

## Personal Profile: Tony Johns

*“With a little help from friends, singer finds his voice again”*

*Tony Johns (right) thought his singing career was over after being diagnosed with spasmodic dysphonia over 20 years ago. But with help from friends, a project that he never thought would be completed, a CD called “Natural” was recently released. Tony was interviewed by the New Castle Herald (see link below) and he also shared his experiences with the NSDA.*



*Photo credit: New Castle Herald*

<http://www.theherald.com.au/story/4385187/johns-rediscovered-his-voice-naturally/>

### **How long have you had SD and what form of spasmodic dysphonia do you have?**

Since 1997 (20 years ago), I still don't know what type I have as I was never conclusively diagnosed or tested. The specialists who administered the Botox injections didn't give me their opinion on what type I had.

### **Looking back, were you experiencing subtle changes in your voice prior to the onset of SD?**

I had very short bouts of symptoms, lasting about two weeks each time, prior to 1997. The first time was 15 years earlier, about 1982. The second time was 10 years earlier, about 1987. From 1987 up to 1997 my voice, especially my singing voice, was the strongest and most stable it had ever been – I was in my thirties at this time.

### **What was the most difficult part of dealing with SD before you were diagnosed? How long did it take you to get diagnosed?**

Explaining to people what was wrong with my voice was the most frustrating problem initially. That and losing my livelihood as a singer! The first throat specialist I consulted put it down to stress – obviously because I sounded stressed! The second specialist removed a cyst from my vocal cords which he said had been caused from an underlying problem. On one occasion in front of a group of trainee doctors he introduced me as a singer with a voice problem that was probably caused by stage fright! The third specialist, who specialized in Botox injections, said it was probably SD and I should try the Botox treatment – that was 3 years after my voice first showed signs of SD.

### **What treatment options have you explored?**

Initially I tried relaxation techniques (e.g. meditation, yoga, hypnosis, breathing exercises, as well as looking into the Bowen Technique, and the Alexander and Feldenkrais techniques). Then I participated in various speech therapy sessions, classes, and courses, one of which was called

'VoiceCraft' which was run by Alison Bagnall from Adelaide. I attended two 1-week courses at the University of NSW and Balmain Hospital that were designed to train speech therapists. I also spent 1 week in Adelaide attending one-on-one sessions with Ms. Bagnall. I attended St. George Hospital to have a 24-hour reflux monitor inserted through my nose into my stomach. I tried acupuncture and remedial massage and regularly had psychological counselling. I had Botox® injections at St. Vincent's Hospital and the Sydney and John Hunter Hospital, Newcastle. The first dose of Botox® saw my voice sounding good for about 2 weeks, after an initial mute period of 3 weeks. The second injection failed as it missed my vocal cords because I was too nervous and tense on that occasion. The Botox® injections weren't a very practical solution as I couldn't schedule my singing career around them. My talking voice was good enough to get me through my other daily activities anyway.

### **What do you wish people understood about having SD?**

That it affects so much more than just your ability to talk! In my case it undermined my confidence and crippled me from attempting to change my life and career. My SD was mild but it was enough to end my singing career, which had been more of a lifestyle than a job for all of my adult life.

### **What impact has SD had on your life? Your career? Your family?**

I'm not proud to say that I went into a sort of Emotional Coma after the onset of SD. It undoubtedly contributed to my marriage breakdown. I still helped in the upbringing of my children and thankfully remain close to all of them (they are all adults now). But now, when I reflect on those past 20 years, the memories are bittersweet as if it were a part of a weird, surreal dream!

### **How has it affected your singing career?**

When I was a child, I would sit on the back fence and serenade the neighbors. In the afternoon I would sit on the front fence and sing to the children walking home from school. When I went to school I sang in the choir and performed in plays. In high school, I was in debating teams and public speaking competitions and sang in my first rock band at age 14. When I left school I sang at parties, weddings, restaurants, hotels, clubs, and concerts. My singing was as much a part of my social life as it was my career. I wrote songs about my personal life, family, friends, and travels. My voice took me around Australia and abroad to England and Europe where I performed to many nationalities, but music was the common language! My voice financed the cost of raising my young family and putting a roof over our heads. My singing voice was average and limited in range, but it was sufficient for the style of music I sang. A singing teacher once commented that my voice was unusual in that it was somewhere between a baritone and tenor and that my singing in a rock band when I was fourteen probably caused that outcome! I still wonder if I hadn't sung through puberty that maybe I would've had a different voice now and not been affected by SD. My talking voice had a very broad Australian accent and was very nasally and was a novelty to my audiences in Europe! In summary: my voice was ME! My essence, my mojo. Whether talking or singing, it was who I was! Although I know that person is still inside me, it intrigues, puzzles, and frustrates me to no end how SD can hinder/obstruct that person from being seen or heard!

**Do you have any advice, or words of wisdom for someone who has just been recently diagnosed with SD?**

I think I spent too much time trying to solve/fix the SD rather than learning to cope with it. Coping mechanisms are an individual thing. So I say don't leave any stone unturned trying to find the coping mechanism that works for you.

**What have been some of your greatest challenges with dealing with SD?**

Learning to avoid those situations/environments where I know my voice will be at its worst. Explaining to people why I can't sing, even the simplest of songs such as 'Happy Birthday' kills me! Also, trying to be assertive without sounding like a crazed maniac!

**What helps you the most in dealing with spasmodic dysphonia?**

Relaxing, which in my case means sailing, fishing, time out on the water, on the boat, watching movies, and doing handyman work around the house. I changed my guitar playing style so that I was playing the melody of the song on the guitar instead of singing it. It was therapeutic to a point, but also tinged me with sadness because there was still a part of me that longed to be singing that melody.

**Have you found any benefits to having SD?**

It improved my guitar playing skills! But unfortunately not to Tommy Emmanuel's or Eric Clapton's level!

**How do you explain spasmodic dysphonia to others?**

I tell them I have a voice disorder that causes tremors in my vocal cords, similar to how Parkinson's causes tremors in someone's hands.

**What inspired you to continue working on *Natural*? What was it like working with your daughter on your new CD?**

I had given up on ever finishing *Natural*, but my friend and record producer convinced me to finish it using other singers when he told me he had preserved the original recording on computer and that it still sounded great and the songs were too good not to be finished! Good friends and music, a wonderful gift that my life has been blessed with! I realized my songs have an energy and a life of their own, even if I'm not singing them and I'm so glad they are out there being heard! As for having my daughter singing on this album? I feel pure joy and love and it dissolves every bit of pain I ever felt from losing my voice to SD!

**Anything else you would like to share?**

Thanks for your interest in my story. It's been therapeutic for me to tell it to you! I'd like to share this with everyone to see if anyone ever experienced the same thing: While I was undergoing a one-week speech therapy course at NSW University, it was the second last day of the course and we spent all afternoon practicing a technique called 'Belting'- a vocal technique where you yell as loud as you can after breathing in deeply then expelling the air using your diaphragm and every bit of energy your body can muster. It's very liberating, exhilarating and also very exhausting! Rock singers often employ this technique.

I often used this technique toward the end of my singing career as it was the only way I could sing a song without my voice locking up. I couldn't maintain it though as it was too draining – it is probably what caused the cyst to form on my vocal cords!

Anyway, we belted all afternoon, and at the same time a severe electrical storm was raging outside. It continued to rage when I made my way back to my hotel room, avoiding the fallen trees and debris on the streets!

Back at my room I practiced other speech therapy exercises that I had learned throughout the course, then played my guitar and sang some songs using a whispering voice. After about an hour I noticed my voice wasn't trembling or breaking so I tried singing in my full voice- I WAS STUNNED! My voice was back – absolutely free of tremors and breaks! I was so shocked I thought I might be imagining what was happening! So I tried singing a John Denver song (Annie's Song), which had always been a challenge for me to sing well, and it came out beautifully! Better than I'd ever sung it, with a beautiful vibrato that I'd never heard in my voice – in fact it didn't even sound like me! This made me think even more that I was imagining what I was hearing! Tears were streaming down my face as I continued to sing unhindered! Tears of pure joy and relief – my voice was back!

To prove I wasn't imagining all this I got in my car and drove back to the university with the intention of singing in the student recreation courtyard so I would have an audience! It was about 9 p.m. and I thought there would still be a few students around. The electrical storm had passed, but there was still a lot of debris on the road and footpath. When I pulled up at the university I played the guitar and sang in my car for a short while just to be sure my voice was still there but there weren't many students around and I started to feel a bit embarrassed at the thought of singing in the university at that time of the night so I went back to my room and went to bed. I was exhausted physically and emotionally!

The next day I excitedly took my guitar to the lecture with the aim of showing my teacher and classmates what had happened to me. I began singing in a whispering voice but as I tried to open up, the tremors returned. I was heartbroken! To rub salt into the wounds everyone commented on how well I played the guitar!

That experience was like the cruelest trick ever played on me! It has never happened to me since that night 17 years ago! I still don't know if I imagined it all. It was like the most beautiful dream I'd ever had that turned into the biggest joke my body ever played on me.

I still wonder if the electrical storm played a role, by somehow affecting the electrical impulses from my brain to my vocal cord muscles? I do know the Belting technique contributed because I still employ it at my gigs when I attempt to join in on the rocky songs we play. I'd be interested if anyone else has had similar experiences where their voice has returned briefly.