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?**

Hospitals, aged care facilities and doctors need to be more accountable and transparent and follow due process in their consultation and decision-making and record keeping. In two cases – both my parents – despite of, or perhaps because of, my being actively involved in their treatment – have had atrocious experiences leading to clinical depression.

In dad's case he was clinically depressed and in hospital he was not allowed to consider his options with family support which resulted in his death.

He could have gone home or to a private hospital using his DVA Gold Card as requested by mum and me. Yet, the geriatrician at [redacted] hospital non-consensually euthanised him without family consultation.

In mum's case she was immobilised, which seems to be a form of restraint (her walker taken away even though she had moderate walking ability), without consultation with her or me as a support. This immobilisation led to extreme anxiety and clinical depression which now seems to be leading to a slow and painful death.

These medical failures also have an ongoing catastrophic impact on others.

Patients/residents, and carers, need to be given clear information as to what they can expect in hospitals and aged care facilities – what are the processes "care plans" etc. and they must be consulted before major changes are made, but this is not occurring. Hospitals and aged care facilities need to be kept accountable and transparent in their practices and offer at least apologies and at times compensation.

Auditing systems do not seem to be working, as the failure to see care plans have not been done in consultation with family/resident is a major oversight. The auditing system is too generic and weak.

The appeal system also needs better transparency as it appears to ignore errors that were made.

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?**

I can't see anything that is working well at this stage.

3. **What can be done better to prevent suicide?**

The problem of non-consensual euthanasia in elderly people who are vulnerable to abuse in the public health system and in aged care must be better considered.

A better functioning health care system and support system would reduce the need for 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.

As per Q1.

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

Lack of rural and regional facilities. Lack of quality mental health practitioners. Lack of accountability and failure to follow due process.

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

If the hospital and aged care systems are transparent, accountable, due process and due consultation is followed and there are clear goals and aims, then family members and carers will be able to negotiate the systems and know their family member, patients, or residents will be safe and receive appropriate care.

The basics – like offering a cup of tea when your parent has died would be a good start.

For more complex grieving processes – other support systems should be available such as the offering of grief counselling, as per dad's medical record notes should have been offered, but which was not offered.

Hospital must have accountable help systems, unlike my experience where no one would help me and the help line did not return my call.

An accountable appeal system is necessary. The Health Complaints Commissioner's office made atrocious errors based on errors given to it by the hospital, and it seems to be supporting what appears to be a corrupt hospital administration.

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

Better, more intensive training

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?

There are currently few 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?

- Transparency and accountability
- Ensuring due process and due consultation
- A more accountable appeals system.
- Less generic and more rigorous auditing systems
- Better training for hospital workers and aged care workers. Greater hours of university lectures would help – some trainee nurses get only 6 hours a week lecture time compared with the 1970s where it was over 20 hours a week.

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?	
As per Q. answers above.	
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 I wish to remain anonymous

Royal Commission into Mental Health

I wish may name, address and personal details to be kept confidential

Introduction

It is not just the 'top end' of mental health that needs investigation and overhaul. My concern is with the failure in public hospitals, the health profession, and aged care to understand and treat depression and anxiety in vulnerable aged patients, which often amounts to abuse, neglect and misconduct.

Mental health in the elderly

1. The lack of diagnosis, support and treatment of elderly people – highly vulnerable people – with varying degrees (or intermittent) dementia, Alzheimer, anxiety disorders, or depression is at critical breaking point.

2. There are systemic failures for elderly people with varying degrees of mental health issues in public hospitals and in aged care. There is a failure and lack of diagnosis, support and treatment in public hospitals and aged care.

3. The impact of Victoria's new euthanasia legislation on mental health on the elderly and vulnerable, including in aged care, should also be investigated and resolved before the legislation is enacted.

4. There also seems to be a failure by many family members to understand and deal with mental health issues of elderly family members. Hospitals, GPs and aged care facilities need to be able to assist family members understand and resolve mental health issues, but it seems many hospital and aged care workers and GPs do not understand it either.

5. There needs to be education and greater support for all people with family members who have mental health issues.

Case 1 – Failure to treat mental health in a public hospital

He threw his (cold) porridge on the floor and was terminally sedated…

I speak from personal experience with my father's mistreatment in a public hospital which resulted in his death. Dad had various degrees of depression over his life; this is supported by his WW2 medical record where he received a fractured skull and is reported as being depressed when he could not play certain sports or follow his career choices. It is also supported by personal observations over 60 years.

Background

Dad was 90 years of age and had some functional decline and breathlessness due to COPD, but he was still driving his car, independently mobile, and having a reasonable lifestyle when he was misdiagnosed by his GP with major bladder cancer and only months to live. Dad acted stoically, but went to bed ready to die – he sunk into clinical depression.

4 weeks after this diagnosis we had a meeting with an urologist who said dad did not have bladder cancer, but he had a lump in a ureter which may be a cancer but this was never confirmed as all blood tests were ok. It was very hard convincing dad that he did not have bladder cancer. He was to see the urologist every 3 months. He was emotionally vulnerable.

Dad developed diarrhoea. Again there was a misdiagnosis - the doctors prescribed Gastro-stop. Finally [redacted] hospital diagnosed faecal compaction and clinical depression. After 5 weeks on anti-depressants dad's mood improved greatly. He needed both family and professional support.

Dad received a small leg wound when he visited the physio – something sharp sticking out cut his leg. The wound became infected and dad developed mild intermittent delirium which concerned us.

We took dad to Western General Hospital outpatients, and he was transferred to [redacted] Hospital. Dad had a DVA gold card but we thought this would be a short stay before he returned home. Living in the western suburbs, there are no nearby private hospitals for aged patients.

The [redacted] hospital geriatrician wanted to stop dad's antidepressants saying he was not depressed. I insisted he remain on antidepressants as I knew his mood had improved dramatically since taking anti-depressants. The geriatrician halved the dose. The geriatrician failed to consider the withdrawal side effects of reducing the antidepressant on a vulnerable person.

The medical report (gained via FOI after dad's death) notes the geriatrician referred dad for a psychologist's assessment, but across his 3 weeks in hospital this never happened.

Dad's leg wound was improving (granulating), and after 2 weeks the hospital held a family meeting with the agenda to move dad to aged care. Mum and I wanted him to go to a private hospital for a second opinion and rehab, but the hospital terminally sedated dad 3 days later without any discussion with mum or me. I arrived 40 minutes after they terminally sedated dad, and despite my requests they would not stop. No one helped when I asked for help. The help line never responded to my voicemail. The staff refused dad a drink of water when he requested it. This was a Friday afternoon, and despite many requests no one came to assist me with my concerns.

It took a week to kill dad. He still had a good appetite when I was there to hand him the food (he spoon fed himself), and he still wanted to go home.

Failures in hospital process for a person with mental health issues

There were major failures in process for a person with mental health issues which resulted in his death.

Early discussions with the hospital following dad's death noted there were systemic failures in process (listed below). The hospital administrator cried when I told her what happened – she said "your dad had options, most people don't". It seems the hopsital involuntarily euthanise people who don't have the option of a private hospital or going home to a family who can care fro them.

Despite discussions with the hospital, AHPRA, and Health Complaints Commissioner's office and Ombudsman, I have not been able to get any resolution or apology - they are ignoring the hospital's errors.

Peer Review of Medical Records

Three doctors (including one psychiatrist) have read dad's medical record and said they do not know why the hospital acted as it did. Dad's vital statistics show he was not imminently dying. Two days before dad died he said he did not know they had withdrawn his normal medicines and he did not know they had put him on a cocktail of sedation drugs.

Systemic hospital failures (for a person with depression):

- The doctors failed to consider Dad's depression and began withdrawing his anti-depressant against my request.
- The doctors failed to consider the effects of withdrawing the antidepressant.
- The doctor's recommended referral to a psychologist (noted in the medical report) was never implemented.
- A Refusal of Treatment Form was not signed.
- There is no MEPOA form in the medical record.
- There are conflicting reports and inaccuracies in the medical record, dates changed without initialling or noting why, and forms incorrectly filled out.
- The medical record has 3 contradictory dates for implementing terminal sedation.
- There was no informed consent to stop treatment.
- Comfort medicine (Spiriva) was withdrawn on day 3 without reason.
- A procedure (removing his large toenail) was done with the patient's consent, after he was said to have no capacity.
- The hospital discussed dad's case with the wrong GP (the GP dad had sacked for misdiagnosis).
- The medical record shows that dad was "conflicted" as to his discharge destination. This was not conveyed to his family. Dad should have been allowed to consider his options with family support.
- There was only one family meeting. The agenda was to discharge Dad to aged care as he was 'not ill enough to stay in hospital'.
- The hospital failed in its responsibility to have a family meeting before any major change of treatment.
- The doctors did not reasonably consider what may have made dad anxious on the day he was terminally sedated:
  - It seems the hospital advised him that he was being sent to a nursing home to die – no wonder he was anxious.

  - The doctors did not consider the side effects of haloperidol on an elderly patient which was given to him the day before he threw his porridge on the floor and terminal sedation. 4 days earlier at the family meeting they said they would not give haloperidol to him as it could have adverse effects.
  - Dad was sick of being in a hospital that was not giving him the emotional support he required.
- There were no major issues – no pain, no vomiting… that warranted terminal sedation without discussion with the patient and family.
- On the day of sedation, the medical record shows dad was sitting out of bed, vital stats were reasonable. Throwing his breakfast on floor (cold porridge) is no reason to start terminal sedation.
- An informed medical decision by the palliative care doctor could not have occurred because dad was already sedated.
- The head nurse gripped and bruised my arm in alarm when she heard dad had been terminal sedated, as she knew he was not imminently dying. The medical record shows she requested someone to help me, but no one came.
- The hospital failed to help me when I asked for help. I requested to speak to the hospital CEO, but no one helped. I was given a brochure, but the help line failed to return my call.
- I was not advised there was a liaison person.
- There were no palliative beds available, so dad was in acute care. The staff did not like us using the kitchen to make a cup of tea, so I brought my own.
- There was no advice to family that dad would likely die. Dad died alone.
- I arrived 10 minutes after dad died.
- There was no support given when dad died, not even the offer of a cup of tea.
- The syringe driver was empty 10 minutes after dad died which means the syringe driver was empty and the hydromorphone given too quickly, or the syringe driver was malfunctioning. There is no guarantee dad died 'peacefully' as noted by the hospital.
- The medical record notes that grief counselling should be given to the family as it would likely be a complex grieving process, but none was offered.

No medical accountability

There are major clinical and procedural failures and a gross failure of duty of care and medical negligence to a mentally vulnerable person. It seems this is not a one off scenario. The funeral director said he hears it all the time.

Ongoing Effect – Vicious Cycle

Dad's clinical care was completely unsatisfactory, malpractice, and resulted in his death. This has had a profound and lasting effect on our family.

Case 2 – Mental Health in Aged Care

My mother is now in aged care. There are systemic failures in aged care which leads to or aggravates mental health issues. There is a lack of diagnosis, support and treatment for those with mental health issues.

Reasons for mental health issues

Mental health issues can be the result of dementia, Alzheimer, infections (often not recognised or treated unless an astute family member picks up behavioural changes and speaks up to request medical tests), home sickness, lack of a personal support or caring environment, immobilisation, or other reasons such as sensory isolation due to untreated deafness or sight problems.

Non-consensual Immobilisation led to Anxiety and Depression

- Mum had medium to moderate walking ability when she entered aged care for Respite at the age of 90. She was mentally bright and happy.

- While in Respite mum was told she could not attend physio or hydrotherapy. I now have been advised this is incorrect – she could have paid for it herself.

- After becoming a permanent resident – mum's knees appear to be hurt by the aged care physio who seemed overzealous pushing and pulling her legs (mum has arthritic knees).

- The physio took away mum's walker without consultation and put her in a wheelchair. Despite me and mum requesting its return it was not returned. After a week of being confined to the wheelchair and the aged care staff doing no exercises with her, she could not walk.

- After immobilisation, mum would ring me in confusion and anxiety many times per afternoon or night asking where her walker was, how would she get to bed… She developed what appears to be 'sundowner's syndrome'.

- Staff discourage mum from going to an external physio. It seems to be too much effort for them to organise a taxi and have mum ready to go.

- Staff discouraged mum from doing physio exercises with me. Her knees are now frozen in right angles and are extremely painful if moved.

- Toileting was regimented to 2 to 3 hourly. Sometimes mum had to wait over an hour after requesting to go to the toilet. She became very anxious and confused and stopped drinking fluids as she was scared of wetting herself.

- Mum's mental tests showed a sharp decrease in cognitive ability after she was immobilised and not allowed to go to the toilet when she needed.

- Mum's fear of drinking led to a sharp weight loss. I kept advising the care manager that mum was shrinking and not drinking enough, but nothing seems to have been done until she was weighed as resident of the month – mum had lost over 10 kgs in 2 months. They started to fatten her up with Sustagen.

- She was diagnosed with depression and is now on anti-depressants.

- I looked into Rehab, and got a doctor's referral as advised, but after a lot of running about I found out that mum could not enter Rehab from an aged care facility – they must come from a hospital.

- I was advised that mum had been measured for a wheelchair by the facility's physio. It never came and then I was advised she could not have it from DVA as she was now high care.

- I was advised by the facility that mum could use a motorised wheelchair if an OT assessed her. I bought one, but it was put in the facility's garage. I organised an OT who rang the facility but was told she could assess mum but that mum could not use the motorised wheelchair in the aged care facility. There is often conflicting advice coming from the same person.

- The CEO criticised the external physio's request for a special wheelchair.

- I had a meeting with the new CEO who asked why mum's care was not sorted in a Care Plan.

- Mum had been in the aged care institution for over a year and no Care Plan had been implemented with her or me. Other family members whose parent in in care said they've been over 10 years without any care plan being done with them. Care Plans are supposed to be done in discussion with the resident and/or family representative and signed by the resident and/or their family representative where possible, and it was possible as I am there daily.

- I requested copies of any prior "care plans" – they appear to be more like case notes done by the care manager reciting, unbeknown to me, informal conversations she had with me and in cases drawing incorrect conclusions.

- Some Care Plans were withheld, and I am advised I need to apply via FOI to get the earlier ones. I requested a FOI form, but eventually was told I'd have to find a generic form off the internet.

- I saw the Extended Care Plan on the 8 May 2019 when making the first Care Plan, and I asked for a copy as it showed mum had moderate-medium walking ability. The Extended Care Plan was changed on 9th May 2019 with parts deleted. This appears to be illegal, as I believe no medical records can be deleted for 3 years.

- Mum waited 3 weeks after my request to see a doctor.
- The care manager criticised me for mum's doctor's appointment and said to take her to clinic if she needed long consultations.
- The aged care physio took away mum's gell cushion without consultation. A nurse said – "it does not belong to your mother, anyone can use it".
- [redacted] emailed and rang the care manager asking what type of cushion it was as I was going to buy one – but the care manager never answered. I bought a cushion as mum was very uncomfortable.

Who picks up the problems?

No wonder mum is anxious and clinically depressed. The aged care system is malfunctioning and has been to date unaccountable and has no systems for mental health assessment or treatment.

Mum is dependent on me to give her a bit of relief each day and keep an eye on what's happening.

Some residents do not have any family. Some residents do not have regular family visits, and many family members just accept deterioration as part of the aging process without understanding there may be underlying causes, or treatment, or activities that could improve their family member's quality of life and mental health.

Many residents just languish in their wheelchairs or rooms being shoved around. Many cannot speak up for themselves, are too afraid to speak up, or do not understand that they could be helped or have a better life.

Lack of specialists

The facility lacked a CEO for the first 10 months of mum's stay. Only a podiatrist regularly attended.

Geriatricians do not visit the town and I had to take mum an hour's drive to see one – this also caused anxiety problems as there are no lifting equipment for wheelchair bound people in hospitals or at the geriatrician's clinic which was at an aged care facility.

Aged care staff seem to have little or no training in mental health issues.

There needs to be regular meeting and reviewing individual residents – Care Plans – with their family carer to compare behavioural changes and assess mental (and physical) health and ensure appropriate treatment.

Accreditation

Aged care accreditation statements are generic and the broad statements means many issues are unlikely to be met.

Both these cases are a result of:

- a chronically failing health and mental health systems;
- a failure to consult;
- a failure to follow due process;
- a failure to treat the person (and family/carer) with respect, dignity and appropriate care which appears to be abuse, neglect and medical misconduct.

Both the public hospital and aged care systems, and appeal processes, need a complete overhaul to stop people developing mental health issues and to ensure due process, transparency and accountability, and better treatment for people with mental health issues.