



**Carers Tasmania Feedback on the
Long-Term Plan for Healthcare in Tasmania 2040**

May 2023



About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge the traditional owners of the lands and waters upon which we work, live, and sustain ourselves. This land was never ceded, and we acknowledge that the Tasmanian Aboriginal people are its continuing custodians. We pay our respects to Elders past and present.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

Please direct any enquiries about this report to:

David Brennan
Chief Executive Officer
Phone: (03) 6144 3700
Email: ceo@carerstasmania.org

Contents

| | | |
|----|---|----|
| 1. | Background | 4 |
| 2. | Introduction | 5 |
| 3. | The experience of carers within health services in Tasmania | 6 |
| 4. | Recommendations | 8 |
| | Consumers and Carers | 8 |
| | Carer Recognition..... | 11 |
| | Feedback on specific pages | 12 |
| 5. | Overview of Recommendations | 19 |

1. Background

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who are frail or aged. A carer may also be a kinship carer of a child under the age of 18. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Commonwealth Carer Gateway program is delivered through Care2Serve, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Introduction

Carers Tasmania is pleased to provide feedback on the Tasmanian Department of Health *Long-Term Plan for Healthcare in Tasmania 2040*¹ (hereafter 'the Plan'). We acknowledge the progress made to date on reforms aimed at advancing and improving health services in Tasmania.

The Plan provides a blueprint with an overarching aim to build a sustainable health system that will meet the needs of people living in Tasmania over the next 20 years. In the Overview section, the Plan states that:

*"It provides system-wide direction and strategy for the delivery of health services to achieve our goal of a sustainable, integrated, and balanced health system that delivers the right care, in the right place, at the right time for our population. It has been developed in partnership with consumers, clinicians, and policy makers across Tasmania."*²

From the outset, the Plan fails to acknowledge that carers are an integral factor contributing to Tasmanian health services and the people who use these services. If carers are not considered, people accessing health services will not be supported holistically. People using health services who have a carer, will likely require more frequent health services unless the wellbeing of carers is considered an intrinsic part of caring for someone ill. We understand that the Plan is intended to be a high-level overarching framework but the overall theme of our feedback points to disappointment with the lack of carer recognition, consideration, and inclusion at this level.

We strongly encourage the Department of Health (DoH) to take appropriate and purposeful action to include carers in their planning, especially following the newly enacted Tasmanian Carer Recognition Act 2023,³ which sets out obligations for State Service Agencies, including the Tasmanian DoH. The DoH must implement specific strategies that enable health staff to formally recognise family and friend carers and routinely refer them to the supports that can be accessed through the Carer Gateway Program. This will result in the health consumer and their carer being more appropriately supported, which to some extent, will reduce the level of strain placed on the health system.

In 2018, the Australian Bureau of Statistics (ABS) revealed that there were 80,100 family and friend carers in Tasmania, representing 15.5% of the Tasmanian population.⁴ Female carers accounted for 41,400 (51.7%) and males accounted for 38,000 (47.4%). The report also estimated that there were 9,300 (11.6%) young carers aged under 25 years in Tasmania.

Put into the context of the health system, that equates to more than 80,000 people in Tasmania who are caring for at least one other person, who is likely to be accessing healthcare services, though carers may care for several people. When considering the number of people being cared for and also that their carers are likely accessing healthcare services for themselves, given the high prevalence of disease burden (arthritis, asthma, diabetes, cancer, heart disease), an ageing population, and high rates of mental ill health, it

¹ <https://www.health.tas.gov.au/sites/default/files/2023-03/Long-Term%20Plan%20for%20Healthcare%20in%20Tasmania%202040%20Exposure%20Draft%20March%202023.pdf>

² Ibid.

³ <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

⁴ Australian Bureau of Statistics (2021) 44300DO006_2018 Disability, Ageing and Carers, Australia: Tasmania, 2018. Released at 11:30am Wednesday 5 February 2020

is logical that there is a significant proportion of people accessing healthcare services in Tasmania who are a carer or have a carer.

It is important to note that the *Tasmanian Carer Recognition Act of 2023*⁵ now recognises carers of people with alcohol or other drug dependence, as well as informal kinship carers of children. We seek for the Tasmanian Department of Health to acknowledge and support these carers in addition to those already generally understood to be carers.

Acknowledging carers, being cognisant of them in planning, and including specific actions in policies and procedures will benefit the health system. Examples of actions the health system and staff could take may include:

- Improving discharge practices to minimise the frequency of failed discharge, re-admission, or additional injury to the carer or the patient
- Health professionals to include carers in conversations about the health of the consumer
- Health professionals listening to observations, concerns, and knowledge from carers about the person they care for
- Equipping carers with the information and skills they need
- Asking carers if they require a referral for carer support to sustain their own wellbeing and caring capacity

These are basic, but influential things that health staff can do to reduce the rate of failed discharge and readmission. It will also ensure that patients receive the right care as health staff will have a more holistic understanding of their situation.

Carers Tasmania has provided several responses across the suite of *Our Healthcare Future* consultations, on hospital discharge planning, and has also provided feedback to the Department of Health (DoH) more broadly, but despite this, the Plan essentially fails to ignore the enormous contribution that unpaid carers in Tasmania make towards the health care and community sector, which has an estimated value of \$2.2B dollars per year.⁶

We have provided a response on some specific aspects of the Plan, highlighting the pages and actions, with recommendations on how these sections can be more carer inclusive. We strongly recommend that the DoH take into consideration and implement these changes.

3. The experience of carers within health services in Tasmania

As previously indicated, Carers Tasmania have provided the DoH with feedback on numerous occasions about negative experiences shared by carers within the health system, particularly around poor discharge practices, which often result in further injury or readmission, and the lack of inclusion of carers as key partners in the care planning team. You can find some of these responses in our submissions to the *Statewide Hospitals Discharge Framework*⁷, *Our Healthcare Future-Advancing Australia's Health*,⁸ *Carer*

⁵ <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

⁶ <https://www.carerstas.org/carer-recognition-bill-2022/>

⁷ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Response-to-the-THS-Statewide-Hospitals-Discharge-Framework.pdf>

⁸ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Response-to-the-Our-Healthcare-Future-Advancing-Tasmanias-Health-June-2022.pdf>

Recognition Legislation Discussion Paper,⁹ and the Response to the Tasmanian Draft Carer Recognition Act,¹⁰ however, we have also raised these issues with the DoH directly.

The following two comments were obtained from Tasmanian responses to *The 2020 National Carer Survey*:

"My needs as a Carer are rarely addressed and I am often treated as an obstacle in providing care to my father, especially when I ask questions to better understand what is happening. Some services do at least try, but they are in the minority."

"After very disappointing care at our only public hospital, my husband refuses to go there again. They are totally understaffed and do not have any concept of how to care for someone with high care needs. We have private health cover and prefer to go to a private hospital but if an ambulance comes to assess my husband, they are required to contact the private hospital to see if they will take him. As they said no in the past; we now order a maxi taxi (he has electric wheelchair) and just head straight to the private hospital emergency dept - and they accept him."¹¹

Tasmanian responses from consecutive *National Carer Survey* in 2022 also highlighted some significant challenges, which were articulated in the following comments from carers:

"I accompanied my husband on all outpatient services but was ignored."

"Being separated in Emergency and long waits over 6 hours had a negative effect on treatment and care."

"Burnie Public Hospital is a farce and treat carers poorly; especially if they are male."

"Community health services are excellent. At the LGH I wasn't allowed in with my 98 year old mother."

"Due to COVID, I was only allowed to visit between 2-6pm, even though I told them I was the person's carer. The doctor visited the person in the mornings when I wasn't allowed in. The nurses weren't allowed to give me any information. Therefore, it was very difficult to find out diagnosis/treatment/tests and ongoing care requirements."

"Following a violent altercation with his brother my son was taken to the ED at the Royal Hobart Hospital with a stab wound. Trying to get through to the staff that I needed to accompany my son as he had an intellectual disability was a nightmare. Covid restrictions made the visit that much harder as the staff insisted I was not permitted to stay with my son. My son was becoming more agitated the longer he waited to be seen and I was worried he may become aggressive towards the staff. The staff seem to be oblivious to the fact that my son did not understand what was happening."¹²

Continued feedback such as this from carers across Tasmania indicates a lack of clear processes that are standard across Tasmanian Health Services to identify, recognise, and include carers supporting someone in a health setting, or to refer them to additional support.

⁹ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Response-to-the-Carer-Recognition-Legislation-Discussion-Paper.pdf>

¹⁰ https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Submission-on-the-Draft-Carer-Recognition-Act-2022_.pdf

¹¹ https://www.carerstas.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

¹² Carers NSW, 2022: 2022 National Carer Survey. Unpublished Dataset. North Sydney: Carers NSW.

4. Recommendations

Consumers and Carers

Recommendation 1:

Implement a clear delineation between consumers and carers that is consistently visible throughout the *Long-Term Plan for Healthcare in Tasmania* and other DoH literature

First and foremost, carers must be formally recognised and supported across policy and practice by Tasmanian health services and staff as outlined by the *Tasmanian Carer Recognition Act of 2023*.¹³

We seek for carers to be identified and included as a group that is separate from consumers. We highlight that the word consumer is largely used throughout the document and other literature from the DoH, but consumers and carers, whilst intrinsically linked to each other, are nonetheless distinct groups who both have different needs and experiences. It is inadequate to reference carers under the banner of 'consumer' as they deserve their own recognition. We stress that there must be a purposeful effort to increase the visibility of carers so that documentation clearly outlines that carers and consumers are both acknowledged and valued. This will help ensure that carers are recognised and encouraged to share their views and experiences about healthcare services in Tasmania.

The National Mental Health Commission's *Consumer and Carer Engagement: A Practical Guide*¹⁴ defines a consumer as "a person with direct experience of a mental illness, and who has received, is receiving, or is seeking mental health services from a mental health service provider." Furthermore, the Guide describes a carer as "any person including a family member and a person under 18 years of age who provides support, assistance, or personal care to a person with a mental illness, or a disability resulting from a mental illness".¹⁵ Although this is specific to mental health carers and consumers, a similar approach should be taken in relation to all carer and consumer cohorts.

It is also important to note that a carer may be both a consumer and carer, especially in Tasmania given the high rates of chronic illness, disease, and the ageing population. Including carers as their own cohort alongside consumers in DoH documentation is an action that will directly align to the newly enacted *Carer Recognition Act 2023 (Tas)*,¹⁶ which aims to increase the recognition of carers across Tasmania and enable them to better access the support and resources they require, as well as ensuring they are included as key partners in planning processes for policies, resources, and services that are relevant to their roles as carers.

¹³ <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

¹⁴ <https://www.mentalhealthcommission.gov.au/getmedia/afef7eba-866f-4775-a386-57645bfb3453/NMHC-Consumer-and-Carer-engagement-a-practical-guide#:~:text=Consumers%20are%20people%20who%20identify,and%20'expert%20by%20experience'>.

¹⁵ <https://www.health.vic.gov.au/mental-health/working-with-consumers-and-carers>

¹⁶ <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

The Carer Recognition Act (Tas) states the following:

“(1) Each Agency is to take reasonable steps to implement the Tasmanian Carer Action Plan and the Carers Charter

(2) Each Agency is to monitor and report to the Minister on the steps taken by the Agency to implement the Tasmanian Carer Action Plan and the Carers Charter

Carers Charter

- 1. Carers should be acknowledged as diverse and are to be treated as individuals with their own needs within, and beyond, their roles as carers.*
- 2. Carers should be consulted in relation to the development and evaluation of policies and programs, and the provision of resources, in so far as those policies, programs and resources affect their role as carers.*
- 3. Carers should be empowered to access information and services that are relevant to them in their role as carers.*
- 4. Carers should be supported to participate in, and contribute to, the social, political, economic and cultural life of Tasmania, if they so desire.*
- 5. Carers should be recognised and respected for their valuable caring role and should be supported in accessing, and engaging in, a wide range of services to ensure their well-being and to maintain their connections to their community.*
- 6. Carers’ knowledge about the persons for whom they are caring should be respected, acknowledging that each carer, and each person being cared for, has both rights and responsibilities.*
- 7. Carers should be able to raise concerns about decisions, and services, that affect them as carers or the persons for whom they are caring, without the carers or such persons suffering adverse repercussions, and those concerns should be dealt with as promptly as is reasonably practicable.”¹⁷*

Every item of the Carers Charter is intended to guide how Tasmanian State Service Agencies, including Tasmanian health services and employees should recognise, consult with, engage, and value feedback from carers.

Carers and consumers may have the same but also different needs. Tasmania is lacking behind in its approach to recognise carers as being different from consumers as other states and territories across Australia already have in place clear frameworks and other literature which acknowledge both carers and consumers and the important roles they both play.

¹⁷ Ibid.

Some of these resources include:

- *Engaging with Consumers, Carers and the Community* (SA Health)¹⁸
- *Consumer, Carer and Family Participation Framework* (QLD Health)¹⁹
- *Consumer, Carer and Community Engagement Framework and Best Practice Guide 2022-2024* (NSW Government)²⁰
- *You Matter: A guideline to support engagement with consumers, carers, communities and clinicians in health* (WA Health)²¹
- *Consumer and Carer Participation in ACT Health Policy Statement* (ACT Health)²²
- *Doing it with us not for us* (VIC DHHS)²³
- *Consumer/Community Participation Guidelines for Consumer Representatives* (NT Health)²⁴

The DoH *Consumer and Carer Participation Framework*,²⁵ which is currently under review as an item in the current *Tasmanian Carer Action Plan*,²⁶ only covers carers supporting a person accessing mental health services and not carers more broadly.

Another item identified in the *Tasmanian Carer Action Plan*²⁷ refers to the development of clinical guidelines for working with carers. However, it appears that as this has progressed, it has been decided somewhere along the line that these guidelines are only planned for carers supporting someone with disability, not all carers of people accessing health services in Tasmania.

In line with the introduction of the *Carer Recognition Act* (Tas), the Ministers Carer Advisory Council (MCAC) has been established to support updates to the current *Carer Action Plan*, as well as being responsible for overseeing the progress by State Service Agencies to achieve items in the action plan. The MCAC includes five carers from across the state who have a range of caring experiences.

We also highlight the document, *The Patient Will See You Now*,²⁸ noting that this has an outdated carer definition and refers to documents that are no longer accessible. These three documents could be updated and expanded alongside the *Long-Term Plan*, to better recognise, acknowledge, include, and support all carers.

¹⁸ https://www.sahealth.sa.gov.au/wps/wcm/connect/6dead9da-d1c2-4cbf-9568-74d2131df162/EngagingwithConsumersCarersandCommunityGuide%26Resources_Apr+2021+%281%29.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-6dead9da-d1c2-4cbf-9568-74d2131df162-nYE-POS

¹⁹ https://www.health.qld.gov.au/__data/assets/pdf_file/0024/444525/part_a.pdf

²⁰

https://www.seslhd.health.nsw.gov.au/sites/default/files/groups/Planning_Population_and_Equity/docs/Consumer_SESLHD_Digital.pdf

²¹ <https://www.health.wa.gov.au/~media/Files/Corporate/general%20documents/health%20improvement/PDF/You-Matter-Guideline.pdf>

²² <https://www.health.act.gov.au/sites/default/files/2018-09/Consumer%20and%20Carer%20Participation%20Policy.docx>

²³ <https://www.health.vic.gov.au/sites/default/files/migrated/files/collections/policies-and-guidelines/d/do-it-with-us-participationpolicy-2006-09---pdf.pdf>

²⁴

<https://digitalibrary.health.nt.gov.au/prodjsui/bitstream/10137/800/1/Department%20of%20Health%20Consumer%20Community%20Participation%20Guidelines.pdf>

²⁵ <https://www.health.tas.gov.au/publications/consumer-and-carer-participation-framework>

²⁶ https://www.dpac.tas.gov.au/__data/assets/pdf_file/0026/246248/Supporting-our-Carers-Action-Plan-2021-24_-JULY-2021.pdf

²⁷ Ibid.

²⁸ https://www.health.tas.gov.au/sites/default/files/2021-10/The_Patient_Will_See_You_Now_THS_Consumer_Engagement_Model_of_Care_DoHTasmania2019.pdf

Examples of how the Plan could facilitate better carer recognition and inclusion:

| Location in the plan | Current wording | Recommended wording |
|------------------------------------|---|--|
| Page 10, Principles | Consumer centred and collaborative | Consumer and carer centred and collaborative |
| Page 10, Strategic ambitions | Partnering with consumers and clinicians | Partnering with consumers, carers and clinicians |
| Page 11, Our priorities for action | 3. Governed with Our Partners to Proactively Meet Demand A safe, high-quality health system designed and governed in partnership with consumers and clinicians. | 3. Governed with Our Partners to Proactively Meet Demand A safe, high-quality health system designed and governed in partnership with consumers, carers, and clinicians. |
| Page 11, Our enablers for action | 6. Delivered by a Valued and Supported Workforce. A consumer-centred health system delivered by an enabled, supported, flexible and valued workforce. | 6. Delivered by a Valued and Supported Workforce. A consumer and carer-centred health system delivered by an enabled, supported, flexible, and valued workforce. |
| Page 12, Action Area 1 | 1.7 Partnering with aged care and disability services | Partnering with aged care, disability, and carer services |
| Page 12, Action Area 3 | 3.2 Partnering with consumers and communities | Partnering with consumers, carers, and communities |

Carer Recognition

Throughout the document, it appears that there is a lack of carer inclusion and recognition of the enormous contributions that carers make to the health system, but also the linkages to carer support which have the ability to play a significant role in supporting the needs of consumers and carers.

For example, on page 17 the list of responsibilities that fall to the Australian Government does not mention carer support. It does mention aged care services, along with residential services and in-home supports. Care2Serve facilitates the booking service for respite in Residential Aged Care settings across Tasmania. This is to help streamline the process of making bookings for carers who are often time-poor and uncertain about how to navigate this process.

In addition, frontline employees of Care2Serve often receive phone calls from carers who have had their loved one discharged from the hospital with inadequate, or sometimes no support. In these instances, it is Care2Serve, funded under the National Carer Gateway

program, who assist in the facilitation of brokering of practical support. Care2serve also play a significant role in supporting carers to connect their family members with other aged care and disability services.

Carers Tasmania's feedback for page 18 is quite similar. It is stated that:

*"Intermediate care requires primary healthcare and hospitals to work together to ensure people receive the care they need in their own homes, for example in a private residence, residential aged care facilities, supported accommodations for disability, or other community settings."*²⁹

There is no mention of the significant role that carers play, nor the support that can be provided by the Carer Gateway service provider. Carer support services play a significant role in referral and navigation for these services. In addition, as already noted, they manage the Residential Respite bookings in Tasmania and provide practical support packages when people are discharged from hospital with inadequate or no supports.

Feedback on specific pages

Recommendation 2:

Implement a plan to strengthen the relationship between the health system and carer support services

On page 18, the 'What we will do' section states that:

"For our health services to work more effectively as a whole of a health system, we are strengthening our relationships with primary healthcare, disability services and aged care. We will also enhance the role of our hospitals for safe and equitable service delivery and ensure mental health services are more integrated with the rest of the health system."

We note that there is no mention of a planned approach to strengthen the relationships between the health system and carer support services. Holistic collaboration needs to occur, to achieve the best outcomes for health consumers and their carers

Recommendation 3:

Ensure all staff in all health services are aware of emergency carer support, so that when they are treating a carer in an urgent or emergency situation, a call to this service can be made if applicable

We refer to page 20, *Action 1.1.3*, which states:

"Through partnerships with the primary healthcare sector, continue to support enhanced access to primary healthcare, including after-hours and urgent care".

It is important to note as a complementary support, that emergency respite care can be provided by Carer Gateway in circumstances where a carer is unable to provide the care they usually would due to illness or injury (e.g. ending up in hospital), especially when the person they care for has high care needs. The phone line for this is managed 24/7 and there is no cost to the carer for this service.

²⁹ <https://www.health.tas.gov.au/sites/default/files/2023-03/Long-Term%20Plan%20for%20Healthcare%20in%20Tasmania%202040%20Exposure%20Draft%20March%202023.pdf>

Recommendation 4:

Liaise with Carers Tasmania when updating HealthPathways so that specific information for and about carers can be included in ways that are accessible

On page 20, *Action 1.1.4 'Strengthening use of HealthPathways in Tasmania'*, we refer to the aim to “*strengthen the educational resources and information for clinicians and patients available in HealthPathways.*”

HealthPathways must include information for GP's and other clinicians, on how to:

- Routinely identify carers
- Understand what carer support is available
- Refer carers for support
- Access specific resources that can be provided to carers.

Carers Tasmania would be more than happy to provide information and resources that are carer specific, as well as guidance on this project.

It is also crucial that the resources available for patients and carers is relevant and can support carers with the information they need to effectively provide practical support, such as personal care, wound care, medication, dietary requirements, movement, follow-up care, and appointments. Specific consideration must be taken to ensure that this information supports people with low levels of literacy, health literacy, and digital literacy in Tasmania.

Recommendation 5:

The DoH and Primary Health Tasmania should liaise with Carers Tasmania to ensure that the Statewide eReferrals project supports the routine identification and referral of carers

Page 22, refers to *Action 1.1.8, Statewide eReferrals Project*. Including a mechanism to routinely identify and refer carers as part of this project is an easy-to-implement process that will significantly assist more carers to access support. Carers Tasmania has provided some initial feedback to Primary Health Tasmania and would value working together on this project.

Recommendation 6:

Continue collaboration between Care2Serve and the Integrated Care Hubs

Carers Tasmania are pleased to advise that Care2Serve is currently providing outreach services at the Peacock Centre Integration Hub on a rotational basis and are hopeful that a consistent approach can be taken across the other hubs. It must be made clear that carers can also access support at these hubs. Care2Serve can provide a wide range of services, to all cohorts of unpaid carers, therefore it is important that this collaborative approach continues.

Recommendation 7:

Ensure that carers are included and recognised as being one of the most significant providers of care at home

We share the following feedback on page 32, *Action 1.7 – Partnering with aged care and disability services* and *1.71 Partnering with the Australian Government*

Carers Tasmania is concerned that formal carer support services are not acknowledged as a key partner alongside aged care and disability services. Carer support provides invaluable navigation and connection to both aged care and disability services and assists carers to sustain their caring roles. Care2serve also broker aged care and disability support across the state for many carers whilst they are waiting for residential respite beds, NDIS, or aged care services to become available to the person they care for. As previously highlighted, Care2serve manage the Residential Respite bookings for the state and also offers emergency respite care for carers who become unwell or injured.

Care2Serve delivers the National Carer Gateway Program in Tasmania as funded by the Commonwealth Department of Social Services. This is an essential Australian Government funded service that should be more widely recognised and referred to within the Tasmanian health system.

Recommendation 8:

In planning for care at home, in the community, and in health settings, the inclusion of processes to identify and support carers (eg routine identification and referral) must be implemented

Page 36 refers to healthcare services that are provided at home. It is critical that the contributions and needs of carers are considered in this area and that carers are recognised in planning around this. Processes must be included to ensure the routine identification of carers followed by referral for support.

It is disappointing that the significant role that carers play in supporting someone at home is not acknowledged in this section. This care often results in time off work or study and financial difficulty, as well as negative physical, social, and emotional impacts.

Page 39 provides an overview of *Preventative health*.

We highlight the importance of the routine identification and referral of carers as early on as possible through the previously discussed ideas such as implementing routine identification and referral for carer support through the Statewide eReferrals project and the updates to HealthPathways.

Out of the 1,024 Tasmanian carers who participated in the *2020 National Carer Survey*, over 50% reported that when they accompanied a care recipient to the GP or hospital, they were not asked about their personal needs.³⁰ Most carers only reach out when they have already reached breaking point, however, if they are referred and connected to carer support in the early stages of their caring roles, they may be able to put strategies and supports in place to enable them to continue caring for longer before reaching crisis, reduce the severity of crisis, or even eliminate the crisis entirely.

³⁰ https://www.carerstas.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

Recommendation 9:

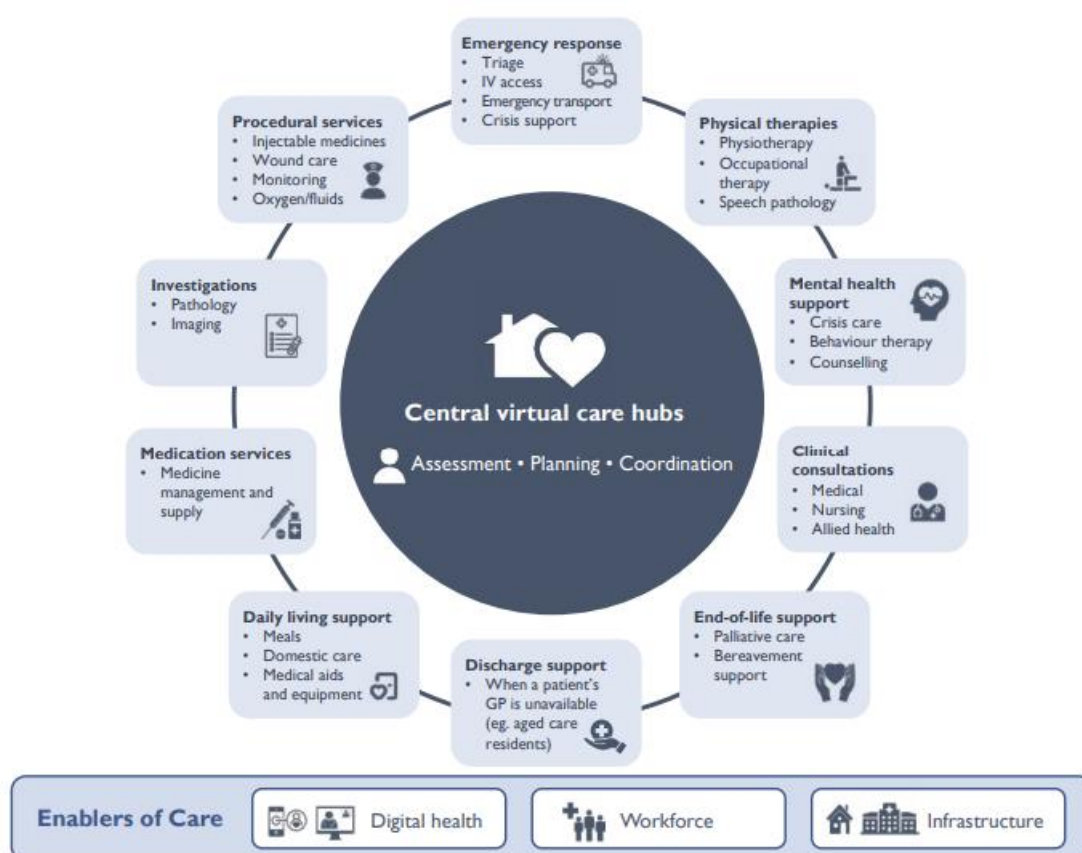
Include processes to identify and support carers in planning for care at home, in the community, and in health settings (e.g. routine identification and referral)

Pages 40 and 41, refer to *Action 2.2 – More care delivered in the home and community*

It is unclear as to what processes will be implemented to support the family and friend carers who will be providing the bulk of care when doctors, nurses, and other specialists are not present. The Central Virtual care hubs should include a process to identify carers and refer them to available support.

We refer to the following figure as shown on page 42.

Figure 8. Home-based and community-based service delivery



Astonishingly, an integral component of care is missing, and that is the care and support provided by carers. We highlight again, the importance of recognising the role of carers in supporting the health of others and seek for this recognition to be elevated and made visible in healthcare service planning and literature. Carers are often the advocate and the person connecting the support to the patient. They are also the person who provides care when health staff and other employees have finished their shift.

Recommendation 10:

Recognise and outline specific actions that will support carers of people with mental ill health or alcohol or other drug dependence

Page 48 refers to *Action 2.4.8 – Mental health and alcohol and other drugs early intervention and prevention*.

We highlight that there is no specific reference to carers of people who experience mental ill health or alcohol or other drug dependence in this section. It is important that they are considered when planning health services for patients in these cohorts. People caring for someone in these circumstances can be extremely vulnerable and complexity is compounded when the person has a comorbidity of both conditions.

The *Tasmanian Carer Recognition Act* recognises carers supporting people in both of these cohorts, and we recommend that specific actions be taken by the DoH to routinely recognise, refer and support them.

Recommendation 11:

Include and recognise carers as a specific and distinct role in the Consumer Health Planning Committee

Pages 49 & 50 refer to consumers, but as previously stated in recommendation 1, we seek there to be a clear delineation between consumers and carers and for consistent visibility of this throughout the *Long-Term Plan for Healthcare in Tasmania* and other DoH literature.

Furthermore, on page 52, *Action 3.2 – Partnering with Consumers and Communities*, is an additional example which only refers to consumers and not carers.

Recommendation 12:

DoH must recognise Carers Tasmania as the Peak Body for all family and friend carers in Tasmania and work in partnership more effectively to hear the lived experience of all caring cohorts

Furthermore, on page 52, *Action 3.2.1* is titled *Consolidating our approach to consumer participation*. We have already emphasised numerous times throughout this response that carers must be recognised and included as a distinct group which is separate to consumers.

It is also important to highlight that in *Action 3.2.2- Embedding the voice of lived experience*, Carers Tasmania is not recognised. Carers Tasmania has been the Peak Body for the more than 80,000 informal family and friend carers in Tasmania since 2018. We emphasise that lived experience as a carer is important across all domains, not just mental ill health and alcohol and other drugs. Carers Tasmania proudly supports and advocates for all informal carers in Tasmania as defined by the *Carer Recognition Act (Tas)*.³¹

Carers Tasmania is eager to work closely with the DoH, specifically to share the valuable lived experience of carers across all cohorts, however, Carers Tasmania is not consistently informed or approached about lived experience activities and various consultations.

Carers often juggle employment, study, or other family responsibilities along with caring. Therefore, they may need longer notice periods to enable them to participate in consultation

³¹ <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

activities. Often, these opportunities are not widely published, with little time for carers to respond.

Recommendation 13:

DoH to ensure communication about digital services are in plain English and that patients and carers are supported to be able to access and use these services

Page 67 refers to *Digital enablers*. Under the aim of *Self-Care*, it is explained that patients and their carers will be able to:

- Make and change their outpatient appointments
- Update their personal information electronically
- And have the tools they need to help make decisions about care

We know that there are low levels of literacy and digital literacy in Tasmania, as well as financial and regional barriers to accessing digital services. In terms of the ability to make and change outpatient appointments, it would be worth seeking feedback from Carers Western Australia to understand the experience from the carer perspective of using the *Manage My Care App*³², to potentially mitigate any issues or barriers for carers and to understand their work over the past 15-years working in hospitals to support carers.

We also suggest that these platforms are also a good opportunity to inform carers of Carer Gateway support and to provide both a link and a phone number that they can use to self-refer.

Recommendation 14:

Collaborate with Carers Tasmania on carer inclusion and experience in the development of the Tasmanian Lived Experience Workforce Framework and further implementation of lived experience carer workers

Page 73 refers to *Action 6.1.5 – Embedding Lived Experience into service provision*

We highlight again that we are the Peak Body for all family and friend carers in Tasmania and that we support and engage with carers across numerous cohorts that intersect with the health system.

Recommendation 15:

Liaise with Carers Tasmania on specific strategies and supports that can be offered to employees of the THS who are in a caring role

Page 74 refers to “*improving the capacity and capability of the health workforce across Tasmania*.” As one in six people in Tasmania are estimated to be a carer, there are likely a significant number of staff employed by the Tasmanian Health Service (THS) who are carers. They must be supported to access the resources they need that will support them to remain employed whilst also undertaking their caring role.

³² <https://www.healthywa.wa.gov.au/managemycare>

Recommendation 16:

Carers must be recognised in the Clinical Services Profiles by the DoH

We highlight that across the three Clinical Service Profile Exposure Drafts,³³ there is no mention of carers. Carers are an enormously supportive, yet highly vulnerable group in terms of health outcomes, and this must be clearly recognised.

Overall, we seek for greater recognition, along with the routine identification and referral of carers by the DoH and all health services staff, along with a visible and consistent approach that refers to actions that recognise and support carers. With improvements proposed to processes and digital pathways, it would be timely to include the identification and referral of carers to Carer Gateway in these processes. This can be easily implemented into referral processes by services such as but not limited to:

- Emergency Department
- THS Outpatient services
- THS Inpatient services
- GP's (noting this is not governed by the DoH)
- Community Health Centres and District Hospitals
- Child Health Centres
- Mental Health and AOD services
- Hospital In the Home Programs
- Community Rapid Response Service

It can't be emphasised enough that the routine identification and referral of carers to Carer Gateway must occur from Tasmanian Health Services. This will provide more carers with the support they need to maintain their caring role and their own wellbeing.

If carers continue to not be recognised and referred for support, they will remain at greater risk of burnout and crisis. Not including and listening to carers in health settings will lead to medical professionals not having the most comprehensive understanding of the needs of patients. When medical professionals do not provide carers with adequate information and resources, carers are at risk of not understanding how to best support the person they care for.

Lastly, we seek for the DoH to liaise more directly and consistently with Carers Tasmania, as the Peak Body representing the more than 80,000 family and friend carers in Tasmania.

³³ <https://www.health.tas.gov.au/publications/long-term-plan-healthcare-tasmania-2040-exposure-draft>

5. Overview of Recommendations

1. Implement a clear delineation between consumers and carers that is consistently visible throughout the *Long-Term Plan for Healthcare in Tasmania* and other DoH literature
2. Implement a plan to strengthen the relationship between the health system and carer support services
3. Ensure all staff in all health services are aware of emergency carer support, so that when they are treating a carer in an urgent or emergency situation, a call to this service can be made if applicable
4. Liaise with Carers Tasmania when updating *HealthPathways* so that specific information for and about carers can be included in ways that are accessible
5. The DoH and Primary Health Tasmania should liaise with Carers Tasmania to ensure that the patient eReferral system supports the routine identification and referral of carers
6. Continue collaboration between Care2Serve and the Integrated Care Hubs
7. Ensure that carers are included and recognised as being one of the most significant providers of care at home
8. In planning for care at home, in the community, and in health settings, the inclusion of processes to identify and support carers (eg routine identification and referral) must be implemented
9. Include processes to identify and support carers in planning for care at home, in the community, and in health settings (e.g. routine identification and referral)
10. Recognise and outline specific actions that will support carers of people with mental ill health or alcohol or other drug dependence
11. Include and recognise carers as a specific and distinct role in the Consumer Health Planning Committee
12. DoH must recognise Carers Tasmania as the Peak Body for all family and friend carers in Tasmania and work in partnership more effectively to hear the lived experience of all caring cohorts
13. DoH to ensure communication about digital services are in plain English and that patients and carers are supported to be able to access and use these services
14. Collaborate with Carers Tasmania on carer inclusion and experience in the development of the Tasmanian Lived Experience Workforce Framework and further implementation of lived experience carer workers
15. Liaise with Carers Tasmania on specific strategies and supports that can be offered to employees of the THS who are in a caring role
16. Carers must be recognised in the Clinical Services Profiles by the DoH