

21st April, 2005.

To:

Senate Select Committee on Mental Health,
Department of the Senate,
Parliament House,
Canberra, ACT 2600

Please find below my Submission to your Inquiry.

I write this Submission with some trepidation, knowing that I have participated in various forms of Inquiry in the past, only to find that in every instance nothing whatever has come of them.

Will this Inquiry become another toothless tiger? I sincerely hope not, as mental health in Victoria/Australia has been overlooked for many, many years.

This may sound pessimistic, but unfortunately it is due to the lack of action in the past from similar Inquiries.

My Submission is in 4 parts:

1. Summary
2. My Story
3. The Experience of Seeking Treatment
4. Recovery.

If there are any questions arising from my Submission, I stand willing to answer those questions to the best of my ability. Do not hesitate to contact me via mail or on the phone number above.

Sincerely,

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1. SUMMARY

I suffered religious scruples from early age to middle age, guilts and fears of God. Needed to confess to ease mental trauma and pain.

I was unaware of my medical condition.

Only treatment was from priests, not from medical profession.

Went to certain priests only, who I felt may show compassion.

At age 19 I was diagnosed by local GP with Anorexia and began treatment.

Specialist physician confirmed diagnosis, admitted me to hospital.

Whilst in hospital where, unknown to me, a psychiatrist appeared once and prescribed pills (1962).

Age 22 (1964) saw another psychiatrist a few times, condition did not improve and scruples as bad as ever.

By the time I was 30 (1972) visited another psychiatrist who kept me waiting every visit about 1½ hours, causing huge anxiety build-up, gave no advice or help, just listened and wrote in his book. He was absolutely useless and a waste of time.

When I was about 42 (1984) saw another psychiatrist at Clarendon Clinic, religious scruples still continued, passed from one psychiatrist to another. All they gave me was medication and no help.

Referred to St. Vincent's Hospital psychiatrist, again no progress.

In 1986 GP got me admitted to a private hospital for 3 months, where again psychiatrist only medicated me to zombie state, finally discharged myself.

Attended another psychiatrist for a few years who prescribed medication and little else, finally he gave up, discharging me saying I was chronic and he could help me no more.

After looking after myself for some time in 1991, in desperation went to Austin Hospital, where another psychiatrist frightened me terribly with gruelling assessments and got it totally wrong.

During all this time still going to priests who were at least removing guilt through confession. Doctors had done nothing to help me in any way.

1993 – Moved to Wodonga where during first visit, local psychiatrist diagnosed me with OCD. He was compassionate and understanding. My anorexia diagnosed as part of OCD. This was the beginning of therapy, which consisted of medication and behavioural techniques. Felt a bit better knowing he was at least able to help somewhat.

1994 – He helped me organize the OCD Support Group.

1995 – After hearing Dr Mike Kyrios, he inspired me to attend STOP Therapy Group at Melb Uni. During the next 3 years, received specialist treatment from skilled clinicians who were (and still are) unavailable in the Albury Wodonga region. This was the start of my Recovery Road

2. MY STORY

I would like to start by writing about my experiences with anxiety and depression and in particular about my Obsessive Compulsive Disorder (OCD).

From the age of nine I had an enormous pre-occupation with religious issues, fears and feelings that I had sinned and must go to confession. I was tormented by fears, thoughts and memories. I would remember all those "*Bad things*" that I thought I had done and needed to go to confession for forgiveness several times a week. It was terrifying. I was scrupulous about the rules of the church and would be horrified about intrusive thoughts that would come into my head, all my thoughts and actions felt like sins. The pain, anguish, fear of God, the fear of hell did not allow my mind any time for rest.

I feel my OCD behaviors developed to deal with anxiety and stressful life events. I felt out of control, having thoughts and feelings that totally consumed me and I had difficulty thinking of anything else. It was distressing, exhausting and time-consuming.

My pre-occupation with my weight and food began around my birthday in September 1961 - age 19 and debilitated my life for the next 35 years.

It began one day when I weighed myself and was aghast at what I saw – 8st 9lbs. With low self-esteem and poor body image I thought I'll have to go on a diet and I did, very rigidly.

The diet crept upon me silently, in patterns and controlling behaviours, unbeknown to me. My weight gradually lessened. What a buzz, it motivated me more.

Four months later I was diagnosed with anorexia and hospitalized at 35kg. Hospitalization had a band-aid effect. The real problem was never diagnosed and therefore never fixed!! Now that I can look back I feel and can see that the anorexia for me was actually OCD, in particular my obsessions and compulsions around food.

When I was diagnosed with OCD it answered all the other distressing actions, thoughts and happenings in my life. I see all the thoughts, patterns and behaviours with the eating as basically the same.

Because my symptoms of anxiety, OCD, scrupulosity, depression and anorexia started at such a young age, I can honestly say that these disorders affected all aspects of my life, and had a major affect on my family.

My family were greatly affected by my OCD, anxiety and other problems. It was hard for them because the disorders affected what I could and couldn't do and affected my mood and they, and I, couldn't really understand what it was all about. So they were sometimes frustrated and angry and confused. And, of course, this made it harder for me, because I didn't know how to answer their questions about it and didn't know how to change. It was difficult for all of us. I think my husband often felt helpless about how to ease my suffering and give me comfort. He helped in practical ways, cooking and cleaning, but dealing with the emotional distress was hard. He also became involved in some of my rituals and avoidance and that was very demanding on him.

Carer needs are exacerbated as their family member with a high prevalence disorder may spend years seeking a diagnosis, may be misdiagnosed and treated inappropriately, and has limited access to treatment services in the public mental health system.

Carers are, therefore, often alone and without assistance for their ill family member and without the support that the family needs to cope with the impact of the disorder, and maintain family relationships.

It is important that carers need to be educated about the disorder and how they can help so that they don't end up feeling angry, confused and depressed which doesn't help the sufferer. They also need help for their own problems and issues.

I moved to Wodonga 13 years ago having lived in Melbourne all my life where I was treated for anorexia. The move to Wodonga changed my life! A local psychiatrist immediately diagnosed my condition as OCD. I had been misdiagnosed for over 30 years. This was the first step on my recovery road. I had never heard of OCD until then, but I now know that many people suffer with OCD, in fact about 600,000 people in Australia.

Many of these people suffer in silence because people with OCD are very aware that their obsessive thoughts and compulsive behaviours are excessive and irrational. When you know this, but feel you can't do anything about it, it makes you feel ashamed and embarrassed. So you don't tell anyone and find ways to hide it. It is often called the hidden disorder. It seems a bit better these days to talk about some mental health problems, but people with OCD still find it very hard to talk to anyone. They are very afraid of being laughed at, scorned, teased and rejected.

3. THE EXPERIENCE OF SEEKING TREATMENT

The experience of seeking treatment is an area I would like to touch on, because the difficulties I, and most other people with anxiety disorders have had, has added to the suffering and burden of these disorders. It is true, that there are better treatments available now. But they are still not accessible to many people especially in rural areas. So people still struggle with obtaining treatment and their problems end up worse and worse.

When I was young, and suffering with scruples, I mainly received a little relief in forgiveness from priests, as there seemed to be no professional recognition that scruples were a psychological condition. At age 19 I was diagnosed by a local GP with anorexia and began treatment. A specialist physician confirmed the diagnosis and admitted me to hospital. Whilst in hospital a psychiatrist appeared once and prescribed pills.

For the next 29 years I was misdiagnosed by nine psychiatrists who did no more than give me medication which often left me in a zombie state. In and out of various hospitals and not once given any program of recovery or indeed any hope of recovery. How could there be – none of them knew what was wrong with me.

During all this I was still going to priests who were temporarily removing the guilt and sins through confession. Doctors had done nothing to help me in any way.

In 1993 we moved to Wodonga. During my first visit to the local psychiatrist he diagnosed me with OCD. He was compassionate and understanding. My anorexia was diagnosed as part of OCD. This was the beginning of therapy, which consisted of medication and behavioural techniques. In 1994 he helped me organize the OCD Support Group. I am very proud of the support group in Albury Wodonga. There we find we are not alone, are in a safe and secure

environment, find more self confidence in ourselves, trust in each other, make friendships and socialise. We accept people for who they are now, not who they will be when they're well.

In 1995 I attended the STOP Therapy Group program at Melbourne University Psychology Clinic. This was the next major step along my Recovery Road. Kathryn l'Anson of the Anxiety Recovery Centre together with Dr Mike Kyrios helped to instill empowerment in me to help me deal with my disorder.

Kathryn has been my 'Lifeline' giving me endless support on the telephone over many years, patiently helping and supporting me in many ways, understanding me, encouraging, teaching, and guiding me.

During the next 3 years I received specialist treatment from skilled clinicians who are unavailable in the Albury Wodonga region.

The STOP Therapy CBT program which ran for 13 weeks, was specially developed for OCD symptoms. It included education, awareness, thinking and exposure therapy which helps you work out ways to face your fears in a gradual and organised way.

Following the STOP Therapy program, several of the clients attended an on-going therapy group program which was facilitated by Kathryn for the final 2 years which aimed to consolidate and further the gains made using cognitive-behavioural techniques and other recovery tools such as the total well-being of our person. The knowledge, support, trust and friendship I received there in the group are a very special part of my life. Feeling better about oneself is so important.

It is essential that people with OCD and people with other anxiety disorders and depression are able to access psychological and medical treatments that are evidence-based and can be tailored to their particular symptoms and experience. For the sufferer, overcoming OCD, even with the help of an experienced therapist and appropriate treatment, can be a very difficult and hard road. It is not as simple as just finding the right technique and following it. The therapy needs to be done over the long term, you need to practice every day, you need help to sort out the other problems in your life that may be affecting your ability to recover, your family needs to know what to do and they need help and support as well. As a client, you have to be motivated and to work really hard to face all the things you fear and have avoided for so many years. Your therapist needs to understand your symptoms and the nature of OCD extremely well, so all the hurdles you face along the way can be discussed and worked through. It's not easy, it's not simple. Recovery is possible, but if the treatment isn't right it may never be achieved.

Members of the Albury Wodonga Support Group suffering various Anxiety Disorders have little or no help to manage their condition. The only support for them is from Members of the Support Group as the waiting list to see a psychiatrist is 4-5 months.

The Public Mental Health System has no Specialist Clinicians to help treat people with Anxiety Disorders, in fact many people are turned away from the Public Mental Health System with no hope of treatment programs or hope of recovery.

Sufferers find themselves on the medical merry-go-round.

4. RECOVERY

I hope you will have gained an understanding from what I have talked about, that OCD and anxiety disorders are more than just a set of symptoms, and so that recovery from these disorders requires more than medication or a set of techniques to reduce symptoms. It may be very difficult for a person to recover if all the other aspects of their life that have been affected by the disorder are not attended to.

For me, recovery is being able to live a normal life. Being able to EAT, a simple thing, like eating! To have ENERGY, to run and walk. Being able to LAUGH. Give SUPPORT, HELP and HOPE to others. Enjoy my family more, and to know that it is easier for them – not having to deal with my behaviours. To be able to leave my house comfortably without checking and checking over and over again and feeling super responsible for many things. To be able to walk out my door to the letterbox, or walk down the street. To be able to make friendships and have people come to my house. To drive the car again, park it, lock it and walk away and put the handbrake on, once only. To say how I really feel and express my needs. The best feeling is being able to do the everyday things of life without any concern, without obsessions and compulsive urges and fears plaguing my every moment. I can now do things that once seemed impossible. I am amazed at how my life has changed. I have found “ME” and discovered within me many gifts that lay buried within me. A mind at PEACE at last, free from the cocoon that bound me, or I could say, from the prison walls that surrounded me.

- Recovery is helped when distress and suffering lessen and a person’s emotional, mental and social well-being are gradually regained.
- Recovery is more than just the reduction of symptoms.
- Recovery involves developing new ways of thinking, of behaving, of living, in response to all the problems that the disorder has created or worsened in a person’s life.
- Recovery is a journey of ups and downs, stops and starts.

People who are recovering say that the people who believed in them when they did not believe in themselves, who encouraged their recovery but did not force it, who tried to listen and understand when nothing seemed to be making sense, were crucial in their recovery. They needed to have someone that could be trusted to be there in times of need.