Michele's Story

Michele told her story in a recorded interview. This is the transcript.

Hi my name is Michele. I have been totally blind since birth. My condition is called Congenital Microphthalmia—which simply means ‘tiny, tiny eyes’.

When I was forming in my mother's womb the eyes, and the motor-works that drive the seeing part of the brain didn't form properly. All those cells just died off and so, seeing is mentally—as well as physically—an alien concept to me. Even if they put normal-sized eyes in my head, and were able to inject or micro-chip new cells into my brain, psychologically it would be incredibly traumatic because I'd have to be rehabilitated—I’d have to learn how to see.

The only way I'd consider having any kind of surgery would be if they could invent some kind of machinery or sunglasses, where I could turn it on and off, depending on how much my brain could handle at any given time. That way, I could teach my brain to see by degrees, starting with opening and closing my eyes for a few seconds and building up from there. Not being used to light, I would imagine I'd end up with terrible headaches if I didn't do it very slowly.

I was about six weeks old when my parents learned I was blind. My Mum picked it up when she was bathing me one morning. She took me to the paediatrician for my six-week check-up, and he sort of evaded the question. He sent my parents to the Children's Hospital, to someone who actually was the best eye specialist at that time, and he was the one who told my parents. It was quite traumatic for Mum and Dad because he told them in a room full of people, but he explained that it would have been far easier for them to fall apart, had he taken them aside.

The first time I was actually aware of the word ‘blind’ in regards to myself was when I went to Kindergarten because I started hearing it in a context other than ‘those things which cover windows’. I didn't really know what it meant, and I didn't really care, I just thought: "Oh well, big deal, it's just a word.”

It wasn't until I found out that I wouldn't be going to the same school as my brother that I realised that there was something different about me; and then, when I went to Townsend School, I learnt things that other kids like my brother didn't learn. I learnt to use a Perkins Brailler, I learnt to read Braille, I learnt to use a cane, and even things like music, which they (kids like my brother) didn't do, I did. I went to a few sighted primary schools for day visits and noticed that if they did music lessons, they'd just sit in a ring and sing songs, whereas we learnt to read Braille music, musical theory and history. We learnt the piano, which we didn't have to pay for, and it was compulsory to join the school choir and we put on high standard productions at the end of each year, one of which was co-written by our music teacher and the seniors of the school.

Townsend had a great library full of Braille books, a bike track, a running track and a really cool adventure playground. I was learning to type at eight years of age whilst sighted kids had to wait till high school. We had a really good Physical Education teacher and a fantastic gymnasium full of equipment, although I absolutely detested doing athletics. We went on some great local excursions. I also had the opportunity to attend a Braille music camp in Mittagong three times, and represented both Townsend School and South Australia in blind athletics.

Nevertheless, I was quite devastated when I first found out what being blind meant. The distance between home and school was an hour's drive so, to me, blindness was tied up with being sent away every day to a school which may as well have been Siberia in my five-year-old head.

I felt as though being born blind was my fault, and that my going to a school so far away was punishment for the sin of blindness. That hour's drive there and back, was far enough for me to feel a sense of rejection, a sense of being punished, partly because I never really was able to form fast friendships with the kids around my area, so I also came to associate blindness with loneliness and isolation. As an adult, this probably sounds harsh or over-dramatic, but these feelings were coming from the heart of a child. At school I seemed to be the kind of kid others liked to tease, and occasionally bully, so I only made very few friends and hardly ever saw them outside of school.

Because of this, I hated school and I hated that side of town. I still have an aversion to that side of town, particularly Brighton. It's so subconscious now, that it's very hard to get rid of. I believe that for most of my life I have been subject to bouts of depression and separation anxiety disorder, which probably explains this dilemma.

For example, I spent the last three years at Minda singing with the Tutti Ensemble and working with Tutti artists, since I am a professional singer. I really love Tutti; but because it's based down near where I went to school, every time I went there, the sense of separation would cut through my defences and crush me just a little more until I was too exhausted trying to fight it to be any use at all there. I have had to say to them, "I can't deal with coming down here anymore, until I've sought professional help in working through this separation anxiety issue".

Also, although I had some fantastic teachers, there were many who never understood me at all, and my education and development suffered as a result. Although I finally found my 'study-legs' when I was integrated into the mainstream system, and even went to university later on, I lived with a complex for many years as the result of being told I was a "no-hoper". I proved them wrong and many of those who had no faith in me now admire me, which makes me feel humbled. However, an example of the lack of support I received indicates how often needs still go unmet in the disability community. I had developed epilepsy when I was two, yet it was not recognised as such by most of the teachers. Only a couple were understanding and supportive when I had a seizure. Most thought I was putting on an act for attention.

I certainly don't believe that people should be defined just by their disability, but it is something that is looking people in the face. They need to know about it, and how various disabilities or medical conditions can affect individuals. There's no point in trying to hide it under the carpet. It will remain a big elephant in the room that will not go away.

There are people at my church who go out of their way to make sure I fit in and feel welcome. But there are a whole lot of others, particularly the young ones, who just pretend that I am not there, because, according to my sighted friends, they are too scared to come up and ask me the obvious question: "What's it like to be blind?"

At church I've got up and done talks, I've taken Rush (my guide dog) in and explained about having a guide dog, I've done the bible readings, I've performed solos on occasions, and still these people won't come up to me. I was talking to one of the Elders about it, and he said, that even though he had been a doctor, he had been afraid to come up and speak to me because he didn't know what to say. It took my offering to perform at our church's Carols in the Park last year for the ice to be broken. I joined his Lenten Bible study this year, and now he's glad that he pushed through his fear because he's really enjoyed getting to know me.

If you get into groups with people that you don't necessarily know very well, whether they like it or not, they have to interact with you. However, it doesn't help when your best friend from high school, for example, tells you that people find you intimidating. Apparently, when we were in matric, until she got to know me on a school camp, she felt quite intimidated by me because I put on this quite gregarious personality, but I'm also quite an introvert in the sense that I will think about things a lot—too much, my Mum says. This is the result of spending so much time alone, both as a child and as an adult—isolation is very common amongst people with a disability, even for extroverts like me.

After school, I tried to get into the singing industry, and I ran into one obstacle after the other; the 1991 recession, and the introduction of poker machines, both of which deprived many musicians of work. Then I ended up straining my voice after singing with a sinus infection, and couldn't speak, let alone sing, for six months.

I've being singing for years. I started off in the school choir, but even before I really realised that I could sing I've always been interested in music—even as a little girl.

Tutti was where I got a big break because I had the chance to do a lot of solo work, a lot of gigs, cabaret, and I certainly learnt a lot about theatre there.

I also had been singing for Tony Doyle Visions doing the Somersault Project and the Sound-waves Project from time to time. The Music Work Project was one of the acts that Tony Doyle has used in these programs, which are generally Community Day Programs for people with disabilities. Tony's passion is to introduce grown-ups and young people with intellectual and physical disabilities to different kinds of music.

In the last few years they've been the two main avenues. I've sung at Blind Welfare concerts, with Tutti and in the Fringe, I've sung at the Adelaide Town Hall at various concerts, I've sung with the Unley Concert Band.

I would like to get some employment singing. I went to Port Wakefield the other day and did some of busking with my friend and I got $75 for about three hours.

I rehearse with a community choir called Just for Fun once a week; they're not professionals, but it's a nice place to relax and just keep my singing skills up when I'm not getting much work. What I love about music is that it's a language that speaks to everyone—even to deaf people.

Singing means everything to me. It's a way of connecting with the world, expressing myself, getting a lot emotion out, whether it's happiness, sorrow, or anger. It's self-expression!

It's a way of connecting with God. Singing is my bread and butter, singing is my means of prayer a lot of the time; it's a means of self-expression, and it's also the place where I am equal with everybody else.

When I sing, there's no blind person there. There's just a singer; they don't see the blind person at all. If I'm just standing there and singing, the first thing that grabs their attention is my voice, not my eyes.

I want to acknowledge the people who trained me, my music teacher, who ran the choir when I was young, the woman who taught me music at Townsend and my singing teacher who I went to for a couple of years—he would use tactile things to try and show me what he meant. I really looked up to him.

In 1993 I started working at Guide Dogs, first as a volunteer for a few months, and then in 1994 I was put on their payroll to work in their Schools Program for two years. In

1996 I went to university after a six-week trip to Germany, the fulfilment of a long-held dream. Although I had actually auditioned for the Conservatorium of Music when I was in matric, I did so because everybody expected me to.

This time around, I decided not to study music because I'd heard from a friend studying there, that they pretty much took over your life (that's how she put it). I'd had enough of listening to people tell me how to live my life, so I chose to do a Bachelor of Arts, majoring in Classical Studies. After university, I studied at TAFE for a while but due to developing Fibromyalgia and Chronic Fatigue Syndrome, I found studying too exhausting, and the need for money forced me to return to the search for employment.

My years after TAFE were those I spent at Tutti. The highlight for me was being part of a team of blind artists who co-wrote and performed a cabaret show called Blind Date which was entered in the 2008 Fringe Festival. We actually became known as Blind Date and became very popular.

I have a marvellous family who have always loved and supported me, even when I had no faith in myself and I didn't trust them. I went through a stage in my teenage years where, because of some of my teachers, I didn't trust any adult, any authority figure, but even then my parents didn't give up on me. They just used to say, "What they say isn't true." I got to a point where I didn't know who Michele Thredgold was, but they would say to me, "Don't try to be like Mary Smith or Jo Bloggs, be like Michele Thredgold." I'd want to scream at them, "I don't know Michele Thredgold; I don't know who she is." But I really held onto that and though at times now I still think, "I don't know who Michele Thredgold is," I say to myself, "Well, I'll just try and be the best Michele Thredgold I can be..." Knowing that God knows who I am because He made me helps restore my sense of identity when I have nothing else to hold onto.

Along with my parents I've had various friends who have helped me along the way in the same way, and then they've moved on. It's always been heartbreaking when they have, but at those times, I've been reminded to trust that God will see me through, that He will help me to grow and learn from each experience, and that He knows what's best for me; and just when I think I can't bear it any longer, He brings someone new into my life to enjoy. I'm grateful for each and every one of the friends God has brought into my life; and that includes my two beautiful retired guide dogs, Finn and Rush, and for Eiffel, my new guide dog (affectionately known as Effie) .

My experiences have taught me the following which I hope to pass on to other blind people who may be trying to cope with their own issues:

Although it is difficult to do, **cast all your burdens on the Lord**, because, however alone and abandoned we may feel at times, He sees our tears, He hears our cries, and

He will not forsake us. I know there are many blind people out there who have either not been brought up in a Christian home (myself included), or who have had bad experiences with Christians or other religious groups. We need to know at soul-level that whether we accept Him or not, God loves us anyway and longs to have a relationship with us. Just because His followers sometimes get it wrong, don't give up on the one who made the universe and made you.

Self-worth is so important in this dog-eat-dog world. It is essential to remember that we are worth something. Whatever we think about ourselves, we are worth something. We are precious and have every right to be on this planet as much as anyone else. I struggled for years with self-worth issues and still fall back at times. However, thanks to the wisdom of some fantastic counsellors, doctors and psychologists, I am still here and looking forward to what tomorrow brings. Asking for help, either to cross a busy road or to work through a painful issue, is not a crime. Refusing to accept that you need it and taking your anger out on others, is.

Follow your dreams. Not all dreams come true. I wanted to gain world acclaim as a singer, have a number one hit, and meet Boris Becker. My more realistic dreams were matriculating, having my six weeks in Germany, obtaining a university degree, and getting a guide dog. Now I would be happy with a husband and children. Therefore, providing your dreams are realistic, when obstacles appear, do your best to find a way around them, and teach others to do the same.

We need to share our skills with one another, instead of judging one another. Some are less capable than others for a number of reasons and this world would be a better place if we tried to find a common denominator and start from there, instead of picking at each other because Mary Smith is less independent than Jane Jones.

Don't let people tell you that you can't do things. Sometimes there are indeed things which are just not possible for us to do, but that may change one day. When I first developed my Boris Becker crush, I wanted to learn to play tennis. The PE teacher at Townsend told me it was impossible. Since then, a ball has been developed which beeps when it is in the air, so now blind tennis is being played in Melbourne. In the United States they're now working on cars for the blind, and you know, I'm looking forward to the day when I will be able to drive a car, even if it means just sitting there and typing in a route, and then sitting back in the front seat and not even turning the steering wheel—I don't care. I never thought I'd be able to use a computer but it's part of my life now. So hope is what keeps us going.

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