

## MY JOURNEY or maybe I should say OUR JOURNEY

My name is Sheila Openshaw I am the Group Leader of Hastings Mental Health Support Group. This evening I am going to take you on my own personal journey in relation to being a Carer to a family member living with a mental illness. But first of all, a little about myself.

I was born into a very loving family consisting of 6 girls and 2 boys, I am the youngest. My parents were both from the Eastern Suburbs of Sydney struggling to make ends meet with 7 children living in a 2 bedroom apartment at Bronte Beach. On the arrival of No. 8 child – myself – they moved into a Housing Commission House west of Sydney.

We had a very normal happy life but not too many luxuries as you can imagine, but there was a lot of love. Mum & Dad had their own worries in life with 2 daughters with disabilities. Mum had German Measles when pregnant with one of my sister's, consequently my sister was born deaf & has never learned to speak. Another sister developed chronic epilepsy.

The worries that my parents had back in those days with my 2 sisters never seemed to affect the way in which they went about their daily lives. They were very kind & caring people and were always out to help others in need. So as children we had excellent role models.

Dad was the Treasurer of the Deaf & Blind Institution at Darlington in Sydney, which is now a site used by the University of Sydney, and Mum – well I think she practically ran all the fundraising events. As children, especially during holiday time we used to walk the back streets of the City of Sydney asking various businesses for either goods or money that we could use towards the annual fete day for the Deaf & Blind children.

Mum would make clothing out of bits of material that she could sell and make money on the fete day. Mum was also an excellent cook so the cake/jam & pickle stall was organized and run by Mum. Dad ran the chocolate wheel with his friend Charlie. I would say that by the time I was able to walk my mother had a raffle book in my hand. So, it was obvious from day one that somewhere along the way, my life was destined to be involved with people with disabilities.

I married at the age of 18 and had my first son at the age of 19, by this time I had moved back to the Eastern Suburbs where my husband & I lived at Bronte Beach. I wanted to follow in Mum's footsteps and have a large family, I always said that I was going to have 10 children but this was not to be.

My second son came along 4 ½ years after the first, I started to think that maybe I could not have any more children. My second child was another beautiful boy and it was this little one, who was going to change my life forever. When this second son was 6 months old, I was approached to enter the Lovely Motherhood Quest to raise money for the Deaf & Blind children. My aim was to raise as much money as I could for these children and do what Mum & Dad had done before me. Yes, it happened, I was crowned the Charity Queen for that year 1973, I had raised the most money \$6,500 dollars. So helping young people with a disability was definitely in my blood.

My second son had a very normal childhood, he was no different to any other child, played soccer, rugby league, participated in public speaking, debating and had extremely good grades at school. As a matter of fact on one occasion when I was out shopping a teacher from his primary school, Our Lady of the Sacred Heart

in Randwick, went out of her way to stop me and say, "I just wanted to let you know what a wonderful son you have, he is such a well behaved young man and always willing to help his fellow students", I felt very proud of him as any mother would.

When my son reached the age of 13 which is a difficult time for most young people, his Dad & I parted company. It was a terrible time for all of us. My 2 sons were shattered, the family unit was breaking up, and my eldest son was in the middle of his HSC examinations, this was not a good time for him either.

There would be times when my youngest son would just crawl under the dining room table and sob his little heart out, and my eldest son would say, "just leave him there Mum, he will be OK". The guilt that I was feeling was unbearable, my beautiful boy was heartbroken. In turn there were times when I needed consoling, and it was this dear little boy that sat beside me on the edge of the bed when I was reading letters from solicitors, that he would put his arm around me and console me. He would pull letters from my hands and say "Mum, you are not reading these letters any more".

The 3 of us managed to get through this very difficult time with the help from family & friends. My boys then became my life, I was determined that they would still have a loving home & a good education, but it was a struggle both emotionally & financially. Then, I met my now husband and best friend, we were married 7 years later. It was during these times that we noticed my youngest son started withdrawing from us. This was especially noticeable during meal times. He would excuse himself and take his dinner into his bedroom and say that he needed to do some study. I accepted this, but deep down I felt he was upset that I had found a new love and was trying to get on with my life. The days started to become more and more difficult. My son's attitude towards me started to become quite hostile, no sooner would I arrive home from work and he would find any reason to begin an argument and upset me. Our relationship was starting to deteriorate. He finished his Higher School Certificate but only just managed to get the mark to pass. He didn't know what he wanted to do as a Career so I told him that whatever he wanted to do I would support him in his decision.

His first job was a mail boy for an Insurance Company at Martin Place in the City. After a while he started to tell us that other people in the mail room were picking on him and how unhappy he was because he didn't feel that he fitted into the work group, he finally left this job.

It was during this period that he would tell us stories that he claimed happened on his way home from work in the City. He felt that everyone was staring at him as he rode home on the Bus. On one occasion he mentioned to us that he was eating an orange on the way home, and because he was eating the orange the person sitting opposite him started to cough uncontrollably, and he felt that he was responsible for it.

Strange stories like this became more and more frequent. We always tried to rationalize his behavior and tried to assure him that no one would be staring at him for no apparent reason. The next position that he held was as a salesperson selling computers but this did not last long either. He then had another sales position with David Jones in Bondi Junction, but once again he lost that job because he was told that he was not suitable, they said he was not a David Jones person – quoting my son's words. It seems obvious now with the benefit of hindsight that things were starting to deteriorate. We just did not realize what was happening and put it down to typical adolescent behavior.

We did not know what to do, so I finally said to him that if there was a training course that he would like to participate in, I would find the money so that he could complete it. He chose a course and decided that he would like to be a Travel Consultant. I borrowed the money and he was enrolled at the Sydney Business & Travel College in the City. After a period of time he started to tell us that the other students in the class were talking about him and when he was out of the room they would scribble and write things in his books.

I felt quite upset about this because I had to borrow \$3,500 for the course, so I called the principal of the College to complain. She told me that the College would not put up with this kind of behavior, so she would investigate the matter and get back to me. The teachers and students at the College were interviewed and soon after I received a phone call, it was not the phone call that I wanted to receive. She said the teachers at the College were quite concerned about him and that these things were just not happening, she continued to say that my son was surly and morose and that I should be very concerned as well. He stayed on at the College and did manage to get his Certificate, so then it was time to obtain a position in that field of work, but this never eventuated.

It was during this time that my Dad became quite ill, Dad for some reason was always worried about my son even though I had never told my parents what was happening with him and all the trouble that I was having. I can remember so well on numerous occasions Dad asking me was he OK and I would reassure Dad that he was, I know in my heart that Dad knew somehow, that something was not quite right. My son loved his Grandfather, as Dad used to step in on occasions and take the boys to soccer or football or even just be there to support them.

In 1991 after a long illness Dad passed away, I often say I am so glad (in a way) that Dad was not around when my son became mentally ill. My son at the time of my father's death, had his own car which he had purchased from the money he had earned at his previous jobs. Dad's funeral was held at Baulkham Hills which was quite a drive from the Eastern Suburbs of Sydney where we were living. Alan & I were staying with Mum at the time so my son had to make his own way to the funeral, but sadly he just was not able to get there on time, he turned up at Mum's home some hours later.

In August 1993 Alan & I decided to get married and my son still had not found any work. He was keeping company with an old school mate and I knew in my heart that this was a person I did not want him to associate with, but I also knew that if I interfered too much, I may lose any relationship that I had with him.

I kept encouraging him to get a job but nothing was happening, he was sleeping in a lot and seemed not to be even trying. Alan & I had planned our Honeymoon, we left and we were gone for 2 ½ months overseas. My son's Dad promised me that he would call him regularly and encourage him to find work. By this time my eldest son had moved out of home.

On returning from our Honeymoon I learnt that wild parties had been happening and still he had not found employment. We discovered that his condition had deteriorated whereby we found in his bedroom the air vents in the building wall, had been covered over, and the carpet had been pulled up to reveal old television antennae wiring, that my son claimed was being used by people next door to listen to his thoughts. I found letters that he had written where he described people were trying to hurt him and follow him in his car.

The next few months were very very trying, the verbal attacks at me seemed to be getting worse and worse. Alan & I decided to get some advice from a Counselor. During our visit we

explained to the Counselor what had been occurring, she then asked us if my son had been hearing voices, we said voices! What are voices!

She recommended to us that we should see a Psychiatrist. That though, was much easier said than done. I knew it wouldn't be easy so I told my son I was concerned about our deteriorating relationship, and asked him if he would please come with me. I didn't tell him that we were seeing a psychiatrist but a Counselor, he agreed to come. We were both interviewed separately; my son was given some medication and told that he would be OK in a couple of weeks. I believed this as I did not know any better.

Nothing improved over the next month, and then on New Years Eve he came to us in quite an anxious state, and said he felt he needed to see a psychiatrist and told us he wanted to go to hospital. He was obviously having his first psychotic episode which was frightening him.

We all drove out to Prince Henry Hospital at Little Bay. Because it was New Years Eve there was limited staff available, so they interviewed my son and admitted him into the psych ward. This was the start of many hospitalizations.

I cannot begin to tell you how it broke my heart to see this young man so unwell and not knowing what was happening to him. I can still see the frightened look on his face sitting in the locked ward as we were asked to leave. Over the course of the next 6 months we had many hospitalizations and many interviews with Doctors, then finally they made a diagnosis that my son had Paranoid Schizophrenia. We did not even know how to spell the word schizophrenia let alone know what the illness was.

We would grab any information that we could get our hands on to educate ourselves. In those days there didn't seem to be as much information available as there is today, it just seemed that you had to learn what you could from the limited information available. One of the first things that I did do was to join a Support Group. We joined two groups they were ARAFMI (Association of Relatives and Friends of the Mentally Ill) and the Schizophrenia Fellowship of New South Wales.

I remember saying to my Mum at the time, "how did you cope when you found out that Dorothy was deaf and could not speak, and also when Carol developed epilepsy". Mum's reply was, "we just did the best we could" so I set my mind to follow in Mum and Dad's footsteps and do the very best that I could.

But, there were times when I just did not know how I was going to cope; I would be driving my son to hospital at all hours of the day and night, waiting in accident and emergency, hours upon hours in the middle of the night. Many times I would be driving home with tears streaming down my face, most of the time vision blurred from all the crying, hoping and praying that this would be the last time this would happen and that one day I would wake up and he would be cured.

I lived in hope, like we all do, I thought I am his Mother I should be able to fix this but I was wrong. In 1995 we decided to leave our jobs in Sydney and come to Port Macquarie to live, my son's Psychiatrist at the time said to me that it would be beneficial for my son to have a much quieter lifestyle without the stimulation of living in a big city, so we made the move.

However, things did not improve. There were continuing attempts at suicide, trying to drown himself in the Canals of the Hastings River, throwing himself in front of cars, poisoning himself on detergents, trips to hospital in the back of a Paddy Wagon and my visit to the Banditos Motor

Cycle Brothel here in Port Macquarie to get him out of some financial trouble that he had got himself into.

My son never wanted to die but just wanted all the pain and mental torture to go away. I will never forget the fear I felt as I sat beside him in the bed in the Accident & Emergency ward just stroking his leg as he lay there recovering and saying to the Nurse, "will he be OK, do you think that he will live" and the nurse replying "I am sorry Mrs. Openshaw, I cannot tell you, I don't know if he will be OK".

Another time my husband & I had been out shopping only to come home and find the Police in our home. My son had thought that we had been involved in a car crash on Matthew Flinders Drive. He rang the Ambulance and Police Service and had everyone running around town looking for the crash that we had been involved in. They traced the call to our home and had my son out on the back verandah reading him the riot act when we returned. I don't think back then that they realized they were involved with a mentally ill person. Thankfully things have improved somewhat today. But I do remember them saying to him at the time that if ever he did anything like this again he would be charged.

The hospitalizations just kept coming, one of the many times that he was in James Fletcher Hospital in Newcastle, we would arrive after driving 3 hours from Port Macquarie, only to be told by my son that he did not want to see us and go away. The nurses there would tell us, just go down the road and have a cup of coffee and when you come back maybe he will change his mind, and she was right, more often than not he did.

Then there were the phone calls from the hospital to say that he had run away, I was frantic and just did not know what to do. My son managed to find a telephone box and called me from Newcastle, during that conversation I tried to obtain from him his whereabouts, street names and possible locations and after hanging up quickly ringing the Police in Newcastle trying to convey to them what had happened, where he may be and could they please get to the phone box as quickly as possible so they could take him back to hospital, but they were never successful and the anxiety about his welfare just grew and grew.

On one occasion when he was missing he made his way down to the wharf of Newcastle Harbor and tried to board a tug that was moored, only to lose his footing and he ended up in the Harbor. He later told us he thought he could hear his Fathers voice calling for help down in the Engine Room of this tug and he needed to get to him. His Dad at the time was an Engineer in the Merchant Navy.

During this episode he had been missing for a couple of days, he had had no food but managed to obtain a pizza from a shop keeper who was kind enough to give him one, I think he thought he was a homeless person. Finally after spending a couple of nights sleeping in a park he was noticed by a very kind lady who worked in a brain injury clinic in Newcastle. She realized that this young man needed help, so she contacted the staff at James Fletcher Hospital and they came to collect him. I was so relieved to know that he was safe again.

Another time he was taken back to James Fletcher he was put in the locked ward for six months, he was so unwell and so heavily medicated that when they brought him out to see us he was just like a robot, two nurses had to hold him up as he shuffled to the waiting room to see us, I couldn't believe what was happening to my beautiful son.

I used to take down photos of his bedroom, his car, or anything else that I could get my hands

on so that he would feel that he was not being forgotten. There was one time whilst on a visit my son in a very rare lucid moment looked at me and said "Mum, you & Dad did this to me", I don't think I will ever forget those words, the sadness and the guilt I was feeling was something that I could hardly bare.

My son was so unwell whilst at James Fletcher, the Doctors felt in order to get him on the road to recovery a series of Electro Convulsive Therapy would benefit him. They had planned to administer a course of 12 treatments, but after 8 sessions he was responding extremely well. My prayers seemed to be finally answered and it was time to bring him home. He was so well I thought it was a miracle but after about a week he began to become unwell again.

This time he was taken down to Maitland Hospital as he was too ill for Port Base and there was no room in James Fletcher Hospital. One evening in the middle of the night we received a phone call from Maitland Hospital to say that he had run away again. My heart just died. We just did not know what to do or where to start looking.

As it turned out he had caught a train down to Sydney, no money in hand, and ended up at the Prince of Wales Hospital in Randwick, realizing that he needed some medication. I had a feeling that he may go to Sydney so I called a friend of mine who worked at the POW Hospital and told her what had happened, so she called over to Accident and Emergency and yes he was there. My friend got him medicated, gave him some lunch and money and made him promise that he would return to Maitland, and after putting him on a bus back to Central called us to let us know that he was on his way back to Maitland Hospital.

He was not responding very well to medication whilst in Maitland so a decision was made that he would have to go to a long term rehabilitation hospital and this was to be Morisset. I remember so vividly walking down the main street of Newcastle crying uncontrollably about this place called Morisset. I didn't know anything about this hospital but somehow in my mind I thought that it was some kind of evil place where people were taken, locked up and the key thrown away.

I was totally inconsolable that day, I am sure that people in the main street of Newcastle must have thought my husband & I had had a very big argument, I remember Alan taking me to David Jones store for lunch but I just kept crying and crying.

This was the start of a very long journey for all of us. My son was in Morisset Hospital for 8 ½ years. However, I must say that Morisset is an excellent rehabilitation hospital and as it turned out it certainly was not the place that I feared. Sure there were a lot of very unwell patients there but the staff were all extremely highly qualified. Nevertheless it was always very difficult for me to have to say goodbye at the conclusion of our visits.

Alan was working in Sydney at the time and I was working here in Port. Alan would fly down to Sydney on a Monday morning, come home Friday evening then the next morning Saturday, we would pack the car and head down to Morisset for the remainder of the weekend. We did this not only for our son but for ourselves as we needed to know that he was OK and let him know that we loved him and supported him.

There were times there too when we had just arrived and wanted to take him out for the day only to be asked by my son as we were driving out the gates of the hospital to take him back, he did not want to go. This would upset me terribly as we only wanted to get him out of the hospital environment just for the day.

There were many meetings and tribunals that we attended in Morisset, if these were on a week day I would work extra hours at work so that I could have the time off to attend. I must say both Hastings Council and Centacare were very sympathetic and good to me; nevertheless I still had to work. We tried very hard to make his stay in Morisset as comfortable for him as we could. We took down a computer for him to use in his bedroom. One time I even organized for a tutor to come in to the hospital and give my son guitar lessons. I was willing to do whatever it took to help him in his recovery.

The years rolled on by but never would I allow him to be alone especially at Christmas, I was always there. During this period I don't think that Alan & I had one Christmas together. Alan spent Christmas with his girls and grandchildren in Sydney. My eldest son & I always tried to make this a happy time together.

As with all Carers of someone with a mental illness there is the financial burden it places upon us. Not everyone is lucky enough to have a job like I did. Even so as you can imagine the emotional and financial strain was enormous.

As time went by my son would start to ask me, "Mum when are you going to get me out of here". He would accuse us of trying to keep him in Morisset but we tried to explain to him that it was totally out of our control. I felt a tremendous amount of guilt every time we said our goodbyes, and did not stop waving to him as we drove out of sight leaving the hospital grounds.

It absolutely broke my heart. I have cried a lot over the years, it is not uncommon for me to just cry at the drop of a hat, I do a lot of this whilst having a shower as I feel that this is my "me" time, a time when I am alone and do a lot of thinking. Alan says that he is going to ban me from having showers.

Only recently I was down in Sydney supporting a friend of mine who was to have major surgery which ultimately did not happen. I went down to support her and we had a few lunches out together with her sister and other friends. There they all were with their little grandchildren, whilst I felt happy I also felt very sad as this is one part of my life that I feel I have done a lot of grieving over, I would just love to have some grandchildren of my own. I guess I will just have to be content in being everyone else's grandmother.

I think we Carers do a lot of grieving ..... I know that I do, grieving for the loss of the life that my son could have had. Disappointments have been another area in my son's life where I have had to step in as his Mum. The disappointments when his Dad says that he can have a holiday with him and then it does not happen. The times when he says he is coming up here to Port to visit him and that doesn't happen. All these incidences have a very profound effect on us as Carers, we are always there picking up the pieces.

Some years ago whilst attending a Public Forum here in Port Macquarie I stood up and asked the then CEO of the Mid North Area Health Service if he could help me in some way to get my son back home from Morisset and looked after here locally. This ultimately led us to be put in touch with the Bed Manager in the Mid North Coast Area Health Service, a lady by the name of Genevieve Beggs. As it turned out, this proved to be a valuable relationship.

Genevieve made several visits to Morisset and acted as a conduit linking two different Area Health Services. Hunter Area Health Service where my son was being cared for and the Mid North Coast Area Health Service, where we wanted my son to be relocated. There appeared to

be a problem between the two Health Services agreeing that the necessary support services here in Port Macquarie were adequate to meet my son's needs.

Finally Genevieve had a break through and systems were put into place to enable my son's return to Port Macquarie. This began on a temporary basis for a few days at a time and then my son would return to Morisset for a week or two and gradually the visits became for a longer period.

The day we drove out of Morisset for the last time was a very happy day indeed, but on the other hand it was full of trepidation, we just did not know what the future would hold. I have often said I am so glad that Dad was not around whilst my son was in Morisset as Dad would have made Morisset his life. I feel sure Dad would have been there for my son every single day.

On returning to Port Macquarie my son went to live in the Group Home Ellamatta in Morton Street, and he lived there for the next 2 years. I cannot praise the staff at Ellamatta enough; they are a wonderful team of people doing a great job. From Ellamatta my son went into housing managed by the organization New Horizons.

He was in the first group of 4 young men who became a part of their HASSI program and I am very pleased to say that he is still a part of their program. It is about 4 years now since he left Morisset and my son has had no further hospitalizations. He has been a volunteer at the Koala Hospital, he is a member of Men shed at Wauchope and has just completed a small course through the guidance of TAFE in building a pushbike which he has said is a gift for me. He attends Billabong Koala Park as a volunteer, and will soon be participating in Guitar Lessons again and doing a small engines reconditioning course, once again at Men shed.

As a Carer to other Carers out there, I would just like to say, there are a lot of services out there in the community for you and your loved ones to access.

For Carers we have Carers NSW who run several programs namely, the Foundations Course, 8 Stages of Healing Program, and the Smiles Program for 8-12 year old young carers. There is the Wellways Program which was run here in Port Macquarie a couple of years ago but is still running in Sydney & other rural areas.

Then we have Commonwealth Respite and Carelink Service who run various Forums for Carers in association with the Schizophrenia Fellowship through their Remind & Education Program. Also Port Macquarie Base Hospital Ward 1A run a program for 1<sup>st</sup> time Carers called Carer Connect which is an 8 Session Course.

For the Consumer we have Karawa Cottage in Church Street, New Horizons, GROW, Mission Australia & Centacare. All of these organizations run various courses to help the consumer on their road to recovery. If I have missed out on mentioning any others, please excuse me.

On a final note, I would just like to say I know and understand just what an impact mental illness has on our lives. My journey has been one of a very steep learning curve and I am sure it will continue well into the future. I have all the same fears and hopes as you do for the future of our loved ones, that is why I am involved with my support group.

My group Hastings Mental Health Support Group comprises both Carers & Consumers. Only in the past year did I decide to invite the consumers to join with the carers, & I must say that it is going very well.

I did my homework first of all by traveling around to visit other groups to see how they managed to combine the two. Alan & I travelled down to the Newcastle Group, to Cessnock, Tamworth & the North Shore Support Group. These groups were happy with the way they were being run, so I thought well I will have to give it a go here in Port, and I am very happy to say that it has been a great success.

We get around 30 – 35 attendees each month. We provide a shoulder to cry on, an education session consisting of a Guest Speaker, and a good old cup of tea cake & biscuits. I have developed a small Library for my Group, I recently purchased from SANE Australia, some of the more up to date videos on quite a few of the mental illnesses and only in the last couple of weeks a set of 3 DVD's on Ron Coleman's Road to Recovery Hearing Voices.

Ron is a Scotsman who has made remarkable progress in dealing with his own mental illness. He has progressed so well that he now runs his own business appearing as a Guest Speaker at International Forums similar to this one, helping both carers and consumers deal with mental illness.

I would like to Thank Port Macquarie Hastings Council for giving me a small grant to have my brochure printed and also the opportunity to purchase the material that I have just mentioned. If anyone here tonight would like to make a donation to my support group so that I can continue to buy materials for my Library please feel free to do so. Your cheque can be made out to Hastings Mental Health Support Group, PO Box 556 PM.

The Schizophrenia Fellowship of NSW has been a great source of strength and inspiration for me, I have made a lot of friends through the Fellowship over the years and we all get together once a year. The next meeting is coming up shortly; this is where we exchange various ideas and ways of coping down this long path of mental illness. I have gained a lot of strength in doing what I do as a Carer, and I feel very proud to have been associated with people with a mental illness, I have always said that the loveliest people I have ever met in my life have been those associated with mental health.

My own personal story as a mental health carer began I suppose, when my youngest son was about 17 years of age, he is now 37 and our journey continues.

I would just like to say thank you for giving me this opportunity to share my journey with you, it has been a pleasure & privilege.

Thank you.