



Caring for Our Island and Our Community

***Carers Tasmania
Submission to the Tasmanian Government's
2010-11 State Budget***

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1. Contributing to Community

Carers Tasmania welcomes the opportunity to provide this submission for consideration as part of the community consultation for the 2010-2011 budget. Carers Tasmania supports the *Our Island Our Home* campaign and the Budget Priority Statement submitted by the Tasmanian Council of Social Services (TASCROSS). Carers Tasmania is a member of TASCROSS, but also contributes independently to the budget consultation process as the only organisation in Tasmania completely dedicated to supporting the needs of carers throughout the state.

In 2008, Carers Tasmania commissioned a research project conducted by Dr Bruce Felmingham and Professor Natalie Jackson to project the need for care support created by the impact of the ageing of the Tasmanian population. This research indicates that the number of people requiring assistance with a core activity, such as communication, mobility or self-care, will increase by 42-57%. This will lead to a total of 34-37,000 extra people who require care by 2028.

Professor Jackson's projections¹ also indicate that the number of carers is anticipated to increase by between 8 to 19% to a total of 80-88,000 in 2028. Of this, around 17-18,000 will be primary carers. The ratio of carers to care-recipients in need will drop by around 23-24%. The challenge for Tasmania will be in how to address the expected shortfall in carer availability at a time when there is increasing service dependence upon unpaid family carers due to the costs of providing formal care, residential and hospital-based services.

Insight gained from research activities, ongoing consultation with carers and data obtained from state-wide service delivery enables Carers Tasmania to offer practical solutions. All programs and service suggestions are based on principles of early intervention and prevention, leading to improved outcomes for carers, especially in areas of health, wellbeing and social inclusion. Accordingly, Carers Tasmania submits the following recommendations for consideration for inclusion into the State Budget for 2010-11:

Recommendation 1: That carers be identified as a population at risk, especially in rural and regional areas, and be identified as a priority group for investment in ongoing outreach services, including health promotion and injury prevention programs.

Recommendation 2: That the Government commit to supporting state-wide access to mental health and wellbeing programs for carers, such as Mindfulness and innovative social connection programs, which have a proven impact on improving social inclusion and reducing depression in carers.

Recommendation 3: That the Government invest in young carers through a state-wide expansion of an innovative program which increases confidence, self-care skills, community inclusion of young carers, and also improves community understanding of care responsibilities.

Recommendation 4: That the Government support the introduction of community hubs and carer awareness training to assist service providers and government departments to provide better supports for family carers.

¹ IMC-Link (2008) *Report on the profile of carers in Tasmania*. Hobart: Carers Tasmania.

2. A Population at Risk

Related Tasmania Together Goals

Goal 1. *A reasonable lifestyle and standard of living for all Tasmanians.*

- *Ensure that all Tasmanians have the economic capacity to enjoy a reasonable standard of living and access to basic services*

Goal 4. *Active, healthy Tasmanians with access to quality and affordable health care services*

- *Improve Tasmanians' health through promotion and support of healthy lifestyle choices*

Goal 5. *Vibrant, inclusive and growing communities where people feel valued and connected.*

- *Recognise and value the many contributions that volunteers and unpaid workers can – and do – make to their community*
 - *Tasmania will have viable rural communities.*
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The ageing of the Tasmanian population is creating an unprecedented demand for support from health and human services. A growing shortage of hospital beds and residential care places means that more people need to be cared for in the community when they can no longer live with complete independence. The need for support may be created by a person having a disability, a chronic medical condition, a mental illness, or profound frailty due to ageing.

Often family and friends need to provide the essential, ongoing, unpaid support needed to help people with care needs to keep living in the community. The person with care needs may also receive formal assistance such as HACC, EACH or CAP packages, but informal family carers still provide the bulk of needed care which can prevent premature entry to formal residential care and reduce extent or frequency of hospitalization.

Support to people with care needs may include (but not be limited to) any of the following activities:

- administering life-sustaining medical care, such as oxygen, tube-feeding or managing medications
- personal care such as showering, toileting or feeding
- mobility assistance, from driving a person to medical appointments to helping them get in and out of a wheelchair
- supporting the person with care needs to make and maintain social connections with the wider community
- supervising a person's safety and physical wellbeing
- emotional support, from supporting someone through painful, invasive medical treatments to encouraging and motivating a person with anxiety or depression
- domestic assistance, such as helping them with shopping, cleaning and gardening
- educational support, assisting children with disabilities to learn or older people with dementia to retain skills and knowledge

Unpaid family carers were estimated at 69,500 people² in 2006, as approximately 15% of the State's population was identified as having a care role by the Survey of Disability Ageing and Carers³. Caring affects people from all areas of society, yet carers are over-represented in the bottom two quintiles of income. This is due to marginalized workforce attachment and the costs incurred when providing care for another person. Carers are also more likely than the rest of the population to have a household income which is mostly dependent upon government income support payments.

Care situations vary greatly in their structure and complexity. The condition requiring care can create different demands, for example an adult with quadriplegia may have very different care needs to an aged person with chronic illness or a child with an intellectual disability. People may also care for more than one person (multiple care) or they may care for people in different generations such as a child with a disability and an elderly parent (sandwich generation carers). People may also vary in their capacity to care. This can be due to their age, their health, their personal resilience, the size of their social networks or their level of support from extended family.

Carers also provide care for different reasons. While many care relationships are based around an emotional relationship, others may be due to familial or cultural obligation. Caring provides many positive benefits to both the carer and the care-recipient, but there can also be negative impacts from the financial, physical, emotional and organizational demands of the care role. The Deakin University study into the health and wellbeing of carers discovered that carers have the lowest levels of wellbeing of any group ever studied in the Australian population⁴.

These findings were also consistent for carers in Tasmania, as confirmed by Felmingham et.al. in 2008⁵. The time needed to care, the cost of providing care, and the isolation created by lack of appropriate supports restricts carers' ability to participate in community life, in employment and in education. These restrictions mean that carers suffer significant long term disadvantage, including much higher rates of ill-health and depression than the average non-carer.

Carers Tasmania has the following program in development which offers a highly cost-effective way of supporting families with caring responsibilities on a state-wide basis, subject to funding:

Healthy Caring Program. This program is specially designed to meet the challenges of Tasmania's rural and regional population. It is based on sound research and elements of best practice service models (already being delivered elsewhere in Australia) which have improved outcomes for carers in both the short and long term. The program offers outreach services which are partnered with existing community and health infrastructure. Where required, an in-home assessment of the care situation can be conducted to help prevent carer injury and enable improved levels of early intervention. Early intervention and improved self-care skills reduces the risk of carers developing the preventable illnesses and chronic medical conditions which are frequently caused by the demands of a care role. Carers Tasmania has the specialist knowledge to help carers to achieve a healthier lifestyle within the constraints of the care role.

Recommendation 1: That carers be identified as a population at risk, especially in rural and regional areas, and be identified as a priority group for investment in ongoing outreach services, including health promotion and injury prevention programs.

² Based on population of 476,481 – source ABS *Census 2006 Quickstats (Tasmania)*

³ ABS (2003) *Survey of Disability, Ageing and Carers* Cat No 4430.0

⁴ Cummins, R., et al (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University

⁵ IMC-Link (2008) *Report on the profile of carers in Tasmania*. Hobart: Carers Tasmania.

3. Making a Difference

Related Tasmania Together Goals

Goal 4. Active, healthy Tasmanians with access to quality and affordable health care services

- Improve Tasmanians' health through promotion and support of healthy lifestyle choices
 - Improve self-assessed physical and mental wellbeing
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The Department of Health and Human Services recognises that a combination of prevention and early intervention is essential for achieving healthy living in vulnerable populations:

We understand that through preventative measures and the earliest possible intervention when required, we can assist in developing a healthier, more resilient and socially inclusive population.

Department of Health and Human Services Strategic Directions 09-12

Carers who are healthy and happy are better able to provide care and support to others. Yet, as discussed previously, research indicates that carers have very high incidence of depression, mainly due to the stress, poverty and isolation created by their caring responsibilities. Depression has a higher than average level of co-morbidity with diabetes, heart disease, and arthritis. People with depression are also more likely to have other lifestyle risk factors such as poor diet, lack of exercise, excessive alcohol consumption or smoking.

Looking after someone with a disability, a chronic medical condition, a mental illness or a terminal illness can often create a great deal of stress and anxiety for the carer. Persistent stress is also known to have a negative impact on physical wellbeing, and can result in the carer suffering from their own chronic illness if left untreated.

Carers Tasmania offers a number of effective supports to assist in improving the health and wellbeing of carers throughout the State, including access to information on caring, education for carers, counselling, support groups and social activities.

Mindfulness training. This 9 week short course was introduced at Carers Tasmania in 2008 and is delivered by qualified counsellors. It offers carers help to manage stress and improve overall wellbeing by reducing the negative impacts of care (such as sleep deprivation and depression). Mindfulness focuses on teaching carers skills to build resilience and coping skills through meditation and breathing techniques. The practicality of the program is highly useful as carers report that the skills learnt can be used anywhere and in any circumstances. It is also accessible for carers with limited resources as it does not depend upon expensive equipment or ongoing investments of time or money.

Carers who have completed the course report significant ongoing benefits, including notable reductions in stress and improvements in coping abilities. Demand for the Mindfulness training is now exceeding current capacity as word-of-mouth spreads about its efficacy. Carers Tasmania is currently seeking funding opportunities to expand the number of courses which can be offered by its trained practitioners. Expansion would greatly assist the identified need for additional supports to improve wellbeing in the North and North-West regions, due to higher levels of isolation and depression experienced by carers in remote and outer regional communities.

Innovation and responsiveness to need is essential for improving health and wellbeing throughout the State. Carers Tasmania is developing new ways of reaching out to families on a state-wide basis; rollout of the following programs is subject to obtaining suitable funding:

Re-Connect: Bringing Carers Back to Community. Carers Tasmania is developing ways to help carers to overcome social and geographic isolation and achieve greater community inclusion. The 'Re-connect' concept is based on principles developed through 'Creativity for Carers', a highly successful program previously delivered in Western Australia and funded by the Office of Women. This program addressed the loss of self-identity caused by long term caring and re-connected carers back into mainstream community activities, including rejoining the workforce or enrolling in educational opportunities.

Carers Tasmania has an opportunity to adapt the model underpinning this program to the needs of carers state-wide. The strength of the model is that it draws upon the existing capacity for involvement in each community, and encourages carers to investigate new options and set realistic goals throughout the duration of the course. Completion of the program is followed up at 6 month and 12 month intervals to discuss progress and future directions.

E-Care Tasmania. Carers Tasmania is investigating options to establish an internet-based website and social network service which offers greater opportunity for peer support to carers who are socially isolated, depressed or living in remote areas. The delivery of a closed social network platform to connect carers offers the opportunity for participation in a moderated environment which can be accessed through a web-connection, but which is not visible to the general public. Such an environment offers greater privacy and improved security for more vulnerable user groups, such as young carers and mature-age carers, to connect to others in a secure domain. The e-service can also include access to reliable and professional support supplied by Carers Tasmania, such as connection to online counselling and information services. It is anticipated that this program can be delivered and users supported through training delivered at Online Access Centres state-wide.

Recommendation 2: That the Government commit to supporting state-wide access to mental health and wellbeing programs for carers, such as Mindfulness and innovative social connection programs, which have a proven impact on improving social inclusion and reducing depression in carers.

4. Investing in Young Carers

Related Tasmania Together Goals

Goal 2. *Confident, friendly and safe communities*

- *Support young people who are at risk.*

Goal 3. *High-quality education and training for lifelong learning and a skilled workforce*

- *Access to and participation in life-long learning that is responsive to individual and community needs.*
- *Ensure education and training provides our workforce with the skills to support our business and industry*

Goal 5. *Vibrant, inclusive and growing communities where people feel valued and connected.*

- *A valued role in community life for Tasmania's young people now and in the future.*
-

Carers Tasmania provides supports for young people caring for family members with disabilities and chronic medical conditions. Young Carers are those carers aged under 25 years old. However, not all Young Carers are in the same situation. Carers aged between 7 and 17 years are usually caring for a parent or sibling, but those aged 18 to 25 years may be caring for a close friend, a relationship partner or their own child with special needs. Often a young person caring for a parent may be in a sole parent household, making them their parent's primary carer.

Many Young Carers appreciate and value the contribution they make in their caring role, yet they often face significant barriers when accessing services. Many struggle to obtain recognition of their caring role from schools, medical practitioners or service providers. Some families fear that disclosure of support needs may lead to the children being placed under Care and Protection Services. Some families also fear community stigma, especially where issues such as mental illness or alcohol and other drug addiction are a concern.

Key strategies for Young Carers are targeted at retaining their connection to school and supporting their transition through teenage years into successful post-secondary education or into the workforce. Success at school is critical for improving long term outcomes for Young Carers, regardless of the care situation they are dealing with. A strategy as simple as having a Young Carer Champion in every school (who has received training and is able to make appropriate referral to support) can make a critical difference between achieving good grades and staying at school or leaving early due to academic failure. Carers Tasmania currently receives limited funding through Commonwealth programs, but this is insufficient to meet the level and diversity of need required across the State. Indeed, Tasmania is the only state which does not offer complementary funding to enable Young Carer support.

Carers Tasmania has delivered a very successful trial program to better support young people with caring responsibilities, under a one-off funding arrangement, but recurrent funding will be required to rollout the program on a state-wide basis:

Self Belief - A Program for Young Carers. This a unique program which has been developed and trialled by Carers Tasmania to meet the needs of young people who are providing care for family members with disabilities or chronic medical conditions. Many young carers come from families with very restricted incomes, or who are quite socially isolated due to the nature of their caring responsibilities. The program takes a number of young carers in groups aged between 10-14 or 12-16. The youth leaders guide and motivate the group through a series of fun and

challenging activities to develop self-confidence, enhance life skills, establish good self-care habits, and offer community connection opportunities.

The first group run by Carers Tasmania had to complete challenges such as cooking a meal for \$20 which was comprised only of ingredients available when their grand-parents were young (i.e. nothing that was pre-packaged). This challenge enabled them to learn healthy shopping and cooking skills. Another challenge involved finding low or no-cost activities in their local area which could be reached by bus. A core outcome for the program involves the young carers developing confidence in their own resourcefulness and ability to solve problems, which also reduces their vulnerability to bullying in school or in the wider community.

A key part of the program involves establishing connections with other groups in the local community. For example, the trial group participated in a sailing experience offered by the Royal Hobart Yacht Club. Carers Tasmania has discovered that offering young people these opportunities enables them to build confidence with new environments and promotes social inclusion as they try things they may otherwise have never experienced. It also offers the hosting group a way to help people experiencing disadvantage and to attract participants into their organisation by developing mentoring opportunities and/or inclusion schemes.

Recommendation 3: That the Government invest in young carers through a state-wide expansion of an innovative program which increases confidence, self-care skills, community inclusion of young carers, and also improves community understanding of care responsibilities.

5. Improving Carer Awareness

Related Tasmania Together Goals

Goal 4. Active, healthy Tasmanians with access to quality and affordable health care services

- Improve the health and wellbeing of the Tasmanian community through the delivery of coordinated and timely services.

Goal 8. Open and accountable government that listens and plans for a shared future

- Provide an opportunity for all Tasmanians to participate in decisions that affect their lives.
 - Government services are accessible and responsive and information is available.
-

People with disabilities, and their families who provide care, have identified the following critical needs:

- Somewhere to live
- Something meaningful to do
- A 'live-able' income
- Someone to talk to and do things with
- The ability to 'take a break' when needed.

Yet, one of the key barriers carers face involves a difficulty in accessing government services and other supports because of the complexity of systems and pathways. Limited resources and time due to the demands of their care roles can place carers at a significant disadvantage compared to the rest of the population. They can also be more vulnerable than other clients when accessing government services because of the high stress and anxiety, and social isolation associated with a caring role.

Community Hubs. The provision of regular community hubs, where all people can come and get legal, financial, housing, and community services advice, have been a great success in other states and territories. The hubs are held in a local community centre, and representatives attend from various community services, government departments, and have even included volunteer lawyers from a Legal Aid service. Any person can just drop in and get free advice and information, or a referral into systems of support. Carer organisations in other states and territories have been a key part of the community hub system, helping carers to navigate the often complex pathways to obtain much-needed services and supports which are appropriate for their needs.

Carer Awareness Training. In addition to development of such projects, Carers Tasmania is committed to the development of carer education for all government departments and other service providers. Education is a key for creating the cultural change needed to foster more 'carer-friendly' environments. Staff participation in a professional development course on carer awareness would assist departments to improve outcomes for families with care and support needs. These courses would also assist in raising personal awareness about the supports available if/when any departmental staff need to undertake a caring role in their personal life, as all of us will either need to receive or provide care at some time in our lives.

Recommendation 4: That the Government support the introduction of community hubs and carer awareness training to assist service providers and government departments to provide better supports for family carers.

6. About Carers Tasmania

Carers Tasmania has a constitutional mandate to represent the needs of family carers. The organization was founded by carers and continues to be led by carers. Governance includes a Board which has members who contribute professional skills in addition to current or past experience of caring situations or an affinity with carers.

Carers Tasmania is a non-profit, community based, incorporated association and registered charity dedicated to improving the quality of life of all family carers' living in Tasmania. Carers are those people who are providing unpaid care for family members or friends with disabilities, mental illness, chronic conditions or illnesses, who have palliative care needs, or who are aged and frail.

Carers Tasmania is the only organization completely dedicated to supporting the needs and representing the views of carers throughout Tasmania. Accordingly, a strong focus on rural and remote regions is embedded in all program design and development. Carers Tasmania provides a diversity of services across all areas of the state, including counselling, information, education and training, health and wellbeing support, and social support.

Carers with diverse needs, such as Young Carers, Indigenous Carers and carers from culturally and linguistically diverse backgrounds (CALD) can access specialist support services especially designed to better meet their needs.

Programs at Carers Tasmania are funded by both Federal and State sources. These include: the Department of Health and Ageing; the Department of Family, Housing, Community Services and Indigenous Affairs; the Department of Health & Human Services; and, the Home and Community Care (HACC) Program.