



Position Paper:

Caring – a job & a half

*Based on the stories
of Mental Health
Carers in Tasmania*

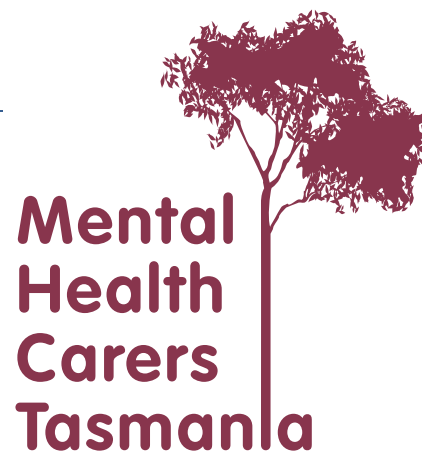
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Mental Health Carers Tasmania

T 03 6228 7448

E admin@mentalhealthcarerstas.org.au



Mental Health Carers Tasmania thanks Tasmania Medicare Local for funding the Caring Voices Project and the following partner organisations for their involvement in the Caring Voices Project Reference Group:



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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)

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 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 identify 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.

Contents

Introduction	7
1. Caring – a job and a half	8
2. Caring is expensive: Mental Health Carers need to work to make ends meet.....	11
3. Many Tasmanian workplaces are supportive of Mental Health Carers but further change is needed	13
4. The episodic nature of mental ill health adds additional challenges for working Carers.....	16
5. Due to lack of system-wide support, some Mental Health Carers are not able to participate in the paid workforce	17
6. By virtue of their caring role, Mental Health Carers are disadvantaged when it comes to employment opportunities.....	18
7. The daily impacts of caring follow Carers into the workplace.....	19
8. Work and the health of Mental Health Carers	20
9. It's about more than flexible workplaces: a culture of empathy and understanding is needed.....	23
Concluding remarks.....	24
Further supporting data related to this position paper	25

Introduction

Caring for a person with mental ill health (and chronic conditions) is “a job and a half”. While Mental Health Carers generally undertake their caring role because of their relationship to the person they care for, out of love, concern and a desire to care, or because of lack of other options - at the end of the day, many also see it as being a job.

Of course there are some fundamental differences: the Carer is not paid, they didn't ‘apply’ for the job and there is no ‘text book’ approach that best describes how to do the job. But like a job, it's time consuming, involves tasks, challenges and complexities, and can be life-defining. There is no doubt that Carers are the ‘invisible workforce’ of the health system.¹

In addition to their caring roles, many Carers are also involved in the paid workforce. Juggling caring with work commitments can be challenging for Mental Health Carers in Tasmania. Challenges which could be largely overcome by more compassionate, supportive and proactive mental health and Carer systems, and a more accepting society that is free from discrimination and stigma.

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.

Our research found

- Caring is a job and a half; in addition 57% of Mental Health Carers participated in the labour force
- Caring is expensive – Mental Health Carers need to work to make ends meet financially
- Many Tasmanian workplaces are supportive of Mental Health Carers but further change is needed
- The episodic nature of mental ill health creates additional challenges for working Carers
- Due to lack of system-wide support, some Mental Health Carers are not able to participate in the paid workforce
- By virtue of their caring role, Mental Health Carers are disadvantaged when it comes to employment opportunities
- The daily impacts of caring follow Carers into the workplace
- It's about more than flexible workplaces: a culture of empathy and understanding is needed
- Caring can have a negative impact on Carer health and wellbeing
- We need to act now to address these issues

1. Caring – a job and a half

Mental Health Carers in Tasmania are doing an incredible job of caring for persons with mental ill health (and chronic conditions). Our research identified many Carers that are involved on a daily basis in caring for their loved ones. Another one of our position papers – *A place to call home* – discusses a range of issues related to living arrangements and the role many Carers play in supporting their loved ones to undertake basic household tasks.

While most Carers spoke about the struggles that come with the caring role, a number of Carers also highlighted the positive aspects of being a Carer. Some Carers had seen improvements in the health of their loved ones. Others spoke about the skills they have gained as a result of their caring roles.

“It has both benefits and difficulties, overall it has enhanced my life to be able to have the privilege to help.”

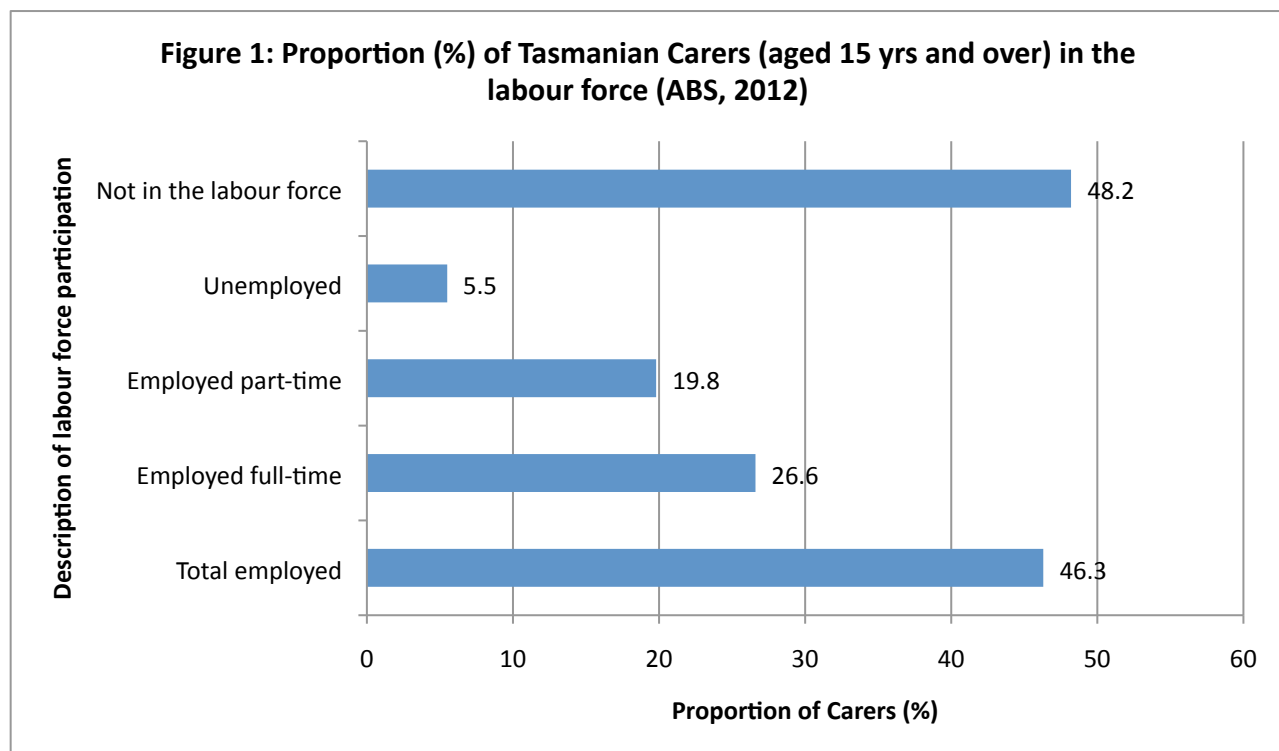
“I am now a much better person for the knowledge and experiences I have gained, and continue to do so.”

“It has brought me an enrichment but a restriction socially and work wise.”



Not only are Carers undertaking the job of caring, but many are also involved in studying, volunteering and/or the paid workforce (in addition to other roles within their families and communities). There's no doubt that Mental Health Carers have more than *"their hands full"*.

Figure 1 provides an overview of (all) Carers' involvement in the Tasmanian labour force.



In our research, 58% of Mental Health Carers (n=108) were employed. Of these 39% were employed full-time, 15% were employed part-time or casually and 3% were self-employed. Some research participants were not in the labour force as they were retired (40%). Others had health issues of their own that prevented them from working.

Many Mental Health Carers spoke about being involved in volunteering roles in the community, while some were also studying.

Studying, volunteering and working can be beneficial for Carers as it can provide opportunities to get some respite from caring, nurture wellbeing, build social connectedness and a sense of self-worth, as well as providing career-related and financial benefits. Our research found that 81% of working Mental Health Carers (n=59) were involved in the paid workforce because they want to:

"Work is important to help me have some normality, feel valued and help finances."

“That’s why I do the community work (volunteering) because then I get validation that I’m a worthwhile person.”

These Mental Health Carers want to work, and importantly they are *able* to. Being *able* to work is a really important consideration for Carers in the paid workforce as it essentially means: being able to create space in their lives to participate in paid work; being able to find a job with sufficient flexibility; having some sense of the need for ‘self care’ and personal growth; as well as the capacity and resilience to take on dual roles.

While many Carers are able to do this – not all are – but this (also) doesn’t mean combining working and caring is without its challenges. **For many Mental Health Carers, juggling the various components of their lives can be very stressful.**³

“As a parent with a child that has mental health issues I find it extremely hard to cope with life.”

“It was horrendous (working full time and caring). I left work because of caring.”

“It is very time consuming role caring for someone with severe mental health issues and working a demanding job – full time – plus looking after family, when you still have younger siblings at home and the demands that come with everyday life; also providing emotional support to the other family members.”

“They call me at work so I have to try to curtail the discussion while at work. Twice my friend rang me at work to say goodbye (intending to kill herself).”

“As a parent with a child that has mental health issues I find it extremely hard to cope with life. Working full time to be able to pay for all of my son’s doctors, medications and special needs is not an easy process when you’re dealing with mental illness plus working full time. How do you fit it all in? I also have my other child to worry about and also worry at how big an impact this is all on him as well. Many times I’ve thought of quitting my job to look after my mental health son but how do I then support him?”

2. Caring is expensive: Mental Health Carers need to work to make ends meet

“My income has decreased vastly and I have much higher living costs.”

Financial needs are an important reason why Mental Health Carers are involved in the paid workforce - 97% of working Carers (n=58) in our research agreed or strongly agreed with the statement: *I work because financially I need to, to make ends meet.*

National data found that 65% of primary Carers reside in households with standardised household income in the lowest two quintiles and 54.9% of primary Carers and 36.9% of all Carers have a government allowance or pension as their main source of income.⁴

Caring almost always leaves families and Carers worse off financially.⁵ Our research found that more than half of Mental Health Carers (55%, n=76) reported having extra expenses as a result of their caring role, and 12% said that their income had decreased. Almost half of Mental Health Carers (45%, n=75) said that caring had made it difficult for them to meet their everyday living costs.

“My daughter is always in need of “something” and I help her before I help myself, she has been sober 4 months but it’s still very costly for medications.”

“At times it has cost me heaps trying to pick up the pieces and also years of mental anguish.”

“My sole income now is the age pension. I’m lucky to have no mortgage and to be quite good at budgeting. However I constantly provide groceries, meals, transport, clothing, etc and have done so for years. I wouldn’t have it any other way but need to trim back my own expenses.”

Some Mental Health Carers spoke about why they continue to support their loved ones financially, including why they give them money upon request:

“I give him money - anything to keep the peace. It helps me as much as it helps him. I find it extremely difficult to say no.”

One Carer spoke about seeking advice from Tasmania’s Elder Abuse Helpline in relation to financial abuse. Being a Carer can also affect financial security in older age, particularly for women.

Most of the Mental Health Carers involved in our research were female (91%). National data found that, in Tasmania in 2012, over 66.8% primary Carers were female.⁶ “The superannuation system in Australia, which is tied to paid employment, financially disadvantages people who take time out of the workforce for caring responsibilities. Estimates from 2009-2010 suggest that the average (mean) superannuation payouts for women are just over half (57%) those of men.”⁷

“Before I retired I was in a high-level government position. When my son became unwell I found it extremely difficult to focus on work and family. Consequently, a couple of years later I changed roles and took on part-time work to reduce stress and increase the time I had available to support my son and his family. The longer-term impact of this was to reduce my superannuation and hence my capacity to provide as much financial support to my son and his family as I would have liked.”



3. Many Tasmanian workplaces are supportive of Mental Health Carers but further change is needed

More than 60% of the Mental Health Carers (n=48) surveyed for the Caring Voices Project reported that their employers knew about and were supportive of their caring roles. Around 80% of working Mental Health Carers (n= 46) felt that they were treated fairly in the workplace; and almost 69% said that their employers were flexible to enable them to successfully combine their caring roles with work commitments (n=45).

“I am fortunate as my (employment) is not 9-5 and involves situations where my partner can often accompany me. I tried holding down a regular job and it was impossible. I would have to leave frequently when my partner became highly distressed and felt unsafe being alone.”

While this is positive, around a third of research participants didn't agree with the statement: *My employer knows about and is supportive of my caring role*, and around 13% strongly disagreed.

“I work full time, I am a mother of a four year old and my partner for whom I am a Carer is the full time home Dad. My partner now has a chronic heart problem following recent heart attacks at age 37 as well as him continuing to manage his mental health and I also have some health issues and (am) awaiting surgery... I am on a good wage, however divide my wage by 2.5-3 and we are minimum income for a household, I receive no government assistance at all. Having to take sick leave and carers leave has seen me in a few situations where I had to take leave without pay which put us back financially as we have a mortgage and a personal loan. Not to mention the additional pressure I am now faced with at work due to my leave trends over the last three years - even though they understand and know my situation. The concept of family friendly and flexible work arrangements is good however it appears to only be something that looks good on paper in my organisation and unfortunately they are not walking the walk and not providing me with any flexible work arrangements (even though I could function 80% of my role at home). My organisation is a very large one and I will name it up and say it is Government!”

Some Mental Health Carers in our research said that they had difficulty finding a job that offered the flexibility they needed. Others commented on lack of employment opportunities in Tasmania in general and some had directly felt the impact of recent government cut backs to the sectors in which they usually sought employment (health, education and arts sectors).

National data identified that of the 109,400 primary Carers who are not employed, 25% indicated they would like to be employed, the majority of which (85.7%) would like to work part-time.⁸ Carers Australia states, “With nearly 20% of Australia's primary Carers identifying the main barrier to re-entering the

workforce while caring as the 'difficulty in arranging work hours', focused efforts are required to ensure that unpaid Carers are afforded the flexibility they need to combine work and care."⁹

"When (the) family member is experiencing a chronic episode it would be great if (my) workplace would allow (me to) work from home. I am limited by the number of carer leave days I can take and often use my annual leave to cover carer needs. This then impacts on me as it reduces paid leave available for myself and family to enjoy when better health allows."

"...there are no alternative care possibilities without my partner and I living apart. He would not cope without me around. There is always difficulty in organising work hours and to not cause distress to the person being cared for. (Other issues include) loss of skills, my own age and my own health conditions. (It's) exceptionally complex and employers would not be interested in trying to negotiate a pathway through."

A few Carers in the Caring Voices Project had not informed their employers of their caring situations, for a range of reasons relating to factors such as confidentiality and cultural norms. For some Mental Health Carers it is very difficult to ask for help. Others seek 'normality' and just want to be able to participate in the workplace as an equal.

"You just want to go to work feeling like an equal – not that people feel sorry for you."

"My employer is unaware that I care for others outside of my full-time role, this is due to my wanting to keep work and home very separate. It is also because I do not wish for my mistakes or failures within the role to be attributed to caring for someone else (not that this has yet been an issue, but people make assumptions rather than ask questions directly)."

"It is very difficult for me to ask someone for help. I'd rather die than ask for help. It is not my style to depend on somebody."

We mustn't forget that employers can be Carers too. The Caring Voices Project involved at least one employer who recognised themselves as a Carer of a number of people they employed who had mental ill health. Through the employer-employee relationship in the workplace, the Carer was able to provide information, be supportive and compassionate, and empower the care recipients (employees) to seek the help they needed.

"I'm the boss of our business. We treat our staff like family. I'm careful not to over step the mark because I am the boss. In the last 6 months I have helped about nine employees. I talk with them...give them information about the better mental health plans. I provide regular support. I feel passionate about the topic. Many have depression. I believe in people. One lady who tried to commit suicide had no family support. I put in place strategies so she could have support. Many people don't know about accessing the mental health plan. They don't understand how the system works. Usually a person will come in, in a state. I listen and I take out an A4 piece of paper and we write down the steps they can take. I give them a game plan. I get a huge sense of reward from seeing these people blossom. It's not my journey it's theirs."

Let's take action: We need Carer-friendly workplaces that embed the principles of Tasmania's Carer Policy 2013 and the Carers Recognition Act 2010.

While it is beyond the scope of the Caring Voices Project to delve into the issue of workforce participation by people with mental ill health, we feel that it is important to mention it, particularly because many Carers will tell you "if you solve the issues for my loved one – you will solve my issues".

National data shows that in 2011-12, 62% of working age Australians with a mental illness were employed, compared to 80% of those without a mental illness. Employment participation rates for this group were lowest in Tasmania at 52%.¹⁰ There are multiple and significant barriers to people with mental illness participating in education, training and employment. These barriers include issues specific to the nature of mental illness; stigma and discrimination; the perceptions, attitudes and understanding of employers; and structural issues associated with poorly coordinated services and financial disincentives to participate in work¹¹

A Federal Inquiry into mental health and workforce participation in 2012, stated:

*"the Committee was struck by how pervasive stigma remains in schools, workplaces and the community as a whole. It is for this reason that this report's leading recommendation is that the Commonwealth Government coordinate a comprehensive and multifaceted national education campaign to target stigma and reduce discrimination against people with a mental illness in Australian schools, workplaces and communities."*¹²

Let's take action: Improving the employment prospects of both people with mental ill health and their Carers requires urgent attention.

4. The episodic nature of mental ill health adds additional challenges for working Carers

Further insights from Mental Health Carers in our research revealed that greater recognition of the complexities of caring for a person with mental ill health and more support to participate in the paid workforce are needed.

“...I worry that one day he may attempt it and I won’t be home to save him.”

A number of Carers stated that they would like to work but that their caring role and the episodic nature of the care recipients’ mental ill health currently prevents them from working. While all Carers can experience challenges associated with caring for someone with a disability, chronic condition or terminal illness, or those who are frail aged, the nature of caring for someone with mental ill health presents unique risks, stresses, complications and isolation for Mental Health Carers.¹³

“The unpredictability of mental health moods make it very difficult for you to work as everyday is different and you are forever getting calls to take over where workers can’t cope.”

“While working I have to leave my child alone and I fear for his wellbeing as he becomes depressed and reclusive at times. He has voiced thoughts of suicide and I worry that one day he may attempt it and I won’t be home to save him.”

A few Carers spoke about the adverse impact of Carers working on the care recipient:

“You couldn’t have a full time job and care...When I was working full time, (names care recipient)’s health suffered because I wasn’t involved in his care. It’s hard unless you’re formally recognised as a Carer. When I was working full time, that was at the expense of (names care recipient)’s health.”

5. Due to lack of system-wide support, some Mental Health Carers are not able to participate in the paid workforce

Being a Carer for a person with mental ill health can be extremely time consuming, unpredictable and challenging and, can have a significant impact on a Carer's capacity (time, money, resources, health and wellbeing) and resilience. While not all Mental Health Carers are *struggling* all of the time, it was very apparent throughout the collection of data for the Caring Voices Project that there are times in the lives of many Carers when asking them to consider being involved in the paid workforce – in addition to the caring role – is quite simply unreasonable. It is unreasonable because the system at this point in time is not able to adequately deal with the needs and issues of persons with mental ill health (and chronic conditions). **Until Mental Health Carers get the recognition and support they need (and their loved ones need) it is unreasonable to expect them to participate in the paid workforce to the same extent that non-carers do.** Indeed, Australian data shows that Tasmanian Carers had a lower labour force participation rate (51.6%) than people who were not Carers (64.2%)¹⁴

"If I want back to work our family would fall apart, it's that simple."

"I am working, get that straight; I just don't get an hourly rate. I have more than a full time job. I have to deal with a person who increasingly has become suspicious and can dream up unreal events, but think they really happened. I have to smile and be relaxed and hide all my fears, grief, anger, resentment, and at least appear relaxed. I do get depressed myself...I am not worried about a job, I am worried about how to make it through the next day!!! I feel like socially I am dead. I feel like I don't know exactly where to go or what to do if I am free on occasion. If I had a little job that I could do well at, and have a vacation from the vacuum of human interaction at home I would jump at it. But, for that to be possible there has to be an actual job offered and I don't have time to look. There has to be enough sorted out very very well, so that I could be free to do a job. In the main I just hope I can survive doing the job I want to do, the one I am trying to do."

"There are not enough hours in the day, nor do I have the energy and capacity to add onto the responsibilities I currently have. My availability is always unpredictable, I am no longer able to make commitments to others with any certainty that I can keep them. There are lots and lots of things I must do to keep us in groceries, the bills paid, the house maintenance and to maintain a car to enable us to get to Doctors. I am the only driver."

6. By virtue of their caring role, Mental Health Carers are disadvantaged when it comes to employment opportunities

Although those involved in the paid-workforce largely felt they were treated fairly by Tasmanian employers (80%, n=46), it was evident in the Caring Voices Project that Mental Health Carers are at a distinct disadvantage when it comes to overall job opportunities. Some Carers are simply not able to even contemplate getting a job, whereas others work less than they might otherwise. It has been reported elsewhere that:

“the provision of unpaid care has a negative impact on unpaid Carers’ participation in employment and work hours. In addition, Carers are more likely to leave employment than reduce their work hours when taking on caring roles. This has a significant impact on the incomes of Carers over their life course putting them at risk of poor mental health and poverty later in life.”¹⁵

Those who are only on casual work arrangements are considerably disadvantaged due to the lack of leave entitlements – which are crucial for many Carers. “Unpaid Carers, particularly women, have significantly lower rates of workforce participation and are more likely to work in part-time and casual jobs as well as in forms of insecure work.”¹⁶

“I can only work casually which gives me the flexibility to call in as unavailable if my husband is too unwell to leave him. Unfortunately this means no holiday or sick pay and no work no pay. You never know how much you will have to live off each fortnight. Financial stress is always there.”



7. The daily impacts of caring follow Carers into the workplace

“The emotional toll caring can sometimes take on you, can also be reflected in your work or work relationships.”

When I’m at work I am tired and often emotionally drained

“Caring for my husband is emotionally really hard. Many tears have been shed, many arguments held and many threats of suicide as you can imagine. Coming to work and being professional and responsible while my family life is falling apart is the biggest issue. He is getting counselling now, so things have improved, but it is a constant source of concern which is distracting me from work.”

“My productivity in the workplace is reduced due to the stress of providing emotional and other support to my partner.”

“You cannot switch off from the constant potential impact of a volatile mental illness so part of your mind is always preparing for the next ‘assault’. This means you can’t always focus 100% on your work requirements.”

For many Mental Health Carers, caring is a 24hr/7day-a-week role, even if they are not physically present with the care recipient all of the time. The caring role does not cease to exist just because the Carer goes to work. For many it is every present in their minds and can impact on their concentration, mindfulness and productivity at work.



8. Work and the health of Mental Health Carers

Our research found that caring for a person with mental ill health often generates feelings of grief for Mental Health Carers. While many Carers spoke about the love they have for the person they cared for, this was often coupled with expressions of deep sadness and loss over the situation. And even though participating in the paid workforce can provide positive outcomes for Carers, we also found that the pathway of workforce participation does not necessary follow a stable path.

“It caused me a lot of grief (to stop working)…I tried to continue working but it was an enormous strain.”

“Grief is a constant companion – that a beautiful talented girl is sinking down through levels of society, making terrible choices and emotionally scarring her children.”

“(The main effect of caring has been) the need to manage the pain and grief of loss – not only initially but over a lifetime.”

The chronic stress that many Mental Health Carers experience places their health and wellbeing 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.¹⁷ Carers often ignored their own health and were 40% more likely to suffer from a chronic health condition.¹⁸ 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 decreased linearly as the number of hours spent caring increased and that there was no evidence that Carers adapt to their situation when caring continues for longer than 2 years.¹⁹ 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:

“What kills me is my loneliness. The workload I can manage with my brains but my soul is hurting.”

“My health is deteriorating due to my age and constant worry (that) my husband will not continue to receive the care he needs.”

"It is stressful and impacts on my own anxiety disorder."

"(Caring has) Exhausted me both mentally and physically. I have just returned to limited employment after seven years of only caring. I felt broken and totally useless after the trauma of caring and witnessing. I now suffer Post Traumatic Stress Disorder."

"It effect all aspects of my life...(it's resulted in a) HUGE increase in stress. (I feel) failure as parent. There's the strain of having to hold down a full time paid position and (be a) full time Carer. There (is) no let up 24hrs/day/7 days/ week... (There is) no time as a Carer to look after one's self and also (I'm) purposely over eating hoping that a severe medical situation would occur, i.e. death so you don't have to be in that situation anymore, as there never seems an end and there is no time to seek out service/help for one's self - all offers of help focus on the patient not the Carer/s."

"...there are many more people out there worse off than myself and even though there are some days where I am just exhausted and I do question how long it will be until I visit (names health service) as a patient myself and then you just keep going...because you have to - feeling at times like I can never actually be sick myself and that life is and will never be about me - feeling of responsibility at times and weight of this (regarding) financial stressors plus having at times to feel like you have to pretend everything is just fine because you don't want to add more stress or pressure to the person you are caring for."

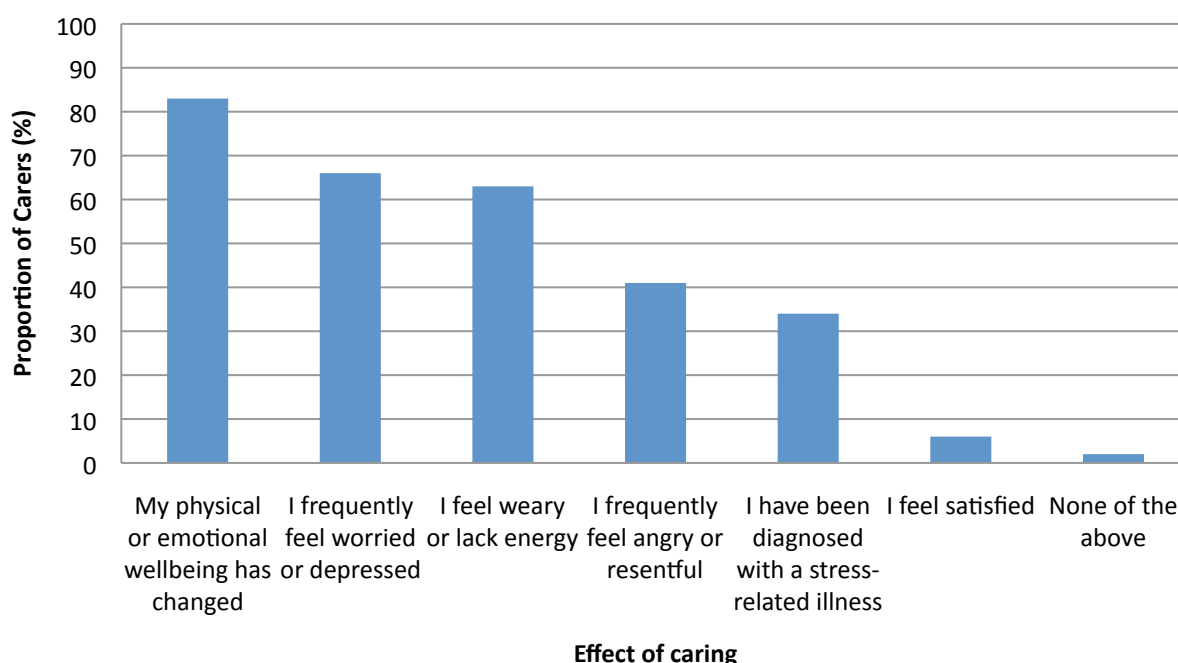
"I am confused about where I went wrong. What do I do wrong on a daily basis to add to this person's mental health condition? I feel I need to tip-toe around so as not to upset the apple cart. I am anxious and feel that I am going on a downhill spiral myself! I lose so much sleep!"

I have lots of unshed tears! It can be hard to find the line between never giving up, never walking out, and becoming exhausted. Tears fall now, that's good, a release."

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 2 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%).

Figure 2: Proportion of Mental Health Carers reporting physical or emotional effects due to caring role (n=64)



9. It's about more than flexible workplaces: a culture of empathy and understanding is needed

Flexible and supportive work arrangements are very important, but we must go beyond this if Mental Health Carers are to be encouraged to participate in the workforce and to feel truly supported in the workplace. Mental Health Carers don't operate in silos. As stated earlier, Carers don't leave their caring role behind when they step into the workplace. Carers need empathy, genuine ongoing support, and to be part of a culture that values and nurtures its working Mental Health Carers. Carers need evidence of a commitment to equality and a system that recognises the interconnectedness of the various components of the caring role.

"We have little family support and few friends. We have moved here from interstate. I am juggling work, supporting husband, trying to get justice for the accident (which led to the caring situation). My work is stressful as a support worker. This has become a great shock to both of us. My job is isolated with no co-worker support."

Our research has shown that many working Carers are experiencing undue stresses associated with their dual roles and responsibilities. More must be done to support Carers to participate in the workforce if they are able to. The Australian Human Rights Commission sums up some of what is needed:

"In order to assist unpaid Carers in the workplace to balance their work and caring responsibilities, it is essential to remove the stigma of caring responsibilities. In order to value unpaid caring, it is necessary to create a cultural change in our society and our workplaces....Leadership from employers in challenging the rigid distinctions between those who undertake paid work and unpaid care will be essential to any cultural shift in our society. There is a strong business case for workplaces to better support unpaid Carers, with gains for efficiency, productivity and diversity, particularly in terms of retaining women workers with caring responsibilities."



Let's take action: Stamp out stigma associated with mental ill health and caring for people with mental ill health.

Concluding remarks

Our research has shown that while many Mental Health Carers value their involvement in the paid workforce, the dual roles are taking their toll. We must do more to support Carers who are able to participate in the paid work force.

In addition, Carers everywhere should be recognised, respected and valued for their caring role (regardless of whether or not they are involved in the labour force). Mental Health Carers give so much in terms of their love, support and assistance to people living with mental ill health, but not only that they are making an enormous contribution financially and socially to our economy and communities.

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

- ✓ We need Carer-friendly workplaces that embed the principles of Tasmania's Carer Policy 2013 and the Carers Recognition Act 2010.
- ✓ Improving the employment prospects of both people with mental ill health and their Carers requires urgent attention.
- ✓ Stamp out stigma associated with mental ill health and caring for people with mental ill health.

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 2012²⁰ – 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.²¹
- 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.²²
- 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 addition 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%).²³

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