

Chapter 6

Do Miracles Happen?

We all skipped Irlen screening because we knew we had Irlen syndrome from what we had already read. Or rather I continually denied its existence in myself whilst Tanya and Sam went with the flow. Sam had his assessment during the end of May. It was a strange experience. There were a few hairy moments when he became tired and refused to participate. Perhaps there was an element of the “Oh no not again” syndrome, from repeatedly being everyone’s guinea pig or from continually being an object of interest. As soon as the tint was right he said “Your face is beautiful mum” as the lenses opened up his narrow span of focus. Interestingly another comment he made was “I really didn’t want purple, it is S**’s favourite colour.” This was one person he would rather forget, so at least I knew he hadn’t chosen these because he liked the colour. We did try to alter his reading prescription, with the tint, at the opticians the following day because he still couldn’t read. The optician turned on the fluorescent light above his head to perform the test. I couldn’t believe the change in his behaviour after seconds of being under the light. He became agitated and then aggressive. If I hadn’t seen this with my own eyes I would never have been convinced. It was amazing how he instantly calmed when Celia (our Irlen diagnostician) put the lenses up to his eyes. Celia was wonderful – so patient and understanding. When the colour was right she checked it over and over to be sure. A stronger prescription for reading gave him a headache so he opted for three overlays and his lenses to begin with. It was more a matter of adjustment to normal perception rather than the strength of his optical prescription.

Sam was so tired he fell asleep for an hour on the way home. I expected him to be really ratty afterwards but he was really happy. He was singing all afternoon and evening. The next day he came down with a bang and the whole week was a bit of a nightmare, he was really stressed out and ratty. His sensory system was extremely hypersensitive. Almost like he’d had a fix of something and now craved it. The wait for his lenses seemed an eternity. When the lenses arrived he couldn’t wait to wear them. As every previous pair of spectacles had bit the dust in temper over the last two years I was really worried. I needn’t have been, he treats these as if they are his most treasured possession, which says everything. Immediately he put them on his whole being changed. The continual stressed look on his face relaxed into a smile. His personality changed almost overnight. Before he got the lenses he only had a visual field of 17” which was disturbed by glare and multiple images. This meant his eyes had

to flit around to take in a whole scene, like fitting together pieces of a jigsaw. People moved around as multiples of five. He focused on one part of a person's face such as an eye or the mouth to gain information. Immediately he wore his lenses his visual field opened up to 12' 6". He could predict where his chinchillas were running and catch them for the first time. He tidied up his room properly for the first time.

The problem didn't seem to be that he had reading difficulties (he had a reading age of 17yrs when he was nine) it was more that he could only read arial text. He had tremendous difficulty reading from white paper. When he did read he missed words, lines or sometimes big chunks so he generally lost the plot. He needed to rely on diagrams and pictures to aid his reading. He had been putting so much effort into being able to see and read that the rest of his sensory system was out of synchrony. It made complete sense that because his vision was poor his other senses tried to compensate. His hearing became more acute so his brain compensated by "tuning out" the everyday noises, he then appeared deaf. Whilst tuning out the everyday noises such as in the classroom, sudden unexpected noises (chair scraping, coughing, car horns) made him jump out of his skin. His tunnel vision meant he became startled when people approach him unexpectedly, again making him jump out of his skin. His body's internal thermostat failed and he felt cold all the time or he experienced the wrong body temperature for the weather conditions. His skin crawled to such an extent that he could not bear clothes without fleecy linings. He was tearing and biting at it to stop the crawling. Having a shower felt like nails entering his skin and baths made his skin dry and sore. Walking around made him feel sick so you can imagine how a car ride might make him feel. All of a sudden all his behaviours made sense. No wonder he was so stressed and anxious.

During the first week in his new lenses we mostly stayed home, venturing out when necessary, to give Sam time to adjust to his new visual perception. We took a couple of trips to his favourite Maplin store, where he noticeably found the lighting much easier. He was beginning to manage self care more. He carried trays of food without a hitch, which previously would have found themselves upturned on the carpet. He played with his chinchillas much more than usual, thoroughly enjoying the experience rather than becoming frustrated at continually losing his pets. At night time he tidied his desk before retiring, cleaned his teeth and set his alarm without prompts. His organisation skills seemed to be developing. He did complain that the lights in one of the toy shops we visited caused him a headache, but declined an offer to wait in the car saying he would bring his baseball cap next time. Sam entertained himself on a playstation game whilst his brother spent his pocket money. He has never liked computer games although he loves computers. At one point I watched him, but felt nauseated myself as usual. When I communicated this as an excuse to move away he said "Oh yes I was like that before I got these glasses". We probably overdid the toy shop visit as neither of us could cope in the fish shop on the way home. White tiles, steel cooking ranges, fluorescent lighting and the background noise of the fryers was overwhelming even for me. Sam chose to head back to the car. By the end of the week Sam was behaving as if he'd had a personality transplant. He was even getting on better with his brother, even to the point of successfully sorting out a misunderstanding (on both sides) without adult intervention. He did blow at the end of the week following three days of frustration over a failed electronic project. He was fine in fifteen minutes rather

than the usual treading on egg shells routine for the rest of the day. Whilst I was ironing a while later, Sam noticed a stain on one of his father's white shirts. It was actually the pattern of the ironing board cover that he could see through the shirt. I asked him if the glasses helped in any other way to which he replied "Yes I don't feel sick whilst I am walking around any more". The poor lamb must have felt ill all his life. No wonder we never picked up when he was actually ill until he needed hospital treatment. At the next trip to the supermarket we had to cope with a total revamp. Sam totally enjoyed the experience. I hated the fluorescent lights but he coped well, instinctively organising me when I got confused. He also stopped his habitual looking over the top of his glasses which was a good indication this pair did work.

Feeling a little more adventurous during the second week we visited the park in bright sunshine. Sam had a few co-ordination problems, banging his head on the bar above the slide (didn't see it), and missing his footing. He became a bit over excited and confrontational with his brother, who retaliated. Sam immediately threw his glasses to the floor blaming Jake. Once I pointed out that I saw the whole incident Sam admitted that his eyes hurt in the sun. He seemed to communicate in such bizarre ways, but at least I could see that now and address the problem. We endured a bit of experimenting with Sam's visual perception in order for me to try to understand what he saw prior to Irlen. When removing his lenses he couldn't see my face at all, describing it as a pink blur. This was interesting because Sam always felt he was poor at art due to being unable to draw faces. When he was younger his painted faces had no features. He couldn't see below my shoulder joints either without his lenses. People must look mighty strange and frightening without lower bodies, or made up of bits. This explained also why he never recognised people he should have known. I asked if he had to read more than once for meaning to which he replied "seven or eight times". This explained his obsession with electronic manuals. It transpired that when he was building EPROM's he had to read and re-read the book for a whole week in order to understand the task. His vision was improving daily leaving him with more time on his hands. I had always thought that Sam worked continuously on a project but now I noticed that he flitted from one activity to another, from reading to TV, to the computer, to soldering. For a complete break he played with the chinchillas. I hadn't realised how much he had compensated for himself. Watching the TV later I noticed that the colour settings for the TV were not so intense and the volume was at half way rather than at the usual three quarters mark. He had to be hearing and seeing better. I asked him if the lenses were not fine tuned enough when I caught him screwing and opening his eyes later. "They are perfect" he answered.

I took Sam to the Metrodome, an activity swimming pool that he likes to visit. We usually have to be careful which pool we attend as most of them are too sensory bombarding for Sam. However, this one has blue tiles, a few halogen spotlights, but mostly natural light from a small glass dome in the centre of the roof. Sam took off his lenses on arrival. I asked him to let me know when his vision began to deteriorate so I could accommodate him. About twenty minutes after arrival he said his vision was starting to get patchy. We used a long sign at the bottom of the pool to estimate visual field. This was a six foot long sign which said DEEP END 1.8 METRES, with a circular NO DIVING sign at each end. Focusing on the 1 in the centre we found the following. After thirty minutes Sam could see from the D to the S but not the two no diving

signs. After forty five minutes he could see from the E to the M. After one hour he could see the ND 1. He did get a bit boisterous (unintentionally I think) after about forty five minutes, but coped much better than usual. One thing I did notice was that he usually rides in the black hole (a water slide down a very long black tube with a small array of coloured lights half way down) . He chickened out of this twice, despite many previous hours of fun. I wondered if he pre-empted the possible blinding effect of coming out into the light from total darkness. He managed two hours in the pool, but did have an accident following me down another slide. He came down faster and we bumped heads as his tyre overturned on impact. I had to explain how the accident happened in order to avoid the blame but I wouldn't have expected him to see it coming as it was near the end of our swim. We would normally have eaten at the pool but Sam couldn't face food. I put this down to the bump and the sensory problems he must have been experiencing. He immediately felt better once he had his lenses on again but it took about fifteen minutes for his sight to fully restore. He slept most of the way home in the car. This was interesting as he slept every time he travelled by car until he was about nine. He was tired for the rest of the day, and a little irritable at times but it wasn't a major problem. When he awoke next morning he noticed how tired and irritable he had felt.

As Sam began to improve his brother was on a decline. The telephone calls from school now complained about his behaviour. I was called into school many times over the course of a few weeks. We had encountered intermittent behaviour problems before but nothing along this scale. When he had been avoiding reading and homework for a few months I was convinced he too had Irlen syndrome. He came out as a borderline case, probably as a result of all the stress we thought we had protected him from. However, my screener told a different story. I only looked at the span of focus part of the test and felt extreme nausea. "What is happening to the page" asked our screener. I couldn't tell her, all I knew was I endured unbelievable eye strain and nausea from trying to keep it all in focus. Still sceptical but unable to deny my physical response I too went along to the Irlen centre for tinting. The experience gave me more of a grip on the understanding. I convinced myself this was all in my head until I felt nauseated again half way through the assessment. I wasn't sure I believed it when the colour was right. Stress that I never acknowledged in myself suddenly released itself allowing my whole body to totally relax. The feeling was so wonderful that I kept the lenses up to my eyes to talk. I expected to be tired after the assessment but I was bounding with energy. I had undertaken the assessment following a night shift and still didn't need to sleep. The next day I hit an all time low, not depressed but very stressed. This was almost like I had been given a shot of something which I now craved. Is there such a thing as an Irlen junkie? When I talked to Tanya she felt like this after her assessment, judging by Sam's behaviour he probably did too. At least I knew I wasn't insane. As luck would have it the sun came out for a few weeks at this point. Just when I didn't need it. I was flitting between giving in to the endless aches and pains (laid on the settee with the curtains closed), and pushing myself to keep going (to focus out the aches and pains). Had I always been like this? I had noticed it more during the last three years. I could not bear to read or use the computer at the time. I rushed my final project to complete my course because I couldn't bear the thought of looking at another book or computer.

Receiving my lenses was a real treat. I saw a blue sky for the first time in

my life. I previously found it impossible to look at the sky. On a white cloudy day I was blinded by the clouds. On a bright sunny day the sky always looked grey. What a lovely experience to see clouds floating in the sky rather than flat against it. The world had more of a three dimensional look about it. My colour perception improved dramatically with my lenses. I used to hate pastel colours because I couldn't tell one from another and they always reflected the light. I never had white, it was always a dirty yellow green glare. Black, and dark colours always looked washed out. I used to throw dark jumpers away after a few washes because I thought I wasn't caring for them properly. All these colours are clear and differentiated from each other with the lenses. Driving was also much more pleasant. I could judge distances and speed easier. Other vehicles no longer appeared without warning, making me jump out of my skin. On the down side I became very self conscious about the lenses. I do tend to suffer with exposure anxiety which is almost like eternal stage fright. I am fine if I can mingle into a crowd but I hate to be the centre of attention. From a general perspective the first week was pretty mixed. It took three days for the aches and pains to diminish, which returned if I tried to work for long periods. I had to experiment a lot with different coloured backgrounds and texts on the computer in order to get the most comfortable combination. I didn't notice a difference in my hearing but Janie noticed that my ability to talk on the telephone was better. My voice lowered by an octave and the eternal struggle for the right words seemed much less. The most noticeable difference to me was that I have spent my entire life feeling the cold, even in summer. With the lenses I experienced the correct body temperature for the weather conditions for the first time in my life. I no longer needed to walk around in many layers of clothing to keep warm. During the evening it was lovely to be able to watch and follow an entire film. Previously the standing joke amongst our friends was how long it would take me to fall asleep when we watched a film together.

During the first few weeks of wearing my lenses I was blinded by the light when I removed them. As time wore on and my brain adjusted to the difference I only sensed a slight darkening down of the environment. I often thought I was kidding myself that I had Irlen syndrome until I took my lenses off. The whole of my environment seemed to close in behind a horrible yellow glare. My eyes flitted around and fought to get my environment into focus. Every piece of furniture bit me as I passed. Every cup I put on the table ended up on the floor. As I looked at my special creamware trinket box on my dressing table there were no defined edges. Around the box was about half an inch of cream fuzziness. It looked like a sponge ball I suppose, all the beauty of the piece was lost. If I concentrated really hard I could bring it into focus momentarily but it soon went again. The area around my eyes was so relaxed with my lenses on. It was strange that outside I still saw bright sunshine. I presumed the lenses would work like sunglasses but how wrong one can be. I also became aware of how much I scowled and looked down to avoid the light. No wonder my mum always described me as sullen. No wonder I was lonely and unhappy as a child. I must have been giving the wrong signals out all my life. I suppose I only got through school because I never got involved. My husband began to ask what was wrong as I lost the Tigger on speed personality that he had obviously grown used to over the years. I did and still do feel strangely calm instead of stressed and agitated as before. Ten days into my new experience Sam asked to visit the Metrodome again which we did. On arrival at the pool we left our lenses in the

lockers of course. I was immediately aware of the light intensity (I have never noticed this here before). In fact my whole environment had a strange yellowish “fog”. I struggled for ages to focus properly. I did manage to see normally (or how I used to see) but it took about half hour to forty minutes. This is about the same length of time it takes Sam’s visual field to shut down. During this adjustment time I was immediately aware of the noise level. It was August so it was busier than usual but this was shear hell. Like a fairground atmosphere. I couldn’t hear myself think. We got into a dark corner to wait for tyres for the main slide. It was a bit easier to talk but judging by the stares of others I was very aware that we were shouting. We went down this slide a few times as it was the quietest and darkest part of the pool. It gave me time to adjust. When Sam commented on how many times we had been on the slide I explained how “bombarded” I felt. He just laughed and said “you’re learning”.

About fifteen minutes later we were messing about in the main pool, which has lots of geysers, showers and waterfalls. Sam pulled me under the shower at the children’s play area. The fine water droplets were like nails entering my skin. Not expecting this I yelled “Ouch!” Again he was laughing, he had the sense to be under the water whilst pulling me into the spray. He pointed out that it didn’t hurt that way, and kept pulling me in until I got it right or desensitised (I don’t know which happened). When I asked if it used to be like this for him he just said “yup” with a smile. By this time my skin was sore and my eyes were sore with the chlorine. It smelt stronger today when we arrived so I don’t know if it was stronger, or that the smell was the result of sensory overload (I remember the smell and the soreness from childhood and I can see why this is often seen as allergy). We went to another part of the pool, where a heavy waterfall from the diving pool spilled from about ten feet high into a shallow pool. Sam wanted us to sit under it which I declined. He goaded me calling me “softy” repeatedly until I succumbed. I actually expected this to hurt more but how wrong I was. The heavy fall onto my back was like being in a Jacuzzi. The massaging effect of the water was so wonderful it took away all the pins and needles pain from the previous shower. It also took away the noise, light intensity and visual bombardment. I became almost unaware of the environment until Sam pulled me out again. I had been there twenty minutes. Without Sam’s presence I wonder how long I would have continued. This is really weird, and in a funny way scary. I seemed to have accustomed myself by this time and I kept an eye on Sam’s vision as I usually do. In fact we looked after each other. We swam around for a while had a great time and then waited for the last wave before lunch. The wave machine commenced and Sam was wedged between two domes. This area brought the biggest waves but the domes enabled stability. I wasn’t sane enough to wedge myself and the waves knocked me of balance. I was sat in shallow water which reached my lower chest. The waves continued hitting me in the eyes. As I almost recovered from the previous wave the next one hit me, which left me no chance of getting out of the way or onto my feet. After the fifth and sixth wave the machine stopped but I was exhausted from the effort. (Was this why I was afraid of the sea as a child?). My eyes were burning from the chlorine, exactly how I remember my “summer eyes” when I was a child. We’d had a super time (from the fun aspect and also the scientific perspective) but this was our cue to exit for lunch. Sam was also beginning to get boisterous which is usually the sign that he needs to leave. I put my lenses on after getting dried and everything calmed over the next half

hour. My sight (even my sore eyes) and hearing improved immediately. My sensory system took longer. On the way home I said to Sam “I think I finally understand how you have felt all these years”. To which he replied “Yeah I know good isn’t it”. For someone who never thought she had sensory difficulties this experience told me all I needed to know.

Driving home was very tiring. In fact I felt general aches and pains all day. During the evening Sam complained of muscle pains even though I hadn’t mentioned them so I took another opportunity to educate him about his sensory system. Interestingly we bought a horrible science book on the way home, called *Bulging Brains*, which he hasn’t really put down. The sensory system is well explained in here. Who needs the National Curriculum!

School must have had this fairground atmosphere for Sam (which I instinctively knew anyway). I don’t remember having these difficulties myself, but hang on. Whole school Assemblies, especially in secondary school. I was OK until the singing commenced then this awful wave of extreme nausea. I never understood why of course. I made sure I stood in the middle of the line somewhere where I could “fidget” especially my hands and feet, and not be noticed. I should have been on the end of the row for a quick exit but I felt safer here. I was fine once we sat down. This didn’t happen in music. I was good at music – played the violin for the orchestra (I have great difficulty reading music now). At lunch time a group of eight or ten of us used to sit against a wall on our coats doing knitting or crochet work. Talk about repetitive “calming” behaviour. I didn’t attend a large school until I was 14. At this school I began to “hang around” and have remained friends with two girls from school.

I always said if the “specialists” had left Sam with his arm flapping he would never have become challenging. He would have found a behaviour more appropriate in his own time. Helen Irlen says you can live with Irlen (underachieving) but adapt to it. My life experience bears this out. Although the glare problem has always been there my Irlen has exacerbated mostly during the last three years but it followed six years of continual chronic stress. The extent of which would only ever be seen in a few families.

The following day I was up and about early but could not get motivated. I was really tired, every muscle in my body ached, my neck glands were painful and I was sneezing a little. I wondered if I might be coming down with a cold or flu. It was strange how all these symptoms began to disappear around 2pm, then the penny dropped. We had really overdosed on sensory bombardment yesterday, the symptoms were the after effects of the swimming. I felt like I was scaling Everest in glue. I remember always wanting to be carried as a child to the dulcet tones of “Just around this corner”. Sometimes the corner never arrived and sometimes dad gave in. Bless him – another very sensitive soul.

By week three it was amazing how much better I had begun to feel, mostly without realising. I couldn’t believe that this was all due to a pair of tinted lenses. My house was cleaner, especially the white kitchen. Incidentally the kitchen was now more bearable. The rear number plates on cars (black on yellow) became much easier to read. The only difficult ones to read were the ones with gold edging around the lettering, making a 3D effect. I could even read the time on my watch, which is two tone gold with black hands. I couldn’t even see this three weeks before. I took a bit of ribbing about being a CIA agent at work. I guess it looks mighty strange to be wearing what look like shades at night, but I work in an intensive care setting and could not see the monitor

tracings clearly without my Irlen lenses. I wonder how I managed without the lenses. No wonder I suffered with migraine. Even my brother was shocked that I didn't bump into things in the dark. It was funny to see the surprised look on the faces of others when they too assumed that the lenses were shades. It was strange how I too took them off in the dark to see better and actually saw better with them on. How can this be?

Sam had been wearing his lenses for ten weeks at this time. The last few days had been full of jokes and surprises. He had been tickling everyone in sight, especially me. I could not remember the last time he was happy like this so it was a real boost. His relationship with his younger brother had improved dramatically. We began to see lots of appropriate rough and tumble play. This was a stage of development both boys had missed so it was a very emotional time for us. Sam always enjoyed rough and tumble play but we avoided it because he always got too rough. My experience in the swimming pool told me that he probably used this to calm his sensory system the way he showed me in the waterfall. To think we stopped this type of play to save ourselves. I am really beginning to respect hindsight and intuition. Obviously his play was still immature but it was another stage of development to revisit (not that he ever visited play the first time around). By week eleven he was getting bored with being out of school and feeling down. He believed that no school would give him a chance because of his behaviour record. Communicatively, he was beginning to process our requests with a bit more ease. We no longer found him sat on the stairs trying to work out what we had asked him to do. He stopped shouting at us to stop putting him under pressure. He was still stumbling over words or phrases that he wished to impart to us, but we knew we were moving forward. The words were there but they just didn't seem to come out. I still had the same difficulties myself, almost like a person who has had a right sided stroke.

During my fourth week I began to venture further afield. I started driving distances again. It was then that I noticed why I always got lost (pre-Irlen). The signs on the motorway were mostly black print on yellow, which was impossible for me to see. I used to transfer the map into a list of instructions before setting off, but then would come unstuck if there was a diversion. The only signs which I could see properly without straining were blue. No wonder I missed the slip roads. No wonder I could make the same trip many times and yet not identify what should have been familiar landmarks. On a good note though – parking became much easier. Other cars stopped scaring me to death by appearing at my side from nowhere. Although the horrible yellow glare had disappeared when I removed my lenses it became very obvious how dependent I was going to be on them. I found it hard to accept that for the last forty three years, some aspects of my perception have been a bit off track. I also felt an incredible surge of guilt that this genetic glitch had found it's way to my son. On the other hand these lenses were making a difference that would change our lives and that had to be good. My swimming experience must have been how life was all the time for Sam and Tanya, yet how do I know mine wasn't the same? I have little personal episodic memory prior to the age of twelve. It is almost like I woke up (or was born) when I was twelve. It is hard to say whether these memories are repressed or just forgotten. Maybe I had nothing to "Hang my memories on to". Some of them are returning as I make the transition but I don't suppose I will find my entire life to date.

We did find that if we undertook vigorous physical exercise we needed a

day of calm to recover. We started cycling again after a long break. After a forty five minute cycle we needed a two hour rest to regain our strength and our vision. We both began to notice when we had overdone it and were able to self correct, which was amazing. I am now aware of all the constant irritability, headaches, aches and pains, nausea and visual disturbance that I have thought was normal, or have blocked out without realising. The payoff has been an overwound sensory system, lapses of attention, loss of hearing (particularly word endings and sometimes whole sentences in the middle of conversations), a bit of dyslexia (poor spelling and punctuation), sometimes a bit of autistic trait behaviour (more pronounced under stress). I am noticeably aware that since wearing my lenses I am communicating more effectively although I have always communicated better on paper.

Two months ago Sam would have balked at the idea of sitting listening to his mother twittering with her friend, yet he came to Tanya's house and thoroughly enjoyed himself. He would previously have refused to go, gone under sufferance and then repeatedly displayed his boredom, both verbally and behaviourally. He opted to stay with us rather than in his usual (negotiated) room alone. About a year ago I actually started to go out without Sam on his choice, now he prefers to come rather than stay home. Super! I wanted to cry when I looked at him now because others were seeing the boy I had always known was in there, trapped within autism. I tried to find alternative explanations for the things we were experiencing. It's almost like I could not totally commit myself to this because it might all be a dream tomorrow. It reminded me of the Steven Spielberg film *Awakenings*.

During the eleventh week of the Irlen experience it was Sam's birthday. This was when we began to see some real changes in his approach to previous problems. He was eagerly awaiting the arrival of a new hard drive for his computer, managing to keep a lid on his emotions even when the courier was an hour behind schedule. His birthday wasn't for a few days but I did say he could fit the new drive when it arrived in order to be up and running by his birthday. This usually alleviates any temper tantrums spoiling his day in the event of him being unable to complete the task on his birthday. He was desperately trying to wait until his birthday but compromised by doing half the job. He fitted the drive lead and sized up the job of slaving the new drive to his old one. The machine wouldn't work so in my usual style I planted the seed of doubt "Sometimes leads can be faulty from the shop". Initially he was negative so I left him to alter his own perception (through a lengthy logical thought process). I was astounded because this seed of doubt stage would have previously evoked a screaming, wailing, running up the street response of "Why don't you kill me I am so crap". Over the years we have become expert at calming this type of situation. He walked out of his room and stood quietly at the top of the stairs obviously puzzled. I could almost see the cogs going round, and then... "SOLUTION - WONDERFUL!" With not the slightest bit of emotional volatility. I praised him to the hilt when it was more appropriate, explaining the difference between in his behaviour to this oh so common missing information/perception problem. I had to keep a tight lid on my own emotions. Sam was making a transition from a topsy turvy world of misperception into a wonderful world of self actualisation. The fact that I was able to explain it to him and that he could see his own transition boosted his confidence no end.

Sam had been left the overnight task of learning as much as he could from

the instruction manual. I arrived home from work the next morning suggesting Sam fit the new drive whilst I slept. He found excuses at first – valid ones – such as the need to remove the mother board for space. When I awoke he was waiting patiently for my help. Not that I am any good at all but I think he just wanted reassurance that I was there for emotional support, just in case. He was pleased that I offered my services (the things mothers do). I was the one who blundered when he offered to let me put a screw in, which I duly lost in the machine. It took forty five minutes to find the screw because it had found it's way onto the back of the speaker magnet. I would have been the worst idiot in the world previously. This would have meant two blowouts in two days, but he never flinched. He just methodically worked out where it would be when we couldn't hear it rattle. Experiences like this one are hard to forget.

The bad mother that I am, I tested Sam's jumpiness three times in one day. During the morning he had his back to me when I sneaked up and nipped his behind. He would have totally freaked at the shock of this previously but he just turned round, smiled, and called me a feeler. At tea time I turned on the kitchen extractor and put chicken portions into the deep fryer at the same time. He commented on the noise which I followed up immediately by tickling his neck. These are wonderful "tormenting" things a mother might do to a son, which I have never been able to enjoy. Sam had developed a wonderful sense of humour and did all of this to me too. How much we have missed out on, and what fun to be fortunate enough to have been given this experience.

By the fourteenth week we were beginning to consider the possibility of Sam returning to school. I wasn't happy that he was gaining anything from being at home in isolation. He has always been a child who tries to socialise, even if his attempts are odd. He has always managed to maintain friendships with children from understanding backgrounds. At home he was obviously lonely, becoming more attached to me as time progressed. This was not a good situation for either of us. Sam is an intelligent young man who doesn't embrace his "difference" very well. He is desperate to be the same as everyone else his age. I knew it was going to be donkey work to enable his reintegration, but I braced myself for yet another battle.

The first port of call was a visit from the Education psychologist. What a fiasco! I think she would have appreciated the old egocentric Sam that had been destroyed years before, because she made little attempt to come to him. It was donkey work trying to get a reciprocal conversation going between them. He sensed her inability, or lack of want to initiate conversation and left intermittently to the loud dulcet tones of "This is not good". I was trying desperately to build a bridge between them for Sam's sake, but the situation was becoming more fraught by the minute. We totally and inadvertently freaked her out with a chinchilla. I assumed she liked animals because she asked about them when we let her in. I advised Sam to introduce them as this usually enables the bridge of communication. However, as he was getting a chinchilla out of the cage (concentrating on catching it) when she said "Don't bring it near me". Obviously Sam didn't hear her because he is monotropic and was concentrating on the task. I heard her but didn't process her actual words because I was concentrating on Sam, in case the animal escaped. By the time her words clicked in my brain she was screaming from the end of the settee that he had no empathy. I sensed she didn't want my explanation about our sensory dysfunction creating this communication failure. Sam is too highly sensing for these situations

to be practical. I don't wonder he doesn't try anymore with this personality type. Although she perhaps didn't realise it she had as many difficulties with communication and perception as we did.

The psychologist proceeded to inform me that the authority would not recognise Sam's dyslexia as he didn't have a reading age of six years. She went on about his test results and of course I argued that he can hold concentration for tests due to the lack of sensory bombardment in test situations, which hinders his classroom progress. I also argued that test are short duration and as such Sam can hold his concentration for the required time. All fell on deaf ears which Sam sensed and left, to the tones of "Do you think this is good?" again. I felt myself thinking "And they say Sam is autistic; what the heck do these people expect?" They certainly don't understand autism or Irlen despite saying they did. All he needed was a positive experience of school to get him back on track and raise his self esteem. How could we hope for that if we couldn't get past the rigid cold fish at the helm? The upshot of this meeting was that if I trekked around the schools to find one who would take him with his track record of challenging behaviour, the authority might be favourable. If only I had the revenue to set up my own school. If only I didn't have to work full time. I think I built this up expecting too much, but wasn't the Educational Psychologist's role to help Sam?

We visited many schools over the next three months, but it was difficult deciding where Sam would fit more appropriately. After four visits to the nearest school run by the National autistic society we opted to try this. Sam's worst experiences of school have been within the special school sector, creating a poor perception of these environments. As a result he was very negative about this school. I could see the sensory bombardment difficulties and unpredictability of the other children, which might be a problem. However, I knew mainstream would cause more pressure, which he wasn't quite ready for. Leaving Sam home for longer would make the situation even more difficult due to his age and the amount of work he had missed. I have never made a more difficult decision in my life. It was so important to get this one right if Sam was going to be rescued rather than have a further blow to his self esteem, which he then might never recover from. There was no-one to turn to for support or to bounce ideas off because the whole family thought I was mad to send him back. They didn't see his face on a morning when the other children were leaving for school. They didn't have to mop up his tears because (in his eyes) he got thrown out of every school for being a bad person. They didn't see Sam.

Having chosen a school we had to wait another four months for a start date which left us time to enjoy our new experience. Sam had a brilliant evening at a bonfire. He really enjoyed the fireworks. We used to allow him to record all this on the video camera to watch later but he didn't ask for it this time. There was noticeably much less Sam tackle to carry around these days – great! He was apprehensive on arrival until my husband took him across to the other children. He quickly got involved, lighting some of the fireworks. He had to take his lenses off due to the rain. Although he said he could see OK he did become giddy after about forty five minutes, becoming the class clown. The others laughed of course perpetuating more of the same behaviour, but he did stop after the second time of asking (and pointing out what he hadn't realised socially). Having said that one of the neurotypical children was worse. Perhaps I worried too much about Sam setting himself up. It was always the emotion

side of his behaviour which set him apart. This was now getting much better, thanks to Irlen lenses.

Talking of dark evenings I noticed around this time that I was finding dawn and dusk a little confusing from a visual perspective. I have always been able to function better during dusk so this threw me a little. I spoke to Tanya about this as Tanya's friend is a professor, studying visual perception. Imagine my surprise at finding that visual difficulties during dusk are totally normal. That this is why most car accidents are said to happen at dusk. It has something to do with dusk being a confusing period (neither dark nor light). Instead of being dusk, nocturnal, winter people we were now experiencing what non – Irlen people take for granted. Talk about the topsy turvy world of Asperger's syndrome. Even this phrase made sense now. Sometimes I got so carried away with this, my whole life felt like a scientific experiment. I felt I could not accept the experience without a reason, which is pretty Asperger if I say it myself. I could not stand to look at white at all now without my lenses. It is amazing what the brain can achieve in compensation.

Tanya, Sam and myself seemed to be experiencing the same at this point in time. It all made sense because Tanya has the worst fragmentation problem seen by the Irlen people, who got the lenses first. Sam was second in both. I have no reduction in visual field but have difficulty with glare, causing everything I see to have fuzzy boundaries (where have I heard that term before?). I suffer from jigsaw fragmentation with my migraine aura. I was the last to get lenses. Sam and I seemed to be completely on the same plane. Tanya was experiencing dry gritty eyes and normal to slightly elevated stress symptoms. This was how I remembered childhood. Sam and I had both gone through a stage of being sensitive to our chinchillas (like mild hay fever) which had now reduced. Both of us had endured dry itchy skin and eyes which had also reduced. We both recognised that nausea was a sign that we were working ourselves too hard visually, and had adapted to this. Tanya seemed to be experiencing similar. It felt like we were coming down a sensory scale. All our previous senses that were blocked were now beginning to work. The TV was now always at half volume instead of three quarters. Small differences in smells were more noticeable, dust made us sneeze. I could just about bear the feel of skin on skin, which was a first for me. Our temperature control was superb, so we were looking forward to a warmer winter. I also noticed at this stage that my skin and hair were becoming soft again. Apart from the patches of psoriasis I always had lovely skin and hair as a child. During the last three years I had increasingly needed to spend more on skin and hair care products to combat the dry ageing look . I'm not a vain person it was just that this was not physically comfortable to live with. My mother's hair and skin dried up prior to her diagnosis of under active thyroid, so I cannot say the thought of a genetic predisposition to this was far away. Not that I would have done anything about it until I had no choice I hate visiting doctors.

I had been taking a break from studying for six months but decided I had to face it sooner or later. My sleep pattern was improving leaving me more refreshed. I managed to stay on task until three PM rather than 10.30 am which was a real boost to my self esteem. I couldn't have managed full time study but the day release I opted for was a steady way forward. After the first day release I almost went straight home as I usually do, but instead accepted an invitation to join my colleagues for a meal. I regretted it as soon as we

walked into the restaurant, as it was bursting at the seams with people. Luckily we were given a nice corner table and I chose (inadvertently) to face the wall. I noticed how much better I could filter the background noise when I wasn't facing the fairground atmosphere. I recovered gracefully, not even knocking a drink over as I usually do. A real boost to my self esteem. I was overwound at sleep time but it was worth it to be part of life instead of always looking on. I felt like I had lived in a parallel universe.

I seemed to be taking more notice and learning more than I ever have in my life. I don't know if the nursing ethos has changed over the years or that I just lacked that awareness. Nurse education takes into account that everyone has their own world. This is in stark contrast to the education system view of the real world and the autistic world. What a difference that makes to accepting differences. The nursing ethos must be a reflection (maybe inadvertent) of the high percentage of medical professionals with a "different" perception. It may also be a reflection of how perceptions change under stress. The nursing world works from this philosophy, as such I believe this rescued me from a world of loneliness and isolation. Nursing taught me how to communicate effectively, how to control my emotions (instead of them controlling me) and how to fine tune my own empathy.

It was almost Christmas, the company I work for had been running my hospital for ten years so of course there was a party to celebrate. I hate parties because I can never tell what is happening within the group I am with, but this was special as I had been with the company ten years. I was tempted to leave my lenses off but decided they would help with the disco lights, and I needed the distance prescription anyway. I was shocked at how much facial agnosia (inability to recognise faces) I have. There were only a handful of people who have been with the company ten years and I come into contact with them all. However, recognising them in different clothes and under different lighting was hell. I realised for the first time how much I pretend when a comment is made about so and so's dress. Faces look different anyway with the lenses but this was freaky. I have to know a person well and see the whole person in familiar surroundings. I seem to pick up queues from their clothing and hairstyle, but often only recognise them after they speak. Without my lenses it is obvious why, all faces are just pink blobs with dark areas round the eye sockets and mouth. I often wondered why my colleagues recollect memories of school friends when I cannot. I wondered how many times I may have been misunderstood as rude for not speaking to people I should know.

OOPS, the potential for a lousy Christmas was imminent. We had decided to upgrade Sam's computer but memory prices had rocketed overnight. The upgrade would take us well over budget. As we broke the news to Sam he immediately began scanning all the latest magazines, internet and suppliers. He was obviously disappointed from time to time, but in no way like he would have been a year before. Six hours and a lot of work later he managed to find all the component parts to upgrade, within budget, settling for a little less memory. He was really beginning to improve in his thought patterns and his organisation skills. He had the computer up and running well in time for Christmas. He even chose to help his father shop for Christmas.

We had a good Christmas. We bought Sam a surprise keyboard for his computer, but in my usual dizzy style I forgot to check the connections. As it failed to connect we heard the usual negatives of "Nothing I ever get works".

“The shop won’t change this” etc. This would have previously escalated quickly into shouting and screaming (faulty perception). I didn’t expect the situation to escalate, nor did I expect Sam to find out when the shop was open and call them himself as he did. He was happy to wait until after Christmas to exchange the keyboard. I can remember a time when we would not have been able to manage this without him screaming up and down the street.

We had been out of circulation for over twelve months so Christmas was an important time for us as a family. We had a house full of guests all day Sunday plus grandma staying all week. Sam really enjoyed a Boxing day party at a friend’s house. He was reluctant to go at first. I made arrangements for him to stay with my mother but he changed his mind at the last minute. I fully expected him to be a total pain (he is usually really annoying and complaining, progressing to naughty in an attempt to leave). There were six families with teenagers and he mixed really well, thoroughly enjoying himself. He even played trivial pursuits with the twelve who were left at eleven pm. This time the previous year with the same friends he was screaming that we were all b*****ds for beating his team. We were the last to leave – at 12.30am. Brilliant! This had never been known!

My advice to anyone prepared to follow our pathway down the Irlen route would be that it probably takes six months to a year to make the transition from the drunken Dali-esque fairground world of that “different” perception. The changes are steady and subtle, but at the same time profound. I feel very different, with a calmness and clear headedness that is new to me. It is not true that I feel like someone else, more that I feel like the real me who always fought to get out. The whole fabric of my thinking and functioning is changing. When I look back I can see what a rough ride the transition has sometimes been. At the time you just put your head down and weather the storm because that is where you are at. Tanya and Sam have been my companions, without whom I might have given up a few times due to my own lack of understanding. It is hard to find the words to express this so that it doesn’t sound completely screwy to those who have not had the good fortune of this experience. Due to our past experience with other types of lens tinting I expected the “awakenings” experience to come to an end. It didn’t, I now found it comfortable enough to take off my lenses now and again in order to play with my visual perception. It was fun to watch clothing walking around without a face attached to it. It was fun to watch the sun playing tricks as it shon through my wet hair following my morning shower. Strands of spaghetti, every colour of the rainbow could hold my attention in a way I never experienced before. I don’t wonder some people with autism do not want this world behind. It was fun to watch people fall into bits at the swimming pool, because I knew I could put on my lenses and see the world in whichever form I choose. I can now choose to live in whichever world I like, so I chose the autism world behind Irlen lenses. In that world there is an unbelievable empathy and compassion for fellow beings which I fear the so called real world will never understand during my lifetime. It is a world where we do not have to live in each other’s pockets to show we care. We instinctively understand each other and reach out when we are needed. Irlen lenses gave me the visual perceptual clarity I dreamed of all my life. Although initially I felt exposed when I wore them, I later hid behind them to prevent my own exposure anxiety.

