

# CHAPTER 10

## If I Had A Magic Wand

Although I have accepted my situation, there are times when I become rather fed up. It is not difficult for me to understand how horses feel when they are made to wear blinkers. It is like walking around with the outside of my eyelids permanently sewn together. Even when I cup my hands around my face, forming a tunnel to protect my eyes from the glare, there is insufficient field of vision for me to actually see my hands. I often try to clear my eyes of what feels like dirt from a dust storm that has lodged in the corners of my eyes. On other occasions, I sit rubbing my eyes for a long time, hoping they will be cleared of whatever is blocking them. The rubbing never changes reality.

Many nights I lie in bed wishing for a surgical team to take to me with their sharp scalpels and cut the skin from my eyelids to open them up; and the child within me wishes that one day I might be struck by lightning to activate my

nervous system into making my eyes normal. The sensation of skin growing over my eyes and my field of vision gradually becoming smaller makes me want to scream, "Give me a break!"

In the midst of adversity, when there is little anyone can do to help, and giving up looks like a good option, there are reminders that life must never be taken too seriously. I recall a memorable incident on a trip to Rockhampton. At the time I still held a current driver's licence, but no longer drove. During the eight hour trip I explained to my chauffeur that I needed to renew my licence. He thought I was kidding and refused to deliver me to the Department of Transport building where they were issued. It took a lot to convince him that I needed it for identification purposes. Identification is a must when signing legal documents and purchasing airline tickets. It was never my intention to drive a motor vehicle. Thinking I was setting him up for a joke, and believing there was no way the government department would give me a licence, he finally agreed to take me. I also believed I would probably be rejected, which would put the issue to bed and make it final.

We arrived at the licence centre and walked into the building with my left shoulder pressed against his right shoulder so I appeared unassisted. I completed the application form with great difficulty. Then, with our shoulders pressed together, we shuffled over to join the long queue. Gradually, we moved closer to the counter. So far so good!

The lady attendant asked me to complete the eye test. I knew my right eye had the best chance, so I squinted with the left eye till it was almost shut and read what I could. "Is that the best you can do?" she asked. That was it. I'd failed.

“Yes. Do you want me to try the next line?”

“No, but that was the limit. You just made it. We suggest you see your eye specialist. Would you like a one year or five year licence, sir?”

‘Hell, I’ll take a ten year one if you have them!’ I thought.

“Five year is fine, madam. Thank you.”

We shuffled to where I was to have my photo taken and within a few minutes I walked out of the building in disbelief. I could not comprehend how a person with about five percent peripheral vision and zero night vision could ever obtain a driver’s licence.

For a government department of an Australian state that refers to itself as the ‘Smart State’, the Queensland Department of Transport is anything but smart. As well as providing driver’s licences to people who most definitely shouldn’t have them, their computerised recording system is hopeless. A few years after I surrendered my driver’s licence, I wrote a letter to the Department of Transport requesting that a copy of my marine boat licence be forwarded to me. One of my remaining dreams is to own a large houseboat. I have missed my visits to the beaches and the bay. Houseboats only move slowly through the water, and while I would need a driver, I could still enjoy the fishing and the atmosphere of the clean fresh air. Vessels that motor at less than ten knots don’t require the driver to hold a boat licence. Regardless, I wanted to secure mine in case the rules changed.

In Queensland, a boat licence is issued for life; there is no requirement for it to be renewed on a regular basis, as for a vehicle licence. Also, the Queensland Government links the boat licence to the vehicle driver’s licence within its computer system. Their job should have been simple. All they needed to do was look at my file, which should have shown that I didn’t have a vehicle licence because I am

legally blind. This fact was stated in my letter as the reason for surrendering it. Their search should have also revealed that I regularly receive taxi subsidy vouchers provided by their department. In order to receive these vouchers my eye specialist verified the state of my eyes. For three weeks I waited for my letter of rejection. When it finally arrived, it was not rejecting my request, but providing a new copy of a speedboat licence that allows me to drive as fast as I like. Amazing! I don't exercise my right to use the licence; for me that right doesn't exist.

The Department of Transport's incompetence didn't stop there. One evening in June, 2006, Lise drove me to Bond University on the Gold Coast to hear Dr Ziggy Switkowski speak on Business Management. He hadn't long retired as Chief Executive Officer of Telstra Communications and had recently been appointed as Chairman of the Uranium Mining, Processing and Nuclear Energy Review for the Australian Government. We were returning to our Forest Lake home at around 9.30pm, and without realising it, Lise was travelling over the speed limit and our car was photographed by a speed camera. It was August before we learnt about the one hundred and fifty dollar fine, which had been apparently issued to me. The Department of Transport advised us that as I was the first name on the car registration, I had to prove I was not driving.

Not only did the department fine a blind person for speeding, but they penalised me three demerit points on a licence I don't possess. The following week, they posted me a small sticker with my new home address, instructing me to place it on the back of my licence. 'Sure, no problems. I'll do that.' I figured that if I accumulate the maximum demerit points, they might request that I surrender the licence I don't have. Still, I wonder why I wouldn't be fined for driving without a licence.

It is important for me to laugh at myself and make light of the situations I find myself in, even when at times I may be hurting inside. After all, there is nothing I can do except continue to live with my condition. Once a year, Lise and I enjoy a bus trip with the Queensland chapter of Retina Australia. Lise likes helping the blind people to have a fun day, particularly those who don't have partners and have to fend for themselves. On one occasion I asked her, "Why do you like taking me on the bus trips?"

"Because no one ever fights over the window seats," was her reply.

It is also important for me to mix with others similar to myself and the bus trips provide such an opportunity. I need to understand what lies ahead, and for me to learn how others cope with the worst situations. The day's outing always leaves me appreciating what I have now. To my astonishment, everyone goes about the activities in a normal manner. There is little consideration given to whether someone may not be able to cope or take part. If it is bushwalking we want, or a trip to the beach, that is what we do. Vision-impaired people can still enjoy the ocean and the views in their own way. It is amazing what we can 'see' through the breezes, smells and sounds around us. Maybe it can't be compared to how it is for sighted people, but we don't know the difference and it doesn't matter. To a blind person it is as good as it is going to get.

I remember attending a trade show at the Brisbane Sofitel Hotel a number of years ago and being impressed by a blind presenter I met. It was during the early period of 'accepting my situation'. The gentleman had absolutely no vision and at the back of his trade stand there was a 35mm camera. (Digital cameras were still a few years away.) I asked him how people reacted when they saw a white cane in one hand and the camera around his neck. He admitted to having a

lot of fun with people over it. Wanting to learn, I asked him to explain how the hell he used the camera. For this man it was only a matter of holding the camera up and taking a photo to his left, another in front and then one to the right. All he wanted was for his family to see where he had been. Their expectations were not high, and his mission was accomplished.

Sometimes it took an enormous amount of courage just to live what I understood to be a normal life. As a man desperate to pass myself off as an everyday guy, it was inevitable that I would do some very dumb things. We can laugh now, but at the time it was serious stuff. In my twenties I had a passion to be an active participant in sport and became a rugby league referee. My main involvement was in the Brisbane rugby league during the early seventies. My close friend Rex Tom, who became a reserve grade referee at Lang Park, used to tell me that I missed more than I saw. This may be why I didn't mind the parents yelling that I was 'a blind bastard'. The joke was on them; I actually was blind, but they didn't realise it.

The dumbest thing I did on a football field happened while refereeing an under thirteens game. The attacking player ran towards his try line and was tackled by an opposing player; as he hit the ground I believed he was actually grounding the ball. I pointed towards the ground at the spot where the ball was and started blowing my whistle hard and long, as referees do when awarding a try. Simultaneously, I noticed we were in fact at the twenty-two metre line, which is a long way short of it being a try. With the whistle still blowing, I raised my arm, pointed in the direction of the attacking team and told the opposing player he was offside. That day I was lucky to get off the field alive!

The most embarrassing moment of all time, without

exception, came while Lise and I were attending a function at Parliament House in Brisbane. The Asia Pacific Award winners, of which our company was one, had gathered for the government minister to conduct his public relations exercise by congratulating all of us and presenting the airline tickets for the Information Technology World Championships in Malaysia. The light level in the function room was low. Lise was speaking with Sue-Anne, the new awards coordinator.

“Sue-Anne, I’d like you to meet my husband, Paul. He is the Managing Director of Cavalier Software.”

I am not sure if Sue-Anne offered her hand, it was too dark for me to see. I pushed my hand forward, grabbed what I thought to be her hand and started shaking .... except .... it was not her hand, but her left boob. This was one of the many times I wished the ground had opened up and swallowed me. Fortunately, Lise was there to vouch for me. Despite such embarrassing incidents, dropping out of the social scene was not a consideration for us; although by 2006, I did become more reserved and faded from the limelight.

My fifty-seventh year marked an important turning point in my life. I developed a need to know more, and understand why my eyes worked the way they did. I was driven by the lack of understanding that some people demonstrated toward my situation. I realise it was not reasonable for me to expect others to understand that which I myself could not. The Retina Australia National Conference was to take place in Canberra, Australia’s capital city, in September 2006. Canberra is a beautiful place in the spring. It stretches over many thousands of hectares of what was once prime cattle grazing land. It is a purpose-designed and developed city with the two main focal points being Parliament House and Lake Burley Griffin, the latter being named after the

original architectural urban-designer of the city. The conference had an impressive line-up of speakers and presented me with a unique opportunity I didn't intend to miss. The keynote speaker was Professor Gerald Chader, Chief Scientific Officer at Doheny Retina Institute, University of Southern California, USA.

Having arrived early for the conference, I was privileged to meet Professor Chader and enjoyed a lengthy informal discussion. I made the point that the outcomes from research and development were unlikely to benefit people of my age, but would be great for the next generation. He suggested I should listen carefully to his presentation the following day as I would be pleasantly surprised, and that I would learn researchers are much closer to solutions than most people realise.

Science was definitely my worst subject at school and I don't profess to have understood everything I heard at the conference. I was amazed at the progress that has been made and that researchers are hopeful of gaining results within ten years. In some areas of research for RP, clinical research is already being carried out: gene replacement, gene therapy, pharmaceutical therapy are all progressing at a rapid rate.

The following is an excerpt from Dr Chader's presentation: *"Electronic photoreceptor cells in the retina die in Retinitis Pigmentosa, but most of the other cells in the rest of the retina layers remain relatively intact for some time. It is possible to implant an electronic light transducer on the retina to take the place of the dead photoreceptor cells. Theoretically, it is possible to place the artificial electronic array on either side of the retina. A group of researchers in the USA are experimenting on bypassing the retina completely and implanting a sensor right in the brain."*



*Great progress is being made in the theoretical aspects of such implants and in animal experiments. I expect we will see human clinical trials in the not-too-distant future!”*

That morning, amongst Professor Chader’s audience were a number of leading Australian scientists and researchers, but most of the audience consisted of everyday RP sufferers like me, and all we wanted was a little hope, which he was successful in providing. Life has taught me that with hope we can live through any ordeal; it keeps us calm, collected and rational in our thinking while waiting for the outcome. If hope is removed from our lives we have nothing, and are no more than lost souls. I wanted to call out to the Professor, “It is exciting, but it is still scary.”

Professor Chader related a wonderful story of hope; it demonstrated why he believed in his work and was excited. In sharing the story I’d like to be able to present the four page complex explanation, instead I can only offer the four line non-scientific layman’s version:

United States researchers and scientists are taking dogs that are born blind and would otherwise be put to sleep due to their condition and are using them for experiments. In many cases they have been successful in making the dogs see. To me this is awesome!

I had a second opportunity to speak with Professor Chader and discussed my frustration with my limited vision as well as another worrying aspect of my anguish. I asked him, “Professor, have you thought a person of my age may not want to be cured?”

“Yes,” he replied, “I have.”

“I am scared as to my ability to handle full sight. I know my limits and I understand how to compensate. The thought of having one hundred and eighty degree sight, seeing in the

dark , not having to worry about glare .... Well, I just don't know."

"Paul, I am confident you will give a different answer the day I stand before you and say, 'You're next.'"

"Yes, I think I will."

I spent time speaking with a couple of parents of RP sufferers over the weekend and the common denominator was, that they all experienced guilt as my own mother had. Mothers feel they have caused the problem and that they gave birth to a son or daughter who was less than perfect and was not able to enjoy a full life. I don't believe there is a disabled person who would ever think this of a parent - maybe in the case of drug related abuse there is a strong possibility of a child blaming a parent, particularly in the case of a child whose disability could have been avoided by applying common sense - but for people with an inherited disability it is not the case. Such people don't live their lives apportioning blame, they see it as the luck of the draw, and simply how life is. They understand that mothers and fathers can't know the make-up and subsequent results of the combination of their genes.

Over the years I have crossed the paths of people who are deaf, wheelchair bound or paraplegic, and in every case each would not swap their disability for another. A blind person will never say, 'I'd rather be deaf', or vice versa. This is because we have all learnt the coping skills appropriate to our own particular situation. I am no different. If there were only a set number of people in the world with disabilities and by me being one of them, it meant someone else was able to live a normal life, I am glad it was me and not another who has had to endure.

The magic wands of researchers and scientists are obvious; they wish for more research money and better

computerized databases for them to access the information which is being discovered daily. During the conference I was overwhelmed to learn of the number of researchers throughout the world working to find a cure for Retinitis Pigmentosa. It only seems like yesterday I visited the Sydney Eye Hospital, and compared to today's standards, I now appreciate the knowledge was not available.

I look back over my fifty-eight years and realise I have had my share of disappointments, as no doubt most people experience. Given the chance to wave a magic wand, there are things in my life I would like to fix. There is nothing I can do about my past, but I can influence the future, and for me that is a challenge that lies ahead. My disappointments were of my own making and were caused by choices I made. There are situations that I would like to rectify, but now other people have some control over the possible outcomes. A person can have almost anything they desire in life providing they work hard; the exception being, if it depends on another person's emotions and feelings who don't hold the same desires.

There is only one question in life I am unable to answer: 'What will I do if and when my lights go out completely?' I do fear where I might be when it happens. Just imagine one day I try to open my eyes and all I see is a blank. I am very aware what it is like; I live it every night and when I am in dark rooms. Imagine me waking one morning to realise that time ran out the night before. In contemplating such a scenario, I keep coming back to the fact that I am still better off than the person who goes to sleep and never wakes the next morning; at least I am here to know about it. Or imagine I am walking alone in the city, crossing a road when suddenly everything is blank and I can't see a thing. This I fear most of all; I know I would freeze and my first word would be, 'Shit!'

Everyone must decide for themselves how they would feel and it is not up to others to suggest they know how a person in my situation would react, or that they understand, because, with respect, they can't.

Since my teenage years, being active and having the capacity to participate and make a contribution have been high on my list of priorities. Up until recently, I had been clear in my mind that I would not want to continue life's journey if I had no vision at all. For me, my world would have ended, the train will have pulled into the station and it would be time to get off. This is why I classified it as 'when the lights go out'. To consider such a final event was never difficult for me. I have lived a life that I am satisfied with and I have said all that I want to say to those who matter and are close to me. There are things I'd still like to do and places I'd like to visit, but if they don't eventuate I won't be concerned.

As you have spent a few hours with me and come to know the person I am, I reiterate: I am pleased with my life and to have shared it with you. I have done my very best in everything I undertook. That is all that can be asked of me. Along the way I had the privilege of helping people, which has been a satisfying experience. There are no doubt those who think I am the worst person in the world, but that's okay. I can live with that.

Voluntarily disembarking from the train that has given me such a wonderful journey through life is no longer on my agenda. I now realise that my special purpose in life was to help others, which I can continue, as it is not reliant on my eyes. I have a small group of close and valuable friends whom I believe would miss me; and when it is my turn, it is them you should be comforting, for they will hopefully be mourning the loss of a friend.

It is impossible for me to tell you now what I will feel or what I will do when my lights go out. I will only know when the day arrives. In the meantime, I value and cherish my three to four percent sight like it is the most valuable asset I have .....

Because it is.

I have never known anyone to ever look back with disappointment on a life full of experiences, although many do look back wishing they'd had the courage to do more.

Paul Funnell is not one of them.

# RETINA AUSTRALIA



Learn More

[www.retinaaustralia.com.au](http://www.retinaaustralia.com.au)

Tax Deductible Donations

1800 999 870