caring voices

Position Paper:

A place to call home

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

Researched and written by
Miriam Vandenberg (Herzfeld)

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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 heart warming. 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 Tasmanians have 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

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Introduction

Everyone needs a place to live - but it's more than that - affordable, appropriate, safe and secure housing provides people with a stable base from which to participate in relationships, education, employment, social activities and recreation.[1]

Adequate housing is a basic human right.[2] It is not just a physical shelter - it is the right to have somewhere to live that is adequate in terms of legal security of tenure, availability of services, materials, facilities and infrastructure, affordability, accessibility, habitability, location and cultural adequacy.[3]

Adequate housing can contribute to psychological wellbeing.[4] Housing can provide a *home* - a protective, safe and intimate refuge where a person can develop a sense of identity, attachment and connection to community.[5] Adequate housing can be a protective factor for mental health. Conversely without it, people are at significant risk of poor mental health – particularly those who are already vulnerable.[6]

A Mental Health Carer is someone who provides <u>unpaid</u> 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 conditions (mental and physical) can compound the caring situation further.

Our research found

- 92% of Mental Health Carers reported experiencing difficulties, challenges or concerns associated with the living arrangements for the person(s) they cared for

- Many Carers are actively involved in either directly providing or trying to source adequate accommodation for the person they care for: 51% of Carers were living with at least one person with mental ill health

- Day-to-day living arrangements take their toll on Carers

- Dealing with accommodation issues has a direct financial impact on Mental Health Carers – with almost half experiencing difficulty meeting everyday living costs

- Living arrangements can place stress on relationships

- Carers of a person with mental ill health sometimes feel unsafe in their homes

- Carers worry about what will happen to the person they care for as they get older, and as the care recipient ages

- Caring affects Carer health and wellbeing: two-thirds of Carers said they frequently felt worried or depressed, and more than a third had been diagnosed with a stress-related illness

- We need to <u>act now</u> to address these issues

1. Most Mental Health Carers reported experiencing difficulties, challenges or concerns associated with living arrangements

Over the past 15 years, the focus of care for persons with mental ill health has shifted from stand-alone psychiatric institutions to family and community settings. Following this 'deinstitutionalisation', the

> *"Accommodation is always going to be an issue for my son and it is actually the thing I worry about the most."*

responsibilities of care have been largely devolved to families. Mental Health Carers are the lynchpin of mental health care and have been required (with little resourcing) to take on the often complex task of supporting the care, safety and treatment of persons with mental ill health.[7]

In our research, about half of Mental Health Carers shared their homes with at least one care recipient (50%, n=101). In other situations, the care recipient lived elsewhere (reported by 38% of Carers) - e.g. independently, in shared housing, extended treatment/accommodation or in other supported accommodation - or only 'sometimes' lived with their Carers (reported by 13% of Carers). Twenty-one percent (21%) of households (where Carers and care recipients lived together) accommodated two or more persons with mental ill health.

> *"My son lives with us 24/7, there is no respite help or anything available here."*

> *"Both (the people I care for) are in stable housing."*

> *"My son lived in below-standard accommodation for two years up until about eight months ago... He now has government housing."*

> *"They're moving here, moving there....living all over the place."*

> *"He has expressed a need to be more independent but due to his financial situation he could not afford suitable private rental at reasonable cost or to buy a house and public housing is near impossible to find in Hobart."*

> *"My son lives in low grade living conditions but I can't manage if he is living with me."*

"I would like him to live with me as this would help his financial situation but his unstable mental health has meant that I have to ask him regularly to leave my home and return to his until he is more stable."

It is widely reported that people with poor mental health often lack secure and stable housing.[8]

Most Carers (92%, n=85) in our research reported experiencing difficulties, challenges or concerns associated with the living arrangements for the person(s) they cared for.

Accommodation issues for people with mental ill health have a direct impact on those who are caring for them - in terms of a Carer's time and resources - including financially; assisting with household tasks for the person they care for and supporting them to manage their daily living arrangements; their relationship with the person and other family members, as well as the wider community; and a Carer's health and wellbeing. The issues and impact of the living arrangements for people with mental ill health on the lives of Mental Health Carers is discussed below.

"He's left the nest before but I'm his one anchor and he's just as likely to turn up at my doorstep tomorrow."

Let's take action: 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 Tasmanians have 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.

2. Mental Health Carers take on the task - and associated stress - of finding or providing accommodation

Our research found that many Mental Health Carers were actively involved in either directly providing or trying to source adequate accommodation for the person they care for. As stated earlier, just over half of Carers reported living with at least one care recipient. This presented numerous challenges on a daily basis and was a major source of stress for Mental Health Carers.

While some Mental Health Carers reported that the person they cared for was currently in stable accommodation, most Carers reported past or recent experiences of unavailable, unstable, inaccessible, unaffordable or uninhabitable accommodation for their care recipient. At times, some Mental Health Carers found it impossible to identify and access adequate housing for their loved ones. Many Mental Health Carers commented on the instability of living arrangements for the person they cared for and the impact this had on their own lives. Stories of care recipients moving from one house to another over short periods of time and homelessness were not uncommon. Indeed, other researchers have reported that poor mental health is a risk factor for homelessness because people with mental ill health often lack secure and stable housing.[9]

Unsuitable living arrangements generate significant ongoing stress for Mental Health Carers, placing their own health and wellbeing at risk.

Our research found that Mental Health Carers believe that Tasmania does not have the range of appropriate accommodation options needed for persons with mental ill health. A number of Carers stated that some form of long-term accommodation, incorporating care and

> *"He needs supported accommodation but Hobart does not have any suitable and available for him."*

treatment, must be provided for those whose psychiatric disability is so severe that they are not able to live with their families or in the community (though others expressed concern about clustering people with mental ill health). Some Carers in our research believed that their caring situations fit this description. While we recognise that there are stakeholders who argue that such accommodation options are already available, our research found that Mental Health Carers are confused and ill-informed about the inpatient and extended treatment/accommodation options that are available in Tasmania and how to access these.

> *"Royal Derwent...that's what we need again. A safe place where people can get their dignity, their pride back. We need a holding place like the Royal Derwent was...the only thing I can get him to now is prison."*

Even if accommodation is available this does not mean it is accessible. In relation to accessing extended treatment/accommodation services, Carers told us their voices were 'falling on deaf ears'. Moreover, there are reportedly inconsistencies in assessment processes and referrals to treatment/accommodation options between and within services across Tasmania. Mental Health Carers expressed significant concern about how service providers assess decision making capacity and administer the issue of 'consent'. Many Mental Health Carers spoke about navigating the complex web of services in Tasmania – something we discuss further in two of our Caring Voices Position Papers: *Caring in a world of government policies* and *Navigating the road to treatment, support & recovery.*

It should be noted, that while this Position Paper is focused on living arrangements, the issues surrounding accessing and engaging with services are related to accommodation/living arrangements, for a number of reasons: 1) some treatment services incorporate accommodation; 2) interaction with services is a critical component of Mental Health Carers' daily life – either because the services are delivered in their home or because the stresses associated with these interactions don't stop at the front door – stresses are brought home; and 3) it is essential that we move away from siloing the lives of Mental Health Carers into parts, and recognise the caring situation as a whole and the connections between its components.

3.   Day-to-day living arrangements take their toll on Mental Health Carers

> "Sometimes I find it very hard to live in the same house as my partner because of his mood swings because he is yet to (be) medicated properly."

> "My husband becomes insecure if the home environment is not neat and tidy with everything in its place. This is restrictive. He suffers some type of post-traumatic stress disorder…He has a low tolerance to unexpected noise, (he's) very jumpy and angry."

> "On occasion I have moved into my daughter's home to provide care for my grandchildren when my daughter is in hospital. Upon her return (usually prior to her being totally well) it is challenging to know how much responsibility to expect her to resume…When I am assured the family are managing OK I return to my own living arrangements."

Our research found that day-to-day life in a household with a person living with mental ill health could be very challenging for Mental Health Carers. The nature of mental ill health meant that a person's emotional state, behaviours and interactions with others was changeable and sometimes unpredictable. As a result, managing a household might not be straightforward and require additional considerations. Tasks might take longer and need to be done differently to accommodate the care recipient. The existence of other health conditions – including chronic disease – could also exacerbate the daily living needs of the care recipient, further tapping into Carers' resources. Living with a person requiring care has been found to be a risk factor for reduced Carer wellbeing.[10]

Even if the person being cared for lived independently, a Mental Health Carer's life was often directly impacted. Many Carers spoke about their daily involvement in supporting the person they cared for to undertake basic household tasks such as cooking, cleaning, attending appointments, paying bills and so forth. This consumed a Carer's time and resources – not only were they having to manage their own household but they were also actively involved in maintaining the household of the person they cared for.

> "There is tending to day to day living issues particularly when the person is in a critical phase, you take on all their extra responsibilities even caring for their pets, which adds extra burden to an already strained relationship."

All of this could take its toll. Indeed, Carers have been described as the 'invisible workforce' of the health system.[11] The estimated cost to government of replacing the 1.32 billion hours of care that unpaid family Carers provided in 2010 would have been $40.9 billion annually.[12]

Persons with mental ill health are at risk of social isolation and may experience stigma or discrimination because of their disorder.[13,14] Many Mental Health Carers spoke about the tendency for the persons they cared for to withdraw and become isolated. Carers spoke about the associated health and wellbeing risks for care recipients of becoming housebound, including weight gain, substance misuse and the diagnosis of chronic conditions such as Diabetes and Asthma. **The constant presence and demands of a person with mental ill health could be overwhelming for Carers and push them to breaking point.**

Mental Health Carers caring for persons that are elderly and residing in aged care facilities present their own unique challenges. Often these care recipients were experiencing a range of health issues – not just mental health – e.g. Chronic Neurodegenerative Disorders such as Dementia, Diabetes and Cardiovascular Diseases. In these situations, Carers' experiences of trying to ensure a comfortable and supportive place for their loved ones to live ranged from very positive – where the Carer felt they were treated as part of the care team, and the care recipient was respected and provided the care and support they needed and deserved; to very negative and dissatisfying – where power dominated and the Carer lost any sense of control over the living and care arrangements.

Such circumstances could be particularly distressing for Mental Health Carers, with little sense of how to work towards a resolution. Most of these Carers were spouses or partners of the care recipient, and some had been in long-term relationships. As such, they were often 'grieving' the loss of their partner – both from the family home and, if Chronic Neurodegenerative Disorders such as Dementia were present, from the relationship. This could exacerbate the sense that accommodation and care arrangements were inadequate. **Mental Health Carers deserve to be treated with empathy and respect, and to have their voices heard.**

"I'm grieving because my wife is not the person I knew."

Some Mental Health Carers – due to long term and repeated dissatisfying experiences with the mental health system – might have lost sight of how to empower a person with mental ill health to strive towards independent healthy living. We found that Carers were at risk of becoming entrenched in the lives of the care recipient and were sometimes unable to know where to turn or how to become 'unstuck'. Many Carers put the needs of the person they cared for ahead of their own.[15] While some Carers recognised the boundaries of their caring role – partly to preserve their own health and wellbeing – for others this was a struggle. Their lives could become almost totally consumed by the life of the person with mental ill health. This was not a healthy situation – neither for the person with mental ill health, nor the Carer. Too often Mental Health Carers were left to do the best job they could without the level of information, support or training needed. How to better equip Carers is sometimes described as being "a vexed question", because each situation is unique, but **Carer support needs better coordination and increased funding.**[16]

Let's take action: 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.

4. Dealing with accommodation issues has a direct financial impact on Mental Health Carers

People with mental ill health are more likely to be on low incomes and may be unable to manage what little money they have. The Australian Bureau of Statistics (ABS) reported that mental ill health increased as levels of socioeconomic disadvantage increased.[17] In 2007-08, 16% of people living in the most disadvantaged areas had a mental or behavioural problem compared with 11% of people living in the least disadvantaged areas.[18] Carers too have been found to be financially worse off.[19]

> *"She only moved out just under a year ago. I still have to run her around and help her with costs. I spend more on her than I do myself."*

Mental Health Carers told us they often supported the person(s) they cared for financially so they could pay their rent and bills, and meet basic living needs. Carers of persons with co-morbidities spoke about the ever increasing cost of medications and health services. This can have an impact on their (the Carer's) own financial stability as well as the level of stress in their lives.

Travel expenses were also an issue for many Mental Health Carers in our research, particularly for those with loved ones in aged care facilities, those living in rural areas or some distance away from their Carers, and those without access to transport. Distance and 'dislocation' have long been recognised as significant barriers for people living in rural areas to accessing appropriate mental health support services.[20]

Another study found that satisfaction with ability to pay for household essentials, to afford the things you would like to have, to save money, to have financial security, and to not worry about income covering expenses, are all severely compromised for Carers compared with a general population sample.[21] Our research found that 54% of Mental Health Carers (n=76) said that they now had extra expenses as a result of their caring responsibilities and **46% said that they had difficulty meeting everyday living costs**. "Household income is a double jeopardy for Carers. Their average household income is lower than is normal within the general population, and their wellbeing is more depressed than is normal due to low income."[22]

When we asked Mental Health Carers about what would assist them in their role as a carer, 48% said they needed more financial assistance (n=63).

> *"He is isolated and doesn't drive – (he has) no licence. I drive to see him and he lives 45 minutes from me and that costs a lot in petrol."*

> *"Caring has been costly. I cashed in my insurance, cashed in my superannuation and eventually had to go on a disability pension. He can't manage money at all. I've been constantly supporting him."*

"I had to make sure there was no access to bank accounts, due to excessive spending by the person."

"He and his partner separated two years ago and he has had difficulty finding accommodation that is cheap but appropriate for this children to spend time with him. Fortunately, about nine months ago he did find a flat that is quite comfortable and appropriate. It is dearer than he would have liked so I supplement his income to help him stay there."

"The situation has contributed enormously to the recent ending of my 15-year relationship, as my partner just couldn't cope with the demands of the situation any longer. My primary feeling after sadness was relief as now I don't need to hide the extent of my role any longer. Although, I'm also aware of how my time is being sucked into the situation, and want to watch this, it's easy to feel guilty and to just soldier on, and to focus more and more so that it becomes a bottomless bucket…I want to ensure my grandson has what he needs towards education, and feel sad that he's growing aware of being in a financially unstable, insecure environment…"

5. Living arrangements can place stress on relationships and contribute to social isolation

Caring for a person with mental ill health impacted on relationships within the family unit as well as the wider community. If the person with mental ill health lived in the same household as the Carer and other family members, the symptoms of the mental ill health condition were at times immediately apparent to others living in and visiting the household.

> *"It is challenging living with a person with a mental illness. It affects your wellbeing, your relationship with your partner and your wider relationships."*

The Australian Institute of Family Studies found that almost one in three female Carers aged 50 or less had separated or divorced since they started caring for a person with a disability, while one in seven over the age of 50 had separated or divorced since they started caring.[23] Our research elicited many stories to illustrate the impact that being a Mental Health Carer has had on relationships.

A number of Mental Health Carers in our research spoke about marriage and relationship breakdown. An Australian study found that in the general population, the wellbeing of people who were separated or divorced was 5 points below the normal range and that the process of caring depressed this by another 16-19 points. [24] Carers often have to deal with strong emotions, like anger, guilt, grief and distress that can spill into other relationships and cause conflict and frustration.[25]

We found that Mental Health Carers may not invite people to visit them at home because they were concerned about how the care recipient would be perceived, to protect the dignity of the person with mental ill health or out of safety concerns. This could cause Mental Health Carers to withdraw and contributed to social isolation, not only for the person with mental ill health, but for Carers themselves.

> *"My youngest is daughter is terrified and feels threatened and often runs outside refusing to come back in. It is hard to invite anyone over especially for her as she doesn't want to put her friends at risk. I have my parents...but they are in their seventies and my Mother carers for Dad. We often argue because we don't have any solutions and I do rely on them. My husband and I divorced due to the difficulties around our children and he still doesn't want to be proactive. It is embarrassing to him."*

> *"My concern is the impact his depression was having on the children. It is constantly difficult to buffer the children from his low moods and complacency."*

> *"I haven't had a girl friend – a female companion - in my life for 20 odd years."*

6.   Carers of a person with mental ill health sometimes feel unsafe in their homes

While research indicates that people receiving treatment for a mental illness are no more violent or dangerous than the general population,[26] violent and aggressive behaviour was reported by a number of Mental Health Carers in our research. This often occurred in the Carers' home and could be very distressing. For some Carers, violence generated fear but it also elicited concern, empathy and love. Indeed, research has shown that the more exposure a person has to someone with mental ill health, the less likely they are to perceive a person as being dangerous.[27] The fact that Carers are witnessing violence may be an indication of the inadequacy of society to adequately deal with mental ill health.

> *"Every day he wants to die, he is depressed, he smashes, throws and destroys things and then is remorseful, wonders why he does not have any friends, hit his siblings, look the list goes on."*

Mental Health Carers reported that violent behaviour can lead to damage and incur household repair costs for Carers.

Sometimes, Mental Health Carers were left with no choice but to call the police for support and assistance to resolve an unsafe situation. This could be a very difficult thing for Carers to do and was generally a last resort.

> *"I had to put a restraining order on him because he threatened to kill me."*

> *"The only option has been prison...it's either living on the street or being locked up."*

> *"The person gets emotionally unstable at times and tends to become fixated on certain aspects of life. The person then can rant and rave about this for several hours which I find somewhat frightening at times. The tirade can involve threats. After the event the person has no recollection of what they said."*

Some Carers also commented on their experiences with the justice system and the implementation of restraining orders. A few Carers spoke about the improvement in the health of their loved ones once they entered the prison system. While this was recognised as a positive outcome to some extent, **it is far from adequate to suggest that a person with mental ill health needs to be convicted of a crime before they are able to access appropriate care, treatment and accommodation.**

Threats of self-harm could also be particularly distressing for Mental Health Carers and others sharing the household. Indeed, the risk of self harm is more significant than killing another person: it has been calculated that the lifetime risk of someone with an illness such as schizophrenia seriously harming or killing another person is just .005%, while the risk of that person killing themselves is nearly 10%.[28]

> "I love him but I'm angry at him and I'm scared of him···In saying I'm scared of him we still live with that bit of hope that someday the tables turn and he'll get the help he needs and will get better."

> "It can be very challenging with other members living in the household at times· It does concern me especially when the person I care for attempts suicide and his sibling is in the house with him."

> "The person lives alone, this causes concern in relation to suicidal thoughts and medical issues."

> "I am very concerned about his isolation and his need to lock himself away that worries me a lot· I have also been placed in danger a couple of times because of his mood swings and his ability to lash out, and become somewhat violent at times because of his frustration and anger· This will pass very quickly but at the time when it has happened it can be very scary for me and I am very sad for him as I know he is just lashing out and he I hope doesn't mean it· He will always apologise to me but I am frightened, on these occasions· I also worry what will happen to him when I am no longer here who will look after him or look out for him who will speak up for him and who will defuse things when they are going wrong for him ???"

> "The violence is stronger and I'm getting weaker, she gets very 'needy' without considering my needs, the emotional torture is never ending."

Let's take action: 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.

7. Mental Health Carers worry about what will happen to the person they care for as they get older, and as the care recipient ages

We found that 82% (n=71) of Mental Health Carers worried about what will happen to the person they care for as the Carer gets older; and 88% (n=73) of Carers worried about what will happen to the person they care for as the care recipient gets older – with most strongly agreeing with these statements (compared to agree, disagree, strongly disagree). Some Mental Health Carers were unsure about their level of concern (around 5%).

> *"It's very scary – we live rurally and remote. In many ways my partner does not deal with people and town based living at all, at some point the land will become too great a responsibility and beyond my health capabilities. I fear the day of having to move greatly also to attain health services."*

Less than a fifth of Mental Health Carers (19%, n=73) had made some kind of plans for the future - for the time when they could no longer care for the person they cared for currently. This finding is supported by other research such as that undertaken by Anglicare (NSW), which found that only one in four ageing parent Carers had a transition plan in place for their care recipient. The researchers state that "One of the most significant causes of stress for ageing parent Carers is the future care and accommodation arrangements for their family member."[29]

Tasmanian Mental Health Carers' concerns into the future related to accessing services, having to move house, deteriorating health and co-morbidities (of both the care recipient and the Carer), social isolation of the care recipient, poor quality housing and maintenance, changes to the nature of relationships with age, living in rural or remote areas (including access to services, the need to relocate and stigma in small communities), inability of the Carer to do as much caring into the future, financial issues, and who will be the care recipient's advocate if the Carer is longer around.

> *"(My) biggest fear is that I die first and she is left alone!"*

> *"I am concerned that they will fall through the cracks, as there is not enough support. I can't trust that the system will work."*

> *"As the person I care for is now overweight, smokes and gets very little exercise I am concerned that he will in later life suffer further disease."*

> *"Only who will be there for him to advocate for him when I no longer am if he doesn't get the help he needs – this is my biggest fear and my heart ache, which I live with constantly. It saddens me to know end."*

8. Housing and the health of Carers

The challenges and barriers to sourcing adequate accommodation for their loved ones generated ongoing stress for many of the Mental Health Carers involved in our research. This places the health and wellbeing of Carers at risk.

International and Australian large-scale studies that focused on the mental health of primary Carers suggest that Carers had higher levels of depression, anxiety and stress, and lower levels of subjective wellbeing than people with no caring responsibilities, with female Carers being at particular risk.[30] Carers often ignored their own health and were 40% more likely to suffer from a chronic health condition.[31] An Australian report by Cummins et al (2007) states that "Carers have the lowest collective wellbeing of any group we have yet discovered". The researchers found that wellbeing decreases linearly as the number of hours spent caring increases and that there is no evidence that Carers adapt to their situation when caring continues for longer than 2 years.[32] Around 60% of Mental Health Carers in our research had been caring for more than 10 years with 19% caring for more than 20 years. Our research generated many stories to illustrate the impact of chronic stress associated with caring on Carer health and wellbeing:

"I worry…I will not be able to cope and this has probably played a part in being put on anti-depressants myself."

"His presence in my house created a massive extra workload and financial demand and seriously exacerbated my stress level and consequently my own illness. Finding an alternative was not possible and no help was available."

"The impact that my son has had on the household has been challenging to say the least. He is passive/aggressive, has a sense of entitlement, swears at me when he doesn't get his way, manipulates, bullies. I have asked him for mediation but he refuses. Here I am attempting to support his mental health at the expense of my own."

"It seems to me the Carer is the forgotten person in the equation – the services for the one with mental ill health (are) poor, the Carers' services (are) worse. If you present as intelligent and "together" then your own health needs get ignored until you reach a point of falling apart totally, this is a cheap way of caring for those with mental ill health and saving the costs to the taxpayer of massive caring obligations."

When we asked Mental Health Carers what physical or emotional effects they had experienced as a result of their caring role, 83% reported that their physical or emotional wellbeing had changed. Two-thirds of Carers said they frequently felt worried or depressed, and more than a third had been diagnosed with a stress-related illness. Only 6% of Carers were satisfied with their current situations. Figure 1 illustrates these findings further.

When we questioned Mental Health Carers about what they needed to assist them in their caring roles, 49% indicated that they needed an improvement in their own health and 60% said they needed more emotional support (n=63). Others indicated they needed more respite (22%,) more physical assistance (27%) and more courses to help them care for a person with mental ill health (40%).

Until we address the problems associated with living arrangements and accommodation for people with mental ill health, Carer health and wellbeing is likely to continue to be placed at risk.

Figure 1: Proportion of Mental Health Carers reporting physical or emotional effects due to caring role (n=64)
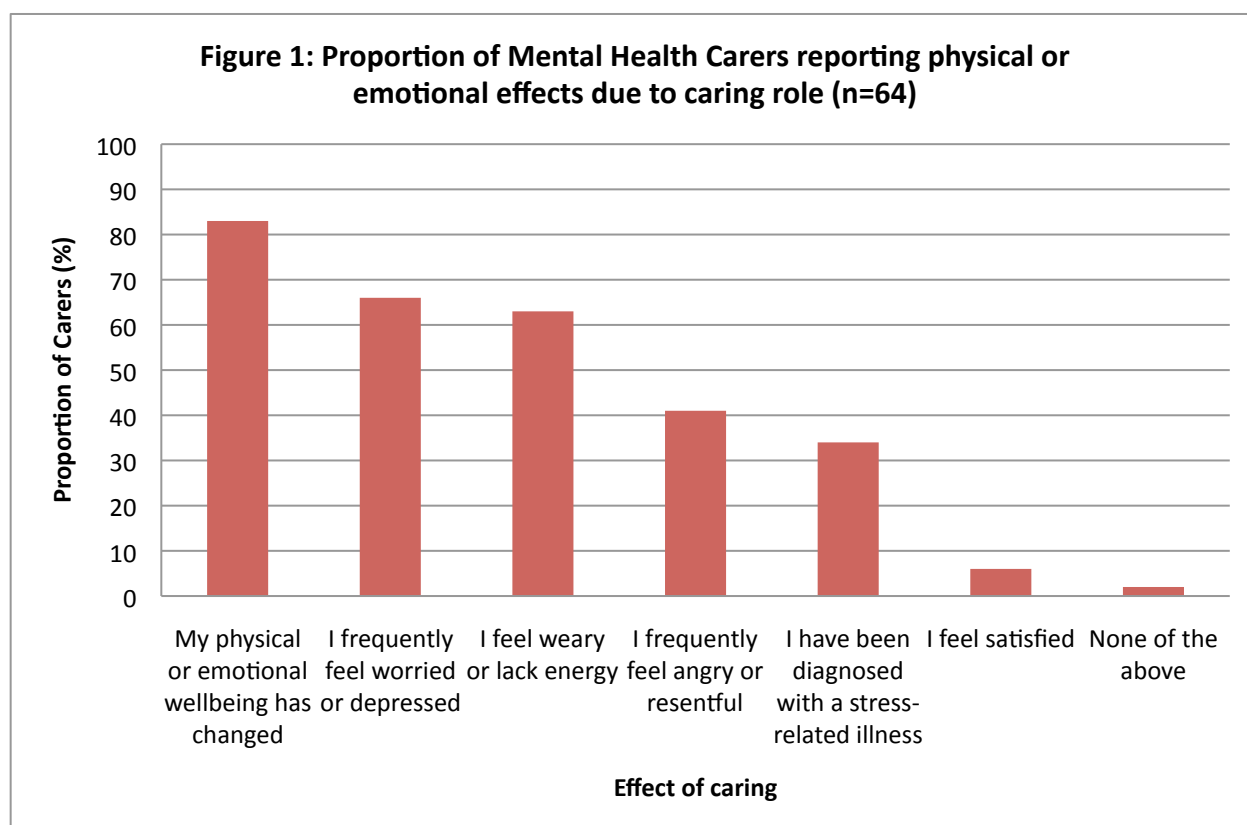
Concluding remarks

Our research has shown that there are many aspects of accommodation and living arrangements for people with mental ill health that require urgent attention. None of these issues are insurmountable. In the first instance it would appear that the priority goal must be to realise every individuals' right to adequate housing – in terms of legal security of tenure, availability of services, materials, facilities and infrastructure, affordability, accessibility, habitability, location and cultural adequacy.[33]

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

✓ 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 Tasmanians have 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.

✓ 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.

✓ 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.

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[34] – 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.[35]

- 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.[36]

- 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 of 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:
  o 68% of Mental Health Carers were caring for at least one person with depression
  o 60% were caring for someone with anxiety
  o 24% were caring for someone with substance use disorder
  o 24% were caring for someone with bipolar disorder
  o 21% were caring for someone with post-traumatic stress disorder
  o 19% were caring for someone with borderline personality disorder
  o 19% were caring for someone with schizophrenia
  o 17% were caring for someone with obsessive compulsive disorder
  o 6% were caring for someone with an eating disorder
  o 2% were caring for someone with schizoaffective disorder
  o 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%).[37]

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