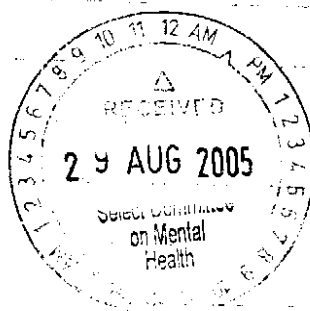




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24.8.05

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

I have been writing to people I believe should be interested in improving the treatment of mental illness, for at least seven years. My interest and concerns began when my brother committed suicide nine years ago. Shortly after my husband was diagnosed with anxiety, stress and depression. So began what I call 'my two years of HELL'. The time my husband was on anti depressants.

Perhaps this isn't how a submission should be presented or what you are after but I feel so strongly about some of my concerns that I believe I must write. I hope you will take the time to read it.

I have several concerns but there is one thing, if implemented, would contribute greatly to lessening many of the mental health problems.

Legislation that compels medical and health professionals to involve a partner, parent, carer

or close loved one in the treatment of mental illness would go a long way to help overcome and/or improve so many things. Confidentiality has its place, but to rigidly adhere to it when treating a patient with a mental illness is not one.

Yes these people do have rights and I would think the most important is to receive the most accurate diagnosis possible followed by the most beneficial and appropriate treatment for each patient. This often isn't happening when medical professionals refuse to involve carers, partners, parents, close loved ones etc. For many reasons patients often don't give their medical professionals an accurate and/or realistic description of their symptoms or how they feel and are behaving. 'What can be the nature of the illness' is just one of many reasons for this.

I believe the inquiry would get an accurate picture of where the mental health system is failing and not meeting community expectations if emphasis was put on what carers and close loved ones have to say.

They are the ones who must cope in very difficult circumstances when mistakes are made and services are lacking. They are aware of problems the medical professionals never hear of. They realise or know that a medical professional has misdiagnosed their loved one, or that the treatment is not working or is making the patient worse. The patient may not realise this but loved ones often do. It is not unusual for the medical

professionals to completely shut them out and they don't seem willing to listen. It is the loved ones that suffer the mental and physical abuse. They are the ones that have to live with the trauma of finding their sons body hanging in the garage, unaware that he had been attending a medical professional for counselling and treatment. They have the memory of police coming to their door with the news their loved one has killed themselves, and the GP knew about the depression but didn't realise how severe it was. They are the ones that have to get on with life knowing they will never understand why their parent, sibling or child died. Others would tell how every day has been HELL since being told of a loved ones suicide and finding out from their medical professional that the loved one had been treated for depression for sometime. They are the ones the medical and health professionals often refuse to listen to and the reason they give is confidentiality.

Carers, loved ones, partners, parents, siblings etc are the ones most likely to be aware of different persona's of a patient. The side of them the psychiatrist, GP or psychologist isn't likely to see. They know the patient can come over as rational, reasonable and believable and quite in touch with reality when most of the time this is not what they are like. What the patient may believe can often be very unrealistic and yet come over as quite plausible. If they are paranoid or having psychotic episodes they can still come over as quite reasonable and these problems aren't always apparent when they visit their health professionals.

I wrote to The Australian Institute of Suicide Research

and Prevention. Part of the letter of reply was 'there is no doubt I share your pre occupation with confidentiality issues. I have raised the same issues with Commonwealth Authorities but this is a very political issue and needs substantial lobbying'.

I don't believe it should be a political issue. The medical professionals can get round confidentiality without the laws being changed. The medical professionals are getting round confidentiality for other illnesses, they are doing it all the time. Many go out of their way to encourage it; but most won't even consider it when mental illness is concerned. I have heard of cases where medical professionals have talked the patient out of bringing a loved one with them when the patient has suggested it.

I recently wrote to the Attorney General about my concerns when confidentiality is rigidly followed, when treating patients with a mental illness. You would know what his reply would be I would think. In case you don't I have enclosed a photo copy of his letter. He believes there is no need to change the act. My point is the medical professionals are not compelled to involve close loved ones so the majority are not and will not, even when they are aware someone may be suicidal.

While they are not compelled to involve a close loved one we will continue to have an unexceptable number of misdiagnosis and mistreatment that could of been avoided. Suicides which may of been prevented will tragically keep happening. It is easy to contribute to a suicide if you are not aware someone may be suicidal.

After my brother killed himself his wife informed his GP of his death. The GP said "oh I knew he was depressed but I didn't realise he was that depressed" This is what happens when medical professionals make no effort to involve those close to the patient when mental illness is concerned.

I heard a distraught and bewildered man on talk-back radio. His eighteen year old son had hung himself the week before. What bewildered this man was that after his sons death, the police told him that four days before his son killed himself they had found the young man contemplating jumping from a bridge. They had taken him for counselling then driven him home. He lived with his parents but they weren't told because of confidentiality. What a cock up. The police knew, the counsellor knew he may be suicidal but the people he lived with had no right to know. The people who were on the spot with him, the people who would of went out of the way to help, they weren't told he was suicidal. For them to of been aware he had contemplated suicide could of quite possibly prevented this suicide. They would of made sure there was nothing easily accessible for him to harm himself with. They certainly wouldn't of left him home on his own and they may of got him some extra help. If only they had known.

My husband became steadily worse on the antidepressants the psychiatrist prescribed for him. When the dose was increased his condition further deteriorated. He began to believe there was nothing wrong with him and that it was me with the problems. I will spare you the hundred or more pages I could write. I am trying to be brief. He now

believed the blackmoods, mood swings, paranoid, irrational and unreasonable behaviour etc that he was experiencing was actually me. He was sure things he had thought said or done had been said thought or done by me. This made some of the things he said quite frightening and scary.

I have written many times that I believe it was only by the grace of God that we didn't end up a murder suicide statistic or my husband a suicide statistic. and I don't believe the psychiatrist had any idea what he was like.

I was becoming convinced it was the medication that he was on that was causing his depression to get worse but part of me felt this couldn't be right as the doctors should know what they were doing. He began to say everything was hopeless and he wouldn't be around to need things. At the same time he believed I was the one with the black moods and moodswings etc. He believed I was the one with the problems but at the same time he began to realise the tablets weren't working. He kept saying "these tablets aren't working, I keep having bad thoughts". I never asked him what those thoughts were as I had heard enough scary things. It was the medication that caused his deteriorating condition and changed his personality considerably for the worse. I don't believe anything justifies the two years of HELL I experienced and I am sure the psychiatrist and GP were blissfully unaware of most of it.

In a situation like this I thought it was the right thing to talk to the medical professionals involved. I had sent a note to the psychiatrist with my husband. It didn't say much and yes the psychiatrist definitely had it. I had naively

believed the psychiatrist would contact me to find what the problem was. The psychiatrist didn't so I went with my husband to see his GP. When in the room with the GP and my husband I realised I wouldn't be able to speak openly or honestly as anything and everything I said would most likely be thrown back at me later, possibly twisted to mean the opposite of what I had said. When my husband had left the room the GP said "I can listen but I can't discuss it because of confidentiality". He made no effort to get my husband's permission. I can assure you I left the doctors thinking maybe my husband was right, maybe I was mad. I might add nothing was changed and my husband kept getting worse. The GP had told me nothing of the illness or where to get information about it or any help or information on how to cope. I was none the wiser on whether his behaviour was usual for the illness. I had found out nothing, except that maybe I was mad. I guess I may of understood if the relationship with my husband had been short but at the time we had been married for more than thirty two years.

I realise now it was naive to think the medical professionals put the care of their patient first, most don't. Confidentiality is their first and main concern. Correct diagnosis and the most beneficial and effective treatment come a poor second and they certainly show no responsibility or duty of care for partners, spouses, parents, siblings, children or any other persons living with their patient.

I believe the medical professionals, and this certainly includes psychiatrists, have little idea of how often they are fooled by patients with a mental illness. They can also be blissfully unaware of problems

those living with the patient are experiencing. It doesn't matter if the patient is fooling them intentionally or if they really believe what they are saying. The end result may be the same misdiagnosis and/or mistreatment and often emotional turmoil for close loved ones.

Medical professionals should be involving partners, carers and close loved ones when mental illness is involved. 'What can be the nature of the illness,' must make this a priority. Now the medical and health professionals put themselves first. They are so scared by privacy legislation and brainwashed to observe confidentiality that correct diagnosis and treatment are not a major concern. They are more concerned with observing confidentiality when dealing with mental illness than they are with other medical conditions. I can see no common sense at all in that thinking.

If medical professionals are not compelled to involve a close loved one, and most will not even when the patient may be a threat to their own safety and wellbeing or to someone else, we will continue to have suicides and murders that should of been prevented. I believe as things are medical professionals find it easier to justify not involving a third person. Our mental health diagnosis and treatment suffer with this attitude and our suicide rate remains unacceptably high.

Partners and close loved ones would be the most valuable diagnostic aid any medical professional could have. In times of far too few resources and not nearly enough money in the health service area and

mental health in particular, it is a shocking waste of a useful resource. One that would cost nothing and probably do more to help than many of the other resources and services available. These people genuinely care and want to help. It is to their advantage to do this. They are often completely shut out and the reason given is confidentiality. I believe the health professionals have been so brainwashed by the need to observe confidentiality that they can't think outside the square and the use of common sense is beyond them.

Confidentiality is rated as more important than a correct and accurate diagnosis and/or treatment. Medical professionals are loath to involve anyone other than the patient, even when they are aware the patient has been contemplating suicide. This is what happened in the case of the young man I mentioned. I have heard of cases where the medical professional has contacted the family after reading of their loved one's suicide. They then inform them that they had been treating the loved one for depression. To me it is closing the stable door after the horse has bolted.

The Attorney General feels the privacy act has provision for medical professionals to divulge information to loved ones etc. Yes it may but most aren't. Why? Perhaps they feel it would be a problem to justify doing it, or what other reason could there be? Unless you have experienced their stupidity or suffered because of it it would be easy to believe there isn't a problem.

The fact is the privacy laws have gone way to far, not only in the area of mental health, but in most areas of our daily

living. Try to deal with Centrelink on behalf of a partner. all the necessary forms were forwarded to them but guess what they haven't got them. H/A H/A. Try to change your phone plan, again all the correct details were given out they haven't got them at the office you ring. I realise there is a need for some regulations but these have got out of hand. No wonder so many in the community suffer high stress levels. Every one is paranoid about the privacy act and top of the list would be the health and medical professionals

I attended a meeting where a carer told how the only way they could get their spouses medical history was through the FOI act. The local politician helped. The spouse had been in a psychiatric ward for several months. When they were to come home the staff and psychiatrist would give the carer no information at all. The carer thought they should be aware of all the medications, why they were given and the dosage. The carer believed this was important not only for the spouses sake but also as the couples three small children would be with them. The psychiatrist and staff said "the patient had been told all this and it was up to them to divulge the information if they wished. It seems these people are certainly not aware how mind numbing some of these drugs are and how they can cause loss of memory and confusion.

I feel how I was treated by the medical professionals is much like the churches treated the victims of sexual abuse, when they told of priests and clergy abusing them. I think the majority of people now believe the church hierarchy handled the situation incorrectly.

they showed a complete lack of understanding, sensitivity or thought for the victims. The churches thought first and foremost of themselves and their protection - they showed no thought for the suffering of those that had been abused and believed they had no duty of care to them. They done little or nothing to prevent the offender reoffending. Often they only moved them to another area where the abusing started on fresh victims. Their first duty they believed was to protect the church.

I believe the medical professionals are doing much the same when they rigidly practice confidentiality. They obviously believe they have no duty of care to the close loved ones of the patient, even if it is caused by their treatment. The first duty it seems is to confidentiality and the protection of themselves. The patients diagnosis and treatment if wrong or if it is causing the patient to change for the worse is of little concern. They can justify confidentiality and justify misdiagnosis and/or treatment with the patient not giving them realistic or accurate information about their condition. It is no concern to them if the illness or medication could be the reason for this. They can justify what they do it doesn't have to make sense.

The inquiry into the Immigration Department found a culture of justification and denial. I believe this could well be said of the mental health systems in Australia. If a patient doesn't tell them they are considering suicide this justifies then not realising this. If they do talk of suicide the medical professionals will get them to enter a no suicide agreement. It may help but to

believe they will abide by it is 'pie in the sky'. Common sense should tell you if someone is depressed they are quite likely not to be thinking rationally, yet medical professionals will enter a no suicide agreement and not notify close loved ones. I believe my husband had the reasoning of a four year old, when he was on anti-depressants, when he was on the highest dosage he was confused and had severe memory loss and acted like the wiring in his brain was mixed up. He often said he couldn't remember much of what the psychiatrist said and he tried to forget what he could remember. Much of this it seems his psychiatrist wasn't aware of or just didn't care. I guess the psychiatrist would deny they should of been aware of this and justify not knowing with confidentiality.

One thing I believe is a necessity in the mental health system is an advocate for carers, partners, parents, spouses and close loved ones. An advocate is needed for these people while medical professionals are not required to involve a third party, when treating a patient for mental illness. I wish there had been someone such as this when my husband was on anti-depressants and the medical professionals shut me out. When you can see a loved ones mental health deteriorating and the health professionals are only worried about confidentiality you need someone who can act on your behalf. Someone the medical professionals must listen to, if this person believes the patient is at risk one way or another. If they believe it is reasonable to assume the patient has been misdiagnosed and/or is receiving unsatisfactory or detrimental treatment they should have the authority to liaise with the

medical professional on the love ones behalf. It may be that the loved one believes the patient is a threat to themselves or others. This may not be obvious when they visit their G.P. or psychiatrist. You may be surprised how quickly a patient can change to suit the circumstance. It is like they only have to press a button to change their persona.

One of the early letters I wrote was to the Health Services Commissioner. A person from one of the mental health organizations I rang unofficially suggested I write to them. I received some forms that had to be signed by my husband. One was to give authority to act on his behalf. I didn't even bother asking him. He was so paranoid about making waves. They might investigate you. Who? I don't know and what we had to fear I have no idea. At the time he would of found it hard to return a faulty appliance that was still under guarantee. He couldn't accept he had suffered depression and he wouldn't have a bad word said about the psychiatrist. My reason for mentioning these things is to try and show that when mental illness is concerned things aren't as simple as they may appear. A person might seem quite normal but their thinking can still be not quite reasonable. I would assume there are many instances, in the mental health area, where health provider service standards are questionable but because of the privacy act very little can be done to have them looked into. No wonder the medical professionals are so keen on observing confidentiality.

In the late sixties I attended a party where many people were drinking to excess. One fellow about to leave the

party was so drunk he was having difficulty getting his car key in the ignition. I told him he shouldn't be driving as he would be a danger to himself and anyone else on the road. No one backed me up, in fact they looked daggers at me. I was the party kilt joy. How dare I. Oh how things have changed.

That little story has nothing to do with mental illness. I do find that when I suggest that confidentiality should be got round when mental illness is concerned, I often receive the same sort of reaction. These people have rights would be the reply I get most often. As I have written many times, yes, I agree, but I would think the importance of an accurate diagnosis followed by the most beneficial treatment that will lead to the most favourable outcome for that particular person must be in their best interest and should come before rigid confidentiality. Confidentiality can cause the patient to have a less favourable outcome than would of occurred if a third person had of been involved. My question then is why are the medical professionals so against it?

I pray it doesn't take as many years for the community to wake up and have it made mandatory that medical and health professionals involve a third person when dealing with patients with a mental illness, as it did to enact the drink driving laws. The drink driving laws are now becoming even more strict.

Lives are saved by the drink driving laws. Many of the people that were their harshes critics can now see that the community as a whole has benefited and that life didn't

stop. It isn't perfect and hasn't solved all the problems but it certainly has made a huge difference. Most people would agree it has prevented many deaths and serious injuries. Many still have their father, mother, siblings or grand parents who otherwise may of been killed had it not been for the introduction of the drink driving laws. We have no idea how many families have not had to suffer the trauma of a drink driver accident because of the introduction of the law but the number would be substantial.

I believe mandatory involving of a third person when treating a mental illness will have the same sort of result.

There is no right or wrong answer. All views have merit. I believe overriding confidentiality, when mental illness is concerned has much more merit than rigid confidentiality. I most certainly ^{am} not against the patient speaking with the medical professional on their own and what they say being kept between the doctor and patient. I believe that is important. I believe the same should happen with the carer, parent, partner etc but this person should be able to discuss their concerns, the medication and diagnosis that has been made and why the decision for the line of treatment was taken. What I am against is the medical professionals blatant disregard for close loved ones. I believe the 'I can listen but I can't discuss it because of confidentiality' attitude is a form of emotional abuse.

When living with someone with an illness such as depression it is important to know if certain behaviour etc is usual for the illness. It is important to know if the medical professional knows what the patient is really like. The 'I can't discuss it

attitude does nothing to relieve the stress loved ones may be suffering and if there is a problem it does nothing to solve it. You need information on the illness and how to cope while living with the sufferer. You need to know who to contact when concerned etc. The 'I can listen but I can't discuss it' approach doesn't provide any of this. It certainly didn't in my case. I believe confidentiality wouldn't be breached discussing this sort of thing. Obviously the GP I seen did. He didn't even recommend I see another GP who had no connection to the case. At the time I was so stress trying to cope with my husbands unbelievable behaviour I wasn't thinking straight I can see things much clearer now eight years later and I now have little respect for anyone who has so little understanding of depression that they shut out close loved ones.

It must be made mandatory that medical and health professionals involve a third person when treating illnesses such as depression. They can get round confidentiality at the moment as the Attorney General has pointed out, but the majority aren't interested and will only do so if they are compelled. The stupidity (perhaps the wrong word in the situation) of confidentiality being rigidly observed, at the patients cost, must be experienced to realise the enormity of the problems it can cause.

Cornelia Rau, I believe, is a good example of how easily the medical professionals can be fooled. As I understand it she didn't fool one but several, including psychiatrists.

Why do you think this was?

1 Medical professionals are easily fooled by someone

with a mental illness.

- 2/ The medical professionals weren't very good.
- 3/ Bureaucracy gone mad
- 4/ Once a decision is made no one will say it may be wrong. This happens in both government circles and the area of health, even when it is obvious there may be a problem.
- 5/ Combination of all or most of the above.

How Cornelia Rau fooled even the experts is happening every day all across Australia. It is very common.

This is why it must be made mandatory that medical and health professionals involve someone close to people who suffer a mental illness

I find it interesting but not unusual that the people in the detention centre with Cornelia realised she was mentally ill, yet the people who should of known didn't

