

## Laughing @ Aphasia

by Barry Cappe

“1,2,7,6,3,10” I say confidently and straight faced to the policewoman (at the same time thinking, they must be getting them straight from school these days they look so young). The milliseconds, that seem like hours, pass. The sweat beads form on my brow. I notice the grimace on her face and I realise, as usual, I have stuffed it up. Immediately, I get ready the spiel in my mind: I have had a stroke; no, not right now; I have speech problems; I have some other problems; it is all recorded on my licence and yes, I am tested each year. Well, that’s easy in my mind but what will happen, what will I say in reality, when my mouth opens?

It is just another day living with aphasia. Two and a half years ago I had a stroke. I am not going to elaborate on that, in here, as that is a book in itself. Also, If you don’t know what aphasia is – look it up on the web. Why do people with aphasia have to be constantly explaining their condition when they can’t even talk? Why do medical conditions have such unpronounceable names? I could give them some new words that they couldn’t pronounce. Also, why is the word ‘unpronounceable’ so long and unpronounceable itself? Why does my newsagent forget to deliver the paper sometimes or land it in a puddle when it is raining? But I digress.

How do I feel now? In one word terrific. Speech wise: having come from lifeless, unable to even cough to attract somebody’s attention, grunting, not caring and childlike to someone who is almost adult human, I’m happy and having fun. After all, maybe I am as well as I am going to get. I am going to make the most of it while I can. Sure occasionally, I can’t remember a word; speak in one-word sentences; speak leaving out verbs, nouns etc; say something when I really mean the opposite; stuff up weights and measures; dates; say something that makes no sense at all and/or make up new words when I can’t think of the correct one. Have you ever sent an email to someone, thanking them for the wonderful lunch you had tomorrow? You see it’s all the same to me tomorrow, yesterday or today. Considering all that, perhaps, I am as not as well as I thought.

Rubbish! I might have lost my normal speech but I have gained another new language. I personally call it ‘stroke’. If you haven’t had one (stroke) you might not know about it. But, if you have you will. It is used when you meet one or you enter a room full of stroke victims. We all speak it in our speech group. I am sure that Claire and Julia (the speech therapists who sit in on the group) leave with the heads spinning and shaking sometimes. It is very caring, not gender based, not aged based, free of status symbols and never written but we all speak it in varying degrees. I don’t know how we all learned it automatically. If one of us needs something and can’t communicate it, usually, another in the group will. Unfortunately, it is not enough to survive in the wide world.

If you have read this far and you suspect this is going to be just an irreverent account of a serious condition, sadly, I suggest that you stop reading now. I am sure that is easy to deduce that from the title, but in reality this is an actual account of one person’s struggle living with aphasia. It might not be best solution for everyone but it works for me. I am talking here about someone who, more sadly (before my stroke), would cross the street to avoid striking a conversation with a handicapped person. Today, I approach them and ask them how they became handicapped. Sometimes it is strained but more than not, it works and we part as new friends.

People say to me that I am lucky because I can write things. Balls! If I was lucky, I wouldn't have had a stroke in the first place. I have worked very hard to get here. I would trade places with anyone of the people who say that. I am just sitting here with my word processor, one and a half finger typing, dictionary, thesaurus and doing the best I can with what I have. Sometimes I type the last paragraph first and the first last or midway through. Then I read it countless times. The process is slow at best.

### In the beginning - Hospital and Rehab.

Waking up in a hospital unable to talk was a frightening thing. There were so many questions that needed to be answered. First one, was I in heaven? Couldn't be, I would have expected better looking attendants than these ones. What were the alternatives? I couldn't ask anybody. All I could do was hope that someone would tell me what was happening. I was totally dependant. I didn't even know who I was. Everything was a blur. So much was happening around me. One day merged with the next.

The doctors kept asking me my name and the day it was. Really, they weren't very smart but I kept pointing at the chart on the end of the bed. It must have been written on that (sorry, old joke). The reality was I didn't know, I couldn't have told them if I did and I just didn't care anyway. I was anxious at just being alive.

One day a nurse told me that I was really lucky to have such a good wife. Well that was news to me. I didn't think about having anyone else, family? She told me she would point them out to me if she could. When Geraldine, my wife, arrived she did exactly that, pointing at Geraldine's back while mouthing 'wife'. Not bad, eh? Around for less than a week and I had scored a wife already. Later, another nurse pointed out my daughter. Despite the fact that they had visited me most days, I didn't know who they were. After both of those reunions my life took a turn for the best.

The nurse aids came to give me a shave, presumably so I would look good for my new wife. They were two young giggling girls. They got started, I was suddenly frightened (by two 'scatter brains' with a razor at my throat) and indicated I would finish it myself (left handed without a mirror). Next time Geraldine came to visit, instead of admiring my handiwork, she went berserk at the results. For some reason, everyone was a bit sheepish after that. Needless to say, thereafter I wasn't allowed to see in a mirror or have my hands on any razors.

Lying around hospital, and ultimately rehab, I had plenty of time to think things through. If you can't communicate with others you have to communicate with yourself to keep from going insane. I could be seen often shuffling around chuckling to myself. I expect it is like being in solitary confinement. I am sure there are notes on my file.

It is a cruel world. In rehab, I befriended (I don't know how, maybe they could speak stroke as well) some people who had shocking injuries. Their state of mind towards the future was incredible. I decided there and then I could live with the other injuries I had. The first thing I had to do was to convince people that I had a speech impediment only, I wasn't dumb! After all, I was better off than non-English speaking migrants, at least I could understand what was being said.

I needed to keep a sense of humour to get me through. At rehab there were some trainee nurses. Every day, I was to get an insulin injection and a trainee, and her sister supervisor, arrived to give it to me (if you don't know about insulin, it is injected in a fatty area of your body, usually the stomach). In front of me the supervisor told the trainee she had selected me because I was good to give injections to and I wouldn't complain or talk back. Thank you very much, I have a trainee who is probably giving me her first injection to a human being; I'll give you 'talk back'. With my belly fully exposed, I studiously watch the nurse as she nervously, and timidly, injects the needle. As she extrudes the liquid into my gut I slowly let my head fall onto my chest. When she withdraws the needle I let out a little sigh, a solitary breath, and remain perfectly still. Dread permeated the atmosphere. The trainee's face was just a priceless moment. After about one millisecond, the Supervisor (having realised what I have done) calls me names, scolds me and tells me now the poor girl will probably remember that experience for ever. With a sly lopsided smile, in my mind, I added - me too.

Oh oh! Now my sense of humour is sick as well.

I will never forget some other things from rehab, in particular one instance when an Occupational Therapist was discussing me with another one. She insisted that conversation was held in front of me. The gist of that was that even though I couldn't communicate very well, she maintained that I knew everything that was happening around me. Looking at me, her colleague was a bit 'gob smacked' by the situation. It is amazing how some things stick in your mind. At last I had met someone who really knew what I going through. There you go! A little gesture you make could be remembered and treasured by somebody else for life.

I understood at that time that my speech would return at some stage. I had so many other issues I really didn't care. All I could think about was going home, hoping everything would be the same as it was before.

#### Home at last! - About seven weeks after the event.

Eighteen hours over the next 12 weeks (1-2 hour per week, 6 weeks home based and six weeks back at rehab) and I was cured. Mind you, I couldn't tell you the time of day but I wasn't looking for any hand outs (lucky, as there were none coming). At that point I realised I would have to do it on my own. I had no interest in the news or other current affairs. My attention span was minimal and basically I was just surviving. Every thing was a huge effort. I could say individual words and some phrases, of course, mixed up at best. I decided to work on other aspects of my health, the speech could wait.

Friends visited regularly (I didn't realise I had that many, in that regard I am extremely lucky). It was great. One particular one was so regular I eventually asked him if I owed him money. Being housebound also gave me an opportunity to sort out the friends that really weren't.

I exercised daily and I had lots of opportunity to practice greetings on people as I walked past. I settled on a couple (good morning/afternoon/evening or g'day) to start with and thereafter I would pretend to be too busy to chat. The only problem was that I was mostly saying the time of the day wrong (afternoon for morning and vice versa). Ah well, it was a start.

I visited my heart specialist. During the visit he asks (theoretically) “if I could cure one thing for you today, what would you like it to be?” Straightaway I replied – my speech. He said I had made the correct choice and added “I have seen speech take years to come back in the past”.

Did I hear right? Years? Here I am, my mobile phone, watch, money, wallet, dignity, speech, spectacles, testicles confiscated and replaced with a solitary card which reads ‘I am Barry, if found please return to ...’ (no-one was even offering a reward) about to face a future of years of no speech. Wow!

Sorry, I am lying, I kept my watch. Time dragged on. I realised then why they wouldn’t tell me how long it would take for my speech to come back. During this period many other achievements were made. On the language front: for about the first 12 months I was a prisoner in my own body.

I visited my endocrinologist (don’t ask – I think it is something to do with what they did to Walt Disney) and when he enquired after my exercise regime I proudly told him (according my eldest sister) I had worked it up to about 40 hours a day. He didn’t comment but studiously kept writing a report.

For some reason, the mute curiosity (me) was invited to a wedding. Having lost some weight, I had nothing to wear that fit me. Geraldine drove me to the city to remedy the situation. After purchasing some shoes I had my first experience with financial transactions. You can pay for things without saying a word, can’t you? The store assistants just stood there staring at me. What was the problem? I had given them fifty dollars and I insisted that I had given them a lot of money and it must be enough. Apparently I needed lots more. Geraldine came to the rescue and we left shoes in hand.

My best friends decided to take me to lunch at a restaurant. Fantastic gesture very memorable. Midway through the meal I asked my friend - “How long have we been friends?”. “Nearly 40 years” he replied. “Do you consider yourself to be my best friend?”. “Yes, why do you ask?”. (wait for it - you can really have some fun if you are a handicapped, brain injured person). “I need you to take me to the toilet” ...that face, honestly - another priceless moment to be had. After some serious throat clearing, he blurts out – “Nobody told me about that!”

#### A year after the event:

I started to read again. If I couldn’t pronounce a word I would keep it going around in my mind until it stayed there. Reading the newspaper out loud was a good help to remind me how much I had to re-learn. Practise! Practise!

You wouldn’t believe it, even when I was alone during the day, there was ample opportunity to practice conversations. Hawkers and canvassers kept ringing me up to talk to me. I must be one of the only people around who actually has marketers hang up on them. There are fewer calls now, maybe they have banned my phone number. One day I had a collector about to send me a donation.

I took every opportunity to listen to the radio, watch TV, read the newspaper. After a while, I couldn’t stay at home any more, I had to get out. I started to studiously

observe people around me. Before long I noticed that people generally mumble, slur and/or shorten their words and don't really say much at all. Check it out yourself. I figured then, if I couldn't pronounce words correctly or compose sentences, I only needed a SSK (Speech Survival Kit) containing a few words to survive and I was going to fake it after that.

I had to venture further out in regaining a life. I love having a coffee during the morning - Cappuccino coffee in particular. There was no way that I could pronounce that. But think about it, easy! – 'good morning, cap please'. Terrific! I was on a roll now, the world was my oyster. At last my life was becoming complete. My confidence was building. One morning while paying for the coffee, Alice, the owner of the café, wanted more than a yes, no, maybe conversation. She asked me what had happened to me. After all, I had disappeared for months, had lost nearly 20 kilos and wasn't the person I used to be. Totally relaxed after a beautiful cup of coffee, of course, I immediately forgot that I couldn't speak and opened up with a mouthful of 'gobbly gook' (verbal diarrhoea). I had blown all my good work in one attempted sentence, I was now painfully aware that I needed to increase my repertoire and I couldn't rely on faking it.

My dear old friend offered to read with me. He would bring his copy of the Herald, find the most convoluted paragraph (or group of paragraphs) he could and I wasn't to go anywhere until I had read it at least twice perfectly. After a while he started throwing questions at me about what I had just read. I must admit at 79 he is a little bit deaf so I was able to get away a bit of stuff. Still, the thought was, and is, extremely appreciated. The exercise dramatically improved my comprehension and now I am an avid reader. Also, in speech, instead of just trying to find a word I started to know the word I was actually looking for.

One day I went into the butchers and ordered 500 tonnes of mince. I could see him imagining the new extension, on his house, from the profits. Straight away I realised I had made a mistake and asked him, is that a lot? Another day he started filling a bag with meat for me, it got bigger and bigger. Eventually, I called out: Oi! what have I ordered?

I must say, wandering around the shopping centres browsing and shopping gave me an independence that I was sadly lacking in my life at the time. Suddenly I wasn't just a burden. I could do the grocery shopping and other things. People don't realise what someone goes through when their then life is terminated prematurely and they have to cope with a new one. The bills don't stop and the income source becomes only a pipe dream. It puts enormous strains on partners, family and/or carers, as suddenly they become the primary provider often with nobody to share their grief. Thinking about it like that, Geraldine is very lucky to have me.

Today – Two and a half years on.

Apart from the many true friends and neighbours, basically just a hand full of special people make my recovery possible. If you have married, or live with, the perfect partner you will know there is nothing to be said about that. You do not need speech to communicate with them. My daughter (the biggest worry wart) ditto. A school mate, my best friend for 41 years who would do absolutely anything for me and vice versa. Lovingly, he has corrected every utterance from my lips for the last two plus years. Frankly, it gives me the s\*\*ts. Bugger! He will know now. Finally my

business friend of 25+ years, who takes the time to coach me to read again and improve my vocabulary and comprehension. Sincerely, thank you all.

Life goes on. I still listen to the radio when I can. Sometimes, I have no idea what I am listening to. Geraldine will comment about something on the radio, although I have heard the same segment, I have to ask her what it was. I can not get up before hearing the 6:00am ABC news despite the fact that I probably can't understand a word of it. It's too fast for me.

Aphasia must be contagious. Each morning I have joggers, and people walking their dogs, passing me and bidding me a 'good afternoon' as they chuckle to themselves. Smart arses!

I don't swear now (any more than I used to).

On the shopping front: last week I ordered 300 kilos of mince. It has obviously something to do with the mince (I must eliminate it from my diet). Who cares? By my calculations at least I have improved a thousand times (tonnes to kilos, ha!) in two years. Shop people will work it out, they want to sell you something.

If I am ever looking for some practise conversation, I take a trip to the supermarket, buy a couple of items and join the express queue. When they ask me "How are you today?" I tell them the whole story blow by blow from the beginning. That will teach them for asking.

I now walk around going about my business not worrying about the fact I might confuse someone from my next answer to their question or open up with a mouthful of garbage. After all, nothing's perfect. If I open my mouth and some garbage comes out, I stop and just say – let me start that again. If someone says something I can't understand, I stare and say – that is easy for you to say.

It is still a bit lonely at times. Sometimes you have something you would love to share with others but the amount of effort required to do so - puts you off. However, I am very confident that I am going to get there. I am well aware that I can laugh because my outcome has been very positive. I see no point in dwelling on the 'what could have been'. Eventually, I expect all the above to be only fading memories. I just want to get on with a normal life.

What does the future hold for me? Who knows? What does the future hold for you? Let us hope and pray it holds plenty of opportunities to help and encourage others to find their place in a meaningful life. I have just joined AAA (Australian Aphasia Association Inc). When my family and friends find out, they will have a good laugh at that. I must admit, I am dreading the first meeting I attend. I can imagine it "I am Barry and I am an Aphasian".

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