



Your trusted voice in mental health

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Submission to the Tasmanian Government's *Our Healthcare Future – Immediate Actions and Consultation Paper*.

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**About Mental Health Families and Friends Tasmania**

Mental Health Families and Friends Tasmania (MHFFTas) is the peak body in Tasmania representing family members and friends of someone with mental ill health (including those with an alcohol and other drug (AOD) use comorbidity).

We work with our community to:

- Promote and improve the wellbeing of family members and friends of people affected by mental ill health through support and education.
- Provide systemic advocacy from a family and friend perspective drawing on lived experience to improve mental health services.

We aim to improve quality of life for the one in five family members, friends, unpaid carers and people living with mental ill health across Tasmania.

**About Families and Friends**

Mental health families and friends are people who provide unpaid physical, practical or emotional support to a family member, friend, neighbour or colleague with mental ill health and/or AOD issues.

We understand that family members and friends are fundamental to the recovery journey of people with mental ill health. Family members and friends are the key educators, advocates, and natural supports for people with mental ill health. They also know the person, and most likely knew them before they became unwell. They hold a unique source of information about the person's life beyond their diagnosis of mental illness, including information about their interests, skills, beliefs and ambitions.

## Introduction

On behalf of mental health families and friends in Tasmania, MHFFTas welcomes the opportunity to provide a submission in response to the Tasmanian Government's *Our Healthcare Future – Immediate Actions and Consultation Paper* (the Paper). We note that our responses are informed by the lived experience of mental health family members and friends. The following submission will address each of the reform initiatives listed below, as they apply to the mental health family member and friend context in Tasmania.

- *Initiative 1:* Increase and better target our investment to the right care, place and time to maximise the benefits to patients.
- *Initiative 2:* Invest in modern ICT infrastructure to digitally transform our hospitals, improve patient information outcomes and better manage our workforce.
- *Initiative 3a:* Develop a long-term health infrastructure strategy for Tasmania.
- *Initiative 3b:* Build a strong health professional workforce, aligned to a highly integrated health service, to meet the needs of Tasmanians.
- *Initiative 3c:* Strengthen the clinical and consumer voice in health service planning.

Throughout our response, MHFFTas will emphasise the importance of extending the notion of right care, place and time to include the natural support networks of individuals engaging in the Tasmanian Healthcare System. If the Tasmanian Government is to provide the best experience for Tasmanian patients, and maximise the overall amount of care provided so it is accessible when and where people need it, family members and friends must be included, supported and considered as equal care partners in a patient's healthcare journey.

### **Reform Initiative 1 - Increase and better target our investment to the right care, place and time to maximise the benefits to patients.**

#### *Right care, place and time*

As a patient's natural support network, family members, friends and unpaid carers are key stakeholders in any healthcare system.

Of strong concern to MHFFTas and our community is the limited consideration given to the vital role of family members and friends within the Tasmanian Healthcare System. At a National level, and within the field of mental health alone, there are an estimated 240,000 mental health family members and friends supporting someone with mental ill health<sup>1</sup>. Since 2017 (when this figure was first provided), and given the recent impacts of CO - VID 19, MHFFTas believe these numbers to have risen significantly. At the time of analysis, it was estimated to cost \$13.2 billion to replace the informal mental health care provided by mental health family members and friends with formal support services<sup>2</sup>. Again, this was within the field of mental health alone. It is with such figures in mind that MHFFTas advocates strongly for the need to consider family members and

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<sup>1</sup> Sandra Diminic, Emily Hielscher, Yong Yi Lee, Meredith Harris, Jaclyn Schess, Jan Kealton, Harvey Whiteford (2017), *The economic value of informal mental health caring in Australia: summary report*, Commissioned by Mind Australia, p. 4, [https://www.mindaustralia.org.au/sites/default/files/publications/The\\_economic\\_value\\_of\\_informal\\_mental\\_health\\_caring\\_in\\_Australia\\_summary\\_report.pdf](https://www.mindaustralia.org.au/sites/default/files/publications/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf)

<sup>2</sup> Diminic *et al*, p. 12.

friends as playing a fundamental role in achieving positive health outcomes in Tasmania, across the full spectrum of care (including preventative health and wellbeing).

The Paper states that ‘we must continue to pursue quality, personalised care that seamlessly links the community and the hospitals, and only uses hospital care when it is required, allowing us to better allocate health resources to improve flow, patient outcomes and patient and staff experiences’<sup>3</sup>.

MHFFtas is in support of person-centred, integrated care. However, the above does not recognise or consider the needs of a patient’s natural support networks, that is, a patient’s family members and friends. This omission is noted throughout the Paper. This is concerning to our community, given that families, friends and unpaid carers are undoubtedly part of the team offering the right care, in the right place, at the right time. Family members and friends are key agents in ensuring that community care is accessible when and where people need it. As an immediate preventative health measure, MHFFtas suggests strong investment in the wellbeing of a patient’s support people. To us, this looks like programs that educate, support and acknowledge family members and friends and their substantial contribution to a patient’s care.

The transition to community-based care proposed by the Department is a positive step. However, if there is an expectation that care will increasingly be provided within a community setting, MHFFtas seeks to highlight the additional impact, if unsupported, this will likely have on family members and friends who already provide hours (often 24/7) of care and support within the home and community. Unsupported family members and friends often experience stress, burn out and fatigue. Family and friend stress and fatigue impacts on a support person’s ability to continue to effectively advocate and support the person they are caring for, as well as negatively affecting their own wellbeing; ultimately placing further pressure on a healthcare system. As families and friends tell us:

*“The practical, physical, economic and emotional demands of supporting a loved one can be enormous. The caring role can have a significantly negative effect on the health and wellbeing of families and friends who provide considerable unpaid support to people with mental health issues, saving the community a great deal of money while receiving very little support themselves.”*

MHFFtas advocates for the repositioning of any model of community care to fully recognise the collective effort of family members and friends, practitioners and a patient in healthcare access and provision and in recovery and rehabilitation.

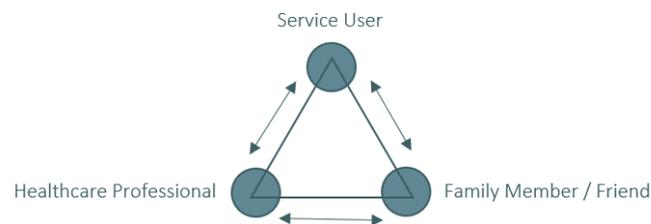
Mental health families and friends are concerned that they are being called upon to offer more support, within the home and within the community while simultaneously experiencing alienation from the system placing increasing pressure on them to do more. It is vital that a shift to a community focused model of healthcare delivery is inclusive of the needs of family members and friends.

In shifting focus to a holistic model of patient, support person and practitioner support, MHFFtas advocates for the adoption of the Triangle of Care model of care provision within the Tasmanian

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<sup>3</sup> Department of Health, Tasmania (2020) *Our Healthcare Future: Immediate Actions and Consultation Paper*, p. 26, [https://www.health.tas.gov.au/\\_\\_data/assets/pdf\\_file/0010/416845/Our\\_Healthcare\\_Future\\_IACP\\_vf\\_21\\_Dec20.pdf](https://www.health.tas.gov.au/__data/assets/pdf_file/0010/416845/Our_Healthcare_Future_IACP_vf_21_Dec20.pdf)

Healthcare System. The Triangle of Care model reminds policy makers to consider the needs of every participant in a patient's healthcare provision and ensures that the unpaid support role is viewed as an essential component of a person's care and recovery journey.



Triangle of Care Model (used with permission from Carers Trust)

With this model in mind, mental health family members and friends share that they are supportive of initiatives such as Hospital in the Home (HiTH), which has been provided as a positive example of effective community-based family member and friend involvement. They tell us:

*'...I am in support of this model as it is inclusive of families and friends... [however] it would be greatly improved if more places were available, and if patients could access the model for longer than a relatively brief intervention'.*

MHFFTas is especially supportive of the use of carer peer workers with lived experience within HiTH programs. We are hopeful that these initiatives will be appropriately resourced into the future.

#### *Use of Telehealth*

The Paper considers barriers to engagement with digital service provision and asks how we can make better use of telehealth so people can receive the care they need, closer to home.

MHFFTAS supports the minimisation of barriers to telehealth services for patients, and the family members and friends supporting them, who wish to receive services digitally. Our community has mixed views on the use of telehealth. Some highlight the benefits of telehealth, especially within the mental health setting where face to face services are not possible, or are difficult. For some, telehealth provides a gentler introduction to obtaining assistance and can be favoured when the patient finds attendance extremely difficult, if not impossible. Telehealth can reduce stress on family members and friends who might experience distress and difficulty getting the person they support to an appointment. Digital service provision also minimises the time involved for a support person where they are responsible for transporting a loved one to an appointment. Others note that, while telehealth has its place, there are cases of mental ill health where digital consultation may lead to many vital cues being missed due to the practitioner not being in the same room as the consumer.

Given the varying views of our community alone, MHFFTas supports the continued consultation of people with lived experience in considering digital engagement and service provision.

### *Access to Primary Care*

The Paper speaks to creating clear pathways into the healthcare system for patients by increasing access to primary healthcare in Tasmania. On this point, MHFFTas views the increasing unaffordability of primary healthcare, with specific reference to the cost of seeing a general practitioner (GP) in Tasmania, as a significant barrier to primary healthcare access. We understand that a decreasing number of GPs bulk bill in Tasmania. Further, GPs are often not available at the time they are needed. As mental health family members and friends continually tell us, this can, and has, resulted in an over-reliance on emergency departments and acute services. While the Paper notes that primary healthcare services delivered by GPs are a Federal responsibility, MHFFTas understands that Tasmanians expect to see strong political advocacy by their State Government at the Federal level on this issue.

### *Language and Preventative Health*

MHFFTas welcomes the inclusion of a Mental Health and Wellbeing Portfolio within the State Cabinet. We are hopeful that this language, with specific reference to the implied importance of wellbeing, will come to inform healthcare reform in Tasmania.

While the Paper asks how health literacy, self-management and preventative health approaches might be incorporated into the Tasmanian Healthcare System, there is little focus on wellbeing as a preventative healthcare measure. The Paper speaks, for the most part, to the physical health of the consumer. Further, the Paper does not often speak to preventative health and wellbeing investment. MHFFTas believes that the notion of right care, place and time and the accompanying mode of care developed must be inclusive of prevention and wellbeing. To this end, we highlight the *Rethink 2020* Tasmanian Mental Health Continuum of Care Model as a best practice example and possible model for adoption across the Tasmanian Healthcare System.

In response to questions about health literacy, MHFFTas supports whole of population approaches to health literacy (for example providing first aid and mental health first aid training). We believe it essential that health literacy initiatives are codesigned by governments, not-for profit representatives, consumers and support people in a way that ensures programs can be received by the many different communities in Tasmania. As a key preventative healthcare measure, MHFFTas would like to see any initiatives extended to the natural support networks of healthcare consumers. As increasing patient complexity is felt across the healthcare system, it is also felt by families and friends who often manage the day to day care of a patient outside of the acute setting. Family members and friends need to be supported with appropriate training to manage these complexities within the home. MHFFTas welcomes the opportunity to work with the State Government in formulating and implementing such an initiative.

**Reform Initiative 2 - Invest in modern ICT infrastructure to digitally transform our hospitals, improve patient information outcomes and better manage our workforce.**

*Personal Information and Service Experience*

Mental health family members and friends tell us that they have concerns about the security of personal information when shared digitally. With this feedback in mind, we note the importance of ensuring that consumers and their supporters are appropriately involved in the digital reform process and receive the education needed to effectively navigate and have trust in the systems developed. Mental health family members and friends have suggested that a series of 'what to expect and who to talk to' documents (available in several accessible formats) would help to improve their experience as a support person interacting with public hospital and health services in Tasmania.

*Self-care and Technology*

MHFFtas suggests that the most effective way to empower patients with their own self-care (via technology or otherwise) is through appropriate access to training, preventative health education and peer support. Further, we note the importance of extending access to self-care initiatives to the natural support networks of a consumer (that is, their family members and friends). During the COVID 19 period, and within the mental health sector, we have seen the success of such initiatives (for example MHFFtas' Online Safe Space Peer Support Program) and their ability to connect and train people digitally.

**Reform Initiative 3a - Develop a long-term health infrastructure strategy for Tasmania.**

The Paper proposes reform to implement accessible and closely integrated service delivery available across the full spectrum of care.

*Integration*

MHFFtas supports a move away from siloed service delivery. We are strong proponents for the concept of community-driven healthcare hubs and 'pop up' or mobile hubs, especially those established in targeted suburbs and servicing regional locations. MHFFtas also notes that some of the most effective examples of hub-based service delivery involve close collaboration with the Not-For-Profit Sector. Not-for-profits are well connected to the communities they support and help to maintain the currency and impact of an initiative. The Tasmanian Government's *Rethink 2020* State Plan for Mental Health in Tasmania provides a recent example of the collaborative and considered hub-based service delivery models that we support.

MHFFtas sees integrated service delivery as a whole of Government issue. We expect an integrated approach to health infrastructure planning to extend across Government portfolios. Within a small population such as Tasmania, health policy cannot be siloed from transport, housing and education initiatives as all have significant implications for the successful outcomes of another. For example, there is little purpose to creating a new set of health initiatives if consumers cannot access them due to lack of transport or the impacts of housing crisis.

As mentioned above, in designing an integrated approach to service delivery, MHFFTas advocates for the adoption of a continuum of care model that is inclusive of prevention and wellbeing (see for example, the Tasmanian Mental Health Continuum of Care Model). We view preventative health as a critical component of any long-term health strategy.

### *Accessibility*

Mental health family members and friends raise accessibility as a key barrier to engaging with healthcare services. Our stakeholders note that many primary and subacute services are not delivered 'out of hours' and are not available on weekends. Further, services can be difficult to physically access when consumers and their supporters are located regionally. MHFFTas understands that this experience is not unique to mental health service provision. When developing modern healthcare facilities in community settings, we hope to see the Tasmanian Government prioritising service accessibility.

In considering how to make services accessible (at the right place and time) adequate community consultation is essential. For example, by allowing sufficient time for stakeholders to respond to calls for consultation, spending times in communities to see where, when and how people gather and involving consultation processes at all stage of the planning and policy cycle. On this last point, MHFFTas again highlights the success of the Tasmanian Government's Mental Health Reform Program and the strong consultation work that has been completed at every point in the project cycle with consumers, family members and friends and the not-for-profit sector supporting them. It is hoped that a similar model is adopted for the Tasmanian Government's health infrastructure strategy.

MHFFTas agrees that effective stakeholder engagement is central to planning the future of healthcare in Tasmania. We look forward to working closely with the Tasmanian Government, Local Government, Not-for-profit Sector, and lived experience representatives (both consumers and their supporters) in setting and enacting Tasmania's long-term health infrastructure priorities.

### **Reform Initiative 3b - Build a strong health professional workforce, aligned to a highly integrated health service, to meet the needs of Tasmanians.**

MHFFTas agrees it is critical that the delivery of healthcare is fully integrated across different care settings. A key component of integration will be ensuring that each provider involved is aware of the community level services available to their patients and the people who support them. Any training initiative requires significant investment in educating the health professional workforce on the services that are currently provided by State and Local Government and the Not-For-Profit Sector.

If it is the Tasmanian Government's intention to build a strong health professional workforce to meet the needs of Tasmanians, the needs of all Tasmanians must be considered. At present, family members and friends feel alienated from the health services accessed by the person they support.

MHFFTas acknowledges work that has commenced in the mental health sector to improve lived experience representation and to consider the needs of a patient's natural support network in healthcare service delivery. However, in practice, mental health families and friends continue to tell us that the Tasmanian Health Service is not inclusive or considerate of their needs.

A workforce that is aligned to meeting the future health needs of Tasmanians must be trained in considering both the patient and informal support network perspective.

*“There is still a need to address how to focus more on patients and families and friends as experts in their unique journey, by education and awareness raising of a tendency towards unwittingly excluding them in preference to a traditional medical top-down model throughout the system. I believe that the health system culture may not be aware of this issue, although it’s by no means universal among all practitioners. Even so it may be a systemic issue.”*

Healthcare teams need to be appropriately supported, resourced and trained to engage meaningfully with their local communities. MHFFTas supports the adoption of peer workers within care teams, specifically carer peer workers with lived experience. An increased allocation of peer workers alongside initiatives which invest in educating staff members in family and friend inclusive practices would provide a good starting point for ensuring the needs of a patient’s informal support networks are met. We see this as a pre-emptive cost reduction and key preventative health measure for Tasmania’s family members and friends providing unpaid support to healthcare consumers. MHFFTas welcomes the opportunity to collaborate with the Department in the provision of such training.

MHFFTas would also note that mental health family members and friends speak to the dedication of staff within the Tasmanian Healthcare System:

*“Even though I’ve had painful experiences where I’ve believed that a family member was marginalised due to assumptions being made around [their] mental state, I am in awe of the skills, knowledge, experience, dedication and kindness of the many individuals who work in the system that I have met.”*

Others have noted staff shortages and a lack of resourcing for appropriate levels of follow up following acute and sub-acute care stating that care experiences involved *“insufficient staff, places available, or follow up when discharged”*.

When considering the health workforce in Tasmania, MHFFTas proposes that a patient’s natural support networks be viewed as an extension of the workforce, and entitled to targeted investment in training and education within this reform initiative. There are times when a family member or friend will provide healthcare consumers with support twenty-four hours a day, seven days a week. Such support often removes the provider from the workforce and has a significant impact physically, emotionally and financially. We view supporting Tasmania’s unpaid caring workforce as a key health workforce innovation initiative. Tasmanian family members and friends are a significant part of the workforce doing the right job in the right setting within any community-based care provision model.

### **Reform Initiative 3c - Strengthen the clinical and consumer voice in health service planning.**

It is our view that better healthcare and community health outcomes in Tasmania cannot be achieved without dual involvement of both patients and the people who support them in an unpaid capacity.

MHFFtas is pleased to note mention of patients and their carers in the Department's discussion of this reform initiative. However, MHFFtas advocates for a change of language when referring to a patient's natural, unpaid, support networks.

MHFFtas has consulted extensively on this issue with people who support those with mental ill health, service providers and Government. Consultation has highlighted the widely expressed view that the term 'carer' does not adequately reflect the relational aspects between patients and their unpaid supporters. Respondents perceived themselves first as kin or a friend, colleague or neighbour rather than as a 'carer' and supported someone experiencing mental ill health and/or AOD issues because of this relationship. Within the mental health and AOD sectors, MHFFtas understands that families and friends often miss out on much needed support because they do not relate to language used to refer to their position (that is "carer") within support services. We do not believe this experience is unique to our sector.

MHFFtas is in strong support of initiatives to strengthen both the consumer and the family and friend lived experience voice in healthcare planning. In doing so, we hope that the Department will consider what a meaningful outcome might look like in practice for consumers, support people, employees, and the community at large. It follows that whole of community engagement must be appropriately resourced to ensure these outcomes are achieved.

To family members and friends, meaningful engagement looks like involvement in service planning throughout the project and policy cycle – that is, from the outset through to service delivery and evaluation.

*"...changes [must be] underpinned by community consultation, both at a macro level such as requested via responding to the Paper, and also at a micro level throughout the healthcare system. Examples of the latter would include processes that respectfully include patients, families and friends, and 'grass roots' community services. They would also be inclusive of CALD, ATSI and other diverse groups."*

Mental health family members and friends recommend supporting consumers and their support networks in engagement by helping participants become familiar with and understand the issues being raised in their care. Our community welcomes the opportunity to provide qualitative information about their lived experience and have suggested that Departments provide coaching in how to present information to Government (for example, in response to a Consultation Paper) prior to calls for consultation.

Mental health family members and friends also express growing concern that they are not always made aware of the services available to them, and the people they support. Further, some mental health family members and friends do not feel that they are well informed about what to expect from Tasmania's healthcare system, how to navigate service provision, as well as preventative health actions they could take to avoid engagement at the sub-acute and acute system levels. MHFFtas strongly advocates for a series of preventative health campaigns and education that are designed to meet the needs of the socially isolated, those with mental ill health, disabilities and or disadvantage. Again, these campaigns and policy responses require whole of Government attention and cannot be considered in portfolio silos alone.

In response to requests for alternative models of consumer participation and representation, MHFFtas provides the MHFFtas Carer Representative Program (CRP – soon to be renamed Mental Health Families and Friend Representative Program) as a positive example of mental health family and friend representation within the mental health sector.

The CRP facilitates engagement by working with Government to place mental health family members and friends on committees and workshops to inform government decision-making, systems reviews and interview processes. Flourish Tasmania provide a similar model for mental health consumer representation. Such models formalise the participation of consumers and their support people in the Tasmanian Government's Mental Health System and could be replicated to ensure that the voice of lived experience is heard and understood within the Tasmanian Healthcare System at large.

Finally, MHFFtas notes the clinical and consumer voice will be most effectively strengthened by collaboration with all levels of Government (Local, State and Federal) alongside the not-for-profit and private sector. This integration will be essential to the success of the Tasmanian Government's immediate reform initiatives and long-term healthcare strategy.

## **Conclusion**

MHFFtas looks forward to working with the Government to plan and implement meaningful change within the Tasmanian Healthcare System.

We conclude by reiterating that investing in the support, education and recognition of family members and friends as pivotal care providers within the Tasmanian Healthcare System will be essential to improving healthcare outcomes across our public health system.

## **Our Vision**

Families and friends of people affected by mental ill health are understood, respected, valued and supported to build their capacities and improve their quality of life.