Your contribution

Should you wish to make a formal submission, please consider the questions below, noting that you do not have to respond to all of the questions, instead you may choose to respond to only some of them.

1. What are your suggestions to improve the Victorian community’s understanding of mental illness and reduce stigma and discrimination?

I have had limited experience with the mental health system so can only comment in relation to the attached submission on my mother’s experience as an elderly woman with dementia. Although dementia is considered as a mental illness, there seem to be many very specific issues that mean the treatment facilities and approaches need to be better tailored to the needs of these usually elderly persons with dementia. In our mother’s case her admission to a psychiatric ward (albeit labelled geriatric) under a compulsory treatment order without consultation with us or anyone else as carers was inappropriate and counter-productive. If dementia is to be regarded as a mental illness then the facilities need to cater for the clients’ needs – familiarity, quiet, stable, comfortable with minimal risks due to their vulnerability. Placing elderly people with dementia in facilities alongside people with a range of mental illnesses who demonstrate strange and frightening behaviours is totally inappropriate. There needs to be more specific facilities to deal with those situations where elderly people with dementia can be admitted in times of crisis or need for acute care.

2. 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?

Our mother’s aged care facility does quite a good job managing her infrequent difficult behaviour, but they need more support in the form of more training for staff, more staff with specialised skills to deal with acute episodes. Treating people in their place of residence as the MHA suggests, people are entitled to the least restrictive form of treatment is better than hospitalisation. For people with dementia, removing them from their familiar environment is counter-productive. In our case, if the hospital had been better able to support the aged care facility with crisis support in place, it would have avoided 18 days of hospitalisation for our mother, the associated financial costs and the trauma and awful experience our mother underwent. The fact that her episode occurred ‘out of hours’ probably contributed to her being hospitalised, but surely crisis services should not only be available but be available 24/7. As more people enter aged care situations the demand for services to prevent hospitalisation of elderly people with dementia will surely increase. Aged care facilities need more support and these services should be available.

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

4. 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.

Particularly for people with dementia, where the condition is irreversible, there needs to be an approach which recognises it as a chronic condition with sometimes periodic crises. People suffering from dementia will find it impossible to achieve some degree of mental well-being if the treatment of their crisis situation **exacerbates** their condition, as demonstrated by our mother's experience. In our mother's case the hospital operated as an almost independent unit, acting with no regard to the wishes or the patient, carers or aged care facility. It seems impossible to achieve integration of services if hospitals and their units feel they can act without consultation or engagement of those who have a legitimate stake in the treatment. Such actions appear arrogant and at odds with achieving integration or easy access and appropriate treatement for patients.

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

Elderly people with dementia are at increased risk because they are may have limited capacity to be actively involved in or negotiate their way through treatment. They are very vulnerable because of age and condition to risks in new environments. I hate to think what would happen to elderly people with dementia like our mother if they did not have family to intervene. As it is I feel upset that we failed our mother in allowing her to be admitted to such inappropriate care. We were ignorant of the processes under the Mental Health Act, and we failed to understand our own and our mother's rights. The hospital seemed to take a purely pragmatic approach, 'what do we do medically with this elderly dementia patient?' rather than respecting her as a person with a family who cares about her. I think major drivers in our mother's case were both the hospital's arrogance and purely pragmatic approach, and our own ignorance about the Mental Health Act.

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

From our experience I would say that carers must be involved. The Act required that we be informed and involved but for whatever reason [redacted] hospital did not do so. The hospital made attempts to appease us but overall they seemed to regard us as a nuisance rather than having a legitimate right to be involved and to represent our mother. The fact that they ignored both the requirements of the Act, did not follow or complete basic procedures, or communicate appropriately meant that we were both disrespected and disempowered. Carers should be treated as supports to the treating agency, not nuisances, we should be involved, not excluded and respected not ignored and disregarded. Carers want the best for the person being treated but that requires services to recognise their importance, fully understand carers concerns, anticipate their need for information, offer both information, advice and opportunities to be involved. Our experience was that the hospital attitude was more about ‘we know best’ and ‘we will tell you what we think you need to know, when we get around to it’

7. What can be done to attract, retain and better support the mental health workforce, including peer support workers?
8. 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?
9. 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?

10. What can be done now to prepare for changes to Victoria’s mental health system and support improvements to last?

With our experience I wish we had known more about the mental health act and how it operates. I actually never thought of dementia as a mental illness that could be covered under the Act. If the system is going to be changed, then people/carers need to know how it operates, who it covers and what it means for them. I understand that people are not likely to engage with these matters if they don’t feel it is relevant to their situation i.e. there is no crisis so I don’t need to know’ which is what I was like until it mattered, and I was found to be ignorant. That is my responsibility, but I think people could be prompted to think about mental health and how it is a widespread issue, that everyone needs to think about even to the extent of identifying how they or loved ones might be affected and then have ways to prepare for it. I think I have seen some recent advertising highlighting that many people are affected by mental health issues, but I know that it is easy to ignore these sorts of media campaigns, as well-intentioned or necessary they may be. However, information through a variety of channels and targeted at specific issues and situations might trigger more involvement. In our case I think I would have been responsive if the aged care facility where our mother lives had raised these matters with us – i.e. implications of the Mental Health Act, nominated persons, advanced care directives for mental health etc. In other words, the relevant issues would have been raised with the target group (carers) about specific issues or relevance to our situation. I hope I would have been responsive to such an approach.

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

Privacy acknowledgement	I understand that the Royal Commission works with the assistance of its advisers and service providers. I agree that personal information about me and provided by me will be handled as described on the Privacy Page. ☒ Yes ☐ No