Position Paper:
Navigating the road to treatment, support & recovery

Based on the stories of Mental Health Carers in Tasmania

APRIL 2015
We would like to sincerely thank all the Mental Health Carers in Tasmania who took part in the Caring Voices Project in 2014-2015. We’ve heard your stories of love, hope, frustration and despair. Through the Caring Voices Project we will work together to make Tasmania a better place to be a Mental Health Carer.

Statistics are people with the tears washed off
Victor Sidel

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April 2015
Overview of the Caring Voices Project

Mental Health Carers have the right to be recognised, supported and respected in systems that work with them – not against them.

About our research methodology

The Caring Voices Project was established to gain further insight into the impact of key components of the caring role on the lives of Mental Health Carers in Tasmania. We invited Mental Health Carers to share their stories and experiences in relation to four key areas:

- The impact on Mental Health Carers of current government policies
- The needs of Mental Health Carers in relation to the transfer of care of their loved ones
- The impact of living arrangements for people with mental ill health on their Carers
- The impact of caring on the working lives of Mental Health Carers.

Our research involved 119 Mental Health Carers from across Tasmania. They spoke to us in person, via the telephone or in writing (including online questionnaires).

The Caring Voices Project resulted in the development of a series of position papers on the four key issues outlined above. This paper is one of these four position papers. We involved Mental Health Carers in both the development of our research tools and the position papers. All the papers are available from Mental Health Carers Tasmania (www.mentalhealthcarerstas.org.au).

Summary remarks

The Caring Voices Project provided a space for Mental Health Carers to share their stories about their experiences with caring for people with mental ill health. The stories were the result of both long histories of caring for someone with mental ill health, as well as more recent events. Some were positive and heartwarming. Others were distressing and confronting. Some were long and complex. And often they were heart-breaking and very troubling. We thank all the Carers who had the courage to talk about their experiences and what were for many, very difficult circumstances.

Through the Caring Voices Project and the resulting position papers, we hope that readers will gain a deeper understanding of what it’s like to be a Mental Health Carer. Of course, until we have lived the experiences it is never possible to know what it is truly like. However, it is possible for all of us to work together to create a more compassionate society. If we work on this we will contribute to embedding a culture of recognition, respect and support for Tasmania’s Carers. A culture that needs to run through, not only our health system, but all of the systems that are implicated in the caring role, as well as the wider community.

One of the exciting things for us in undertaking this research is that we can use these findings to work for change. We believe that we can make Tasmania a great place to be a Mental Health Carer. There are numerous opportunities to do better. A commitment to Carer recognition, mental health reforms and the changing landscape of health services delivery, are among the opportunities we have to ensure that we raise the voices of Mental Health Carers to make the systems work better for them.
We look forward to seeing greater collaboration between systems, sectors, portfolios and services. It is not just for the health system to deal with mental ill health. This is an issue that requires a true commitment to working together. Health is determined by many factors – most of which lie outside of the health system and many of which are beyond the control of the individual. That’s why we look to governments for leadership on action on the social determinants of mental health – such as income, housing, transport, employment, access to health services and so forth.

Let’s take action

We conclude by summarising some of the actions that have arisen from our research. These are not all that is needed but they provide an opportunity to make a positive start:

Position Paper: Caring in a world of government policies

✓ We urge the Australian and Tasmanian Governments to provide adequate resources for the implementation of the Carer Recognition Act 2010 and the Tasmanian Carer Policy 2013, and to comprehensively evaluate the impact of the Carer Recognition Legislation/Policy on the lives of Carers (page 12).
✓ Further clarification, consultation and education is needed in relation to the issues of consent, confidentiality and Carer rights as they relate to the Mental Health Act 2013 and other relevant Carer recognition legislation/policies (page 15).
✓ Carers needs to be recognised in a broad spectrum of government policies - not just those related to Carer recognition or health - because caring implicates many government policies. It’s time to be serious about Carer recognition (page 20).
✓ As part of the Rethink Mental Health Project, policy developers should indentify how to overcome barriers to accessing services for those with mental ill health and their Carers (page 28).

Position Paper: Navigating the road to treatment, support & recovery

✓ Mental Health Carers must be recognised, respected, involved and supported as part of the ‘care team’ for their loved ones (page 13).
✓ We urge those in charge of health service delivery to revisit the concept of case management. Mental Health Carers need access to long-term case managers that can work with people with mental ill health and their Carers on the journey to treatment, support and recovery (page 16).
✓ Support people with mental ill health and their Carers to ‘break the repetitive cycle’ by providing person-centred, long-term treatment plans and case management, and acting on the underlying causes of severe mental ill health. Perpetuating a system that continues to say that it is acceptable to repeatedly present to Tasmanian hospital emergency departments (often with the involvement of police) is not good for anyone (page 19).
✓ We urge the Tasmanian Government to explore opportunities to enhance cooperation between State and Territory health services in the interest of the health and safety of persons with mental ill health and their Carers (page 21).
Position Paper: A place to call home

- Adequate housing is a human right. As a community, we need to recognise the importance of a place to call home, particularly for good mental health. We must strive to ensure that all have Tasmanians access to adequate housing. We need to provide additional targeted support to people who are vulnerable, such as those living with mental ill health and their Carers. We must work together to solve this problem and we need committed leadership (page 9).

- Carer support needs better coordination and increased funding. Carers need more emotional (as well as financial and practical) support. Carers need to be recognised in their own right as well as for their role in caring for people with mental ill health (page 14).

- Collaborate - involving stakeholders from health, human services, police, education, economic development and the justice system - to explore better ways to prevent and respond to safety concerns and other complex problems associated with mental ill health (page 19).

Position Paper: Caring – a job & a half

- We need Carer-friendly workplaces that embed the principles of Tasmania’s Carer Policy 2013 and the Carers Recognition Act 2010 (page 15).

- Improving the employment prospects of both people with mental ill health and their Carers requires urgent attention (page 15).

- Stamp out stigma associated with mental ill health and caring for people with mental ill health (page 23).

Limitations of our research

While the Caring Voices Project may be limited by its sample size we also note that our sample was much larger than numerous studies reported in the literature. Our experiences in collecting data for the Project illustrated that sharing one’s experiences of caring for a person with mental ill health can be a highly emotive (and at times, painful) experience and we are grateful to the Carers who were able to participate in this process. We have sought to add strength to our Carer stories by triangulating some of our data and quoting relevant literature on research undertaken elsewhere. However it should be noted, that the primary purpose of this research was to simply publish what Mental Health Carers told us. There was no randomisation involved in the selection of our sample and there is likely to be some self-selection bias. Not all Carers involved in our research chose to answer all questions. Sample sizes are noted as ‘n’. The resourcing available to undertake the Caring Voices Project was significantly limited given the complexity of the issues surrounding the care of people with mental ill health.

Acknowledgements

The Caring Voices Project was undertaken by Mental Health Carers Tasmania in partnership with Carers Tasmania, Council on the Ageing (COTA Tas) and Tasmania Medicare Local (TML). The Project was funded by Tasmania Medicare Local.
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Introduction

As part of the Caring Voices Project, we asked Mental Health Carers in Tasmania about their experiences when the person they cared for was transferred between services or back to the community, as their needs or conditions changed. This position paper presents the findings of this research.

The Caring Voices Project Reference Group believes that in undertaking their caring roles Carers have the right to be recognised, valued and supported to enable them to fulfil their caring responsibilities. Studies from around the world have shown that Carers often struggled to cope with the demands of mental ill health, and while Carers have legal and moral rights that should enable them to fulfil their caring responsibilities effectively, too often they experience barriers to realising these rights.1 Where rights are not being upheld, there are barriers to effective care.2

Our research found

- More than half of Mental Health Carers did not feel respected or listened to in relation to the transfer processes for the persons they cared for
- Lack of continuity and cooperation generates significant stress for Carers
- Mental Health Carers are concerned and stressed when the person they care for is transferred without a treatment plan
- Mental Health Carers feel trapped in a repetitive cycle
- Mental Health Carers are forced to play the waiting game
- It should be easier to gain cooperation between health service providers across jurisdictions
- Mental Health Carers’ rights are not being met
- Mental Health Carers are expected to be the unpaid health workforce but get little or no training and support
- We need to act now to address these issues. Improving communication is a good place to start

A Mental Health Carer is someone who provides unpaid physical, practical or emotional support to a family member, friend, neighbour or colleague with mental ill health.

Given the strong association between mental and physical health, it is unsurprising that a number of Mental Health Carers in our research were also supporting care recipients with physical ill health – including a range of chronic conditions. Indeed, nowhere is the relationship between mental and physical health more evident than in the area of chronic conditions.* In our research 30% of Mental Health Carers were caring for people with mental ill health as well as another physical health condition.

We would also like to point out that the impacts on Mental Health Carers of caring for someone with mental ill health are similar to other Carers – such as people who are caring for someone with a chronic condition but who do not suffer from mental ill health. However other factors – such as the nature of mental ill health, community stigma, substance misuse, the exclusion of Carers by mental health services and deficiencies in the system – have been found to increase the risks, stress and isolation for Mental Health Carers.** The presence of multiple health conditions (mental and physical) can compound the caring situation further.

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1. Mental Health Carers are often not listened to or included in transfer processes for the person they care for

The literature provides some guidance on what might be considered effective caring. This includes (among other things) being involved and included as a source of knowledge, sharing information, being involved in risk management and balancing rights.\(^3\)

Wilkinson and Mc Andrew (2008) argue that in order to care effectively, greater recognition of the expertise that family Carers hold is required: “they are a source of knowledge, and experts in knowing the loved one and the person behind the illness.”\(^4\)

Rowe (2011) also identified barriers to effective caring, citing various studies:

“Gray et al. (2008) found that Carers were often discouraged from approaching services, and that if they were not taken for granted, they were seen as troublemakers and as part of the problem. Lyons et al. (2009), when investigating how service users and carers define a mental health crisis, found that carers felt isolated with nowhere to go, and that they felt not listened to, not taken seriously and were ignored by professionals. Carers were hidden and invisible, trapped and isolated in the narrow confines of the role (Gray et al. 2009). They lacked timely support, and according to Pinfold et al. (2007) were expected to just cope. They were seen as pushy and demanding, prejudged if they tried to share information, and had to persevere in contacting services (Slade et al. 2007). The family carer experience it seems was one of being alone, an outsider, detached and expected to cope after discharge (Wilkinson & McAndrew 2008).”

As part of the Caring Voices Project, the data supported much of what these other studies identified. Only 4% of Mental Health Carers (n=71) indicated that over the last 12 months, they had always been made to feel part of the ‘caring team’ by the health and community services professionals who provided services to the person(s) they care for. Sixty-eight percent (68%) of Carers (n=74) in our research did not agree or were unsure whether services recognised and respected their needs – with 45% disagreeing with the statement: Where relevant, it is apparent to me that services recognise and respect the needs of Mental Health Carers.

Furthermore, we found that Mental Health Carers were twice as likely to disagree than agree with a statement that asked them whether they felt respected and listened to during times when their loved one was being moved from one service to another or transferred back to the community.
Of the 40 Mental Health Carers that had experiences where the person(s) they were caring for had been moved from one service to another or transferred back to the community, as their needs or conditions changed, 58% disagreed or strongly disagreed with the statement: *Overall I would say that as a Mental Health Carer, I felt respected and listened to during this time (or these times) and I was fully included in the transfer/discharge process.* Around a third of Carers agreed with this statement.

Mental Health Carers spoke about a wide-range of transfer experiences and the surrounding circumstances, including:

- how the nature of mental ill health can contribute to the complexity of the situation and interfere with cooperation (by the care recipient)
- the involvement of the police
- failure of the system to recognise the underlying factors that are contributing to ill health (social determinants of health such as housing, education, employment, income and so forth) including historical factors such as family breakdown, attachment, community stigma etc.
- the difficulty of establishing boundaries as part of the caring role
- unreasonable transfer arrangements back to the community (e.g. in the early hours of the morning with no plan)
- lack of cooperation between health services in different states and territories in Australia
- poor coordination, lack of continuity and repeated presentations
- lack of skills of services’ staff as well as Carers
- poor communication and interpersonal experiences; and more.

The main themes that arose are discussed in this paper but it is beyond the scope of this project to explore all of these issues in detail. Having said that, one thing stands out - these experiences point to failures in the current system to adequately recognise, involve and support Mental Health Carers in the care and treatment of their loved ones.

“My son has been an inpatient at the (health service named) many times but there has been only one occasion when I was contacted before he was discharged and that was from the Emergency Department when no bed was available in the Psych Ward. I was asked to go in and collect him if I didn't mind having him at home with me – he was in a very bad state and, although I was anxious, I agreed because I was not happy to leave him in Emergency any longer. Every other time before and since that occasion the staff have told him he can go home and he has arranged with one of us to collect him. No-one on the ward ever meets with any of us.”

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*Mental Health Carers Tasmania*
“They put a ‘little note’ in her hand, put her out on the street at 4am and rang me.”

“The person I care for discharged themselves from a facility and I was not kept informed. The person I care for was given little to no follow up after leaving a facility and became unwell again soon after. I believe this would have led to suicide had he not had Carers.”

“(Names health service) (took) my brother’s care down a notch (and this) put him into a state of fear, his sessions were lessened and he felt like he was being put out to pasture. The voices had not changed, he was in a state of ‘this is not going to get any better’. He was told there were not enough staff and others had to be seen - granted this is a problem but I was not notified of this change and ended up with a distraught brother as well as trying to contact the doctor to talk it through with him. That never became an option, I was unable to see him. Being forewarned would have at least made the change, a little easier.”
Mental Health Carers involved in the Caring Voices Project commonly reported that health services’ workers did not listen to them and even that they didn’t believe them. Carers felt that their concerns were dismissed and their contribution to and valuable insights into the specific needs of the person they cared for were often ignored by service providers. This exacerbates Carers’ feelings of distress about the health status of their loved ones.

“To get the GP to really listen to the situation I had to break down in front of him and my partner had to - in a mild way - lose his temper for the GP to take us seriously...and then my partner was taken off his medication and put onto a new one at a time that was really inappropriate and my partner was very mentally unstable and I could not afford to take additional leave from work to care for my partner and my son.”

“The service providers don’t see you as a worthwhile person. I’ve got to argue for everything and you’ve got to be in tears and that’s appalling.”

“...I have never been acknowledged as my ex partner’s Carer and thus never involved in her transition between services. This has been very difficult over the years as it means that services are only aware of my ex’s account of the issues she faces, which is not always very accurate.”

Mental Health Carers spoke about the need for a more “humane” system, driven by compassion and a high level of interpersonal skills. A study by Gunasekara et al (2013) highlighted the need for renewed attention to the “basics of relationships”. The authors urged health services workers (in this case nurses) to make time to really get to know the people for whom they provide care, and to work to maintain passion for mental health care. “It seems likely that attention to the simple things has the potential to improve levels of satisfaction among service users, decrease distress, and support the development of an environment which can nurture recovery,” they conclude. Of course, as part of the Caring Voices Project we recognise that this must be underpinned by appropriate policies and resources, as well as a supportive culture. However, our research confirmed the need for the development of a more holistic and supportive environment that can nurture recovery.

Some Mental Health Carers in our research provided examples of health services’ workers speaking to them in ways they considered very inappropriate. Sadly this may be contributing to the emergence of an obstructive culture, which – if not addressed – could become entrenched. Mental Health Carers spoke about the need for cultural change within the Tasmanian health services system. Indeed, those who’d had experiences with services in other Australian States and Territories reported experiencing a more supportive and engaging service culture.
Examples of inappropriate language, lack of communication and poor interpersonal skills, as well as stigma and even racism emerged from our research data. This is most concerning and reinforces the need for wide-ranging as well as targeted strategies, which reach beyond the health system.

“The hospital told them ‘we only take mad people not bad people’.”

“(They said to him) ‘Go back to where you came from you black bastard’.”

“The attitude in (the) Tasmania(n) (health services system) towards (the) Melbourne (system) is absolutely appalling.”

“I’ve got a file of things that happened that should never have happened. There was a lot of racism.”

“(The) stigma was appalling. We had a GP who said to (our daughter who has an eating disorder), ‘that’s what girls like you do to attract the boys’.”

“(There is) so much stigma there still.”

As an example of the need to recognise the underlying causes of poor health (the social determinants of health) in the health care system, one issue that arose repeatedly in the Caring Voices Project was access to transport. Carers often spoke about transport as an important component of treatment and transfer planning – a barrier that was not consistently recognised by health services’ workers.

“(There) was no recognition of (the) distance (he) lived away from (the) service from which (the) discharge was happening.”

Again, adequate Carer involvement in identifying such barriers should be standard practice. Our research identified a range of other barriers to accessing health, wellbeing, community and government services for the person they cared for. These are outlined in our paper: Caring in a world of government policies.
It is worth pointing out that some Mental Health Carers also expressed concern that care recipients were not always listened to:

“He discharged himself from hospital twice as he felt he was not being listened to, as he was telling nurses and doctors that the medication he was on was not working and was actually making him feel worse than before he entered hospital as an inpatient. They did not increase the dosage so he discharged himself - he said he would rather be miserable at home than being miserable in hospital. This happened at two different hospitals.”

The Caring Voices Project provided a space for Mental Health Carers to share their stories (both positive and negative) about service interaction and transfer experiences. What emerged as a common theme was dissatisfying, inappropriate and ineffective service experiences. Having said this we did identify isolated stories of satisfaction with services.

“Her anxiety is now well managed and she is now an advocate for creating awareness of mental health and wellbeing. I am incredibly proud of her.”

“They (the service) have persevered. They’ve followed up. They’ve given him hope…They’ve helped him without cosseting him. They’ve bonded with him. They’ve also followed up with me. They support me. (They recognised) we are a package…She (the health worker) makes sure I’m on a straight and narrow path…She’s just been consistently there and sharing the loud because he has been a huge load and for me the lovely thing is that they accept him as a person and they help him practically.”

“…My doctor alerts her staff so when my brother makes that call they get the nurse to see him by going to his place of residence or making an immediate appointment or visit, whatever is needed. (It’s) a wonderful, caring, humane approach.”

**Let’s take action:** Mental Health Carers must be recognised, respected, involved and supported as part of the ‘care team’ for their loved ones.
2. **Lack of continuity and poor coordination generates significant stress for Mental Health Carers**

Concern about continuity within service systems is a consistent feature of health and social care research internationally.\(^8\)

Continuity has been defined as the experience of a co-ordinated and smooth progression of care from the service user’s perspective and involves:

- excellent information transfer following the patient (continuity of information)
- effective communication between professionals and services, and with patients (cross-boundary and team continuity)
- the ability to be flexible and adjust to the needs of the individual over time (flexible continuity)
- care from as few professionals as possible, consistent with other needs (longitudinal continuity)
- one or more named individual professionals with whom the patient could establish and maintain a therapeutic relationship (relational or personal continuity).\(^9\)

Continuity is a multi-faceted concept influenced by a range of interrelated factors including individual characteristics and circumstances, different care trajectories, the structure and administration of services, the wider context of ‘the whole person’, as well as professionals’ characteristics and behaviour, and service users’ own satisfaction and judgements.\(^3\)

We recognise that it may not be possible to see the same health services’ workers every time, and that the quality of the relationships with health services’ workers is ultimately what matters when it comes to continuity (e.g. trust, the professional’s style, their communication skills and the time they make available)\(^3\). However our research found that changes in individual health workers, according to Carers, can have a significant impact on people with mental ill health. Many Mental Health Carers spoke about the need for health services workers to develop relationships and trust with their care recipients – something which, they report, does not appear to be consistently happening at present.

Our research supports the findings of others that health services should work ‘with’ people with mental ill health and their Carers to assess needs and preferences and facilitate contact and continuity as appropriate - not deliver continuity ‘to’ service users. Ensuring that service users and their Carers experience continuity should not be an optional extra: it should be a core component of the effective and efficient delivery of health-care. Health services’ workers should understand the components of continuity, and be supported to act on that understanding to deliver person-focused care.\(^10\)
"(I experience difficulties) mainly when (the) psych worker changes. (This) really upsets her. (She is) lucky to have a great psychologist at the moment who, even though he went into private practice, took her with him at Medicare rates so she would not suffer (the) trauma of getting to know someone all over again!"

"I did request that my son not be transferred from (names health service) to the (names health service) as I felt he was well looked after where he was. My concern was he would then have to spend time getting to know the staff at the new centre and they would then need to spend time getting to know him. He had already had two different psychiatrists and four or five different case managers. He was transferred anyway. It has now been over 12 months since his transfer and he has not yet met face to face with his psychiatrist. It is unfair that people with mental (ill) health have so many different case managers and doctors. You miss the consistency. If you had cancer or a cardio problem this just wouldn’t happen and yet it is so vitally important to know someone well, when they experience mental health problems."

Some Mental Health Carers also expressed their concern about the lack of coordination of care and treatment. Again, if Carers are listened to and involved in treatment and transfer planning, important information is more likely to come to light.

"(There are) so many people helping him – he probably has too many. What he needs is one person that he can go to all the time…he’s probably got too many. One does this and one does that. They’re treading on each others’ toes. They don’t know the other person that’s involved."

"They often don’t pay enough attention to the medications that are being given and what their interactions are or what else is going on in a person’s life. One GP gave her pain medication that made her feel suicidal…she couldn’t get another appointment with him and was dealing with the receptionist…it’s so demoralising."

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“*My daughter has presented to the emergency department hundreds of times. Only once was a referral made for alcohol abuse, and this failed (because) when we arrived they weren't aware we were coming; I took time off work for the appointment (only) to have our/my expectations fail again and to feel like we weren't important enough. It concerns me that my daughter doesn't have a centralised or coordinated level of support. It appears to me that all the services start from the beginning again (and that there is) no access to information. There seems to be (a) lack of an individualised and coordinated care plan.”*

“*Probably my own main and on-going problem is an apparent total lack of communication between health professionals in different fields. My wife has an immune system problem, plus a number of other medical / physical things; I am certain that there is interplay between these and her mental problems, yet the only thing I see on medical referrals in the list of ailments / history is ‘anxiety’. ‘Anxiety’???? Recently Chronic Post-Traumatic Stress Disorder (which can be confused with Borderline Personality Disorder) was re-rated to be right up in the top handful of serious mental illnesses - yet there is no apparent sharing of this information between physical health practitioners at all. I think that better communication might lead to better handling of people in this situation.”*

Let’s take action: We urge those in charge of health service delivery to revisit the concept of case management. Mental Health Carers need access to long-term case managers that can work with people with mental ill health and their Carers on the journey to treatment, support and recovery.
3. Mental Health Carers are concerned and stressed when the person they care for is transferred back to the community without a treatment plan

In our research, a number of Mental Health Carers reported experiences where the person they were caring for was still unwell at the time when they were transferred back to the community. Carers spoke about their loved ones being transferred without any treatment or adequate treatment, and/or an ongoing treatment plan, and without any communication with themselves as the Carer. This created significant stress for Carers as well as frustration as many know from experience that more often than not, there will be a “next time” in the near future.

“*My son was discharged from hospital when he was clearly unwell and started to walk home. I was unaware of this until he called to have me pick him up. After this episode he relapsed badly and was readmitted to hospital after a particularly severe psychosis. If he had received better treatment in hospital the first time, he may not have suffered again with the trauma of police becoming involved in his admission.*”

“(There was) no discharge discussion (or) plan. (They are) sending the person home when (they are) still very unwell/unsafe.”

“When my son went into detox some years ago to try to get help he was let out too soon (and) I think this resulted in him resuming his old lifestyle. I was trying to inform the mental health professionals that I think this would occur and my voice fell on deaf ears. There was nothing in place for him when he came home – he was living with me at this stage.”

While research indicates that people receiving treatment for a mental illness are no more violent or dangerous than the general population, violent and aggressive behaviour was reported by a number of Mental Health Carers in our research. Some Carers told us that transfer to the community without adequate treatment and forward planning can be followed by acts of aggression and violent behaviour. This was particularly the case where Carers had to call the police to assist them to admit their loved ones to hospital. A number of Carers spoke about their concerns, and sometimes fears of ‘retaliation’.

“When he gets out he’s got a grudge against me and so what he does is he hides behind my garden shed and stalks me…*(If he’d been treated on time), I’m positive this road would not have been travelled. Positive!”
4. Mental Health Carers feel trapped in a repetitive cycle

With appropriate treatment and support, people with mental ill health have a far greater chance of recovery. In fact, our research identified a number of stories of successful treatment.

“(As a result of the treatment) She’s more independent, more self caring, capable of looking after the children, building relationships back with the family, less intrusive, it’s more peaceful in the house. I have more freedom, more independence. It’s (the treatment has) had an emotional, social and financial impact.”

However, we also identified that there were people with mental ill health in Tasmania who, according to their Carers, were not getting the treatment and support they needed. For many Carers, they felt like they were trapped in repetitive cycle. This is very concerning as we know from other research that if mental ill health advances without intervention, “the likelihood of treatment resistant symptoms, permanent psychosocial delay and a life-time reliance on health and social systems increases”.12

Moreover long duration of untreated mental ill health can compromise a person’s long term health and quality of life. Again this is where the experience and involvement of the Carer in service interactions for the care recipient is paramount; recognition of mental ill health and the need to seek help often comes sooner among family members than the person experiencing symptoms.13 We would also suggest that ‘breaking the cycle’ of repeated presentations to health services would be in the interest of the health system and governments for economic reasons.

“At no time in my 10+ years of caring for my daughter have I ever considered myself a Carer, and that I had needs, or that I had rights as a Carer to represent my daughter...My daughter is often homeless, needing to run away from a fear or mess that she creates. I can recall two or three occasions when she engaged in counselling with a professional, but then they either moved away, got relocated or she moved. And the process starts over again.”

“The constant discharge cycle confused me, knowing that the same behaviour would continue again and again.”
As part of being caught in a repetitive cycle, numerous Mental Health Carers spoke about their experiences with Tasmanian hospital emergency departments. Carers expressed their concerns about waiting times, involvement of police, attitudes of staff, lack of communication, and unsatisfactory outcomes in relation to referrals, treatment planning and transfers. All of these experiences can contribute to frustration and distress.

“We’ve had a number of examples of discharge from the emergency ward—without a referral…Over a period of one month, she had a significant number of ambulance, police and emergency staff having to put themselves at risk four or five times a week. The confusion for me was what did she have to do to be made safe from this cycle of binge drinking and self harm? The constant discharge cycle confused me, knowing that the same behaviour would continue again and again. It was traumatic and abusive, and I felt in danger. The staff at the hospital appeared to not register that she had a mental illness, and as a Carer I was not given the opportunity to be involved in any meaningful treatment plan (it didn’t exist).”

“When (names care recipient)’s on an order, that helps to get into hospital. But when he’s not on an order it’s so hard to get someone into hospital. By the time anyone notices he’s like a (very disturbed person in crisis).”

Let’s take action: Support people with mental ill health and their Carers to ‘break the repetitive cycle’ by providing person-centred, long-term treatment plans and case management, and acting on the underlying causes of severe mental ill health. Perpetuating a system that continues to say that it is acceptable to repeatedly present to Tasmanian hospital emergency departments (often with the involvement of police) is not good for any one.
5. Mental Health Carers are forced to play the waiting game

Waiting for help, support and to access services - waiting for anything and everything - was a general theme that emerged throughout the Caring Voices Project. As stated above, waiting for help can increase risks for mental health patients and their Carers.

“You’re programmed to wait – to have good waiting behaviour – to be patient. You have low expectations of service providers but high expectations of service delivery. You should always aim for the top but know the reality is here.”

“I am at the point where I don’t want my son to be here anymore and that sounds awful, but how bad do things have to get before help is finally given? If you abandon or abuse a child, authorities step in straight away. This experience is wearing me down and all I am supposed to do is play the waiting game. To get to the point that if they find him respite, I don’t want him back, but now I go to work for respite and that’s not how it should be.”

“I spend a lot of my time waiting, waiting in doctors rooms… waiting on the telephone to straighten out a Centrelink query or mistake they made, waiting to get a doctor’s appointment, waiting for the prescriptions to be filled.”

“(We needed) reduced wait times for support. Having to wait four weeks in between appointments for counselling support is not appropriate particularly when (the) psychologist forgets what the previous session covered. The failure of the support system for my husband has created a barrier to further access to support. He has lost faith in the system and no longer willing to engage in seeking treatment or support. This in turn impacts on us as a family.”

“A professional at (names health service), promised to make an appointment for my son to see a psychologist – months ago, (this) still hasn’t happened; meanwhile my son has had three new case managers from there in as many months! – and is still waiting to see the third one, and find out who he or she is!!!”
6. Lack of cooperation between jurisdictions is contributing to harm and trauma for Mental Health Carers in Tasmania

A number of Mental Health Carers in our research described experiences where they were caring remotely (the care recipient and the Carer were living in different states or territories in Australia) or had moved from interstate along with the person they were caring for. In these situations, Carers sometimes needed to negotiate the transfer of information (history) about the care recipient and their mental ill health between health service providers in different jurisdictions. On a number of occasions this proved to be difficult or impossible – for reasons which were not apparent. For some Carers, this was considered the direct cause of harm and trauma.

“It’s an attitudinal/ownership thing – the hospitals don’t communicate. I’ve had to coordinate all that.”

“It’s ridiculous not to communicate across borders. It’s like moving countries. ‘You’re out of our jurisdiction so that’s the end of our responsibility’.”

“The doctor refused to refer back to this doctor (in another state).”

Let’s take action: We urge the Tasmanian Government to explore opportunities to enhance cooperation between State and Territory health services in the interest of the health and safety of persons with mental ill health and their Carers.
7. Mental Health Carers’ rights are not being met

In our paper, *Caring in a world of government policies*, we discuss the impact of Tasmania’s Mental Health Act 2013 on Mental Health Carers and outline the provisions for the recognition of Mental Health Carers. We also note that there are other policies and legislation that should require services to recognise Carers including The Carer Recognition Act 2010, Tasmanian Carer Policy 2013 and National practice standards for the mental health workforce.

In line with data presented in our other paper, we want to reinforce the issue of ‘conflicting rights’ in this position paper as it was repeatedly raised in response to questions we asked Mental Health Carers about transfer processes.

Just to recap without repeating ourselves entirely, the key points in relation to rights that are discussed in our paper, *Caring in a world of government policies* include:

- Mental Health Carers felt that their rights to be acknowledged and treated with respect were often not recognised by health services
- Mental Health Carers said they had been excluded from involvement in service interactions because care recipients were exercising their rights
- There were times when Mental Health Carers disputed health services’ staff assessments of capacity
- Mental Health Carers felt powerless to access support and treatment for their loved ones because the care recipient did not acknowledge the seriousness of their mental ill health and refused to access help
- If services’ workers don’t recognise and listen to Mental Health Carers, extensive and important information may be overlooked.

As stated in our other paper, we **suggest that further clarification, consultation and education is needed in relation to the issues of consent, confidentiality and Carer rights.**

“The main issue is because my daughter looks normal society treats her this way even when she has told them her disability she has been accused of lying by bus drivers, security guards, shop assistants and even workers who say she seems fine. Then overload will hit and everyone will run to ask me what to do, ‘why is she rocking in a corner, taking her clothes off, screaming like a devil’? Now she has lost trust in the very people who are supposed to know what to do in a crisis. Now she lies in bed for two weeks (and) cries that she wants to kill herself.”
“Services have this inability to look at the family grouping. The person/patient or client is the primary person always and their privacy and wishes are always first and that’s not a problem with me but providers need to look at the whole picture because they belong to a grouping. If they belong to a grouping than that group often picks up what happens afterwards.”

“(I’ve) never been involved. As a forensic patient and the likelihood that my son has not given (names health service) consent to involve me, means it’s all beyond my control. The current psychiatrist didn’t believe me when I told him about the derogatory voices my son tells me about because in the eight years (the) psych had known him, he had not told the doctor.”

“(Names health service) was very reluctant and difficult to get any help from when my brother was very unwell. I requested to see his doctor (and) was told that was impossible. I then wrote a letter outlining my brother’s behaviour and how urgent it was. He got in some days later - (this is) not acceptable.”
8. Mental Health Carers are expected to be the unpaid health workforce but get little or no training and support

We often refer to Carers as the ‘invisible workforce’ of the health system.\textsuperscript{14} This is true not only in terms of the hours of care they provide but also in terms of the skills that they both acquire and contribute. Many Mental Health Carers in our research spoke about the skills they had acquired as a result of their caring roles – which provides yet another very good reason to involve Carers in policy and service development.

“I’m now a much better person for the knowledge and experiences I have gained and continue to do so.”

“It’s taught me what the really important things in life area...people matter, caring matters. Each individual is really important and equal to everyone else and we should support each other. That’s what caring has taught me. I’ve had a difficult life but I’ve had a bloody amazing life.”

In some cases, Mental Health Carers also spoke about the specific roles they are “expected” to undertake with very little or no training and support. This was the case generally with Carers telling us about the need to become ‘mental health workers/psychologists/psychiatrists/counsellors/meditation teachers/care coordinators’ and so forth, and also specifically for those involved with treatments such as Family-Based Therapy (for young people with eating disorders). While Carers value structured, skills-based interventions, they need appropriate support and guidance if they are to play an active role in such treatments.\textsuperscript{15}

“Most of the time when he was having his medical things people were asking me about what I can do to help him at home but they weren’t listening to me. They were saying he doesn’t need the service. I was worried and scared. They were saying he’ll just have to learn to breathe and learn to calm down. Then in comes me to teach him that. I don’t think that should be part of my job.”

“Why am I as a Carer providing low cost services to the government (when I’m) not supported in my role better?”
“(The) patient was discharged from (names health services) to go back to (a) private health facility; the arrangement(s) for transfer were not made by staff. Arrangements (were) left up to me the Parent/Carer, which became very difficult, as the psychiatrist was on holidays and staff at the private mental health facility refused to take the patient back without the psychiatrist's agreement: (This) meant that I had to take time off from my paid work to look after my daughter and try and arrange for another psychiatrist and private facility to accept my daughter. As there was not a bed immediately available she had to be cared for at home until a bed became available. (It was) very difficult as she was still in an unstable mental health state, having just taken an overdose - a position no Parent/Carer should have been faced with.”

“(Our daughter) went into hospital for three or four weeks and came out and it was all about Family Based Therapy. Now that’s all great. I’m all for that but we don’t get any support with it….We are expected overnight to become psychologists, psychiatrists, Family Based Therapists and do it all from home but we get nothing. There’s no support for us to say this is what’s expected of you. It’s all through Dr Google.”

Our research found that when they first became Mental Health Carers, many research participants said they were at a loss as to where to go for help and support. The Caring Voices Project identified some harrowing stories and we can’t help but feel that some of these situations could have been prevented with early intervention and more holistic care. It is critical that ‘new’ Carers are enveloped in a person-centred approach to the care and treatment of their loved ones and themselves, supported with information, assisted to identify their boundaries so they can maintain their own health and wellbeing, and that they are listened to and consulted. Together navigating the road to treatment, support and recovery need not be so fraught.
9. Improving communication would go a long way to preventing problems

As part of the Caring Voices Project we asked Mental Health Carers if they could think of ways that problems encountered during transfer processes could have been prevented.

• Improve communication

The number one way that Mental Health Carers believe problems associated with service interactions and the transfer of their loved ones can be prevented is to improve communication. This includes communication with Carers, with the care recipient, between services, with those outside of the health care system (police, housing and other social support/human services, and the community sector) and across jurisdictions.

“If the doctors listened to what I said in the first place - that he has been tried on so many different medications over the years and nothing has worked. I warned them that if something does not happen very soon, then he would lose hope and would discharge himself and would go back to drinking to self-medicate. They heard me, but I don’t think they really listened. They did not explore my comments with me. I felt that they did not take me seriously. I even told the doctor in the Emergency Department at the (names health service) once that if he was sent home without any medications he would become extremely suicidal. I took him to the Emergency Department because he had overdosed on my medication, which has amphetamine-like effects. She discharged him despite me begging her to make him stay overnight in (names health service) or send him to a private hospital. I told her that if she sent him home I would be unable to work because I would be on 24/7 suicide watch making sure he didn’t hurt himself. She discharged him with no medication or follow-up plan.”

“I just need to know where to get help from. I have no idea where to start.”

“There needs to be communication from staff in mental health facilities to Carers when dealing with someone who at times is a danger to themselves. We cannot rely on the person we are caring for to communicate issues/incidents.”
“Having health professionals look at and take seriously a person’s mental health conditions... show empathy and really listen to both the patient and the Carer because the patient is the expert and the Carer is usually the advocate!”

“Communication is a big one. Communication with carer and consumer...The consumer (and Carer) comfortable with the knowledge they will be heard, helped and followed up when the consumer is unwell or having difficulty during (admission) and after.”

“Better communication between services. More involvement allowed between patient and specialists.”

“Better procedures around discharge of mental health patients in particular contacting the primary Carer/responsible person before turning the patient out on the street.”

Other practical ways that Mental Health Carers believe service interaction problems could be prevented included:

- **Better resourcing of services**

  “We need to better equip our hospitals with staff, funding and training. There needs to be a support process set in place, and followed.”

  “I think the safety nets that are available for people in the community who do suffer from mental illness are not wide enough therefore people will slip through and this then becomes hard for the family who are left to pick up the pieces and try and put things back together with little or no resources.”

  “That the services had longer time period - more psychology session/specialist help/ringing in - touching base - they’ve got so many people on that and they are so under pressure.”

  “There just are not enough services for people with mental health issues.”

“The obvious solution is for staff to include at least one family member in the transition planning process.”
“Poor services overall rurally, (it is a) difficult pathway to find access to services (in rural areas).”

• A stronger focus on early intervention

“For newly diagnosed or on first presentation of a person with mental health issues, a counsellor should be available to talk to the Carer about what may happen and how and where to go for help to manage the needs of the person going forward. There was no such information for me when my son first became ill and I always thought a package or plan prepared for him and me could make it easier to help support him find his way through the maze of services and find the most suitable areas/treatments available at the time.”

“As someone who does not use the internet myself, I have no idea what services are out there.”

• Improved continuity and long term case management

“You need staff that both the Carers and the person with mental health problems can related to well. And you need to have the same staff for a period of time and not just a case manager for a few weeks.”

“Staff at (names health service) should have made the arrangement to have the patient transferred back to the care of the psychiatrist and (the) facility that she had been under at time of attempted suicide.”

“My son has chronic and severe bi-polar disorder, is frequently hospitalised ... Yet he has never been offered a case manager by (names health service). This is a serious problem as he can access no services in the community, and would benefit from having someone outside the family supporting him, especially in relation to his compliance with his medication regime.”
“Maybe if there was some sort of program whereby his case was followed up by a professional worker who would have come to see him this may have prevented my son going back to the old lifestyle. Also if he was given medication this may have prevented him going back to that lifestyle, he is obviously depressed he is depressed because he feels guilt, he feels guilt because he is unable to have his son in his life so for him nothing has changed in 10yrs. This may have had a different outcome if his stay in detox was longer or if he had of been discharged with medication and reviewed on a regular basis, maybe even in his own home as this seems to be a safe place for him.”

“More help and support from the time that he left the hostel in Hobart, someone should have put a support person in place for when he arrived up here, so that he had support from the word go.”

- **Enhanced skills of workers within the mental health system** (including interpersonal skills and cultural competencies)

“Better understanding of mental health issues across the medical profession including front of counter staff, GP’s, hospital staff, and mental health team requiring better communication skills.”

“She (the care recipient) has met some very disappointing people in that time...some attitudes from medical people that are not in the least bit helpful.”

“I look forward to the day when the medical profession are more knowledgeable and more skilled in understanding mental illness. Where patients can go and have the very best treatment that actually assists their recovery, where this is possible.”

“They weren’t accepting of (my son’s) religious diversity...they thought he was being wacko.”
• System-wide and cultural change, including moving beyond a medical model of care

“By taking a more holistic policy and service view the transition would have been much improved.”

“If someone presents more than three times in one week - they are made to engage in a program to detox, to see professional mental health staff and counselling to set some firm goals (if only it were that easy). With benefit of hindsight, it would have been helpful if the emergency team could have added some additional crisis intervention and support to my daughter as the Child Protection interventions being placed (rightly so) but adding to destructive cycle of events.”

“My ex partner is living off his disability pension and is in no way being stimulated to make his life better. He is in no way being pushed by any government organisation to get into any program. I feel like they are just throwing money at him to keep him quiet. He is only a young man and I do believe that despite his mental illness (Borderline, Bipolar) he is very capable of having responsibilities and learning to cope with, in his eyes, difficult situations. Money is not a solution to a problem such as mental illness.”

“(The person’s) needs are not in the crisis category but more to do with raising quality of life (however) there are limited services available.”

• Stop talking and take action

“People need to stop talking about consumer engagement and health literacy and just start doing it (and doing it properly).”
Concluding remarks

Legislation and policies have laid the foundation for Mental Health Carers to be recognised and respected for their caring roles. Carers particularly need to be included at critical times such as when their loved ones are transferred between services or back to the community.

The issues that arise out of the caring role are interconnected. Until we build a mental health system that recognises these connections, and the importance of addressing the underlying causes and contributors to poorly treated mental ill health - such as housing, income, education, employment, transport, social inclusion, cultural identity and equality - we will continue to provide only band-aid solutions.

We urge all Tasmanians - community, governments, non-government organisations and businesses - to recognise the role they can play in providing better support and assistance to our Mental Health Carers.

Let’s take action

✓ Mental Health Carers must be recognised, respected, involved and supported as part of the ‘care team’ for their loved ones.

✓ We urge those in charge of health service delivery to revisit the concept of case management. Mental Health Carers need access to long-term case managers that can work with people with mental ill health and their Carers on the journey to treatment, support and recovery.

✓ Support people with mental ill health and their Carers to ‘break the repetitive cycle’ by providing person-centred, long-term treatment plans and case management, and acting on the underlying causes of severe mental ill health. Perpetuating a system that continues to say that it is acceptable to repeatedly present to Tasmanian hospital emergency departments (often with the involvement of police) is not good for anyone. is not go

✓ We urge the Tasmanian Government to explore opportunities to enhance cooperation between State and Territory health services in the interest of the health and safety of persons with mental ill health and their Carers.
**Further supporting data related to this position paper**

**Who was involved in the Caring Voices Project?**

- The Caring Voices Project involved 119 Mental Health Carers. The Australian Bureau of Statistics (ABS) reported that there were 73,800 Carers in Tasmania in 2012\(^{16}\) – that is people caring for family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail. It is not known how many of the Carers in ABS data were Mental Health Carers.

- Data for the Caring Voices Project were collected through 95 online or postal questionnaires, and 24 telephone or face-to-face interviews.

- In our research, 91% of Mental Health Carers identified as female and 9% identified as male. In comparison, in Australia in 2012, 56% of all Carers were female and 43% were male.\(^{17}\)

- Most Mental Health Carers in our research were aged 55-64 years (29%) and 45-54 years (28%). Carers under 25 years of age also participated in the project (2%). In comparison, the ABS reported that the proportion of Australians who were Carers generally increased with age until the age of 65 years, increasing from 2.5% of those aged under 15 years to 23.7% of those aged 55 to 64 years.\(^{18}\)

- Mental Health Carers in the Caring Voices Project were most likely to be parents, followed by partners/spouses of the care recipient. Other relationships included being the child, sibling, grandparent, other family member or friend of the person they were caring for. One person was an employer to a number of care recipients.

- Most Mental Health Carers lived in the south of the state (58%), 21% lived in the north and north-east, and 19% in the north-west and west.

- 30% of Mental Health Carers lived more than 10km away from a town or city. Carers resided in most local government areas in Tasmania including: Break O'Day, Brighton, Burnie, Central Coast, Circular Head, Clarence, Derwent Valley, Devonport, Glenorchy, Hobart, Huon Valley, Kingborough, Launceston, Longford, Meander Valley, Northern Midlands, Sorell, Waratah-Wynyard, West Coast and West Tamar. Living within close proximity to a town did not equate to the availability all necessary services.

- 1% of research participants identified as being from Aboriginal or Torres Strait Islander origin. One Carer was caring for a person with mental ill health who was off Aboriginal decent.

- 23% of Mental Health Carers were born outside of Australia and 7% spoke a language other than English at home.
Who do Mental Health Carers care for?

- 76% of Mental Health Carers in our research cared for one person with mental ill health, 21% cared for two persons, and 3% cared for three persons. One person cared for numerous people: “nine in the last six months”. Most respondents (69%) recognised themselves as the primary Carer for the person(s).

- Mental Health Carers reported caring for people with a range of mental health conditions, and according to the Carers, often care recipients had more than one condition:
  - 68% of Mental Health Carers were caring for at least one person with depression
  - 60% were caring for someone with anxiety
  - 24% were caring for someone with substance use disorder
  - 24% were caring for someone with bipolar disorder
  - 21% were caring for someone with post-traumatic stress disorder
  - 19% were caring for someone with borderline personality disorder
  - 19% were caring for someone with schizophrenia
  - 17% were caring for someone with obsessive compulsive disorder
  - 6% were caring for someone with an eating disorder
  - 2% were caring for someone with schizoaffective disorder
  - 11% were uncertain or were caring for someone with an undiagnosed mental health condition.

Some Carers reported that some conditions such as anxiety or depression were symptoms of other illnesses such as schizophrenia. As part of this research we are not able to verify the true extent of the diagnosed conditions of the persons being cared for.

- In addition to mental ill health, 30% of Carers were caring for a person with other physical health conditions (in additional to mental ill health). Eight percent (8%) of Carers were caring for someone who also had a Chronic Obstructive Pulmonary Disorder, 8% of Carers were caring for someone who also had a Chronic Neurodegenerative Disorder, 6% of Carers were caring for someone who also had a Cardiovascular Disease and 7% of Carers were caring for someone who also had Diabetes. Some Mental Health Carers reported that the person they care for also had an acquired brain injury (4% of Carers), intellectual disability (6% of Carers) or Autism Spectrum Disorder (12% of Carers).

- 60% of Mental Health Carers had been caring for more than 10 years and 19% had been caring for more than 20 years, with a number having been Carers for between 30 and 40 years.

- Mental Health Carers’ main reasons for caring related to the nature of the relationship (e.g. *I am his Mother, he is my son*); out of feelings of love, care and a desire to be the person’s Carer, as well as a sense of obligation (e.g. *As a wife, we’re in this together. Don’t have a ‘reason’ as such, just a priority that as a family unit we’re all there to support each other, help the ones we love achieve a happier healthier life*); no other choice (e.g. *We have no family in this country so the role falls entirely on me*); and because of system-failure in the eyes of the Carer (e.g. *Main reason is that I am his mother and I want the best for him... (and) the ‘best’ does not currently exist within the mental health system in Tasmania*). In the National Carer Survey, the ABS reported that, of the many reasons primary Carers reported for taking on the role of the main informal care provider, the most common was a sense of
family responsibility (63%). The next most common reason was a feeling they could provide better care than anybody else (50%), followed by a feeling of emotional obligation to undertake the role (41%).

References


2 Ibid.
3 Ibid.
4 Ibid.
6 Ibid.
9 Ibid.
10 Ibid.
13 Ibid.
17 Ibid.
18 Ibid.
19 Ibid, Table 43.