despite the fact that everyone in the village and the community police knew this, and helped keep an eye on him wandering around, the GP refused to let me discuss Andrew with him. I complained to the Community Police (who had often helped me find him when he disappeared, or was chased by children) that he really needed help, that things were getting increasingly desperate, and that I had now left my job at the University to look after him, but was losing control of a worsening situation. They asked if I wanted to put a 'cause for concern' note to the Social Work department, and this then (eventually) generated an intervention, and, cutting the story short, to a diagnosis of Asperger's. Clearly, this delay has meant that the situation for him, (and for me) has gone on for years without any help, and windows for opportunity have been missed.

He finds faces and social situations stressful and unrewarding, though he does respond to animals. He has no interests except his routines, and avoids change as if his life depended on it. He is able to talk at length ('at' rather than 'to' you) on the rare occasions when he stops marching up and down. He is never aggressive, but his current appearance, with wild hair and long beard with old clothes doesn't work in his favour. He tends to stick with routines (washing too much, or washing too little) however I think input

from someone else might provoke a different response. I would like to see if with help from others we can make at least some changes. Although I think it will be difficult to get him to see anyone, I am desperate to try and get him to engage with someone or something else to try and channel his obsession in to something more productive, that might give him some pleasure, and perhaps prompt him, for example, to change his clothes and to make some changes to his appearance.

He needs to be able to survive when I am not around (he is 27 and I am 60), and I would like to see if I can get him to engage with someone else, and work on getting him into a situation where he is more able to look after himself. It is very possible that he will refuse to see anyone, as before, but after some effort, he did sit down and speak to the psychiatrist for some time, on his visits, and I am keen to try and gradually get him to engage with someone else through outreach support, and channel some of that obsessive interest in detail into something that might be more productive.

- Jane

Sarah, Age 27

Our daughter, Sarah, was diagnosed with dyspraxia at 5 and Asperger's at 7. She is now 27 years old, living independently and working voluntarily and with a paid job a few hours a week. We also now realise that she also has ADHD although we did not pursue this diagnosis as it was masked by the other difficulties. We have had various successes throughout our interactions with the Health Service but the gulf of understanding between Health professionals and Asperger's is extremely wide. This is a summary of our experiences with NHS Lothian services in the last ten years.

We probably needed help years before we asked but our first direct request for assistance with our daughter's anxiety was when she was 17 and attending college in Fife. They had advertised themselves as having Autism Specific support but from the first day it was a disaster and we should have removed her immediately. It had taken so long to find somewhere that would accept her that we were willing to overlook the lack of preparation at the start of term. On induction day, all students had to surrender their electronic items e.g. music systems, alarm clocks, TV etc. These were not returned until the following week as we were told they had to be checked for safety reasons. There was no organised social event, no one to greet new students, no on site café open instead they were expected to organise themselves. Most of the students were 16 or 17 and it was their first time away from home and they needed a little support to start their new lives in higher education.

Although the course was full time, only 2.5 days per week were spent in practical or teaching sessions. This left a lot of free time and Sarah could not cope with the lack of structure. We were in constant contact with social services in Edinburgh for the whole course but as Sarah was in full-time education they did not take responsibility. Eventually, we were advised to send Sarah to local stress classes for people with depression but she was too young to be eligible. The situation deteriorated and we were receiving multiple phone calls in the middle of night from Sarah saying she wanted to die and one call during the day from Cupar Station saying she was going to jump under a train. Sarah was referred to a psychologist who advised her to take anti-depressants, because there was a 6 month waiting list for other appropriate therapies. We agreed that Sarah should take anti-depressants and she came back home to stay with us again. By coincidence, we learnt that we could self-refer Sarah, if we knew of a person or service we thought was suitable. On this basis, a therapist at the Young People's Unit at the Astley Ainsley accepted Sarah for cognitive behaviour therapy. The therapy was helpful and her anxiety decreased with a lot of support at home.

The next few years were spent trying to find meaningful activity for Sarah at home but it was difficult as we were both working but we encouraged her to take driving lessons, go to the gym, do short courses etc. It was very hard as we only had 10 hours support a week which was erratic and the staff changed on a monthly basis. This meant she had no "buddy" for the other 6 days and 14 hours. The biggest gap was a lack of friends or social life. We signed her up with Venture Scotland who provided outdoor activities for young people aged 18 to 30 who have fallen by the wayside. Sarah loved the experiences of sitting round a camp fire in the woods, joining bonding activities and going to a bothy in Loch Etive but most important of all there were people who she could talk to. Unfortunately, one was a young man with a difficult

background, who told her she was beautiful and within 3 weeks she had moved in with him. He gradually manipulated Sarah so that she dis-owned us and she stopped communicating. We knew her life was dreadful and she was becoming depressed but she was not listening because she wanted to be independent. We were told by the social worker we had no authority as she was an adult and we should mind our own business.

The decline to a deep depression continued for another 2 years until we persuaded her to see our GP. He advised her to take anti-depressants and Sarah agreed because she trusted him. This was enough to give her the confidence to come back home to live with us again. Sarah was very depressed and could not cope with spending time alone. She could not sleep properly and had no confidence in herself. It took 3 years for Sarah to recover with help from some very capable support workers and her whole family.



During this time Sarah passed her driving test, achieved a European Computer Driving License certificate, attended various well organised courses at the Edinburgh University Settlement and carried on going to the gym. She took part in the half-marathon moon walk with her support workers and had a brilliant time. We thought it was time to come off the anti-depressants and went to see the GP to ask for counselling support or Cognitive Behavioural Therapy again. He referred us to the community learning disability service but they said they

could not take people with autism. We were then referred to the mental health service but they replied that they could not take people with autism but referred us to the National Autistic Society (they do not offer counselling).

We went back to our GP again and said we were very unhappy with the reply and wrote to our MP and MSP about the lack of appropriate services for people with autism. It took nearly 18 months to receive an acknowledgement from NHS Lothian who told us they would be looking into the issue. It took many letters and visits to the MSP surgery, hours and days of our time, as well as the support of our GP. That was 2010 and as a consequence she does now meet an occupational therapist who has helped her with visits to the dentist and the GP for general health checks. This has been very successful and is another story worthy of several pages. It demonstrates how tenacious parents need to be on behalf of their family member with a mental health problem. I am sure we would not have received even this modest amount of help without a fight. It is exhausting, frustrating and extremely time consuming.

Sarah is still taking anti-depressants and as far as we know there is no plan to reduce the dose or offer family behaviour therapy. Our family has had an eventful journey and we have all learnt a great deal about how to communicate effectively and find our way through the bureaucratic maze.

-Sandra

Connor, Age 20

My brother has Asperger's Syndrome. This makes him act differently to what society expects. He finds basic situations in life a challenge, for example, when he is meeting a new crowd of faces for the first time he finds it much harder than it should be to socialise. He can, however, excel himself in other situations which others may find difficult, for example, he has a fantastic memory for dates and figures. He can tell you which day your birthday fell on ten years ago or the registration numbers of all my dad's old cars.

Understanding my brother is not that easy because of his unusual knowledge and his lack of social understanding. I can't stress the number of times people have asked me 'What is wrong with him?' All I can actually say without going into detail is that he has Asperger's. This question was even harder to answer during primary when I wasn't quite sure what was wrong with him; I just thought that he was being himself and that was normal for me.

The things which I have to adapt to are ridiculous. Having to constantly wash my hands as my brother fears they might have food smells on them (for example, after eating chocolate or sweets), not touching any of his possessions again in case I contaminate them and having to listen to him apologise profusely when he knows he has done no wrong. To diffuse these situations I need to lead him astray of his worries, for example, if I don't accept his apologies if he believes he's done something to upset me. So I distract him through changing the conversation to another topic which he finds more interesting (such as cars). I feel like I have to voice my opinions every day as he asks me numerous questions as if it was an interrogation. Exhausted, this leaves me with only three words to say, 'I don't know!'

As I have grown older I have become more aware of what he goes through on a daily basis. For example, how he reacts to everyday situations which seem normal to me but sometimes, to him it is like his Everest. I find it difficult to deal with when he picks up little worries which he makes into a big deal (the saying 'making mountains out of mole hills' comes to mind when he gets upset about something). So I have to go along with these certain rules that he has until this worry goes away and gets replaced with a new one. The way that he perceives the world around him is very simple; everything is either in black or white, right or wrong. I find it hard to connect with him as he can't understand facial expressions and won't pick up on any sarcasm used. He will perceive my humour as a fact which ends up leading to a communication breakdown. Trying to explain the point that I have made causes him to become confused and gives him a handful of mixed emotions. The best way to handle this situation is by not letting the conversation drag on and trying to change the subject which is not always as easy as you think it would be, as he wants to definitely make sure what I am talking about.

With my brother being diagnosed with Asperger's, from an early age I have been made to feel like I am the older sibling - for example, having to take greater responsibilities than him. However, it would have been cruel to have thrown him in at the deep end as he is not that socially equipped. He could not cope in the house for a weekend by himself. I feel I have greater expectations put upon me, like producing better exam results to allow me to go for a decent career (which of course I want). It feels like a weight has been dumped on me, putting pressure on me succeeding. I want this taken off my shoulders.

The thing that frustrates me is that it looks like he has an easy time! He spends a lot of his time going to such clubs like a gourmet club in which they go to different restaurants trying their foods. Nowadays, you scarcely see him about the house. On a Monday he lies in his bed until about two o'clock in the afternoon



when he thinks it is a suitable time to have breakfast! But that is just my emotional judgement and how I perceive his situation. And it's not fair that I judge him on a situation he hasn't created; his college course which he was doing last year is no longer running due to the financial downturn. I do get jealous and annoyed that to me he seems to not do as much challenging work like I do at school, even though I know that he finds it difficult to cope with day to day living. He finds it really hard to socialise with people as he gets confused reading their body language. He won't realise if someone is in a bad mood, until they lose their temper with him. He exasperates people by asking them to repeat themselves over and over again. Then he worries that he has made them cross in the first place and apologises profusely.

I find the innocence of what he says funny. He once thought that GCSE stood for 'General Conflict Secondary Education' but the sad thing about that is he didn't know what he said was funny and took my laughter as an insult like he had done something wrong. But what I like most about Connor is that he is able to keep himself in his own bubble which he lives inside; he is not bothered about what goes on around him. Big political issues like the SNP wanting to make Scotland independent mean nothing to him. In fact he is more interested in when his next meal will be ready. But when he does come out of his bubble his biggest concern is mainly not to fall out with anyone, so he is a delight to talk to. But he gets easily paranoid about whether he has upset you or not and this is where you need to be patient with him as he is very fragile in the sense that he will get all upset and won't forget about it. I would say that Connor's Asperger's and Connor as a person has affected me positively as living with him has taught me to have the time and understanding for others.

This could be why I don't find having a brother with Asperger's difficult to cope with, probably because I have known him all my life and don't know any different from living with a brother without Asperger's. I would probably find it strange not dealing with his worries which he has on a regular basis. Even though it is annoying answering the same questions constantly on a topic which interests him, for example, his fascination with cars or his love of the Simpsons, I actually find it enjoyable when he takes my word for it and won't answer me back (especially when I have no idea if I am right or wrong!).

I would love it if there was a way to prevent Asperger's or a cure for it. However I would rather Connor not taking the option of being cured as it would probably dramatically change his personality. He would most likely be a different person from whom he is now: one of the kindest people I know, and I would hate to see his personality become any different.

-Sam

George (17) & Lewis (20)

I have two sons, one diagnosed with Asperger's at age 12, he is now 17, the other only recently diagnosed with PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified, basically, sub threshold autism), he is 20 and also has dyslexia, dyspraxia and dysgraphia.

The diagnostic process for my younger son at 12, followed many tests and assessments which were neither here nor there, perhaps his reading age being that of a 16.5 year old at age 9/10 years of age, made it more difficult. However there were classic signs of autism spectrum disorder (ASD) when I began to read about it, after having been told that there was such a thing as 'Asperger's' by a family counsellor at my older son's high school.

When an ADOS test was carried out just as my son was reaching 12, a definite Asperger's diagnosis was the result. I knew nothing about ASD at all and was sent home with virtually no information. The day before the result of the ADOS tests my son had been excluded from school, the head mistress told me 'not to let it spoil your weekend'. It did.

However, life improved vastly that day due to an agreement with my sons' dad to try home education. I have never looked back and neither has my son, happiness is too weak a word, he was a different boy and has been a joy ever since.



It otherwise would not have been my choice if school had been good and happy and safe for him, and had they understood his sensory issues and the need for him to be himself, work at his own pace, and had they allowed him to follow his interests instead of limiting and restricting his enthusiasm to learn! He is now a dedicated learner and an expert on the subjects he has pursued.

My older son had huge problems with learning and coping at school but he stayed all the way to 16, having had a pretty horrendous time with being bullied and unable to pursue subjects he wanted to,

due to the lack of support. He was eventually placed in the behavioural support part of the school, though his behaviour was not an issue, quite the opposite. It did mean though, that he was able to cope due to small class sizes and with less expectation on him to produce written work.

Agricultural college (he was very keen on doing outdoors work having volunteered with British Trust for Conservation Volunteers and having done outdoors survival courses) came after school and for one year was okay, he liked the routine, even getting up at 6am every morning. The second year ended badly as the learning support tutor, who had called him lazy in his first year, just would not put the right amount or type of support in place for him. The absolute bare minimum, in fact almost zilch support meant he was set up to fail. An official complaint got us nowhere and it was too late by then.

The next year was a different college and a basic skills course for people with learning support needs. In terms of staff understanding his needs more and making a friend even maybe two, this course was great. He is now in a six month job and may go back to college when that ends.

Life has been a pretty traumatic roller coaster for all of us, and of course the financial impact was detrimental until two years after the first diagnosis, when someone at the job centre told me about Disability Living Allowance, and our lives improved ten-fold. Money isn't everything but our lives took a turn for the better then as I had been unable to go out to work or pursue a career, which meant that we could not have holidays or replace essential items.

Once my younger son was diagnosed I could understand a bit more how the two boys were often at loggerheads and perhaps dealt with things a bit better. It's always in retrospect that you can see how bad things were, how you coped or at times did not cope, and also how awful it was for the boys, with their respective additional support needs, especially at school for six hours a day, nightmare.

It had always been quite clear, by the way that the staff in the schools treated me and to a lesser extent the boys' father, that being a single parent with kids with quite serious learning support needs, was actually in their eyes the fault of the family situation and not in fact the result of any condition. That still upsets me as they could have advised more, given information about where to go for support and been much supportive instead of judging us. I found family and some friends very judgemental and have lost some friends along the way, that has been very isolating for me, the lack of career means you don't meet new people either.

One of the main and saddest issues I find with sons having ASD, is the lack of friendships for them, everyone needs at least one or two good reliable friends.

I wouldn't change the boys for the world and they each have their immense qualities. They are very different to each other, have quite different ways of dealing with their various diagnoses but are much better friends to each other since they have gotten older. Their diagnosis does not define the boys but it puts some perspective on life's trials and tribulations, which pose more of a challenge than is ideal at times.

I've met some great people through PASDA, it's been brilliant for me and the boys, couldn't do without it, even if sometimes I can't always be as involved as I'd like.

- Julie



Maria, Age 41

Our 41 year old daughter has Asperger's Syndrome, undiagnosed until the age of 33. This is the story of her lifelong struggle to understand herself, and other people's attitude to her.

She was puzzled by the way she was treated, i.e. bullied by other children, or made unhappy by people thinking she was rather slow, or not as intelligent as they were. She was well read from an early age but did not volunteer answers in class, which puzzled the teachers. She was always fit and healthy and could have won at running at the school sports, but always hung back at the last moment, as she thought some other girl deserved to win. At High School she started well, but by year three she was in a lower class and could not cope with the bad behaviour of other pupils. She left school at nearly 16 with one O level, studied at home and achieved another three O levels on her own. Then she went to Further Education College and achieved three Highers.

Next stage was at Queen Margaret College, where she found it difficult to study with the class. Sometimes she was allowed to study in the College Library. She achieved an HND in Information Studies. A good part of her life has been virtually self-educated, having been helped and encouraged at home to see how important it was for her future.

Unfortunately, the future held further struggles, and after getting a well paid job, with a two year contract, her mental health broke down, and at the end of two years her contract was not renewed and she lost the job. Again her colleagues were puzzled by her, although she is a good worker and a pleasant person to get on with. After one or two other attempts to hold down a job she became unemployed, and her mental health was not good. All these events puzzled us, her parents, but we were unable to see a solution to her problems.

She was buying a flat in Edinburgh but decided to sell up, and travelled to Australia, using her own money. She did this, she said, to "find herself". She travelled solo and got around the Australian East coast up to the north. Whilst there she fell ill with Ross River Fever and came home after three months.

A few months later she travelled to New Zealand. This time she was allowed to work in a hotel, but due to a misunderstanding she was sacked as she was not able to defend herself against criticism. She then experienced a mental breakdown, and was admitted to a mental hospital, where she was kindly treated. After a short stay, she travelled again to visit distant relatives in Napier, who looked after her for a few months, but her mental health problems returned. After seven months in New Zealand, she came home to us her parents in the Scottish Borders. She was examined in the Borders and given medication and a monthly visit by a psychiatrist, who diagnosed her as having Borderline Personality Disorder, a diagnosis which she did not agree with. After some time, she became determined to get another diagnosis. She managed to get someone from Edinburgh, who immediately diagnosed Asperger Syndrome. This was not accepted by the psychiatrist who was treating her. She was eventually assigned a social worker, who was very nice and she trusted him.

The three of us went to see our MSP in the Borders and he took the case as far as he could in a debate in the Scottish Parliament and mentioned her by name. He also called a meeting with the head of social



work Borders, and the head of the Borders Health Service. It was after that she was given help to move to live in Edinburgh.

Our daughter has now been living in Edinburgh for the past six years. Those years have been difficult for her and ourselves, by trying to help her, we feel that we have made life more difficult for her. A turning point was reached when we joined PASDA, and attended courses run by Autism Initiatives. A better understanding of how to support our daughter was reached. Latterly, she has had help from support workers, which has benefitted her a great deal.

Life for our daughter has been very difficult, but with continuing help and care we feel that the future for her is brighter.

- Mr & Mrs Stewart

Tom, Age 20

Tom had no friends in high school and was much taunted about his unruly hair. This upset him so he would cry, so the taunting just accelerated.

When he was 14 he said he was going to commit suicide... I can tell you this was a shock as I was driving at the time and my first thought was be cool and don't crash the car! The following morning I contacted his guidance teacher at school to let her know what he had said. She referred him to the school psychologist who met with him about six times and then she "gave up" as she was getting nowhere with him. I never had any contact with the psychologist and she would not give any information to me as it was 'confidential'.

Around this time he became more fixated with time and routine. He showered every morning but never washed his face or cleaned his teeth. He had to be reminded (and still does) to do this every day. Every evening, at 8.30pm, he would go for a shower and be in there for at least 30 minutes. So much so we could set our clocks by him!

Again, he continued to do really well academically (getting 90% in maths and 95% in physics, not that he ever told me this; you only got this information at Parent's night!) and all his teachers loved him but never made any comment about his social skills or lack of friends.

When he was 16 (going into 5th year) I was really concerned that he only had a short time left in the school world and then what would happen to him. At this time I contacted the speech therapist he had seen when he was younger and we agreed to embark upon another year of sound therapy. There was a marked difference in his understanding of language as previously he did tend to take things literally and did not appear to hear the tone of your voice or notice any animation or facial expression. He also did not understand jokes and now, in the main, can have quite a keen sense of humour.

When he was 17 I went to the GP to ask for support in having Tom seen by the psychiatrist but he was not helpful. About six months later I went back and saw another GP who agreed to meet Tom and supported my concerns regarding his Asperger's. We then had to seek his permission to be referred and he took a few weeks to decide (I did ask him regularly and I am sure he just agreed to be tested to shut me up). He was then referred shortly before his 18th birthday) and the diagnosis was made that day. He met once more with the psychiatrist (about 3 months later) and we have not seen anyone since.

Interestingly I was the one who was keen to have him diagnosed. This was mainly so he would be able to access any support group/benefits and so he was 'in the system' when I wasn't around. The one thing I



did not consider was the effect it would have on Tom.... He found this really difficult to get his head round and even now I am not sure he fully understands what Asperger's means and he doesn't seem to have a real interest in finding out more. I cannot believe that I did not think of him when doing this and yet I was doing this for him!

Tom left school after 6th year and went on to college for two years. He has just recently finished and sadly did not pass his Film Studies course. He has then opportunity to resit and he is going to do this (although there is a cost incurred). He is also supposed to be looking for employment but this is not happening at the moment. He has just registered with the job centre to help him.

In January this year he announced that he was gay. I have to say that this did come as a bit of a shock so I decided not to ignore it and equally not to make a big fuss of it either. The main problem I have is that he may be seen to be vulnerable and another concern is that he does not seem to have any idea about sexually transmitted diseases. I suggested that he contact a support service for some advice but he thought I was sending him there so they would 'talk him out of it'. I assured him this was not the case and like everything with Tom he needs time to think about and consider these things before he decides what action to take, usually after much pushing and persuading by me. If I did not do this then he would never make a decision or do anything.

The relationship between Tom and his brothers is quite strange. He does not see much of his older brother, Dan, and when he does they have limited conversation although Tom does like to be around him and joins in any games they may be playing. In fact when Dan is around it is the most we see of Tom outside his room even if he is just hovering on the outskirts of whatever is going on. Adam is his immediate younger brother and on the whole they get on okay. They have limited conversation but Adam does seem to have some understanding of Tom's difficulty and makes some kind of allowance for this. That said he does not let him away with stuff when Tom is just being silly.

John, his youngest brother is quite different with Tom. They really do not appear to like each other and at every opportunity John has something to say, usually against Tom and then Tom retaliates. This can become quite heightened and very nasty and it causes me the most pain and upset when I see how they are with each other and, of course, Tom then uses this as an excuse to go to his room. I do try to encourage him to stay downstairs and join us but he very rarely does.

It's almost as if Tom has no real sense of self. He does not appear care about his appearance, or what he wears and regularly needs to be reminded to change his t-shirt; to wash his face; to clean his teeth and to shave, almost on a daily basis.

So, that is where we are. Trying to get employment for Tom, support for his personal hygiene, support and advice for his sexual health and trying to get some greater level of self-worth and independence for him.

-Brenda

Scott, Age 41

As a single parent of three sons, a major part of my parenting philosophy and long term planning, was that, taking into account of Scott's support needs due to his learning disability, I aimed to try and help him experience and enjoy life in the way that his two younger brothers were able to do. So when first Matthew and then Peter moved on to university, I started working towards making it possible for Scott to develop more independence in his life too.

The timing was right and we were able to move forward. This was 1997 and Scott was 26 years old.

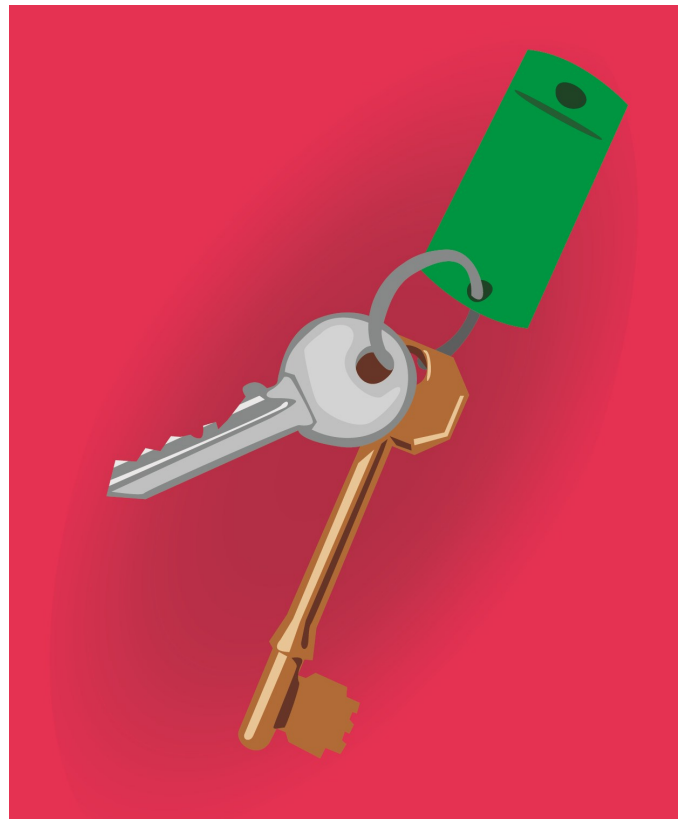
Contact was made with the social work department and we were allocated a social worker with the specific remit of helping to find suitable accommodation for Scott. We had skills assessments done and Scott and I worked on helping him acquire some basic domestic competence.


He moved into a shared flat in a stair of six flats run by Haven Housing with a support worker every day at first then three times weekly. At first he spent probably 50% of his time still at home mostly because he wasn't too sure about his flatmate but when he moved out and Scott had the flat to himself, he spent less time at home - he was attending college classes at this time. I supported him for quite some time by helping with shopping and doing laundry but he was keen to do what he could himself. Another lad moved in and I didn't have the same freedom to be in and out of the flat.

It wasn't long before it became apparent to me that this was not the best arrangement and it caused Scott a lot of stress. It was about this time, after a long time with niggling doubts in my mind that I managed to persuade his GP to investigate the possibility of Asperger's. He also made a referral for another social worker to look at Scott's support needs. She agreed with me about exploring Asperger's and was also instrumental in getting Scott moved to a single flat in Tollcross with Dunedin Canmore Housing Association. He was allocated one hour per week support from Health and Social Care - this was December 1999.

Scott coped reasonably well and although he could feel lonely, that was less stressful than living with someone else. I often feel guilty about not being fully aware of the added difficulties he must have faced because of the unknown aspects of Asperger's. At this point I managed to get an extra hour of support for him – two hours per week now!

Trying to get a diagnosis of Asperger's was a tortuous process and like almost everyone else's experience, meant constant badgering, meetings and stating the case for Scott's support needs many times and to





many different people but overall, I think we were relatively lucky in achieving what we did. He was eventually diagnosed in November 2001 and we were pointed in the direction of *Number 6*, Autism Initiatives' One Stop Shop for adults with Asperger's.

Scott has managed to deal fairly well with some aspects of independent living but there are areas that need much more supporting but one of the drawbacks of encouraging his independence is that he doesn't want me to be much involved in his domestic life.

Scott lived in Tollcross for over five years but conditions in the building deteriorated and I became very concerned for his welfare. Drug dealers had moved in and the police became involved. Scott moved back to stay with me and I began another battle to try to get him moved to a safer environment. Eventually he was offered a single flat in Rosemount Buildings, not too far away but a much safer environment and he moved there in 2006.

Many of the challenging aspects of living independently remain and may never be satisfactorily resolved but I still feel that it was the right thing to do for him and for me. I have no doubt that the positive, loving relationship that we enjoy (most of the time!) would have been much more difficult to sustain had we still been living together.

- Anne

Rachel, Age 24

I am a parent of three children the eldest of which is my daughter, a 24 year old student living in Glasgow at present due to her studies. She was diagnosed with Asperger's at the end of her final year at university while struggling through a teaching degree.

After failing yet another school placement she sought help from a university counsellor who initially thought she was suffering from social anxiety. We arranged for her to see a psychiatrist and she spent a number of weeks as a day patient at a private clinic where she was encouraged to join in group sessions to talk about her feelings and emotions and was started on antidepressant medication. She found the group situations so stressful that she started self harming and the medication gave her suicidal thoughts.



The therapists failed to pick up on her underlying Autistic Spectrum Disorder and made the situation much worse by criticising her for not trying hard enough and for crying and rocking when things got too much.

Her counsellor was appalled and after seeing her more often started to see the signs of ASD. She was referred to the university psychiatrist who agreed with the counsellor and an assessment at the Autistic Resource Centre in Glasgow was arranged. After three interviews with a speech therapist and autism specialist she was given a diagnosis of Asperger's. This came as a slight surprise to us, her family, but initial relief to her as she now knew why she was different from her friends. We always thought that she was awkward, had rigid ideas and was socially shy with difficulty communicating her thoughts and feelings but it was never enough to seek help for or to make us think there was a serious problem and we didn't know much about ASD then. I have been told it is often more subtle and therefore more difficult to recognise in girls which made me feel slightly less guilty. It was only when she had to live independently and cope herself at university and come face to face with being assessed and giving presentations, making

phone calls etc. that her difficulties came to the fore.

However her mental health problems didn't go away and because she was referred to yet another psychologist who had little knowledge of how to treat someone with ASD and a delay in receiving post diagnostic information/training due to funding problems she only got worse and also lost her part time job as they couldn't give her the support she needed. This lowered her self esteem even more and led to an increase in her self harm.

The first PASDA meeting I attended was the evening of the day I had driven back from Glasgow where my daughter had allowed me to attend the last 10 minutes of her final meeting with a trainee psychologist

and her supervisor. I was told that my daughter had given them a letter in which she said that she wanted to end her life. They admitted that they didn't know how to help her because she couldn't talk face to face to them about her feelings and emotions.

I had to drive back to Edinburgh with her after receiving this shocking news and was told not to discuss it but to keep her medication from her.

I was numb with shock, felt helpless and didn't know where to turn but on entering the PASDA meeting I was immediately made to feel welcome and I felt a huge weight had been lifted off my shoulders because there I had found other parents who had gone through similar experiences and were facing the same kind of challenges with their sons/daughters and who understood the stress that I was going through.

Shortly after that PASDA got funding to employ a development worker. She has a lot of experience working with adults with ASD. She has had one to one chats with myself and other parents to help us understand our son/daughter's behaviour and how they see the world and meets our children to get a better understanding of their specific difficulties. She has organised support groups for parents, partners and siblings, information sessions and workshops to help us with stress and learn relaxation techniques, arranged talks from professionals and organisations which might be helpful to us or our sons and daughters and recently organised training sessions to enable us to understand and support our children with the challenges they face.

Joining PASDA hasn't solved all my problems and anxiety but it has given me support, good advice, pointed me in the right direction to find help and resources and helped me to come to terms with the diagnosis. To know that someone is there to phone or email when I have problems and other parents to talk to has been a life saver for me and I'm sure other parents would agree.

If we didn't have our development worker and our recently employed project assistant with all their expert advice, support and time that they spend researching and organising people and resources that might be of help, our lives would return to despair, uncontrolled anxiety, loneliness, helplessness, fear of the future which by the way are what some of our sons/daughters experience on a daily basis.

What happened with my daughter next

My daughter was allocated a community psychiatric nurse (CPN) and attended counselling services run by a charity for her self harm, both of which I had to fight for her to receive (with my newly found confidence through PASDA). She was either told that she lived in the wrong part of Glasgow or that the service wouldn't benefit her. The CPN did admit that she didn't know enough about ASD to help my daughter but asked her to teach her about her difficulties and received training from the ARC. It would have been wonderful if there had been someone to turn to who was an expert in autism to help but there only seems to be a handful of these people in the country and they are limited to a certain area by funding.

You have no idea how frustrating this can be until you are faced with it. It's like being told your child has a heart condition but the only cardiologist that can help doesn't cover the area you live in so you will have to see a general physician instead who doesn't know anything about it or how to treat it.

She continued to see her university counsellor and slowly came out of crisis.

Her GP has been supporting her also since I wrote to her by giving her longer appointments and emailing her with results etc. to save her phoning (which she is too anxious to do). About a year after her diagnosis she was invited to attend a post diagnosis group for adults with ASD at the ARC which she found very beneficial and also embarked on a part time post graduate course in autism at Strathclyde University.

We encouraged her to go on a college course learning web design which was something she was interested in before she embarked on her degree. This turned out to be very successful and she made friends on the course. She has an HND now and is continuing her studies at university doing computer animation.

She received support from the National Autistic Society as the college tutors weren't particularly helpful in producing lecture notes etc. Disabled student benefits helped her financially and she now receives Disability Living Allowance. We still have to help her with college tuition fees and living costs.

Her self esteem was given another boost through attending Project Ability, which is an art project for people with mental health difficulties in Glasgow. They helped her to make her drawings into several books which are sold through their shop and several of her paintings have been shown in exhibitions. Unfortunately the project has had to close recently due to funding issues which is a big blow to her!

So to sum up, although my daughter has lots of problems she is managing to function independently, cope with studying and has friends. Although, without support from her family, friends, the ARC, the NAS and her psychiatric nurse she would struggle. I feel more able to cope and less anxious through the support of PASDA and while I am worried about the future for her and whether she will ever be able to sustain a career and cope with all that life throws at us, I do feel more optimistic.

-Lorna

PASDA became a Registered Scottish Charity in 2011. We support parents, carers and other family and friends of adults (over-16's) with autism spectrum conditions living in Edinburgh and the Lothians.

For more information, please contact us at:

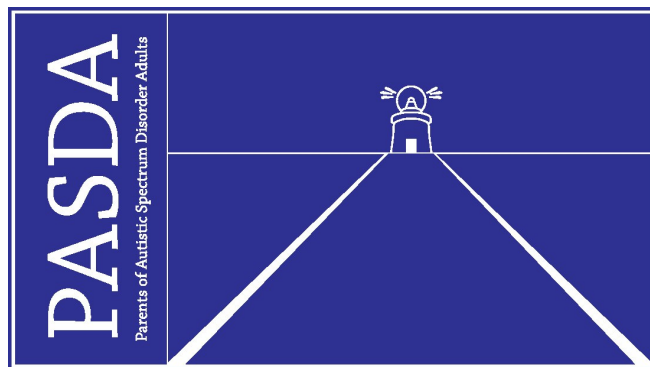
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