Submission to the Royal Commission into Victoria's Mental Health System

Royal Commission into Victoria's Mental Health System
PO Box 12079, A'Beckett Street, Victoria 8006
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Representing Victoria's mental health carers

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About Tandem

Who we are

Tandem is the Victorian peak body representing mental health carers of people living with mental health issues.

What we do

- We advocate for carer involvement in planning and care, participation in system change, and support for families and friends.
- We promote and support the development of the mental health carer workforce and leadership.
- We inform and empower mental health carers to access the National Disability Insurance Scheme (NDIS).
- We promote and collaborate on the delivery of training on family inclusive practices for mental health professionals.
- We provide information, education and training to mental health families, friends and supporters.
- We support and advocate for the diverse needs of families, friends and supporters of people living with mental health issues.
- We collaborate on research and policy development on matters relating to mental health carers.
- We raise community awareness about the important role of families, friends and supporters in mental health recovery.
- We administer the Carer Support Fund which provides financial assistance to families, friends and supporters of people registered with Area Mental Health Services in Victoria.

Glossary of Terms

Carer	A carer may be, and will continue to be, primarily the person's wife, husband, partner, son, daughter, parent, neighbour, friend, … their child or children. It doesn't matter how many hours are spent each week providing support. Carers may live with the person they are caring for, providing assistance with daily needs, or may visit the person regularly. Carers are people who invest time, energy and support, generally in an unpaid capacity. However, some may receive Centrelink benefits to enable them to continue in their caring role. Carers are often hidden. Children who become carers face particular difficulties in being recognised and having their needs met. In culturally diverse communities, care may involve the entire community and may provide additional challenges during the process of identifying who is a carer. Adapted from *A Practical Guide for Working with Carers of People with a Mental Illness*, p.6
Co-design	Co-design is a creative process to actively involve all stakeholders (e.g. services, consumers, carers) in a collaborative **design and re-design** process to help ensure the result meets their needs and is usable'.
Compassion	1. Recognising suffering 2. Understanding the universality of suffering in human experience 3. Feeling for the person suffering and emotionally connecting with their distress 4. Tolerating any uncomfortable feelings aroused (such as fear, disgust, distress, anger) so that we remain accepting and open to the person in their suffering and 5. Acting or being motivated to act to alleviate the suffering. *Strauss, Lever Taylor, Gu, Kuyken, Baer, Jones, and Cavanagh (2016).*
Compassionate leadership	Compassionate leadership means creating the conditions – through consistently listening, understanding, empathising and helping – to make it possible to have tough performance management and tough conversations when needed. Staff indicate they only see their leaders when something goes wrong and that even if they do listen, nothing changes after the conversation. Compassionate leadership ensures a collective focus and a greater likelihood of collective responsibility for ensuring high-quality care. Adapted from: <u>https://www.kingsfund.org.uk/audio-video/michael-west-collaborative-compassionate-leadership</u>
Family	Family is culturally grounded; for example, Australian Aboriginal nations each have rich, complex and nuanced kinship and family structures which prescribe relationships and responsibilities people have to each other and the land. Family includes the consumer and those with a significant personal relationship with the consumer. This includes biological relatives and non-biological relatives, intimate partners, ex-partners, people in co-habitation, friends, those with kinship responsibilities, and others who play a significant role in the consumer's life. Some family members may identify themselves as a '*carer*' in a consumer's life, others will identify more so with the characteristic of their relationship (for example: parent, child, partner, and sibling). **Department of Health & Human Services, Mental health lived experience engagement framework (2019)**
Family carer Workforce	Family carer workforce is a collective term for family carer workers in a range of roles. Family carer workers provide support and connection for people who are in a consumer's family, some of whom may identify as a carer. Family carer workers may do this directly through providing peer support, or indirectly through leadership, advocacy, education, and research. Lived experience as a carer is an essential part of the selection criteria, with other skills and knowledge required depending on the role. *Strategy for the Family Carer Mental Health Workforce in Victoria CMHL (2019), p.3.*
Relational recovery	Relational recovery is a model which emphasises the interpersonal aspects of recovery, recognising that people's lives and experiences cannot be separated from the social contexts in which they are embedded. Adapted from *Price-Robertson, Obradovic, & Morgan. (2016). Relational recovery: Beyond individualism in the recovery approach. Advances in Mental Health. 15.*

Tandem's key asks:

Victoria's mental health system is broken. To fix this system we need to ensure all services are:

Safe: Change the current punitive, crisis driven system to one which has sufficient, dedicated, accessible and therapeutic services to provide a safe environment for all.

Inclusive: Mental health services must include family and friends in recovery. These groups need to be recognised as a critical part of treatment and recovery teams.

Fair: Everyone has the right to access services. The provision of mental health services must be fair. They need to treat everyone fairly, regardless of their location, gender, sexuality, cultural background, drug and alcohol issues, and economic status.

Funded: We need to change the culture of the mental health system. It needs sufficient funding to provide the compassionate care people require. We must ensure that the responsibility does not fall to families, police, and emergency departments.

Executive Summary

Tandem, the peak body for mental health carers in Victoria, welcomes this Royal Commission into the Mental Health System in Victoria as an urgent opportunity to change the system to one which is properly resourced and demonstrates compassion for all in need. We urge the Commission to be bold, and make recommendations to truly transform the system as it is. This is a once in a generation opportunity.

Our members and supporters, both individual carers and organisations, have told us, through consultations – inclusive of urban, regional and rural members – that the mental health system in Victoria is in many ways broken. It currently only operates in crisis. When it does operate, it is largely experienced as unsafe and not inclusive of families and friends who care for people with mental health issues, poorly funded, and unfair.

For people experiencing acute mental distress and their carers, the system is deeply flawed. It relies on police, ambulance and emergency departments. The system communicates poorly with carers and family. It is underfunded and experienced by many as uncaring. It leaves people behind, unable to access the few beds, in a bed-based system. At best, it is transactional. At its worst, it is experienced as destructive.

The impacts of the failed system ripple through our community, our courts and our hospitals. Victorian's need a mental health system which has responsive, compassionate, and accessible services, available everywhere, when people need it.

Carers, the family and friends of those with mental health issues, are predominantly women, and often face substantial impacts in every part of their lives, including their own mental health. The system fails carers, when it fails those they care for.

Victoria can potentially have a world class mental health system. This system must be safe, inclusive, fair and well-funded. It must challenge the stigma that those with mental health issues and their carers face. It must have the resources to address all people's issues and to ensure that families and friends are seen as a critical part of the team that treat and manage mental health issues.

Unless we address these issues with real funding and a change of culture, they will continue to ripple through our community, damaging people and their families and supporters. Ultimately, failing to ensure people's right to a decent quality of life is upheld.

Introduction

"Families are at the end of their tether with this broken system." – Aunt & carer, 64 years of age

Tandem, the peak body for mental health carers in Victoria, welcomes the decision by the Premier Daniel Andrews and Minister Martin Foley to call a Royal Commission into the broken system that is also out of date in terms of international innovative best practice in mental health care. This is a once in a lifetime opportunity for reform to ensure Victorians get the services they need, when they need them. We need a new, fit for purpose system, based on compassion and contemporary thinking.

This submission to the Royal Commission into Victoria's mental health system is predominantly informed by extensive consultation with Tandem members throughout the state who are either family[1] or friends (mental health carers[2]) with experience of supporting someone living with a mental health issue, or who currently is, or has been engaged with, the Victorian mental health system in the past.

It includes those supporting people at risk of suicide, or who have tragically lost family or friends, to suicide. For every death by suicide, it is estimated that as many as 30 people attempt to end their lives. In Victoria, this means 65,000 suicide attempts every year[3]. After a suicide attempt, its family and friends who have the most contact with the person. If they are properly informed and resourced, they can play a major role in suicide prevention. Provision of information, education and support to families and carers post discharge has the potential to be a major suicide prevention strategy.[4]

"Despite regular, severe self-harm episodes spanning several years my brother was repeatedly discharged to either me, his sister, a 23-year-old mother with young children, or to his wife who was at home with their 6-week-old baby. It's idiotic. There was no support for families to deal with this and our children were exposed to many violent episodes. We were told there was 'nowhere to send him' so they sent him home and he took his own life."
– Sister, carer & consumer, 45 years of age

"My life has literally been in a state of depression so much, that at times it would be easier to simply not be on earth. This is not an option, but sounds easier than constantly dealing with my lot."
– Mother & carer, 53 years of age

Tandem has also contributed and supports a number of other organisational submissions including those by:

- Mental Health Victoria
- Victorian Council of Social Services
- Council for Homeless Persons.

Tandem also acknowledges the assistance of Dr Melissa Petrakis[5].

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[1] See Glossary

[2] ibid

[3] Lifeline, 2015

[4] Victorian suicide prevention framework 2016–25

[5] Petrakis, 2019, A Systematic Literature Review: Family and Carer Interventions

Culture of the mental health system in Victoria

Tandem believes that in order to fix our broken system we must acknowledge that we currently have a service delivery culture which is doing harm. It is, at best, transactional rather than compassionate.[6]

We suggest, that for mental health services to be fixed, they need to become safe havens of therapeutic healing, inclusive and fair. For that to occur, we must insist on a substantial increase in funding, alongside fundamental cultural change, and compassionate leadership. Without both, our system will continue to do harm.

Compassionate leadership means creating the conditions – through consistently listening, understanding, empathising, and helping – to make it possible to have tough performance management and tough conversations when needed. Compassionate leadership ensures a collective focus and a greater likelihood of collective responsibility for ensuring high-quality care:

> *"Compassionate leadership requires courage. The courage to listen to tough messages from those we serve and lead. The courage to explore their understanding of the challenges they face and to have our own interpretations challenged and rejected. And the courage to accept that practicing compassionate leadership will first and foremost address the most apparently intractable workplace challenges such as excessive workload, staff shortages and ever-increasing demand. Putting such leadership into action demonstrates not the myths, but the magic of compassionate leadership"[7]*

Our mental health workforce, including the consumer and family carer workforce[8] is arguably amongst the most motivated and skilled in Victoria. However, we impose on them a dominant command and control style that has the effect of silencing their voices, suppressing their ideas for new and better ways of delivering care and suffocating their intrinsic motivation and fundamental altruism. Released, their motivation and creativity can ensure commitment to purpose and performance. Their voices are needed alongside consumers and their family and friends, to tell us how care can best be improved.

As commissioners you have witnessed many testimonies around the state. You will have heard stories of a Catch 22, when the only option available to people exacerbates the issues it is seeking to address. Families experience chaos as they try to find the right door, in fact any door, which will lead to support. They then report challenges in dealing with police, ambulance and other service providers who are clearly under resourced, and struggling to deal with the impact of our broken mental health system. People spend hours waiting in overcrowded and stressful emergency departments, only to be discharged, sometimes without the knowledge of their family, on powerful medication. Often, the process repeats over and over, with the person's condition continuing to deteriorate.

It is the view of Tandem that this is a service based culture, which is punitive, chaotic and most importantly, one which exacerbates the acute issues people are facing. It isn't compassionate. It's often brutal This is in part caused by underfunding and under-resourcing, but also a culture of transaction and process over people's experience.

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[6] See Glossary

[7] Don Berwick, Prerana Issar, Sam Allen, Sussex Partnership Trust, King's Fund webinar, May 2019.

8 See Glossary

But it's not working for our members or consumers. It places huge stresses, and mental health impacts, on police, ambulance, those who work in the Emergency Departments and the mental health clinicians. It ostracises families and friends, and causes tremendous further pain and anxiety for the consumer.

People with mental health issues need care, they need people to take the time to understand their condition, and otherwise they're unable to heal.

Family and friends are in despair. They recount examples of staff who did their best and were compassionate, but that sadly, these experiences are the exception.

Families and friends almost universally report being denied basic information, which would aid them to care, build stronger relationships, or just understand what's going on. On the ground, this means people being discharged from hospitals in the middle of the night, sometimes hundreds of kilometres away from their only family support or any shelter, without even a phone call to that family.

Tandem believes that Victoria deserves a world class mental health system. One in which we can expect the same compassionate therapeutic care that wraps around its clients and their families when services are treating cancer. Services in which mental health issues are identified early, treatment options are carefully explored and support is offered to the whole family. A world in which public awareness campaigns around the spectre of mental illness and its prevention are rolled out, and a broad suite of bio-psychosocial supports and therapies contribute to the highest quality of care.

Extensive worldwide evidence exists that indicates that shared understandings of recovery, developed in a social context in partnership with consumers, carers, and clinicians, improve results. Investigating new ways of working to increase staff contact time with service users and carers to improve a focus on relational recovery[9] is key to a compassionate Safe Inclusive, Fair and Funded mental health system going forward.

Our system must be transformed from the crisis driven one that we currently have to one with:

● Compassion at its core and compassionate leadership at the helm
● No wrong door to accessing care
● A system that recognises that family and friends are a critical part of the recovery journey and consequently are entitled to respect, kindness, information and support

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[9] See Glossary

SAFE

Tandem members have told us that to be SAFE services must provide:

Compassionate care for all: change the current punitive, crisis based system to one which has sufficient, dedicated, accessible and therapeutic services to provide care for all. This includes:

- Limiting the use of police, and emergency departments to fill the gaps, using seclusion and restraint as a last resort, and eradicating sexual assault within facilities of care.

- Ensuring that there is a full complement of consistent, caring professionals always available, including where possible, those with a lived experience, who are able to provide care for those experiencing mental health distress and their families, friends and carers. Ensure these workers understand the history of the consumer, and are encouraged to consult the family regarding this history.

- Actively reshaping of the culture of mental health services, to ensure that staff have compassionate leadership and have the resources, training and support to care for people with mental health issues appropriately.

- Providing women only wards, and wards which ensure cultural safety to people from culturally diverse and Aboriginal communities

- Ensuring there are adequate beds available and remove wait lists for accessing services. Remove the incentives hospitals have to discharge early, without consulting families and carers. Create environments which are conducive to healing, not sites of further distress and anxiety.

- Supporting staff and carers. Ensuring that there's sufficient care and support for staff and carers including children and young people to cope with difficult environments.

- Tailoring treatment plans responding to individual bio-psycho-socio-cultural factors (Aboriginal, Multicultural, LGBTIQ+, faith, disability, Drug and Alcohol, rural and regional)

- Providing whole-of-person treatment - Physical, social and emotional issues addressed together.

INCLUSIVE

Family and friends frequently report exclusion from care planning, information relating to discharge and report a lack of compassion in the system and feeling like adversaries rather than partners in recovery.

Tandem recognises that some services and staff in the mental health system already seek to deliver compassionate family inclusive practice. These services must be universal, and the practices that they have pioneered need to be showcased, incentivised and supported. Moving from a crisis driven, and transactional system, to a compassionate culture, with appropriate multidisciplinary staffing levels, and addressing resource shortfalls is essential if we are to facilitate holistic and inclusive practice.

The literature notes that it is important to adopt a framework for family-focused care in services. It must be inclusive of children, and it must recognise the diverse roles consumers hold outside a sick role, including parenthood. Recognising that mental illness, and indeed health and wellbeing, occur within families. Even a single-session intervention can make a very impactful contribution[8]

Families are a hub of caregiving in mental health. The majority of this care is provided by women, with a large proportion of these being single mothers. Given the life span of mental illness, children also play an important role. There are also issues across the lifespan if we fail to engage and support children of families affected by a parental mental illness[10]

The intensity, stressful and all-consuming nature of mental health caring should not be overlooked and importantly not minimised by excluding families and friends who are providing care for someone with a mental health issue. Research indicates they are coping with intense and chronic, isolation, grief, loss, guilt, devastation, fear, worries, and sense of responsibility. As a result, it is important that they are not only included, but that their challenges are also addressed[11]

> *"Time and time again, I have been sucked in by services to be involved. Then they spit me out when I demand too much for my daughter, complain too much or when they think they've got it under control. But all of a sudden when it is too hard for them, they throw her back to me without support."*
> – Mother & carer, 67 years of age

> *"There is a need for more family inclusive services that include carers in the treatment process. I was never included in my brother's treatment, yet I was expected to pick up the pieces when they discharged him to me."*
> – Sister & carer, 35 years of age

> *"Families need to be valued and supported. There used to be funding for carer support workers, for education, for trips away where you could learn as well as meet other people with shared experiences of caring. We need these programs back so families can get information and feel respected."*
> – Mother & carer, 40 years of age

In an acute inpatient setting, families particularly need – yet do not routinely receive – evidence-based therapeutic conversation interventions[10] their inclusion is critical though at this time, phase of illness and stage of care and diagnosis, and contact with services[11]

Effective models exist and must be rolled out across the state. An inclusive model which has been designed to respond to acute crisis by holding meetings involving the person in distress their family, other natural supports and multidisciplinary team members is Open Dialogue. This model has been partially trialled at Alfred Health – Headspace. This model, has the client at the centre and therapeutic relationships are developed where the client feels safe, understood, valued and respected. Family and friends are engaged, involved and supported and viewed as sustainable networks[12]

Family continue to tell us that they feel locked out of the system and marginalised in decision making processes that directly and indirectly affect them. Involving family in all aspects of service planning has multiple benefits, including reducing stress and anxiety and improving the skills and knowledge of carers in providing support to the mental health consumer in their everyday life outside the clinical/therapeutic setting. Where 'family' members are LGBTIQ we have heard accounts of additional difficulties in being provided with information and support which can lead to trauma and PTSD for both the consumer and the person supporting them. This has also been reported by those who have English as a second language.

Further to this our consultations have uncovered that many in the workforce feel ill-equipped, overstretched and not supported to deliver compassionate care and services that include family and friends in a meaningful and helpful way. This then leads to negative outcomes for all concerned. This must change.

Carers continually report issues regarding the privacy provisions of the Mental Health Act, and we urge the Commission to review this legislation, and its implementation in the culture of mental health services. Families consistently report being told that they do not have any rights to basic information around the patient. They report this as incredibly disempowering, and preventing recovery, and often making difficult situations worse. This extends to all aspects of care, whether it is mental health tribunals, admission and discharging in hospitals, challenges with the legal sector and the medication provided. The Mental Health Act currently holds an exemption that families can [italics - emphasis] be communicated with, but all too often, they are not.

Tandem members have told us that to be INCLUSIVE services:

Must include family and friends in recovery. Family and friends need to be recognised as a critical part of recovery teams. This can be achieved by:

- Consulting on, informing and discussing important decisions, including changes in treatment and medication, admission and discharge into hospital, long term treatment and management plans and mental health tribunal hearings
- Addressing the culture of exclusion within some mental health services for friends and family carers.
- Acknowledging family and friend carers as a critical part of the treatment team.
- Providing contemporary therapeutic and support options in all services
- Providing consistent services across the state regardless of postcode, socioeconomic status, culture or gender
- Providing outreach services, and consult with family and friend carers, as standard practice on discharge.
- Providing more services in the community for people with mental health issues, friends and family carers.
- Not punishing people for having mental health issues

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[10] Sveinbjarnardottir, Eydis Kristin, Svavarsdottir, Erla Kolbrun & Wright, Lorraine M. (2013). What are the benefits of a short therapeutic conversation intervention with acute psychiatric patients and their families? A controlled before and after study. *International Journal of Nursing Studies, 50*, 593-602. doi:10.1016/j.ijnurstu.2012.10.009

[11] Taylor, Rumina, Mellotte, Harriet, Griffiths, Maria, Compton, Agnes & Valsraj, Koravangattu. (2016). Carers matter: Promoting the inclusion of families within acute inpatient settings. *Journal of Psychiatric Intensive Care, 12*, 69-77. doi:10.20299/jpi.2016.014

[12] Swann, World Social Work Day 2018

FAIR

Everyone has the right to access services. The provision of mental health services must be fair. They need to be accessible by everyone, regardless of their location, gender, sexuality, cultural background, drug and alcohol issues, and economic status, fairly.

"We live in a rural area, with no services. My son keeps pleading with me to get him help. He tells me that he doesn't want to die, saying "you don't know how hard I am trying to not do something, I'm really fighting it". I have nowhere else to turn, I am trying everything but there is no help available. It's just not right we can't get help."
– Mother & carer, 46 years of age

Tandem members have told us that to be FAIR services must:

- Be accessible to all Victorians regardless of age, socio-economic status or postcode
- Tailor recovery plans respecting psycho-sociocultural factors, the wishes the consumer and their family and friends.
- Treat the whole person – physical and emotional
- Provide supportive environments, not punitive ones.
- Provide appropriate levels of funding and resources to meet demand for mental health system support
- Ensure General Practitioners have adequate mental health and family inclusive practice training
- Ensure there are high quality, integrated and accessible services in regional and rural areas
- Guarantee culturally safe services for Aboriginal and Torres Strait Islander people and those from other marginalised groups
- Expand the Family carer workforce across the state, and across programs including dedicated positions to address particular cohorts in response to local population data such as Aboriginal, Multicultural, LGBTIQ
- Address cultural disadvantage by incentivizing and mandating use of interpreters, supporting bi cultural staff and expanding the Family Carer workforce

FUNDED

"More funding is needed to allow workers to do their jobs properly and make sure the services are there and are accessible. If consumers had better access to these supports, the family wouldn't experience so much stress and hardship"
– Aunt & carer, 63 years of age

"Carers themselves bear immense and cumulative stress that must affect their own mental and physical health. The cost of this to our health system must be enormous. It makes good economic sense to support carers more and give them more support and education and help and recognize their central role in mental health care."
– Mother & carer, 56 years of age

"As a result of the overloaded and under resourced workforce, clinicians often give up and discharge consumers from their service before even giving them the chance to build rapport. Unfortunately, this means that the only way to get any proper access to and support from services is through a treatment order, because if there is an order in place they have to help."
– Mother & carer, 83 years of age

The most glaring problem with the mental health system is the lack of funding. To fix the broken system, we need to:

- Urgently address the shortfall in inpatient mental health beds. Victoria currently has less than half of the international standard for adequate care.
- Reduce wait times in hospitals. Redesign and resource Emergency Departments to provide respectful, culturally appropriate and compassionate responses to people in mental health crisis and their family and friends.
- End inappropriately early discharges from hospitals by an Investment in facilities that are comparable to Victoria's best practice general health facilities. Ensure that services are resourced to provide high-care discharge processes that include family and carers where appropriate. End the discharge to homelessness and housing insecurity.
- Mandate investment in workforce, in staff training and staff support so that consumers, families and carers receive therapeutic and compassionate care.
- Mandate investment in a range of contemporary family inclusive therapeutic models including Single session family therapy and open dialogue across Victoria
- Mandate Investment in a range of Psychological therapies such as cognitive approaches to relapse prevention with families
- Mandate Investment in Family psycho-education non-judgmental information provision & support Investment in Family support groups - peer support with some agency co-facilitation assistance
- Mandate Investment in Peer support group peer-led and peer-delivered intentional support groups Investment in stage of life appropriate supports for consumers and family tailored to: child, adolescent, young adult, adult, aged
- Mandate Investment in a range of Cultural, spiritual or religious groups supporting and exploring shared understanding of mental illness and health

- Mandate investment in Community Care Units. Appropriate supported facilities for high needs patients/consumers, and those who need long term care.
- Invest in Housing: Provide secure shelter for people who require on-going psychiatric support and rehabilitation. The current 'supported accommodation' options are grossly inadequate
- Expand investment in the PARC (Prevention and Recovery Care Centres) these centres need to have a culture of compassion and focus on increasing access, family inclusion and therapeutic step up and step-down options available. Women only, youth PARCS and culture specific PARCs need further support and investment.
- Secure Investment in a consistent state-wide model of Hospital Outreach Post-suicidal Engagement (HOPE) initiative which assists consumers and their family and friends
- Secure Investment in PACER, CATT and outreach teams 24 hours a day 7 days a week across Victoria
- Mandate Investment in the support and complementary and ancillary services that are needed for compassionate, whole person approach.
- Mandate a significant investment in Family Carer workers across Victoria as part of holistic multidisciplinary teams. Currently, the Family Carer workforce is grossly over extended and under resourced to meet demand
- Support Investment in evidence based family interventions for example Multiple family group
- Support Investment in Individualised psychoeducation and support
- Support investment in services that support family with the maintenance of their own emotional and physical wellbeing. These include respite, peer support, psychosocial education, assessment, planning and direct service to assist carers in identifying their own support needs, particularly mutual support and self-help services.

"We also need accessible supports for siblings, as care and attention often goes to the unwell child. Siblings need support too."
– Mother & carer, 47 years of age

"My experience is one of intergenerational trauma, constantly battling with the mental health system to get myself and my family member's access to meaningful mental health support."
– Sister & carer, 65 years of age

"The impact of trying to get my daughter help all these years has been immense and I have gone through so much trauma. She has worn me down, even my personality, my attitude. I just don't feel like myself anymore."
– Mother & carer, 74 years of age

"My experience has been one of frustration at trying to navigate Victoria's overburdened and 'broken' mental health system."
– Mother & carer, 43 years of age

"The carer, is usually the middle person between all the intersecting services. As a carer you end up case managing your own family member to the best of your abilities and it becomes you (unpaid) job to follow up appointments, take medications and make sure services are coordinating their treatment approach... Families need education and support"
– Aunt & carer, 40 years of age

Conclusion

"I love my daughter and I want the best for her. Before the mental illness then drugs took over, we had a good relationship. I miss that person. I have lost someone important in my life, because the supports weren't there when we asked again and again for help."
– Mother & carer, 68 years of age

We encourage and support you, the commissioners, to make recommendations ensuring the mental health and wellbeing needs of Victorian consumers and their family and friends are heard. We ask you to have the courage to be bold and embrace this opportunity.

Unless a solid and contemporary investment is made in the mental health service system based on cultural transformation and a shift from crisis driven brief encounters to compassionate, and therapeutic engagement with consumers and their family and friends, we will continue to see the carnage of human suffering which is a feature of our current mental health system. We are better than that.

A safe, inclusive, fair and appropriately funded contemporary world leading mental health system for Victoria is possible.

"Having to monitor his medication compliance created significant conflict in our relationship. Once my son was back in clinical care, it was such a relief. I did not have to continue the role of medication monitoring and I was able to be a mother again."
– Mother & carer, 72 years of age

References

1. Department of Health & Human Services, (2019), Mental health lived experience engagement framework.

2. *A Practical Guide for Working with Carers of People with a Mental Illness*, p.6.

3. Lifeline, 2015.

4. Victorian suicide prevention framework 2016–25.

5. Petrakis, 2019, A Systematic Literature Review: Family and Carer Interventions

6. *Strauss, Lever Taylor, Gu, Kuyken, Baer, Jones, and Cavanagh (2016).*

7. Don Berwick, Prerana Issar, Sam Allen, Sussex Partnership Trust, King's Fund webinar, May 2019.

8. *Strategy for the Family Carer Mental Health Workforce in Victoria CMHL (2019), p.3.*

9. *Price-Robertson, Obradovic, & Morgan. (2016). Relational recovery: Beyond individualism in the recovery approach. Advances in Mental Health. 15.*

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12. Swann, World Social Work Day 2018.