

# 2019 Submission - Royal Commission into Victoria's Mental Health System

## Organisation Name

N/A

## Name

[REDACTED]

### **What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?**

"Dementia and Rehabilitation The policy of refusing people with dementia rehabilitation after hospitalisation is discriminatory. Apparently this is true whatever the person's age. I ask you to recommend that people with dementia be entitled, by policy (of hospitals and rehabilitation centres), to be put in a rehabilitation program when needed. My personal experience is of asking for my mother to have rehabilitation after breaking her upper femur and having a hip replacement. I am my mother's medical power of attorney. Before that she fell and had bleeding to the brain in November 2018. She was then 89 years old (now 90) and after three weeks in hospital and surgery I asked for her to be put in rehabilitation in a private hospital in Geelong. She has a Veterans Affairs Gold Card. I felt that at her age having been lying in a hospital bed for three weeks and having had surgery and very little exercise or movement it would be dangerous for her to go back to her nursing home without some muscle building exercise. At that stage she was put in the rehab ward, however it was over Christmas and she got very little supervised physical activity due to the holidays. She kept asking to go home to her room at the nursing home, and she was a bit difficult to handle, so they discharged her with not much rehab. However she did enjoy the exercise sessions she did get there. My mother has always loved exercise and is very strong and fit for her age. She habitually does self-motivated exercise sessions herself, daily, from a routine she learned in her youth. Though weakened from her time in hospital, and inadequate rehab, she resumed her (pre-operative) normal life in the nursing home; going for walks and visiting other residents, taking herself to the toilet and giving herself a shower. She was determinedly independent even though she had been told/asked to request assistance when going to the bathroom and not to walk around the facility alone. She learned how to avoid pressure mats put down to alert staff she was getting out of bed. In her weakened state it was rather inevitable she would have an accident. In January she fell and broke her upper femur. She went to hospital and was given a partial hip replacement. She was only in hospital for a short time when they told me they were discharging her. I asked the surgeon to recommend she go to rehab. He told me they don't take people with dementia into rehab, but on my insistence he sent a recommendation. The rehab refused to take her because she has a level of dementia. By now they knew her. I was shocked. It is a private hospital and she has a gold card, meaning all her expenses are covered. Why would they refuse the business? I was told it is because people with dementia are unable to formulate and stick to enacting a rehab plan for themselves. However in my mother's stint in rehab she was taken for walks and into the exercise room and directed by the physio to do her exercises. When she attempted to get up and walk on her own she was told she was not allowed to and made to go back to bed. So it seemed illogical to me that she was being refused because of being unable to self-motivate. You will not easily find an elderly woman more motivated to exercise than my mother. The problem is more keeping her from over doing it. She told me she looked forward to her supervised exercise sessions and whenever she was taken for walks by the physiotherapists, while still in the hospital ward, she walked and tried to achieve the maximum.

After her partial hip replacement she was sent home within days again, weak and depleted due to having had an operation and lying in bed again. As it is virtually impossible to keep her from walking when no-one is there to stop her, she tried to go to the toilet alone and fell within 24 hours and was taken back to hospital with a dislocate hip. I felt that if she had had some rehab she would have been stronger and more balanced in her walking and may not have fallen. The hospital personnel I talked to gave the opinion that the nursing home should provide rehabilitation. They do not seem to understand that this is patently not possible because of the low staffing levels in aged care facilities. After the hip was re-located she was again sent home within a couple of days. At the hospital they only took her for a couple of short walks. I tried to walk her as much as I could so that she would be stronger when she got home, because I know there is not the staffing level to properly supervise her in the nursing home. Again I asked for her to be given some rehab. Again this was refused because of her dementia. However she only has a mild form of dementia and has a reasonably good memory. For example she could remember that she was due to have a rehab session when she was in that ward and she looked forward to it. She was always happy when a physio came to take her for an assessment walk and tried to show off her ability. She is always keen to prove her fitness and always took great pride in it. She got home to the nursing home un-rehabilitated and after less than 24 hours fell and dislocated her hip again. They fixed it and put a brace on her to hold it in place. We moved her to another room in the nursing home nearer the nurses station, where she could be more closely supervised. She soon fell again, after a couple of days, and was taken back to hospital where she was given another operation and a robust full hip replacement. One I was assured was locked and unbreakable. Again I asked, and they refused, to give her rehab. I asked about other rehab facilities in her regional area (██████) and was told no-one would take her because of her dementia. So after nearly 3 months spent largely in hospital, and with little exercise and no rehab, she was sent back to the nursing home again. The physios there have only minimal time to spend with each resident and have told me they could get a much better result if they had more physios who could spend time to get residents fitter and more able to self ambulate. By this time my mother was much weakened and was only able to walk assisted obviously with a wheely walker. Which she had been using for over a year. She had already had a few dislocations which had stretched her muscles and sinews and she had no rehab to build them up again. Inevitably she fell and incredibly managed to break her total hip replacement (the most robust and unbreakable one the surgeon assured me). Back to hospital and after much consultation the osteo surgeon said it was unfixable and she would have to live with a permanently dislocated hip. So my mother was sent back to the nursing home in the condition in which she was sent to hospital. With a dislocated hip and in great pain. The pain has receded and scar tissue has built around the dislocate hip. However she is permanently unable to walk for the rest of her life. She has to be assisted in all things. Apart from being able to feed herself. For a person like my mother to find herself bed bound is torture. She is deeply unhappy and frustrated. She still gets out of bed, despite alarms and crawls around and tries to pull herself upright and is found in chairs she was not put in. She is an accident waiting to happen. Alarms go off but there is not enough staff to get here to stop her in time. I believe it is quite possible that if she had been allowed to have re-habilitation after her first and even all the subsequent hospitalisations and operations and enabled to build up her muscle strength and stability she may well still be walking and able to shower and toilet herself. She would still be able to walk around and socialise and still get out on bus excursions or be taken out for breaks in the wide world by her family. The cost to the system of restricting her right to rehabilitation has been huge. She has had numerous operations, and is now needing a much higher level of personal care. She is living in her worst nightmare. I ask you to recommend that people with dementia be given supervised rehabilitation in a rehabilitation centre after

hospitalisations. Even if it does require a slightly higher level of supervision. It should be a human right for all people, including those with dementia, to have adequate rehabilitation after hospitalisation to enable them to get home to the highest quality life they can have. "

**What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?**

"There needs to be better public education about dementia - including paid carers. Due to the hospital staff and doctors not giving my mother rehabilitation after hospitalisation she has become physically disabled and this severely affects her mental health. Despite her dementia she was happy in her aged care facility. She often told me so. Since becoming physically disabled she is very very distraught mentally and has developed much higher anxiety, depression and has constant suicidal desires. She begs everyone she talks to, including her family, to 'put her down'. She wants us to kill her. This was not the case before. She was making the best of her life in the aged care facility. The attitude that a person with dementia cannot do a physical rehabilitation program has caused a huge deterioration in her mental health. "

**What is already working well and what can be done better to prevent suicide?**

N/A

**What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.**

"When people with dementia are cared for and managed by carers (paid or family) with a deeper understanding of dementia and how to talk to and manage the person it minimises the anxiety experienced by the person. I watch the difference between the interactions of my mother with those who know the right techniques and those who don't. There is a big difference. Most families are not well educated enough about how to adapt to a loved one developing dementia. We are left to our own devices to learn how to do so. Some never do and this causes everyone, carers and cared for, huge stress and anxiety."

**What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?**

"Because dementia affects primarily the old there is a level of fatalistic acceptance of the mental health symptoms and not enough effort to allay them. It is kind of ""Well she is old so why bother.""

**What are the needs of family members and carers and what can be done better to support them?**

Better education of the symptoms and effective ways of relating and managing the person.

**What can be done to attract, retain and better support the mental health workforce, including peer support workers?**

Better pay and better training. As well as adequate levels of staffing.

**What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?**

"People with dementia get very little support and encouragement to keep up social participation. Developing new models of housing people with dementia, especially when advanced, in which they continue to mix in a heterogeneous community of all ages, etc would be a good direction to go in. "

**Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?**

N/A

**What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?**

N/A

**Is there anything else you would like to share with the Royal Commission?**

Remember to keep dementia in your list of priorities when recommending changes to the mental health system.