



## **Carers Tasmania submission to the Royal Commission into aged care quality and safety**

**March 2019**

## Introduction

Carers Tasmania is the peak body for informal carers in Tasmania.

A carer is a person who is providing, or who has provided, unpaid care and support to a family member or friend who is living with a disability, mental illness, chronic condition or life-limiting illness or who are frail and aged.

As well as peak body work, Carers Tasmania supports carers across the caring journey. A carer of someone who is ageing may begin their caring journey providing companionship and “checking in” to see if the person is ok. Gradually or suddenly, depending on the health of the older person, caring can develop into assisting the person to maintain social commitments, attending medical appointments extend to helping them with cooking and shopping. It may even extend to the provision of personal care, the time commitment and consequences significantly increasing for the carer.

When care needs are significant, it may become the role of the carer to assist the ageing person to navigate the age care system. This can involve arrangements for assessments, co-ordinating medical and associated appointments, helping to manage Home Care Packages, and furthermore assisting in the process of entering a residential aged care facility. This is a whole different layer of caring responsibility and can be complex, stressful and time consuming to navigate.

A carer often remains heavily involved, even when the person has external support such as an aged care package in their own home. The need to provide significant care may be exacerbated by long wait lists for a Home Care Package, the person having a lower level package than they require, or not being able to access lower level interim services such as Community Home Support Packages as there is no availability in the service type or types needed. For the person eligible and for the carer, this is a significant issue. This remains the case for many people despite funding increases in December 2018, with supply still unable to meet the critical shortages in home care and home support<sup>1</sup>. Carers Tasmania is aware of many carers who “burn out”, unable to continue to care whilst waiting for a home care package, with the person then having no option but to enter residential care.

Carers rarely cease their caring relationship when the person enters residential aged care. Carers usually remain the closest emotional tie, and continue to provide emotional and social support, attend medical and related appointments, and often become involved in liaison and advocacy with the aged care facility. They also “fill the gaps” in the care when facilities are short staffed. For example, a carer may often plan their visits to coincide with mealtimes to ensure the person will have the assistance they need, as it may be the only way they will have dedicated support to eat.

The contribution of carers is economically significant, with the replacement costs valued at \$60.3 billion in 2015, and a forecast of the demand for informal care outstripping supply in the next ten years<sup>2</sup>. This is well known and often acknowledged, by Government and the sector, but a consistent culture of carer awareness and inclusion does not yet exist.

Carers often perform their role without full acknowledgment, inclusion and support with significant cost to their wellbeing. The Australian Unity Personal Wellbeing Index shows carers had the

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<sup>1</sup> Community Care Review December 2018: <https://www.australianagenda.com.au/2018/12/17/10000-home-care-packages-funded-in-550m-aged-care-boost/>

<sup>2</sup> Deloitte Access Economics 2015: The economic value of informal care in Australia in 2015

lowest personal wellbeing index of any group, with the highest levels of stress, anxiety and depression<sup>3</sup>.

## The Wellbeing of Australians (Carer Health and Wellbeing)

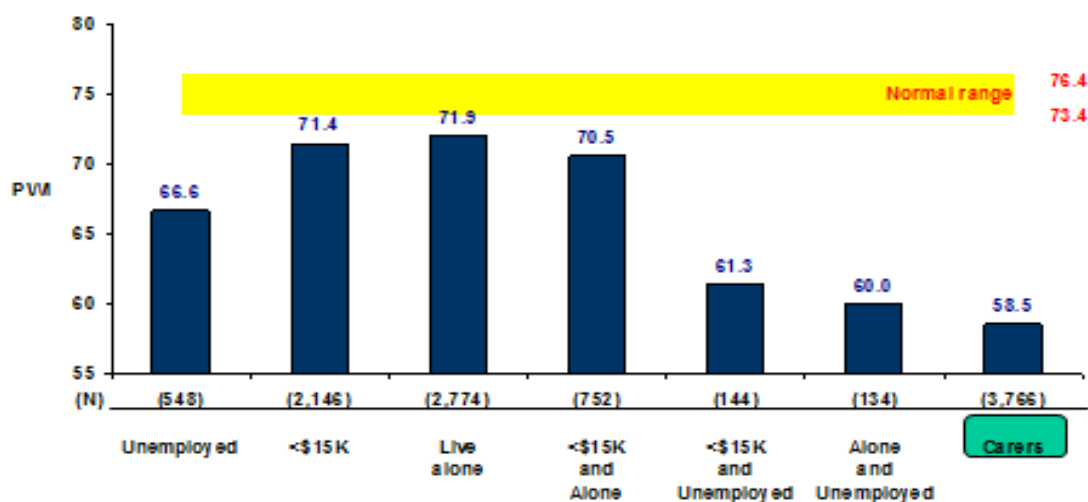


Figure 1. Personal Wellbeing Index

The situation in Tasmania is amplified by the make-up of the Tasmanian population. Tasmania has the oldest population in Australia per head of capita with 19.4 % aged 65 or more and the highest median age of 42 years<sup>4</sup>. Tasmania's population is ageing faster than the Australian average, with those aged over 65 increasing by 34% from 2011 to 2016, compared to a 1.7% increase for the whole of Australia<sup>5</sup>. There are some regions, such as Triabunna – Bicheno, where almost a third of the population is 65 years and older<sup>6</sup>.

It is not surprising, therefore, that Tasmania has approximately 85,500 carers, representing 16.4% of the population. This is highest per capita rate of carers across all states and territories<sup>7</sup>.

A major concern for Tasmania is the projected increase in diagnosed cases of dementia. According to the Australian Institute of Health and Welfare, cases of dementia in Australia are projected to rise to almost 400,000 by 2020 and tripling between 2011 and 2050<sup>8</sup>. The impact on

<sup>3</sup> Cummins, R Deakin University 2007. Report Revised 2015 – What makes us Happy; Australian Unity

<sup>4</sup> Australian Bureau of Statistics: 2016 Census QuickStats Tasmania

<sup>5</sup> Australian Bureau of Statistics: 2011 Census Quickstats Tasmania

<sup>6</sup> Australian Bureau of Statistics: 2015 Population by Age and Sex, Regions of Australia 3235.0

<sup>7</sup> Australian Bureau of Statistics 2015: Disability, Ageing and Carers Australia: Summary of Findings Data Cube 443300do030

<sup>8</sup> Australian Institute of Health and Welfare 2012: Dementia in Australia

Tasmania will be significant. In fact, dementia is already one of two joint leading causes of death for females in Tasmania in 2016<sup>9</sup>.

Older Australians have articulated a desire to retain their independence, and in the case of people with dementia, their home is critical to their quality of life. Continuing to live in their family home and share their lives with loved ones is of primary significance in enabling a person with dementia to cope with the challenges of loss of memory function. Carers become critical in supporting a person to continue to live independently<sup>10</sup>. Consequently, the need for adequate supports for carers to sustain them in their role is also critical.

The role of family carers and their needs in supporting people with dementia should not be underestimated. Dementia Australia's 2015 paper demonstrates the vast majority of people with dementia are living in the community, (91%) rely on an informal carer, and nearly a quarter of those people do not access any formal care services. 81% of co-resident informal carers provide more than 40 hours of care per week. However, the report stated 54% of carers of people with dementia are of working age, and only 56% of these were employed at the time of the survey<sup>11</sup>. This time out of the workforce can have significant social and financial consequences for the carer and indicates the need for adequate supports and the need for carer friendly workplaces.

The Australian Bureau of Statistic's 2015 Survey of Disability, Ageing and Carers, found 76% of primary carers over the age of 65 were the partner of the person they care for. More than a third of primary carers between the ages of 70 – 79 were providing 40 hours or more of care a week, and just under a third were providing more than 60 hours of care. 42% of carers over the age of 80 were providing 40 or more hours of care, and 34% provided 60 or more hours<sup>12</sup>.

Therefore, a significant proportion of Tasmanians require or provide care, and potentially both. For these reasons, Carers Tasmania is highly invested in being a part of the conversation regarding Aged Care Quality and Safety.

As part of a national network of associations, Carers Tasmania was asked by Carers Australia to provide input into the Terms of Reference for the Inquiry.

Carers Tasmania sent an email to its members, and was surprised by the immediate response, receiving over fifty replies in two days. Some respondents were currently caring for someone receiving support at home or in residential care. Others were no longer caring as the person had died, but they wanted to share their thoughts and experiences. Interestingly, several people were caring for a family member and work in aged care. It is the voices of these people that inform our feedback to the Commission.

The following are all issues raised by carers.

## Quality

Significant concern was expressed regarding the quality of residential services. Comments made are consistent with many of the concerns and recommendations in the Aged Care Workforce Strategy<sup>13</sup>. There is significant distress demonstrated in some of the comments. Respondents express the need for residential and home care staff to be engaged and empathic, and that adequate remuneration and provisions for career advancement may assist with the calibre of

<sup>9</sup> Communities Tasmania 2018: Women and Girls in Tasmania Factsheet 2018

<sup>10</sup> Gabriel, M., Stirling, C., Faulkner, D., Lloyd, B. 2014: Future housing and support needs of people with dementia

<sup>11</sup> Dementia Australia 2015: Caring for Someone with Dementia: The economic, social and health impacts of caring and evidence-based supports for carers.

<sup>12</sup> Australian Bureau of Statistics: 2015 Survey of Disability, Ageing and Carers

<sup>13</sup> Aged Care Workforce Strategy Taskforce 2018: A matter of care: Australia's Aged Care Workforce Strategy

staff in the sector. Respondents suggested the need for staff to be adequately trained in dementia, mental illness, cognitive impairment and end of life care. This was seen to be necessary for staff in both community and residential settings.

*“If you walk in a home, it is evident that young and cheap labour makes for higher levels of profitability. And then you see the few well trained, experienced nurses and carers, go over and beyond, yet need to battle every day with insubordinate younger staff who are paid a pittance and are not shown/mentored into a career path.”*

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*“I’ve compiled the following list based on my negative experience of 3 different aged care homes in Launceston in the space of 10 months:*

- *Staffing levels are grossly insufficient - particularly the overnight shift.*
- *Aged care nurses and carers need more training in mental health issues, particularly anxiety & depression*
- *Aged care nurses need more training in medications (including for mental health) not just administer them*
- *Aged care staff need to be screened more carefully before being employed*
- *A change of ‘culture’ and ‘attitude’ is required and respect for residents, by carers and nurses, needs to be restored*
- *Doctors need to visit residents more often and have more input into the residents’ care plans.”*

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*“I have worked in the aged care industry and my Grandfather was cared for in a nursing home. When I worked in aged care there was not enough time for personal care which resulted in inadequate care, bed sores, and not having incontinence aids changed regularly. Many carers (paid care workers) I came across were only in it for the money and did not show compassion, respect, or patience towards the person being cared for. When I saw inappropriate situations happening, I put in a complaint, and was bullied and ostracised in my workplace. When working in the aged care industry, there is not enough time to give the appropriate care to someone. but I could not sit and chat with an older person. Many are yearning for one on one time, because of the time limits on care. I was always rushing from one person to another, not having enough time to provide the care these people deserve”.*

*“I supported my elderly Dad at home for many years. He then moved into aged care, but after three weeks deteriorated dramatically and ended up at a mental health assessment facility for older people, where we had significant concerns about his care. Dad had a fall and suffered a broken hip, this led to pneumonia and he died. A coroner's inquest was held with recommendations made for the facility to implement. This was an absolutely heartbreaking, gut wrenching and tragic time for my Dad, my sister and me. My sister and I were left traumatised by the experience and aghast that our Dad went from a mobile, quiet but aware aged man in May 2013 when he entered aged care to a psychotic, delusional and disengaged person who passed away two months later (July 2013). His fall was not even reported to ambulance and hospital authorities until 8 hours later with no accurate information as to whether Dad had sufficient pain management and/or support during this time (as noted by Coroner's as well as Medical Health Complaints report). I still feel at some level, that my sister's non-Hodgkin's lymphoma was impacted by this ongoing stress and she passed away last year with a lingering anger and sorrow about how everything unfolded for our Dad.”*

The need for training in supporting people with anxiety and depression was also raised as was one carer's story of their family member being abused.

*“The Commission should consider how to best and appropriately support elderly people with mental health/psychological difficulties that is respectful and non-confrontational. The methods I witnessed only served to exacerbate the problems and increase the confusion and anger within the elderly.”*

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*“My Grandfather (diagnosed with Alzheimer's) was physically abused by a carer (caught in the act), and no appropriate discipline was actioned, the carer was still employed at the workplace, and a quick decline in my Grandfather's health followed”.*

Carers also expressed concerns regarding the quality of care provided in a for profit environment.

*“Last year the nursing home was owned by a Not for Profit Organisation and the care was more personal and those that needed it were given the attention. At the end of last year, a For Profit Organisation, took over and the care and attitude changed. The staff had hours cut and there were staff cuts as well. I think this greatly impacted on the care my grandmother received and the fact that she choked on her food and passed away.”*

Carers Tasmania has heard carers say their previous experiences with aged care and the recent media attention has resulted in mistrust and a reluctance to access services, potentially resulting in greater responsibilities for them with potential impact on their wellbeing.

*Because of what we have seen in this industry, my family are ensuring our mother will not go into a nursing home and will be lovingly cared for at home.*

Carers Tasmania's consultation with its Family Carers Peak Advisory Council regarding this submission also revealed a number of recommendations from stakeholders representing Tasmania's diversity.

Recommendations included the need for aged care services to be "culturally and linguistically appropriate", and implement the actions recommended in the National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) backgrounds<sup>14</sup>.

The word carer does not exist literally or conceptually in some languages, and studies have shown ageing carers from culturally and linguistically diverse backgrounds rely mostly on family members rather than utilising formal respite due to a lack of suitable options and stigma. This suggests residential facilities and services providing home care supports need to provide targeted support to this client group with a holistic approach that routinely includes and supports carers and families.

Similarly, people who identify as LGBTI and their carers have specific needs. LGBTI people are more likely to be carers and rely on intimate partners and friends as carers. This is attributed to older LGBTI people having less contact with biological family and may be less likely to have children. It has also been attributed to their historical experiences of discrimination – which have contributed to delays accessing formal services due to fear of discrimination. Latrobe University's evidence-based resource "An Extra Degree of Difficulty – An evidence-based resource exploring the experiences and needs of Older LGBTI carers and the carers of older LGBTI people is a valuable resource which could be used to improve the outcomes for this group."<sup>15</sup> Recommendations include:

- That the LGBTI community are routinely consulted in the development of services that affect them.
- Government mandated templates and documentation is LGBTI inclusive
- That there is provision of information to LGBTI carers to assist them to locate LGBTI inclusive supports, and that they have sufficient opportunities for respite and debriefing
- That service providers use the LGBTI Self-Assessment and Planning Tool to implement strategies to provide inclusive services
- The need for services to have clear leadership around the provision of LGBTI inclusive service delivery, and provide a welcoming space
- For there to be specific supports for LGBTI carers and those supporting carer groups be skilled in providing an inclusive environment
- For the layers of grief experienced by older LGBTI carers to be recognised and that support is provided.
- For LGBTI carers be recognised when providing care and are included in decisions about care
- That services in rural and remote areas are supported to develop creative ways of supporting LGBTI carers.

### **Adequacy of home care supports**

Regular feedback from carers to Carers Tasmania's Carer Support Staff is that in-home care needs to be more flexible than it currently is, and that the supports provided should occur at a time that is convenient for the person rather than the service provider. Feedback also raised a concern that workers require more clinical training:

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<sup>14</sup> Commonwealth of Australia (Department of Social Services) 2015: National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse backgrounds

<sup>15</sup> Barret, C; Cramer, P (2015) An extra degree of difficulty: An evidence-based resource exploring the experiences and needs of older LGBTI carers and the carers of older LGBTI people. Australian Research Centre in Sex, Health and Society, Latrobe University, Melbourne Australia

*“My 96-year-old disabled mother lives with me and my husband, neither of us young, and I have no relatives to assist. We rely entirely on the help of an in-home service provider. Some of their staff are excellent but others have no training. Very few of them know, for example, how to recognise symptoms of stroke, heart attack or other likely medical emergencies when they take their charges out of the home for outside activities. They do not have basic training in dementia, which is not always obvious to a casual observer in its early stages. Neither are they trained in specific handling methods for elderly people.”*

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*“Perhaps the plight of people being cared for at home should also be looked at. I have recently had my own struggles with a system that is inflexible and has a “one size fits all” attitude. It is difficult to get help and understanding. The system promises the moon and delivers little.”*

With an increase in the self-management of home care packages, carers are often in the position of having an additional role of administration and management, along with the practical support they usually provide. While carers with administrative experience may be well placed to take on this role and have positive outcomes as a result of greater choice and control, the associated tasks can be complex, and carers can feel out of their depth. Regular training for carers in this area may be beneficial in ensuring they are equipped to take on this role.

*“We were on a wait list for two years before my husband was allocated a Level 4 Home Care Package. Before we had one hour a week of support through home and community care, and the support staff would turn up at any time, sometimes forgot to come, and there was only one company in my regional area. When the package came through, I investigated self-management, and I now have a service provider assist me manage the package. I had an advocacy agency help me set up the package, and it was amazing what a difference that made. Together, we had good outcomes. We usually pay the accounts and are reimbursed at the end of the month. If there is any reason, we are unable to pay, the organisation will pay the provider directly, which is very helpful. We tend to use local people to help us, I have put adds up in the shops. This works well in the remote area where we live. It also means we are charged the standard rates charged in the community, not the inflated rates charged when service providers know you have a package. I make sure those who provide personal care are qualified and have a police check. I have been able to negotiate to use the package to purchase necessary equipment, medications not on the PBS, and have been able to use funds for home modifications, because there was funding available in my account to do so. I don’t think enough people know about this option”.*

One carer has recently raised the issue of the vulnerability of those with dementia requiring care when care is provided at home. Paid support workers do not undergo random drug testing and could take the medication of the person or consume alcohol belonging to the person with dementia, without supervision or accountability. After thinking this through, the carer spoke to the service provider and installed Arlo cameras which she could log into from her mobile phone, with a sign stating cameras were in use were on display. These cameras were purchased with funding from the package. Strategies to address these vulnerabilities may be something for the Commission to consider.

A need for a preventative approach was expressed by a carer facing challenges associated with living in a regional area.



*“We live in a regional area. One major issue we had was that Dad's local GP would often prescribe him medications, but this could be confusing for Dad if neither my sister nor I could travel to be there to support him. He often told us that he was taking medications, but he had no idea why. He would go to the Doctor but put on a brave stoic face and I often felt that the GP was not reading between the lines. I believe that Community Health nurses need to be following up and monitoring the elderly within their homes in regional communities, particularly those like my Dad who lived alone. I always lobbied for this to happen, saying that community health needs to be just that - a proactive service. I was always informed that the local nurses could only visit if Dad had a wound.”*

### **Carer Inclusion**

Interestingly, part of the unifying vision of care in the Aged Care Workforce Strategy is “We strive to enable people to properly care — for their neighbours, friends or family”. However, there are no strategic actions focused on the needs of carers within this strategy.

Carers are increasingly identified as key players in aged care and are even included in the definition of consumers. However, this does not often translate to a culture of carer awareness which would include the routine identification, inclusion and support of carers. The need for carer inclusion may be more obvious when care is provided at home but is just as important in residential care as this feedback demonstrates:

*“Facilities need to have awareness that families do need to be involved with clear communication and two-way conversations e.g. planned family meetings to share concerns and review status. It was assumed that we were disinterested, and we were often overlooked or perceived as confrontational when we were simply confused and lost within a system that was alien to anything we had ever experienced before. This was even more difficult to process as my sister and I were two highly educated women with so called excellent communication skills used to dealing with systems as we both had leadership positions within government departments. We continually felt concerned for other families who could not advocate for themselves given how amazingly difficult and confusing we were finding our journey!!”*

The carer often has unique insights into the needs of the person requiring care. The Statement for Australia's Carers in the Carer Recognition Act 2010 makes it clear the relationship between the carer and the person for whom they care should be recognised and respected. It also states carers should be considered as partners with other care providers in the provision of care, acknowledging their unique knowledge and experience<sup>16</sup>. It is unlikely the majority of aged care providers are aware of this Act. The Act could be part of the routine orientation and training of staff and embedded into the culture of aged care services.

It is interesting to note that 56% of complaints to the Aged Care Complaints Commission in 2017 – 2018 were from representatives or family members<sup>17</sup>. Better outcomes for family members could occur with routine engagement in everyday interactions and inbuilt mechanisms for feedback such as the provision of consumer and carer forums that would provide feedback to managers and staff on issues as they arise.

<sup>16</sup> Australian Government 2010: Carer Recognition Act 2010

<sup>17</sup> Aged Care Complaints Commissioner: Annual Report 2017 - 2018

The Royal Commissions' Background Paper 1 – Navigating the Maze: An Overview of Australia's Current Aged Care System<sup>18</sup> acknowledges most of the care and support required by older people is provided by informal carers, and the economic contribution carers provide with this labour. The Commission goes no further regarding the need to identify, include and support carers. This indicates the need for a cultural shift for a truly carer inclusive society, that values and supports those making such a significant contribution.

### **Access to respite**

Carers NSW's 2016 national survey of carers' respite needs found that more than one in three of its 1,803 respondents had never used respite. The most common reasons were not knowing where or how to access it and being unable to find anything that suits the needs of the person requiring care<sup>19</sup>.

This may become even more difficult under upcoming reform. Current information on the Integrated Carer Support Service model suggests under this new system there will be no central point organising respite, and carers will be required to contact each aged care facility unless they have a case manager. This will place a further burden on carers, who already find navigating the system challenging.

Carers Tasmania is aware carers have significant issues with residential/cottage respite, including there being a minimum of seven days booking for residential respite. Carers don't always need or want this amount of respite.

Also, whilst they might really need a break from their caring role, they can be reluctant to use it. If the carer perception is the quality of the care provided is inadequate, and the experience is distressing for the person requiring the care, using respite can be perceived to create more difficulties for the carer upon their return home, and therefore avoided.

One suggestion from a carer was the development of a "series of respite homes rather like, hotels for the elderly or disabled" where domestic and personal assistance were provided but the "emphasis is on giving the clients a happy experience of companionship and stimulation for the duration of their stay. Such places could offer activities for non-residents to extend social activities for those living at home who don't have family available to support them during their work hours.

### **Financial issues**

Carers often find themselves dealing with significant bureaucratic processes in facilitating a family member's access to services. While these may fall outside the scope of the commission, they must be acknowledged as having significant impact on the stress levels of carers. Examples:

- One carer reported waiting eight months for daily fees and means testing to be processed by Centrelink, impacting on the capacity of ability of the facility to correctly invoice them.
- Self-funded retirees have voiced concerns that they are charged exorbitant fees as a result of their capacity to pay. One Carer told Carers Tasmania the person he cared for had a level three package consisting of five hours support per week. He calculated he was paying one hundred and twenty dollars per hour for this assistance. His perspective was that he would be better outside the aged care system.

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<sup>18</sup> Royal Commission into Aged Care Quality and Safety

<sup>19</sup> Carers NSW 2016: National survey of carers' respite needs.

- One carer told Carers Tasmania the aged care facility was charging her mother an extra fee of \$56 per day as an accommodation bond, until her house was sold. Carers Tasmania understand that the process for collecting this fee is determined by the aged care provider, with some facilities happy to accrue this with interest and be paid when the house is sold. However, this facility is currently unwilling to do so. This bond is additional to the basic daily fee of \$56 and accommodation costs. As the carer had been caring for her parents for over six years, and living with them for three years, she is applying to be a protected person, and would be eligible to remain in their home for up to two years. However, her mother will only have capacity to pay this extra \$56 per day for three to four months, putting pressure on the family for the house to be sold, and creating housing issues for the carer.
- A carer explained she was living interstate, and on a DSP and moved to care for her mother in Tasmania. When she moved initially, she maintained her rental property interstate as it would be cheaper than breaking her lease and putting her belongings in storage. She moved into the house owned by her mother to care for her. Once living with her mother, she became concerned about what would happen to her when her mother passed away, as her brother is the executor of the will, and there is conflict in the family. She sought free legal advice but couldn't find anyone with the knowledge she needed and had to pay for a lawyer. She was advised that her brother could legally have her removed from the house within 12 hours of her mum passing, and in her circumstances, would be facing homelessness. Based on this advice, and after significant challenges with guardianship and the public trustee, the carer and her mother have moved into a rental property where she is no longer quite as vulnerable. However, the carer is concerned how she will be able to afford to rent her property when her mother passes away. She is intending to try and source one day of work per week whilst she is caring to try to accumulate the financial reserve to cope when this does occur. This carer suggested there should be financial support for eligible carers needing to relocate to care for family, free legal advice adequately equipped with carer related knowledge, and a "carer credit" styled scheme that would compensate for the loss of wages and superannuation whilst caring. She believes this support reduce her vulnerability and still be more cost effective to the Australian Government than her mother entering residential care.

## Conclusion

Carers Tasmania acknowledged the important role informal carers play in the lives of older people remaining in the community, and of those accessing services at home or in a residential facility.

By virtue of their relationship and their role, carers are likely to witness and be impacted by the quality and safety of aged care, as demonstrated by the carer voices woven through this submission. The carer perspective and lived experience is therefore important in this Inquiry.

Carers also have a place in this Inquiry in their own right. We are a long way from the routine recognition, identification, inclusion and support of carers which would sustain them in their role.

The quality and safety of those requiring care may also be significantly improved with their involvement.