

Living With Hydrocephalus

a Presentation By Andrea Fox

Good Evening, and welcome, my Name is Andrea Fox and I am a member of the Dublin Branch. Today I would like to talk to you about my experiences of living with Hydrocephalus. These experiences are just mine and it may be different for others. The talk I am going to divide up into three areas.

(1): Childhood/Primary School

(2): Secondary and College

(3): My current life

(1): My first is my childhood experiences. When I was born I was never diagnosed with Hydrocephalus or any other form of disability. It wasn't until my 7 week check up in Our Ladies Hospital that the doctor measured my head and informed my parents of my condition. It was all very new to my parents. I was put on a drug to help reduce the swelling but after one month this was not a success and my very first V.P shunt was put in. Because my parents were not very knowledgeable of my disability they asked no questions and reared me just like they did my brothers. I started into a mainstream school at the age of 4 years. I was unaware of having Hydrocephalus so took part in everything that I wasn't supposed to do. Mum said I loved school and was always a happy child. Although school had its challenges it wasn't until 3rd class that I found each day hard. So at the age of 8 mum decided to explain to me about the shunt and that's my school was so hard for me. She used the words ***I was a special child*** and that I will have many a hard day. My weakest subjects were: Maths English and Irish. If I had have been given the chance to drop Irish I would have. My homework each night would take me from the time I got home from school until late that night. One thing that will always stick in my mind was having to write about the news. That was one part of my homework I really struggled with as I had to try and remember what was said. Mum came up with a great idea of taping the news so that I could play it back at my own pace and write each sentence slowly. At the age of 10 I had a bleed to my head, when I came out of recovery I couldn't remember who I was or the basic day to day things, like walking, or remembering different things I had done. The biggest

shock of all was when I returned to school I remembered nothing from my handwriting to reading and even my co-ordination had gotten worse. I knew that the learning process had to begin all over again. With the help of one teacher in primary she used to buy the resources I needed to help me recall what I had previously learnt. To overcome my fear of reading in class she used to give me the passage to read at home so that I would be well prepared for the next day. While I was doing my homework I had to ensure that I was in a quiet place so that I could concentrate on what had to be done. After a full year I had come along way. I continued to work extra hard, I spent many times crying but mum and dad supported me a lot. We had to sit a final exam for our entrance into Secondary but with exams being one of my weaknesses I failed my entrance exam into the secondary I wanted to go to.

(2): Secondary:

The word Secondary I feared from day one. This was because the secondary school I had to go to was more academic than what I could cope with. However I had made my mind up that I would take each day as it came. The first two weeks I will always remember the change of subjects and the amount of books I had for each day. But the biggest thing of all was trying to use my memory to recall where each classroom was. There were so many corridors and each room looked the same. I came up with a great system to help me overcome these problems, the first was with my timetable and what books I needed for each subject. I decided to colour coding my timetable (example I would colour the subject English in yellow and for each book and copy related to English I put matching colour stickers. This was one less thing I had to worry about. And finally to overcome my sense of directions to each classroom I use to take landmarks. (Just make sure the landmarks you use are not moving objects ☺). Each day brought a new challenge but I overcame this by preparing my day in advance. The year of my Junior Cert I seemed to be struggling with, it was having to remember everything and to write down the answer in a certain amount of time. I had a lovely resource teacher who took it upon herself to help me to prep for my exams. She knew that the novels in English reading was one of my weaknesses, and so showed me how to make bullet points onto a sticky pad at the end of each second page. This meant that at the end of the chapter I only had to put the notes all together. Although it was challenging and frustrating at times, I loved school work and never dreaded attending any day. I sat my Junior Certificate with everyone else in my class without any extra time, but I am happy to say I passed with flying colours. During the next 3 years leading up to my Leaving Cert, I did extra tuition after school. It was suggested to me that I drop Irish and Maths to foundation level. It wasn't as easy as it sounds but the formulas that you were required to remember were given to me. During Secondary we were always asked what we wanted to be when we grow older, this was something I never really thought about, But the big day finally arrived I was older and now I had to take control of my decisions in

life. I got my Leaving Certificate results while away in Spain, I was dreading it as I had found the exams so hard. However I am happy to say I passed with honours and passes. Grades didn't really bother me as long as I passed. I went onto do a PLC Course in Crumlin College on Computers and Business studies. I enjoyed the course but I found the theory end of it very draining and hard to remember, It wasn't like primary or secondary, it didn't consist of the method I loved so much and that was Show Me Don't Just Tell Me. During the year I had to get work experience I took up my placement in a local Computer Training Centre, where the boss let me assist him with teaching the children the computers. I loved it and went on to do some work outside of college for him. I realised that the dream I always had in the back of my mind was to help teach others. I left college after the first year I knew college was not for me so in order to fulfil my dream I went onto doing part time and home study course in Computers and Special Needs. While doing my courses I worked at many a job from cleaning in a local pub, to office work and much more and cleaning in a local garda station. If it wasn't for the help of my parents I would not have got through it all. After 3 years of studying at my home pace I went onto follow my dream. In 2006 I set up my own little computer training business catering for adults, Senior Citizens and children aged 6years up. Many of who have some sort of learning difficulty. I knew it would be tough but after being told in a job I would never be a trainer, I was more determined to prove them wrong. The very first year was the most challenging, although I knew my computer work I still had a lot to learn. Both my brothers work with computers, but whenever I was stuck I used to be told to RTFM. (Read the F Manual). I used to get upset and wondered why they just couldn't help me. Looking back on it now it was the best thing they could have done for me, as it made me stronger and research more into how things worked. I started off my teaching adults, I loved the Senior Citizens. I had one business man aged 72 when he started (he knew a little but not very much). He was my biggest challenge but a very rewarding challenge to I ever taught. Because about 1 year ago he ended up bed ridden and could not come out of the house to do his business work but now that he had become a computer Nerd he did it all from home. (Many a night I got a SOS phone call) but I always able to talk him to it. He helped me grow stronger with the business side. (Even thought I tricks how to dodge the tax man 😊 mind you not that I do). I then took on the children who find learning very difficult, I know as I was one of those children and I knew how hard it can be for them. I started to research for different types of application software that would help them with their school work. When the business started to take off I found it difficult to keep track of day to day students and topics I had to cover. So Dad bought me a mini PDA which I used to record what I had done and what was to be covered next week. Also I used the calendar on both the PDA and my Mobile Phone to record class times. School nowadays has changed a huge amount since I was in school, I know this as I worked as Special Needs Assistant for a year and throughout that time I even learnt more about special needs and daily challenges. This is why I will always continue to teach and research different resources for them, and I will continue to follow my dream. Now that I am 29, and I am going old (just like my brothers keep reminding me) each day is still a challenge, so in

order to stay on top of everything, I plan my day in advance and take notes for everything I am required to remember.

The social end of living with Hydrocephalus I did not mention in my speech. Socially I found it hard to tell people about my disability and so I used to hide myself away in my room. It wasn't until I joined the Association that I moved out of my comfort zone and started to live my life and have some fun without the worry of what others thought of me. I have to say if it wasn't for the help of both Claire my family support and the Youth and Repite services I would not have become less dependant on mum and more dependant myself about things I do. Life can be very hard and confusing from time to time and my days can have very difficult tasks to take on. But I always try to stay positive.

Finally I would like to thank you all for your attention today and for Mr. Kennedy who gave me this chance to talk to you today. I hope that this information will benefit in some way to you all. I have left handouts listing tips and educational resources that I find very helpful.

MY FINAL WORDS I WOULD LIKE TO LEAVE YOU WITH TODAY IS EVERYONE IS DIFFERENT BUT NO MATTER HOW HARD YOU FIND THINGS FOLLOW YOUR DREAM AND IT WILL COME TRUE. IT WONT BE EASY BUT FOR EVERY PIT FALL YOU COME ACROSS THEIR IS A LIGHT AT THE END OF THE TUNNELL.

Hydrocephalus Handouts

Tips and Tricks to help with everyday life.

By Andrea Fox

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School and College:

- When reading novels or English stories, highlight important parts of the page you are reading about so that if you are asked to pick an important piece in the book you will find it much easier to find.
- The “Show Me Don’t Just Tell Me” method is a good way to get through everyday work; this can include home things like cooking, ironing, washing, or in school work. Seeing things done first then memorising and visualising makes it much easier to recall again at a later stage.
- Take landmarks around the school or when out on your own. Look for a particular picture to help direct you to what way you should be going to. (just make sure the landmarks cant’ move)
- Colour code your school timetable and both the books and copies the same colour relevant to the subject. (e.g all English books and copies I will put a red sticker on them and colour English red on my timetable).
- Practice reading the night before class so that if you are asked on the spot to read you will be familiar with the words.
- Visualise things such as pictures in a history book this will help you remember what you have read about in the chapter and help you write about it in exams. Visualising is a great way of being able to remember and understand things.

- PDA and Mobile Phones are a great way to keep track of appointments, Set reminders on the phone so that it will beep at you the day before.
- Spellchecker programs on a computer are a great way of helping to spell a word.
- Learn through fun and games. (snap cards for memory games etc)
- **Practice, Practice, Practice**. This is the best way to remember how to do things, as you are using all senses in your body, such as touch, sight, smell etc. The more you do it the more you can visualise and remember.

Daily Tips

- Personally for my living with Hydrocephalus I can't do on the spot things, this includes, going out on a night out or a trip into town without notice. I have to plan my day in advance; this may include where to meet people, what transport to take etc.
 - I used to panic when going out on my own on the bus for fear I would forget to get off or get off at the wrong spot. To help me overcome this I pick particular stops or signs that I know to look out for when coming near my stop.
 - Remembering things can be difficult a lot of the time for me but I have found note taking is very helpful. Especially when I have to go shopping I write down a list of what I need, but if it comes to cereals I might make an additional comment such as the packet with the red strip on it.
 - Hospital Appointments: I have a habit of forgetting my hospital appointment dates so now I use either the calendar on my phone or my PDA to set a reminder about a week before and another one the day before.
 - Before doctors or hospital appointments I write down the questions or concerns that I have before entering the waiting room, this is so that I don't panic or leave out the important things.
 - When asking questions I find it hard to understand what the person is asking so I try to either break down the question into smaller chunks or just ask the person to repeat it in an easier way.
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Computer Software and Companies

- Computer Applications I have used
- **Clicker 5:** Clicker is an educational program that allows teachers or parents to set up homework and school work onto the laptop or computer in advance, the child is then required to click on the relevant words or phrases.
- Clicker has also got several packages to add to the main program. Clicker Phonics is software that has 8 levels of phonics lessons, it includes writing, reading and recording what you have read, Story book making. They also have a program called Out and About the home, this software teaches you how to cook using recipes, sort and organize shopping lists, and also to do calculations from a shop. It is a fun program and suitable for all ages (even I love it 😊)
- **Penfriend:** This is a predictive spelling key or CD Rom that is installed on the computer and when opened by the student it recognises the first two or three letters of the word being typed and then offers suggestions of words spelt similar.
- **Wordshark or Starspell:** Both these programs are used to practice spelling. Wordshark is where the student will learn spellings from the basic to advance in the fun of typing.
- **Nessy Fingers:** This is for children and adults with disabilities, it teaches you touch typing but in a easy step by step method.

Companies:

www.jacksonstechnology.com

www.edtech.ie

www.cricksoftware.com

www.dyslexia.com