



Your trusted voice in mental health

MHFFTas  
ABN: 16 163 816 900  
2 Terry Street Glenorchy  
Tasmania 7010  
Phone: 03 6228 7448  
[admin@mhfamiliesfriendstas.org.au](mailto:admin@mhfamiliesfriendstas.org.au)  
[mhfamiliesfriendstas.org.au](http://mhfamiliesfriendstas.org.au)

Submission to the Tasmanian Government's *Carer Recognition Legislation Consultation Paper*.

**Authorised by:**

Maxine Griffiths, AM

Chief Executive Officer

03 6228 7448 | 0437 010 934 | [CEO@mhfamiliesfriendstas.org.au](mailto:CEO@mhfamiliesfriendstas.org.au)

<https://mhfamiliesfriendstas.org.au> | 2 Terry Street | Glenorchy, Tasmania 7010

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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 and/or drug use through support and education.
- Provide systemic advocacy from a family and friend perspective drawing on lived experience to improve mental health and AOD 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 and/or drug use 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 and/or AOD issues. Family members and friends are the key educators, advocates, and natural supports for people with mental ill health and/or AOD issues. 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 and/or drug use, 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 *Carer Recognition Legislation Consultation Paper* (the Paper). We note that our responses are informed by the lived experience of mental health and AOD family members and friends. The following submission will address each of the questions listed below, as they apply to the mental health and AOD family member and friend context in Tasmania.

- *Question 1:* How can we ensure that Carer Recognition Legislation makes a practical difference to carers and care relationships?
- *Question 2:* Do you think that the definition of carer in Supporting Tasmanian Carers should be used in the Carer Recognition Legislation? If not, what do you think the definition should be?
- *Question 3:* Do you think the Tasmanian Carer Policy 2016 Principles require updating? If yes, what do you think should be included and/or removed?
- *Question 4:* Do you agree with the addition of carers with a lived experience on the Group?
- *Question 5:* How do you think the governance structure could be improved to ensure it is effective?
- *Question 6:* Do you agree with the proposed reporting format, or do you have any suggestions for how it could be improved?
- *Question 7:* How do you think Carer Recognition Legislation can help to ensure that the difficulties experienced by carers are considered in decision making during a crisis such as COVID-19?
- *Question 8:* Do you have any other suggestions to help us develop the Carer Recognition Legislation?

### Question 1:

It is essential that the Carer Recognition Legislation (the Legislation) speaks to the Triangle of Care; including outlining the importance of adopting the Triangle of Care Model and understanding what it means in practice for service and care provision. The Triangle of Care Model reminds us to consider the unique needs of every participant in a consumer's care provision and ensures that the unpaid support role is viewed as an essential component of a consumer's care and recovery journey.

A concern for our cohort, mental health and AOD families and friends, is that while services agree that families and friends are integral, the Triangle of Care Model is not always applied and practiced. A possible reason for this is the conflict between practitioners' understanding of confidentiality law and the adoption of the Triangle of Care. To enhance the Legislation's impact on families and friends, highlighting how confidentiality and Triangle of Care provisions can coexist, would be beneficial. For example, confidentiality law does not prohibit a service provider from:

- gaining information that a family member or friend is willing to share,
- ensuring that families and friends are supported when decisions that will impact the family member or friend are made,
- offering support to families and friends; or
- referring families and friends to external support.

This is particularly important when reflecting on the Tasmanian Carer Policy (2016) principle 1, 3, 4, 5, and 8.

It is also important to MHFFTas to understand the purpose and scope of the Legislation. For example, who is the Legislation holding accountable, and how? MHFFTas is concerned that, without the intention of the Legislation being clear, it may be perceived as being tokenistic (if it is, in effect, only holding the Government accountable to itself without a wider application). To ensure that the Legislation makes a practical difference to all families and friends, we wonder if the Legislation will be applied to the community sector more broadly, and, if so, how it's application will be monitored (for example, through funding contract key performance indicators).

#### **Question 2:**

The concern MHFFTas have around the definition of 'carer' in Supporting Tasmanian Carers, is that families and friends do not recognise or identify with the term 'carer'. This was illustrated though an extensive consultation with our stakeholders, which saw the organisation transition from name Mental Health Carers Tasmania to Mental Health Families and Friends Tasmania. This consultation highlighted two key drivers for change. The first was the need to better capture the unique lived experience of mental health families and friends, as mentioned above. The second came directly from the widely expressed view that the term 'carer' did not adequately reflect the relational aspects between people with mental ill health and their supporters. Respondents perceived themselves 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.

We would suggest that the definition be:

*A family and friend is someone who provides unpaid care and support to family members and friends who live with a disability, mental ill health, chronic or life limiting condition, alcohol or drug use, or who are frail and aged.*

#### **Question 3:**

Again, MHFFTas stresses the importance of language, specifically the language we use to refer to people who provide support. This is true for the entire Tasmanian Carer Policy document. As illustrated above, for our cohort, the term carer does not resonate with families and friends in Tasmania. To ensure that the document remains inclusive, terminology should be considered.

Regarding the current suggestions, MHFFTas would welcome the change of wording to Principle 4. MHFFTas would also welcome its move to Principle 2, as listening to the lived experiences of families and friends, it is the coexistence of the two roles that creates difficulty. For example, one gets forgotten or overlooked for the other.

In response to the suggestion for Principle 10, MHFFTas would welcome the addition of the following:

"It is also a responsibility of Government agencies to seek out appropriate support, and to engage with the carer peak bodies."

#### **Question 4 and 5:**

MHFFTas wholeheartedly supports the addition of families and friends with lived experience supporting someone on the Group. To ensure all voices are heard, we would encourage the involvement of separate representatives who hold lived expertise in supporting someone with

mental ill health, AOD use, a disability, a chronic or life limiting condition, or who are frail and aged. The appointment of separate lived experience representatives acknowledges the unique differences in the experience of someone who supports another who is frail (for example) compared to someone who supports a person experiencing mental ill health and/or drug use.

We encourage this because we know from listening to the lived experiences of our cohort, that the experiences of families and friends who support someone living with mental ill health and or AOD use, differ from those who support someone living with a disability, a chronic or life limiting condition and/or someone who experiences frailty. For example, the episodic and often unpredictable nature of supporting someone living with mental ill health and/or AOD use is significantly different to other conditions where the support is often routine and predictable. We also know that the mental health and AOD families and friend voice can get missed if not appropriately represented.

We would also encourage the inclusion of a paragraph that summarises how people with lived experience would be involved in the Group. The reasoning behind this is to ensure the lived experience representative is remunerated and recognised appropriately for their contribution and time. MHFFtas also suggests the possibility of appointing co-chairs from both government and lived experience backgrounds to the Group. This approach assists in the effective governance of a group and the equitable inclusion of both lived and clinical/government expertise. A co-chair appointment also sets a strong culture and tone that lived expertise will be equally heard and valued alongside government input

#### **Question 6:**

Broadly, MHFFtas agrees with the proposed reporting format. However, we believe that to answer this question effectively, it is important to understand the intention of the Supporting Tasmanian Carers Action Plan. For example, who is the Legislation and Plan holding accountable, to whom, and for what purpose?

We would also encourage clarity and confirmation on what would happen once the Government reported annually to the Group. For example, what would happen if progress or standards had not been met, and how else will the Government keep its stakeholders, families and friends, updated on its progress?

#### **Question 7:**

MHFFtas suggests that the Legislation ensures that lived experience is central to, and involved in, all relevant decision-making processes and reference groups (noting the necessity of a broad representation of families and friends). As mentioned above, mental health and AOD families and friends' needs and experiences differ greatly from families and friends who support someone living with a disability, and those families and friends' needs and experiences differ from families and friends supporting someone living with a chronic or life limiting condition, and so on.

#### **Question 8:**

None.

## Conclusion

MHFFtas welcomes the work that is being done by the Government on the Carer Recognition Legislation.

We conclude by reiterating the importance of family and friend lived experience involvement in all decision-making discussions, now and in the future. We would also like to emphasise that the knowledge, experiences and needs of families and friends differ depending on the “condition” the person they support is living with. Consequently, that diversity needs to be represented when decisions are being made.

MHFFtas looks forward to continuing its work with the Government to plan and implement meaningful change for support people in Tasmania.

## Our Vision

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