

Silence.....

In the minutes following the emergency caesarean no-one spoke, my child made no sound. The hospital staff got on with their jobs, of saving a life, and I felt lost, wanting an answer, to hear my baby cry.

Later, after being transferred to a specialist hospital in London, we were warned of physical disability, and possible deafness, caused by oxygen deprivation and strong antibiotics. The physical disability seemed something we could get our heads around, being deaf was a different concept. To live in a world without sound, not to hear what we take for granted.

Then and there my husband and I vowed we would fight to give our daughter the best opportunities in life, to ensure she fulfilled her true potential, and if it meant me filling shelves at night in the supermarket, rather than returning to my marketing job, so I could be with her by day, and him by night that is what we would do.

The staff told us to talk to Beth, tell her about our life, our plans, her future...and so we did. A little girl with a lot of machines helping her to stay alive. Our girl is a survivor and gradually the equipment was removed. My husband and I sat by our daughter's cot and when suddenly at 4 days she made a sound we started to laugh. We made another vow, this time never to tell her to shut up or be quiet. We must have been mad! And so our communication journey began.

Beth was born at full term, from early on she was very alert, her eyes followed me, she seemed to be trying to reassure me all would be well. At around 6 weeks she smiled, a normal developmental milestone achieved, she also seemed to react to sounds by turning, a visit to the audiologist confirmed Beth could hear some sounds, but her hearing would need to be monitored, on-going, as she developed. As time went on Beth was animated, babbling a lot and things appeared good, it was clear she had a cheeky personality. We began to wonder if the doctors were wrong and everything would be fine.

At 13 weeks I knew something wasn't quite right, my husband told me I was worrying unnecessarily, but deep inside I had doubts. We visited the paediatrician for another, very regular, check-up to be told Beth had cerebral palsy, but the severity and implications might not be known for some years. I didn't really think at this stage that the CP might impact Beth's speech development.

At about a year old we were finally told Beth had a high frequency hearing impairment. This means she had difficulty hearing some sounds such as f, s and th. It seemed hearing aids wouldn't work, 16 years ago they amplified all sounds not just the missing ones. We were given guidance on avoiding background noises, drawing Beth's attention to things and people speaking, and looking at Beth when we spoke to her. We were asked to write down what she said. By the age of 2 it was clear she was having difficulty with words – for instance squirrel was 'quirel' and thank you was 'ank u'. But I also noticed she sometimes said something and then never repeated it.

Initially this seemed to bear out the hearing problems as the sounds she couldn't voice were the ones she couldn't hear, but as time went on we found she was experiencing more and more problems with speech production. Good Morning was Goo Morr-i. Her own name – Bethany was challenging and was shortened to Beth and pronounced as 'Beh'. Grandma was, and still is, 'Gaa' from the beginning and end of the word.

These challenges didn't stop Beth from communicating continuously at home, she was never quiet and we always knew what she wanted. She was inventive. From an early age I would hold her on the kitchen work surface in front of an open cupboard so she got the item she wanted. She made up her own signs for needing a drink or food.

By 2 Beth was playing creatively and was a sponge like other children, picking up and copying things she saw others do. I was back at work and her child minder also did some hair dressing at home, we often found ourselves laid on the floor in our own home having our

hair brushed and dried, answering Beth's questions like how are you? What are you doing today? How was your holiday? and then making an appointment in the diary to come again. As parents we discussed with the Paediatrician Beth's start in education. We were all convinced Beth was cognitively able and going to a special school or nursery was not right at that stage. At 2 and a half Beth started in the village nursery with a 1 to 1 assistant. Somehow she made herself understood, although she was quiet but laughed a lot, played with others and joined in with group singing.

I think because we understood Beth we didn't really understand the communication challenges she would face in life. We hadn't had much contact with the speech and language therapist, one day when Beth was just 3 I went along with her to the children's centre, I was really shocked when the therapist told me Beth needed a communication board to make choices. She showed me a picture of a board with a glass of milk and a glass of orange. I was furious and confused, out of the blue it seemed my daughter was to be consigned to pointing at symbols in order to communicate, did they not understand that she made herself understood?

My way of dealing with issues is to educate myself, to do as much research as possible and to ask questions. Thank goodness for the internet. I started out trying to find as much information as possible about cerebral palsy and speech impairment. By the time we next saw the paediatrician I guessed that Beth had dysarthria. This was confirmed by the consultant and with a diagnosis we knew what we were dealing with.

I began to ask questions about speech and the use of technology, the Speech and Language therapist moved on and we got someone new. This was someone who listened and observed just how communicative Beth was, between us we got our general practitioner, the family doctor, to pay for Beth to go to a specialist assessment centre. By this time she was 3 and 9 months. We travelled into London not sure what to expect. After a very long morning Beth progressed from trying out an eye pointing frame, to a big mac switch to using a simple voice operated communication aid which she used to tell us she wanted to go to McDonalds, as she was hungry. We left with a recommendation that she needed some electronic form of communication device if she was to make the most of opportunities in school. On the way home guess where we stopped?

Shortly after this we were asked to supply, to education, all papers we had relating to Beth's diagnosis, to support her school placement. The local authority sent along to planning meeting for entry into the village mainstream school their IT consultant, a lady we now know is well regarded in the field of augmentative and alternative communication. Within a week she spent an afternoon with Beth at our home making her own assessment.

These meetings heralded a very important introduction to what has become a key part of all our lives, a communication aid for when we didn't understand what Beth was trying to say. I have to admit that whilst we were initially very enthusiastic at home and I programmed words around what we did each weekend and holiday I was happy if it didn't always come home from school during the week as we used it very little at home except if we had visitors on a weekend. I think our first big communication glitch came when Beth was 6 and she came home from school really excited. She started to tell me about what she had done in school and after about 15 minutes we were both in tears. I went into see the teacher the next day to discover that they had been doing about Queen Elizabeth the First and beheading. Events like these changed the way we communicated with school and from that time on during primary education we got home a weekly list of topics to be covered in class, nothing very detailed but in geography it might say volcanic eruptions and in science floating and sinking experiment.

When Beth got to 7 that we realised things had to change. We became aware the device wasn't being used at school, that first communication aid was enormous and bigger than

Beth, along with her computer at school she was a little girl isolated from her peers by her equipment. The 1 to 1 staff understood her speech well in context of the curriculum so didn't bother to get it out. The turning point for us at home was that Beth's social interaction suddenly blossomed and not everything she wanted to say was in context. Like every other child she was proactive in wanted to talk about things she was interested in. We developed strategies to get to establish context and then we were OK, often this was by asking her to tell us the same thing in different words or ways.

An example of this was when she came home from school at 7 and told me she had a new boy in her class. She got over very quickly that his name was Ben but I couldn't get verbally his surname or family name. We didn't have the communication aid and she was unable to spell it – spelling is another topic but she learns every word as a whole word. As she was unable to sound it out she made me take her to her book case and she got out a Beatrix Potter book called The tale of Jeremy Fisher. His name was Ben Fisher. Clever girl as the 'f' and 'sh' were sounds she couldn't hear or sound out.

At about this time we also went to our first 1 Voice event. 1 Voice is a national charity that supports families with children who use augmentative and alternative communication. They do social weekends and have invited role models. Beth had a great time meeting for the first time ever other children and adults who had communication aids. This gave us all much to think about, from how she used her device to knowing we could have high expectations for Beth. Some of the adults we met had their own businesses and lived independently and we realised that Beth could too. One Voice became firmly embedded in our family calendar and has been an annual pilgrimage ever since.

In England we often say things happen in threes. The other thing that happened was that whilst playing with the software we discovered word prediction settings and Beth loved this. Instead of having to go through pages and pages to find individual words she could start to type in on the touch screen the words she wanted and these came up with accompanying symbols. As Beth later told us this made so much more sense for her when she was learning to read and write in class but to speak she had to use pictures.

So we moved forward with great impetus. We began by employing a young teenage girl in the school holidays for an hour each morning. She spent the first 20 minutes doing a speech and language programme and then the rest of the time using the communication aid with Beth. They took it in turns to speak using it, finding their way around the package and playing typical games such as pretending to order in McDonalds, doing shopping lists, playing class teacher and pupil etc. This gave Beth much greater confidence with her device and when we had guests around to the house she no longer was urged to perform like a monkey but was becoming a true communication partner.

It was also around this time I started to think about Beth's communication in more depth. Answering questions was fine but good functional communicators need to be proactive and ask questions. I started by asking around the professionals I knew how they thought we should progress, as it was no-one really had any ideas. My sales and marketing background led me to introduce Beth to Rudyard Kipling's 6 wise men that had stood me well in my career and the concept of open questions. It seemed a sensible way forward for us to ask Beth only questions that needed a full answer (unless practicability said yes or no was essential). In turn we encouraged her to do the same by learning that if she adopted the 6 wise men questions she would get people to give her fuller answers, as we know its impossible to answer a why question with yes or no.

I keep six honest serving-men
(They taught me all I knew);
Their names are What and Why and When
And How and Where and Who.

Things seemed to be moving along well, Beth's system was coming up to 5 years old and the IT consultant recommended we moved to something that would make her seem less isolated in school. First we trialled a tablet with the same communication software but the volume made it unusable except for 1 to 1 conversations. The decision was made to change to a smaller device which would be both a communication aid and a tablet, this was probably in hindsight not a good decision. What we hadn't appreciated was the new system had completely different software and initially did not have any word prediction. Beth had to start learning a new symbol system from scratch and was not amused! It also meant she lost all her social narratives, those 'do you remember when' stories about holidays and events that are essential to us all. It was a trying time but also a huge learning curve.

By now Beth was 10 and it we were planning for her to go to mainstream secondary school. Again, as seems to often happen in Beth's life, 3 things happened. With the IT consultant we identified it was crucial that the staff at the higher school were not scared of all the equipment, that it was easily identifiable and acceptable to them. After the hiccup with the tablet we were all pleased when it was decided a laptop was best and a lightwriter communication aid. This meant the staff would be able to programme the laptop when Beth wasn't using it and she would always have a communication system available.

The lightwriter caused some consternation in school as Beth was not the best speller. As mentioned she had to learn every word as a whole word, but in fact the need to type into the lightwriter every new word meant we put in place a strategy which we still use today. We say the word, Beth lip reads it, we programme it together and then she uses it in a contextually appropriate sentence. Her spelling improved overnight.

The third thing that happened about this time was that Beth was given digital hearing aids, suddenly she could hear around 97% of what was going on around her. It was both enlightening and frightening to find out what she hadn't heard before; the crunching of stones underfoot, the sound of birds singing and water splashing. These particularly helped with the spelling but the biggest change was that the volume went down on the TV. Beth had always preferred to watch films and programmes with people and was never very keen on cartoons, now we discovered it was because previously she had only picked up odd sounds from cartoons and was able to make more sense of a programme with real people. Suddenly she spent hours watching faces on TV. We hadn't realised but it seems she had been lip reading since she was a baby and now she was adding in the missing sounds.

Around this time we started planning every day out, doctors visit, shopping trip and much more. Who might she meet, what might she want to say, what might she be asked. Those wise men came in very handy! In preparation for going to secondary school and meeting lots of new people we sat down with the speech and language therapist and 2 of Beth's classmates and came up with a list of questions you might ask a new friend. We then practiced these at home and helped programme in answers if she was asked these questions – do you have brother, sisters, pets? What class are you in? Where do you live? Do you travel to school by bus/train/car?

Particularly for hospital visits I became very adept at looking out of a window or at the floor when Beth came to ask her questions. The consultants soon learned that if Beth had questions she expected to be answered and not for them to always talk to me. Likewise if she was in hospital at the time of the ward round she would sit with her communication aid on her knee and before the team of doctors and nurses began to discuss Beth I would say that she was cognitively able, but had a speech impairment and was deaf, so could they always talk to her full face on so she could lip read and if she wanted to ask a question they should wait whilst she programmed it into her device. I also started to ask Beth around this time if I could speak on her behalf, or explain things more fully which made sure that I was modelling to others that when discussing Beth she was still the one in charge.

At 10 Beth had quite a lot of time off sick (again). We watched a lot of a TV programme called Tracey Beaker, a drama about a young girl in care. Tracey was encouraged by her social worker to write her life story to help her understand what had happened to her and come to terms with her Mum not being there for her. Beth decided to do the same and worked feverishly over several days, writing herself, typing and when she was too tired to do the physical input telling me what to write. I found this very traumatic, I had never realised how sad and lonely she was and had been all of her time at school, how she didn't really have friends, how difficult everything was at times including communication. When her story was finished I typed it up for her, I mentioned it to the then Chair of Communication Matters, the UK branch of ISAAC, and the friend asked to see it. She suggested that it was something that would be very enlightening for others if it was published in the Communication Matters Journal.

At 11 the publication of her story began a career (and I do mean a career) in public speaking for Beth. Initially she was asked to speak about the article at a family day for children who use AAC. She so enjoyed the experience that she asked to do it again. The ISAAC biennial conference in Germany was due the next year in 2006 and so we submitted a paper for Beth to present her story, it was accepted and we saw our girl blossom at 12 into a confident young woman who delivered her speech with panache and answered her own questions. She continues to do this and says she enjoys it so much because people sit and listen carefully and quietly and then ask appropriate questions at the end and wait for her to answer. I guess the ultimate in quality time and listening!

The interesting and worrying thing for us at 12 was that this confident young woman at home and in the community was being reported by school as quiet and only speaking when she was spoken to. There was little accommodation for her disability, she was expected to deliver the same work in the same time frames, often she worked for 3 hours a night and 15 hours a weekend on homework so was always exhausted and often classwork was unfinished. She had taken into school her presentation from ISSAC only to find that the staff didn't think it was her own work and could not believe that she had presented it herself. This lack of belief and low expectations led to low self-esteem and over the course of several months what we now know was depression. The lack of specialist knowledge in a mainstream school led to their thinking the inability to understand her spoken speech and the speed at which she could type out her answers meant she had possibly a learning difficulty and nothing to say, or both. A change of school to a specialist placement has over time remedied that, but we have still had to support Beth to learn strategies to interrupt conversations politely, to pre-programme key phrases. Especially to not take it personally if she gets ignored or spoken over, because it happens to us all, not just to those with communication challenges.

It was Beth's decision to move to a specialist school. Following ISAAC she wrote poetry about her feelings and did a lot of deep thinking. She was able to tell us and key staff in education that she knew her school was not right for her as they didn't understand her needs. They didn't listen to her and she no longer wanted to be the only person in a wheelchair or using a communication aid in school. She wanted to be with others like her and needed to move.

We have encouraged Beth to make decisions since she was a little girl. As an only child we have been able to give her quality time, we have listened to her views, explained situations and given her options. We often have conversations about things like what she liked or didn't like about a film we saw, what went well or could be improved on a piece of school work or a presentation, how she felt about a situation and how we felt to compare it.

One challenge has been to get Beth to speak out when something isn't right. When she was younger she would try to be like her peers and resolve things herself, but when it didn't work bottle things up. This led to rare but difficult to manage emotional moments when she started

to howl, to cry with frustration and could not be calmed. It only happened once in primary school the other occasions at home when things just got too much. We have moved from Beth describing all emotions as happy and sad when she was younger to an age appropriate vocabulary, but this verbal emotional expression was slow in coming and has taken a lot of time to develop. Some physical problems over the years have now been diagnosed as dystonia. In early puberty she began to have more issues and she can now identify the cause and deal with it appropriately. She self-medicates for pain, goes to bed early if she is tired and most importantly when she is stressed she will confidently tell trusted members of staff at school how she feels, and why. She knows they will take her seriously and we can discuss issues on the phone when she calls home.

Perhaps the biggest change academically and socially came when Beth got new hearing aids 2 years ago, these were even better than the first digital ones and now she hears virtually everything. Suddenly in 4 months her vocabulary jumped by 4 years. This has posed more challenges and she now uses the communication aid regularly at home for context. Out of the home she uses it really well in spontaneous conversation with strangers as well as people she knows well.

Beth still prefers to be verbal but she judges what each communication partner needs. If she thinks they can understand she perseveres with speech, but she always knows when someone doesn't understand. She has learned in class to be able to jump into have her say and if she is talked over by others she is remarkably insightful saying that everyone gets talked over sometimes, so why should she be different.

As you have heard Beth as matured into a teenager we have had much to be very proud about, but there have been times when, just like her, I have wanted to cry from anger and frustration. Anger at the way others have treated her and undermined her communication attempts, and frustration when I cannot understand what she wants to say to me.

Particularly when we are in the car Beth often wants to talk. It is not always comfortable to have a communication aid on your knee for long journeys. What I find most upsetting is if she tries to tell me something and I don't get it. Sure we have strategies to help me understand which have developed from the ones she used as a child, to give me context, use a different word or to spell words but if she says 'forget it, it doesn't matter' I am beside myself. She has tried to communicate and so it is important. We have been known to stop at the next service station or pull over onto the side of the road (not on a motorway, of course) so we can have the conversation.

A key time for talking is when Beth is relaxing in the bath. She likes to soak and for me to sit and have a chat, its quality time with no interruptions but it is not without its challenges. The bath is not a good place for electronic equipment. A good example of this is when she wanted to talk about being more social, I was lost without the communication aid and needed the context. After a few attempts when I clearly couldn't get it Beth started to talk about Lisa, a good friend, then about Lisa her social worker. When I said social worker she shouted yes and we established that the word she wanted was social and thankfully we were back on track but not without a good 5 minute detour. Nowadays we have a laminated waterproof letter card she designed which is perfect for spelling. It lives by the taps so is always available, is see through so I know where she points to, I call out each letter as she frames her topic and then we are off until there is another word I don't understand.

I've mentioned that Beth uses both a high tech communication device and a letter card, and that she also uses props. We went to the ISAAC conference in Canada in 2008 and Beth was incensed afterwards that everyone seemed to only talk about communication as high or low tech. She immediately went on a campaign to remind people about how we all communicate, using facial expression, eyes, gesture, sign language, body language. I know I have always gesticulated a lot when I talk, take away my hands and I become lost for words. What Beth

showed me was that her communication is just like ours, everything comes together into a total package, the bit where help is needed is the physical voice output, some of the time. The times when this is more key is when she is tired or had enough. It was only when she went to special school at 11 that she learned she could say yes or no just with her eyes. I know when she uses her eyes she is exhausted, the other signs she is tired is her voice gets quieter and quieter until it virtually disappears and using her lightwriter is a physical effort so she doesn't bother. Beth asks three questions before deciding to speak using AAC,

- Is what I have to say important?
- Can I be bothered?
- Will I have time to prepare it?

If she gets 3 yeses then she will use AAC but if not she will use sign, gesture, body language or other means because she says being understood is more important than having well constructed sentences said out loud.

Every individual is unique, we as a family are a close unit. We have learned to be patient, to listen carefully and to facilitate good interaction. Parents don't get trained to communicate, it is just something we are all expected to do. In fact I now find it strange that physiotherapists and occupational therapists input into a child's development from a few months old but speech is often left until much later. Communication is a right for us all, children have the right to say I am tired, I have had enough, I need a break or a drink or food. Speech therapy should not be seen to only become important when speech production fails to develop typically. Is it more important to express your basic needs and desires or hold a spoon or walk? I would now claim communication must come first for everyone. Those very early words from the nursing team in neo-natal set us on our way, talk to Beth, share your life and dreams for her future. Without the input of the teacher for the hearing impaired at 13 months would we have known the value and importance of good communication strategies when we later found these had promoted lip reading and good functional interaction? We have never knowingly thought lets work on communication but I am delighted that in hindsight many of the things we did have provided the building blocks for Beth to dream of living independently, having her own home and having a career.