

theatre nemo

promoting good mental health and wellbeing through the performing arts

Isabel's story_



This is my story as a Mother. The reason for writing it is to help people, especially professionals working in the mental health field to understand the effects mental illness has on the whole family. Please listen to us, work with us, help and support us.

On the 9th July 1969 John was born, I looked at him and thought I had never seen anything so wonderful and beautiful; my heart was bursting with love. John grew up very physically strong but emotionally very caring and gentle.

I will try to give you a brief insight of the eight years John was ill, there were hundred of incidents, I have picked only a few.

John was a gentle soul, who because of traumatic events that had happened to him, became very emotionally and mentally ill and yet people educated in the mental health field sat round a table making judgements on him, they never saw John, they only saw the results of his illness and more importantly they never saw the system's failure to intervene with understanding and to offer the right treatment at the right time.

My son John was around 22 years old when we first noticed he was becoming very withdrawn around the family, he was not communicating in his usual way, he would stare out the window for hours muttering to him self. At this time my husband was dying, he had cancer and the stress of the situation was very difficult for the whole family. On seeing how bad John's mental health had become I tried repeatedly to get help for him by contacting our G.P. The G.P refused to do anything until John made an appointment to see her. John was too unwell to recognise that he was ill so this was not a realistic expectation.

I would sit up all night talking to John, trying to reassure him and to try and understand what he was feeling and why. During these times through all the rambling, I could read some of the messages he was trying to give me.

For one and a half years I was seeking answers and explanations which never came, I chapped on every door I could find, called every help line in the phone book but the answer was the same from everyone, you have to go through your G.P. Very often they would say, "*if he is acting the way you say, the police will pick him up and they may direct him to the services*". And sure enough John was picked up on many occasions for breach of the peace but he just went through the court and out the other side with no account or notice taken to his mental health.

How did this affect me as a mother, there are no words to describe the panic and the fear and the helplessness I felt. The tension when he was in the house and the heart wrenching fear when he went out, what would he do, would he be safe.





I felt a failure as a mother! I should be able to fix this, I should be able to protect my child, make it better but I couldn't, I cried a lot.

John's mental health disintegrated further, it was all beginning to get quite frightening. John was convinced we were not his family, we looked like them and spoke like them, but he knew we had taken them away and were impersonating them and out to kill him. We had to call the emergency doctors out on three occasions within the one week. That got the G.P's attention and for the first time she came out to see him, not with good grace: "*Hurray up, I've got people who are ill to visit*" was her first remark to him. The service, treatment and understanding didn't get much better over the next six years.

The G.P spoke to John alone for about fifteen minutes, she then came into the kitchen and asked me to sign a form to have John sectioned, At last! I thought this is what I've been waiting for, a chance to speak to someone who would understand my son's pain. Unfortunately this is not what happened, the doctor on call spoke to me first, asked me questions about the way John was behaving, as you can imagine I was very upset, there was such a lump in my throat, I could hardly speak and hardly breathe. Thinking I was helping I told the doctor some of the things John had told me, which I thought had contributed to him becoming mentally ill. In my naivety I thought the doctor would digest this information, get to know John over a space of time and having something to work on with John would get to the root of John's paranoia. This didn't happen. As soon John went into the room, the Doctor said, "*your mum tells me...*" And went on to repeat what I had said. John denied that he had said any of this. The Doctor spoke to me again and very coldly said he had spoken to John who had denied any of this was true. By this time I was in a state of near collapse the trauma of seeing the trust leaving my sons eyes, I had betrayed him. How did I feel, confused, guilty unable to rely on my own thoughts even though I knew they was right.

John was kept in for 48 hours observation but walked out next morning, staff followed him out to stop him but he said he was going to get a lawyer and they just let him go that was the end of any medical intervention for about a year.

John didn't come back to the house for about three days after this, when he did, he was dirty, hungry and angry, "*why was I spreading lies about him and trying to get him locked up*". If I thought things were bad then they got ten times worse, we just went from one crisis to the next.

Over the next few years John was in and out of hospital and was put on a care plan.

I couldn't tell you what happened over the next couple of years, I just went from day to day trying to find yet another method to cope...

We were all living on the edge of a knife, dealing with my husband's death and John's terrible illness. By this time John was drinking a bottle of Actifed Syrup a day to help him sleep, he didn't want to hear the voices. We didn't understand about voices or people coming in through the ceiling or trying to poison him. When we asked for advice the doctors would say "*well its not really happening*". We already knew it wasn't really happening but we also knew that to John it was real, it was happening and it was a terrifying experience for him.

By now John was self medicating with drugs, I don't think he particularly cared what he was taking, and it certainly wasn't for recreational purposes or for fun. John didn't have any fun in that eight years, everything he did was his own struggle against hurting people. I went up to his flat one day he had boarded up all his windows and he had cut his wrist and with his own blood had written all over the walls, Hurt! Pain! Fear! Everything he possessed was smashed.

"I can feel the pain of the whole world", he said.

In trying to get help for John I told the care team about this at one of the care planning meetings, when I got the minutes of the meetings (after John had died, I requested all the reports they had on him). They had translated that to "*John's mother said he is writing hate messages on his wall.*" (It may be worth noting that in all the reports there was not one positive thing said about John). Now John was not only mentally ill he is also abusing himself with drugs.

About a year before John died he was really in a bad way, was totally paranoid was running about trying to save the world, I don't know what he was doing but he never stopped, sometimes not sleeping for days on end. He was not on any medication; care in the community was none existent his CPN didn't want to know. I contacted John's CPN on many occasions but he would just say to me, "*my door is always open*".

By this time I wanted to scream, shout, threaten and I did, but the reaction to that was, "*we can give you some medication.*"

How bad were things just living day to day, I can give you an example of how I degenerated into a neurotic bundle of nerves. Any one who has lived with this will understand. One day I was getting my coat to go out when John came banging on the door which he did regularly four or five times a day and night, I just couldn't face it and stood rooted in the cupboard where I was getting my coat, he banged on the door and shouted through the letterbox, then he would stop for a while then start again, I didn't move in case the floor boards creaked and he knew I was there and not letting him in, I was in the cupboard for about an hour, I waited for a while to make sure he was away, then the door was chapped again and again and again. I was in a state of panic I wanted to scream, my back was aching my legs were going into a cramp. I couldn't come out now. How could I explain not opening the door? I couldn't think what to do. Then the phone rang, I got such a fright and thought my heart had stopped beating. The phone stopped ringing and I waited. Could I creep out now? Then I heard a voice shouting through the letterbox "*Mum, mum are you alright?*". It was my younger son. John had gone away and it was Hugh that had been chapping the door, then phoning. He knew I was in the house as the keys were in the lock. I opened the door and just collapsed into his arms.

What a state to be in and all that had happened was that my own lovely son who was very ill had come to the only place he knew, the only place he had left to turn to, and I was in such a state of total and utter despair at that moment I couldn't even open the door to him. As I sit here writing this the tears are falling, I want to scream all over again "*somebody help us.*"

So now we have John who by this time is totally confused, he thinks he is trapped in an alien universe where he is trying to save the world and people are trying to kill him, to stop him saving the world. Left without any support or medication for nearly a year he became homeless, living in old derelict buildings, needing washed needing physical medical care (by this time he didn't even have a G.P). He had burned his hand very badly, stuck things in his eye, battered his head against walls, fell off buildings, fractured his skull, broken his Jaw all to stop the voices that were telling him to hurt people. He was killing himself bit by bit.

The sad thing is that John did frighten people, the way he spoke, the way he acted, the way he looked, he frightened me sometimes, even though I was sure he would never harm me.

At the last care planning meeting we ever had, I informed all the agencies of my fears that John was losing control and my fear that something would happen if they didn't listen to me and get some help for John. I told them (them being C.P.N, social work, homeless team, housing officers), I had contacted my M.P and Councillor and the Mental Welfare Commission. By the end of that week John was in Barlinnie. He had seen a man putting a young child into his car seat the child was screaming, John thought he was abducting the child and punched him (I often wonder if that man's mental health has been affected by the incident). John was lifted by the police and spent six months in Barlinnie waiting for psychiatric reports, which were all different. It went on and on.

Can you imagine the horror of being so mentally ill and instead of the help, understanding and support you need you are locked up with your voices and psychoses with virtually no human contact.

Now John is not only mentally ill and on drugs he is also a criminal!

John attempted suicide in prison, shortly after this he was transferred to Leverndale Hospital where he spent five months. He walked out on the 12th May 2000, went across to the park and took his own life.

Just another statistic?

I felt abused, confused, terrorised, powerless, guilty, totally and utterly frustrated because I couldn't get my deep concerns and anxiety across to professionals. I didn't know the words to use, then suddenly it was too late: the system failed my son and it has damaged my family and me.

I and others feel all (and more) of the emotions I have written. People are going through the same as we speak. Living with knowing it could and should be different, is the worst penalty and it haunts us all.

As I said, John was a gentle soul, creative and talented in writing and singing beautiful songs, but this illness disguised the real John.

What was missing in the services that could have helped John? Something he could relate to that wasn't clinical and taking control of him (that is the way John saw the services).

Complaining and moaning about the services was no good, we had to do something and so Theatre NEMO was born. This has been a great journey for all of us as a family. What John and others suffered through his illness hasn't been in vain, because of our knowledge and understanding of people's need to be treated as people, Theatre NEMO has become very successful. I believe John's memory is guiding us on the right path. We are helping others to understand that recovery is a journey everyone can take in their own time and in their own way. We all need to recover from some of life's traumas, you don't need to be diagnosed mentally ill to need a bit of gentle recovery.

We have recovered. Theatre Nemo is now working in the Community in Psychiatric Wards and in Prisons. The support from all the staff we have come into contact with has been fantastic, there are so many good people working to change things for the better. It is a great privilege and honour for me, my family, friends and all the wonderful members of Theatre NEMO to get this chance to help bring about change.

I am now very happy (sometimes sad) and content, I love doing the work with Theatre NEMO.

Isabel McCue,

Founder of Theatre NEMO

And John's Mother always.